HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster Disclosure Method.

Julia Turner
Student number: 3706469

A mini thesis submitted in partial fulfilment of the requirements for the degree of Master in Public Health in the School of Public Health, Faculty of Community and Health Sciences, University of Western Cape.

Supervisor: Prof. Brian van Wyk

3 April 2021

KEYWORDS

Adolescents
Antiretroviral therapy
Disclosure
Stigma
HIV
Adherence
Parents
Caregivers
Communication
Health care workers

ABSTRACT

Background

Despite the known benefits of adolescents knowing their HIV status, parents and caregivers (PCG) often delay the disclosure of their children’s HIV status to them due to the fear of stigma and discrimination, the belief that the child thinks they will die, and the lack of disclosure skills. This delay can affect the children’s adherence to treatment, physical health, mental health and can enable unknowing transmission. The Mini Flipster Disclosure Method (MFDM) was developed to assist healthcare workers (HCWs) in supporting the disclosure of an adolescent’s HIV status by their parent or caregiver. This involves a process of educating the child or adolescent about HIV and how it can be successfully managed before informing them that they have HIV. The current study described the experiences of HIV-positive adolescents of the MFDM and those of their caregivers and HCWs in Mpumalanga.

Methodology

A descriptive qualitative study was conducted involving semi-structured interviews with 21 adolescents and their PCG and HCW after the adolescent had been disclosed to using the MFDM. The sample population was purposively identified from three public primary healthcare clinics in Nkomazi district in Mpumalanga. Data was transcribed in full and subjected to reflexive thematic analysis.

Results

The MFDM successfully facilitated disclosure to adolescents with HIV and was positively experienced by most adolescents. The HIV knowledge content was appropriate and succeeded in redressing adolescents’ negative misconceptions about HIV as well as mitigating stigma and fostering hopeful expectations of a normal life with HIV. Parents and caregivers reported relief and happiness after disclosure, and gratitude for HCW support during the MFDM process, to dispel their initial fears and prevent delay of disclosure. Further, PCGs were grateful that the MFDM promoted positive PCG-adolescent relations.

Conclusion

The MFDM was successful in sensitively supporting disclosure to adolescents about their HIV status in the presence of a parent or caregiver. We recommend that HCW be trained to use the MFDM to support PCG to disclose to their adolescent children between 10-16 years, living with HIV, and to assist them to dispel negative HIV myths and counter stigma.

DECLARATION

I declare that *HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster Disclosure Method* is my work, has not been submitted for any degree or examination at any other university, and that all the sources I have used have been indicated in the text and acknowledged in the references section.

Full Name: Dr Julia Turner
Date: April 2021

Signature: ______________________________

ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to my supervisor, Prof Brian van Wyk, from the University of Western Cape. His expert guidance and support have been invaluable. I would also like to acknowledge my initial supervisor, Lucia Knight, and thank her for her faith in me. I also thank my editor, Richard Weir, for tirelessly editing my mini-thesis - his contribution is sincerely appreciated.

Importantly, I thank the study participants for their invaluable contributions and eagerness to assist present and future adolescents.

Finally, I thank James and my parents, Brigid and Peter, for their unwavering support, and Dr Leon Levin and Dr Marnie Vujovic, my mentors in adolescent HIV disclosure, from whom I have learnt the delicate art and science of caring for this vibrant but sensitive patient sector.

TABLE OF CONTENTS

GLOSSARY OF ABBREVIATIONS

ALHIV – Adolescents Living with HIV
ART – Antiretroviral Therapy
BMREC - Biomedical Ethics Research Committee
CHC – Community Health Centre
CLHIV – Children Living with HIV
HCW – Healthcare Worker
HCP – Healthcare Practitioner
MFDM – Mini Flipster Disclosure Method
MHD – Mental Health Disorder
MTCT – Mother to Child Transmission
NGO – Non-governmental Organisation
PCG – Parent or Caregiver
PHC – Primary Healthcare
PLHIV – People Living with HIV
PMTCT – Prevention of Mother to Child Transmission
SRH – Sexual and reproductive health
TB - Tuberculosis

DEFINITIONS

For consistency, the following definitions, described in the South African disclosure guidelines, are used (1).

Newborns: Birth - 28 days
Infants: 28 days – < 1 year
Toddlers: 1 – < 3 years
Early Childhood: 3 – 5 years
Middle Childhood: 6 – 9 years
Early Adolescence: 10 – 14 years
Late(r) Adolescence: 15 – 19 years

PCG: Parent or caregiver

The parent, legal guardian, or person responsible for providing primary care to the child/adolescent living with HIV.

HCW: Healthcare worker

Any trained healthcare practitioner (HCP) providing disclosure services within a facility or community (nurse, doctor, counsellor, social worker, or psychologist).

Non-Disclosure:

The child is unaware of their illness and its effect on their body.

Partial Disclosure:

The child is made aware of their illness without naming HIV.

Full Disclosure:

The child is made aware of their illness, which is called ‘HIV’.

Health Promoting Disclosure:

The child knows everything about a disease that is appropriate for their age. They are equipped in a supportive manner with skills to take age-appropriate responsibility for their health.

Complete Disclosure Process:

The child is guided through a process, from the stage of non-disclosure to the stage of health-promoting disclosure, within a children's rights framework.

CHAPTER 1: INTRODUCTION

1.1 Background

South Africa has the highest burden of HIV in the world, with a prevalence of approximately 13% in the general population (7.8 million people living with HIV (PLHIV)) and an even higher prevalence of 26.3% in women of childbearing age (between 15 and 49 years) in 2020 (2,3). Rates of mother to child transmission (MTCT) have reduced by approximately 80% from 2004 to 2017 due to the effective use of antiretroviral therapy (ART) and the national prevention of mother to child transmission (PMTCT) programme (2,4). However, the 2018 estimate of children living with HIV (CLHIV) and on ART in South Africa was 161,823 children (<15 years); it is anticipated that these children would grow into adolescents living with HIV (ALHIV), which has a unique set of challenges (4).

HIV treatment and management has evolved drastically over the last 15 years. With early initiation of ART and much-improved ART regimens, children have the potential for good long-term clinical outcomes and normal life expectancy (5). However, long-term, persistent adherence to treatment and the psychosocial impact of living with HIV have become the most difficult challenges facing ALHIV (6–8).

Inconsistent adherence to ART can lead to treatment failure, ARV resistance (and ultimately, morbidity and mortality), and the transmission of HIV to offspring and sexual partners (9,10). Currently, the best measure of treatment adherence is the quantification of HIV RNA (viral load) in the patient's blood. High HIV viral load (VL) suppression rates (percentage of PLHIV with a VL<1000 copies of HIV RNA/ml) indicate an effective treatment of HIV, which predicts a good prognosis and a negligible chance of transmitting HIV to sexual partners and offspring (2). The 2017 Human Sciences Research Council survey showed an HIV VL suppression rate (VL<1000) of 62% nationally, indicating that a low proportion of patients are adequately adherent to their treatment (2). Several studies have shown 0% HIV transmission rates to a sexual partner when the HIV-positive partner's VL is < 200 copies/ml and have given rise to the popular movement, *Undetectable = Untransmittable* (U=U) - although classically, the term 'undetectable' is reserved for an HIV RNA VL<50 copies/ml (11,12).

PLHIV face many psychosocial challenges, including coming to terms with having HIV, coping with the uncertainty of the disease's course, dealing with community-level stigma, the impact on sexual relationships, and for many, the mental burden of maintaining secrecy about their diagnosis (13,14). These challenges can negatively affect a patient's quality of life and mental health (8). Additionally, the need to adhere to a lifelong treatment regimen can cause anxiety, frustration and impact a PLHIV's psychological and social wellbeing (15). Conversely, psychosocial challenges are likely to interfere with treatment adherence, which is detrimental to the quality of life and health (9,15,16).

Adolescents are at a particularly vulnerable stage of life and experience many age-related psychosocial challenges, including establishing their identity and preparing for the stage of intimacy as described in Erikson's stages of psychosocial development (15,17). Combined with this, the HIV VL suppression rates in adolescents (51% in 0-14 years, and 49% in 15-25 years) are generally lower than in adults (63% in 25-49 years, and 73% in over 50 years) throughout South Africa (2). There is, therefore, a need to improve adolescents' adherence to treatment and their psychosocial wellbeing.

HIV disclosure is the process of telling someone their HIV-positive status, which includes an HIV-infected person being told that they have HIV, as well as an HIV-infected person disclosing their status to their family, friends, work, school, partner or general community (18). Disclosure to ALHIV is very important so that the adolescent knows why they need to take treatment, how to look after their health, how to prevent transmission to others so that they can, ultimately, become independent, autonomous young adults (18–20). However, HIV disclosure to a child or adolescent living with HIV (C/ALHIV) can harm their psychosocial health and adherence to treatment (18,21). Parents or caregivers (PCG) often delay disclosure due to fears of upsetting the child, the child blaming and stigmatising the parent, the child inappropriately disclosing to other people, the belief that the child will think they will die, as well as the PCGs' lack of disclosure skills (21,22). Non-disclosure and delayed disclosure can affect an adolescent's adherence and mental health, as the adolescent does not understand why they should take treatment, and adolescents who discover their HIV status before being disclosed to by their PCG may feel lied to, access incorrect HIV information, and experience emotional distress (18).

The South African National Department of Health's (SANDoH) *Disclosure Guidelines for Children and Adolescents in the context of HIV, TB and non-communicable diseases,* recommend disclosure by the PCG from 10 years old, dependant on if the child is of normal cognisance and maturity (1). However, telling a child they have HIV is a daunting task that may have serious consequences if not done appropriately. It is, therefore, very difficult for PCGs, who do not have any training to take on this task. For this reason, the SANDoH recommend that healthcare workers (HCW) support the PCG to disclose to the adolescent (1). Previous research has, however, noted that HCWs also require support in this difficult task (23,24). The current research study focusses on disclosures in the context of perinatally infected children being told their HIV status.

1.2 Disclosure methods

There are many ways in which adolescents can be disclosed to - it can be intentional or accidental, planned or unplanned (1,18,23,25). Unplanned disclosures have been described in the literature, for example, when a PCG tells their child their HIV status in a moment of frustration while trying to convince the child to take their medication (23,25). Disclosure can occur through a process, or it can be a once-off encounter (1,18,23,25). Most guidelines recommend that it be a process - that allows for relationship-establishment before disclosure and ongoing support. Disclosure can be performed at home by a PCG, or in a healthcare facility by a HCW or a HCW and PCG together (23). Anecdotally, another method is disclosure by peers: where HIV-positive adolescents who know their status build a relationship with the patient, disclose their own status first and teach the patient about HIV, before disclosing the patient's HIV status; a PCG or HCW may also assist with full disclosure.

Various interventions have been developed to support the disclosure procedure:

- Specific psychotherapy groups for PCGs have been used to build competence and enable them to disclose to their adolescents (8).
- Storybooks for C/ALHIV have been used to disclose to adolescents, and HCWs have been provided with training and guides to disclose or to support PCGs to disclose to their adolescent. One such system is the Mini Flipster Disclosure Method (MFDM), which is described below and used in this study.

1.3 Description of the Mini Flipster Disclosure Method

The *Mini Flipster Disclosure Tool for Adolescents Ages 12 and up (MFDT)*, a picture-based flipchart tool, was created by psychologist Marnie Vujovic, based on a method developed by paediatric HIV specialist Dr Leon Levin, both from the non-governmental organisation (NGO) Right to Care (26). The tool's purpose is to assist HCWs in supporting PCGs to disclose the HIV-positive status to the adolescent in their care (26). It was piloted in a tertiary hospital in Gauteng and rolled out for use by Right to Care social workers, nurses and doctors, and Department of Health (DoH) staff in the Free State and Mpumalanga provinces of South Africa.

The Mini Flipster Disclosure Tool (MFDT) has five sections:

1) Partial disclosure
2) Full disclosure
3) Post disclosure session 1
4) Post disclosure session 2
5) Giving support

Sections 1-4 pertain to the four sessions, which should be performed consecutively, with variable time intervals. While the partial disclosure session need not be more than 15 minutes, disclosure and full disclosure sessions may take an hour or more depending on the needs of the C/ALHIV. Partial disclosure can be repeated many times over many years to allow for increasing levels of understanding as the child matures. Post disclosure sessions should follow full disclosure by a few days or weeks. The MFDT should be used with The Talk Tool, which outlines how to engage and prepare the PCG beforehand, how the sessions should run, and the session's contents. The MFDT is structured such that one side of the flipchart displays a picture for the child to look at, while the other side displays a narrative for the HCW to tell the child/adolescent (26). The MFDT is written in English, however, skilled users often translate the contents into local languages for the benefit of the patient. The narrative begins with partial disclosure, in which an explanation is given to the child about why they need to take medication; 'HIV' is not yet mentioned (26). The flipchart story continues to inform audiences that "soldier" cells in the child's body protect against "germs"; that the child was born with a germ that kills their soldier cells, and that their medication helps to "keep their body strong and helps to make more soldier cells" (26).

At the beginning of the full disclosure session, in which the germ (HIV) is identified, the adolescent is asked what they know about viruses and which virus they think they might have. The HCW then discusses various illnesses to ascertain what the child knows about HIV; the child is then taught about HIV, dispelling all myths and inaccuracies. The pictures and narratives in the MFDM explain:

- How HIV affects the body.
- How ART works.
- That if people with HIV take their treatment every day and their viral load is suppressed, they will not become sick.

Myths and stigma around HIV are dispelled by explaining how HIV can and cannot be transmitted, and that ART works very well to prevent illness and death.

In the post-disclosure section, further education addresses concerns the patient may have about the lifestyle implications of being HIV-positive. From life-expectancy, HIV transmission to babies or sexual partners, and daily life, the flipchart’s narrative very clearly articulates that an HIV-positive person enjoy the same quality of life as someone without HIV, provided they take their treatment. While this information is detailed in the MFT post-disclosure section, this information should be shared before full disclosure if the child does not already understand this.

The healthcare worker helps the child to understand that anyone can have HIV. They then ask the adolescent if they think they might have HIV. Once the adolescent has come to terms with the possibility of being HIV-positive and understanding that it does not change who they are or their life projection, the parent/caregiver is encouraged to confirm that the child has HIV (26). Appendix O shows examples of pages in the Mini Flipster Disclosure Tool. The pages that show dialogues face the HCW, and the pages with large pictures face the C/ALHIV and PCG while the HCW is talking. A small version of the large picture is shown in the top right-hand corner of the corresponding page facing the HCW to show what the child is viewing.

If PCG are willing, they are involved in the final task of disclosing to the C/ALHIV as, once the HCW has taught the C/ALHIV about HIV they can ask the child “do you want to ask your PCG if you have HIV?” At this point the PCG can confirm that the C/ALHIV has HIV, and can disclose their own status as well if they are willing.

C/ALHIV who are ready for disclosure can be identified by PCG and HCW, however, usually, HCW need to counsel PCG on its importance and instigate the process. In this study, C/ALHIV’s, aged 10-19 years, files were audited to determine whether they have been disclosed to or not, if they had not their PCG were contacted by a HCW to offer support with disclosure. If the PCG agreed, they were booked for an appointment. For all of the full disclosures the MFDT session on full disclosure was used, for those who had not previously had partial disclosure, the partial disclosure sessions were used as well.

1.4 Problem Statement

SANDoH disclosure guidelines recommend that full disclosure should occur when the adolescent is approximately 10 years old. However, many parents and healthcare workers delay disclosure which means that there may be adolescents (up to the age of 19) who require disclosure (1,18). It is imperative to describe HIV-positive adolescents' experiences of MFDM to highlight what is helpful and how it could be improved. This experiential information can help healthcare workers better understand a very vulnerable patient sector and advance their knowledge of approaching disclosure to young patients. Furthermore, the gathered information will assist healthcare workers to improve the tool and all aspects of the disclosure process to provide adolescents with the most beneficial and least traumatic experience.

1.5 Aim and Objectives

The current study describes HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster Disclosure Method as well as their PCG's experiences.

The objectives of this study are to:

- Describe adolescents' experiences of being disclosed to using the Mini Flipster Disclosure Method.
- Describe adolescents' knowledge of, and attitudes towards, HIV before and after the Mini Flipster Disclosure Method.
- Describe the perceptions and experiences of parents/caregivers using the Mini Flipster Disclosure Method in terms of receiving disclosure support from healthcare workers.
- Develop recommendations on how the Mini Flipster Disclosure Method can be improved.

1.6 Outline of the mini thesis

Chapter 1: Introduction introduces the research study, an overview of the Mini Flipster Disclosure Method, the research aim, and objectives.

Chapter 2: Literature Review presents a literature review of adolescent disclosure, including benefits and risks, barriers and enabling factors, timing, process, and an overview of guidelines and tools available.

Chapter 3: Methodology outlines the research methodology, including the study design, sampling, data collection and data analysis.

Chapter 4: Results presents the findings of the study according to the main themes and sub-themes.

Chapter 5: Discussion provides a detailed discussion of the main findings in relation to available literature.

Chapter 6: Conclusion and Recommendations presents recommendations and research study conclusions.

1.7 Researcher's position

The researcher is a medical doctor working for Right to Care NGO, she works with Dr Levin and Dr Vujovic. The researcher did not develop the MFDM but has used the method multiple times previously and thought it an effective method of disclosure, she therefore wishes to explore PCG and adolescent's experiences of the MFDM.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Disclosure of HIV status to a vertically infected child or adolescent (MTCT) is a daunting task and is fraught with complexities. In this literature review, the researcher will outline the current knowledge of disclosure rates in South Africa, the benefits and risks of disclosure, barriers and enabling factors for disclosure, the timing of disclosure (ideal age) The review will also address the process of disclosure (who should do it and how it should be done), analyse disclosures which were not performed well and, finally, provide an overview of disclosure guidelines and tools available.

2.2 Disclosure rates in South Africa and internationally

Population-wide disclosure rates are not fully known; however, several studies have shown varying rates between countries, as documented in Table 2.1 below. In a longitudinal cohort study in two urban South African HIV clinics based in academic institutions, it was found that “compared with children ages 4–5 years, children age 6 years had 3.0 times, children age 7 years had 6.7 times, and children aged 8–9 years had 7.8 times the adjusted hazard of receiving disclosure” and that overall, 70% of children aged 4-9 years old, knew their HIV status (27). This rate of disclosure among this age group is higher than that in non-academic institutions, indicating that these clinics aim to disclose to all children *by* age 10, whereas the national guidelines recommend full disclosure *from* age 10 (1,27). It was also found in this study that girls had 1.4 times the adjusted hazard of receiving disclosure versus boys (27). This could relate to the commonly held belief that adolescent girls mature quicker and become sexually active sooner than adolescent boys do.

Table 2.1 Comparison of HIV disclosure rates to children and adolescents found in studies in different countries (19)

Country (year)	Target population	Disclosure rate
USA (2002)	6-18 years	43%
Zambia (2007)	11-15 years	48/127 (37.8%)
Nigeria (2011, University College Hospital	>6 years	13/96 (13.5%)
Nigeria (2018, University College Hospital)	6-17 years	54/200 (27%)
Ghana (2018)	6-17 years	24/103 (23%)
Tanzania (2018)	6-17 years	102/309 (33%)
Oakland, California, USA (2020)	6-18 years	26/36 (72%)

Source: Oladokun R. The "Why, When and How To" of HIV Disclosure: Perspectives From the North and South. In: International Workshop on HIV & Paediatrics. 2020.

2.3 Benefits of disclosure

It is widely agreed that the benefits of disclosure usually outweigh any potential risks as long as the adolescent is of normal cognisance, maturity and mental health (1,18,20–22,28–30). Benefits of disclosure include:

1) Improved adherence to medication, and general healthcare, being able to take part in medical decisions, take control of, and responsibility for, their own health;
2) Knowledge of the 'truth', acceptance of their diagnosis, improved psychosocial wellbeing and mental health;
3) Being able to discuss and set life and treatment goals;
4) Allowing for access to health education, sexual and reproductive health (SRH) education, social support, and participation in adolescent peer support groups;
5) The prevention of unknowing transmission of HIV to partners, babies and siblings;
6) Prevention of the adolescent finding out their HIV-positive status themselves and accidental disclosure; and
7) Improved focus and performance at school (1,18,20–22,28–30).

Disclosure has been found to improve an adolescent's self-esteem and be a predictor of virologic suppression after transitioning to the adult HIV programme (31). The benefits of disclosure for PCGs include relief, acceptance from and reconciliation with their C/ALHIV, cessation of secrecy, reduced depression and improved mental health, and better communication with the adolescents in their care (18). The benefits of disclosure that HCWs experience include the ability to discuss treatment and adherence openly, to discuss SRH and how to prevent transmission, and the ability to make psychosocial referrals (18).

The Children's Act in the Constitution of the Republic of South Africa outlines several rights regarding a child's ability to "access information regarding the causes and treatment of his or her health status" and their right to the best quality health care, including that "every decision made in a child's life should be in the best interest of the child" (1). As the benefits of disclosure usually outweigh the risks, and following the principles of beneficence, non-maleficence, autonomy and the right to know about one's own health, it is usually considered ethically correct to disclose an adolescent's HIV status to them. Similarly, given the above-mentioned benefits for a C/ALHIV, this means that one should not refuse to disclose HIV status to an adolescent for the sake of anyone else (including the sake of the PCG) (1). International policies such as the United Nations Convention on the Rights of the Child (CRC) legally binds South Africa to uphold children's rights and "*ensure that appropriate disclosure becomes an integrated component of comprehensive child and adolescent HIV management*" (1).

2.4 Potential risks and negative effects of disclosure

It is noted in multiple studies and guidelines that post-disclosure outcomes are not always easy and positive (18). The child or adolescent may experience negative reactions such as feeling sad or depressed, fearful or distressed; they may also fear death and loss of a future (18,32). A World Health Organization (WHO) synthesis of four studies, representing over 150 children between the ages of 5and 19 years found that the respondent's immediate reactions to learning of their HIV status as: *"sadness and worry (35.9%), followed by neutral/normal (28.2%), shocked (16.0%), angry (14.7%), confused (8.3%)"*; whereas only 6.4% experienced initial positive reactions such as relief (30). However, a Puerto Rican study reported *"a dissipation of children's confusion and anger, a reduction of negative emotions, and an increase in feelings of normality (70.0%) and in positive emotions (47.5%)"* six months after a supportive intervention (30,33). Further, suicidal ideation after disclosure has been observed in a qualitative study in Uganda, which was attributed to feelings of hopelessness and bitterness (25). When considering the potential risks of adolescent disclosure, it is plausible that adolescents may have similar reactions to adults who have been newly diagnosed with HIV. A longitudinal study exploring adult women's reactions to being diagnosed with HIV found initial responses involved devastation, shock and indignation; which progressed into long-term depression, shame, suicidality and increased drug and alcohol use (34).

Other cited risks of disclosure to adolescents include being impacted by stigma (internalised, perceived or directly experienced), withdrawing from peers, showing an increase in behavioural problems and rebellion, blaming their parent for infecting them, and stigmatising, discriminating against, or becoming violent against the parent (18,32,35). Due to these above-mentioned risks, it is understandable that PCGs and HCWs alike are fearful of disclosing to C/ALHIV. However, given the fact that the benefits of disclosing have been shown to outweigh the potential risks, the need for appropriate disclosure methods and post-disclosure support are clear (1,18,30,32,35).

Based on findings in the literature, it follows that two causes for these above-mentioned risks and negative effects on mental health are the beliefs that HIV is a dreaded disease and HIV-related stigma (23,25,36,37). Conversely, non-dreaded diseases, without stigma, do not face such challenges. It is, therefore, worth building a deeper understanding of these two causes and how they affect disclosure.

HIV as a dreaded disease

HIV was a dreaded disease when morbidity and mortality rates were high, and no form of treatment or control had been discovered (38). However, there are currently over 32 effective antiretroviral medications, on which life expectancy for PLHIV is in keeping with, or longer than, their HIV-negative contemporaries (38). Following these advances, HIV disclosure should no longer be performed in the manner one would use for an incurable or poor-prognosis illness. Furthermore, because HIV is still widely perceived as life-threatening, this belief needs to be actively corrected during the disclosure process (35).

HIV-related stigma

Stigma is a bias held by others that reduces a person to someone who is different, tainted, and deserves to be denigrated to a lower social status (39). Stigma can be categorised into three types:

1) Internalised stigma;
2) Perceived stigma; and
3) Externalised or enacted stigma (37).

Internalised stigma refers to a person accepting negative connotations as applicable to themselves; perceived stigma is when a person imagines or anticipates that others are thinking or will think negatively about them; and externalised or enacted stigma is when other’s negative attitudes and actions directly impact an individual (37). Examples of all three are seen in the literature relating to HIV: with internalised stigma causing PLHIV to have a negative view of themselves, perceived stigma preventing PLHIV from disclosing their status, and externalised stigma resulting in a loss of social and economic support and stability (36).

In a South African study, Saal et al. found the prevalence of stigma reported by adolescent females was as follows; perceived stigma (21.1%), internalised stigma (16.6%) and discrimination/ externalised stigma (4.2%) (37). The cause of stigma related to HIV is likely related to the pervasive perceptions of HIV being associated with immorality and casual sexual relationships, as well as homosexuality and intravenous drug use (36). Unfortunately, children and adolescents are not immune to learning these perceptions from friends, family and the greater community. In addition, HIV prevention education given in schools often focusses on the negative aspects of HIV, as motivation for children to refrain from sexual activities to avoid a ‘life-threatening illness’, which may result in increased stigma and discriminatory labels (40). Within a social context of negative HIV knowledge and stigma, a C/ALHIV’s HIV disclosure is likely to be more shocking and upsetting than in a context where the child does not already hold negative connotations of HIV. This impact of stigma is seen in multiple studies, including in a qualitative study by Vaz et al. which took place in Kinshasa, Democratic Republic of Congo (DRC). In this study, an 11-year-old female is quoted post-disclosure, saying: “*That hurt me a lot. Because this illness, it is for the debauchers, but me, at this age, I cannot have this illness*” (20). Stigma has a huge impact on the adolescent’s emotional well-being and adherence to ART, and can lead to mental health disease and suicidality (36,37,41). HIV stigma, therefore, needs to be taken into consideration when disclosing their HIV status to C/ALHIV.

In summary, while the benefits of disclosure outweigh the risks, there are still significant dangers to a C/ALHIV’s mental health. Most of these risks emanate from archaic beliefs that HIV has a poor prognosis, as well as unfounded HIV-related stigma. Consequently, the correction of these false perceptions should decrease the risk to C/ALHIV mental health.

2.5 Barriers to disclosure

The disclosure of HIV status to a C/ALHIV is usually considered as breaking bad news. It is well-described in the context of HCWs who often deal with this situation, that it is normal to:

1) Avoid or delay breaking bad news; and
2) Have fears such as being blamed, of eliciting a reaction, not knowing how to do it, expressing emotions, not having all the answers, and feeling uncomfortable due to sympathy for the person receiving bad news (42).

It is understandable that PCGs and HCWs may experience these same fears which may act as barriers to disclosure (35).

The Disclosure of HIV Status Toolkit for Paediatric and Adolescent Populations by the Elizabeth Glazer Paediatric AIDS Foundation (EGPAF) categorises barriers to disclosure as either health facility-related barriers or community-related barriers. In contrast, the SANDoH disclosure guidelines indicate "PCG issues", "HCW issues", and "health system issues" (1,18). HCW-related barriers include a lack of training, guidance and tools, HCWs not feeling comfortable to support disclosure, lack of time, negative staff attitudes, and limited psychosocial support (1,18,43).

Community or PCG-related barriers include parental feelings of guilt and shame, discomfort to disclose, beliefs that the child is too young, concern for the child's mental health post-disclosure, fear of negative reactions, fear of blame and rejection, and fear of the child and family being stigmatised if the child does not keep their HIV status a secret (1,18,35,43). It can also be more difficult if the caregiver is not a biological parent or where consent to disclose is difficult to obtain (1).

Health facility and health system-related barriers include poor implementation of policies and guidelines, lack of adolescent- and youth-friendly environments (including private spaces for confidentiality), and poor linkage and referral pathways between facility and community services (1,18).

Stigma is a cross-cutting barrier emerging in HCW-, community- and PCG-related factors and has been highlighted in multiple studies worldwide, (21,36,37). The SANDoH disclosure guidelines seek to directly address some of these barriers by providing a framework of support for HCWs, child- and adolescent-friendly healthcare services and a framework of support for PCGs and their families (1).

2.6 Enabling factors for disclosure

Multiple enabling factors for disclosure have been identified and can be classified as reasons for disclosing, enabling factors and positive predictors. Reasons for disclosure, identified in a Zambian study looking at enablers and barriers to disclosure by Mweembe et al., include "*inquiries by adolescents as to why they were taking medication, threats by adolescents not to take HIV medication, desire to promote treatment self-efficacy amongst adolescents as well as facilitating adoption of safe sexual behaviour among adolescents*" (43). Enabling factors include PCG access to, knowledge of, and experience with HIV-related support programmes in facilities and communities, as well as adolescents' knowledge of HIV (43). In a review of disclosure rates in two tertiary hospitals in Johannesburg, South Africa, it was found that older age, female gender, and someone at the child's school or creche knowing the child's HIV status, were positive predictors of disclosure (27).

When disclosing to a child, it can be beneficial to disclose the PCG's HIV status too. However, this comes with its own set of enablers and barriers (35). An integrative literature review by Zanon et al. found that "*cognitive ability and maturity of the child, the strength of family ties, parental illness and death, the discovery of HIV status by third parties, stigma and prejudice, negative reactions from the children, and the fear of losing parental power*" influenced the decision to disclose the parents' HIV diagnosis to their children (35).

2.7 Timing of disclosure

Timely disclosure is necessary to "*facilitate HIV [and SRH] education and avoid problematic reactions if disclosures were late and/or inadvertent*". However, PCGs are often reluctant to disclose to young children in the fear that they will not understand, or may disclose to others indiscreetly (1,18,24). There has been much debate worldwide regarding the best time or age to disclose to a child. The WHO recommends that children should be fully disclosed to when they go to school (from 6 years) based on the argument that children from 6 years up can understand concepts of illness and health; and from 8 - 9 years can understand the concept of death (30).

Conversely, the SANDoH recommends partial disclosure from 3 years old and full disclosure from 10 years onwards (1,30). The SANDoH disclosure guidelines emphasise that the disclosure process must be started as soon as possible after diagnosis and warns that delaying disclosure makes the process more difficult, potentially traumatic, and can lead to poor adherence and treatment failure (1). Table 2.2 shows the recommended ages for partial and full disclosure in different African countries (18).

Table 2.2 Recommended ages of partial and full disclosure in different African countries (19)

Country	**Reference**	**Age of partial disclosure (years)**	**Age of full disclosure (years)**
Cameroon	*National guideline on the prevention and management of HIV 2015*	7-11	12-13
Lesotho	*2016 Test and treat guidelines*	5-9	10
Malawi	*National guidelines for clinical management of HIV children and adults 2016*	5-7	11-13
Rwanda	*National guidelines for prevention and management of HIV and sexually transmitted infections 2016*	8-10	11-14
Tanzania	*HIV services for adolescents 2018*	4-6	8-10
Uganda	*Uganda HIV testing services policy and implementation guidelines 2016*	None	12
Zambia	*Zambian national guidelines for HIV counselling and testing of children*	5-7	7+

Source: Oladokun R. The “Why, When and How To” of HIV Disclosure: Perspectives From the North and South. In: International Workshop on HIV & Paediatrics. 2020.

Specific concerns raised in the literature regarding the timing of disclosure include the complexity of assessing cognitive and emotional readiness, the necessity that adolescents know their HIV status before they reach sexual debut to avoid unknowing transmission of HIV, and the worry that if children are disclosed to at too young an age, they will not be able to keep a secret (1,18,30).

The Disclosure of HIV Status Toolkit for Paediatric and Adolescent Populations by the Elizabeth Glazer Paediatric AIDS Foundation (EGPAF), recommends that partial disclosure starts from 6 years, with the aim of full disclosure by 12-14 years (18,35). This recommendation is based on cognition and maturity, the need for the child to be adherent and look after themselves, the impending sexual debut, and the finding that by 10 years old, adolescents can keep secrets (18).

Aligning with this recommendation is the finding that children’s brains are still adapting and developing and reach the highest developmental stage after 12 years, in which they develop the ability for logical reasoning. However, it must be noted that some adolescents desire autonomy and reach sexual debut before reaching 12 years (18,35). In a Ugandan qualitative study, it was observed that older adolescents (over 12 years) had worse reactions to their disclosure, a higher chance of reporting suicidality, and more anger at their PCG for concealing their status for a long period of time (25). As adolescents get older, they are also more able to find answers to their questions and, therefore, might discover their diagnosis in a manner other than disclosure (18).

It is important to remember the legal and ethical rights for children and adolescents to access information about their own health and have age-appropriate autonomy around their health (1). Many studies have shown that adolescents like to be told the truth about their own health and to be involved in their own health-care decision-making, and that delaying disclosure can undermine an adolescent's autonomy (1,35).

2.8 Disclosures that were not done well

The literature reports many disclosures which were not regarded positively, most of which lacked preparation and ongoing support, and describe once-off events that are not well planned. Some were performed at home in moments of frustration, usually when the C/ALHIV did not take their treatment (20) and some were performed by family members who did not provide information about HIV (23). Kidia et al. quote an 18-year-old male who was disclosed to at home: "*My grandmother told me at home. I was watching TV. My grandmother came up to me and said, 'Hey, A, do you know that you're HIV-positive?' I said, 'Okay.' She said it twice: 'You're HIV-positive.' I just said, 'Okay' (boy A, 18).*" (23).

Some disclosures by PCGs at home are brief, do not include much information on HIV or any assessment of the adolescent's knowledge of HIV before disclosure; these disclosures typically result in confusion and disbelief (20). Adolescents also reported the following negative outcomes:

- that once they were told they had HIV, they were shocked and they could not remember any other information after that;
- that when they were told they were "HIV-positive", they did not know if it meant they had HIV or not; and
- that they did not believe their diagnosis until they were told by an HCW (23,25).

2.9 Process of disclosure

2.9.1 Who should do disclosure

There is much debate in the literature about who should disclose to children and adolescents, but the most commonly advocated-for people are PCGs, HCWs or peers (1,18,23,25,30,35,44). While some experts believe disclosure to be the PCG's responsibility, some adolescents have reported poor experiences of disclosures by PCGs who had no support (20,23,25). The SANDoH disclosure guidelines recognise that PCGs usually require assistance. Therefore, they state that healthcare providers (which can include doctors, nurses, social workers, psychologists or counsellors) should prepare and support the PCG to disclose to the C/ALHIV (1). This aligns with most international guidelines which recommend that disclosure be done jointly by the HCW and PCG (1,18,30,44). Anecdotally, another method of disclosure is peer-led: HIV-positive adolescents, who already know their HIV status, build a relationship with the adolescent, disclose their own status first and teach the patient about HIV before disclosing patient's status to them; a PCG or HCW may assist with full disclosure. This method, though, is not well-described in the literature.

Most of the literature on this topic shows that PCG desire disclosure support from HCW to initiate the process, provide correct information, answer difficult questions and offer additional psychosocial support if necessary (4,8,11). Furthermore, Mutumba et al. describe that most PCGs required HCWs to take the lead in the disclosure process, allowing the PCG to take a more passive role (25). In a study by Kidia et al., some HCWs felt that they did not have time to disclose and that it was the PCG's responsibility. Still, adolescents reported preferring disclosure to take place in the clinic with the support of an HCW to receive accurate information and so that the diagnosis is more believable (23).

2.9.2 How disclosure should be done

The literature varies and is often vague about how disclosure should be performed. The thinking about disclosure has needed to change over time in accordance with the growing understanding and improved treatment of HIV. Initially, disclosing HIV status was compared to paediatric oncology disclosure models, as both involved disclosing a life-threatening illness with poor prognoses (46). However, as the treatment of HIV has evolved and prognosis improved, the disclosure process has required modification. While previously, one needed to break bad news to a child and prepare them for morbidity and mortality in an honest but sensitive manner, the current requirement is to reassure the child or adolescent that prognosis is good, the effects on quality of life are minimal, and that HIV-related stigma is unfounded. In addition, previously, many of the children were sick and, therefore, did not require convincing that they had an illness. In contrast, nowadays, most children and adolescents on ART are very healthy and may have difficulty believing that they have an illness such as HIV (18,23,25).

In summary, the literature consulted agree that disclosure should be age-appropriate, and follow a gradual progression over time, starting with pre-disclosure and advancing through planning and preparation, partial disclosure, assessment for full disclosure-readiness, full disclosure, post-disclosure to ongoing support. (1,7,18,23,30,44,47–50). Furthermore, the need for age-appropriate language, excellent counselling skills, awareness of emotions, an appropriate space and ongoing support are strongly advocated (1,7,18,23,30,44,47–50).

A few tools and guidelines which document these phases and how they should be implemented have been developed internationally. Many tools document, specifically, what should be said to assess readiness and prepare for disclosure, explain partial disclosure, and how to educate about HIV. However, very few mention precisely what should be said to tell a C/ALHIV that they have HIV (full disclosure), or the need to dispel myths and stigma around HIV *before* full disclosure (1,7,18,23,30,44,47–50).

2.9.3 Need for guidelines and support on disclosure

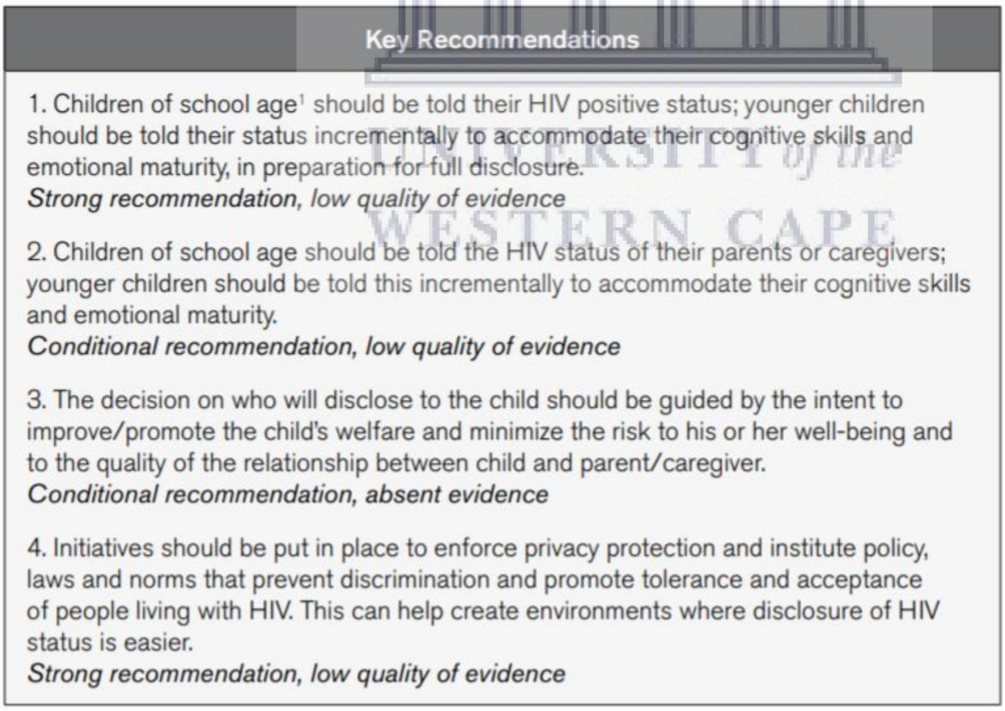
To provide information and support for PCGs in the disclosure process, HCWs have themselves been found to require and seek out disclosure training, guidelines and tools (7,23,24,35). Further to this, Vygotsky and Vaz et al. posited that due to specific social contexts, the exact verbal and non-verbal methods of information and support given to adolescents are important influencers of their understanding of their diagnosis and its implications, and should therefore be considered during HCW training (20,51). HCWs also report the need for guidance on how to improve adolescent-provider relationships to create a supportive environment for disclosure to take place (25,37) and a need for improving counselling, providing peer support, and stigma-reduction interventions (25,37).

2.10 Guidelines and tools for disclosure

An array of guidelines and tools have been created worldwide to assist PCGs and HCWs with disclosure. However, few have been evaluated or validated, and even fewer so in a South African context (1,7,18,26,28,33,49,52). Most of these guidelines describe the definitions and types of disclosure and the barriers and benefits of disclosure. Additionally, most refer to disclosure as a process, and list the elements which should be included in each stage, usually referred to as partial disclosure, full disclosure, and post-disclosure, but very few provide the recommended wording for telling the child they have HIV. A few of the commonly used guidelines and tools available in the public domain will be discussed.

The WHO released the *Guideline on HIV disclosure counselling for children up to 12 years of age* in 2011 which summarised the literature to date, provided a set of recommendations and a list of knowledge gaps that require further research (30). The guideline committee concluded that available evidence was of low quality, and thus key recommendations were made based on the consensus by the guideline committee and international experts (figure 2.1). The main recommendations were that it was beneficial for school-aged children (6 years and older) to undergo full disclosure of their HIV status and be disclosed to about their PCG's HIV status. Due to a lack of evidence, they did not conclude who should perform disclosure, how it should be done, or include any details of what could be said to disclose to adolescents, and recommended further research.

Figure 2.1 Key recommendations from the WHO *Guideline on HIV disclosure counselling for children up to 12 years of age* (2011) (30).



Key Recommendations

1. Children of school age[1] should be told their HIV positive status; younger children should be told their status incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure.
Strong recommendation, low quality of evidence

2. Children of school age should be told the HIV status of their parents or caregivers; younger children should be told this incrementally to accommodate their cognitive skills and emotional maturity.
Conditional recommendation, low quality of evidence

3. The decision on who will disclose to the child should be guided by the intent to improve/promote the child's welfare and minimize the risk to his or her well-being and to the quality of the relationship between child and parent/caregiver.
Conditional recommendation, absent evidence

4. Initiatives should be put in place to enforce privacy protection and institute policy, laws and norms that prevent discrimination and promote tolerance and acceptance of people living with HIV. This can help create environments where disclosure of HIV status is easier.
Strong recommendation, low quality of evidence

Source: World Health Organization. Guideline on HIV disclosure counselling for children up to 12 years of age [Internet]. Geneva; 2011 [cited 2020 Oct 28].

The SANDoH disclosure guidelines provide a legal and ethical framework for adolescent disclosure and outline a contextual framework for support (1). The aim for successful disclosure is for it to be intentional, timely, truthful, family-centred, prepared, age/development appropriate, and linked to appropriate support (1). The guidelines call for a four-step process to be recycled on an ongoing basis to further disclosure as the child matures, namely:

1) Planning and Preparation
2) Assessment and Disclosure Plan
3) Disclosure and Health Promoting Tasks
4) Support and Follow up.

Integral to steps 1, 2 and 3 is the availability of a disclosure tool for the HCW to use. The SANDoH disclosure guidelines detail the need for excellent counselling skills, emotional awareness, thorough planning, education, and ongoing support, amongst other aspects. Yet, they do not explain what should be said to tell a child or adolescent that they have HIV (1).

The Disclosure of HIV Status Toolkit for Paediatric and Adolescent Populations, by the Elizabeth Glazer Paediatric AIDS Foundation (EGPAF), is a comprehensive 74-page document comprising seven sections:

1) Background including benefits and disadvantages of disclosure
2) Guidance and checklists for HCW
3) Guidance and checklists for PCG
4) Guidance and checklists for supporting horizontally infected adolescents to disclose to their PCG
5) Guidance and checklists on supporting adolescents to disclose their status to their peers, school, work and community
6) Guidance and checklists on supporting adolescents to disclose to their partner
7) Appendices including job aids, disclosure readiness assessments, role-playing scenarios and references to additional resources (18).

Despite recommending more steps than the SANDoH guideline, it also does not provide an example of what should be said in order to tell a child or adolescent that they have HIV and does not suggest discussing HIV before full disclosure (1).

The *Paediatric HIV Disclosure Manual* by the Paediatric Department of Siriraj Hospital, Thailand, provides an overview of a four-step disclosure model (49):

1) Identify children eligible for disclosure, and propose disclosure counselling to PCG
2) Assess the readiness of child and PCG, and prepare for disclosure
3) Full disclosure performed either by PCG at home or by the PCG-counsellor team in the hospital

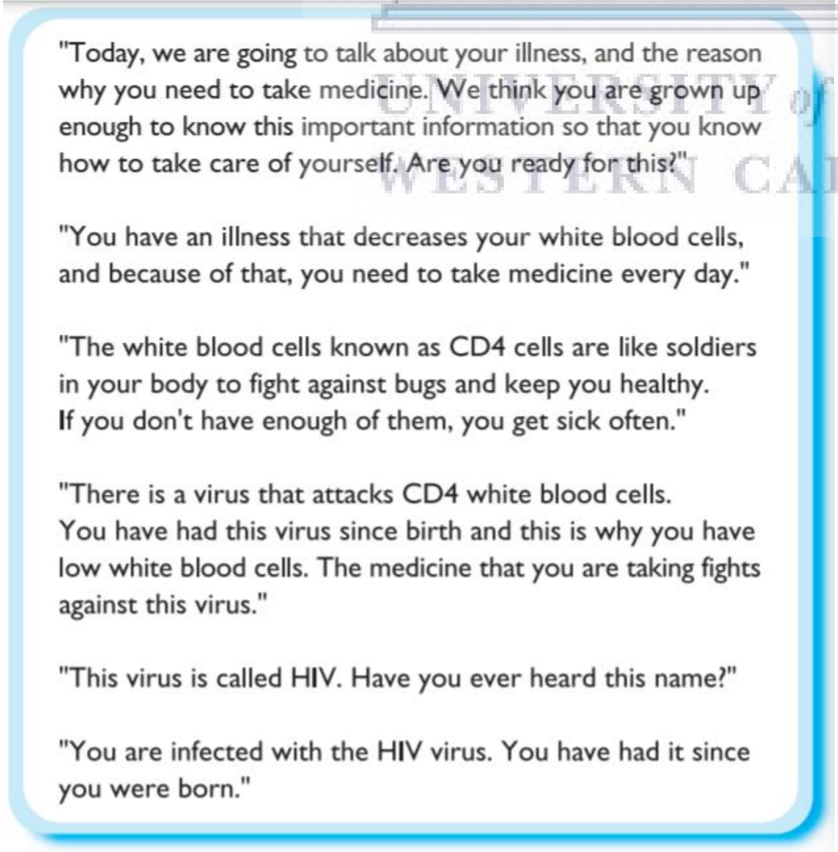
4) Monitoring and evaluating.

The preparation phase emphasises building rapport with the caregiver and child, and investigating their relationship and coping mechanisms (49). The disclosure phase focuses not only on disclosing HIV status but also on helping the child to understand it positively. This manual is one of a few that provides exact wording which can be used to tell the patient their HIV status (50). The manual explains that the child has a virus that kills their CD4 cells, which are like soldiers that look after their body, and that the virus is called HIV. Only after this does the manual prompt the counsellor to assess the child's knowledge about HIV and to then educate and address misconceptions.

The main differences, therefore, between Siriraj Hospital Manual and the MFDM is that:

1) The MFDM educates about HIV and addresses misconceptions *before* full disclosure, whereas the Siriraj Hospital Manual educates about HIV and addresses misconceptions *after* disclosure; and
2) The MFDM uses a picture-based tool.

Figure 2.2: An example dialogue to be used by a counsellor to disclose to an adolescent from the *Paediatric HIV Disclosure Manual* by the Paediatric Department of Siriraj Hospital, Thailand (49)



"Today, we are going to talk about your illness, and the reason why you need to take medicine. We think you are grown up enough to know this important information so that you know how to take care of yourself. Are you ready for this?"

"You have an illness that decreases your white blood cells, and because of that, you need to take medicine every day."

"The white blood cells known as CD4 cells are like soldiers in your body to fight against bugs and keep you healthy. If you don't have enough of them, you get sick often."

"There is a virus that attacks CD4 white blood cells. You have had this virus since birth and this is why you have low white blood cells. The medicine that you are taking fights against this virus."

"This virus is called HIV. Have you ever heard this name?"

"You are infected with the HIV virus. You have had it since you were born."

Source: Thailand Pediatric HIV Disclosure Working Group. Paediatric HIV Disclosure Manual [Internet]. Boon-yasidhi V, Chokepailbulkit K, McConnell M, Angsukittitavorn S, Klumthanom K, editors. Bangkok: Aksorngraphic and Design Publishing House; 2010 [cited 2021 Jan 20]. 1–96 p.

Most partial disclosure tools start with a description of the child's illness in terms of "soldiers" (white blood cells) in the body which protect the body, a "bad germ" (HIV) which attacks the "soldiers", and medicine which makes the "bad germs" sleep. At the stage of full disclosure, the "bad germ" is identified as HIV (26,52).

One such tool is a child-friendly, picture-based storybook titled *Why I take my medicines,* developed by the International Training and Education Centre for Health (I-TECH) in conjunction with the Namibian Ministry of Health and the US President's Emergency Plan for AIDS Relief (PEPFAR) (7,52). It allows for a progressive reading of chapters at subsequent clinic visits: the first chapters cover partial disclosure (the story of the "soldiers" and "bad germs"; the final chapter identifies the germ as "HIV").

An evaluation of this tool within a comprehensive framework of HCW training, adolescent readiness assessment, and documentation of disclosure progress, was conducted in four facilities in Namibia (7,52). PCG and HCW satisfaction with the story book tool was high, with its benefits identified as:

1) Being age-appropriate (use of pictures and simple language);
2) Educating children and PCGs about HIV and importance of treatment adherence;
3) Being a useful communication aid; and
4) Providing a natural progression from partial to full disclosure (7,52).

The storybook contains a page which teaches that children who take their medication every day can live healthy lives, finish school, have a job and get married if they wish (52). This was reported as useful by PCGs, that it gave the child "hope that they can still achieve their goals" (7). This section precedes the naming of HIV and is, therefore, very useful for teaching a child from a young age that they can have a normal future. What is uncertain is whether an older adolescent in a setting of high HIV-related stigma, myths and negative connotations, will be able to align their negative perceptions of HIV with learning that their medication will allow them to live a normal life, or whether they will internalise their negative preconceptions and continue to think that HIV will impact their quality of life, morbidity and mortality.

While many disclosure tools recommend that stigma be addressed openly with adolescents, ‘HIV’ is usually only mentioned for the first time when telling the adolescent that it is the name of their illness (18,28,49,52). If adolescents do indeed become “shocked” after hearing they have HIV and do not remember any information after that, as reported by an adolescent in Kidia et al., it will be too late to try to dispel the negative myths and stigma around HIV (23).

In a qualitative study based in Uganda by Mutumba et al., some adolescents experienced disclosure at home with a PCG and often little HIV education, and some were disclosed to by an HCW who followed a method of assessing adolescents’ preconceptions of HIV and correcting them before disclosing (25). In the comparison of both groups of adolescents’ reactions, it was found that “*respondents who were knowledgeable about HIV and its treatment seemed less likely to react negatively to the disclosure, compared to respondents who had scanty knowledge or who harboured misconceptions about HIV and/or ART*” (25). Similarly, in a qualitative study set in Kinshasa, Democratic Republic of Congo, one adolescent reported being prepared for her disclosure by the HCW helping her research different chronic diseases, including HIV, leading up to disclosure by the adolescent’s mother (20). This was reported to be beneficial compared to the rest of the adolescents who were not educated on HIV before full disclosure and who were reported by PCGs to have reacted with “surprise” or “weeping”, because the child did not understand how they could have acquired HIV (20).

Most guidelines and tools cited in the literature, including the MFDM, are similar in terms of preparation, pre-disclosure and post-disclosure interventions, though aspects of full disclosure differ significantly.

Elements of each of these tools which have proven especially beneficial include:

1) HCW support for PCGs in the disclosure process;
2) The use of a picture-based tool;
3) Clear guidance and example wording of what can be said to disclose HIV status to an adolescent; and
4) A method of assessing an adolescent’s knowledge and misconceptions about HIV and addressing these *before* full disclosure.

2.11 Summary

From the current literature review, the benefits of HIV status disclosure to adolescents outweigh the potential risks. Furthermore, risks can be decreased by enabling time-appropriate disclosure performed in the best possible manner. Many barriers need to be overcome for timeous disclosure to take place, including PCG or community-related factors, HCW and healthcare system-related factors.

Recommendations regarding the ideal timing of full disclosure vary between 6 and 14 years, while SANDoH recommends 10 years. Disclosures performed without adequate preparation, on-going support, age-appropriate education and a process of addressing stigma and misconceptions of HIV have resulted in a higher risk of negative reactions from adolescents including confusion, disbelief, sadness, worry, and suicidal ideation. Various guidelines, methods and tools are available to provide direction on readiness assessments, preparation, partial disclosure, full disclosure, and ongoing support.

With a focus on the stage of full disclosure, aspects of each of these tools have proven especially beneficial, including:

1) Guidance for HCW to support PCG in the disclosure process;
2) The use of a picture-based tool;
3) Clear example wording of what can be said to disclose HIV status to an adolescent; and
4) A method of assessing adolescents' knowledge and misconceptions about HIV and addressing these *before* full disclosure.

The MFDM is unique in that it contains all four of the above-mentioned features. This research study aims to describe HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster Disclosure Method.

CHAPTER 3: METHODOLOGY

3.1 Study Design

A descriptive qualitative study design was chosen for the current study because this allowed the researcher to gain insights into adolescents' experiences of the disclosure method from their perspectives, acknowledge their individual contexts, and allow for flexibility in sampling and data collection (53–55). Furthermore, it allowed for the use of thematic analysis to describe and interpret the adolescents' experiences, develop insights on how and whether the MFDM works, and induce meaning from new, unanticipated responses (54,56,57). Descriptive qualitative research methods typically allow for flexibility in sampling and data collection methods to secure rich data; for example, a diverse range of participants and interview methods may provide richer data than a large sample of similar participants interviewed in the same manner (54).

A descriptive study design allowed the researcher to increase the sample size and to gain important insights from PCGs and HCWs which otherwise may have been overlooked. While it was useful to have the option of flexibility to gain richer insights, a formal sampling method and data collection process was ultimately adhered to as it provided sufficiently rich data and ensured consistency and coherence (54). Data was collected through semi-structured interviews that accommodate the flexibility necessary to align with the specific age, gender, maturity, and other contextual aspects of the interviewee and allow the researcher to capture insights that were not anticipated or known before conducting the interviews. Furthermore, descriptive qualitative study designs are considered appropriate when conducting research on sensitive topics, such as finding out one's HIV status. Semi-structured interviews can allow for sensitive discussion and adaptive probing whilst being mindful of the participants' emotions. Descriptive qualitative studies have been seen to provide rich and useful information in similar studies regarding HIV-positive adolescents' perceptions in, among other countries, South Africa, Kenya and Zambia (21,29,36,58).

3.2 Study Setting

This study was conducted in three public primary healthcare (PHC) clinics in the Nkomazi sub-district of Mpumalanga. Figure 3.1 shows that all three clinics are close to the borders of Mozambique and Eswatini. The majority of the catchment population are black South Africans who speak siSwati as their native language and English or Afrikaans as their second language (59). The population density in Nkomazi is 82 people/km^2, with 35% being under 14 years old, and only 25% of those over 20 years old having completed matric (59). It is an economically poor area with a 34%

unemployment rate in those who are economically active and a 42% youth unemployment rate (59). Most houses are formal dwellings (92%), 7% with a flush toilet, 43% with piped water inside the house, and 83% with electricity for lighting (59).

Clinic A and B are designated as community health centres (CHC), which means that they offer PHC services as well as 24-hour maternity, emergency and casualty services; CHCs refer patients to district hospitals when necessary. All three facilities are managed by professional nurses; and staffed by professional and enrolled nurses, counsellors, pharmacists or pharmacy assistants. Additionally, CHCs each have a visiting doctor once a week. The HIV services provided at these facilities include HIV prevention, testing, treatment and management for paediatric, adolescent and adult patients.

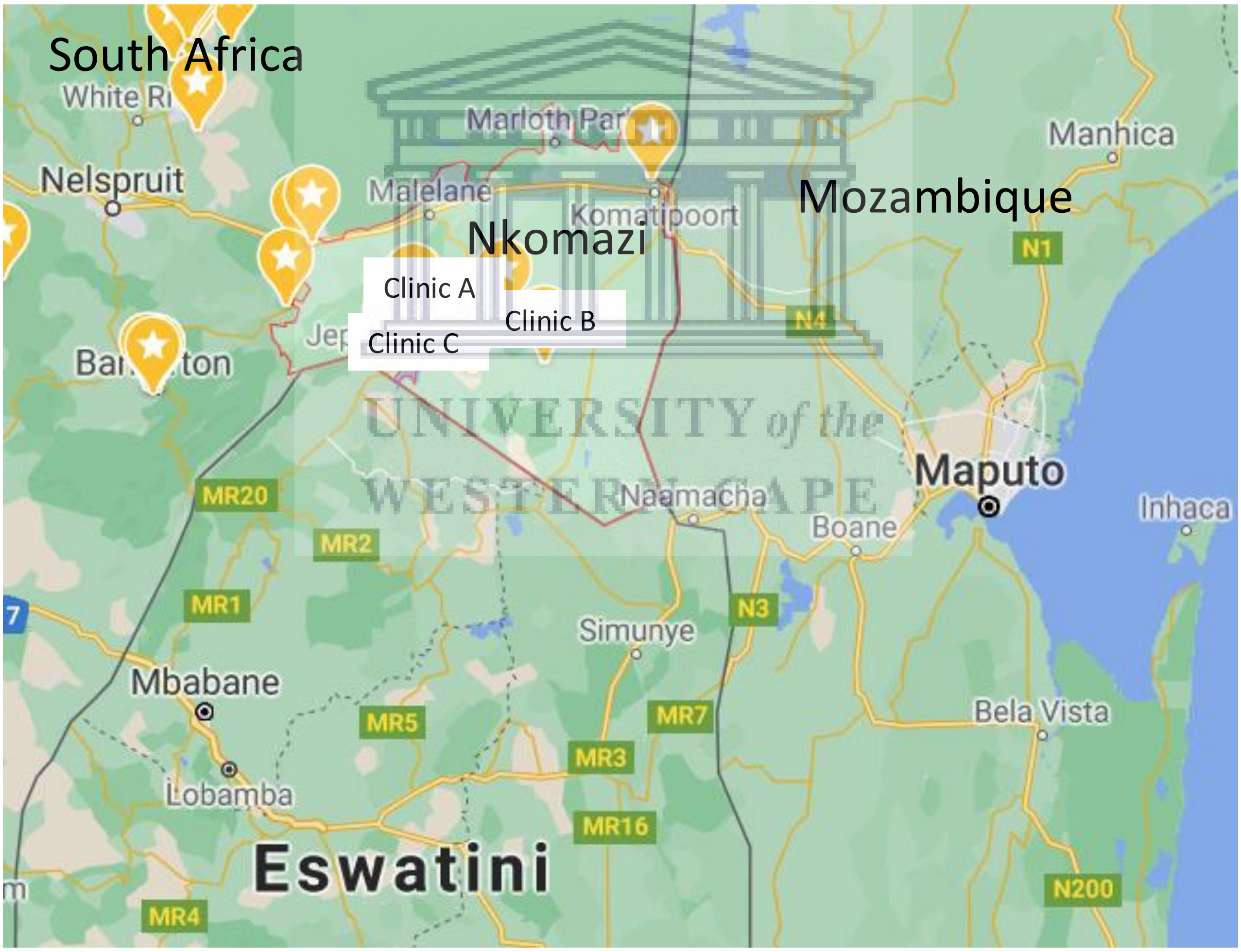


Figure 3.1 Geographic location of clinics A, B and C, in Nkomazi sub-district, Mpumalanga.

Table 3.1 shows the statistics for the three clinics as of October 2020. Monthly headcounts of visiting patients vary from 2350 to 4047, with much lower numbers of children and adolescents (a maximum of 875 and 450, respectively. The total numbers of patients on ART who are on record at the clinics range from 1890 to 3445, with small paediatric and adolescent components (a maximum of 44 and 130, respectively). The total viral load suppression rate for PLHIV on ART for October 2020 averaged 91%, and the viral load suppression rate in adolescents ranged from 56% to 100%. This wide viral load suppression-rate variance is due to the very low number of adolescents having their HIV viral load tested monthly. HIV VL suppression rates for PLHIV on ART are generally lower in adolescents than in adults, as is seen throughout South Africa (85% (15-24 years) versus 87% (25-49 years) and 89% (50-64 years)) (2). The HIV VL suppression rate for PLHIV on ART in the Ehlanzeni district of Mpumalanga where this study took place is 83% compared to 87% nationally (2).

Table 3.1 Statistics for Clinics A, B and C, as of October 2020 (60)

	Monthly headcount			**Total HIV-positive on ART**			**Monthly viral load suppression rate (< 1000 copies/ml)**	
	Total	**0-9 years**	**10-19 years**	**Total**	**0-9 years**	**10-19 years**	**Total**	**10-19 years**
Clinic A	4047	875	450	2890	34	88	91%	75%
Clinic B	3576	738	365	3445	44	130	92%	56%
Clinic C	2350	528	221	1890	21	89	91%	100%

Source: DHIS October 2020 (60)

3.3 Study Population and Sampling

The primary study population and index participant was identified as an:

- HIV-positive adolescent;
- Aged between 10 and 19 years old;
- Residing in Mpumalanga South Africa; and
- Had their HIV status disclosed to them using the MFDM between 22 and 26 June 2019.

The secondary study populations were the PCGs who attended the same disclosure session with the adolescent and the HCW who facilitated the disclosure process.

Purposive sampling methods were employed to identify and recruit eligible adolescents from each health facility. The files of all HIV-positive adolescents aged between 10-19 years in all three clinics were reviewed to determine whether they had been disclosed to or not. If disclosure had not yet taken place, the adolescent's PCG was contacted to determine if they would agree to bring their adolescent to the clinic for disclosure in a process facilitated by an HCW. Those who agreed were booked for appointments.

Upon arrival for their appointment, the PCGs were counselled by trained social workers about the importance of disclosure, and the MFDM was explained to them. The PCG was then asked whether they agree to disclose their child's and their HIV status. All PCGs agreed and were seen privately, with their adolescent, by Right to Care clinicians for the disclosure process.

Right to Care supported all three clinics that took part in the study. Additionally, all the participating HCWs were Right to Care staff, trained in adolescent disclosure, who assisted the clinics in facilitating disclosure.

Once the disclosure had been completed, the adolescents and PCGs were informed of the study and asked if they would be willing to participate. The HCW who facilitated the disclosures were also informed and asked to participate.

3.4 Data Collection

Semi-structured interviews were conducted with adolescents, their PCG involved in the disclosure process and the HCW who facilitated the disclosure. This interview style was chosen as the ideal data collection method as it ensures that the important aspects are covered but also provides the flexibility for:

1) Capturing unanticipated insights;
2) Deviation for different participants and their contexts; and
3) Being sensitive to the emotions of the adolescent and adapting where necessary. (55).

Participants were given the option of being interviewed on the same day as their disclosure took place or on another day. All participants chose to participate on the same day, because they did not want to have to come back to the clinic on a separate occasion. The interviews were conducted either immediately or within 30 minutes after disclosure. Full disclosure sessions took between 45 min and 1 hour 30 min. Each interview was conducted in a private consultation room in the clinic, and lasted between 15 and 30 minutes.

Most interviews with adolescents and PCG were conducted in siSwati or English by either a social worker, counsellor or nurse trained in counselling HIV-positive adolescents and adults (and is therefore knowledgeable, sensitive and understands confidentiality). Three of the adolescents, who spoke fluent English, were interviewed by the primary investigator, a medical doctor with experience working with adolescents with HIV. The other interviewers consisted of two social workers who have experience in conducting qualitative interviews (one with a masters degree in qualitative research, now busy with a PHD), and 2 counsellors with no previous experience in conducting qualitative research interviews, however they were guided by the social worker who is busy with a PHD in qualitative research. Care was taken to use simple language in all the interviews and medical jargon was avoided. All of the HCW and a small number of PCG chose to write their own answers to the questions on the interview guide, rather than being interviewed, as it allowed more freedom of expression and anonymity.

Interview capture sheets were numbered so that each member of the adolescent, PCG, HCW triad had the same number on their interview capture sheet. This allowed triad interview data to be triangulated without documentation of patient names. The adolescent, PCG and HCW were each interviewed separately, although sometimes concurrently with different interviewers.

Interview guides were used (see Appendices I, J and K) to provide structure and a measure of conformity across interviews while also allowing flexibility and freedom to elicit the adolescents' and PCGs' views with minimal interviewer bias.

The adolescent interviews (see Appendix I) explored how the adolescent felt about the HIV-status disclosure process, which aspects of the MFDM impacted them positively or negatively, and how the process could be improved.

The PCG interviews explored their perceptions of how the disclosure process went, their feelings before and after disclosure, which aspects of the MFDM they found helpful and unhelpful, and how they thought the process could be improved (see Appendix J).

The interviews for HCWs explored their perception of how the disclosure went and what could have been improved (see Appendix K). Basic demographic information such as the adolescent's age, the relationship between the attending PCG and the adolescent, and the patient's family circumstances was also captured. The adolescents’ most recent HIV viral load was captured as an indicator of ART adherence.

3.5 Data Capturing

The interviewers handwrote verbatim accounts of the participants’ responses during the interviews, and interviews in siSwati were translated into English during this initial transcription. All the HCWs and a small number of PCGs wrote down their own responses to the interview questions on the interview guide (see Appendix J and K); this was allowed, according to participant preference, as it was thought to allow greater anonymity and freedom of expression while decreasing interviewer bias.

3.6 Data Analysis

Handwritten transcripts were captured in a Microsoft Excel spreadsheet, simultaneously organised into initial themes relating to underlying concepts. Thematic analysis was chosen as the method of analysis as it was most consistent with the purpose of the study (describing and interpreting adolescents’ experiences of being told their HIV status using the MFDM). Furthermore, thematic analysis also allows for inductive and deductive reasoning, focussing on description and interpretation, manifest and latent content, and the context of the observations. The study is mainly deductive in nature as the researcher had an existing assumption that the MFDM was successful for most adolescents and wanted to explore this hypothesis in more detail and observe what specific aspects made it successful (54). Simultaneously, the researcher wanted to be open to making unanticipated observations of adolescents’ experiences of the MFDM and to induce new meanings from those experiences (54,61). The researcher aimed to emphasise the context of these adolescent experiences and integrate manifest and latent content to create meaning from these interviews (54).

Transcripts were reviewed repeatedly to familiarise the researcher with the data; concepts were identified and coded and then categorised into initial themes relating to underlying concepts. Themes were reviewed and refined, then analysed and named and, finally, woven together to provide insights and a narrative to answer the research question. Frequent consultations of the transcripts also ensured that the themes elicited reflected the interviewees’ responses. Transcripts were initially read and coded in their participant triads to create context, improve understanding of latent content, and to triangulate findings between the adolescent, PCG and HCW. Codes were then linked across all adolescent interviews, all PCG interviews and all HCW interviews to compare, contrast, and identify themes (54). In some instances, codes and themes were analysed again from the viewpoint of the adolescents, the PCGs and the HCWs, for further comparison and interpretation.

3.7 Rigour

Several methods were used to ensure rigour throughout the research to improve credibility, transferability, dependability and confirmability (19). To ensure trustworthiness in the thematic analysis, transcripts were compared to the data to check for accuracy, that coding was thorough and comprehensive; data and analysis were compared to make sure they match, and the claimed methodology and reported analysis was checked for consistency (18). The credibility of the data was strengthened through the application of triangulation and researcher reflexivity (19,20). By interviewing the adolescents, PCGs and HCWs, the researcher was able to triangulate the data, compare these three parties' perceptions, and explore the relationships between each party during the disclosure process. The researcher was acknowledged as playing an active role in thematic analysis, and the researcher’s beliefs and prior assumptions were disclosed to acknowledge researcher reflexivity (18,20). The researcher’s prior assumptions had been that the MFDM was a useful method for disclosure because adolescents and parents seemed to be content and relaxed during and after the process. Additionally, the researcher was not the same clinician who performed the disclosure with the adolescents. A detailed audit trail was maintained, and the researcher kept a reflective journal to document feelings and findings exposed during the interview process and to reflect on possible areas of bias (20). All instances of controversial interpretation and bias were confidentially discussed with the researcher’s direct supervisor as a method of peer debriefing (19).

As the researcher is an HIV clinician who performs adolescent disclosures using the MFDM, reflection and discussion with the supervisor of the mini thesis was imperative to minimise the impact of preconceived ideas (20).

3.8 Ethics considerations

Ethics approval was granted from the University of Western Cape Biomedical Ethics Research Committee (see Appendix M), and permission to use the data was granted by the Mpumalanga Provincial Department of Health (see Appendix N).

The ethics principles of autonomy, beneficence, non-maleficence, and justice were adhered to in this study (59). To ensure autonomy, informed consent was obtained from all participants, and assent from adolescent participants under 18 years old (see Appendices A-H). Informed consent was obtained by a nurse, counsellor or social worker. Information sheets were provided and explained to participants in English or siSwati. Information sheets explained that the information obtained could be used for research purposes. Participants did not experience any harm or deviation in care if they did not consent to participate in the study, nor did they receive any remuneration if they provided consent for participation.

Regarding beneficence, it was explained that although the research would not necessarily benefit the participants directly, the aim is to benefit future adolescents, PCGs and HCWs by learning how to improve disclosure processes. It was also noted that the participants may have benefitted from the discussion during the interview, as any incorrect or insufficient knowledge was addressed and corrected, and their emotions were explored and managed.

To uphold non-maleficence, it was important to ensure privacy and confidentiality and minimise the participant' costs, the risk of stigmatisation and negative emotions. In this study, participants only provided their time and opinions. Strict confidentiality and anonymity were enforced to ensure that no participants were stigmatised for their participation or for their HIV status. The participants were addressed and interviewed confidentially in the same clinic consultation rooms that they are usually seen in so that there was no increased risk of being identified as being HIV-positive, and no identifying data such as names, identity numbers or dates of birth were collected. The interviews were coded for recording purposes, and the collected data was stored in password-protected computers to which only the direct research team had access. Concurrently, the consent forms were stored separately from the interview transcriptions in a locked cabinet in a secured office.

Another potential risk of participating in this study was of experiencing negative or overwhelming emotions due to the sensitive nature of the topics discussed (Appendices O, P and Q). To mitigate this risk, the interviewers where chosen for their experience in counselling adolescents with HIV; they also maintained cognisance of the participant's emotions during and after the interview. Each participant could choose to terminate their involvement at any time or not to answer questions. The social workers, nurse and doctor conducting the interviews applied counselling skills such as normalising, reflecting emotions and showing empathy. All participants were offered further counselling and support, and participants who were observed to be upset were given additional attention and support. Participants were referred to a psychologist, counsellor or social worker if deemed appropriate or upon request to discuss any negative emotions aroused by the discussion. One adolescent was referred to a psychologist.

The principle of justice was applied by ensuring that the participants and communities involved were selected fairly and without bias. The primary intervention, disclosure using the MFDM, was already planned for clinics A, B and C irrespective of the research study. In addition, it was deemed just to conduct the study with these participants so that findings can be disseminated and more healthcare workers can provide effective disclosure and benefit a wider spread of adolescents and PCGs.

The primary investigator is trained in research methods by the University of Western Cape, and has completed a Good Clinical Practice (GCP) Certificate (59). There were no financial or other incentivisation involved in the completion of this research study (59). As the primary investigator is a medical doctor, they are aware that the first priority is the study participants' health and wellness, and the second is the research study (61).

CHAPTER 4: RESULTS

4.1 Description of study participants

From 1 July to 23 June 2019, the files of all HIV-positive adolescents aged between 10-19 years at three clinics in the Mpumalanga province of South Africa were reviewed. It was found that 93 adolescents were not disclosed to about their HIV status.

As depicted in Figure 4.1, 58 adolescents attended their clinic appointments between 23 and 26 June 2019, and 30 full disclosures were performed using the MFDM. The reasons for 28 adolescents not receiving full disclosure were:

1) Adolescent’s PCG not present;
2) Adolescent considered emotionally or cognitively immature for full disclosure; and/or
3) Adolescent already knowing their HIV status.

ALHIV who were considered too immature to receive full disclosure received partial disclosure, which is a process of explaining to the patient, in simple terms, that they were born with a condition which affects their immune system, and that they need to take medication every day to keep their immune system strong, so that they stay healthy. The adolescents who already knew their HIV status received post-disclosure counselling and aspects of the MFDM were repeated to make sure they had not missed out on any key information.

Of the 30 adolescents who had full disclosure, nine did not consent to participate in the study. They stated that they did not wish to stay at the clinic any longer and none wanted to return on another day to receive disclosure.

The remaining 21 triads (comprising an adolescent, PCG and HCW) were interviewed, cumulatively resulting in 63 interviews (21 adolescents, 21 PCGs and 5 HCWs) as described in Table 4.1.

The median and mode age of adolescents was 13 years, and slightly more than half were male (52%). All participants were black South Africans living in the Nkomazi district and spoke siSwati as their first language. Almost half of the participants (48%) had received partial disclosure previously. Ten adolescents (48%) had virologic suppression (VL<1000 copies/ml) which indicates a favourable response to their ART, four (19%) had virologic failure (VL>1000 copies/ml), and seven (33%) did not have a recent VL documented. Most participating adolescents lived with one parent (n=9; 43%) and only 14% lived with both parents (n=4).

Figure 4.1 Realisation of study sample

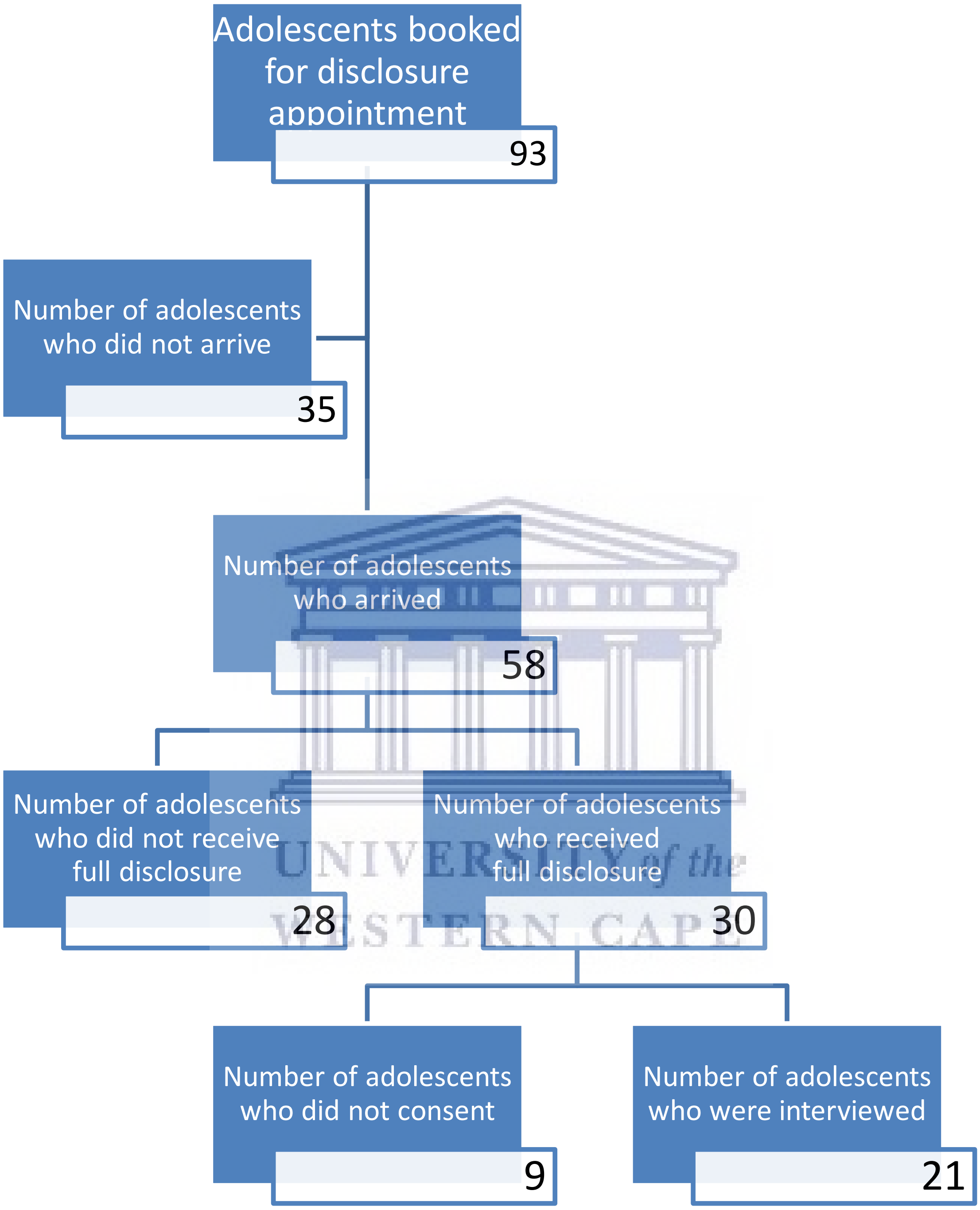


Table 4.1 Sociodemographic characteristics of participants

Adolescents (N=21)			
		n	**Percentage (%)**
Age (in years)	10-11	5	24
	12-14	12	57
	15-16	3	14
	Not recorded	1	5
Gender	Male	11	52
	Female	10	48
Latest HIV viral load (in copies/ml)	<1000	10	48
	>1000	4	19
	Not recorded	7	33
Primary Care Giver	Both parents	4	19
	One parent	9	43
	No parents	4	19
	Not recorded	4	19

Parents or Caregivers (N=21)			
		n	**Percentage (%)**
Relationship	Mother	14	67
	Father	2	10
	Grandmother	1	5
	Aunt	1	5
	Sister	1	5
	Cousin	1	5
	Not recorded	1	5
Gender	Male	2	10
	Female	17	81
	Not recorded	2	10
HIV status	On ART	15	71
	Not on ART	2	10
	Not recorded	4	19

Health Care Workers (Total: 5)

		n	Percentage (%)
Profession	Doctor (medical officer)	2	40
	Doctor (paediatrician)	1	20
	Social worker	2	40
Gender	Male	4	80
	Female	1	20
Age (in years)	30-34	2	40
	35-40	2	40
	50-55	1	20
Number of adolescent HIV disclosures performed previously	<5	1	20
	5-30	1	20
	>30	3	60

The majority of participating PCGs were female (n=17; 81%) and mothers (n=14; 67%). Two PCGs were fathers, and the remainder comprised grandmothers, aunts, sisters or cousins. Most PCGs (n=15; 71%) were HIV-positive and on ART.

The five HCWs were trained and experienced in facilitating adolescent disclosure using the MFDM. The HCWs consisted of:

- A paediatrician specialising in paediatric and adolescent HIV, and who has performed close to 100 disclosures previously;
- A medical doctor who has worked in HIV medicine for over 5 years and has performed between 5-30 disclosures previously;
- A medical officer with limited experience in HIV medical practice but who had performed between 1-5 disclosures previously; and
- Two social workers who provide adolescent HIV services and have previously performed between 30-50 disclosures combined.

Of the HCWs, four were male; two aged between 30-34 years, two between 35-40 years and one between 50-55 years.

4.2 Main findings

Table 4.2 shows the themes and sub-themes identified during thematic analysis. The main themes are categorised according to whether they emerged before, during or after full disclosure to the adolescent. The sub-themes that emerged *before* the disclosure process described the adolescents' knowledge and perceptions of HIV, the PCG's views on HIV disclosure, the ideal timing of disclosure, and the reasons given to adolescents for taking medication.

The sub-themes that emerged *during* the disclosure process described the adolescents' reactions to knowing their PCG's and their own HIV status, the PCG's reactions to disclosing their own and the adolescents' HIV status, and the positive experiences of the MFDM.

The sub-themes that emerged *after* the disclosure process described the knowledge gained by adolescents about living with HIV and treatment adherence and the methods of strengthening the PCG-adolescent relationship.

Table 4.2. Main themes and sub-themes

Category	Theme	Sub-theme
4.2.1 Before disclosure	Adolescents' knowledge and perceptions of HIV	• Dreaded disease • Weight loss • Negative impact on quality of life • Transmission of HIV • Perception of low HIV risk
	PCG's views on HIV disclosure	• Necessary, but PCG lacks skills • Difficult and painful process • Concern for effect on child's mental well-being • Fear of stigma
	Timing of disclosure	• Age of disclosure • Before sexual debut • Before child finds out themselves
	Reasons given for taking HIV medication.	• Avoidance of giving a reason • Other illness • Necessary to prevent illness and death
4.2.2 Experience	Adolescents' reactions to knowing their PCG's HIV status	• Disbelief • Acceptance and curiosity

of disclosure		• Found it helpful
	PCG reactions to disclosing their HIV status to the adolescent	• Initially nervous • Coped well
	Adolescent’s reactions to being told their own HIV status	• Disbelief and sadness • Acceptance and happiness • Curiosity and need for answers
	PCG reactions to disclosing their child’s HIV status	• Calmness, relief, happiness and gratitude • Anxiety, discomfort and distress
	Positive experiences of the MFDM	• Satisfaction • Good use of visuals • Appropriate HIV education before disclosure • Friendliness of HCW • Benefits of HCW-support for PCG
4.2.3 After disclosure	Knowledge about living with HIV and treatment adherence	• Dealing with stigma • ‘Normal’ prospects • Longevity • The importance of adherence • Appropriate onward disclosure • Prevention of HIV transmission
	Strengthening PCG-adolescent relationship	• Emphasis of PCG’s innocence • Reconciliation between PCG and adolescent

4.2.1 Before Disclosure

4.2.1.1 Adolescents' limited knowledge and negative perceptions of HIV

A few participating adolescents reported knowing "not much" or "nothing" about HIV at the beginning of the disclosure session. The rest held negative perceptions about HIV, such as it:

1) Being a disease that causes illness and death;
2) Causes weight loss; and
3) Having negative effects on people's ability to live a normal life.

Many participants knew that HIV was transmitted sexually.

4.2.1.1.1 Dreaded disease

Participating adolescents believed that "HIV kills" and makes people very sick, demonstrating that they perceived HIV to cause severe morbidity and mortality.

> "*You get it through sex, and it kills"* – Adolescent female, 14 years.

> *"It kills and makes us sick"* – Adolescent male, 13 years.

4.2.1.1.2 HIV causes weight loss

Many adolescents had perceptions of HIV-positive people experiencing loss of appetite, weight loss and becoming wasted.

> *"Someone with HIV will lose weight, have no appetite and get very sick"* – Adolescent male, 12 years

> *"People with HIV become thin"* - Adolescent female, 15 years

4.2.1.1.3 Negative impact on quality of life

Adolescents perceived HIV to have far-reaching negative effects on a person's quality of life, specifically impacting their ability to live a normal life, including having an education, a career and a family.

One adolescent participant thought that having HIV meant that a person would be so severely ill and debilitated that they could not partake in normal activities or attend school.

> “*I’ve seen it on TV that it makes a person very sick, not able to do anything, not able to go to school”* - Adolescent male, 10 years

An adolescent was concerned that being HIV-positive would prevent her from following her dream of becoming a nurse. She sought verification from the HCW on whether this was true or not.

> *“[She asked if] she [can] be a nurse even though she is HIV-positive”* – Male, social worker, referring to an 11-year-old female adolescent.

Another adolescent was concerned that her HIV status would impact her ability to get married, have children, and, therefore, asked the HCW about this.

> “[she asked] “*will I be able to have kids and a family?””* – Female, doctor, referring to a 10-year-old female

4.2.1.1.4 Transmission of HIV

Most adolescents knew that HIV was transmitted through unprotected sexual intercourse. However, none of them acknowledged that HIV could be transmitted from a mother to a child.

> *“Someone who has HIV is someone who slept with someone else who is HIV-positive”* - Adolescent male, 16 years

> *“HIV can spread through the body; you get it when you have unprotected sex”* - Adolescent female, 15 years

One HCW brought to light the myth believed by a 13-year-old adolescent about the possibility of acquiring HIV by sitting next to someone who is HIV-positive.

> *“She said she heard on the radio people die from HIV, and she thought it can be spread by sitting next to someone with HIV”* – HCW, referring to a 13-year-old female adolescent.

4.2.1.1.5 Perception of low HIV risk

Adolescents perceived themselves, their parents and HCW to be unlikely to have HIV. This depicts a phenomenon known as "othering" (62). An HCW reported that a 12-year-old male "*was shocked"* when he was disclosed to because he believed that *"HIV affects older people".* Some HCWs also reported that the adolescents had the perception that the HCW could not have HIV and, therefore, took a long time to believe that absolutely anyone could have HIV. There was also the perception that an HIV-positive person would appear outwardly different to an HIV-negative person.

> *"She struggled to believe that any of us or her or her father could have HIV… She also thought that you could tell if someone had HIV by looking at them. I had to repeatedly ask her whether I myself could have HIV, until she accepted that I could, that she wouldn't be able to know by looking at me."* - HCW who disclosed to a 15-year-old female.

4.2.1.2 PCG prior perceptions of disclosure

Before embarking on the disclosure process, PCGs had many preconceived notions about disclosure. These notions can be categorised into:

1) Acceptance that disclosure was necessary, but the PCG lacked the required skills;
2) Concern that disclosure would be a difficult and emotionally painful process;
3) Worry that that it could impact the child's mental health; and
4) Fear of stigmatisation.

4.2.1.2.1 Necessary, but PCG lack skills

PCGs reported feeling that they should disclose to their child and wanted to disclose but that they did not have the skills to do it. This conflict between what they should do and what they felt capable of doing left them feeling both frustrated and guilty.

> *"I've been wanting to tell her but didn't know how."* - Mother of a 10-year-old female.

> *"I felt confused about how to start and end. Not sure how to say it so she will accept it and understand"* - Father of a 15-year-old female.

> *"I felt stuck and frustrated and paining (sic) at the same time"* - Mother of a 14-year-old female.

4.2.1.2.2 Difficult and painful process

Many PCGs reported fearing that disclosing to their children would be a difficult and painful process.

> *"I thought it was going to be difficult and scary and painful"* - Mother of a 12-year-old female.

> *"I thought it would be difficult and shocking"* - Sister of a 13-year-old female.

4.2.1.2.3 Concern for the child's mental well-being

PCG revealed that they were very worried that revealing a child's HIV status to them would cause emotional trauma, so much so that the child might become suicidal.

> *"I was afraid to tell her what she has, thinking maybe she can be suicidal"* - Mother of a 14-year-old female.

> *"I was afraid the child will be hurt when he knows the truth"* - Mother of a 13-year-old male.

> *"She was very nervous before the disclosure because she said she knows her daughter is very sensitive and thought her daughter would cry. She was very scared because she knows a teenager who committed suicide when she found out her status before her mother had told her when she went to the clinic to test with her boyfriend."* - HCW referring to the mother of a 10-year-old female.

4.2.1.2.4 Fear of stigma

PCGs were aware of the stigma surrounding HIV in their communities and feared that their children would experience stigmatisation if they disclosed their HIV status to others.

One mother mentioned her fear of her child disclosing to others, specifically to friends, and that it would lead to her child being stigmatised by those same friends.

> *"I was afraid; I thought that if I told her she will tell her friends and they will regret her"* – Mother of an 11-year-old female

4.2.1.3 Timing of disclosure

The cited factors that influence timing of disclosure were:

1) Age for disclosure;
2) Need for disclosure before sexual debut; and
3) Before the adolescent discovers their HIV status through other means.

4.2.1.3.1 Age of disclosure

Most of the adolescents in the study reported that they felt ready for disclosure when disclosure took place. The most common ages at disclosure were 12 and 13 years. This corresponded with the recommendations made by the participant PGCs and the adolescents themselves: at 12 years, according to PCGs and at 13 years, according to adolescents.

Table 4.3 compares the adolescent’s age at the time of disclosure to the adolescents’ and PCGs perceptions of the ideal age for disclosure. The table is colour-coded as follows:

- Green: the ideal age was the same as the adolescent’s age
- Blue: the ideal age was younger than the adolescent’s age
- Orange: the ideal age was older than the adolescent’s age.

The majority (n=13) of adolescents suggested that adolescents should be disclosed to at the same (n=5) or younger (n=8) age than their current age, and the majority (n=12) of PCGs thought that adolescents should be disclosed to at the same (n=6), or younger (n=6) age than their adolescents.

Table 4.3 Realised vs desired age of disclosure by adolescents and parents and caregivers

Age at disclosure (in years)	Adolescents' perception of ideal age of disclosure (in years)	PCGs' perception of ideal age of disclosure (in years)
10	7	5
10	12	12
10	10	-
11	-	-
11	20	11
12	5	6
12	13	12
12	18	12
12	10	13
13	13	-
13	12	10
13	18	13
13	13	18
14	12	12
14	13	14
14	14	14
14	14	16
15	14	12
15	18	13
16	9	
unknown	10	

Two PCGs argued that children should be fully disclosed to from a very young age, such as at 5 years old, so that they grow up knowing their status. Their adolescents were aged 10 and 12 years, respectively, at the time of their disclosure.

> *"Children should understand from a young age, like 5, and grow up knowing"* – Mother of a 10-year-old male.

Some HCWs reported that 10-year-olds were more difficult to disclose to as they required more time and more careful explanations to understand HIV and concepts such as stigma and the risks of onward disclosure.

> *"She was quite young and took a while to understand some of the details on HIV but remained happy the whole time. I think she did not yet know too much about the stigma related to HIV, so she just believed everything I told her, and she did not seem upset by it. We did have to explain to her that this is personal information between herself, her mother and the clinic staff, so she should discuss with her mother before she tells other people, and she is allowed to lie and not tell people. because some people don't understand about HIV and will think it means she is going to die."* – female, HCW, referring to a 10-year-old female.

4.2.1.3.2 Before sexual debut

Most PCGs reported that one of the most important reasons adolescent should know their HIV status is that they know their HIV status before a sexual debut and can thereby prevent themselves from unknowingly transmitting HIV.

> *"They should be told that the medication they are taking is for HIV so that if they get into a relationship, they will tell their partner about their status"* - Mother of a 14-year-old female.

Only one adolescent (14-year-old female) admitted to being sexually active, while four did not comment on sexual activity and the rest (18 adolescents) denied sexual activity. Regarding the disclosure with the adolescent who was already sexually active, the HCW reported that the disclosure went *"well initially but only afterwards when I was chatting to her mom, did she get a bit teary."* She was referred to a counsellor for further therapy. Both the 14-year-old girl and her mother said that they think adolescents should be told their status at 12 years and, according to the mother, adolescents should be *"told to avoid unprotected sex and blood and sharing of needles."* The 14-year-old female reported that how the HCW facilitated her disclosure was "*very good"*, and when asked if she would like the HCW's assistance in disclosing her HIV status to her sexual partner, she replied "Yes".

4.2.1.3.3 Before child finds out themselves

Many PCGs were aware that they should reveal a child's HIV status before their child figures it out themselves or is inadvertently disclosed to.

> *"The father was initially reluctant to disclose to his daughter, but he changed his mind when I asked if he thought she might figure it out herself soon. After thinking about it, he replied that she had started asking questions and he is scared she will figure it out and, therefore, concluded that it was time to disclose to her."* – HCW referring to the father of a 15-year-old female.
>
> *"It is important for the child to be aware before friends take part in her finding out."* – Mother of a 12-year-old female.
>
> *"She wanted to tell her daughter the truth because she was scared she would figure it out herself because her daughter came home from school and told her that people with HIV have to take treatment like she does."* - HCW referring to the mother of an 11-year-old female.

4.2.1.4 Reasons for taking medication

Before PCGs have told the children under their care that they have HIV, they might need to give the child an alternate reason for taking their medication daily. PCGs gave varied reasons, which were categorised into the following subthemes:

1) Avoiding giving a reason;
2) Other illness; and
3) Medication being necessary to prevent illness and death

4.2.1.4.1 Avoidance of giving a reason

The majority of PCGs reported that they had managed to avoid giving a reason for why their child needs to take medication.

> "*I didn't tell him anything and I was avoiding his questions about his medication"* - Cousin of a 13-year-old male.

> *"I told him he must take medication for the rest of his life but didn't tell him what for"* - Mother of a 13-year-old male.

Some PCGs did not feel that there was a need to give a reason for their child taking medication, as the child considered it normal.

> *"There was no need to explain as she was used to seeing me and her sister taking medicine."* - Mother of an 11-year-old female

4.2.1.4.2 Other illness

Many PCGs named other well-known illnesses such as influenza, tuberculosis (TB), herpes and ulcers as the reason the child should take medication.

> *"I told the child that this medication is for ulcers and she must take it every day and if not so then she will die"* - Mother of a 14-year-old female.

> *"I told her she has a terrible flu that needs her to take her medication daily"* - Mother of a 10-year-old female.
> *"I was telling her the medication is for bone growth and prevents herpes"* – Mother of a 12-year-old female.

> *"I told her that it was TB treatment."* - Mother of a 14-year-old female.

4.2.1.4.3 Necessary to prevent illness and death

Other PCGs did not name an illness but simply implored the child to take their medicine to stay healthy or to prevent them from getting sick.

> *"You must take your medication otherwise you will become sick"* - Father of a 15-year-old female.

> *"I told the child that she must take the medication every day to keep the disease suppressed"* – Aunt of a 10-year-old female.

4.2.2 Experience of disclosure

4.2.2.1 Adolescents' reactions to disclosure of PCG HIV status

The disclosure of a PCG's HIV status was not performed uniformly across the participant group, nor was it performed in the same way or at the same stage. The MFDM allows for flexibility in this regard because not all PCGs are mothers, have HIV or are willing to disclose their status. Some HCW allow the PCG to disclose when they are ready, which is usually after the child has learnt their status, and the PCG tells them that they also have HIV to help them not feel isolated. One HCW specifically encouraged an HIV-positive PCG to disclose their status and to allow the adolescent time to accept it before disclosing the adolescent's status. This was to gauge the adolescent's understanding and acceptance and address concerns before disclosing the adolescent's status.

The most common reactions the participating adolescents had to finding out their PCG has HIV were:

1) Disbelief;
2) Acceptance and curiosity; and
3) Found it helpful

4.2.2.1.1 Disbelief

Many adolescents struggled to believe that their PCG could be HIV-positive, and HCWs reported that it took some time and convincing before the adolescent believed.

> *"She struggled to believe that any of us or her or her father could have HIV."* - HCW referring to a 15-year-old female and her father.

> *"She took a while to believe that she or her mom could have HIV"* - HCW referring to a 10-year-old female.

4.2.2.1.2 Acceptance and Curiosity

Most adolescents were reported to have coped well and accepted the news that their PCG is HIV-positive.

> *"She handled it fine when her father disclosed his status but when he disclosed her status, she cried for a few minutes."* - HCW referring to a 15-year-old female and her father.

Some adolescents reacted with acceptance and inquired about how their PCG acquired HIV.

> "*She was smiling and asked lots of questions including why she got HIV and not her younger sister. She also asked her mother how she got HIV."* - HCW referring to a 10-year-old female

4.2.2.1.3 Found it helpful

According to one HCW, it is ideal for the PCG to disclose their HIV status first (if they are HIV-positive) and let the adolescent come to terms with it before telling the adolescent that they have HIV. Even when the caregiver was not a parent, it was beneficial to disclose that they were HIV-positive.

> *"It helped when the aunt disclosed her own HIV status"* - HCW reporting on a 10-year-old female and her aunt.

An HCW noted that it was a useful step in the disclosure process but that it could have been even more helpful if the adolescent had had more time to come to terms with the PCG's status before learning of their own HIV status.

> *"I think it might have been better if the mother had been there as well or if it could have been done in two parts to give her a bit of time to come to terms with her father's disclosure first, before finding out her own status."* – Female, doctor, referring to a 15-year-old female, one of the two adolescents who cried.

An HCW noted that an adolescent was "*still happy*" after learning of her mother's HIV status, and that this allowed the mother to feel relieved and content and gave the mother the courage to progress to disclose her daughter's status. The phrase "*still happy*" in this context is thought to mean that the adolescent was calm and had not reacted poorly or become sad.

> *"She looked happy when she saw that her daughter was still happy"* – HCW referring to the mother of a 10-year-old female

4.2.2.2 PCG reactions to disclosing their HIV status to the adolescent

PCGs were understandably nervous about disclosing their HIV status to the child in their care. The most common PCG reaction was that the PCG was initially nervous but, ultimately, coped well. It was not possible to completely differentiate between reactions to the disclosure of the PCG's HIV status and the disclosure of the child's HIV status as most reactions were similar and were discussed in the interview under the single topic of 'Disclosure' without differentiating which disclosure they were referring to.

4.2.2.2.1 Initially nervous

Most PCGs reported feeling nervous about disclosing their HIV status to their child.

> "*She was nervous and scared to even confirm that the name of the sickness is HIV"* - HCW referring to the mother of an 11-year-old female.

4.2.2.2.2 Coped well

Most PCGs were noted to have coped well with disclosing their own status to the child in their care. Most were also able to answer questions posed to them by their children. "*Coping well*" is a phrase that was used by HCWs to describe their perception of how the PCG dealt with disclosure. This perception was based on external cues but cannot be assumed to fully reflect the PCGs' emotional experience. Based on their descriptions, their definition of "*coping well*", seems to include happiness or a lack of negative emotions such as sadness or distress, or active, appropriate or admirable participation.

> *"The mother coped very well and she disclosed her own status to her daughter first and then her daughters status. She also answered her daughter when she asked her how she got HIV and said that she slept with someone who had HIV."* - HCW referring to a mother and her 10 -year-old daughter

> *"Her father coped well, he was strong and supportive. He disclosed his own status first and*

> *then hers. He comforted her when she was crying. He asked her to forgive him and her mother."* - HCW referring to the father of a 15-year-old female

> *"The mother coped very well. She took part in the conversation and explained to the child how she became positive"* - Mother of an 11-year-old female

4.2.2.3 Adolescent's reactions to being told their own HIV status

HCWs thought that most adolescents reacted very well to being told their HIV status. Several specific reactions were noted, and a five-stage process was identified:

1) Disbelief
2) Sadness
3) Acceptance
4) Happiness
5) Curiosity

In about half of the adolescents, the first one or two stages were not evident, and they only showed acceptance and happiness. Most, but not all, progressed to happiness though some showed different combinations and stage orderings.

4.2.2.3.1 Disbelief and sadness

A small number of adolescents demonstrated disbelief and sadness, before progressing to acceptance and happiness.

> *"She participated very well and understood everything. At first she struggled to believe that any of us or her or her father could have HIV. She handled it fine when her father disclosed his status but when he disclosed her status she cried for a few minutes. She then said she wanted to talk to all of us some more and ask some questions about why she has HIV and not her brothers. After a few more minutes of talking to myself and her father, she accepted and started smiling again. She gave us all a big hug when she left."* - HCW referring to a 15-year-old female

> *"He was sad and in denial"* - HCW referring to a 12-year-old male.

> *"He was shocked because he thought HIV affected older people"* - HCW referring to a 12-year-old male.

One adolescent was noted to have reacted well initially, but later became sad.

> *"[She reacted] well initially, but only afterwards when I was chatting to her mom did she get a bit teary"* - HCW referring to a 14-year-old female.

4.2.2.3.2 Acceptance and happiness

All adolescents eventually accepted their diagnosis, and most, but not all, progressed to happiness.

> *"The child reacted positively and asked a lot of questions"* - HCW referring to a 10 -year-old male.

> *"The child appeared calm and understanding of the disclosure"* - HCW referring to a 16-year-old male.

> *"The child reacted well. She took a while to believe that she or her mom could have HIV. She was smiling and asked lots of questions…"* - HCW referring to a 10-year-old female.

One adolescent reported feeling happy that he was disclosed to, and elaborated further that he would be very angry if he was not told about his HIV status.

> *"[I feel] happy because now I know my status. If he didn't tell me then I would have been very angry".* – Adolescent male, 14 years old.

Adolescents were able to respond positively to their diagnosis because they knew that HIV was treatable.

> *"[I feel] happy [because I know] that if I take my medicine my soldiers will be strong"* – Adolescent male, 13 years old.

An adolescent reported feeling good because she has gained knowledge about her own health.

> *"[I feel] happy because now I know my status"* – Adolescent female, 11 years old.

4.2.2.3.3 Curiosity and questions

A few adolescents reacted to their disclosure by asking various questions. The dominant questions were:

1) Method of child's HIV acquisition;
2) Method of PCG's HIV acquisition;
3) Reason for child being infected and not siblings;
4) The effect of HIV on their future career; and,
5) Treatment

Child's method of HIV acquisition

One of the most common questions asked by the adolescents was "How did I get HIV?".

> *"She asked a lot of questions about treatment and where she got HIV from"* - HCW referring to a 13-year-old female.

PCG's method of HIV acquisition

A few adolescents directly asked their mothers how they (mother) became infected with HIV.

> *"She answered her daughter when she asked her how she got HIV, and said that she slept with someone who had HIV."* - HCW referring to the mother of a 10-year-old female

> "*She took part in the conversation and explained to the child how she became positive*". - HCW referring to the mother of an 11-year-old female

Reason for child being infected and not siblings

Two of the adolescents wanted to know why they are infected with HIV and not their siblings.

> *"He asked why he got HIV and not his younger sister".* - HCW referring to an 11-year-old male.

Effect on future

A few adolescents asked about whether they can still have the future they had hoped for, specifically regarding their plans for a family and a career.

> *"She asked if she can be a nurse even though she is HIV-positive"* – HCW referring to an 11 -year-old female.

> *"She wanted to know if she can still have kids and a family"* – HCW referring to a 15 -year-old female.

Treatment related

Another common theme of questions raised was regarding the treatment for HIV, including what happens to a person who does not adhere to ARV treatment.

> "*He asked what happens to a person if they stop taking their treatment"* – HCW referring to a 10-year-old male.

4.2.2.4 PCG reactions to disclosing their child's HIV status

PCG reactions to telling their child that they are HIV-positive were generally positive, and centred on either:

1) Being calm and coping well, experiencing relief, happiness and gratitude
2) Discomfort, feeling nervous, uncomfortable and emotional.

On all occasions, the negative emotions, such as nervousness or discomfort, eased into calmness and positive reactions as the process went on.

4.2.2.4.1 Calmness, coping well, relief, happiness and gratitude

The majority of PCGs were noted to be calm and to cope well. Furthermore, after the disclosure, the strongest theme was one of relief and happiness that disclosure had taken place, and that it was not as difficult and painful as they had expected. This relief and happiness led them to feel grateful that the HCWs support had enabled the process.

> "*The mother was calm"* – HCW referring to the mother of a 16-year-old female.

> "*The caregiver seemed to be relaxed."* – HCW referring to the mother of a 10-year-old male.

As mentioned previously "coping well" is a phrase that was used by HCW which seems to include happiness, or a lack of negative emotions like sadness or distress, or active, appropriate, or admirable, participation.

"The mother coped very well. She took part in the conversation and explained to the child how she became positive." – HCW referring to the mother of an 11-year-old female.

"Her father coped well, he was strong and supportive… He comforted her when she was crying." – HCW referring to the father of a 15-year-old female.

Many PCGs reported a sense of release or relief after disclosing, as they felt freed from the burden of secrecy.

"It was painful to me to tell my baby that he is HIV-positive but now I am so happy it released me because now he knows his HIV status", - PCG of a male adolescent (unknown age)

"I felt relieved now because I've been wanting to tell her but didn't know how." - Mother of 10-year-old female.

"I was so relieved after the disclosure session because the child was asking me questions about the medicine he is taking"- Male cousin of 13-year-old male.

"Now I feel free" - Mother of a 14-year-old male.

Many PCG reported feeling happy that they had disclosed and happy that the disclosure had not elicited the negative reactions they had feared.

"I am very happy now because it would be very difficult for me to explain to my child". - Mother of an 11-year-old female.

"She looked happy when she saw that her daughter was still happy," - HCW referring to the mother of a 10-year-old female.

Most PCG expressed gratitude towards the HCW for supporting them through the process of disclosure.

"The mother was calm and appreciated my assistance" – HCW referring to the mother of a

16-year-old male.

> *"Because alone I wouldn't do it. I was afraid to hurt the child. The HCW helped me a lot"* - Mother of a 13-year-old male.

4.2.2.4.2 Anxiety, discomfort and distress

According to HCWs at the clinics where the study took place, a few of the PCGs appeared nervous, uncomfortable or emotional when they needed to confirm that the adolescent has HIV. In all instances, the nervousness, discomfort and distress improved as the session progressed, and the PCG reported feeling glad that they disclosed to their child and that the disclosure was done well or very well.

> *"She was nervous and scared to even confirm that the name of the sickness is HIV"* – HCW referring to the mother of an 11-year-old female.

> *"She was nervous and didn't know what to say, yet she confirmed to the child that it is an HIV treatment".* – HCW referring to the mother of a 14-year-old male.

> *"She was uncomfortable at first but as the session progressed, she participated"* - Mother of a 14-year-old female.

4.2.2.5 Experiences of the MFDM

Most adolescents and PCGs had positive experiences of the MFDM and specifically attributed this to the use of visuals, HCW friendliness, appropriate HIV education before disclosure, and the benefits of HCW-support for the PCG.

4.2.2.5.1 Satisfaction

The majority of PCGs and adolescents reported high levels of satisfaction with the MFDM. All PCGs thought the disclosure process was very good, especially since the HCWs were friendly and used pictures to explain HIV to adolescent in their care. All but one of the adolescents were glad that they were told their HIV status, and all believed it would help them to adhere to their medication. Almost all adolescents reported that the disclosure process was very good.

The most common answer to the questions to adolescents on what was unhelpful, made them feel worse or how the MFDM could be improved, was, *"Nothing*", *"It was done well*", "*Everything was fine", "It was the right way, he did it, by teaching me with a different disease first",* and *"They told me in the best way".*

Reports from PCGs were similarly complimentary:

> *"There was nothing that was not helpful, I feel it is all good";*
> *"Just the way they did it is best"*;
> "*He explained everything very well with a good manner";*
> "*The HCW could not have told the child in a better way"; and*
> *"It was good the way it was done."*

Only one adolescent did not think it was good that she was told her HIV status. She reported feeling "*sad because it was unexpected*," but that there was nothing the healthcare worker could have done better.

4.2.2.5.2 Good use of visuals

One of the most commonly mentioned benefits of the MFDM was the use of pictures to provide education to the adolescent. Many PCGs commented on the pictures being helpful to engage their child, particularly the younger children.

> *"It was helpful for the doctor to show pictures to my child and make her answer questions on what she sees and thinks"* - Mother of an 11-year-old girl.

> *"It was helpful that the HCW used a poster to show the child, to help the child remember."* - Mother of an 11-year-old female.

4.2.2.5.3 Appropriate HIV education before disclosure

A few mothers and one adolescent commented on the order of information in the MFDM as particularly helpful, stressing that it was useful to teach the child about HIV before telling them that they have HIV.

> *"He started by teaching him about disease and then told him [he has HIV]. It was good because I think he took it easily"* - Mother of a male adolescent (unknown age)

> *"I think it is the right way that they used by teaching about a different disease first and then after that to tell him/her truthfully"* – Mother of a 14 -year-old female

4.2.2.5.4 Friendliness of HCW

Another theme identified regarding what the HCW did that was helpful to the disclosure process is the friendliness of the HCW.

> "*They were so friendly and explained it very carefully"* - Mother of 13-year-old male

4.2.2.5.5 Normalisation of the adolescent

Many PCGs and adolescents particularly appreciated hearing from the HCW that they were still normal.

> *"[I liked that they told me] that if you take your medication you live a normal life*" – Adolescent male, 12 years old.

> *"[It was helpful that he] told the child that life goes on and that she is still a normal person like everyone"* – Aunt (guardian) of a 10-year-old female

4.2.2.5.6 Benefits of HCW support to PCG

A dominant structural theme concerns the participants' views on who should do the adolescent's disclosure. All but one of the PCGs believed that disclosure should be performed by the HCW and PCG together; most adolescents agreed. Only two adolescents thought PCG should disclose alone and one adolescent believed it should be an HCW alone.

The mother who said she thought PCG should disclose to their adolescents, gave the reason, "*I know my child".* However, she also commented that "*everything that the HCW said was helpful",* and the HCW reported that the mother *"was nervous and didn't know what to say, yet she confirmed to the child that it is an HIV treatment*". There was, therefore, little suggestion that PCG should do the disclosure without the HCW.

Most PCGs reported feeling very relieved that the HCW helped them because they were afraid and did not know how to tell their child. The specific benefits of HCW support to PCG were categorised into 6 sub-themes, namely:

1) PCG being too afraid to do the disclosure alone:

   "*Alone I wouldn't do it. I was afraid to hurt the child. The HCW helped me a lot*" - Mother of 13-year-old male.

2) PCG not knowing how to tell their child they have HIV:

   "*The doctor helped me on how to tell my child, because I would not on my own. It was good that I was there to hear what the child heard"* - Mother of a 14-year-old female.

   "*I am very happy now that he has met with this HCW, because it would be very difficult for me to explain to my child"* – Mother of a 14-year-old female.

3) HCW being able to provide information on HIV:

   "*Because HCW are the professionals and know how to teach about everything until she understands"* - Father of a 15-year-old female.

   "*HCWs can be able to address all the details about HIV"* Cousin of a 13-year-old male.

   "*The HCW can explain the disease properly"* - Mother of a 12-year-old male.

4) PCG not knowing how to answer their adolescent's questions:

   "*I want my child to understand and I alone cannot give her the reasons"* - Mother of an 11-year-old female.

   "*Because I would not be able to answer some of the questions alone"* mother of an 11-year-old female.

5) HCW helping PCG to talk to their adolescent:

“The HCWs can help you talk better with your child than when you are alone” – Mother of a 10-year-old female.

6) Increasing the validity of the disclosure:

“I think he can be sure about his status and believe that it is true” - PCG of a young male age unknown.

4.2.3 After Disclosure

4.2.3.1 Knowledge about living with HIV and treatment adherence

The knowledge gained by adolescents during the MFDM process was categorised into the following themes:

1) Dealing with stigma;
2) The ability to live a normal life;
3) Understanding that they will not get sick or die if they take their medication;
4) The importance of adherence to treatment;
5) How and when to disclose to others; and
6) How to prevent HIV transmission.

4.2.3.1.1 Dealing with stigma

It was noted that adolescents appreciated knowing that they are still normal and no different to other teenagers, even though they have HIV.

> "[*I feel*] *very well, because I know that if you take your medication you live a normal life"* – Adolescent male, 12 years.

Some teenagers took a while to understand that people with HIV do not look different to others and that HIV-positive people cannot be identified by sight alone.

> "*She also thought that you could tell if someone had HIV by looking at them, I had to repeatedly ask her whether I myself could have HIV, until she accepted that I could, that she wouldn't be able to know by looking at me"* - HCW describing a 15-year-old female.

PCGs were glad that their adolescents had understood that being HIV-positive does not make them abnormal.

> "*I'm glad that he knows that he is still a normal person and can still live long as long as he takes his medication correctly"* – Mother of a 12-year-old male.

4.2.3.1.2 'Normal' future prospects

Some adolescents reported satisfaction with disclosure as they understand that they can still live a normal life, including having a family and a career.

> *"I felt shocked and afraid at first but now I'm fine. I know that if I take my medication well, I will live a normal life and be a policeman and have a wife and children as I want to."* - Adolescent male, 13 years.

> "*I feel fine as I have been told that with taking medication well, I will be fine and I can be a teacher if I want."* - Adolescent female, 14 years.

A mother reported that she found it particularly helpful that her daughter had learnt that HIV does not need to prevent her from achieving her goals and having any career she wishes.

> "*That life goes on and she is still the same human being like other kids, and can do anything, and achieve her goals"* - Mother of a 14-year-old female.

4.2.3.1.3 Longevity of life

Understanding that people with HIV can live a long, healthy life with normal life expectancy was very important to the adolescents and PCGs.

> *"I feel happy… because I know that if I take my medication I will live as long as, and as well as a person without HIV" – Adolescent male, 13 years.*

> *"That I'm HIV-positive and it's not the end of the world, and that if I take my medication right I will live long,"* - Adolescent male, unknown age.

PCGs were grateful that their adolescents had learnt that they can live long, healthy lives with HIV, rather than thinking they will die young.

> *"[I think this disclosure was good] because they need to know the truth about their health so that they will not think they are going to die"* - Mother of a 13-year-old.

> *"They should be told that being HIV is not a death sentence; they can still live a normal life like everyone else"* - Mother of a 10-year-old female.

This theme links closely with theme 1.1 [the belief that HIV has high severity and mortality] and reiterates the need for the HCW/PCG to address this point very well before disclosing to them.

4.2.3.1.4 The importance of adherence to treatment

All the adolescents and PCGs interviewed reported thinking that adolescents knowing their HIV status will help them to adhere to their treatment. PCGs were very appreciative of how the HCW disclosed to the child as they believed it would help them adhere to their medication. PCGs also found it helpful that the HCW told the adolescents about the importance of ART adherence.

> "*The HCW did everything well since he encouraged good adherence and supported my child to take medicine accordingly"* - Mother of 14-year-old male.

4.2.3.1.5 Appropriate onward disclosure

PCGs found it very important and helpful that the HCW discusses when and to whom the adolescent must or can disclose their HIV status.

> *"It was good that he was told that the medication that he is taking is for HIV so that if he gets into a relationship, he will tell his partner about his status"* - Mother of a 14-year-old male.

4.2.3.1.6 Prevention of HIV transmission

Many PCGs thought that the most important reason adolescents should know their status was to avoid unknowing transmission of HIV. As discussed in 3.1, this was also an important factor supporting adolescents knowing their HIV status at an earlier age (before sexual debut). Most PCGs mentioned that one of the helpful things the HCW did was explain how HIV is transmitted so that the adolescent can avoid transmission of HIV.

> *"They should be told that the medication they are taking is for HIV so that if she gets into a relationship, she will tell her partner about her status"* - Mother of a 14-year-old female.

4.2.3.2 Strengthening PCG-adolescent relationship

Many elements of the disclosure process can affect the relationship between the adolescent and their PCG. Some occurrences were noted to strengthen the relationship and some to weaken it. It is very important to strengthen the PCG-adolescent relationship because the PCG will be their main support structure once they leave the clinic. Two methods identified were through the HCW emphasising that the PCG is not to blame for the adolescent having HIV and facilitating reconciliation between PCGs and adolescents.

4.2.3.2.1 Emphasis of PCG innocence

PCG found it beneficial that the HCW explained that it was not the PCG's fault that the adolescent contracted HIV.

> "*He helped me to tell my baby about his HIV status and how important it is to take treatment very well… He told him that it is not your mom or dad's fault that you got HIV"* – PCG of an adolescent of unknown age and gender.

4.2.3.2.2 Reconciliation between PCG and adolescent

The opportunity for honest communication and reconciliation was seen when a father asked his daughter to forgive him and her mother when he explained how she acquired HIV. This open communication demonstrates that he felt guilty and wanted to show his daughter that he was sorry and wanted to reconcile and move forward in a loving relationship. The father expressed his love for her by comforting her when she was upset. The daughter smiled and gave her father and HCW a hug at the end, which indicated forgiveness and gratitude, and signified that a bonding experience had taken place.

> "*Her father coped well, he was strong and supportive. He disclosed his own status first and then hers. He comforted her when she was crying. He asked her to forgive him and her mother…after a few more minutes of talking to myself and her father she accepted and started smiling again. She gave us all a big hug when she left."* – HCW referring to a father and his 15-year-old female adolescent.

4.3 Summary of main findings

The research's main findings were that the MFDM successfully facilitated HIV status disclosure to adolescents and supported HCWs and PCGs during the disclosure process.

The indicators of success were:

1) High levels of adolescent and PCG satisfaction with the MFDM;
2) High occurrence of neutral and positive adolescent reactions to disclosure;
3) PCGs' emotional transition from fear to relief;
4) Use of partial disclosure instead of deception;
5) Adolescents' growth in knowledge and change of attitudes towards HIV;
6) Disqualification of myths and stigma around HIV before disclosure to reduce the harmful impacts of disclosure on mental health;
7) Timeous disclosure;
8) Effective HCW support for PCGs;
9) Adolescents' understanding the importance of adherence and how to prevent HIV transmission; and
10) The importance of strengthening the PCG-adolescent relationship through disclosure.

CHAPTER 5: DISCUSSION

5.1 Introduction

In this chapter, the researcher discusses this study’s main findings, which aimed to describe HIV-positive adolescents’ experiences of finding out their HIV status through the Mini Flipster Disclosure Method. The results will be discussed in relation to the study objectives and compared with existing literature.

The objectives of this study were:

- To describe adolescents’ experiences of being disclosed to using the MFDM;
- To describe adolescent’s knowledge of and attitudes towards HIV before and after exposure to the MFDM;
- To describe the perceptions and experiences of parents/caregivers with the MFDM, and of being supported by HCWs to disclose HIV status to their adolescents; and
- To develop recommendations on how the MFDM can be improved.

5.2 Adolescents’ experiences of being disclosed to using the Mini Flipster Disclosure Method

Five distinct stages were identified in adolescents’ reactions to disclosure, namely:

1) Disbelief;
2) Sadness;
3) Acceptance;
4) Happiness or contentment; and
5) Curiosity.

These stages reflect a general transition from negative emotions to positive emotions. Positive emotions are described by the Oxford Dictionary of Positive Psychology as “*pleasant or desirable situational responses*”, and negative emotions, described by the Psychology Dictionary as emotions which are “*unhappy and lead to mental ill health*” (63,64). Contrary to other literature, more than half of the adolescents showed no evidence of the negative emotions in the first or second stage (disbelief and sadness) and displayed only neutral emotions (acceptance and curiosity) and positive emotions (relief and happiness or contentment).

The emotional health of the adolescents post-disclosure is an indicator of the success of the MFDM, which could be due to several factors.

In particular, the slow build-up of information about HIV allows the adolescents to gradually internalise that they might have HIV and progressively come to terms with the notion. This aids in moving the adolescent through the stage of disbelief to acceptance. Accepta

While a lack of evidence of sadness shown externally (such as crying, a sad facial expression, or withdrawal) cannot be assumed to depict a lack of sadness internally, the presence of signs of happiness, such as smiling and showing affection towards PCG and HCW, and reports of happiness, and feeling "*good*", are more compelling indicators of emotional wellbeing.

The observed lack of sadness is thought to be due to the dismissal of misconceptions and negative connotations of HIV before disclosure, which is discussed in section 5.3. Most, but not all, adolescents progressed to stage 4 of the noted reactions to disclosure (happiness and contentment), while some showed different combinations and orders of these stages. Happiness was related to being glad that they knew their status rather than being deceived, which aligns with literature and policies around the adolescents' right to access information on their own health and reach autonomy. Positive experiences described by adolescents were confirmed by observations by PCGs and HCWs.

The transition through multiple stages of emotions can be likened to the Kubler-Ross five stages of grief model which includes denial, anger, bargaining, depression and acceptance, although these usually occur over a much longer time-frame than the emotions witnessed in the disclosure session (65). The emotions stemming from this study were much more positive on the spectrum of emotions than those in the Kubler-Ross's five-stage model (63,65). It would be beneficial to observe the adolescents' emotions over a longer period, post-disclosure, to discover whether further emotional stages occur. It is likely that acceptance itself is a process, that would be built on over time and during the post disclosure sessions.

The five stages observed in this study are in stark contrast to other literature-described responses to being told one has HIV (30,66). There was a higher predominance of neutral to positive emotions observed in this study than those described in the WHO (2011) review of literature which combined four studies, representing over 150 children (5-19 years). The WHO review found immediate reactions to be predominantly "sadness and worry (35.9%), followed by neutral/normal (28.2%), shocked (16.0%), angry (14.7%), confused (8.3%) and positive (e.g. relief, 6.4%)" (30).

A qualitative study set in Uganda also found a much higher proportion of negative reactions to disclosure; some adolescents reported contemplating suicide after disclosure due to feelings of hopelessness and bitterness (25). This study's findings were also much more positive than those of a longitudinal study exploring adult women's responses to being diagnosed with HIV, which observed initial devastation, shock, and indignation, which progressed into long-term depression, shame, suicidality, and increased drug and alcohol use, which generally lasted months and sometimes years (34). There are many reasons why adolescent disclosure may elicit better responses than adult diagnosis, including better support and more education.

It is not known how our study participants' mental health faired in the weeks or months post-disclosure; however, in the literature, adolescents' mental health status have been seen to improve over time rather than worsen (30,33). This was described in a study by Blasini et al., which found that in a follow-up six months after a supportive intervention saw "a dissipation of children's confusion and anger, a reduction of negative emotions, and an increase in feelings of normality (70.0%) and in positive emotions (47.5%)" (30,33). In future studies using the MFDM, it would be of value to perform follow-up interviews with the adolescents disclosed to in order to assess and compare long-term outcomes with other studies.

5.3 Adolescent's knowledge of and attitudes towards HIV before and after the MFDM

In contrast to many disclosures performed by PCGs, described in the literature where the adolescents did not receive much, if any, information on HIV (20), the adolescents in this study underwent a positive improvement in knowledge of and attitudes towards HIV, namely:

1) From little to substantial knowledge of HIV.
2) From all negative to positive or neutral attitudes towards HIV.
3) From believing HIV to be a dreaded disease with severe morbidity and mortality, even with treatment, to understanding that PLHIV can live healthily with normal life expectancy when taking ART.
4) From believing that PLHIV cannot live a normal life, including having a family and a career, to the contrary.
5) From holding stigmatised views of PLHIV to understanding that PLHIV are no different to others and are not bad people.
6) From believing that HIV is transmitted through sexual intercourse to understanding alternate

modes of transmission, including mother to child transmission.

The most important shift in knowledge and attitudes was the rejection of HIV-related myths, stigma and "othering" (62). Adolescents' knowledge of and attitudes towards HIV before disclosure were tainted with negative myths and stigma, including that HIV is a dreaded disease, that it causes dramatic weight loss, untimely death and morbidity, affects the quality of life and prospects, and that the predominant method of transmission is through sexual intercourse. The literature describes the persistence of archaic beliefs in Africa, of HIV being a dreaded disease, with high morbidity and mortality, even in a time of availability of highly effective ART and draws connections between the predominant impression of HIV being transmitted through sexual intercourse, and stigmatising perceptions of HIV being indicative of casual sexual relations and immorality (67).

In addition, most adolescents in this study perceived themselves to be at low risk of HIV. The concept of people perceiving themselves to have a low risk of a certain illness is widely cited regarding HIV and is known as "othering" (62). It is closely related to the stigmatised beliefs that people with HIV must appear or behave differently, be immoral, and be less worthy than others (39,62). These two concepts of stigma and othering will be discussed in more detail regarding how they were addressed in the MFDM.

5.3.1 Stigma addressed through the MFDM

Stigma can be described as an attribute that reduces a person to someone who is different, tainted, and deserves to be denigrated to a lower social status (39). To identify myths and stigma believed by adolescents and correct their knowledge and attitudes before disclosing, the MFDM includes a prompt to ask adolescents what they know about HIV (see MFDT page 17 in Appendix O). If myths and stigmatised beliefs are identified, the HCW should address these before moving on. Commonly, therefore, points documented in MFDM post-disclosure sessions, regarding PLHIV being able to live to an old age, live a normal life, and have HIV uninfected babies, are addressed pre-disclosure, as well as post-disclosure (see MFDT page 21, 25, 33 and 43 in Appendix O).

In a qualitative study set in Uganda, some adolescents experienced disclosure at home with a PCG often with little HIV education and others were disclosed to by a HCW who assessed their preconceptions of HIV and corrected them before disclosing (25). It was found that "*respondents who were knowledgeable about HIV and its treatment seemed less likely to react negatively to the disclosure, compared to respondents who had scanty knowledge or who harboured misconceptions* *about HIV and/or ART*" (25). Similarly, in a qualitative study set in Kinshasa, DRC, one adolescent reported being prepared for her disclosure by the HCW helping her research different chronic diseases, including HIV, leading up to her disclosure by her mother (20). This was reported to be beneficial compared to the rest of the adolescents who were not prepared in any way and were reported by PCGs to have reacted with "*surprise*" or "*weeping*", because the HIV disclosure was unexpected or the child did not understand how they could have acquired HIV (20).

It can be argued that if the adolescents in this study were told their HIV status without first dispelling any incorrect knowledge and perceptions identified, they might have internalised their stigmatized beliefs of HIV and changed their view of themselves and their PCG. This would likely be distressing and impact negatively on their mental health. It is noted in literature "that the act of informing boils down to the initial moment of disclosing the disease," which draws attention to the moment of disclosing HIV status within the entire disclosure process (35). Therefore, it is beneficial to note how the adolescents' knowledge and perceptions of HIV changed during the MFDM process and that their preconceptions were corrected *before* the point of disclosing their HIV status. Post-disclosure, the adolescents displayed new understandings that anyone can have HIV, that it doesn't mean they are different or bad, that people with HIV can have normal prospects including, careers and families, and live as long and healthily as those without HIV.

5.3.2 "Othering" and "am I normal?" addressed through the MFDM

Adolescents with 'othering' beliefs that they could not have HIV themselves also needed to understand that anyone can have HIV, even their PCG or themselves. Some HCWs reframed this positioning for the adolescents in a stepwise manner, from 'others' to 'themselves', by initially explaining that the HCW themselves could have HIV, the PCG could have HIV, and in fact, does have HIV, and lastly, that the adolescent could have HIV, and does.

In other studies, it has been seen that adolescents who were first told their PCG HIV status had more positive reactions to their own disclosure (25). The researcher noted that many adolescents in the study were initially in disbelief and took a while to believe that their HCW could be HIV-positive, that their PCG could be HIV-positive, and that they themselves could have HIV. This finding is in keeping with other studies, which have found that some adolescents react in disbelief that they could have HIV (1,18,23,25,30). Closely related to the "othering" belief is the notion that people with HIV are different (39,62). This can lead the adolescents to ask themselves, "*If I have HIV, am I normal?*".

Being told they are different to others could be internalised by an adolescent to mean that they are abnormal, and would likely be seen as a failure by the adolescent and result in loneliness (1).

It follows that it is important to stress to an adolescent that having HIV does not make one different or abnormal. This study exposed that adolescents were happy to know that they are still normal, just like other children and teenagers, and can continue to live a normal life with HIV. PCGs also reported feeling relieved and grateful that the HCWs reassured their adolescent that they are still normal and no different from other children.

While most disclosure guidelines mention the importance of addressing myths, stigma and "othering", they do not stress the need to address them *before* fully disclosing to the adolescent. This lack of clarity is a potential gap as it is well-described that immediately after breaking bad news, the receiver's ability to absorb new information is impaired.

In addition, particularly in early-adolescence, emotions dominate over logic when stress is encountered (1). Therefore, it can be expected that if adolescents are told they have HIV while still believing that it is a dreaded disease, they are likely to become traumatised and unlikely to absorb any information afterwards to correct their beliefs. In keeping with this, it was noted by a few mothers and one adolescent participating in the study that it was beneficial that the adolescents were taught correct information about HIV *before* being told that they have HIV. Adolescents reported that learning that HIV is easily treated helped them to feel happy about their diagnoses.

It is likely that the high levels of satisfaction with the disclosure process, and the positive experiences and reactions of adolescents and their PCG is a result of this technique to reduce trauma to the adolescents and, consequently, to the PCG.

It is also noted that the MFDM tool may not emphasize this enough, and that HCW who are not adequately trained on the use of the tool, may not sufficiently explore adolescents' prior knowledge and perceptions, and may not adequately address stigma, myths and "othering" before full disclosure.

It is also possible that some adolescents may not voice the entirety of their prior knowledge and perceptions about HIV. Therefore, an identified gap in the MFDM is the lack of a clear statement emphasising the importance of debunking all myths *before* disclosure, including stigma and "othering", and specifically telling children that PLHIV can live as long as people without HIV, that they can have families, HIV-negative offspring, and careers. Furthermore, the adolescent should be questioned on these points to ensure full comprehension before continuing with the disclosure process.

5.4 High levels of satisfaction of parents/caregiver on the MFDM of being supported by HCW to disclose HIV status to their adolescents

The dominant findings of PCG perceptions and experiences of the MFDM were high levels of satisfaction, PCG emotional transition from fear to relief, the importance of partial disclosure rather than deception, the benefits of HCW support to PCG, the appropriate timing of disclosure, and the strengthening of the PCG-adolescent relationship.

5.4.1 High levels of PCG satisfaction with the MFDM process

Very high levels of satisfaction with the MFDM were observed from PCGs. All PCGs thought that the disclosure was done well or very well, which portrays higher satisfaction levels than seen in most other studies in the literature (23,25,48). Most PCG attributed their positive experiences to the good use of visuals, HCW friendliness, appropriate HIV education before disclosure, normalisation of HIV, and the benefits of the HCW support.

Good use of visuals

One of the most commonly mentioned benefits of the MFDM was the use of pictures to provide education to the adolescent. In a similar response to the I-TECH disclosure storybook described in the literature, children and PCG particularly valued the use of pictures to engage children and teach them about their illness in a stimulating, memorable, child-friendly manner (7,52). In the I-TECH tool evaluation, it was noted that PCGs also appreciated the picture-based tool, and learnt from the experience (7,52).

Friendliness of HCW

PCGs were particularly grateful for the friendliness of the HCWs and commented that it was beneficial to the disclosure process. The friendliness of HCW is likely due to the MFDM training in which HCW are taught to be friendly, happy and positive, when engaging with children and adolescents, and to build rapport with the child and communicate in an age-appropriate, sensitive manner. While most guidelines emphasise the need to establish rapport and teach HCWs elements of child-counselling skills (such as anticipating negative emotions and providing a sensitive space for listening, reflecting and normalising their emotions), what has not been looked at in great detail in the literature, or this study is the effect of the HCW being positive about the diagnosis, rather than displaying a tone and body language which infers negativity around the diagnosis. This unexplored aspect should be investigated in further research.

5.4.2 PCGs' emotional transition from fear to relief

Most PCGs reported knowing that they should disclose to their C/ALHIV but refraining because of their many fears that:

1) They were not capable;
2) It would be a difficult and painful process;
3) It would be damaging to their child's mental health and possibly fatal;
4) It could lead the C/ALHIV to stigmatise and blame the PCG; and
5) Could lead to stigmatisation of the C/ALHIV and PCG if the C/ALHIV inappropriately disclosed to others.

These fears lead to anxiety, and the conflict between what they thought they should do and what they felt capable of doing, left them feeling both frustrated and guilty. These fears are in keeping with those described in the literature (1,18,29,35). It is well described in the context of HCWs who have to break bad news to patients that it is normal to avoid or delay breaking bad news and to have several fears, including a fear of being blamed, of eliciting a negative reaction, of not knowing how to do it, of expressing emotions, of not having all the answers, and of feeling uncomfortable due to sympathy for the person receiving bad news (42).

The above-mentioned fears, anxiety, frustration and guilt, and the long-term burden of deceiving their children and keeping HIV a secret from them are likely to lead to negative effects on the PCGs mental health. Similar fears and burdens of secrecy have been documented in the literature and have been seen to lead to long-term mental health impacts for PCGs, including depression (18,46).

In contrast to these negative emotions experienced before disclosure and occasionally during the disclosure process (such as discomfort and nervousness), all PCGs were seen to cope well and experience positive emotions after disclosure, such as relief, happiness and gratitude. Due to the intense anxiety experienced before disclosure, it is understandable that PCGs felt relief once the full disclosure session was complete, and they realised that their fears had not materialised and their adolescents had reacted much better than expected. In addition to relief, some PCGs felt liberated from their burden of secrecy, frustration and guilt, which concurs with the literature (18,46).

5.4.3 Ensuring adolescents understand the importance of adherence and how to prevent HIV transmission

All adolescents in the study reported that knowing their HIV status would help them adhere to their treatment, which is surprising considering that early adolescence is a stage where action-consequence relationships are not fully understood or internalised (1). PCGs were highly appreciative of the HCW disclosing to the child as they believed that it would help the adolescent adhere to their medication; many specifically thanked the HCW for explaining the importance of ART adherence to their adolescent.

Many PCGs also thought that the most important reason adolescents should know their HIV status was to avoid unknowing transmission of HIV. As discussed in 3.1, this was also an important factor in PCGs believing adolescents should know their HIV status at an earlier age (before sexual debut). Most PCGs mentioned that a particularly helpful aspect of HCW support was explaining how HIV is transmitted, so that the adolescent can avoid unknowing transmission.

5.4.4 Benefits of HCW support to PCG

Literature shows much debate on who is best suited to disclose HIV status to adolescents, with PCG, HCW and peers as common recommendations(1,7,18,23,29,30,35). Kidia et al. found many negative adolescent experiences when disclosed to by a PCG without any support from someone with disclosure experience (23). In contrast, this study's findings indicate disclosure is more successful when performed by a PCG and HCW together, specifically a trained HCW guiding and supporting a PCG.

Peers were not involved in these disclosures, and therefore their role was not assessed in this study. Almost all PCGs reflected that disclosure should be performed by the HCW and PCG together, and most adolescents agreed. A dominant barrier to disclosure identified was the PCG not feeling capable and feeling fearful of the process of full disclosure. In keeping with this, many PCGs reported being grateful for the assistance of the HCW. The specific reasons given by PCGs as to why disclosure should be performed by PCG and HCW together, fall into six sub-themes, namely:

1) PCG being too afraid to do the disclosure alone;
2) PCGs not knowing how to tell their child they have HIV;
3) HCWs being able to provide information on HIV;

4) PCGs not knowing how to answer their adolescent's questions;
5) HCWs helping PCGs to talk to their adolescent; and
6) HCWs increasing the validity of the disclosure.

Elements of the above have been mentioned in literature; for example, a study in Uganda reported adolescents being more likely to believe their HIV status if an HCW disclosed to them than if it was their PCG (25).

5.4.5 Readiness and timing of HIV disclosure

In this study, the MFDM was performed on adolescents ranging from 10-15 years old. While the MFDM states that it is for adolescents over the age of 12 years, it was still seen to be beneficial for full disclosure in children from 10 years; this aligns with the SANDoH disclosure guidelines which recommend full disclosure from 10 years old (1).

It should be noted that the partial disclosure section of the MDFM can be used on patients as young as 3 years old in alignment with the SANDoH disclosure guidelines (1). All adolescents in this study were over the age of 10, and most adolescents reported being glad they were disclosed to, and recommended other adolescents be disclosed to at approximately the same age. This suggests that they were ready for disclosure and felt that their current age was appropriate for disclosure. We can assume that this means the adolescents did not need to wait any longer and that it was beneficial that this intervention prevented delaying disclosure further. However, there is also the possibility that earlier disclosure could have been preferable, but this was not possible to determine from this study. This study also did not explore whether the MFDM for full disclosure would be suitable for patients below 10 years old.

Two HCWs noted that it was more difficult to disclose to 10-year-olds than those over 10 years old as they were slower to understand detailed information about HIV and concepts such as stigma. However, the 10-year-olds were reported to understand by the end of the session, and had positive responses without displaying any negative emotions. In contrast, the older adolescents were more likely to display negative emotions; a 14-year-old female and a 15-year-old female were the only two adolescents to cry.

The 14-year-old who was reported to have reacted "*well initially but only afterwards when I was* *chatting to her mom did she get a bit teary*" was the only adolescent who reported being sexually active. Her sexual activity and fear of disclosing to her partner likely increased her emotional burden. For her benefit and that of her sexual partner, earlier disclosure would have been preferable. This affirms guidelines that call for disclosure at younger ages, before adolescents reach sexual debut (1,18,30). The importance of disclosing before the adolescent reaches their sexual debut and before they inadvertently find out their HIV status were highlighted by PCGs as being reasons why adolescents should be disclosed to, which aligns with guidelines and literature (1,18,30).

The 15-year-old was the only adolescent who was not glad that she was disclosed to, and stated that she thought adolescents should be disclosed to at age 18; however from this study and the literature, it seems that reactions are worse the older adolescents become (25). In a Ugandan qualitative study by Mutumba et al., older adolescents (over 12 years) had worse reactions to their disclosure, a higher chance of reporting suicidality, and more anger at their PCG for concealing their HIV status for a long period of time (25). It is also noted in literature that as adolescents get older, they are more likely to find answers to their questions and, therefore, might discover their diagnosis in an alternate manner (18).

In summary, regarding the study's small population of 21 adolescents, it seems that HCWs were able to use the MFDM with adolescents aged 10-16. The 10-year-olds took longer to grasp information and concepts but reacted positively to their diagnosis, whereas those older (over 14 years) were more likely to react with negative emotions and be sexually active.

5.4.6 Strengthening of the PCG-adolescent relationship

Many elements of the disclosure process can affect the relationship between the adolescent and their PCG. Positively, it was noted that some elements of the MFDM strengthened that relationship, which is important as PCGs are adolescents' predominant support structure once they leave the clinic. Beneficial aspects of the MDFM included explaining that it was not the PCG's fault that the adolescent contracted HIV and that the PCG loves them very much, which is why they have been bringing them to the clinic to get the best treatment for so many years.

It is also beneficial to address stigma and explain that anyone including the adolescents PCG can have HIV and it does not mean they did anything wrong.

It is described in the literature that disclosure can be an opportunity to strengthen the PCG-adolescent relationship as it improves honest communication, can help to identify appropriate roles and responsibilities, helps to explain the PCG situation and previous actions, and can create an opportunity for teamwork for the pair to tackle a common goal (35). These benefits were witnessed in this study, as many PCGs felt relieved to speak honestly with their adolescents and show signs of how they love and care for them. When their adolescents did not respond with anger and blame, as many PCGs feared, they were relieved and happy that their adolescent still loved them.

5.5 Limitations of the study

As this is a descriptive qualitative study, purposive sampling methods were used to gain insights into a specific issue (adolescents and PCG experiences of HIV disclosure using the MFDM). This sampling method is suitable for this type of study. However, the findings cannot necessarily be viewed as generalisable. The study sample was selected from a localised geographical region in Mpumalanga, South Africa and relates to black South African adolescents from rural, low socioeconomic status households. However, the MFDM is not specific to language, education level or socioeconomic status, and it is therefore expected to be transferable to other settings in South Africa and probably the Southern African region.

Efforts were made to improve rigour and reduce bias, described in Chapter 3; however, there is a possibility of recording bias as data was transcribed and translated simultaneously by the interviewers. While there is a possibility of omission and recording bias, there is no anticipated reason for this from the interviewers. Interviewers, 2 of which have master's degree level qualitative research skills, were reminded to transcribe and translate verbatim accounts of the participants answers. While efforts were made to avoid bias, analysis bias may be present as data was analysed by one person, the principle investigator, a clinician who performs adolescent disclosure and works for the NGO that developed the MFDM, and who had prior assumptions that the MFDM was beneficial to adolescents and PCG. The researcher endeavoured to remain cognisant of this potential bias while analysing the data.

Seeing as the HCW using the MFDM had all been trained on the use of the tool and had had previous experience of doing disclosures with the tool, it is possible that the HCW may have nuanced their use of the tool and that each HCW might have a different style and manner of communicating.

This study does not aim to compare all disclosure methods and tools, but rather to look into the acceptability and perceived effectiveness of the MFDM, why it is acceptable or not, and how it can be improved.

In the light of these limitations, the study’s findings will likely be of value to healthcare workers in South Africa and other countries, as the insights gained add to the currently small pool of knowledge on this topic.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

Adolescent HIV disclosure is complex and requires careful consideration to protect the adolescent's and PCG's emotions and mental health. A few guidelines and tools are available internationally and share the consensus that disclosure should be a process of preparation, partial disclosure, full disclosure, post-disclosure and ongoing support. Appropriate timing of full disclosure differs across guidelines from 6-14 years, but there is agreement that it is often inappropriately delayed. Findings from this study indicate the importance of disclosing before adolescents are sexually active and suggest that older adolescents (over 13 years) were more likely to have negative responses to disclosure than younger adolescents (10-13 years).

Most PCGs reported knowing that they should disclose to their C/ALHIV but delaying due to their many fears that:

1) They were not capable;
2) It would be a difficult and emotionally painful process;
3) It would be damaging to their child's mental health and possibly fatal;
4) It could lead the C/ALHIV to stigmatise and blame the PCG, and;
5) Could lead to stigmatisation of the C/ALHIV and PCG if the C/ALHIV inappropriately disclosed to others.

In contrast, however, PCGs in this study had positive experiences of disclosure using the MFDM and reported feeling relieved, happy and grateful for HCW support.

PCGs in this study had not used a partial disclosure model as described in guidelines and tools, including the MFDM. This resulted in PCGs either not giving their C/ALHIV a reason for taking medication, telling them their medicine prevents them becoming ill or dying, or deceiving them by naming other illnesses.

Prior to disclosure, adolescents had little knowledge of HIV, all of which was negative, and revolved around severe morbidity and mortality and sexual transmission. The adolescent patients also had stigmatised perceptions that PLHIV are different to others and cannot live a normal life, including having a family and a career. During disclosure, adolescents underwent a profound change of knowledge of and attitudes towards HIV; they learned that:

- HIV can be transmitted from mother to child;
- PLHIV can live healthily with a normal life expectancy when taking ART;
- PLHIV can live a normal life including having a family and a career; and
- PLHIV are no different to others and are not bad people.

HIV disclosure is considered a process and as such the adolescent's understanding of these concepts will be built on in the following post disclosure sessions.

Most literature to date shows a predominance of negative emotional reactions from adolescents after full disclosure. In this study the MFDM, however, was highly successful and resulted in more positive reactions from adolescents compared to other studies in the literature. The key elements which led to success are that:

1) The MFDM assisted HCWs to support PCGs with disclosure
2) The MFDT, like the I-TECH storybook, used age-appropriate pictures to engage children and adolescents.
3) The MFDM facilitated discussion about HIV before full disclosure. This enabled HCWs to address adolescents' negative misconceptions about HIV *before* telling them they have HIV. In particular, it was found important to minimise stigma and "othering" and build understanding that people with HIV can have a normal life expectancy, careers and families (62).

Other benefits of the MFDM include promoting the PCG-adolescent relationship and ensuring that adolescents understood the importance of adherence and how to prevent HIV transmission.

6.2 Recommendations

Given the importance of HIV disclosure to C/ALHIV and the need for PCG and HCW support, as described in the literature, these study findings should be used to guide HCWs and policymakers. The recommendations below are, therefore, aimed at improving paediatric and adolescent HIV programmes.

6.2.1 Support for PCG

HCWs and policymakers should be aware of the importance of supporting PCGs in the disclosure process and should not expect PCGs to manage this task alone. Disclosure should be included in HCW skills training and the process of support from partial to full disclosure should be discussed with PCGs as soon as possible after starting infants, C/ALHIV on ART so that PCGs do not feel alone with the burden of disclosure and end up deceiving their children. Previous literature has found that HCWs themselves lack the skills necessary to perform or support disclosure (7,25). Therefore, it is recommended that the MFDM or similar model, with accompanying training, should be used to enable HCWs to manage the disclosure process appropriately.

6.2.2 Optimised timing of full disclosure

This study indicated that HCWs and policymakers should ensure that disclosure is not inappropriately delayed. In keeping with the SANDoH disclosure guidelines, ALHIV should be fully disclosed to from 10 years of age and before sexual debut. Consideration should be given to the finding that adolescents over 13 years of age were more likely to cry and feel sad after full disclosure. The MFDM can be used on adolescents from 10 years old and was in this study successfully used on adolescents aged 10-16 years of age.

6.2.3 Wide-spread adoption of addressing negative HIV-related misconceptions and stigma

Considering the perseverance of stigma and negative misconceptions about HIV, HCW, policy makers, guideline and tool developers should ensure that HIV related myths and stigma are addressed and corrected before full disclosure to ALHIV. In addition, the MFDT should be modified to emphasise that HCWs should check with adolescents that myths, stigma and “othering” has been rejected before full disclosure. Methods of doing this include asking the adolescent if they think the HCW or their friends or teachers could have HIV, and if so would it mean that they are going to get sick or die, cannot get married and have children, cannot follow any career, are different to others, or are bad people?

6.2.4 Further research

In this study interviews were conducted on the same day as the disclosure, which minimises recollection bias and improves quality of findings, but could also have missed longer-term outcomes. In future studies, value may be added by holding follow-up interviews with the same adolescents at a later time point.

Some aspects of the MFDM were noted to strengthen the PCG-adolescent relationship. However, further research should be conducted to gain more insight on additional methods of strengthening the PCG-adolescent relationship before, during and after, disclosure.

Finally, we recommend that HCW be trained to use the MFDM to support PCG to disclose to their adolescent children between 10-16 years, and to assist them in dispelling negative HIV myths and counter stigma.

References

1. Department of Health SA. Disclosure guidelines for children and adolescents in the context of HIV, TB and non-communicable diseases [Internet]. Pretoria; 2016. Available from: https://chivasouthafrica.org/wp-content/uploads/2020/01/1.-HIV-disclosure-guideline-for-children-and-adolescent-2016_1-1.pdf
2. Simbayi L, Zuma K, Zungu N, Moyo S, Marinda E, Jooste S, et al. South African national HIV prevalence , incidence , behaviour and communication survey , 2017. Cape Town: HSRC Press; 2019.
3. Department of Statistics SA. Stats SA [Internet]. 2020 Mid-year population estimates. 2020 [cited 2020 Dec 15]. Available from: http://www.statssa.gov.za/
4. US Presidents Emergency Plan for AIDS Relief. South Africa country operational plan (COP) 2018: Strategic direction summary [Internet]. 2018. Available from: https://za.usembassy.gov/wp-content/uploads/sites/19/South-Africa-COP18-Strategic-Direction-Summary-SDS-public-version-3.22.18-w-watermark.pdf
5. Keal J, Dongen N van, Sorour G, Levin L, Dunlop J, Technau K. The changing face of paediatric HIV: A review of the evolving clinical characteristics of a paediatric and adolescent patients at a clinic in Johannesburg, South Africa. Rev Antivir Ther Infect Dis [Internet]. 2020;9:46. Available from: https://academicmedicaleducation.com/node/3911
6. Willis N, Milanzi A, Mawodzeke M, Dziwa C, Armstrong A, Yekeye I, et al. Effectiveness of community adolescent treatment supporters (CATS) interventions in improving linkage and retention in care, adherence to ART and psychosocial well-being: A randomised trial among adolescents living with HIV in rural Zimbabwe. BMC Public Health [Internet]. 2019 Jan 28 [cited 2021 Feb 12];19(1):117. Available from: https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-019-6447-4
7. O’Malley G, Beima-Sofie K, Feris L, Shepard-Perry M, Hamunime N, John-Stewart G, et al. If I take my medicine, I will be strong: Evaluation of a pediatric HIV disclosure intervention in Namibia. J Acquir Immune Defic Syndr. 2015 Jan 1;68(1):1–7.
8. Nicastro E, Continisio GI, Storace C, Bruzzese E, Mango C, Liguoro I, et al. Family group psychotherapy to support the disclosure of HIV status to children and adolescents. AIDS Patient Care STDS. 2013 Jun 1;27(6):363–9.
9. Schaecher KL. The Importance of Treatment Adherence in HIV. Am J Manag Care. 2013;19(12 Suppl):s231-7.

10. Wessels J, Sherman G, Bamford L, Makua M, Ntloana M, Nuttall J, et al. The updated South African National Guideline for the Prevention of Mother to Child Transmission of Communicable Infections (2019). S Afr J HIV Med [Internet]. 2020;21(1):a1079. Available from: https://doi.org/10.4102/sajhivmed.v21i1.1079Copyright: © 2020. The Authors. Licensee: AOSIS. This work is licensed under the Creative Commons Attribution License.%0A %0A%0A(15) (PDF) The updated South African National Guideline for the Prevention of Mothe

11. Rodger AJ, Cambiano V, Phillips AN, Bruun T, Raben D, Lundgren J, et al. Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): Final results of a multicentre, prospective, observational study. Lancet. 2019 Jun 15;393(10189):2428–38.

12. Cohen MS, Chen YQ, McCauley M, Gamble T, Hosseinipour MC, Kumarasamy N, et al. Antiretroviral therapy for the prevention of HIV-1 transmission. N Engl J Med [Internet]. 2016 Sep 18 [cited 2021 Feb 24];375(9):830–9. Available from: http://www.nejm.org/doi/10.1056/NEJMoa1600693

13. Remien RH, Mellins CA. Long-term psychosocial challenges for people living with HIV: Let’s not forget the individual in our global response to the pandemic. AIDS. 2007;21(Suppl 5):S55-63.

14. Oladipo SE, Amoateng AY, Kalule-Sabiti I. The psychosocial challenges of people living with HIV/AIDS in North-West province of South Africa. J Psychol. 2014;5(2):161–8.

15. McCoy B, McAteery C, Sang F, Nyandiko W, Vreeman R. Measuring symptoms of depression, anxiety, and PTSD among children and adolescents living with and affected by HIV in sub-Saharan Africa: A systematic review. Rev Antivir Ther Infect Dis. 2020;9:70.

16. Southern African HIV Clinicians Society. Guideline: Adherence to antiretroviral therapy in adolescents and young adults [Internet]. Johannesburg; 2017. Available from: https://www2.sahivsoc.org/Files/Adolescent (LONG)_Guidelines_2017_WEB2.pdf

17. Beyers W, Seiffge-Krenke I. Does identity precede intimacy? testing Erikson’s theory on romantic development in emerging adults of the 21st century. J Adolesc Res [Internet]. 2010 May 2 [cited 2021 Feb 6];25(3):387–415. Available from: http://journals.sagepub.com/doi/10.1177/0743558410361370

18. Elizabeth Glaser Paediatric AIDS Foundation. Disclosure of HIV status toolkit for paediatric and adolescent populations [Internet]. Washington, DC: Elizabeth Glaser Paediatric AIDS Foundation; 2018. p. 1–74. Available from: https://www.pedaids.org/wp-

content/uploads/2019/01/NewHorizonsDisclosureToolkit_FINAL.pdf

19. Oladokun R. The “why, when and how to” of HIV disclosure: perspectives from the north and south. In: International Workshop on HIV & Paediatrics [Internet]. Conference proceedings on the internet; 2020. Available from: https://academicmedicaleducation.com/hiv-pediatrics-2020

20. Vaz LME, Eng E, Maman S, Tshikandu T, Behets F. Telling children they have HIV: lessons learned from findings of a qualitative study in sub-Saharan Africa. AIDS Patient Care STDS. 2010 Apr 1;24(4):247–56.

21. Madiba S. The impact of fear, secrecy, and stigma on parental disclosure of HIV status to children: A qualitative exploration with HIV positive parents attending an ART clinic in South Africa. Glob J Health Sci. 2013;5(2):49–61.

22. Domek GJ. Debunking common barriers to paediatric HIV disclosure. J Trop Pediatr [Internet]. 2010;56(6):440–442. Available from: https://doi.org/10.1093/tropej/fmq013

23. Kidia KK, Mupambireyi Z, Cluver L, Ndhlovu CE, Borok M, Ferrand RA. HIV status disclosure to perinatally-infected adolescents in Zimbabwe: A qualitative study of adolescent and healthcare worker perspectives. PLoS One. 2014;9(1):e87322.

24. Enane L, Apondi E, Toromo J, Omollo M, Bakari S, Morris C, et al. Healthcare worker perspectives on adolescent disengagement from HIV care in western Kenya: A qualitative study. Rev Antivir Ther Infect Dis. 2020;9:83.

25. Mutumba M, Musiime V, Alexander Tsai C, Byaruhanga J, Kiweewa F, Bauermeister JA, et al. Disclosure of HIV status to perinatally-infected adolescents in urban Uganda: A qualitative study on timing, process, and outcomes. J Assoc Nurses AIDS Care. 2015;26(4):472–84.

26. Vujovic M, Levin L. Mini flipster disclosure tool for adolescents ages 12 and up. Johannesburg: Right to Care; 2016. 1–47 p.

27. Wu M, Shiau S, Strehlau R, Liberty A, Patel F, Burke M, et al. Disclosure to South African children about their own HIV status over time. Rev Antivir Ther Infect Dis [Internet]. 2020;9:72. Available from: https://academicmedicaleducation.com/node/3911

28. Duffy MH, Bergmann H, Sharer M. Toolkit for transition of care and other services for adolescents living with HIV. Arlington: USAID, AIDSTAR-One; 2014. p. 52–82.

29. Mburu G, Hodgson I, Kalibala S, Haamujompa C, Cataldo F, Lowenthal ED, et al. Adolescent HIV disclosure in Zambia: Barriers, facilitators and outcomes. J Int AIDS Soc. 2014;17:1–9.

30. World Health Organization. Guideline on HIV disclosure counselling for children up to 12 years of age [Internet]. Geneva; 2011. Available from: https://apps.who.int/iris/bitstream/handle/10665/44777/9789241502863_eng.pdf;jsessionid=184A9362E15CD6D6D170A3728EEAA03C?sequence=1

31. Zanoni B, Archary M, Sibaya T, Musinguzi N, Haberer J. Factors associated with virologic failure and loss to follow up for adolescents living with perinatally-acquired HIV during transition to adult care: A prospective analysis. Rev Antivir Ther Infect Dis [Internet]. 2020;9:85. Available from: https://academicmedicaleducation.com/node/3911

32. Petersen I, Bhana A, Myeza N, Alicea S, John S, Holst H, et al. Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: A qualitative investigation. AIDS Care. 2010 Aug;22(8):970–8.

33. Blasini I, Chantry C, Cruz C, Ortiz L, Salabarria I, Scalley N, et al. Disclosure model for pediatric patients living with HIV in Puerto Rico: Design, implementation, and evaluation. J Dev Behav Pediatr. 2004;25(3):181–9.

34. Stevens PE, Hildebrandt E. Life changing words: Women's responses to being diagnosed with HIV infection. Adv Nurs Sci [Internet]. 2006 [cited 2021 Feb 13];26(3):207–21. Available from: https://journals.lww.com/advancesinnursingscience/Abstract/2006/07000/Life_Changing_Words__Women_s_Responses_to_Being.4.aspx

35. Zanon BP, Batista De Almeida P, Netto De Brum C, Cardoso De Paula C, Maris De Mello Padoin S, Quintana AM. Disclosure of the diagnosis of parental HIV. Rev bioét [Internet]. 2016 [cited 2021 Feb 16];24(3):557–66. Available from: http://dx.doi.org/10.1590/1983-80422016243155

36. Callen G, Sang F, Munyoro D, Chory A, Aluoch J, Scanlon M, et al. A qualitative examination of perceived stigma and its impact on health status and care preferences among Kenyan adolescents living with HIV. Rev Antivir Ther Infect Dis [Internet]. 2020;9:83. Available from: https://academicmedicaleducation.com/node/3911

37. Saal W, Toska E, Pantelic M, Roberts K, Shenderovich Y, Cluver L. The association between HIV-status disclosure and stigma experiences among adolescents living with HIV in South Africa. Rev Antivir Ther Infect Dis [Internet]. 2020;8:7. Available from: https://www.virology-education.com/wp-content/uploads/2019/11/Abstract-Book-Adolescence.pdf?utm_medium=email&utm_campaign=website&utm_source=sendgrid.com

38. Marcus JL, Leyden WA, Alexeeff SE, Anderson AN, Hechter RC, Hu H, et al. Comparison

of overall and comorbidity-free life expectancy between insured adults with and without HIV infection, 2000-2016. JAMA Netw open. 2020 Jun 1;3(6):e207954.

39. Skinner D, Mfecane S. Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. SAHARA J. 2004 Nov 1;1(3):157–64.

40. Abadia-Barerro C, Larusso M. The disclosure model versus a developmental illness experience model for children and adolescents living with HIV/AIDS in São Paulo, Brazil. AIDS Patient Care STDS [Internet]. 2006;20(1):36–43. Available from: https://www.researchgate.net/publication/7346992_The_Disclosure_Model_versus_a_Developmental_Illness_Experience_Model_for_Children_and_Adolescents_Living_with_HIVAIDS_in_Sao_Paulo_Brazil/link/5506e8470cf2d7a281226368/download

41. Songtaweesin W, Thisayakorn P, Saisaengjan C, Pholphet K, Nadsasarn R, Lonhin S, et al. Mental health management integration into adolescent HIV treatment services in Bangkok, Thailand. Rev Antivir Ther Infect Dis [Internet]. 2020;9:73. Available from: https://academicmedicaleducation.com/node/3911

42. Buckman R. How to break bad news: A guide for health care professionals [Internet]. Baltimore: Johns Hopkins University Press; 1992. 15–29 p. Available from: https://books.google.co.za/books?hl=en&lr=&id=5rO_lay4MhMC&oi=fnd&pg=PA15&dq=shock+after+hearing+bad+news&ots=gRL86H_6UE&sig=V2xtLB45gQ271CpBzV2sQ0GmSnA&redir_esc=y#v=onepage&q=shock after hearing bad news&f=false

43. Mweemba M, Musheke MM, Michelo C, Halwiindi H, Mweemba O, Zulu JM. “When am i going to stop taking the drug?”: Enablers, barriers and processes of disclosure of HIV status by caregivers to adolescents in a rural district in Zambia Global health. BMC Public Health [Internet]. 2015 Oct 7 [cited 2021 Jan 31];15(1):1028. Available from: http://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-015-2372-3

44. Lungu E. Knowledge is power! Enabling adolescents to know their HIV status. In: International Workshop on HIV and Adolescence [Internet]. Virtual: Virology Education; 2020. Available from: https://academicmedicaleducation.com/hiv-adolescence-2020

45. Baets AJ De, Sifovo S, Parsons R, Pazvakavambwa IE. HIV disclosure and discussions about grief with shona children: A comparison between health care workers and community members in Eastern Zimbabwe. Soc Sci Med [Internet]. 2018;66(2):479–91. Available from: https://doi.org/10.1016/j.socscimed.2007.08.028%0A

46. Lipson M. Disclosure of diagnosis to children with human immunodeficiency virus or acquired immunodeficiency syndrome. J Dev Behav Pediatr. 1994;15(3 Suppl):S61-5.

47. Abebe W, Teferra S. Disclosure of diagnosis by parents and caregivers to children infected with HIV: Prevalence associated factors and perceived barriers in Addis Ababa, Ethiopia. AIDS Care - Psychol Socio-Medical Asp AIDS/HIV. 2012 Sep 1;24(9):1097–102.

48. Bikaako-Kajura W, Luyirika E, Purcell DW, Downing J, Kaharuza F, Mermin J, et al. Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. AIDS Behav. 2006 Jul;10(7 Suppl):s85-93.

49. Thailand Pediatric HIV Disclosure Working Group. Paediatric HIV Disclosure Manual [Internet]. Boon-yasidhi V, Chokepailbulkit K, McConnell M, Angsukittitavorn S, Klumthanom K, editors. Bangkok: Aksorngraphic and Design Publishing House; 2010. 1–96 p. Available from: http://www.cqihiv.com/Final_Pediatric_HIV_Eng.pdf

50. Menon A, Glazebrook C, Campain N, Ngoma M. Mental health and disclosure of HIV status in Zambian adolescents with HIV infection: Implications for peer-support programs. J Acquir Immune Defic Syndr. 2007 Nov;46(3):349–54.

51. Vygotsky L. Mind in society: The development of higher psychological processes [Internet]. Cole M, John-Steiner V, Scribner S, Souberman E, editors. Cambridge, Massachusetts: Harvard University Press; 1978. 52–57 p. Available from: file:///Users/nourmohanna/Downloads/PS400 W2 Vygotsky.pdf

52. I-tech, PEPFAR, Namibian Ministry of Health. Why I take my medicine? Windhoek: I-tech; 2014. 1–44 p.

53. Draper A. The principles and application of qualitative research. In: Nutrition Society [Internet]. London; 2014. p. 641–6. Available from: https://www.researchgate.net/publication/7906248_The_principles_and_application_of_qualitative_research

54. Vaismoradi M, D P, Ms N, Bs N, Turunen H, D P, et al. Content analysis and thematic analysis : Implications for conducting a qualitative descriptive study. Nurs Heal Sci. 2013;15:398–405.

55. Kim H, Sefcik J, Bradway C. Characteristics of qualitative descriptive studies: A systematic review. Res Nurse Heal [Internet]. 2017;40(1):23–42. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5225027/#R80

56. McKinlay J. Appropriate Research Methods [Internet]. Behavioral & Social Sciences Research. 2015. Available from: https://obssr.od.nih.gov/wp-content/uploads/2016/05/Appropriate-Research-Methods.pdf

57. Sale JEM, Lohfeld LH, Brazil K. Revisiting the quantitative-qualitative debate: implications

for mixed-methods research. Qual Quant [Internet]. 2002;36:43–53. Available from: https://doi.org/10.1023/A:1014301607592%0A%0A

58. Enane L, Apondi E, Omollo M, Toromo J, Bakari S, Okoyo J, et al. Adolescents disengaged from HIV care in Kenya: qualitative insights. Rev Antivir Ther Infect Dis [Internet]. 2020;9:80. Available from: https://academicmedicaleducation.com/node/3911

59. Bosnjak S. The Declaration of Helsinki - The cornerstone of research ethics. Arch Oncol [Internet]. 2001;9(3):179–84. Available from: http://scindeks-clanci.ceon.rs/data/pdf/0354-7310/2001/0354-73100103179B.pdf

60. Department of Health SA. District Health Information System (DHIS). Department of Health SA; 2020.

61. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol [Internet]. 2006;3(2):77–101. Available from: http://eprints.uwe.ac.uk/11735/2/thematic_analysis_revised_-_final.pdf

62. Petros G, Airhihenbuwa CO, Simbayi L, Ramlagan S, Brown B. HIV/AIDS “othering” in South Africa: The blame goes on. Cult Heal Sex [Internet]. 2006 Jan [cited 2021 Feb 7];8(1):67–77. Available from: https://www.tandfonline.com/doi/abs/10.1080/13691050500391489

63. Fredrickson M, Cohn B. Oxford handbook of positive psychology [Internet]. 2nd ed. Lopez S, Snyder C, editors. New York: Oxford University Press; 2009. 13 p. Available from: https://books.google.co.za/books?hl=en&lr=&id=6IyqCNBD6oIC&oi=fnd&pg=PA13&dq=Cohn+%26+Fredrickson,+2009+oxford+dictionary+of+positive+psychology&ots=IND7PFW9rC&sig=O2neQMM1Nl01egdZ_VTaIyD3h2s&redir_esc=y#v=onepage&q=Cohn %26 Fredrickson%2C 2009 oxford dic

64. Pam N. Negative emotion. Psychology Dictionary [Internet]. Psychology Dictionary. 2013 [cited 2021 Feb 13]. Available from: https://psychologydictionary.org/negative-emotion/

65. Kübler Ross E, Wessler S, Avioli L V. On death and dying. JAMA J Am Med Assoc [Internet]. 1972 Jul 10 [cited 2021 Feb 13];221(2):174–9. Available from: https://jamanetwork.com/journals/jama/fullarticle/343400

66. Vaz L, Corneli A, Dulyx J, Rennie S, Omba S, Kitetele F, et al. The process of HIV status disclosure to HIV-positive youth in Kinshasa, Democratic Republic of the Congo. AIDS Care - Psychol Socio-Medical Asp AIDS/HIV. 2008 Aug;20(7):842–52.

67. McHenry M, Nyandiko WM, Scanlon ML, Fischer LJ, McAteer CI, Aluoch J, et al. HIV stigma: Perspectives from Kenyan child caregivers and adolescents living with HIV. J Int

Assoc Provid AIDS Care. 2017;16(3):215–25.

Appendix A: Information Sheet for Parents and caregivers

INFORMATION SHEET FOR PARENTS/ CARE-GIVERS

Project Title: HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster disclosure method.

What is this study about?

This study is being conducted by myself Dr Julia Turner and the Right to Care HIV Medical Advisers. The study aims to explore the views of HIV-positive adolescents and young adults who have been told their HIV status, their parents/caregivers who were participated in the disclosure process and the health care workers who supported the disclosure process. We would like to share this information with other health care workers so that health care workers can use this information to improve the way they tell young people about their HIV status.

As your child is under 18 years old, we require consent from you, (a parent or primary care-giver) as well as assent from your child, for you and your child to be able to participate in the study.

What will you and your child be asked to do if you agree to participate?

Once you and your child have signed the forms to consent to participate, you and your child will be asked a few questions in a short interview lasting between 15 minutes and 30 minutes. The questions will be about how you found the disclosure process and how you think it could be improved. Your child's medical records will also be reviewed to see what treatment they have been on and what their blood results are.

Would my participation in this study be kept confidential?

Yes, you and your child's participation will be kept confidential. No identifying data such as your names and dates of birth, will be recorded.

In accordance with legal requirements and/or professional standards, if there is information that comes to our attention concerning current child abuse or neglect or potential harm to your child or others we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

What are the risks of this research?

The only anticipated risk to you and your child by participating in this research study is the possibility of triggering negative emotions due to the sensitive nature of HIV and disclosure. You or your child can let us know at any stage if you/they are feeling uncomfortable. If we suspect any negative emotions which require referral to a social worker, counsellor or psychologist, we will refer.

What are the benefits of this research?

This research is not designed to help you or your child personally, but the results may help health care workers learn more about the perspective and experiences of HIV-positive adolescents and their parents/caregivers in order to improve how they are told about their HIV status.

Do you and your child have to be in this research and may you/they stop participating at any time?

You and your child's participation in this research is completely voluntary. You or they may choose not to take part at all. If you decide to participate in this research, you and your child may stop participating at any time. Neither of you will be penalised if you decide not to participate in the study.

What if I have questions?

Please feel free to ask any questions now or at any stage.

Please contact Julia Turner at: Tel: 0829576698, E-mail: Julia.Turner@righttocare.org

Or Dr Leon Levin at: Tel: 0823526642, E-mail: Leon.Levin@righttocare.org

Appendix B: Consent form for parents and caregivers

RECORD OF INFORMED CONSENT TO CONDUCT AN INTERVIEW

Consent form

Title of Research Project: HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster disclosure method.

I was given a copy of the *INFORMATION SHEET FOR PARENTS/ CARE-GIVERS TO MINORS.* It has been described to me in language that I understand. My questions about the study have been answered. I understand what my and my child's participation will involve and I agree to participate myself and to let my child participate, of my own choice and free will. I understand that my and my child's identities will not be revealed to anyone. I understand that I or my child may decide to no longer participate in the study at any time without giving a reason and without fear of negative consequences or loss of benefits to me or my child.

Parent/ primary care-giver's name____

Parent/ primary care giver's signature _______________________________________

Date____________________________________

Appendix C: Information sheet for minors

INFORMATION SHEET FOR A MINOR (UNDER 18 YEARS OLD)

Project Title: HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster disclosure method.

What is this study about?

This study is being conducted by myself Dr Julia Turner and the Right to Care HIV Medical Advisers. The study aims to explore the views of HIV-positive adolescents and young adults who have been told their HIV status, their parents/caregivers who were participated in the disclosure process and the health care workers who supported the disclosure process. We would like to share this information with other health care workers so that health care workers can use this information to improve the way they tell young people about their HIV status.

As you are under 18 years old, we require consent from your parent or primary caregiver as well as assent from you, for you to be able to participate in the study.

What will you be asked to do if you agree to participate?

Once you have signed the forms to consent to participate, you will be asked a few questions in a short interview lasting between 15 minutes and 30 minutes. The questions will be about how you found the disclosure process and how you think it could be improved. Your medical records will also be reviewed to see what treatment you have been on and what your blood results are.

Would my participation in this study be kept confidential?

Yes, your participation will be kept confidential. No identifying data such as your name and date of birth, will be recorded.

In accordance with legal requirements and/or professional standards, if there is information that comes to our attention concerning current child abuse or neglect or potential harm to you or others we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

What are the risks of this research?

The only anticipated risk to you and your child by participating in this research study is the possibility of triggering negative emotions due to the sensitive nature of HIV and disclosure. You can let us know at any stage if you are feeling uncomfortable. If we suspect any negative emotions which require referral to a social worker, counsellor or psychologist, we will refer.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help health care workers learn more about the perspective and experiences of HIV-positive adolescents in order to improve how they are told about their HIV status.

Do you have to be in this research and may you stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. You will not be penalised if you decide not to participate in the study.

What if I have questions?

Please feel free to ask any questions now or at any stage.

Please contact Julia Turner at: Tel: 0829576698, E-mail: Julia.Turner@righttocare.org

Or Dr Leon Levin at: Tel: 0823526642, E-mail: Leon.Levin@righttocare.org

Appendix D: Assent form for minors

RECORD OF INFORMED CONSENT TO CONDUCT AN INTERVIEW

ASSENT FORM

Title of Research Project: HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster disclosure method.

I was given a copy of the *INFORMATION SHEET FOR PARENTS/ CARE-GIVERS TO MINORS.* It was described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be revealed to anyone. I understand that I may decide to no longer participate in the study at any time without giving a reason and without fear of negative consequences or loss of benefits to me.

Participant's name____

Participant's signature ____

Date_____________________________________

Appendix E: Information sheet for adolescents over 18 years old

INFORMATION SHEET FOR AN ADULT (OVER 18 YEARS OLD)

Project Title: HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster disclosure method.

What is this study about?

This study is being conducted by myself Dr Julia Turner and the Right to Care HIV Medical Advisers. The study aims to explore the views of HIV-positive adolescents and young adults who have been told their HIV status, their parents/caregivers who were participated in the disclosure process and the health care workers who supported the disclosure process. We would like to share this information with other health care workers so that health care workers can use this information to improve the way they tell young people about their HIV status.

As you are under 18 years old, we require consent from your parent or primary caregiver as well as assent from you, for you to be able to participate in the study.

What will you be asked to do if you agree to participate?

Once you have signed the forms to consent to participate, you will be asked a few questions in a short interview lasting between 15 minutes and 30 minutes. The questions will be about how you found the disclosure process and how you think it could be improved. Your medical records will also be reviewed to see what treatment you have been on and what your blood results are.

Would my participation in this study be kept confidential?

Yes, your participation will be kept confidential. No identifying data such as your name and date of birth, will be recorded.

In accordance with legal requirements and/or professional standards, if there is information that comes to our attention concerning current child abuse or neglect or potential harm to you or others we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

What are the risks of this research?

The only anticipated risk to you and your child by participating in this research study is the possibility of triggering negative emotions due to the sensitive nature of HIV and disclosure. You can let us know at any stage if you are feeling uncomfortable. If we suspect any negative emotions which require referral to a social worker, counsellor or psychologist, we will refer.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help health care workers learn more about the perspective and experiences of HIV-positive adolescents in order to improve how they are told about their HIV status.

Do you have to be in this research and may you stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. You will not be penalised if you decide not to participate in the study.

What if I have questions?

Please feel free to ask any questions now or at any stage.

Please contact Julia Turner at: Tel: 0829576698, E-mail: Julia.Turner@righttocare.org

Or Dr Leon Levin at: Tel: 0823526642, E-mail: Leon.Levin@righttocare.org

Appendix F: Consent form for adolescents over 18 years old

RECORD OF INFORMED CONSENT TO CONDUCT AN INTERVIEW

Consent form

Title of Research Project: HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster disclosure method.

I was given a copy of the *INFORMATION SHEET FOR ADOLESCENTS OVER 18 YEARS OLD.* It has been described to me in language that I understand. My questions about the study have been answered. I understand what my and my child's participation will involve and I agree to participate myself and to let my child participate, of my own choice and free will. I understand that my and my child's identities will not be revealed to anyone. I understand that I or my child may decide to no longer participate in the study at any time without giving a reason and without fear of negative consequences or loss of benefits to me or my child.

Parent/ primary care-giver's name____

Parent/ primary care giver's signature ____

Date____________________________________

Appendix G: Information sheet for health care workers

INFORMATION SHEET FOR HEALTH CARE WORKERS

Project Title: HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster disclosure method.

What is this study about?

This study is being conducted by myself Dr Julia Turner and the Right to Care HIV Medical Advisers. The study aims to explore the views of HIV-positive adolescents and young adults who have been told their HIV status, their parents/caregivers who were participated in the disclosure process and the health care workers who supported the disclosure process. We would like to share this information with other health care workers so that health care workers can use this information to improve the way they tell young people about their HIV status.

We require consent from you if you are willing to participate in this study.

What will you be asked to do if you agree to participate?

Once you have signed the forms to consent to participate, you will be asked to either be asked a few questions in a short interview or complete a 2 page questionnaire. The questions will be about how you found the disclosure process and how you think it could be improved. It will also ask for some basic information about the adolescent you disclosed to, such as their social situation, and whether their viral load is suppressed or not.

Would my participation in this study be kept confidential?

Yes, your participation will be kept confidential. No identifying data such as your name and dates of birth, will be recorded. There are multiple health care workers participating in this study so there will be no way of knowing which feedback is regarding which disclosure.

What are the risks of this research?

The only anticipated risk to you by participating in this research study is the possibility of triggering negative emotions about HIV and the disclosure process. You can let us know at any stage if you are feeling uncomfortable. If we suspect any negative emotions which require referral to a social worker, counsellor or psychologist, we will refer. You will have access to the general results of the study once it has been completed but you will not have access to the actual questionnaire responses from the adolescents you disclosed to.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help you and other health care workers learn more about the perspective and experiences of HIV-positive adolescents and their parents/caregivers in order to improve how they are told about their HIV status.

Do you have to take part in this research and may you stop participating at any time?

Yes, your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. You will not be penalised if you decide not to participate in the study.

What if I have questions?

Please feel free to ask any questions now or at any stage.

Please contact Julia Turner at: Tel: 0829576698, E-mail: Julia.Turner@righttocare.org

Or Dr Leon Levin at: Tel: 0823526642, E-mail: Leon.Levin@righttocare.org

Appendix H: Consent form for health care workers

RECORD OF INFORMED CONSENT TO CONDUCT AN INTERVIEW

Consent form

Title of Research Project: HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster disclosure method.

I was given a copy of the *INFORMATION SHEET FOR HEALTH CARE WORKERS.* It has been described to me in language that I understand. My questions about the study have been answered. I understand what my and my child's participation will involve and I agree to let my child participate of my own choice and free will. I understand that my child's identity will not be revealed to anyone. I understand that I or my child may decide to no longer participate in the study at any time without giving a reason and without fear of negative consequences or loss of benefits to me or my child.

Health care worker's name_______________________________________

Health care worker's signature _______________________________________

Date___________________________________

Appendix I: Adolescent interview guide

Adolescent Interview Guide

Questionnaire number:

We would like to find out how we as health care workers can improve on the way that we tell young people about their HIV status.

- Do you think it was good that you were told that you have HIV?

- Who would you have liked to tell you that you have HIV?

  Prompt:

  Parent/caregiver alone
  Health care worker alone
  Parent/caregiver and health care worker

- How do you feel about the way that the health care worker told you about your HIV status?

- Did you know that you had HIV before this?

  Prompt:
  - how did you find out?

  - How did you feel about it?

  - Who did you talk to about it?

- What did you know about HIV before this?

- How did you feel after being told you have HIV?

- What did the health care worker say or do that made you feel happy?

- What did the health care worker say or do that made you feel sad?
- How could the health care worker have told you in a better way?
- Do you think that knowing your HIV status will help you to take your medicine everyday?

- How old do you think children should be when they are told their HIV status?

- Would you like to attend a support group with other HIV infected teenagers?

- Would you like to have a private session with a doctor/nurse or counsellor?

- Are you sexually active?

- Would you like help with disclosing your HIV status to your sexual partner

- Would you like to talk to someone again today?

- Is there anything else you would like help with?

Appendix J: Parent/caregiver interview guide

Parent / Caregiver Interview Guide

We would like to find out how we as health care workers can improve on the way that we tell young people about their HIV status.

- How did you feel about telling your child they have HIV, before today?

- What did you tell your child about their medication before this?

- Do you think it was good that we told your child that he/she has HIV?

- What were your reasons for your answer above?

- Who do you think should tell your child they have HIV? And why?
  Prompt: you, HCW or you and the HCW?

- How do you feel about the way that the health care worker told your child about his/her HIV status?

- What did the health care worker say or do that was helpful?

- What did the health care worker say or do that was not helpful?

- How could the health care worker have told your child in a better way?

- Do you think that knowing his/her HIV status will help your child to take his/her medicine everyday?

- How old do you think children should be when they are told their HIV status?

- What do you think they should be told?

Appendix K: Health care worker interview guide

Health Care Worker Interview Guide

- Does the parent/ caregiver seem willing for disclosure to take place? If not, why?

- Does parent give consent to disclose their own status?

- Does parent give consent to disclose that the child got HIV from the mother?

- What was the last viral load?
- Was partial disclosure done previously and at what age?
- Why did the child think they were taking medication?

- What did the child know about HIV?

- How did the child react to disclosure?

- What was the child's facial expression?

- How did the parent/ caregiver cope?

- What is your perception of how the disclosure went?

- What questions did the child ask?

What questions did the mom ask?

- What myths about HIV did the child believe?

- Any other comments about the disclosure process?

Appendix L: Permission letter to Mpumalanga Department of Health

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2809, Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

Letter requesting permission to perform research study in Mpumalanga Department of Health clinics.

Dear Mpumalanga Provincial Department of Health

This letter serves as an application for permission to perform the following study in DoH clinics in Ehlanzeni.

Study Title: HIV-positive adolescents' experiences of finding out their HIV status through the Mini Flipster disclosure method.

The objectives of the study are:

- To describe adolescents' experiences of being disclosed to using the Mini Flipster disclosure method.
- To describe how the adolescent's knowledge of and attitudes to HIV changed through the Mini Flipster disclosure process.
- To describe the adolescents' thoughts on how the MFDM could be improved.
- To explore the perceptions and experiences of health care workers on the mini-flipster method of supporting parents/caregivers to disclose HIV status to their adolescents.

Please see the attached protocol for details including methodology for sampling, data collection and analysis, and ethical considerations. Ethics permission will be granted by the University of Western Cape Biomedical Research Ethics Committee (UWC BMREC) before the study is carried out.

If you have any further questions, please don’t hesitate to contact me or UWC BMREC:

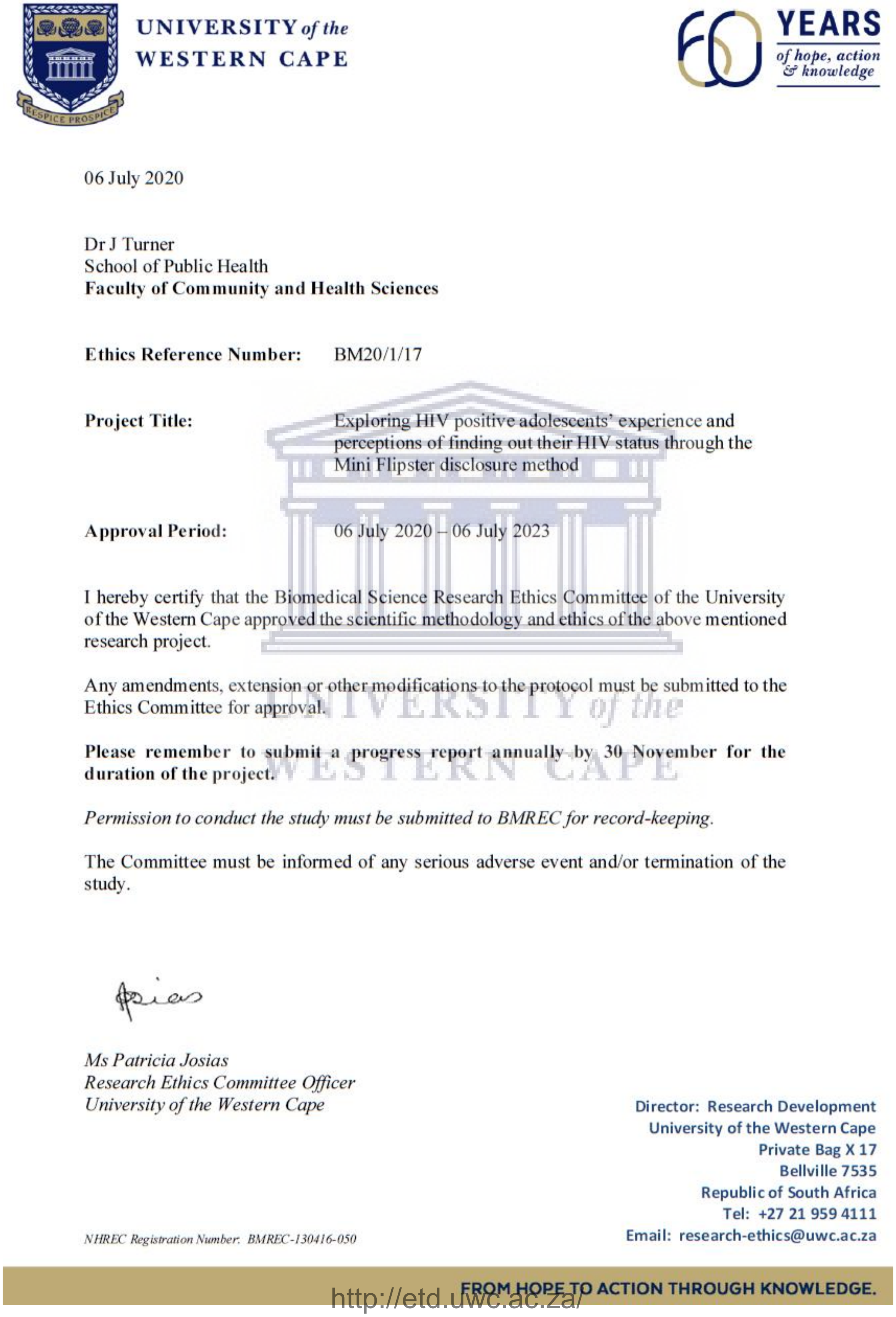
Right to Care Office
Helen Joseph Hospital 1 Perth Rd
Aukland Park 2092 Johannesburg Julia.Turner@righttocare.org 0713517967

Biomedical Research Ethics Committee University of the Western Cape
Private Bag X17 Bellville
7535
Tel: 021 959 4111
E-mail: research-ethics@uwc.ac.za

Kind regards

Dr Julia Turner

Appendix M: Ethics Clearance Letter from BMREC UWC



UNIVERSITY *of the*
WESTERN CAPE

RESPICE PROSPICE

60 YEARS
of hope, action
& knowledge

06 July 2020

Dr J Turner
School of Public Health
Faculty of Community and Health Sciences

Ethics Reference Number: BM20/1/17

Project Title: Exploring HIV positive adolescents' experience and perceptions of finding out their HIV status through the Mini Flipster disclosure method

Approval Period: 06 July 2020 – 06 July 2023

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report annually by 30 November for the duration of the project.

Permission to conduct the study must be submitted to BMREC for record-keeping.

The Committee must be informed of any serious adverse event and/or termination of the study.

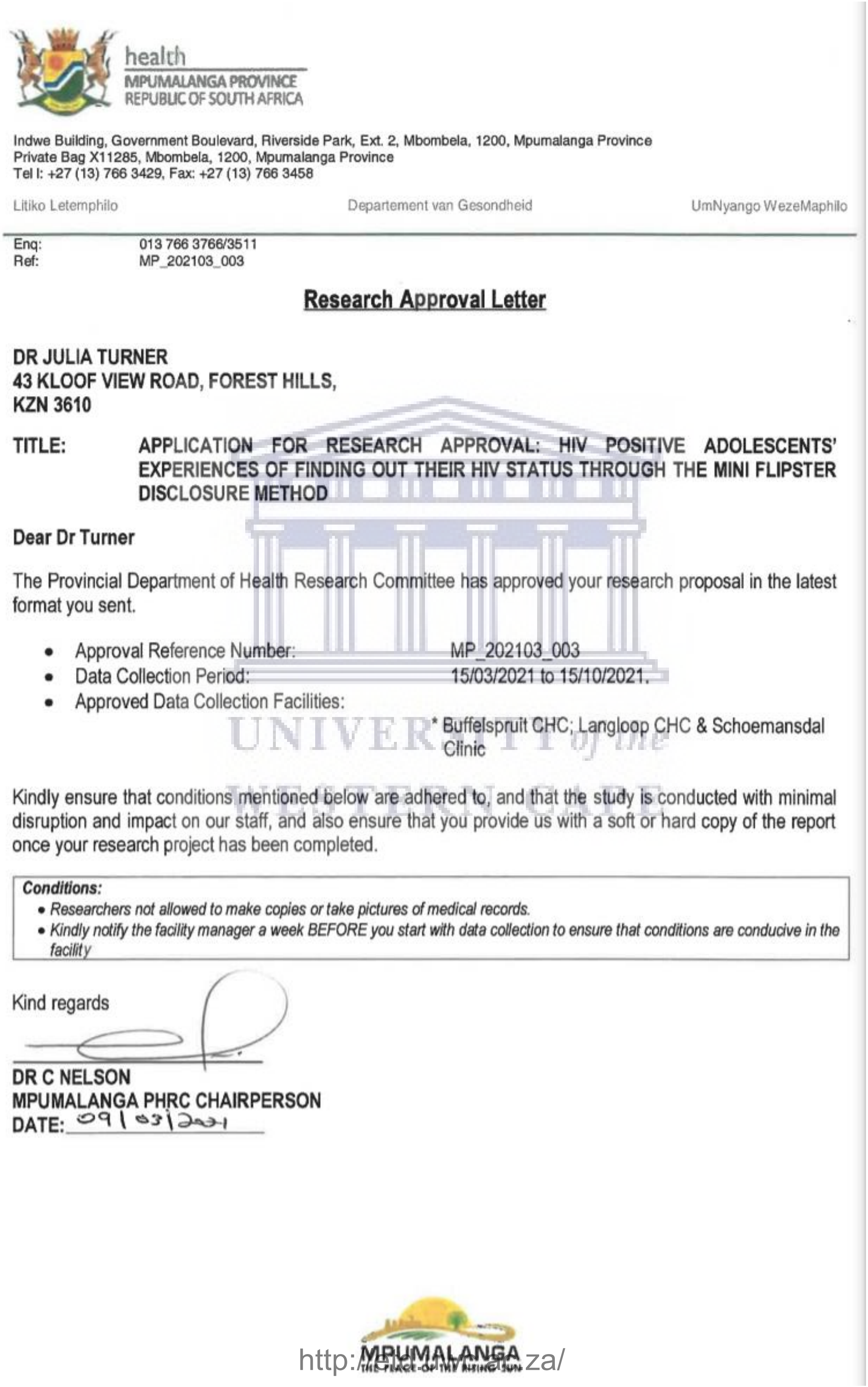
Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

Director: Research Development
University of the Western Cape
Private Bag X 17
Bellville 7535
Republic of South Africa
Tel: +27 21 959 4111
Email: research-ethics@uwc.ac.za

NHREC Registration Number: BMREC-130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

Appendix N: Research Approval Letter from Mpumalanga Provincial Department of Health



health
MPUMALANGA PROVINCE
REPUBLIC OF SOUTH AFRICA

Indwe Building, Government Boulevard, Riverside Park, Ext. 2, Mbombela, 1200, Mpumalanga Province
Private Bag X11285, Mbombela, 1200, Mpumalanga Province
Tel l: +27 (13) 766 3429, Fax: +27 (13) 766 3458

Litiko Letemphilo Departement van Gesondheid UmNyango WezeMaphilo

Enq: 013 766 3766/3511
Ref: MP_202103_003

Research Approval Letter

DR JULIA TURNER
43 KLOOF VIEW ROAD, FOREST HILLS,
KZN 3610

TITLE: APPLICATION FOR RESEARCH APPROVAL: HIV POSITIVE ADOLESCENTS' EXPERIENCES OF FINDING OUT THEIR HIV STATUS THROUGH THE MINI FLIPSTER DISCLOSURE METHOD

Dear Dr Turner

The Provincial Department of Health Research Committee has approved your research proposal in the latest format you sent.

- Approval Reference Number: MP_202103_003
- Data Collection Period: 15/03/2021 to 15/10/2021.
- Approved Data Collection Facilities:
  - * Buffelspruit CHC; Langloop CHC & Schoemansdal Clinic

Kindly ensure that conditions mentioned below are adhered to, and that the study is conducted with minimal disruption and impact on our staff, and also ensure that you provide us with a soft or hard copy of the report once your research project has been completed.

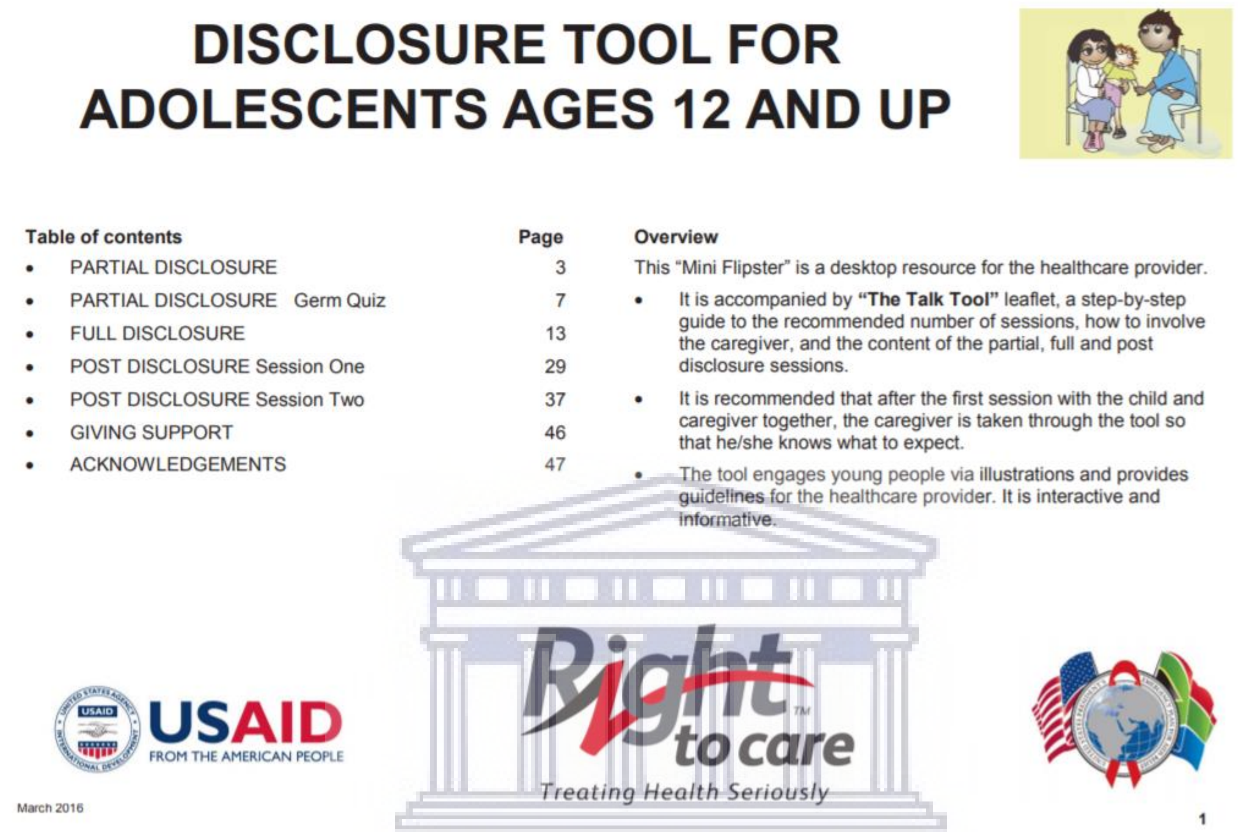
Conditions:
- *Researchers not allowed to make copies or take pictures of medical records.*
- *Kindly notify the facility manager a week BEFORE you start with data collection to ensure that conditions are conducive in the facility*

Kind regards

DR C NELSON
MPUMALANGA PHRC CHAIRPERSON
DATE: 09/03/2021

MPUMALANGA
THE PLACE OF THE RISING SUN

Appendix O: Examples of 'dialogue' and 'animation' pages from the "Mini Flipster Disclosure Tool for Adolescents Ages 12 and up"



DISCLOSURE TOOL FOR ADOLESCENTS AGES 12 AND UP

Table of contents **Page**

Overview

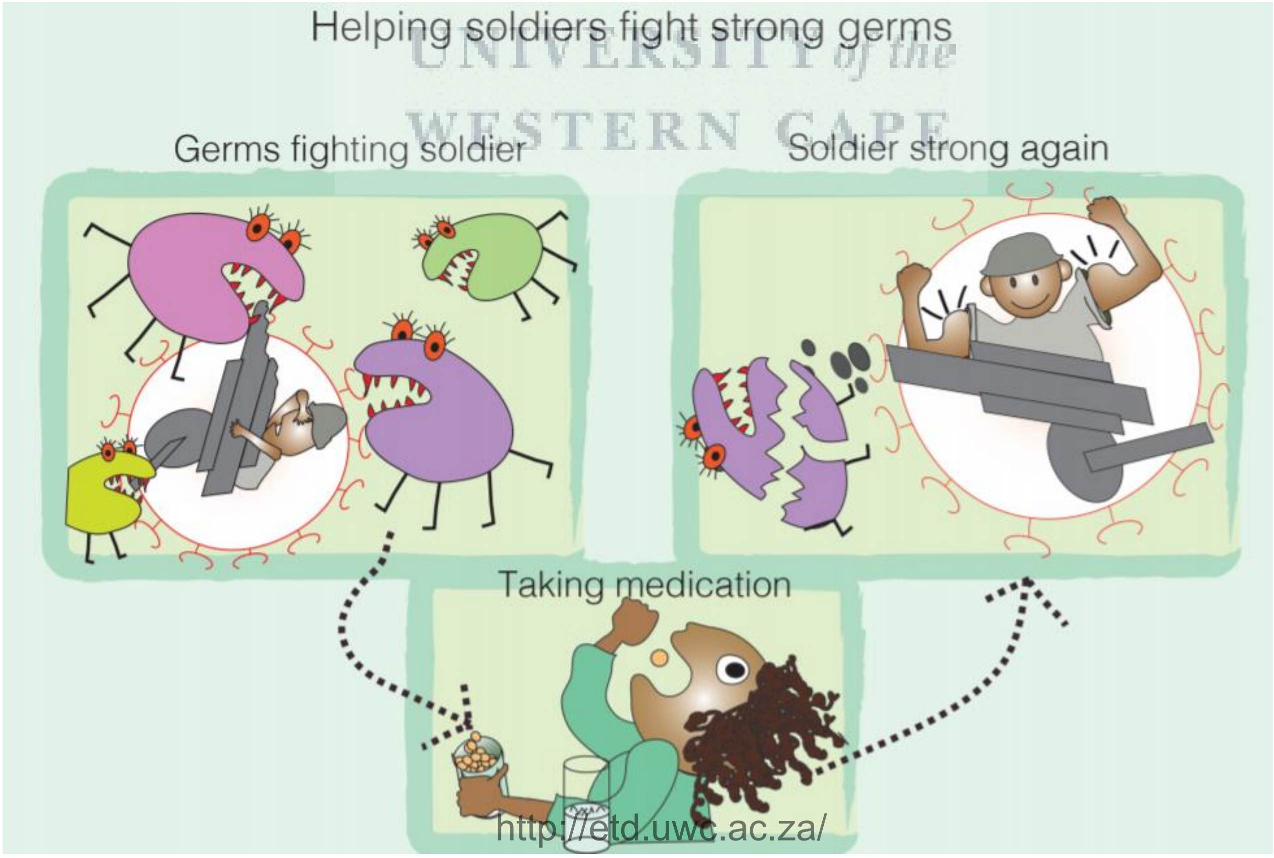
This "Mini Flipster" is a desktop resource for the healthcare provider.

- It is accompanied by **"The Talk Tool"** leaflet, a step-by-step guide to the recommended number of sessions, how to involve the caregiver, and the content of the partial, full and post disclosure sessions.
- It is recommended that after the first session with the child and caregiver together, the caregiver is taken through the tool so that he/she knows what to expect.
- The tool engages young people via illustrations and provides guidelines for the healthcare provider. It is interactive and informative.

USAID FROM THE AMERICAN PEOPLE

Right to care Treating Health Seriously

March 2016



FULL DISCLOSURE

healthcare provider / caregiver /child

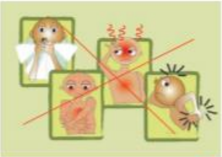
1 Do you remember what we talked about last time?

Allow the young person to answer.
If necessary remind the young person by saying: **"You were born with very few soldier cells in your body, so your body could not fight germs and you were getting sick. You are not sick now because your medicine is keeping your soldier cells strong so they can fight germs and keep you well"**

2 There are different kinds of germs. The germ that was killing the soldier cells (white blood cells) in your blood is called a **VIRUS.** You got sick often when you were small because you had this virus in your blood.

3 Today we are going to talk about the name of this virus. **What sickness do you know where the body can't fight germs so we get sick?**

Allow the young person to answer e.g. measles, flu and so on.
Note: If the young person mentions HIV straight away say: **"We are going to talk about that soon but first let's think about some different sicknesses together"**



4 You mentioned.....(**name the sicknesses).** Why do you think you don't have **......(name of sickness**)?

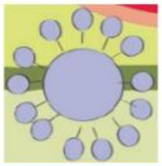
Give child time to answer

5 You don't have ....because ....

(refer to table and read what is written in column B corresponding to that disease)

Be prepared to respond appropriately if the illness named is not on the table or discuss one or two of the illnesses on the table if the young person can't think of any himself/herself.

A	B	C
ILLNESS	**RESPONSE-You don't have this sickness because...**	**MOST COMMON SYMPTOMS**
Influenza - "Flu"	Flu only lasts about 1 week.	Temperature, runny nose, headache, body aches.
Chicken Pox	The rash of chicken pox only lasts about a week.	Itchy rash, temperature for about a week.
Measles	The rash of measles only lasts about a week.	Rash on the body, white spots in the mouth, temperature, runny nose, red eyes and a dry cough.
Ear Infection	Only lasts a couple of months at most and we don't treat it for years.	Painful ear, discharge from the ear, headache, temperature.
Bronchitis	Children with bronchitis cough a lot and don't need treatment for many years.	Wet, phlegmy cough, painful chest when coughing.
Tonsillitis	You have a sore throat with tonsillitis and we don't treat it for years.	Sore throat, swollen glands, white spots on the tonsils, temperature.
Asthma	Asthma is common but it doesn't kill the soldier cells.	Cough, tight chest, wheeze and shortness of breath that comes and goes.
Cancer	Cancer and its treatment does kill the soldier cells, but the treatment also lasts a year or two.	Many different symptoms depending on the type of cancer.
TB	TB can weaken your soldier cells, and it could be that you have had TB, but you don't take medicine for TB for years and years.	Cough for a long time, night sweats and loss of weight.



6	So we have decided that it is not…….. **So then what else could it be?**	If the child mentions another illness refer back to **5** on previous page.
7	There is one illness we have not spoken about. **It is called HIV.**	**Note:** If young person has mentioned **HIV** earlier acknowledge this.
8	Let's talk about HIV. **Maybe you know a lot about HIV from school?**	Find out what the young person knows
9	**Ok, can you tell me how you think HIV makes a person sick?**	**Note:** if the young person is unsure, assist with information

---

10	HIV kills off the soldier cells, the white blood cells we spoke about that protect us from germs. **(Such as the flu germ or the TB germ etc.).** When the soldier cells in the body become too few they can't protect us from germs and we get sick. **Doesn't this sound like the story about germs and soldier cells we have talked about before?**	Allow the child to answer
11	Remember we said that HIV is a virus that kills off soldier cells in the blood. **Could this VIRUS in your blood be HIV? What do you think?**	**Note:** If the young person still does not think it is HIV ask: **"Why not?"** Take note of the responses and say: **Okay, let's talk a bit more about HIV.** Continue with discussion below.
12	**Is there a treatment for HIV?** **Does it work well?**	Encourage the young person to respond.

13

Yes, there is a medicine that works very well. It works so well that people who have the HIV virus in their blood and who take their medicine every day are well and fit and live normal lives. You won't be able to tell if a person has HIV.
They don't look sick and they don't feel sick because the medicine makes sure their army of soldier cells stays strong.

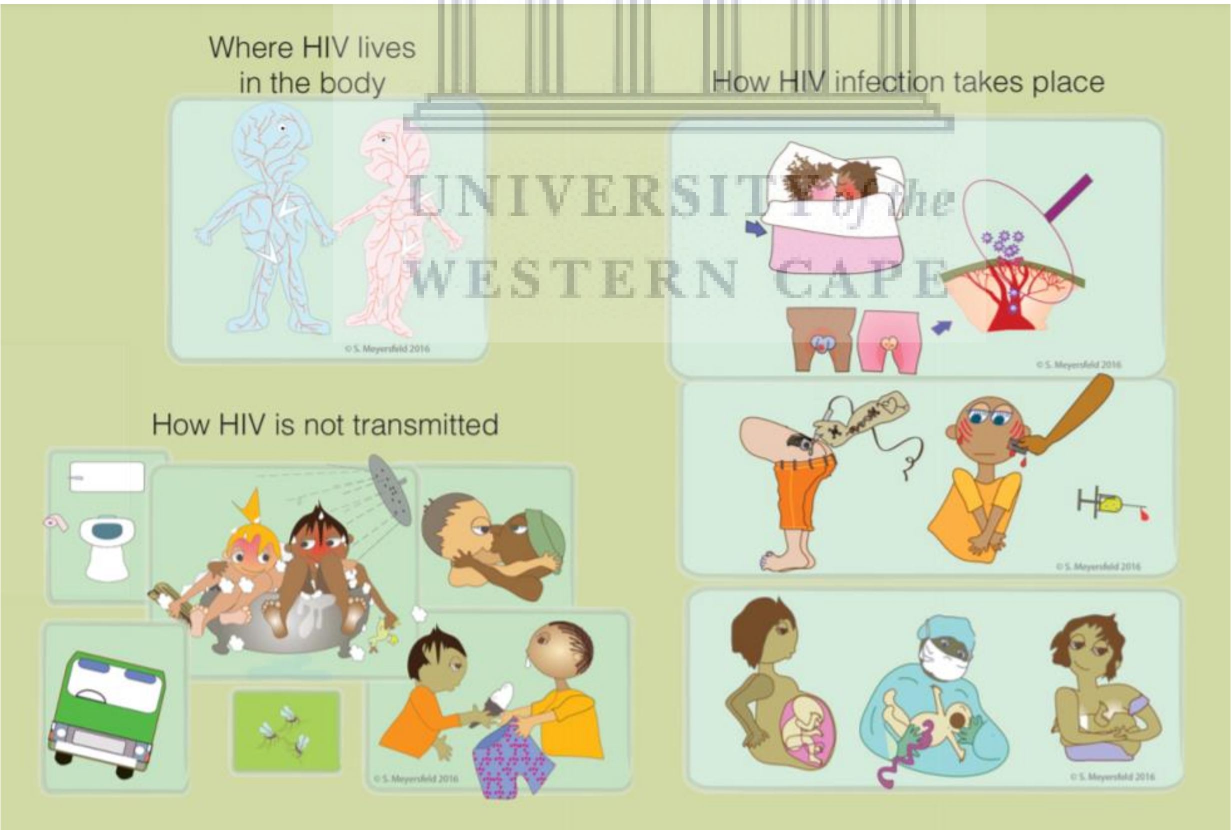
So you are taking medicine every day and you are not sick.
You feel well. **Could this be HIV medicine?**

Encourage young person to respond. If young person says **"No"**, say: **Ok we will talk about that again a little later**

14

Let's talk about where people get HIV from ?

Allow the child to answer and provide information: e.g. needle sharing, tattoos, scarification, having sex without a condom.



15

Many mothers and fathers in the world have the HIV virus. Mothers can pass the virus on to their child during pregnancy, in childbirth or when the mother is breast feeding. But it is nobody's fault, not the mother or the father.

So let us see now. We said you have a germ or VIRUS in your blood that can kill your soldier cells so you will get sick. We agreed that the HIV VIRUS can kill the soldier cells in a person's body so they get sick.

You told me that you are not sick, but you are taking medicine. We talked about HIV medicine that works so well it keeps a person healthy for years and years. When a person takes this medicine they are well, just like you.

We agreed that there are many ways an adult or young person can get the HIV virus.

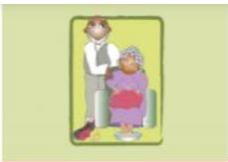
So, what do you think?
Could this virus that you have be the HIV virus? What do you say Mama /Gogo?

Irrespective of the young person's answer to questions regarding the possibility of this being the HIV virus, ask mother or caregiver to confirm that this is HIV.

Remember that according to the South African Guidelines the final disclosure should be done by the caregiver. Support the caregiver to tell the young person that he or she has the HIV virus and is taking medication to keep him or her strong and healthy.

The caregiver must be prepared for this stage in the process.
See "Talk Tool" Session 2

If necessary and if this has been agreed beforehand the healthcare provider can disclose to the young person at this point. It is very important to read **page 46** in preparation in order to contain and reassure the young person. Allow the young person time to take in the new information. Contain the reaction with empathy.



16

Today you have learned that the virus called HIV is living in your body. You might feel scared, or sad or shocked right now.
It is quite normal to have these feelings.

Give the caregiver an opportunity to interact with the child

17

Your gogo/mother/father wants you to know that you have HIV even though it might be hard to think about right now.
She/he cares about you so much that s/he wants you to know why you must visit the clinic and why it is important to take medicine.
S/he cares about you so much that s/he wants you to stay well.

Invite input from parents/grandparent

18

Do you know that people used to be very scared of HIV?
People used to think it was a very strong virus and that people with HIV would not live long.
But now we know that is not the case. These days people can live until they are old (Gogos or grandfathers) as long as they take their medicine.

5

Rather you must have lots of soldier cells.
The soldier cells we have been talking about have another name too, they are called CD4 cells. What the doctors/ nurses want to see is a high CD4 count because that means you have lots of strong soldiers to keep you well. You can make sure your CD4 count is high if you take your medicine every day.
How long do you think that a person who has HIV can live?

Allow young person to answer.
Remember that young people may have a family member or parent who has died from AIDS so check the reason for their answers and provide information if necessary
e.g. "Sometimes a person does not find out until it is too late that they have the virus in their blood. When this happens the medicine might not work."

6

People used to be very scared of HIV. They used to think it was a strong virus and that people who had it in their blood would die. But that is not true. If you take your antiretroviral medicine every day you can live a long and normal life.
Young people like yourself would also worry that they could not become mothers and fathers one day because maybe the baby would get the HIV virus. These days a person with HIV can have a family of their own if they want. As long as a person is taking his/her medicine properly, he/she cannot pass the virus onto their partner or to the baby. A nurse/ doctor can guide a person on how to safely have a baby without HIV.

7

Do you remember from the last time that we talked about support.

What kind of support do you think is important?

Encourage the young person to respond.
*Explain that it is **good to have support** so the young person can remember to take medicine.*
Discuss how mother/caregiver and young person can be a ***winning team*** where everyone works together to keep the soldier cells (white blood cells) strong.
Ask the young person and caregiver for ideas on working together.

8

Yes, it is very important for a young person like yourself to know that you have support.

Is there maybe another person you would like to tell about your HIV?

Note:
If the young person says there is **nobody else** he or she would like to share this information with, **affirm that he or she has the right to decide who should know his/her HIV status** and nobody can make a person tell their status if they do not want to.

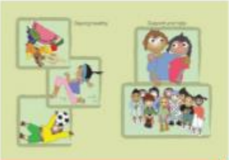
If the young person indicates that **there is someone** they would like to tell explore the reasons and decide together if **this is a person they can trust** – a person who will understand and help.

Bring the session to a close:

Check if the young person has any questions.
Make an appointment for a second post disclosure session.

POST DISCLOSURE

Session Two



7

A person with HIV can live a long and healthy life if they take their medication, eat well and exercise.

Ask the young person what they see for themselves in the future e.g. **university, a job, a car. Encourage the young person towards his or her goals**

8

Yes, as long as you take your treatment HIV can't stop you from having these things. They are all possible. You can be in a relationship, you can have HIV negative babies one day. You can succeed in your studies. You can live until you are old.

Before moving on to the next discussion ask the young person if there is anything else she/he would like to know. Provide information where necessary

9

Remember that last time we met we talked about support. People need support so they don't feel alone. They need support so they can get advice and information when they need it; so they can share and learn from others and talk about the things that worry them or make them sad.

Ask the young person how he or she is supported.

POST DISCLOSURE

Session Two

10

There are many different kinds of support for example a parent or caregiver or a trusted adult. **Another kind of support is a support group.**

Ask the young person what they know about support groups .

11

At this clinic we have a support group where young people of your age can come together to talk about many things.

Ask the young person if they would like to hear more about the group.
Suggest that they might like to find out more by attending a session.
Refer to group if the young person would like to attend.
Ensure that all the necessary information is provided: time, place and so on.

If a group is being run at the facility and it is possible to ask the group facilitator to join the post disclosure discussion to explain more about the group to the young person, this would be ideal.

Note: If the facility does not have a group this section can be left out. The healthcare provider can discuss other supportive networks e.g. within the community

12

As well as a support group it can be good to talk to a counsellor. If you like I can make an appointment for you to see a counsellor on your own.

Make an appointment for one-on-one counselling if the young person indicates that s/he would like this