UNIVERSITY OF THE FREE STATE

FACULTY OF HEALTH SCIENCES

DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH

TITLE: THE DISCLOSURE OF HIV STATUS TO VERTICALLY INFECTED HIV POSITIVE CHILDREN BEFORE THE AGE OF 12 YEARS AT PELONOMI CENTRE OF EXCELLENCE

Submitted in fulfilment of the requirements in the Master's Degree MMed in the Department of Paediatrics in the Faculty of Health Sciences at the University of the Free State.

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DECLARATION

I, Tshepho Lesiba Laurence Bodiba, declare that the coursework Master's Degree mini-dissertation that I herewith submit for the Master's Degree qualification MMed Paediatrics at the University of the Free State is my independent work, and that I have not previously submitted it for a qualification at another institution of higher education.

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ABSTRACT:

HIV is a chronic infection which, although cannot be cured, can be controlled with life-long treatment, provided there is good adherence. Good adherence requires a holistic approach. The patients need to have adequate food, good social support system and participation in their treatment decisions. The lack of any of the above-mentioned factors can have deleterious effects. This is particularly a problem in children. Adherence is dependent on the carer when they are still young. Once they get to teenage years, they start asking questions. The National Department of Health has provided guidelines on step-wise disclosure for children. This study explored the prevalence of disclosure to vertically infected children from 6 to 18 years of age.

The study was conducted in a South African tertiary hospital paediatric HIV clinic in Bloemfontein, Pelonomi Hospital. Data was collected in the form of a questionnaire, which was completed by the caregiver, and in those that met the criteria the children filled a different section. Convenient sampling method was used.

The results showed a better outcome (76% disclosure prevalence, 65% being full disclosure), compared to the other studies (Western Cape, South Africa, 23.7%, 2019 and Zimbabwe, 29.6%, 2019). The difference in the level of care of the current study compared to the previous studies, which were mostly primary level of care, could contribute to the results as well. Of note is that the patients in this study were complicated patients, most of whom were on second line treatment.

The suggested average age of disclosure by the children themselves was 12, which is higher than the South African guidelines of full disclosure by the age of 10 years. The best person to disclose and the place where it should be done was also suggested by the children. This study augments the platform that has been set for the authorities to implement a disclosure program into paediatric HIV care.

KEYWORDS:

HIV (Human Immunodeficiency Virus)

PMTCT (Prevention of Mother-To-Child Transmission)

HIV Status Disclosure

Treatment Adherence

HIV in Children

ARV (Antiretroviral)

AIDS (Acquired Immune Deficiency Syndrome)

ALHIV (Adolescents living with HIV)

Vertical Transmission

Paediatric HIV

ABBREVIATIONS

HIV:	Human Immunodeficiency Virus
AIDS:	Acquired Immune Deficiency Syndrome
PMTCT:	Prevention of Mother-To-Child Transmission
MTCT:	Mother-To-Child Transmission
eMTCT:	Elimination of Mother-To-Child Transmission
ALHIV:	Adolescents living with HIV
ART:	Anti-Retroviral Treatment
ARV:	Anti Retroviral
WHO:	World Health Organisation
PCG:	Patient Caregiver
HCP:	Health Care Professional
IMCI:	Integrated Management of Childhood Illnesses
PICT:	Provider Initiated Counselling & Testing
COE:	Centre of Excellence
FSDOH:	Free State Department of Health
UFS:	University of the Free State
HSREC:	Health Science Research Ethics Committee

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EXECUTIVE SUMMARY

HIV (Human Immunodeficiency Virus) has now become a chronic condition that can be controlled and no longer is a death sentence. Mother-to-child transmission (MTCT) of HIV, even though markedly reduced by the Prevention-of-mother-to-child transmission (PMTCT) programs, still remains a reality for various reasons. This, together with the pre-PMTCT infections, means that we now have a growing population of adolescents living with HIV (ALHIV). The challenge lies in following the age appropriate disclosure at each contact, and providing support to the carer with disclosure related issues.

The South African Department of Health has given clear guidelines on disclosure; however, it remains a challenge as there are many issues to be considered. It has been proven beyond reasonable doubt that disclosure of HIV status to children has positive effects on their psychosocial well-being, adherence to treatment and survival. This includes disclosure to the child about his/her own HIV positive status as well as the parent's/caregiver's status.

The literature review in this mini-dissertation explores the different studies that have been conducted, mostly in South Africa, and their outcomes regarding disclosure age of HIV status to children. This study mainly served to adequately define the problem in our setting, so that the authorities can appreciate the magnitude of the challenge in order to mobilise resources to address the problem.

Chapter 1

INTRODUCTION & LITERATURE REVIEW

Disclosure is the first step for children transitioning into adolescents and young adults who successfully manage their own HIV care[1]. This implies that a good approach to disclosure will most likely drive the success of the treatment in children and adolescents.

Disclosure Guidelines

South African Department of Health has developed extensive guidelines for disclosure, which elaborates. This document provides step by step description of addressing disclosure to children. Disclosure has been divided into a 4-step process[2]:

1. Preparation and planning
2. Assessment and disclosure plan
3. Appropriate disclosure and health promoting task
4. Follow up and support

In each counselling session, the 7-step process should be followed. The health care worker should listen more to the child as this will give a good indication of the knowledge of the child and degree of maturity. Of importance is to have extensive knowledge on HIV, the legal aspects of working with children and a deep understanding of the disclosure process. They must also be prepared to answer questions in an age appropriate language[2].

The table below shows levels of disclosure, which is a gradual process, taking the child's context into consideration:

Disclosure Level	Definition
Non-Disclosure Age: Less than 3 years	The child is unaware of their illness and its effect on their body.
Partial Disclosure Age: 3 to 9 years	The child is made aware of their illness without actually naming HIV.
Full Disclosure Age: 10 years and older	The child is made aware of their illness which is named as HIV. Aimed to be by the age of 10.

Health Promoting Disclosure	The child knows everything about their 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 nondisclosure to the stage of health-promoting disclosure within a children's rights framework.

Disclosure levels[2]

Legal and ethical considerations

The child care act (Children's Act Children's Act (No. 38 of 2005) as amended by children's Amendment Act (No. 41 of 2007) states you may not disclose a child's HIV status without the consent, unless the child is being tested because there is a suspicion that a healthcare worker may have contracted HIV through contact with the child[3]. It is the only instant in the Act, where the "best interest of the child" does not come first. The ultimate goal of these guidelines is optimal disclosure, which that is prepared, health-promoting, age-appropriate, takes place within a supportive and enabling environment and is handled according to the complexity of the situation[2].

Background

Mother to child transmission

Second to unprotected heterosexual sex (which accounts for 90% of HIV infections), mother to child transmission of HIV is responsible for the highest HIV incidence in sub-Saharan Africa each year[4]. Approximately 90% of HIV infections in children are a result of vertical transmission from a mother to her infant[4].

Elimination of mother-to-child transmission

Elimination of mother-to-child HIV transmission (eMTCT) is now viewed as a realistic public health goal, even for countries with limited resources[5]. Research has shown that provision of the most effective ARV regimen for HIV-positive pregnant women can reduce the risk of vertical infection of HIV to less than 2% in non-breastfeeding mothers and to 5% in breastfeeding mothers[5]. PMTCT ARV coverage for Sub-Saharan African countries in 2012 was reported at 65%, well below the 90% global target[6]. South Africa has made big strides and is close to achieving the goal of providing ARV regimens to 90% of pregnant women living with HIV. The PMTCT service coverage for South Africa was reported at 83% in 2012[6]. In 2017, the coverage was estimated to be more than 95% (76 to >95%)[7]. The aggressive expansion of the PMTCT program was followed by a reduction in vertical transmission of

HIV and a significant reduction in the infant and child mortality rate by 55% from 2009 (45 per 1000) to 2020 (25.7 per 1000)[8].

Disclosure studies

A study that was conducted in the Western Cape province of South Africa in 2019 showed HIV status disclosure prevalence of 23.7% among children from 3 to 14 years of age[9]. Even though there are no national targets for disclosure prevalence, 23.7% is quite low. An older study in South Africa conducted in 2013 showed that the average age of disclosure of HIV status to children in South Africa is well above the recommended 10 years as per South African guidelines[10] In another South African study in 2015, health care workers suggested a wide range of appropriate ages for disclosure, and a large proportion suggested an age above 10 years of age[11]. None of the South African studies on disclosure was conducted in the Free State province.

According to a National department of Health survey, the reasons for the low disclosure rates in South Africa are as follows[12]:

1. Patient caregiver (PCG) issues:
   - Fear of the emotional effects of disclosure on the patient[13].
   - Fear of the consequences of disclosure to others e.g. the child then discloses to family and community[13]. This indirectly discloses the mother's HIV status if the caregiver is the biological mother.
   - Issues of guilt, blame and shame[10].
   - PCGs are, by definition, not always biological parents.

2. Health Care Professional (HCP) issues:
   - Lack of access to policies or guidelines to assist them in the disclosure process[14].
   - HCPs often miss the opportunity to educate PCGs about the importance of disclosure and the disclosure process[15].
   - Lack of staff, skills and tools to provide age-appropriate counselling services to children[14].

3. Health systems issues[12]as identified by the National Department of Health:

- Poor implementation of available policies and protocols (e.g. Integrated Management of Childhood Illness (IMCI), Provider-Initiated Counselling and Testing (PICT) to identify

Children and Adolescents Living with HIV within facilities and communities

- Lack of Child and Adolescent-Friendly Spaces to provide appropriate disclosure services.
- Poor referral and linkage systems to strengthen disclosure processes between facility and community level.

In Romania, it was shown that the risk of death is reduced by half over a 3-year period in children whose status had been disclosed. The improved outcome was attributed to better access to treatment and improved adherence[16]. In a meta analyses of two studies in France and Zambia, psychological stress was less reported in children whose status had been disclosed, once again showing disclosure does not only reduce death, but improves quality of life[17,18].Literature suggests that disclosure has to be done in a step-wise, age appropriate manner according to the child's cognitive and emotional maturity[15].

Ideally, with the progress that has been made in HIV research, the MTCT of HIV should have been eliminated by now. Goga et al showed that the national risk of intra-uterine MTCT was 0.9%, which translates to 245 HIV-positive neonates per 100 000 live births[19]. This suggests that a lot of effort still needs to be put in to reach elimination of mother to child transmission. It should therefore be anticipated that there will still be vertical infections until such time that EMTCT has been achieved.

This therefore raises the need to optimise the treatment provided for such children so that complications can be prevented and their dignity and quality of life can be restored. Provision of antiretroviral therapy (ART) is only one aspect of the approach to treatment. Psychosocial wellbeing plays a role of utmost importance and has a great influence on the success of the ART. Disclosure of HIV status to a child directly impacts his psychosocial wellbeing[18]. Whether disclosure is currently done in the study population in a step-wise approach and acceptable manner to children is not known.

HIV disclosure in children remains a challenge as there are many obstacles, ranging from health care system failure, patient and caregiver issues as well as health care worker related obstacles. Research has been conducted in different areas of South Africa, and that has proven that we are still a long way from meeting the SA target of full disclosure by the age of 10 years[20,10].

Since the effective roll out of ARVs, paediatric mortality has improved and HIV vertically infected children are living into adulthood[21]. According to UNAIDS[22] statistics, there was an estimated 240 000 children who were HIV positive in South Africa in 2015 It was 369 000 in 2012[12]. For these children, the reality is a lifelong commitment to ARV treatment. Mother-to-child transmission caused 12 000 (9600 - 22 000) new infections in children, with a total of 270 000 children living with HIV in 2016[7].In 2018, an estimated 260,000 children (aged 0 to 14) were living with HIV in South Africa, 63% of whom were on treatment[7].

The key challenges regarding disclosure of HIV status to children were identified as follows:

- The HIV related stigma,
- Social factors (changing caregivers and caregiver roles, vulnerable caregivers, institutionalised children),
- Concomitant co-morbidities, and
- Lack of counselling skills, both from caregivers and health care workers[15].

Disclosure that is not tailored to the child's development and understanding of illness and the effects of medication can have a negative impact, just as non-disclosure[15]. A child's understanding is not synchronous with age and disclosure has to be tailored to the cultural context of the child. In terms of the bearer of the news to the child, there is no literature that compares disclosure by a health care worker versus disclosure by a caregiver, or the characteristics and qualities of a person who is eligible to disclose the HIV status to the child. It has, however, been stipulated that the health care worker is more in favour of full disclosure and the caregiver more in support of the step-wise approach. The wellbeing of the child should be born in mind in making such decisions[15].

In a 2015 study that was conducted in South Africa, Madiba and Mokgatle[11] had assessed the perception of disclosure from the health care worker and majority of the health care workers believed it was the responsibility of the caregiver to disclose to the child. The role of the health care worker is to support the caregiver through the process, empowering them with information so that they are prepared to answer even the embarrassing questions that the child might ask regarding the disease[11,15]. The recommended age of disclosure was below 10 years by half of the health care workers, and above 10 years by the other half. It would have been interesting to know the cultural background of the participants, and see if there was any influence on the age recommended age of disclosure.

In a 2013 study on HIV disclosure among South African children, 40% knew their status. Of these, 50% learned of their HIV status between the ages of 11-17 years, 44% were between the ages of 6 to 10 and only 5% below the age of 6[10]. The prevalence of disclosure has not improved when compared with later studies[9]. In a qualitative multi-centre study in South Africa and Botswana, all caregivers to HIV positive children whose statuses were not disclosed, felt that it was good practice to disclose, and some of the reasons above were quoted as the challenges[20]. This shows that if support and guidance is provided by the health care worker, disclosure will be possible at the appropriate age. In a study conducted in Ghana, children preference for early disclosure averaged at age 10, despite the initial disclosure experience of shock and disappointment[21]. There was improved medication adherence despite the challenge of limited knowledge about HIV transmission, financial difficulty and food insecurity[21].

In a Cape Town based study in 2006, Moodly et al[22] found that only 26% of the patients above 6 years knew their HIV positive status. These results are similar to a recent study in Western Cape[9]. This shows that disclosure has not improved in the past 13 years. In this study, caregivers saw disclosure to their children as primarily their responsibility, but most needed the health care worker's support in the process. However, only 25% of the caregivers had initiated discussion of disclosure issues with a health care provider[19]. Greater attention to the issues surrounding disclosure of HIV status to children is needed to improve the care of this vulnerable group[19].

With regard to the person disclosing to the child, a study conducted in Zimbabwe in 2019 demonstrated that 76% reported being the one to disclose to the child[23]. Out of that group, 33% of the caregivers prepared the child to receive the information, most of whom requested help from the healthcare worker, and some from friends and family[23]. Majority of the caregivers in this study felt that disclosure was very good for them and the child[23]. In the same study, only 17% of children knew how they were infected with HIV and that they can infect others.

The ARV coverage in South African children aged 0 to 14 years was 13% in 2010 and 44% in 2013[24]. In 2018 there was an estimation of 270 000 children living with HIV in South, of which 63% were on ARVs[5]. This shows progressive improvement with the target being 90% coverage. South Africa is showing progress to reaching the UNAIDS 90–90–90 Fast-Track targets by 2020. "The aim of this strategy is to ensure that 90% of people living with HIV are tested and know their status, that 90% of people living with HIV are receiving treatment, and 90% of people on treatment have a suppressed viral load[25]". To achieve the 90% of viral suppression disclosure prevalence will need to be improved.

Disclosure policy at Pelonomi Centre of Excellence

At the time of the study, there were no institution specific disclosure guidelines at the centre. The national guidelines we followed where possible.

RESEARCH QUESTION

This was the first study in the Free State Province that explored the disclosure patterns and compared the findings to the rest of the country, where there have been such studies. It was also determined from the HIV positive children themselves what the recommended age of disclosure should be. This was only done in retrospect on those children who were cognitively matured and already knew their status and older than 12 years.

AIMS AND OBJECTIVES

AIM

The aim of the study was to calculate the prevalence of HIV status disclosure in the two different age groups (6-12 years and 12-18 years) and obtain the suggested disclosure age from the patients themselves (for those who already knew their status, and were above the age of 12 years at the time of the data collection), while some of the challenges related to disclosure were identified.

THE OBJECTIVES WERE TO:

- Determine the prevalence of disclosure and non-disclosure of HIV status to children from 6 – 12 years. In this case age appropriate partial disclosure (age-appropriate) was regarded as disclosure.
- Determine the prevalence of disclosure and non-disclosure of HIV status to children from 12 – 18 years. Disclosure was regarded as full disclosure in this case.
- Determine the reasons for non-disclosure of HIV status to the children from 6 – 12 years and 12 – 18 years.
- Determine the appropriate age of disclosure from the children who knew their status (above 12 years of age)
- Determine the most appropriate person to give the news, based on the patients' own experience.

HYPOTHESIS

The study aimed to prove the hypothesis that disclosure of HIV status to vertically infected children was done much later than the recommend 12 years of age.

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Chapter 2

DISCLOSURE OF HIV STATUS TO VERTICALLY INFECTED CHILDREN AT PELONOMI CENTRE OF EXCELLENCE

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Competing interests

None

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ABSTRACT

Background: HIV status disclosure is an important step in growing children and adolescents as they begin to manage their own medication. Non-disclosure has been associated with poor treatment adherence, virological failure and poor outcomes.

Objectives: This study explored the prevalence of disclosure to vertically infected children from 6 to 18 years of age.

Methods: This was a cross-sectional descriptive study, conducted in a South African tertiary hospital paediatric HIV clinic in Bloemfontein. Data was collected in the form of a questionnaire, completed by the caregiver, and in some; the children completed a different section. Convenient sampling method was used.

Results: The results showed a higher prevalence of disclosure of 76%, as compared to the preceding studies. This has several possible reasons. Firstly, these studies were conducted in different eras, which could indicate that the stigma surrounding HIV infection has improved. Secondly this study was conducted at a tertiary level facility while the previous studies were mostly conducted at primary care level. Lastly, the patients included in this study were complicated patients, most of whom were on second line of treatment.

Conclusion: The suggested average age of disclosure by the children themselves was 12, which is higher than the SA guideline of 10. The best person to disclose and the place where it should be done was also suggested by the children. This study serves to identify preventing disclosure as per SA guidelines. This will assist authorities to better implement disclosure program into paediatric HIV care, with the ultimate goal of achieving higher disclosure prevalence.

INTRODUCTION

Disclosure is the first step for children transitioning into adolescents and young adults who successfully manage their own HIV care[1]. This implies that a good approach to disclosure will most likely drive the success of the treatment in children and adolescents. The South African disclosure guidelines recommend that children are disclosed to prior to the developmental age of 10 years[2]. Provision of anti-retroviral therapy (ART) is only one aspect of the approach to treatment. Psychosocial wellbeing plays a role of utmost importance and has a great influence on the success of the ART and disclosure of HIV status to a child directly impacts his psychosocial wellbeing[2].

It is recommended that children should get a step wise disclosure from the age of 3 years, with full disclosure by the age of 10 years. This has to take the child's maturity into consideration[2]. Disclosure that is not tailored to the child's development and understanding of illness and the effects of medication can have a negative impact, just as non-disclosure[3]. A child's understanding is not synchronous with age and disclosure has to be tailored to the cultural context of the child. There are different stages of disclosure and acceptable age (cognitive): non-disclosure up to 3 years, partial disclosure from 3 to 10 years and full disclosure from 10 years and above[2].

A study that was conducted in the Western Cape province of South Africa in 2019 showed HIV status disclosure of 23.7% among children from 3 to 14 years of age[4]. Even though there are no national targets for disclosure prevalence, 23.7% is quite low. With regard to the person disclosing to the child, a study conducted in Zimbabwe in 2019 demonstrated that 76% of caregivers reported being the one to disclose to the child[5]. Out of that group, 33% of the caregivers prepared the child to receive the information, most of whom requested help from the healthcare worker, and some from friends and family[5]. Majority of the caregivers in this study felt that disclosure was very good for them and the child[5]. In the same study, only 17% of children knew how they were infected with HIV and that they can infect others.

In terms of the bearer of the news to the child, no literature was found that compares disclosure by a health care worker versus disclosure by a caregiver, or the characteristics and qualities of a person who is eligible to disclose the HIV status to the child. It has, however, been stipulated that the health care worker is more in favour of full disclosure and the caregiver more in support of the step-wise approach[6]. The wellbeing of the child should be born in mind in making such decisions.

The key challenges regarding disclosure of HIV status to children were identified as follows[6]:

- The HIV related stigma,

- Social factors (changing caregivers and caregiver roles, vulnerable caregivers, institutionalised children),
- Concomitant co-morbidities, and
- Lack of counselling skills, both from caregivers and health care workers[6].

Aim:

The aim of the study was to calculate the prevalence of HIV status disclosure in the two different age groups (6-12 years and 12-18 years) and obtain the suggested disclosure age from the patients themselves (for those who already knew their status, and were above the age of 12 years at the time of the data collection), while some of the challenges related to disclosure were identified.

The objectives were to:

1. Determine the prevalence of disclosure and non-disclosure of HIV status to children from 6–12 years. In this case age appropriate partial disclosure was regarded as disclosure.
2. Determine the prevalence of disclosure and non-disclosure of HIV status to children from 12–18 years. Disclosure was regarded as full disclosure in this case.
3. Determine the reasons for non-disclosure of HIV status to the children from 6–12 years and 12–18 years.
4. Determine the appropriate age of disclosure from the children who knew their status (above 12 years of age)
5. Determine the most appropriate person to give the news, based on the patients' own experience.

STUDY METHODS

Study design

This was a cross-sectional, descriptive study with the questionnaire as the data collection tool. This study method was ideal for this project as it did not require a lot of time and contained multiple variables. The cost of conducting the study was also minimized.

Study setting

The clinic runs on Mondays and Wednesdays. On each of the clinic days, approximately 25 patients fall within the study age group. The patients' waiting period is estimated to be 1 to 3 hours before leaving the clinic. They arrive and report to the nursing staff, their appointments are confirmed and files obtained. Some patients go directly to the pharmacy after getting the files, while others wait for consultation with the doctor.

While patients were waiting, consent was obtained and data collected. Data was collected before and/or after consultation. This required the appointment of a research assistant for 1 month, twice a week, working from 8 am until 11 am. The research assistant is a trained HIV counsellor and could therefore assist with questions the caregivers or patients might have had during the consultation.

The caregiver was called to the consulting room while the child was waiting in the waiting area under the supervision of nursing staff. The child would only be called in if he/she had been disclosed to and would be participating in the study, after the caregiver had finished filling in the questionnaire.

Study population

The population included in this study was HIV positive children from the age of 6 up to 18 years, who were on HIV treatment at Pelonomi Centre of Excellence (COE) at the time of data collection. This clinic serves as referral centre for all complicated cases of paediatric HIV in central South Africa. Therefore, patients who are newly diagnosed do not fall into the scope of the clinic services and were not included in the study population.

According to the records at the clinic, 381 children are treated at the clinic with the number of children between 6 and 18 years estimated at 285.

Inclusion criteria:

- Children between the age of 6 to 18 years
- Proven HIV positive status
- Patient receiving HIV treatment at Pelonomi Centre of Excellence

- Caregiver was available to give consent
- Children who were able to provide assent
- The caregiver that brought the child at the visit of data collection must have brought the child at the previous two visits as well

Exclusion criteria

- Patient age not within the 6 - 18 years age group
- The parent/caregiver was not present or was unable to provide consent
- Patient was not able to provide assent

Sampling

The convenience sampling method was used. Every patient that presented to the clinic during the period of the data collection was requested to participate in the study. Patients' names were not captured on the questionnaires in order to maintain confidentiality.

Sample size

A sample size of 120 patients was anticipated, however, due to most patients requiring assistance to complete the questionnaire, the sample size was then reduced to 52.

Measurements and data collection

The researcher, being a registrar in the Department of Paediatrics and Child Health, was not available at the time of data collection. A research assistant was therefore appointed to collect data with the help of the doctors and the nursing personnel at COE.

The research assistant that was appointed was an individual with basic medical knowledge, HIV trained counsellor with understanding of confidentiality as this study involved information of a sensitive nature. The research assistant was not a full time professional appointed in the department of health. The study supervisor is the consultant in charge of the clinic and assisted with overseeing and supervision to the research assistant.

This study used the survey type of measurement with a questionnaire as the data collection tool. The questionnaire was divided into 2 sections, A and B. Section A was completed by the caregiver, and if the child was above 12 years of age and knew their status, then the child completed section B. The questionnaires were filled mainly by the caregivers/children themselves, however, assistance with completion of the questionnaires was provided by the research assistant whenever necessary. The questionnaires were available in English, Sesotho and Afrikaans. The study was conducted over two weeks, with the research assistant based at COE.

Measurement Errors

- Questionnaire error: Ambiguous questions on the questionnaire

  This error was reduced by first piloting the questionnaire and questions were adjusted accordingly. The size of the pilot was 5 patients and the questionnaire was reviewed after the results of the pilot. The data from the pilot was included in the main study.

- Data transfer error: Entering the data onto the computer.

  The double entry data verification system was used to ensure that the data was accurately entered in the computer for statistical analysis.

- The pilot questionnaires were entered on the Excel spreadsheet to run a trial of the data analysis.

Bias

- Non-responder bias

  Patients who default their clinic dates and treatment were likely to be reluctant to participate.

  All patients and their caregivers were assured that the questionnaires are anonymous.

- Selection bias

  The patients attending COE represent a very specific group of complicated paediatric HIV cases.

  Excluding patients who came without a caregiver or with different caregivers at each visit could possibly select for more adherent patients who were more likely to disclose

- Drop out bias

This type of bias was a possibility, but not likely. The patient could decide not to complete the questionnaire fully.

Possible confounders/Limitations

- Caregiver

  Some patients were brought by caregivers who were not well informed about the patient's condition on the day of the data collection. This was reduced as follows: the caregiver who filled in the questionnaire had to be the same one who brought the patient the previous two visits.

- Psychological response to disclosure

  Some patients could have been disclosed to but in denial at the time of the data collection. This could affect the results of the study. The date of disclosure was noted on the questionnaire and this was taken into consideration as far as possible when results were interpreted.

- The different levels of disclosure did not take into consideration whether it was age appropriate, as the maturity also has an influence, which is out of the realm of this study.

Pilot study

A pilot study was conducted with 5 participants which was submitted to the Biostatistics department of the University of the Free State for analysis. No changes were necessary after the pilot study and the pilot sample was added to the study.

Data analysis

The data was collected from completed questionnaires (See appendix 2). The analysis was done by University of the Free State Department of Biostatistics. To maintain confidentiality, questionnaires were allocated study numbers and no patient names were used during data collection and analysis.

Ethical aspects

- There was no harm caused as a result of this study. In the unlikely instance that the questions asked were to raise emotions from either the caregiver or the patient, psychological consultation would be arranged as a matter of urgency. Fortunately, it was not necessary.
- The researcher was honest and open about the research, the possible outcomes and how they will affect the practice in the management of the disclosure in children with HIV.
- The results of the study are available to participants upon request.
- If a problem was to be identified, perhaps psychosocial issues arising from disclosure, the patient and family would be referred to the relevant practitioner for further intervention. There was no such a challenge.
- The patient and caregiver had a right to withdraw of the study at any given point. They would be asked for reasons, which they would not be obliged to answer.
- There was no conflict of interest that could affect the outcomes of the results.

Caregiver consent and child assent

Before consent was obtained, the caregiver and/or the participant were given the information sheet, and the research assistant was available to read the information or explain.

- Consent was obtained from the caregiver, for all the participants under the age of 18 years.
- Assent was obtained for the participants from 6 years to 18 years.

Permission from the appropriate authorities

This study protocol was submitted to the Health Sciences Research Ethics Committee (HSREC) at the University of the Free State and approval was granted [UFS-HSD2017/1551]. The study protocol was also submitted to The Free State Provincial Department of Health (FSDOH) and approval was granted. The study commenced only after FSDOH and final HSREC approval were granted.

RESULTS

Study findings

A total of 52 patients were enrolled in the study. The age of the study participants ranged from 6 to 18 years with a mean age of 13 years. More males (59.6%, n=31) participated than girls (40.4%, n=21).

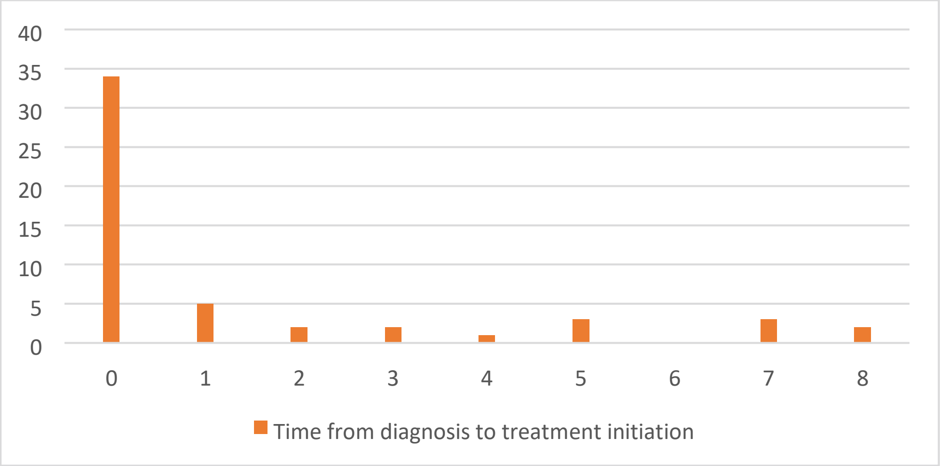

FIGURE 1: Time (in years) between diagnosis and initiation of treatment.

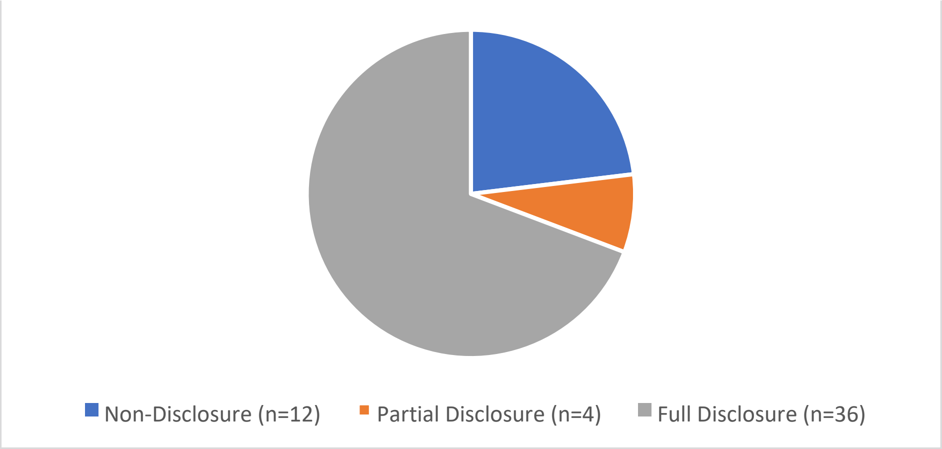

FIGURE 2: Levels of disclosure

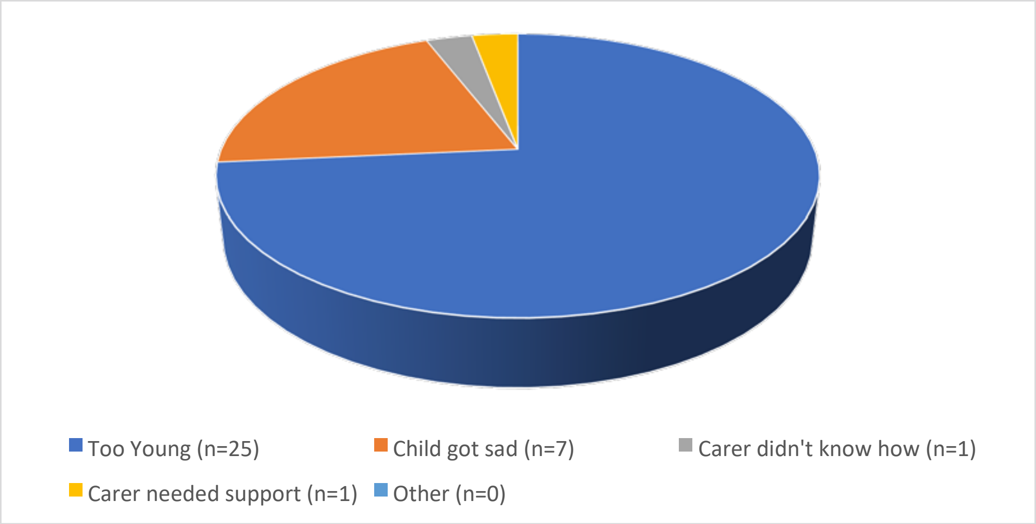

FIGURE 3: Possible factors that made disclosure difficult for the caregivers.

TABLE 1: Age (years) of the children at which disclosure was done.

Age (Years)	Number fully disclosed (n)	Percentage (%)
5	5	12.5
6	3	7.5
7	3	7.5
8	4	10.0
9	1	2.5
10	6	15.0
11	2	5.0
12	5	12.5
13	1	2.5
14	0	0.0
15	4	10.0
No response (Did not answer)	6	15.0

Place of Disclosure

Majority (75.0%, 30/40) of the children were disclosed to at home. Those who were not disclosed to at home were eight (20.0%). Two (5.0%) participants did not answer this question.

TABLE 2: Person who disclosed the status to the child.

Person who disclosed	Number (n)	Percentage (%)
Parent	28	70.0
Caregiver (Other than parent)	5	12.5
Healthcare worker	5	12.5
Other	0	0.0
No response (Question not answered)	2	5.0

Planned vs accidental disclosure

There were no accidental disclosures reported, but two responders who had indicated that disclosure had been done, did not answer the question. Thus, planned disclosure happened in 38 (95%) cases.

TABLE 3: Reasons for non-disclosure (n = 12).

Reason	Number (n)	Percentage (%)
Too young	10	83
Emotionally immature	6	50
Don’t know how	3	25
Protecting the child	0	0
Dr/Nurse should do it	4	33

TABLE 4: Age & Stage of disclosure

Age	Non-disclosure frequency	Partial disclosure frequency	Full disclosure frequency
6	2	0	0
7	1	0	2
8	1	1	0
9	2	1	2
10	0	0	2
11	2	0	4
12	1	0	1
13	2	0	3
14	0	0	8
15	0	0	5
16	0	1	3
17	0	1	3
18	1	0	3
Totals:	12	4	36

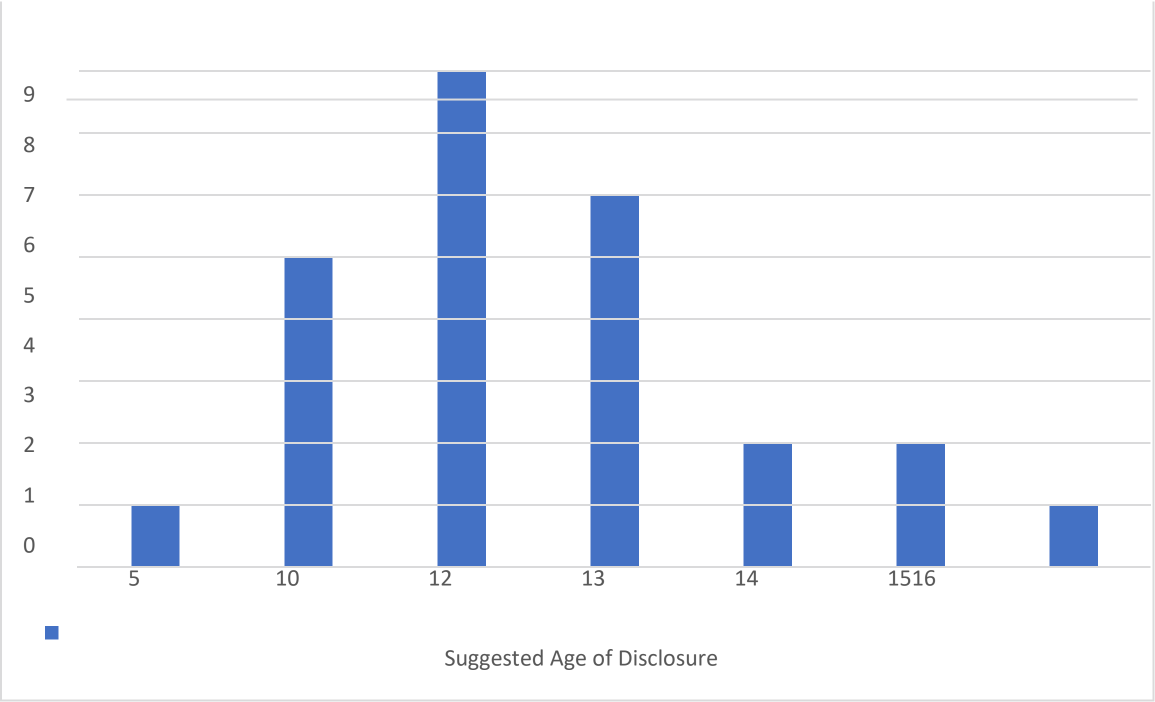

FIGURE 4: Suggested age of disclosure

The children who already knew their status were asked to suggest the ideal age of disclosure.

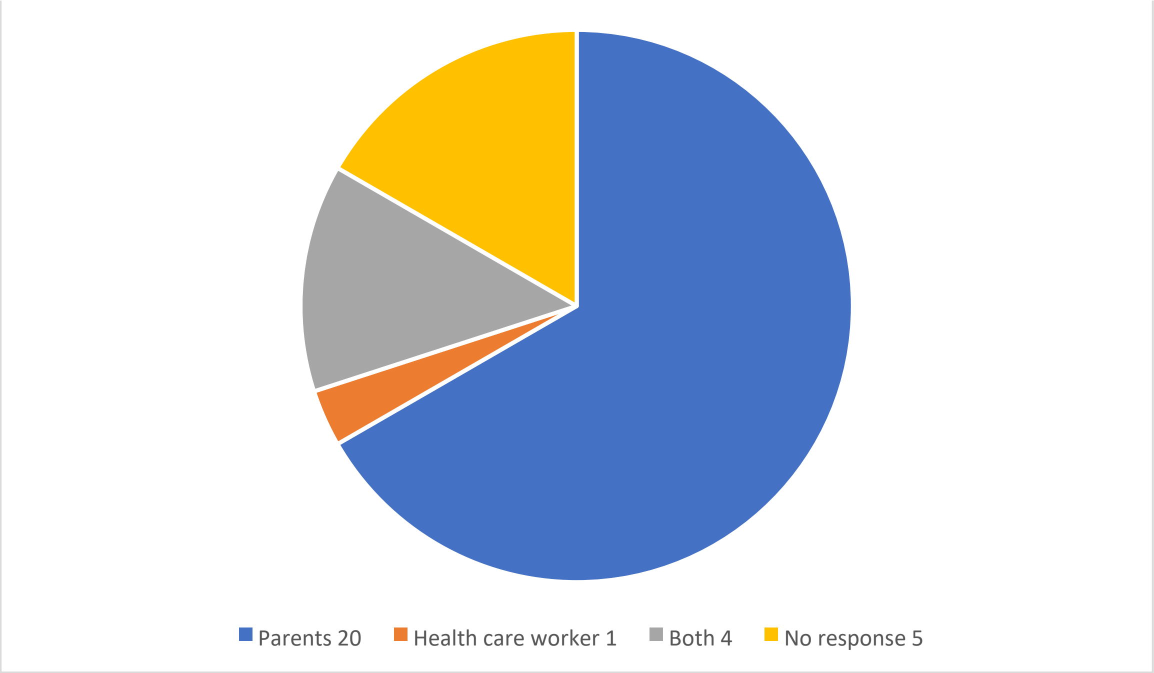

FIGURE 5: Best person to disclose to child

The children who already knew their status were asked to suggest who the best person would be to disclose their status to them.

DISCUSSION

The main aim of this study was to assess whether disclosure is being done as per South African/WHO guidelines. The participants in the study were 52 in total. It was not assessed whether this was a true representation of the patients attending the clinic or not. The age distribution was from 6 years to 18 years. Partial disclosure was expected in children below 12 years and full disclosure in those above 12 years of age. It was expected that the children would be in the different stages of disclosure, appropriate not only for age but cognitive maturity as well.

The time that had lapsed between diagnosis and initiation of treatment is wide, with majority (65%) having been initiated within a year after diagnosis (see figure 1). This reflects the previous HIV ARV guidelines whereby initiation of treatment was guided by the clinical or immunological staging[7]. Patients were not started on the treatment based on a positive HIV test alone. Some patients possibly defaulted follow up dates before HIV treatment could subsequently be initiated.

In terms of disclosure, 36 of the 52 patients were fully disclosed to (69.2%), 4 (ages: 8, 9, 16 and 18 years) were partially disclosed to (7.7%) and 12 (Ages: 2 x 6 years, 7, 8, 2 x 9 years, 2x 11 years, 12, 2 x 13 years, 18 years, respectively) were not disclosed to (23%). The total number of patients in whom disclosure was initiated (partial and full disclosure) was 40 (76.9%), see figure 2. The average age of full disclosure was 13.4 years. Whether the disclosures that were done were age-appropriate, particularly regarding partial disclosure, is a question that can be researched in the future studies. This study simplified the disclosure stages by generalizing, however, to get a true reflection of the deficit one would need to categorize patients by age and stage of disclosure. Strictly speaking if a child is not fully disclosed to by the age of 12 years (WHO guidelines) or 10 years (SA guidelines), it should count as non-disclosure, taking maturity into consideration.

For the patients that were disclosed to, the biggest challenge was the age factor. More caregivers selected the child being too young as one of the factors that made disclosure difficult (25 out of 40 participants). 21 of the 25 patients responded on the age at which disclosure was done, ranging from 5 to 15 years, with an average age of 8.6 years (13 of them were below 10 years of age). Seven out of the 40 stated that the child got sad. There was an overlap with some patients choosing both. Similarly, the most common reason for non-disclosure was also the age of the child age. Most caregivers believed that the child was too young to be disclosed to (83%), as per figure 3. In retrospect this question was leading and it should rather have asked whether it was difficult or not; not assuming it was difficult for caregivers.

The age at which disclosure was done ranged from 5 years to 15 years with even distribution through the years (see figure 4). This suggests that there is not really emphasis on disclosure, or the age of disclosure. There was no correlation between the stage of disclosure and the age in this study (See table: 4.

The children themselves were asked what the appropriate age of disclosure should be, and this seems to be in keeping with the WHO guidelines. The suggested age ranged from 5 years to 16 years. The average age is 12 years and most of the suggested ages (76%) lies between 10 and 13 years (see figure 4). The suggested person to disclose is the parent (80%), see figure 5.

This study has shown a much better prevalence of disclosure in comparison to the previous studies as discussed in the literature review In a South African study that was conducted in 2019, the disclosure among children was 23%. This was rather low, even though there are no national targets. In this study the disclosure rate is 65%, which is better. It is however, a different setting with regard to the type of patients that were participating in the study. In this study, it was patients with complicated disease, mostly on the second line of treatment. The possibility is that the caregivers are more likely to disclose to the child as they hope to improve adherence.

The staff working at the Pelonomi Centre of Excellence is more skilled and experienced in HIV management and take time to encourage the carers to disclose to the children. The time of study also contributes to the differences in the results, in that the community attitude towards the condition could be improving, leading to reduction in stigma. The children have echoed the WHO guideline of full disclosure by the age of 12 years. The preferred place of disclosure was at home.

Study limitations

1. Time constraints: The researcher has a full-time job out of the research area; therefore, it was not feasible to allocate enough time to cover the initial sample size as per protocol.
2. Financial limitations: The research assistant was appointed to help with data collection and was paid per hour, that lead to the number of participants being reduced for affordability as the researcher was paying from his own pocket.
3. The high number of caregivers that could not complete the questionnaires independently lead to the research assistant spending more time assisting them and further reduced the total number of participants with the given budget and time.

Recommendations

Further studies are needed to dig deeper into this aspect of HIV treatment in children.

- A study that would contribute largely to the issue of disclosure is to assess the perception and understanding of HIV by South African children. This will inform the concept of disclosure to children in a South African context.

- Assessing the HIV education in primary school curriculum would also be an idea to investigate as this can help with the children's understanding of the condition and make disclosure easier while reducing the stigma.
- There can be a follow up study that compares successful disclosure process to the unsuccessful one. This would identify the methods that work in south African children.

CONCLUSION

This study provides valuable insight that could inform the better implementation of guidelines and practice of disclosure of HIV status to children. Although compared to previous studies, there has been an overall improvement in disclosure to children, there is certainly a need to prioritise disclosure and a need to improve disclosure rates in our clinic. . In a country with such limited resources, it is difficult to allocate professionals who are well trained in matters of disclosure to children – this should be a skill that everyone is able to acquire

The steps of implementation of results, based on the outcome of the study are as follows:

- The disclosure is to be regarded as a process and not an event.
- Disclosure to begin as early as 3 years and full disclosure by the developmental age of 10 years.
- Integrated disclosure plan into the treatment plan of the children. Regarding disclosure as important and checking viral load.

This study also emphasized the importance of parents/caregivers in the management of disclosure in HIV infected children. Gaining trust and involving the parents will go a long way in improving the outcome. They should be regarded as partners, and not just be instructed. It is recommended that more studies on possible solutions be conducted for this challenge to be adequately addressed. Most importantly, facilities that provide health care to this particular population have to be adequately resourced in order for this challenge to be overcome.

ACKNOWLEDGEMENTS

The staff at Pelonomi Centre of Excellence, thank you for your assistance and cooperation. You are all indeed excellent at what you do.

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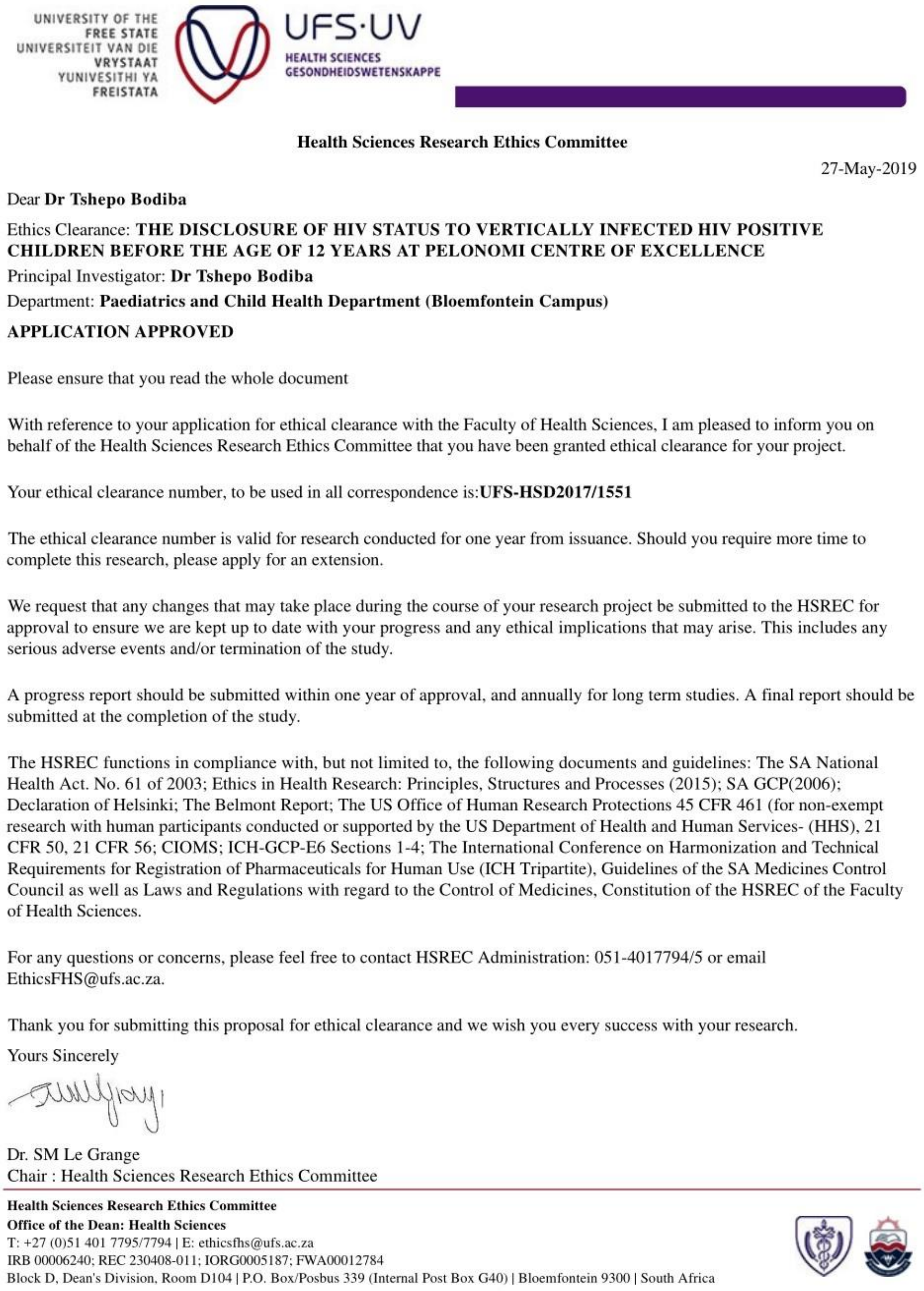
APPENDIX A: LETTER OF APPROVAL FROM HSREC



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YUNIVESITHI YA
FREISTATA

UFS·UV
HEALTH SCIENCES
GESONDHEIDSWETENSKAPPE

Health Sciences Research Ethics Committee

27-May-2019

Dear **Dr Tshepo Bodiba**

Ethics Clearance: **THE DISCLOSURE OF HIV STATUS TO VERTICALLY INFECTED HIV POSITIVE CHILDREN BEFORE THE AGE OF 12 YEARS AT PELONOMI CENTRE OF EXCELLENCE**

Principal Investigator: **Dr Tshepo Bodiba**

Department: **Paediatrics and Child Health Department (Bloemfontein Campus)**

APPLICATION APPROVED

Please ensure that you read the whole document

With reference to your application for ethical clearance with the Faculty of Health Sciences, I am pleased to inform you on behalf of the Health Sciences Research Ethics Committee that you have been granted ethical clearance for your project.

Your ethical clearance number, to be used in all correspondence is:**UFS-HSD2017/1551**

The ethical clearance number is valid for research conducted for one year from issuance. Should you require more time to complete this research, please apply for an extension.

We request that any changes that may take place during the course of your research project be submitted to the HSREC for approval to ensure we are kept up to date with your progress and any ethical implications that may arise. This includes any serious adverse events and/or termination of the study.

A progress report should be submitted within one year of approval, and annually for long term studies. A final report should be submitted at the completion of the study.

The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on Harmonization and Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

For any questions or concerns, please feel free to contact HSREC Administration: 051-4017794/5 or email EthicsFHS@ufs.ac.za.

Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.

Yours Sincerely

Dr. SM Le Grange
Chair : Health Sciences Research Ethics Committee

Health Sciences Research Ethics Committee
Office of the Dean: Health Sciences
T: +27 (0)51 401 7795/7794 | E: ethicsfhs@ufs.ac.za
IRB 00006240; REC 230408-011; IORG0005187; FWA00012784
Block D, Dean's Division, Room D104 | P.O. Box/Posbus 339 (Internal Post Box G40) | Bloemfontein 9300 | South Africa

APPENDIX B: DESCRIPTION OF THE STUDY (INFORMATION DOCUMENT)

Study title: The disclosure of HIV status to vertically infected HIV positive children before the age of 12 years at Pelonomi centre of excellence

Thank you for your interest in participating in our study. It forms part of the qualification in MMED Paediatrics, with The University of Free State. This is a study done by Dr TLL Bodiba, which identifies the number of children with HIV who know their HIV status before the age of 12 years. The results from the study will help the department to understand the depth of the problem of disclosure and can make informed policies to help the patients better. The results may also be published and/or presented.

Be assured that participation in this study is voluntary and you may stop being part of the study at any time, and that will not affect the service that you get from the hospital. The information that you provide will be treated with confidentiality and your details and /or your child’s details will not be revealed to anyone. There will not be any side effects and counseling will be provided if needed.

Please note that your participation in this study is completely voluntary and you will not be paid for it. You will not need to pay to participate in the study. Upon your request from the paediatrics department at University of Free State, the results of the study can be made available to you.

Dr TLL Bodiba (Paediatrics Registrar)

0769411258

APPENDIX C: QUESTIONNAIRE

Please read the questions carefully.

Answer by making an X in the box next to your chosen answer. There are questions where you can choose more than one answer.

SECTION A: FOR THE CAREGIVER

1. How old is your child: ……………………………………………………….
2. Gender of your child: ☐ Male ☐ Female
3. Which year was your child diagnosed with HIV: ……………………………….
4. When were the ARVs started: …………………….
5. What does your child know about his/her HIV status (Choose one):

☐ A Nothing (Non-Disclosure)
☐ B I gave an explanation other than HIV (Partial Disclosure)
☐ C Knows that he/she has HIV and is on ARVs for that (Full disclosure)

If question 5 is answered as B or C, please continue with question 6 to 10.

If question 5 is answered as A, jump to question 11.

6. What made it difficult to tell the child about his/her HIV status (You can choose more than one)?

☐ Still too young to understand. ☐ I was feeling bad for him/her

The ☐ child became sad. I ☐ needed support.

☐ Didn’t know how to start. ☐ Other, Specify:

……………………

7. At what age did you tell him/her: ……………………………………

8. Where was the information given (Choose one):

☐ Home ☐ Health facility

9. Who told the child (Choose one):

☐ Parent

☐ Care giver (Not parent), Specify:

……………………………………………………..

☐ Health Care Worker, Specify:

………………………………………………………….

☐ Other, specify:

………………………………………………………………………………

10. Was this planned or did it happen by accident (Choose one):

☐ Planned Disclosure ☐ Accidental Disclosure

11 .If not told, please state reason/s (You can choose more than one):

☐ Still too young.
☐ Emotionally immature.
☐ Don’t know how to.
☐ Protecting the child.
☐ Doctor/Nurse should do it.
☐ Other, Specify: …………………

SECTION B: FOR THE CHILD

ONLY ANSWER 11 & 12 IF ABOVE 12 YEARS OF AGE, AND STATUS KNOWN TO THE CHILD.

11. At what age is the best time to be told about you HIV positive status: ……….

12. Who is the best person to give you such news (Choose one):

☐ My parent/s

☐ Health care worker alone

☐ My parent/s and Health Care worker

APPENDIX D: CONSENT FORM

Consent to participate in the study.

Study title: The disclosure of HIV status to vertically infected HIV positive children before the age of 12 years at Pelonomi centre of excellence.

You have been asked to participate in a research study.

You were informed by: …………………………………………………………..

The research has been explained to you fully and you understand that there will not be compensated for participation. Your participation is voluntary and you will not lose any benefits if you choose not to participate.

You may contact Dr TLL Bodiba at 0769411258 if you have any questions about the research.

You may contact the Secretariat of the Ethics Committee of the Faculty of Health Sciences, UFS on 051 405 2812 if you have any questions about your rights as a study participant.

If you agree to participate, you will be given a signed participant information sheet, which is a summary of the research study. The results of the study may be published in an academic journal and made available to the authorities.

I agree to participate. ☐

Name & Signature of Caregiver:

……………………………………………………………………………

Name & Signature of Witness:

…………………………………………………………………………….

APPENDIX E: ASSENT TO PARTICIPATE IN THE STUDY.

Study title: The disclosure of HIV status to vertically infected HIV positive children before the age of 12 years at Pelonomi centre of excellence.

You have been asked to participate in a research study.

You were informed by: …………………………………………………………..

The research has been explained to you fully and you understand that there will not be compensated for participation. Your participation is voluntary and you will not lose any benefits if you choose not to participate. You may contact Dr TLL Bodiba at 0769411258 if you have any questions about the research.

You may contact the Secretariat of the Ethics Committee of the Faculty of Health Sciences, UFS on 051 405 2812 if you have any questions about your rights as a study participant. If you agree to participate, you will be given a signed participant information sheet, which is a summary of the research study. The results of the study may be published in an academic journal, presented and made available to the authorities.

I agree to participate. ☐

Name & Signature of the child:

……………………..………………………………………………….

Name & Signature of Witness:

……………………………………………………………………………

How do you feel about being part of the study? (Tick one below)

☐ GOOD

☐ UNSURE

☐ BAD

APPENDIX F: ASSISTANT RESEARCHER CONTRACT & CONFIDENTIALITY CLAUSE.

Study title: The disclosure of HIV status to vertically infected HIV positive children before the age of 12 years at Pelonomi Centre of Excellence.

You have been appointed as a research assistant for the study as above.

You understand that you will have access to sensitive and highly confidential information about the patients' health.

Everything learnt during the study, from participants' demographic data, HIV status and other medical information and the research itself may not be discussed beyond the purpose of the study.

You will be remunerated at a rate of R70 per hour and there will be no benefits as you are employed informally. The study and the information obtained will remain the property of UFS and Dr TLL Bodiba.

☐ I agree to be bound by the above.

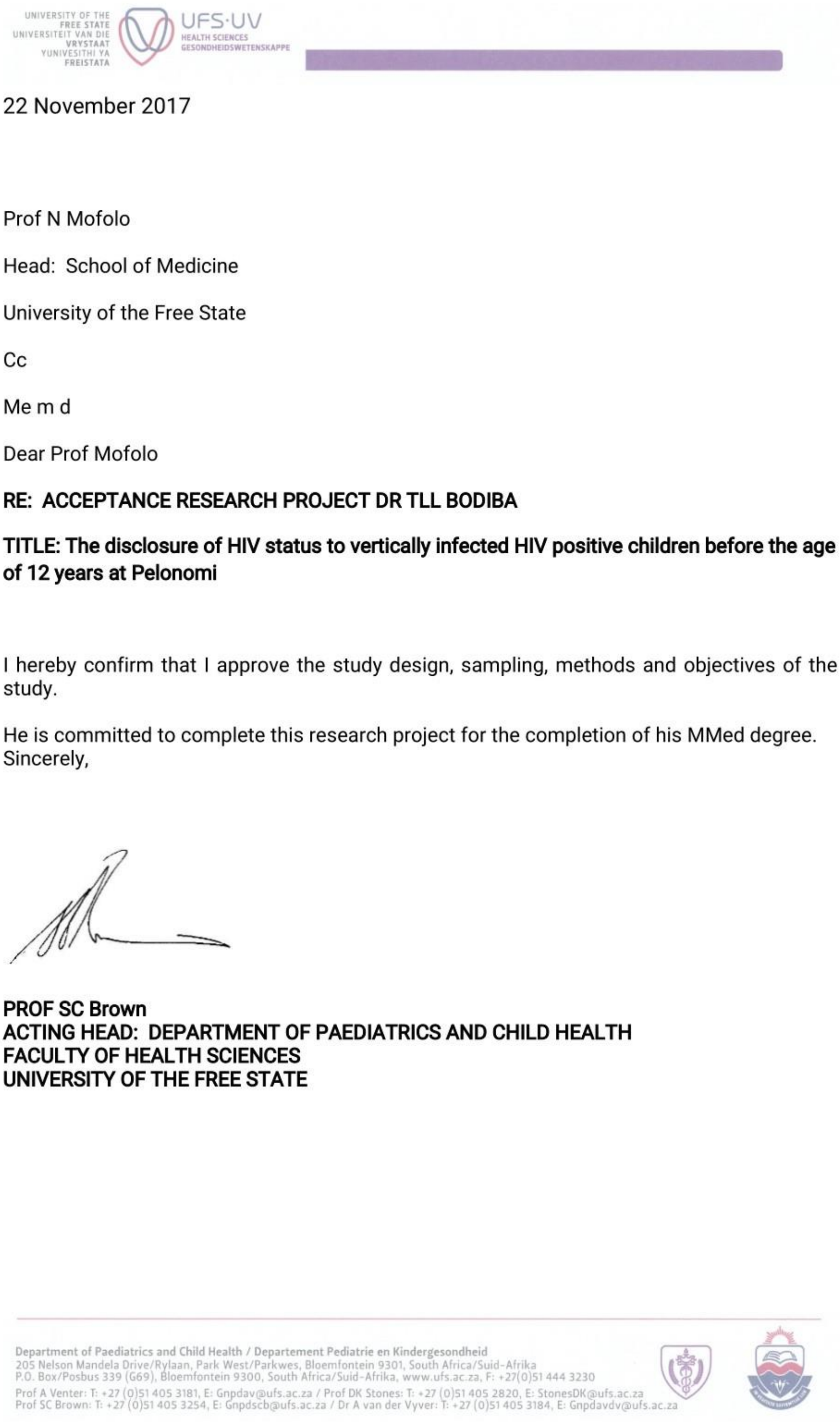
Name:
………

Nursing council
number:……………………………………………………………………………………….

ID No:
……….

Signature: ……………………………………………… Date:………………………………………
Name & Signature of the witness:
………………………………………………………………………

APPENDIX G: HOD APPROVAL



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22 November 2017

Prof N Mofolo

Head: School of Medicine

University of the Free State

Cc

Me m d

Dear Prof Mofolo

RE: ACCEPTANCE RESEARCH PROJECT DR TLL BODIBA

TITLE: The disclosure of HIV status to vertically infected HIV positive children before the age of 12 years at Pelonomi

I hereby confirm that I approve the study design, sampling, methods and objectives of the study.

He is committed to complete this research project for the completion of his MMed degree.
Sincerely,

PROF SC Brown
ACTING HEAD: DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH
FACULTY OF HEALTH SCIENCES
UNIVERSITY OF THE FREE STATE

Department of Paediatrics and Child Health / Departement Pediatrie en Kindergesondheid
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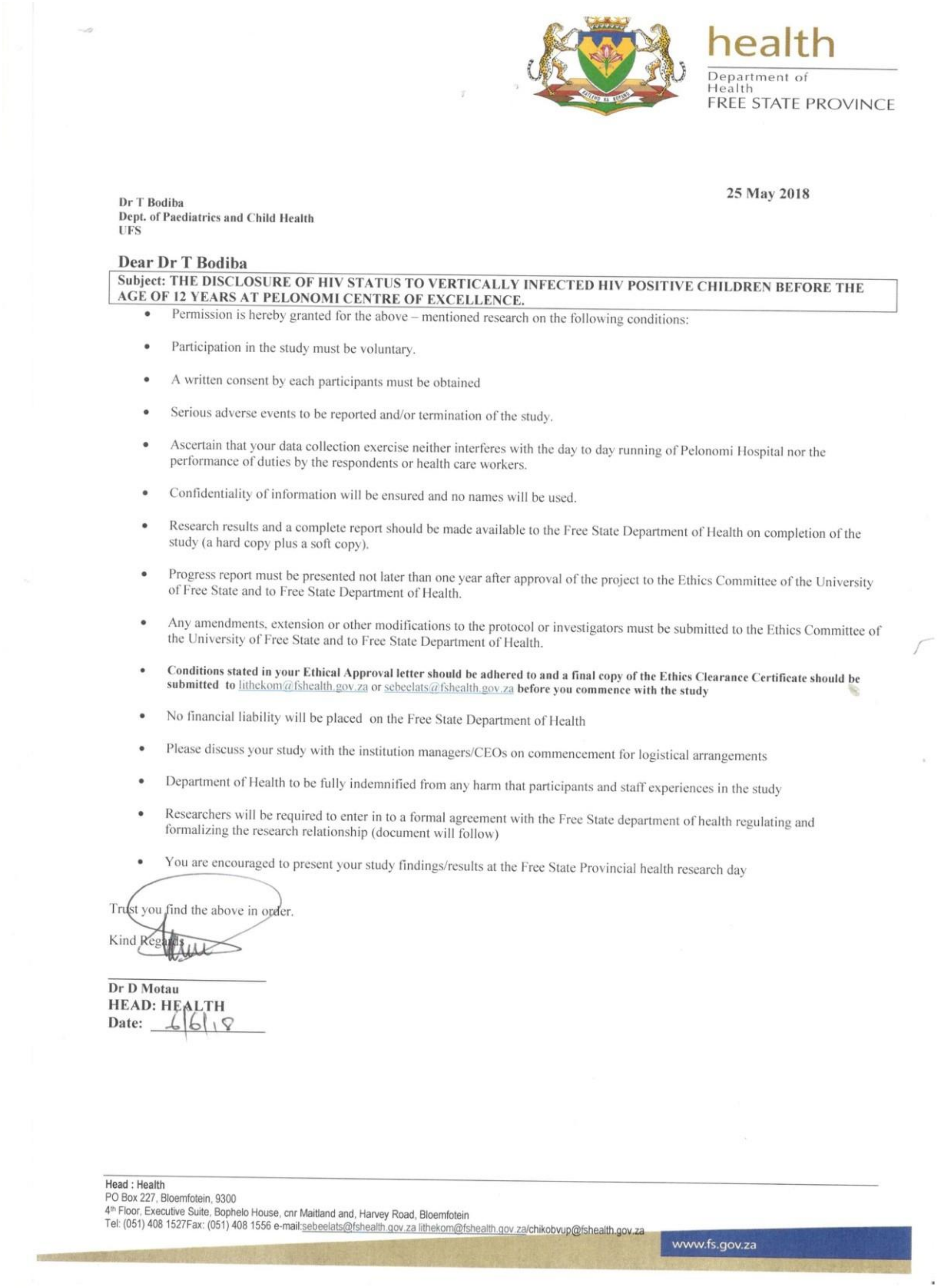
APPENDIX H: FSDOH APPROVAL



health
Department of
Health
FREE STATE PROVINCE

25 May 2018

Dr T Bodiba
Dept. of Paediatrics and Child Health
UFS

Dear Dr T Bodiba

Subject: THE DISCLOSURE OF HIV STATUS TO VERTICALLY INFECTED HIV POSITIVE CHILDREN BEFORE THE AGE OF 12 YEARS AT PELONOMI CENTRE OF EXCELLENCE.

- Permission is hereby granted for the above – mentioned research on the following conditions:
- Participation in the study must be voluntary.
- A written consent by each participants must be obtained
- Serious adverse events to be reported and/or termination of the study.
- Ascertain that your data collection exercise neither interferes with the day to day running of Pelonomi Hospital nor the performance of duties by the respondents or health care workers.
- Confidentiality of information will be ensured and no names will be used.
- Research results and a complete report should be made available to the Free State Department of Health on completion of the study (a hard copy plus a soft copy).
- Progress report must be presented not later than one year after approval of the project to the Ethics Committee of the University of Free State and to Free State Department of Health.
- Any amendments, extension or other modifications to the protocol or investigators must be submitted to the Ethics Committee of the University of Free State and to Free State Department of Health.
- **Conditions stated in your Ethical Approval letter should be adhered to and a final copy of the Ethics Clearance Certificate should be submitted to** lithekom@fshealth.gov.za or sebeelats@fshealth.gov.za **before you commence with the study**
- No financial liability will be placed on the Free State Department of Health
- Please discuss your study with the institution managers/CEOs on commencement for logistical arrangements
- Department of Health to be fully indemnified from any harm that participants and staff experiences in the study
- Researchers will be required to enter in to a formal agreement with the Free State department of health regulating and formalizing the research relationship (document will follow)
- You are encouraged to present your study findings/results at the Free State Provincial health research day

Trust you find the above in order.

Kind Regards

Dr D Motau
HEAD: HEALTH
Date: 6/6/18

Head : Health
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APPENDIX I: PROTOCOL APPROVED BY HSREC

UNIVERSITY OF THE FREE STATE

FACULTY OF HEALTH SCIENCES

DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH

THE DISCLOSURE OF HIV STATUS TO VERTICALLY INFECTED HIV POSITIVE CHILDREN BEFORE THE AGE OF 12 YEARS AT PELONOMI CENTRE OF EXCELLENCE

FOR THE DEGREE: MASTER OF MEDICINE IN PAEDIATRICS

AUTHOR: TSHEPHO LESIBA LAURENCE BODIBA

STUDENT NO: 2014206896

SUPERVISOR: DR RIANA VAN ZYL

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EXECUTIVE SUMMARY

HIV (Human Immunodeficiency Virus) has now become a chronic condition that can be controlled and no longer a death sentence. Mother-to-child transmission (MTCT) of HIV, even though markedly reduced by the Prevention-of-mother-to-child transmission (PMTCT) programs, still remains a reality for various reasons. This, together with the pre-PMTCT infections, means that we now have adolescents living with HIV (ALHIV). The challenge lies in deciding the appropriate age for their HIV status to be disclosed to them.

The World Health Organisation (WHO) has given clear guidelines on disclosure; however, it still remains a challenge as there are many issues to be considered. It has been proven beyond reasonable doubt that disclosure of HIV status to children has positive effects on their psychosocial well-being and survival. This includes disclosure to the child about his/her own HIV positive status as well as the parent's/caregiver's status.

The literature review in this protocol will explore the different studies that have been conducted, mostly in South Africa, and their outcomes regarding disclosure age of HIV status to children. This study mainly serves to adequately define the problem in this particular study setting, so that the authorities can appreciate the magnitude of the challenge in order to mobilise resources to address the problem.

We recommend that more studies on possible solutions be conducted for this dilemma to be adequately addressed. Most importantly, facilities that provide health care to this particular population have to be adequately resourced in order for this predicament to be overcome.

INTRODUCTION & LITERATURE REVIEW

It has been shown that the average age of disclosure of HIV status to children in South Africa is well above the recommended 12 years as per WHO guidelines[18]. Health care workers have suggested a wide range of a disclosure appropriate age, and a large proportion suggested an age above 12 years of age[14]. Ideally, with the progress that has been made in HIV research, the MTCT of HIV should have been eliminated by now. As per background and literature review, it is clear that there are still challenges regarding the PMTCT program in South Africa[3]. It should therefore be anticipated that there will still be vertical infections until such time that the challenges have been addressed.

In the meantime, there will be children who get vertically infected. This therefore raises the need to optimise the treatment provided for such children so that complications can be prevented and their dignity and quality of life can be restored. Provision of anti-retroviral therapy (ART) is only one aspect of the approach to treatment. Psychosocial wellbeing plays a role of utmost importance and has a great influence on the success of the ART. Disclosure of HIV status to a child directly impacts his psychosocial wellbeing. Whether the disclosure is currently done in a step-wise approach and acceptable manner to children is not known.

HIV is a retrovirus that causes immunodeficiency and ultimately AIDS if not treated. There is currently no cure for HIV, and researchers throughout the world are working tirelessly to discover the cure or a vaccine. Currently, the best treatment is antiretroviral (ARV) drugs. These have been proven to suppress the replication of the virus, provided they are taken indefinitely and regularly[5].

HIV is transmitted as follows[5]:

- Unprotected sexual intercourse
- Body fluids (blood, plasma, vaginal fluids, semen), not saliva and urine.
- Mother to child (Vertical transmission). This is the method of transmission that will be considered for the purpose of this study.

HIV in South Africa

HIV was first recognized in South Africa in 1981.As stated by Simelela and Venter[1], currently South Africa has the largest concentration of people living with HIV (estimated 12.3% of the total population).

Mother to child transmission

After unprotected heterosexual sex (which accounts for 90% of HIV infections), mother to child transmission of HIV is responsible for the highest HIV incidence in sub-Saharan Africa each year[5].

Approximately 90% of HIV infections in children are a result of vertical transmission from a mother to her infant[5].

Prevention of mother-to-child transmission

Elimination of mother-to-child HIV transmission (eMTCT) is now viewed as a realistic public health goal, even for countries with limited resources[7]. Research has shown that provision of the most effective ARV regimen for HIV-positive pregnant women can reduce the risk of vertical infection of HIV to less than 2% in non-breastfeeding mothers and to5% in breastfeeding mothers[7]. PMTCT ARV coverage for Sub-Saharan African countries in 2012 was reported at 65%, well below the 90% global target[6]. South Africa has made big strides and is close to achieving the goal of providing ARV regimens to 90% of pregnant women living with HIV. The PMTCT service coverage for South Africa was reported at 83% in 2012[6]. In 2017, the coverage was estimated to be more than 95% (76 to >95%)[21].

There has been a marked increase in the life expectancy in South Africa after 2004, from 56 to 61 years, as a result of the improved access to ART[2]. This followed the political will and commitment towards HIV and ART. The aggressive expansion of the PMTCT program was followed by a reduction in vertical transmission of HIV and a significant reduction in the infant and child mortality rate by 25% from 2009 to 2012[2]. The rate of vertical HIV transmission in a South African study was 5.1%[3]. This was higher than in the developed world, and was associated with advanced disease at presentation and late initiation of ART. No vertical transmission occurred among women who received more than 8 weeks of Highly Active Antiretroviral Therapy (HAART)[3].

Sibeko and Moodley[4] found that 47.9% of women attended the first ante-natal care only after 20 weeks and 28.7% did not attend antenatal care throughout the pregnancy at all. This emphasizes the challenge faced by programs aiming to eliminate MTCT, and therefore, vertical transmission of HIV remains a reality in the South African context. HIV disclosure in children remains a challenge as there are many obstacles, ranging from health care system, patient care giver and health care worker related. Research has been conducted in different areas of South Africa, and that has proven that we are still along way from meeting the WHO target of full disclosure by the age of 12 years.

Since the effective roll out of ARVs, paediatric mortality has improved and HIV vertically infected children are living into adulthood[8]. According to UNAIDS[9] statistics, there was an estimated 240 000 children who were HIV positive in South Africa in 2015. It was 369 000 in 2012[15]. For these children, the reality is a lifelong commitment to ARV treatment. Mother-to-child transmission caused 12 000 (9600 - 22 000) new infections in children, with a total of 270 000 children living with HIV in 2016[21].

The WHO has compiled guidelines based on the available literature on disclosure of HIV status to children. A study in Romania has shown that the risk of death is reduced by half over a 3-year period in children whose status has been disclosed. The improved outcome was attributed to better access to treatment and improved adherence[10]. In a metanalyses of two studies in France and Zambia, psychological stress was less reported in children whose status was disclosed, once again showing disclosure does not only reduce death, but improves quality of life[11,12]. Literature suggests that disclosure has to be done in a step-wise, age appropriate manner according to the child's cognitive and emotional maturity[13].

The key challenges regarding disclosure of HIV status to children were identified as follows:

- The HIV related stigma,
- Social factors (changing caregivers and caregiver roles, vulnerable caregivers, institutionalised children),
- Concomitant co-morbidities, and
- Lack of counseling skills, both from caregivers and health care workers[13].

Disclosure that is not tailored to the child's development and understanding (and this is not synchronous with age) of illness and effects of medication can have a negative impact, just as nondisclosure[13]. The disclosure also has to be tailored to the cultural context of the child. In terms of the bearer of the news to the child, there is no literature that compares disclosure by a health care worker versus disclosure by a caregiver, or the characteristics and qualities of a person who is eligible to disclose the HIV status to the child. It has, however, been stipulated that the health care worker is more in favor of full disclosure and the caregiver more in support of the step-wise approach. The wellbeing of the child should be born in mind in making such decisions[13].

In a 2015 study that was conducted in South Africa, Madiba and Mokgatle[14] have assessed the perception of disclosure from the health care worker and majority of the health care workers believed it was the responsibility of the caregiver to disclose to the child. The role of the health care worker is to support the caregiver through the process, empowering them with information so that they are prepared to answer even the embarrassing questions that the child might ask regarding the disease[13,14]. The recommended age of disclosure was below 10 years by half of the health care workers, and above 10 years by the other half. It would have been interesting to know the cultural background of the participants, and see if there was any influence on the age recommended age of disclosure.

The guidelines from the WHO are thus as follows[13]:

"Children of school-age 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." School-age children are defined as those with the cognitive skills and emotional maturity of a normally developing child of 6-12 years. There are other guidelines by the WHO regarding other aspects of the disclosure. However, for the purpose of this study; only the age of disclosure of the child's positive HIV status to the child will be covered.

The WHO report on the "Global Update on HIV Treatment 2013" estimated that 151 860 of South African children were on ARVs by December 2011[16]. This increased to 166 000 in 2012. Currently there is an estimation of 270 000 children living with HIV in South Africa[21]. In a study on HIV disclosure among South African children, 40% knew their status. Of these, 50% learned of their HIV status between the ages of 11-17 years, 44% were between the ages of 6 to 10 and only 5% below the age of 6.

Table 1: Levels of disclosure[15]:

Disclosure Level	Definition
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 actually naming HIV.
Full Disclosure	The child is made aware of their illness which is named as HIV.

Health Promoting Disclosure	The child knows everything about their 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.

According to a National department of Health survey, the reasons for the low disclosure rates in South Africa are as follows[15]:

4. Patient caregiver (PCG) issues:
   - Fear of the emotional effects of disclosure on the patient[17].
   - Fear of the consequences of disclosure to others e.g. the child then discloses to family and community[17]. This indirectly discloses the mother's HIV status if the care giver is the biological mother.
   - Issues of guilt, blame and shame[18].
   - PCGs are, by definition, not always biological parents.

5. Health Care Professional (HCP) issues:
   - Lack of access to policies or guidelines to assist them in the disclosure process[16].
   - HCPs often miss the opportunity to educate PCGs about the importance of disclosure and the disclosure process[13].
   - Lack of staff, skills and tools to provide age-appropriate counseling services to children[16].

6. Health systems issues[15] as identified by the National Department of Health:
   - Poor implementation of available policies and protocols (e.g. Integrated Management of Childhood Illness (IMCI), Provider-Initiated Counseling and Testing (PICT) to identify Children and Adolescents Living with HIV (C&ALHA) within facilities and communities
   - Lack of Child and Adolescent-Friendly Spaces (C&AFS) to provide appropriate disclosure services.

- Poor referral and linkage systems to strengthen disclosure processes between facility and community level.

In a qualitative multicentre study in South Africa and Botswana, all caregivers to HIV positive children whose statuses were not disclosed, felt that it was good practice to disclose, and some of the reasons above were quoted as the challenges[17]. This shows that if support and guidance is provided by the health care worker, disclosure will be possible at the appropriate age.

In a Cape Town based study in 2006, Moodly et al[19] found that only 26% of the patients above 6 years knew their HIV positive status. In this study, caregivers saw disclosure to their children as primarily their responsibility, but most needed the health care worker's support in the process. However, only 25% of the caregivers had initiated discussion of disclosure issues with a health care provider[19]. Greater attention to the issues surrounding disclosure of HIV status to children is needed to improve the care of this vulnerable group[19].

PROBLEM STATEMENT

There has never been a study in the Free State Province that explored the disclosure patterns and compared the findings to the rest of the country, where there have been such studies. It has not been determined from the HIV positive children themselves what the recommended age of disclosure should be. This can only be done in retrospect on those children who are cognitively matured and know their status. This also needs to be done as follows:

- In patients above the recommended age of disclosure by the WHO (12 years).
- The patients must already know their HIV status.

AIMS AND OBJECTIVES

AIM

The aim of the study is to calculate the prevalence of HIV status disclosure in the two different age groups (6-12 years and 12-18 years) and obtain the suggested disclosure age from the patients themselves (for those who already know their status, and are above the age of 12 years), while identifying the challenges related to disclosure.

OBJECTIVES

- Determine the prevalence of disclosure and non-disclosure of HIV status to children from 6 – 12 years. In this case partial disclosure (age-appropriate) will be regarded as disclosure.
- Determine the prevalence of disclosure and non-disclosure of HIV status to children from 12 – 18 years. Disclosure will be regarded as full disclosure in this case.
- Determine the reasons for non-disclosure of HIV status to the children from 6 – 12 years and 12 – 18 years.
- Determine the appropriate age of disclosure from the children who know their status (above 12 years of age)
- Determine the most appropriate person to give the news, based on the patients' own experience.

STUDY METHODS

Study design

This will be a cross-sectional quantitative study with the questionnaire as the data collection tool. This study method is ideal for this project as does not require a lot of time and contains multiple variables. The cost of conducting a study is also minimized.

Study population

The population included in this study will be HIV positive children from the age of 6 up to 18 years, who are on HIV treatment at Pelonomi Centre of Excellence (COE). This clinic serves as referral center for all complicated cases of paediatric HIV in central South Africa. Therefore, patients who are newly diagnosed do not fall into the scope of the clinic services and will not be included in the study population. According to the records at the clinic, 381 children are treated at the clinic with the number of children between6 and18 years being 285.

Inclusion criteria:

- Children between the age of 6 to 18 years
- Proven HIV positive status
- Patient should be receiving HIV treatment at Pelonomi Centre of Excellence
- Caregiver should be available to give consent
- Child should be able to provide assent
- The caregiver that brought the child at the visit of data collection must have brought the child at the previous two visits as well

Exclusion criteria:

- Patient age not within the 6-18 year age group
- The parent/caregiver is not present or is unable to provide consent
- Patient is not able to provide assent

Study setting

The clinic runs on Mondays and Wednesdays. On each of the clinic days, approximately 25 patients fall within the study age group. The patients' waiting period is estimated to be 1 to 3 hours before leaving the clinic. They arrive and report to the nursing staff, their appointments are confirmed and files obtained. Some patients go directly to the pharmacy after getting the files, while others have to wait for consultation with the doctor.

While patients are waiting, consent can be obtained and data collected. Data will be collected before and/or after consultation. This will require the appointment of a research assistant for 1 month, twice a week, working from 8 am until 11 am.

The caregiver will be called to the consulting room while the child is waiting in the waiting area under the watch of nursing staff. The child will only be called in if he/she has been disclosed to and is participating in the study, after the caregiver has finished filling in the questionnaire. The caregiver will not be present when the child is answering the questionnaire.

Sampling

The convenience sampling method will be used. Every patient that presents to the clinic during the period of the data collection will be requested to participate in the study. If 15 patients agree to participate per clinic day, for a sample size of 120 patients, 8 clinic days will be required. Patients' names will not be used to maintain confidentiality.

Sample size

A sample size of 120 patients will be obtained, over a period of 8 clinic days (4 weeks).

Measurements and data collection

The researcher, being a registrar in the Department of Paediatrics and Child Health, will be collecting data, with the help of a fellow registrar (rotating at the HIV clinic at the time of data collection) and the nursing personnel at COE.

A research assistant will be appointed to coordinate the data collection in the clinic. The research assistant will be an individual with basic medical knowledge and understanding of confidentiality as this study involves information of a sensitive nature. The research assistant will not be a full time professional appointed in the department of health. A moonlighting or research nurse would be appointed. The study leader is the consultant in charge of the clinic and will assist with the identification of potential study subjects and supervise the research assistant.

This study will use the survey type of measurement with a questionnaire as the data collection tool. The questionnaire is divided into 2 sections, A and B. Section A is completed by the caregiver, and if the child is above 12 years of age and knows their status, then the child will complete section B. The questionnaires will be filled mainly by the caregivers/children themselves, however, assistance with completion of the questionnaires will be provided by the research assistant if necessary. The questionnaires will be available in English, Sotho and Afrikaans.

The study will run over a month from the date of final Health Sciences Research Ethics Committee approval, with the research assistant based at COE.

Measurement Errors

- Questionnaire error: Ambiguous questions on the questionnaire

  This error will be reduced by first piloting the questionnaire and adjusting the questions accordingly if there are any difficulties or ambiguity. The size of the pilot will be 5 patients and the questionnaire will be reviewed after the results of the pilot. The data from the pilot will be included in the main study.

- Data transfer error: Entering the data onto the computer.

  The double entry data verification system will be used to ensure that the data is accurately entered in the computer for statistical analysis.

- The pilot questionnaires will be entered on the Excel spreadsheet to run a trial of the data analysis.

Bias

- Non-responder bias

  Patients who default their clinic dates and treatment may be reluctant to participate. These patients and their caregivers will be assured that the questionnaires are anonymous.

- Membership bias

  The patients attending COE represent a very specific group of complicated paediatric HIV cases.

- Drop out bias

  This type of bias is a possibility, but less likely. The patient may decide not to complete the questionnaire fully. This may not be detected at the time of the collection as it will be dropped into a box for the study participants to remain anonymous.

Confounders

- Care giver

The patient may be brought by a caregiver who is not well informed about the patient's condition on the day of the data collection. To reduce this, the care giver who fills in the questionnaire will have to be the same one who has brought the patient the previous two visits.

- Psychological response to disclosure

  Some patients may have been disclosed to but in denial at the time of the data collection. This will affect the results of the study. The date of disclosure will be noted on the questionnaire and this will be taken into consideration as far as possible when results are interpreted.

Budget

- Research Assistant: With a payment rate of R 100 per hour for Monday and Wednesday, the estimated total pay for the 8 clinic days will be R 800.
- A total number of 15 copies (3 pages each) of questionnaires for the pilot, a further 450 copies (3 pages per questionnaire, with 30 questionnaires extra) for the study and 150 copies of consent and description of the study, respectively, will be required for this study.

  With the cost of photocopying estimated at 50 cents per page, the total cost of photocopying will be estimated at R 400.
- Total needed: R1 200
- This budget will be requested from the research committee.

Item	**Estimated Cost**
Research Assistant	R 800
Printing and Photocopying	R600
Total	**R1400**

DATA MANAGEMENT AND ANALYSIS

The data will be collected from completed questionnaires (See appendix 2). Descriptive statistics namely means and standard deviations or medians and percentiles will be calculated for continuous data. Frequencies and percentages will be calculated for categorical data. The analysis will be done by the Department of Biostatistics.

REPORTING RESULTS

The results of the study will be presented in the form of a thesis, poster and possibly a presentation at a congress. The ultimate goal is to publish in a relevant journal. The authorities will be presented with the results so as to guide the policy-making process.

ETHICAL ASPECTS

The ethical principles will be highly regarded in this study.

- There is no harm that is anticipated as a result of this study. In the unlikely instance that the questions asked raise emotions from either the caregiver or the patient, psychological consultation will be arranged as a matter of urgency.
- The researcher will be honest and open about the research, the possible outcomes and how they will affect the practice in the management of the disclosure in children with HIV.
- The participants will be given the results of the study, upon request, once the study is completed.
- If a problem is identified, perhaps psychosocial issues arising from disclosure, the patient and family will be referred to the relevant practitioner for further intervention.
- The patient and care giver has a right to drop out of the study at any given point. They may be asked for reasons, which they are not obliged to answer.
- There is no conflict of interest that might affect the outcomes of the results.

Caregiver consent and child assent

Before consent is obtained, the caregiver and/or the participant will be given the information sheet, and the research assistant will be available to read the information or explain.

- Consent will be obtained from the caregiver, for all the participants under the age of 18 years.
- Assent will be obtained for the participants from 6 years to 18 years.

Permission from the appropriate authorities

This study protocol will be submitted to the Health Sciences Research Ethics Committee (HSREC) at the University of the Free State for approval.

The study protocol will then be submitted to The Free State Provincial Department of Health (FSDOH) and after provisional approval is granted, final approval will be applied for at the HSREC.

The study will commence only after FSDOH and final HSREC approval has been granted.

IMPLEMENTATION OF FINDINGS

There is a need to provide guidelines for the disclosure approach. In a country with such limited resources, it is difficult to allocate professionals who are well trained in matters of disclosure in children.

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APPENDIX J: INSTRUCTIONS TO AUTHORS – SAHIVMED (AOSIS)

https://sajhivmed.org.za/index.php/hivmed/pages/view/submission-guidelines#part_1

Original Research Article full structure

Title: The article's full title should contain a maximum of 95 characters (including spaces).

Abstract: The abstract, written in English, should be no longer than 250 words and must be written in the past tense. The abstract should give a succinct account of the objectives, methods, results and significance of the matter. The structured abstract for an Original Research article should consist of five paragraphs labelled Background, Objectives, Method, Results and Conclusion.

- Background: *Why do we care about the problem?* State the context and purpose of the study. (What practical, scientific or theoretical gap is your research filling?)
- Objectives: *What problem are you trying to solve*? What is the scope of your work (e.g. is it a generalised approach or for a specific situation)? Be careful not to use too much jargon.
- Method: *How did you go about solving or making progress on the problem*? State how the study was performed and which statistical tests were used. (What did you actually do to get the results?) Clearly express the basic design of the study; name or briefly describe the basic methodology used without going into excessive detail. Be sure to indicate the key techniques used.
- Results: *What is the answer*? Present the main findings (that is, as a result of completing the procedure or study, state what you have learnt, invented or created). Identify trends, relative change or differences on answers to questions.
- Conclusion: *What are the implications of your answer*? Briefly summarise any potential implications. (What are the larger implications of your findings, especially for the problem or gap identified in your motivation?)

Do not cite references and do not use abbreviations excessively in the abstract.

Introduction: The introduction must contain your argument for the social and scientific value of the study, as well as the aim and objectives:

- Social value: The first part of the introduction should make a clear and logical argument for the importance or relevance of the study. Your argument should be supported by use of evidence from the literature.
- Scientific value: The second part of the introduction should make a clear and logical argument for the originality of the study. This should include a summary of what is already known about the research question or specific topic, and should clarify the knowledge gap that this study will address. Your argument should be supported by use of evidence from the literature.
- Conceptual framework: In some research articles it will also be important to describe the underlying theoretical basis for the research and how these theories are linked together in a conceptual framework. The theoretical evidence used to construct the conceptual framework should be referenced from the literature.
- Aim and objectives: The introduction should conclude with a clear summary of the aim and objectives of this study.

Research methods and design: This must address the following:

- Study design: An outline of the type of study design.
- Setting: A description of the setting for the study; for example, the type of community from which the participants came or the nature of the health system and services in which the study is conducted.
- Study population and sampling strategy: Describe the study population and any inclusion or exclusion criteria. Describe the intended sample size and your sample size calculation or justification. Describe the sampling strategy used. Describe in practical terms how this was implemented.
- Intervention (if appropriate): If there were intervention and comparison groups, describe the intervention in detail and what happened to the comparison groups.
- Data collection: Define the data collection tools that were used and their validity. Describe in practical terms how data were collected and any key issues involved, e.g. language barriers.
- Data analysis: Describe how data were captured, checked and cleaned. Describe the analysis process, for example, the statistical tests used orsteps followed in qualitative data analysis.

- Ethical considerations: Approval must have been obtained for all studies from the author's institution or other relevant ethics committee and the institution's name and permit numbers should be stated here.

Results: Present the results of your study in a logical sequence that addresses the aim and objectives of your study. Use tables and figures as required to present your findings. Use quotations as required to establish your interpretation of qualitative data. All units should conform to the **SI convention** and be abbreviated accordingly. Metric units and their international symbols are used throughout, as is the decimal point (not the decimal comma).

Discussion: The discussion section should address the following four elements:

- Key findings: Summarise the key findings without reiterating details of the results.
- Discussion of key findings: Explain how the key findings relate to previous research or to existing knowledge, practice or policy.
- Strengths and limitations: Describe the strengths and limitations of your methods and what the reader should take into account when interpreting your results.
- Implications or recommendations: State the implications of your study or recommendations for future research (questions that remain unanswered), policy or practice. Make sure that the recommendations flow directly from your findings.

Conclusion: Provide a brief conclusion that summarises the results and their meaning or significance in relation to each objective of the study.

Acknowledgements: Those who contributed to the work but do not meet our authorship criteria should be listed in the Acknowledgments with a description of the contribution. Authors are responsible for ensuring that anyone named in the Acknowledgments agrees to be named.

Also provide the following, each under their own heading:

- Competing interests: This section should list specific competing interests associated with any of the authors. If authors declare that no competing interests exist, the article will include a statement to this effect: *The authors declare that they have no financial or personal relationship(s) that may have inappropriately influenced them in writing this article.* Read our **policy on competing interests**.

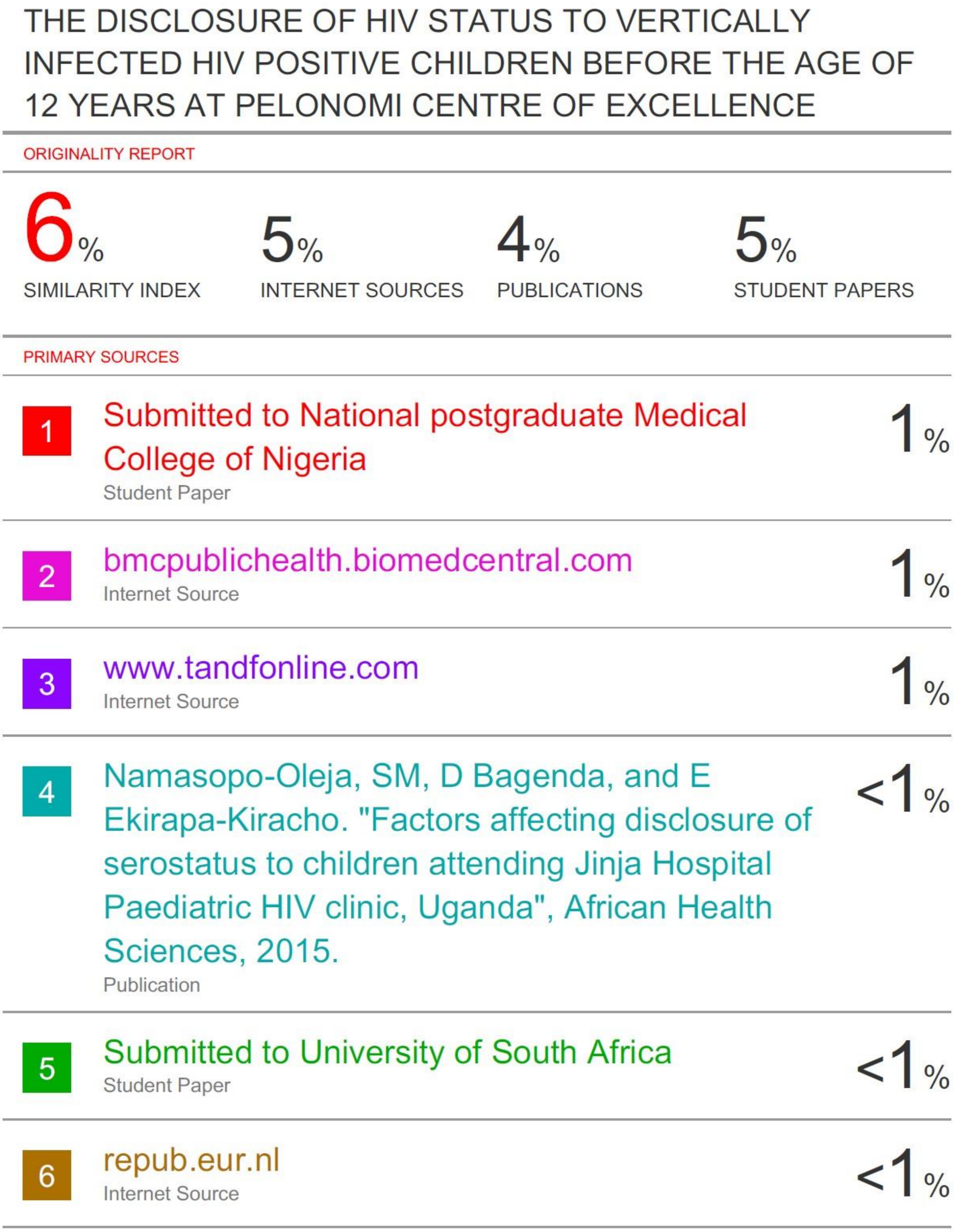
- Author contributions: All authors must meet the criteria for authorship as outlined in the **authorship** policy and **author contribution** statement policies.

- Funding: Provide information on funding if relevant

- Disclaimer: A statement that the views expressed in the submitted article are his or her own and not an official position of the institution or funder.

References: Authors should provide direct references to original research sources whenever possible. References should not be used by authors, editors, or peer reviewers to promote selfinterests. Refer to the journal referencing style downloadable on our *Formatting Requirements* page.

APPENDIX K: TURNITIN REPORT



THE DISCLOSURE OF HIV STATUS TO VERTICALLY INFECTED HIV POSITIVE CHILDREN BEFORE THE AGE OF 12 YEARS AT PELONOMI CENTRE OF EXCELLENCE

ORIGINALITY REPORT

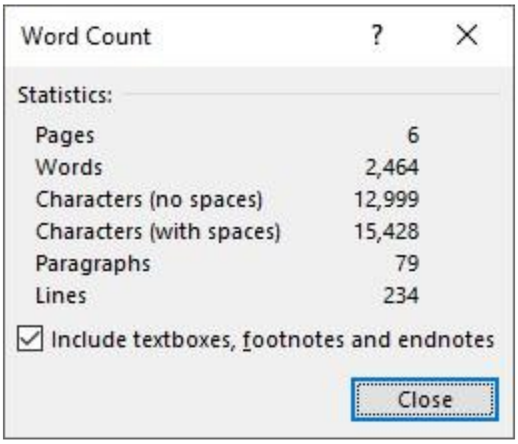
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS
6%	5%	4%	5%

PRIMARY SOURCES

1	Submitted to National postgraduate Medical College of Nigeria Student Paper	1%
2	bmcpublichealth.biomedcentral.com Internet Source	1%
3	www.tandfonline.com Internet Source	1%
4	Namasopo-Oleja, SM, D Bagenda, and E Ekirapa-Kiracho. "Factors affecting disclosure of serostatus to children attending Jinja Hospital Paediatric HIV clinic, Uganda", African Health Sciences, 2015. Publication	<1%
5	Submitted to University of South Africa Student Paper	<1%
6	repub.eur.nl Internet Source	<1%

APPENDIX L: PROOF OF WORD COUNT

Chapter 1

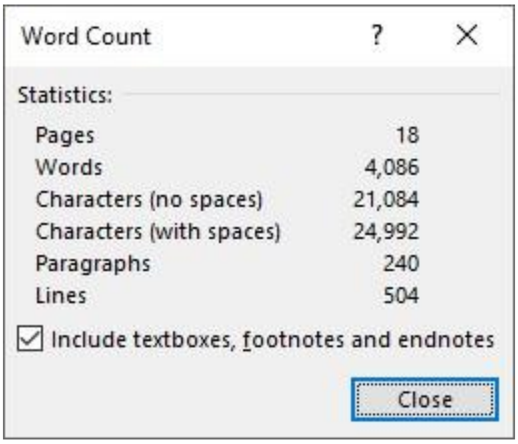


Statistics:

Pages	6
Words	2,464
Characters (no spaces)	12,999
Characters (with spaces)	15,428
Paragraphs	79
Lines	234

☑ Include textboxes, footnotes and endnotes

Chapter 2



Statistics:

Pages	18
Words	4,086
Characters (no spaces)	21,084
Characters (with spaces)	24,992
Paragraphs	240
Lines	504

☑ Include textboxes, footnotes and endnotes