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An exploration of HIV status disclosure to the infected minors by parents/caregivers/guardians in Thulamela Municipality

BY

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A mini-dissertation submitted in fulfilment of the requirement for the degree:

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DECLARATION

I, Mphego Nkhetheni Patricia, declare that the mini dissertation proposal titled "***An exploration of HIV status disclosure to the infected minors by parents/caregivers/guardians in Thulamela Municipality"*** hereby submitted for the degree masters of Public Health at the University of Venda has not been submitted for any degree at this University or any institution; that it is my work in design and execution and the sources that I have quoted have been indicated and acknowledged by complete references.

Signature: ____________________ **Date: 24 August 2021**

PREFACE

This mini-dissertation is presented in article format and comprises three sections: Section A presents the thesis overview, Section B provides the manuscripts/articles with their journal guidelines for authors and Section C presents the conclusion, limitations and recommendations of the thesis.

Section A: Mini-Dissertation Overview

This section provides the overview that details the background, problem statement, purpose and objectives of this study, research design and methods and the ethical considerations.

Section B: Paper/Article/Manuscript

This section has a total of one manuscript submitted to HIV & AIDS Review - International Journal of HIV-Related Problems. The manuscript is titled "*The barriers and facilitators of disclosing HIV positive status to minors: An exploratory study of primary caregivers in South Africa*"

Section C: Conclusion, Recommendation and Mini-Dissertation Limitations

This last section presents conclusions from this mini-dissertation, makes dynamic recommendations and presents the study limitations reflecting in all that was presented within each section and is informed by the whole research process.

PUBLICATIONS

Nkhetheni Patricia Mphego, Lufuno Makhado, Ntsieni Stella Mashau, Leepile Alfred Sehularo. 2021. The barriers and facilitators of disclosing HIV positive status to minors: An exploratory study of primary caregivers in South Africa. HIV & AIDS Review - International Journal of HIV-Related Problems ***(Accepted for Publication)***

DEDICATIONS

The study is dedicated to my mom dearest Miss T.C. Rampfumedzi for the support she has given me and for being there for me when I needed her the most throughout the study.

I also dedicate this study to my lovely three children: Siliga Phathutshedzo, Siliga Mulweli and Siliga Vhuhwavho for their understanding and their encouragement.

Lastly, I dedicated this study to all the readers. May the Lord Almighty, Lord of Glory bless you all in abandoned. I love you

Thank you all.

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I would like to thank God who gave me strength and good health throughout the whole study

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LIST OF ACRONYMS AND ABBREVIATION

AIDS - Acquired Immunodeficiency Syndrome

ART - Antiretroviral Treatment

BENP - Basic Education National Policy on HIV and TB

HIV - Human Immunodeficiency Virus

ISHP - Integrated School Health Policy

NSP - National Strategic Plan

PMTCT- Prevention of Mother-To-Child Transmission

SA - South Africa

SDG - Sustainable Developmental Goal

TB - Tuberculosis

ABSTRACT

The disclosure of Human Immunodeficiency Virus status can be a problematic issue; it may cause a stressful and anxious situation in one's life before and after the process of disclosure of Human Immunodeficiency virus. To disclose Human Immunodeficiency virus status to your child or guardian children become more difficult as they may fear stigma come and many questions that may arise after disclosure of Human Immunodeficiency Virus. The purpose of the study was to explore and describe the barriers and facilitators of disclosure of Human Immunodeficiency Virus status by parents, caregivers, and or guardians to propose the strategies to promote disclosure of Human Immunodeficiency Virus status to the infected minors. The study was qualitative, descriptive, explorative and contextual designs were employed. The study was conducted in one of the Health Centers which was selected in Thulamela Municipality, at Vhembe district. Non-probability, purposive sampling was be used to select 30 caregivers, parents, and guardians however sampling size was determined by data saturation when 22 participants interviewed. The study made use of a Semi-structured in-depth interview for data collection instrument and was pre-tested at the same selected clinic using four parents, caregivers, and guardians of the Human Immunodeficiency Virus-infected minors and the findings also make part of the study. Trustworthiness was ensured through credibility, dependability, conformability, and transferability and ethical consideration were adhering to throughout the study. Data were analysed through thematic analysis and four themes emerged from the data which included; psychosocial challenges related to Human Immunodeficiency Virus disclosure, barriers that hinder Human Immunodeficiency Virus disclosure, facilitators of Human Immunodeficiency Virus disclosure and suggestions to improve Human Immunodeficiency Virus disclosure. The findings of the study show that parents/caregivers/guardians encounter several barriers regarding the disclosure of the Human immunodeficiency Virus to infected minors. The recommendations were based on the findings of the study.

Keywords: Caregivers, Disclosure of HIV status, Guardians, Minors living with HIV, Parents of children living with HIV

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SECTION 1: OVERVIEW OF THE STUDY

1.1 INTRODUCTION

This section of the study presents the background of the study, problem statement, and rationale of the study, aim of the study which includes research questions, the significance of the study and definition of key concepts. It also entails the methodology of the study which include the following: research approach, research designs, study setting, target population, sampling, sample size, criteria for inclusion, data collection methods, pre-test, measure to ensure trustworthiness, data analysis methods, ethical considerations and plan for dissemination and implementation of the results

1.1.1 Background of the study

South Africa has a relatively higher burden of human immunodeficiency virus (HIV) infection. HIV is a public health problem that affects everyone regardless of age, gender, and ethnicity. Disclosure of one's HIV status is critical which may cause a stressful and anxious situation in one's life before and after the disclosure (Rendina et al.,2017). Disclosure of HIV status poses a challenge to parents, caregivers, and guardians who face a stressful process of informing the HIV infected minors who are under their care about their HIV status, it also can put pressure and strain on the relationships of children and their parents, caregivers and guardians (Watt et al., 2017). Many parents, caregivers, and guardians are not disclosing HIV status to the infected minors; most of the children living with HIV who are on ART do not know their HIV status. This study seeks to provide an exploration of HIV status disclosure to the infected minors in Thulamela Municipality. HIV is a worldwide health challenge; the initiation of PMTCT helps to reduce the new HIV infection of children, hence there is still newly infection of children with HIV disease especially for those mothers who did not attend the antenatal services during pregnancy. In Asia HIV prevalence is low at 0.3% however, an estimated 3.5 million people are living with HIV hence 71% are children (Pendse et al., 2016).

Sahay (2013) indicated that disclosure of HIV status to children in India poses complex challenges because of issues pertaining to transmissibility, maternal guilt, parent's own HIV status and potential for social stigma and isolation among others. The disclosure was reported to be high in a study conducted among 145 HIV-infected children studied 75.3% in India. According to Taukeni and Ferreira (2016), they estimated about 35 million people are living with HIV and AIDS which 70.6% are from Sub-Saharan Africa and 2.3 million living with HIV are children. According to Nazarali (2016) in Sub-Saharan Africa disclosure of HIV status is often viewed as a discrete event even though the number of people living with the HIV epidemic grows bigger and the majority of HIV-positive children are unaware of their HIV status, even if currently receiving treatment. The Ministry of Health in Uganda indicates that 176.948 children under 15 years living with HIV and are not informed yet. The challenge of

HIV-infected children increased in Uganda. Children living with HIV who are school-aged and into adolescence have access to life-saving drug therapies (Kyaddondo, 2014).

Appiah et al. (2019), stated that in Ghana disclosure of HIV status to children is very low as there are 43% of children living with HIV who are on ART whose HIV status has been kept secret and many of those children grow into adolescents not knowing their HIV status. According to statistics from South Africa(2017), an estimated 280,000 children (aged 0 to 14) were living with HIV in South Africa, only 58% of who were on treatment. New infections have declined among South African children, from 25,000 in 2010 to 13,000 in 2017. This is mainly due to the success of prevention of mother-to-child transmission (PMTCT) programs. The rate of mother-to-child transmission stood at 1.3% in 2017, down from 3.6% in 2011. This puts South Africa on track for eliminating mother-to-child transmission. As it stands, for every child-initiated on to treatment, 1.4 is newly infected with HIV.

Children are also affected by HIV through the loss of family members and they become more vulnerable to the disease as they need support and protection; however, those who are expected to protect them may be the ones who expose those children in danger of being infected by HIV. In South Africa, more than 2 million children have been orphaned by HIV and AIDS (Taukeni & Ferreira, 2016). According to the National Department of Health (2016), there is a low disclosure rate of HIV status to the infected minors in South Africa, most of the parents, caregivers and guardians are have fear of emotional impact, consequences of disclosure, and issues of guilt, shame and blame for HIV disease,

South Africa adopted Sustainable Developmental Goal 3 in September 2015 where South Africa decided to tackle the HIV epidemic, where one of their goals is to end the spread of HIV disease. However, South Africa has a range of relevant policies and interventions geared towards fighting the HIV and AIDS scourge in place e.g. The National Strategic Plan on HIV/ AIDS and STIs 2000-2005, the integrated school health policy, Basic Education National Policy on HIV and TB of 2013 and the Prevention of Mother-to-child-Transmission (PMTCT) program. These policies are an indication that the South African government and its partners have the intention to address the HIV pandemic. According to District Health Barometer (2017), 65.5 % of children living with HIV are on ART. However, there is a need for identification of the barrier and facilitators of disclosure of HIV status to the infected minors and the need to propose strategies to promote disclosure of HIV status to the infected minors.

1.1.2 Problem statement

Families and individuals are going through enormous stress as a result of the infected minors and continue caring for them as well as the trauma of death thereof. At some points, HIV-infected minors complain about the use of antiretroviral treatment every day while others are not taking treatment. As a result, some of the caregivers also complain about the non-adherence to the treatment prescribed for HIV-infected minors. The reason for the non-adherence is rooted in the issue of or lack of awareness about the reason for taking the treatment as per the prescription (Rane, Hong, Govere and Thulare, 2018). The health sector in Thulamela Municipality as the whole world needs to combat and bring the spread of HIV to a complete halt as envisaged by Sustainable Development Goal No. 3 of the United Nations.

Despite the availability of Sustainable Development Goal 3 above set by the United Nations, considering the issue that a significant number of minors who are HIV infected are not aware of their status, Parents caregivers and guardian's accusations of infidelity, risk of violence are often cited as acute fears associated with disclosure of HIV status (Moitra, LaPlante and Stein, 2018). The non-disclosure to those who are HIV-infected by the caregivers, may place those minors at risk of new infection and relapse from not strictly taking their medication. HIV status disclosure to the infected minors poses a greater challenge to parents, caregivers and guardians. It is going to be very difficult to reach that Sustainable Development Goal 3 if the disclosure of HIV status to the infected minors is not properly and effectively addressed. Thus, warrant the researcher to explore further the barriers and facilitators of disclosure of the HIV status to the infected minors which the parents, caregivers and guardians have.

1.1.3 Rationale of the study

It has been evident that the study conducted in Thulamela Municipality were focused on the challenges when caring for people living with HIV. The study conducted by Ramakulukusha (2015) focused on challenges faced by HIV-positive parents regarding status disclosure to their children and Mafune, Lebese and Nemathaga (2017) conducted a study about the challenges faced by caregivers of children on ART therapy at Mutale Health care facilities. Few data are available on disclosure of HIV diagnosis of HIV infected children six years after the commencement of paediatric ART in public health facilities. The researcher identified a gap regarding the disclosure of HIV status to minors, which shows that caregivers are not well supported when they have to disclose HIV status to the infected children. After the researcher has reviewed literature about the disclosure of HIV status to the infected minors, little is known in Thulamela Municipality regarding the disclosure of HIV status to the infected minors. This situation needs attention.

1.1.4 Aim of the study

The purpose of the study was to explore and describe the barriers and facilitators of disclosure of HIV status to the infected minors by caregivers, parents and guardians to propose the strategies to promote disclosure of HIV status to the infected minors.

1.1.4.1 Research questions

- What are the barriers that hinder parents/caregivers/guardians to disclose HIV status to infected minors?
- What are the facilitators of disclosure of HIV status of the infected minors?
- What can be the relevant strategies for promoting the disclosure of HIV status to the infected minors?

1.1.5 Significant of the study

It is anticipated that the study would contribute to the identification of challenges faced by parents/ caregivers/ guardians toward the disclosure of HIV status to the infected minors. HIV disclosure becomes more significant because of the multiple benefits of disclosure for the children and their caregivers. Caregivers might be relieved of living with the secret. Disclosure might inform adherence to antiretroviral (ART) medications and influences children’s participation in health care decision-making. The disclosure also might create awareness for children to understand HIV infection and make sense of their disease-related experiences as well as the importance of taking medication. Children who are aware of their HIV positive status might have better abilities to seek social support, improved coping skills and practice safer sexual practices to prevent secondary transmission Yaw Appiah et al (2019). Department of health might benefit from the study as the spread of HIV might be controlled. Disclosure might assist policy and guideline developers on issues pertaining to the disclosure of HIV to infected minors. The identified barriers might serve as a basis upon which programmes to improve the quality of life of parents, caregivers and guardians of children on ART will be developed.

1.1.6. Definition of key concepts.

The key concepts that are used in the study are defined as follows:

- **Barriers to disclosing HIV status to infected minors**

Barriers can be defined as something that prevents or hinders from doing or performing something. In this study barriers are the thing that hinders parents, caregivers and guardians to disclose HIV status to the infected minors.

- **Caregiver, parents and guardians**

According to the National Department of Health (2016) caregivers, parents and guardians refer to the person who cares for and lives with a child whose HIV infected. In this study, caregivers are people who are taking care of HIV infected minors.

- **Disclosure of HIV**

Disclosure is a gradual process of giving children age-appropriate information regarding their illness (National Department of health, 2016). In this study disclosure of HIV is when the caregivers are informing minors about their HIV status.

- **HIV infected Minors**

In this study, HIV infected minors are children who are living with HIV under the age of 18 years. Minors refer to children under the age of 18 years (children's Act, no.38 of 2005).

1.2. METHODOLOGY

This section includes the research designs which the researcher was used to collect data. It is composed of various sub-headings which were as follows: research design and approach, study area target population and sampling methods, instrument, data collection methods, data analysis method, ethical consideration, pre-testing, plan for dissemination and implementation of results references, a timeline and the budget.

1.2.1 Research approach

A qualitative research approach was employed to enables the researcher to collect first-hand information from the participants. Qualitative research would help the researcher to have a better understanding about the barriers and facilitators of disclosure of HIV status to the infected minors, getting in-depth information and it also allows the researcher to interview the participants where the researcher have a chance to get clarification and probe over what the participants would be saying. Qualitative research is the research that attempts to collect descriptive data in respect of a particular phenomenon to develop and understand what is being observed or studied (Maree, 2016). According to Hancock, Oddefor & Windridge (2014), qualitative research is an approach that is systematically used to describe life experiences and situations to give them meaning.

1.2.2 Research designs

The study was making use of the explorative, descriptive and contextual design. According to Peniel (2015), research design can be defined as the plan, structure and strategy of investigation purporting to answer research questions and control variance. Research designs articulate what data is required, what methods are going to be used to collect and analyse the data and how all of these will answer the research question (Van Wyk, 2016).

1.2.2.1 Explorative study

The study was explorative since the researcher was exploring the barriers of the caregivers regarding the disclosure of HIV positive status to the infected minors. According to Maree (2016), an explorative study is a large proportion of social research conducted to explore a topic or provide basic familiarity with the topic. Explorative studies are undertaken when a new area is being investigated or when little is known about an area of interest, it is used to investigate the full nature of the phenomenon and other factors related to it (Swanson, 2015).

1.2.2.2 Descriptive study

The study was descriptive design since the researcher was giving the parents, caregivers and guardians of the HIV infected minors an opportunity to describe their barriers regarding the disclosure of HIV status to infected minors. According to Kim & Boyd (2017), a descriptive study is a type of research that involves either identifying the characteristics of an observed phenomenon or exploring possible associations amount two or more phenomena.

1.2.2.3 Contextual study

The study was contextual in nature since the researcher was interviewing the parents/caregivers/guardians of the children who are infected with HIV at one of the community health centres where they are receiving treatment since the parents/ caregivers/ guardians were not known by the researcher. Contextual studies mean carrying out research that helps you understand and explain where, how and why your ideas fit in other practices past and present (Khatir, 2013).

1.2.3 Study setting.

The study was conducted at the selected community health centres situated in Thulamela Municipality. Thulamela Municipality is a Category B municipality situated within the Vhembe district of Limpopo Province. Community Health Centre will be selected because of its higher number of parents, caregivers, and or guardians who are collecting medication for their HIV infected minors. Community Health Centre was given a code name by the researcher for confidentiality and ethical issues are given the sensitivity of the issue in hand. Community Health centres render health services such as antenatal services, HIV and AIDS treatment, optimistic services, Dental services and other general health services. According to Bejane (2013), study settings refers to the place where the study would be conducted.

1.2.4 Target population

For the purpose of the study, the target population were all parents, caregivers and guardians who are caring for HIV infected minors and receiving care and treatment for their infected minors at a selected community health care centre around Thulamela Municipality. The researcher was selecting a health care centre that has high numbers of parents/caregivers/guardians who are caring for HIV infected minors. Target population refers to all the members who meet the criteria specified for the research (Alvi, 2016). According to Bejane (2013), the target population is the entire set of individuals who meet the sampling criteria.

1.2.5 Sampling

According to Alvi (2016), sampling is the procedure through which a sample is extracted from the population. Sampling involves the selection of several study units from a defined study population (Maree, 2016). The researcher made use of non-probability sampling. According to Stephanie (2015), Non-probability sampling is a sampling technique where the odds of any member being selected for a sample cannot be calculated. The researcher used non-probability sampling since not all caregivers are going earn the chance to be included in the study, however, only parents, caregivers and guardians who are caring for HIV infected minors were included in the study purposefully. Though, the sampling technique for this study was purposive sampling for both the community health centre and the parents/caregivers/guardians of the infected minors.

The community health centre was selected from eight clinics within Thulamela category B Municipality based on the higher number of parents/caregivers/guardians are caring for HIV infected minors.

1.2.5 Sample Size

The researcher was anticipated to interview 30 participants to meet the aim and the objectives of the study, however, the actual number of the participants in the study were determined by data saturation at the 22nd participant. According to Masuku and Singh (2014), the sample size is an important feature of any study or investigation in which the aim is to make inferences about the population from a sample.

1.2.6 Criteria for inclusion

For the purpose of the study, the participants was all parents, caregivers and or guardians caring for HIV infected minors in a selected community health centre aged 18 years and above who were willing to participate and who are receiving HIV treatment for their children at a selected health centre.

1.2.7 Data collection methods

The researcher made use of a semi-structured in-depth interview to enable the participants to express their viewpoints about the barriers and facilitators of disclosure of HIV status to the infected minors and it enables the researcher to make use of open-ended questions to obtain data from participants. The data were collected through interview methods. According to Abawi (2013), an interview is a way of collecting data through listening to individuals, recording, filming their responses or a combination of methods.

As the researcher was using semi-structured in-depth interviews for the study. According to de Jonckeere and Vaughn (2019), a semi-structured interview is a method of interview in which consist of a dialogue between researcher and participants, guided by an interview guide and supplemented by follow-up questions, probes and comments. The interview guide was used during data collection so that the researcher would be able to ask similar questions to all participants. The researcher also served as a research instrument during data collection by observing the non-verbal cues, probing, summarizing and paraphrasing some of the responses of the participants.

1.2.8 Pre-test

The researcher conducted a pre-test study to check if there was no mistake within the interview guide and if the questions were appropriate for the study. A pre-test is a method of checking that questions work intended and are understood by those individuals who are likely to respond to them (Hilton, 2015).

1.2.9 Measures to ensure trustworthiness.

According to Anney (2014), trustworthiness is when a research project reflects the reality and ideas of participants. Anney (2014) states that trustworthiness involves the following elements:

1.2.9.1 Credibility

According to Anney (2014), credibility can be defined as the confidence that can be placed in the truth of the research findings. To achieve credibility the following procedure would be followed:

- The prolonged engagement was ensured where the researcher went to the participants during data collection and spend 45 to 60 minutes with them. At that particular time researcher was able to build a good working relationship with them when collecting data. Persistent observation is where the researcher was using a voice recorder and the researcher was observing all non-verbal communication done by the participants

- Triangulation was employed where the researcher used journals, books and first-hand information from the participants regarding the study, using a voice recorder, observation and notes taking for data collection and probe more regarding the study.
- Member check, the researcher were playing back the voice recorder to confirm the responses, also go back to the informants to check the interpretation with them and check notes that were written down to add some additional voluntary information or to remove if there was a need.
- Peer debriefing is where the researcher was allowing colleagues who are at the same level with, who understand the nature of the study to check the research findings.

1.2.9.2 Transferability

The researcher explained the purpose of the study, study setting, participants sampling and target population in detail so that the research would allow independent checking peers to ensure trustworthiness. Transferability refers to the extent to which the findings can be applied in another context (Anney, 2014).

1.2.9.3 Dependability

Dependability is established using audit trails where the researcher would keep safe all documents used when collecting data such a field notes, recorder etc. The researcher would make use of an independent co-coder to cross-check the transcripts to see if there were similarities in the findings. This is where the researcher provides the audience with evidence that if it were to be repeated with the same respondents in the same context the findings would be similar (Anney, 2014).

1.2.9.4 Conformability

Conformability was ensured through the process where the researcher transcribed all the presented information as it is presented by the participants. According to Anney (2014), conformability refers to the degree to which the results of an inquiry are confirmed. It promotes freedom from bias in research procedures and results.

1.2.10 Data analysis methods

The researcher employed the six steps of qualitative data analysis by Cresswell (2016) to analyse data that was collected from the participants, the steps were as follows:

- The first step of the researcher was transcribing the data from the handwritten field notes, voice recorder and also including non-verbal cues.
- After the researcher has transcribed, the researcher read all the notes or data which would allow the researcher to reflect on the overall meaning of what the participants have said.
- In the third step, the researcher was started coding all of the data. After coding, the researcher was using a coding process to generate a description of the setting as well as categories or themes for analysis; this was involving a detailed rendering of information about people, places in a setting.
- Thereafter, the researcher was advancing how the description and themes would be presented in the qualitative narrative.
- Finally, the researcher was interpreting the data to generate the study findings.

1.3 ETHICAL CONSIDERATIONS

Ethics is a branch of philosophy that deals with the conduct of people and guides the norms or standards of behaviour of people and relationships with each other (Akaranga & Makau, 2016). According to Temesgen (2016), ethics is one of the important aspects that need to be included in the research, about creating a mutually respectful, win-win relationship in which participants are pleased and protected. The following ethics would be considered in the study to protect the right of the participants:

1.3.1 Ethical clearance

The researcher subjected the proposal to the School of Health Sciences (SHS), Higher Degree Committee (SHDC), Executive SHDC and UHDC of the University of Venda proposal approval and research ethics committee for approval and quality check. The researcher obtained permission to conduct the study from the Limpopo provincial Department of Health.

Furthermore, the researcher also sought permission from the Thulamela District Department of Health to conduct the study. The researcher obtained permission from the managers of the selected CHC to conduct the study.

1.3.2 Informed consent

Informed consent referred to the prime responsibility of the researcher and the standard procedure in professional codes of ethics (Showkat, 2017).

- **Information letter**

The researcher explained the nature of the study, purpose/ the aim of the study in detail to the participants. The assurance of confidentiality as the researcher would keep the information provided confidentially at all times. The researcher ensured voluntary participation where the participants were allowed to withdraw at any time during the study if they feel they don't want to participate anymore. It also entailed the issue of the venue, duration and time that was taken during the study.

1.3.3 Principle of justice: fairness in subject selection

According to McRae (2017), this principle entails the issue of treating the participants fairly and the right to privacy. The researcher was treating all participants equally and fair also ensures their right to privacy by keeping the information produced by participants safe and secret, not using the real names of the participants or their identity documents. That will be done by ensuring confidentiality and anonymity to the participants.

1.3.4 Freedom from harm

This involves the protection of the participants from any form of harm or injury; it might be physical, psychological or emotional.

The researcher was protecting the participants during the study from any harm if the participants produce sensitive information and start to cry the researcher stopped the interview and come back another day to continue the interview and if the researcher found out that there was a need for help to the participants, would refer them to the relevant stakeholders.

1.4 PLAN FOR DISSEMINATION AND IMPLEMENTATION OF RESULTS.

The results would be presented at an appropriate conference and submitted to a journal for peer review and publication. A research technical report would be presented to the Thulamela Department of Health HIV programme.

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SECTION 2: MANUSCRIPT

2.1: Author Guidelines

The manuscript for this mini-dissertation followed the author guidelines of and was submitted to the HIV & AIDS Review - International Journal of HIV-Related Problems

AIMS AND SCOPE

HIV & AIDS Review is the official journal of the Polish AIDS Research Society (PTN AIDS). It is published quarterly. HIV & AIDS Review publishes several types of paper: original papers, preliminary communications, epidemiology - population studies, psychological and socio-medical aspects of HIV and AIDS, educational aspects, patient-physician relationship, conference or workshop summaries, product investigations- scientific evaluations on medical and pharmaceutical products, case reports, letters to the Editor, reviews and special reports. A limited number of articles either by invitation or following your suggestions will be of a more "tutorial" format written by experts for scientists seeking an introduction into or clarification on some important issues in HIV-related research areas.

All articles accepted for publications are published free of charge.

CRITERIA FOR MANUSCRIPTS

The Editorial Board of HIV & AIDS Review takes under consideration for publication original articles with the understanding that neither the manuscript nor any part of its essential substance, tables or figures have been published previously in print form or electronically and are not under consideration by any other publication or electronic medium. This restriction does not apply to abstracts or press reports published in connection with scientific meetings. Copies of any closely related manuscripts should be submitted to the Editor along with the manuscript that is to be considered by HIV & AIDS Review.

HIV & AIDS Review discourages the submission of more than one article dealing with related aspects of the same study.

Each submission should include the statement signed by the first author that the work has not been published previously or submitted elsewhere for review and a copyright transfer.

CATEGORIES OF ARTICLES

Accepted papers are published in the following journal sections:

- original papers (not more than 10 pages)
- review articles (not more than 8 pages)

- preliminary communications for rapid communication of preliminary data (not more than 4 pages)technical notes (not more than 2 pages)
- letters to the Editor for comments on recent articles (not more than 1 page)
- case reports (not more than 8 pages)

ETHICAL REQUIREMENTS

When reporting experiments on human subjects, authors should indicate whether the procedures followed were in accordance with the Helsinki Declaration of 1975, as revised in 2000 (concerning the ethical principles for the medical community and forbidding releasing the name of the patient, initials or the hospital evidence number) and with the ethical standards of the responsible committee on human experimentation (institutional and national). The authors presenting case studies are obligated not to disclose patients' personal data. Regarding photographs, in case of any doubt that the picture inadequately protects the patient's anonymity his consent is required for publication.

Papers describing animal experiments can be accepted for publication only if the experiment conforms to the legal requirements in Poland as well as with the European Communities Council Directive of November 24, 1986, or the National Institute of Health Guide (National Institute of Health Publications No. 80-23, Revised 1978) for the care and use of Laboratory Animals for the experimental procedure. Authors must provide a full description of their anaesthetics and surgical procedures.

CONFLICT OF INTEREST

Authors are expected to describe sources of the research funding, the role of the potential sponsor in planning, executing and analysis of the study, and the influence (bias) the funding organization had on the content of the article. Other relationships (such as employment, consultancies, stock ownership, honoraria, paid expert testimony) providing potential sources of conflict of interest in relation to the submitted article should also be revealed.

CONTRIBUTORS

Each author is required to declare his or her individual contribution to the article: all authors must have materially participated in the research and/or article preparation, so roles for all authors should be described. The statement that all authors have approved the final article should be true and included in the disclosure.

REVIEW PROCESS

Received manuscripts are first examined by the HIV & AIDS Review editors. Manuscripts with insufficient priority for publication are rejected promptly. The registered manuscripts are sent to 2-3 independent experts for scientific evaluation.HIV & AIDS Review uses a double-blind review process in which authors do not know the identity of their reviewers, nor do the reviewers know the identities of the authors. Submitted papers are accepted for publication after a positive opinion of the 2-3 independent reviewers. The evaluation process usually takes 1-3 weeks.

MANUSCRIPT PREPARATION

Submission to HIV & AIDS Review proceeds totally online and you will be guided stepwise through the creation and uploading of your files. The system automatically converts your files to a single PDF file, which is used in the peer-review process.

Article structure

Original papers should be organized in a standard form with separate:

Title

- Abstract (200-250 words, structured) and Keywords
- Introduction
- Material and methods
- Results
- Discussion
- Conclusions
- Disclosures and acknowledgements
- References

Case studies should be divided to the following sections:

- Title
- Abstract (150-200 words, structured) and Keywords
- Introduction
- Case description
- Conclusions
- References.

Review papers should be divided to the following sections:

- Title

- Abstract (200-250 words) and Keywords
- Introduction
- Aim of the work
- Brief description of the status of knowledge
- Conclusions
- References.

Abstract

Abstracts for Original Articles should be structured, structured words and should consist of four paragraphs labelled: Introduction, Material and Methods, Results, Conclusion. Each section should begin on a new line and briefly describe, respectively, the purpose of the study, how the investigation was performed, the most important results and the principal conclusion that authors draw from the results.

Keywords

The author need to provide a maximum of 5 keywords from the Medical Subject Headings [MeSH] catalogue of the Index Medicus.

Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors build footnotes into the text, and this feature may be used. Should this not be the case, indicate the position of footnotes in the text and present the footnotes themselves separately at the end of the article.

Tables

Tables should be numbered according to their sequence in the text. The text should include references to all tables. Each table should be provided in a separate file.

Illustrations

- The desired position of the figures and tables in the text should be indicated in the left margin.

- When possible, group several illustrations on one block for reproduction; figures and photographs should be attached as separate printouts (in the electronic version, as separate files); figures should be saved in one of the following formats: .cdr, .tif, .jpg, .ai, .bmp or .eps. Photographs sent in the electronic form should be of the resolution of 300 dpi and in .tif or .jpg format. Do not place figures and photographs in MS Office files. Like all other figures, a block should be prepared within a rectangular frame to fit within a single or double column width of 84 and 174 mm, respectively, and a maximum page height of 226 mm.

- Each figure should include a scale magnification bar; do not use magnification factors in the figure legends.

- All figures, whether photographs, graphs or diagrams, should be numbered consecutively throughout.

References

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Web references

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

References in a special issue

Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

Reference formatting

References should not exceed 30 items in the case of original articles, 50 items for review articles, and 20 items for case reports. The recommended style for references is Index Medicus/NLM:(http://www.nlm.nih.gov/bsd/policy/cit_format.html). Reference items should be put in a list according to the order in which they are cited in the text. Each item should contain the following: a) surnames and first letters of names (without a dot) of all authors when there are six or fewer; when there are seven or more, list the first three, then „et al.”; b) full title of the paper in original (capital letters should not be used at the beginning of each word, only the first word should begin with a capital letter); c) abbreviated name of the journal in which the paper was printed in the form specified by Index Medicus; and d) year of publication, volume, full numbers of the first and last pages of the cited passage.

If the cited work is available only online, the DOI number should be given, and in the case of lack thereof - the URL with access date.

Reference to a journal publication:

Nightingale VR, Sher TG, Mattson M, Thilges S, Hansen NB. The effects of traumatic stressors and HIV-related trauma symptoms on health and health-related quality of life. AIDS Behav 2011; 15: 1870-1878.

Reference to a book:

Strunk W, White EB. The Elements of Style. 4 ed. Longman, New York 2000.
Reference to a chapter in an edited book:

Mettam GR, Adams LB. In: Jones BS, Smith RZ (eds.). Introduction to the Electronic Age, EPublishingInc., New York 2009, pp. 281-304.

Reference to a conference:

Heidemann J, Ye W, Wills J, Syed A. Research challenges and applications for underwater sensor networking. In: Proc. IEEE Wireless Communication and Networking Conf., 2006.

Proofs

Corrections to the proofs should be restricted to printer’s errors only; other alterations will be charged to the authors. In order to maintain rapid publication, proofs should be returned within 48 hours, preferably by e-mail, fax or courier mail. If the Publisher receives no response from the authors after 10 days, it will be assumed that there are no errors to correct and the article will be published.

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2.2 MANUSCRIPT

Title of the manuscript: The barriers and facilitators of disclosing HIV positive status to minors: An exploratory study of primary caregivers in South Africa. Submitted to HIV & AIDS Review - International Journal of HIV-Related Problems ***(Accepted and awaiting issue assignment and publication)***

The barriers and facilitators of disclosing HIV positive status to minors: An exploratory study of primary caregivers in South Africa

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ABSTRACT

The disclosure of the Human Immunodeficiency Virus (HIV) status can be a problematic issue; it may cause a stressful and anxious situation in one's life before and after the process of disclosure of HIV. To disclose HIV status to your own child or children become more difficult as they may fear stigma and many questions that may arise after disclosure of the HIV. The purpose of the study was to explore and describe the barriers and facilitators of disclosure of HIV status by parents, caregivers and or guardians to propose the strategies to promote disclosure of HIV status to the infected minors. The study employed a qualitative exploratory-descriptive design. Participants were purposively selected in one of the Community Healthcare centres in Thulamela Municipality. Twenty-two participants were interviewed during data collection. Data were analysed through thematic analysis and four themes emerged from the data which included; psychosocial challenges related to HIV disclosure, barriers that hinder HIV disclosure, facilitators of HIV disclosure and suggestions to improve HIV disclosure. It is important to design HIV status disclosure strategies that would improve parents/caregivers/guardians' skills and knowledge through health promotion and the involvement of key stakeholders in the process.

Keywords: Barriers, Disclosure, HIV status, Minors living with HIV, Parents.

INTRODUCTION

South Africa has a relatively higher burden of human immunodeficiency virus (HIV) infection. HIV is a public health problem that affects everyone regardless of age, gender and ethnicity [1]. Disclosure of one's HIV status is critical which may cause a stressful and anxious situation in one's life before and after the disclosure [2]. Disclosure of HIV status poses a challenge to parents, caregivers and guardians who face a stressful process of informing the HIV infected minors who are under their care about their HIV status, it also can put pressure and strain on the relationships of children and their parents, caregivers and guardians [3]. Many parents, caregivers and guardians are not disclosing HIV status to the infected minors; most of the children living with HIV who are on ART do not know their HIV status [4]. This study seeks to provide an exploration of HIV status disclosure to the infected minors in Thulamela Municipality. HIV is a worldwide health challenge; the initiation of PMTCT helps to reduce the new HIV infection of children, hence there is still new infection of children with HIV disease especially for those mothers who did not attend the antenatal services during pregnancy. In Asia HIV prevalence is low at 0.3% however, an estimated 3.5 million people are living with HIV hence 71% are children [5].

Sahay [6], indicated that disclosure of HIV status to children in India poses complex challenges because of issues pertaining to transmissibility, maternal guilt, parent's own HIV status and potential for social stigma and isolation among others. The disclosure was reported to be high in a study conducted among 145 HIV infected children studied 75.3% in India. According to Taukeni and Ferreira [7], they estimated about 35 million people living with HIV and AIDS which 70.6% are from Sub-Saharan Africa and 2.3 million living with HIV are children. According to Nazarali [8] in Sub-Saharan Africa disclosure of HIV status is often viewed as a discrete event even though the number of people living with the HIV epidemic grows bigger and the majority of HIV-positive children are unaware of their HIV status, even if currently receiving treatment. The Ministry of Health in Uganda indicate that 176.948 children under 15 years living with HIV and are not informed yet [8]. The challenge of HIV infected children increased in Uganda. Children living with HIV who are school-aged and entering adolescence have access to life-saving drug therapies [9].

Appiah et al. [10] stated that in Ghana disclosure of HIV status to children is very low as there are 43% of children living with HIV who are on ART whose HIV status has been kept secret and many of those children grow into adolescents not knowing their HIV status. According to Statistics South Africa [11], an estimated 280,000 children (aged 0 to 14) were living with HIV in South Africa, only 58% of who were on treatment. New infections have declined among South African children, from 25,000 in 2010 to 13,000 in 2017. This is mainly due to the success of the prevention of mother-to-child transmission (PMTCT) programmes. The rate of mother-to-child transmission stood at 1.3% in 2017, down from 3.6% in 2011. This puts South Africa on track for eliminating mother to child transmission. As it stands, for every child-initiated on to treatment, 1.4 is newly infected with HIV.

Children are also affected by HIV through the loss of family members and they become more vulnerable to the disease as they need support and protection; however, those who are expected to protect them may be the ones who expose those children in danger of being infected by HIV. In South Africa, more than 2 million children have been orphaned by HIV and AIDS [7]. According to the National Department of Health [12], there is a low disclosure rate of HIV status to the infected minors in South Africa, most of the parents, caregivers and guardians are have fear of emotional impact, consequences of disclosure and issues of guilt, shame and blame for HIV disease,

South Africa adopted Sustainable Developmental Goal 3 in September 2015 where South Africa decided to tackle the HIV epidemic, where one of their goals is to end the spread of HIV disease. However, South Africa has a range of relevant policies and interventions geared towards fighting the HIV and AIDS scourge in place e.g. The National Strategic Plan on HIV/AIDS and STIs 2000-2005, the integrated school health policy, Basic Education National Policy on HIV and TB of 2013 and the Prevention of Mother-to-Child-Transmission (PMTCT) programme. These policies are an indication that the South African government and its partners have the intention to address the HIV pandemic. According to District Health Barometer [13], 65.5 % of children living with HIV are on ART. However, there is a need for identification of the barrier and facilitators of disclosure of HIV status to the infected minors and the need to propose strategies to promote disclosure of HIV status to the infected minors.

Problem statement

Families and individuals are going through enormous stress as a result of the HIV infected minors and continue caring for them as well as the trauma of death thereof. At some points, HIV infected minors complain about the use of antiretroviral treatment (ART) every day while others are not taking treatment. As a result, some of the caregivers also complain about the non-adherence to the treatment prescribed for HIV infected minors. The reason for the non-adherence is rooted in the issue of or lack of awareness about the reason for taking the treatment as per the prescription [14]. The health sector in Thulamela Municipality needs to combat and bring the spread of HIV to a complete halt as envisaged by Sustainable Development Goal No. 3 of the United Nations, just like the whole world.

Despite the availability of the above Sustainable Development Goal 3 set by the United Nations, considering the issue that a significant number of minors who are HIV infected are not aware of their status, the following are often cited as acute fears associated with disclosure of HIV status: parents/caregivers/guardian's accusation of infidelity, and risk of violence [15]. The non-disclosure to those who are infected may place those minors at risk of new infection and relapse from not strictly taking their medication. HIV status disclosure to the infected minors poses a greater challenge to parents, caregivers and guardians. It is going to be very difficult to reach that Sustainable Development Goal 3 if the disclosure of HIV status to the infected minors is not properly and effectively addressed. Thus, warranted the researchers to explore HIV status disclosure to the infected minors. The purpose of the study was to explore and describe the barriers and facilitators of disclosure of HIV status to infected minors by the parents/caregivers/guardians at a selected community health centre (CHC) to recommend measures to promote disclosure of HIV status to the infected minors.

MATERIAL AND METHODS

The exploratory-descriptive design to understand better the barriers and facilitators of the disclosure of HIV status to infected minors was used.

Setting

The study was conducted at one of the CHCs located within the Thulamela Municipality, Vhembe District, Limpopo province of South Africa. The CHC was selected because of its higher number of parents, caregivers, and or guardians who are collecting medication for their HIV infected minors. The selected CHC renders additional health services such as antenatal services, HIV and AIDS management and other general health services.

Population and sampling

The population included all parents/caregivers/guardians who were 18 years of age and above, caring for HIV infected minors who were receiving ART at a selected CHC within the Thulamela Municipality. Participants were purposefully selected and data saturation occurred after interviewing 16 participants and five more participants were interviewed to see if new information emerged making the total sample 22 participants.

Data collection and analysis

In-depth individual semi-structured interviews were conducted with 22 participants. The audio recorder was used to capture verbal communication. Field notes were taken; non-verbal cues observed during the interview were recorded. Data were analysed through the thematic analysis technique. It was firstly transcribed in Tshivenda and translated to English by a Language expert. The authors went through the field notes, transcripts and then combine similar information to form themes. An independent coder was used by the researcher to ensure the appropriateness of the theme [16].

Measures to ensure trustworthiness

Trustworthiness was ensured through credibility, dependability, conformability and transferability [17]. The prolonged engagement was achieved by spending 45-60 minutes with each participant during the interview. Researchers made use of different methods of data collection such as audio recorders, field notes and interviews. The purposive sampling technique was used to select the participants who were key informants to the study which helped researchers to ensure transferability.

Ethical consideration

An ethical clearance (SHS/20/PH/10/2505) was obtained from the university ethics committee. Ethical principles such as informed consent, freedom from harm, confidentiality, privacy, anonymity and the right to withdraw from the study were ensured.

RESULTS

Demographic characteristics of the participants

Twenty-two participants were interviewed during the data collection period. Their characteristics were predominantly female who are collecting medication for their HIV infected children from the selected CHC in Thulamela Municipality. The participants were mainly parents (n=17) followed by caregivers of HIV positive minors (n=4) and a guardian (n=1). Participant's ages ranged from 23 to 53 years of age, and the employment status included employed (n=8), however, most participants were unemployed (n=14).

Table 1: Characteristic Of participants

Item	Age	Employment status	Relationship with the HIV+ child
1	53	Self-employed	Caregiver
2	24	Unemployed	Parent
3	33	Unemployed	Parent
4	23	Unemployed	Parent
5	30	Self-employed	Parent
6	34	Domestic worker	Parent
7	25	Unemployed	Caregiver
8	27	Unemployed	Parent
9	42	Salesperson	Parent
10	31	Unemployed	Parent
11	34	Self-employed	Parent
12	26	Unemployed	Parent
13	43	Unemployed	Caregiver
14	32	Self-employed	Caregiver
15	47	Unemployed	Guardian
16	24	Salesperson	Parent
17	35	Unemployed	Parent
18	35	Unemployed	Parent
19	36	Self-employed	Parent
20	22	Unemployed	Parent
21	31	Unemployed	Parent
22	27	Unemployed	Parent

Barriers and facilitators of HIV status disclosure

Four (4) themes and 14 sub-themes emerged from the data (Table 2), and include psychosocial challenges related to HIV status disclosure to the infected minors, barriers that hinder HIV status disclosure, facilitators of HIV status disclosure and suggestions to improve HIV disclosure.

Table 2: Themes and sub-themes emerged from the data

Themes	Sub-themes
1. Psychosocial challenges related to HIV disclosure	1.1. Parents feel hopeless
	1.2. Parents blame themselves
	1.3. Fear of stigma due to HIV positive status
2. Barriers that hinder HIV disclosure	2.1 Age of HIV positive child
	2.2 Lack of strategy to disclose HIV status
	2.3 Non-disclosure to other family members
3. Facilitators of HIV disclosure	3.1 Assertiveness
	3.2 Parents accepting and disclosing their own HIV status
	3.3 Children participating in support groups
	3.4 Involvement of social workers
4. Suggestions to improve HIV disclosure	4.1 Establishment of support groups for children living with HIV
	4.2 Parental involvement in support groups
	4.3 Provision of incentives for taking medication
	4.4 Health education

Theme1: Psychosocial challenge related to HIV disclosure.

As themes and sub-themes indicated in Table 2, the reported psychosocial challenge related to HIV status disclosure were feelings of hopelessness, parents blaming themselves and fear of stigma due to HIV positive status. The sub-themes from this theme are described as follows:

- **Parents feel hopeless**

HIV status disclosure is a very sensitive issue that makes one feels burdened and anxious. Parents/caregivers/guardians experienced the psychosocial challenge as they feel hopeless when it comes to disclosing HIV status to their children who are living with HIV, one of the parents who participate in the study says:

> *"I feel heartbroken and hopeless thinking about how am I going to tell him the kind of medication he is taking".* **(Participant 2 Parent)**

- **Parents blame themselves**

Some of the parents blame themselves for infecting their children with HIV disease which happens through Mother-to-child infection during birth and another parent reported that:

> *"When looking at the child, I blame myself and feel bad that my child is going to die".* **(Participant 8 Parent)**

- **Fear of stigma due to HIV positive status**

Parents/caregivers/guardians also have fear of stigma due to HIV positive status where people might not want to associate themselves with you because of the sickness, being rejected or isolated by family members, friends and community. Some participants say that:

> *"The child would never be free at all in her life if I tell her, her HIV status, her friends will discriminate and isolate her, they will not play with her anymore".* **(Participant 15 Guardian)**

> *"Another thing is that their friends' will no longer play with her because their parents will say don't play with her, she will get you infected".* **(Participant 22 Parent)**

> *"She is a child. I fear that she would not keep the secret, she would tell whoever her diagnosis".* **(Participant 5 Parent)**

Theme 2: Barriers that hinder HIV disclosure

Participants reported barriers that hinder them to disclose HIV status to their children as age of the child, lack of strategies to disclose HIV status to the children and non-disclosure to other family members:

- **Age of the child living with HIV**

Age of the child is seen as the barrier to parents/caregivers/guardians in disclosing HIV status to their children who are living with HIV. Some of the participants say:

> *"For now I can't say that there is a difficulty when talking to the child because the child is too small to talk about her HIV status".* **(Participant 1 Caregiver)**

> *"Here I had put the urge to disclose the HIV status to him at halt because he is too young"* **(Participant 20 parent)**

> *"Is that the child is too young to tell her about the disclosure of HIV".* **(Participant 3 Parent)**

> *"The child is too young to tell him about his HIV status"* **(Participant 5 Parent)**

- **Lack of strategy to disclose HIV status**

The other barrier that hinders the disclosure of HIV status to the infected minors by parents/caregivers/guardians is that they lack a strategy to disclose HIV status, participants do not know how and when to start telling their children why are they taking medication and or what kind of medication they are taking. The other parent reported that:

> *"I don't have the way or strategy on how I have to tell my child about HIV status"* **(Participant 3 Parent)**

- **Non-disclosure to other family members**

The non-disclosure to other family members is also seen as the barrier that hinders HIV disclosure to their children, as being HIV positive within the family, creates tension and become a source of embarrassment between family members. A participant says:

> *"The other thing is that I didn't explain to my family members what is the diagnosis of the child fearing that they would not accept my child-like other"* **(Participant 4 Parent)**

Theme 3: Facilitators of HIV disclosure

Assertiveness, parent acceptance and disclosure of own HIV status, participation of children in a support group and the involvement of the Social Workers were reported by parents/ caregivers/ guardians as the facilitators of HIV status disclosure to infected children.

Here underneath are sub-themes the emerged from this theme:

- **Assertiveness**

Being assertive as parents/caregivers/guardians helps them to be able to talk to their HIV infected children about their HIV status and the type of medication they are taking every day:

> *"Being assertive is the attitude that helps me to be able to talk to my child why is she taking medication".* **(Participant 10 Parent)**

- **Parents accepting and disclosing their own HIV status**

Some participants reported that accepting the disease and disclosing their own HIV status helps them to be able to talk to their children about their HIV status:

> *"If I accept and disclose my status of HIV it will help me to be able to talk to the child about her HIV status".* **(Participant 3 Parent)**

> *"Accepting your diagnosis makes it easier for you to be able to talk with whomever about your HIV status".* **(Participant 11 Parent)**

> *"I think if you accept that you are sick and your child is also sick and make peace with it, it will make it easy for me to talk about the HIV status with the child".* **(Participant 7 Caregiver)**

> *"You can't disclose to everybody but your family members so that they can help the child when you are absent".* **(Participant 11 Parent)**

> *"One can take it easy and accept the situation fast".* **(Participant 9 Parent)**

- **Participation of children in support groups**

The participation of children in support groups makes an impact on HIV status disclosure by parents/caregivers/guardians. They felt is more supportive when they gathered, sharing their experiences and children also meet on a group of the same disease, they can realise that he/she is not the only one suffering in such particular situation. Children would be able to understand and adhere to their treatment:

> *"I may take her to the Health Care Centre in which there is a support group for children who are living with HIV for her to meet with other children who have the same disease as hers so that she can see and realise that she is not alone".* **(Participant 1 caregiver)**

> *"what I think it can be done is that this thing of joining the support group is better so that when children who are of the same diagnosis meet and talk to each other, sharing their experience".* **(Participant 4 parent)**

> *"This is the best way here in the support group where the child meets with other children who are living with the same disease as his".* **(Participant 5 parent)**

> *"My child understands our situation mostly when we come to the support group where they give medication within the group and children saw that the medication is the same to all group members"* **(Participant 7, Caregiver)**

- **Involvement of Social Workers**

The involvement of social workers by parents/caregivers/guardians makes it easy for them to be able to disclose HIV status to their infected children. Parents reported that:

> *"But when he grow-up, I will take him to the social worker's office so that they may help me to disclose his status".* **(Participants 5, parent)**

> *"Is when those people who are social workers help parents with children who are living with HIV to explain to children about the HIV status of the children".* **(Participant 6, parent)**

> *"But sitting down with the child and social workers, I can explain to the child what is happening".* **(Participant 10, parent)**

Theme 4: Suggestions to improve HIV disclosure.

Participants have several strategies that they suggest thinking may promote the disclosure of HIV status to the infected minors such as, the establishment of support groups for children living with HIV, parental involvement, the provision of incentives for taking medication, health education, HIV treatment/medication compliance and teaching children about medical conditions at school

- **Establishment of support groups for children living with HIV**

The establishment of support groups for children living with HIV was suggested by some parents as they think it may be the best way of helping them to be able to disclose HIV status to their children who are HIV infected:

> *"Things like this the support group is the best way helping parents to talk to their children".* **(Participant 7 Caregiver)**

> *"The best way there must be a support group in the Community Health Care Centre like that one of Sibasa Community Health Centre situated at Makwarela Location, where they*

> *took the children who are living with HIV to a trip for example (Kruger National Park)".* **(Participant 1 Caregiver)**

> *"When we bring children to the support group as parents, we should meet so that we share our experiences on how to disclose the HIV status to the children, it may help us".* **(Participant 5 Parent)**

> *"In a time when we do our meeting with other parents who are caring for children living with HIV, sharing our experiences and children meet in their groups, it helps that child can see he/she is not alone".* **(Participant 8 Parent)**

- **Parental involvement in support groups**

The parent/caregiver/guardian's involvement within the support groups is reported to have the potential to aid the process of HIV status disclosure to children living with HIV. This was revealed to help parents, caregivers and guardians of these children while emphasizing the need to disclose to them. Participants expressed that:

> *"Even when we are at the Health Care Centres they say as parents we have to tell the children their status".* **(Participant 2 Parent)**

> *"We as parents must have as many meetings in a form of support groups as possible and not take it for granted because this meeting is helping so much".* **(Participant 8 Parent)**

> *"The meeting of parents who are caring for children who are living with HIV".* **(Participant 3 Parent)**

- **The provision of incentives for taking medication.**

One of the parents reported that he made use of the provision of incentives for his child to take medication and it helps him to have a chance to tell his child about medication:

> *"I buy some incentives like samba things, that he loves, then I call him inside the house where there are no other people and tell him that this medication cannot be taken when there are other people".* **(Participant 2 Parent)**

- **Health education**

Health education was taken as one of the things that may improve the disclosure of HIV status to the infected children, as parents would obtain knowledge on how to disclose HIV status to children and the significance of taking medication. Through health education, parents would be taught about the process of HIV status disclosure to infected minors:

> *"I think we come here to the clinic for medication we are supposed to be gathered together by nurses and teach us the importance of taking medication".* **(Participant 19 Parent)**

> *"I think we need to be gathered together and taught on how to live with children who are living with HIV so that we will not separate them from others".* **(Participant 3 Parent)**

> *"Like this, we have to be gathered and taught on how to talk with the children living with HIV. Taught how to start disclosing HIV status of our children".* **(Participant 20 Parent)**

> *"There must be an education for parents of children who are living with HIV, for them taught about how to talk with the children because the ways of talking are different some are harsh and some are cool. So, education on how to disclose HIV status to the infected minors is important to the parents".* **(Participant 10 Parent)**

- **HIV treatment/ medication compliance**

Having HIV treatment or compliance on medication is also seen as the strategy that improves the disclosure of HIV status, some of the parents say:

> *"So we have to follow our treatment to live better".* **(Participant 7 Caregiver)**

> *"Accepting that we are sick we have to take medication as we are supposed to".* **(Participant 11 Parent)**

> *"We are fortunate because it happens to us when there is a medication that makes us live long, other people died because there was no medication, what's important is for us to comply with HIV medication".* **(Participant 7 Caregiver)**

> *"Taking treatment every day, gives me the chance to talk to her". (Participant 21Parent)*

> *"I am grown-up, unlike her, I know the importance of taking medication, I think it will help me to tell her about taking medication".* **(Participant 14 Caregiver)**

- **Teaching children about medical conditions at schools**

Teaching children about different medical conditions at schools, to help them know different chronic illnesses that people may live with, can help improve the process of HIV disclosure:

> *"I also think that there must be a curriculum at school that teaches our children about all kinds of chronic diseases so that children living with HIV must see that they live with HIV others may suffer from another chronic disease".* **(Participant 7 Caregiver)**
>
> *"There must be some class at school that teach children about the chronic disease that may help them understand better that is not only HIV which people live with".* **(Participant 22 Parent)**

DISCUSSION

The study revealed that the disclosure of HIV status to the infected minors is a very difficult situation that strains parents/caregivers/guardians; it creates tension between themselves and their infected children. For that participants reported experiencing psychosocial challenges regarding the issue of disclosure of HIV status to infected minors, the feeling of hopelessness, blaming themselves for infecting their children and fear of stigma due to HIV positive status. Studies also stated that parents/caregivers/guardians have several psychosocial challenges regarding the disclosure of HIV status, having their fear, asking themselves too many questions on what is going to happen to their children when they disclose the HIV status of their children [18, 19]. Parents/caregivers/guardians fear that their children will suffer emotional trauma, fear of social rejection and they would live with the burden of thinking that they are going to die. They also fear the stigma that come due to HIV positive status.

Several barriers to disclosing HIV status to the children were described by parents/caregivers/guardians such as the age of the child, lack of strategies to disclose HIV status and non-disclosure to other family members. The study conducted by Madiba [20] stated that parents/caregivers/guardians did not disclose HIV status to infected minors because they feel anxious and they lack skills on how and when to disclose HIV status to their children. Gyaimfi et al. [21] study revealed that parents/caregivers/guardians are not disclosing HIV status to their infected minors because they think children are too small and they are not asking questions about the medication they consume daily and parent/caregivers/guardians concluded that there is no need for disclosure. Ibrahim et al. [22] also stated that inadequate knowledge to deal with the disclosure of HIV status is another reason why parents/caregivers/guardians are not disclosing HIV status to their children because not knowing about HIV and AIDS makes people have a negative perception towards people living with HIV like isolation, rejection and discrimination and it creates tension between family members.

Parents/caregivers/guardians reported several suggestions of HIV status disclosure to infected minors as well as the facilitators of HIV status disclosure. They suggested the establishment of support groups for the children living with HIV. Most of them think that support groups may help them during the process of HIV status disclosure. Being assertive, accepting and disclosing own HIV status and the involvement of the Social Workers may assist as parents/caregivers/guardians revealed that they are unable to disclose HIV status by themselves. The study conducted by Adromilehin et al. [23] stated that the HIV status disclosure process would be facilitated by having knowledge acquired through Health Care Facilities. The parents/caregivers/guardians also suggested that Health Education must be done through Health workers or Social workers helping them with knowledge on how and when to disclose HIV status to their children and the importance of taking medication. Galea et al. [24] also stated that it is important for parents/caregivers/guardians to have information about HIV so that they would be able to tell their children why they are taking medication.

Parents/caregivers/guardians reported that being on HIV treatment and or complying with medication, the teaching of children about medical conditions at school may help and improves the process of HIV status disclosure and help children to understand their illness. Mweemba et al [25] and Aderomilehin et al [23] stated that the HIV status disclosure process would evolve when children are able to ask questions about their sickness, the detailed questioning about their HIV status is also facilitated by the knowledge they acquire through health education.

CONCLUSION

The study was aimed at exploring and describing the HIV status disclosure to infected minors and to propose strategies to promote disclosure of HIV status to infected minors in selected CHC within the Thulamela Municipality. Psychosocial challenges regarding the disclosure of

HIV status encountered by parents/caregivers/guardians were regarded as the reason why they are not disclosing HIV status to their children. Feeling of hopelessness, fear of stigma due to HIV status and the lack of strategies to disclose HIV status were also seen as a threat when it comes to disclosure of HIV status to infected minors. Being assertive, accepting and disclosing own HIV status, participating in support groups by HIV infected children and the involvement of the Social Workers were used as the facilitators of HIV status disclosure by parents. The suggestions to improve HIV status disclosure were reported as the establishment of support groups for children living with HIV, Health Education, parental involvement, and provision of incentives for taking medication, being on HIV treatment or medical compliance and teaching children about medical conditions at school. HIV guidelines and HIV programmes for the disclosure of HIV to infected children need to be reviewed to prepare parents/caregivers/guardians for the process of HIV status disclosure for their children.

The study shows that parents/caregivers/guardians do not have knowledge and skills on how and when to start with the process of HIV status disclosure to the infected children. It is important to design HIV status disclosure strategies that would improve parents/caregivers/guardians' skills and knowledge by promoting health education and the involvement of Social workers as well as the Health Care providers during the process of HIV status disclosure of infected children, also the establishment of support groups for children living with HIV as children would be able to mingle with their peers and learn from their experiences.

Limitations

The sensitivity of the study was one of the limitations as people still have a negative perception of being HIV positive and sometimes, they are not free to talk about it. The study targeted parents/ caregivers/guardians who are caring for HIV infected minors, most of them aged from 22 to 35 and unemployed, they are unable to express their experiences regarding HIV status disclosure to their children. Despite the limitation of the study, parents/caregivers/guardians reported some strategies that can shape intervention to promote the disclosure of HIV status to infected minors.

Acknowledgement

The authors are thankful to the parents/caregivers/guardians who took the time to participate and share their experiences in this study

Conflict of Interest

There is no conflict of interest to be declared.

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SECTION 3: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

3.1 INTRODUCTION

The following section is the conclusion of the mini-thesis titled: The barriers and facilitators of disclosing HIV positive status to minors: an exploratory study of primary caregivers in South Africa. The purpose was to explore and describe the barriers and facilitators of HIV status disclosure to the infected minors to recommend ways to improve the HIV status disclosure to minors. This section provides the conclusion of the overall mini-dissertation, limitations, recommendations and summary.

3.2 CONCLUSIONS

The conclusions were subdivided according to the manuscript and the general conclusion of the whole mini-dissertation as follows:

3.2.1 Conclusion: Manuscript One: The Barriers and Facilitators of Disclosing HIV Positive Status to Minors: An Exploratory Study of Primary Caregivers in South Africa

The study was aimed at exploring and describing the barriers and facilitators of HIV status disclosure to infected minors and to propose the strategies to promote disclosure of HIV status to infected minors in a selected CHC within the Category B Thulamela Municipality. The psychosocial challenge related to the disclosure of HIV status encountered by parents/caregivers/guardians were regarded as the reason why they are not disclosing HIV status to their children. Feeling of hopelessness, fear of stigma due to HIV status and the lack of strategies to disclose HIV status were also seen as a threat when it comes to the disclosure of HIV status to infected minors. Being assertive, accepting and disclosing own HIV status, participating in support groups by HIV infected children and the involvement of the Social Workers were used as the facilitators of HIV status disclosure by parents. The suggestions to improve HIV status disclosure were reported as the establishment of support groups for children living with HIV, health education, parental involvement and the provision of incentives for taking medication, being on HIV treatment or medical compliance and teaching children about medical conditions at school. HIV disclosure guidelines and HIV programmes for the disclosure to infected children need to be reviewed in order to prepare parents/caregivers/guardians for the process of HIV status disclosure for their children.

The study shows that parents/caregivers/guardians do not have knowledge and skills on how and when to start with the process of HIV status disclosure to the infected children. It is important to design HIV status disclosure strategies that would improve parents/caregivers/guardians' skills and knowledge by promoting Health education and the involvement of Social Workers as well as the Health care providers during the process of HIV status disclosure of infected children, also the establishment of support groups for children living with HIV as children would be able to mingle with their peers and learn from their experiences.

3.2.1 General Conclusion

The research questions of the study were answered as being HIV positive still has many challenges within the communities, it results in many burdens such as fear of isolation, stigma due to HIV positive if people know about it, which lead to non-disclosure of HIV positive status to infected children by their parents/caregivers/guardians. This shows when participants reported several barriers that hinder them to disclose HIV positive status to their children. Things that assist parents/caregivers/guardians to disclose HIV positive status were described and Participants proposed several strategies that they think it's could promote disclosure of HIV positive status to infected children. The study findings show that parents/caregivers/guardians do not have enough support regarding the disclosure process of HIV positive status to their children as promised to them by the South African National Strategic Plan on HIV, STIs and TB. Most of the participants reported that they do not know how and when to disclose HIV positive diagnosis to their children as the children asking the kind of medication they are taking every day. World Health Organisation informed policy guidelines on HIV status disclosure to children, which guideline provide strong evidence that shows that the disclosure of HIV positive status of children need someone who has skill and knowledge about the process as the disclosure may cause harm to the children. To meet one of the government purposes of ending the spread of HIV in Sustainable Developmental goal 3 of ending the spread of HIV, parents/caregivers/guardians of children who are living with HIV need skills, knowledge and enough support during the process of HIV positive status disclosure to their children

3.3 LIMITATIONS OF THE STUDY

The sensitivity of the study was one of the limitations as people still have a negative perception of being HIV positive and sometimes they are not free to talk about it. The study targeted parents/ caregivers/guardians who are caring for HIV infected minors, most of them aged from 22 to 35 years and unemployed, they are unable to express their experiences regarding HIV status disclosure to their children and most of them show to have no knowledge on how and when to disclose HIV positive status to their children. Another limitation is that the study focused only on parents/caregivers/guardians and does not include the views of children regarding their health. The study was also conducted in one of the selected community health centres in Category B Thulamela Municipality, it does not cover the whole community. Despite the limitation of the study, parents/caregivers/guardians reported some strategies that can shape intervention to promote the disclosure of HIV status to infected minors.

3.4 RECOMMENDATIONS

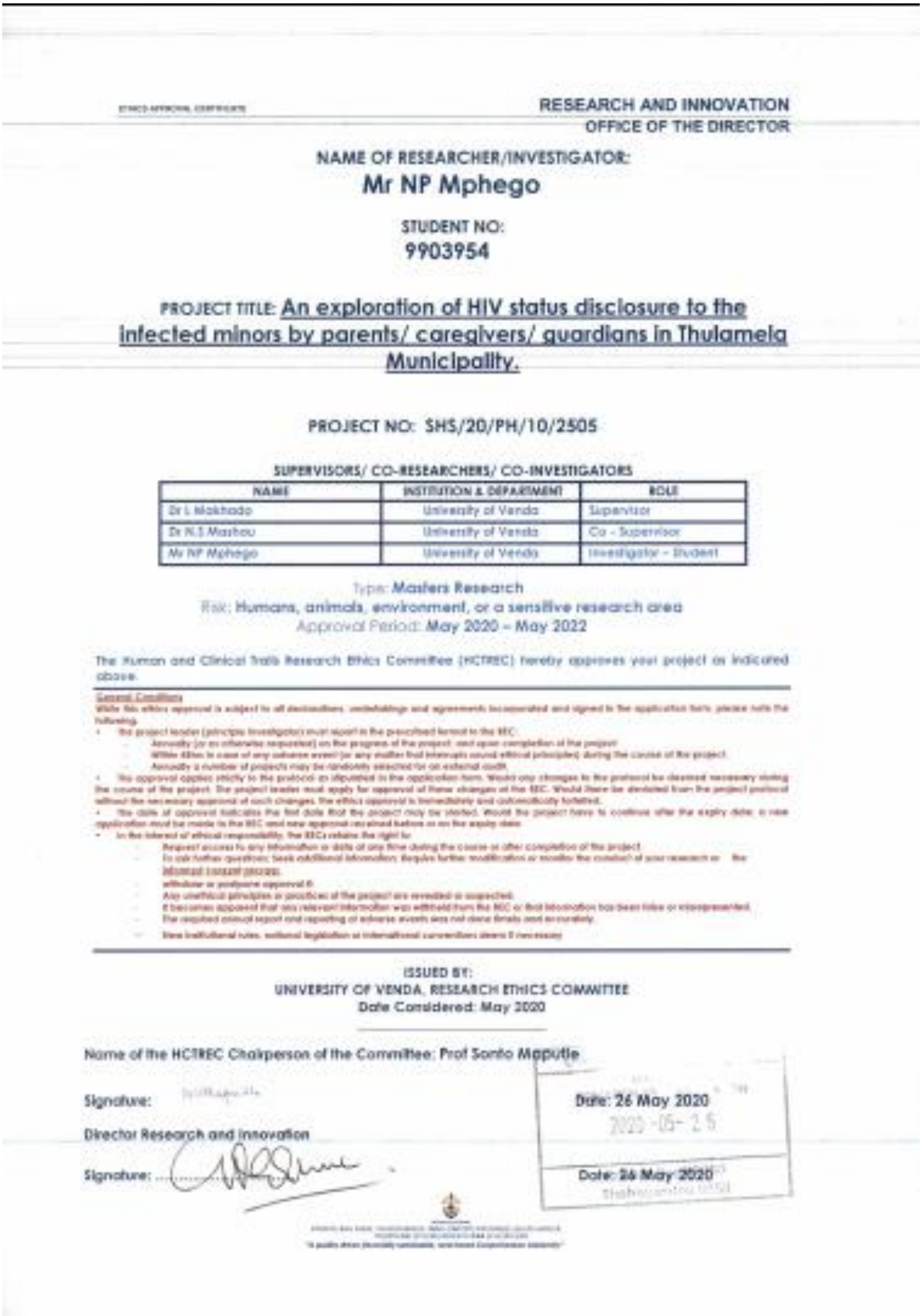
The study recommends proper training of parents/caregivers/guardians regarding the disclosure of HIV positive status to their children to promote the norm of HIV status disclosure. It is further recommended that there must be recruitment for more staff in the Health Care system to provide constant Health Education especially to parents/caregivers/guardians for children living with HIV regarding the process of HIV status disclosure to their children. As suggested by the study findings that there is a need for other stakeholders like Social Development to join hands and work with the Health Care system through continuous campaigns to reduce HIV-related discrimination and stigma. Another recommendation is that Health care providers must be more involved in preparing the parents/caregivers/guardians for the process of HIV positive status disclosure to their children and further studies are required to explore the views of the children regarding their health.

3.5 SUMMARY OF THE STUDY

The study is about the barriers and the facilitators of disclosing HIV positive status to minors by primary caregivers and the section include a conclusion, general conclusion, limitations and recommendations. Looking at the study findings, people living with HIV still encounter challenges such as discrimination, stigma, which hinders the process of HIV positive status to minors, because parents/caregivers/guardians fear that they might be burdening the children with stressful and life-threatening issues. Despite the barriers that hinder the process of HIV status disclosure, parents/caregivers/guardians are being forced by the situation to disclose HIV positive status to their minors not because they want to or they know how to disclose, where they are facilitated by being on HIV medication which required to be taken every day. Such a situation also shows that parents/caregivers/guardians do not have enough support or are not being educated regarding the process of HIV status disclosure. The study findings also reveal that there is a need for more involvement of health care providers during the process of HIV positive status disclosure to prepare the primary caregivers for the disclosure process.

APPENDICES

APPENDIX A: ETHICAL CLEARANCE



ETHICS APPROVAL CERTIFICATE

RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Mr NP Mphego

STUDENT NO:
9903954

PROJECT TITLE: **An exploration of HIV status disclosure to the infected minors by parents/ caregivers/ guardians in Thulamela Municipality.**

PROJECT NO: SHS/20/PH/10/2505

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Dr L Makhado	University of Venda	Supervisor
Dr N.S Mashau	University of Venda	Co - Supervisor
Mr NP Mphego	University of Venda	Investigator – Student

Type: **Masters Research**
Risk: **Humans, animals, environment, or a sensitive research area**
Approval Period: **May 2020 – May 2022**

The Human and Clinical Trails Research Ethics Committee (HCTREC) hereby approves your project as indicated above.

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE
Date Considered: May 2020

Name of the HCTREC Chairperson of the Committee: Prof Sonto Maputle

Signature:

Date: 26 May 2020

2020 -05- 2 5

Director Research and Innovation

Signature: ....

Date: 26 May 2020

APPENDIX B1: LETTER OF PERMISSION (PROVINCIAL DEPARTMENT OF HEALTH)

P.O.Box 1335

Sibasa

0970

Enquiries: Mphego N.P

Cell: 072 8347 851

Email: mphegon43@gmail.com

Supervisor: Prof L.Makhado

Email: lufuno.makhado@univen.ac.za

Requisition for permission to conduct research: Limpopo province Department of Health.

I Mphego Nkhetheni Patricia, a masters student at the University of Venda request permission to conduct research at the District Hospital in Limpopo Province.

The title of the study is **The Barriers and Facilitators of Disclosing HIV Positive Status to Minors: An Exploratory Study of Primary Caregivers in South Africa**

The purpose of the study is to describe and explore the barriers and facilitations that hinders parents, caregivers and guardians regarding the disclosure of HIV status to infected minors and coming up with recommended ways to promote the disclosure of HIV status.

The researcher will conduct the study at one of the Health Centres in Thulamela Municipality, Vhembe District of Limpopo province. Community Health centres provide health care services such as dental services, antenatal services, antiretroviral treatment, etc. the researcher will collect data through a semi-structured interview.

The researcher will present the proposal to the Department of Public Health, School of Higher Degree committee and the University Higher Degree Committee for approval and quality assurance. Then the researcher will submit the proposal to the University of Venda Ethics Committee for ethical clearance.

If there is any query on the matter which is not reflected in this correspondence, the contact details are as follows:

Researcher : Mphego N.P

Cell number : 072 8347 851

Email : mphegon43@gmail.com

Co-supervisor : Dr Mashau NS.

Email : ntsieni.mashau@univen.ac.za

Thank you in your anticipation

APPENDIX B2: LETTER OF PERMISSION (VHEMBE DISTRICT DEPARTMENT OF HEALTH)

P.O.Box 1335

Sibasa

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Enquiries: Mphego N.P

Cell: 072 8347 851

Email: mphegon43@gmail.com

Supervisor: Dr.L. Makhado

Email: lufuno.makhado@univen.ac.za

Requisition for permission to conduct research: Limpopo province Department of Health.

I Mphego Nkhetheni Patricia, a Master of Public Health Student at the University of Venda request permission to conduct research at the District Hospital in Limpopo Province.

The title of the study is “**An exploration of HIV status disclosure to the infected minors in Thulamela Municipality”**

The purpose of the study is to describe and explore the barriers and facilitations that hinders parents, caregivers and guardians regarding the disclosure of HIV status to infected minors.

The researcher will conduct the study at one of the Health Centres in Thulamela Municipality, Vhembe District of Limpopo province. Health Centre provides health care services such as dental services, antenatal services, antiretroviral treatment, etc. the researcher will collect data through a semi-structured interview.

The researcher will present the proposal to the Department of Public Health, School of Higher Degree committee and the University Higher Degree Committee for approval and quality assurance. Then the researcher will submit the proposal to the University of Venda Ethics Committee for ethical clearance.

If there is any query on the matter which is not reflected in this correspondence, the contact details are as follows:

Researcher : Mphego N.P

Cell number : 072 8347 851

Email : mphegon43@gmail.com

Co-supervisor : Dr. Mashau N.S

Email : ntsieni.mashau@univen.ac.za

APPENDIX C:

APPENDIX D: UNIVEN INFORMATION SHEET AND INFORMED CONSENT FORM

RESEARCH ETHICS COMMITTEE

UNIVEN Informed Consent

Appendix C

LETTER OF INFORMATION

Title of the Research Study : **An exploration of HIV status disclosure to the infected minors by parents/caregivers/ guardians in Thulamela Municipality.**

Principal Investigator/s/ researcher : **Mphego N.P (PDGM)**

Co-Investigator/s/supervisor/s : **Prof. L. Makhado**
Dr N.S Mashau

Brief Introduction and Purpose of the Study:

The disclosure of Human Immunodeficiency Virus status can be a problematic issue; it may cause a stressful and anxious situation in one's life before and after the process of disclosure of Human Immunodeficiency virus. To disclose Human Immunodeficiency virus status to your own child or guardian children become more difficult as they may fear stigma come. The study is about an Exploration of HIV status disclosure to the infected minors by parents/ caregivers/ guardians in Thulamela Municipality. The purpose of the study is to explore and describe barriers and facilitators of HIV status disclosure by parents/caregivers/ guardians in one of the community Health settings Thulamela Municipality, Vhembe District.

Outline of the Procedures :

The study is qualitative in nature, using explorative and description designs. The study will be conducted in one of the community Health centres in Thulamela Municipality, Vhembe District Limpopo Province. Non-probability, Purposive Sampling will be used to select 30 participants who will be in the study. The study will make use of the Semi-structured individual in-depth interview to collect data. 45-60 minutes will be used to collect data. Data will be analysed using the thematic analysis method. Trustworthiness will be ensured through Credibility, dependability, conformability and transferability and ethical consideration will be adhering to throughout the study.

Risks or Discomforts to the Participant:

There are no risks that are anticipated during data *collection.*

Benefits:
It is anticipated that the study would contribute to the identification of the barriers and facilitators that hinders parents/ caregivers/ guardians regarding the disclosure of HIV status to the infected minors. HIV become more significant because of the multiple benefits of disclosure for the children and their parent/ caregivers/guardians may be relieved of living with the secret

Reason/s why the Participant May Be Withdrawn from the Study:

The participants will be ensured that if they feel like they do not want to participate, they are free to withdraw and no action would be taken against them.

Remuneration:
Participants will not receive any monetary or other types of remuneration during or after the study.

Costs of the Study:
Participants will not be liable to cover any cost regarding the study.

Confidentiality :
Confidentiality will be ensured to the participants whereby the researcher will not use the names of the participants, no need for an identity document. The researcher will also ensure to the participants that the information shared will not be used against them and will be kept safe.

Research-related Injury: no injuries were anticipated during data collection.

Persons to Contact in the Event of Any Problems or Queries:

Please contact Dr. L. Makhado, My Supervisor (tel no.015 962 8828 or 084 552 6260) or the University Research Ethics Committee Secretariat on 015 962 9058. Complaints can be reported to the Director: Research and Innovation, Prof GE Ekosse on 015 962 8313 or Georges Ivo.Ekosse@univen.ac.za

General:

Potential participants must be assured that participation is voluntary and the approximate number of participants to be included should be disclosed. A copy of the information letter should be issued to participants. The information letter and consent form must be translated and provided in the primary spoken language of the research population

CONSENT

Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, (***Ms Mphego NP***), about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: SHS/20/PH/10/2505
- I have also received, read and understood the above written information (*Participant Letter of Information*) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerized system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

Full Name of Participant	Date	Time	Signature
I, ……………………..	**……………**	**…………**	**…………………..**

(***Mphego Nkhetheni Patricia***) herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Full Name of Researcher

…………………….. Date**……………….** Signature**…………………**

Full Name of Witness (If applicable)

…………………….. Date **……………….** Signature**…………………..**

Full Name of Legal Guardian (If applicable)

………………… Date**………………** Signature**…………………….**

Please note the following:

Research details must be provided in a clear, simple and culturally appropriate manner and prospective participants should be helped to arrive at an informed decision by use of appropriate language (grade 10 level- use Flesch Reading Ease Scores on Microsoft Word), selecting of a non-threatening environment for interaction and the availability of peer counseling (Department of Health, 2004)

If the potential participant is unable to read/illiterate, then a right thumb print is required and an impartial witness, who is literate and knows the participant e.g. parent, sibling, friend, pastor, etc. should verify in writing, duly signed that informed verbal consent was obtained (Department of Health, 2004).

If anyone makes a mistake completing this document e.g. a wrong date or spelling mistake, a new document has to be completed. The incomplete original document has to be kept in the participant's file and not thrown away, and copies thereof must be issued to the participant.

References:

Department of Health: 2004. *Ethics in Health Research: Principles, Structures and Processes*

http://www.doh.gov.za/docs/factsheets/guidelines/ethnics/

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APPENDIX D: CONFLICT OF INTEREST FORM

CONFLICT OF INTEREST

Conflictofinterestiswhenanindividual'sprivateorpersonalinterestsandprofessionalobligationsaredivergentto such an extent that an independent observer may have doubt as to whether or not the individual's professional actions are influenced by personal considerations, financial or otherwise.

I, **Nkhetheni Patricia Mphego** (Staff/student number: 9903954) would like to disclose the following conflict of interests:

Indicate YES or NO and state the nature of the conflict and explain how it will affect the integrity of the research.

There is a conflict of interest due to either myself or a close family members benefiting in terms of:	**YES**	**NO**
Funds or research sponsorship Explain:		No
Use of UNIVEN facilities Explain:		No
Purchasing of major equipment by the University for this project Explain:		No
Delay of dissemination of the results resulting in benefit Explain:		No
Discounts or concessions Explain:		No
Employment Explain:		No
Other Explain:		No

Mphego Nkhetheni Patricia **23/03/2020**

Principal Investigator/Researcher Date

Dr T Tshitangano **23/03/2020**

HOD Date

APPENDIX E: INTERVIEW GUIDE

Interview guide

Section A

Introduction

The researcher will introduce herself to the participants and the reason for coming to the Health centre. The researcher will explain the title, nature and the purpose of the study and also ensure confidentiality issues to the participant in order to make the participant feel free to participate in the study.

Biography

The researcher will ask the age of the participant in order to make sure is the right person to be interviewed. Also, ask if the participant is caring for HIV infected minor.

Section B

1) What do you know about disclosure of HIV status?
2) What are the barriers that hinder you to disclose HIV status to infected minors?
3) What are the facilitators of the disclosure of HIV status to infected minors?
4) What do you think can be done to help you to the disclosure of HIV status to infected minors?
5) Is there anything you want to say other than what we have discussed?
6) The researcher will conclude the session by appreciating the effort and time of the participants.
7) The researcher will give an announcement on the dissemination of the results

APPENDIX F: SAMPLED TRANSCRIPT

PARTICIPANT 13

R: What do you know about disclosure of HIV status?

P13: "I know nothing about disclosing HIV, but to me, it was not that difficult because I suffered a lot with the child, he is the person who was always sick for two years and the doctors said he was suffering from TB until he reach the age of eight when he got tested and they find out that he is HIV positive. I asked myself how my child become positive while I am negative by that time I tested and find that I am positive also by that time they didn't give treatment to anyone whose CD4 count was good they gave treatment to my child first and now it's about two years while he is taking the medication and is not long I started taking treatment."

R: What are the barriers that hinder you to disclose HIV status to the infected minors?

P13: Something that makes me not telling the child that he is sick is that he may ask how come, what happened for him or how did he become sick such sickness. But the child is too close to me I think it may not be that difficult to tell him."

R: What are the facilitators of the disclosure of HIV status to the infected minors?

P13: "The meeting of parents who are caring for children who are living with HIV, bringing the children along so that we meet and children meet, and we share our experiences that make children understand their situation and make it easy for parents to be able to talk with their children."

R: What do you think can be done to help you to disclose HIV status to infected minors?

P13: "I see that meeting with each other is better because we are learning from each other and it helps us to be open to our children."

R: Is there anything that you think can be done to encourage you to disclose?

P13: I think just that as I indicated.

Is there anything you want to say other than what we have discussed?

"I think when we are having those meeting there must be some sport for our children, I think it will encourage them and shows them that being HIV positive does not mean you are not able to be something in life."

R: Okay, is there anything else you would like to share?

P13: Not at the moment

R: Okay thank you for your time and the discussion we had.