

**EFFECT OF AN EDUCATIONAL INTERVENTION USING A CHECKLIST ON  
KNOWLEDGE, ATTITUDE AND SELF EFFICACY OF NURSES ENGAGING IN  
THE PROCESS OF DISCLOSURE AMONG CHILDREN WITH PERINATAL HIV  
AT A DISTRICT HOSPITAL IN SOUTHWESTERN UGANDA**

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


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**Declaration**

I declare that the Effect of an Educational Intervention Using a Checklist on Knowledge, Attitude and Self-efficacy of Nurses Engaging in the Process of Disclosure among Children with Perinatal HIV at a District Hospital in Southwestern Uganda is my personal work and that it has not been submitted before for any other degree at any other institution of higher learning or university for any academic award.


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## Acknowledgements

I Praise My LORD, who gave me strength and grace to complete this dissertation and reach this milestone in my life.

*“I can do all things through Christ who strengthens me”, Philippians 4:13.*

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## **Dedication**

To all my family members and friends.

To all nurses that support HIV disclosure in children who have acquired the virus from their biological parents. May God reward you immeasurably!

## Abstract

**Background/Purpose:** HIV disclosure to children who are infected is very crucial in order to maintain their own health and prevent HIV transmission. There are a number of difficulties that nurses have when it comes to the disclosure process, such as when and how best to support caregivers informing children about their HIV status. The study's objective was to evaluate the effectiveness of an educational intervention using a checklist on the knowledge, attitude and self-efficacy of nurses' engaging in the process of disclosure among children with perinatal HIV at a district hospital in Southwestern Uganda.

**Theoretical/Conceptual Framework:** Bandura's Self-efficacy Theory was used. The theory is based on four fundamentals which include actual performance of a behavior, vicarious experience, verbal encouragement and emotional states.

**Method:** A quantitative quasi-experimental, pre and post-interventional study was conducted to evaluate the effectiveness of an educational intervention on nurses' self-efficacy at a district hospital in Southwestern Uganda. Using consecutive sampling, 20 nurses (n=20) working in HIV care managing children and adolescents with perinatal HIV participated by completing a self-administered questionnaire. The intervention included an educational session followed by individual coaching by the researcher. IBM SPSS Statistic (version 24) was used for analysis. Paired T-test and Wilcoxon Signed Ranks Test were used to compare knowledge, attitude and self-efficacy of nurses before versus after the educational intervention.

**Results:** There was a significant improvement in nurses' knowledge, attitude and confidence towards pediatric HIV disclosure in children after the educational intervention and coaching using the disclosure checklist for the ongoing disclosure support process. Findings showed that nurses knew when to start disclosure, the information to share at a specific age and how to support the disclosure process using the disclosure checklist. Before the intervention the mean percent for nurses' knowledge was 50 and after the intervention it improved to 67. The statistical significance achieved the P-value of 0.001. 95% CI:  $50 \pm 8.410$  before intervention and 95% CI:  $67 \pm 5.702$  after intervention. The mean for attitudes before the intervention was 2.51 and after the intervention it improved to 2.89. The Wilcoxon signed rank test result of achieved the P-value of 0.002. 95% CI:  $2.51 \pm 0.140$  before intervention and 95% CI:  $2.89 \pm 0.184$  after intervention. Self-efficacy means score before the intervention was 2.55 and after the educational intervention it increased to 2.93. The Wilcoxon signed rank test result of achieved the P-value of 0.002. 95% CI:  $2.55 \pm 0.136$  before intervention and after 95% CI:  $2.93 \pm 0.149$ .

**Conclusion:** The study revealed that using a checklist is an important approach to ensure nurses develop a positive attitude, confidence and knowledge of the key aspects to include in the disclosure discussion. Disclosure is a critical component of the care and support that children living with HIV should receive from nurses and using a disclosure checklist is useful during the process.

**Recommendations:** Based on the study findings, it is recommended that nurses need to utilize the disclosure checklist to support caregivers informing children living with HIV of their own status. The importance of nurses' proactive role in disclosure to children of their HIV status needs to be emphasized.

**Key Terms:** Children, perinatal HIV, disclosure of pediatric HIV status, nurses' knowledge about pediatric HIV disclosure and nurse' self-efficacy on pediatric HIV disclosure.

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### **Acronyms and Abbreviations Commonly Used in This Paper**

AIDS- Acquired Immunodeficiency syndrome

ART- Antiretroviral Therapy

ARV- Antiretroviral

CD4 - Clusters of differentiation 4

HIV- Human Immunodeficiency virus

MOH- Ministry of Health

MTCT-Mother-To-Child Transmission

PASS-Pediatric ART Saturation Strategy

PLHIV-People Living with HIV

REC-Research Ethics Committee

SPSS- Statistical package for Social Sciences

SSA- Sub-Saharan Africa

UNAIDS- Joint United Nations Programme on HIV/AIDS

UNICEF- United Nations International Children's Emergency Fund

WHO- World Health Organization

## Chapter One: Introduction

HIV positive pediatric disclosure is the process of revealing human immunodeficiency virus (HIV) status to children who have acquired HIV from their biological mothers during pregnancy, childbirth or even breastfeeding (Amankwah-Poku, 2021). Disclosure in children refers to the process of sharing their HIV status with them, often by caregivers, healthcare providers or family members. Guidelines recommend individualized, age-appropriate disclosure, considering the child's cognitive, emotional, and social development (Namukwaya et al., 2017). Nurses, caregivers and family members must work together to ensure sensitive and supportive disclosure, minimizing potential negative impacts (Beebwa, 2021). Globally, in 2022, a total of 39 million people were living with HIV, with 37.5 million adults in the age between 15 years of age or older and 1.5 million children between 0–14 years old (UNAIDS, 2023). Approximately 2 million children do not know they are HIV-positive, the World Health Organization (WHO) claims that, despite the organization's compelling evidence-based information regarding the benefits of HIV disclosure (Finnegan et al., 2019).

In Uganda, an estimated 1.4 million people are HIV positive, and 52,000 new infections are reported annually. It was reported that 160,000 children had contracted HIV in 2018 (Wamala et al., 2021). According to a study about HIV status disclosure to children conducted in Southwest Uganda, 69% of children are not aware that they are HIV positive (Namukwaya et al., 2017). Pediatric HIV training for nurses has been conducted but with limited emphasis on disclosure in children with perinatal HIV (Beebwa, 2021). Nurses have an attitude that their role is only to offer health talks and nursing care but not to participate in disclosure resulting in delay or even non-disclosure to children with positive HIV status (Mutambo & Hlongwana, 2019). The

aim of this research is to evaluate the effect of an educational intervention on self-efficacy of nurses on the use of tool to engage in the disclosure process among children with perinatal HIV at a district hospital level in Southwestern Uganda.

### **Background to the Study**

The act of disclosing involves uncovering or revealing or even bringing to light (Mutambo & Hlongwana, 2019). The process should take some time to inform children infected with the HIV virus of their positive status. It entails adequate and ongoing family communication. Respecting the family's needs, wants, and expectations is crucial for nurses. The disclosure procedure ought to take place prior to the child learning about their own diagnosis. According to the WHO, children between the ages of 6 and 12 ought to be informed of their HIV status, and by the time they are 12 years old, at the latest, the disclosure procedure need to have been conducted in a compassionate and encouraging manner (Bulali, 2018).

The epidemiology of HIV in children has changed significantly since the virus was initially identified in this age group. Sharing child's HIV status with caregivers and nurses is one of the most psychosocial obstacles that caregivers and nurses of children living with perinatal HIV confront, especially in cases where the child's survival has risen and the child is growing into adolescence and adulthood. Children with prenatal HIV had a limited survival period at the start of the HIV epidemic, and disclosing their status was not carefully thought through. In 1999, guidelines were established by the American Academy of Pediatrics indicating that school-age children and teenagers ought to be made aware of their HIV status. Enhancing trust and keeping children in the dark about their HIV status were among the benefits of disclosing their status to children that the study found (Wiener et al., 2007).

According to Khangale et al. (2022), HIV infections are on the rise in Sub-Saharan Africa (SSA), where 85% of new cases among children occur and more than 1.7 million children are HIV positive. Between 13% to 60% of perinatal HIV-positive children in SSA are aware that they are HIV positive; the remaining children are not informed of their condition (Khangale et al., 2022). Additionally, Uganda reports an unparalleled number of children living with HIV, with about 150,000 children between the ages of 0 and 14 affected (Nabunya, 2020). In Uganda, 43,000 or so of the country's under-15-year-old children receive ART. In Southwestern Uganda, a research on HIV status disclosure to children revealed that just 31% of perinatal HIV-positive children had received this information (Namukwaya et al., 2017).

A study conducted in Barbados noted nurses' limited knowledge on HIV disclosure in children, their negative attitude and consequent inequity, and uncooperative actions that have a negative impact on the standard of pediatric patient care (Huq et al., 2019). Nurses' confidence to disclose was impacted by inadequate knowledge, and their inconsistent approach to disclosure caused confusion and uncertainty due to the absence of HIV standard operating procedures and their dependence on individual experience (Khangale et al., 2022; Madiba & Diko, 2021). Nurses and other child caretakers continue to experience psychological and emotional difficulties as a result of HIV non-disclosure. Given that disclosure involves informing the child about a potentially fatal and communicable disease, many parents and caregivers' worry that providing HIV information to a child who has tested positive for the virus could cause stress for the child (Okechukwu et al., 2018).

Around the world, a large number of nurses are unsure about how to carry out the disclosure process (Kairania et al., 2023; Khangale et al., 2022). The well-being of a child who is

HIV positive may be impacted by minimal or no disclosure, which could prevent them from accepting their condition and from receiving pediatric HIV therapy (Yami, 2022). It has been shown that nurses are better at explaining HIV than caregivers and are able to psychologically prepare children before disclosing the virus. Because of their training, which included expectedly sufficient knowledge and counseling abilities, nurses were perceived as being in a better position to handle negative responses to disclosure. In this study, caregivers reported that in order to get ready to start and assist with children's disclosure to children with prenatal HIV, they needed help from nurses (Appiah et al., 2021).

In accordance with Okechukwu et al. (2018), HIV disclosure should be an ongoing procedure that takes the child's developmental stage and cognitive capacity into account. A Sub-Saharan African study revealed that nurses had time constraints when offering HIV disclosure services to children (Khangale et al., 2022; Mutambo & Hlongwana, 2019). Nurses have a perception that disclosing to children with HIV is not their role and leave it pending for parents to handle on their own resulting in delay or even non-disclosure.

Children who are infected can better adhere to antiretroviral medication when they are informed about the disease and can participate in HIV care when disclosure is made in a timely and safe manner. HIV declaration enhances access to social support and is linked to responsible sexual conduct in children and teenagers (Kairania et al., 2023; Khangale et al., 2022; Madiba & Diko, 2020). It is critical that children living with HIV comprehend their status as they grow into adolescence and maturity so they can assume some responsibility for overseeing their own therapy (Madiba & Diko, 2020). To make sure that the children and their caregivers reap the

advantages of disclosure, it is critical to raise awareness among nurses about the need to assist caregivers of children who have perinatal HIV in the disclosure procedure.

As children get older and more knowledgeable, little to no disclosure could unintentionally lead to disclosure. Accidental disclosures can come from overhearing conversations with their caregiver or peers, which can lead to mistrust of adults, which can hinder treatment comprehension, engagement, and adherence (Guta et al., 2020).

According to Guta et al. (2020), telling a child they are HIV positive can be emotionally taxing for caregivers who worry that their child will not keep the diagnosis a secret from them. Delaying disclosure, according to Madiba and Diko (2020), raises the risk of HIV secondary transmission, causes children to become resentful and angry toward their caregiver, and results in medication refusal.

Pediatric HIV training has been conducted for healthcare providers regarding the disclosure process in infected children. A study carried out in Dar es Salaam, Tanzania noted that most HIV training conducted is not standardized and offers little or no information about disclosure in children with perinatal HIV and also differs in content and duration (Ismail et al., 2021). Nurses' confidence and their capacity to initiate or promote disclosure among children with perinatal HIV are negatively impacted by inadequate training about the disclosure process in children (Khangale et al., 2022; Madiba & Diko, 2021).

A study done in Namibia showed that to improve disclosure in children with perinatal HIV, a disclosure form was attached to each child's care file. This guided nurses to monitor the extent of HIV disclosure to the child. It was noted that this helped nurses to remember to check the extent of disclosure done and guided them to strengthen the continuity across clinic visits.

The study showed that incorporating a readiness assessment form helped health nurses to assess the readiness of the child to participate in the process of disclosure (Beima-Sofie, et al., 2017). The strategy of incorporating disclosure process checklist forms in children's ART files can be an effective guide for nurses to monitor disclosure progress in children with perinatal HIV (Beima-Sofie, et al., 2017). This study will use the same strategy to enhance the nurses' self-efficacy on children with perinatal HIV who are disclosed to.

### **Statement of the Problem**

Two million children living with prenatal HIV worldwide are unaware that they are positive for the virus. The percentage of children with perinatal HIV in SSA who disclose their positive status varies from 13% to 60% (Doat et al., 2019; Khangale et al., 2022). In Southwestern Uganda, 69% of perinatal HIV-positive children are unaware that they are HIV positive (Namukwaya et al., 2017). A significant advantage of disclosure is adherence to therapy with a lower chance of death. Emotional health and the practice of safer sex to lower the risk of contracting other sexual infections are additional advantages. Delaying disclosure might make children angry and resentful of the caregiver in addition to making them refuse to take their medication. This may have a negative impact on health and raise the possibility of HIV spreading to further children.

Numerous investigations have shown that nurses' lacking expertise and have poor attitude which affect their confidence to disclose to children with perinatal HIV. Nurses have not been actively engaged in disclosure and this has affected their self-efficacy on HIV disclosure in children with perinatal HIV. Pediatric HIV training has been conducted for healthcare providers. However, training conducted is not standardized and offer little or no information about

disclosure in children with perinatal HIV. According to a South African study, nurses are unconfident and ignorant about disclosing HIV to infants who are still in the prenatal stage. According to the study, a lot of nurses lost confidence in their ability to disclose HIV in children with perinatal HIV, which made them unwilling to do so.

Despite the critical role of nurses in providing comprehensive care to children born with HIV, a significant gap exists in their knowledge, attitude and self-efficacy in disclosing HIV status to these children. This deficiency can lead to delayed or inadequate disclosure, compromising the child's physical and emotional well-being and hindering their ability to adhere to anti-retroviral therapy and maintain a healthy lifestyle. The intention behind this research is to ascertain how an educational intervention affects nurses' self-efficacy in using a tool to facilitate disclosure among children who are HIV positive.

### **Purpose of the Study**

This study seeks to describe the effect of an educational intervention using a checklist on knowledge, attitude and self-efficacy of nurses engaging in the process of disclosure among children with perinatal HIV at a district hospital in Southwestern Uganda.

### **Research Question**

What is the effect of an educational intervention using a Checklist on nurses' knowledge, attitude and self-efficacy to engage disclosure among children with perinatal HIV at a district hospital in Southwestern Uganda?

## **Specific Objectives**

The study aims to:

- Identify the effect of an educational intervention on nurses' knowledge to engage in disclosure among children with perinatal HIV at a district hospital in Southwestern Uganda.
- Determine the effect of an educational intervention on nurses' attitude to engage in disclosure among children with perinatal HIV at a district hospital in Southwestern Uganda.
- Ascertain the effect of an educational intervention on nurses' self-efficacy to engage in disclosure among children with perinatal HIV at a district hospital in Southwestern Uganda?

## **Significance of the Study**

This study may be significant because it addresses the critical gap in nurses' knowledge, attitude, and self-efficacy in disclosing HIV status to children born with HIV. The findings of this study may improve nurses' competencies in HIV disclosure, ultimately enhancing the quality of care and outcomes for children living with HIV. The study's conclusions might have a bearing on nurses' ability to disclose HIV to children who are perinatally infected as well as the nursing profession as a whole. The results could also serve as a guide for creating a hospital disclosure policy that nurses could utilize when telling children about HIV during the perinatal stage of the disease. The results may also help with the education and training of other clinic personnel about HIV disclosure in children.

The findings might be useful in educating children living with HIV about how they contracted the virus and how to live a healthy life with it, as well as helping nurses reveal pertinent information to them. Children with perinatal HIV may benefit from this in terms of their physical and mental wellbeing.

Findings may be significant to society at large as many children with perinatal HIV are reaching adulthood. Children with perinatal HIV should know their HIV status so that by the time they become sexually active they may avoid further HIV transmission or even vertical transmission to their own children in the future.

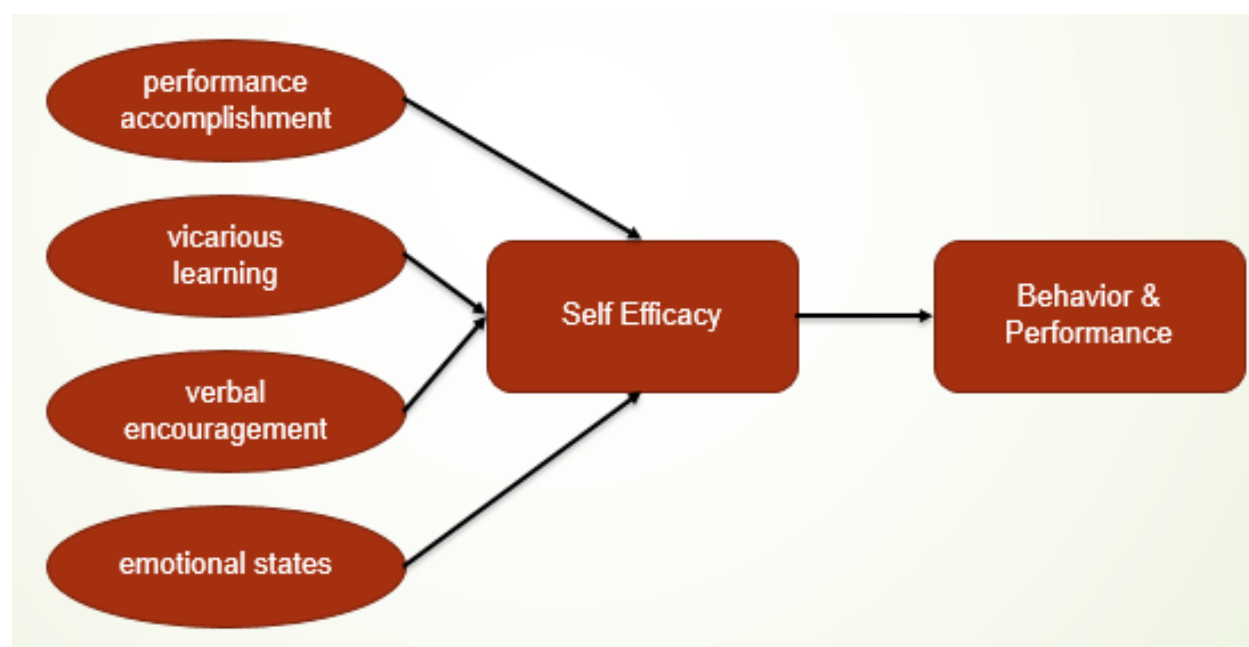
### **Theoretical Framework**

Self-efficacy theory (see figure 1) is a subclass of social cognitive theory as proposed by Bandura (1986). An individual's assessment of their ability to organize and carry out actions is known as their self-efficacy. Confidence in one's ability to impact motivation, actions, and social environments is known as self-efficacy. Every facet of the human experience is impacted by these cognitive self-evaluations, including the goals people seek, the amount of effort they put forth to achieve goals, and the likelihood of reaching particular behavioral performance levels. The premise of self-efficacy theory is that individuals can choose to have control over their actions. The idea can be applied in a number of contexts to analyze and forecast changes in health-related behavior and management. The self-efficacy hypothesis consists of two components: outcome expectations and self-efficacy. The idea states that the reason the two components were separated is that although people may think that a particular conduct will lead to a particular end, they may not be aware that they are capable of carrying out the behavior necessary to accomplish that particular outcome (Peterson & Bredow, 2017).

Bandura (1986) suggested that conclusion about one's self-efficacy is based on four fundamentals which include actual performance of a behavior, vicarious experience (visualizing other people performing a similar behavior), verbal encouragement and emotional states. While behavioral and contextual factors have a significant impact on outcomes, self-efficacy theory also highlights the relative importance of personal characteristics (Peterson & Bredow, 2017).

***Figure 1: Self-efficacy Theory***

***Self-efficacy Theory***



*Note.* (Bandura, 1997, as Cited in Staples et al., 1998).

***Relationship among Components of the Framework***

Performance accomplishment, verbal encouragement, vicarious learning, and emotional states are the four main sources of self-efficacy. The connections between the various elements of the framework that this study used are described in more detail below.

**Performance Accomplishment.** Performance accomplishment is the term used to describe data from a person's personal assessment that is derived from their own mastery achievements. Expectations of mastery are lowered by repeated failures and raised by prior achievements. Performance accomplishment is regarded to have the biggest impact on self-efficacy since it symbolizes one's perception of past experiences' success or failure. Strong efficacy expectations can be developed by repeated successes, which lessen the detrimental effects of sporadic failures. Self-efficacy beliefs are not established by performance alone. An individual's assessment of their own self-efficacy is impacted by numerous factors, including the amount of work required, prior successes and failures, perceptions of one's own competence, and the perceived difficulty of the task. Still, there's nothing that boosts self-efficacy more effectively than experiencing expertise firsthand. Having a strong sense of self-efficacy necessitates having prior experience overcoming challenges through perseverance (Peterson & Bredow, 2017).

**Vicarious Learning.** Modeling is a term used to describe vicarious learning, which can lead to viewers expecting that they can learn from what they have seen and so enhance their own performance. Observing how others behave, particularly those we hold up as role models, provides us with our second source of self-efficacy. When we see people who are similar to us work hard and achieve success, it makes us believe that we are also capable of learning the skills necessary to thrive in that field. Witnessing others successfully accomplish a task that was once thought to be difficult is known as a vicarious experience. One is more likely to internalize at least some of the positive self-beliefs of positive role models in their lives. This may boost one's confidence in their ability to carry out specific tasks (Peterson & Bredow, 2017).

**Verbal Encouragement.** Verbal encouragement describes actions used to persuade someone that they can successfully complete a task by making suggestions. Common strategies for social persuasion include coaching and providing performance evaluations. Coaches and other significant individuals in our lives might help us believe more strongly that we possess the necessary skills for success. Persuaded that we are capable of mastering a particular activity increases our likelihood of exerting ourselves and sticking with it when issues emerge. Receiving encouraging verbal comments while completing an apparently difficult task helps someone believe they have the abilities and know-how necessary to complete the work successfully. A person's self-efficacy is impacted by both positive and negative feedback regarding their performance or capacity for performance. Self-efficacy can be raised by positive feedback persuasion at any age, but the sooner the better. According to Peterson and Bredow (2017), verbal persuasion is more likely to promote the development of self-efficacy the earlier it is used.

**Emotional States.** A person's perception of their own talents in a given circumstance can be influenced by their holistic well-being, which encompasses all facets of life, including their bodily, psychological, and mental health. One's subjective self-efficacy is influenced by their current state of affairs. According to Bandura (1977), how emotional and physical reactions are perceived and interpreted matters more than their overall intensity. Individuals who possess a strong sense of self-efficacy are likely to see their arousal as a motivating tool for achievement, whereas those who struggle with self-doubt may see it as a crippling force. According to self-efficacy theory, improving one's ability to control anxiety and elevate mood in difficult situations can increase one's sense of self-efficacy (Peterson & Bredow, 2017).

**Self-efficacy.** A person's belief about what she or he can accomplish provides a foundation for one's well-being, personal accomplishment, and motivation. People's perceptions of their own abilities can influence how much work they put into tasks and how long they stick with them. When faced with a task, people who believe in their own abilities are more inclined to put in more effort or even give up than those who do not. The definition of self-efficacy is one's assessment of one's own capabilities to execute a specific behavior pattern (Peterson & Bredow, 2017; Staples et al., 1998).

**Behavior and Performance.** Outcome expectancies and perceived self-efficacy are important behavioral factors. While self-efficacy is one's ability to successfully complete the task necessary to produce an outcome, outcome expectancy is the degree to which one believes that a given event will occur. When people think they possess the abilities needed for success, they perform better. Self-efficacy influences one's willingness to put up the effort to change dangerous behavior and the tenacity to persevere in the face of setbacks and disappointments that could deplete motivation (Peterson & Bredow, 2017).

### ***Operationalizing the Theory to this Study***

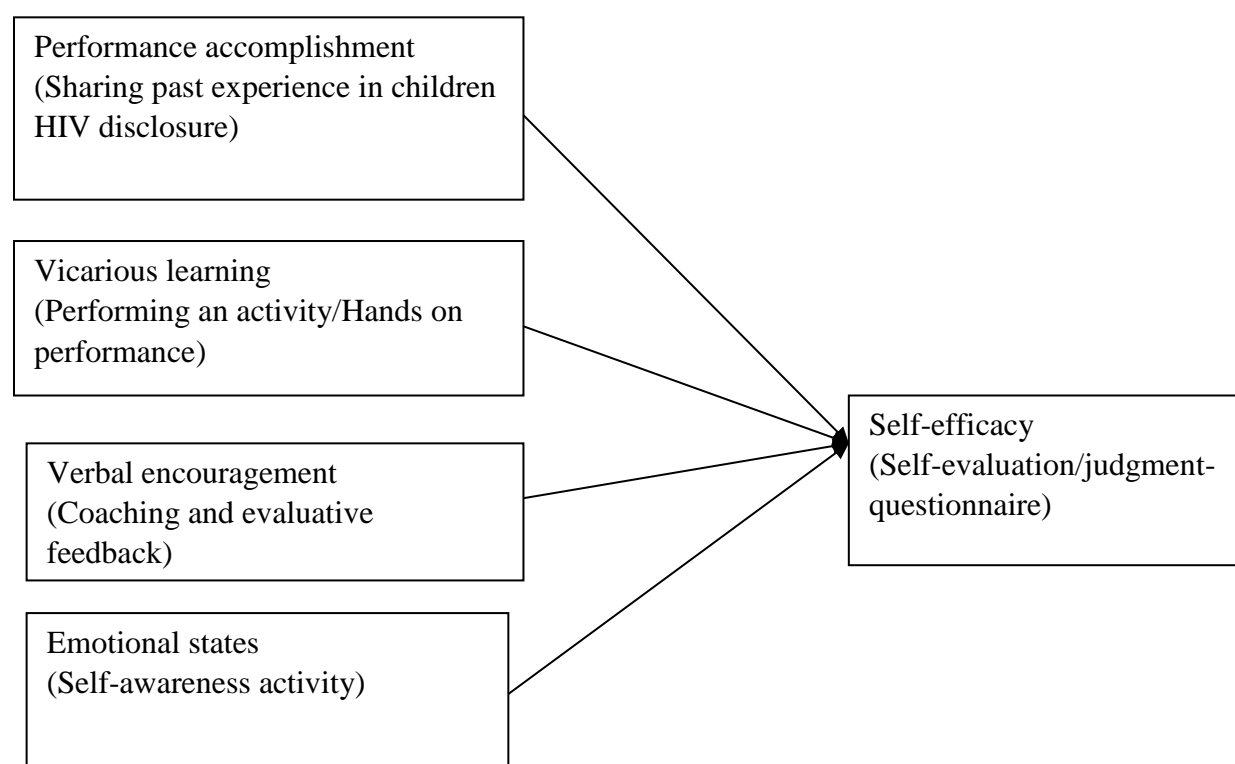
Understanding of nurses' perceived self-efficacy of disclosing to the infected children will be ascertained through use of a questionnaire. An educational intervention will be conducted with a focus on the description of what HIV disclosure in children with perinatal HIV is, its types, when it should be done, how long it may take to complete the process, barriers involved, benefits of disclosing and the impact of not disclosing in children with perinatal HIV.

During the educational intervention, participants will divide into small groups and discuss their own thoughts about the barriers and benefits. Then I will have each small group share with

the large group what transpired from the discussion. That will help the participants to be engaged in the learning process. After that, I'll go into further detail regarding the advantages and obstacles of HIV disclosure in children so that nurses are aware of the procedure. This research seeks to evaluate if the implementation of an educational intervention has an effect on self-efficacy of nurses using a tool to participate in the process of disclosure among children with perinatal HIV at a district hospital in Southwestern Uganda.

**Figure 2: Operationalized Self-efficacy Theory**

**Operationalized Self-efficacy Theory**



*Note.* (Bandura, 1997, as cited in Staples et al., 1998)

During this study, the concepts of the self-efficacy theory (see figure 2) will be operationalized as follows:

**Performance Accomplishment.** The performance accomplishment component included nurses discussing their experiences on disclosure to children with perinatal HIV and their levels of knowledge about disclosure. This included what nurses had performed before in relation to disclosure, what the process felt like, how long it took them to complete the process, how easy the process was and whether the process was successful or not.

**Vicarious Learning.** Vicarious learning entailed nurses' exposure to disclosing HIV status to children with perinatal HIV. It included nurses' observation experience and learning obtained from conducting the disclosure process.

**Verbal Encouragement.** Verbal encouragement or persuasion included nurses' motivational factors that contributed to one's continuous participation in HIV disclosure on children with perinatal HIV. Verbal encouragement also included compliments or feedback from fellow colleagues with or without the coach or superiors available during their small group discussions. This informed the study whether feedback offered regarding the disclosure was a motivating factor and what influence it had towards knowledge and attitude of nurses.

**Emotional States.** In this study, emotional state referred to how nurses reacted and felt about disclosing HIV status to children. Nurses' mood or emotions was ascertained during the pre-intervention survey. Understanding nurses' reactions towards HIV disclosure in children facilitated the packaging of an educational intervention in a way that fit with the needs of the children.

**Self-efficacy.** Self-efficacy was considered as nurses were performing a self-evaluation assessment of what they thought they could do to ensure disclosure in children with perinatal

HIV. This was done before and after the intervention and guided nurses to judge their performance capability and ability to establish self-efficacy expectations.

The study focused on self-efficacy as a component of self-efficacy theory leaving out the outcome expectation as another component of the theory.

### ***Definitions of the Key terms used in the Study***

Key terms like children, perinatal HIV, disclosure of pediatric HIV status, disclosure of HIV positive status, nurses' knowledge about pediatric HIV disclosure and nurse' self-efficacy on pediatric HIV disclosure are defined. Definitions clarify the meaning of some important study concepts.

**HIV Positive Status Disclosure.** The act of disclosing an HIV status to children is regarded as disclosure for the purposes of this study. This will involve complete disclosure, meaning that the children will know their HIV status, the virus's name, the care and treatment involved, how they contracted it, and how to live a positive life with it.

**Children.** In the study children are considered as persons aged 6 to 18 years of age, and with consideration of the child's capability to know the disease. A child in this study is being referred to as one who is still below 18 years but not less than 6 years.

**Pediatric Disclosure.** Pediatric disclosure, as used in this study, speaks of a child's understanding of his or her HIV status. This entails disclosing an HIV positive child's status.

**Perinatal HIV.** Perinatal HIV means the spread of HIV from an HIV-positive mother to her child during pregnancy, childbirth, and or breastfeeding, according to this study. HIV transfer from mother to child is another term for this. Perinatal HIV infection in a child indicates HIV transmission from mother to child.

**Nurses' Knowledge about Pediatric HIV Disclosure.** In the study this means the fact or condition of nurses' understanding of disclosing children that they have a positive HIV status with familiarity gained through experience and training. The study defines nurses' knowledge about pediatric HIV disclosure as how much is known to a nurse regarding notifying the child of his/her HIV positive status.

**Nurse' Self-efficacy on Pediatric HIV Disclosure.** According to the study, this refers to nurses' comfort level administering tests on or informing prenatal HIV-positive children of their positive status due to familiarity developed through experience. According to the study, this idea refers to a nurse's comfort or confidence in informing a child that they are HIV positive.

### **Summary**

Chapter one described the introduction of the study, the background to the study and the problem statement. The chapter stated the purpose of the study, study objectives and the significance of the study to nurses, children with perinatal HIV, society and nurse leadership. The chapter also described the theoretical framework and its variables. Chapter two will review the literature related to disclosure in children with perinatal HIV while chapter three will focus on research methods that will be used for the study.

## **Chapter Two: Literature Review**

The following chapter presents reviewed literature obtained with the use of relevant keywords and phrases to search for different studies, utilized PubMed, CINAHL, PsycINFO databases and put summaries from reviewed articles into a matrix for a clear flow and compilation. The literature reviewed was related to the effect of an educational intervention on self-efficacy of nurses in regards to knowledge and attitude on using a tool to engage in the process of disclosure among children with perinatal HIV at a district hospital in Southwestern Uganda. The chapter describes the following the four topics: Globally and in Uganda many children with perinatal HIV are growing into adulthood due to the introduction of antiretroviral therapy. It is very crucial to inform children with perinatal HIV of their status as soon as possible for their well-being and to enhance clinical results such medication compliance, virus suppression, and patient care retention. Nurses, while critical to disclosure are not adequately engaged in the disclosure process because they lack knowledge and experience. The chapter also describes educational interventions that have been conducted to improve pediatric HIV disclosure.

### **Children with Perinatal HIV Growing into Adulthood**

The topic begins with what perinatal HIV means and how it occurs, incidence of HIV-positive children, the history of HIV in children and why many children are surviving into adulthood. It includes the information about HIV that children that are growing into adulthood with the virus should receive and what is expected to be done in consideration of their needs.

### *Description of Perinatal HIV and How it Occurs*

Since the 1980s, when the first HIV case was discovered, the majority of HIV infections in children have been passed from mother to child through breastfeeding and childbirth. HIV therapy and viral load have an impact on HIV transmission during lactation (Njom Nlend, 2022). Even after two years of breastfeeding, there is a 20% chance that the child will contract HIV if neither the mother nor the child is receiving treatment for the virus. According to a recent study involving women undergoing treatment, the risk of HIV transmission is 0.6% for mothers who breastfeed their child for a year and 0.3% for those who do so for six months (Sibiude et al., 2023). Although it doesn't completely eliminate the risk, an undetectable burden does. HIV treatment lowers the mother's viral load, lowering the baby's exposure to the infection throughout pregnancy, delivery, and breastfeeding (Njom Nlend, 2022). Furthermore, certain anti-HIV medications can stop the virus from spreading by crossing the placenta and entering the baby's body. HIV-related illnesses, low CD4 counts, high HIV viral loads, STIs, and bacterial vaginosis are some of the variables that can raise the risk of HIV transmission. The viral load is quite high shortly after infection, thus women who get HIV while pregnant or nursing have a higher chance of infecting others. In 2021, 81% of HIV-positive pregnant women worldwide have access to ART in order to safeguard their own health and avoid passing HIV to their unborn child during pregnancy and childbirth (Sibiude et al., 2023).

Mukwevho et al. (2023) state that antiretroviral medication during pregnancy, labor, delivery, and nursing can prevent a significant amount of mother-to-child HIV transmission. Mothers who discontinue HIV treatment while pregnant or nursing are mostly to blame for the majority of new infections among infants (Centers for Disease Control and Prevention, 2022;

Njom Nlend, 2022). About 18% of new infections in Uganda are caused by mother-to-child transmission (MTCT), and conventional antiretroviral medication has improved quality of life and decreased morbidity and mortality for both mothers and their offspring (Centers for Disease Control and Prevention, 2022; Njom Nlend, 2022). Antiretroviral medication is widely available and frequently used, which has contributed significantly to the survival of these children. Large numbers of HIV-positive children have survived into adolescence and early adulthood thanks to ART, but many still struggle to take their medications due to stigma, lack of psychological support, lack of disclosure, and forgetfulness (Kairania et al., 2023; Mukwevho et al., 2023).

### ***Incidence of HIV in Children***

There were around 39 million HIV-positive people in the globe in 2022. Of these 37.5 million were adults and 1.5 million were children under the age of fifteen. Moreover there were 53% women in the population. UNAIDS announced new worldwide targets for HIV treatment in 2020: Ninety-five percent of HIV-positive individuals should be aware of their status, 95% of those receiving treatment should have a suppressed viral load. According to the 95-95-95 cascade, worldwide, 90% of people who tested positive for HIV were aware of their condition, 94% of them were receiving treatment, and 94% of them had their viral load reduced (Frescura et al., 2022; UNAIDS, 2023).

Globally, 2.58 million of the anticipated 39.0 million PLHIV in 2022 were children, aged 0 to 19. About 274 children died from AIDS-related causes and about 740 children contracted the virus every day in 2022. These statistics are primarily due to insufficient access to HIV prevention, care, and treatment services (UNICEF, 2023). In 2019, the majority of the 1.8 million children under the age of 15 living with HIV were located in eastern and southern Africa

(Bajaria et al., 2020; Lemma et al., 2020). In the world in 2019, there were about 1.7 million children between the ages of 10 and 19 who were HIV positive (Bajaria et al., 2020; Kairania et al., 2023). In 2020, there were about 150,000 new infections in children aged 0 to 14 and 44,000 of the approximately 620,000 people and children living with HIV in Ethiopia were under the age of 15 (Guta et al., 2020; Lemma et al., 2022). 160,000 children in Uganda are expected to be living with HIV, which represents 7% of the 1.4 million PLHIV in the nation (UNAIDS 2023).

In the US and Europe, the rate of prenatal HIV transmission has been reduced to 1% or less with the use of HIV medications and other tactics (Koayet al., 2021; Mukwevho et al., 2023). Due to greater availability to ART, the number of children receiving it in Uganda rose from 43,803 in 2014 to 66,203 in 2019 (Kairania et al., 2023). The impact of utilizing ART has decreased HIV/AIDS-related mortality among children in the nation from 17,000 in 2010 to 4,800 in 2019, despite the fact that there is still a gap in ART access (Kairania et al., 2023).

According to estimates, 150,000 children and 19.3 million women worldwide were predicted to be HIV positive in 2020, with sub-Saharan Africa accounting for 84% of new HIV infections in children. The number of children contracting HIV has decreased significantly, from an estimated 490,000 in 2000. This has been mainly achieved by increasing the availability of antiretroviral therapy (ART) to pregnant women living with HIV and by expanding services for PMTCT, which prevents mother-to-child transmission of HIV. In 2020, 85% of pregnant HIV-positive women worldwide had access to ART (Morales et al., 2022). According to UNAIDS 2020, mother-to-child transmission of HIV resulted in 5,500 new pediatric infections in Uganda (Centers for Disease Control and Prevention, 2022).

### *History of HIV in Children*

Due to children's limited life rates at the beginning of the HIV epidemic, those with prenatal HIV were not given much thought when to disclose their status. Similar to the oncology tendency, early in the AIDS epidemic, long-term survival was unexpected, and many parents, nurses and caregivers believed it was preferable to keep HIV positive status a secret from children in order to shield them from the stigma and emotional strain of being an HIV positive person. Most HIV-positive children in the 1980s passed away before turning five. Changes in disclosure policies started in the mid-1990s with the introduction of new medicines and significant reductions in the mortality and morbidity of HIV-positive children (Wiener et al., 2007).

As children developed into teens and adults, disclosure concerns about sexuality and pubertal development, fear of transmission and contagion, and the need to encourage adherence to intricate and frequently harmful regimens surfaced. Talks between caregivers and providers concerning transparency became a key topic of discussion within treatment institutions. The ethics of nondisclosure particularly worried healthcare professionals when some parents and guardians started requesting that they refrain from discussing HIV and AIDS with their school-age children. A rift developed even within the professional community between those who thought the child should be informed of their status right away and those who were worried about the timing and ramifications of disclosing their diagnosis (Wolters & Brouwers, 2005).

Providers acknowledged that children with HIV were at risk for considerable cognitive impairment, which would affect their capacity to comprehend and absorb information about their illness, in addition to worries about stigma and the emotional fallout from disclosure. Eventually,

after taking into account the experiences of other pediatric chronic illnesses, such as cancer, it was determined that disclosing information to children is good for their self-esteem and can encourage them to take an active role in their own medical care (Wiener et al., 2007).

### ***Why HIV Positive Children Thrive into Adulthood***

Since 2000, the number of fatalities among children aged 0–4 has dropped by almost 70% thanks to increased access to ART and earlier treatment beginning (Doat et al., 2019). Many children are living into adolescence and even adulthood, which has led to a rise in concerns about their health and well-being as well as the risk that sexual intercourse poses to others (Vreeman et al., 2019). The necessity to be informed of one's HIV positive status has increased as children who are positive for the virus grow into adolescents and adults (Abegaz et al., 2018; Madiba & Diko, 2020; Vreeman et al., 2019).

Although knowing one's HIV status has an impact on treatment compliance, health habits, and a child's overall prognosis, many Ugandan hospitals do not currently have clear rules and procedures in place for telling a child they have been diagnosed with HIV. According to studies, children who are disclosed to improve their ART adherence, engage in care longer term, and are better equipped to prevent HIV transmission in others and themselves (Madiba & Diko, 2020; Vreeman et al., 2019). According to these official standards, HIV counselors and other medical specialists should collaborate with the caregiver to create a disclosure strategy that considers the child's and caregiver's needs and objectives (Bulali, 2018).

Summarily, the section above showed the need for disclosure as children living with HIV continue to grow into adolescents and adults. This is important in this study as a way to evaluate the effect of an educational intervention on self-efficacy of nurses using a tool to engage in the

process of disclosure among children with perinatal HIV at a district hospital in Southwestern Uganda.

### **Early Disclosure of HIV Status to Children with the Virus: Critical for their Well-being**

The section explains disclosure more fully; when it occurs, by whom, where, what it entails the disclosure statistics and the benefits of HIV disclosure in children. As children living with HIV grow into adolescents and adults the need to know why they are taking ARTs increases and this has a positive impact if done before the child discovers on his/her own.

#### ***Description of Disclosure***

When a child who has received HIV from their original mother is told of their status, it is known as disclosure. This can happen during pregnancy, childbirth, or even breastfeeding. When a child is told they have HIV, it is referred to as HIV disclosure among children. It involves complete disclosure, meaning that the children must know their HIV status, the virus's name, the care and treatment they had after contracting it, and that they must also be positive for the virus. If a child or their caregiver states that the child is aware of their HIV infection status, the child is deemed to have had full disclosure. If a child or their caregiver states that the child is unaware of their HIV status or that they have a chronic condition, then the child is deemed to have had no disclosure (Sumbi et al., 2021). First, nurses talk with caregivers who are frequently the child's biological parents about the disclosure procedure. Over the course of two partial disclosure sessions, they help them reveal to the child or, with the caregiver's permission, they disclose to the child themselves. Children learn about their bodies, health, immunity, the need to take medication, and the importance of routinely visiting the clinic for blood tests and medical

consultations during these partial disclosure sessions. Visual aids are used to illustrate everything, while terminology like HIV, AIDS, CD4, and ARTs are left out.

A full disclosure session is held when children are deemed ready to learn about their HIV status. During this session, all relevant information regarding the child's health status, illness, course of treatment, and mechanisms of transmission is disclosed (Sumbi et al., 2021). Research indicates that compared to children in higher-income nations, less children in low- and middle-income countries are aware of their status. On the other hand, postponing the disclosure procedure has a negative impact on child outcomes, such as viral suppression and access to HIV care (Bajaria et al., 2020).

HIV status disclosure to children is a delicate and significant matter that needs to be carefully considered. It is imperative that children living with HIV be gradually and developmentally appropriate informed of their condition, taking into account their age, level of cognitive capacity, and emotional maturity. Families must communicate effectively and continuously during the disclosure process, which should take place over time (Bulali, 2018). The disclosure process ought to take place prior to the youngster learning about their own diagnosis. According to the World Health Organization (WHO), children between the ages of 6 and 12 should be informed of their HIV status, and at that age, the disclosure procedure should be provided in a compassionate and encouraging way (Bulali, 2018).

For children living with HIV/AIDS, disclosure dramatically enhances quality of life and treatment compliance. Even though there are many advantages to disclosure, telling a child about their own HIV status is frequently postponed. Children living with HIV who enter puberty and engage in sexual activity run the risk of HIV infection. Therefore, being aware of one's HIV

serostatus is a crucial component of HIV prevention, which may help teenagers engage in less high-risk sexual activities. According to a case control study involving 309 HIV-positive children, children who were informed of their status had a higher quality of life than children who were not (Budhwani et al., 2020).

### ***Prevalence of HIV Disclosure in Children with HIV***

According to the Guta et al. (2020) survey, 81% of people living with HIV worldwide were aware of their condition. One systematic analysis found that the overall rate of HIV-positive status disclosure to HIV-infected children was low in low- and middle-income countries, ranging from 1.7% to 41%. A smaller number of studies, carried out in several Ethiopian cities, revealed that between 16.3% and 49% of children recognized they were HIV positive (Abegaz et al., 2018; Amankwah-Poku et al., 2021; Doat et al., 2019; Guta et al., 2020; Madiba & Diko, 2020). Disclosure to children with perinatal HIV varies from 13% to 60% in Sub-Saharan Africa (Madiba & Diko, 2020). Nonetheless, the 2023 study found that HIV disclosure to children in Sub-Saharan Africa continues to be low and varies from 1.2% to 72% (Kairania et al., 2023). In Uganda, the percentage of children who disclose their status varies between 26% and 43%. A study conducted in the southwest of the country revealed that only 31% of children aged 5 to 17 had received this information, and nearly half of them were unaware of their status (Kairania et al., 2023).

Even though children with perinatal HIV frequently attend clinics and receive lifelong antiretroviral therapy (ART), a significant percentage of them in Sub-Saharan Africa are uninformed of their diagnosis. However, positive health outcomes have been linked to disclosure (Mabaso et al., 2021). Disclosure among children with PHIV has remained a global issue,

particularly in SSA, despite the World Health Organization's guidelines to offer developmentally appropriate information about HIV status from the age of six to twelve years (Kalembo et al., 2018; Tucho et al., 2021).

### ***Benefits of HIV Disclosure in Children***

According to Kairania et al. (2023), there were opinions that regular interactions with children about sexual health education were a good socio-cultural influencer and that disclosure fosters responsibility in the child to promote ART adherence. One of the first stages in treating HIV in children living with the virus as a chronic illness is disclosing one's status. Disclosure has a number of advantages, such as enhance ART compliance, better retention to care, better mental health results, decreased mortality and disease progression, and a decrease in high-risk sexual behavior (Kairania et al., 2023). It also results in adherence counseling as well as extra peer and family member provided psychosocial support.

Positive outcomes like increased self-esteem, a deeper understanding of HIV and improved coping mechanisms have all been linked to disclosure. Additionally, there is a beneficial correlation between disclosing one's serostatus and lowering unprotected anal and vaginal sex, enabling partner HIV testing and enhancing ART adherence by decreasing the need to conceal medicine from partners (Kairania et al., 2023). Since adherence is the most reliable indicator of patient survival and is essential to optimizing the clinical advantages of ART, there is a critical relationship between disclosure and adherence to ART (Kairania et al., 2023). Research has indicated that disclosing an HIV positive child's diagnosis to their peers can have good long-term effects on the child's quality of life (Abegaz et al., 2018; Amankwah-Poku et al., 2021; Doat et al., 2019; Guta et al., 2020; Madiba in Diko, 2020). One of the main health

benefits of disclosure is improved treatment adherence at a lower risk of death. Children who are exposed to HIV during pregnancy benefit from early and safe disclosure because it increases their knowledge of the virus and empowers them to take an active role in their own care and treatment (Abegaz et al., 2018; Amankwah-Poku et al., 2021; Doat et al., 2019). HIV disclosure in young people is also favorably correlated with having more access to community and other structures' social support networks (Guta et al., 2020; Madiba &Diko, 2020; Appiah et al., 2021).

### ***Impact of HIV Non-disclosure in Children***

Amankwah-Poku et al. (2021) stated that children infected with HIV may experience serious harm to their physical and mental health if their status is kept a secret. Uninformed children about their HIV status may not obtain treatment or medical interventions in a timely manner, and they may experience delayed access to antiretroviral therapy (ART). This can lead to a higher risk of disease progression, opportunistic infections, and higher death rates. Children who are unaware of their HIV status may not grasp the necessity for constant drug intake, which can result in uneven adherence to antiretroviral therapy (ART), which is essential for treating the virus and halting its development. Unaware HIV-positive children may participate in activities that increase the risk of HIV infection in others, such as risky sexual behavior or sharing needles. This adds to the general spread of HIV and continues the cycle of transmission. If children are not told they have HIV, it can make them feel alone and stigmatized. It can make it difficult for them to get in touch with the right mental health resources, which could result in worry, despair, and low self-esteem.

Children who are not told the whole truth about their sexual health are less able to make educated decisions about safe sex practices, HIV prevention, and contraception. Specialized

counseling and assistance are necessary for children living with HIV to help them manage the difficulties of having the infection. They are prevented from using services that can meet their specific requirements and assist them in creating healthy coping strategies due to non-disclosure. The failure to disclose a child's HIV status has led to subpar health outcomes for children living with the virus, including low adherence and psychological well-being. These negative outcomes can have a substantial impact on the health of children who are infected (Amankwah-Poku et al., 2021; Madiba & Diko, 2020).

In summary, when children know their HIV status as they grow into adolescents, they might take on part of the accountability for overseeing their own care. When children start antiretroviral therapy (ART) without being told they have HIV, they could act out, refuse to take medication, or stop going to the HIV clinic altogether. Delaying disclosure increases the risk of HIV secondary transmission, can result in the unintentional disclosure of HIV, can cause feelings of resentment and hostility toward the caregiver.

### **Nurses' Limited Engagement in the Disclosure Process**

This section elaborates the reasons nurses should take part in HIV disclosure process, how nurses are critical in disclosure and why nurses are not engaged in disclosure. While some research highlights that the caregiver has the primary responsibility for disclosing information to their child, in many situations, caregivers find the procedure challenging, which causes them to put off disclosing information to children (Madiba & Diko, 2021). This explains why caregivers say they require professional help from nurses during the disclosure process.

### *Nurses' Impact on Pediatric HIV Disclosure*

The disclosure process revolves around nurses, who play a crucial role in assisting and preparing the caregiver. Nurses possess the ability to proficiently convey intricate and delicate information to patients and their relatives (Madiba & Diko, 2021). To make sure that the child and their caregivers are aware of the diagnosis and its ramifications, they can use age-appropriate language and strategies (Kalembo et al., 2018). Throughout the disclosure process, nurses can provide the child and their family with emotional support. They can respond to any worries, anxieties, or inquiries that come up, easing tension and fostering wellbeing. When it comes to giving children living with HIV ongoing care, nurses are essential. Nurses build a trustworthy rapport with the child and family early on by taking part in the disclosure process, which makes it easier for them to support and collaborate on the child's healthcare journey. Families can be taught by nurses about HIV care, including how to take medication as prescribed, the value of routine monitoring, and how to stop HIV transmission. Nurses can also offer information and connections to community organizations that focus on HIV in children, counseling services, and support groups. Additionally, they can ensure that children living with HIV receive the necessary medical treatment, extra assistance, and accommodations in school settings by advocating for their needs and rights. Nurses who participate in the disclosure process can help the community develop empathy and understanding by bringing attention to the special difficulties these children face (Beebwa, 2021; Kalembo et al., 2018; Okechukwu et al., 2018).

Nurses' perception that disclosure is the caregiver's duty, may cause them not be sufficiently involved in the disclosure process, which has been linked to their lack of initiative in informing children of their positive HIV status. According to the 2011 WHO recommendations,

anyone acting in the child's best interests may disclose an individual's HIV status to them. Research has shown that a large number of primary caregivers struggle with the disclosure process and need a lot of help from nurses (Kalembo et al., 2018; Madiba & Diko, 2021). Dread of depriving their child of the joy of living without knowing they are positive and dread of disclosing their own status to others were mentioned by caregivers of children with perinatal HIV revealed to more people, and the reluctance to confront their child or incite animosity with them as barriers to telling them they are HIV positive (Kalembo et al., 2018).

Nurses treat children living with HIV and their families medically and psychologically which make them play a key role in the disclosure process. Because of this, nurses are in a unique position to help the primary caregiver make decisions about who, what, and when to reveal to their child. Research has indicated that a considerable number of nurses do not participate actively in the disclosure procedure, though (Beebwa, 2021; Kalembo et al., 2018; Okechukwu et al., 2018). According to a study done in Kenya, primary caregivers' inability to disclose to their child was hampered by nurses' lack of professionalism and empathy (Kalembo et al., 2018; Ngeno et al., 2019). However, research evaluating nurses' experiences disclosing HIV to children in sub-Saharan Africa has shown that the main obstacles are a lack of standardized disclosure policies and materials, a lack of time, a lack of primary caregiver cooperation, inadequate instruction and expertise regarding the disclosure procedure (Beebwa, 2021; Kalembo et al., 2018; Okechukwu et al., 2018). According to 98% of nurses who took part in the study conducted in Malawi, it's critical to disclose a child's HIV status (Kalembo et al., 2018). 37% of the nurses said they had never told children about HIV during the perinatal stage.

Lack of disclosure training and a uniform disclosure method were identified as challenges by the study for nurses to fully be involved in the disclosure process (Kalembo et al., 2018).

### ***Barriers to Nurses Involvement in Pediatric HIV Disclosure***

According to Madiba and Diko (2020), one of the main obstacles to the early commencement of disclosing to children is nurses' lack of expertise on pediatric HIV disclosure. Nurses disagreed on when to begin the process of disclosing information to children with HIV during pregnancy and on who should do so (Khangale et al., 2022; Madiba & Diko, 2021; Mutambo & Hlongwana, 2019). Nurses believe that their job is to assist children understand HIV and to support and prepare the caregivers of children who are HIV positive throughout pregnancy. Nevertheless, their capacity to fully engage in disclosure to children is hampered by a lack of training and disclosure rules (Madiba & Diko, 2021; Appiah et al., 2021; WHO, 2011).

Given that many children living with HIV are growing up to be adolescents and engaging in sexual activity, nurses recognize the importance of HIV disclosure in preventing the spread of the virus to both themselves and other people. But their contribution to the process is lessened by their ignorance, inexperience, and lack of time (Shallo & Tassew, 2020). Without specific evidence-based regulations dictating who, when, how, where, and under what circumstances infected children should be informed about their HIV status, nurses face difficulties. While some nurses believed that parents or caregivers should take the lead in the disclosure process, Okechukwu et al. (2018) noted that nurses generally believed that disclosure should be a shared duty. It is rarely known by nurses that it is their obligation to inform children with positive HIV status (Mutambo & Hlongwana, 2019).

Nurses lack the self-assurance to inform or raise awareness of HIV in perinatal infants. Children become confused as a result of inconsistent information given to them by nurses who rely too much on their own judgment and expertise (Madiba & Diko, 2021; Mutambo & Hlongwana, 2019). Very few nurses in Uganda receive official training on how to facilitate the disclosure of an HIV diagnosis to a child who is infected, despite the country's rapid expansion of HIV services for children. Furthermore, there are no tried-and-true strategies for assisting caregivers and HIV-positive children in Sub-Saharan Africa throughout the disclosure process, despite the World Health Organization's recommendation that children find out their status by the age of 12 (Madiba & Diko, 2020; Tucho et al., 2021). Research indicates that nurses may not be offering HIV services to children because they are not well-versed on how to interact with children and their caretakers. According to a Ghanaian study, nurses were unclear on the terminology or methodology to employ, especially while offering health education and counseling following HIV disclosure (Mutambo & Hlongwana, 2019). It is hard for primary caregivers to make decisions about their children since nurses aren't well trained in HIV testing and disclosure support services.

Nurses sometimes have demanding schedules and little time with children, which limits the time to actively get involved in informing children born with the virus of their HIV status. A diagnosis of HIV must be disclosed with consideration, patience, and continued support. Due to nurses' heavy workloads, they might not feel able to give this delicate condition the attention it needs. Madiba & Diko (2021) state that nurses emphasized how difficult it was to provide disclosure to children in their facilities because to personnel shortages, heavy workloads, and time limits. In a prior South African study, there were timing limits mentioned as a deterrent to

provide disclosure support to children (Mabaso et al., 2021; Appiah et al., 2021). Should the child remain unaware of their HIV status, it will probably have a negative impact on their adolescent years, increasing the likelihood of treatment failure and poor adherence and retention. Research has shown that when children are not told their HIV status, they stop taking antiretroviral therapy (ARTs) and their viral loads become non-suppressed (Madiba & Diko, 2021; Appiah et al., 2021).

In summary, the way nurses tackle the problem of preparing families to disclose their children's HIV to them is influenced by their own patterns of knowledge regarding HIV disclosure in children and how they comprehend the disclosure process. Due to a lack of appropriate knowledge and abilities to engage with children and their caretakers, nurses are unable to provide HIV services to children.

### **Pediatric HIV Training Lacks Disclosure Focus**

This section explains efforts that have been made to address disclosure in children with HIV. It elaborates the policies and other strategies that have been put in place to improve pediatric HIV disclosure.

The American Academy of Pediatrics (AAP) established guidelines in 1999 that encouraged HIV disclosure by adolescence. In 2011, the World Health Organization (WHO) developed guidelines for starting the disclosure process when a child turns six, with the goal of full disclosure by age twelve. WHO provides guidelines on disclosure, emphasizing the importance of medically and psychologically appropriate disclosure to children. However the guidelines put in place by World Health Organization, have not been available to nurses for use in the clinical area during the disclosure process (Appiah et al., 2021; WHO, 2011). Countries

have developed legal and policy frameworks to protect the rights of children living with HIV, including access to information about their health status. These frameworks aim to ensure the child's best interests and promote the rights of children to participate in decisions related to their health.

Various organizations have developed training programs for healthcare providers to enhance their capacity to support appropriate and effective disclosure. These programs were designed to equip nurses with the necessary information. The study done in Dar es Salaam, Tanzania showed that pediatric HIV disclosure has been incorporated in the training curriculum for nurses during the HIV training in clinical settings (Ismail et al., 2021). However, the content incorporated in the curriculum includes a short session about pediatric HIV disclosure with no time for practical and case discussions. This makes it more difficult for nurses to become sufficiently skilled to completely support disclosing a child's HIV positive status. HIV training conducted from the clinical area is not standardized and offer little or no information about disclosure in children with perinatal HIV and also differ in content and duration (Ismail et al., 2021).

Nwanja et al.'s study from 2023 made note of the various approaches that had been taken separately to increase children's treatment coverage. Targeted community-based testing was employed by the Pediatric ART Saturation Strategy (PASS) to reach disadvantaged and orphaned child families in Southern Nigeria (Nwanja et al., 2023). The only marginally customized advice provided to nurses and caregivers on how to handle the disclosure issue with these adolescents was that complete disclosure is welcomed and should happen at "developmentally appropriate" periods. WHO recently released new guidelines on HIV testing

and counseling for teenagers; however, these guidelines only deal with disclosing children's HIV status to others, not with disclosure to the children themselves (Khangale et al., 2022). Attempts have been made to offer parents and caregivers' education, counseling, and psychosocial support, realizing the vital role caregivers play in encouraging disclosure. To assist parents in navigating the disclosure process and managing their own emotions, training programs were created (Khangale et al., 2022).

A number of education-based treatments, including process-oriented disclosure, an iterative construct, and a theoretical framework, have been implemented to enhance the disclosure knowledge and abilities of nurses and caregivers. Paintsil et al. (2020) report that for the instructional and intervention sessions, the study used audiovisual aids such as an HIV cartoon book and other educational materials showing HIV as a chronic condition. The interventions were carried out to direct nurses in helping caregivers disclose their HIV status to infected children (Paintsil et al., 2020).

In summary, some interventions have been tried but with limited involvement of nurses in the pediatric HIV disclosure yet they are critical personnel to enforce and support the disclosure process. Disclosing HIV status to HIV-positive children continues to be a major challenge facing families and nurses.

The proposed study seeks to evaluate the effect of an educational intervention on nurses' self-efficacy regarding disclosure among children with perinatal HIV. If non-disclosure is permitted to continue, it will have detrimental effects for the affected teenagers as well as the country as a whole. This is due to the fact that withholding information will result in non-adherence to treatment, which will have a negative impact on outcomes such as treatment

failures, the emergence of drug-resistant strains, an increase in viral load, and an increased risk of HIV transmission to the general public. The study therefore seeks to evaluate the effect of an educational intervention on nurses' self-efficacy in regards to knowledge and attitudes regarding disclosure among children with perinatal HIV.

### **Summary**

In conclusion, chapter 2 conclusively discussed what perinatal HIV means and how it occurs, the incidence of children living with HIV, the history of HIV in children and included the information that children growing into adulthood with HIV should receive and what is expected to be done in consideration of their needs. In this chapter the disclosure process was explained; that is when it occurs, by whom, where and what it entails. As children living with HIV grow into adolescents and adults the need to know why they are taking ARTs increases and this has a positive impact if done before the child discovers on his own. The literature review revealed reasons as to why nurses should take part in HIV disclosure process and why nurses are not engaged in disclosure. The chapter also explained efforts that have been made to address disclosure gaps in children with perinatal HIV. Chapter three will describe the methodology to be used in this study.

### **Chapter Three: Methodology**

The following chapter describes the methodology that was used in the study. This includes the method and design, study setting, the study population, sampling and sample size calculation. Chapter 3 also describes the procedure of data collection and data collection tools that were used in this study, data analysis plan and how ethical issues were handled.

#### **Research Design**

The research design was a quantitative quasi-experimental, pre and posttest interventional study. Quantitative quasi-experimental is a method used when actual experimental designs with random assignment are impractical or unethical and is preferred to examine cause-and-effect correlations. Quasi experimental study design was used because the study aimed at evaluating the effectiveness of an educational intervention on nurses' self-efficacy. The research design was prediction since this study aimed at identifying and determining the effect of an educational intervention on the self-efficacy of nurses using a tool to engage in the process of disclosure among children with perinatal HIV at a district hospital level in Southwestern Uganda (Polit & Beck, 2019).

#### **Study Population**

The study population included nurses engaged in the care of children living with perinatal HIV at district level hospital in Southwestern Uganda. The self-efficacy of nurses, their knowledge and attitude on the use of a tool to engage in HIV disclosure process was considered in this study. This was because nurses were commonly involved in the care of children with HIV at a district hospital level rather than in regional referral hospitals where counselors were many and assigned to conduct disclosure.

## **Study Setting**

The research setting for this study was a district hospital in Southwestern Uganda that provided HIV services to children with perinatal HIV. This setting was chosen purposively because it had 160 children of ages 6-12 years who should have started the disclosure process and some even reaching the completion of this process. The setting was appropriate for this study because it had approximately 20 nurses involved in the care of children with perinatal HIV who were chosen to provide the necessary information needed for the study. This study used the setting because the site targeted had a large number of children with HIV which meant that nurses who worked in the setting provided care and support for a good number of children regularly (Polit & Beck, 2019).

## **Sample**

The study included 20 participants who were nurses working on children living with perinatal HIV at district level hospital in Southwestern Uganda. This was because nurses involved in the care of children with perinatal HIV would be suited to provide necessary answers for the research question in this study.

## ***Sampling Frame***

As the setting had only 20 nurses working at any given time, consecutive sampling helped reduce bias. This was because consecutive sampling included all available participants allowing an equal opportunity for each nurse in the target population to be part of the sample group (Andrade, 2021; Hamed, 2021).

### ***Sample Size***

Maximum size I hoped to attain was 20 nurses as that was how many would be working during any given time. I used Slovin's formula in this study  $n=N/(1+(N*e^2))$ ,  $n=20/(1+(20*0.05^2))$ ,

$$n=19$$

$n$ =sample size,  $N$ =population size (20),  $e$ =acceptable margin error (0.05)

This desired sample size potentially allowed for a quantitative research methodology to be used and allowed for the collection of numerical data that could be analyzed statistically. Statistical analyses were performed to determine the significance of the findings.

### ***Inclusion Criteria***

The inclusion criteria were all nurses managing children with perinatal HIV because they could provide valuable insights with their knowledge and attitude of disclosure in these children. This study did not have exclusion criteria.

### ***Data Collection***

Once I received approval from REC and permission from the hospital, I began the data collection process. I organized HIV clinic staff meetings within the HIV clinic waiting area as an assistant HIV clinic in-charge. HIV clinic staff were approached to take part in these meetings within the afternoon and evening hours due to the workload that they had in morning hours. While in the introductory meeting, I oriented staff about the study, informed them about the rationale for conducting it and thereafter invited them to participate in the study. Because I am an assistant in-charge of the department, I identified a research assistant, explained to him about the study, the target population, procedures involved, and discussed with him the consent form,

how to keep them afterwards and assigning codes to identified participants. I also explained more of what research assistant was expected to do during the data collection, addressed concerns he raised and assigned him a role to have eligible participants willing to take part in the study sign consent forms. Then I introduced the study, and then I left the meeting and the research assistant had willing participants complete the informed consent (Appendix A). He assigned them codes to use to complete the questionnaires (Appendix B) and collected pre intervention data thereafter.

The research assistant who had been trained by the researcher put the completed consent forms in an envelope and the completed questionnaires in another envelope. These envelopes were given back to me. I kept the envelope with the signed consent forms sealed throughout the study.

After an educational intervention, the research assistant invited the participants to come into the designated place and they completed the questionnaire during two time periods. He thereafter reached out to participants who had missed the two time periods. This was done in the afternoon hours from the HIV clinic area. Codes assigned to participants for pretest were the same codes used even for the posttest after the educational intervention. The research assistant had a master list with the codes and the participants' names in an envelope that participants utilized to remember their codes when completing the post-test questionnaires. After data collection, all completed questionnaires were given to the researcher in an envelope. For each additional time, the research assistant added them to the original envelope until they were complete. All the envelopes of the informed consent forms and the questionnaires for both pre and post testing were kept by the researcher under key and lock within the researcher's office

and only accessed by the researcher and research assistant until data collection was over. Pre-test and post-test intervention data collection was completed in three weeks.

### **Intervention**

In the first week, I offered the teaching session for all nurses for about 2 hours. Nurses who missed out the first session were organized and the session was repeated the following day for two hours as well. Because this study utilized Bandura's self-efficacy theory (1986), nurses were asked what they knew and had experienced during HIV disclosure in children. In sharing their disclosure stories, they came to appreciate the accomplishment performance component of self-efficacy. When they shared how they reacted and felt about disclosing HIV positive status to a child they experienced what Bandura described as the emotional state of self-efficacy. An intervention plan (Appendix C), teaching plan (Appendix D), a power-point presentation (Appendix E) for teaching pediatric HIV disclosure checklist for assessment and topics to guide the process (Appendix F) are attached.

I taught nurses about a pediatric HIV disclosure guiding checklist for assessment, topics used in the disclosure process, benefits of using the checklist and demonstrate how to use it. I used flip charts with diagrams and pictures to explain the power point presentation and participants were actively involved in case study discussions. When participants were engaged in case study discussions, they achieved what Bandura explained as the vicarious learning component of self-efficacy. During the teaching session, I watched out for those most enthusiastic, asking questions and responding to questions put up during the discussions and the case studies. I approached them after the teaching session and equipped them to be role models to nurses and the other nurses experienced vicarious learning when they observed the role models conducting disclosure.

I was also be available in times of need for any clarification and worked with participants individually to provide assistance and support as they used the pediatric HIV disclosure checklist in the clinic. In providing assistance and support to participants, I ensured that they received feedback and compliments regarding their performance while using the disclosure checklist. When feedback and compliments were given, participants appreciated the verbal encouragement component of self-efficacy as described by Bandura (1986).

During the second week, each individual was assigned a child to take through the disclosure process which allowed them to apply the teaching, while I gave them personal assistance and answered question or concerns that were raised. This was done on a pediatric HIV clinic day specifically on a Thursday. Afterwards, participants had a chance to share their emotional state from the pediatric HIV disclosure exercise with me. Participants also shared their experience on disclosure to children using a guiding checklist and their level of knowledge about the whole process. The participants were then allowed to carry out disclosure process at their convenience after intervention before the post intervention data collection was done. I followed up in the third and fourth week to check the progress on the use of the disclosure guiding checklist using children's ART files.

### **Data Collection Tool**

I created the study questionnaire (Appendix B) using guidance from existing literature on HIV status disclosure to children (Beima-Sofie et al., 2017; Kalembo et al., 2018; Madiba & Diko, 2020). The researcher employed a self-administered questionnaire because it was an economical method, lowered the possibility of interviewer bias affecting the participants, and decreased the number of insufficient responses from nurses who were afraid of receiving

negative feedback on some touchy issues (Saunders & Kulchitsky, 2021). There were closed-ended questions on the survey. Research questions best addressed with closed-ended questions are those that yield data most readily examined using quantitative statistical metrics.

### ***Item Analysis***

The first section had six questions (questions 1-6) concerning demographics data. The section consisted of 6 items that included gender, age in years, years of experience, highest level of education, prior training about HIV disclosure in children and where and when the training was conducted. This information helped in contextualizing the study's findings and describing the socio-demographic factors and the nurses' ability in Pediatric HIV disclosure. I used descriptive method to describe the participants based on specific categories (age-20-29, 30-39, 40+, sex-female or male, level of education- certificate, diploma or bachelor's degree, years of experience-<5years, 5-9years, 10+ and prior training-Yes or No).

The second section had 10 questions (questions 7-16) regarding knowledge about pediatric disclosure and 1 point was awarded for each correct response. Then the score was computed and converted into percentages. Participants who scored >80% were considered to be highly knowledgeable, 70-79% having better knowledge, 50-69% fairly knowledgeable and < 49% less knowledgeable (Fang et al., 2021; Guyatt et al., 2011).

The third section (questions 17-26) used a Likert scale with the 'strongly disagree' option awarded 1 point and successive ratings earning 1 more value for each option until 'strongly agree' was given 4. Finally, the total score of each participant was computed and a mean score calculated. Participants who scored >3.5 were considered to have an excellent attitude, 3-3.4 Good attitude, 2.5-2.9 fair attitude and <2.5 poor attitude (Fang et al., 2021; Guyatt et al., 2011).

In the last section (question 27-36) concerning self-efficacy questions, I used the Likert scale with the 'strongly agree' option awarded 4 points and successive ratings earning 1 point less value for each option until 'strongly disagree' was given 1. Finally, the total score of each participant was computed and a mean score was calculated. Participants who scored  $>3.5$  were considered to be highly confident, 2.5-3.4 moderately confident, and  $<2.5$  having a low level of confidence (Fang et al., 2021; Guyatt et al., 2011).

To configure the software to receive the data, a codebook was made. The variables in the data, their labels, and their attributes were all covered in the codebook. This was to make it more likely that the data was accurately examined and coded. By inputting data from the pilot research into the program, I tested the codebook. This meant entering the sections of demographics, knowledge, attitude and self-efficacy and the answer choices under each one of them.

## **Quality and Error Control**

### ***Pilot Plan***

The questionnaire was in English and I piloted it among 10 nurses from a different facility but with similar characteristic features of the respondents. Selection of nurses who participated in this pilot was based on those who had had time in caring or managing children with HIV. The questionnaire was completed in 20 minutes which gave an estimation of the time the study participants took to complete the questionnaire. I organized a short meeting with nurses in the pilot after they had completed the questionnaire. I asked these nurses about the questionnaire and they ably said that the questions were clear for them to attempt. Two participants raised a concern about the instructions for the sections of attitude and self-efficacy that I needed to make it clear how participants were to respond by ticking or writing a yes or no.

I revised the two sections and reviewed with the advisors for approval before the final questionnaire was administered to study participants. I conducted the pilot study to make the questionnaire clearer, final and complete for the study. The results of the pilot study were entered into SPSS to formulate the codebook and test the performance of the questionnaire. The results of the pilot study were shared with the supervisors for approval before conducting the actual research study.

### ***Validity***

In order to address validity and make sure that every facet of the constructs was covered in the study instrument, I completed a thorough literature review (Polit & Beck, 2019). To further ensure validity, I ensured that the key concepts were well defined. The course faculty helped in the development of the tool at each step. The content validity was used to ensure the validity of the questionnaire. This included review of the questionnaire by HIV pediatric experts to ensure that it covered all relevant aspects of disclosure in children with perinatal HIV. Experts evaluated it and provided feedback and they confirmed that all significant aspects in pediatric HIV disclosure were included in the questionnaire. The faculty also reviewed the questionnaire for approval of further additional adjustments before it was used with participants (first the pilot study and then the actual research study).

### ***Reliability***

A quantitative metric called reliability examines how free scores are from measurement errors (Polit & Beck, 2019). Participants can easily complete a trustworthy questionnaire, which helps to accomplish the targeted research objectives. The internal consistency of the questionnaire was calculated using Cronbach's alpha from the pilot study data and the result was

0.81. Internal consistency measures how much a questionnaire's items evaluate distinct aspects of the same qualities. It is usually based on correlations between multiple items on the same test. The reliability of the questionnaire and its items is indicated by its internal consistency score of 0.81. Reliability helped me to confirm the integrity of the questionnaire.

### **Data Analysis**

After data entry, coding, and verification, IBM SPSS Statistics (version 24) were used for analysis. In order to check for errors at this stage, two data entry personnel double entered the data.

### ***Demographic Data***

The first section had demographics data. Descriptive methods were used to describe the participants based on specific categories. I used frequencies and percentages to analyze the characteristics of age, gender, years of experience, any prior training about HIV disclosure and time when this training occurred (Polit & Beck, 2019). Frequencies and percentages were obtained for demographic data to describe the distribution in the study population and they were reported in the form of tables.

### ***Knowledge***

For knowledge scores, each individual's overall score was calculated by percent and also by assigning a category. The overall group scores were looked at by calculating the mean percentage and also by looking at the distribution in categories. Findings were presented in a table format and compared the pre-test and post-test data to identify the effect of the intervention to learn more specifically how the knowledge was after intervention. For pre-test and post-test, the performance of each question was analyzed. I looked at what percentage of participants got

each question correct and what percentage of participants got the question wrong. The questions with higher percentages were areas the participants knew well. The questions with the lower percentages were considered areas where the participants had little knowledge. A comparison statistic (paired t- test) was used to look at the effect of the intervention on knowledge. The statistical significance was set at a p-value of  $<0.05$ .

### *Attitude*

For attitude scores, each individual's overall score was calculated by mean and also by assigning a category. The overall participants' scores for pre-test and post-test were analyzed by looking at the overall mean and the distribution in categories and the mean for each using the pretest responses. Findings were presented in a table format and compared the pre-test and post-test data to identify the effect of the intervention to learn more specifically how the attitude was after intervention. For pre-test and post-test, I analyzed the performance of each question. The 'strongly agree' response reflected a positive attitude and the 'strongly disagree' response indicated a more negative attitude. However, there were six questions stated negatively in the questionnaire and their scoring was reversed. I looked at what questions reflected the positive attitude and questions that indicated a more negative attitude. Then the effect of the intervention to learn more specifically how participants' attitude had been impacted was carried out by comparison. A comparison statistic to look at the effect of the intervention on attitude was done using Wilcoxon signed-rank test and the statistical significance was set at a p-value of  $<0.05$ .

### *Self-efficacy*

For the self-efficacy scores, each individual's overall score was calculated by mean and also by assigning a category. The overall participants' scores for pre-test and post-test were also

analyzed by looking at the overall mean and the distribution in categories. Findings were presented in a table format and compared the pre-test and post-test data to identify the effect of the intervention to learn more specifically how self-efficacy was after intervention. For pre-test and post-test, analysis of the performance of each question was done. However, there were three questions stated negatively in the questionnaire and their scoring was reversed. I looked at what questions participants had very comfortable or confident responses and what question they had moderate and low-level comfort or confidence answers. The questions with high confidence or comfort answers were areas the participants felt highly confident. The questions with the moderate and or low-level confidence responses were considered areas where the participants had limited confidence in perinatal HIV disclosure. A comparison statistic to look at the effect of the intervention on self-efficacy was done using Wilcoxon signed-rank test and the statistical significance was set at a p-value of  $<0.05$ .

### **Ethical Considerations**

Ethical considerations are a set of guidelines that direct study designs and procedures in research (Wu et al., 2019). Ethical issues in this study included ethical approval, informed consent, privacy, confidentiality, benefits, risks, incentives and social or cultural issues.

#### ***Ethical Approval***

I received the administrative clearance (Appendix G) from the study setting before submission of the proposal. The proposal was submitted to Research Ethics Committee (REC) of Uganda Christian University (UCU). After receiving permission from REC, the letter of introduction from the head of the nursing department of UCU was obtained and presented it at the study site.

### ***Informed Consent***

I explained the research study, its objectives, and the purpose and then invited nurses to the study. Because I was an assistant in-charge of HIV department, I let the research assistant have willing participants sign a consent form if they agreed to be in the study (Appendix A). Informed consent is a procedure through which a competent participant after having received and understood related information about the study can voluntarily provide his or her willingness to participate in the study (Palmeirim et al., 2020). The consent form contained the title of the study, the name and contacts of the principal investigator, purpose of the study, expected duration of the participant's participation, potential benefits and risks that are anticipated for this study and rights of the participant to withdrawal and contact information for ethical concerns. Obtaining an informed consent meant that participants entered research study voluntarily with full information about what the study meant for them to take part, and that they gave consent before they participated in the study.

### ***Privacy***

According to Adarmouch et al. (2020), privacy is the subject's ability to manage who can view, touch, or receive information about them. It also refers to an individual's right to restrict access to their personal data. Because I am an assistant in-charge of the department, if I collected data nurses would be worried to submit the questionnaire with their knowledge and attitude clearly identified. I introduced the study and let the research assistant collect consent forms before administering the questionnaire. Both of these were returned to me for safe keeping. I ensured the research assistant was trained and informed to keep questionnaires safe. As the

contact information of the researcher and supervisor were given, participants were free to raise any concerns or issues.

Each participant was given a code as a unique identifier to use on the pretest. Using codes helped to keep participants' identities private, minimized the bias and hence helped to meet the purpose of the study. Codes assigned to participants for pretest were the same codes used even for the posttest after the educational intervention. The research assistant kept a paper with participants' names and their codes placed in an envelope. When completing their posttest, the research assistant used that paper in the envelope with specific names and codes to remind participants of their codes from pretest.

### ***Confidentiality***

During data collection and analysis, completed questionnaires and consent forms were kept safe under key and lock. After the study, I burnt the completed questionnaires and signed consent forms. When the data was generated electronically I ensured documents were put in a folder, a password was created to limit access to the folder and I was the only one to access it. However, data was shared with the statistician and faculty as needed. In publishing and presentation, I ensured that I avoided using participants' names or the identification of the setting to ensure confidentiality.

### ***Benefits***

Participants benefited through improvement in knowledge, change in attitude and confidence to conduct and support the disclosure process in children with perinatal HIV. The study findings also enhanced nurses' knowledge, attitude and confidence in a tool to conduct

disclosure in children with perinatal HIV and contributed to the design of further interventions to improve disclosure.

### ***Risks***

There was minimal risk to participating in this study although the participant could have experienced some emotional distress when discussing previous disclosure experiences. In such a situation, I provided appropriate support by offering a private session in which to talk about their experiences.

### ***Incentives***

The participants were not paid but were given a token of appreciation of 10000shs at the time of submission of post-test questionnaires. The token was for their time given to participate in the study.

### ***Social or Cultural issues***

There were potentially two social or cultural issues in the study. The first being the power issue of my role as their assistant in-charge as stated under privacy section. When the research assistant administered the questionnaire, it also minimized participants' fears of losing jobs if I learnt that they lacked self-efficacy in pediatric HIV disclose as their in-charge. The research assistant assured participants that only codes were used on questionnaires and that I did not know who filled which questionnaire hence keeping it secure and safe for participants. Then the second social or cultural issue was potential difficulties that would arise from disparate educational backgrounds. I was aware that nurses involved in this study were primarily at the certificate, diploma and undergraduate levels. However, I used English clear to participants to minimize any potential difficulties resulting from disparate educational backgrounds.

***Conflict of Interest***

This study did not involve any conflicts of interest.

**Summary**

Chapter 3 summarized methods that were used in the course of this study including the research design, study population, the study setting, sample, sampling frame, sample size, inclusion criteria for the study participants and the intervention process. Chapter 3 covered data collection tools, pilot plan, validity, reliability, data analysis, and ethical issues that included informed consent, privacy, and confidentiality. Chapter 3 also covered potential benefits, potential risks, use of incentives and social or cultural issues. Chapter 4 will discuss the results of the data collected.

## **Chapter Four: Presentation of Results**

The following chapter describes results from the study of nurses who manage children living with perinatal HIV seeking to describe the effect of an educational intervention using a checklist on their knowledge, attitude and self-efficacy. The data was entered into SSPS and analyzed. This chapter describes the demographics of the study participants and then according to the three objectives that guided the study. The first objective identified the effect of an educational intervention on nurses' knowledge. The second objective determined the effect on nurses' attitude and the third one ascertained the effect on nurses' self-efficacy when engaging in the process of disclosure among children with perinatal HIV.

### **Demographic Data**

Demographic data that I collected is presented as frequency and percent. The data describes the demographic characteristics of the participants in this study as shown in Table 1.

The participants' age ranged from 20 to 50 with half of them (50%) aged between 20- 29 years. Sixty-five percent of the participants were females. Ninety percent of the participants had no previous training in disclosure for children with perinatal HIV and 50% had a diploma in nursing as their highest qualification. Sixty percent had 0-5 years' experience of working with children living with perinatal HIV.

**Table 1: Demographic Distribution of Study Participants***Demographic Distribution of Study Participants (N=20)*

Category	Frequency(F)	Percent (%)
Age in years		
20-29	10	50
30-39	6	30
40+	4	20
Gender		
Female	13	65
Male	7	35
Work experience in pediatric HIV care (Years)		
0-5	12	60
6-10	7	35
11+	1	5
Previous training in pediatric HIV disclosure		
Yes	2	10
No	18	90
Highest level of Education		
Certificate in Nursing	8	40
Diploma in Nursing	10	50
Bachelor's degree in Nursing	2	10

**Knowledge**

The knowledge section describes the effect of an educational intervention on nurses' knowledge when engaging in disclosure of children with perinatal HIV. This section includes the descriptive findings, statistical findings and the analysis of the performance by each question. The section explains the participants' knowledge before and after the intervention to elaborate the effect of the intervention.

***Descriptive Findings***

The descriptive findings section describes the participants' overall pre and post test scores. In addition, the comparison of participants' knowledge by categories is given.

The mean percent before the educational intervention was 50 (Appendix H). The mean percent post-intervention was 67 (Appendix I). The mean (Appendix J) improved percentage by 16.

**Table 2: Comparison of Nurses' Knowledge by Categories**

*Comparison of Nurses' Knowledge by Categories (N=20)*

Category	Pre-Test		Posttest		% Change
	F	%	F	%	
Knowledge levels					
Highly knowledgeable (>79%)	3	15	6	30	15
Better Knowledge (70-79%)	1	5	4	20	15
Fairly knowledgeable (50-69%)	7	35	10	50	15
Less knowledgeable (<50%)	9	45	0	0	-45

As shown in Table 2, before the educational intervention only 15% were categorized as highly knowledgeable and after the intervention 30% became highly knowledgeable. Thirty-five percent were in the fairly knowledgeable category before the intervention and after intervention fifty percent (50%) of the participants were categorized as fairly knowledgeable. Prior to intervention, 45% were less knowledgeable but afterwards no one was in the less knowledgeable category regarding disclosure in children with perinatal HIV.

### ***Statistical Findings***

The statistical findings section describes the comparison of mean for knowledge of the participants before and after the educational intervention. Table 3 shows the performance in terms of mean percent to explain the difference the intervention had on the participants' knowledge towards the disclosure process in children with perinatal HIV.

**Table 3: Comparing Mean for Knowledge Before and After the Educational Intervention**

*Comparing Mean for Knowledge Before and After the Educational Intervention using a Paired T-Test (N=20)*

	Mean (%)	SD	P- value	CI
Before Intervention	50	19.19		50 ± 8.410
After Intervention	67	13.01	<0.001	67 ± 5.702

A paired t –test was performed to compare performance of nurses for knowledge. The statistical significance achieved the P-value of 0.05. Before the intervention the mean percent was 50 and after the intervention it improved to 67 indicating the positive effect the intervention had on the participants. The two-tailed P value equals 0.001. By conventional criteria, this difference is considered to be very statistically significant. 95% CI: 50 ± 8.410 before intervention and 95% CI: 67 ± 5.702 after intervention. The confidence interval after the intervention (61.298-72.702) is entirely above the confidence interval before the intervention (41.59-58.41). This suggests that the intervention had a statistically significant effect, and the population mean increased after the intervention.

#### ***Analysis of Performance of Knowledge Questions***

The analysis of performance of knowledge questions section compares the participants' performance against each knowledge statement. The effect of the intervention on nurses' knowledge (Appendix K) is shown in the post-intervention column.

From the comparison of performance against each knowledge statement shown in Appendix K, the knowledge statement that WHO recommends HIV disclosure to start from age

6 had the lowest percentage (25%) before intervention but afterwards it scored a higher percentage (80%). Before the intervention, the knowledge statement about what pediatric HIV disclosure is scored the highest percentage (75%) and after the intervention the percentage increased to 100%.

### **Attitude**

The attitude section describes the descriptive findings, statistical findings and the analysis of the performance of each question. The section identifies the participants' attitude before and after the intervention. I had six questions in this attitude section that were negatively worded and I reversed the responses during the scoring as described in the data analysis of the attitude section in chapter 3.

### ***Descriptive Findings***

The descriptive findings section includes the overall attitude scores pre and post intervention and the changes that resulted, as well as the categorical information before and after and their changes. The overall individual pretest attitude scores are presented in the Appendix L. In the pre-intervention scores (Appendix L), 15% of the participants had a good attitude and 45% were categorized to have poor attitude towards disclosure in children with perinatal HIV. Initially, none of the participants had an excellent attitude towards pediatric HIV disclosure. After the educational intervention (Appendix M), 15% of the participants were categorized to have an excellent attitude and 40% had a good attitude towards pediatric HIV disclosure. The mean for attitudes before the intervention was 2.51 and after the intervention it improved to 2.89. The mean improved by 0.38.

**Table 4: Comparison of Nurses' Attitude by Categories***Comparison of Nurses' Attitude by Categories (N=20)*

Category	Pre-test		Posttest		Change
	Frequency	%	Frequency	%	%
Excellent attitude (>3.4)	0	0	3	15	15
Good attitude (3-3.4)	3	15	8	40	25
Fair attitude (2.5-2.9)	8	40	6	30	-10
Poor attitude ( <2.5)	9	45	3	15	-30

Before the intervention the majority had either a poor (45%) or fair (40%) attitude and no one had an excellent attitude. Afterward the majority had either an excellent (15%) or good (40%) attitude. As shown in table 4 there was a decrease in the change percentage for participants in the poor and fair attitude category (-30% and -10% respectively) with most participants in the good and excellent attitude category.

### ***Statistical Findings***

This section includes the comparison of the attitude before and after the intervention using the mean and standard deviation. It describes the effect of educational intervention on participants' attitude towards pediatric HIV disclosure as shown in Table 5.

**Table 5: Comparing Mean for Attitude Before and After the Educational Intervention**

*Comparing Mean for Attitude Before and After the Educational Intervention (N=20)*

Wilcoxon Signed Ranks Test (W) on Attitude

	Mean	SD	P-value	CI
Attitude Before the Intervention	2.51	0.32		2.51 ± 0.14
Attitude After the Intervention	2.89	0.42	0.002	2.89 ± 0.18

As shown in Table 5 the mean for attitudes before the intervention was 2.51 and after the intervention it improved to 2.89. The value of z is -2.87. The p-value is .002. The result is significant at  $p < .05$ . The value of W is 28. The critical value for W at  $N = 20$  ( $p < .05$ ) is 60. 95% CI:  $2.51 \pm 0.140$  before intervention and 95% CI:  $2.89 \pm 0.184$  after intervention. The confidence interval after the intervention (2.706-3.074) is entirely above the confidence interval before the intervention (2.37-2.65). This suggests that the intervention had a statistically significant effect, and the population mean increased after the intervention.

#### ***Analysis of Performance of Attitude Questions***

When comparing the pre and post-intervention data shown in Appendix N, before the intervention the attitude statement about whether participants felt adequately trained had 5% agreement and afterwards 95% of the participants agreed reflecting a more positive attitude. The attitude statement of *I believe my role as a nurse includes helping with the disclosure process* had 40% of participants disagreeing before the intervention and afterwards, 100% agreed with this statement. Initially, forty-five percent of the participants agreed to the attitude statement of *I*

*believe the caregiver is entirely responsible to disclose HIV positive status to the child and afterwards this increased to 65%.*

### **Self-efficacy**

The self-efficacy section describes the descriptive findings, statistical findings and the analysis of the performance by each self-efficacy question. The section explains the participants' level of confidence to participate in the disclosure process before and after the educational intervention.

### ***Descriptive Findings***

The self-efficacy section describes the overall self-efficacy scores pre and post intervention and the changes that resulted, as well as the categorical information before and after and their changes. The overall individual pretest self-efficacy scores are presented in the Appendix P.

**Table 6: Comparison of Nurse Self-efficacy Pre and Post Intervention Scores**

*Comparison of Nurse Self-efficacy Pre and Post Intervention Scores*

Category	Pretest		Posttest	
	<i>f</i>	%	<i>f</i>	%
Highly confident (> 3.4)	00	0	3	15
Moderately confident (2.5-3.4)	11	55	16	80
Low level of confidence (< 2.5)	9	45	1	5

In the pre-intervention self-efficacy scores (Appendix P and Table 6), 55% of the participants had moderate level of confidence and 45% were categorized to have low level of confidence towards disclosure in children with perinatal HIV. None of the participants was highly confident before the intervention. Following the educational intervention (Appendix Q and Table 6), 15% of the participants were categorized as highly confident. Eighty percent (80%) of the participants had moderate level of confidence and only 5% had low level of confidence.

### *Statistical Findings*

The statistical findings section includes the comparison of self-efficacy before and after the intervention using the mean and standard deviation. It describes the effect of educational intervention on participants' confidence towards pediatric HIV disclosure as shown in Table 7.

#### **Table 7: Comparing Mean for Self-efficacy Before and After the Educational Intervention**

*Comparing Mean for Self-efficacy Before and After the Educational Intervention using A Wilcoxon Signed Ranks Test (N=20)*

	Mean	SD	P-value	CL
Self-efficacy Before the Intervention	2.55	0.31		2.55 ± 0.136
Self-efficacy After the Intervention	2.93	0.34	0.002	2.93 ± 0.149

The overall self-efficacy scores indicate a significant change after the intervention was carried out (Table 7). Self-efficacy means score before the intervention was 2.55 and after the educational intervention it increased to 2.93. The value of  $z$  is -2.77. The  $p$ -value is .002. The

result is significant at  $p < .05$ . The value of  $W$  is 26. The critical value for  $W$  at  $N = 19$  ( $p < .05$ ) is 53. The result is significant at  $p < .05$ . 95% CI:  $2.55 \pm 0.136$  before intervention and after 95% CI:  $2.93 \pm 0.149$ . The confidence interval after the intervention (2.781-3.079) is entirely above the confidence interval before the intervention (2.414-2.686). This suggests that the intervention had a statistically significant effect, and the population mean increased after the intervention.

### ***Analysis of Self-efficacy Performance by Question***

Comparing the pre and post-intervention data shown in the Appendix R, self-efficacy statement of *I am comfortable in guiding caregivers of children with perinatal HIV* had 70% of the disagree scores (Appendix S). After the intervention it scored 85% agrees indicating how participants felt more confident in supporting the pediatric HIV disclosure process. Self-efficacy statements of *I am able to answer questions and provide accurate information about HIV* had 65% before intervention and afterwards it decreased to 55%. Sixty-five percent of the participants agreed to the self-efficacy statement of *I am confident in collaborating with other healthcare professional* before intervention and afterwards this increased to 70% agree scores.

### **Summary**

Chapter Four has presented the three study objectives considering the effect of educational intervention on nurses' knowledge, attitude and self-efficacy towards disclosure in children with perinatal HIV. There was a significant improvement in nurses' knowledge, attitude and confidence towards pediatric HIV disclosure in children after the teaching using the disclosure checklist for ongoing disclosure support process. Chapter Five presents the discussion, recommendations, and the conclusion from the study.

## **Chapter Five: Discussion, Recommendations and Conclusion**

Chapter Five discusses the demographics and the results that were obtained in the study, following each study objective. The guiding objectives were to identify the effect of an educational intervention using a checklist on nurses' knowledge, attitude and self-efficacy to engage in disclosure among children with perinatal HIV at a district hospital in Southwestern Uganda. Chapter Five also describes the recommendations, limitations of the study, areas for further study and the conclusion section.

### **Demographics**

The majority of the participants in the research were aged 20-29 years which implies a young generation of nurses new in the field with most of them having less than 5 years of work experience in pediatric HIV disclosure. The young nurses that participated in this study is a similar finding in other private district hospitals. The majority of the study participants were females which is also common in most district hospitals. The majority of the participants responded that they had not had a previous training in pediatric HIV disclosure. Lack of prior training in pediatric disclosure could affect their attitude, confidence and knowledge regarding the disclosure process. In a similar vein, Madiba and Diko's study from 2021 in rural health areas in South Africa found that most study participants lacked formal education in pediatric disclosure, and several had never revealed anything to children. Additionally, Madiba and Diko observed that healthcare professionals' confidence to report was impacted by their lack of abilities. When it comes to training on HIV disclosure in children, the majority of the nurses in the study held a diploma in nursing, which suggests a higher degree of understanding than

certificate holders. This result is in line with research done in Barbados, where Huq discovered that higher education was linked to greater knowledge (Huq et al., 2019).

### **Effect of an Educational Intervention on Nurses' Knowledge to Engage Disclosure**

There was an improvement on nurses' knowledge after an educational intervention on disclosure using a checklist to engage in disclosure among children with perinatal HIV. The confidence interval suggests that the intervention was effective. Before the intervention, the majority of the nurses did not know fundamental information such as the age to start disclosure in children with perinatal HIV. The majority of the participants reported that the primary obstacles to disclosure were the absence of a standard tool for disclosure and a lack of training on disclosure. The finding from the study is consistent with studies conducted in South Africa and Malawi that noted that the two biggest obstacles to disclosure were the absence of a standard tool for disclosure (84%) and the lack of training on disclosure (Kalembo et al., 2018; Madiba & Diko, 2021).

After the intervention all nurses who participated in the study reported that pediatric HIV disclosure means telling a child about their own HIV diagnosis; with more than a half stating that guidelines or protocols specific to pediatric HIV disclosure are important resources in facilitating the disclosure process. Before the intervention the majority of the nurses reported that there were no clear guidelines or protocols for nurses to use during the disclosure process which made it hard for them to support caregivers during the process. After the intervention nurses knew when to start disclosure, the information to share at a specific age and how to support the disclosure process using the disclosure checklist. This could mean that using that using a disclosure checklist would be very helpful and useful to guide pediatric HIV disclosure. This finding agrees

with a study done in Washington, D. C. (Elizabeth Glaser Pediatric AIDS Foundation, 2018).

The confidence interval suggests that the intervention enhanced nurses' understanding about pediatric HIV and it developed their skills to disclose HIV status to children in a sensitive and supportive manner.

### **Effect of an Educational Intervention using a Checklist on Nurses' Attitude**

There was improvement on nurses' attitude on pediatric HIV disclosure using a checklist to engage in disclosure among children with perinatal HIV after an educational intervention. This suggests that the intervention had a statistically significant effect, and the population mean increased after the intervention. From the confidence interval calculated, the intervention improved nurses' attitudes towards pediatric HIV disclosure, improving children's adherence and hence improving their well-being. The majority of the participants reported that they did not feel adequately trained to facilitate pediatric HIV disclosure before the intervention but afterwards there was a significant improvement. After the educational intervention, all participants believed that it was the role of the nurse to support the pediatric disclosure process. This finding aligns with the study done in Malawi that noted that 98% said it was important to tell children about HIV status (Kalembo et al., 2018).

Before the intervention the majority of the nurses did not believe that fear of negative reactions from the child is a big barrier among caregivers for pediatric HIV disclosure to be performed. This may have affected the nurses' attitude believing that the caregiver was entirely responsible for disclosure. This aligns with the study done in Malawi that noted that 37% of the participants said they had never told a child about their status, and roughly half estimated that the rate of HIV disclosure at their facility was 25% or less. However after the intervention there was

a significant improvement in nurses' attitude regarding concerns surrounding the delay to disclose. Nurses agreed that caregivers' fear of negative reaction from the child was a big barrier in pediatric HIV disclosure and it could mean nurses' improved attitude in supporting caregivers in the disclosure process. The results contrast with a study carried out in South Africa, where nurses were aware that caregivers were finding the disclosure process challenging, which caused them to postpone disclosing information to children (Madiba & Diko, 2021). Additionally, according to Madiba and Diko, nurses wanted to assist the disclosure but lacked the necessary knowledge, and their confidence to do so was impacted by the absence of pediatric disclosure skills and protocols.

After the intervention, almost all nurses participating in the study reported that pediatric HIV disclosure should not be a direct one-time conversation. The study findings revealed that using the disclosure checklist would be a reminder to the nurses that disclosure among children with perinatal HIV is a gradual process and age appropriate information should be considered. After the intervention nurses' attitude improved and they agreed that disclosure is not a one-day activity but rather a process that needs preparation and with different topics of discussion before it can be completed. This finding is consistent with a study conducted in the Masaka region of Uganda, which developed a four-step provider-assisted and counseling-based child disclosure model. This model included preparation for disclosure, readiness assessment, eligibility screening and invitation, and post-disclosure follow-ups (Kairania et al., 2023).

### **Effect of an Educational Intervention using a Checklist on Nurses' Self-efficacy**

There was improvement on nurses' self-efficacy towards disclosure among children with perinatal HIV after an educational intervention. This suggests that the intervention had a

statistically significant effect, and the population mean increased after the intervention. Nurses' confidence was improved considering the mean before and after the intervention raising expectation that more children will be informed about their HIV status, enabling them to make informed decisions about their care.

Nurses reported that it was crucial to let children know if they have HIV. The majority of the participants reported that they were able to address the emotional needs of a child during the disclosure process with the disclosure checklist used during the intervention. Participants reported confidence in providing an ongoing support to children even after disclosing HIV status. The majority of the study participants agreed that they were comfortable tailoring the disclosure process to the developmental stage. This result is consistent with research from Malawi, which showed that thorough training and standardized disclosure materials gave healthcare professionals the knowledge and assurance they needed to assist primary caregivers with the disclosure process and better prepare them to offer emotional support to children living with HIV (Kalembo et al., 2018).

The findings reveal that the study participants' self-efficacy improved after the educational intervention and introduction of the checklist and the majority of them reported that they were confident to explain HIV and its implications to children in an age appropriate manner. The study participants were able to address the cultural and religious issues after the intervention and the majority of them said they were able to prepare both the caregiver and children for the disclosure conversation. A cross-sectional study carried out in Malawi found that it was the best practice for nurses to collaborate with primary caregivers when disclosing HIV status to children, which is in line with the findings of the current study (Kalembo et al., 2018).

### **Application of the Theoretical Framework**

The intervention in this study used concepts from the Bandura's self-efficacy model. Participants were mentored, encouraged for the good work done and had hands on coaching that resulted in an improvement in their knowledge, attitude and self-efficacy towards HIV disclosure among children. In this study, nurses were eager to be coached and mentored with actual clients and documenting in the children's ART files. However I felt that the disclosure documentation component could be merged with clients file rather than improvising a separate sheet to document the process. This would help nurses' remember to document the disclosure discussions and keep the flow of information captured.

### **Recommendations**

To improve the support and care provided to HIV-positive children, nurses managing clients with HIV should have easier access to training on pediatric HIV care, including the disclosure process. If nurses are to be actively involved in the disclosure process, they must have thorough training on pediatric HIV disclosure procedures and communication skills.

The results of this study indicate that coaching and mentoring can enhance nurses' comprehension in addition to continuous training, particularly if they receive practical instruction and demonstration. The significance of nurses' involvement in HIV care and disclosure for children should be highlighted, and instead of relying on doctors, counselors, or pediatricians to take the lead, nurses should be empowered to act in these capacities. This can be achieved by providing the required knowledge and promoting oversight.

There is need for the Ministry of Health to formulate a tool that can be used during the training, mentoring/coaching as a way to encourage the disclosure of status to children living

with HIV. Age should be one of the factors to be considered in developing a national disclosure framework/tool. This is because the majority of nurses still question the age that disclosure should be commenced in children born with HIV as was observed during the educational intervention. MOH should develop and implement standardized protocols for pediatric HIV disclosure. This would require development of context-specific policy guidelines informed by the WHO recommendations on disclosure to children. Such guidelines will serve as a resource for nurses to provide standardized training to the family caregivers.

The hospital administration will need to develop policies and guidelines for pediatric disclosure ensuring consistency and standardization across the hospital. The hospital may have to monitor and evaluate disclosure practices indenting areas for improvement and providing feedback to nurses.

### **Limitations**

One of the study's drawbacks is that we used nurses' self-reported questionnaire responses as the primary source of data, which may have resulted in response bias. Despite all efforts to ensure secrecy, it is plausible that the necessity for social acceptability, particularly when it comes to a delicate study subject like HIV in children, influenced some of the responses.

Because of the limited sample size, the study's validity may be questioned and the results may be imprecise. This can make it impossible to extrapolate the results. The intricacy of the statistical model required to address the research topic may be too sophisticated for a small sample size to take into account.

Some participants missed sessions and later had separate sessions and this could result in some participants receiving a different dose of the intervention, which could have impacted their

outcome. However much I standardized the content and delivery method for use in the separate sessions to ensure that all participants received the same information. There is a small likelihood that this could impact the dose of intervention given somehow.

### **Areas for Further Study**

More research is needed to address the issue of disclosure of their HIV status to children. This research explored nurses' knowledge, attitude and self-efficacy using a disclosure checklist to engage in disclosure among children with perinatal HIV at a district hospital in Southwestern Uganda. Research can also be done with nurses to find out how they feel about telling children from 6 years of age that they are HIV positive and to find out how differently they understand the role and importance of the HIV information. It may also be necessary to conduct research in various Ugandan regions in order to evaluate and address the various cultural obstacles to child rights, particularly the disclosure of HIV status in various contexts.

There may be need for studies to explore nurses' practices of the disclosure process. This would help identify gaps in the healthcare system and inform policy makers and stakeholders on how to tackle the problem.

### **Conclusion**

The study revealed that using a checklist in the disclosure process of HIV in children is an important approach to ensure nurses develop a positive attitude, confidence and knowledge of the key aspects to include in the disclosure discussion. The majority of the participants agreed that children have the right to know about their HIV status and to participate in their own treatment, and that disclosure is important for adherence. This study is vital because, in the era of HIV/AIDS, disclosure is a critical component of the care and support that children living with

HIV should receive. Although disclosure affects children's quality of life, it is also crucial to keep them from spreading HIV to other people because they do not know their status. I envisage that a pediatric HIV disclosure checklist may greatly assist nurses to engage with primary caregivers in the disclosure process. This may in turn ensure adherence to treatment, facilitate resilience and enhance mental wellbeing of HIV infected children.

### **Summary**

Chapter Five has presented the demographics and the results that were obtained in the study following each study objective. The chapter has also described the application of the theoretical framework, recommendations, limitations of the study and the areas for further study.

### References

- Abegaz, B. F., Walle, T. A., Ambaye, A. W., & Tilahun, D. (2018). HIV positive status disclosure and associated factor among HIV infected children in pediatric ART clinics in Gondar town public health facilities, North West Ethiopia. *Journal of Infection and Public Health*, 12(6):873-877. <https://doi.org/10.1016/j.jiph.2019.05.018>
- Adarmouch, L., Felaefel, M., Wachbroit, R., Felaefel, M., Wachbroit, R., & Silverman, H. (2020). Perspectives regarding privacy in clinical research among research professionals from the Arab region: An exploratory qualitative study. *Biomed Central Medical Ethics*, 21(27). <https://doi.org/10.1186/s12910-020-0456-9>
- Amankwah-Poku, M., Klutsey, D.A., & Asante, K.O. (2021). Disclosure and health-related outcomes among children living with HIV and their caregivers. *AIDS Research Therapy*, 18(13). <https://doi.org/10.1186/s12981-021-00337-z>
- Andrade, C. (2021). The inconvenient truth about convenience and purposive samples. *Indian Journal of Psychological Medicine*, 43(1):86-88. Doi:10.1177/0253717620977000
- Appiah, S. C. Y., Ivanova, O., Hoelscher, M., Kroidl, I., & Dapaah, J. M. (2021). Disclosure of HIV/AIDS status to infected children in Ghana-A north-south comparison of barriers and enablers. *Children and Youth Services Review*, 122; 105753, <https://doi.org/10.1016/j.childyouth.2020.105753>, <https://www.sciencedirect.com/science/article/pii/S0190740920321757>
- Bajaria, S., Exavery, A., Toroka, N., Barankena, A., Charles, J., & Kikoyo, L. (2020). Factors associated with HIV status disclosure to orphans and vulnerable children living with

- HIV: Results from a longitudinal study in Tanzania. *AIDS Research and Treatment*, vol. 2020, Article ID 6663596, 10 pages. <https://doi.org/10.1155/2020/6663596>
- Bandura, A. (1977). *Social learning theory*. Englewood Cliffs, NJ: Prentice Hall.
- Bandura, A. (1986). *Social foundations of thought and action: A Social Cognitive Theory*. Englewood Cliffs, NJ: Prentice Hall. ISBN 978-0-13-815614-5.
- Beebwa, E., Muzoora, C., Ashaba, S., Groves, S., & Atwine, F. (2021). Knowledge, attitude, and preferred strategies towards HIV/AIDS prevention among children attending secondary schools in Southwestern Uganda. *African Health Sciences*, 21(3), 1067-1073. <https://dx.doi.org/10.4314/ahs.v21i3.14>
- Beima-Sofie, K., Wagner, A.D., Soi, C., Liu, W., Tollefson, D., Njuguna, I. N., Ogutu, E., Gaitho, D., Mburu, N., Oluoch, G., Mwaura, P., Cherutich, P., Oyiengo, L., John-stewart, G. C., Nduati, R., Sherr, K., & Gimbel, S. (2022). Providing “a beam of light to see the gaps”: Determinants of implementation of the systems analysis and improvement approach applied to the pediatric and adolescent HIV cascade in Kenya. *Implementation Science Communications*, 3(73). <https://doi.org/10.1186/s43058-022-00304-3>
- Budhwani, H., Mills, L., Marefka, L. E. B., Eady, S., Nghiem, V. T., & Simpson, T. (2020). Preliminary study on HIV status disclosure to perinatal infected children: Retrospective analysis of administrative records from a pediatric HIV clinic in the Southern United States. *BioMed Central Research Notes*, 13(253). <https://doi.org/10.1186/s13104-020-05097-z>
- Bulali, R. E., Kibusi, S. M., & Mpondo, B. C. T. (2018). Factors associated with HIV status disclosure and its effect on treatment adherence and quality of life among children 6–17

years on antiretroviral therapy in Southern highlands zone, Tanzania: Unmatched case control study. *International Journal of Pediatrics*, vol. 2018, Article ID 8058291, 10 pages. <https://doi.org/10.1155/2018/8058291>

Centers for Disease Control and Prevention. (2022). Uganda significantly reduces rates of mother-to-child transmission of HIV with CDC support. <https://www.cdc.gov/globalhivtb/who-we-are/success-stories/success-story-pages/ugandapmtct.html#:~:text=The%20UNAIDS%202021%20Spectrum%20estimates,treatment%20during%20pregnancy%20and%20breastfeeding.>

Doat, A-R., Negarandeh, R., & Hasanpour, M. (2019). Disclosure of HIV status to children in Sub-Saharan Africa: A systematic review. *Medicina*, 55(8):433. <https://doi.org/10.3390/medicina55080433>

Elizabeth Glaser Pediatric AIDS Foundation. Disclosure of Pediatric and Adolescent HIV Status Toolkit. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation, 2018.

Fang, Y., Liu, P., & Gao, Q. (2021). Assessment of knowledge, attitude, and practice toward covid-19 in China: An online cross-sectional survey. *American Journal of Tropical Medicine*, 104(4): 1461–1471 doi: 10.4269/ajtmh.20-0452

Finnegan, A., Langhaug, L., Schenk, K., Puffer, E.S., Rusakaniko, S., Choi, Y., Mahaso, S., & Green, E. P. (2019). The prevalence and process of pediatric HIV disclosure: A population-based prospective cohort study in Zimbabwe. *PLOS ONE*, 14(5): e0215659. <https://doi.org/10.1371/journal.pone.0215659>

Frescura, L., Faussett, G. P., Feizzadeh A., A., El-Sadr, W., Syarif, O., & Ghys, P. D. (2022).

Achieving the 95 95 95 targets for all: A pathway to ending aids. *Public Library of Science One*, 17(8), 1–11. <https://doi.org/10.1371/journal.pone.0272405>

Guta, A., Areri, H. A., Anteab, K., Abera, L., & Umer, A. (2020). HIV-positive status disclosure and associated factors among children in public health facilities in Dire Dawa, Eastern

Ethiopia: A cross-sectional study. *PLoS ONE*, 15(10): e0239767.

<https://doi.org/10.1371/journal.pone.0239767>

Guyatt, G. H., Oxman, A. D., Vist, G., Kunz, R., Brozek, J., Alonso-Coello, P., Montori, V., Akl, E. A., Djulbegovic, B., Falck-Ytter, Y., Norris, S.L., Williams Jr, J. W., JoergMeerpohl, D. A., & Schünemann, H. J. (2011). GRADE guidelines: Rating the quality of evidence—study limitations (risk of bias). *Journal of Clinical Epidemiology*, 64(4):407-15.

DOI: 10.1016/j.jclinepi.2010.07.017

Hamed T. (2021). Data collection methods and tools for research: A step-by-step guide to choose data collection technique for academic and business research projects. *International Journal of Academic Research in Management (IJARM)*, 10(1), pp.10-38. fhal-03741847

Huq, E. K., Moriyama, M., Harris, E. E., Shirin, H., & Rahman, M. M. (2019). Evaluation of nurses' knowledge and attitude toward HIV-infected patients in Barbados. *Journal of the International Association of Providers of AIDS Care*, 18. DOI:

10.1177/2325958219880592

- Ismail, N., Matillya, N., Ratansi, R., & Mbekenga, C. (2021). Barriers to timely disclosure of HIV serostatus: A qualitative study at care and treatment centers in Dar es Salaam, Tanzania. *PLoS ONE*, *16*(8): e0256537. <https://doi.org/10.1371/journal.pone.0256537>
- Kairania, R., Onyango-Ouma, W., Ondicho, T.G., Kagaayi, J., & Kigozi, G. (2023). ‘Mummy told me that I have HIV, that is the only thing she told me’: Experiences of HIV status disclosure to children in Masaka Region, Uganda. *PLoS ONE*, *18*(5): e0285990. <https://doi.org/10.1371/journal.pone.0285990>
- Kalembo, F.W., Kendall, G.E., Ali, M., & Chimwaza, A. F. (2018). Nurses’ perspectives and practices regarding the disclosure of HIV status to children in Malawi: A cross-sectional study. *BioMed Central of Health Services Research*, *18* (540). <https://doi.org/10.1186/s12913-018-3354-9>
- Khangale, H. M. M., Raliphaswa, N. S., & Tshililo, A. R. (2022). HIV Status disclosure to adolescents who are perinatally infected in Rustenburg Sub District Northwest province. *Children*, *9*(12):1989. <https://doi.org/10.3390/children9121989>
- Koay, W. L. A., Zhang, J., Manepalli, K. V., Griffith, C. J., Castel, A. D, Scott, R. K., Ferrer, K. T., & Rakhmanina, N. Y. (2021). Prevention of perinatal hiv transmission in an area of high HIV prevalence in the United States. *Journal of Pediatrics*; *228*:101-109. doi: 10.1016/j.jpeds.2020.09.041
- Lemma, T., Silesh, M., Taye, B.T., Desta, K., Kitaw, T. M., & Tekalign, T. (2020). HIV serostatus disclosure and its predictors among children living with HIV in Ethiopia: A systematic review and meta-analysis. *Front Public Health*, *10*(859469). doi: 10.3389/fpubh.2022.859469

- Mabaso, M., Maseko, G., Sewpaul, R., Naidoo, I., Jooste, S., Takatshana, S., Reddy, T., Zuma, K., & Zungu, N. (2021). Trends and correlates of HIV prevalence among children in South Africa: Evidence from the 2008, 2012 and 2017 South African national HIV prevalence, incidence and behaviour surveys. *AIDS Research and Therapy, 18*(97). <https://doi.org/10.1186/s12981-021-00422-3>
- Madiba, S., & Diko, C. (2020). The consequences of delaying telling children with perinatal HIV about their diagnosis as perceived by nurses in the Eastern Cape: A qualitative study. *Children, 7*(12), 289. <https://doi.org/10.3390/children7120289>
- Madiba, S., & Diko, C. (2021). Telling children with perinatal HIV about their HIV serostatus: Nurses' practices and barriers to disclosing in a South African rural health district. *Journal of Primary Care & Community Health, 12*. [doi:10.1177/2150132720984757](https://doi.org/10.1177/2150132720984757)
- Morales, J. A., Hamahuwa, M., Moyo, N., Mutanga, J. N., Schue, J. L., Maunga, S., Thuma, P. E., Moss, W. J., & Sutcliffe, C. G.(2022). Factors associated with antiretroviral therapy use among pregnant women in rural and urban settings in Southern Province, Zambia: 2016-2019. *Tropical Medicine of International Health, 27*(10):902-912. Doi: [10.1111/tmi.13816](https://doi.org/10.1111/tmi.13816)
- Mukwevho, A.C., Maputle, M. S., & Ramathuba, D.U. (2023). Growing up with HIV: Experiences of transition from adolescence to adulthood at selected primary health facilities in Limpopo Province, South Africa. *Children, 10*(798). <https://doi.org/10.3390/children10050798>

- Mutambo, C., & Hlongwana, K. (2019). Nurses' perspectives on the barriers to providing HIV services to children in Sub-Saharan Africa. *AIDS Research and Treatment*. Article ID 8056382, 10 pages. <https://doi.org/10.1155/2019/8056382>
- Nabunya, P., Byansi, W., Sensoy, B. O., McKay, M., Ssewamala, F. M., & Damulira, C. (2020). Factors associated with HIV disclosure and HIV-related stigma among children living with HIV in Southwestern Uganda. *Psychiatry*, *11*(772). doi: 10.3389/fpsyt.2020.00772
- Namukwaya, S., Papparini, S., Seeley, J., & Bernays, S. (2017). "How do we start? And how will they react?" disclosing to young people with perinatally acquired HIV in Uganda. *Front Public Health*; *5*:343. Doi: 10.3389/fpubh.2017.00343
- Ngeno, B., Waruru, A., Inwani, I., Nganga, L., Wangari, E. N., Katana, A., Gichangi, A., Mwangi, A., Mukui, I., & Rutherford, G. W. (2019). Disclosure and clinical outcomes among young adolescents living with HIV in Kenya. *The Journal of Adolescent Health*, *64*(2), 242–249. <https://doi.org/10.1016/j.jadohealth.2018.08.013>
- Njom Nlend, A. E. (2022). Mother-to-child transmission of HIV through breastfeeding improving awareness and education: A short narrative review. *International Journal of Women's Health*, *14*:697-703. doi: 10.2147/IJWH.S330715
- Nwanja, E., Nwaokoro, P., Akpan, U., & Toyo, O. (2023). Improved access to HIV diagnosis and linkage to antiretroviral therapy among children in Southern Nigeria: A before-after study. *BioMed Central Pediatrics*, *23*(253). <https://doi.org/10.1186/s12887-023-04050-w>
- Okechukwu, A. A., Kwaghe, V., & Dike, A. U. (2018). Health care providers' perception and practice of HIV disclosure to sero-positive children and adolescents in a tertiary health

- facility in Abuja, Nigeria. *Journal of Clinical Research in HIV AIDS and Prevention*,  
DOI: 10.14302/issn.2324-7339.jcrhap-18-2202
- Paintsil, E., Kyriachildes, T.C., Antwi, S., Renner, L., Nichols, J. S., Amissah, K., Kusah, J. T.,  
Alhassan, A., Ofori, I. P., Catlin, A. C., Gan, G., Lartey, M., & Reynolds, N. R.(2020).  
Clinic-based pediatric disclosure intervention trial improves pediatric HIV status.  
disclosure in Ghana. *Journal of Acquired Immune Deficiency Syndrome*,84(1):122-131.  
doi: 10.1097/QAI.0000000000002316
- Palmeirim, M.S., Ross, A., Obrist, B., Mohammed, U. A., Ame, S. M., & Keiser, J.  
(2020). Informed consent procedure in a double blind randomized anthelmintic trial on  
Pemba Island, Tanzania: Do pamphlet and information session increase caregivers  
knowledge? *BioMed Central Medical Ethics*, 21(1). <https://doi.org/10.1186/s12910-019-0441-3>
- Peterson, S. J., & Bredow, T. S. (2017). *Middle Range Theories: Application to Nursing  
Research* (5<sup>th</sup> ed.). Philadelphia: Wolter's Kluwer health/Lippincott Williams & Wilkins.
- Polit, D., & Beck, C. (2019). *Resource manual for nursing research: Generating and assessing  
evidence for nursing practice*. Lippincott Williams & Wilkins.
- Saunders, C., & Kulchitsky, J. (2021). Enhancing self-administered questionnaire response  
quality using code of conduct reminders. *International Journal of Market  
Research*, 63(6), 715-737. <https://doi.org/10.1177/14707853211055060>
- Shallo, S. A., & Tassew, M. (2020). HIV positive status disclosure and its associated factors  
among children on antiretroviral therapy in West Shoa Zone, Western Ethiopia. A mixed

- method cross-sectional study. *Journal of Multi-disciplinary HealthCare*,13:507-517. doi: 10.2147/JMDH.S258851
- Sibiude, J., Le Chenadec, J., Mandelbrot, L., Hoctin, A., Dollfus, C., Faye, A., Bui, E., Pannier, E., Ghosn, J., Garrait, V., Avettand-Fenoel, V., Frange, P., Warszawski, J., & Tubiana, R. (2023). Update of perinatal human immunodeficiency virus type 1 transmission in France: Zero transmission for 5482 mothers on continuous antiretroviral therapy from conception and with undetectable viral load at delivery. *Clinical Infectious Disease*, 76(3): e590-e598. doi: 10.1093/cid/ciac703. PMID: 36037040.
- Staples, D. S., Hulland, J. S., & Higgins, C. A. (1998). A self-efficacy theory explanation for the management of remote workers in virtual organizations. *Journal of Computer-Mediated Communication*, 3(4). <https://doi.org/10.1111/j.1083-6101.1998.tb00085.x>
- Sumbi, E. M., Venables, E., Harrison, R. Garcis, M., Iakovidi, K., van Cutsem, G., & Chalachala, J. L. (2021). It's a secret between us: A qualitative study on children and care-giver experiences of HIV disclosure in Kinshasa, Democratic Republic of Congo. *BioMed Central Public Health*, 21(313). <https://doi.org/10.1186/s12889-021-10327-5>
- Tucho, W. A., Tekelehaimanot, A. N., & Habte, M. B. (2021). Disclosure status and associated factors among children on antiretroviral therapy in Ethiopia, *Pediatric Health, Medicine and Therapeutics*, 12: 299-306, DOI: 10.2147/PHMT.S314259
- UNAIDS Global AIDS Update 2023. Geneva: Joint United Nations Programme on HIV/AIDS. Licence: CC BY-NC-SA 3.0 IGO.

- UNICEF, (2023). <https://data.unicef.org/topic/hivaids/global-regional-trends/#:~:text=Of%20the%20estimated%2039.0%20million,were%20children%20aged%200%2D19.>
- Vreeman, R. C., Scanlon, M.L., Tu, W., Slaven, J., McAteer, C., Aluoch, J., Ayaya, S., & Nyandiko, M. E. (2019). Validation of an HIV/AIDS stigma measure for children living with HIV and their families. *Journal of the International Association of Providers of AIDS Care, 18*. doi:10.1177/2325958219880570
- Wamala, K., Nuwamanya, R., & Muwanga, M. (2021). Prevalence of HIV and associated risk factors among infants born to HIV positive mothers attending Entebbe Regional Referral Hospital. *Student's Journal of Health Research Africa, 2*(3), 11. <https://doi.org/10.51168/sjhafrica.v2i3.40>
- WHO. (2011). Guideline on HIV disclosure counseling for children up to 12 years of age. Available at <https://www.ncbi.nlm.nih.gov/books/NBK304307/>.
- Wiener, L., Mellins, C. A., Marhefka, S., & Battles, H. B. (2007). Disclosure of an HIV diagnosis to children: History, current research, and future directions. *Journal of Developmental and Behavioral Pediatrics, 28*(2), 155–166. DOI:10.1097/01.DBP.0000267570.87564.cd
- Wolters, P. L., & Brouwers, P. (2005). Neurobehavioral function and assessment of children and adolescents with HIV-1 infection. *Textbook of Pediatric Care*. Cambridge: Cambridge University Press.
- Wu, Y., Howarth, M., Zhou, C., Hu, M., & Cong, W. (2019). Reporting of ethical approval and informed consent in clinical research published in leading nursing journals: A

retrospective observational study. *BioMed Central Medical*

*Ethics*, 20(94).[https:// doi.org/10.1186/s12910-019-0431-5](https://doi.org/10.1186/s12910-019-0431-5)

Yami, D. B., Tuji, T. S., Gelete, B. W. M., & Workie, K. B. (2022). Disclosure status of HIV-positive children and associated factors among children in public health facilities in East Arsi zone, Oromia regional state, South Eastern Ethiopia: A cross-sectional study. *SAGE Open Medicine*, 10.<https://doi.org/10.1177/20503121211106>

## **Appendix A: Informed Consent**

**Title of research study:** Effect of an educational intervention on self-efficacy of nurses using a tool to engage in the process of disclosure among children with perinatal HIV at a district hospital in southwestern Uganda.

**Principle investigator, contact information and affiliation:** My name is Kanyesigye Dianah. This research is being conducted as part of the requirements towards the completion of the degree of masters in nursing science I am pursuing at Uganda Christian University-Mukono. My email address is [Kanyesigyedialdp13@gmail.com](mailto:Kanyesigyedialdp13@gmail.com) and contact is 0789401445. University address is Uganda Christian University, P.O Box 4, Mukono.

**Introduction and purpose of study:** The purpose of the study is to identify and determine the effect of using a tool to engage in the process of disclosure among children with perinatal HIV.

**Description of the research:** This is predictive study meaning a research design that seeks to identify an effect that can forecast a specific outcome. The research design will be prediction since my study aims at identifying and determining the effect of an educational intervention

**Subject participation:** You were selected as a possible participant because you work with children living with perinatal HIV at Kisiizi hospital. If you agree to participate you will have a pre-test, an intervention and be required to conduct disclosure and then undergo a post-test that will take about 20 minutes.

**Potential Benefits** Participating in the study may enhance your knowledge and confidence in conducting disclosure among children with perinatal HIV.

**Potential Risks and Discomforts:** There is minimal risk to participating in this study such as emotional distress in such a situation; in such a situation, I will provide appropriate support by giving offering a private session in which to talk about your experiences. 10000shs will be given as a token of appreciation for participation in this study after you submit the post-test questionnaire.

**Confidentiality:** The records obtained from the study will be kept confidential and your name will not be included in any publications or presentations.

**Rights of participants:** The participation in this study is voluntary. If you agree to participate in the study, you will still be free to withdraw anytime before pre-test or even the post-test. Your participation in the study will be highly appreciated.

**Contact information for ethical concerns or to withdraw consent:** The study has been approved by UCU's REC. You can also contact the Head of Department Dr Elizabeth Nagudi Situma for more information on 0789830754

**Authorization statement:**

I have read this consent form and I agree to be a participant in this study. I have been given the opportunity to ask questions regarding the study, and I have received answers to my questions. I acknowledge that I am aware of what this study involves, that I am at least above 18 years old, and that I have received a copy of this Informed Consent form.

**Signature lines and dates for:**

**Participant:**.....**Date:**.....

**Researcher:**.....**Date:**.....

## **Appendix B: Questionnaire to Assess Knowledge, Attitude and Self-Efficacy**

### **SECTION A: Demographic Data**

*Please circle or write the relevant information*

1. Gender
  - a) Male
  - b) Female
  
2. Age in years  
.....
3. Years of experience as a nurse  
.....
4. Highest level of education
  - a) certificate in nursing
  - b) diploma in nursing
  - c) degree in nursing
  - d) master in nursing
  
5. Have you had any training about HIV disclosure in children?
  - a) Yes
  - b) No
  
6. If yes to the above question, when and where did the training occur?  
.....

### **SECTION B: Knowledge about Pediatric HIV Disclosure**

*Circle the most correct answer (s)*

7. What is pediatric HIV disclosure?
  - a) Revealing a child's HIV status to their parents
  - b) Telling a child about their own HIV diagnosis
  - c) Informing healthcare providers about a child's HIV status
  - d) Disclosing HIV prevention methods to children
  
8. At what age is it generally recommended by WHO to start disclosing a child's HIV status?
  - a) 6 years old
  - b) 10 years old
  - c) 12 years old
  - d) 18 years
  
9. Which of the following is a potential challenge for nurses in pediatric HIV disclosure?
  - a) Fear of hate from the child's family
  - b) Fear of negative reactions from the child
  - c) Uncertainty about the caregiver's level of understanding

- d) Uncertainty about time and where to disclose from
10. Which of the following is the most potential benefit of pediatric HIV disclosure?
- a) Increases the child's understanding of her/his HIV status and her/his wellbeing
  - b) Increases adherence to treatment regimen
  - c) Enhances the child's relationship with the caregiver and the health worker
  - d) Increases child's keeping clinic appointments
11. When engaging in the HIV disclosure process with children, what is the nurse's primary concern? Choose the most correct answer
- a) To promote psychosocial support of the child and the caregiver
  - b) To inform the child about their own HIV status
  - c) To prepare the child to freely disclose her/his HIV status to others
  - d) To promote emotional support and healthy coping strategies
12. What is (are) the primary concern(s) of parents/caregivers regarding pediatric HIV disclosure?
- a) Fear of hate and mistrust
  - b) Child's inability to comprehend the information
  - c) Fear of stigma and discrimination
  - d) Lack of information or words to use
13. What key consideration is most important when preparing for pediatric HIV disclosure discussions?
- a) Assessing the child's cognitive and emotional development
  - b) Assessing child's performance in class
  - c) Understanding child's behavior and ability to keep the secrets
  - d) Assessing child's knowledge and fears about HIV
14. What type of resources can assist nurses in facilitating pediatric HIV disclosure conversations?
- a) conducive or designated area where pediatric HIV disclosure can be conducted
  - b) Guidelines or protocols specific to pediatric HIV disclosure discussions
  - c) Availability of the pediatric specialist
  - d) Availability of a trained pediatric counselor
15. Which approach is generally recommended for initiating discussions about pediatric HIV disclosure with children and their families?
- a) Organized and well planned direct approach and one-time conversation
  - b) Gradual, developmentally appropriate preparation over time
  - c) Parent to child approach to protect the child's innocence
  - d) Counselor to caregiver and child approach
16. What are the potential emotional responses that a child may experience following pediatric HIV status disclosure?

- a) Fear, anxiety, or sadness and understanding
- b) Fear, Joy, fear, trust, anger and hate
- c) Resistance, anger, happy and disgust
- d) Denial, excitement and mistrust

### SECTION C: Attitudes towards Pediatric HIV Disclosure

*Please rate your agreement with the following statements by ticking*

Ser. No	Statement	Strongly disagree	Disagree	Agree	Strongly Agree
17	I believe that pediatric HIV disclosure should be a direct one time conversation				
18	I believe my role as a nurse includes helping with the disclosure process.				
19	I believe pediatric HIV disclosure is a complex and delicate process that should be conducted by only a counselor.				
20	I don't feel adequately trained to facilitate pediatric HIV disclosure				
21	I believe that children have a right to know their HIV status.				
22	I do not believe that pediatric HIV disclosure should be supported by healthcare professionals.				
23	I believe the caregiver is entirely responsible to disclose HIV positive status to the child				
24	I believe that HIV is God's judgment against extramarital sex or homosexuality				
25	I don't believe disclosing a child's HIV status is important for their overall well-being.				
26	I believe my role includes providing emotional support to children during the disclosure process.				

### SECTION D: Self-efficacy in Pediatric HIV Disclosure

*Please rate your confidence level in performing the following activities by ticking*

Ser. No	Statement	Strongly disagree	Disagree	Agree	Strongly agree
27	I am comfortable in guiding caregivers of children with perinatal HIV in the disclosure process.				

28	I am not confident in explaining HIV and its implications to children in an age-appropriate manner.				
29	I am able to address the emotional needs of a child during the disclosure process.				
30	I am able to prepare both caregiver and child for the disclosure conversation.				
<b>Ser No.</b>	<b>Statement</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
31	I am comfortable providing ongoing support to children after the disclosure.				
32	I am able to answer questions and provide accurate information about HIV to pediatric patients.				
33	I am confident in collaborating with other healthcare professionals in the disclosure process				
34	I do not have the ability to address cultural or religious considerations in pediatric HIV disclosure.				
35	I am able to support children throughout the disclosure process.				
36	I am not comfortable in tailoring the disclosure process to the developmental stage and emotional needs of each child with perinatal HIV				

**THANK YOU FOR COMPLETING THE QUESTIONNAIRE**

### Appendix C: Intervention Plan

Venue: C.O.U Kisiizi Hospital

Duration		Activity	Resources persons	Remarks
Week 1	30 minutes	<ul style="list-style-type: none"> <li>❖ Have a general staff meeting</li> <li>❖ Introduction of topic, share the organized power point and ensure set objectives are achieved</li> </ul>	All staff working in HIV clinic	Clear introduction for the topic of discussion
	1 hour and 30 minutes	<ul style="list-style-type: none"> <li>❖ Discuss the case scenarios</li> <li>❖ Demonstrate the disclosure checklist and have a return demonstration using a case study</li> <li>❖ Questions and answers</li> </ul>	Staff working in HIV clinic	Group discussions and hands on with the use of the checklist
Week 2	2 hours (on a pediatric HIV clinic day)	Each participant will be assigned a child/adolescent to take through the disclosure process to assess the learning. This will be done on pediatric HIV clinic day to complete	Quiet place and sample to practice on	Completed guiding topics
	30 minutes	Discussion with each participant after the hands on practice to go through the documentation and share the experience of the whole process and respond to any inquiries or challenges encountered	Forms filled from the disclosure process	Well filled forms and documentation complete
Week 3	15 minutes	Follow up after another HIV pediatric clinic day to see the progress on the use of the checklist and the documentation to confirm the success of the intervention	Children's disclosure filled forms and the documentation of the forms	Disclosure forms filled and well documented

### Appendix D: Teaching Plan

Date	Time	Category of learners	Topic	Expected Number of Staff = 20		Number of staff Present	
				Male	Female	Male	Female
Tuesday (Afternoon time)	2 hours	Nursing staff working in HIV clinic	Pediatric HIV disclosure process				
	30 minutes		Description of pediatric HIV disclosure, the process of disclosure, who, where and when to disclosure				
	5minutes		Explanation of the different levels of disclosure				
	5minutes		Description of the benefits of pediatric HIV disclosure				
	<b>5minutes</b>	<b>Break time</b>					
	5minutes		Description of the appropriate age and outline outcomes of non disclosure				
	5minutes		Exploration of the barriers to pediatric HIV disclosure and outline the age appropriate disclosure information				
	10 minutes		Discussion of disclosure documentation and discuss the disclosure process using a case study and to explain the emotional responses that a child may experience following pediatric HIV status disclosure				
	10 minutes		Exploration of the important considerations during HIV disclosure in children and				

			knowledge and attitudes about participating in the disclosure process				
	20 minutes		Discussion of the child/adolescent disclosure checklist and a case study				
	5 minutes		Conclusion				

**Topic:** pediatric HIV Disclosure Process

**Objectives: By the end of the session nursing staff will be able to:**

- 1) Describe pediatric HIV disclosure, the process of disclosure, who, where and when to disclosure
- 2) Explain the different levels of disclosure
- 3) Describe the benefits of pediatric HIV disclosure
- 4) Outline outcomes of non disclosure
- 5) explore barriers to pediatric HIV disclosure
- 6) Outline the age appropriate disclosure information
- 7) Discuss disclosure documentation and discuss the disclosure process using a case study
- 8) Explain the emotional responses that a child may experience following pediatric HIV status disclosure
- 9) Explore the important considerations during HIV disclosure in children
- 10) Explore own knowledge and attitudes about participating in the disclosure process
- 11) Discuss the child disclosure checklist
- 12) Highlight facts about disclosure
- 13) Demonstrate with a case study
- 14) Summarize the disclosure checklist and the whole power point

**Teaching Methods:**

- Lecture
- Illustration/Demonstration using case study

**Teaching Aids:**

- Projector

### References

Bulali, R. E., Kibusi, S. M., & Mpondo, B. C. T. (2018). Factors associated with HIV status disclosure and its effect on treatment adherence and quality of life among children 6–17 years on antiretroviral therapy in Southern highlands zone, Tanzania: Unmatched case control study. *International Journal of Pediatrics*, Article ID 8058291. <https://doi.org/10.1155/2018/8058291>

Lemma, T., Silesh, M., Taye, B.T., Desta, K., Kitaw, T. M., & Tekalign, T. (2022). HIV serostatus disclosure and its predictors among children living with HIV in Ethiopia: A systematic review and meta-analysis. *Front Public Health*. 2;10:859469. doi: 10.3389/fpubh.2022.859469

Manual on Paediatric HIV Care and Treatment for District Hospitals (2011). Addendum to the pocket book of hospital care of children. Geneva: World Health Organization. Disclosure and psychosocial support for children. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK304124/>

Okechukwu, A. A, Kwaghe, V., & Dike, A. U. (2018). Health care providers perception and practice of HIV disclosure to sero-positive children and adolescents in a tertiary health facility in Abuja, Nigeria. *Journal of Clinical Research in HIV AIDS and Prevention* - 3(3):1-11. <https://doi.org/10.14302/issn.2324-7339.jcrhap-18-2202>

Yetti, K., Lindayani, L., & Huan, M-C. (2020). Children HIV disclosure: Should the children know their HIV status prior treatment and what are the information have to be told? *Clinical Ethics*; 15(3):162-166. Doi:[10.1177/1477750919897381](https://doi.org/10.1177/1477750919897381)

#### Main Content

Objective	Teachers activity	Staff activity	Remarks
Create rapport	<ul style="list-style-type: none"> <li>• Greet staff</li> <li>• Introduce myself</li> <li>• introduce the purpose of the intervention</li> </ul>	Greet and have self-introductions with each one sharing how many times they have participated in disclosure and how the experience has been	Respond to greetings
Review of staff knowledge about Pediatric HIV disclosure	Ask staff questions ask staff if anyone can share an example of disclosure that went well or one that didn't go well to explore their experience	Staff answer questions	Any comments

Discuss Pediatric HIV disclosure	Ask staff questions about disclosure, what it is, its importance and barriers involved	Respond to questions	Respond to any issues that may arise
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## Appendix E: PowerPoint Presentation for Intervention

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**Disclosure in children with perinatal HIV**

By Kanyesigye Dianah  
Master Student at Uganda Christian University-  
Mukono.

**Learning Objectives cont'd**

- Explore own knowledge and attitudes about participating in the disclosure process
- To discuss the child/adolescent disclosure checklist
- To highlight facts about disclosure
- Discussion about a case study
- Summary about the disclosure checklist and the whole power point

**Learning Objectives**

- To describe pediatric HIV disclosure, the process of disclosure, who, where and when to disclose
- To explain the different levels of disclosure
- To describe the benefits of pediatric HIV disclosure.
- To outline outcomes of non disclosure
- To explore barriers to pediatric HIV disclosure.

**Pediatric HIV Disclosure**


- A process whereby a child gains knowledge of HIV status. A process of telling a child about their own HIV diagnosis (Lemma et al., 2022).
- A gradual process of giving children age-appropriate information regarding their illness, leading to full disclosure when the child has the cognitive and emotional maturity to process this information (Lemma et al., 2022).

**Learning Objectives cont'd**

- To outline the age appropriate disclosure information
- Discuss disclosure documentation and discuss the disclosure process using a case study
- To explain the emotional responses that a child may experience following pediatric HIV status disclosure
- To explore the important considerations during HIV disclosure in children.

**When should disclosure start**

The guideline recommends that disclosure process should start when the child is 5 years old and be completed at the age of 12 years (Bulali et al., 2018).



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### Who should disclose

- Research indicates that the child's caregiver or parent is considered to be the best person to disclose (Bulali et al., 2018).
- In some cases caregivers like to disclose in partnership with a health worker or would like the healthcare worker to lead the disclosure process.

This should be decided when preparing the disclosure plan.

### Process of disclosure cont'd

There are 4 steps in the process namely:

- Step 1: Preparation and planning
- Step 2: Assessment and disclosure plan
- Step 3: Disclosure and health promoting tasks
- Step 4: Support and follow up (Yeti et al., 2020).

### Process of disclosure

Disclosure does not have a rapidly-reached end point, therefore disclosure should be handled as a cyclical process.

### Process of disclosure cont'd

**Step 1: Preparation and planning**

- Build rapport with the child and the caregiver.
- check the readiness of the caretaker and the child.

### Process of disclosure cont'd

- Disclosure should follow a plan or process.
- HIV disclosure should be seen as a process, not one time or event of informing children about their disease.
- NB: Parent are more likely to view disclosure as a single event rather than a process.

### Process of disclosure cont'd

**Step 1: Preparation and planning cont'd**

- Provide information
- Question, listen, and respond
- Discuss general ways of handling change and stress with the child
- If the caretakers want the provider team to assist, a planned appointment should be made for the disclosure

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**Process of disclosure cont'd**

**Step 2: Assessment and disclosure plan**

- Assess the caregiver's knowledge regarding pediatric HIV disclosure and her readiness to disclose to the child.
- Assessing children's perceptions, concerns, and attitudes about their disease

**Process of disclosure cont'd**

**Step 3: Disclosure and health promoting tasks cont'd**

- Reassure the child that s/he must lead a life like all children, and can go to school, play games, hold hands and hug other children without transmitting the infection.
- Informing children of their HIV status and discussing the meaning of HIV infection

**Process of disclosure cont'd**

**Step 2: Assessment and disclosure plan cont'd**

- Draw a clear plan of whom to disclose to the child and make schedules or appointments with her to support the disclosure process
- Assessing the child's cognitive and emotional development and the cultural influences

**Process of disclosure cont'd**

**Step 3: Disclosure and health promoting tasks cont'd**

- Providing health education about living with HIV, the importance of adherence and prevention of HIV transmission
- Assessing and supporting the children's and caretakers' emotional reactions
- Discussing coping strategies

**Process of disclosure cont'd**

**Step 3: Disclosure and health promoting tasks**

- Start disclosure process as soon as possible, paying attention to nonverbal expressions of anxiety and denial.
- Encourage and stimulate questions from the child. If the child does not ask questions, ask him about his fears.
- Explain that medicine will fight against the infection and needs to be taken very regularly.

**Process of disclosure cont'd**

**Step 4: Support and follow up**

- Assess positive or any negative outcomes in both the caregiver and the child
- Review understanding of the child about their HIV status.
- Monitor how well they are coping with the diagnosis and treatment disease and identify needs for any further referrals and peer support.

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**Levels of Disclosure**

- **Non-disclosure:** The child is unaware of their illness and its effect on their body
- **Partial disclosure:** The child is made aware of their illness without actually naming HIV (Yetti et al., 2020).

**Potential benefits of pediatric HIV disclosure cont'd**


- Improved attitudes and quality of life
- Children fare better within Social and Educational contexts.
- Promoting self-confidence and resilience. Children become a part of their health management and plan and as a result their opinions are taken into account.

**Levels of Disclosure cont'd**

- **Full disclosure:** The child is made aware of their illness which is named as HIV
- **Complete disclosure process:** The child is guided through a process, from the stage of non-disclosure to the stage of health-promoting disclosure within a children's rights framework (Yetti et al., 2020).

**Potential benefits of pediatric HIV disclosure cont'd**

- To promote emotional support and healthy coping strategies



**Potential benefits of pediatric HIV disclosure**

- Enhancing treatment adherence hence reduced mortality and morbidity
- Reducing stigma and discrimination increasing psychosocial functioning of child and family.
- Empowering the child with information and knowledge, reducing stigma and victimization.

**Outcomes of non-disclosure**

- ◆ Poor prognosis
- ◆ Non-Adherence
- ◆ Treatment failure
- ◆ Poor family relationships
- ◆ Child's privacy is threatened as other may assume his/her status based on the status of the child's parent/s

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#### Outcomes of non-disclosure cont'd

- ◆ Risk of HIV transmission.
- ◆ Stigma and victimization.
- ◆ Children are not considered a part of their own health management.
- ◆ Poor retention to care and treatment.



#### Age-appropriate Disclosure

- A 6-year-old child will learn of their infectious illness (a germ) with a related task of taking medication daily (partial disclosure).
- A 10-12year-old child, who is able to read names of his or her medication, will learn how ART works, and how he/she can participate in his own adherence to medication (full disclosure).

#### Barriers to pediatric HIV disclosure

- Fear of negative reactions from the child
- Fear of negative reactions from the child's family
- Uncertainty about the child's level of understanding
- Negative attitudes of HCPs who are known to be unfriendly

#### Age-appropriate Disclosure cont'd

- A 12-year-old adolescent, who is entering adolescence will need to know that he or she has HIV, and that condom use or delay of sexual debut is recommended if exploring sexual activities.
- An individual at this stage of adolescence will also need to understand the legal implications of infecting an HIV negative person (full disclosure)

#### Barriers to disclosure cont'd

- Limited knowledge and skills to handle and encourage disclosure process
- Absence of guidelines and policies on the HIV disclosure process.
- Parents fear of stigma and discrimination for their children
- HCPs and children's caregivers thought of child's inability to comprehend

#### Disclosure documentation

- Documenting the disclosure plan is good practice.
- It serves as a legal record to support the decision making and consent processes



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#### Case study

- A 7 year old comes to your clinic for ART refill and you receive a report from the caregiver that she has started refusing medicine. The mother reports that she has started asking why she takes medicine yet siblings are not taking it.
- As a nurse what comes in your mind? How would you support the child and the caregiver? Which information would you provide to the caretaker?

#### Important considerations during HIV disclosure in children

- Use age-appropriate language: Tailor language and explanations to match the child's developmental level. Avoid using medical jargon.
- Start with general information: Begin the conversation by discussing HIV in a general context. Use age-appropriate explanations to help the child grasp the concept.

#### Emotional responses that a child may experience following pediatric HIV status disclosure

- Fear, anxiety, or sadness
- Relief and understanding
- Resistance or denial



#### Important considerations during HIV disclosure in children

- Address emotions and concerns: Acknowledge and validate any fears, worries, or emotions expressed by the child during the disclosure process.
- Discuss treatment plan: Explain the importance of adhering to medication regimens, potential side effects, and regular medical visits for monitoring health status.

#### Important considerations during HIV disclosure in children

- Engage caregivers: Involve caregivers early in the process. Discuss their knowledge about HIV/AIDS, address any concerns or fears they may have.
- Create a safe environment: Where the child feels comfortable expressing emotions or asking questions without fear of judgment.

#### Important considerations during HIV disclosure in children

- Involve support systems: Discuss available resources such as counselors and other support groups for children living with HIV/AIDS that can provide additional assistance.
- Follow-up and ongoing support: Offer ongoing support to both the child and their family after disclosure is made. Encourage them.

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**Attitude during the disclosure process**

- Communication skills play a key role in relationship with children and their caregivers
- Patience is a critical trait during disclosure
- Confidence and non-judgmental
- Observant and listening skills
- Trust and respectful

**CHILD/ADOLESCENT Disclosure Checklist Cont'd  
(apply to 6-12 years)**

Client/Provider	Response	Comments
Is the caregiver comfortable with disclosing HIV status to the child?	Yes No	If yes, inform the mother the is a good parent and make comfortable and start the process. If no, ask the caregiver what her fears are and counsel her to address the goal.
Is the caregiver willing to do HIV disclosure to the child herself/whether she needs the nurse to do it?	Yes No	If yes, allow her time to do it and drink before up on subsequent visit. If no, plan start disclosure and support the caregiver to disclose to the child.
Determine the caregiver's knowledge about HIV and discuss the benefits and risks of disclosure.		Provide information based on the response from the caregiver.

**Addressing self efficacy during the disclosure process**

- Self-efficacy is a form of belief that a person has about their respective capabilities to improve their life achievements.
- With knowledge and skills gained about pediatric HIV disclosure, one's ability to support and conduct the process improves and becomes perfect with time.

**CHILD/ADOLESCENT Disclosure Checklist Cont'd (6-9 years)**

Client/Provider	Response	Comments
Monitor for child's response.	Yes No	
Assess what the caregiver has processed, if anything, with the child regarding his or her HIV status or medication status.		Provide based on response goal.
Offer verbal or written caregiver, disclosure of her feelings of guilt and help her to address them.		Encourage her to address considering the response goal.
Evaluate the child/child functioning in school.		
Ask the child how much she knows about HIV/AIDS.		

**CHILD/ADOLESCENT Disclosure Checklist**

**DISCLOSURE ASSESSMENT (to be filled out by nurse/health provider)**

- Name of the child:.....
- Client ART File No:.....
- DOB/Age:.....Gender:.....
- Name of the healthcare provide.....Date:.....

**CHILD/ADOLESCENT Disclosure Checklist Cont'd (6-9 years)**

Client/Provider	Response	Comments
Explain to the child that there are viruses that are referred to as HIV. (HIV is a part of the blood that can weaken the immune system, and explain that the medicines that are taking helps control the virus and help her to stay healthy.		
Use simple language when possible, use role-plays help her to explore the concept of someone who is getting better by the correct medicines stopping them.		
If parent disclosure is being done, skip the full disclosure step and focus on adherence, medication and correct managing ongoing health.		

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**CHILD/ADOLESCENT Disclosure Checklist Cont'd (10-12years)**

Event/condition	Readiness	Discussion
Ask the adolescent if they know about HIV or the health and care system, and find out what information they would like to know. Have they been asked about the illness?		
Find out about the adolescent's beliefs and attitudes about HIV and whether or in the community find out about their usual and safe behaviors.		
Confirm the adolescent's understanding of HIV, its impact on the mother's health, ability to reproduce, sex of a friend or friend's education, ask about the adolescent's performance at school.		
Has the child/adolescent previously received education about HIV?		
Independently confirm with the adolescent and caregiver that they are ready for the visit.		

- CHILD/ADOLESCENT Disclosure Checklist Cont'd (10 years)**
- ✓ "Do you know what HIV is? Can you explain it in your own words?"
  - ✓ "Have you ever heard about someone who has HIV? What do you know about it?"
  - ✓ "Is there anything specific that worries or scares you about having HIV?"
  - ✓ "Would you like me to explain how HIV affects the body and immune system in more detail?"

**CHILD/ADOLESCENT Disclosure Checklist Cont'd (10-12years)**

Event/condition	Readiness	Discussion
Build on the provider's knowledge about chronic illness and/or issues with full disclosure, starting with and explaining how it impacts the care system and how to obtain it.		
Discuss mode of transmission, more specifically, vertical transmission. Place an emphasis on understanding the mother's role within the family and the community, and explain that HIV is not passed to other people's food.		
Allow the caregiver and the child to ask questions and provide necessary information as possible.		

- CHILD/ADOLESCENT Disclosure Checklist Cont'd (10-12 years)**
- ✓ "Are there any people in your life whom we should involve in this discussion, such as a parent, guardian, or other family member?"
  - ✓ "Are there any activities or hobbies that might be affected by having HIV? How can we support and adapt those activities for your well-being?"

- CHILD/ADOLESCENT Disclosure Checklist Cont'd (6-9years)**
- ✓ "How are you feeling right now?"
  - ✓ "Do you have questions for me regarding your health and the medications you are taking?"
  - ✓ "What medications or treatments are you taking recently?"
  - ✓ "Do you know why take the medications?"
  - ✓ "Do you understand why it's important to take medication consistently and on time?"

**CHILD/ADOLESCENT Disclosure Checklist Cont'd**

**SUMMARY OF ASSESSMENT**

- Readiness of the caregiver: .....
- Findings from the Child/Adolescent (How much is already known to the child/adolescent, key issues/concerns raised by the child from the assessment and how the child feels about the process) .....

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**CHILD/ADOLESCENT Disclosure Checklist Cont'd**

**DISCLOSURE SESSION RECORD**

• Name of the child:.....Age:.....

• ART File No:.....

• Name of the healthcare provider:.....

**Summary of Sessions conducted (Disclosure process)**

**Each Session capture the following**

- Date
- Any comments
- Disclosure topics covered?

**Facts Pediatric HIV disclosure cont'd**

**After Disclosure**

- Take a pause to observe the child's immediate reaction and be ready to support an emotional response with words of reassurance.
- Provide encouragement and reassurance and encourage the caregiver to be supportive of the child at home.
- Remind the child and caregiver of the benefits of disclosure, as discussed earlier in the toolkit.
- Provide enhanced adherence counseling reinforcing messages about the benefits of taking medications, seeing a medical provider regularly, and living healthy lifestyle.

**CHILD/ADOLESCENT Disclosure Checklist Cont'd**

- information given to child/adolescent (include words used)
- information given to the caregiver
- Child/adolescent's response and questions
- Health promoting tasks given to child/adolescent and caregiver
- Current level of disclosure
- Follow up plan and linkages

**A case study**

A 11 year old girl comes to HIV clinic for ART refill and you notice the low mood. She opens up to you that she is tired of taking treatment while she is not sick. She adds that there are four siblings at home that do not take treatment and she wonders why she takes the medicine and for how long she will have to do this. The caregiver also reports she has started refusing to come to hospital saying she does not know understand why she has to keep swallowing pills.

**Facts about Pediatric HIV disclosure**

**Throughout and after disclosure**

- Pause periodically, and ask the child what he or she is feeling at the moment, without rushing answers; accept silence.
- Observe the caregiver's emotional response and provide support and reassurance.

**A case study cont'd**

- What would you think as a health worker and how would you support this child and the caregiver?
- discuss what strategies they have used in the past to get children to open up to them and share feelings

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#### Summary of How to utilize the Checklist.

- Review of the checklist as a group (Attached as word document)
- The checklist includes assessing caregiver's readiness to disclose to the child, how much is known about HIV in children for the caregiver and the child herself.
- The checklist triggers the nurse to give information considering gaps identified from the assessment.
- Recording the summary of assessment done and keeping track of the progress until full disclosure is achieved.

#### References cont'd

- Lemna, T., Slesh, M., Taye, B.T., Desta, K., Kitaw, T.M., Tekalign, T. (2022). HIV serostatus disclosure and its predictors among children living with HIV in Ethiopia: A systematic review and meta-analysis. *Front Public Health*, 2;10:859469. doi: 10.3389/fpubh.2022.859469
- Bulali, R. E., Kibusi, S. M., & Mpondo, B. C. T. (2018). Factors associated with HIV status disclosure and its effect on treatment adherence and quality of life among children 6–17 years on antiretroviral therapy in Southern highlands zone, Tanzania: Unmatched case control study. *International Journal of Pediatrics*, Article ID 8058291. <https://doi.org/10.1155/2018/8058291>

#### Summary

The disclosure counseling process emphasizes educating the children about their HIV diagnosis, facilitating communication between the caretaker and the children, and assessing and managing the impact of the disclosure.

#### References cont'd

- Manual on Paediatric HIV Care and Treatment for District Hospitals: Addendum to the Pocket Book of Hospital Care of Children. Geneva: World Health Organization; 2011. 11. Disclosure and psychosocial support for children. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK304124/>

#### References

- Okechukwu, A. A., Kwaghe, V., & Oke, A. U. (2018). Health care providers perception and practice of HIV disclosure to sero-positive children and adolescents in a tertiary health facility in Abuja, Nigeria. *Journal of Clinical Research in HIV AIDS and Prevention* - 3(3):1-11. <https://doi.org/10.14802/jsc.2014-7399.jcrhsp-18-2202>
- Yeti, K., Lindeyani, J., & Huang M-C. (2020). Children HIV disclosure: Should the children know their HIV status prior treatment and what are the information have to be told? *Clinical Ethics*, 15(3):162-166. doi:10.1177/1477759919887981

ANY QUESTIONS????

**Appendix F: Guiding Checklist Tool in Pediatric HIV Disclosure Process**

Name of the child:.....

Client ART File No:.....

DOB/Age:.....Gender:.....

Name of the Nurse completing the form:.....Date:.....

<b>CHILD Disclosure</b>			
<b>Issues to address</b>	<b>Response</b>		<b>Comments</b>
<b>For caregivers of children aged 6-12years</b>			
Is the caregiver comfortable with disclosing HIV status to the child	Yes or No	<p>If yes, inform the mother this is a gradual process and not a onetime event and start the process</p> <p>If no, ask the caregiver what her fears are and support her to achieve the goal</p>	
Is the caregiver willing to do HIV disclosure to the child herself or whether she needs the nurse to do it?	Yes or No	<p>If yes, allow her time to do it and do the follow up on subsequent visits</p> <p>If no, then start disclosure and support the caregiver to disclose to the child</p>	
Determine the caregiver’s knowledge about HIV and discuss the benefits and risks of disclosure		Provide information based on the response from the caregiver	

Is HIV mother to child transmission	Yes or No	If the mother is the caregiver, discuss any of her feelings of guilt and help her to address them.	
Assess what the caregiver has discussed, if anything, with the child regarding his or her HIV status or medications to date.		Proceed based on responses given	
<b>For children 6-9years of age</b>			
Evaluate the child's daily functioning in school		To understand the child's learning abilities, his/her relationships with others and the activities child is involved to rule out self stigma and other disabilities as a result of living with HIV.  Support accordingly	
Ask the child how much she knows about her/his health.		Provide the talk based on how much is known and how much needs to be known at that certain age the child will be on (Partial disclosure starts from here)	
Explain to the child that there are viruses (can be referred to as bugs, disease particles) in the blood that can weaken the immune system, and explain that the medicines they are taking help to control the viruses and help him or her stay healthy.		Use simple language to explain the virus in the body	
Use simple drawings when possible (no artistic skills required) to explain the concept of immune cells being attacked by the virus and medications stopping them.		With partial disclosure that starts from 6 years use drawings to be understood by the child and use simple words to explain more about the virus	
If partial disclosure is being done, skip the full disclosure steps and focus on adherence to medications and care and messaging on staying healthy.		Partial disclosure ends here. Reschedule to proceed to full disclosure another time.	

		Emphasize adherence at the end of each session.	
<b>For children 10-12 years</b>			
Find out about the adolescent's relationship with their peers in school and/or at home or in the community. Find out about their mood and daily behaviors.		Assess the child's relationships at school, community and at home. Support the child and the caregiver based on responses.	
Confirm that the adolescent is psychologically stable (e.g., no recent family member's death, divorce, or separation; loss of a friend; or distant relocation). Ask about the adolescent's performance at school.		To ensure a clear environment for the disclosure process (privacy is key when conducting the process)	
Has the child/adolescent previously received disclosure information?	Yes or No	If yes what she was told and what feels she did not understand from the previous discussion  If no, proceed to the next issue	
Independently confirm with the adolescent and caregiver that they are ready for disclosure.		Provide information that helps the child and the caregiver understand enough about the disease (what the disease is, how is spread, which treatment is used and for how long one takes the treatment among other topics)	
Assess what the adolescent already knows about his or her health and HIV status, and find out what information the adolescent has about the medicines he or she has been taking and about the illness.		Full disclosure starts with asking again how much is already known	
<b>NB: This form must be referred to during each disclosure session to avoid unnecessary repetitions and to keep track of what has been done and what needs to be done.</b>			

<ul style="list-style-type: none"> <li>✓ "Can you tell me what medications or treatments you have been taking recently? "</li> <li>✓ "Do you understand why it's important to take medication consistently and on time?"</li> <li>✓ "Do you know what HIV is? Can you explain it in your own words?"</li> <li>✓ "Have you ever heard about someone who has HIV? What do you know about it?"</li> <li>✓ "Is there anything specific that worries or scares you about having HIV?"</li> <li>✓ "Would you like me to explain how HIV affects the body and immune system in more detail?"</li> <li>✓ "Are there any people in your life whom we should involve in this discussion, such as a parent, guardian, or other family member?"</li> <li>✓ "Are there any activities or hobbies that might be affected by having HIV? How can we support and adapt those activities for your well-being?"</li> </ul>	<p>Yes or No (Questions are asked once during the disclosure process but questions with no responses will be carried forward into other sessions until they have a yes response).</p>	<p>For a no response to any question, the provide information to ensure the child understands clearly.</p>	
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<b>SUMMARY OF ASSESSMENT</b>	
Readiness of the caregiver:	
Findings from the Child/Adolescent (How much is already known to the child/adolescent, key issues/concerns raised by the child from the assessment and how the child feels about the process)	


### DISCLOSURE SESSION RECORD

Name of the child:.....Age:.....

ART File No:.....

Name of the healthcare provider:.....

Summary of Sessions conducted (Disclosure process)			
Session 1: Date			Any comments
	Disclosure topics covered?		
	Information given to the caregiver		
	Caregiver's questions and response		
	Information given to child/adolescent (Include words used)		
	Child/adolescent's response and questions		
	Health promoting tasks given to child/adolescent and caregiver		
	Level of disclosure		
	Follow up plan and linkages		
Session 2: Date			
	Disclosure topics covered?		
	Information given to the caregiver		
	Caregiver's questions and response		
	Information given to child/adolescent (Include words used)		

	Child/adolescent's response and questions		
	Health promoting tasks given to child/adolescent and caregiver		
	Follow up plan and linkages		
	Level of disclosure		
<b>Session 3: Date</b>			
	Disclosure topics covered?		
	Information given to the caregiver		
	Caregiver's questions and response		
	Information given to child/adolescent (Include words used)		
	Child/adolescent's response and questions		
	Health promoting tasks given to child/adolescent and caregiver		
	Level of disclosure		
	Follow up plan and linkages		

## Appendix G: Permission from the Study Site

Uganda Christian University  
P.O. BOX 4,  
Mukono-Uganda  
19<sup>th</sup> March 2024.

To The Chairman Research Committee,  
C.O.U Kisiizi Hospital,  
P.O Box 109,  
Kabale.

*27/3/2024  
Kanyesigye Dianah has  
been given administrative  
permission for data collection  
for the study*

**Kisiizi Hospital  
Chairman Education  
& Ethics Committee**

Dear Sir,

Re: **Administrative Permission For Research Data Collection**

I here by request for administrative permission for research data collection. I am pursuing a Master's Dgree in Nursing Science at Uganda Christian University, Reg. No. RM21M11/015. My research topic is: Effect of an educational intervention using a checklist on knowledge, attitude and self-efficacy of nurses engaging in the process of disclosure among children with perinatal HIV at a district hospital in Southwestern Uganda

This is one of the requirements of the university for their students to get administrative permission from sites where they hope to collect research data from before final approval by University Research Ethics Committee (REC). Once my research proposal is approved by the University REC, I will come back to seek further permission to collect data.

Thank you for your positive consideration.

Yours faithfully,  
*Kanyesigye Dianah*  
.....

**Kanyesigye Dianah**  
Tel: +256789401445/+256770842061/+256756670572  
Email: kanyesigyedialdp13@gmail.com





**Appendix J: Effect of intervention on Knowledge of nurses**

S/N	Pre-intervention		Post-Intervention		% Change
	Raw Scores	Percentage	Raw scores	Percentage	
1	9	90	7	70	-20
2	5	50	5	50	0
3	4	40	6	60	20
4	8	80	6	60	-20
5	6	60	8	80	20
6	5	50	7	70	20
7	4	40	5	50	10
8	3	30	6	60	30
9	6	60	9	90	30
10	5	50	8	80	30
11	4	40	6	60	20
12	3	30	8	80	40
13	2	20	7	70	50
14	8	80	8	80	0
15	7	70	7	70	0
16	6	60	6	60	0
17	5	50	9	90	40
18	4	40	5	50	10
19	3	30	6	60	30
20	3	30	5	50	20
Mean		50		67	16

### Appendix K: Comparison of Performance against each Knowledge Statement

Statement of Question	Pre-intervention		Post-intervention	
	Correct: N (%)	Wrong: N (%)	Correct: N (%)	Wrong: N (%)
Pediatric HIV disclosure means telling a child about their own HIV diagnosis	14(70)	66(30)	20(100)	00(0)
Age 6 is generally recommended by WHO to start disclosing a child's HIV status	05(25)	15(75)	16(80)	04(20)
Fear of negative reactions from the child is a potential challenge for nurses in pediatric HIV disclosure	06(30)	14(70)	10(50)	10(50)
The most potential benefit of pediatric HIV disclosure is that it Increases adherence to treatment regimen	12(60)	08(40)	12(60)	08(40)
When engaging in the HIV disclosure process with children, the nurse's primary concern is to promote emotional support and healthy coping strategies	11(55)	09(45)	12(60)	08(40)
Fear of stigma and discrimination is the primary concern(s) of parents/caregivers regarding pediatric HIV disclosure	08(40)	12 (60)	14(70)	06(30)
Assessing the child's cognitive and emotional development is the key consideration is most important when preparing for pediatric HIV disclosure discussions	12(60)	18(40)	11(55)	09(45)
Type of resources can assist nurses in facilitating pediatric HIV disclosure conversations Guidelines or protocols specific to pediatric HIV disclosure discussions	11(55)	09(45)	15(75)	05(25)
Gradual, developmentally appropriate preparation over time approach is generally recommended for initiating discussions about pediatric HIV disclosure	12(60)	08(40)	13(65)	07(35)
Fear, anxiety, or sadness and understanding are the potential emotional responses that a child may experience following pediatric HIV status disclosure	09(45)	11(55)	11(55)	09(45)

**Appendix L: Nurses' Individual Attitude Pretest Scores**

<b>PAR TICI PAN TS' COD ES</b>	<b>Q N 17</b>	<b>Q N 18</b>	<b>Q N 19</b>	<b>Q N 20</b>	<b>Q N 21</b>	<b>Q N 22</b>	<b>Q N 23</b>	<b>Q N 24</b>	<b>Q N 25</b>	<b>Q N 26</b>	<b>TOT AL</b>	<b>MEA N</b>	<b>Category (attitude)</b>
1	4	2	1	1	3	3	1	3	2	4	24	2.4	Poor
2	2	1	2	1	3	2	3	3	3	2	22	2.2	Poor
3	4	3	4	1	4	1	1	1	2	3	24	2.4	Poor
4	2	3	3	2	4	4	1	4	1	4	28	2.8	Fair
5	2	2	1	1	3	3	2	2	2	3	21	2.1	Poor
6	1	3	4	2	3	3	3	4	4	3	30	3.0	Good
7	3	3	3	2	3	3	3	3	3	4	30	3.0	Good
8	4	4	1	1	4	1	1	3	2	4	25	2.5	Fair
9	2	3	1	2	4	3	1	3	2	3	24	2.4	Poor
10	3	3	3	1	3	2	3	3	2	2	25	2.5	Fair
11	3	2	2	1	3	3	2	2	4	3	25	2.5	Fair
12	3	3	3	3	1	2	2	4	3	4	28	2.8	Fair
13	2	2	1	1	3	2	1	3	2	3	20	2.0	Poor
14	2	3	3	1	3	3	2	3	3	2	25	2.5	Fair
15	3	4	3	2	4	1	1	1	2	4	25	2.5	Fair
16	2	1	1	1	4	4	1	4	2	1	21	2.1	Poor
17	3	4	2	2	3	3	4	3	4	4	32	3.2	Good
18	4	2	3	2	4	1	2	2	2	3	25	2.5	Fair
19	2	3	1	1	3	3	3	2	1	4	23	2.3	Poor
20	3	2	2	2	4	2	1	4	2	2	24	2.4	Poor
Total	54	53	44	30	66	49	38	57	48	62		50.1	
mean	2.7	2.7	2.2	1.5	3.3	2.5	1.9	2.9	2.4	3.1		2.5	

**Appendix M: Nurses Individual Attitude Posttest Scores**

<b>PARTICIPANTS' CODES</b>	<b>QN 17</b>	<b>QN 18</b>	<b>QN 19</b>	<b>QN 20</b>	<b>QN 21</b>	<b>QN 22</b>	<b>QN 23</b>	<b>QN 24</b>	<b>QN 25</b>	<b>QN 26</b>	<b>TOTAL</b>	<b>MEAN</b>	<b>Category (Attitude)</b>
1	3	3	2	3	3	1	2	4	1	3	25	2.5	Fair
2	4	3	2	1	4	3	2	2	1	3	25	2.5	Fair
3	4	4	4	4	3	4	2	3	4	3	32	3.5	Excellent
4	3	3	3	2	3	3	3	2	1	3	26	2.6	Fair
5	2	3	3	2	3	3	2	2	1	1	22	2.2	Poor
6	3	4	1	3	3	1	2	4	2	3	26	2.6	Fair
7	3	3	4	3	4	4	4	3	3	4	33	3.5	Excellent
8	2	3	4	3	3	3	4	3	3	3	31	3.1	Good
9	3	3	3	3	3	3	4	4	2	4	32	3.2	Good
10	3	4	4	3	3	2	3	4	2	4	32	3.2	Good
11	3	3	2	2	3	3	2	3	3	3	27	2.7	Fair
12	3	4	4	4	4	3	3	3	3	4	35	3.5	Excellent
13	3	3	3	2	1	3	1	4	2	2	24	2.4	Poor
14	3	4	2	4	3	3	3	4	2	3	31	3.1	Good
15	4	3	3	3	3	3	4	3	3	2	31	3.1	Good
16	3	3	4	1	3	3	3	4	2	4	31	3.0	Good
17	3	4	4	3	3	3	4	2	2	2	30	3.0	Good
18	4	3	1	2	1	3	3	2	1	1	21	2.1	Poor
19	3	3	4	4	3	3	3	3	1	4	31	3.1	Good
20	3	4	3	3	2	2	3	4	1	2	27	2.7	Fair
Total	62	67	60	55	58	56	57	63	40	58			
Mean	3.1	3.4	3.0	2.8	2.9	2.8	2.9	3.2	2.0	2.9			

### Appendix N: Comparison of the Performance for each Attitude Statements

Statement	Pretest				Mean	Posttest				Mean	Change
	SA	A	D	SD		SA	A	D	SD		
I believe that pediatric HIV disclosure should be a direct one time conversation	4	7	8	1	2.7	4	14	2	0	3.1	0.4
I believe my role as a nurse includes helping with the disclosure process.	3	9	6	2	2.7	7	13	0	0	3.4	0.7
I believe pediatric HIV disclosure is a complex and delicate process that should be conducted by only a counselor.	2	7	4	7	2.2	8	6	4	2	3.0	0.8
I don't feel adequately trained to facilitate pediatric HIV disclosure	0	1	8	11	1.5	4	9	5	2	2.8	1.3
I believe that children have a right to know their HIV status.	8	11	1	0	3.3	3	14	1	2	2.9	-0.4
I do not believe that pediatric HIV disclosure should be supported by healthcare professionals.	2	9	5	4	2.5	2	14	2	2	2.9	0.4
I believe the caregiver is entirely responsible to disclose HIV positive status to the child	1	5	5	9	1.9	5	8	6	1	2.9	1.0
I believe that HIV is God's judgment against extramarital sex or homosexuality	5	9	4	2	2.9	8	7	5	0	3.2	0.3
I don't believe disclosing a child's HIV status is important for their overall well-being.	3	4	11	2	2.4	1	13	5	1	2.0	-0.4
I believe my role includes providing emotional support	8	7	4	1	3.1	8	6	4	2	2.9	-0.2

to children during the disclosure process.										
--	--	--	--	--	--	--	--	--	--	--

**Appendix O: Total Agrees Against the Disagrees for Attitude Scores**

Pre-intervention				Post-intervention			
A & SA	%age	D & SD	%ages	A & SA	%age	D & SD	%age
11	55	9	45	18	90	2	10
12	60	8	40	20	100	0	0
9	45	11	55	14	70	6	30
1	5	18	90	13	65	7	35
19	95	1	5	17	85	3	15
11	55	9	45	16	80	4	20
6	30	14	70	13	65	7	35
14	70	6	70	15	75	5	25
7	35	13	65	14	75	6	30
15	75	5	25	14	75	6	30

## Appendix P: Self efficacy Pretest Scores

PAR TIC IPA NTS ' CO DES	Q N 27	Q N 28	Q N 29	Q N 30	Q N 31	Q N 32	Q N 33	Q N 34	Q N 35	Q N 36	TO TA L	MEA N	Category (Confidence)
1	4	2	2	2	3	2	2	2	3	2	24	2.4	Low
2	2	1	3	3	2	2	4	1	3	2	23	2.3	Low
3	1	3	2	2	2	3	3	4	2	4	26	2.6	Moderate
4	2	2	3	3	3	2	2	3	3	3	26	2.6	Moderate
5	1	3	1	1	2	3	3	2	2	2	20	2.0	Low
6	2	2	3	2	3	2	2	2	2	3	23	2.3	Low
7	1	1	3	3	2	3	3	3	3	2	24	2.4	Low
8	2	3	4	2	2	3	3	3	3	4	29	2.9	Moderate
9	2	2	3	2	3	3	3	3	4	3	28	2.8	Moderate
10	3	3	2	3	2	3	3	2	3	3	27	2.7	Moderate
11	3	2	2	2	3	1	3	2	3	1	22	2.2	Low
12	2	4	3	3	4	3	3	3	4	1	30	3.0	Moderate
13	3	1	4	2	3	3	2	2	3	4	27	2.7	Moderate
14	2	3	4	3	3	3	2	3	2	3	28	2.8	Moderate
15	4	3	3	2	2	4	3	1	4	4	30	3.0	Moderate
16	1	2	2	3	3	2	3	4	3	3	26	2.6	Moderate
17	2	3	2	2	2	1	3	1	4	1	21	2.1	Low
18	2	4	2	2	2	3	2	2	2	2	23	2.3	Low
19	3	1	3	3	3	4	2	1	1	2	23	2.3	Low
20	2	2	4	2	4	3	3	3	4	3	30	3.0	Moderate
Total	44	47	55	47	53	53	54	47	58	52			
Mea n	2.2	2.4	2.8	2.4	2.7	2.7	2.7	2.4	2.9	2.6			

**Appendix Q: Nurses' Self-efficacy Post test Scores**

PARTICIPANTS' CODES	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	TOTAL	MEAN	Category (Confidence)
	N 27	N 28	N 29	N 30	N 31	N 32	N 33	N 34	N 35	N 36			
1	4	4	3	3	3	2	1	3	3	2	28	2.8	Moderate
2	3	3	3	3	3	2	3	3	4	2	29	2.9	Moderate
3	2	1	3	3	3	3	2	2	3	3	23	2.5	Moderate
4	1	4	1	4	1	2	3	4	3	3	26	2.6	Moderate
5	4	3	2	3	2	1	3	3	3	2	26	2.6	Moderate
6	3	3	4	4	3	4	4	3	4	3	33	3.5	High
7	4	2	3	1	3	4	3	4	3	3	27	3.0	Moderate
8	4	2	2	4	4	4	2	3	3	4	32	3.2	Moderate
9	3	3	2	2	3	1	4	1	3	2	24	2.4	Low
10	3	3	3	3	3	3	3	3	3	3	30	3.0	Moderate
11	3	4	3	3	2	1	3	3	3	4	27	2.7	Moderate
12	4	4	1	2	3	1	2	3	2	3	25	2.5	Moderate
13	4	4	4	4	3	3	4	3	3	4	32	3.6	High
14	3	3	3	4	4	4	4	3	3	4	33	3.5	High
15	3	4	1	4	3	2	1	4	3	3	28	2.8	Moderate
16	4	3	4	3	3	3	4	3	1	3	31	3.1	Moderate
17	1	4	3	4	2	3	4	3	3	3	30	3	Moderate
18	3	3	4	2	4	1	3	1	4	3	28	2.8	Moderate
19	4	4	3	3	2	3	1	4	2	2	28	2.8	Moderate
20	4	3	4	3	1	4	3	3	3	3	31	3.1	Moderate
Total	58	61	55	62	55	50	55	58	58	59			
Mean	3.2	3.2	2.8	3.1	2.8	2.6	2.9	3	3	3			

**Appendix R: Comparison of each Statement in Self-efficacy Section**

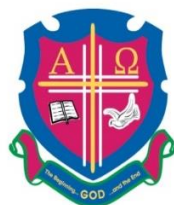
Ser. No	Pretest				Mean	Posttest				Mean	Change
	SA	A	D	SD		SA	A	D	SD		
I am comfortable in guiding caregivers of children with perinatal HIV	2	4	10	4	2.5	9	8	1	2	3.2	0.7
I am not confident in explaining HIV and its implications to children in an age-appropriate manner.	2	7	7	4	2.4	8	9	2	1	3.2	0.8
I am able to address the emotional needs of a child	4	8	7	1	2.8	5	9	3	3	2.8	0.0
I am able to prepare both caregiver and child for the disclosure conversation.	0	8	11	1	2.4	7	9	3	1	3.1	0.7
I am comfortable providing ongoing support to children after the disclosure.	2	9	9	0	2.7	3	11	4	2	2.8	0.1
I am able to answer questions and provide accurate information about HIV	2	11	5	2	2.7	5	6	4	5	2.6	-0.1
I am confident in collaborating with other healthcare professionals in the disclosure process	1	12	7	0	2.7	6	8	3	3	2.9	0.2
I do not have the ability to address	2	7	7	4	2.4	4	13	1	2	3.0	0.6

cultural or religious considerations											
I am able to support children throughout the disclosure process.	5	9	5	1	2.9	3	14	2	1	3.0	0.1
I am not comfortable in tailoring the disclosure process to the developmental stage	4	7	6	3	2.6	3	11	5	1	3.0	0.4

**Appendix S: Total Agrees Against the Disagrees for Self-efficacy Scores**

<b>Pre-intervention</b>				<b>post-intervention</b>			
<b>A &amp; SA</b>	<b>%ages</b>	<b>D &amp; SD</b>	<b>%ages</b>	<b>A &amp; SA</b>	<b>%ages</b>	<b>D &amp; SD</b>	<b>%ages</b>
6	30	14	70	17	85	3	15
9	45	11	55	17	85	3	15
12	60	8	40	14	70	6	30
8	40	12	60	16	80	4	2
11	55	9	45	14	70	6	30
13	65	7	35	11	55	9	45
13	65	7	35	14	70	6	30
9	45	11	55	17	85	3	15
14	70	6	30	17	85	3	15
11	55	9	45	14	70	6	30

## Appendix T: Dissertation Correction Compliance Report



# UGANDA CHRISTIAN UNIVERSITY

A Centre of Excellence in the Heart of Africa

## UGANDA CHRISTIAN UNIVERSITY SCHOOL OF RESEARCH & POSTGRADUATE STUDIES

### Dissertation correction compliance report by the candidate (POST VIVA FORM)

**Date:** 15TH April 2025

**Name of Candidate:** KANYESIGYE DIANAH    **Reg. No:** RM21M11/015

**Title of Dissertation:** Effect of an Educational Intervention Using a Checklist on Knowledge, Attitude and Self-efficacy of Nurses Engaging in the Process of Disclosure among Children with Perinatal HIV at a District Hospital in Southwestern Uganda.

SN	COMMENTS BY EXAMINER	EXTERNAL	ACTION TAKEN	INDICATOR
1	<b>Overall structure and presentation</b> The abstract effectively summarizes the study but could provide more detail on key statistical findings and methodology		I added tests used for comparison of data before and after the intervention. Added the software used for data analysis and also more key statistical findings in the results paragraph.	Page 5 under methodology and results (abstract section)
2	<b>Overall structure and presentation</b> On page 11, the acronyms should be presented alphabetically.		The acronyms are now presented alphabetically	Page 11 (Acronyms section)
3	<b>Introduction and problem statement</b> The problem statement could more explicitly highlight the research gap.		The research gap is explicitly highlighted (Added a precise and clear paragraph	Page 18 (last paragraph under

		summarizing the problem statement in the problem statement last section)	problem statement section)
4	<b>Introduction and problem statement</b> On line 278, please define “HIV positive disclosure” rather than merely “disclosure”	Responded to this by defining HIV positive disclosure	Page 12 (first line under chapter one)
5	<b>Introduction and problem statement</b> Lines 278-285 all reference the same author. There is a danger of plagiarism in this. Please utilize some other sources as well.	I have utilized other sources for lines 278 to 285 (added two other sources)	Page 12 (first paragraph under chapter one)
6	<b>Introduction and problem statement</b> The significance of the study is well-articulated, but the research gap could be more explicitly highlighted.	I have added more highlight concerning the research gap	Page 19 (last paragraph on page 19 under significance section)
7	<b>Introduction and problem statement</b> The statement of the problem does not clearly define the specific gap being addressed. Is the focus on attitude, self-efficacy, or lack of training? While these concepts are mentioned, the main issue remains unclear and 2 Assessment Criteria Score % Comments requires more precise articulation to strengthen the problem statement	Have added in a paragraph clarifying the issue being addressed indicating focus on nurses’ knowledge, attitude and self-efficacy precise to strengthen the problem statement.	Page 19
8	<b>Introduction and problem statement</b> The research question shouldn’t mention the method ‘checklist’, rather stick to the dependent and independent variables and the population. • The research questions and study aims need to be revised.	The educational intervention is using a checklist and it is not a method it is the intervention – Karen Drake	
9	<b>Introduction and problem statement</b> The conceptual framework currently stops at "self-efficacy," but it does not illustrate the overall outcome of improved self-efficacy. There seems to be a missing box or step that connects improved self-efficacy to the intended outcomes or impacts of the study. Please	The study focused on self-efficacy as a component of self-efficacy theory leaving out the outcome expectation as another	

	consider adding this element to provide a more complete and logical flow within the framework.	component of the theory.	
10	<b>Literature review</b> Lines 628-638 should incorporate the methods and strategies used for collecting and synthesizing this literature	I have incorporated the methods and strategies I used for collecting and synthesizing this literature.	Page 29 (First paragraph under chapter 2)
11	<b>Literature review</b> Lines 640-643 can be removed. Apply this approach to all sections of the literature review—eliminate introductory statements and go directly into the review	Good Academic and APA writing in the Literature – introduces each section and then concludes with a summary – Karen Drake	Page 29, 34 and 40
12	<b>Literature review</b> The literature review should position the study within the broader academic discourse and help identify existing gaps that the research seeks to address.	The literature review explains what pediatric HIV disclosure is all about, prevalence, its impact, benefits among others but importantly points out that nurses' involvement in disclosure remains a big challenge due to lack of knowledge on how to carry it out, pointing out poor attitude towards the process itself calling it a caregiver's role and also not comfortable to carry it due to limited knowledge towards the whole process.	Pages 29 to 48
13	<b>Methodology</b> Lines 1068 to 1071: Avoid using the first person when writing. Apply this throughout the document, particularly in intermittent sections, and use third-person or passive voice	APA pg. 118 "Use Active voice as much as possible" Also it encourages the use of the first person "I" and even encourages it. "To avoid ambiguity, use the first person	Pages 49 to 64

		rather than the third person when describing the work you dis as part of your research. See page 120. – Karen Drake	
14	<b>Methodology</b> <b>Line 1066: Clarify the meaning of these terms and justify why they were chosen for the study.</b>	I have clarified about the quantitative quasi-experimental as a method used when actual experimental designs with random assignment are impractical or unethical and is preferred to examine cause-and-effect correlations. Quasi experimental study design was used because the study aimed at evaluating the effectiveness of an educational intervention on nurses' self-efficacy	Page 48 (Research design section)
15	<b>Methodology</b> <b>Line 1088: Explain why purposive sampling was used in a quantitative study.</b>	The study used consecutive sampling because consecutive sampling included all available nurses involved in managing children with perinatal HIV allowing an equal opportunity for each nurse in the target population to be part of the sample group. It is acceptable to say that the setting was choseb purposively - Polit and Beck p. 254. "Sites can first be sampled purposively, and the people can be sampled	Page 49 (under Sampling frame section)

		by some other method. Karen Drake	
16	<b>Methodology</b> Line 1093: A sample size of 20 is quite small for a quantitative study. Provide a justification for this.	The target population was small but considering the research question a sample of 20 was sufficient to provide meaningful insights within that context necessary answer for the research question in this study.	Page 50
17	<b>Methodology</b> Line 1098: There is an inconsistency between the sampling methods—purposive sampling was mentioned earlier, yet this line states consecutive sampling. Clarify which method was used. Additionally, you state that each participant had an equal opportunity to participate; is this accurate given the sampling method?	Consecutive sampling was used to include all available nurses allowing them an equal opportunity for each nurse in the target population to be part of the sample group	Page 49 (under Sampling frame section)
18	<b>Methodology</b> Line 1104: The sample size was calculated as 20, yet it is also stated that this was the number of nurses available. What was the purpose of this calculation?	The purpose of the calculation was to determine whether the required sample size was feasible given the research context, resources and timeline. To also detect statistically significant effects or differences given the expected effect size.	Page 49 (under Sampling frame section)
19	<b>Methodology</b> Line 1119: "I organized HIV clinic staff meetings within the HIV clinic waiting area as an assistant HIV clinic incharge." Does this mean you hold this position at the facility? If so, discuss any potential limitations this might introduce in the study.	Yes I happen to be a departmental in charge. <ul style="list-style-type: none"> <li>• Potential limitations may include</li> <li>• Participants may provide</li> </ul>	Page 49 and page 82

		<p>biased responses.</p> <ul style="list-style-type: none"> <li>• They may feel pressured to provide responses that they think the boss/researcher wants to hear, rather than their true opinions or experiences.</li> </ul> <p>However the research investigator employed a self-administered questionnaire because it was an economical method, lowered the possibility of interviewer bias affecting the participants, and decreased the number of insufficient responses from nurses who were afraid of receiving negative feedback on some touchy issues</p> <ul style="list-style-type: none"> <li>✓ Used codes to keep participants' identities private, minimized the bias and hence helped to meet the purpose of the study.</li> </ul>	
20	<p><b>Methodology</b> The information about the intervention lacks clarity. Was this intervention developed by the</p>	<p>This intervention was developed by the researcher with</p>	Page 53

	<p>researcher, or has it been previously used elsewhere? If it is standardized, where else has it been applied, and what has been its effectiveness in other studies? Also, since the intervention was delivered by the principal investigator, how were potential biases accounted for? Some participants missed sessions and later had separate sessions—how might this have influenced the study results? Clearly define the core components of the intervention, as this will determine its scalability to other areas in Uganda.</p>	<p>support and review by HIV pediatric experts to ensure that it covered all relevant aspects of disclosure in children with perinatal HIV. Experts evaluated it and provided feedback and they confirmed that all significant aspects in pediatric HIV disclosure were included. The faculty also reviewed for approval before use in the study</p> <p>I educated participants about the intervention and the research process to minimize expectation bias. Data collection methods also minimized participant-investigator interaction such use of codes to keep participants' identities private, minimized the bias and hence helped to meet the purpose of the study.</p> <p>Some participants missed sessions and later had separate sessions and this could result in some participants receiving a different dose of the intervention, which can impact their outcome. To address</p>	
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		<p>this, I standardized the content and delivery method for use in the separate sessions to ensure that all participants received the same information.</p> <p><b>Core components of the intervention</b> included;</p> <ul style="list-style-type: none"><li>• Description of pediatric HIV disclosure, when to conduct it, who and what the process involves and the steps involved before we confirm complete/full disclosure.</li><li>• The intervention also included benefits of disclosing, outcomes of not disclosing, barriers that tend to contribute to delayed or partial disclosure. It included key components to consider when disclosing HIV</li></ul>	
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		<p>status to the child.</p> <ul style="list-style-type: none"><li>• The intervention included a disclosure checklist that can be guide to nurses when conducting the disclosure and different things to talk about in line with children's age.</li><li>• Had case studies and group discussions included in intervention to help nurses' practice critical thinking and problem-solving related to HIV disclosure. It involved providing nurses with mentorship and coaching opportunities to practice their skills and receive feedback.</li><li>• The intervention aimed at educating nurses on the principles and</li></ul>	
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		best practices of pediatric HIV disclosure, including age-appropriate communication and emotional support to enhance their knowledge, attitude and self-efficacy.	
21	<b>Methodology</b> The description of how the tool was utilized is clear but explain how these findings were translated into measurable outcomes.	Disclosure checklist nurses used after the intervention were filled in children's ART files and they communicated the understanding of the tool and the ability to use it. Follow up done in the third confirmed the documentation on the disclosure checklists for children nurses had engaged applying the learning that had been given during the intervention.	
22	<b>Methodology</b> Lines 1236-1245: How was content validity ensured even after expert review? A content validity index would have been useful. If this was not done, mention it as a limitation.	I did not calculate the content validity index which was a limitation in the study.	Pages 56
23	<b>Methodology</b> The methods section suggests that surveys were conducted at different time points post-evaluation. Specify the exact timeline—were the assessments conducted after days, weeks, or another duration?	First week (first day and second day-Pretest and intervention done) Second week (Thursday-pediatric clinic day for hands on	Pages 53 and 54

		coaching and mentorship) Third and fourth week (Thursdays for follow up on the progress) Intervention was all done in one month	
24	<b>Methodology</b> Confirm whether the data met the criteria for the statistical tests used, as this is not mentioned.	<p><b>Under Knowledge section using the paired t-test:</b> The two-tailed P value equals 0.001. By conventional criteria, this difference is considered to be very statistically significant.</p> <p><b>Under the attitude section using Wilcoxon Signed Ranks Test:</b> The p-value is 0.002. The result is significant at <math>p &lt; .05</math>. The value of W is 28. The critical value for W at <math>N = 20</math> (<math>p &lt; .05</math>) is 60. The result is significant at <math>p &lt; .05</math>.</p> <p><b>Under the self-efficacy section using the Wilcoxon Signed Ranks Test:</b> The p-value is .002. The result is significant at <math>p &lt; .05</math>. The value of W is 26. The critical value for W at <math>N = 19</math> (<math>p &lt; .05</math>) is 53. The result is significant at <math>p &lt; .05</math>.</p> <p>This means that the data met the criteria</p>	Pages 68, 71, 73 and 74

		for the statistical tests used considering before and after intervention differences.	
25	<p><b>Methodology</b>  Lines 1321-1322: "Because I am an assistant in-charge of the HIV department, I let the research assistant have willing participants sign a consent form if they agreed to be in the study." This raises an ethical concern due to a potential power imbalance. Address this issue.</p>	<p>The research investigator identified a research assistant, explained to him about the study and the intended population, procedures involved, and discussed with him the consent form, how to keep them afterwards and was assigned to give codes to eligible and identified participants. The research investigator also explained more of what research assistant was expected to do during the data collection, addressed concerns he raised and assigned him a role to have eligible participants willing to take part in the study sign consent forms.</p>	Pages 52
26	<p><b>Methodology</b>  The section on quality/error control is missing and should be included</p>	<p>Responded to this by adding the section on quality/error control</p>	Page 57
	<p><b>Data presentation and analysis</b>  Confidence intervals should be added to Tables 2, 3, 4, 5, 6, and 7, as they are key estimates in the study. This will also help illustrate the impact of the small sample size and potential random error.</p>	<p>Have added the confidence intervals to tables 3, 5 and 7.</p>	Pages 68, 71, 73 and 74

27	<p><b>Discussion and findings</b> Each discussion section should include implications for nursing to enhance the study's relevance. • The discussion should compare the study's figures with values from similar research. Currently, there are no statistical comparisons, making it difficult to assess how the findings align with previous studies. Confidence intervals should be reported to strengthen these comparisons.</p>	<p>Have included implications for nursing to enhance the study's relevance and added in some values from similar research. Have reported about confidence intervals to strengthen these comparisons</p>	<p>Pages 76, 77, 78, 79</p>
28	<p><b>Discussion and findings:</b> Lines 1659-1666 lack clarity and their relevance to the discussion is unclear. This section should be revised for coherence.</p>	<p>The section makes a summary of how the theoretical framework was applied throughout the study</p>	<p>Page 79</p>
29	<p><b>Discussion and findings:</b> Some key limitations remain unaddressed, as noted in previous comments. Ensure all significant study limitations are discussed.</p>	<p>The research investigator identified a research assistant. This raises an ethical concern due to a potential power imbalance. The intervention was delivered by the principal investigator educated participants about the intervention and the research process to minimize expectation bias. Data collection methods also minimized participant-investigator interaction such use of codes to keep participants' identities private, minimized the bias and hence helped to meet the purpose of the study. Some participants missed sessions and later had separate</p>	<p>Pages 76, 77, 78, 79 and 82</p>

		<p>sessions and this could result in some participants receiving a different dose of the intervention, which can impact their outcome. To address this, I standardized the content and delivery method for use in the separate sessions to ensure that all participants received the same information</p> <p>Yes I happen to be a departmental in charge.</p> <ul style="list-style-type: none"><li>• Potential limitations may include</li><li>• Participants may provide biased responses.</li><li>• They may feel pressured to provide responses that they think the boss/researcher wants to hear, rather than their true opinions or experiences.</li></ul> <p>However the research investigator employed a self-administered questionnaire because it was an economical method, lowered the possibility of interviewer bias</p>	
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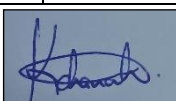
		<p>affecting the participants, and decreased the number of insufficient responses from nurses who were afraid of receiving negative feedback on some touchy issues</p> <ul style="list-style-type: none"> <li>✓ Used codes to keep participants' identities private, minimized the bias and hence helped to meet the purpose of the study.</li> </ul>	
30	<p><b>Conclusion &amp; Recommendations:</b> Include specific implementation strategies for nursing education and hospital administration to strengthen this section. • Ensure that recommendations are directly derived from the findings. This is why discussing implications for practice in the discussion section is crucial—it helps make recommendations more relevant and easier to formulate.</p>	<p>I have included specific implementation strategies for nursing education and hospital administration and recommendations are directly derived from the findings</p>	<p>Pages 81, 82 and 83</p>
31	<p><b>Conclusion &amp; Recommendations:</b> Revise the conclusion to clearly highlight the key findings based on the study objectives</p>	<p>Conclusion clear</p>	<p>Pages 81, 82 and 83</p>
32	<p><b>References and appendices</b> The reference list is well-organized and adheres to UCU guidelines. • Minor citation inconsistencies need correction</p>	<p>References clear</p>	<p>Page 85</p>

SN	COMMENTS BY INTERNAL EXAMINER	ACTION TAKEN	INDICATOR
1	However, the time period between pre intervention, data collection and the post intervention was not clearly stated. It's important to know whether the participants were allowed to carry out disclosure at freedom after intervention before the post intervention data collection was done.	I have specified it that the participants were allowed to carry out disclosure at freedom after intervention before the post intervention data collection was done in the document under intervention section	Page 53
2	However, there is need to add more real tested variables in the boxes of operationalizing the Self-efficacy theory.	Have added more tested variables in the boxes of operationalizing the Self-efficacy theory	Page 25
3			
4			
5			

SN	COMMENTS BY VIVA VOCE PANNEL	ACTION TAKEN	INDICATOR
1	Are you using faith interchangeably with ethics	No, faith and ethics are not interchangeable, though they can overlap. Faith is a belief in something without concrete evidence, while ethics are principles of right and wrong conduct, often based on reason and societal norms.	
2	The 20 participants, why did you pick 20. If you can manage you can study the whole population	The target population was 20 and all the 20 participated in the study because all nurses involved in the care of children with perinatal HIV would be suited to provide necessary answers for the research question in this study	Page 50
3	How did the self-efficacy inform the model you used in your study	Self-efficacy gave a deeper understanding of the reasons nurses were not taking part in disclosing HIV status to a child which informed the research investigator the effective way to intervene and align strategies to	

		support nurses to address knowledge, attitude and confidence challenges when it come pediatric HIV disclosure.	
4	It is very important to also consider doctors in such studies	An area to consider for future studies	

**KANYESIGYE DIANAH**  
Candidate's Name



Signature

**Karen B. Drake**



Supervisor's Name    Signature