



**ASSESSMENT OF DISCLOSURE PROCESS OF HIV STATUS OF THE INFECTED
CHILDREN AND ADOLESCENTS IN SELECTED HEALTH CENTER IN RWANDA**

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DECLARATION

I do here by declare that this research report submitted in partial fulfillment of the requirement for a Master's degree in Pediatrics Nursing in the School of Nursing and Midwifery at University of Rwanda is my original work and it has not previously been submitted elsewhere. Also, I do declare that a complete list of references is provided indicating all sources of information quoted or cited.

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DEDICATION

This thesis is dedicated to my beloved husband, Gilbert RWANGARINDA who has been a complete angel and true partner throughout this entire process and to my lovely children Chloe INEZA SANGWA, and Clovis IMENA SANGWA who I beg a big pardon for my absence to them when they were in need of my care. They have truly shown me that love has no boundaries and surpasses both space and time.

I strongly dedicate this to my beloved parents for their advice, sacrifice and encouragement that made me to attend this level.

May the almighty richly bless you.

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ABSTRACT

Introduction: With Accessibility of antiretroviral drugs HIV infected children and adolescents live longer. HIV diagnosis disclosure is progressively more important and usual concern.

Problem Statement: Disclosure of HIV status to children and adolescents is crucial for treatment adherence and it improves health status. In different countries including Rwanda the prevalence of disclosure of HIV status to infected children has been found to be low. Despite, proved effect of disclosure, a big number (36%) of caregivers don't disclose HIV status to their children in Rwanda.

The aim of the study: To assess the process of HIV status disclosure to infected children and adolescents in Kigali city.

Significance of the study: When HIV positive status is disclosed to children, it helps them to regulate, contribute in decision-making in their treatment opportunity considering their age in, and access and receive suitable support. Furthermore, appropriate HIV status disclosure may improve social functioning and school performance by the children and adolescents.

Research Methodology: Descriptive cross sectional design using a quantitative approach was used. The study was done in selected health center in Kigali city. The target population was healthcare providers working in ARV services, caregivers of infected children and adolescents and those infected children and adolescents. A simple random sampling method was used to select four health center from each district from Kigali city and a census method was used for study participants. A validated and reliable questionnaire was adopted and used. Data analysis was done using both descriptive and inferential statistics.

Results: Of the 103 caregivers, 77 (70.6%) had disclosed the HIV status to their children. Among 109 children and adolescent with HIV status, 60 (77.9%) continued to take medications as usual after disclosure. In multivariate analysis, no variable was statistically associated with adherence to treatment. Lack of formal guideline and training on HIV disclosure were identified as barriers for healthcare workers during this process. For caregivers, non-disclosure process was mostly associated with stigma and lack of support from healthcare worker.

Conclusion: Lack of formal guideline and training on HIV disclosure, as well as lack of support from healthcare worker, were reported, further research in this domain, will be of interest.

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LIST OF ABBREVIATIONS

AIDS:	Acquired Immunodeficiency syndrome
ART:	Antiretroviral Therapy
ARV:	Antiretroviral
CMHS:	College of Medicine and Health Sciences
DHS:	Demographic Health Survey
HIV:	Human Immunodeficiency virus
HCWs:	Healthcare Workers
IRB:	Institutional review board
SPSS:	Statistical package for Social Sciences
PLHIV:	People Living with HIV
PLWHA:	People Living With HIV/AIDS
UNAIDS:	United Nations Program for HIV and AIDS
UR:	University of Rwanda
WHO:	world health organization

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CHAPTER 1: INTRODUCTION

This chapter is an introduction to the study. It gives as an outline to the study and includes definition of key terms, describes the background, formulates the problem statement and discusses the significance of the study. It also includes the research question and objectives.

1.2 Background

Acquired Immunodeficiency Syndrome (AIDS) is a public health threat worldwide with 36.7 million people living with HIV in 2016 (UNAIDS, 2016). In 2015, there was a total number of 2.1 million with new HIV infections globally. According to (WHO, 2011), among those people living with HIV, 67% are from Sub-Saharan Africa. In 2012, 2.1 million adolescents aged between 10 and 19 years were living with HIV and 82% of this number are from Sub Saharan Africa (Idele et al, 2014). There was a substantial decline in AIDS related deaths globally from 1.5 million in 2010 to 1.3 million in 2015 (UNAIDS, 2016). This decline has been associated with access to antiretroviral therapy. With this access children and adolescent may survive to adulthood. However, if these children and adolescent are not aware about their HIV status, they cannot have access to these medications.

Communicating HIV related information to children and adolescent remains a big challenge as the majority of caregivers think that they can't disclose this information to their children and adolescent. According to (Vaz *et al.*, 2012), HIV status disclosure is conceptualized as either a single event or a process. In their study, (Biadgilign *et al.*, 2011), indicated that adherence to antiretroviral therapy (ART) enhance post-disclosure but the emotional and psychological effects of disclosure are variable (Biadgilign *et al.*, 2011).

According to Atwiine et al. (2015), questions such as “when to disclose?”. “How and how much to inform?” have been hot for several occasions. It has also cited that healthcare providers and caregivers on conflicting ends of a range of disclosure, in conflict for no or negligible disclosure, despite the fact that the first refers the awareness and participations in decision-making in appropriate way about treatment which is the right of the child. The Benefits of disclosure of their HIV positive status to children was emphasized in 1999 by the American Academy of

Pediatrics in “Disclosure of illness status to children and adolescents with HIV infection”. Taking into consideration some variables of the children/adolescents such as age, psychological maturity, the density of family dynamics, and clinical background, it is indispensable to disclose illness status to children (Nzota *et al.*, 2015). According to (Gyamfi and Okyere, 2015), The benefits of disclosure include improved medication adherence, increase trust in caregivers, responsibility to sexual behavior and improved health by maximizing available support.

The benefits of disclosure to children are on their self-esteem and will help them to adhere on treatment. As stated by (UNSAID 2013), studies done in Africa have recognized age of the child, stigma and discrimination, fear that the child will tell other the diagnosis, and believe that the child has a right be informed their status, and Rwanda treatment guideline encourage disclosure to children at 7 years. A study done in Rwanda showed that 64% of children living with HIV had their status disclosed to them by parents while 35.8% did not. A big numbers of parents (80%) initiate that disclosing status improve adherence. The majority of parents 67% attended psychosocial support groups and accordingly disclosure status was highly associated with psychosocial support group attendance (Ingabire 2014).The same study found a significant association between disclosure status and viral load outcome, with 64.4% of children living with HIV showed weight gain greater or equal to 4 Kg after disclosure

According to Doku, Dotse and Mensah, 2015, many caregivers are unwilling to tell their children that they are HIV positive. The main reasons was that children are too young, may have emotional disturbance, may request explanation on how they got the infection, and this can lead to intentionally reveal the secret, exposing the family on stigma and discrimination. As supported by (Vaz *et al.*, 2012), a half of caregivers don’t provide health related information to their children. However the majority of these think that they are the ones to disclose this information and they need support from health care providers.

The child’s age, supposed capability to understand the meaning of HIV infection and factors associated to caregivers, like education level, awareness about their own HIV status and view point about children’s capacity are significant associated with disclosure (Atwiine *et al.*, 2015).

Some barriers hinder caregivers to disclose information related to HIV status to their children, these include fear that the child would intentionally reveal the secret about HIV status to others, fear of stigma and the child's emotional or physical health are general barriers to disclosure.

A study done in Kenya (Study *et al.*, 2014), revealed that healthcare providers had limited guidance but wide familiarities in disclosure, allowed individualized disclosure practices, invested significant time on disclosure even with clinical load, and outcomes associated with unintentional disclosure were noted. For move to ward to disclosure that respect caregiver worries and values but child-centered were advocated by healthcare providers. Unintentional disclosure to children was the motivation to hurry in case when healthcare professionals thought that the diagnosis can be suspected and reported to have several and several continual impact.

This study aims to assess the disclosure process of HIV status to infected children and adolescents in Kigali City and the results target to certainly contribute to the improvement of the care provided to HIV positive children and adolescents.

1.3 Problem statement

Disclosure of HIV status to children and adolescents is crucial for treatment and it improves health status. In different countries the prevalence of disclosure of HIV status to infected children has been found to be low (Vaz *et al.*, 2012; Vreeman *et al.*, 2013). A study done in Rwanda found that 64% of caregivers disclose HIV status to their children and was found to improve adherence (Ingabire and Mutessa, 2014) . Despite, proved effect of disclosure, a big number (36%) of caregivers don't disclose HIV status to their children. Social stigma, fear of psychological harm, fear of transmission related questions are some factors related to non-disclosure. Some author emphasize on professional support disclosure process to caregivers. Studies point out the need for professional support to caregivers with regards to disclosure (Ingabire and Mutessa, 2014; Gachanja and Burkholder, 2016). How the disclosure process is done also may be the reason of disclosure on non-disclosure and may affect how HIV infected children and adolescent adhere to the treatment.

However, no study is done in Rwanda to find out how the process is done, who is involved in this process, what support is needed, and whether this process impacts the treatment adherence.

Therefore, this study assessed the disclosure process of HIV status to infected children and adolescents, in order to provide the information related associations of disclosure process to the treatment adherence.

1.4 Aim of the study

The aim of this study is to assess HIV disclosure process to infected children and adolescents in Kigali City.

1.5 Research objectives

1.5.1 Main objective

To assess HIV disclosure process to infected children and adolescents in Kigali City.

1.5.2 Specific Objectives

1. To describe the patterns of HIV disclosure process to infected children and adolescent
2. To determine the associations of the HIV disclosure process on ART adherence among children and adolescent
3. To identify barriers encountered by healthcare workers and caregivers during HIV disclosure process

1.6 Research questions

1. What are the patterns of HIV disclosure process to infected children and adolescent?
2. What are the associations of the HIV disclosure process on the ART adherence among children and adolescent?
3. What are the barriers encountered by healthcare workers and caregivers during the HIV disclosure process?

1.7 Significance of the study

When children are disclosed their HIV positive status, it helps them to regulate, contribute in decision-making in their treatment opportunity considering their age in, and access and receive suitable support. Furthermore, appropriate HIV status disclosure may improve social functioning and school performance by the children and adolescents.

It is as well significant also important to society at large knowing that a rising number of HIV infected children getting adolescence and adulthood. For further transmissions prevention and second generation vertical transmissions, children require on awareness of their HIV positive status by 7 years old, the moment they become sexually active.

The recommendations of this study could help healthcare workers and caregivers with infected children and adolescents as well as those children and adolescents to understand the disclosure process in relation to the implementation and look at some strategies intend at increasing the number of HIV infected children and adolescents who are aware about their status, and their support and care can be improved in similar study area.

The policy makers such as Ministry of health could use the results and recommendations of the study in strengthening and improving of the present guidelines and policies concerning HIV disclosure process in children and adolescents in Rwanda's health facilities.

Finally, the result from this study will be beneficial to the researcher through enlarging the scientific knowledge about Disclosure process of HIV status to infected children and adolescents and conduct research in similar fields of knowledge.

1.8 Definition of key terms

Adolescent: WHO, 2016 define adolescent as young people from 10 to 19 years old. In this study adolescent is also someone aged from 10 up to 19 years old.

Child: The United Nations convention of child right (2010) defined a child as an individual under eighteen years old, except under the law related to the child, many of them is attained in advance. In this study a child is someone aged from 7 to 15 years old in HIV /AIDS publications (e.g. UNAIDS, 2013), where they consider fifteen years as a cut-off point for children. In this case those persons do not need the consent from parents to be aware on their status because they can have counseling and testing voluntary.

Disclosure: Izabela Z. et al. (2011) define disclosure as the process of disclosing, identifying recognition or revealing; clarifying things. For this study, the ward was referred as the act of making aware to children and adolescents their HIV status, and was involved full disclosure with the children knowing that they have HIV/AIDS.

Healthcare worker: according to (Gyamfi and Okye 2015) a healthcare worker is “a person who attends the wounded, sick, injured, or disability. In this study, healthcare worker refers to someone trained as a healthcare worker nurses, physician, social worker, counselor.

Caregiver: a person who gives help and protection to someone (such as a child, an old person, or someone who is sick). For this study a caregiver was every person who is in charge of helping the child and adolescents in all his needs

1.9 Subdivision of the project

This research proposal is divided into six main parts:

Chapter 1: includes the introduction, background to the study, problem statement, objective of research, significance, definition of key terms and the conclusion of chapter one.

Chapter 2: includes literature review which include introduction, theoretical literature, empirical literature, critical review and research gap identification and conceptual framework.

Chapter 3: includes research design, description of the study population, sample and sampling technique, instrument/tool for data collection, validity and reliability, data collection process, , ethical aspect of the research, problems with data collection, Method to be used to analyse the data.

Chapter 4: Results Presentation

Chapter 5: Discussion

Chapter 6: Conclusion and Recommendations

1.10 Conclusion

Disclosure process of HIV positive to infected children is a significant phase of paediatric HIV/AIDS therapy and support, be aware on disclosure process of HIV status to infected children and adolescents in this view, could inform tactical implementations to improve recent practice in all areas where the study result can be transferred.

CHAPTER2. LITERATURE REVIEW

2.1 Introduction

The numbers of people living with HIV worldwide continue to grow in 2015, reaching an estimated 33.4 million (UNAIDS, 2016).

Among 2.4 million and 3.0 million citizens were infected in 2015, the report show deaths from HIV infections of people between 1.7 million and 2.4 million. A great number of 67% with HIV/AIDS Infected people is in Sub-Saharan Africa, in children (91%) are newly infected worldwide and 68% of new infections are adults in this area. Sub-Saharan Africa still carries the (UNAIDS, 2016).

An increase of 2.1 million of HIV infected children fewer than 15 was estimated in 2015, in that year among of them 240 mille and 610 mille are reported for new infection. The report from UNAIDS 2016, declared that by vertical transmissions 90% of infection occur in children and their number has been increased gradually. The accessibility of ARV drugs is behind the reason of declining of AIDS related death in children even if there is a peak about 2000 to 2002 of new infection (UNAIDS, 2016).

However availability of ARV treatment increase, the issue of disclosure of HIV status to children and adolescents become important for treatment adherence and preventing HIV vertical transmissions and poor outcomes (Cantrell *et al.*, 2013). In a study done in Rwanda entitled “*Adherence to highly active antiretroviral therapy and its correlates HIV infected pediatric patients in Rwanda*”, has reported that disclosure had been made to 68children out of the 390 participants (21%) (Binagwaho *et al.*, 2012).

From the pediatric HIV literature two conceptualizations of disclosure came out. The first approaches talk about disclosure as a single event, the provision of the diagnosis of HIV or AIDS to an individual. The last one is disclosure as a process. Therefore, for this study HIV status disclosure-related processes by healthcare providers and caregivers will now be assessed. Disclosure as a process has been documented in two different ways. One way is from the perspective of the caregivers and is the process undertaken to disclose, which incorporates the time until full disclosure.

The other is from the perspective of the children and is the process of information received, which can, but does not necessarily include events both before and following disclosure (Bhattacharya, Dubey and Sharma, 2011).

2.2 Theoretical framework

The theoretical framework is the structure that can hold or support a theory of a research study. It introduces and describes the theory that explains why the research problem under study exists. HIV disclosure can be seen as a complex, multidimensional process of making a decision about whom to inform about one's serostatus, and why, when, where and how to disclose (Eustace and Ilagan, 2010). Several descriptive frameworks have been proposed to identify factors affecting disclosure likelihood. According to the disease progression theory (Serovich, Lim and Mason, 2009), PLWHA are likely to disclose only as their illness advances and the secret about their HIV diagnosis can no longer be kept. This theory, which has been supported by studies conducted during the pre-ART era revealing an association between worsening health and increased likelihood of disclosure (Hays et al., 1993), may be less applicable in light of the current widespread availability and effectiveness of ART (Przybyla, 2009). The competing consequence theory (Serovich, 2001) has also found support in the growing literature on disclosure. It posits that PLWHA are more likely to disclose if the perception of expected benefits outweighs the potential risks (Emlet, 2006).

Building on previous theories, while expanding on the decision-making process for disclosure, Kimberly and Serovich (1995) proposed a framework that outlines the disclosure process in six steps: 1) adjustment to the diagnosis; 2) evaluation of personal disclosure skills; 3) evaluation of the appropriateness of disclosure; 4) assessment of the circumstances for disclosure; 5) anticipation of potential reactions of disclosure recipients, and 6) identification of the motivations for disclosure. Bairan and colleagues (2007) proposed a model based on types of social relationships to explain HIV disclosure. According to this model, social relationships are categorized as sexual and nonsexual, with different disclosure levels and patterns based on the nature of the relationship with the confidant (Bairan et al., 2007).

More recently, the Disclosure Processes Model (DPM) has been proposed to conceptualize disclosure as a single process within a continuous series of lifetime events that involves decision-

making and outcome processes (Chaudoir & Fisher, 2010). The DPM highlights the impact on each disclosure event of: antecedent goals (approach or avoidance goals) affecting the likelihood of discrete disclosure events, the disclosure event itself, mediating processes such as social support, outcomes at the individual, dyadic or contextual levels, and a feedback loop (Chaudoir et al., 2011). As such, this 5 model provides a comprehensive framework for studying when and why interpersonal and verbal disclosure will be favorable for HIV-positive individuals, while putting special emphasis on connections between all aspects of the disclosure process (Chaudoir & Fisher, 2010).

2.2 Empirical literature

2.2 1 the patterns of HIV disclosure process to infected children and adolescents

2.2.1.1. Appropriate age for disclosure

The World Health Organization guideline for HIV status disclosure to infected children and adolescents” strongly encourage disclosure of HIV infection status to school-age children, and recommend that children and adolescents should know their HIV status (WHO, 2011).

Child age has significant associated with disclosure, with older children being more likely to have been disclosed to (Cantrell *et al.*, 2013). The age of 10 was considered to be crucial in some studies of the area, with Cantrell et al. reporting that caregivers felt that children younger than 10 would not be able to understand if disclosed to. The median age of disclosure for those who were aware of their status was 10 years (10-13), but those who had not yet disclosed felt that 12 (10-14) years was the appropriate age of disclosure. In one study conducted IN South Africa, caregivers felt that general discussion with children should occur at the age of 11, and HIV-specific disclosure at 12 (Woldemariam, 2012).

A study done in India, found that the majority of caregivers stated that the appropriate age of disclosure was the mid-teenage years (Eustace and Ilagan, 2010), while another study involving both parents/caregivers and healthcare providers found that “The participants preferred that partial disclosure occurs from the age of 10 years and full disclosure from the age of 14 years, health care worker were significantly more open to full disclosure and disclosure at a younger age (Gachanja and Burkholder, 2016).

Chronological age, however, may not be the only important factor, so it would be difficult to identify the appropriate age for all children. The WHO guideline for HIV status disclosure to infected children and adolescents recommends that not only age but also psychosocial maturity needs to be taken into account amongst other factors (WHO, 2011). Fifty percent (50%) of health workers and 59.9% of community members in one study considered the "...majority of HIV infected children to be less emotionally mature than their uninfected counterparts", with 49.5% thinking that "... the majority of HIV-infected children are as intelligent as their uninfected counterparts while 45.7% thought them to be of lower intellectual capacity." The perception of emotional maturity and intellectual capacity of children living with HIV would affect the age of disclosure (Gachanja and Burkholder, 2016).

2.2.1.2 Who should disclose

In many studies, the majority of respondents identified parents or primary caregivers as the appropriate persons to disclose children's HIV Status to them. In a study south Africa to determine the perception of caregivers, 42% indicated caregivers as appropriate "... to reveal the infection status" (Woldemariam, 2012).

Madiba et al. (2015), state that when assessing the perception of caregivers in South Africa, 83% felt that parent/caregiver should be the one to discuss HIV status with the child, while 16% felt a healthcare provider, i.e. doctor, nurse or counselor, would be best. (Gross *et al.*, 2015)

De Baets et al. found in their study in Eastern Zimbabwe that "Up to a third of the participants would prefer to initiate HIV disclosure and discussions about grief with their own children without any assistance." As to who they would like to help them with the disclosure process, 51.3 to 55.7% would like to involve the healthcare worker, while 42.3 to 52.2 % would like a family member. Interestingly, the family members chosen were a father's sister (36.7%) or a grandmother (40%), rather than a partner (4.8 to 14.8%). This study brings about the interesting concept that, as in many things, those family dynamics that are different from the Western style need to be considered, as they may hinder the mother from disclosing. In a study by Myer et al. involving healthcare workers, three quarters recommended that caregivers should disclose to the child.

2.2.1.3 How to disclose

Disclosure needs to be a process rather than a single event, according to different papers. For Cantrell et al., it needs to take place over a period of time that takes into account different phases of the child's life and entails ongoing communication with families. The process may even last several years, "depending on the cognitive development of the child." The paper emphasizes the importance of "respect [for] family needs, wishes and expectations as well as community norms and pressures." It also cautions that rushing the process before the family is ready might endanger the ongoing care of the child (Cantrell *et al.*, 2013).

Nzota et al., also advises against disclosure being a single revelation, favoring instead a gradual process that should be culturally sensitive and take into account each individual child's context. Pfaff suggests considering the broader context, i.e. who else needs to be told in the family, as well as considering such factors as whether the child already suspects, is asking questions, or his/her age. In summary, disclosure needs to involve planning, discussions with the parents, helping parents deal with any outstanding issues, and preparing them for possible questions (Nzota *et al.*, 2015).

2.2.2 HIV disclosure process on the ART adherence among children and adolescent

Previous study indicates that, the association between adherence to ART and disclosure is not clear. There are several reasons disclosure might be associated with non adherence. Disclosure is a traumatic event for many children and can be accompanied by feeling of anger, hopelessness and rebellion, which may lead to temporary or longer-term adherence problems. The negative effect of HIV related stigma, including effort to keep the diagnosis secret by hiding or taking medicines, may also impact adherence to therapy for disclosed children more than non-disclosed children. In addition the study done by (Smith Fawzi *et al.*, 2016), sited that adherence issues may be compounded by other adolescent-specific factors such as increased incidence of depression and generally poor medication adherence among this age group.

The similar results was found in the study done by (Gachanja and Burkholder, 2016) where the author mention that disclosure may lead to improve adherence, including increased responsibility over medication-taking and better access to social support.

Pediatric HIV providers often recommend disclosure of HIV status to children and adolescents as necessary to building trusting provider-patient and family relationships and developing disease management skills that facilitate adherence.(Vaz *et al.*, 2008) In the only longitudinal study to assess adherence pre and post-disclosure, Vaz et al reported that approximately 58% of children and their care givers adherence improved post disclosure however, adherence was assessed by self and proxy-report among a small sample of only 40 children and healthcare workers felt that adherence improved 25% of cases. Furthermore, since the study assessed disclosure after an intensive, supportive disclosure intervention, its results may not be representative of the majority of disclosure experiences.

In addition the focus of other research has been on adherence to ART (Vreeman *et al.*, 2013) Where they found that adherence assessment items are rarely validated, that proxy-report (for example care giver-reported) often overestimate adherence and that children and adolescents reported more non adherence than their caregivers do. But these findings may be shaped by several cultural-specific biases.

In particular, children and adolescents in this setting with strong cultural; traditions requiring children to obey adults (caregivers and healthcare workers) may be more vulnerable to social desirability pressure to report higher adherence.(Nzota *et al.*, 2015) In addition, despite clinical protocols recommending private interviewing of children and adolescents about adherence, children and adolescents are rarely questioned in private as was required for completion of the evaluations within this study. Finally, many of children and adolescents involved In this study were in the care of grandparents and other extended family their rather than biological parents these non biological parents may feel less pressure to report adherence.

2.2.3 Barriers to HIV positive status disclosure

2.2.3.1 Support from Healthcare Workers

Within data with regard to nature of support health care workers could give to caregivers during HIV status disclosure process came up with two themes: disclosure as a shared responsibility for caregivers and health care workers and counseling and education as main forms of support (Gyamfi and Okyere, 2015).

In the study done by Vaz et al. (2008) different participants report that healthcare workers and caregivers had role to play in disclosure process. Usually required some form of assistance from healthcare workers during the process of disclosure. Caregiver disclose by guidance of healthcare worker. Same study mention that lack of formal education, lack the knowledge and skill for disclosure for most of parents, and need the assistance of healthcare workers. When the healthcare workers are implicated in the disclosure it is easier for the child to accept the diagnosis. Thought health education and counseling by pre-test and post-test counseling for both caregivers and children make them to understand more the need of disclosure (Gyamfi and Okyere, 2015).

2.2.3.2 Benefits and Barriers to disclosure

For proper support on disclosure healthcare workers needs to identify benefits to disclosure and the reasons caregivers delay or do not disclose to children and adolescents their HIV status.

Some studies mention the psychosocial impact of HIV status disclosure to children and adolescents where they fare better after disclosure considering to children unaware of their HIV positive status (Vaz *et al.*, 2012). Other publications report knowing their HIV positive status help children and adolescents to be less depressed in their future and increase their access to social support (Nzota *et al.*, 2015). Few studies show that psychological and emotional distresses are experienced by children who are not informed of their status than those who know their HIV positive status. Some mention that poor adherence, coping and psychological outcomes are associated with postponing or nondisclosure of HIV positive status.(Well-being *et al.*, 2010)

For proper disclosure process the reason for delaying or not disclosure by caregivers need to be identified. Here most frequent reason will be discussed (John-stewart *et al.*, 2013).

2.2.3.3 Stigma

Stigma was identified by many studies to be the main cause on delaying to disclosure by caregivers (Gachanja and Burkholder, 2016). In this study they mention that isolation, fear of discrimination and social rejection are the barriers to disclosure.

Discrimination beside the child and the entire family was realized to be the cause of panic that caregivers have to not disclose to their children thinking that those children will disclose their status to others, and the family secret will be known (Gyamfi and Okyere, 2015).

As stated in a study done in South Africa, 73% of caregivers fear that their HIV status will be disclosed by the child and in big families with HIV negative and HIV positive members this is sensitive to them. The author declared that “as HIV infection remains highly stigmatized in many communities, disclosure of pediatric HIV infection may also be accompanied by threats to the child’s physical and/or psychological health” (Madiba et al., 2015).

In “*HIV/AIDS, Stigma and children: a literature review*”, the author states that “...stigma and discrimination play an important role in determining the process and effects of disclosure” and that “... stigma , discrimination and expected stigma and discrimination play a major role in parental and children’s decision making on, and the impact of, disclosure of HIV-status”. This means that stigma can be experienced by children still without it by secondary disclosure re (Vreeman *et al.*, 2013).

2.2.3.4 Formal guidelines on HIV disclosure for children and adolescents

One of major concerns of HCWs was the lack of formal guidelines on HIV disclosure for children and adolescents to guide them on when and how to prepare and support caregivers to disclose to children (Vaz *et al.*, 2012).

We found that recent published World Health Organization disclosure guidelines for children have not yet been adopted and utilized by HCWs in all the health facilities. Additionally, HCWs in many sub-Saharan countries are hardly ever trained in pediatric HIV and disclosure of children and adolescents, and lacked skill to assist caregivers to disclose (Madiba and Mokgatle, 2015).

Attending workshops and receiving training will give HCWs skills and increase their confidence in assisting caregivers to disclose but also support HIV-infected children to understand the disease (Cantrell *et al.*, 2013).

The need of guideline on HIV disclosure was mentioned by (WHO, 2011), where we found that healthcare workers know that disclosure decisions are complex because of family relations, parents skills, stigma, and fear about children's emotional and maturational ability to understand and cope with the nature of the illness.

Without the support of definitive, evidenced-based policies and guidelines on when, how, and under what conditions children should be informed about their own or their caregivers' HIV status, HCWs challenged by the complicated issues facing by families. As a result, many HCWs are uncertain how to counsel clients about the disclosure process. Thus may often miss opportunities to assist parents in dealing with these issues and explaining to caregivers the need for HIV status disclosure their children. The lack of disclosure finally negatively affects the well-being of the child, including access to pediatric HIV treatment, care and adherence to treatment.

2.2.3.5 Emotions associated with disclosure

Studies revealed that fear of emotional and psychological difficulties on children are among barriers to disclosure (Cantrell *et al.*, 2013). Caregivers are afraid of depression that children may suffer after knowing their HIV positive status; they think that children may lose the will for living (Woldemariam, 2012). The same author mentions that 53.4% of caregivers fear that the child can have psychological consequence after disclosure.

According to (Gyamfiet al, 2015), for optimal development as the social support system that a child depend on can be interrupted by HIV infection which has a direct effect on psychological functioning and neuro-cognitive functioning.

2.2.3.6. Lack of knowledge

According to (Atwiine *et al.*, 2015) even though caregivers appreciate that children need to know their HIV positive status, they understand that they need a help as they don't know how to disclosure. For that reason they have tendency to push it back.

Some of them wish that children can know their HIV positive status personally (Nzota *et al.*, 2015). The research that have been done by (Manyando *et al.*, 2012), on barriers to disclosure it stated that Caregivers felt that they do have a limited knowledge on HIV infection, they think that they can't respond to all questions asked. This lack of knowledge and understanding for confronting HIV/AIDS information in an appropriate way of developmental cause caregivers to have anxiety (WHO, 2011).

2.3 Conceptual framework

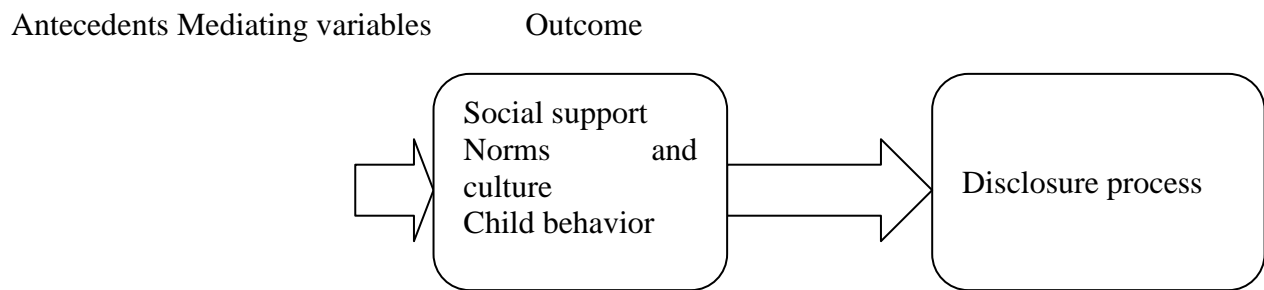


Figure 2. 1: Conceptual Framework

Source: Researcher, 2017

The conceptual framework (figure 2.1.) shows the relationship between independent and dependent variables. It shows the variables that influence the HIV disclosure process. These variables are categorized into antecedents and mediating variables. While categorizing these variables, some are related to the child or adolescent, others are related to the caregivers and others are related to the social or community factors. Age of the child is one of the factors that influence HIV disclosure, as some caregivers prefer to disclose the HIV status to the old children. Lack of knowledge, skills and support from other people also influences the decision to disclose or not the HIV status. Emotions from the caregivers, fear of outcome after disclosure may prevent the caregivers to disclose this information. Society, norms and culture that an individual lives may facilitate the HIV disclosure process or may result in discrimination and stigmatization and consequently delay or prevent the HIV disclosure.

Finally, how the child behave may influence the decision to disclose or not the HIV disclosure process which in turn may affect the adherence or non-adherence to treatment. All of these factors may positively or negatively affect the decision to disclose or not the HIV status.

CHAPTER 3: METHODOLOGY

3.1 Introduction

The chapter three of this proposal discusses the methodology that was used in conducting the study. Methods in research show the type of data to be collected and how those data were generated, collected and analyzed; it gives the information on how the study was performed and the justification of the chosen study design and other methodological choices (Azevedoa *et al.*, 2011; University of Southern California, 2016). It describes the study design, study area, the study population, the sample size to be used and the sampling strategies that were used to obtain the sample. This chapter also discussed data collection procedure and tool to be used in data collection, data analysis, and ethical consideration.

3.3 Research design

Study design shows the basic strategies that was used in research to answer the research questions or to test hypotheses (Polit and Beck, 2010). A descriptive cross sectional study design, and with quantitative approach, was used.

3.3 Research setting

The study was carried out in selected health centers from Nyarugenge with 8 health centers, Gasabo with 16 health centers and Kicukiro district with 8 health centers, the 3 district of Kigali city. Health centers are primary health care systems of Rwanda. Kigali city was chosen due to its high prevalence of HIV when comparing to other provinces (DHS , 2015)

3.4 Study population

The term ‘population’ is defined as the total aggregation of cases in which are searcher is interested (Polit and Beck, 2010).Population of the study were included healthcare workers working in different health centers in three mentioned districts of Kigali City who worked in ARV service, Caregivers with HIV infected children and adolescents, as well as these children and adolescents themselves.

On average, one health center can have 3 health workers working in ARV service and , this implicates 36 nurses from 12 health center in total. Among 12 health center from Kigali City, each can receive 6 children and adolescent from 7 to 19 per week, within two week of data collection for all health center 144 were children and adolescents, this number were corresponding with their caregivers.

3.5 Sampling

3.5.1 Sample size and sampling strategy

Sampling is the procedure of choosing study subjects from the population to be included in the study sample and to represent the entire population (Polit and Beck, 2010). A simple random sampling was used to select four health centers in each district. A census method was used to identify the study participants. This was used due that the participants in these mentioned health center were small hence no sample size was calculated. Thereafter, all health workers within the mentioned health centers working in ARV service were considered in this study. All caregivers with HIV infected children and adolescents, as well as these children and adolescents who were at the health center during one month, the time of data collection and freely to participate in the study were considered.

3.6 Data collection

3.6.1 Data collection instrument

This study used three adopted validated questionnaire with permission from (Vreeman *et al.*, 2013; Madiba and Mokgatle 2015). The first questionnaire was for caregivers with 36 questions, the second questionnaire was for healthcare workers had 15 questions and the third questionnaire was for children and adolescents had 14 questions.

A self-administered questionnaire was translated and back translated from English to Kinyarwanda to make the instrument more understandable for the participants and to ensure data quality. The questionnaire had both open and closed ended questions. The questionnaires were designed as follow:

Questionnaire 1

Section 1 described Socio Demographic Characteristics and Background information of caregivers, Section 2 were questions about patterns of HIV disclosure process, and section 3 were questions on treatment adherence and barriers.

Questionnaire 2

Section 1 described Demographic data for healthcare providers, Section 2 the patterns of HIV disclosure process, and barriers to disclosure was asked to the healthcare providers working in ARC service.

Questionnaire 3

Section 1 was Socio Demographic Characteristics and Background information of the child, Section 2 was the questions about the patterns of HIV disclosure process, Section 3 treatment adherence.

3.6.1 Data collection procedure

After obtaining the ethical approval from Institutional review board (IRB) of University of Rwanda/ College of Medicine and Health Sciences (UR/CMHS) and the area of study, the purpose of the study and other related information were explained to the study participants, also explained about the consent form insisting on their rights, confidentiality and anonymity, then participants who accepted to participate in the study were requested to put their names and signature on the consent form. Parents/caregivers with under 18 years old infected children and adolescents signed and returned a form consenting to the involvement of their child and assent forms for children less than 18 years were provided and signed. After participants were met in the prepared room with privacy and self administered structured questionnaire was provided at the same day of data collection, and while correcting data the researcher ensured that the instructions that were given, is clear and homogenous for all participants so that they could complete the questionnaire without any difficulty. After completing the questionnaire the researcher ensured to collect herself the filled questionnaire by going to the place where the participants were given a sit.

3.7 Data analysis

Data was double checked for completeness and then they were coded, entered and analysed in SPSS version 20. Continuous variables were summarized using mean and standard deviation while categorical variables were summarized using frequency and percentage. In bivariate analysis, appropriate statistical was used.

3.8 Ethical considerations

The study was approved by Institutional review board (IRB) of the College of Medicine and Health sciences, University of Rwanda after reviewing the study protocol and other relevant documents prior to data collection procedure.

A permission letter to carry out the study was obtained from the district authorities in charge of health centers. Both written consent and assent were stated after getting permission. The aim, significance and the purpose of the research were clearly explained to the participants in this study. Participation in the study was voluntary and participants were free to withdraw at any time. No identification details were required as a measure to ensure anonymity. All given information were kept with confidentiality, and all participants signed an informed consent, parents/caregivers will sign and return a form consenting to the involvement of their child and assent forms for children under 18 years.

3.6 Data management

Data were obtained by using questionnaire which was checked if the answers were complete at all study area. The data for each day were entered and stored in the computer that had password to secure information collected from participants. The data were controlled every time to prevent errors. Data will be stored in the computer that will have password to secure information collected from participants. Data entry and data manipulation were highly checked for regular errors until the researcher finished doing analysis and reporting the findings. Data would be kept for 10 years then after they would be considered as useless.

3.7 Data dissemination

Data could be disseminated through presentation of findings in college of medicine and health sciences, the results findings could also be disseminated in the area of research. Furthermore, this study could be published in a conference as an abstract presentation and could be published as an article in a national or international journal.

3.11 Limitations of the study

The cross-sectional nature of the study does not allow us to fully explore the process of disclosure, but only to capture it at a particular moment in time. Current conceptualizations of disclosure do not distinguish between different paths taken toward full disclosure, only noting that there is a process. The sample size was small. Small sample sizes may fail to detect differences at analysis, making it difficult to generalize results beyond the study sample.

CHAPTER 4: PRESENTATION OF RESULTS

4.0 Introduction

This chapter gives a summary of the main findings of the study. It includes the presentation of data from caregivers, data from children and adolescents and data from healthcare workers, data were explained in the tables with descriptive statistics and inferential statistics were used to describe and interpreted the data that were collected from respondents on 109 children and adolescents, 34 healthcare workers and 103 caregivers in Kigali City.

4.1 Demographic characteristic of study participants

Of the 109 children and adolescents who participated in the study, the majority 76 (69.7%) were female, while 33 (30.3%) were male. The age range: 10-14 has participated in the study on a larger number 60 (55.0%), while the age range: 14-19 years old has participated in the study on 31 (28.4%). When asked their religion, majority 62 (56.9%) were protestant, among respondents 107(98.2%) have attended school. When asked the highest education level attained, the majority 64(59.8%) attained primary education. As shown in Table 1.

Among 34 healthcare workers who participate in the study, female presented in large proportion 22 (64.7%) while male were 12 (35.3%). Professional qualification was asked and 19(55.9%) are nurses, counselor 8 (23.5%), and Social workers 7 (20.6%), the totality of participants responded working in ART service. As indicated in table 1.

Of the 103 care givers who participate in the study reported their age and a large number 57 (55.3%) were between 31 and 40 years old, and one (1.0%) was more than 50. Regarding gender large proportion 64 (62.1%) were female, while 39(37.9%) were male. The marital status of participants was assessed and a large majority 50(48.5%) reported being married, followed by widowed 24(23.3%), and divorced were 19(18.4%). Participants were asked their religion, and protestant were 35 (34.0%), and catholic were 62(60.2%). Among respondents 101(98.1%) have attended school. When asked the highest education level attained, the majority 94(91.3%) attained primary education. Among respondents, the majority 67(65.0%) reported that the relationship that they have with the child is biological mother, biological father 31(30.1%), grandmother 3(2.9%) and sister 2(1.9%) as presented in table 1.

Table 4. 1: Demographic characteristics of respondents

Variables		Children & Adolescents		Caregivers		Healthcare workers	
		Frequency	Percent	Frequency	Percent	Frequency	Percent
Age group	7-10 years old	18	16.5				
	10-14 years old	60	55.0				
	14-19 years old	31	28.4				
	≤ 30 years			2	1.9	10	29.4
	31-40 years			57	55.3	24	70.6
	41 & older			44	42.7	0	0
	Total	109	100.0	103	100.0	34	100.0
Gender	Male	33	30.3	39	37.9	12	35.3
	Female	76	69.7	64	62.1	22	64.7
	Total	109	100.0	103	100.0	34	100.0
Religion	Catholic	41	37.6	35	34.0		
	Protestant	62	56.9	62	60.2		
	Muslim	4	3.7	6	5.8		
	No religion	2	1.8	0	0.0		
	Total	109	100.0	103	100.0		
Ever attend school	Yes	107	98.2	101	98.1		
	No	2	1.8	2	1.9		
	Total	109	100.0	103	100.0		
Highest education level	Primary education	64	59.8	94	93.1		
	Secondary education	33	30.8	5	5.0		
	Certificate	0	0.0	2	2.0		
	University	10	9.3	0	0.0		
	Total	107	100.0	101	100.0		
Marital status	Never married			6	5.8		
	Married			50	48.5		
	Cohabiting			4	3.9		
	Divorced/separated			19	18.4		
	Widowed			24	23.3		
	Total			103	100.0		
Occupation	Not employed			37	35.9		
	Subsistence farmer			16	15.5		
	Business person			44	42.7		
	Civil servant			6	5.8		
	Total			103	100.0		
Monthly income (FRW)	< 30 000			66	64.1		
	30 000-100 000			27	26.2		
	> 100 000			10	9.7		
	Total			103	100.0		
Relationship with the child	Biological mother			67	65.0		
	Biological father			31	30.1		
	Grandmother			3	2.9		
	Sister			2	1.9		
	Total			103	100.0		
Professional qualification	Professional nurse					19	55.9
	Counsellor					8	23.5
	Social worker					7	20.6
	Total					34	100.0
Service	ART service					34	100.0

4.2 Prevalence and Patterns of HIV disclosure process to infected children and adolescent (N=103)

Table 4. 2 Prevalence of disclosure among children (N=103)

Disclosure status	Frequency	Percent
Yes	77	70.6
No	32	29.4
Total	109	100.0

The proportion of children and adolescents who know their HIV status 77 (70.6) was greater than those who do not know their HIV status 32(29%). As shown in table 4.2.1

Table 4. 3 Patterns of HIV disclosure process to infected children and adolescent (N=103)

Variable	HIV disclosure				p-value	
	Yes		No			
	N	%	N	%		
Age	7-10 years old	6	7.8	12	37.5	<.0001
	10-14 years old	50	64.9	10	31.3	
	14-19 years old	21	27.3	10	31.3	
Sex	Male	22	28.6	11	34.4	.548
	Female	55	71.4	21	65.6	
Religion*	Catholic	29	37.7	12	37.5	.017
	Protestant	46	59.7	16	50.0	
	Muslim	0	0.0	4	12.5	
	No religion	2	2.6	0	0.0	
Ever attended school	Yes	75	97.4	32	100.0	.357
	No	2	2.6	0	0.0	
Reason for coming to Health centre*	I come to take medications	6	7.8	22	68.8	.000
	My parents told me to come here	0	0.0	2	6.3	
	I have an appointment given by the health care worker	2	2.6	0	0.0	
	I come to take ARV medications	69	89.6	8	25.0	

*: Fisher's Exact Test used.

Among 109 children and adolescents who participate in the study the majority aged 10-14 years old 50 (64%, $p < 0.000$) know their HIV positive status compared to aged 7-10 years old 6 (7.7%) and the minority aged 7-10 years old 6 (7.8), high number of protestant 46 (59%, $p = 0.017$) know their HIV, compared to Catholics 29 (37.7%,). Most participants 69 (89.6%) reported that the reason for coming to the health center was to take ARV medications, while others 6 (7.8%) reported that they come to take medication, few of them 2 (2.6) reported that they come for an appointment given by health workers . As indicated in table 4.2.2

Table 4. 4: Disclosure among caregivers (103)

Variables	Disclosure		No		p-value	
	Yes	No	N	%		
Age	≤ 30 years	2	2.4	0	0.0%	0.704
	31-40 years	46	56.1	11	52.4%	
	41 & older	34	41.5	10	47.6%	
	Total	82	100.0	21	100.0%	
Gender	Male	30	36.6	9	42.9%	0.597
	Female	52	63.4	12	57.1%	
	Total	82	100.0%	21	100.0%	
Religion*	Catholic	24	29.3%	11	52.4%	0.098
	Protestant	52	63.4%	10	47.6%	
	Muslim	6	7.3%	0	0.0%	
	Total	82	100.0%	21	100.0%	
Ever attend school	Yes	80	97.6%	21	100.0%	1.000
	No	2	2.4%	0	0.0%	
	Total	82	100.0%	21	100.0%	
Highest education level*	Primary education	73	91.3%	21	100.0%	0.738
	Secondary education	5	6.3%	0	0.0%	
	Certificate	2	2.5%	0	0.0%	
	Total	80	100.0%	21	100.0%	
Marital status*	Never married	3	3.7%	3	14.3%	0.423
	Married	40	48.8%	10	47.6%	
	Cohabiting	4	4.9%	0	0.0%	
	Divorced/separated	16	19.5%	3	14.3%	
	Widowed	19	23.2%	5	23.8%	
	Total	82	100.0%	21	100.0%	
Monthly income (FRW)	< 30 000	48	58.5%	18	85.7%	0.067
	30 000-100 000	25	30.5%	2	9.5%	
	> 100 000	9	11.0%	1	4.8%	
	Total	82	100.0%	21	100.0%	
Relationship with the child*	Biological mother	50	61.0%	17	81.0%	0.444
	Biological father	27	32.9%	4	19.0%	
	Grandmother	3	3.7%	0	0.0%	
	Sister	2	2.4%	0	0.0%	
	Total	82	100.0%	21	100.0%	
	Source of information*	Health worker	81	98.8%	21	
Radio	1	1.2%	0	0.0%		
Caregivers has discussed with healthcare providers about disclosure of HIV status*	Yes	82	100.0%	20	95.2%	0.204
	No	0	0.0%	1	4.8%	
it is important to disclose HIV sero-positive	Yes	82	100.0%	20	95.2%	0.013
	No	0	0.0%	1	4.8%	
child ever ask questions about why he/she has to take medicines	Yes	52	63.4%	30	36.6%	0.051
	No	30	36.6%	14	66.7%	
Caregiver has problems with giving the medicines to the child not knowing the reason for taking medicines	Yes	57	69.5%	19	90.5%	0.039
	No	25	30.5%	2	9.5%	
child ever has problems taking the medicines on time or taking them every day	Yes	34	41.5%	14	66.7%	0.039
	No	48	58.5%	7	33.3%	

* Fisher's exact test used

Among 103 caregivers who participate in the study the majority aged 31-40 years old 46 (56%) has disclosed HIV positive status to their children compared to aged >40 years old 34 (41.5%). Biological mother 50 (61.0%) was disclosed HIV positive status to their children. Healthcare workers 81 (98.8%) were the most source of information about HIV positive status disclosure. When asked if the child ever ask questions about why he/she has to take medicines, most of them 52(63.4%, 0.051) said yes while 30 (36.6%) reported no. when asked if they do not give the medicines because they do not want to give them in front of other people 57 (69.6%) said yes who said no were 25(30.4%). Among respondents 76 (73.8%) reported having problems with giving the medicines while 27(26.2%) reported not having problems because the child does not know why he/she is taking them. When asked if the child ever had problems taking the medicines on time or taking them every day, among them 34(41.5%)said yes, those who said no were 48(58.4%). As shown in table 4.2.3

4.3. Disclosure process and adherence

Table 4. 5 Adherence among children by sociodemographic and disclosure variables

Variable	Adherence				p-value	
	Yes N	%	No N	%		
Age	7-10 years old	2	5.0	16	23.2	0.001
	10-14 years old	19	47.5	41	59.4	
	14-19 years old	19	47.5	12	17.4	
Sex	Male	15	37.5	18	26.1	0.211
	Female	25	62.5	51	73.9	
Religion	Catholic	13	32.5	28	40.6	0.037
	Protestant	23	57.5	39	56.5	
	Muslim	4	10.0	0	0.0	
	No religion	0	0.0	2	2.9	
Ever attended school	Yes	40	100	67	97.1	0.277
	No	0	0	2	2.9	
Education level	Primary education	19	47.5	45	67.2	0.013
	Secondary education	19	47.5	14	20.9	
	university level and above	2	5.0	8	11.9	
Disclosure status	Yes	28	70.0	49	71.0	0.911
	No	12	30.0	20	29.0	

Variables significantly associated with disclosure and adherence were children and adolescents' old age (p=0.001), old age (14-19 years old: 19, 47,5%) adherent more than young age (7-10

years old 2 6%) , religion (p=0.037),and education level (p=0.013). However, disclosure status was not associated with adherence (p=0.911). As indicated in table 4.3.1

Table 4. 6 Logistic regression analysis of children’s adherence with significant variables (N=109)

Variable	Adherence	Odds Ratio	P>z	95% Confidence interval
Age	7-10 years old	1		
	10-14 years old	3.6	0.116	0.73 – 18.00
	14-19 years old	4.1	0.204	0.46 – 36.40
Religion	Catholic	1		
	Protestant	1.9	0.195	0.72 – 4.97
	Muslim	1		
Education level	Primary education	1		
	Secondary education	3.37	0.11	0.76 – 14.96
	university level and above	0.92	0.924	0.15 – 5.46

Adherence increase with age. Older children and adolescents are four times more adherent compared to young children. (14-19 years old OR 4.1 P=0.204, CI 0.46-36.40), (10-14 years old OR 3.6, p=0.116, CI 0.73-1800); (7-10 years old OR 1,). However this is not statistically significant.

Protestant are four times more adherent than Catholic and Muslim Ratio (OR 1.9, p=0.195.CI 0.72-4.97). However this is not statistically significant.

Secondary education are three time more adherent than primary education. Odd Ratio (OR 3.37, p=0.11.CI 0.76-14.96). However this is not statistically significant. As shown in table 4.3.2

Table 4. 7 Adherence to HIV treatment among children and adolescents (N=109)

Variable	Frequency	Percent
If yes, Who informed you of your HIV status?		
Caregiver	49	63.6
Health care worker	28	36.4
What were your behaviour after this disclosure?		
I continued to take medications as usual	60	77.9
I felt of leaving these medications	8	10.4
I felt of dying	9	11.7
Do you ever miss taking the medicines that you are supposed to take?		
Yes	28	36.4
No	49	63.6
Do you ever refuse to take the medicines that you are supposed to take?		
Yes	23	29.9
No	54	70.1
Do you ever not take the medicines because you do not want to take them in front of other people?		
Yes	39	50.6
No	38	49.4
Total	77	100.0
Do you ever have problems taking the medicines because you do not know why you are taking them?		
Yes	16	20.8
No	61	79.2
Do you ever have problems taking the medicines on time or taking them every day?		
Yes	8	10.4
No	69	89.6

Among participants, the majority 69 (89.6%) reported that the reason for coming to the health center is for taking ARV medications, 6 (7.8%) reported that they come to, take medication, 2(2.6)reported that they come for appointment given by health worker.

Respondents were asked who informed them their HIV status, a large majority 49 (63.6%) reported caregivers, health care workers were 28 (36.4%). Respondents were asked their behavior after disclosure who continued to take medications as usual were 60(77.9.0%), who felt of leaving these medications were 8(10.4%), who felt of dying were 9(11.7%). Among respondents the majority 49(63.6.%) did not miss taking the medicines that they are supposed to take, while 28 (36.4) miss taking the medicines that they are supposed to take.

When asked if they refuse to take the medicines that you are supposed to take, the majority 54(70.1) reported no While 23(29,9) reported yes.

When asked if they do not take the medicines because you do not want to take them in front of other people 39(50.6%) said yes, while 38(49.4%) said no. When asked if they have problems taking the medicines because you do not know why you are taking them the majority 61(79.2%) said no while 16(20.8%) said yes. When asked the problems they have of taking the medicines because they do not know why you are taking them, who said yes were 8(10.4%), while 69(89.6%) said no. as shown in table 4.3.3

4.3.4 HIV Treatment adherence among children and caregivers

Table 4. 8: HIV Treatment adherence among children and caregivers

Adherence		Frequency	Percent
Among children	Yes	40	36.7
	No	69	63.3
	Total	109	100.0
Among caregivers	Yes	53	51.5
	No	50	48.5
	Total	103	100.0

HIV Treatment Adherence was higher reported by caregivers 53 (51.5%) compared to HIV treatment adherence reported by children and adolescents 40 (36.7%). As indicated in table 4.3.4

4.4. Barriers encountered by health worker and care givers in HIV status disclosure process

Table 4. 9 Barriers encountered by health workers (N=34)

Variable		Frequency	Percent
Have you disclosed to the child his/her HIV status	Yes	16	47.1
	No	18	52.9
	Total	34	100.0
Is there a disclosure guideline available at the health centre?	No	21	61.8
	Yes	13	38.2
	Total	34	100.0
Have you received specific training on HIV/AIDS?	Yes	18	52.9
	No	16	47.1
	Total	34	100.0
Have you ever had a child living with HIV virus as a patient	Yes	30	88.2
	No	4	11.8
	Total	34	100.0
Have you ever discussed with parents about disclosure of his/her living with HIV	Yes	31	91.2
	No	3	8.8
	Total	34	100.0
A child born with HIV can live to age 10 beyond	Yes	34	100.0
Age of disclosure	8-10 years	31	91.2
	11-14 years	3	8.8
	Total	34	100.0
Who should disclose their HIV positive status to children	Parents/Primary caregivers	8	23.5
	Health care providers	1	2.9
	both together	25	73.5
	Total	34	100.0
What is the role of health care workers in disclosure?	supporting caregivers to disclosure	11	32.4
	helping the child to accept their status	23	67.6
	Total	34	100.0
What are reasons for delaying disclosure	Afraid of stigma	10	29.4
	caregivers lack support to disclosure	13	38.2
	fear of outcomes	9	26.5
	afraid the child will tell others about their HIV diagnosis	2	5.9
	Total	34	100.0
What are support needed by health care workers to facilitate disclosure to children and adolescents?	guidelines on disclosure counselling for children	6	17.6
	counselling to be able to deal with HIV-infected children	6	17.6
	workshop and training on HIV management to increase their confidence in assisting caregivers to disclose	20	58.8
	training on disclosure counselling to support HIV-infected children and adolescents to understand the disease	2	5.9
	Total	34	100.0

Among 34 healthcare workers who participate in the study, majority of them 21 (61.8%) reported that there is no HIV positive disclosure guideline available at their health center. A high number 18 (52%) reported to have specific training on HIV/AIDS disclosure. Majority of participants 31 (91.2%) reported that the appropriate age of disclosure is from 8-10 years old. Most healthcare workers 31 (91.2%) reported that they have been discussed with the parents about HIV disclosure to their children, the majority of participants 25 (73%) reported that both caregiver and healthcare worker should involve in HIV positive disclosure. when asked the role of healthcare worker in HIV positive disclosure, the majority 23 (67.6%), reported that is for helping the child to accept their status, while 11 (32%) report that is to support caregivers to disclose. on question about the reason of delaying disclosure, the majority 13 (38.2%) reported that is caregivers lack support from healthcare workers to disclose, while 10 (29.4%) reported afraid of stigma, 9 (26.5%) reported fear of outcomes. Lack of workshop and training on HIV management to increase their confidence in assisting caregivers to disclose, was the most barrier encountered by healthcare workers 22 (58.8%), in disclosure process. As indicated in table 4.4.

Table 4.4.2 Barriers encountered by care givers (N=103)

Table 4. 10: Barriers encountered by care givers

Variables	Disclosure				
	Yes		No		
	N	%	N	%	
Age	≤ 30 years	2	2.4	0	0.0%
	31-40 years	46	56.1	11	52.4%
	41 & older	34	41.5	10	47.6%
	Total	82	100.0	21	100.0%
Relationship with the child*	Biological mother	50	61.0%	17	81.0%
	Biological father	27	32.9%	4	19.0%
	Grandmother	3	3.7%	0	0.0%
	Sister	2	2.4%	0	0.0%
	Total	82	100.0%	21	100.0%
What do you feel is an important reason that prevents you to don't want to disclose to your child his/her HIV status ?	Stigma	46	56.1%	11	81.0%
	Child is too young	34	41.5%	10	19.0%
	Fear of emotional distress	2	2.4%	0	0.0%
	Lack of knowledge	0	0%	0	0.0%
	Total	82	100.0%	21	100.0%
child ever ask questions about why he/she has to take medicines	Yes	52	63.4%	30	36.6%
	No	30	36.6%	14	66.7%
Caregiver has problems with giving the medicines to the child not knowing the reason for taking medicines	Yes	57	69.5%	19	90.5%
	No	25	30.5%	2	9.5%
child ever has problems taking the medicines on time or taking them every day	Yes	34	41.5%	14	66.7%
	No	48	58.5%	7	33.3%

As mentioned in table 4.4.2., among 103 caregivers who participate in the study the majority 46 (56.1%) reported that stigma was the main barrier to disclose, while 34 (41.5%) reported child is too young as a barriers for HIV positive status disclosure, lastly fear of emotional distress was the barrier for HIV positive status disclosure reported by 2 (2.4%) care givers.

CHAPTER 5 DISCUSSION

5.0 Introduction

This chapter was discussion to the findings. The main concern of this study was to assess the disclosure process of HIV positive status to infected children and adolescents in selected health center in Kigali City. Particularly attention was firstly to explore the patterns of HIV disclosure process to infected children and adolescents, secondary to determine the effect of HIV disclosure process on the ART adherence among children and adolescents. Lastly to identify the barriers uncounted by healthcare workers and caregivers during HIV disclosure process.

5.1 Patterns of HIV disclosure process to infected children and adolescents

While children with HIV survive to adolescence and adulthood at unprecedented rates, disclosure of HIV status is an indispensable element of pediatric HIV management. The patterns of HIV positive disclosure process was explored in this study, and came up with the findings which says that the proportion of children and adolescents who know their HIV status 77 (70.6) was greater than those who do not know their HIV status 32 (29%).

The results are consistent with the study done in Kenya (Vreeman *et al.*, 2013), which highlighted the lower level of disclosure. This low level of disclosure could be explained by the fact that most caregivers prefer to delay disclosure up to when a child has reached nine years or older since they believe that, older children have cognitive maturity and are able to understand the importance of taking ARVs.

Indeed, our findings show that older children knew their status more frequently than younger children. This data obtained was in agreement with other studies in Ghana (Vreeman *et al.*, 2013), Uganda (Kallem *et al.*, 2012) Tanzania (Nzota *et al.*, 2015), (Ingabire and Mutessa, 2014), likely as result of increasing maturity, independence and responsibility for self-care that required knowledge of their status. In contrast to the study done in Kenya, which mentions that, a significant number of HIV-infected children including older than ten years old remain unaware of their HIV positive status.

This could be explained by the fact that most likely, caregivers were not sure how to disclose the HIV positive status to infected children and adolescents or did not know that disclosing the HIV-positive status to infected and adolescents was necessary. This unawareness of their HIV positive status has implications on their ability to adhere to HIV treatment (Vreeman *et al.*, 2013).

Our results describe that majority of respondent were caregivers 63.6%, who had informed HIV status to their children, while health care workers were 28 (36.4%). Our data were consistent with many studies (Yenealem, 2012; Madiba and Mokgatle, 2015), where they mention that the majority of respondents identified parents or primary caregivers as the appropriate persons to disclose children's HIV Status to them. In a study south Africa to determine the perception of caregivers, 42% indicated caregivers as appropriate "... to reveal the infection status" (Woldemariam, 2012).

5.2 The association between HIV disclosure process and the ART adherence among children and adolescent

Our study have came up that adherence increase with age where children and adolescents' old age ($p=0.01$), old age (14-19 years old: 19, 47,5%) adherent more than young age (7-10 years old 2 6%) , However, disclosure status was not associated with adherence ($p=0.911$), in this study, the results are in good agreement with other studies done in Kenya (Vreeman *et al.*, 2013), in Zimbabwe (Gross *et al.*, 2015)which highlighted the same results shows that the association between adherence to ART and disclosure is not clear. There are several reasons disclosure might be associated with non adherence.

Disclosure is a traumatic event for many children and can be accompanied by feeling of anger, hopelessness and rebellion, which may lead to temporary or longer-term adherence problems (Smith Fawzi *et al.*, 2016). The negative effect of HIV related stigma, including effort to keep the diagnosis secret by hiding or taking medicines, may also impact adherence to therapy for disclosed children more than non-disclosed children. In addition the study done by (Smith Fawzi *et al.*, 2016), cited that adherence issues may be compounded by other adolescent-specific factors such as increased incidence of depression and generally poor medication adherence among this age group.

The similar results was found in the study done by (Gachanja and Burkholder, 2016) where the author mention that disclosure may lead to improve adherence, including increased responsibility over medication-taking and better access to social support. Pediatric HIV providers often recommend disclosure of HIV status to children and adolescents as necessary to building trusting provider-patient and family relationships and developing disease management skills that facilitate adherence (Vaz *et al.*, 2008).

In the only longitudinal study to assess adherence pre and post-disclosure, Vaz et al reported that approximately 58% of children and their care givers adherence improved post disclosure however, adherence was assessed by self and proxy-report among a small sample of only 40 children and healthcare workers felt that adherence improved 25% of cases. Furthermore, since the study assessed disclosure after an intensive, supportive disclosure intervention, its results may not be representative of the majority of disclosure experiences.

Our finding reports of adherence differed significantly depending on whether adherence was caregiver- reported or child reported. A systematic review on adherence to ART (Vreeman *et al.*, 2013) found that adherence assessment items are rarely validated, that proxy-report (for example care giver-reported) often overestimate adherence and that children and adolescents reported more non adherence than their caregivers do. Similar finding was reported in our study where children and adolescent reported less non adherence 36.7% than care givers 51.5%, but these findings may be shaped by several cultural-specific biases.

In particular, children and adolescents in this setting with strong cultural; traditions requiring children to obey adults (caregivers and healthcare workers) may be more vulnerable to social desirability pressure to report higher adherence. (Nzota *et al.*, 2015)

In addition, despite clinical protocols recommending private interviewing of children and adolescents about adherence, children and adolescents are rarely questioned in private as was required for completion of the evaluations within this study. Finally, many of children and adolescents involved I this study were in the care of their biological parents (93%.0%) and rather than grandparents and other extend family. These biological parents may feel less pressure to report adherence.

5.3 Barriers uncounted by healthcare workers and caregivers during HIV positive status disclosure process.

Our results describe that the majority of healthcare workers (61.8%) reported that there is no HIV positive disclosure guideline available at their health center, and the lack of workshop and training on HIV management to increase their confidence in assisting caregivers to disclose, was the most barrier encountered by healthcare workers (58.8%), in disclosure process.

These results are consistent with other studies from sub-Saharan countries (Vaz *et al.*, 2012), Madiba and Mokgatle, 2015) where they mention that the involvement of HCWs in disclosure to infected children and adolescents has been gradually increasing, even though the lack of training on disclosure counseling of children and adolescents (Bhattacharya, Dubey and Sharma, 2011). Consistent with previous studies, one of major concerns of HCWs was the lack of formal guidelines on HIV disclosure for children and adolescents to guide them on when and how to prepare and support caregivers to disclose to children (Vaz *et al.*, 2012). We found that recent published World Health Organization disclosure guidelines for children have not yet been adopted and utilized by HCWs in all the health facilities. Additionally, HCWs in this study and in many sub-Saharan countries are hardly ever trained in pediatric HIV and disclosure of children and adolescents, and lacked skill to assist caregivers to disclose (Madiba and Mokgatle, 2015). Attending workshops and receiving training will give HCWs skills and increase their confidence in assisting caregivers to disclose but also support HIV-infected children to understand the disease (Cantrell *et al.*, 2013).

The need of guideline on HIV disclosure was mentioned by (WHO, 2011), where we found that healthcare workers know that disclosure decisions are complex because of family relations, parents skills, stigma, and fear about children's emotional and maturational ability to understand and cope with the nature of the illness.

Without the support of definitive, evidenced-based policies and guidelines on when, how, and under what conditions children should be informed about their own or their caregivers' HIV status, HCWs challenged by the complicated issues facing by families. As a result, many HCWs are uncertain how to counsel clients about the disclosure process.

Thus may often miss opportunities to assist parents in dealing with these issues and explaining to caregivers the need for HIV status disclosure their children. The lack of disclosure finally negatively affects the well-being of the child, including access to pediatric HIV treatment, care and adherence to treatment.

Our findings demonstrate that a half of caregivers who participate in the study reported that stigma was the main barrier to disclose, other mentions that the child is too young as a barriers for HIV positive status disclosure, lastly fear of emotional distress was the barrier for HIV positive status disclosure reported by caregivers.

Consistent with findings from other studies (Vreeman *et al.*, 2013; Madiba and Mokgatle, 2015; Rugema *et al.*, 2015), Where caregivers delay disclosure because they believe that when children and adolescents learn about their HIV status they will be hurt. One other common reason mentioned by caregivers reported that the reason to delay disclosure, they believe that child is too young; they also mean that the child is unable to understand the negative consequences of an HIV diagnosis. Age was often not used in determining the child's ability to understand HIV/AIDS because it was subjective. This point of view noticeable in this study where HCWs recommended an older age between 8-10 years old as the right age to tell children about their HIV status. The data suggest that age is not necessarily the determining factor for disclosure and should not used to guide caregivers in decision to disclose HIV status to children and adolescents.

Other reason cited by caregivers to why they delay disclosure to children was similar to our findings. These included fear of stigma , lack of disclosure skills, self blame and guilt for infecting the child with HIV, and fear of being rejected by the child (Madiba and Mokgatle, 2015; Vreeman *et al.*, 2013, Vaz *et al.*, 2012). There is a need develop appropriate disclosure interventions to address caregiver's deep seat fears of disclosing to their HIV infected children and adolescents (Vreeman *et al.*, 2013).

A contrast to some report , within data with regard to nature of support health care workers could give to caregivers during HIV status disclosure process came up with two themes: disclosure as a shared responsibility for caregivers and health care workers and counseling and education as main forms of support (Gyamfi and Okyere, 2015). Our study does not mention those findings.

In the study done by Vaz et al. (2008) different participants report that healthcare workers and caregivers had role to play in disclosure process. Usually required some form of assistance from healthcare workers during the process of disclosure. Caregiver disclose by guidance of healthcare worker. Same study mention that lack of formal education, lack the knowledge and skill for disclosure for most of parents, and need the assistance of healthcare workers. When the healthcare workers are implicated in the disclosure it is easier for the child to accept the diagnosis. Thought health education and counseling by pre-test and post-test counseling for both caregivers and children make them to understand more the need of disclosure.(Gyamfi and Okyere, 2015).

CHAPTER 6. CONCLUSION AND RECOMMENDATIONS

6.0 Introduction

This chapter provides the summary of the study. It also presents the major research findings, the conclusions drawn as well as the recommendations made by the researcher, based on the findings, conclusion, and recommendations of areas of further research. Key components of this chapter are conclusion, recommendations for policy change, strengths and limitations of the study and recommendation for further research.

6.1 Conclusions

The purpose of this study was to assess HIV status disclosure process for infected children and adolescents in selected health center from Kigali City. In conclusion, it is evident that this study has shown that a low prevalence of disclosure of HIV status to children and adolescents, while highlighting how disclosure may be related to key outcomes such as medication adherence, experience of stigma. They give the highest responsibility of disclosure to caregivers and healthcare workers

Healthcare workers pointed that the lack of guidelines and training on disclosure counseling of children and adolescents affect their ability to participate fully in disclosure which often results in delayed disclosure to children and adolescents. It is expected that when they are trained and participate fully in disclosure, children and adolescents can be informed of their HIV status in an appropriate susceptible manner. To facilitate disclosure, adoption of the World Health Organization disclosure guidelines for children and adolescents.

These guidelines should form the basis for training of HCWs to equip them with appropriate skills to support caregivers in disclosing HIV status to children and to ensure that they are counseled suitably to accept their condition.

6.2 Recommendations

These are based on the conclusions and solutions to the problem. The suggestions were appropriate measures to strengthen identified weaknesses, eliminate or solve conflicts or introduce innovative ideas and practices in the research.

From the findings and conclusions, the following recommendations were drawn regarding disclosure process for HIV infected children and adolescents.

In order to improve the care and support of children living with HIV virus, training in pediatric HIV care, including disclosure needs to be more widely available. The training can be included in already existing programmes, but designed to reach a wider audience. Using already existing guidelines would help to improve the practice of disclosure of HIV status to children and adolescents. This could be done through training but also mentoring and coaching.

Caregivers need to be empowered and supported so that they can be the ones to disclose to their children. HCWs needs to be more practical in discussing issue of disclosure with caregivers at young age, depending on the maturity of the child, rather than waiting for parents to ask for advice.

More data are needed to better understand the impact of disclosure and to inform disclosure support interventions as children and their families go through this challenging process.

Research needs to be conducted into different regions of Rwanda so as to assess and address the different cultural challenges to child rights. Especially disclosure of HIV status in different contexts.

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APPENDICES
ETHICAL CLEARENCE



COLLEGE OF MEDICINE AND HEALTH SCIENCES

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 16/01/2017
Ref: CMHS/IRB/094/2017

NDAYISHIMIYE Flora
School of Nursing and Midwifery, CMHS, UR

Dear NDAYISHIMIYE Flora

RE: ETHICAL CLEARANCE

Reference is made to your application for ethical clearance for the study entitled "*Assessment Of Disclosure Process Of HIV Status To Infected Children And Adolescents In Kigali City*".

Having reviewed your protocol and found it satisfying the ethical requirements, your study is hereby granted ethical clearance. The ethical clearance is valid for one year starting from the date it is issued and shall be renewed on request. You will be required to submit the progress report and any major changes made in the proposal during the implementation stage. In addition, at the end, the IRB shall need to be given the final report of your study.

We wish you success in this important study.

For Professor Kato J. NJUNWA
Chairperson Institutional Review Board,
College of Medicine and Health Sciences, UR



JB Gahutu
IRB via-Chair

- Cc:
- Principal College of Medicine and Health Sciences, UR
 - University Director of Research and Postgraduate Studies, UR

DATA COLLECTION APPROVAL

REPUBLIC OF RWANDA



Kicukiro, February 20th, 2017

Ref. n° 249.../ 07.0103.0.../17

CITY OF KIGALI
KICUKIRO DISTRICT
P.o Box: 657 Kigali

NDAYISHIMIYE Flora

UNIVERSITY OF RWANDA COLLEGE OF MEDICINE AND HEALTH SCIENCES

Tel: (+250) 788570336

RE: Data Collection Approval

Dear Madam,

Reference is made to your letter dated February 14th, 2017 requesting the authorization to conduct a research on «*Assessment of disclosure process of HIV status to infected children and adolescents in Kigali City*», Case Study of Kicukiro, Masaka, Gahanga and Gikondo Health Center in Kicukiro District.

After examining your request and according to the Law N° 45/2013 of 16/06/2013, stating on statistical activities organization in Rwanda, we have the pleasure to inform you that you are authorized to conduct your research in the District.

In order to assure the accuracy of collected data you should submit your research draft to the District before submission of the final report to your University.

Thank you for your collaboration.


Dr. NYIRAHABIMANA Jeanne

Mayor of Kicukiro District



Cc:

- Vice Mayor (all)
- Executive Secretary of the District
- Statistics Service.

Website: www.kicukiro.gov.rw

Email: info@kicukiro.gov.rw

Hotline: 4575

TO WHOM IT MAY CONCERN



COLLEGE OF MEDICINE AND HEALTH SCIENCES

SCHOOL OF NURSING AND MIDWIFERY

Kigali, on 30 / 01 / 2017

Ref. No: 58./ UR-CMHS/SoNM/17

TO WHOM IT MAY CONCERN

Dear Sir/Madam,

Re: Request to collect data

Referring to the above subject, I am requesting for permission for **NDAYISHIMIYE Flora**, a final year student in the Masters of Science in Nursing at the University of Rwanda/College of Medicine and Health Science to collect data for his/her research dissertation entitled **Assessment of disclosure process of HIV status to infected children and adolescents in Kigali city**.

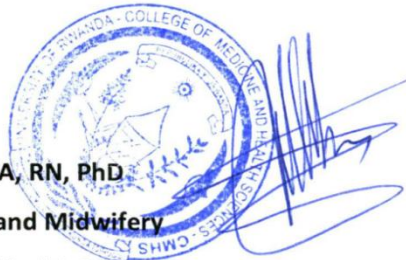
This exercise that is going to take a period of 2 months starting from 13th February 2017 to 12th April 2017 will be done at **Remera, kinyinya, Muhima, Gihogwe, Biryogo, Centre medical social CORUNUM, Kabusunzu, Kicukoro, Masaka, Gatenga, Gikondo health center**.

We are looking forward for your usual cooperation.

Sincerely,

for

Dr. Donatilla MUKAMANA, RN, PhD
Dean, School of Nursing and Midwifery
College of Medicine and Health Sciences



Email: schoolofnursingandmidwifery@ur.ac.rw, P.O.Box: 3286 Kigali-Rwanda, Website: www.ur.ac.rw

REPUBLIC OF RWANDA

Gasabo, 01/02/2017
Ref N° 1554/070102/2017



KIGALI CITY
GASABO DISTRICT
WEBSITE: www.gasabo.gov.rw
E-mail: gasabo_district@yahoo.com
BP. 7066 KIGALI

Mrs. **NDAYISHIMIYE Flora**
Tel. 0788570336
University of Rwanda
KIGALI

Subject: Response to your letter.

Dear Flora,

With reference to your letter received on 13th February 2017 requesting for the permission to carry out research on Assessment of disclosure process of HIV status to infected children and adolescents in Kigali City;

I would like to inform you that the permission you asked for has been granted.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Augustin Ingabire', written over a blue rectangular stamp.

NTAGANZWA J.M. VIZIMBERA
Director of H.R & Administration



INGABIRE Augustin;

Executive Secretary of Gasabo District.

Cc:

-Director of Health in Gasabo District

KIGALI



CARITAS DE L'ARCHIDIOCESE DE KIGALI

B.P. 3378 Kigali Tél. : (250) 25257 86 51 ;
(250) 78 874 33 21

E-mail : caritaskigali@yahoo.fr; Web : www.caritas-cdjp-kigali.rw

N. Ref /SANTE /023/2017

Kigali on 4th April 2017

To: Madam, NDAYISHIMIYE FLora

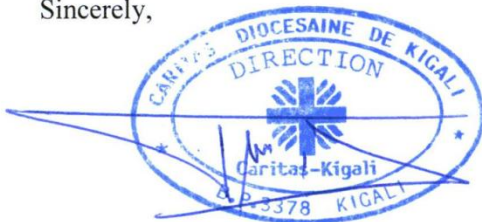
Re: Answer to your letter of April 4th, 2017

Dear Madam,

This is the answer to your letter received on April 4th, 2017 in which you request for an authorization to collect data for your final research project in Kicukiro, Masaka and Gikondo health centers.

It is our pleasure to inform you that you are authorized to collect those data from 4th April 2017 to 30th April 2017 in the health centers mentioned above and wish you good work.

Sincerely,



Father Donatien TWIZEYUMUREMYI
Director of Caritas Kigali

CC:

- Head of Kicukiro Health center
- Head of Masaka Health center
- Head of Gikondo Health center

INFORMED CONSENT FORM

Dear Research Participant,

You are invited to participate in a research entitle: ASSESSMENT OF DISCLOSURE PROCESS OF HIV STATUS TO INFECTED CHILDREN AND ADOLESCENTSIN KIGALI CITY. This research is being conducted as part of the requirements towards the degree of Masters in Pediatrics from University of Rwanda.

The result of this study might contribute to the design of further interventions to improve the care of children and adolescents living with HIV virus. If you agree to participate, you will be asked to complete a self administered questionnaire that will take 10-15 minutes of your time. There is no financial compensation for your participation in this research.

The record from this study will be kept as confidential as possible and your name will not be included in any publications.

Participation in this study is voluntary. If you decide to participate, you are free to withdraw at any time. Your participation in this study will be highly appreciated.

The researcher in this study is Flora NDAYISHIMIYE and can be contacted at 259788570336 for any clarification.

Statement of Consent

I have read the above information. I consent voluntarily to participate in the study.

Participant’s Name:.....

Participant’s Signature.....

Person to contact:

Chairperson of the CMHS IRB: **0788 490 522**

Deputy Chairperson: **0783 340 040**

Supervisor: **0788749398**

KWEMERA UBUFATANYE MUBUSHAKASHASTI

Kuwo tugiye gufatanya mubushakashasti,

Uratumiwe mubufatanye mubushakashasti bugendereye : Kumenya uko abana n'ingimbi bo mumujyi wa Kigali babana n'ubwandu bw'agakoko gatera sida bamenyeshwa mo igisubizo cyuko banduye. Ubu bushakashasti bukozwe murwego rwo yo kuzura ibisabwa ku mpamyabushobozi yo kurwe rw ikiciro cya gatatuza kaminuza mubyerekeranye n'ubuzima bw'abana muri Kaminuza y U Rwanda.

Ibizava murubu bushakashasti bizafasha mukurushaho kwita k'ubuzima bw'abana n'ingimbi babana n'ubwandu bw'agakoko ka sida. Ubufatanye bwawe, uradufasha gusubiza ibibazo biragutwara iminota 10-15, y'igihe cyawe, nta bihembo biteganyijwe kubwicyo gikorwa.

Ibizava murubu bushakashasti bizabikwa mwibanga, izina ryawe ntaho rizagaragara ntanaho rizatanzwa.

Ubufatanye ni kubushake. Ushaste no ku dakomeza ubufatanye wavamo ntakikubangamiye.ubufatanye bwawe n'ubufasha bukomeye.

Umushakashasti ni Flora NDAYISHIMIYE, aboneka kuri numero y'itumanaho 0788570336.

Uwemeye ubufatanye

Njywemazegusoma neza ibijyanye n'ubu bushakashasti nemeye ubufatanye kubushake.

Abantu wakwifashisha uramuste ugize ikibazo:

Uhagarariye ubushakashatsi muri kaminuza : **0788 490 522**

Umwungirije: **0783 340 040**

Researcher: 0783376267

Supervisor: 0788402547

CHILD ASSENT FORM

I am NDAYISHIMIYE Flora, a graduate student at the University of Rwanda/ College of Medicine and Health Sciences in Masters of Sciences in Nursing/ Pediatric Specialty. I am inviting you to participate in my research study. Participation in this study is voluntary. If you decide to participate, you are free to withdraw at any time. Your participation in this study will be highly appreciated.

I am now going to explain the study to you. Please feel free to ask any questions that you may have about the research; I will be happy to explain anything in greater detail.

For this study we will assess disclosure process of HIV status to infected children and adolescents in Kigali city. The result of this study might contribute to the design of further interventions to improve the care of children and adolescents living with HIV virus. We will keep your answers private. No problem will happen to you as part of this study. Your parent/caregiver was asked if it is Ok for you to be in the study. Even if they say Ok, it is still your choice whether or not to take a part.

If you decide you want to be in this study, please sign your name.

I,, want to be in this research study.

.....

(Signature)

(Date)

.....

(Name of Parent/ Caregiver)

.....

Researcher explaining study (Name and Signature)

(Date)

KWEMERA UBUFATANYE MUBUSHAKASHASTI

Kuwo tugiye gufatanya mubushakashasti,

Uratumiwe mubufatanye mubushakashasti bugendereye : Kumenya uko abana n'ingimbi bo mumujyi wa Kigali babana n'ubwandu bw'agakoko gatera sida bamenyeshwa mo igisubizo cyuko banduye. Ubu bushakashasti bukozwe murwego rwo yo kuzuzwa ibisabwa ku mpamyabushobozi yo kurwe rw ikiciro cya gatatucya kaminuza mubyerekeranye n' ubuzima bw' abana muri Kaminuza y U Rwanda.

Ibizava murubu bushakashasti bizafasha mukurushaho kwita k' ubuzima bw'abana n'ingimbi babana n'ubwandu bw'agakoko ka sida. Ubufatanye bwawe, uradufasha gusubiza ibibazo biragutwara iminota 10-15, y' igihe cyawe, nta bihembo biteganyijwe kubwicyo gikorwa. Ibizava murubu bushakashasti bizabikwa mwibanga, izina ryawe ntaho rizagaragara ntanaho rizatanzwa. Umubyeyi wawe yatwemereye ko wadufasha murububu bushakashasti, nubwo yabyemeye wowe kuba wabyemera cyangwa ntubyemere ntangaruka byakugiraho.

Ubufatanye ni kubushake. Ushaste no ku dakomeza ubufatanye wavamo ntakikubangamiye.ubufatanye bwawe n'ubufasha bukomeye.

Umushakashasti ni Flora NDAYISHIMIYE, aboneka kuri numero y'itumanaho 0788570336.

Uwemeye ubufatanye

Njywemazegusoma neza ibijyanye n'ubu bushakashasti nemeye ubufatanye kubushake.

Abantu wakwifashisha uramuste ugize ikibazo:

Uhagarariye ubushakashatsi muri kaminuza : **0788 490 522**

Umwungirije: 0783 340 040

Researcher: 0783376267

Supervisor: 0788402547

STUDY QUESTIONNAIRE: ASSESSMENT OF DISCLOSURE PROCESS OF HIV STATUS TO INFECTED CHILDREN AND ADOLESCENTS IN KIGALI CITY.

Instructions: Below are questions related to HIV disclosure process. Questions are itemised, please tick the most appropriate answer using (×) sign or another given instructions in the corresponding box. **(CAREGIVER QUESTIONNAIRE)**

Section A: General information

Questionnaire number.....

Date

Health Center.....

Section B: Socio Demographic Characteristics and Background information of caregivers

1. Age
2. Sex:
 - a. Male
 - b. female
3. Name of village where the caregiver is coming from.....
4. What is your marital status?
 - a. Never married?
 - b. Married
 - c. Cohabiting
 - d. Divorced/separated
 - e. Widowed
 - f. Other (specify)
5. What is your religion?
 - a. Catholic
 - b. Protestant
 - c. Muslim
 - d. Others(specify)
6. Have you ever attend school?
 - a. Yes
 - b. No
7. If yes what was the highest education level attained?
 - a. Primary education
 - b. Secondary education
 - c. Certificate
 - d. University level and above

8. What is your occupation?
- a. Not employed
 - b. Subsistence farmer
 - c. Business person
 - d. Civil servant
 - e. Other (specify)

9. what is your Monthly income
- a. < 30 000
 - b. > 30 000
 - c. 30 000-100 00
 - d. > 100 000

Socio demographic characteristics and background information of the child

10. What relationship do you have with the child?
- a. Biological mother
 - b. Biological father
 - c. Grandmother
 - d. Grandfather
 - e. Other (specify)

Proportion of Caregivers who have disclosed HIV status to infected children

11. Have you heard about disclosure of HIV sero-positive to a child living with HIV?
- a. Yes
 - b. No
12. If yes, what was your source of information?
- a. Health worker (doctor, nurse, social worker, counsellor)
 - b. Radio
 - c. Television
 - d. Newspapers
 - e. Others specify.....
13. Have you actually been discussed with healthcare providers about disclosure of HIV sero-positive to a child living with HIV?
- a. Yes
 - b. No
14. Do you think it is important to disclose HIV sero-positive to a child living with HIV?
- A. Yes (if yes go to question No.15)
 - B. No (if no go to question No 16)
15. If yes give
 reasons.....
16. If no give
 reasons.....
17. Have you disclosed to your child his/her HIV sero-positive?
- a. Yes
 - b. No

18. If no, what was the reason for not telling his/her HIV status?

- a. stigma
- b. fear of negative reaction from the child
- c. It may disturb the child psychologically
- d. May hurt child

19. do you have any plan of telling your child in future that he/she is HIV positive?

- a. Yes (if yes go to question 30)
- b. No

20. What age are you planning to do that?

- <7 years old
- 7-10 years old
- 10-13 years old
- years old >19 years old 13-19
- Never

21. Have you discussed about the soldiers of the body with your child?

- a. Ye
- b. No

22. Have you told your child the name of the disease?

- a. Yes
- b. No

23. At which age was she/he disclosed sero-positive? <7 years old

-
- 7-10 years old
- 10-13 years old
- 13-19 years old

24. At which level did the child know his/her HIV sero=positive status?

- a. Not in school
- b. Primary level
- c. secondary education
- d. other (specify)

25. What was the health of the child at the time of fully disclosure his/her HIV ser-positive status

- a. Very ill (admitted at the health facility)
- b. Ill (not admitted to the health facility)
- c. had no sickness
- d. others (specify)

26. What prompted you to disclosure the HIV sero-positive status of the child to him/her?

a. health care workers

b. old enough

C. family support

d. low CD4 count of a child

e. poor adherence to ARVs

f. others (specify)

27. Who did the disclosure to the child?

a. Physician

b. Nurse

c. Counsellor

d. Family friend

28. Where was disclosure done?

a. Home

b. Hospital

c. school

d. other (specify)

29. Why do you think is not possible for caregiver to inform the child his or her HIV positive status

.....
30. Which process have you use to inform the child his/her HIV positive status?

a. How it started till the child understood he/she is infected?

31. Does the child know that he//she taking medicines for HIV?

a. Yes

b. No

32. If the child does not know that he/she has HIV, what explanation do you give for coming to the health canter or for taking medicines?

a.

b.

33. Does the child ever ask questions about why he/she has to take medicines?

a, Yes

b. No

34. Does the child ever refuse to take the medicines he/she is supposed to take?

a. Yes

b. No

35. Do you ever not give the medicines because you do not want to give them in front of other people?

- a. Yes b. No

34. Do you ever have problems with giving the medicines because the child does not know why he/she is taking them?

- a. Yes b. No

35. Does the child ever have problems taking the medicines on time or taking them every day?

- a. Yes b. No

36. What do you feel is an important reason that prevent you to don't want to disclose to your children their HIV status that needs to be addressed in discussing disclosure?

- a. Stigma
- b. Their belief the child is too young
- c. Guilt
- d. Fear of emotional distress
- e. Lack of knowledge and skill
- f. Other , please specify.....

You can look at your articles and see which barriers to put

THANK YOU FOR COMPLETING THE QUESTIONNAIRE

URUPAPURO RW' IBAZWA

UBUSHAKASHASTI BWEREKERANYE NO KUREBA UBURYO ABANA N'INGIMBI BABANA N'UBWANDU BW'AGAGAKOKO GATERA SIDA BABWIRWA KO BANDUYE MIMUJYI WA KIGALI.

IBAZWA RY'ABABYEYI

Amabwiriza

1. Tanga igisubizo cyimwe kuri buri nteruro
2. Uzuza mugakazu kamwe ukurikije aho wunva igisubizo cyawe kikunyuze muri buri interuro ukoresheje akamenyetso (urugero: +)

Icyicoro cya 1: Amakuru rusange

Numero y'urupapuro rw'ibazwa

Itariki

Ikigonderabuzima.....

Icyicoro cya 2 : Imyirondoro y'umwana

1. Imyaka
 - a. <30
 - b. 31-40
 - c. 41-50
 - d. >51
2. Igitsina:
 - a. gabo
 - b. gore
3. Izinary'umudugu utuyemo.....
4. Irangamimerere yawe?
 - a. Ntiwigeze ushaka?
 - b. Urubatse
 - c. Mubana k'ubwumvikane
 - d. Watandukanyen'uwobashakanye
 - e. Umupfakazi
 - f. Ibindi(Bivuge)
5. Ukwemera kwawe?
 - a. Umugatolika
 - b. Umuporotesitanti
 - c. Umuyisilam
 - d. Ibindi (Bivuge)
6. Waba warageze mu ishuli?

- c. Yego
- d. Oya
7. Niba ari yego n'ayahe mashuri warangije?
- e. Amashuliabanza
- f. Amashuliy'isumbuye
- g. Seritifika
- h. Kaminuzakuzamura
8. Ukora iki?
- f. Ntakazi
- g. Umworozi
- h. Urikorera
- i. Civil servant
- j. Ibindi (Bivuge)
9. Winjiza angahe kukwezi
- e. < 30 000
- f. > 30 000
- g. 30 000-100 00
- h. > 100 000
10. Upfana iki n'umwana?
- f. Mama we umubyara
- g. Papa we umubyara
- h. Nyirakuru
- i. Sekuru
- j. Ibindi (Bivuge)
11. Waba warigeze kumva kubyerekeye kubwira umwana ko yanduye agakoko gatera SIDA?
- b. Yego b. Oya
12. Niba ari yego. Ninde wabikubwiye?
- f. Umuganga
- g. Radio
- h. Television
- i. ibinyamakurubyanditse
- j. Ibindi (Bivuge).....
13. Waba warigeze uganira n'baganga kubyerekeye no kubwira abana ko banduye agakokogatera SIDA?
- b. Yego b. Oya
14. Wumva bifite akamaro kubwira umwana ko yanduye agakoko gatera SIDA?
- C. Yego (niba ari yego subiza ikibazo cya No.15)
- D. Oya (niba ari oya jya kukibazo cya No 16)
15. Niba ari yego tanga impamvu.....
16. Niba ari oya, niyihe mpamvu ituma utamubwira uko ahagaze?

- a. kumuha akato
- b. Ubwoba bw'uko umwana abyakira
- c. bishobora kwangiza umwana mu mutwe
- d. bishobora kumubabaza

17. Waba ufite gahunda yo kubwira umwana wawe koyanduye virus itera SIDA?

- a. Yego (niba ari yego jya ku kibazo cya 30)
- b. Oya

18. Ni kuyihe myaka azaba afite kugirango ubimubwire?

- <imyaka 7
- Hagati y'imyaka 7-10
- Hagati y'imyaka 10-13
- Hagati y'imyaka 13-19
- >imyaka 19
- Ntatarimwe

19. Waba waraganiriye n'umwana wawe ibyerekeye n'abasirikare b'umubiri?

- b. Yego
- b. Oya

20. Waba warabwiye umwana wawe izina ry'indwara?

- c. Yego
- d. Oya

21. Ni kuyihe myaka yamenye ko abana n'ubwandu??

- <7 years old
- 7-10 years old
- 10-13 years old
- 13-19 years old

24. Umwana yamenye ko yanduye agakoko gatera sida yiga mu mwaka wa kangahe?

- a. Ntiyiga
- b. Amashuliabanza
- c. Amashuliya'isumbuye
- d. Ibindi (Bivuge)

25. ubuzima bw'umwana bwari bumeze gute igihe yabwiye byuzuye ko yanduye agako gatera SIDA?

- a. Arembyecyane (arikwamuganga)
- b. Arwaye (Atarajyakwamuganga)
- c. Atarwaye
- d. Ibindi (Subanura)

37. Wigeze ugira imbogamizi mu guha umwana imiti bitewe nuko atazi impamvu ayifata?

b. Yego b. Oya

38. Umwana yabayarigeze agira ikibazocyogufatiraimitikugihacyangwakuyifataburiminsi?

a. Yego b. Oya

39. Ni iki wumva cy'ingenzi gituma utabwira umwana koyanduye agakoko gatera SIDA cyaganirwaho?

a. guhabwa akato?

b. Kumva ko umwana akiri muto

c. Impfunwe

d. uko umwana yabyakira

e. ubumenyi budahagije

f. Ibindi, sobanura.....

MURAKOZE GUSUBIZA IBI BIBAZO

STUDY QUESTIONNAIRE: ASSESSMENT OF DISCLOSURE PROCESS OF HIV STATUS TI INFECTED CHILDREN AND ADOLESCENTS IN KIGALI CITY

Section A: General information

Questionnaire number.....

Date

Health Center.....

Section B: Socio Demographic Characteristics and Background information of the child

1. Age
 - a. <7 Years old
 - b. 7-10 years old
 - c. 10-14 years old
 - d. 14-19 years old
2. Sex:
 - c. Male
 - b. female
3. Name of village where the child is coming from.....
4. What is your religion?
 - i. Catholic
 - j. Protestant
 - k. Muslim
 - l. Others(specify)
5. Have you ever attend school?
 - e. Yes
 - f. No
6. If yes what was the highest education level attained?
 - i. Primary education
 - j. Secondary education
 - k. Certificate
 - d. university level and above
7. Why do you come for visits at the health center at ARV service?
 - a. I come to take medications
 - b. My parents told me to come here
 - c. I have an appointment given by the health care worker
 - d. I come to take ARV medications
 - e. I don't know
 - f. Others (specify)

8. Have you been told that your illness is HIV?
- a. Yes
 - b. No
9. If yes, Who informed you of your HIV status?
- a. Caregiver
 - b. Health care worker
 - c. Others (specify)
10. What were your behaviour after this disclosure?
- a. I continued to take medications as usual
 - b. I felt of leaving these medications
11. Do you ever miss taking the medicines that you are supposed to take?
- a. Yes
 - b. No

If yes, Why?

12. Do you ever refuse to take the medicines that you are supposed to take?
- a. Yes
 - b. No
13. Do you ever not take the medicines because you do not want to take them in front of other people?
- a. Yes
 - b. No
 - c. If yes, what are the reasons?
 - a. I don't want to be rejected by friends or family members because of my illness
 - b. I don't want other children to know my status?
 - c. I feel like other children will avoid playing with me because of my HIV status?
 - d. Others (Specify): _____
14. Do you ever have problems taking the medicines because you do not know why you are taking them?
- a. Yes
 - b. No
- If yes, what are those problems?

15. Do you ever have problems taking the medicines on time or taking them every day?

a. Yes

b. No

URUPAPURO RW' IBAZWA

UBUSHAKASHASTI BWEREKERANYE NO KUREBA UBURYO ABANA N'INGIMBI BABANA N'UBWANDU BW'AGAGAKOKO GATERA SIDA BABWIRWA KO BANDUYE MIMUJYI WA KIGALI.

IBAZWA RY'ABANA N'ABANGAVU

Amabwiriza

1. Tanga igisubizo cyimwe kuri buri nteruro
2. Uzuza mugakaze kamwe ukurikije aho wunva igisubizo cyawe kikunyuze muri buri interuro ukoresheje akamenyetso (urugero:)

Icyicoro cya 1: Amakururusange

Numero y'urupapuro rw'ibazwa

Itariki

Ikigonderabuzima.....

Icyicoro cya 2 : Imyirondoro y'umwana

1. Imyaka:
 - a. <7 Years old
 - b. 7-10 years old
 - c. 10-14 years old
 - d. 14-19 years old
2. Igitsina:
 - a. gabo
 - b. gore
3. Izina ry'umudugudu utuyemo.....
4. Ukwemerakwawe?
 - a. Umugatolika
 - b. Umuporotesitanti
 - c. Umuyisilamu
 - d. Ibindi (Bivuge)
5. Waba warageze mu ishuli?
 - a. Yego
 - b. Oya
6. Niba ari yego n'ayahe mashuri warangije?
 - a. Amashuri abanza
 - b. Amashuri y'isumbuye
 - c. Seritifika

- d. Kaminuza kuzamura
7. Kubera iki uza kukigo nderabuzima muri serivise ya ARV?
- a. Gufata imiti
- b. Ababyeyi bambwiye ngo nze hano
- c. Abashinzwe ubuzima bambwiye kuzahano
- d. Gufata imitiya y'ubwandu
- e. Ntabwo mbizi
- f. Ibindi (Bivuge)
8. Waba warabwiye ko ubana n'ubwandu bw'agakoko gatera SIDA?
- a. Yego
- b. Oya
9. Niba ari yego, ninde wakubwiye ibyerekeye ko ubana n'ubwandu bw'agakoko gatera SIDA?
- a. Ukurera
- b. ushinzwe ubuzima
- c. Ibindi (bivuge)
10. Witwaye ute umaze kubimenya?
- a. Nakomeje gufata imiti nkuko bisanzwe
- b. Numvishe nareka gufata imiti
- c. Nahise ntekereza ko ngiye gupfa
- d. Ibindi.....
11. Ujya wibagirwa gufata imiti?
- a. Yego
- b. Oya

Niba ariyego, kubera iki?

.....

12. Waba warigeze kwanga gufata imiti?

- a. Yego
- b. Oya

13. Wigeze wanga gufata imiti kubera kwanga kuyifata abandi bantu bakureba?

- a. Yego
- b. Oya

14. Niba ariyego, ni'iyihe mpamvu?

- a. sinifuzaga ko banyanga kubera uburwayi bwanjye.
- b. Sinashakaga ko abandi bana bamenya ko mbana n'ubwandu
- c. Natekerezaga ko bagenzi banjye bakwanga kujya bakina nanjye kubera uburwayi bwanjye
- d. Ibindi(bivuge):_____

15. Wigeze ugira ikibazo cyo gufata imiti kuberako utazi impamvu uyifata?

a. Yego

b. Oya

Niba ari yego, nibihe bibazo?

.....
.....

16. Waba ugira imbogamizi mugufatira imiti kugihe cyangwa kuyifata buriminsi?

a. Yego

b. Oya

STUDY QUESTIONNAIRE: ASSESSMENT OF DISCLOSURE PROCESS OF HIV STATUS TO INFECTED CHILDREN AND ADOLESCENTS IN KIGALI CITY.

Instructions: Below are questions related to HIV disclosure process. Questions are itemised, please tick the most appropriate answer using (×) sign or another given instructions in the corresponding box. **(HEALTHCARE WORKER QUESTIONNAIRE)**

Section A: General information

Questionnaire number.....

Date

Health Center.....

SECTION B: DEMOGRAPHIC DATA

Please tick the relevant information

1. Gender

- a. Male
- b. Female

2. Age in years

- a. 15-20 years
- b. 21-30 years
- c. 31-40 years
- d. >40 years

3. Professional qualification

- a. Professional Nurse
- b. Counselor
- c. Social worker
- d. Other (specify)

4. What service are you working in?

- a. ART service
- b. outpatient service
- c. maternal ward
- d. antenatal care
- e. other, please specify....

5. Is disclosure guidelines available at the health center?

- a. Yes
- b. No

6. Is the formal guidelines help you to guide how to prepare and support caregivers to disclose to children?

a. Yes

b. No

7. Have you received specific training on pediatric HIV disclosure process?

a. Yes

b. No

8. Have you ever had a child living with HIV virus as a patient?

a. Yes

b. No

9. Have you ever discussed with parents about disclosure of hi/her living with HIV?

a. Yes

b. No

10. A child born with HIV can live to age 10 beyond

a. Yes

b. No

c. unsure

11. Age of disclosure

a. 5-7 years b. 8-10 years

c. 11-14 years d. 15-19 years

12. Who should disclose their HIV positive status to children?

a. Parents/ Primary caregivers

b. Health care providers

c. Both a and b together

d. Other please specify _____

13. What is the role of healthcare worker in disclosure?

a. supporting caregivers to disclose

b. helping the child to accept their status

c. providing continuous health education to children

d. providing ongoing counseling to caregivers and children

e. educating the child about the disease

f. providing information to caregivers and children

14. What are reasons for delaying disclosure?

- a. Afraid of stigma
- b. caregivers lack support to disclose
- c. fear of outcomes
- d. afraid the child will tell others about their HIV diagnosis
- e. fear of hurting the child

15. What are support needed by healthcare workers to facilitate disclosure to children and adolescents?

- a. Guidelines on disclosure counseling for children
- b. Counseling to be able to deal with HIV-infected child
- c. workshop and training on HIV management to increase their confidence in assisting caregivers to disclose
- d. Training on disclosure counseling to support HIV-infected children and adolescents to understand the disease.

URUPAPURO RW' IBAZWA

UBUSHAKASHASTI BWEREKERANYE NO KUREBA UBURYO ABANA N'INGIMBI BABANA N'UBWANDU BW'AGAGAKOKO GATERA SIDA BABWIRWA KO BANDUYE MIMUJYI WA KIGALI.

IBAZWA RY'ABABYEYI

Amabwiriza

1. Tanga igisubizo cyimwe kuri buri nteruro
2. Uzuza mugakaze kamwe ukurikije aho wunva igisubizo cyawe kikunyuze muri buri interuro ukoresheje akamenyetso (urugero:)

Icyicoro cya 1: Amakururusange

Numero y'urupapuro rw'ibazwa

Itariki

Ikigonderabuzima.....

Igika B: Imyirondoro

Hitamo igisubizo igikwiye

1. Igitsina:
 - a. Gabo
 - b. Gore
2. Imyaka
 - a. Imyaka15-20
 - b. Imyaka 21-30
 - c. Imyaka 31-40
 - d. >Imyaka40
3. Professional qualification
 - a. Professional Nurse
 - b. Counselor
 - c. Social worker
 - d. ibindi (bivuge)
4. Ukora muyihe servise?
 - a. Servise ya ART
 - b. serviseya outpatient
 - c. serviseya materinite

d. antenatal care

e. Ibindi, bivuge

5. Ese hari umurongongerwaho wokumenyesha abarwayi kobababana n;ubwandu bw'agakoko gatera SIDA mufite mu kigonderabuzima?

a. Yego b. Oya

6. Waba warahawe amahugurwa kur iHIV/AIDS?

a. Yego b. Oya

7. Waba warigeze kugira umurwayiw'umwana ubanana gakokogatera SIDA?

a. Yego b. Oya

8. Waba waraganiriye nababyeyi kubyerekeye no kumubwira ko abananagakokogatera SIDA?

a. Yego b. Oya

9. Umwana wavukanye agakoko gatera SIDA ashobo rakubahokurenzaimyaka 10

a. Yego b. Oya

c. Ntagihamya

10. wumva Imyaka yo kubimenyesha aruihi

a. imyaka 5 kugeza 7 b. imyaka 8 kugeza 10

c. imyaka 11 kugeza 14 d. Imyaka 15 kugeza 19

11. Ninde ugomba kubwira abana ko bafite agakoko gatera SIDA?

a. Ababyeyi/ Primary caregivers

b. abaganga

c. Bombi a na b barikumwe

d. Ibindi, bivuge _____

12. Inshingano z' umuganga mukubwira un_____na ko yanduye nizihe

a. gufasha ababyeyi gutanga ayo makuru

a. supporting caregivers to disclose

b. gufasha abana kwiyakira

c. Gutanga inyigisho zihoraho kubana

d. Gutanga ubujyanama buhoraho kubabyeyi n'abana

e. Kwigisha abana ibyerekeye n'indwara

f. Guha amakuru ababyeyi n'abana

13. Ni iyihe mpamvu ituma habaho gutinda kubimenyesha abana?

a. gutinya akato

b. ababyeyi badafite ubufasha buhagije

c. Ubwoba bw'ukobizagenda

d. Ubwoba bw'ukoumwana azabwira abandi ko yanduye agakokogatera SIDA

e. Ubwoba bwo kubabaza umwana

14. Ni ubuhe bufasha bukenewe n'abaganga ngo bafashe kubwira abana nabangavu ko babana n'ubwandu bw'agakoko gatera SIDA?

a. umurongo ngenderwaho mukubwira abana ningimbi ko baban anubwandu

b. Ubujiyanama kuburyo bitwara kubabana nababana n'agakokogatera SIDA

c. amahugurwa ahoraho mubyo kwita kubabana