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COLLEGE OF HEALTH SCIENCES

SCHOOL OF PUBLIC HEALTH

Prevalence, Associated Factors, Barriers and Facilitators of Disclosure of HIV Status to Sexual Partners among Young People Living with HIV/AIDS in Care at an Urban HIV Clinic, Kampala, Uganda

 \mathbf{BY}

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DECLARATION

I **Moses Mugerwa** declare that this research is my original work and has not been presented to any institution either partially or in total for any academic award, publication, or other use. Appropriate references have been given where information from other studies has been used. I therefore, submit this research in partial fulfilment of the requirements for the award of Master of Public Health at Makerere University.

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DEDICATION

This work is dedicated to my family especially my lovely mum Ms. Teopista Nakazibwe, my dear wife, Mrs. Jeninnah Mugabirwe and my children, siblings and friends who have been by my side, and the people living with HIV who accepted to build on the existing body of knowledge by offering time to participate in this research.

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ACRONYMS AND ABBREVIATIONS

ART Anti-Retroviral Therapy

C.O.E Center of Excellence

HIV Human Immunodeficiency Virus

IDI In-depth Interview

KI Key Informant

KII Key Informant Interview

MoH Ministry of Health

MSM Men Who Have Sex with Men

PHDP Positive Health Dignity and Prevention

PI Principle Investigator

PLWHA People Living with HIV/AIDS

PMTCT Prevention of Mother to Child Transmission

UNAIDS United Nations Programme on HIV/AIDS

UPHIA Uganda Population Based HIV Impact Assessment

U=U Undetectable = Un-transmissible

WHO World Health Organization

OPERATIONAL DEFINITIONS

Desire to disclose HIV status: This referred to the strong wish of a person living with HIV to share his/her status with another person.

Disclosure of HIV status: In this study, this referred to a person living with HIV/AIDs informing another person of his or her positive HIV status.

Recent HIV diagnosis: This meant a diagnosis of HIV that occurred less than a year from the date of the study interview with the participant.

Sexual partner: This is a person with whom someone has had sexual intercourse such as spouse, girlfriend or boyfriend, or any other that they may be with in a casual sexual relationship.

Undetectable = Un-transmissible (U=U): This meant that if the viral load of a person living with HIV was undetectable, they would not transmit HIV to their sexual partners.

Young People Living with HIV: This referred to people aged between 18 and 24 years living with HIV for this study.

ABSTRACT

Background: HIV/AIDs remains of great public health concern globally. The disclosure rates of positive HIV status by young people living with HIV (YPLHIV) to their sexual partners are low. This has consequences of poor ART adherence, interruptions in HIV care, viral non-suppression and ultimately new HIV infections. Disclosure among YPLHIV is influenced by various factors and different barriers and facilitators. Few studies have been done about disclosure to sexual partners among YPLHIV and worse still they are limited in Uganda. The objective of this study was to assess the prevalence, associated factors, barriers and facilitators of disclosure of HIV status to sexual partners by YPLHIV at the HIV clinic at Baylor Uganda.

Methods: The study used a mixed methods parallel approach. Using quantitative methods, 281 randomly selected sexually active YPHIV aged 18 to 24 years were interviewed for prevalence and factors associated with disclosure of HIV status to their sexual partners while 16 in depth interview were done to assess barriers and facilitators. Quantitative data was analyzed in STATA v.17 using modified Poisson regression to determine factors associated with HIV status disclosure. IDIs were conducted to assess the barriers and facilitators of HIV status disclosure to partners and analyzed using thematic analysis by the help of NVivo software.

Results: The prevalence of HIV status disclosure to sexual partners was 45.2%. Having a known HIV negative partner (aPR=0.6, P<0.001), being a complete orphan (aPR=1.4, P=0.022), knowing one's HIV status for >1 year (aPR=0.7, P<0.001), and having few sexual partners (aPR=1.7, P=0.013) were associated with HIV status disclosure to sexual partners. Health worker/peer support, nature and status of relationship, protection of sexual partners against contracting HIV, need for social and financial support were the major facilitators while fear of the sexual partners reaction, knowledge of undetectable HIV viral load being equal to no HIV transmission (U=U), the lack of confidence to open up, and negative influence from health worker and parents and nature of the relationship with the partner were the major barriers to disclosure.

Conclusion: There was a low HIV status disclosure rate among YPLHIV to their sexual partners at the clinic and it was influenced by various factors such as partner's status, number of sexual partners, orphan hood and duration knowing one's HIV status while lack of confidence, fear of partner's reaction and negative parent/health workers' influence were among the barriers. Counselling about disclosure to sexual partners, comprehensive health education, and creating supportive environments are crucial in improving disclosure rates, ultimately ensuring continuity of HIV care, and reducing HIV spread to sexual partners of YPLHIV.

1 CHAPTER ONE: INTRODUCTION

1.1 Introduction:

By 2021, 38.4 million people were living with HIV globally and out of these 1.5 million people living with HIV were newly infected (UNAIDS,2022) implying that the burden of HIV/AIDs remains a public health concern globally. Of the new infections, 1.3 million were among people aged 15+ years hence majority of the new infections are through the sexual route of transmission. Close to 25.6 million people living with HIV reside in the Sub Saharan Africa making it the region with the highest burden of HIV at 66% compared with other parts of the world (UNAIDS, 2022). In SSA, the prevalence of HIV status disclosure to partners ranges from 32% to 86.5% in different countries (Alemayehu *et al.*, 2014; Id *et al.*, 2019; EGPAF, 2017; Ambissa *et al.*, 2021). In Uganda, the HIV prevalence ranges from 2.1% in the Karamoja region to as high as 8.1% in the central region. (UPHIA, 2022).

The HIV burden is high among youth with an incidence being high among youth aged 15 to 24 years (8% and 25% for males and females respectively) globally. Also to note, adolescent girls and young women aged 15–24 years are greatly 3 times more endangered by the epidemic compared to their male age mates with over 4900 new infections weekly globally. (UNAIDS, 2022) By 2021, the prevalence of HIV was 2.0% among young women and 0.3% among young men aged 15 to 24 years in Uganda. Worse still, the viral load suppression is poor in this group at 54.7%, with rates of only 57.8% among young women and 43.5% among the young men according to the UPHIA report of 2020.

Disclosure of HIV status involves process of voluntary sharing one's positive HIV status with a significant other person. This person may be a relative, sexual or marriage partner, friend or health worker among others (Adam *et al.*, 2021; John and Chipwaza, 2022). Disclosure to sexual partners may be done individually or with assistance by another person such as a relative, health care provider and peer among others. (Kyaddondo *et al.*, 2013)

Disclosure also enables getting social support, proper adherence to ART and clinic appointments, and ultimately promoting prevention of HIV transmission(John and Chipwaza, 2022; Izudi *et al.*, 2021; Naigino *et al.*, 2017). Disclosure to sexual partners in particular enables an HIV negative partner two take precautionary measures and have safe sex, consistent condom use and to support their partner living with HIV socially, while for the HIV positive person, it aids prevention of reinfection with possibly drug resistant HIV strains. (Ssali *et al.*, 2010; Atwijukiire *et al.*, 2022)

1.2 Background:

In Uganda prevalence of HIV status disclosure to sexual partners has been reported as low as 57% (Ngonzi *et al.*, 2019) and may vary up to 83.7% (Batte et al., 2015) while for YPLHIV, (Ankunda, Atuyambe and Kiwanuka, 2016) found a very low prevalence of 31%, sero-status disclosure to partners in Kampala. The barriers to HIV status disclosure to partners generally include fear of the unknown outcomes that may include stigma, rejection, blame, abandonment, domestic violence, withdrawal of social and financial support and shame (Maeri et al., 2016, Rahmalia *et al.*, 2022). Also lack of disease symptoms facilitates concealing of one's status since the partner may not see signs of HIV infection and disease. (Rahmalia *et al.*, 2022)

Non-disclosure of HIV status to sexual partners may have consequences such as poor adherence to ART, taking ART in hiding, poor negotiation for safe sex, poor coping skills and psychological stress (Thoth *et al.*, 2014) leading to an increase in both vertical and sexual HIV transmission. Non-disclosure is associated with being in an abusive sexual relationship, not living with the partner, unsafe sexual practices such as multiple sexual partners, sex under influence of drugs like alcohol and inconsistent condom use during sexual intercourse, low social support from partner and also not knowing partner's HIV sero-status (Ambissa *et al.*, 2021).

Information about disclosure of positive HIV status to sexual partners among YPLHIV is scarce globally. Locally, studies have found disclosure as low as 31% among YPHLIV aged 15 to 24 years in Uganda (Ankunda, Atuyambe and Kiwanuka, 2016). Factors associated with disclosure among YPLHIV in Uganda may include number of sexual partners, knowing HIV status of the partner, socio economic dependency on the partner, HIV disease status, level of education, marriage or relationship status and poor communication skills (Deribe, Lingerh and Dejene, 2005; Kadowa and Nuwaha, 2009; Kiula, Damian and Msuya, 2013; Batte *et al.*, 2015; Id *et al.*, 2019) Non-disclosure to sexual partners in this group may lead to poor adherence to ART and interruption of routine HIV care by the YPLHIV.

Routinely, young people have been counselled by health workers, linked to peers for support and also helped by significant other people to disclose their positive HIV status to sexual partners. (Kyaddondo *et al.*, 2013). Media campaigns have been conducted and provision of IEC materials have also been used to encourage disclosure of positive HIV status to sexual partners. However, despite these efforts the disclosure rates remain sub optimal, and there is scarcity of data about the associated factors, barriers and facilitators of disclosure of positive HIV status to sexual partners of YPLHIV.

This study therefore sought to understand the prevalence of disclosure, its determinants, as well as barriers and facilitators of positive HIV status to sexual partners among YPLHIV in care at the Baylor Uganda HIV clinic so as to help health care providers understand and leverage on this information to improve rates of HIV status disclosure of positive HIV status to sexual partners by the YPLHIV in care.

2 CHAPTER TWO: LITERATURE REVIEW

2.1 Prevalence of disclosure of positive HIV status to sexual partners among people living with HIV

In Africa, the prevalence varies and has been reported to be as high as 90% in some parts of Sub Saharan Africa (SSA). The prevalence of HIV status disclosure to sexual partners varied between 76.3% and 86.5% in Ethiopia in the general population and among pregnant women respectively. (Endalamaw *et al.*, 2021; Ambissa *et al.*, 2021) In a study by Kidman and Violari, 2020, they characterized HIV disclosure among 250 youth with perinatally-acquired HIV (PHIV; age 13-24 years) living in Soweto, South Africa. Results showed that, 36% had self-disclosed their HIV status to at least one person and only 12% of sexually-active PHIV had disclosed their HIV status to their romantic partners. It was also not clear whether HIV disclosure alone led to positive impact.

Another study by Mengwai, Madiba and Modjadji, 2020 investigated the motivation to disclose or the decision to withhold one's HIV serostatus to one's partners and assessed the implications of non-disclosure on young peoples' sexual behavior and access to treatment. They conducted a cross-sectional survey with 253 youth aged 18–25 years receiving antiretroviral therapy in a health district in North West Province, South Africa. Their study results revealed that the prevalence of disclosure was low at 40% and they had various reasons for disclosure while over half (55%) had no intentions to disclose at all.

Another study carried out by (Genet, Sebsibie and Gultie, 2015) to assess the disclosure of HIV-positive status and its associated factors to sexual partners among 324 patients attending antiretroviral therapy (ART) at Mekelle Hospital, Tigray, Ethiopia showed that the overall HIV status disclosure to sexual partner was 57.4%. Among those who disclosed their HIV status, 58% of them told their partner after 1 month after diagnosis concluding that an HIV-positive status disclosure to a sexual partner in their study was lower than what was reported in other studies in Ethiopia. In Uganda the prevalence of HIV status disclosure to sexual partners in general is unknown however varies in different areas and has been reported as low as 57% (Ngonzi *et al.*, 2019) and may be as high as 83.7% (Batte *et al.*, 2015). Ngonzi *et al.*, 2019 did a mixed methods study among pregnant women whose age ranged between 18 to35 years attending antenatal care at Mbarara Regional referral hospital and this population indicated different social needs and did not account for the males.

Ankunda *et. al.* found a low prevalence of 31%, sero-status disclosure to partners in their study about sexual risk related behavior among YPLHIV aged 15 to 24 years in Kampala in 2016, lower than 73% found by (Naigino *et al.*, 2017) who carried out a mixed methods study. They also found out that 30% of the pregnant women reported unsafe sexual practices. Ankunda et al (2016) studied YPLHIV 15-24 years, however, they did not explore how disclosure was done and the outcomes. In Uganda, the prevalence of HIV status disclosure to partners in general reported in the studies of Batte *et al.*, 2015 as high as 83.8% whereas (Ankunda, Atuyambe and Kiwanuka, 2016) found a low prevalence of 31% disclosure of their HIV status to their partners. However, there is no data about disclosure to sexual partners by YPLHIV at the Baylor clinic.

2.2 Factors associated with disclosure of positive HIV status to sexual partners among people living with HIV

In a cross sectional study done in 2010, in Morogoro, Tanzania and it was found that being aged less than 25 years, knowing one's HIV status prior to pregnancy or discussion with partner about testing prior to the actual test favored disclosure of HIV status while socio economic dependency on the male partner was a great inhibitor to disclosure (Kiula, Damian and Msuya, 2013). Some of these factors also sufficed when Deribe, Lingerh and Dejene, 2005 conducted a cross sectional mixed methods study in Ethiopia and found that among men, knowing the partner's status and prior discussion on testing services to actual testing were the main motivators.

Among women, having had advanced HIV disease, low level education, being married or in a long-term relationship favored disclosure (Kiula, Damian and Msuya, 2013) similar to findings by Batte *et al.* (2015) in Uganda in which level of education affected disclosure though their study was limited to mothers within 2 years postpartum period. According to Dessalegn *et al.*, 2019, having enrolled on ART, being married or cohabiting were associated with higher rates of disclosure to partner but their study involved people of older age groups up to 60. These and other factors may significantly affect disclosure among YLHIV either positively or negatively.

Knowing of a partner's HIV status is likely to increase the chances of disclosure to one's partner (Id *et al.*, 2019, Genet, Sebsibie and Gultie, 2015) as is consistent condom use with partners (Greene *et al.*, 2020). Adeniyi *et al.*, 2021, in their study reported that use of leisure substances including alcohol may also negatively affect disclosure to partners and adherence to ART on the contrary was negatively associated with disclosure of positive HIV status to their sexual partners. This opposed findings in Debre where good adherence to ART was associated positively with disclosure to sexual partners (Shifraew *et al.*, 2021).

Dependence on partners for economic support such as rent, food and school fees were associated with a low disclosure rate as reported in Tanzania (Kiula, Damian and Msuya, 2013). In a cross-sectional study done in Mekelle Hospital in Ethiopia, it was found that the longer a person spent in HIV care and on ART, the higher were the odds of disclosing to their sexual partner (Genet, Sebsibie and Gultie, 2015). The education status of both the PLWHA and their partners may influence disclosure of HIV status to the partner. In a study done in Brazil, the illiterate PHLIV was more likely to disclose to his/her partner while having a literate spouse/sexual partner favored disclosure to them (Reis *et al.*, 2021).

2.3 Barriers and facilitators of disclosure of positive HIV status by people living with HIV to their sexual partners

Routine counseling by health care providers is one of the facilitators of disclosure of positive HIV status to partners of PLWHA (Alemayehu *et al.*, 2014). Gender differences also influence disclosure of HIV status as noted by Maeri *et al.*, (2016) who further reported that both men and women feared blame and accusation while women mainly feared rejection and gender-based violence as the frequently reported barriers to HIV status disclosure to partners. Also, barriers to disclosure among men included fear of their partners knowing about their infidelity while for women it was fear of partner violence and deprivation of social economic support from the partners. This concurs with Mengwai *et al.* (2020) who found that YPLHIV aged 18 to 25 years withheld disclosure due to fear of abandonment, stigma and discrimination, accusations of unfaithfulness, and partner violence.

Knowing a partner's HIV status may positively influence their partner living with HIV to disclose to them hence a facilitator for disclosure (Naigino *et al.*, 2017). Disclosure was found to be easier when facilitated by health workers at the facilities. No wonder couple's counselling and testing is encouraged as a start for disclosure in presumed hard situations (Maeri et al,2016). Having heard about HIV status disclosure by someone else to their partner may facilitate positive HIV status disclosure to one's partner. This could be from a friend, over mass media such as radio, television, newspapers or posters in the health facilities and even, social media (Taggart *et al.*, 2015).

Having an abusive relationship with the sexual partner may negatively influence one's intention to disclose and thereby creating a barrier to disclosure of positive HIV status to the partner(s). The fear of intimate partner violence and accusations of infidelity were among major barriers to HIV status disclosure as reported among women (Maeri et al., 2016; WHO, 2004). In the study

conducted by Rahmalia *et al.*, (2022) on women living with HIV in Indonesia, they found that fear of rejection was a barrier to disclosing HIV status to partners by these women. Perception that the current relationship has no prospects was found as a barrier to disclosure among postpartum women in South Africa (Adeniyi *et al.*, 2021).

Self- stigma or perceived external stigma may also be a barrier to disclosure of HIV status for many YPLHIV. There is fear that after disclosure their status may not be kept secret and they may be stigmatized and discriminated against by their partners and possibly other people in the community. In addition, some men felt it was their personal responsibility to protect their partners from HIV by informing them of their HIV status (Halkitis *et al.*, 2017). Similarly, postpartum mothers living with HIV reported fear of rejection, stigma, judgement, being in new or casual relationships, and having violent spouses among barriers to disclosure of HIV status to their partners (Adeniyi *et al.*, 2021).

In the study among PLWHA in Tanzania, they frequently reported harmony at home, desire for freedom to take medication in the presence of the partner and fear of partner finding out from other people or accidentally finding the ARV drugs as facilitators for disclosure of HIV status to spouses while fear of stigma, blame, rejection, abandonment, partner violence, were among the barriers reported (Sanga *et al.*, 2021). These are similar to some barriers found in a study about men who have sex with men as their partners (Halkitis *et al.*, 2017).

Dependence on the partner by YPLHIV for economic support may either facilitate or on the contrary be a barrier to HIV status disclosure to their partner. (Kadowa and Nuwaha, 2009) This may be due to the expectation of increment of support or on the contrary fear of losing this financial support (WHO, 2004). Financial independence may on the other hand facilitate disclosure of HIV status to one's partner as there may be a perception of having no financial gains to lose. Having a strong family support system possibly is a great facilitator of disclosure of HIV status to one's partner. (Li Li, 2007) This may be due to good social support and alternative economic support compared to YPLHIV with unstable families or extended family systems where the resources may be insufficient. Family members may even avail support in terms of disclosing the YPLHIV's status to the partner (Maman, van Rooyen, & Groves, 2014).

2.4 Summary of literature review

Considering available literature, disclosure rates are varied across different populations and geographical locations in Africa. On average, it is between 46% and 90% and as low as 31% among YPHLIV aged 15 to 24 years in some studies in Uganda. Most studies reviewed focused on pregnant and postpartum women, and adolescent girls and young women disclosing of HIV status to their partners. Only a few include males, yet minimal studies have been done in Uganda about this topic especially among YPLHIV.

While a number of studies have explored barriers and facilitators of disclosure of positive HIV status to sexual partners, very little has been done among of YPLHIV. Moreover, most of the available literature is older than 5 years, yet issues surrounding HIV are very dynamic. Hence this study is intended to close such gaps in literature by generating more information about the barriers, facilitators and current prevalence as well as factors associated with HIV status disclosure to partners among YPLHIV aged 18 to 24 years in care at the Baylor-Uganda urban HIV clinic.

3 CHAPTER THREE: PROBLEM STATEMENT, JUSTIFICATION, CONCEPTUAL FRAMEWORK

3.1 Problem statement

In Uganda , disclosure of HIV status to sexual partners has been as low as 31.1 % among young people living with HIV (Ankunda, Atuyambe and Kiwanuka, 2016). The magnitude of non-disclosure in the Baylor Uganda HIV clinic is unknown, yet it is one of the leading facilities in the country that treats HIV in young people. Moreover, non-disclosure affects adherence to ART and also leads to interruption of care. As a result, YPLHIV get high viral loads and this may result in ill health and transmission of HIV to their sexual partners. Several barriers to disclosure have been documented and may include fear of abandonment, physical violence, and stigmatization, loss of emotional and financial support, discrimination, accusations of unfaithfulness among others. (Deribe, Woldemichael, Wondafrash, Haile, & Amberbir, 2008; Dessalegn et al., 2019; Mengwai et al., 2020; Ngonzi et al., 2019; WHO, 2004).

YPLHIV (15-24) have the worst VL suppression rates among adults in Uganda (UPHIA, 2021), despite routine and intensified adherence given as standard of care. This partly is due to non-disclosure to sexual partners as commonly reported by PLHIV at the HIV clinics, moreover it affects adherence to ART and continuity in care. If disclosure rates of HIV status to sexual partners are improved, retention in HIV care at the clinic may improve as well as adherence to ART, ultimately improving viral load suppression rates and reduction in new HIV infections to sexual partners of YPHIV already in care.

At the Baylor Uganda HIV clinic, routinely, healthcare providers encourage disclosure through counselling and health education, create awareness about importance of status disclosure to sexual partners, routine counselling by health workers and peers to disclose their status to their sexual partners and linking them to HIV testing services. They are also provided IEC materials and reproductive health services such as STD treatment and condoms for safe sex practice. Despite these known benefits of HIV status disclosure to sexual partners and efforts undertaken by staff, the current prevalence and factors that influence HIV status disclosure to sexual partners by YPLHIV at the clinic is unknown. Worse still, there are no studies done specifically about disclosure of HIV status to sexual partners by YPLHIV in Uganda hence a study to determine the prevalence of their HIV status disclosure to sexual partners & understand why was handy.

This study therefore sought to determine the prevalence of HIV status disclosure to sexual partners and associated factors, barriers and facilitators among youth living with HIV in care at Baylor Uganda HIV clinic. Findings will help YPLHIV to know and plan to overcome the barriers to disclosure to their partners and the health workers to understand hence improve the disclosure to sexual partners among YPHLIV in their care, their viral load suppression and retention in care.

3.2 Justification of the study

Non-disclosure to sexual partners is among the causes of poor adherence hence high viral load among YPLHIV. Low viral load suppression rates among YPLHIV who are sexually active and of reproductive age fuels the HIV epidemic through new infections. This study is important in generating new information and giving insights about HIV status disclosure to sexual partners by YPLHIV in care. It has therefore added to the existing pool of knowledge about HIV status disclosure to sexual partners among YPLHIV and PLHA in care in general.

This information may be used by health care service providers in HIV clinics when counselling or assisting YPLHIV to disclose their HIV status to their sexual partners. This will help YPLHIV to overcome the barriers to disclosure to their partners, improve the disclosure rates among YPHLIV. Ultimately this will improve adherence to ART and continuity of care locally in the ART clinics and at national level, thereby accelerating the epidemic control of HIV in the HIV care programs.

3.3 A conceptual framework of factors, barriers and facilitators that influence HIV status disclosure to sexual partners among people living with HIV:

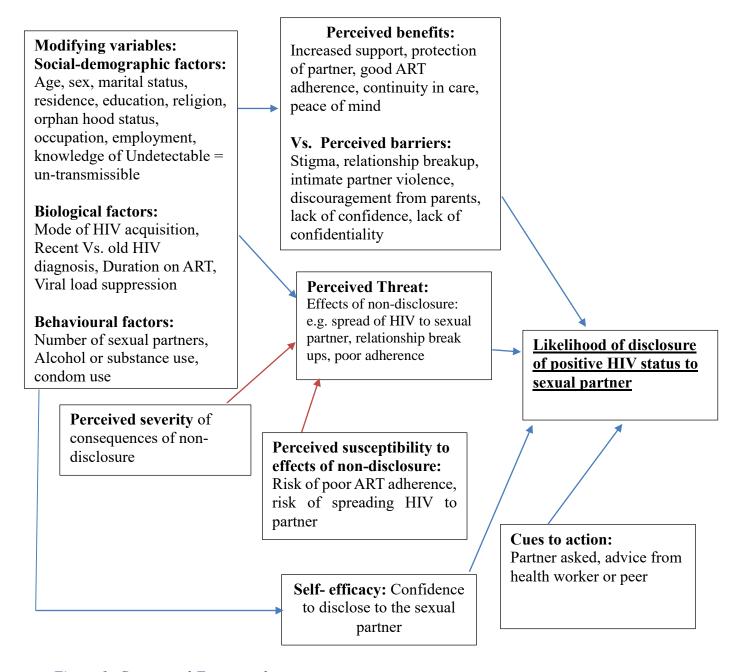


Figure 1: Conceptual Framework

Narrative: Using the health belief model shown in *figure 1*, different modifying factors that may contribute to one's intention to disclose their positive HIV status to their sexual partners may be socio- demographic, biological and behavioral. Socio-demographic factors such as age affect one's intention and readiness to disclose their HIV status to their partners based on their level of maturity and exposure in sexual or intimate relationships. Regarding gender, males and females play different gender roles. Depending on what to perceived threat, both genders may choose to disclose or not.

YPLHIV who have attained higher education level may possibly understand the importance of disclosure due to access to much information concerning HIV and disclosure more than those of lower education levels. YPLHIV in different occupations may differ in understanding the consequences of non-disclosure and hence might disclose better than others without enough knowledge. Being employed and financially independent may favor disclosure among YPHLIV to their partners since they may be able to live a fulfilled life even without a partner while those that are dependent on their partners may fear to disclose in view of losing their support financially. Other factors such as tribe, residence and religion may influence one's desire to disclose HIV status to partners due to the traditions and norms instilled in the YPLHIV by their societies. Mode of HIV acquisition can also influence one's feelings of guilt given the moral attachment of HIV infection acquisition such as being immoral if contracted through sexual intercourse versus innocently getting infected vertically.

Newly diagnosed YPLHIV may not easily disclose compared to those with old HIV diagnosis as they may still be in denial and have higher rates of self-stigma. Similarly, longer duration on art, and good viral load suppression status may positively influence one's confidence to disclose their status to their partner. Behavioral factors such as having multiple sexual partners and alcohol or substance use may negatively affect one's intention and ultimately ability to disclose. Various barriers such as fear of abandonment, stigma, poor communication skills, and experience of violence in the current or previous relationship can negatively impact one's desire to disclose their HIV status to their partners. While facilitators such as having a supportive partner, access to information, counselling, supportive families will enable disclosure to partners. These when balanced with different cues to action such as sharing of information among peers and support from relatives or counselors directly or be influenced by environmental factors, they influence self-efficacy and hence the likelihood of YPLHIV to disclose their HIV status to their partners.

4 CHAPTER FOUR: RESEARCH QUESTIONS AND OBJECTIVES OF THE STUDY

4.1 Research Questions

- 1. What is the prevalence of disclosure of HIV status to sexual partners among young people living with HIV in care at the clinic?
- 2. What factors are associated with disclosure of HIV status to sexual partners among young people living with HIV in care at the clinic?
- 3. What are the barriers and facilitators of disclosure of HIV status to sexual partners by young people living with HIV at the clinic?

4.2 General Objective

This study was aimed at determine the prevalence, associated factors and barriers and facilitators of disclosure of HIV status to sexual partners among young people living with HIV in care.

4.3 Specific Objectives

- 1. To determine the prevalence of reported disclosure of HIV status to sexual partners among young people living with HIV in care at the clinic
- 2. To determine the factors associated with reported disclosure of HIV status to sexual partners among young people living with HIV in care at the clinic
- 3. To identify barriers and facilitators of disclosure of HIV status to sexual partners by young people living with HIV in care at the clinic

5 CHAPTER FIVE: METHODOLOGY

In this chapter, methods for the different objectives were handled separately beginning with those of objectives 1 and 2 (prevalence and associated factors of HIV status disclosure) and those of objective 3 (barriers and facilitators of HIV status disclosure) were handled last.

5.1 Study design

The study used a mixed methods parallel design involving quantitative and qualitative methods. Quantitative methods were used to determine the prevalence and factors associated with reported disclosure of one's HIV status to their partner(s). On the other hand, qualitative methods were used to explore barriers and facilitators of disclosure using in-depth interviews among YPLHIV.

5.2 Study site

The study was carried out at Baylor Uganda HIV clinic located at Mulago National Referral Hospital within Kampala, Uganda. The clinic provides high quality pediatric, adolescent and adult health care, and clinical research to a clinic population of about 8,473 people living with HIV including the adults and/or caregivers to the children who are also living with HIV. Young people living with HIV (15 to 24 years) attending the clinic were about 2,974, approximately 35.1% of the clinic population at the time of the study.

The clinic serves a population that is composed mainly of residents of Kampala metropolitan and surrounding areas. Kampala district had a low HIV Viral load suppression prevalence of about 76.0% among adults aged 15 or more, versus the recommended 95% (UPHIA, 2021). This could partly be due to non-disclosure of HIV status to spouses or sexual partners. The clinic set aside special days in the week on which most YPLHIV were scheduled for their clinic visits and reviews.

On these days, the youth receive different counselling services about adherence, continuity of care and disclosure to significant others and most so their sexual partners. They also receive HIV testing services for their partners and sexual and reproductive health services such as family planning, condoms and sexually transmitted diseases testing and treatment. The challenge however that is, their specific barriers and determinants for disclosure are not clearly known to the health care service providers.

5.3 Study population

The study population was males and females living with HIV aged between 18 and 24 years old who were attending care and receiving antiretroviral therapy (ART) at Baylor Uganda HIV Clinic, Mulago, irrespective of mode of HIV acquisition, in current sexual relationships, or had been in a sexual relationship in the past 12 months prior to the study. According to the UPHIA report of 2022, the HIV prevalence among young adults could have been as high as 2.9% and 0.8% among young women and men respectively and yet the viral load suppression in this group is the lowest at 57.8% and 43.5% among female and male young people living with HIV respectively among the adult population living with HIV in Uganda (UPHIA, 2022).

5.4 Methods for objectives 1 and 2

5.4.1 Sample size determination

To determine the prevalence and factors associated with positive HIV status disclosure, a total of 281, minimum number of participants based on the calculation below were interviewed. The study sample size (n) was determined using the Leslie Kish formula as presented below:

$$\frac{n=z^2\times p\times q}{\delta^2}$$

Where:

n- The calculated study sample size.

z- The standard normal value at 5% level of significance.

 δ - The maximum permissible error.

p— The estimated prevalence of disclosure of HIV status among YPLHIV to their partners.

q=(1-p)— The estimated prevalence of non – disclosure of HIV status among YPLHIV to their partners. Following the adoption of prevalence estimates from a systematic review done by Endalamaw et al. (2021) about disclosure among PLWHA in general to their partners in Ethiopia. It showed a 76.03% prevalence of disclosure to partners. This was considered for calculation of 281 participants as (n) for this study as follows;

$$n = \frac{1.962 \times (0.7603) \times (1 - 0.7603)}{(0.05)^2}$$
$$= 280.0432818624 \approx 281$$

5.4.2 Sampling procedure

An appointment (EMRx) system was used on every clinic day to identify and approach potential participants and screen them for sexual activity, potential participants who reported recent sexual activity or being in an intimate relationship were asked to participate in the study. A sampling frame was then made and from this a study sample for the day was generated by assigning potential participants numbers that were randomly selected to get the day's interviewees. This was repeated on different days until the desired number of 281 participants was achieved for the first and second study objectives. The number of participant's interviewed varied on the different days depending on how busy the clinic was.

5.4.3 Inclusion and exclusion criterion

5.4.3.1 Inclusion criteria

The participants in the study included young men and women living with HIV aged between 18 and 24 years who at the time of the study were attending and receiving ART at Baylor Uganda HIV Clinic, Mulago. It did not matter the duration on ART but had to be in an intimate relationship then, or had been in a sexual relationship in the prior 12 months and consented to participate in the study.

5.4.3.2 Exclusion criteria

YPLHIV with mental impairment were excluded since this would affect their ability to comprehend the study procedures, offer informed consent to participate in this study and respond with proper judgement.

5.4.4 Study variables

5.4.4.1 Dependent variable

The dependent variable in this study was disclosure of HIV status to sexual partners by young people living with HIV aged 18 to 24 years. It was a categorical nominal variable measured as **'YES'** (coded as "1") and **'NO'** (coded as "0") depending on if the participant answered yes or no to having ever disclosed their HIV status to their sexual partner irrespective of how the disclosure was done.

5.4.4.2 Independent variables

The independent variables included socio-demographic characteristics (such as age, gender, marital status, religion, residence, education, occupation, employment, orphan hood status), awareness of undetected HIV viral load being equated to un-transmissible HIV infection (U=U)

and caregiver/treatment supporter), behavioral factors (e.g. nature of intimate relationship, sexual debut, previous relationships, substance use, disclosure to household member(s), disclosure to a friend(s), history of gender based violence), stigma and biological factors (such as mode of acquisition of HIV and new or old HIV diagnosis). In addition, history of HIV testing, ART status, recent Viral Load suppression status (VLSS) were also assessed and their measurement was as per table below.

Table 1: Measurement of study variables

| Category | Description | Measurement (see appendix II for codes) |
|--------------------|-----------------------------|--|
| Dependent variable | disclosure of HIV status to | Categorical nominal |
| Dependent variable | sexual partners | |
| | Socio-demographic | Age in full years (Numerical discrete |
| | characteristics | ratio) |
| | | Gender (Categorical nominal) |
| | | Marital status (Categorical nominal) |
| | | Religion (Categorical nominal) |
| | | Education level (Categorical ordinal) |
| | | Tribe (Categorical nominal) |
| Independent | | Palace of origin (Categorical nominal) |
| variables | | Residence setting (Categorical nominal) |
| | | Parents alive (Categorical nominal) |
| | | Employment status (Categorical nominal) |
| | Biological factors | All items therein (Categorical nominal) |
| | Behavioral factors | All items therein (Categorical nominal) |
| | Reasons to disclose my | All items there in (Categorical nominal) |
| | status to my sexual/ | |
| | intimate partner/spouse | |

5.4.5 Data collection method and tool:

Data was collected between February and April of 2023 at the Baylor Uganda C.O.E clinic by conducting face to face interviews.

To determine the prevalence and factors associated with HIV status disclosure to their sexual partners, an electronic pre-tested, researcher-administered structured questionnaire (see appendix ii) was used to collect data. It was made electronic using Kobo Toolbox software. Some of the questions were adopted from previous similar studies through review of literature. The information that was collected included the socio- demographic variables such as age, marital status, residence, employment, education level, religion and tribe. It also included the disclosure status to sexual partners (disclosed or not disclosed), to whom, reasons for disclosure or non-disclosure, partner's HIV status, sexual behavior and clinical variables among others.

The outcome variable was disclosure of positive HIV status to one's sexual partner(s), in both casual relationships and long-term relationships. Partnership status was a key explanatory variable, this looked at the nature of the relationship, multiple partnerships, and the living arrangements of the couple. Another key explanatory variable was the use of a condom during the last sexual encounter and consistency in condom use during sexual encounters of YPLHIV. Also, the duration on ART would aid the researcher to ascertain levels of HIV status disclosure because it comes with preparing and getting comfortable with one's own life and other people to open up.

After identifying potential participants, they were handed over to a research assistant in a separate or private room away from the routine clinic waiting area. The research assistant would then provide the potential participant (a YPLHIV) with information about the study and his or her consent was sought to participate. Information about the prevalence and factors associated with disclosure of HIV status by YPLHIV to their sexual partners was then collected using structured questionnaires administered by the researcher or research assistants in a face to face interview in a safe private space.

5.4.6 Data management

All questionnaires were checked for completeness, accuracy or errors at the end of every session. The information was entered and stored electronically on a password protected personal computer. Data collected was downloaded in MS Excel spreadsheet consisting of variables of interest such as disclosure of HIV status, socio-demographic characteristics (such as age, sex, residence, occupation, education level, religion and social support) and mode of HIV acquisition

among others. The data was then exported to STATA version 14.2, checked for normality and subsequent statistical analysis was done.

5.4.7 Data Analysis

Socio-demographic and other characteristics were summarized based on their type. Categorical variables were summarized using percentages and frequencies while numerical variables were summarized using means and standard deviations.

Objective one:

Prevalence of HIV disclosure was summarized as proportions, confidence intervals and presented using a pie chart.

Objective two:

A Poisson regression model, which was both bi-variable and multivariable, was used to examine factors associated to the disclosure of HIV status to sexual partners. Prevalence ratios (Incidence Rate Ratios) were reported as a result. From the bi-variable analysis, all factors that were significant at p < 0.2 or had potential risk factors (biological plausibility) were included in the multivariable regression model. The final level of statistical significance was set at $\alpha \le 0.05$.

5.4.8 Quality control and assurance

The data collection tool and the informed consent form were written in English however, they were interpreted to Luganda (the local language mainly used in Kampala and surrounding areas) for the participants who were not well conversant with English during the face to face interviews. They were reviewed by academic supervisors and mentor to ensure that they were appropriate for the study and adjustments were made for the semi structured questionnaire after it was pretested in an HIV clinic setting. Before data collection, it was ensured that there was an approved protocol with data collection tools to be used to collect the data, and guidance was shared with the research assistants on how to record and store it in the most appropriate and uniform way.

An approved semi-structured questionnaire was used to collect the required data for prevalence and factors associated with disclosure of HIV status to sexual partners. The semi structured questionnaire was pre-tested from the HIV clinic of St. Daniel Comboni Hospital, in Bushenyi District among YPLHIV aged 18 to 24 years to identify any missing important data fields and necessary adjustments were made. Standard measurements were used where applicable and maintained for consistency in recording responses to all questionnaires. The researchers ensured consistency with the required data formats and standard measurements for uniformity of records

and to avoid and minimize errors that may have occurred at further steps of data use after data collection. The data questionnaires were cross checked at the end of every interview to ensure that all data fields were filled and edited accordingly.

5.5 Methods for objective 3:

5.5.1 Research methods:

5.5.1.1 Study population:

The study population was males and females living with HIV aged between 18 and 24 years old who were attending care and receiving antiretroviral therapy (ART) at Baylor Uganda HIV Clinic, Mulago.

5.5.1.2 Selection of participants

To explore barriers and facilitators of positive HIV status disclosure, 16 participants were purposively sampled from the participants interviewed for study objectives 1 and 2 considering maximum variation in age, sex, occupation and nature of sexual relationship. Their selection was based on their understanding of the topic, experiences and willingness to participate in the IDIs. They were recruited for the in-depth interviews until data saturation about the topic was achieved.

5.5.1.3 Data collection tool

Qualitative data was collected using an in-depth interview guide. This was used to explore the barriers and facilitators of HIV status disclosure to their sexual partners.

5.5.1.4 Data collection procedures:

In-depth interviews were conducted using an interview guide, the discussions were recorded using a voice recorder as audio and short hand-written notes were made whenever these were acceptable to the participants. The voice record was later transcribed and translated and stored as word documents for analysis.

5.5.1.5 Data management

The audio recorded interviews were transcribed and simultaneously translated to word documents and stored as PDF documents for easy storage and analysis. Access to all data was only limited to the study team involved in collection, transcription for audio recorded information and analysis and stored in password protected documents.

5.5.1.6 Data analysis

To explore the barriers and facilitators of HIV status disclosure by YPLHIV to their partners, data from the in-depth interviews (IDIs) was analyzed as follows. After IDIs, the audio recordings were transcribed and translated to word documents. They were proof read and reread several times for familiarization with the data. Different codes were generated and these were used in developing a code book. The code book was fed into NVivo software alongside all transcripts. The transcripts were then all coded and codes merged to generate different categories and the finally emerging themes. The data was then analyzed by thematic analysis approach.

5.5.2 Quality control and assurance

The data collection tool and the informed consent form were written in English however, they were interpreted to Luganda (the local language mainly used in Kampala and surrounding areas) for the participants who were not well conversant with English during the face to face interviews. The in-depth interview guide was adjusted slightly in the subsequent interviews after the initial first interviews. The interviewers followed the interview guide and only made necessary adjustments in the course of the subsequent interviews to generate as much information about important issues and asked questions in a non-stigmatizing but simple manner so as to obtain as much correct information and allow participants to be as free as possible. The research team was also asked to take extra precautions especially when collecting, recording, and storing data so as not to miss any information during in-depth interviews.

5.6 Ethical Considerations

Approval for this study was sought from the Higher Degrees Research and Ethics Committee (HDREC) of Makerere University School of Public Health. Similarly, permission was sought formally from research directorate of Baylor Uganda to conduct the study at their health facility ART clinic. Informed consent was sought from potential participants before taking part in the study. Data collection was conducted with utmost privacy and participant information was treated with confidentiality during data collection, storage and analysis. Unique participant identifiers were used when collecting and storing data and only the research team had access to the participants' confidential data. Data was stored under lock and key and only on research specific computers and hard drives.

5.7 Dissemination of study findings

This dissertation report was prepared for submission to Makerere University Directorate of Research and Graduate Studies as a partial requirement for the award of a degree of Master of Public Health. A debrief was done as a continuous professional development (CPD) session to the clinic staff at Baylor Uganda, HIV clinic where the study was conducted. A manuscript was prepared for publication in a scientific journal as well as presentation at different fora and scientific conferences whenever an opportunity is available.

6 CHAPTER SIX: RESULTS

6.1 Results for Results for Objectives 1:

Socio-demographic characteristics of the participants:

The mean age of study participants was 21 years with 1.9 standard deviation. The majority (61.2%) of participants were females, lived in urban areas (74.4%), and were coming from central Uganda (68.7%). By religion, Catholics comprised the majority (28%) A bigger number of participants were single (73.7%) though sexually active. The study sample was fairly learned as about 76.1% of the study participants had attained secondary and above levels of education while majority were casual workers (43.8 %) as per table 2.

Table 2: Socio-demographic Characteristics of participants

| Variable | Overall (N=281) | Disclosure status | |
|--------------------------|-----------------|-------------------|------------|
| | | Yes (n=127) | No (n=154) |
| Gender n (%) | | | |
| Male | 109 (38.8) | 30 (23.6) | 79 (51.3) |
| Female | 172 (61.2) | 97 (76.4) | 75 (48.7) |
| Marital status | | | |
| Divorced/Separated | 5 (1.78) | 4 (3.2) | 1 (0.7) |
| Married/ Cohabiting | 69 (24.56) | 46 (36.2) | 23 (14.9) |
| Never married/ Single | 207 (73.67) | 77 (60.6) | 130 (84.4) |
| Education level | | | |
| Primary and below | 67 (23.84) | 32 (25.2) | 35 (22.7) |
| Secondary and above | 214 (76.16) | 95(74.8) | 119 (77.3) |
| Location | | | |
| Rural | 72 (25.6) | 29 (22.8) | 43 (27.9) |
| Urban | 209 (74.4) | 98 (77.2) | 111 (72.1) |
| Current Employment n (%) | | | |
| Business | 10 (3.6) | 7 (5.5) | 3(2.0) |
| Casual work | 123 (43.8) | 56 (44.1) | 67 (43.5) |
| Formal employment | 13 (4.6) | 5 (4.0) | 8 (5.2) |
| Student | 81 (28.8) | 30(23.6) | 51 (33.1) |
| Unemployed | 54 (19.2) | 29(22.8) | 25 (16.2) |
| Religion, n(%) | | | |
| Anglican | 70 (24.9) | 27 (21.3) | 43 (27.9) |
| Born again/Pentecostal | 73 (26) | 33 (26.0) | 40 (26.0) |
| Catholic | 79 (28.1) | 38 (30.0) | 41 (26.6) |
| Moslem | 51 (18.2) | 23 (18.1) | 28 (18.2) |
| Others | 8 (2.9) | 6 (4.7) | 2 (1.3) |
| Place of Origin | | | |
| Central | 193 (68.7) | 89 (70.1) | 104 (67.5) |
| Northern | 8 (2.9) | 3 (2.4) | 5 (3.3) |
| Eastern | 38 (13.5) | 17 (13.4) | 21 (13.6) |
| Western | 42 (15)) | 18 (14.2) | 24 (15.6) |
| | | | |

Majority (90%) of the participants reported that they were infected with HIV through the mother to child transmission (MTCT), took ARVs once daily (91.1%), used anti-retroviral (ARV) drugs for more than five years by the time of the study (93.6%) and with a suppressed VL (87.5%). Almost all (98%) the participants were in WHO treatment stage 1. Much as over 39.1% of the participants had more than one sexual partner, only 68 (24.2%) participants reported consistent condom use. Only a few participants used alcohol (15.7%) and other leisure substances (4.3%) as in the table 3.

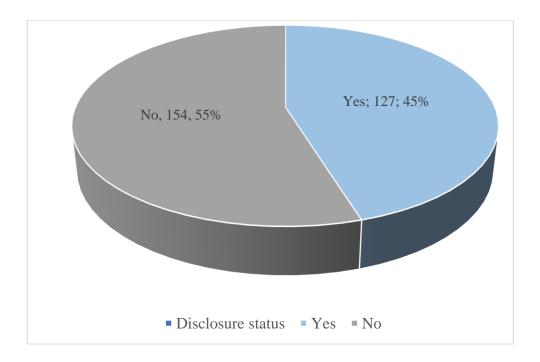
Table 3: Other characteristics of Young People Living with HIV/AIDS in care at Baylor Uganda who participated in the Study

| Variable | Overall N=281) | Disclosure status | |
|------------------------------|----------------|-------------------|------------|
| | · | Yes (n=127) | No (n=154) |
| Mode of HIV infection, n | | | |
| (%) | | | |
| Consensual sex | 14 (5) | 9 (7.1) | 5 (3.3) |
| Mother-to-child transfusion | 253 (90) | 112 (88.2) | 141 (91.6) |
| Others | 14 (5) | 6 (4.7) | 8 (5.2) |
| ART frequency, n(%) | | | |
| Once | 256 (91.1) | 111 (87.4) | 145 (94.2) |
| Twice | 25 (8.9) | 16 (12.6) | 9 (5.8) |
| Duration on ART, n(%) | | | |
| ≤5 years | 18 (6.4) | 10 (7.9) | 8 (5.2) |
| >5 years | 263 (93.6) | 117 (92.1) | 146 (94.8) |
| WHO treatment stage, n(%) | | | |
| Stage 1 | 276 (98.2) | 124 (97.6) | 152 (98.7) |
| Stages 2 and 3 | 5 (1.8) | 3 (2.4) | 2 (1.3) |
| Recent Viral load | | | |
| suppressed | | | |
| Yes | 246 (87.5) | 113 (89.0) | 133 (86.4) |
| No | 20 (7.1) | 10 (7.9) | 10 (6.5) |
| I don't know | 12 (4.3) | 2 (1.6) | 10 (6.5) |
| Not applicable | 3 (1.1) | 2 (1.6) | 1 (0.7) |
| Knowledge of U=U, n(%) | | | |
| False | 8 (2.9) | 2 (1.6) | 6 (3.9) |
| I don't know | 63 (22.4) | 19 (15.0) | 44 (28.6) |
| True | 210 (74.7) | 106 (83.5) | 104 (67.5) |
| Number of sexual partners | | | |
| More than two | 49 (17.4) | 15 (11.8) | 34 (22.1) |
| One | 171 (60.9) | 82 (64.6) | 89 (57.8) |
| Two | 61 (21.7) | 30 (23.6) | 31 (20.1) |
| Condom use, n(%) | | | |
| All the times | 68 (24.2) | 19 (15.0) | 49 (31.8) |
| At most times | 24 (8.5) | 12 (9.5) | 12 (7.8) |
| Never | 96 (34.2) | 50 (39.4) | 46 (29.9) |
| Some times | 93 (33.1) | 46 (36.2) | 47 (30.5) |
| Use of Alcohol n(%) | | | |
| No | 237 (84.3) | 102 (80.3) | 135 (86.7) |
| Yes | 44 (15.7) | 25 (19.7) | 19 (12.3) |
| Use of leisure substances | | | |
| other than alcohol, n(%) | | | |
| No | 269 (95.7) | 122 (96.1) | 147 (95.5) |
| Yes | 12 (4.3) | 5 (3.9) | 7 (4.6) |
| | | | |

Prevalence of HIV status disclosure to sexual partners:

Overall, disclosure of HIV status among study participants was low. The prevalence of HIV status disclosure among the study participants was 45.2% (95% CI: 39.2-50.9) as per figure 2 below.

Figure 2: Pie chart showing prevalence of HIV status disclosure by YPLHIV to their partners



Results for objective 2: Factors associated with HIV status disclosure to sexual partners of YPLHIV.

At multivariable analysis, religion, place of origin, orphan hood status, duration knowing one's own HIV status, viral load suppression status, knowledge of U=U, number of sexual partners and known partner's HIV status were significant predictors of disclosure of one's positive HIV status to their sexual partner(s).

Participants who knew their spouse/partner was not living with HIV versus one who knew their partners as living with HIV had a 40% lower prevalence of disclosure to their sexual partners (aPR= 0.6, 95% CI: 0.459, 0.727, P<0.001). YPLHIV who had only one or no biological parents alive were 1.4 times more likely to disclose their HIV status to their sexual partners than those who had both parents alive (aPR=1.4, 95% CI: 1.045, 1.746. P= 0.022). YPLHIV who had known their HIV status more than a year prior to the study were less likely to disclose their HIV status to their sexual partners compared to those who had known in a year or less (aPR= 0.2, 95% CI: 0.138, 0.447. P <0.001).

Those who reported not to know about undetectable viral load being equated to un-transmissible HIV had lower prevalence of disclosure of their HIV status to their sexual partners of 0.7 times that of those who reported that it was true (95% CI: 0.505, 0.998, P= 0.049). YPLHIV who had one sexual partner or two sexual partners had 1.5 times 1.7 times respectively, higher prevalence of disclosure of their HIV status to their sexual partners than those with more than two sexual partners. (95% CI: 0.962, 2.274. P=0.075) and (95% CI: 1.124, 2.636. P= 0.013) respectively. These findings are as reflected in table 4.

Table 4: Factors associated with HIV status disclosure to sexual partners among YPLHIV.

| Variables n (%) Gender | Yes (n=127) | cPR (95%CI), P-value | aPR (95%CI), P-value |
|---|-------------|----------------------------|----------------------------|
| Female | 97 (76.4) | 2.0 (1.470, 2.857) < 0.001 | 1.2 (0.916,1.698) 0.159 |
| Marital status | , | | , , |
| Never married/single | 77 (60.6) | 1 | |
| Married/cohabiting | 46 (36.2) | 1.8 (1.405, 2.287) < 0.001 | 1.1 (0.845, 1.378) 0.539 |
| Divorced/separated | 4 (3.2) | 2.2 (1.339, 3.453) 0.002 | 1.3 (0.622, 2.894) 0.453 |
| Religion | , | | , , , |
| Anglican | 27 (21.3) | 1 | 1 |
| Catholic | 38 (30.0) | 1.2 (0.857, 1.814) 0.248 | 1.6 (1.156, 2.132) 0.004 |
| Moslem | 23 (18.1) | 1.2 (0.765, 1.787) 0.47 | 1.6 (1.066, 2.258) 0.022 |
| Born again/Pentecostal | 33 (26.0) | 1.2 (0.794, 1.730) 0.425 | 1.2 (0.829, 1.622) 0.387 |
| Others | 6 (4.7) | 1.9 (1.181, 3.201) 0.009 | 1.7 (1.173, 2.560) 0.006 |
| Place of Origin | , , | | , , , |
| Central region | 89 (70.1) | 1 | 1 |
| Eastern region | 17 (13.4) | 1.0 (0.660, 1.427) 0.878 | 1.1 (0.802, 1.514) 0.551 |
| Western region | 18 (14.2) | 0.9 (0.634, 1.361) 0.707 | 1.2 (0.805, 1.670) 0.428 |
| Northern region | 3 (2.4) | 0.8 (0.328, 2.018) 0.656 | 1.9 (1.113, 3.317) 0.019 |
| Both parents alive | ` ' | | , , , |
| Yes | 35 (27.6) | 1 | 1 |
| No | 92 (72.4) | 1.4 (1.009, 1.844) 0.044 | 1.4 (1.045, 1.746) 0.022 |
| Duration knowing own HIV | 7 | | , , , |
| status | | | |
| =1 year</td <td>4 (3.15)</td> <td>1</td> <td>1</td> | 4 (3.15) | 1 | 1 |
| >1 year | 123 (96.85) | 0.7 (0.375, 1.201) 0.179 | 0.2 (0.138, 0.447) < 0.001 |
| VL suppressed | | | |
| Yes | 113 (89.0) | 1 | 1 |
| No | 10 (7.9) | 1.1 (0.687, 1.724) 0.718 | 0.8 (0.511, 1.116) 0.159 |
| I don't know | 2 (1.6) | 0.4 (0.101, 1.298) 0.119 | 0.4 (0.192, 0.928) 0.032 |
| If your VL is suppressed, | | | |
| you cannot spread HIV to | | | |
| your sexual partner (U=U) | 106 (02.5) | 1 | 1 |
| TRUE | 106 (83.5) | 1 | 1 |
| FALSE | 2 (1.6) | 0.5 (0.148, 1.661) 0.255 | 1.2 (0.536, 2.697) 0.655 |
| I don't know | 19 (15.0) | 0.6 (0.401, 0.891) 0.012 | 0.7 (0.505, 0.998) 0.049 |
| Number of sexual partners | 15 (11 0) | 1 | 1 |
| More than Two | 15 (11.8) | 1 | 1 |
| One | 82 (64.6) | 1.5 (0.966, 2.375) 0.07 | 1.5 (0.962, 2.274) 0.075 |
| Two | 30 (23.6) | 1.6 (0.962, 2.574) 0.071 | 1.7 (1.124, 2.636) 0.013 |
| Partner's HIV status | 05 (50.4) | 1 | 1 |
| Positive | 85 (79.4) | 1 | 1 |
| Negative | 22 (20.6) | 0.6 (0.558, 0.722) < 0.001 | 0.6 (0.459, 0.727) < 0.001 |

6.2 Results for Objective 3: Barriers and facilitators of HIV status disclosure to sexual partners

As part of the qualitative component for this study, a total of 16 in-depth interviews were conducted. Most of the participants (81.2%) were aged between 21-24 years, majority being male 9 (56.2%) and females 7(43.8%). With regard to relationships, 7 (43.8%) reported being in casual or boyfriend/girlfriend relationships with just a quarter (25%) reporting to be married. Findings are reported below beginning with the barriers.

Participants reported barriers to disclosure, which are categorized mainly in five themes i.e. 1) fear of the reaction of sexual partners, 2) the lack of confidence to open up, 3) knowledge of undetectable HIV viral load being equal to non-transmission of HIV (U=U) 4) negative influence from relatives/caregivers, and 5) nature of the relationship with the partner.

Fear of the partners' reaction following disclosure of HIV status:

Most of IDI participants reported fear of the partners' reaction as a barrier to disclosure of their HIV status to the partners. Those who thought that disclosure could lead to relationship break up or worse still intimate partner or gender-based violence and death preferred not to disclose. How the YPLHIV perceived the magnitude of effects of disclosure or non-disclosure also either inhibited them from disclosing to their sexual partners as seen in the excerpts below.

"Still those thoughts of maybe he can kill me or he can leave me and such things". **Female IDI**22 years

"...but now it's still scaring me because I was very ready, but still I have to first get advice and every person I get..., even that friend of mine just told me don't bother the man will kill you." female IDI 22 years

Lack of confidence to open up affects disclosure:

It was also found that many YPLHIV lacked the confidence to discuss their HIV status before their sexual partners. While some were just shy and they found it hard to open up to their sexual partner and as such some of the participants had low self-efficacy and fear of the unknown outcome were barriers to disclosure to their partners.

"The first point is fear, you ask yourself how I am going to tell her ...you can even meet her when you are ready to disclose to her, but due to fear you fail to tell her and change the topic...." Male IDI-21 years

Some participants were influenced by the lack of confidentiality of their partners not to disclose to them about their status for fear that they would tell their private information to non-significant other persons.

"... because if someone gets to know your status, some of them are not good in keeping secrets, ... and start to talk about you and you know how rumors move in the community". Female IDI 23years

Uncertainty about society and community response, in particular stigma. They reported fear to be stigmatized by the partners and the society amongst which they stay. They felt to be at a threat of being discriminated against and complicating their life after disclosure in the community. "Me I fear to be discriminated and they told me... but people would say that "you have bought samosas from Nalongo who is HIV positive..." Female IDI 22 years

Knowledge of undetectable HIV viral load being equal to non-transmission of HIV: Some participants who knew that with a suppressed HIV viral load, there is minimal risk of transmission, did not perceive their partners to be susceptible to consequences of non-disclosure especially HIV infection and therefore this inhibited disclosure of HIV status to their sexual partners as they saw no threat to their health or that of their partners.

"Personally, I might fail to tell her that I am HIV positive; my viral load is suppressed because I take my drugs well and I cannot spread HIV ..." Male IDI-20 years

"... the level I am at, I cannot spread HIV because I adhere well to my treatment.". Male IDI-20 years

Negative influence from relatives/caregivers:

Other (few) participants, expressed the fear of partner reaction to have come from their relatives, who thought the consequences might be severe. Consequently, being discouraged them from disclosing their HIV status to their partners. This also negatively impacted on their decision to disclose as reported by some YPLHIV during the IDIs.

"...before going there, my grandmother told me that do you want the man to cut you into pieces after telling him or to kill you? Since then, I have never told him anything about that because my grandmother made me afraid, she told me scary words". Female IDI 22 years

"Because there is my aunt, I had told that let me go and disclose it to the man, but she told me to ask God to have mercy on you, to keep quiet and not to tell him. People die with their secrets, that's what she told me and every person I share it with just says don't bother". Female IDI 22 years

Some participants reported that upon advice from health care providers, they would delay disclosure to their partners until an appropriate time when ready to disclose.

"So, when I got him, there is a counsellor here whom I consulted... ... she told me when time comes you will tell him but don't tell him now." Female IDI 24 years

Nature of the relationship with the partner:

For some participants, perceiving their relationships as not being long term negatively influenced them from disclosing their HIV status to their sexual partners. This is because they perceived themselves to be at risk of consequences of disclosure.

"...laughs, I am waiting for everything to finish, we first do give away (traditional pre-wedding ceremony) then we wed, ah..." Female IDI 24 Years

Similarly, **facilitators** on the other hand were also categorized in four major themes namely: 1) health worker and peer support, 2) nature and state of relationship with partner, 3) protection of sexual partners against contracting HIV, 4) need for social and financial support.

Health worker and peer support:

Assistance from peers and health workers facilitated disclosure to sexual partners as reported by majority of the participants. This could be in form of advice or helping them to openly communicate with their partners. Sharing knowledge about disclosure of HIV status to sexual partners was found to be an important facilitator for YPLHIV to disclose. To some, it was the wakeup call (cue to action) that they should actually disclose to their partners.

"I am thankful because we used to have meetings here every Saturday and they helped me to take away that fear. In those meetings there was a lady who told us that, any one should not fear to disclose to his or her partner that he has HIV." Male IDI 23 years

"You may find they (health workers) can even explain to her better than me and manage to convince her that the level I am at, I cannot spread HIV because I adhere well to my treatment. Maybe that can make it easy for me as an individual than it would be when I go alone" Female IDI 21 years

Nature and state of relationship with partner:

Many YPLHIV perceived having long term relationships leading to marriage or having children as being less susceptible to consequences of disclosure. As a result, this facilitated them to disclose to their partners as it was perceived beneficial in the long run to have healthy relationships and families.

"...I have a child so we sit and see where the wrong is, then I advise her in case she is not taking well her drugs and tell her that you have taken the medicine very well because you are breast feeding..." Male IDI 25 years

"My problem is about giving birth, if I am to give birth, in the hospital how do I do it?" **Female**IDI 24 Years

A participant in a healthy relationship reported that her sexual partner asked about her HIV status and this was a reminder for her to open up. In this case, partners taking charge of their health and initiating discussions about HIV status or testing was a facilitator but also a cue to action to YPLHIV disclose to their sexual partners.

"And I wanted to tell him that time because he also insisted on me to go for testing." Female IDI 24 years

While for some participants, non-disclosure of their status to their partners would be the reason their partners would break up with them. Winning trust in the relationship facilitated such participants to disclose to their partners as they perceived disclosure as beneficial in this way.

"...because there is a boyfriend I got and my siblings did not want him for me and they disclosed to him, then he got very angry because I had not told him, so I told this one because I didn't want to repeat the same mistake." **Female IDI-24 years**

"... I feared that if I don't tell her she will land on my documents because I have a book which we use, she can read it and even sees the drugs. so, I said if I hide it and she finds out, it will be very dangerous and it can make her feel bad, so that is why I told her ..." Male IDI 23 years

Also, interestingly, a participant reported ending a relationship as a benefit HIV status disclosure and that this would facilitated some YPLHIV to disclose to their sexual partners. He reported that the sexual partners would not continue with the relationship if they learnt about his positive HIV status.

"There are even people who always intend to get rid of people... You can find someone, they are HIV positive, but the pressure they get from the wife prompts them to tell them the truth and for the sake of getting rid of her." Male 19 years

Protection of sexual partners against contracting HIV:

Much as most participants were less worried about reinfection and cross infection with HIV from the interviews, some participants thought that their partners were at risk of contracting HIV infection from the YPLHIV if they had not disclosed to them and this was what them to disclose to their sexual partners about their HIV status.

"I told my girlfriend, I have ever told her that I am infected with HIV..., for her she is negative and me I am infected, so to protect her from getting infected," Male **IDI 20 years**

"So, don't fear to disclose to your partner and it also helps to reduce the spread of HIV". Male IDI-24 years

Need for social and financial support:

While some YPLHIV did not disclose for fear of loss of support, a number of participants perceived disclosure as beneficial as it would increase support from their partners. This support could be in form of basic needs, finances, psychosocial support as well as adherence support to their ARVs as reported during the interviews.

"You tell a person when at least you need assistance from that person ..." Male IDI 23 years

"...we help each other in reminding me about time for my drugs, about my appointment and encouraging me because I may delay to see the counsellor but we sit together and agree".

Male IDI-24 years

7 CHAPTER SEVEN: DISCUSSION OF RESULTS:

Prevalence of HIV status disclosure to sexual partners:

The prevalence of HIV status disclosure among YPLHIV to their sexual partners was approximately 45.2%. This rate was higher than the prevalence rates found in previous studies conducted by Ankunda et al. (2016) in Kampala (31%) and Greene et al. (2019) in Nairobi among women (34%) but comparable to prevalence rates of 46.2% among women living with HIV in Côte d'Ivoire (Becquet et al., 2007) and 40% in South Africa (Mengwai, Madiba, & Modjadji, 2020).

In comparison to studies conducted in Southern Ethiopia (90%), Ethiopia (86.5% and 82.5%), and Côte d'Ivoire (73%) (Alemayehu et al., 2014; Ambissa et al., 2021; Dessalegn et al., 2019; EGPAF, 2017), the disclosure rate in this study remained very low. The difference in disclosure rates could be due to difference in the locations and age difference of the study populations. However, the low disclosure rate in this study can be partly attributed to barriers reported by YPLHIV in the study such as lacking the confidence to disclose and fear of stigma, relationship break up and intimate partner violence among others as noted in the IDIs.

Factors associated with positive HIV status disclosure to sexual partners:

In this study religion, place of origin, orphan hood status, duration knowing one's own HIV status, viral load suppression status, awareness of U=U, number of sexual partners and known partner's HIV status were significant predictors of disclosure of one's positive HIV status to their sexual partner(s) at multivariable analysis.

Female gender was independently found to be a significant predictor, which aligns with studies conducted in other regions, such as Zimbabwe and South Africa (Shamu et al., 2014)(Mengwai, Madiba and Modjadji, 2020), where women living with HIV showed a higher prevalence of disclosing their positive status to partners. This could be attributed to traditional gender roles and the desire to gain trust from potential spouses, making women more inclined to open up about their status. Gender differences were also found to influence HIV status disclosure to sexual partners in East African communities, as reported by Maeri et al. (2016).

Having ever been married independently was positively associated with disclosure of HIV status to sexual partners as it was with YPLHIV who had one sexual partner at multivariable analysis. This finding is consistent with studies conducted by Kiula, Damian and Msuya, 2013, Id *et al.*,

2019 and Endalamaw *et al.*, (2021) who reported higher rates of disclosure among individuals in long-term relationships or marriage.

Partial or total orphan status was positively associated with disclosure of one's HIV status to sexual partners in this study. The explanation for this may be more need for social and financial support from their partners as compared to those with both parents alive. This concurs with findings among YPLHIV in South Africa in which social support from the family was found to negatively affect disclosure to their sexual partners (Kidman and Violari, 2020). Knowledge of one's HIV status for a longer period was negatively associated with disclosure of HIV status to sexual partners. This agrees with findings in South Africa by Adeniyi *et al.*, 2021, who in their study reported that adherence to ART on the contrary was negatively associated with disclosure of positive HIV status to their sexual partners. This might be a result of having a good health status which may help conceal signs and symptoms of HIV from the sexual partners.

The lack of awareness that the analogy of U=U is true was negatively associated with HIV status disclosure to sexual partners by YPLHIV. People who know that when one's VL is suppressed, the risk of HIV transmission is minimal, may be more willing to open up to their sexual partners about their HIV status as they can easily enlighten them and also convince them to stay in the relationship. In this study, having a detectable viral load and not being aware of their most recent VL status were negatively associated disclosure of positive HIV status to sexual partners. This could be due to poor adherence to ART by participants who had not disclosed to their partners more so if they were living together. This was in agreement with Melis Berhe *et al.*, 2020 who found that having a suppressed VL was positively associated with disclosing HIV status to sexual partners among PLHIV in Ethiopia. Knowledge of a sexual partner's HIV status as negative was negatively associated with disclosure of positive HIV status to sexual partners. This may be due to fear of breaking up of their relationships and intimate partner violence as it came out in the IDIs.

Originating from the northern part of the country was positively associated with disclosure of to sexual partners. This could be as a result of the different culture and morals, social support and upbringing in the different regions of the country. Similarly, subscribing to Catholic faith and Islam were positively associated with disclosure to sexual partners. This still may be due to the morals and role of religious leaders in these sects towards the fight against HIV.

Barriers and facilitators of HIV status disclosure to sexual partners

The barriers to disclosure of HIV status to sexual partners cited by YPHLIV which included fear of partners' reactions after disclosure, this could have been stigma and discrimination, breaking up of relationships, intimate partner violence such as emotional violence and physical harm among others. On the other hand, some participants had the will to disclose but lacked the confidence to open up about the positive HIV status before the partners while others could not confide in their partners.

Surprisingly, there was hesitancy to disclose confidence given by the knowledge of U=U that they would not infect their partners since they were well adherent on ART. These could explain the low disclosure rates observed in this study and are similar to those from earlier studies elsewhere. (Thoth *et al.*, 2014)(Deribe *et al.*, 2012) (Mengwai, Madiba and Modjadji, 2020) The facilitators of disclosure of HIV status to sexual partners as mentioned during IDIs by YPHLIV such as the need for support both socially and financially which may explain why those who had both parents alive were less likely to disclose their HIV status to their sexual partners.

Prevention of HIV transmission to the sexual partners just like in earlier studies elsewhere (Mengwai, Madiba and Modjadji, 2020) came out commonly among the facilitators for HIV status disclosure to the partners. proper adherence to treatment, health care providers' and peer support (Kidman and Violari, 2020) (Melis Berhe *et al.*, 2020), knowledge of U=U, winning trust, discussions about HIV with partners and prospects of long term and positive relationships (Endalamaw *et al.*, 2021) like in earlier studies were also found in this study and may explain why some of the participants disclosed to the partners. Contrary (Maman, van Rooyen, & Groves, 2014) who found that family members may avail support in terms of disclosing the YPLHIV's status to their partner, in this study, we found that some parents prohibited YPHLIV to disclose to their sexual partners.

Study limitations:

Reported disclosure of HIV status to sexual partners was a limitation because, due to the sensitive nature of the topic concerning HIV infection and sexual relationships, there is a possibility that participants may have provided socially acceptable responses. However, efforts were made to minimize this by clearly explaining the study objectives, justifying its importance in helping other young people living with HIV, and ensuring confidentiality.

Viral load suppression status was based on reports of most recent VL from participants yet it may fluctuate in between visits to the clinic or scheduled tests. This could be solved by including bio specimen collection of blood for VL testing in future studies to get the actual representation of how VL status may influence disclosure of HIV status to sexual partners.

Study strengths:

The study used data collected primarily and hence were able to get as much variables and thoughts as possible from the participants. Also, a mixed methods approach was employed which generated explanation for the rates of disclosure to sexual partners through detailed discussion with some of the participants in the in-depth interviews through triangulation of results/findings.

8 CHAPTER EIGHT: CONCLUSION AND RECOMMENDATIONS

8.1 Conclusion

In conclusion, this study revealed a low HIV status disclosure rate of 45% among young people living with HIV in care at the Baylor Uganda HIV clinic. Having both parents alive, long duration knowing one's own HIV status, having an unsuppressed viral load, high number of sexual partners and having known a partner's HIV status as negative were negatively associated with disclosure of IV status to sexual partners. Fear of partner's action after disclosure, lack of confidence to disclose and knowledge of the U=U analogy were among the major barriers to disclosure of HIV status to sexual partners. Addressing these barriers and promoting open communication, comprehensive health education, and supportive environments are crucial in improving disclosure rates, ensuring continuity of HIV care, and reducing HIV spread to sexual partners of YPLHIV. If not addressed, these observed low disclosure rates are likely to worsen and negatively impact the current achievements of HIV prevention and epidemic control.

8.2 Recommendations

In order to improve the rates of HIV status disclosure among young people living with HIV (YPHIV), it is essential to empower YPLHIV in care with knowledge that with an undetectable HIV viral load, they may not infect their sexual partners (U=U), counsel them about proper adherence to maintain suppressed HIV viral loads, stick to one sexual partner and the importance of disclosure of one's HIV status to their sexual partner. Especially the YPLHIV with negative sexual partners should be supported to disclose to them.

This can be done by health care service providers, parents and peers through peer to peer interactions. Additionally, it is crucial for health workers to raise awareness in communities about the reduced risk of HIV transmission if PLHIV are supported to adhere to their ART and continue in care so as to alleviate fears of sexual partner reactions when disclosed to about one's positive HIV status. These actions may improve the disclosure rates of HIV status to sexual partners, promote adherence to anti-retroviral therapy (ART), and ultimately reduce HIV transmission.

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APPENDICES

Appendix I: Informed Consent for Participation in HIV status disclosure study among Young People Living with HIV (YPLHIV)

TOPIC: Prevalence, Associated Factors, Barriers and Facilitators of Disclosure of HIV Status to Sexual Partners among Young People Living with HIV/AIDS in Care at an Urban HIV Clinic, Kampala, Uganda

INTRODUCTION: I am Moses Mugerwa, a student of Master of Public Health at Makerere University, School Public Health. Currently I am conducting research on experiences, barriers, facilitators and factors associated with HIV status disclosure to sexual partners among young people living with HIV aged 18 to 24 years in care at the Baylor Uganda clinic.

PURPOSE: This research study aims to determine the prevalence, factors associated with reported disclosure and explore experiences, barriers and facilitators of disclosure of HIV status to sexual partners among young people living with HIV in care at Baylor Uganda HIV clinic.

PROCEDURES: As a participant, you will be asked to participate in a 15-20-minute interview today and share your views on the topic of discussion. There are no right or wrong answers to the questions asked during the interview and all your opinions will not be judged. All information will be kept confidential. Note that you may further be asked to participate in another interview exploring barriers and facilitators of disclosure of HIV status to partners.

RISKS OF PARTICIPATION: There are less than minimal risks associated with the study. While Participants may get emotional during the interview, you do not have to answer questions that make you feel uncomfortable or offended but you are requested to answer as much as possible. Your information and views will be treated with confidentiality.

BENEFITS: There are no direct benefits to being in this research study but your participation in this study may help improve disclosure and its outcomes among people living with HIV and especially those in your age category.

REIMBURSEMENT: You will be compensated with 10,000/= (Ten thousand shillings only) for your time while participating in this research study.

CONFIDENTIALITY: During this research study, information will be collected from you but only I or my research staff will access it. However, should there be a risk anyone else gets access to it outside of this study, each participant is assigned a unique study identification number that we will use on all data collection forms. Only research staff will know your study identification number. No names or identifying information will be included in public reports

of this research. All research forms will be stored in locked cabinets and password-protected computer files that only research staff can access.

VOLUNTARY PARTICIPATION: Your participation in this research study is voluntary and you will not be coerced to participate if you do not wish to. Declining to participate will not affect the services you receive from this clinic. Even after you agree to participate in the research or sign the informed consent document, you may decide to leave the study at any time without any penalty.

CONTACT INFORMATION: If you have any other questions or concerns about this study, or your rights as a research participant you may contact the Principal Investigator Moses Mugerwa on telephone number 0773181442. If you have any questions concerning your rights as a research participant that have not been answered by the investigator or if you wish to report any concerns about the study, you may contact me or you may also reach out to the Makerere University School of Public Health, Higher Degrees Research and Ethics committee (HDRECH) IRB on Telephone number 0393291397.

SIGNATURE: I have read or been informed about this research. I have had the opportunity to ask questions about it and my questions been answered to my satisfaction. I hereby consent to voluntarily participate in this research study and understand that I have the right to withdraw at any time without any consequences.

| Name of study participant | Signature | Date |
|---------------------------|-----------|------|
| | | |
| Name of the Researcher | Signature | Date |

Appendix II: Research Questionnaire on the study of factors associated with HIV status disclosure among Young People Living with HIV (YPLHIV)

Introduction:

Dear respondent, my name is **Moses Mugerwa**, a final year master's student at Makerere University conducting a study titled; "Prevalence, Associated Factors, Barriers and Facilitators of Disclosure of HIV Status to Sexual Partners among Young People Living with HIV/AIDS in Care at an Urban HIV Clinic, Kampala, Uganda"

The study is in partial fulfilment of the requirements for the award of a Master of Public Health of Makerere University. You have been identified as one of the people who can provide important information. I kindly request you to answer the questions sincerely and accurately. The information will only be used for academic purposes and it will be treated with maximum confidentiality. Thank you for your kind cooperation.

| Participant's Number: | Date: |
|-----------------------|-------|
| | |

| Serial No. | Question | Response | Code |
|------------|-------------------------------|-----------------------------------|------|
| DEMOGR | APHIC CHARACTERISTIC | S (circle or tick all that apply) | |
| 1 | Gender | 1) Male | 1 |
| | | 2) Female | 2 |
| | | | |
| 2 | Age (in years) | 4) 26 - 17 - 17 - 17 | |
| 3 | What is your marital status? | 1) Married/ cohabiting | 1 |
| | | 2) Single | 2 |
| | | 3) widowed | 3 |
| | | 4) Divorced/ separated | 4 |
| 4 | What is your religion? | 1) Anglican | 1 |
| | | 2) Catholic | 2 |
| | | 3) Moslem | 3 |
| | | 4) Born again | 4 |
| | | 5) Others | 5 |
| | | (specify) | |
| 5 | What is your highest level of | 1) None | 1 |
| | education you attained? | 2) Primary | 2 |
| | | 3) Secondary | 3 |
| | | 4) Tertiary | 4 |
| 6 | Employment status | 1) Formal employment | 1 |
| | | 2) Casual work | 2 |
| | | 3) Student | 3 |
| | | 4) Unemployed | 4 |
| 7 | What is your tribe | 1) Muganda | 1 |
| | | 2) Musoga | 2 |
| | | 3) Munyankole | 3 |
| | | 4) Mukiga | 4 |
| | | 5) Mutooro | 5 |
| | | 6) Acholi | 6 |
| | | 7) Lango | 7 |
| | | 8) Alur | 8 |
| | | 9) Karamajongo | 9 |
| | | 10) Mugisu | 10 |
| | | 11) Other (specify): | 11 |
| 0 | Tudianta a 1 C 1 1 | 1) C 1 | 1 |
| 8 | Indicate your place of origin | 1) Central region | 1 |
| | | 2) Eastern region | 2 |
| | | 3) Western region | 3 |
| | | 4) Northern region | 4 |
| | | 5) Other (specify): | 5 |

| 9 | Where are you staying | | |
|-------|----------------------------------|--------------------------------------|---|
| | Currently (district)? | Please list: | |
| 10 | Is it an urban or rural setting? | 1) Urban | 1 |
| | | 2) Semi-urban | 2 |
| | | 3) Rural | 3 |
| 11 | Are both your parents still | 1) Yes (Non – Orphan) | 1 |
| | alive? | 2) Only mother alive | 2 |
| | | 3) Only father alive | 3 |
| | | 3) Both died | 4 |
| 12 | Who are you currently | 1) Both parents | 1 |
| | staying with? | 2) Mother only | 2 |
| | | 3) Father only | 3 |
| | | 4) Guardian | 4 |
| | | 5) Spouse/partner | 5 |
| | | 6) Siblings | 6 |
| | | 7) Close relative (uncle, aunt, etc) | 7 |
| | | 8) Alone | 8 |
| | | 9) Others | 9 |
| | | (specify) | |
| 13 | Who in your circles do you | 1) Parent | 1 |
| | know that is living with | 2) Sibling | 2 |
| | HIV/AIDs? | 3) Friend | 3 |
| | | 4) Spouse/partner | 4 |
| | | 5) Workmate | 5 |
| | | 6) Close relative (uncle, aunt, etc) | 6 |
| | | 7) None | 7 |
| | | 8) Others. Specify: | 8 |
| 14 | How did you know that they | 1) The person told me | 1 |
| | are living with HIV? | 2) Someone else told me | 2 |
| | | 3) Accidentally got to know (e.g. | 3 |
| | | Came across medicines, medical | |
| | | documents, others) | |
| | | 4) Others | 4 |
| BIOLO | GICAL FACTORS (circle or tick | all that apply) | |
| | | | |

| 15 | When did you learn that you | 1) 3 months ago | 1 |
|----|-----------------------------|-------------------------|---|
| | were living with HIV? | 2) 6 months ago | 2 |
| | | 3) A year ago | 3 |
| | | 4) More than a year ago | 4 |

| | with HIV? | 2) Non-consensual sex (e.g. rape, defilement) | 2 |
|-------|---------------------------------|---|---|
| | | 3) Blood transfusion | 3 |
| | | 4) Mother to child transmission | 4 |
| | | 5) Other (please specify): | 5 |
| 17 | Are you taking antiretroviral | 1) Yes | 1 |
| | medication (ARVs)? | 2) No | 2 |
| | | If No go to question 20 | |
| 18 | How many times do you take | 1) Once a day | 1 |
| | your ARVs in a day? | 2) Twice a day | 2 |
| | | 3) Other (Specify): | 3 |
| 19 | How long have you spent | 1) Less than 3 months | 1 |
| | taking ARVs? | 2) 3 to less than 6 months | 2 |
| | | 3) 6 to 12 months | 3 |
| | | 4) More than 1 year, < 5 years | 4 |
| | | 5) More than 5 years | 5 |
| 20 | What is the current WHO | 1) Stage I | 1 |
| | HIV clinical stage (look to | 2) Stage II | 2 |
| | patient record)? | 3) Stage III | 3 |
| | | 4) Stage IV | 4 |
| | | 5) Not specified | 5 |
| 21 | Has your most recent viral | 1) Yes | 1 |
| | load been suppressed? | 2) No | 2 |
| | | 3) I don't know | 3 |
| | | 4) Not applicable | 4 |
| 22 | If my viral load is | 1) True | 1 |
| | undetectable, I cannot spread | 2) False | 2 |
| | HIV to my partner(s) | 3) I don't know | 3 |
| | | 4) Not applicable | 4 |
| BEHAV | VIORAL FACTORS: (circle or ticl | x all that apply) | |
| 23 | Do you currently have a | 1) Yes | 1 |
| | sexual partner(s)? | 2) No | 2 |
| 24 | How many sexual partners | 1) One | 1 |
| | do you have? | 2) Two | 2 |
| | - | 3) More than one | 3 |

1) Consensual sexual intercourse

How did you get infected

16

| 25 | Have you ever talked to your | 1) Yes | 1 |
|----|------------------------------|--|---|
| | partner(s) about HIV | 2) No | 2 |
| | testing? | | |
| | | | |
| 26 | When do/did you carryout | 1) I don't / never test at all | 1 |
| | HIV testing with your | 2) Always before sexual intercourse | 2 |
| | partner(s)? | 3) After sexual intercourse | 3 |
| 27 | Do you take alcohol? | 1) Yes | 1 |
| | | 2) No | 2 |
| | | If No, go to question 29 | |
| 28 | How often do you take | 1) Daily | 1 |
| | alcohol? | 2) Once a week | 2 |
| | | 3) Twice a week | 3 |
| | | 4) Other (please specify): | 4 |
| 29 | Have you used or currently | 1) Yes | 1 |
| | use any leisure substance(s) | 2) No | 2 |
| | other than alcohol? | | |
| | | If yes, go to question 32 | |
| 30 | What substance(s) exactly? | 1) Cigarettes | 1 |
| | , , | 2) Marijuana | 2 |
| | | 3) Cocaine | 3 |
| | | 4) Shisha | 4 |
| | | 5) Other (please specify): | 5 |
| 31 | If yes, how often do you use | 1) Once a month | 1 |
| | these substance(s)? | 2) Once every 2 weeks | 2 |
| | , , | 3) Once a week | 3 |
| | | 4) More than once a week | 4 |
| | | 5) Daily | |
| 32 | Did you use a condom | 1) Yes | 1 |
| | (protection) at your last | 2) No | 2 |
| | sexual encounter? | | |
| 33 | How often do you use a | 1) At all times | 1 |
| | condom during sexual | 2) At most times | 2 |
| | intercourse? | 3) Some times | 3 |
| | | 4) Never | 4 |
| | | EXUAL PARTNERS (circle or tick all that apply) |) |
| 34 | Have you ever disclosed | 1) Yes | 1 |
| | your HIV status to someone? | | 2 |
| | | If No, go to question 40 | |
| 35 | If yes, who was this person? | 1) Parent | 1 |
| | | 2) Sibling | 2 |
| | | 3) Friend | 3 |

| | | 4) Workmate | 4 |
|----|--|--|--------|
| | | 5) Close relative (uncle, aunt, grand | 5 |
| | | parent, etc) | |
| | | 6) Others | 6 |
| 36 | Have you ever disclosed | 1) Yes | 1 |
| | your HIV status to your | -, | |
| | sexual partner(s)? (this could | 2) No | 2 |
| | be your spouse, boyfriend/ | 2) 110 | 2 |
| | girlfriend, other sexual | | |
| | partner) | | |
| 37 | Have you disclosed your | | |
| 31 | HIV status to your most | 1) Yes | 1 |
| | recent sexual or intimate | -, | |
| | partner? | 2) No | 2 |
| | partier. | | |
| 38 | If you have more than 1 | | |
| | partner in the recent 1 year, | | |
| | have you disclosed your HIV | 1) Yes | 1 |
| | status to all your sexual or | 2) N- | 2 |
| | intimate partner(s)? (this | 2) No | 2 |
| | could be your spouse, | | |
| | boyfriend/ girlfriend, other | | |
| | sexual partner) | | |
| 39 | If you have ever disclosed | I heard about disclosure on the radio | 1 |
| | your HIV status to your | 2) I was advised by a counsellor or health | 2 |
| | intimate partner, what mostly | worker | 2 |
| | pushed you to disclose? | 3) I saw an advert4) I became ill | 3 4 |
| | | 5) My partner asked me about my HIV status | |
| | | 6) I shared about it with a friend or relative | 6 |
| | | 7) Others (specify) | 7 |
| 40 | If you disclosed your status to your | 4) | _ |
| | sexual partner, were you helped by anyone? | 1) Yes | 1 |
| | | 2) No | 2 |
| | | 2) 110 | 2 |
| | | | |
| 41 | If you were helped by | 1) Biological parent | 1 |
| | another person to disclose to | 2) Guardian | 2 |
| | your partner, who was it? | 3) Sibling | 3 |
| | | 4) Counsellor / Health worker | 4 |
| | | 5) Friend | 5 |
| | | 6) Close relative (uncle,aunt, | 6 |
| | | grandparent, etc) | |
| | 1 | 7) Others (specify): | 7 |

| 42 | If you have ever disclosed to your partner, how did you | I personally talked to my sexual partner about my HIV status | 1 |
|-----|---|--|--------|
| | make your intimate partner know your HIV status? | 2) Someone helped me to directly talk to my external partner about my HIV status | 2 |
| | | I intentionally exposed/showed my HIV clinic records or ARVS | 3 |
| | | My partner accidently saw my HIV clinic records or ARVS | 4 |
| | | 5) I asked my partner to escort me to the clinic, then he got to know | 5 |
| | | 6) We took an HIV test together | 6 |
| | | 7) My partner found out from another | 7 |
| | | person/people without my consent 8) Others, Specify: | _ |
| | | o) others, speerly | 8 |
| 43 | If you have a recent or | 1) I am just not ready to tell | 1 |
| | current sexual partner you | 2) My partner may stigmatize me because of | 2 |
| | have not disclosed your HIV | my status 3) My partner may abandon/reject me | |
| | status to, what are the | because of my status | 3 |
| | reasons? | 4) My partner may withdraw social support | 4 |
| | | 5) My partner may physically harm me | 5 6 |
| | | 6) I believe it is not necessary7) Others, specify: | 7 |
| | | ,, others, specify. | , |
| 44 | Reasons to disclose n | ny status to my sexual/intimate partner/spouse | |
| A). | I feel stressed of hiding my | 1) Yes | 1 |
| | status | 2) No | 2 |
| B). | I need financial support | 1) Yes | 1 |
| | | 2) No | 2 |
| C). | I do not attend my HIV clinic | 1) Yes | 1 |
| | visits freely | 2) No | 2 |
| D). | Adherence to treatment may | 1) Yes | 1 |
| | be affected if I don't disclose | 2) No | 2 |
| E). | I need to pan for my future | 1) Yes | 1 |
| | | 2) No | 2 |
| F). | I need social support from | 1) Yes | 1 |
| (C) | my partner | 2) No | 2 |
| G). | I need to protect my partner | 1) Yes | 1 |
| | from getting infected with HIV | 2) No | 2 |
| 45 | Do you know your current or | 1) Yes | 1 |
| | most recent partner(s) current HIV status? | 2) No | 2 |

| 46 | Please indicate your | 1) Positive for HIV | 1 |
|----|-----------------------|---------------------|---|
| | partner's HIV status. | 2) Negative for HIV | 2 |

- 47. Please choose any other suggestions for HIV Status Disclosure to Sexual partners among young people living with HIV (circle or tick all that apply)
 - 1) Sensitisation of the community against stigmatizing PLWHA
 - 2) Health facilities to provide ongoing counseling sessions tailored to disclosure of HIV status to our partners
 - 3) Health workers to anonymously disclose and test our partners when we fear to do so in confidentiality
 - 4) Educate the communities that if one's HIV viral load is undetectable, they cannot spread

HIV

| 5) | Any other | ways? | (kindly o | outline): | | | | | |
|----|-----------|-------------------|-----------|-----------|---|---|---|---|---------------|
| | ••••• | • • • • • • • • • | | | • | • | • | • | • • • • • |
| | | | | | | | | | |

Thank you for your time and participation in this study!

Appendix III: Informed consent for Participation in an In-depth Interview

INTRODUCTION: My name is Moses Mugerwa, a student of Master of Public Health at Makerere University School Public Health is currently conducting research on 'Prevalence, Associated Factors, Barriers and Facilitators of Disclosure of HIV Status to Sexual Partners among Young People Living with HIV/AIDS in Care at an Urban HIV Clinic, Kampala, Uganda'

PURPOSE: This research study aims to determine the prevalence, factors associated with reported disclosure, and explore barriers and facilitators of disclosure of HIV status to sexual partners among young people living with HIV in care at Baylor Uganda HIV clinic.

PROCEDURES: You will be interviewed about facilitators and barriers to HIV status disclosure to intimate partner(s) of young people living with HIV. As a participant, you will be asked to participate in a 30 to 40-minute interview and share your views on the topic of discussion. There are no right or wrong answers to the questions asked during the interview and all your opinions will not be judged. For purposes of capturing experiences for this part of the study, the discussion may be recorded so that it is later written out to capture as much detail as possible. All information will be kept confidential.

RISKS OF PARTICIPATION: There are less than minimal risks associated with the study. While Participants may get emotional during the interview, you do not have to answer questions that make you feel uncomfortable or offended but you are requested to answer as much as possible. Your information and views will be treated with confidentiality.

BENEFITS: There are no direct benefits to being in this research study but your participation in this study may help improve disclosure and its outcomes among people living with HIV and especially those in your age category.

REIMBURSEMENT: You will be compensated with 10,000/= (Ten thousand shillings only) for your time while participating in this research study.

CONFIDENTIALITY: During this research study, information will be collected from you but only I or my research staff will access it. However, should there be a risk anyone else gets access to it outside of this study, each participant will be assigned a unique study identification number that we will use on all data collection forms. Only research staff will know your study identification number. No names or identifying information will be included in public reports of this research. All research forms will be stored in locked cabinets and password-protected computer files that only research staff can access.

VOLUNTARY PARTICIPATION: Your participation in this research study is voluntary and you will not be coerced to participate if you do not wish to. Declining to participate will not affect the services you receive from this clinic. Even after you agree to participate in the research or sign the informed consent document, you may decide to leave the study at any time without any penalty.

CONTACT INFORMATION: If you have any other questions or concerns about this study, or your rights as a research participant you may contact the Principal Investigator, Moses Mugerwa on telephone number 0773181442. If you have any questions concerning your rights as a research participant that have not been answered by the investigator or if you wish to report any concerns about the study, you may contact me or you may also reach out to the Makerere University School of Public Health, Higher Degrees Research and Ethics committee (HDRECH) IRB on telephone number 0393291397.

SIGNATURE: I have read or been informed about this research. I have had the opportunity to ask questions about it and my questions been answered to my satisfaction. I hereby consent to voluntarily participate in this research study and understand that I have the right to withdraw at any time without any consequences.

| Name of study participant | Signature | Date | |
|---------------------------|-----------|------|--|
| | | | |
| | | | |
| Name of the Researcher | Signature | Date | |

Appendix IV: In – depth Interview Guide for study participants

Topic: Prevalence, Associated Factors, Barriers and Facilitators of Disclosure of HIV Status to Sexual Partners among Young People Living with HIV/AIDS in Care at an Urban HIV Clinic, Kampala, Uganda

Introduction: Moses Mugerwa, conducting research about the above topic at Baylor College of Medicine Children's Foundation-Uganda (Baylor-Uganda). He is the principal investigator inviting you to participate in this study. The research is done in partial fulfilment of the requirements for the award of Master of Public Health of Makerere University.

Purpose of doing this interview:

The purpose of this interview is to find out your experience with HIV status disclosure to your sexual partner(s). We also want to find out your perception of what motivates or inhibits young people living with HIV from to disclosing to their partners, current practices of disclosure and the outcomes for those who disclose to their partners.

Interview Procedure:

You will be interviewed about barriers and facilitators of HIV status disclosure to sexual partner(s) of young people living with HIV. You will be interviewed alone for about 30-45minutes. Please allow us to record this conversation so that we accurately capture your responses.

Notes for the Interviewer

- Please inform the interviewees the session will be recorded. Please have a note book and pen, fully charged voice recorder and back up available. The interview can last up to 45minutes.
- Greet the participant and introduce yourself. For example, "Good morning/Good afternoon.
 I am ______ (name and designation)".
- 3. "If it is okay with you, I will be tape recording our conversation. The purpose of this is so that I can get all the details but at the same time be able to carry on an attentive conversation with you. I assure you that all your comments will remain confidential. I will be compiling a report which will only contain your answers, without any reference to your name or child's name.
- 4. The interview guide questions are to enable you guide the participant through the conversation. You are encouraged to allow the participants to express themselves as much

as possible by using phrases such as; Tell me more, Did you mean this...?, Do you have anything else in addition to what you have said?

| Participant's Study Number: |
|--|
| Interview Guide Questions: |
| 1. Please tell me about yourself (name, age, relationship status, and occupation/job). Interviewer to complete this table with responses from question 1. |
| a). Age (years): |
| b) Sex: (tick as appropriate) Male Female |
| c) Relationship status |
| d) Occupation |
| 2. Please tell me what you know about HIV. (Check for disease burden, treatment, it's not |
| curable, infection prevention for sexual partners). |
| 3. Kindly share with me, when and how did you come to learn that you are living or |
| infected with HIV? What influenced you to ascertain your HIV status? (some people may |
| be born with HIV, ask about when he/she was disclosed to and who disclosed to them) |
| 4. Tell me about who you have told about your HIV status? |
| (If they have not mentioned, ask if they disclosed to their current/most recent |
| sexual/intimate partner) Are there other people you wanted to disclose your status to, but |
| felt you couldn't? Please tell me more about that. |
| 5. When did you disclose your status to your partner? |
| 6. What prompted you to disclose to your partner? (if not disclosed yet ask if anything has |
| made the participant wish to disclose to their partner) |
| 7. What would help a young person living with HIV to disclose his/her HIV status to |

8. What would constrain a young person living with HIV to disclose his/her HIV status to his/her sexual/intimate partner? (explore the limiting factors for disclosure)

his/her sexual/intimate partner? (explore about what aids/enables disclosure)

- 9. What challenges do you think a young person living with HIV would face when they want to disclose his/her HIV status to the sexual/intimate partner(s)?
- 10. If you disclosed your status to your sexual/intimate partner, kindly tell me, how did you go about it? What were the challenges you faced?

- 11. If you were to help a fellow young person to disclose to their partner, what would you consider before you help him disclose?
- 12. What were some of the outcomes you when you disclosed to your partner? What was the reaction of your partner? What did/does your partner think about your HIV infection status? (Interests; How did you feel? How did he react? What changed in their life or health and that of their partner's)
- 13. Is there anything else you would like to tell me about disclosure of positive HIV status to partners?

Thank you for participating in this interview.

| Name of study participant | Signature | Date | | |
|---------------------------|-----------|------|--|--|
| | | | | |
| Name of the Researcher | Signature | Date | | |

Appendix V: Staffing and Workplan

| Responsible | Activity | Output | Timelines | | | | | |
|--------------|-----------------|-----------------|-----------|-------|------|------|------|------|
| Staff | | | May/ | July/ | Sep/ | Nov/ | Jan/ | Mar/ |
| | | | Jun | Aug | Oct | Dec | Feb | Apr |
| | | | 2022 | 2022 | 2022 | 2022 | 2023 | 2023 |
| Principal | Proposal | Final copy of | | | | | | |
| investigator | development | research | | | | | | |
| (PI), | | proposal | | | | | | |
| supervisors | | | | | | | | |
| PI | Proposal | PowerPoint | | | | | | |
| | presentation | presentation to | | | | | | |
| | and clearance | faculty | | | | | | |
| PI, Research | Data collection | Questionnaires | | | | | | |
| assistants | | | | | | | | |
| PI, Research | Data cleaning | Data sheets | | | | | | |
| assistants | and entry | | | | | | | |
| PI, Data | Data analysis | Information | | | | | | |
| analyst | | about the | | | | | | |
| | | research topic | | | | | | |
| PI | Report writing, | Report | | | | | | |
| | dissemination | Dissemination | | | | | | |
| | and publication | of the report | | | | | | |
| | | Published paper | | | | | | |

Appendix VI: Proposed Budget

| Category | Budget item | Quantity | Unit cost | Freq | Total cost UGX | Justification |
|---|---|----------|--------------|------|----------------------|---|
| | Refreshments during training sessions | 3 | 20,000 | 2 | 120,000 | A refreshment was provided for the research assistants (RAs) during the training at a rate of UGX.20,000 per day for 2 days |
| Training | Transport refund for research assistants during training | 3 | 20,000 | 2 | 120,000 | The research assistants were trained on the data tools and on ethical conduct concerning data collection. A transport refund of 20,000 was given each of the 3 research Assistants for each day they attend. After the training, we piloted the study and modified questionnaires to be sure that the right information would be collected. |
| Data collection for all objectives | Allowance for Research assistants collecting quantitative data | 2 | 25,000 | 45 | 2,250,000 | Two Research Assistants were be engaged for about 45 days. Each RA is expected to consent, collect and extract data for 141 clients to make a sample size of 281. Each Research Assistant will be compensated with UGX. 25,000 @day for 45 days |
| | Allowance for the Research assistant collecting qualitative data | 1 | 30,000 | 5 | 150,000 | One Research Assistant will be engaged for 5 days. He consented participants and conducted indepth interviews for 16 participants. He was compensated with Ugx. 30,000@ day for 5 days. |
| | Airtime for the PI | 1 | 100,000 | 1 | 100,000 | Airtime for the days of the research enabled the PI to communicate and coordinate with the rest of the research team. |
| | Airtime for the research assistants | 3 | 30,000 | 1 | 90,000 | This was used by the research assistants to make appointments with clients for in-depth interviews, communication and coordination of study activities |
| | Transport for the Research assistant | 3 | 10,000 | 45 | 1,350,000 | Research Assistants were refunded Ugx. 10,000 for transport to and from Baylor Uganda Clinic during the 45 days of data collection. |
| | Transcribing and translating | 1 | 85,000 | 15 | 1,275,000 | A research assistant with experience in qualitative research conducted in-depth Interviews with the PI and transcribed as well as translated the data. |

| | Participant's time compensation | 301 | 15,000 | 1 | 4,515,000 | Participants (281 for Objectives 1&2, 20 for Objective 3) were compensated for their time at a rate of UGX. 10,000 per participant and Ugx 5,000 for refreshment as they waited to be interviewed. | |
|--------------|---|-----|---------|---|------------|--|--|
| | Data cleaning and analysis | 1 | 800,000 | 1 | 800,000 | The PI worked with the Biostatician cleaned and analysed the collected data. | |
| | Dissemination of study findings at the study site | 5 | 20,000 | 1 | 100,000 | 4 booklets containing the study report will be printed and shared with the university, study site, funding programe and a personal copy. | |
| | Subtotal | | | | 10,870,000 | | |
| | Purchase of notebooks, pens, plastic file, folders, flip chart and markers | 1 | 150,000 | 1 | 150,000 | Notebooks, pens, flip charts, and markers were used during the training of RA and during data collection | |
| Materials to | Sanitizer | 1 | 50,000 | 1 | 50,000 | COVID-19 and Ebola prevention measure. | |
| use | External Hard drive | 1 | 260,000 | 1 | 260,000 | This was used for storage of study data | |
| | Photocopying materials | 1 | 150,000 | 1 | 150,000 | Study protocol, questionnaires and consent forms were photocopied | |
| | Box files | 3 | 7,000 | 1 | 21,000 | The box files were used to file study documents | |
| | Subtotal | | | | 610,000 | | |
| | Grand total | | | | 11,480,000 | | |