ANTI-RETROVIRAL THERAPY ADHERENCE AND HIV STATUS DISCLOSURE AMONG WOMEN AGED 18 TO 35 YEARS IN SELECTED HEALTH FACILITIES IN KAMPALA DISTRICT

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OPERATIONAL DEFINITIONS

Adherence: is the extent to which a person's behavior taking medications, following a diet and or executing lifestyle changes, corresponds with agreed recommendations from a health care provider (WHO).

Status disclosure: the action of one making his/her HIV status known to a friend or relative.

Status Non-disclosure: refers to HIV seropositive persons who do not reveal their HIV sero-status to anybody else.

Viral load suppression: is defined as having less than 200 copies of HIV per milliliter of blood.

Resistance to ART: is defined as reduced effectiveness of specific antiretroviral drugs due to mutation of the HIV strain in a human being.

Selected health facilities in Kampala: these are 11 HIV-Care general health facilities in Kampala namely; Makerere University Joint AIDS Programme, The AIDS Support Organization, Reach out Mbuya, China–Uganda Friendship Hospital–Naguru, Kiruddu National Referral Hospital, and Kampala Capital City Authority clinics (Kiswa, Kisenyi, Kawaala, Kitebi, Komamboga, and Kisugu Health Centres.

ACRONYMS

HIV- Human Immunodeficiency Virus

AIDS- Acquired Immunodeficiency Syndrome

ART- Anti-Retroviral Therapy

WHO- World Health Organization

MoH- Ministry of Health.

UNAIDS- Joint United Nations Programme on HIV/AIDS.

DECLARATION

I, Nakyobe Joyce Bbosa, do hereby declare that, to the best of my knowledge, this dissertation is my original research work. Everything in this write up is as a result of my hard work through reading various literature including my personal knowledge and interpretation of the contents of the topic in the field of research under the guidance of my supervisors. I am therefore certain that no work of this kind has been produced or submitted to this University or any other institution of higher learning for an academic qualification. I henceforth submit it to the faculty of public health, nursing and midwifery in partial fulfilment of the requirements for the award of a master's degree in public health of Uganda Christian University.

Author: NAKYOBE JOYCE BBOSA.

Signature: 

Date :……25 Jul 2025

CERTIFICATION

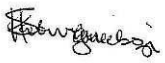
This is to certify that the research dissertation entitled:

"Anti-Retroviral Therapy Adherence and HIV Status Disclosure Among Women Aged 18 to 35 Years in Selected Health Facilities in Kampala District"

has been conducted under our supervision and is hereby submitted in partial fulfillment of the requirements for the award of a Master's Degree in Public Health of Uganda Christian University.

The study is the original work of Nakyobe Joyce Bbosa (RJ21M21/016) and has met the required academic and ethical standards as set by the Faculty of Public Health, Nursing, and Midwifery.

Supervisor:
Prof. Samuel Kabwigu
MBChB, MMed, PhD, FCOG (ECSA)

Signature: 
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Thank you all.

ABSTRACT

This study examined the association between HIV status disclosure and antiretroviral therapy (ART) adherence among 369 women aged 18–35 receiving HIV care in Kampala, Uganda, using secondary data from the 24-month BONE: CARE prospective cohort study.

Although ART adherence improved over time, peaking at 83.6% at month 21 and 81.8% at month 24 HIV status disclosure remained low. At baseline, only 32.5% of participants had disclosed their status, and just 5% of initial non-disclosers disclosed by study end. Multivariable analysis showed that women aged 25–35 years (aPR = 1.10, p = 0.048) and employed women (aPR = 0.92, p = 0.033) were more likely not to disclose their HIV status.

The findings highlight persistent psychosocial and economic barriers to disclosure despite improved adherence. Comprehensive interventions focusing on stigma reduction, empowerment, and targeted support services are needed to promote both HIV status disclosure and sustained ART adherence among young women living with HIV.

CHAPTER ONE: INTRODUCTION

1.0 Introduction

Antiretroviral therapy (ART) has significantly reduced HIV-related morbidity and mortality; however, its effectiveness depends on consistent adherence to treatment and disclosure of HIV status to sexual partners and support networks. In 2024, an estimated 40.8 million people were living with HIV worldwide, of whom approximately 21.0 million were women aged 15 years and older (World Health Organization [WHO], 2025). During the same year, 1.3 million new HIV infections were recorded globally, with adult women accounting for more than half a million new infections. This highlight the persistent vulnerability of women, especially young women, to HIV acquisition and adverse health outcomes.

The burden of HIV is disproportionately concentrated in the WHO African Region, which accounted for 26.3 million people living with HIV in 2024, representing nearly two-thirds of the global burden (WHO, 2025). The region also recorded approximately 650,000 new HIV infections and 380,000 HIV-related deaths in the same year. Eastern and Southern Africa remain the epicenter of the epidemic, where gender inequality, poverty, and limited access to health services intersect to heighten the risk of HIV among young women. Although global HIV-related deaths have declined by more than 50% since 2010, HIV continues to claim approximately 630,000 lives annually, underscoring the need for sustained improvements in treatment outcomes (WHO, 2025).

Sustained ART adherence is central to achieving viral suppression, preventing drug resistance, reducing HIV transmission, and improving quality of life among people living with HIV (Schrubbe et al., 2023). The World Health Organization 2021 recommended 95% adherence to ART needed to achieve optimal treatment outcomes and meet the global 95–90–86 treatment cascade targets. In 2024, approximately 77% of people living with HIV globally were receiving ART, while only 73% had achieved viral load suppression, indicating persistent adherence gaps even among those accessing treatment (WHO, 2025). Among adults, ART coverage reached 78%, yet viral suppression remained suboptimal, reflecting challenges related to consistent medication use and long-term engagement in care. Women demonstrate relatively higher ART coverage compared to men, with 83% of adult women living with HIV receiving ART globally in 2024 (WHO, 2025). However, higher treatment coverage does not necessarily translate into optimal adherence, particularly among young women.

Despite efforts to improve ART adherence, numerous studies highlight persistent challenges; Economic and Structural Barriers: Financial constraints often limit access to medication, transportation to healthcare facilities, and nutritional support, which are all necessary for ART adherence (MacCarthy et al., 2018). Unemployment and economic dependency on partners may increase the risk of non-adherence, as women may lack financial autonomy to prioritize their healthcare (Kim et al., 2017). Psychosocial and Stigma-Related Barriers: Women living with HIV often experience internalized stigma and discrimination, discouraging them from adhering to ART (Nordberg et al., 2020). Mental health issues, including depression and anxiety, are linked to poor ART adherence, as they reduce motivation and engagement with healthcare services (Waldorn et al., 2021). Relationship and Family Dynamics: Studies indicate that partner support enhances ART adherence, as women who disclose their HIV status often receive reminders, encouragement, and financial support for treatment (Kalichman et al., 2019, Schruble et al., 2023).

Conversely, women who do not disclose their HIV status to their partners often struggle with adherence due to the need for secrecy and fear of stigma (Musheke et al., 2013). Despite existing interventions, adherence challenges persist, highlighting the need for holistic interventions that address economic, psychological, and social factors influencing adherence. HIV status disclosure plays a critical role in HIV care and prevention, as it facilitates: Partner involvement in treatment and care, which enhances adherence (Kim et al., 2017), Reduction of HIV transmission risk, particularly in serodiscordant relationships where preventive measures can be taken (WHO, 2021), Improved mental health outcomes, as disclosure has been associated with reduced stress and better coping mechanisms (Maman et al., 2024).

Despite these benefits, research consistently shows low disclosure rates among women, largely due to; Fear of Stigma and Discrimination such as social stigma remains one of the greatest barriers to disclosure, particularly in societies where HIV-positive women face blame, discrimination, and isolation (Nordberg et al., 2020). Women fear being rejected by partners, families, or the community, leading to secrecy about their HIV status (Maman et al., 2024). Intimate Partner Violence (IPV) Concerns: Research has found that HIV-positive women are at a higher risk of IPV, particularly in relationships where gender-based violence is prevalent (Hatcher et al., 2020). The fear of physical, emotional, or financial abuse discourages many women from disclosing their status (Yonga et al., 2022). Economic Dependence on Partners: Many women remain financially dependent on their partners, and disclosure may jeopardize their financial security, especially if the partner reacts negatively (Musheke et al., 2013). In some cases, non-disclosure is a strategic decision to maintain household stability and avoid potential economic hardships (Kim et al., 2020).

Although numerous studies have examined barriers to ART adherence and HIV status disclosure, there remains limited evidence on how these factors specifically impact women aged 18 to 35 years in selected health facilities. Existing research has largely focused on general trends, without addressing: Longitudinal trends in ART adherence among young women, the proportion of women who disclose their HIV status over time, the influence of demographic factors (e.g., age, education, income, and employment status) on disclosure and adherence decisions.

To address these gaps, this study aims to: Analyze self-reported ART adherence trends over a 24-month period to understand behavioral patterns and adherence barriers, determine the proportion of women who disclose their HIV status and examine changes in disclosure rates over time and identify the key factors influencing HIV status disclosure and non-disclosure, including socioeconomic status, relationship dynamics, and employment. By linking ART adherence with HIV disclosure behaviors, this study will provide critical insights for policymakers, healthcare providers, and community based organizations to design targeted interventions that improve ART adherence, promote safe HIV disclosure, and enhance the well-being of women living with HIV.

1.1. PROBLEM STATEMENT

HIV remains a significant public health challenge, particularly among women of reproductive age, who face unique barriers to antiretroviral therapy (ART) adherence and HIV status disclosure. Research has shown that consistent adherence to ART is critical for viral suppression, reducing transmission risk, and improving health outcomes (WHO, 2021). However, adherence rates remain suboptimal among young women, often due to social stigma, economic dependency, medication fatigue, and relationship dynamics (Kagee et al., 2011; Waldorn et al., 2021). Similarly, HIV status disclosure plays a vital role in treatment success, as it enables partner support, facilitates adherence, and reduces transmission risk. Despite these benefits, many women struggle with disclosure due to fear of rejection, intimate partner violence (IPV), and social discrimination (Musheke et al., 2013; Hatcher et al., 2020).

Studies indicate that women who disclose their HIV status are more likely to adhere to ART and access social support services (Armoon et al., 2022). However, research also shows that HIV status disclosure remains low, particularly among women in relationships where gender dynamics, economic dependency, and stigma shape disclosure decisions (Maman et al., 2024; Nordberg et al., 2020). Despite existing interventions to encourage disclosure and improve adherence, there is limited evidence on how age, education, income, employment status, and relationship factors uniquely affect HIV disclosure and adherence among young women in resource-limited settings. Additionally, few studies have examined longitudinal

adherence trends and how demographic and social factors evolve over time to influence disclosure decisions.

To address these gaps, this study sought to: analyze self-reported ART adherence trends over a 24month period to understand behavioral patterns and barriers to consistent adherence, determine the proportion of women who disclose their HIV status and assess changes in disclosure rates over time and identify key factors influencing HIV disclosure and non-disclosure, including socioeconomic status, relationship dynamics, and employment.

By linking ART adherence with disclosure behaviors, this study will provide critical insights for healthcare providers, policymakers, and community-based organizations to design targeted interventions that enhance ART adherence, promote safe disclosure, and improve health outcomes for women living with HIV.

1.2 **CONCEPTUAL FRAMEWORK**

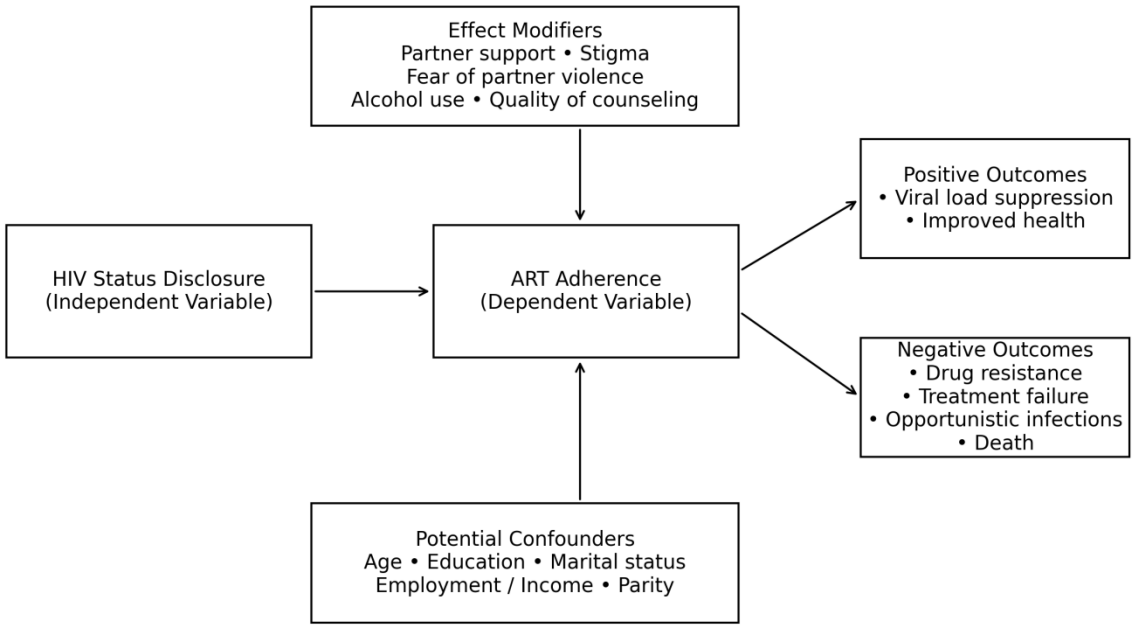

Figure 1. Conceptual framework

Figure 1: Conceptual framework illustrating the relationship between HIV status disclosure and antiretroviral therapy (ART) adherence. HIV status disclosure acts as the independent variable influencing ART adherence (dependent variable). Potential confounders (age, education, marital status, employment/income, and parity) and effect modifiers (partner support, stigma, fear of intimate partner violence, alcohol use, and quality of counseling) may influence this relationship. ART adherence leads to either positive outcome such as viral load suppression and improved health, or negative outcomes including drug resistance, treatment failure, opportunistic infections, and death.

1.3. OBJECTIVES

1.3.1. Major objective

To assess the association between HIV status disclosure and drug adherence among young women (age 18-35 years) in selected health facilities in Kampala district.

1.3.2. Specific objectives

- To analyze self-reported ART adherence trends over a 24-month.
- To determine the proportion of women who disclose their HIV status.
- To identify key factors influencing HIV disclosure and non-disclosure.

1.4. RESEARCH QUESTIONS

1. What are the self-reported ART adherence trends over a 24-month period?
2. What proportion of women disclosed their HIV status?
3. What are the key factors influencing HIV disclosure and non-disclosure?

CHAPTER TWO: LITERATURE REVIEW

2.0. Introduction

The effectiveness of antiretroviral therapy (ART) in managing HIV/AIDS has been widely established, yet adherence to ART and disclosure of HIV status remain significant challenges among young women. Studies have shown that consistent ART adherence leads to viral suppression, reduces transmission risk, and improves overall health outcomes. However, adherence is often compromised due to social, economic, and psychological barriers. Similarly, HIV status disclosure plays a critical role in partner support and treatment adherence, yet many women struggle with disclosure due to fear of stigma and relationship consequences. This literature review explores existing research on ART adherence, HIV disclosure, and factors influencing these behaviors among young women.

2.1. ART Adherence Among Women Living with HIV

2.1.1. Importance of ART Adherence

ART adherence is essential for achieving viral suppression and reducing HIV transmission. The World Health Organization (WHO) recommends at least 95% adherence to prevent drug resistance and treatment failure (WHO, 2021). Studies indicate that women who consistently adhere to ART experience lower HIV-related complications and have reduced risks of opportunistic infections (schruble et al., 2023).

2.1.2. Barriers to ART Adherence

Despite its benefits, adherence to ART remains sub-optimal among young women. Multiple studies have identified key barriers, including:

i. Socioeconomic Factors: Financial constraints limit access to medication, transportation to healthcare facilities, and nutritious diets that support ART effectiveness (MacCarthy et al., 2018). Unemployment and economic dependence on partners increase the risk of non-adherence, as women may lack financial autonomy (Kim et al., 2017).

ii. Psychosocial and Behavioral Factors: Mental health issues, such as depression and anxiety, have been linked to poor ART adherence (Waldorn et al., 2021). Fear of stigma and discrimination prevents many women from attending clinic appointments or taking ART openly (Kagee et al., 2011).

iii. Relationship and Family Dynamics: Women who do not disclose their HIV status to partners often struggle with adherence due to the need for secrecy (Musheke et al., 2013). Partner support has been shown to enhance ART adherence, as women with supportive partners are more likely to adhere to their medication regimen (Armoon et al., 2022).

2.1.3. Strategies to Improve ART Adherence

Various interventions have been suggested to improve adherence:

- Peer support groups provide a platform for sharing experiences and motivation (Mbah et al., 2021).
- Mobile health (mHealth) interventions, such as SMS reminders and adherence tracking apps, have been effective in improving ART adherence (Bärnighausen et al., 2019).
- Community-based adherence programs have demonstrated success in supporting women with ART adherence challenges (Gelana et al., 2023).

3. HIV Status Disclosure Among Women Living with HIV

3.1. The Role of HIV Disclosure in Treatment and Prevention

HIV status disclosure is a critical component of HIV care and prevention, as it facilitates; Improved ART adherence, since disclosed status allows for partner and family support (Kim et al., 2017). And reduction of HIV transmission risk, particularly in serodiscordant relationships where preventive measures can be taken (WHO, 2021).

3.2. Barriers to HIV Status Disclosure

Studies indicate that many women delay or avoid disclosing their HIV status due to various challenges:

i. Fear of Stigma and Discrimination; Women often fear being rejected by partners, family, or the community (Nordberg et al., 2020). In addition, Cultural norms in some settings blame women for HIV transmission, increasing disclosure reluctance (Maman et al., 2024).
ii. Intimate Partner Violence (IPV) Risks; Studies have shown that HIV-positive women face a higher risk of IPV, particularly in relationships where gender-based violence is already present (Hatcher et al., 2020). The fear of physical or emotional abuse discourages many women from disclosing their status (Yonga et al., 2022).
iii. Economic Dependence; Women who rely financially on their partners may avoid disclosure out of fear of abandonment or loss of support (Musheke et al., 2013).

3.3. Factors That Promote HIV Status Disclosure

Several studies highlight factors that encourage disclosure:

- Strong healthcare counseling programs increase the likelihood of disclosure (Hardon et al., 2019).
- Supportive partners and family networks contribute to higher disclosure rates (Kim et al., 2017).
- Community-based education programs reduce stigma and promote acceptance of people living with HIV (Kimera et al., 2025).

4. Factors Influencing HIV Status Disclosure and Non-Disclosure

Several factors influence whether women disclose their HIV status to their partners:

i. Age; Younger women may have different relationship expectations and may be more open to disclosure compared to older women (Miller et al., 2021). Studies suggest that older women (25–35 years) are more likely to withhold disclosure due to concerns about long-term relationship stability (Nabaggala et al., 2020).

ii. Marital and Relationship Status; Women in stable, long-term relationships may feel more obligated to disclose (Kalichman et al., 2019). Those in casual relationships may choose to withhold disclosure due to uncertainty about their partner's commitment (Musheke et al., 2018).
iii. Employment and Economic Independence; Employed women are more likely to disclose their status due to reduced financial dependence on partners (Kim et al., 2020).
iv. Community and Cultural Factors; In communities where HIV stigma remains high, disclosure rates tend to be lower (Hardon et al., 2019). Public health campaigns and anti-stigma initiatives have been shown to improve disclosure rates (WHO, 2021).

5. Gaps in the Literature and Need for the Current Study

While previous research has explored barriers to ART adherence and HIV status disclosure, there is limited evidence on how these factors specifically impact women aged 18 to 35 years in selected health facilities. Additionally, most studies have focused on general trends, without examining:

- Longitudinal trends in ART adherence among young women.
- The proportion of women who disclose their HIV status over time.
- Statistical associations between demographic factors and disclosure decisions.

This study seeks to address these gaps by:

1. Analyzing self-reported ART adherence trends among young women over 24 months.
2. Determining the proportion of women who disclose their HIV status and identifying changes over time.
3. Examining the factors influencing HIV status disclosure and non-disclosure, including age, relationship status, and economic independence.

The findings will provide critical evidence-based recommendations for improving ART adherence, promoting HIV status disclosure, and strengthening healthcare interventions for women living with HIV.

CHAPTER THREE METHODOLOGY

3.0. Introduction

This chapter describes the methodology used to investigate the relationship between HIV status disclosure and antiretroviral therapy (ART) adherence among women aged 18 to 35 years in selected health facilities in Kampala District. It outlines the study design, study area, population, sample size determination, sampling criteria, data collection methods, data management and analysis techniques. The chapter also highlights the ethical considerations undertaken during the conduct of the research. The chosen methods were guided by the study objectives and were designed to ensure the collection of valid, reliable, and relevant data that could address the research questions effectively.

3.1. Study design

A secondary data analysis using data from a cohort study conducted in 11 HIV-Care general health facilities in Kampala district was performed. The primary study was a prospective cohort study in Uganda whose main objective was to determine Intramuscular depot medroxyprogesterone acetate accentuates bone loss associated with tenofovir disoproxil fumarate-containing antiretroviral therapy initiation in young women living with HIV (the BONE: CARE study) (Flavia et al., 2022). A total of 474 participants were recruited between March 30, 2016, and Oct 19, 2017; 521 enrolled, of which 452 (87%) were women living with HIV.

The clinics were public health care centers and these included; Makerere University Joint AIDS Programme, the AIDS Support Organization, Reach out Mbuya, the China– Uganda Friendship Hospital–Naguru, the Kiruddu National Referral Hospital, and Kampala Capital City Authority clinics (Kiswa, Kisenyi, Kawaala, Kitebi, Komamboga, and Kisugu Health Centres.

3.2. Area under study

The Makerere University Joint AIDS program is a private-not-for-profit- Company limited by guarantee under Makerere University College of Health Sciences, working towards consolidation of HIV/AIDS and TB prevention, care and treatment services (mjap.mak.ac.ug).

The AIDS Support Organization is a non-government organization set up in 1987 to offer HIV counseling and medical services to people infected and affected by HIV and AIDS (tasouganda.org). Reach out Mbuya is a community Health Initiative formerly known as Reach out Mbuya Parish HIV/AIDS working with the urban and rural poor communities. It is currently in 6 districts (www.reachoutmbuya.org).

Uganda Friendship Hospital- Naguru is an urban general hospital built between 2009 and 2012 to enable in decongestion of Mulago National Referral Hospital. It is located in Naguru, nakawa division, kampala, central region. The hospital is head by an executive director (MOH).

The KCCA clinics are located in the different Kampala divisions. The facilities have at least 18 staff who are headed by a senior clinical officer, who runs a general outpatient clinic and a maternity ward. These provide basic preventive, promotive, and curative care. There are provisions for laboratory services for diagnosis, maternity, and first level referral cover. They serve Kampala City which is home to more than 3.7 million people during the day (UBOS, 2019). Each of these facilities provides HIV Care services on a daily basis to an average of 100 persons living with HIV/AIDS from which participates will be enrolled.

3.3. Population under study/Sample size

Since was a secondary research a census of all eligible participants from the primary dataset was used. Primary study enrolled 452 participants. All participants' files were assessed for eligibility and data 369 participant charts were eligible for analysis.

3.4. Inclusion criteria

All women in the BONE:CARE study who filled in the baseline study discloser questionnaire and followed up through the entire follow-up period were considered.

3.5. Exclusion criteria.

All women in the BONE:CARE study who did not fill the baseline questionnaire or whose follow up was loss during the period of the study were excluded.

3.6. Data Management

Data was originally collected using Open Data Kit (ODK) and stored at the MU-JHU server. Data was exported to excel before being imported into Stata for data cleaning and analysis. Data was later imported into Stata software where it was cleaned and coded accordingly.

3.7. Statistical Analysis

Generally, data was presented using tables, charts and figures. Continuous variables were summarized using mean and standard deviation if normally distributed and median (interquartile range) if otherwise. Categorical variables were summarized using frequencies and percentages.

Self-reported adherence to ART among young women in the selected health facilities in Kampala district was calculated by getting the number of women who did not skipped any of their medications during a particular visit divided by the number of women who attended that visit and this was reported as a percentage. This was done for all the visits from month 1 through month 24.

Proportion of women who disclosed their status during the study was calculated as the number of women who reported disclosing their HIV status to their partners during the study period divided by the total number of women who are still under follow up by month 24. This excluded women who had disclosed their HIV status to their partners at entry into the study (baseline).

To determine the factors associated with HIV status non-disclosure to partner, a modified Poisson regression model was used because the proportion of women who did not disclose to their partners by month 24 was more than 10%. Bivariate and multivariable models were constructed. Variables that had $p \leq 0.2$ at bivariable analysis were considered for multivariable analysis unless a variable was a known confounder as informed by literature and or had known biological plausibility. At multivariable analysis, variables that had $p \leq 0.05$ were considered statistically significant and these were the factors associated with HIV non-disclosure in this study.

3.8. Ethical considerations

The primary study protocol was approved by the Uganda Virus Research Institute Ethics Committee (GC/127/16/09/524), Uganda National Council for Science and Technology (HS 1942), and the Human Research Ethics Committee at the University of the Witwatersrand, South Africa (M150858). Written informed consent for study participation was obtained from all participants (Flavia et al., 2022).

Uganda Christian University Research Ethics Committee (REC) approval for the secondary study was obtained from Uganda Christian University (UCUREC-2022-425**)**. Administrative permission to conduct this study was obtained from the Makerere University-Johns Hopkins University (MUJHU) Research Collaboration administration. Access to data was restricted and participant identification numbers (PID) on study data collection tools was used instead of participant names to ensure confidentiality. An informed consent waiver was obtained from the REC as this was be retrospective data.

3.9. Dissemination process

The research results were compiled into a report which was printed in a number of copies. One copy was shared with university library, the second copy to Makerere University- John Hopkin University Research Collaboration and other copies to the directors of all the 11 research site where the participants were enrolled. The findings will also be presented and published in peer-reviewed journals.

CHAPTER FOUR RESULTS

4.0. Introduction:

This chapter presents the findings of the study on the association between HIV status disclosure and adherence to antiretroviral therapy (ART) among women aged 18 to 35 years in selected health facilities in Kampala District. The results are based on secondary data obtained from the BONE: CARE study, which followed a cohort of young women living with HIV over a 24-month period.

The findings are organized according to the study objectives and include: sociodemographic characteristics of participants, trends in ART adherence, patterns of HIV status disclosure, and the factors associated with both disclosure and non-disclosure. Data are presented using tables, figures, and descriptive summaries, followed by statistical analyses where applicable

4.1. Sociodemographic

Secondary analysis was done between July 2023 and May 2024 from a total of 474 participant charts. Participants charts were analyzed as shown in figure 1.

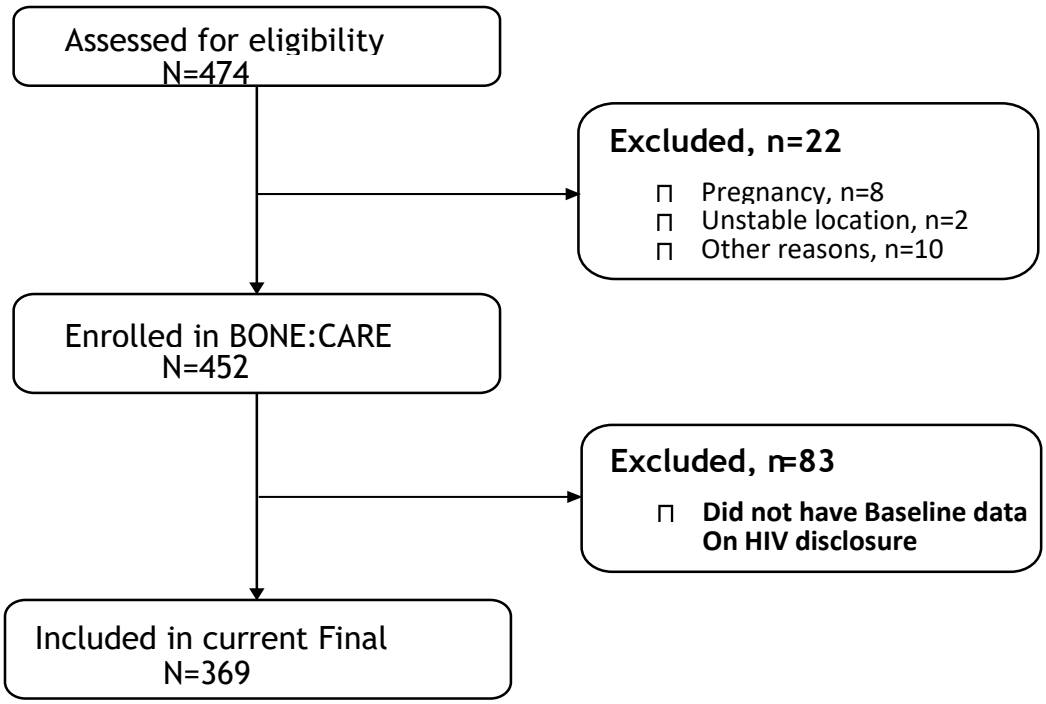

Figure 2. Enrollment into the analysis

A total of 369 participants were enrolled in this study. The mean age was 26.7 years with a standard deviation of 4.1 years. Majority of the participants were aged between 25 and 35 years (65.3%). Regarding education, 175 (47.4%) attained secondary education while 18 (4.9%) attained tertiary education. Majority of the participants (45%) were married/cohabiting, 79 (21.4%) were single while 80 (21.7%) had a casual partner. A big percentage of the women (30.6%) were engaged in trading/vending work and more than half (72.6%) earned an income. Baseline characteristics of study participants are presented in table 1 below.

Table 1. Baseline characteristics of study participants

Characteristic	Did not disclose	Disclosed	Total
	N=247	N=122	N=369
Age (Years)			
Mean (SD)	26.6 (4.1)	26.9 (4.1)	26.7 (4.1)
Median (IQR)	27.0 (23.0, 30.0)	27.0 (23.0, 30.0)	27.0 (23.0, 30.0)
18-24	88 (35.6)	40 (32.8)	128 (34.7)
25-35	159 (64.4)	82 (67.2)	241 (65.3)
Education level			
None	16 (6.5)	6 (4.9)	22 (6.0)
Primary	99 (40.1)	55 (45.1)	154 (41.7)
Secondary	120 (48.6)	55 (45.1)	175 (47.4)
Tertiary	12 (4.9)	6 (4.9)	18 (4.9)
Marital Status			
Single	67 (27.1)	12 (9.8)	79 (21.4)
Married/Cohabiting	80 (32.4)	86 (70.5)	166 (45.0)
Causal partner	64 (25.9)	16 (13.1)	80 (21.7)
Divorced/separated/widowed	36 (14.6)	8 (6.6)	44 (11.9)
Occupation			
Housework	56 (22.7)	27 (22.1)	83 (22.5)
Trading/vending	67 (27.1)	46 (37.7)	113 (30.6)
Bar/Hotel/Salon	74 (30.0)	18 (14.8)	92 (24.9)
Student	5 (2.0)	2 (1.6)	7 (1.9)
Other	45 (18.2)	29 (23.8)	74 (20.1)
Earns an income			
No	64 (25.9)	37 (30.3)	101 (27.4)
Yes	183 (74.1)	85 (69.7)	268 (72.6)

Data are presented as mean (SD) or median (IQR) for continuous measures, and n (%) for categorical measures

4.2. Self-reported level of adherence to ART among young women in the selected health facilities in Kampala district

Figure 2 below shows the self-reported adherence to ART among women in selected health facilities in Kampala district. At every visit, clinicians offered an adherence questionnaire to participants where they reported how well they swallowed their prescribed ARVs. Self-reported adherence was highest at month 21 (83.6%), followed by month 24 (81.8%). Between months 1 and 18 inclusive, self-reported adherence ranged 71.8% to 79.7% as shown in figure 2 below.

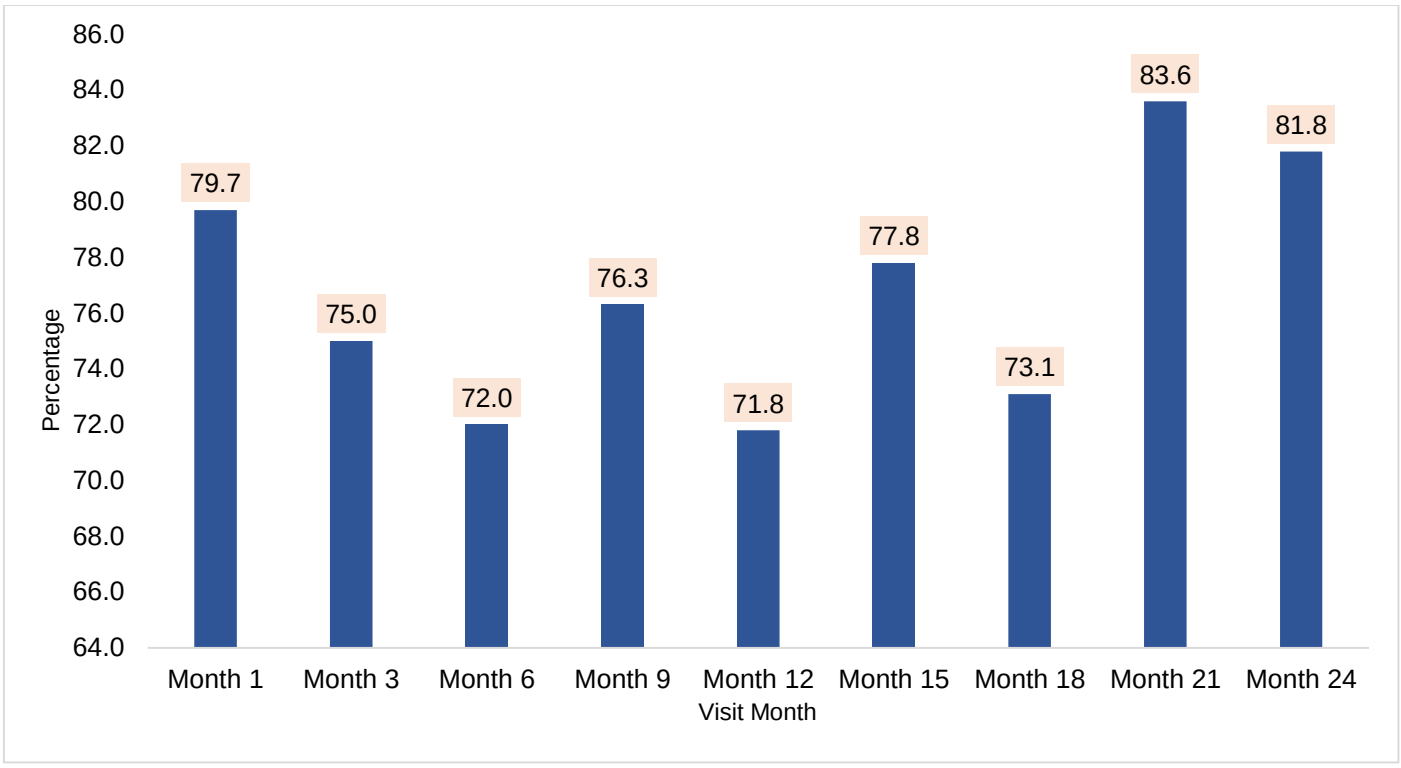

Figure 3. Self-reported adherence by visit month.

4.3.1 Proportion of women who disclosed their HIV status and changes in disclosure rates over time.

At baseline, only 32.5% (107/329) had disclosed their HIV status to their partners and 67.5% had not. During the study period, only 5% (11/222) of those who had not disclosed their HIV status to their partners disclosed by end of the 24 months of follow up as shown in figure 3 below.

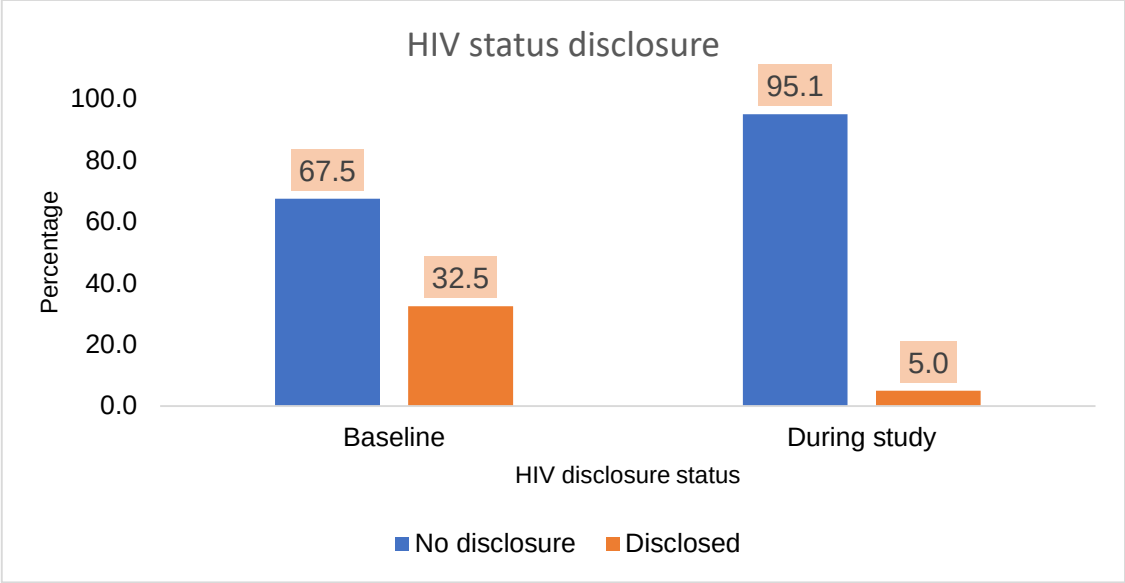

Figure 4. Proportion of HIV status disclosure at baseline and at 24 months

At baseline, only 32.5% (107/329) had disclosed their HIV status to their partners and 67.5% had not. Cumulatively, this proportion increased from 32.5% to 35.9% (Figure 3 below).

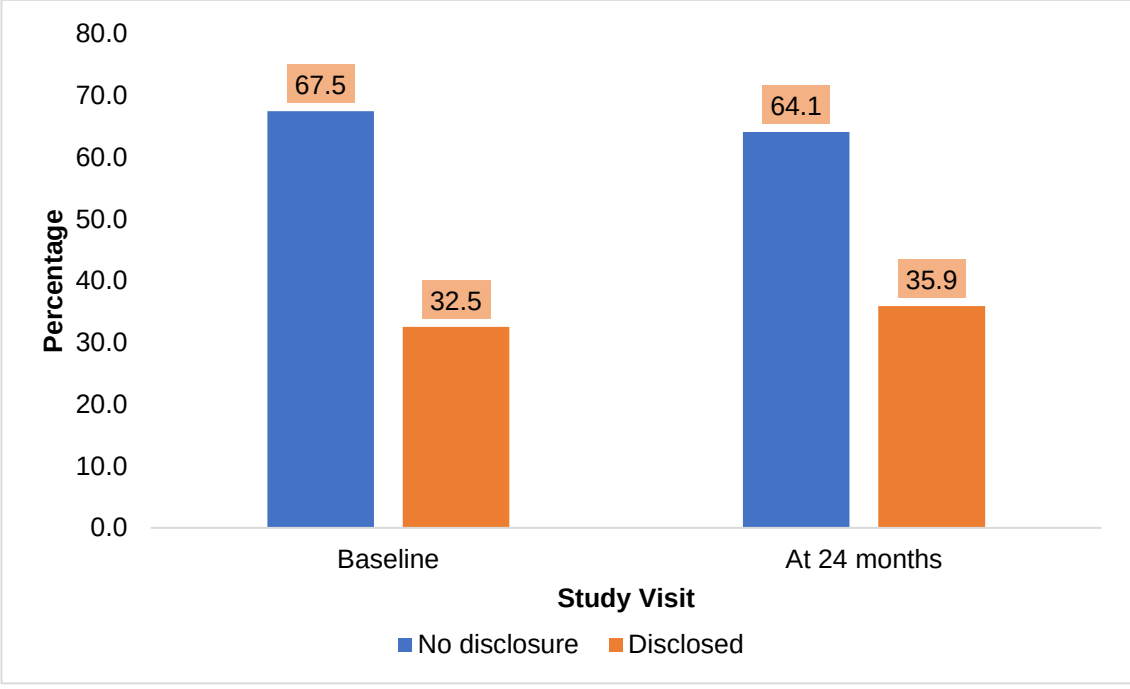

Figure 5. change in the HIV status disclosure at baseline and at 24 months

4.3.2 Trends in HIV status disclosure over the study period

Figure 4 presents the trends in HIV status disclosure (to anyone) over the study period. At baseline, 107 out of 329 participants had disclosed their HIV status, representing a disclosure rate of 32.5%. At Month 6, there were only three participants eligible for disclosure assessment (had data on HIV disclosure), and none had disclosed their status (0.0%). By Month 12, 20 out of 92 participants (21.7%) had disclosed their status, increasing to 26.5% (30/113) at Month 18, and 27.7% (18/65) at Month 24.

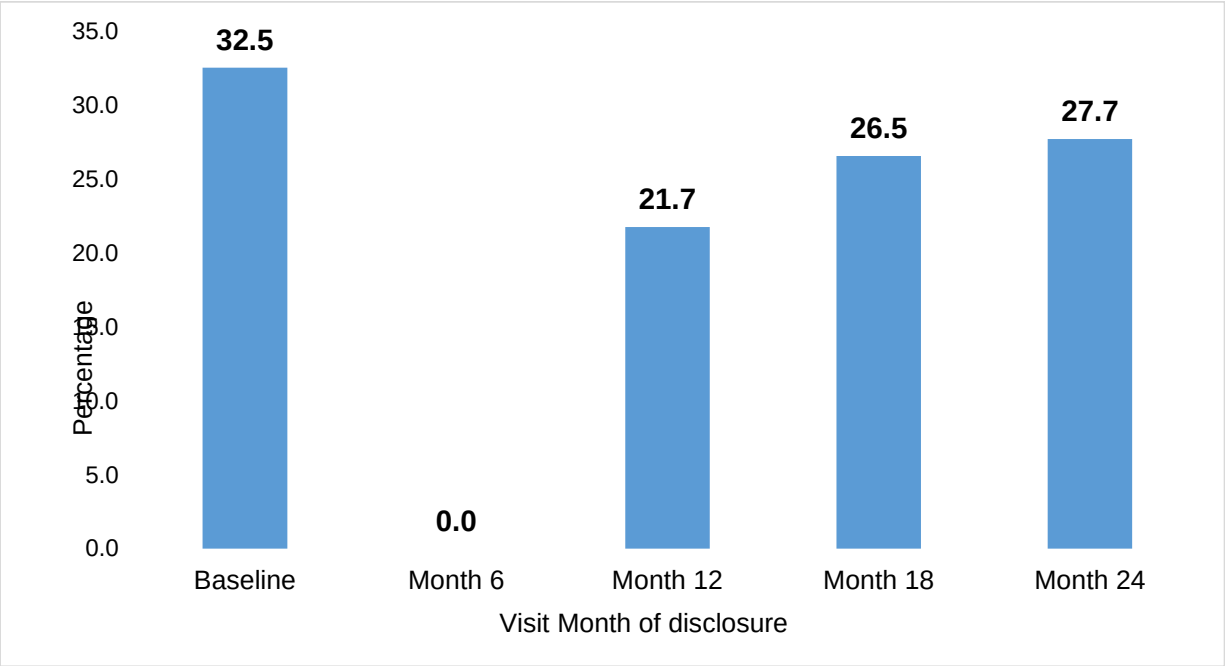

Figure 2. Trends in HIV status disclosure (to anyone) over the study period

4.4.1 Factors affecting HIV status disclosure by end of study period.

Following the bi-variable analysis in Table 3. No statistically significant factor was found affecting HIV disclosure by end of study since all the p-values were above 0.05.

Table 3. Bi-variable analysis of the factors affecting HIV disclosure Status

Characteristic	Odds Ratio	95% CI	p-value
Age (Years)			
18-24	Ref		
25-35	0.30	(0.09, 1.07)	0.063
Age (continuous)	0.85	(0.72, 1.00)	0.053
Marital Status			
Single	Ref		
Married	1.38	(0.39, 4.85)	0.616
Education level			
Below Secondary	Ref		
Secondary and above	0.71	(0.21, 2.40)	0.580
Earns Income			
No	Ref		
Yes	0.89	(0.23, 3.50)	0.873
Employment Status			
Not employed	Ref		
Employed	1.36	(0.28, 6.51)	0.699
Parity			
0	Ref		
1-2	1.73	(0.20,14.80)	0.617
3-8	0.66	(0.07, 6.65)	0.724
Parity (continuous)	0.85	(0.54, 1.32)	0.460
Alcohol use			
Yes	Ref		
No	2.05	(0.43, 9.74)	0.368
Ever smoked			
No	Ref		
Yes	1.52	(0.18,12.83)	0.699
Average Monthly Income	1.00	(1.00, 1.00)	0.869

4.4.2 Factors affecting HIV status non-discloser by end of study period.

Table 4 shows the bi-variable and multivariable analysis of the factors affecting non-disclosure of HIV status to partner during the study period. From the bivariate analyses, we

did not find any variable that was independently associated with HIV status non-disclosure to partner since all the p-values were greater than 0.05. However, when adjusted for the known confounders - marital status, employment status and average monthly income, we found age (p=0.048) and being employed (p=0.033) as the factors associated with HIV non-disclosure by month 24 since their p-values are less than 0.05. Bi-variable and multivariable analysis of the factors affecting non-disclosure of HIV status are presented in table 4 below.

Table 4: Bivariable and multivariable analysis of the factors affecting non-disclosure of HIV status

Characteristic	cPR	95% CI	p-value	aPR	95% CI	p-value
Age (Years)						
18-24	Ref					
25-35	1.07	(0.99, 1.15)	0.093	1.10	(1.00, 1.21)	0.048
Age (continuous)	1.01	(1.00, 1.01)	0.033			
Marital Status						
Single	Ref					
Married	0.98	(0.93, 1.04)	0.609	1.02	(0.95, 1.09)	0.595
Education level						
Below Secondary	Ref					
Secondary and above	1.02	(0.96, 1.08)	0.584			
Earns Income						
No	Ref					
Yes	1.01	(0.94, 1.08)	0.876			
Employment Status						
Not employed	Ref					
Employed	0.99	(0.92, 1.05)	0.676	0.92	(0.86, 0.99)	0.033
Parity						
0	Ref					
1-2	0.97	(0.87, 1.08)	0.555			
3-8	1.02	(0.92, 1.11)	0.755			
Parity (continuous)	1.01	(0.99, 1.02)	0.340			
Alcohol use						
Yes	Ref					
No	0.97	(0.92, 1.03)	0.298			
Ever smoked						
No	Ref					
Yes	0.98	(0.84, 1.13)	0.744			
Average Monthly Income	1.00	(1.00, 1.00)	0.896	1.00	(1.00, 1.00)	0.882

cPR – Crude prevalence ratio, aPR – adjusted crude ratio, CI: Confidence interval

CHAPTER FIVE DISCUSSION

5.0. Introduction:

This chapter provides an interpretation of the key findings presented in the previous chapter, in relation to the study objectives and existing literature. The aim is to contextualize the results on ART adherence and HIV status disclosure among women aged 18 to 35 years attending selected health facilities in Kampala District.

The discussion explored the implications of the findings, compared them with those of similar studies, and identified possible explanations for observed trends and associations. Particular attention was given to the barriers and facilitators of ART adherence and HIV disclosure, as well as the influence of demographic and socio-economic factors. The findings were further discussed in the context of public health interventions and policy recommendations for improving care and outcomes among young women living with HIV.

This study sought to examine self-reported ART adherence trends, HIV status disclosure patterns, and factors influencing both disclosure and non-disclosure among women aged 18 to 35 years in selected health facilities in Kampala district. The findings revealed that ART adherence improved over time, but HIV status disclosure remained low, with age and employment status being significant predictors of non-disclosure. These results align with previous research indicating that women face multiple barriers to HIV disclosure and treatment adherence, including fear of stigma, economic dependency, and relationship concerns (Musheke et al., 2013; Armoon et al., 2022).

5.1. Self-Reported ART Adherence Trends

Self-reported ART adherence improved gradually, reaching its highest levels at month 21 (83.6%) and month 24 (81.8%). This aligns with prior studies suggesting that continued patient engagement in HIV care, access to adherence counseling, and ongoing treatment support contribute to improved long-term ART adherence (Mbah, et al., 2021; WHO, 2021). However, fluctuations in adherence between months 1 and 18 (ranging from 71.8% to 79.7%) suggest that barriers to adherence persist, particularly in the early stages of ART initiation. These

findings are consistent with research by Kagee et al. (2011) and Nordberg et al. (2020), which highlights that medication fatigue, stigma, and financial instability contribute to inconsistent ART adherence.

5.2. HIV Status Disclosure Patterns.

Only 32.5% of women had disclosed their HIV status at baseline, while 67.5% had not. Even after 24 months of follow-up, only 5% of the initially non-disclosing women chose to reveal their status. These findings are consistent with prior research, which highlights that HIV disclosure remains a significant challenge for women due to fear of stigma, rejection, and intimate partner violence (IPV) (Musheke et al., 2013; Armoon et al., 2022).

HIV status disclosure among young women remained consistently low throughout the 24-month follow-up period, with very few new disclosure events occurring after baseline. While a proportion of participants had disclosed their HIV status at enrollment, the majority of women who had not disclosed initially remained undisclosed over time. This stability suggests that disclosure is not a gradual process that naturally evolves with prolonged engagement in HIV care or continued antiretroviral therapy (ART) use, but rather a decision that is often made early and then sustained.

These findings align with existing literature indicating that HIV disclosure commonly occurs shortly after diagnosis or treatment initiation, with limited uptake thereafter (Musheke et al., 2013; Kagee et al., 2022). Once non-disclosure is established as a coping strategy, it becomes increasingly difficult to reverse, particularly in contexts characterized by persistent stigma and gendered power imbalances. Among young women, disclosure decisions are strongly shaped by anticipated partner reactions and concerns related to safety, relationship stability, and economic security (Maman et al., 2024).

The extremely low rate of new disclosure during follow-up likely reflects enduring psychosocial and relational barriers that are not resolved through routine clinical care. Fear of stigma, blame, abandonment, and intimate partner violence remains a major deterrent to disclosure and may persist or intensify over time (Hatcher et al., 2020). In addition, missing disclosure

data at several follow-up points may further obscure disclosure dynamics, as non-disclosure and disengagement from follow-up are often linked (Yonga et al., 2022).

Overall, the absence of an upward trend in disclosure highlights the limitations of time-based expectations and underscores the need for deliberate, gender-responsive interventions that address structural, relational, and psychosocial barriers rather than relying on ART duration alone (WHO, 2021).

5.3. Factors Influencing Non-Disclosure

While bivariate analysis did not reveal any statistically significant factors influencing HIV disclosure, multivariable analysis identified age and employment status as key predictors of non-disclosure. Women aged 25–35 years were more likely to not disclose their HIV status (aPR = 1.10, p = 0.048) compared to younger women aged 18–24 years. This finding aligns with prior research by Nordberg et al. (2020) and Miller et al. (2021) suggesting that younger women have more progressive attitudes toward disclosure, whereas older women have greater concerns about long-term relationship stability. The study also identified that women who were employed had lower odds of nondisclosure (aPR = 0.92, p = 0.033), indicating that financial independence empowered women to disclose their HIV status without fear of economic repercussions (MacCarthy et al., 2018). Employment also provides greater autonomy in decision-making, which was linked to higher disclosure rates in prior studies (Kim et al., 2017).

Absence of statistically significant associations between many socio-demographic and relational variables and HIV status disclosure is consistent with emerging evidence that disclosure is a complex, context-dependent process that is not reliably explained by traditional quantitative predictors alone. While earlier studies reported associations with age, marital status, education, or employment, more recent longitudinal and mixed-methods research demonstrates that these relationships are neither uniform nor stable over time.

Several studies from sub-Saharan Africa report patterns similar to the present analysis, in which commonly measured demographic and socioeconomic variables did not retain statistical

significance in multivariable models. Musheke et al. (2013) found that although marital status and economic dependence appeared influential descriptively, they did not consistently predict disclosure once relational context and perceived partner reactions were considered. This supports the current findings that disclosure decisions are shaped less by demographic characteristics and more by perceived safety and social support.

The lack of statistically significant predictors also mirrors findings by Kagee et al. (2022), who noted that disclosure often occurs early after treatment initiation and then plateaus, resulting in very few new disclosure events during follow-up. This low outcome variability limits the ability to detect statistical associations, even for theoretically relevant variables.

Existing literature further indicates that disclosure is mediated by psychosocial and relational factors not adequately captured by standard survey measures. Maman et al. (2024) showed that fear of stigma, anticipated negative partner reactions, and concerns about relationship dissolution were stronger determinants of disclosure than education, income, or employment status. Similarly, overlapping vulnerabilities such as economic dependence and power imbalances may attenuate independent effects in multivariable models (Kim et al., 2017).

Finally, missing disclosure data may be non-random, as women who do not disclose may also avoid reporting disclosure-related information due to fear or disengagement, potentially biasing estimates toward the null (Hatcher et al., 2020; Yonga et al., 2022). Overall, the findings align with contemporary understanding that HIV disclosure among young women is driven by complex, interrelated psychosocial and relational factors rather than single demographic predictors.

These findings emphasize the need for strengthened adherence interventions, including: Community-based adherence support programs, which have been shown to improve ART adherence among women facing economic and social barriers Gelana, G.G., and Jun, S. (2023). Integration of mental health counseling, Counseling and support services that equip women

with safe disclosure strategies (Hardon et al., 2019) and partner involvement programs that encourage couple-based HIV counseling and testing (Kimera et al., 2025).

5.4. Chapter Six Limitations of the Study

Although the study was originally designed as a longitudinal study, there was considerable missing data on the outcome of interest for this analysis across follow-up visits. As a result, longitudinal analysis methods such as mixed-effects models or generalized estimating equations (GEE) could not be applied. To address this, a cross-sectional approach using modified Poisson regression model was employed at the end of the study, considering available data from both baseline and follow-up visits.

While this approach allowed for estimation of disclosure proportions and identification of associated factors, it limited the ability to assess temporal trends and causal inferences over time. Nonetheless, the findings provide valuable insights into HIV status disclosure patterns within this cohort and can inform future research designed to prospectively address these gaps.

Lastly, the study was consisting of only Ugandan women, which might limit the generalizability of our findings. However, the results are more likely to generalize to other populations in sub-Saharan Africa than studies done on other continents.

CHAPTER SIX CONCLUSION AND RECOMMENDATION

6.1 Conclusion

This study investigated the relationship between HIV status disclosure and adherence to antiretroviral therapy (ART) among women aged 18 to 35 years in selected health facilities in Kampala District. Using secondary data from the BONE:CARE study, the research provided important insights into behavioral trends, disclosure patterns, and the sociodemographic factors influencing adherence and non-disclosure.

ART adherence improved progressively throughout the 24-month follow-up, with the highest levels reported at months 21 (83.6%) and 24 (81.8%). Despite improved adherence, HIV status disclosure remained consistently low. At baseline, only 32.5% had disclosed their HIV status to their partners, and only 5% of the initial non-disclosers reported disclosure by the end of the study period. Multivariable analysis showed that women aged 25–35 years (aPR = 1.10, p = 0.048) were more likely to withhold disclosure compared to those aged 18–24 years. Similarly, employment status (aPR = 0.92, p = 0.033) was a significant factor, with employed women being less likely to conceal their HIV status.

The findings highlighted the need for holistic interventions that go beyond clinical support to address social, economic, and psychological factors affecting HIV disclosure. Interventions that promote financial independence and reduce stigma can empower women to disclose their HIV status, thereby improving ART adherence and health outcomes. This study underscores the importance of integrating community-based programs, mental health support, and gender-sensitive approaches into HIV care. Counseling services and targeted education can provide women with safer avenues to disclose their status and improve treatment adherence.

This research contributes to the growing body of evidence on HIV care by: Offering longitudinal insights into ART adherence and disclosure behaviors among young women in an urban Ugandan setting. Identifying age and employment status as predictors of HIV non-disclosure, which are critical for tailoring interventions. And providing evidence for policy

and program development aimed at improving HIV care outcomes through targeted psychosocial support and empowerment strategies.

6.2 Recommendations

Future research should; Explore psychological and social determinants of HIV disclosure using qualitative methods, examine the role of healthcare providers in supporting disclosure and improving ART adherence and investigate interventions aimed at reducing stigma and IPV, which remain major barriers to disclosure. These findings provide a foundation for targeted interventions that improve ART adherence, encourage safe disclosure, and enhance the well-being of women living with HIV.

In conclusion, addressing the complex interplay between ART adherence and HIV status disclosure among women requires multidimensional and sustainable approaches. By identifying and addressing the unique barriers faced by young women, stakeholders can strengthen public health efforts aimed at achieving better HIV treatment outcomes and reducing transmission.

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APPENDIX 1. ADHERENCE QUESTIONNAIRE

Study ID NIH-□□□-□

Date □□/□□□/□□

DD / MMM / YY

Visit Code: ……

HIV Status Disclosure Form

1. What was the tribe of the participant?	Muganda …….……1 Musoga ……2 Munyankole …….3 Munyarwanda……...4 Mukiga……..5 Mutoro ……6 Munyoro……7 Mugisu ……8 Itesot ……9 Langi ……..10 Others (specify) …….….11
2. Was the participant currently living with her sexual partner?	Yes……...1 No……..0 Not applicable…….…..9 (specify_____
3. Had the partner ever tested for HIV?	Yes……...1 No……..0 (skip to

	Do not Know…….7 (skip to
4. If yes, what was your partner's HIV status?	Positive……....1 Negative……..0 Don't know……7
5. What was the participant's HIV status at the time of recruitment? (if positive continue with question 6, if negative skip to question 9)	HIV infected ……..1. HIV un infected……....2 (skip to 29)
6. When did the participant first test HIV positive?	Date: _____ (dd/mm/yy) Duration in months: _____
7. was the participant currently on ART	Yes……....1 No……..0
8. Did the participant belong to any HIV peer group/ association?	Yes……....1 No……..0
9. Did the participant think it important to disclose her HIV status?	Yes……....1 No……..0
10. Was the participant worried about other people finding out about her HIV status?	Yes……....1

	No……..0
11. Had the participant ever told anyone about her HIV status? (If no skip to 24)	Partner/spouse……..…..1 Parent…….…..…2 (skip to 16) Other relative……..….3 (skip to 16) (specify) _____
12. If yes to whom? (Circle all codes that apply)	Friend…….……..4 (skip to 16) Employer…….……..5 (skip to 16) Neighbor……..…..…6 (skip to 16) Other (specify) _____7 (skip to 16)
	Positive /supportive…….1 Negative ……2 Indifferent……3
13. If the participant had told her **partner**, what was the reaction?	Was kind ……....1 Accepted it ……..…2 Got support……3 Increased support ……..4
14. If the reaction was positive, what was it?	Partner decided to test for HIV as well ……5
	Became angry ……....1 Blamed me ……..…2 Stigma ……3 Violence ……4

15. If the reaction was negative, what was it?	Abandonment …….5 Neglected by partner……..6 Breakup of relationship …..7 Separated with partner…….8 Other ……...9 (specify)_____
16. What happened when you **told another person/s** about your HIV status?	Got support……..1 Increased support……2 Abandonment……...3 Stigma……..……...4 Indifference……..….5 Other ……...6 (specify) _____ Not applicable …….9
17. What was the primary reason for disclosure?	To obtain social/emotional support……..….1 Out of moral obligation ...2 Someone found out/asked if I am HIV positive……3 Was initiating ART…….4 Other ……..5
18. Was the participant in know of her partner's HIV status before disclosure (if disclosed to partner)?	Yes ……1 No ……...0

19. For how long was she HIV positive before disclosing her status to her **partner**? (skip to 24 if uninfected)	Immediately after knowing my HIV status ……...1 Less than 6 months ……..2 Less than one year ……3 Between 1 to 2 years ……...4 More than 2 years ……5
20. For how long was HIV positive before disclosing her status to **any one**?	Immediately after knowing my HIV status ……1 Less than 6 months ……..2 Less than one year ……3 Between 1 to 2 years ……...4 More than 2 years ……5
21. Did she think that initiating ART made it important for her to disclose?	Yes …….……1 No ……..……..0
22. Was your disclosure influenced by a community member who recently disclosed their HIV status?	Yes …….……..1 No ……...0
23. How many people so far had she told about your HIV status at baseline? (on individual basis)	……(fill) Don't know……99

24. What was the reason for not telling her partner about her HIV status?	Fear of separation ……1 Partner dead…….2 Separated/ not staying with partner ……..3 Fear of stigmatization…..4 Other ……5 (specify)_____ No response…….....8 Not applicable…….…..9
25. If she had not disclosed to anyone, did she have any fears?	Yes ……..…..1 No……2
26. If she feared, what could be the reason behind the fear to tell anyone at least?	Domestic violence……...1 Partner abandonment ……..2 Community rejection ……..3 Accusation of infidelity …..4 Stigma/discrimination …….5 Other……..…..6 (specify): _____)
27. If she was to disclose, who would she have preferred telling about her HIV status?	Partner ……1 Parent……2 Other relative…….……3 Friend……..……4 Employer……..…..5

28. Would she have liked the interviewing staff to assist her with telling other people about her HIV status?	Other (specify) _____6 Yes ……..……1 No……2 N/A……..…..9

Comments:

_____

_____

_____

_____

_____

_____

_____

_____

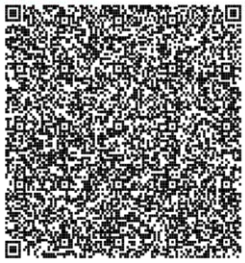
Interveiwer's initials & date_____/_____

QC I's initial's & date _____/_____QC II's initials & date _____/ _____

APPENDIX 1. REC APPROVAL LETTER

UGANDA CHRISTIAN UNIVERSITY

A Centre of Excellence in the Heart of Africa



28/02/2023

To: Nakyobe Joyce Bbosa
UCU
+256757500761

Review Type: Initial Review

Re:UCUREC-2022-425: ANTI-RETROVIRAL THERAPY ADHERENCE AND HIV STATUS DISCLOSURE AMONG WOMEN AGED 18 TO 35 YEARS IN SELECTED HEALTH FACILITIES IN KAMPALA DISTRICT., 1.0, 2022-11-24

I am pleased to inform you that the Uganda Christian University REC, through expedited review held on **23/02/2023** approved the above referenced study.

Approval of the research is for the period of **28/02/2023** to **28/02/2024.**

As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for rereview and approval **prior** to the activation of the changes.
3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit: ratio must be submitted to the REC.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on

file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.

5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of **28/02/2024** in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.
6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by Uganda Christian University REC:

No.	Document Title	Language	Version Number	Version Date
1	Protocol	English	1.0	2022-11-24
2	Data collection tools	English	1.0	2022-11-24

Yours sincerely,

Prof. Peter Waiswa

For: Uganda Christian
University REC