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Navigating Disclosure Obstacles Encountered by Individuals with HIV at Kakomo Healing Centre IV in Kabale District

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ABSTRACT

HIV/AIDS remains a pressing global health concern, particularly impacting socio-economic development in various African nations, Uganda included. Revealing one's HIV-positive status to a family member or relative is crucial for adherence to effective antiretroviral therapy, which significantly enhances the survival and well-being of those living with HIV. To evaluate the hurdles faced by individuals with HIV at Kakomo HC IV in Kabale District regarding disclosure and to curtail new infections in this community, a descriptive cross-sectional study was conducted. The study sampled individuals living with HIV at Kakomo HC IV randomly, utilizing a pretested questionnaire as the data collection instrument. The gathered data underwent coding, sorting, entry, and analysis through statistical software (SPSS), presented via tables and charts. Findings revealed that only 40 (50.6%) were adequately prepared before disclosing their status, while 30 (37.0%) neither prepared nor disclosed to anyone. 61 (63.5%) received education on the importance of disclosure during clinic visits, but 26 (46.4%) neither disclosed nor received such education. Barriers to disclosure primarily stemmed from anxiety about blame, stigma, fear of losing a partner, and violence among 18 (54.5%), 19 (52.8%), 30 (39.0%), and 2 (18.2%) individuals, respectively. Despite 62 (43.4%) intending to disclose to someone, 88 (98.9%) faced barriers to disclosing their status. Misconceptions in 51 (31.9%) communities and potential discrimination by families in the same proportion highlighted the challenges. Consequently, 123 (76.9%) still fear others spreading word of their HIV-positive status. Understanding disclosure motivations is crucial, requiring tailored strategies for decision-making based on the discloser's needs and their intended audience. The significance of support, proximity, and relational dynamics between the discloser and the recipient emphasizes the necessity for a secure environment during disclosure.

Keywords: HIV/AIDS, Antiretroviral therapy, HIV-positive, HIV status, Stigma.

INTRODUCTION

HIV is referred to as Human Immunodeficiency Virus (HIV), which is the most dangerous virus and is the major cause of AIDS in human life[1, 2]. It continues to spread worldwide and is one of the serious health challenges. Although much of the news on AIDS is encouraging, the challenges have continued [3] Disclosure is defined as the willingness of people living with HIV/AIDS (PLWHA) to reveal their seropositive status to another person [4]. An individual who has accepted the diagnosis may be likely to disclose his/her status as a coping action to regain control over his/her life. Disclosing one's HIV seropositive status has been described as a complex issue and a 'double-edged sword', which could either have a positive or negative outcome, or both.

Globally, there were 36.7 million people living with HIV in 2023[2, 5–7]. This was a high of 33.3 million in 2010. These increments in the number of patients resulted from continuing new infections, people living longer with HIV, and general

population growth [8]. 1.1 million people died of AIDS in 2015. There were about 2.1 million new infections in 2015, or about 5700 new infections per day. In developed countries, an average of 79% of HIV-positive patients disclosed their HIV status to other people [9]. Whereas in developing countries, the rates of disclosure of HIV serostatus were very low compared to developed countries.

Sub-Saharan Africa, the hardest-hit region, is home to nearly 70% of people living with HIV but only about 13% of the world's population [1, 10]. The rates of HIV-positive disclosure serostatus ranged from 16.7% to 86%, with an average of 49%, as almost half of the HIV-positive patients do not expose their serostatus to other people, including their sexual partners [11].

In Africa, the situation is even worse, with Ethiopia having a large and very vulnerable population with more than half a million (671,941) HIV-positive population, 14,405 new HIV infections, and 24,813 deaths in 2016, with a very low percentage of HIV-positive patients disclosing their serostatus to other people, including their sexual partners [12]. In Tanzania, 41% of HIV-positive women living with the infection had disclosed to their partners, and the most common reasons for disclosure status were age, level of education, and financial independence, particularly for women, to be important factors in predicting HIV serostatus disclosure [13].

HIV status disclosure has been reported to benefit PLWHA in several ways, including psychological, emotional, and material support from family and other community members and freedom to use ARV medications [4, 14]. In Uganda, an estimated 1.3 million people were living with HIV in 2017, and an estimated 26,000 Ugandans died of AIDS-related illnesses (UNAIDS, 2018). Men were disproportionately affected, with only 8.8% of adult women living with HIV disclosing their HIV-positive serostatus to their partners compared to 4.3% of men. Disclosure of Human Immunodeficiency Virus (HIV) positive status has a key role in the prevention and control of HIV/AIDS. The failure of people infected with HIV to disclose their positive status can expose their sexual partners and other relatives who have close contact with them to the virus. There are different factors that affect the disclosure of their HIV status; such as marital status, knowledge of partner HIV status, fear of negative outcomes of disclosure, communication skills, initiation of antiretroviral, receiving ongoing counseling, and duration of HIV-related care follow-up are some of the identified reasons [15].

Similarly, a growing body of research has explored the disclosure experiences of people living with HIV and AIDS in Kabale District. Results suggested that most people, particularly men living with HIV, do not disclose knowledge of their seropositive status to their partners [16]. The decision to disclose seropositive status among men is a complex process influenced by multiple factors such as knowledge of the partner's HIV status, anticipated support, and being the head of the household. The current study, therefore, seeks to assess disclosure challenges faced by people living with HIV/AIDS at Kakomo Health Centre IV located in Ndorwa West in Kabale District, western Uganda. HIV/AIDS remains a global public health issue with devastating effects, especially on the socio-economic development in several African countries, including Uganda [17, 18]. Disclosure of HIV-positive status to at least one family member or relative is paramount for adherence to highly active antiretroviral therapy (HAART), which increases the survival and quality of life of people living with HIV [19–22]. The Government of Uganda has deployed qualified health workers and provided HIV prevention and testing materials in various hospitals recently to promote, among other things, HIV seropositive disclosure to family members or relatives through multi-sectoral collaborative efforts together with other key stakeholders such as peer educators, social workers, opinion leaders, community members, and the PLWHA themselves. Despite the above efforts in

place and the importance of HIV seropositive status disclosure, still, most PLHIV conceal their seropositive status from their family/relatives. In Kakomo Health Centre IV, a recent Health Management Information System (tool 105) report indicated that, of 100% of PLHIV, only an estimated 55% disclosed their HIV seropositive status, although health workers working in the ART clinic provide routine health education talks on the importance of HIV seropositive status disclosure to PLHIV on every ART clinic day (HMIS, August 2018). This has resulted in 30% of new HIV infections occurring yearly, poor retention, and an increased number of unsuppressed viral load clients on care due to non-adherence to ART. No clear documentation exists on what exactly influences non-disclosure of HIV seropositive status among PLHIV, and this has motivated the researcher to assess disclosure challenges faced by PLWHA at Kokomo HC IV in Kabale District to make some relevant recommendations to the stakeholders for implementation.

METHODOLOGY

Study Design and Rationale

The researcher employed a cross-sectional study design and used a quantitative method of data collection and analysis. This was because data was obtained at one point in time and did not involve any manipulation of respondents.

Area of Study

The study took place in Kakomo Health Centre IV in Kabale district. Kakomo Health Centre IV is located in Ndorwa West County approximately 15 km from Kabale-Katuna road has a bed capacity of 18 and serves people of different socio-economic backgrounds. The health facility offers various services including OPD, LAB, medical, MCH, ANC, and FP among others. The staffing level comprises Clinical officers, nurses, midwives, Laboratorytechnologists, laboratory assistants, Records assistants, and other supportive staff. The Bakiga tribe is the dominant ethnic group in the facility although other tribes can be found. This area was chosen because many PLWHs are available and few seem to have shared their seropositive status with others.

Study Population

The study included all adult clients living with HIV-positive illness who consented to participate in the study.

Sample Size Determination

The sample size was determined by Kish Leslie [23] formula since the catchment population of the art clinic at KAKOMO HC IV was not known.

$$n = \frac{Z^2P(1-P)}{d^2}$$

Where;

n = minimum sample size required.

Z = standard normal deviation set at 95% confidence level corresponding to 1.96

P = expected prevalence (portion)

d = acceptable marginal error.

P=21% Based on Kabaale Hospital Study (Ignatius Wadunde, 2018),

Z = 1.96,

d = 5%

$n = (1.96)^2(0.21)\ (1-0.5)/(0.05)^2 = 161$patients

Sampling Procedure

Due to the availability of respondents, the researcher used a convenient sampling method to select the required number of respondents. The researcher selected all the potential respondents who met the study criteria and included them in the study. This continued until a total number of 32 respondents was achieved on a daily basis.

Inclusion Criteria

The study included all HIV-positive clients already enrolled in ART and attending HIV services at Kakomo Health Centre IV who agreed to consent to participate in this study.

Exclusion Criteria

All children below 18 years who are HIV positive and already enrolled on ART and are attending HIV services at Kakomo Health Centre IV.

Definitions of Variables

The variables are defined as dependent and independent variables. The dependent variables include; HIV seropositive disclosure status and independent variables include; individual-related factors, community-related factors, and health service-related factors

influencing HIV seropositive status among PLWH.

Research Instruments

The researcher used self-structured administered questionnaires for data collection because theycover a wide range of respondents, save time, and minimize interactions with respondents.

Data Collection Procedures

A self-administered questionnaire was designed and pre-tested for validity and thereafter was used for data collection. The questionnaires were administered by the researcher in Kakomo Health Centre IV where selected subject respondents are available. Each respondent was given an equal chance to participate in the study by picking any PLWH above 18 yearsold who came for HIV services. Consent was obtained from all the respondents.

Data Management

At the end of each day, completed tools were organized and kept under safe custody before entry. The researcher checks for completeness, errors, and omissions of the data collected with an interview schedule before entry and analysis.

Data Analysis and Presentation

Data collected was compiled, processed, and analyzed for the outcome of the variables using a non-programmable scientific calculator and computer statistical software package for social scientists and the results were presented in bar graphs, figures, tables, frequencies, percentages, and pie charts based on the kind of the tool used. Data editing, checking, and cleaning were done before entry into computer statistical programs. These methods are preferred by the researcher because they are convenient and easy to use.

Ethical Consideration

An introductory letter was obtained from the University Faculty administration which was then presented to the in charge of Kakomo Health Centre IV. Permission was granted upon reaching the facility and the facility charge introduced me to the clients who fully explained, the purpose of the study then their consent was obtained, and other principles of ethics put into consideration like confidentiality, autonomy, beneficence, and non-maleficence among others, to ensure clients are not affected negatively in the research process.

RESULTS

Table 1: Social demographic characteristics of the study participants

Variables	Frequency (n=160)	Percentage (%)
Patient's Age		
18-25	18	11.3
26-30	18	11.3
31- 35	19	11.9
36-40	45	28.1
41 & above	60	37.5
Gender		
Male	75	46.9
Female	85	53.1
Marital State		
Single	91	56.9
Married	31	19.4
Widow	19	11.9
Divorced	19	11.9
Education Level		
Primary level	75	46.9
Secondary	85	53.1
Occupation		
Employed	111	69.3
Unemployed	49	30.7
Religion		
Muslim	70	43.8
Christian	90	56.2

The Individual related disclosure challenges faced by PLWHA in Kakomo HC IV in Kabale District.

As shown in figure 1, majority 56.9% of the study participants had disclosed or shared their positive HIV health status (test results) with someone while 43.1% had never.

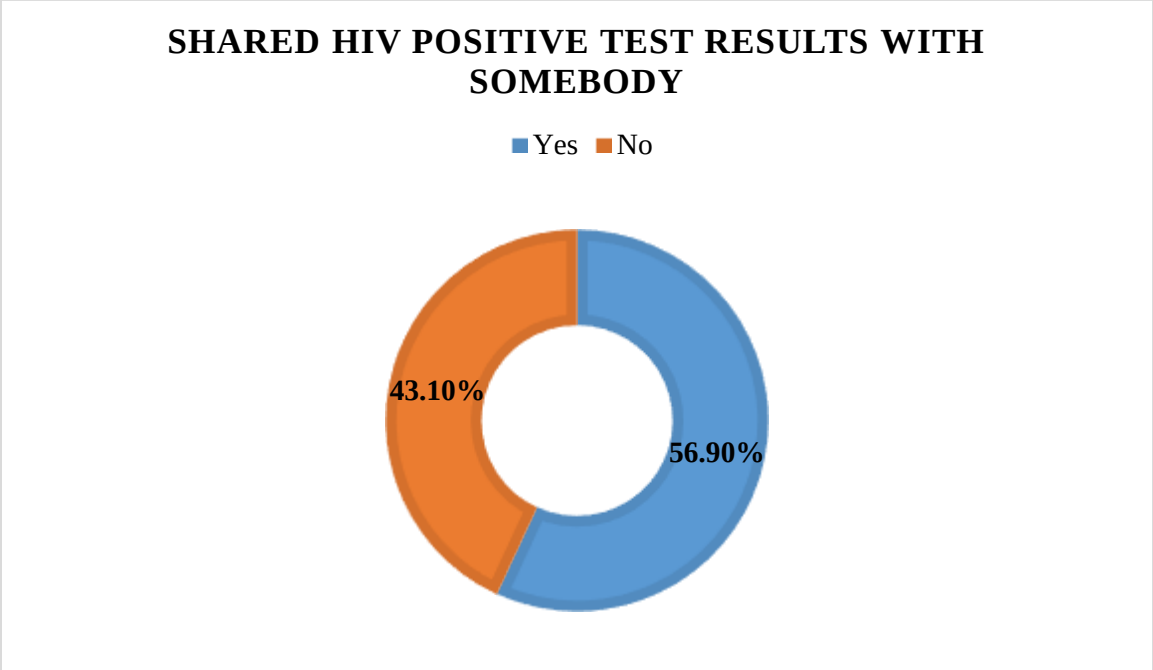


Figure 1: Level of HIV + Status Disclosure among PLWHIV in Kakomo HC IV, Kabale District

Accordimg to the study findings; majority of those who never disclosed; 46(54.1%), 26(28.6%), 12(63.2%) and 19(100.0%) were females by gender, either singles, widowed and divorced by marital status and mostly 51(63.8%) moslems by religion. The majority 70(79.5%) of those who had disclosed to some was mostly owing to it being a doctor's recommendation, followed by a Partner's illness/death 21(36.2%) while 0(0.0%) shared because of their sickness.Disclosure is mostly hindered because victims mostly 18(54.5%), 19(52.8%), 30(39.0%) and 2(18.2%); are anxious about blame, stigma, and fear of losing a partner and violence respectively.Despite 62(43.4%) planning to disclose to someone and 88(98.9%)planning to disclose further, 88(98.9%) have ever been denied an opportunity having disclose their HIV-positive results with someone.

Table 2: Individual-related disclosure challenges faced by PLWHA in Kakomo HC IV in Kabale District.

Variable		Shared about the HIV + results disclosure	
		Yes [N(%)]	No [N(%)]
Gender	Male	52(69.3%)	23(30.7%)
	Female	39(45.9%)	46(54.1%)
Marital Status	Single	65(71.4%)	26(28.6%)
	Married	19(61.3%)	12(38.7%)
	Widow	7(36.8%)	12(63.2%)
	Divorced	0(0.0%)	19(100.0%)
Religion	Muslim	29(36.2%)	51(63.8%)
	Christian	62(77.5%)	18(22.5%)
Reason For Testing	My sickness	0(0.0%)	14(100.0%)
	My Partner's illness/death	21(36.2%)	37(63.8%)
	Doctor's recommendation	70(79.5%)	18(20.5%)
Hinderance To Disclosure	Stigma	17(47.2%)	19(52.8%)
	Fear to lose a partner	47(61.0%)	30(39.0%)
	Blame	15(45.5%)	18(54.5%)
	Violence	9(81.8%)	2(18.2%)
Plan To Disclose	Yes	81(56.6%)	62(43.4%)
	No	10(58.8%)	7(41.2%)
Ever Denied Oppoertunity Owing To Hiv+	Yes	88(98.9%)	1(1.1%)
	No	3(4.2%)	68(95.8%)

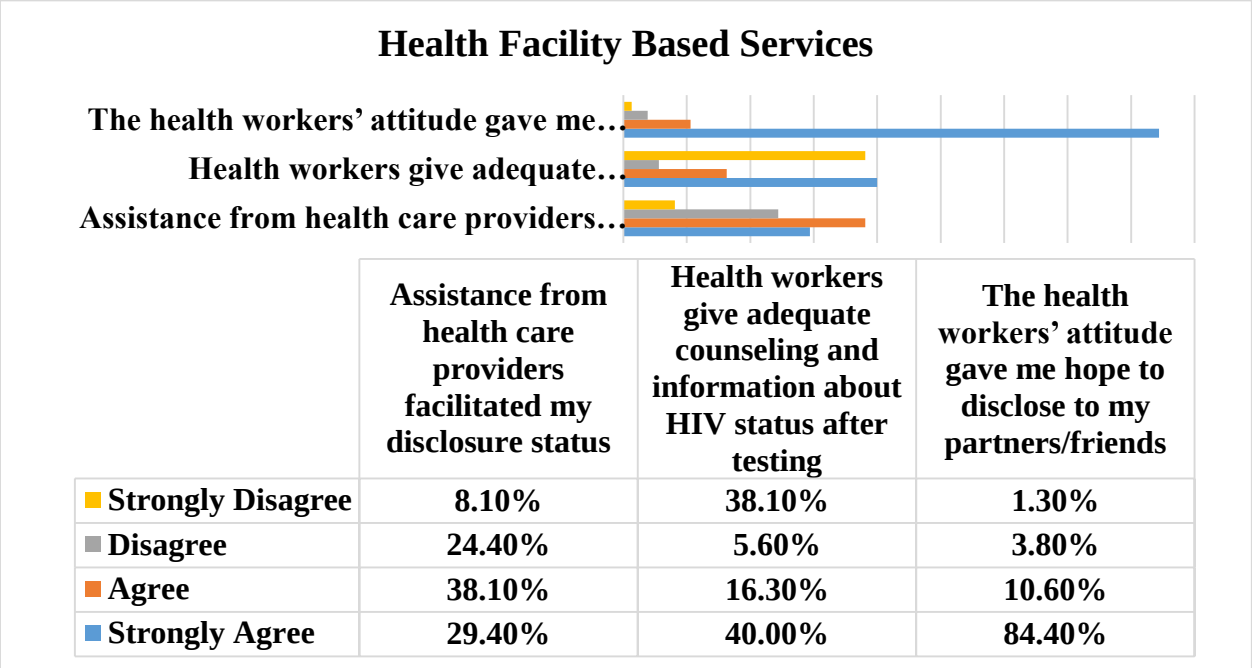
The Health Facility-related disclosure challenges faced by PLWHA in Kakomo HC IV in Kabale District.

According to the study findings, only 40(50.6%) had been well prepared before disclosure whereas 30(37.0%) were neither prepared nor did they disclose their HIV-positive results with anybody. [P-value=0.115; OR=0.60(0.32-1.13)]. The majorityof 53(67.1%) support the health workers to visit their families to discuss, counsel and do HIV status and did share their results with somebody. Furthermore, 61(63.5%) agreed to have received education on the importance of HIV status disclosure during clinic visits. 26(46.4%) had neither disclosed nor educated on its importance during such clinic visits. However, supporting health worker visiting family to discuss, counsel and do HIV test proved to be statistically significant [P-Value=**0.021, OR=2.16(1.12-4.16)]**

Table 3: Health Facility-related disclosure challenges faced by PLWHA in Kakomo HC IV in Kabale District.

Variable		Shared about the HIV + results Disclosure		P-Value	OR [95% C.I]
		Yes [N(%)]	No [N(%)]		
Prepared for disclosure during the clinic visit?	Yes	40(50.6%)	39(49.4%)	0.115	0.60(0.32-1.13)
	No	51(63.0%)	30(37.0%)	Ref	1
Support health worker visiting family to discuss, counsel and do HIV test	Yes	53(67.1%)	26(32.9%)	**0.021**	**2.16(1.12-4.16)**
	No	35(48.6%)	37(51.4%)	Ref	1
I get health education on the importance of HIV status disclosure during clinic visits	Yes	61(63.5%)	35(36.5%)	0.226	1.51(0.773-2.95)
	No	30(53.6%)	26(46.4%)	Ref	1

Similarly, it was strongly agreed that; 47(29.4%) received assistance from health care providers which facilitated their HIV positive status disclosure. 64(40.0%) added that Health workers give adequate counseling and information about HIV status after testing, while 135(84.4%) revealed that its the health workers' attitude that gave them hope to disclose to their partners/friends.



	Assistance from health care providers facilitated my disclosure status	Health workers give adequate counseling and information about HIV status after testing	The health workers' attitude gave me hope to disclose to my partners/friends
Strongly Disagree	8.10%	38.10%	1.30%
Disagree	24.40%	5.60%	3.80%
Agree	38.10%	16.30%	10.60%
Strongly Agree	29.40%	40.00%	84.40%

Figure 2: Health Facility based activities

The Community Related Disclosure Challenges faced by PLWHA in Kakomo HC IV in Kabale District

According to the study findings, a considerable number strongly agreed that 24(15.0%) families were supportive after disclosure and reminded the victims to take their pills, and 22(13.8%) Community members encouraged and consoled the victims after disclosure.However, 51(31.9%) Communities had a wrong impression of life owing to HIV-positive status disclosure and 51(31.9%) Families would discriminate against the victims after knowing their HIV status thus 123(76.9%) continue to fear that people

could go around talking about their HIV positive status.

Table 4: Community-Related Disclosure Challenges Faced by PLWHA in Kakomo HC IV in Kabale District

Variable	Response			
	Strongly Agree	Agree	Disagree	Strongly Disagree
My family was supportive after disclosure and reminded me to take my pills	24(15.0%)	95(59.4%)	21(13.1%)	20(12.5%)
Community had a wrong impression of my life owing to my HIV status	51(31.9%)	46(28.8%)	62(38.8%)	1(0.6%)
I fear that people go around talking about my HIV	123(76.9%)	25(15.6%)	8(5.0%)	4(2.5%)
Community members encouraged and consoled me after the disclosure	22(13.8%)	91(56.9%)	26(16.3%)	21(13.1%)
Families would discriminate against me after knowing my HIV status	51(31.9%)	47(29.4%)	60(37.5%)	1(0.6%)

DISCUSSION

The individual-related disclosure challenges faced by PLWHA in Kakomo HC IV in Kabale District

According to the study findings, the majority of those who never disclosed (54.1%, 28.6%, 63.2%, and 100.0%) were females by gender, either single, widowed, or divorced by marital status and mostly (63.8%) Muslims by religion. This complements a study by Mburu et al. [24] in which it was concluded that HIV-infected patients find it hard to disclose their HIV status soon after diagnosis. Similarly, Sanga et al. [25]put it that for disclosure to happen, it depends on several factors, which include age, socioeconomic status, level of education, marital status, social relations, knowledge, cultural factors, and acquaintance with the importance of HIV disclosure.

Furthermore, PLHAs showed that Muslims are stigmatized more often if their partners die from AIDS. Cultural beliefs often prevent Muslims, especially women, from attending HIV/AIDS clinics and disclosing their status [26]. Also, women may be ill-treated if they disclose their HIV status to their male sexual partners due to gender imbalances and discrimination in many communities [13]. Women who had more than six lifetime sexual partners were less likely to disclose their status [12, 21]. Disclosure is mostly hindered because victims (54.5%, 52.8%, 39.0%, and 18.2%) are anxious about blame, stigma, fear of losing a partner, and violence, respectively.

In a similar way, in a survey done by USAID [19], shame (39%), blame (27.6%), low self-esteem (19.4%), and guilt (16.0%) were expressed by patients upon disclosure preparedness. Many HIV-positive individuals (63%) find it desirable to share information about their HIV status with their partners immediately. Others (21.9%) took time to weigh potential negative consequences while the rest (8%) were reluctant to disclose, especially those in relatively new relationships [27]. According to WHO [28], fear, stigma, and lack of understanding inhibit people from sharing their status, thus placing their loved ones at the risk of getting the disease.

After HIV testing, most people fear to disclose their status for fear of being blamed for infidelity and promiscuity

[29]. When a patient is diagnosed with HIV seroreactive, the close people get worried about the possibility of being infected with the disease [30]. The couples are also worried about the chances of transmission, which causes blame on who might have brought the disease. Some have been forced not to share their status at all for fear of mistreatment, mistrust, or isolation [31].

According to the study by Evangeli and Roei. [32] on determinants of HIV seropositive disclosure status, results revealed that 76.1% of the HIV-positive pregnant women who had not disclosed their results two months after diagnosis said that they never intended to disclose to their partners for fear of abandonment. Despite a considerable number (43.4%) planning to disclose to someone and only 8.9% planning to disclose further, the majority (98.9%) had ever been denied an opportunity to disclose their HIV-positive results with someone.

PLHIV may suffer stigma from co-workers and employers such as social isolation, and discrimination like termination from work or refusal of employment[32]. Other studies by Tibebu et al. [33] show discrimination in household activities and healthcare workers respectively. In Kenya, it was found that women of lower socioeconomic status had a higher disclosure rate than women of higher socioeconomic status. In a study conducted in Tanzania among HIV-positive women, lower income was negatively associated with disclosure [34].

The health facility-related disclosure challenges faced by PLWHA in Kakomo HC IV in Kabale District.

According to the study findings, only (50.6%) had been well prepared before disclosure whereas 37.0% were neither prepared nor did they disclose their HIV-positive results with anybody. This complements a study done among HIV-positive pregnant women in Ethiopia showed that HIV disclosure to their sexual partners was associated with adequate counselling [6]. Similarly, the Majority (67.1%) support the health workers visiting their families to discuss, counsel and do HIV status and did share their results with somebody. This supports findings in a study by Kiula et al., [35] in which HIV disclosure of positive status causes tension among partners, women being more vulnerable as disclosure can lead to either an extension of former violence or new conflict specifically associated with HIV serostatus disclosure. Furthermore, 61(63.5%) agreed to have received education on the importance of HIV status disclosure during clinic visits. 26(46.4%) had neither disclosed nor educated on its importance during such clinic visits. However, supporting health worker visiting family to discuss, counsel and do HIV test proved to be statistically significant with 2.16(1.12-4.16) times more likely for one to disclose their HIV-positive status. This adds to findings by Patel et al., [36] which suggest that being symptomatic at baseline was associated with disclosure of HIV status to their sexual partners.Similarly, it was strongly agreed that a considerable number (29.4%) received assistance from health care providers which facilitated their HIV-positive status disclosure. Only 40.0% revealed and added that Health workers give adequate counselling and information about HIV status after testing, while 135(84.4%) revealed that it's the health workers' attitude that gave them hope to disclose to their partners/friends. The research finding by Gultie *et al* [37] found that only 30.8% of participants agreedthat assistance from healthcare providers facilitated their disclosure status and the majority agreed that enrol with disclosure support groups would assist them in facilitating disclosure. A similar study by Odiachi *et al* [38] found show the highest number of participants prefer contract referral disclosure where the Health Care Provider provides assistance. A study by Gass et al.,, [39] in the United States of America found thatthe majority of participants prefer contract referral where HCP allow the index patient a short period of time to contact, notify and refer sexual partners, then advise the contact of their exposure maintaining the anonymity of the index case.

The community-related disclosure challenges faced by PLWHA in Kakomo HC IV in Kabale District

According to the study findings, a considerable number strongly agreed that 24 (15.0%) families were supportive after disclosure and reminded the victims to take their pills, while 22 (13.8%) community members encouraged and consoled the victims after disclosure. Positive behavior from partners, friends, and neighbors after the revelation of participants' HIV status motivates disclosure[36] . According to Norman et al. [40], in a study on factors related to HIV disclosure, 1 out of 16 respondents depended on their neighbors and friends for support after family member's abandonment on HIV disclosure; neighbors had been filling in the support gap through child care and food sharing. However, while there are many advantages and reasons for disclosing one's status, there are also risks and reasons for deciding not to disclose [22].

In this study, only 31.9% of communities had a wrong impression of life owing to HIV-positive status disclosure, and a considerable number (31.9%) of families would discriminate against the victims after knowing their HIV status. Ford et al. (2012) found that 4 out of 10 PLHIV fear disclosing their HIV serostatus due to the fear of abandonment when they need support the most, while Patel et al., [36] show that 25% of women fear disclosing due to economic support. Some people are willing to disclose their status given they can receive social support, which they may lose after disclosure. Furthermore, more than half (76.9%) of the participants continue to fear that people could go around talking about their HIV-positive status. This is comparable to a study by Bbosa et al.[31], in which it was concluded that HIV disclosure of positive status causes tension among partners, with women being more vulnerable as disclosure can lead to either an extension of former violence or new conflict specifically associated with HIV serostatus disclosure.

CONCLUSION

The findings suggest that the reasons for disclosure may differ by the target of disclosure or nondisclosure, highlighting the need for tailoring interventions and strategies for improving disclosure decision-making according to the specific needs of the disclosers and who they are disclosing. The prominence of support, closeness, and social distance between the discloser and the disclosure target highlights the need for people to feel safe when disclosing.

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