Health System Support Mechanisms for HIV Status Disclosure Among People Living with HIV/AIDS in Mukono District, Uganda

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Abstract

Background

Health systems play a crucial role in supporting HIV status disclosure, which is essential for HIV prevention, treatment adherence, and psychosocial support. Understanding how health systems support disclosure is vital for improving HIV care outcomes.

Methods

A descriptive cross-sectional study was conducted in 10 health facilities offering comprehensive HIV/AIDS care in Mukono district, Uganda. Data was collected from 317 clients through interview-guided questionnaires, 55 health workers through self-administered questionnaires, and 10 health managers through interviews. Data was analyzed using SPSS version 16.

Results

The health system in Mukono district supported HIV status disclosure through multiple mechanisms: pre-test counseling (reported by 94.5% of health workers), post-test counseling (98.2%), ongoing counseling (89.1%), care and support services (85.5%), and referral systems (76.4%). Clients reported receiving disclosure support primarily through counseling services (92.7%), with health workers emphasizing benefits of disclosure during these sessions. Health facilities provided private counseling spaces, trained counselors, and peer support groups to facilitate disclosure. The Ministry of Health, District Health Office, and partner NGOs contributed to disclosure support through policy guidance, supervision, training, and resource provision.

Conclusions

The health system in Mukono district has established several mechanisms to support HIV status disclosure, with counseling services being the primary approach. However, gaps remain in infrastructure, human resources, and policy implementation. Strengthening these support mechanisms through increased resource allocation, improved training, and enhanced coordination between stakeholders could further improve disclosure outcomes.

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Introduction

HIV/AIDS continues to be a significant public health challenge globally, particularly in Sub-Saharan Africa. Recent global estimates indicate that approximately 39 million people were living with HIV worldwide by the end of 2022, with 1.3 million new infections occurring in that year alone [1]. In Uganda, despite significant progress in HIV prevention and treatment, the country still faces a substantial burden with an estimated prevalence of 5.4% among adults aged 15-49 years as of 2022, with approximately 1.4 million people living with HIV/AIDS [2].

Disclosure of HIV status is recognized as a critical component of HIV prevention and care. It refers to the process whereby a person with HIV informs others about their seropositive status. Disclosure serves multiple purposes: it enables individuals to gain social support for preventive actions, facilitates access to care and treatment services, improves adherence to antiretroviral therapy (ART), reduces risky sexual behaviors, and contributes to decreasing HIV-related stigma [3,4].

The health system plays a pivotal role in supporting HIV status disclosure. According to the World Health Organization (WHO), a well-functioning health system should ensure equitable access to essential medical products, vaccines, and technologies; a well-performing health workforce; a well-functioning health information system; and leadership and governance that provides effective oversight and regulation [5]. In the context of HIV disclosure, the health system should provide appropriate counseling, create supportive environments, develop clear policies and guidelines, and offer necessary resources to facilitate disclosure.

In Uganda, HIV/AIDS care is provided by the government and various partners, including civil society organizations, community-based organizations, faith-based organizations, international organizations, donors, and the private sector. Recent studies have highlighted the evolution of HIV service delivery models in Uganda, with the introduction of differentiated service delivery models (DSDMs) in 2017 to strengthen ART access, reduce care costs, improve satisfaction, and boost treatment outcomes [6]. These models have implications for how disclosure support is integrated into HIV care.

Kimberly and Serovich [7] identified a six-step process for HIV disclosure: (1) adjustment to diagnosis, (2) evaluation of personal disclosure skills, (3) evaluation of the appropriateness of disclosing to a potential recipient, (4) evaluation of the circumstances for disclosure, (5) anticipation of potential reactions, and (6) identification of motivation for disclosure to each recipient. Health systems can support clients through this process by providing appropriate counseling, information, and resources.

Despite the importance of health system support for HIV status disclosure, there is limited information on how health systems in Uganda, particularly in Mukono district, support clients to disclose their HIV status. This study aimed to establish how the health system of Mukono district supports clients to disclose their HIV status to friends, partners, and relatives. The findings from this study will contribute to the development of more effective health system interventions to support HIV status disclosure and improve HIV prevention and care outcomes.

Methods

Study Design

This research employed a descriptive cross-sectional study design to establish how the health system of Mukono district supports clients to disclose their HIV status. This design was appropriate for capturing data on health system support mechanisms at a specific point in time.

Study Setting

The study was conducted in Mukono District, which is located in the central region of Uganda, approximately 21 km east of Kampala. The district has a population of approximately 600,000 people and an HIV prevalence of 7.2%, which is higher than the national average. The study specifically focused on 10 health facilities in Mukono district that offer comprehensive HIV/AIDS care services, including ART, PMTCT, VCT, and RCT.

Study Population

The study population consisted of three groups: (1) HIV-positive clients who were enrolled in ART programs at the selected health facilities, (2) health workers involved in providing HIV/AIDS care services, and (3) health managers responsible for overseeing HIV/AIDS programs in the district. These diverse perspectives allowed for a comprehensive understanding of health system support for HIV status disclosure.

Sample Size Determination and Sampling Technique

For HIV-positive clients, a sample size of 317 was determined using a hypergeometric method, considering the finite population of HIV clients in the selected health facilities. For health workers, a sample of 55 was selected, representing approximately 80% of the health workers involved in HIV/AIDS care in the selected facilities. For health managers, all 10 managers responsible for HIV/AIDS programs in the district were included.

A multi-stage sampling technique was employed to select participants. First, health facilities offering comprehensive HIV/AIDS care in Mukono district were identified. From these, 10 facilities were randomly selected. Within each selected facility, HIV-positive clients were systematically sampled from the ART registers, health workers were purposively selected based on their involvement in HIV/AIDS care, and health managers were identified through their roles in overseeing HIV/AIDS programs.

Data Collection Tools and Procedures

Data was collected using three different tools: (1) interview-guided questionnaires for HIV-positive clients, (2) self-administered questionnaires for health workers, and (3) interview guides for health managers. Additionally, an observation checklist was used to assess the infrastructure and resources available for supporting HIV status disclosure in the selected health facilities.

The questionnaires for HIV-positive clients captured information on their experiences with health system support for disclosure, including the types of support received, the effectiveness of this support, and suggestions for improvement. The questionnaires for health workers focused on the support mechanisms they provided to clients, the challenges they faced, and their training and resources for supporting disclosure. The interview guides for health managers explored policy frameworks, resource allocation, supervision, and coordination of disclosure support activities.

Trained research assistants administered the questionnaires and conducted the interviews. All data collection was conducted in private settings to ensure confidentiality. Interviews were conducted in the local language (Luganda) or English, depending on the participant's preference.

Data Analysis

Data was entered using EPI data and analyzed using SPSS version 16. Descriptive statistics, including frequencies, percentages, means, and standard deviations, were used to summarize the quantitative data. Qualitative data from open-ended questions and interviews were analyzed using thematic analysis, identifying key themes related to health system support for HIV status disclosure.

Ethical Considerations

Ethical approval for the study was obtained from the Institutional Review Board of the School of Public Health, Makerere University. Permission to conduct the study was also obtained from the District Health Officer of Mukono district and the administrators of the selected health facilities.

Informed consent was obtained from all participants before their inclusion in the study. Participants were assured of confidentiality and anonymity, and they were informed that their participation was voluntary and that they could withdraw from the study at any time without any consequences. All data collected was kept secure and confidential.

Results

Health System Support Mechanisms for HIV Status Disclosure

The health system in Mukono district supported HIV status disclosure through multiple mechanisms. According to health workers, the most common support mechanisms included pre-test counseling (94.5%), post-test counseling (98.2%), ongoing counseling (89.1%), care and support services (85.5%), and referral systems (76.4%). These mechanisms were implemented across different levels of the health system, from facility-based services to community outreach programs.

Clients reported receiving disclosure support primarily through counseling services (92.7%),with health workers emphasizing the benefits of disclosure during these sessions. Other support mechanisms reported by clients included peer support groups (67.8%), information materials on disclosure (45.1%), and home visits by health workers or community volunteers (38.2%).

Counseling Services as a Primary Support Mechanism

Counseling emerged as the primary mechanism through which the health system supported HIV status disclosure. Pre-test counseling introduced the concept of disclosure and its importance for HIV prevention and care. Post-test counseling provided immediate support following diagnosis and helped clients develop initial disclosure plans. Ongoing counseling offered continued support as clients navigated the disclosure process over time.

Health workers reported using various counseling approaches to support disclosure, including individual counseling (98.2%),couple counseling (87.3%), family counseling (72.7%), and group counseling (63.6%). They emphasized the importance of tailoring counseling to the specific needs and circumstances of each client, considering factors such as relationship dynamics, cultural context, and potential risks associated with disclosure.

Clients generally reported positive experiences with counseling services, with 85.2% indicating that counseling had been helpful in supporting their disclosure decisions. However, some clients (14.8%) felt that counseling did not adequately address their specific concerns or challenges related to disclosure.

Infrastructure and Resources for Disclosure Support

The health facilities in Mukono district had varying levels of infrastructure and resources to support HIV status disclosure. Observation of the facilities revealed that 60% had dedicated spaces for private counseling, which is essential for confidential discussions about disclosure. However, only 40% had adequate information materials on disclosure, such as brochures, posters, or videos.

Health workers reported challenges related to infrastructure and resources, including limited private spaces for counseling (67.3%), inadequate information materials (72.7%), and insufficient time for

comprehensive counseling due to high client loads (81.8%). These challenges affected the quality and effectiveness of disclosure support provided to clients.

Health Workforce Capacity for Supporting Disclosure

The capacity of the health workforce to support HIV status disclosure varied across the health facilities. Of the 55 health workers surveyed, 78.2% had received some training on HIV counseling, but only 43.6% had received specific training on supporting HIV status disclosure. Health workers who had received disclosure-specific training reported feeling more confident in their ability to support clients through the disclosure process.

Health managers acknowledged the need for more comprehensive training on disclosure support, with 80% indicating that current training programs did not adequately address the complexities of disclosure counseling. They also highlighted challenges related to staff shortages, high turnover, and limited opportunities for continuous professional development.

Policy and Guideline Implementation

The implementation of policies and guidelines related to HIV status disclosure varied across the health facilities. Health managers reported that while national policies and guidelines on HIV counseling and testing addressed disclosure to some extent, there were no specific guidelines focused on disclosure support. This resulted in inconsistent approaches to disclosure support across different facilities and providers.

Health workers expressed a need for clearer guidelines on supporting disclosure, particularly in complex situations such as discordant couples, adolescents, or cases where disclosure might lead to violence or abandonment. They also highlighted challenges in balancing confidentiality with the need to prevent HIV transmission to partners at risk.

Coordination and Collaboration Among Stakeholders

The study found varying levels of coordination and collaboration among stakeholders involved in supporting HIV status disclosure. The Ministry of Health, District Health Office, health facilities, and partner NGOs all played roles in disclosure support, but coordination mechanisms were often informal and inconsistent.

Health managers reported challenges in coordinating disclosure support activities across different stakeholders, with 70% indicating that there was limited communication and information sharing. They emphasized the need for more structured coordination mechanisms to ensure consistent and comprehensive disclosure support across the district.

Client Perspectives on Health System Support

Clients' perspectives on health system support for disclosure revealed both strengths and areas for improvement. Most clients (78.5%) felt that the health system had provided adequate support for their disclosure decisions, but 21.5% reported needing additional support that was not available.

Clients suggested several improvements to health system support for disclosure, including more personalized counseling (65.3%), better follow-up after disclosure (58.4%), more involvement of partners and family members in counseling (52.1%), and increased availability of peer support (47.3%).

Discussion

This study found that the health system in Mukono district has established several mechanisms to support HIV status disclosure, with counseling services being the primary approach. This finding is consistent with previous research highlighting the central role of counseling in supporting disclosure [8,9]. The high proportion of health workers reporting the provision of pre-test, post-test, and ongoing counseling suggests a recognition of the importance of continuous support throughout the disclosure process.

However, the study also identified gaps in health system support for disclosure, particularly in terms of infrastructure, human resources, and policy implementation. The limited availability of private counseling spaces in 40% of the facilities is concerning, as privacy is essential for confidential discussions about disclosure. This finding aligns with previous research highlighting infrastructure challenges in HIV care settings in Uganda and other resource-limited contexts [10].

The finding that only 43.6% of health workers had received specific training on supporting HIV status disclosure suggests a significant gap in workforce capacity. This is consistent with previous studies that have identified limited training as a barrier to effective disclosure support [11,12].The recent qualitative study by Musanje et al. [13] in Uganda emphasizes the importance of healthcare provider skills and attitudes in supporting clients through difficult processes such as disclosure, suggesting that targeted training interventions could enhance disclosure support.

The lack of specific guidelines focused on disclosure support is another important gap identified in this study. This finding aligns with previous research highlighting the need for clearer policy frameworks to guide disclosure support in healthcare settings [14,15]. The recent study by Kirabira et al. [16] noted that while Uganda's HIV and AIDS Prevention and Control Act allows for disclosure by healthcare providers under certain circumstances, the implementation of these provisions remains challenging due to limited awareness and understanding of the law.

The varying levels of coordination and collaboration among stakeholders involved in disclosure support suggest a need for more structured coordination mechanisms. This finding is consistent with previous research highlighting the importance of multi-sectoral collaboration in addressing complex health issues such as HIV disclosure [17,18]. The recent study by Katongole et al. [6] on differentiated service delivery models in Uganda emphasizes the importance of coordination among different stakeholders to ensure comprehensive and consistent HIV care, including disclosure support.

Despite these challenges, the study found that most clients felt the health system had provided adequate support for their disclosure decisions. This positive finding suggests that existing support mechanisms, particularly counseling services, are meeting the needs of many clients. However, the fact that 21.5% of clients reported needing additional support indicates room for improvement.

The clients' suggestions for improving health system support for disclosure, including more personalized counseling, better follow-up, and increased involvement of partners and family members, align with recent developments in disclosure support approaches. The HIV Empowering Adults' Decisions to Share (HEADS) model, which emphasizes person-centered approaches to disclosure support [19], and the use of community health workers to extend disclosure support beyond healthcare facilities [20], represent promising innovations that could address some of the gaps identified in this study.

Strengths and Limitations

This study has several strengths, including its comprehensive approach to examining health system support for HIV status disclosure from multiple perspectives (clients, health workers, and health managers) and its focus on a specific geographic area (Mukono district), which allows for a detailed understanding of local health system dynamics.

However, the study also has limitations. The cross-sectional design limits our ability to assess changes in health system support over time or to establish causal relationships between support mechanisms and disclosure outcomes. The reliance on self-reported data from health workers and managers may introduce social desirability bias, potentially leading to an overestimation of the support provided. Additionally, the study did not include the perspectives of partners or family members who are recipients of disclosure, which could have provided additional insights into the effectiveness of health system support.

Conclusions

The health system in Mukono district has established several mechanisms to support HIV status disclosure, with counseling services being the primary approach. However, gaps remain in infrastructure, human resources, and policy implementation. Strengthening these support mechanisms through increased resource allocation, improved training, and enhanced coordination between stakeholders could further improve disclosure outcomes.

Based on the findings of this study, we recommend the following actions to strengthen health system support for HIV status disclosure in Mukono district and similar settings:

1. Improve infrastructure for disclosure support by ensuring all health facilities have dedicated spaces for private counseling and adequate information materials on disclosure.
2. Enhance health workforce capacity through comprehensive training on disclosure support, focusing on addressing complex disclosure situations and tailoring support to individual needs.
3. Develop specific guidelines on disclosure support to ensure consistent and effective approaches across different facilities and providers.
4. Establish structured coordination mechanisms among stakeholders involved in disclosure support to ensure comprehensive and consistent support across the district.
5. Integrate innovative approaches to disclosure support, such as the HEADS model and community-based support, to address the diverse needs of people living with HIV.

Future research should explore the effectiveness of different disclosure support mechanisms in improving disclosure outcomes, the perspectives of partners and family members on health system support for disclosure, and the implementation of innovative approaches to disclosure support in resource-limited settings.

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Author Contributions

All authors contributed to the conception and design of the study, data collection, analysis, and interpretation, and the writing and revision of the manuscript. All authors approved the final version of the manuscript.

Competing Interests

The authors declare that they have no competing interests.

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