



Stigma and Discrimination of HIV/AIDS Recipients of Care in Western Uganda: Experiences and Roles of Expert Clients

Humphrey Atwijukiire ¹, Hajarah Jemba Nalubega¹, Vicensio Byaruhanga¹, Prossy Atwiine¹, Kennedy Muhame¹, Peninah Mpumwire¹, Eliphaz Bukombi Muhindi¹, Vallence Niyonzima ²

¹Nursing Department, Bishop Stuart University, Mbarara City, Uganda; ²Nursing Department, Mbarara University of Science and Technology, Mbarara City, Uganda

Correspondence: Vallence Niyonzima, Tel +256777842830, Email vnnyonzima@must.ac.ug

Purpose: Stigma and discrimination (SAD) remains a major challenge facing HIV/AIDS management in most countries of sub-Saharan Africa. Expert clients can potentially play a role in the fight against SAD. Our study explored the experiences and the role of expert clients in reducing SAD among people living with HIV/AIDS enrolled on care in health facilities in Western Uganda.

Participants and Materials: We conducted a phenomenological qualitative study among (12) twelve purposively selected expert clients at four health facilities in Sheema district, Western Uganda. In-depth interviews were conducted using an interview guide. Data were transcribed verbatim, translated to English, manually coded and analysed manually by thematic content.

Results: Four themes emerged describing the experiences of expert clients in reducing HIV/AIDS SAD; 1) Feeling of inner satisfaction, 2) Challenging work environment, 3) Acquisition of skills and 4) Disclosure dilemma. The roles of expert clients in reducing HIV-related SAD included 1) Facilitating status disclosure, 2) Identifying and helping clients with stigma/discrimination, 3) Linking patients to the health care system and 4) Promotion of positive living.

Conclusion: Expert clients had numerous experiences and play a key role in the fight against SAD. Expert clients should be included as one of the stakeholders in the efforts to reduce or eradicate SAD in the management of HIV/AIDS.

Keywords: expert clients, HIV, stigma, discrimination, experiences, roles

Introduction

HIV/AIDS is associated with stigma and discrimination (SAD) with sub-Saharan Africa (SSA) having high rates.¹ HIV causes a variety of negative psychological consequences such as stress, fear, worry, anxiety and depression, as well as social consequences on the women and their families.² Globally, less than 10% of people living with HIV report internalized stigma or experience stigma and discrimination in healthcare and community settings.³ HIV SAD toward people living with HIV (PLWHIV) persists in families, communities and healthcare settings. These were reflected in negative labelling, separation of personal belongings, avoidance, denial of treatment, and rejection of PLWHIV by healthcare providers, family, and community members.⁴ HIV stigma is a devalued attribute, which has negative impacts on both uninfected and infected people within a given society through its concomitant stigma mechanisms.⁵ Stigma mechanisms reflect how people respond to the knowledge or the fact that they either have (HIV infected) or do not have (HIV uninfected) the devalued attribute.⁵ HIV-related SAD is a potential barrier to HIV prevention and treatment, which results in lower rates of HIV testing and poor ART adherence.^{6,7}

HIV-related SAD has a negative impact on the health, and well-being of people living with HIV, and it impedes the HIV response at every step, limiting access to testing, treatment, and preventive measures, increasing the risk of HIV acquisition and progression to AIDS;⁸ however, expert clients can potentially reduce the HIV-related SAD.⁹

Uganda introduced an expert client initiative in 2005 within government-funded public health care settings.¹⁰ Expert clients are people living with HIV (PLWH) who are stable on ART and using their experience and skills to help other PLWH achieve better treatment outcomes⁹ They are also known as peer support groups¹¹ in other settings. The key role of expert clients was to work alongside the frontline health workers to address stigma and discrimination among PLWH.¹² However, staff shortages have led many health facilities to shift tasks to expert clients (ECs). In Uganda, stigma and discrimination against people with HIV/AIDS is high according to a survey by NAFOPHANU, 2015. This study reported that more than half (54%) of the participants experienced some form of discrimination or prejudice as a result of having HIV. Despite all evidence-based interventions to incorporate SAD-reduction activities into healthcare settings, HIV-related SAD persists and there is evidence of a temporal trend of increasing stigma among PLWH.¹³

Ever since the introduction of expert clients in HIV/AIDS management in Uganda, there has been no documentation of their roles and experiences in the fight against SAD. The limited information on how the expert clients have contributed to the reduction of SAD is likely to affect its implementation. This study sought to explore the experiences and roles of expert clients in reducing SAD among HIV/AIDS care recipients in Sheema district, Western Uganda.

Materials and Methods

Study Design

We employed a phenomenological qualitative approach to explore the experiences and roles of expert clients in reducing HIV-related SAD. Phenomenological research is a qualitative research approach that seeks to understand and describe the universal essence of a phenomenon. The use of qualitative design has been found appropriate to explore participants' understanding, interpretations, values and meanings regarding HIV stigma and discrimination facing them in their daily lives and is effective when exploring participants' perspectives and deep insight of their real-life experiences.¹⁴ Between July and August of 2020, we conducted this study in the Sheema district of Western Uganda.

Study Setting

We conducted the study at four public health facilities (Kabwohe HC IV, Kyangyenyi HC III, Kigarama HC III, and Bugongi HC III) in Sheema district, South Western Uganda. The selected health facilities have expert clients and offer HIV care to PLWH. Sheema district is one of the districts with the highest prevalence of HIV in south western Uganda. We conducted the study at the health facilities with the highest numbers of HIV/AIDS care recipients. Sheema district is 299.4 km from Kampala, the capital city, and 36.1 km from Mbarara city. It is bounded on the west by Bushenyi, on the north by Buhweju, on the south by Ntungamo, on the southwest by Mitooma and on the east by Mbarara. The health facilities offer voluntary counseling and testing (VCT), antiretroviral (ARV) distribution, treatment of sexually transmitted infections (STIs), opportunistic infections (OI) treatment, and health education services.

Inclusion and Exclusion Criteria

We purposively enrolled expert clients working at the selected health facilities within the Sheema district. Our trained researchers enrolled the expert clients through the in-charges at their health facilities. Adult participants aged over 18 years who had worked for at least 6 months as expert clients were enrolled. We considered 6 months because we believed that expert clients would have gathered enough experience related to their work in that time. The study excluded participants who were away from the health facilities at the time of data collection.

Sample Size

We had a target of enrolling 20 participants; however, saturation of data was achieved after interviewing 12 participants. Polit and Beck assert that a small sample size of 6–12 participants is adequate for qualitative studies in homogeneous populations as the emphasis is put on the richness of the data collected rather than the number of subjects.¹⁵

Sampling Criteria and Data Collection

We purposively recruited expert clients that had worked in the health facilities for more than six months. We collected data using an in-depth interview guide developed from the existing literature. The interview guide was translated into a local language (Runyankole) for the participants who could not understand English to freely give information. The interview guide was pilot tested on three (3) expert clients at Mbarara Regional Referral Hospital, and final adjustments were made to make the questions clear to the participants.

Using the interview guide, the participants were asked questions and their responses were captured using an audio recorder. We conducted interviews in a quiet place, and each lasted between 45 and 60 minutes. For bracketing purposes, the research team documented the participants' experiences and non-verbal cues. Data was collected by trained and experienced researchers and interviews were conducted at participant's time and place of convenience. The researchers did not repeat interviews.

Data Management and Analysis

The recorded interviews were transcribed verbatim immediately after the interviews. The researchers listened to the recordings and compared them with the transcripts to ensure that the transcribed information was from the recordings. The transcripts were translated from Runyankole to English and back translated to Runyankole by independent translators to check for consistency. To minimize bias, data was transcribed and coded by different researchers. Study participants were also provided with the transcripts to verify whether the information they had shared during interviews is what was captured.

The data was analyzed by thematic content. This was done through the following steps: Reading and rereading the participants' descriptions of the phenomenon to acquire a feeling for their experience and roles and making sense of their accounts. Thereafter, similar statements were coded and similar codes were grouped together to form sub themes. Finally, related sub themes were merged to form themes, that describe the experiences and roles of expert clients in reducing HIV-related stigma and discrimination.

Ethics and Approvals

The study was conducted under the 2013 Declaration of Helsinki. It was approved by the Mbarara University of Science and Technology research ethics committee (MUREC 17/10-20). Regulatory clearance was obtained from the Uganda National Council for Science and Technology (RESCLEAR/01). Administrative clearance was sought from the District Health Officer, Sheema district. Written informed consent was obtained from the potential participants prior to recruitment into the study. They were also informed of why they should participate in the study and publication of their anonymized responses.

Results

Demographic Characteristics of the Participants

Twelve (12) participants were purposively recruited into the study. All the participants were married aged between 32 and 68 years. Eight (8) of the participants had reached post primary level of education. All participants were on ART for more than 5 years, and many of them had worked as expert clients for more than two years.

In this study, we explored experiences and the role of expert clients in reducing SAD among people living with HIV/AIDS enrolled on care in health facilities in Western Uganda and the findings of the study are detailed below:

Experiences of Expert Clients in Reducing HIV Stigma and Discrimination

Four themes emerged and these are as follows: Feeling of inner satisfaction, Challenging working environment, Disclosure dilemma and acquisition of skills.

Feeling of Inner Satisfaction

This theme emerged from the sub themes: satisfaction and gaining confidence.

Participants experienced satisfaction when they saw the clients, they had helped to overcome stigma and discrimination returning to their normal ways, living happily and resuming their work. In addition, participants reported a general improvement in the health status of the PLWH they assisted.

The most important thing is seeing the people I bring become ok, return to their normal ways and see the person become happy and start working again (Male, 66 years)

Participants gained confidence through their constant interactions with different people, attending meeting with health workers and involving themselves in counseling clients in health facilities and in their homes. This helped them to gain confidence in helping clients who present with stigma and/or discrimination at the different health facilities.

Constant interactions with different people, attending meeting with health workers has helped me to become confident, I can stand in a group of people and talk freely, (Male, 54 years)

Participants reported gaining enthusiasm as they executed their roles as expert clients and realized the need to help other clients overcome stigma and discrimination associated with HIV/AIDs. Participants also reported being taught HIV preventive measures, its mode of spread and afterwards they also taught their colleagues.

We attended workshops and learnt how someone can be of help to others. They taught us how to love ourselves, and we also do the same to people who are stigmatized (Female, 48 years)

Most of the participants reported that they had become popular within their work places and the surrounding communities where they serve as expert clients. This made it easy for them to assist clients with SAD.

Am popular all over the district as the best councillor and expert client, everyone knows me, I even travel to nearby districts to extend my work their when am invited' (Male, 54 years)

Challenging Working Environment and Inadequate Resources

Participants described their role as a hard task because they were seen as people who were going to die the next day. They were not readily accepted in the communities. Even when they were accepted, they were challenged with limited resources to facilitate their work as expert clients.

Initially, it was hard, you would talk to people, but they would ignore us and as if we were going to die, we were discrimination but we continued with our work (Female, 36 years)

Participants reported limitations in resources that would be used to aid them in their role as expert clients in health facilities and the communities. These were, lack of air time to aid communication, transport means to aid in movement, protective gears (gumboots and umbrellas) to use during rainy seasons while making outreaches as their work involved moving to the different villages.

Transport is the major challenge to me and sometimes you want to use a phone to look for them yet no airtime, also when it rains, we can't move (Female, 50 years)

Participants were faced with lower levels of community awareness about the roles of expert clients in addressing HIV-related stigma and discrimination. This, however, hindered their work as they were not welcomed by the members of the community and people living with HIV. They also reported that it made their work slow, tiresome and demanding a lot of efforts. This was evidenced by reports from the participants.

People in my community, don't respond when invited, they think you are going to give them allowances, they rarely attend to us, it's hard for us (Male, 43 years)

Our study showed that participants at some point could not exercise their duties as they should in reducing HIV stigma and discrimination. This was because some areas had poor accessibility network such as roads and are very distant from health centres. Such areas made it difficult for the expert clients and little was done there.

In some areas you feel like not going there because of long distance so that day is missed or even you don't go there at all (Female, 40 years)

I only use my personal motorcycle and fuel and, in most cases, if I don't have money for fuel the work distorted (Male, 45 years)

There are numerous challenges that expert clients encounter during their work. Most of the challenges are due to the geographical terrain that makes transport difficult while others are due to lower levels of awareness about HIV within the community.

Some areas are hard to reach however much I try to go there (Female, 32 years)

Disclosure Dilemma

The participants expressed the fact that encouraging stigmatized clients to disclose was a big challenge. It required a lot of time and frequent visits to the clients.

I start by counseling the person in relation to his or her status, on the importance of letting the family members know, until the whole family is aware. The reason is because the client is in total confusion (Male, 57 years)

Discordant couples also found it hard to disclose to the spouses and other members of the family. This was because they feared to be rejected and discriminated by their intimate partners. This is evidenced by failure of one of the couples disclosing to the other as reported by participants.

I take time and go slow, first by asking the client whether she wants her partner to know her status and many hesitate to disclose their HIV status immediately (Male, 38 years)

The secrecy around HIV status and disclosure was further reinforced in expert client–client interactions during home visits. Expert clients and their clients would talk in “code” in order to conceal the client's HIV status. This still poses a major bottleneck that expert clients must deal with to facilitate disclosure among couples.

Acquisition of Skills

Participants reported that they acquired a number of skills as they executed their roles as expert clients. These skills include RCT, pregnancy testing, leadership, communication among others. These have helped expert clients to address stigma and discrimination among clients with HIV. This is evidenced by participants stating.

I have acquired many skills like test HIV using a strip, I always go to villages to test those who fail to come to the facility and when found positive the results are brought health centre to prepare them to start medications (Female, 48 years)

The participants reported that they help health workers in dispensing drugs at the health facilities and for the clients who do not turn up for their drugs, the expert clients take for them drugs in their homes, from where they do other activities like counseling that all drive towards reducing HIV-related stigma.

When there are very many clients at the health centre, we help the health workers to dispense the drugs (Male, 43 years)

Roles of Expert Clients in Reducing Stigma and Discrimination

The roles of expert clients in reducing HIV-related stigma and discrimination were grouped into four thematic areas, and they included 1) Facilitating disclosure, 2) Identifying and helping clients with stigma/discrimination, 3) linking clients to the health care system, and 4) Promotion of positive living.

Facilitating Disclosure

Participants reported that they conducted health education sessions for their clients to equip them with knowledge related to HIV stigma and how to overcome it. During such sessions, emphasis was always put on disclosure and how to mitigate stigma and discrimination. This was evidenced by participants stating:

One of my duties is teaching clients about their lives, how to stay with HIV without getting distractions and stigmatized and how they can advise other people suffering from HIV/AIDS related stigma (Female, 50 years)

Participants highlighted counseling as one of their major roles to reduce stigma and discrimination related to HIV/AIDS. They reported that they do counseling both at health facilities and during home visits.

Our roles are counseling, updating files and appointment groups, updating registers, and also preparing drugs for people that are going to come to the health centres, sorting their files and measuring their weight (Male, 57 years)

Participants also identified carrying out home visits as one of their roles in reducing stigma and discrimination. Through these visits, they were able to discover and mitigate most of the common challenges faced by HIV clients that would contribute to increased stigma levels.

I always visit families with disagreements specifically counseling the people who are not in good terms with the HIV client and I make sure that everything is ok there before I go (Male, 66 years)

Linking Clients to the Health Care System

Most of the participants reported that in order to reduce HIV stigma, they trace lost clients and follow them up in the villages, where they are counseled, try to bring them back to health centers or take for them drugs.

If I identifying someone who is dodging, I go and look for him or her and bring them to the health facility and those who fail to come, I make sure that I take for them drugs. (Female 32 years)

Participants reported one of their roles as testing for HIV, especially for those people who find it hard to visit health centers for the fear of stigma.

... I always go to villages to test those who fail to come to the facility and when found positive the results are brought here to prepare that person to start medication (Female, 48 years)

Participants identified fear to pick medication from health centre as a manifestation of HIV-related stigma. The expert clients have addressed this challenge by taking drugs to clients in their homes as narrated.

...Those who fail to go to the health facility, I make sure that drugs are picked and taken to him/her.... (Male, 40 years)

Promotion of Positive Living

Participants reported creating community awareness, through community meetings, which is an important aspect as far as reducing HIV stigma and discrimination is concerned. They reported;

I usually collaborate with local leaders and we call general meetings sensitize the population to always treat people living with HIV like others and how help someone living with HIV (Female, 50 years)

Participants reported role modeling as one of the approaches to reduce HIV stigma and discrimination. They, therefore, in addition to the work they do act as living examples to instill hope in the majority of stigmatized and discriminated clients.

The things they see me do, the way I respect myself, even the person am counseling can get to learn something from me, now my son is joining the university. (Male, 54 years)

Participant reported increased stigma levels due to false information. They therefore resorted to dispelling false information as a way of reducing HIV stigma and discrimination.

A person having 'kyisipi' goes to the witch doctor because they think they were bewitched I talk to them settle them down and encourage them to go to the hospital for testing and give the right information (Male, 66 years)

My brothers and friends died because of ignorance and when I was taught, it made came out to tell other clients the truth about HIV (Male, 57 years)

Discussion

Expert clients are significant contributors to the health and wellbeing of PLWH.⁹ In Uganda and other sub-Saharan African countries, expert clients are increasingly utilized to deliver services within differentiated care models.^{16,17} Expert clients receive training comprising their roles such as communication, counselling skills, and other HIV-related content (HIV treatment adherence, stigma and disclosure, and HIV linkage to care).^{9,18} Our study found similar roles, but little was reported on their experiences; thus, our findings provide an insight into their experiences and roles in reducing HIV SAD, which is key in HIV management.

Experiences of Expert Clients in Reducing Stigma and Discrimination

In this study, we explored experiences and the role of expert clients in reducing SAD among people living with HIV/AIDS enrolled in care in health facilities in Western Uganda. The findings indicated that serving as an expert client provided inner satisfaction. This was as a result of successfully helping PLWH deal with HIV-related stigma and discrimination. This was attributed to the fact that expert clients gained confidence through their role and were willing to help other PLWH overcome SAD¹⁹ since they were “like them”. This is similar to the findings of a study done in Malawi, which reported that overall expert clients were relatively well accepted as service providers by the clients, mainly because they were seen as more responsive to the client’s request.²⁰

Expert clients were able to carry out a number of tasks alongside health workers, which included taking vital signs, following up on lost clients in the community, and dispensing drugs at the health facilities.²¹ With low staffing levels of health professionals in health facilities, the assistance rendered by expert clients is likely to improve service delivery to clients with HIV/AIDS, especially in low-and-middle-income countries. PLWH interact with expert clients easily since PLWH believe that they are like them. Expert clients gained experience similar to that of formal health professionals.²² In addition, expert clients took on a wide range of tasks and performed them well, with positive outcomes for ART delivery, following up of clients and counseling about the disadvantages of feeling stigmatized. To effectively and efficiently integrate the expert clients into the HIV care system, they should be offered initial and continuous training by the health workers.

Expert clients face a number of challenges, including inadequate transport means and lack of facilitation. This was attributed to the fact that expert clients work as volunteers in the majority of the health facilities. This is likely to have negative implications on the effectiveness of expert clients in providing service to the HIV clients in health facilities. Key challenges experienced by expert clients in execution of their roles include lack of commodities and supplies, which negatively affect their outputs.²³ Expert clients were faced with lack of respect, poor education and training, poor stakeholders’ involvement; poor access to the communities, unsatisfactory incentives; lack of support and supervision, lack of equipment and supplies and social barriers due to culture, language, and political structures.²⁴ Certain conditions must be observed if expert clients are to contribute to sustainable service delivery, such as collaborative planning, definition of scope of practice, selection and educational requirements, registration, licensure and certification, recruitment and deployment, adequate and sustainable remuneration, as well as mentoring and supervision.

The fear of being stigmatized discourages PLWH from disclosing their HIV status to their spouses, families, friends, and health care workers and getting the health care services and support they need. Similarly, a study in southwestern Uganda showed that stigma at the workplace remains a challenge to all people living with HIV, including expert clients.²⁵ To facilitate disclosure, PLWH normally undergo a series of counseling sessions by health workers and expert clients. PLWH felt stigmatized to disclose their HIV status.^{26,27} Stigma negatively affects HIV care HIV, and this therefore calls for efforts to reduce stigma and discrimination related to HIV.

In their work, expert clients experienced a lot of challenges, such as a lack of support in terms of resources, training, stakeholder assistance, communication channels, funding, and monitoring. In other studies, it was reported that many different barriers to community-based HIV care were reported and they were stigma and nondisclosure; inadequate support (lack of resources, inadequate training, inadequate funding, and inadequate monitoring).^{12,28} This greatly hindered the work of the expert clients. Significant efforts should be made to mitigate these barriers by addressing HIV-

related stigma, introducing updated and relevant training, strengthening the supervision of expert clients and committing to the funding and resources needed for successful community-based.

Roles of the Expert Clients in Reducing Stigma and Discrimination

Conceptualizing the role of expert clients in terms of reducing HIV-related SAD shows that they play a vital role in HIV care.²¹ Their roles include facilitating disclosure, identifying and helping clients with stigma and discrimination, linking clients to the health care system, and promoting positive living. Similarly, other studies showed that trained health workers shifted tasks to expert clients, which included HIV testing, pre- and post-test counselling, enrolment of patients into care, adherence counselling for patients on ART, and patient tracking. Previously, expert clients working in clinics as PLHIV volunteers had provided psychosocial support to newly diagnosed HIV-positive people; with task shifting, they had to double as HIV counsellors and nursing assistants.^{18,29} This has positively impacted the HIV care system by reducing the health worker load at the facilities and increasing service delivery to people living with HIV.

Expert clients are not only able to give peer support, counseling, and encourage disclosure among other clients, but they also gained more confidence and better knowledge sharing skills. Hence, they act as role models, giving hope to clients and family caregivers. Similarly, a study in Eswatini found that the adolescent service delivery techniques used by expert clients include navigating issues of disclosure, serving as role models, tailoring speech and behavior, building rapport and trust, resolving adherence challenges, and promoting resilience and independence.⁶ This promotes disclosure among the family members, strengthens the social support system and facilitates positive living.³⁰ Expert clients were seen as a source of support for PLWH.²⁵ Expert clients would visit the homes of the nondisclosed PLWH to facilitate or encourage disclosure.⁹ Furthermore, expert clients were able to draw on their own personal experience to support other women and their families, hence creating an approachable and rich source of advice concerning disclosure, psychological health, adherence, infant care, and navigating health services.^{31,32} Expert clients have significantly enabled disclosure and this has helped to reduce HIV-related SAD, especially if appropriate steps were followed during the process of disclosure.

The roles of expert clients in reducing HIV SAD have extended beyond the health facilities.²⁷ They act as extension health workers and help in establishing linkages between the community and the health facility in the sense that they help deliver the drugs to those who do not come to the ART clinic to pick their drugs on clinic days. A Horizons study found that youth members of Zambian groups known as “anti-AIDS clubs” can be trained to provide care and support to people with HIV and help foster their acceptance within families and communities. They helped with domestic chores, bathed HIV-infected patients and dressed their wounds, and provided information, support, and referrals to family members. It was found that as a result of observing the activities of the youth caregivers and interacting with them, family members became more involved in their relative’s care.³³ Expert clients served as an important linkage between the health facilities and the community.³⁴ As a result, expert clients lead to increased acceptance of HIV services at the community level, and this significantly reduces stigma and discrimination. Health policymakers should implement such interventions to extend HIV services to the community.

Expert clients played an important role in health education and community awareness, HIV-specific education, such as information about living with HIV, ART, and its side effects, as well as HIV coinfections (Tuberculosis).¹² In their role, expert clients build on their knowledge acquired during facility-based HIV/ART workshops and trainings. To enhance their work, expert clients should be provided with monthly refresher training to keep them updated and provided with resources to use while conducting health education sessions in the communities.

Study Strengths

This was the first study conducted in southwestern Uganda to explore the experiences and roles of expert clients towards the reduction of stigma and discrimination among HIV/AIDS care recipients. The study was conducted in the local language (Runyankole) familiar to the participants, and each interview was given enough time to allow participants to give enough information. The participants were purposively selected to get reliable data concerning the research topic.

Study Limitations

The key limitation in this study was the small number of expert clients studied, which could have affected the richness of the data. This was overcome by giving participants enough time during the interviews to narrate in detail their experiences and roles in reducing HIV stigma and discrimination.

Conclusion and Implication

Expert clients play a key role in the fight against SAD. Their involvement as an integral part of the HIV care system is useful in reducing HIV-related SAD among PLWH in a resource poor-setting.

Full integration of expert clients into the HIV care system should be considered. There is a need by the Ministry of Health to operationalize and support the functions of expert clients in the health care system. There is a need to prepare expert clients educationally and emotionally to enable them to provide quality and sustainable services in reducing HIV stigma and discrimination.

Abbreviations

ECs, Expert clients; HIV, Human Immunodeficiency Virus; NAFOPHANU, National Forum of People Living with HIV/AIDS Networks in Uganda; PLWH, people living with HIV; SAD, Stigma and Discrimination; WHO, World Health Organization.

Ethics and Approvals

The study was conducted under the 2013 Declaration of Helsinki. Approval was sought from the Mbarara University of Science and Technology research ethics committee (MUREC 17/10-20). Regulatory clearance was obtained from the Uganda National Council for Science and Technology (RESCLEAR/01). Administrative clearance was sought from the District Health Officer, Sheema district. Written informed consent was obtained from the potential participants prior to recruitment into the study. They were also informed about the publication of their anonymized responses.

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Author Contributions

All authors made a significant contribution to the work reported in the conception, study design, execution, and acquisition of data, analysis and interpretation. All authors took part in drafting, critically reviewed the article; gave final approval of the version to be published; agreed on the journal to which the article has been submitted; and agreed to be accountable for all aspects of the work.

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Disclosure

The authors report no conflicts of interest in this work.

References

1. UNAIDS D. UNAIDS; 2018.

2. Fauk NK, Mwanri L, Hawke K, Mohammadi L, Ward PR. Psychological and social impact of HIV on women living with HIV and their families in low- and middle-income asian countries: a systematic search and critical review. *Int J Environ Res Public Health*. 2022;19(11). doi:10.3390/ijerph19116668
3. UNAIDS D. Report; 2021.
4. Fauk NK, Ward PR, Hawke K, Mwanri L. HIV stigma and discrimination: perspectives and personal experiences of healthcare providers in Yogyakarta and Belu, Indonesia. *Front Med*. 2021;8:625787. doi:10.3389/fmed.2021.625787
5. Mahamboro DB, Fauk NK, Ward PR, et al. Moral judgement: qualitative exploration of the experiences of HIV stigma and discrimination among married men living with HIV in Yogyakarta. *Int J Environ Res Public Health*. 2020; 172:636. doi:10.3390/ijerph17020636
6. Katz IT, Ryu AE, Onuegbu AG, et al. Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *J Int AIDS Soc*. 2013;16(3 Suppl 2):18640. doi:10.7448/IAS.16.3.18640
7. Binduru SR Prevalence of HIV related stigma and associated factors among HIV positive pregnant and lactating women at Soroti hospital and TASO Soroti-Uganda; 2018.
8. Fauk N Risk factors and the impact of HIV among women living with HIV and their families in Yogyakarta and Belu district, Indonesia. Doctoral dissertation, Ph. D. Dissertation. Adelaide, Australia: Flinders University; 2022.
9. Ahmed CV, Weissinger G, Teitelman A, et al. Expert client service delivery practices among adolescents living with HIV in Eswatini: a thematic analysis. *Child Youth Serv Rev*. 2022;132:106309. doi:10.1016/j.childyouth.2021.106309
10. World Health Organization, Pefpar, Unaid. *Task Shifting: Rational Redistribution of Tasks Among Health Workforce Teams: Global Recommendations and Guidelines*. Geneva: World Health Organization; 2007.
11. Fauk NK, Merry MS, Siri TA, et al. Facilitators to accessibility of HIV/AIDS-related health services among transgender women living with HIV in Yogyakarta, Indonesia. *AIDS Res Treat*. 2019;2019:6045726. doi:10.1155/2019/6045726
12. Ngcobo S, Scheepers S, Mbatha N, Grobler E, Rossouw T. Roles, barriers, and recommendations for community health workers providing community-based HIV Care in Sub-Saharan Africa: a review. *AIDS Patient Care STDS*. 2022;36(4):130–144. doi:10.1089/apc.2022.0020
13. Chan BT, Tsai AC, Siedner MJ. HIV treatment scale-up and HIV-related stigma in sub-Saharan Africa: a longitudinal cross-country analysis. *Am J Public Health*. 2015;105(8):1581–1587. doi:10.2105/AJPH.2015.302716
14. Jamieson L. Using qualitative methodology to elucidate themes for a traditional tooth gauging education tool for use in a remote Ugandan community. *Health Educ Res*. 2006;21:477–487. doi:10.1093/her/cyh073
15. Sartorius B, VanderHeide JD, Yang M, et al. Subnational mapping of HIV incidence and mortality among individuals aged 15–49 years in sub-Saharan Africa, 2000–2018: a modelling study. *Lancet HIV*. 2021;8(6):e363–e375. doi:10.1016/S2352-3018(21)00051-5
16. Casale M, Carlqvist A, Cluver L. Recent Interventions to improve retention in HIV care and adherence to antiretroviral treatment among adolescents and youth: a systematic review. *AIDS Patient Care STDS*. 2019;33(6):237–252. doi:10.1089/apc.2018.0320
17. Willis N, Milanzi A, Mawodzeke M, et al. Effectiveness of community adolescent treatment supporters (CATS) interventions in improving linkage and retention in care, adherence to ART and psychosocial well-being: a randomised trial among adolescents living with HIV in rural Zimbabwe. *BMC Public Health*. 2019;19(1):1–9. doi:10.1186/s12889-019-6447-4
18. Dlamini-Simelane T, Moyer E. Task shifting or shifting care practices? The impact of task shifting on patients' experiences and health care arrangements in Swaziland. *BMC Health Serv Res*. 2017;17(1):016–1960. doi:10.1186/s12913-016-1960-y
19. Neuman M, Obermeyer CM. Experiences of stigma, discrimination, care and support among people living with HIV: a four country study. *AIDS Behav*. 2013;17(5):1796–1808. doi:10.1007/s10461-013-0432-1
20. Tenthani L, Haas AD, Tweya H, et al. Retention in care under universal antiretroviral therapy for HIV-infected pregnant and breastfeeding women ("Option B+") in Malawi. *AIDS*. 2014;28(4):589–598. doi:10.1097/QAD.000000000000143
21. Landes M, Thompson C, Mwinjiwa E, et al. Task shifting of triage to peer expert informal care providers at a tertiary referral HIV clinic in Malawi: a cross-sectional operational evaluation. *BMC Health Serv Res*. 2017;17(1):017–2291. doi:10.1186/s12913-017-2291-3
22. Selke HM, Kimaiyo S, Sidle JE, et al. Task-shifting of antiretroviral delivery from health care workers to persons living with HIV/AIDS: clinical outcomes of a community-based program in Kenya. *JAIDS*. 2010;55(4):483–490. doi:10.1097/QAI.0b013e3181eb5edb
23. Celletti F, Wright A, Palen J, et al. Can the deployment of community health workers for the delivery of HIV services represent an effective and sustainable response to health workforce shortages? Results of a multicountry study. *AIDS*. 2010;24(1):S45–S57. doi:10.1097/01.aids.0000366082.68321.d6
24. Khumalo GE, Lutge EE, Naidoo P, Mashamba-Thompson TP. Barriers and facilitators of rendering HIV services by community health workers in sub-Saharan Africa: a meta-synthesis. *Fam Med Community Health*. 2021;9(4):2021–2958.
25. Twinomugisha B, Gwanzura-Ottmøller F, Daniel M, Karimi-Sari H. Exploring HIV-related stigma and discrimination at the workplace in Southwestern Uganda: challenges and solutions. *Adv Public Health*. 2020;2020:1–10. doi:10.1155/2020/8833166
26. Knettel BA, Wanda L, Amiri I, et al. Assessing the influence of community health worker support on early antiretroviral therapy adherence, anticipated stigma, and mental health among people living with HIV in Tanzania. *AIDS Patient Care STDS*. 2021;35(8):308–317. doi:10.1089/apc.2021.0028
27. Feyissa GT, Abebe L, Girma E, Woldie M. Stigma and discrimination against people living with HIV by healthcare providers, Southwest Ethiopia. *BMC Public Health*. 2012;12(1):522. doi:10.1186/1471-2458-12-522
28. Knettel BA, Fernandez KM, Wanda L, et al. The Role of community health workers in HIV care engagement: a qualitative study of stakeholder perspectives in Tanzania. *J Assoc Nurses AIDS Care*. 2021;32(6):682–692. doi:10.1097/JNC.0000000000000267
29. Mwai GW, Mburu G, Torpey K, Frost P, Ford N, Seeley J. Role and outcomes of community health workers in HIV care in sub-Saharan Africa: a systematic review. *J Int AIDS Soc*. 2013;16(1):18586. doi:10.7448/IAS.16.1.18586
30. Nabunya P, Byansi W, Sensoy Bahar O, McKay M, Ssewamala FM, Damulira C. Factors associated with HIV disclosure and HIV-related stigma among adolescents living with HIV in Southwestern Uganda. *Front Psychiatry*. 2020;11:772. doi:10.3389/fpsy.2020.00772
31. Cataldo F, Sam-Agudu NA, Phiri S, Shumba B, Cornelius LJ, Foster G. The roles of expert mothers engaged in Prevention of Mother-to-Child Transmission (PMTCT) programs: a commentary on the INSPIRE studies in Malawi, Nigeria, and Zimbabwe. *J Acquir Immune Defic Syndr*. 2017;1(75):S224–S232. doi:10.1097/QAI.0000000000001375
32. Feyissa GT, Lockwood C, Woldie M, Munn Z. Reducing HIV-related stigma and discrimination in healthcare settings: a systematic review of quantitative evidence. *PLoS One*. 2019;14(1):e0211298. doi:10.1371/journal.pone.0211298

33. Pulerwitz J, Michaelis A, Weiss E, Brown L, Mahendra V. Reducing HIV-related stigma: lessons learned from Horizons research and programs. *Public Health Rep.* 2010;125(2):272–281. doi:10.1177/003335491012500218
34. Kyakuwa M, Hardon A, Goldstein Z. "The Adopted Children of ART": expert clients and role tensions in ART provision in Uganda. *Med Anthropol.* 2012;31(2):149–161. doi:10.1080/01459740.2011.603399

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