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"I Haven't Told Other People. I Want to Keep My Dignity": HIV Related Stigma Among the Elderly in Uganda

Noeline Nakasujja[1,*], Janet Nakigudde[1,*], Isaac Byangire Lwanga[2,*], Vincent Sezibera[3,*]

[1]Department of Psychiatry, Makerere University College of Health Sciences, Kampala, Uganda; [2]Infectious Diseases Institute, Makerere University College of Health Sciences, Kampala, Uganda; [3]Centre for Mental Health, National University of Rwanda, Kigali, Rwanda

*These authors contributed equally to this work

Correspondence: Noeline Nakasujja, Department of Psychiatry, Makerere University College of Health Sciences, P.O. Box 7072, Kampala, Uganda, Email drnoeline@yahoo.com

Purpose: Numerous studies focus on stigma, HIV disclosure's impact on treatment compliance, especially in younger groups. Limited research exists about older individuals. We therefore explored issues related to disclosure of HIV status and HIV-related stigma in the elderly.

Patients and Methods: This was an exploratory qualitative study, employing Straussian Grounded Theory. We enrolled individuals aged 60 and above, living with HIV and receiving care from the Infectious Disease Institute, Uganda. We conducted 4 focus group discussions to explore HIV related stigma and self-disclosure in participants using questionnaires that we had developed and pilot-tested. The discussions were audio recorded, transcribed and translated. Using NVivo software package for qualitative analysis, we developed primary and secondary nodes and subsequent emergent themes.

Results: We recruited 38 participants for the focus group discussions. Emergent themes were: types of disclosure, reasons for disclosure or non-disclosure, who was disclosed to and the reasons for disclosure, experienced stigma and resolving dissonance in non-disclosure.

Conclusion: Our findings reveal HIV-related challenges for the elderly due to stigma and disclosure. There is need to combat this situation by normalizing societal expectations, roles and sexuality in the elderly as a way of fighting HIV/AIDS related stigma.

Keywords: HIV, disclosure, elderly, enacted-stigma, anticipated-stigma, internalized-stigma

Introduction

HIV prevalence trends in Uganda have shifted significantly, with new infections now predominantly occurring among individuals aged 30–40 years, compared to the 15–25-year age group previously observed.[1] The expansion of antiretroviral therapy (ART) access has allowed many individuals living with HIV to survive into old age, resulting in an increasing population of elderly people living with HIV.[2]

Despite these advancements, stigma remains a pervasive issue that significantly impacts the well-being and treatment adherence of these individuals.[3] Stigma, as it pertains to HIV, is not merely an individual experience but a social process characterized by exclusion, rejection, and adverse judgment from society.[4]

Scambler and Hopkins[5] elaborate on stigma domains, which include conceptual decisions (the perception by others that those with HIV are flawed), theoretical contexts (the social narratives around HIV), and biographical focus (the personal history that influences stigma experiences). These domains are crucial in understanding the broader social and cultural implications of stigma, particularly for older populations in Uganda, who are often viewed through a lens of assumed asexuality and moral responsibility.

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In the hidden distress model, Scambler further highlights that individuals experiencing stigma often attempt to conceal their condition to avoid discrimination, an action that may temporarily reduce enacted stigma but ultimately leads to cognitive dissonance and psychological distress.[6]

For many elderly individuals in Uganda, this struggle is compounded by societal expectations and cultural norms surrounding age and behavior. The widespread assumption that older adults are not sexually active further stigmatizes those who are diagnosed with HIV, as it conflicts with cultural ideals of wisdom and moral behavior expected of older people.[7] This perception creates double stigma for the elderly, who must navigate both the stigma associated with HIV and the stigma of deviating from societal norms related to aging and sexuality.

Katz et al[8] demonstrated how stigma serves as a barrier to effective HIV management, leading to delays in seeking care, interruptions in treatment adherence, and difficulties in accessing support. While younger people living with HIV may receive targeted interventions, older adults, despite accounting for 18% of the adult HIV population, are often overlooked.[9] These older adults continue to face high levels of stigma, impacting their ability to disclose to their family members[10] and fully engage in healthcare services and social support systems. Despite their growing numbers, there is limited research on the specific experiences and challenges faced by this population, especially in the context of HIV disclosure and stigma management.

This study aims to fill this gap by exploring the social and cultural dimensions of HIV stigma and disclosure among the elderly in Uganda. By understanding the stigma dynamics within this population, the study seeks to inform tailored interventions that address the unique challenges faced by elderly individuals living with HIV.

Materials and Methods

Study Site

The study was carried out at the Infectious Diseases Institute (IDI) of Makerere University, located in Kampala, Uganda. Established in 2002 by the Academic Alliance for AIDS Care and Prevention in Africa, the IDI was founded by a team of infectious disease experts with funding support from Pfizer. Initially an independent entity, the IDI transitioned to become an integral part of Makerere University's College of Health Sciences in 2004.

The IDI has reduced stigma of the patients at its premises by providing a private entrance to its unit within the teaching hospital. This entrance is strategically designed to be discreet, ensuring that patients can access services without drawing public attention, thereby supporting their privacy and minimizing stigma.

At the time of the study the clinic had approximately 1200 individuals aged over 50 years. In April 2012, a Senior Citizens Clinic was established to run on Thursdays, though a few clients would also be seen on the other clinic days. The institute also runs a private outpatient clinic that runs on Wednesdays for individuals who may prefer to access care after working hours or those who prefer further anonymity.

Study Design and Procedure

We used an exploratory qualitative research approach employing Straussian Grounded Theory design for data collection and analysis. We generated a list of all individuals who were over the age of 50 years from the clinic registry data base, from which we identified all adults aged 60 and above by consecutive sampling. Eligible individuals needed to have been attending the clinic for over 6 months and willing to participate after the study purpose had been explained to them. We then contacted these individuals by phone to determine their interest in participating, and those who agreed were invited to provide informed consent.

We formulated questions to explore self-disclosure and stigma in the elderly. These were pilot tested with two older adults attending the clinic in the local language before actual data collection to test understanding. We conducted 4 focus group discussions (FGDs) each comprising of 10 participants based on gender: male, female, and 2 mixed gender groups. One FGD was comprised of English speakers, mostly males. The other three FGDs were conducted in the local language; Luganda.

The FDGs were conducted in separate rooms for each group, where individual voluntary consent for participation was obtained after we had given an explanation about the study. Confidentiality was maintained throughout the process by ensuring that discussions took place in private settings and that no personal identifiers were recorded. Participants were also reminded to respect the privacy of others in the group and were explicitly encouraged not to discuss anything mentioned during the discussions elsewhere. For those who could not read and write, a thumbprint was used to sign for their willingness to participate in the study.

Data Management and Analysis

The data was recorded using audio tapes; it was then translated and transcribed. The transcribed data was then cleaned to remove errors in typing. A few focus group members each from one of the four focus group discussions were invited to listen to the transcripts or to read their transcripts to ascertain a true deliberation of what had transpired in the group discussions. The data was coded by two of the researchers (NN and JN). The data was analyzed using Straussian Grounded Theory (Strauss and Corbin). We followed a systematic approach that involved open coding, axial coding, and selective coding to identify themes and relationships within the data. The NVivo software facilitated the organization and development of primary and secondary nodes. This iterative process allowed us to derive emergent themes from the participants' discussions related to stigma, disclosure, and non-disclosure experiences.

Ethical Considerations

We obtained approval from the School of Medicine Research and Ethics Committee (SOMREC), Makerere University College of Health Sciences as well as the Scientific Research Committee of the Infectious Disease Institute (IDI) and the Uganda National Council for Science and Technology (UNCST). Informed consent was sought and obtained from all study participants, including permission for the publication of anonymized responses and direct quotes. The study was carried out in conformity with the World Medical Association Declaration of Helsinki. Confidentiality during the data collection process was ensured by removing personal identifiers from the transcripts. The necessity to keep discussed ideas in the focus group meetings was emphasized as was respect of the privacy of fellow participants. The discussions were conducted in private rooms.

We offered participants compensation equivalent to 2.5 USD to cover their transport costs and time commitment and refreshments, which was in line with Uganda National Council for Science and Technology (UNCST) guidelines.

Results

The FDGs were conducted among 38 participants, 27 (71.1%) of whom were males with a mean age was 64.4 years; while that of the females was 63.8 years (Table 1). The mean age of living with HIV was 9 years.

Table 1 The Demographic Characteristics of the Participants

Characteristic	Frequency	Percentage (%)
Sex		
Males	27	71.1
Females	11	28.9
Employment		
Peasant farmer	12	31.6
Formal employment	8	21.1
Own business	13	34.2
None	5	13.1
Mean Age		
Males	64.4	
Females	63.8	

Emergent Themes of Disclosure

We found the major themes revolving around the following: the stigma types, who was disclosed, the types of disclosure to and the coping style for individuals who had not disclosed (Table 2).

Stigma Types

Enacted Stigma

Embedded in enacted stigma are the behaviors and attitudes of others that include prejudices and discriminatory acts. When the community members learned of participants' HIV status, they would tell others of how they would acquire their property in the event of their death. Implicit in the quotations below are the underpinnings of HIV disclosure and enacted stigma:

> There is someone I disclosed to and he went on telling people how I was going to die and how he was going to take over the business. One might disclose to people who are eagerly awaiting to grab property after the death (Male participant, mixed gender group).
>
> Some man on our village went on telling people that they could go ahead and look for money to buy off my piece of land since I was already infected with HIV and was going to die! (Female participant, female group).

Anticipated Stigma

The anticipation of being judged or discriminated many times results in management strategies of non-disclosure that may be inconveniencing and maladaptive. For example, a number of participants were not obtaining accessible services in their home localities because they wanted to maintain their non-disclosure status as indicated here:

> I stay in Entebbe and I am aware that there are HIV treatment centres near my home but I prefer to travel and come to Mulago because not many people know me here and therefore there is less talking about my HIV status. (Male participant, male group).

Anticipated stigma further eroded the would-be social support of the elderly. Many of them did not want their adult children to learn of their HIV status. Due to the non-disclosure, the support that the elderly would otherwise obtain from their adult children was not accessed as indicated below:

> My family does not know, even my neighbours do not know. All they know is that sometimes I come to Mulago (Female participant, female group).

Table 2 Summary of Emergent Themes Related to HIV Stigma and Disclosure Among the Elderly

Theme	Description
Enacted Stigma	Others' negative behaviors and attitudes when participants' HIV status was known, including prejudice and discrimination.
Anticipated Stigma	Fear of judgment or discrimination, leading participants to avoid revealing their status and accessing services
Internalized Stigma	Personal shame and discomfort about aging and sexuality, making it hard for elderly individuals to share their HIV status.
Who Was Disclosed To	Participants often disclosed their status to their older children for support with treatment, but rarely disclosed publicly.
Types of Disclosure	Many learned of their HIV status through medical testing rather than voluntary testing.
Disclosure vs Non-Disclosure	Those with lower socio-economic status were more likely to disclose due to their societal roles and responsibilities.
Resolving Dissonance in Non-Disclosure	Non-disclosure caused distress; some participants coped by confronting others or engaging in risky behaviors.

Internalized Stigma

The values and beliefs regarding sexuality in the elderly increase the older person's stigma and this in turn influenced their discomfort at disclosing their HIV status as shown below:

> I have not told other people. I want to keep my dignity. (Male participant, mixed gender group).
>
> What makes me fearful is the idea that our sons-in- law should learn of our status! The young people should be the ones to carry the virus but when it is us, then it becomes very difficult to disclose. (Female participant, female group).

Who Was Disclosed To?

Elderly HIV patients commonly disclosed to their older children though some did not despite having spent many years in HIV care. For some who disclosed, the need arose because the children were offering them support in accessing HIV treatment:

> I told my children because they are the ones that look after me. (Female participant, female group).

There was only one participant who was comfortable disclosing publicly that they had HIV and that there was a need for people to be tested so that they would know their status and start on treatment.

> I regularly give talks about HIV and I am not ashamed telling people that I have HIV……… and then I ask people if they know their status. (Female participant, female group).

HIV advocacy drives to the community could be done by the elderly. We noted a participant who publicly talked about HIV testing while distancing themselves from being HIV positive. He was advocating for good moral behaviour of the youth because this was expected of him as an adult and not because he had HIV/AIDS.

> I normally talk about how the youth ought to protect themselves from contracting the deadly HIV/AIDS but this is because I am a priest and it is expected of me at this age but not because I have HIV/AIDS. (Male participant, male group).

Types of Disclosure

The majority of participants did not voluntarily test for HIV, but rather discovered their status through scenarios in which they developed symptoms that made their spouses, children and or health providers suspect and test them for HIV. Hence, for the majority of the participants, it was "circumstantial forced disclosure" to as shown in the two excerpts below:

> I was frequently falling sick! So my wife insisted that we get tested. On getting tested, she was negative but I turned out to be positive (Male participant, mixed gender group).
>
> I developed a mental health problem, and afterwards developed herpes zoster. I told one of my daughters and she decided to bring me to hospital. I was tested and when I saw her crying, I knew I was sick! (Male participant, male group).

Disclosure vs Non-Disclosure

Participants of a lower socio-economic status as indicated by their occupation were more likely to disclose than participants who were of a higher social economic status. Higher social economic status usually bestows public responsibilities and role modelling. To openly disclose an HIV status would mean that they were morally falling short of their social duties. The disclosure would therefore jeopardize their function in society:

> Yes, I have grandchildren, if I my in-laws learn about it, it will be a shame to me and daughters and sons. I am important in society so if I disclose then everyone will talk about the fact…. (Female participant, female group).

HIV disclosure in old age becomes hard because of the roles that the elderly have in society. Anticipated stigma was coupled with ageism in further preventing the elderly from disclosing their HIV status. Culture further causes a hindrance in HIV status disclosure among the elderly, especially in Uganda where sex is not openly talked about. For an individual known to have HIV to then speak of it would imply irresponsible and unprotected sexual activity:

> …. our cultures are so different.…. there are things that we don't go on spreading and talking about. We don't talk about sex and talking about having HIV is talking about sex (Female participant, mixed group).

Resolving Dissonance in Non-Disclosure as a Way of Coping

It was clear that when the elderly did not do self- disclosure, they were burdened with distress which some expressed through sarcasm and confrontational behaviour as indicated in the quotation below:

> When someone talks about me having HIV, I ask them if they have a padlock on their zipper. If they do, then they will not get it (HIV). But as long as they don't have a padlock on their trouser zipper, they can get it at any time. (Male participant, male group).

Still as a way of coping with the disclosure vs non-disclosure, others were angry and went on rampage and would have unprotected sex with multiple partners despite the numerous counselling and educations sessions they had with clinicians:

> Women need to protect themselves. Why come and sleep with me if they think that I have HIV and that they don't have it? It is their responsibility to refuse to sleep with me! (Male participant, male group).

Discussion

We explored HIV stigma in the elderly and its effects on disclosure in this population. Emergent themes were stigma types, the people that are disclosed to, the types of disclosure, disclosure vs non-disclosure and resolving dissonance as a means of coping.

An elderly individual with HIV/AIDS was often seen as one who would be dying soon. In a low resourced setting, the looming death of a relative or business associate was related to who would benefit from the deceased's property. Therefore, HIV status disclosure carried the distress of knowing that others would anxiously await an affected person's demise. Whereas disclosure challenges have been alluded to elsewhere,[11] this link to poverty has not been highlighted in HIV literature.

With the hidden distress theoretical mechanism of non- disclosure, patients attempt to pass as part of a normal population,[6] and this was evident in this study population. Efforts and care to keep their secrecy in obtaining treatment inconvenienced them in travelling long distances to obtain HIV care even when this was time consuming and expensive. This care and secrecy have been alluded to in previous literature.[9,12] It is also possible that this eroded the social support that they would otherwise obtain from their localities.

Our findings show that self-perception was affected by disclosure of one's HIV-positive status. Through enacted stigma, they then perceived themselves to be too old to be with HIV/AIDS.[13] Previous research has pointed out the double-faced stigma of having HIV/AIDS and then being an ashamed elder with the infection.[14,15] This finding implies that in certain instances it might be less stigmatizing and distressing for a younger person to have HIV/AIDS.

Previous studies have showed that elderly patients with HIV were less likely to disclose their HIV status to their relatives, partners and church members and mental health workers.[16] Whereas these studies indicate HIV/AIDS disclosure when seeking for social support,[17] a number of participants in this current study had forced disclosure under medical complications. Presumed asexuality by the community also implied that the older person had not lived to others' expectations. To willingly disclose their HIV status was like denouncing one's moral obligations as an elder in the community. This finding of HIV disclosure and ageism has not been alluded to in previous literature.

Social economic status appeared to have an impact on HIV disclosure in the elderly. The more affluent and socially placed, the harder it was to disclose one's HIV status. It was possible that this segment of individuals had much more at stake in terms of property, fame and were looked upon as responsible successful elders in the community who were the advisers in the community.

Study Limitations

This study is inherently interpretative due to its qualitative nature, focusing on exploring participants' subjective experiences rather than establishing causality. The findings are shaped by both participant narratives and researcher interpretations. The findings may not be generalizable to populations of the older adults with different cultural dynamics.

Recommendations

There is need to incorporate age-related HIV/AIDS counselling with a stigma component for the elderly considering the increasing number of older adults attaining old age with the disease and others contracting HIV/AIDS as they grow into old age.

Conclusion

Our study highlights that HIV-related stigma among the elderly in Uganda is multifaceted, encompassing enacted, anticipated, and internalized forms of stigma. We found that stigma impacts the elderly's decision-making regarding disclosure, often resulting in non-disclosure due to fear of judgment and property loss, and it also influences their healthcare-seeking behaviors. These findings suggest that stigma in this population is not merely an individual experience but is deeply embedded within socio-cultural norms and economic concerns. Addressing these issues requires tailored interventions that not only promote HIV testing and treatment but also aim to shift societal perceptions of aging, sexuality, and HIV to reduce stigma among older adults.

Data Sharing Statement

The data that support the findings of this study are available on request from the corresponding author, [NN].

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Author Contributions

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

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Disclosure

The authors report no conflicts of interest in this work.

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