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Research Article

HIV-Related Stigma Among Youth Living With HIV in Western Uganda

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Abstract

We present an explanatory theory for HIV-related stigma from the perspectives of youth living with HIV/AIDS (YLWHA) in Western Uganda, on which the fight against this relentless stigma in this age group and locality can be founded. A constant comparative method was used to analyze textual data from in-depth interviews with 35 YLWHA, selected from three health facilities. A stigma process model for YLWHA was developed with the stigmatizing feelings and behaviors as the core category. Concepts delineating causes, consequences, and moderators of HIV-related stigma emerged from the data to complete the stigma process. The specific focus on YLWHA and contextual characteristics adds new dimensions to the understanding of HIV-related stigma that are scant in existing HIV-related stigma models. In light of our findings, research is necessary to identify context-specific strategies to overcome the deep-rooted causes of stigmatizing views and behaviors in all social spheres of YLWHA within Western Uganda.

Keywords

HIV; youth; qualitative; grounded theory; Uganda; stigma; interviews

Introduction

Despite global efforts to reduce HIV-related stigma, it continues to wreck the well-being of people living with HIV/AIDS (PLWHA) and thwarts potential support to them (Earnshaw & Chaudoir, 2009). This stigma has been found to stifle disclosure of HIV status, adherence to antiretroviral therapy (ART) medication, prevention of HIV transmission, and social support (Britto et al., 2016; Katz et al., 2013), and as a result, it compromises the quality of care and quality of life (QoL) of PLWHA.

In his pivotal work, Goffman (1963) defined stigma as "attributes that are deeply discrediting to an individual in society creating a deviant social persona" (p. 3). HIV-related stigma stems from socially endorsed knowledge about the diminished status of PLWHA and it is manifested in discounting, discrediting, and discriminating of such people and those they associate with (Steward et al., 2008). Because the epistemology of HIV/AIDS is created through social interactions, the construction, experience, and consequences of HIV-related stigma can vary across social contexts (Steward et al., 2008). For instance, a study conducted in five African countries showed that incidences of HIV-related stigma differed significantly between the urban and rural settings (Naidoo et al., 2007). In addition, prior studies show that stigma operates at the intersect of social factors such as culture, power, and differences (Parker & Aggleton, 2003). It is rooted in the prevailing notions of normalcy and it has the propensity to dehumanize PLWHA as well as ostracizing them from society. Extant literature highlights how fear of infection, lack of basic HIV/AIDS knowledge, and sociocultural beliefs drive HIV-related stigma (e.g., Campbell et al., 2005; Nyblade et al., 2008). Also, context-specific worldviews and belief systems around HIV/AIDS give rise to, and maintain, the negative attributes and disvaluing social behaviors. Consequently, stigma processes may be significantly diverse across social contexts, rendering it vital to understand the particular social dynamics at play.

Research on HIV stigma among youth living with HIV/AIDS (YLWHA) is particularly relevant because this group continues to grow due to high HIV incidences in adolescents (Harrison & Li, 2018) and due to the scaling up of ART (Peter et al., 2017), which has transformed HIV from a fatal to a lifelong infection (Bakanda et al.,

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2011). Both vertically and behaviorally infected youths are currently growing into adulthood, even in resource-limited countries such as Uganda (Rutakumwa et al., 2015) and are confronting inimitable social contexts such as schools and workplaces in which stigma appears to become a major concern. Although youths' experiences of HIV-related stigma may mirror those of adults, peculiarities exist due to being born and growing up with HIV (for the perinatally infected), the adolescence stage in which stigma may interfere with identity formation, and schooling (Earnshaw et al., 2018; Fielden et al., 2011). Moreover, the onset of romantic relationships characteristic of this age group becomes a predicament due to fear of rejection that may follow a voluntary or involuntary status disclosure (Ramaiya et al., 2016).

HIV/AIDS has been posited as a concealable stigmatized disease (Quinn & Earnshaw, 2013) that carries a huge lingering disclosure dilemma to and for YLWHA (Pachankis, 2007). Within the home, YLWHA are often shielded from others who would stigmatize them by keeping their HIV status a secret and lying about their health condition (Hejoaka, 2009). However, as these youth, leave home, secrecy is defied by a wider social sphere in which they start to operate. At school and other social domains, these youth are always under constant scrutiny from their peers due to heightened social contacts (Kennedy & Itkonen, 1994) and as such secrecy crumbles exposing YLWHA to the full impact of HIV-related stigma.

Studies have identified that the HIV status of youths is often involuntarily disclosed by their frequent illnesses, unique and daily medication (Abubakar et al., 2016), as well as the indiscretion of those they trust to disclose to (Mutumba et al., 2015). This inadvertent disclosure always evokes stigmatizing views and attitudes not only from others ("stigmatizers") but also from YLWHA themselves ("stigmatized"). The social influences rendering HIV/AIDS a stigmatized health condition have a far-reaching impact on the overall QoL and on the support provided or withheld from YLWHA. A study from Thailand showed that children living with HIV were discriminated against and rejected from school because parents of other children feared HIV transmission to their children (Wattradul & Sriyaporn, 2014). Baxen and Haipinge (2015) also found stigmatization of HIV-positive children as a key barrier to their schooling. As noted in this study, children living with HIV were reportedly teased, bullied, and gossiped about by other students and some of their teachers. Maughan-Brown and Spaull (2014) reported that HIV-positive children were avoided or shunned by their friends. Moreover, stigma may cause YLWHA to postpone educational and vocational goals (Hosek et al., 2002) or to be denied opportunities to achieve these goals. Furthermore, HIV-related stigma is a key predictor of psychosocial and behavioral outcomes among YLWHA such as risky sexual behavior and drug abuse (Earnshaw et al., 2018).

Due to these social connotations, a contextualized theory of the stigma process is necessary to act as a framework to guide stigma-reducing interventions. Many stakeholders in the HIV/AIDS research community note that fighting HIV-related stigma is a crucial step toward fighting the HIV pandemic (Cameron, 2000). Yet, absence of a clear understanding of the stigma process for YLWHA may preclude the fight against its root causes, especially in contexts where it is perpetuated by parents, caretakers, peers, and teachers who would otherwise be supportive to YLWHA. This may undermine interventions that support QoL of YLWHA. There is currently no contextualized explanatory theory for the HIV stigma process among YLWHA in Uganda. In this article, we seek to fill this gap. We intended to answer the following question:

> **Research Question 1:** How does HIV-related stigma occur for YLWHA in Western Uganda?

We report a grounded theory study on HIV-related stigma in Western Uganda, upon which further interventions to improve QoL for YLWHA can be rooted.

Method

Study Design, Settings, and Participants

This qualitative study was guided by grounded theory techniques. We followed the guidance of Charmaz (2006), Glaser and Holton (2004), and Strauss and Corbin (1997) to develop a grounded theory of HIV-related stigma for YLWHA in Western Uganda. We employed semistructured interviews, conducted between July and October 2018 with a purposively selected sample of YLWHA, aged 12 to 19 years. We selected this age range to target youth within the secondary school age group (secondary schools being future sites for our interventions) but we included all YLWHA regardless of school attendance. In addition, full disclosure of HIV status to those perinatally infected is expected by at least 12 years (Mutumba et al., 2015). The interviews were conducted in three purposively selected ART-accredited health facilities (HFs) in Kabarole district. The district is located in Western Uganda at approximately 300 km by road from the capital Kampala. It is close to the western border with the Democratic Republic of Congo (DRC) and it is a main stopover for people in transit between DRC and Uganda. The district is a tourist hub in the region due to several tourist attraction sites within and in close proximity. Kabarole district has an estimated total population of 469,239 according to the national census

Table 1. Characteristics of Study Participants ($n = 35$).

Characteristic	Frequency (%)
Age (years)	
12–13	6 (17)
14–15	6 (17)
16–17	10 (29)
18–19	13 (37)
M (*SD*)	16.2 (2.37)
Sex	
Males	19 (54)
Females	16 (46)
Source of HIV infection	
Perinatal	31 (88)
Rape	1 (3)
Unknown	3 (9)
Schooling status by time of interview	
In school	13 (37)
Dropped out of school	20 (57)
Never gone to school	2 (6)
Location	
Urban	12 (34)
Periurban	10 (29)
Rural	13 (37)

(Uganda Bureau of Statistics [UBOS], 2017). It is geographically stratified into the urban, periurban, and rural areas. Residents in the urban and periurban areas are mainly traders and they also engage in hospitality services. The rural dwellers are mainly subsistence farmers. At 11.3% in the general population, the HIV prevalence of Kabarole district is 5.8% higher than that of the western region where the district is located and 5% higher than the national prevalence of Uganda (Kimera et al., 2019). Selection of the HFs was done in a way that ensured wide and diverse geographical coverage with one HF selected in the urban, periurban, and rural settings. HFs with a large number of HIV-positive youth in care, based on records from the District Health Office, were selected to ensure a large pool from which participants attending and not attending school and those with varied characteristics of age and sex were selected (Table 1).

In each HF, we planned to interview at least 10 YLWHA but three more were selected from the rural HF and two more from the urban HF to achieve saturation. The selection of participants was based on the inclusion criteria of being aged 12 to 19 years, having been on ART for at least 6 months (to have sufficient experience of ART as a possible link to HIV-related stigma), being able to communicate in the local languages (Rutooro and Luganda) or English, and having no mental health vulnerabilities as judged by health care workers. We excluded potential participants who were not aware of their HIV status (to prevent inadvertent disclosure), had other chronic conditions such as cancer as these are also stigmatized, had active TB disease to mitigate the risk of contagion, and whose parents (in case of minors) or themselves did not consent/assent. Interview guidelines focused on how YLWHA understood and experienced HIV-related stigma and their perspectives on causes of stigma but were continuously adapted to explore new leads of emerging concepts.

Data Collection

At each HF, the ART clinic in-charge assigned a health care worker to oversee the participant recruitment and data collection process. We interviewed eligible participants following their clinic appointment in a private quiet room at the HF. An audio-recorded interview that lasted between 1 and 1½ hours was conducted in a language preferred by the participants. The main researcher, a native speaker of Luganda and fluent in English, together with his assistant, a native speaker of Rutooro and fluent in English, conducted the interviews. During each interview, nonverbal cues such as physical appearance, demeanor, speech tone, and aptitude were recorded in a notebook to create a participant profile. In case a participant needed psychosocial support, they were referred to a peer counselor who was always available at the HF. Each participant was reimbursed for transport with the equivalent of US$7.

Data Management and Analysis

Data collection and analysis proceeded concurrently. Following each interview, the audio files were transcribed verbatim. Interviews conducted in local languages were translated to English and all transcripts were checked against the original audio recordings to ensure accuracy. Preliminary analyses involving constant comparisons of incidence with incidence, code with code, codes with categories, and reflections on the collected data were done to develop theoretical ideas and to produce memos that guided further participant recruitment, interview of subsequent cases, and theoretical development. In progressing with the interviews, we focused our inquiry to saturate the categories of our emerging theory.

In the final analysis, two authors read the transcripts several times to get immersed in the data and independently coded all the interview transcripts using the software NVIVO version 10. Open coding of line by line, sentence by sentence, and paragraph by paragraph was done as close to the data as possible, with minimal abstraction and using in vivo codes in some cases. Although we had extensive theoretical foreknowledge about the phenomenon of stigma and a guiding interest of how this stigma occurs for YLWHA, we restricted the application of preformed concepts and ideas to remain

Table 2. The Coding Structure That Was Used.

Open Codes	Axial Codes	Selective Codes
Ignorance about HIV/AIDS Associating status with death Associating status with weakness in society Distrusting YLWHA Differing/othering Blaming YLWHA for their infection Seen as a spiritual problem Fearing infection	Social knowledge, beliefs, and fears	Cause of HIV-related stigma
Having signs of the disease Taking HIV drugs Frequent illnesses Reminding YLWHA about their status Talking carelessly about HIV/AIDS Involuntary status disclosure	Physical health, treatment, and careless talk from "others"	Conditions/triggers for HIV-related stigma
Being seen as failures in life Insults Mistreating YLWHA Taunting/belittling Bullying/teasing Laughing at YLWHA Feeling worthless Seen as worthless Talking about YLWHA Expecting others to talk about them Discrimination	Demeaning, gossiping, and discrimination	Resulting stigmatizing feelings and behaviors
Contemplating suicide Nonadherence to treatment Sorrow/worry/sadness Parental/caretaker neglect Blaming their parents Losing hope Isolating themselves Losing friendship Changing homes Dropping out of school	Hopelessness, isolation, and change of environment	Consequences of HIV stigma
Lying about their status Planning medication Avoiding suspicions	Secrecy	Moderating factors for conditions/ triggers of stigma
Being with others like them Ignoring Positive contribution to community Rationalization Distraction Sensibilizing "stigmatizers" Support from others to deal with stigma Counseling	Coping, support, and sensibilization	Moderating factors for consequences of HIV-related stigma

Note. YLWHA = youth living with HIV/AIDS.

sensitive to the contextual conceptions of HIV-related stigma in the data. Writing of memos was used to document conceptual and theoretical ideas that emerged during the coding. Axial coding (Strauss & Corbin, 1997) followed, involving discussions, harmonization, and categorization of the open codes in an iterative manner. The formed categories were then labeled, their dimensions established, and connections between categories and subcategories identified. In the final stage of selective coding, we selected a core category as the resulting stigmatizing feelings and behaviors. We then used a selective code family of 6Cs (cause, contexts, contingencies, consequences, conditions, and covariances; Hernandez, 2009) in adaptation to knit formed categories as this suited our data to develop a theory. Table 2 presents the coding structure that was followed.

Ethics

Ethical approval was obtained from Uganda National Council of Science and Technology (reference number SS 4587) and the Institutional Review Boards of The AIDS Support Organization in Uganda (TASOREC/009/18-UG-REC-009) and Vrije Universiteit Brussel in Belgium (B.U.N 143,201,835,870). Informed written consent/assent was sought from YLWHA as well as the parents/caretakers of minors. Data were anonymized in the audio recordings, transcripts, and reports and they were confidentially kept.

Findings

We identified the *resulting stigmatizing feelings and behaviors* as the core category and five other categories were arranged around this core to develop the theory. Our developed model (Figure 1) shows that within schools, homes, and community in Western Uganda, HIV-related stigma is experienced by YLWHA through demeaning, rumoring/gossiping, and discrimination. Negative attitudes, fear, and ignorance around HIV/AIDS cause it, whereas the physical health, medication, and negative talks about HIV from others trigger it. Ultimately, stigma leads to personal withdrawal, change of environment, hopelessness, and despair. Secrecy is employed by YLWHA to prevent stigma, whereas individual coping strategies, sensitization, and psychosocial support ameliorate its consequences.

The Resulting Stigmatizing Feelings and Behaviors

This category had three major properties: demeaning, gossiping, and discrimination. Participants reported several scenarios in which their peers, caretakers, and other community members portrayed them as worthless. They reported being deterred from schooling, working, and other social activities with HIV-negative peers. This deflated their morale and caused them to believe that they were lesser human than others. A number of demeaning statements such as "victims," "skeleton," "walking dead," and "ghost" were reportedly used to reduce the worth and potential of YLWHA in society.

Within schools, teasing—although directed to all students—was a common demeaning act to which YLWHA were more prone due to their suspicious acts aimed at obscuring their HIV-positive status. School-going YLWHA noted that teasing was usually done to expose their "hidden secrets" in public. In this respect, secrecy appeared to trigger stigmatizing acts despite being employed by YLWHA to prevent them.

> *It is also like bullying. They are like "okay he does this and he does not want us to know. Then let the whole dormitory know" and not knowing that it will not stop in the dormitory. It will extend to the entire school, even outside school. Students always want to unveil anything about a fellow student and expose it*. (16-year-old male, urban clinic, attending boarding school)

Demeaning additionally took the form of peers laughing at YLWHA especially when they exhibited known physical signs of HIV/AIDS such as being emaciated, skin rashes, and persistent cough.

> *At school, children used to laugh at me because I am very small. That affected me a lot and I hated all of them. I did not have any friend. That made me to hate school*. (14-year-old female, periurban clinic, school dropout)

Such visible bodily signs that differentiate them from their peers were also triggers of stigma. Due to their internalized awareness of difference and worthlessness, YLWHA were more sensitive to those laughing at them even when it was not related to their HIV status.

Gossiping was also reported as a stigmatizing act that YLWHA expected and experienced. Participants reported suspecting others to talk about them even when they could not confirm it. It was reportedly more prevalent among school peers and staff who found YLWHA strange due to their poor health and medication needs and thus tried to gather more information about the health of these youth. Participants noted that gossiping leads to unintended disclosure of their status, increasing the incidences of stigma.

> *No, I do not get information but I know they talk even though I do not get to know. So, when some people find me here [ART clinic], they may go back to their homes and talk but for me I may not get to know that they talk about me*. (19-year-old male, rural clinic, school dropout)

Discrimination also appeared as a stigmatizing act for YLWHA. Participants reported that within schools, fellow students did not want to share a seat, scholastic materials, and laboratory equipment with them, whereas at home and larger community, they were not allowed to mix and play with other HIV-negative children and they were often given inferior things. Participants perceived discrimination to arise from irrational fear of infection, as expressed in the following quote:

> *They have that mentality that when you're staying with a sick person [person with HIV] or sitting with them you also become infected. In Uganda I can say that most of the people are educated, but they have low thinking and even my friends, that's what they thought. And whenever you would bring the topic for slim [local term for HIV/AIDS], they*

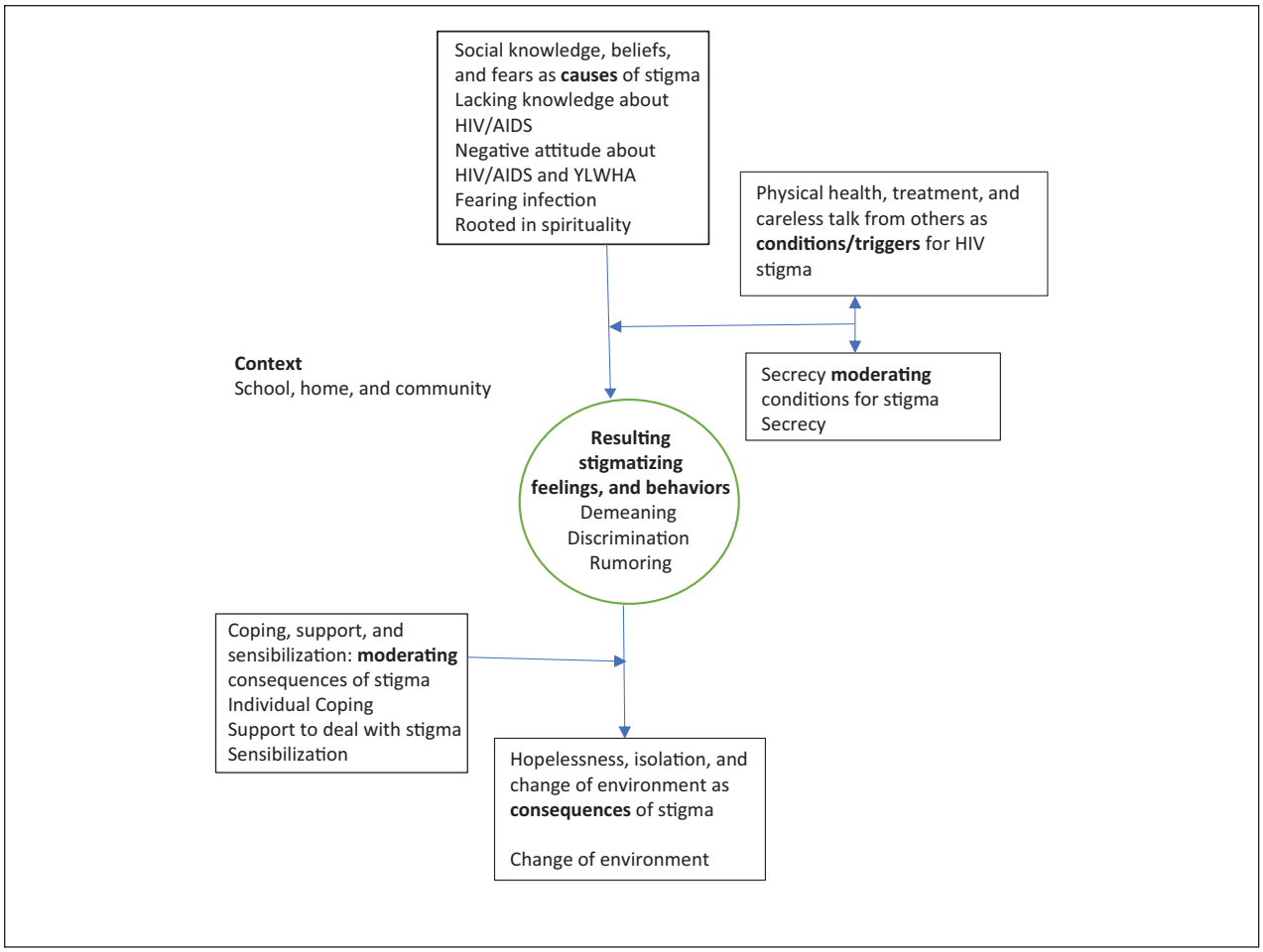

Figure 1. The HIV-related stigma process model for YLWHA.
Note. YLWHA = youth living with HIV/AIDS.

would just keep quiet and they move and go away. (19-year-old male, periurban clinic, school dropout)

Social Knowledge, Beliefs, and Fears as Causes of HIV Stigma

Narratives of participants indicated that stigma occurred due to the negative social framing of HIV/AIDS, fear of infection, and ignorance. Several instances depicting negative attitudes about HIV/AIDS were noted in both YLWHA and HIV-negative persons. In their society, the condition was often associated with death. For most YLWHA, this was further underpinned by loss of a parent to HIV/AIDS, confirming their fears. They always saw themselves as having a shortened life, and a similar attitude about them was held by HIV negative individuals.

People in the village used to say to me that, "for you your mother has died of HIV and you are also left with few days," I also thought I would die in less than a month after my mother had gone [died] and whenever I got sick with cough or malaria, I would think that my time has come. (15-year-old female, urban clinic, school dropout)

Participants noted that this perception is related to historically negative depictions of HIV/AIDS in society, dating back in time when treatment was not available and a diagnosis of HIV would be seen as a death sentence.

Moreover, the whole public perception of HIV/AIDS as associated with promiscuous, morally deviant behaviors of those infected also evokes stigma due to attribution of blame. Many female participants alluded to scenarios where others perceived that HIV was deservedly earned by YLWHA due to their sexual immorality.

Equally, the reputation of HIV/AIDS as a highly communicable condition and historically uncontrollable disease would be responsible for spreading fear for infection in their society, in turn buttressing stigmatizing attitudes and behaviors toward YLWHA. People feared to be infected and the YLWHA feared to be held responsible for infecting others. Moreover, others were felt to distrust YLWHA and suspect them of ill intentions as illustrated in the quote below:

Like if you are HIV positive and some one knows it, it's not bad but they always suspect you, like you may infect others, you may do it intentionally for someone to be infected. They think we are bad hearted people, that we want others to be like us. (13-year-old female, rural clinic, in day school)

In most cases, this fear was unfounded and driven by ignorance about the ways in which HIV is transmitted. Participants reported that others think that they can be infected by sitting, playing, or sharing things such as a pen or a pencil with YLWHA. In a few cases, genuine fear was alluded to when a YLWHA was suspected of having a sexual relationship with another person's sexual partner.

Like you cannot get friends who like you, you may get a friend and maybe they are in relationship with another girl. They can say that maybe you are having a relationship with that person, they think you are going to infect them. (18-year-old female, urban clinic, school dropout)

Causes for HIV-related stigma were also found in spirituality. Participants stated that HIV/AIDS was seen by some people as a curse, inflicting a negative image onto them. This was because in perinatal transmission—the majority of cases in this study—more than one person in the family is infected, causing others to see this as a cursed family. YLWHA also reported that other people think that HIV/AIDS is not a disease for young people, and as such, those who have it are cursed as expressed in the following quote:

Our parents/guardians feel ashamed when other people see us. Some people also think we are cursed and should not come and mix with other people. (19-year-old male, periurban clinic, in boarding school)

The categorization of us and them (othering) was conspicuously depicted in this category as a cause of stigma portrayed in both YLWHA and HIV-negative individuals. Othering often resulted in discrimination and isolation, limiting the interactions between YLWHA and the HIV-negative individuals. YLWHA often wanted to associate with others like them and those without HIV acted likewise. The quote below illustrates this:

They say that if it was possible to put marks on those sick people so that they can identify them, that it would be easy to avoid HIV. (18-year-old female, urban clinic, in day school)

Physical Health, Treatment, and Careless Talk From Others as Conditions/Triggers for HIV-Related Stigma

Causes of stigma as outlined above were always present in all social spheres of YLWHA but they were perceived to become more effective only in the presence of other factors. These stigma triggers were found to be related to the physical health and treatment of YLWHA as well as inconsiderate talk about HIV/AIDS from others. Participants referred to visible indicators of the disease as triggers, and perceived that the more HIV identifiers were present, the likelier they were to be stigmatized. They reported that whenever they suffered recurrent illnesses such as cough, flu, and malaria to which they are more prone, their peers and caretakers started to worry about them infecting others and consequently discriminated them.

"I started falling sick, for her [caretaker] she never cared at all and she started removing me from her children and she said 'ha' this one has become sick" (19-year-old male, urban clinic, school dropout).

In several cases, especially at school, these triggers were the basis of suspecting HIV infection and the eventual isolation of YLWHA. Being seen by others at the ART clinic and regular taking of drugs also triggered stigma through inadvertent disclosure and internalized feelings of suffering, respectively. The desire to conceal their status to avoid stigma broached more stress especially in boarding schools where it was a challenge to hide their drugs.

Like my medicine is always in my case, so when am taking the medicine in the dormitory, someone can hear that tin of the tablets and says that what are you taking and then they could say that, that person is HIV-positive. (18-year-old female, urban clinic, in a boarding school)

Stigma was also triggered by various forms of careless talks from others. Within school, the teachers were found to fissure the trust of secrecy whenever some YLWHA confided in them causing YLWHA to feel betrayed. With or without knowing that YLWHA existed in their classes, some teachers spoke carelessly about HIV/AIDS in a way that caused negative feelings in YLWHA and made their peers develop disvaluing ideas about them. They often had misconceptions about HIV/AIDS that were also found in the larger society, or talked about it jokingly. YLWHA also noted that stigma was usually prompted in them when others keep reminding them that they are sick (have HIV/AIDS).

I get bad thoughts whenever I am told that I am HIV positive by people all the time and this at times brings me to sleep without taking my medicine. (17-year-old male, rural clinic, school dropout)

Secrecy: Moderating Conditions/Triggers for Stigma

The concept of secrecy was found to moderate the relationship between conditions/triggers for stigma and the

resulting stigmatizing feelings and acts. Participants narrated how they achieved secrecy by concealing their status at home, school, and in the community. They endeavored to "live normally" with their peers by avoiding actions, people, and things that would reveal their status. For instance, many preferred to access ART from HFs further away from their villages. Some perceived that being mixed with other patients at the HF would prevent them from being identified as HIV positive but others preferred to stay with known HIV-positive peers who would not divulge information about them. This portrays a dual struggle in these youth for social inclusion in the community and safety in a peer group, as evident in the following testimony:

> *. . . but if we were mixed, people would not know whether you have come for treatment for HIV or malaria or cough but whoever they see us down here [ART clinic], they know that we have HIV. So, when they see you, they are like "oh you are also here." I do not want that*. (19-year-old male, rural clinic, school dropout)

Whenever suspected of being HIV positive, YLWHA employed lies to maintain secrecy. They lied to their peers at school that they had other diseases such as sickle cells to account for their slimness and daily medication. They concocted several lies for school authorities to grant them leave permits to visit ART clinics and to stay at home or in the dormitories whenever they felt too weak to attend class.

Because being seen taking antiretrovirals was a condition/trigger for stigma as already discussed above, most YLWHA devised means of concealing their medicine and swallowing it in secrecy. At school, this involved keeping medicine in their dormitory or with school nurses who they trusted to maintain confidentiality. At home, many reported having their own bedrooms, which they locked to prevent other family members from seeing their medicine. The quote below shows how one participant achieved secrecy in a boarding school:

> *To avoid others seeing my drugs, I remove them from the suitcase when am going to dress up, then I put them under my pillow and I cover them under my bed and when I come back from class, I just open the pillow, take my drugs and I go back*. (18-year-old female, urban clinic, boarding school)

The heightened vigilance to maintain secrecy illustrated above also appeared to evoke stigmatizing feelings from YLWHA and stigmatizing acts from others.

Coping, Support, and Sensibilization: Moderating Consequences of Stigma

Participants experienced that secrecy was rarely effective and oftentimes unintended disclosure occurred, leading to stigma. In addition, secrecy evoked stigmatizing feelings within YLWHA and was a trigger of suspicious behavior. YLWHA employed other strategies to deal with stigma to minimize its impact on their well-being. We identified individual coping strategies, sensibilization of "stigmatizers," and support from other people to enable YLWHA deal with stigma.

Individual coping involved ignoring stigmatizing statements and actions from others. Some YLWHA engaged in rationalization of their status, remarking that they were not the only ones with HIV/AIDS and that some other people suffer from more life-threatening chronic diseases, as illustrated in the following quote:

> *I used to feel that I am completely useless and unwanted among other people but now when I look at other people also suffering from other chronic diseases like diabetes, high blood pressure, I feel that at least for me if I have my drugs, I am better off.* (19-year-old male, periurban clinic, in day school)

For the school-going YLWHA, coping also involved engaging in distractive activities such as games, sports, club activities, and reading books at school that kept them busy all the time and prevented them from thinking about their condition as illustrated in the quote below:

> *Me I am always busy. So, once I am feeling well, I cannot spend like 30 minutes or 3 hours doing nothing. Therefore, it prevents my mind from being idle and thinking a lot*. (19-year-old male, periurban clinic, boarding school)

In few instances, YLWHA noted that they worked tirelessly to make a positive contribution to society to feel and be seen as valuable people in society.

> *I was playing volley ball and the teacher came and told me that for you, you're sick and I felt bad and I told him that Sir I also want to play and he said you're sick and I told him that you put me there and I play. They first told me to sit on the bench and they played the first round and the second they involved me in and am the one who won for them the cup at school and the one who is sick. Sick people can do a lot of things except the words of the people that have made them to go down*. (19-year-old male, urban clinic, school dropout)

Sensibilization of others on the way HIV is spread, the potential of YLWHA, and how best to handle YLWHA were reportedly stated as measures to tackle ignorance, a perceived origin of HIV stigma, and thus to effectively reduce stigma. Participants proposed sensibilization of teachers, peers, and community members to combat this root cause at the societal level.

> *All people need to be told about HIV, how it is spread, how it can be avoided and how to live with it for those like us [those*

with HIV], people have to know that it is bad to discriminate children with HIV because they [HIV positive youth] also did not want to get it, it just happened to them. (16-year-old female, periurban clinic, school dropout)

In addition, YLWHA reported receiving support from other people that enabled them to deal with stigma. This support was usually in the form of counseling that enabled them to accept their status, think, and act positively about their status as well as learning to ignore negative statements and actions directed toward them.

Hopelessness, Isolation, and Change of Environment as Consequences of Stigma

We identified three major dimensions in which consequences of stigma were reported. These were hopelessness, personal withdrawal, and change of environment. Most participants reported that stigma caused them to feel sad and worry a lot. They often blamed their parents for transmitting the infection to them and some attempted to commit suicide.

But whenever I would be mistreated or discriminated, I would feel miserable and think about my deceased parents in a way of blaming them for transmitting the disease to me. I could even pray that God takes my parents to hell because they are the ones that caused this miserable life for me. (19-year-old male, rural clinic, in day school)

This stigma-induced hopelessness caused many to resent medication leading to poor adherence. It was also reported that stigma caused some parents and caregivers to neglect YLWHA because by associating with them they would also be stigmatized. It was further identified that stigma leads to both social isolation and self-isolation. Many participants reported loss of friendship because they were often isolated by their peers and in some cases, they isolated themselves. The quote below illustrates self-isolation:

I would be weak at school; I would feel lonely and sad and children would come to me and I would send them away. (14-year-old female, periurban clinic, school dropout)

Some YLWHA reported change of environment as an outcome of stigma. The school-going YLWHA reported changing school whenever they would be stigmatized at school and in some cases, stigma caused them to completely drop out of school. Change of school was also noted in HIV-negative students whose parents feared that they would contract HIV on learning that some student at school had it as illustrated in the quote below:

So, if some children tell their parents that at school there is a sick person [HIV positive person], they warn the children not to interact with us. One parent removed a child from a school where there was a sick student. (18-year-old female, rural clinic, school dropout)

Some participants reported running away from one caretaker home to another whenever they felt mistreated due to their HIV condition.

The change came when I ran away from that home where I was mistreated at about 15 years of age. I moved to my uncle's place and stayed with them but he also had children. I was not mistreated but life was still hard for me. Get a meal a day maybe lunch or supper would be a miracle. This uncle had many children and he would also return home very late. So, I decided to go to my grandmother where I am staying now. (17-year-old male, rural clinic, school dropout)

Discussion

We developed a theory grounded in empirical data, to explain the stigmatization process for YLWHA in the context of Ugandan schools, homes, and larger community. In our model, the resulting stigmatizing feelings and behaviors emerged as the core category. Concepts delineating causes and consequences of HIV-related stigma were arranged around this core in a linear relationship and other categories: Conditions/triggers and moderating factors were found to affect the cause and consequence relationships with the core category. Hereunder, we illustrate how our theory relates to other conceptualizations and studies on HIV-related stigma and we highlight implications of our findings to studies on HIV-related stigma and antistigma interventions. Our theory lends special attention to the age group and context-specific undertones of HIV-related stigma that are scarce in existing models. We argue that the stigmatization process for PLWHA bears distinctiveness in different age groups and contexts.

Similar to the conceptualization by Earnshaw and Chaudoir (2009), we found three categories in which stigmatizing feelings and behaviors could be situated: (a) internalized feelings of difference and disvalue among YLWHA, (b) expected prejudicial treatment from others, and (c) actual acts of discrimination and mistreatment. Devaluation of individuals with a socially discreditable identity such as HIV/AIDS is central to the stigma theory as postulated by Goffman (1963). Our study identified various attitudes, statements, and overt acts that depicted YLWHA as worthless social deviants. Because these attitudes have persisted for as long as the HIV infection itself, they are inherently endorsed and expected by YLWHA, yielding internalized and anticipated stigma (Earnshaw & Chaudoir, 2009). One property of stigmatizing behavior we found unique in our model was teasing and laughing at YLWHA by their HIV-negative peers.

These acts further entrenched the sense of worthlessness in YLWHA. Such peculiar conduct could be explained by the social attribution of HIV acquisition to immoral acts for which the bearers are held responsible (McDonell, 1993; Mupenda et al., 2014), and scorn rather than empathy is directed to them by society. The attribution model (Weiner et al., 1988) posits that people are likely to respond negatively to those they believe are responsible for their stigma. Future research needs to focus on how social attribution affects YLWHA who may be erroneously blamed for the infection for which they had no control over (e.g., in case of perinatal infections and rape). We additionally found that HIV/AIDS and those living with it were usually the center of attention and gossip, especially in school contexts where the HIV status was hard to obscure. This reflects findings of a study with adolescents living with HIV conducted in Botswana and Tanzania (Midtbø et al., 2012). Because HIV/AIDS is conceptualized as a concealable stigmatized identity (CSI; Quinn & Earnshaw, 2013), information control (Goffman, 1963) is vital, yet such measures breed suspicion and gossip from others and high vigilance to uphold on the side of YLWHA. We found that secrecy was employed to prevent enacted stigma, however, it intensified negative feelings of difference in YLWHA. These youth could not live a "normal life" like others while concealing their status. This corroborates the CSI model (Quinn & Earnshaw, 2013), wherein depression, stress, and anxiety are presented as internalized outcomes that affect the mental health and behavioral outcomes of individuals with such stigmas. Discrimination affects all PLWHA, although for YLWHA, it is such a quandary when it is endorsed by figures of authority from whom they would expect embrace and support. As a form of enacted stigma (Earnshaw & Chaudoir, 2009), discrimination arises from social inequalities. The role of social power in reproduction and maintenance of inequalities described by different authors (e.g., Link & Phelan, 2001; Parker & Aggleton, 2003) was evident in our findings. For instance, teachers were found to engage in various stigmatizing acts at school and so did parents/caretakers at home. The theory of vulnerability in the context of HIV developed by De Santis (2008) further illuminates our findings that HIV makes youth, who are vulnerable members of society, even more vulnerable. Therefore, interventions need to be focused on empowering YLWHA by addressing not only their HIV-related concerns but also their position in society.

This study adds the knowledge that the root causes of HIV-related stigma should be understood in a contextualized manner because the social framing of HIV/AIDS and worldviews about it are diverse. The contextual causes found in this study have also been reported elsewhere (Thi et al., 2008) and relate to the social knowledge, beliefs, fears, and attribution of responsibility for the infection. The negative social framing of HIV/AIDS that associates the infection with shame and suffering is responsible for sprouting negative feelings and behaviors in YLWHA and others. Such negative social attitudes have been built over time due to the emphatic primary prevention campaigns aimed at deterring people from behaviors that heighten the risk of HIV acquisition (Thi et al., 2008), lack of knowledge about medical advances that have led to improved HIV prognosis with ART, and loss of loved ones to HIV/AIDS. Despite the expanse in knowledge about HIV/AIDS and information sources, we found that perceiving HIV/AIDS as a moral issue is still causing much of the stigma oriented toward YLWHA. Similar beliefs have tenancy in religion were PLWHA are believed to be cursed (Muturi & An, 2010) or to be serving a punishment for their sins (Kopelman, 2002). Such perceptions lead to a biased view of YLWHA and undermine efforts to fight HIV-related stigma. We found discrimination to arise from irrational fear of infection, indicative of lack of basic knowledge about HIV/AIDS as also reported by Letamo (2004). This raises concerns regarding the role of community sensibilization and education campaigns about HIV/AIDS. A review of HIV stigma interventions (Brown et al., 2003) revealed that most studies reported superficial changes in attitudes toward PLWHA as a result of improved knowledge but little change in deep-seated fears that sprout stigma. The lack of a clear localized meaning of stigma and the use of euphemisms also distort antistigma messages (Hosek et al., 2002). Stein (2003) notes that HIV stigma has changed form into a "dirty secret." The implication of this to researchers and antistigma campaigners is how to measure and uncover the "hidden truth." Our results also point to genuine fears of infection whenever a disclosure of HIV status was voluntarily or involuntarily made in a romantic relationship. HIV-related stigma and disclosure challenges in a sexual relationship have been widely studied in adults (e.g., King et al., 2008; Mayfield Arnold et al., 2008) but limited evidence exists for youth in many sub-Saharan countries. It is a unique challenge for this group because they are yet to form stable relationships in which trust for disclosure could be built. Interventions need to involve sexual partners of YLWHA partners on how to manage the post disclosure in a sexual relationship without stigmatizing YLWHA.

Our model also suggests that causes of stigma described above could not operate without specific conditions/triggers. These stigma triggers were physical health, treatment, and negative talk from others. In the model of the dynamics of HIV/AIDS stigma developed by Holzemer and colleagues (2007), conditions that revealed

or caused HIV/AIDS to be suspected in PLWHA triggered stigma. Our model illustrates a unique balance between secrecy and HIV triggers that feeds into contextual causes for stigmatization to occur. We found that stigma triggers were more effective in school contexts where secrecy often flopped. The management of ART in the face of stigma is also a contentious line of discussion for YLWHA. Some studies (e.g., Abadía-Barrero & Castro, 2006) have esteemed ART medication as a key strategy to fight HIV-related stigma because it changes HIV from a fatal to a manageable chronic condition and improves the physical well-being of those with HIV. Our findings conjure a paradox to this view and portray ART medication as a key trigger for stigma among YLWHA. In support of our findings, a South African study reported that the value of ART medication was much appreciated by patients and health care professionals but for the others, it elicited stigmatizing views and actions (Gilbert & Walker, 2010). The need to depict an untainted image before others preoccupies YLWHA at the peril of their own well-being and as a result many discard their medicine (Adejumo et al., 2015; Fields et al., 2017).

Whenever secrecy failed or when YLWHA chose to disclose their status, strategies to minimize the consequences of stigma on their lives were pertinent. Our model presents coping, support, and sensibilization as concepts of moderating the consequences of HIV-related stigma. A number of coping strategies reported here have been confirmed elsewhere and they included the following: (a) emotion-focused coping, for example, ignoring "stigmatizers" (Makoae et al., 2008), and distractive activities (Mutumba et al., 2015); (b) appraisal-focused coping, for example, rationalization about their status (Midtbø et al., 2012); and (c) problem-focused coping, for example, delight in achievements and positive contribution to their society. The notion of "positive living" (Levy & Storeng, 2007) should be built from individual coping and psychosocial support (Mosack et al., 2016) from people around YLWHA. Sensibilization of "stigmatizers" was perceived to reduce stigma in our study. This strategy has been widely used in stigma-reducing interventions but dismal results have been reported. Effective sensibilization should be multileveled, conducted within living spaces (homes), across living spaces (community), and key intersects such as schools where different social structures influence or reinforce one another on outcomes such as school dropout. Sensibilization should strive to demystify extant social framings and worldviews about HIV/AIDS and those infected.

Finally, our theory presents hopelessness, isolation, and change of environment as concepts in the consequences of HIV-related stigma. Similar concepts have been reported (Abubakar et al., 2016; Ramaiya et al., 2016). The change of environment reported in this study occurred whenever YLWHA felt that their individual coping and support from others was not sufficient to overcome the stigma they felt and received. They thus moved with the anticipation of better living situations and to break existing stigmatizing social networks.

Study Strengths and Limitations

We recruited participants with varied demographic characteristics, which allowed us to get rich data. The grounded theory methodology also enabled us to gain insight into the contextual nature of the stigma process. Our study, however, had a number of limitations. First, we based on only experiences of YLWHA to study stigma. Comprehensive findings could be obtained by additionally studying the perceptions of parents, caretakers, teachers, and peers of YLWHA because these were reported to carry stigmatizing attitudes and behaviors in this study. Second, we used a single qualitative approach, which could not allow for triangulation unlike a multimethod approach. Third, we only recruited youths who were aware of their HIV status due to ethical concerns. Stigma experiences of youth on ART and unaware of their status were not captured and, therefore, our findings cannot be generalized to them.

Conclusion

Our developed theory bears several similarities and distinctiveness with existing HIV-related stigma models and studies. The specific focus on YLWHA and contextual characteristics adds new dimensions in the understanding of HIV-related stigma. In light of our findings, research is necessary to identify context-specific strategies to overcome the deep-rooted causes of stigmatizing views and behaviors in all social spheres of YLWHA in Western Uganda. The involvement of the entire community is necessary for effective antistigma interventions. Measures to strengthen resilience in the context of stigma are also warranted and they should be hinged on the individual coping strategies of YLWHA, psychosocial support from others, and sensibilization of all.

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Availability of Data and Materials

The data set generated and analyzed during the current study is not publicly available because we did not seek consent from participants to share the data publicly. However, this data set is available from the corresponding author on reasonable request.

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