

HIV/AIDS Stigma Reduction as a Risk Factor for New HIV Infections: A Lived Experience Study of HIV Positive Young Women in a Rural Setting

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Abstract

Background: HIV/AIDS-related stigma is a global problem among HIV patients with far-reaching implications. However, there is an increase in HIV infections, especially among young women.

Objective: This study aimed at exploring the influence of HIV-related stigma on new infections among HIV-positive young women in a rural setting.

Methods: A cross-sectional exploratory research design was used. In-depth interviews were used to collect data and analysis was done using a thematic approach.

Results: The results showed that acceptance, counselling, and social support are some of the ways HIV-positive young women used to cope with stigma. The results also showed that while HIV-related stigma reduction has influenced positively some HIV-positive young women, to others as HIV-related stigma reduces, young women living with HIV are likely to get involved in risky sexual activities thus increasing HIV transmission.

Conclusions: As HIV-related stigma reduced, young women living with HIV are likely to get involved in risky sexual activities thus increasing HIV transmission. Based on the results, there is a need to understand the negative effects of HIV-related stigma reduction as this may have implications for the control of the HIV pandemic. Also, further research is needed to understand whether lessening HIV-related stigma encourages risky sexual behaviours among young women.

Keywords: Coping, HIV, Stigma, Uganda, Young Women

Introduction

Globally, an estimated 1.8 million young people are living with HIV with 30% of all new infections occurring among young men and women aged 15-24 years [1]. New HIV infections continue in some regions and among key populations [1]. In 2017, the Sub-Saharan Africa region accounted for 25% of the global burden of new infections among young women and adolescents [2, 3]. In 2018, an estimated 1.4 million people lived with HIV, young women, in particular, are disproportionately affected [4]. While there have been efforts to scale up prevention and treatment initiatives in Uganda, there are alarmingly new infections. Between 2005 and 2018, the number of new infections in Uganda increased by 10% [5]. Recent UNAIDS data show that almost 570 young women get infected with HIV weekly in Uganda [6]. To achieve an HIV/AIDS-free

society there is a need to understand the burden of new infections in young women [7].

Between 2000 and 2010 Uganda was one of few countries worldwide that managed to greatly reduce its HIV epidemic [5]. However, statistics in 2012 showed that Uganda was one of the two countries in Africa where new HIV infections were on the rise with a prevalent rate of 7.3% [8]. This trend was attributed to stagnant actions and complacency of the government [9]. However, due to renewed commitment to decrease the pandemic, the prevalence rate decreased to 6.7% [10]. Consequently, Uganda made significant progress in the HIV epidemic response by preventing newly infected cases and reducing HIV-related mortality and fatality [11]. HIV-related stigma was equally tackled to increase ART up-

take with great success [4]. These achievements, however, are under threat from new HIV infections. Currently, Uganda has about 170,000 young men and women living with HIV and the figures are likely to increase because more of them remain susceptible to new infections [12]. A third of these infections are mostly registered among young women aged 15-24 [13]. Significant drivers of the upsurge of new infections in this key population include gender disparity, violence against women, and relationship with older men [14]. However, it is still not clear how stigma reduction influences new HIV infections.

Young women in post-conflict northern Uganda are more at risk for HIV infections. The region was affected by a protracted brutal civil war that claimed tens of thousands of lives and many others displaced [15]. The war described as the “worst forgotten humanitarian crisis in the world” lasted from 1986 to 2006. A recent report on HIV infections shows that HIV is persistently concentrated around the northern and central parts of Uganda [16]. The prevalence of HIV infections in the region is higher than the national average [17]. Reduction in HIV-related stigma which has for long been cited as a major barrier to accessing prevention, care and treatment services, may now be a contributing factor to new HIV infections. However, there seems to be limited literature to support this assertion [11]. This study attempts to fill the gap by exploring whether a reduction in HIV-related stigma influences HIV transmission among young women, especially in a rural setting.

Methods

A cross-sectional exploratory research design was employed to explore coping strategies and the influence of stigma reduction on new HIV infections among young women attending outpatient Aboke health centre IV. The study setting was Aboke health centre IV, Kole district, northern Uganda which is located approximately 30 kilometres to the West of Lira City. The period of data collection was August 2020.

Participants

Study participants were HIV-positive young women aged between 15 and 24 years old within the catchment area of Aboke Health Center IV, Kole District. A total of 30 HIV-positive young women attending Aboke health centre IV participated in the study. The sample size was estimated using the saturation principle as applied in a qualitative study [18]. Participants were purposively selected to get those who were capable of giving a richer narrative of their stigma experiences, coping strategies, and how stigma reduction influences HIV infections.

Instrument

Data was collected using an interview guide comprising three main sections; socio-demographic characteristics, HIV-related stigma coping strategies, and how stigma reduction influences HIV infections among young women. The researcher developed the interview guide using guidelines provided by Huberman and

Miles [19]. Also, the development of an interview guide was based on the literature on stigma and coping strategies with input from experts who had experiences with HIV-related stigma. The guide was translated and back-translated to establish consistency.

Ethics Approval and Consent to Participate

Ethical clearance was granted by the institutional review board of Gulu University (GUREC-047-20). Written informed consent was obtained from all the participants before data collection. Privacy and confidentiality were maintained during the entire process of data collection and analysis. Interviews were audio-taped with participants' permission. Standard operating procedures of COVID-19 prevention were maintained including observance of social distancing and wearing of face masks.

Procedure

Lira university graduates trained in micro-research and fluent in both English and Langi conducted face-to-face in-depth interviews in a private setting. The interviews lasted for 25-30 minutes and responses from the participants were recorded using a voice recorder. Participants were asked to express how they coped with stigma and how stigma reduction influences their sexual activities. They were approached on clinic days after permission was granted by the District Health Officer of Kole District. Interviewers continuously probed and watched the body language of respondents to elicit rich and accurate perspectives on HIV-related stigma reduction experiences and how it influences their sexual activities. Given the nature and availability of the respondents, every participant meeting the inclusion criteria was selected until saturation was achieved. However, patients who were severely ill were excluded from the study.

Data Analysis

Audio recordings of the interviews were transcribed and later translated into English. To assess the quality and dependability of transcripts two separate experts reviewed the translation. A seven-phase data analysis framework described by Braun and Clarke was used [20]. After reading and transcription of recorded data into a written document, data was coded which enabled the researchers to identify categories and patterns within the data. Different colours were used to distinguish between themes. Thereafter, themes were identified, reviewed, and named. Lastly, synthesis of the themes, analysis of data, and interpretation of results followed to provide an understanding of stigma reduction and its influence on HIV Infections among young women.

Results

Sociodemographic Characteristics of Study Respondents

We interviewed a total of 30 participants who were HIV positive. Of the 30 participants interviewed, The ages ranged between 17 to 24 years old and majority (18) were peasant farmers (Table 1).

Table 1: Sociodemographic Characteristics of Study Participants

Variables	Participants N=30
Age in years	
16-20	07
21-24	21
41-60	05
60 and above	11
Gender	
Male	13
Female	17
Occupation	
Student	03
Causal Labourer	09

Prevalence of Stigma after Testing HIV Positive

HIV-related stigma as a phenomenon was considered to be a major barrier to reaching those who are at risk or infected with HIV/AIDS. Although HIV-related stigma is a general phenomenon that affects people living with HIV/AIDS, its reduction in this paper was presumed to precipitate new HIV infections among young women in Kole district in Uganda.

Participants narrated feelings of the stigma associated with HIV infections which highlighted the negative public view of the disease. Some of the participants' narratives reflect instances of experiencing severe stigma when they were first tested with HIV. This is because the disease is associated with promiscuity. Young women diagnosed with HIV had a fear of being found out because this would lead to community rejection. For some of the participants, the situation was overwhelming, challenging, and grappled with stigma. Hence, they were faced with the dilemma of either disclosing the status or not. Based on the interviews a 22-year-old participant narrated her predicament as follows:

“At first I did not believe I could disclose my status because I thought that my people would think I was infected as a result of prostitution. But that is what they think anyway, they would call me immoral..... But after receiving counselling services, I disclosed to my mother, my brother, and later my friends. I believe everyone in the village now knows my status”.

Another 20-year old said;

“The first few weeks or months when I tested positive, I believed that everyone knew I had the disease. I literally reminded in the house, I did not want to see anybody including my closest friend. I felt rejected by all people. But with time I liked myself and I was very happy. My husband who is HIV-negative supported me in this process of self-acceptance. I realized that HIV is another disease”.

HIV-Related Stigma Coping Strategies Used by Young Women Living with HIV

Participants' narratives show that for some time after the diagnosis, most young women perceived HIV as a “death sentence” and thus had no hope of survival. However with counselling services and social support the situation lessened. They felt better with a more positive outlook and coped better with HIV-related stigma. Hence it can be argued that although HIV-positive young women are challenged with stigma, they were determined to overcome it and live a normal life. In this regard, a 21-year-old HIV positive young woman expressed:

“..... I don't think anyone should blame me for being HIV positive because I don't know where this disease came from. I now live my life and don't care what others are saying.... they can go to hell, for all I care about is my life”.

Counselling

Many participants stated that counselling was done thoroughly by trained counsellors. Intense counselling, therefore, was vital in overcoming HIV-related stigma. A 24 old positive young woman recounted how she overcame stigma through the assistance of friends and professional counsellors;

“Trust me I have outgrown stigma and I can see a bright future. That stress ended with help of friends and counsellors”

Another 24-year single mother of one was more determined to live confidently after counselling. She was also determined to stamp out HIV in the community. She said;

“After receiving counselling, am now assertive and confident enough, I walk with my head up and I will fight this disease because I don't want to see another person getting infected with or die of HIV in my community”.

Acceptance

Accepting HIV status was an important method to cope and deal with stigma. One respondent underscored the importance of self-acceptance;

“.... I realized I need to help myself or else I would die very fast. I simply accepted my status, live for my child and loved ones”

Another 21-year participant said;
Today I tell my story without fear, I have accepted my status and everyone knows am sick but not dead. I'm very healthy and I take care of myself. I have accepted it and I don't stigmatize myself at all, this is just one of the many challenges I have to deal with.

Some women accepted their status because of the availability of HIV management and treatment. They believed that HIV would not significantly impact their lives. A 22-year-old said;
“To be sincere am no longer bothered about my HIV status because am aware of the available treatment. I have realized HIV is not a life-threatening disease as many people think”.

Social support

Amidst reports of stigma, family support proved to be invaluable for other young girls living with HIV. The participants' narratives show that positive support extended to them by family members, health professionals, and friends is valuable in dealing with stigma. Consequently, they overcame the HIV-related stigma as an 18-year-old young woman said;
“My people helped me so much and perhaps that's why am still alive and healthy. They supported me morally, materially, or otherwise. My friends told me never to mind what other people are saying, after all, am not alone and am not going to die soon”

Another one added;
“I feel like I do not even have the disease due to the massive support I have from family and friends. These close friends understand what is happening in my life and have helped me feel good. My family members give me food in time and they make sure I take my drugs on time”.

The influence of HIV-related stigma reduction on new infections among young women

Overcoming HIV-related stigma had both positive and negative ramifications for young women in a rural setting in northern Uganda. The reduction of HIV-related stigma has led to increased adherence to therapy and thereby potentially reducing the risk of HIV transmission and fatality. One 21 year participant said;
“Am now quite content with my HIV status, I have accepted and I don't care about peoples' prejudice. I have been living with the disease for a few years now. Am on regular treatment and without a doubt am fine”

Another participant added;
“Am not traumatized by my HIV status, I know the medical support available. Many people have lived with it for many years; trust me I will live too with a condition”.

Another 24-year participant said;
“The more you hide your status because of stigma, the higher the chances of death. I have to stand tall and tell myself, I have HIV and it is alright. After all, there is a medication that will make me live a normal life”.

Negative consequences

Explicitly, participants overcame the issue of stigma and seem to be more open to life. For these participants, this is a plus but there is now a worry that a 'normal life' may be causing new HIV infections among young women. Some participants even reached a point of believing that because the community is no longer ostracizing them, they are not HIV positive and can have sex without any guilt of transmission. Some young women reported that they pushed HIV problems out of their minds and believe that they are HIV negative and could not transmit the disease to others. One young woman aged 20 years old put it this way;

“Am I HIV positive? Yes, I was tested positive but I don't believe that I have the disease... I live my normal life, I enjoy sex normally....after all, am still a young and attractive lady. Am a good-looking woman, I began having sex, this is the truth, I have a partner from the neighbourhood and he doesn't care about my status”.

Some participants agreed that people in the community do not treat them differently. They freely associate and as a result, they can have unprotected sex as a 24-year young woman said;
“Nothing is going to happen if I have unprotected sex, I have sex regularly and am not worried about the future. There are some old notches I need to settle first, and then I can die”

Other participants recounted that they know they have the disease but they need to have fun just like others in the same age bracket as respondent aged 18 years old said;
“Yes am infected, but that status is not going to change, not now, not ever. I have to enjoy life just like my age mates. Some have boyfriends, others have many boyfriends and others are happily married thus enjoying what “nature” provided. I need to be happy for as long as men like me”.

Yet still another 21 year old said;
“I realized that having sex was the way though at first, I was scared but at the same time, I felt that I need to have fun. I decided to move on and follow my desires regardless of the consequences. I don't need stress anymore; I need a normal life too”.

Some participants even decided to get involved in risky sexual activities like having unprotected sex thus increasing HIV transmission. Most women reported engaging in sex with regular or casual partners without using condoms. They reported higher-risk sexual activities as a 23-year-old participant said;

“..... this is not a big deal, many men who originally did not want

to come near me or associate with me are now so close, I mean very close. I think that they (men) think it is just a disease and nothing more. I feel the same too, what else, I live with this condition, those who get sick, they will get medication just like me”.

Overcoming HIV-related stigma however impacted HIV-positive pregnant mothers positively. Some participants after overcoming the issues related to the stigma did not only initiate the process of acceptance of their HIV status but also lived a responsible life. They understood the importance of taking medicine on time and not engaging in unsafe sexual activities. A 23-year-old said;

“Before I received professional counselling, I was very sick and I felt rejected by the community. But when I consulted my counselor, I felt very good and strong. I realized that I had to live responsibly; I needed to live longer and also protect my loved ones from getting infected”.

Other participants also narrated that they enjoy sex but they use condoms. Some participants also narrated that they used their protection if men disagreed. They attributed this to health education and counselling.

“When I was diagnosed with HIV, I wanted to have with everyone and did not want to take ARV. But this changed when I received counselling and heard some good and educative information over the radio. I can’t afford to infect others as I will be destroying myself too. I carry with me condoms and I make sure they are used and used properly”.

Discussion

New HIV infections continue to rise in the world and among key populations including young men and women aged 15-24 years with young women being disproportionately affected [4]. This study highlights positive coping strategies used by HIV-positive young women in a rural setting to reduce the effects of HIV-related stigma and how reductions in HIV-related stigma influence new HIV transmission. In sum, the common stigma coping strategies used by HIV-positive young mothers were acceptance, social support, and counselling. Acceptance of HIV status aids individuals in positively changing their situation. Besides, the supportive environment implied that the young women living with HIV lived a positive life and adhered to medical schedules [21]. Therefore efforts towards instilling positive attitudes toward people living with HIV in the community may lead to acceptance of these people and thus receive the required support [22]. Findings from this study support existing literature [21, 23]. In agreement with our findings, previous studies revealed that HIV-positive patients with support were more likely to reduce psychological problems [24].

Our results revealed that overcoming HIV-related stigma had a positive impact on young women’s sexual activities in a rural setting in northern Uganda. HIV-related stigma is a serious challenge

in addressing HIV infection. However, its reduction is necessary to achieve the goal of ending HIV/AIDS by 2030 [25]. There is evidence to show that stigma is associated with low quality of life [26]. It may prevent the patients from seeking medical care and contributes to fewer interactions with peers, friends, family, and community members [4, 23]. This implies that HIV-related reduction can improve the quality of life in HIV-positive people. In line with our results, Mak et al reviewed several HIV stigma interventions aimed at reducing stigma in HIV-positive people and found that they had positive effects [27].

Paradoxically, our results in this study demonstrate that a reduction in HIV-related stigma increases risky sexual behaviours thus increasing the spread of the disease. It seems that stigma reduction contributes to psychological and social or psychosocial adjustments among young women living with HIV. The perceived threats of HIV and HIV-related stigma have lessened with increased treatment and campaigns against stigma. It is also important to note that reduced stigma seems to empower young women to discuss their sexual desires. There is an increase in optimism and the belief that HIV treatment eliminates the risk of HIV transmission [28]. The findings indicate that as HIV-related stigma lessens many have renewed sexual desires. Unfortunately, some engage in unprotected sex thus increasing the transmission of the disease.

The study limitations included the use of a cross-sectional design and the inclusion of only positive young women from a single outpatient health centre in a rural setting. The results may not be generalized to HIV-positive young men and old women. Mixed research studies may contribute to a better understanding of the topic. Future research should include all categories of people living with HIV for the generalization of results.

Conclusion

Reduction in HIV-related stigma is crucial in promoting positive living among young people. However, there are now concerns that lessening this HIV-related stigma is associated with increased risky sexual behaviours, especially among young women. While HIV-related reduction has influenced positively some HIV-positive young mothers, to others as HIV-related stigma reduces, young women living with HIV are likely to get involved in risky sexual activities like having unprotected sex thus increasing HIV transmission. There is therefore the need to understand the negative effects of HIV-related stigma reduction as this may have far-reaching implications for the transmission and control of the HIV pandemic. Also, further research is needed to understand whether lessening HIV-related stigma encourages risky sexual behaviours among young women.

Consent for publication

This manuscript doesn’t any personal data of the participants

Availability of data and material

This data set is part of a bigger study. However, the data sets analyzed are available from the corresponding author on realistic request.

Competing interests

There is no competing interest

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Authors' contributions

AK conceptualized the study and was involved in the data collection, analysis, and drafting of the manuscript. MAK participated in proposal writing, analysis, and drafting of the manuscript. All authors read and approved the final manuscript.

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