REVIEW PAPER

Impact of stigma on HIV treatment seeking behavior among the youth living with HIV and AIDS in sub-Saharan Africa: critical review of literature

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Abstract

An estimated 11.8 million youths in sub-Saharan Africa are living with HIV and AIDS, and more than one-half of those newly infected with HIV today are between 18 and 24 years. This study reviewed research assessing the impact of stigma on HIV treatment seeking behavior among youths in sub-Saharan Africa. The review highlighted particular stigma issues that young people face. Also, it analyzed the causes and consequences of stigma, and identified skills to cope with stigma and to build modalities for a change of behavior. The review include original articles published between 1988 and 2019 on HIV and AIDS stigma, which were found on various internet sites. The review determined that in developing countries, social and economic factors have an impact on HIV infection, including mainly older grandparents and their role as caregivers of orphaned children as a result of parental HIV infection. Therefore, there is a need to incorporate culturally sensitive modalities that assure target populations' ability to respond to local understandings of key issues associated with HIV and AIDS stigmatization. Stigma among the youth remains a barrier to all essential components, which constitute a good prevention program, and much detailed research on stigma reduction is required to improve components of a good prevention program. Health education campaigns should integrate a change from fear to care for people living with HIV/AIDS, especially among healthcare personnel. More prevention activities should be situated in rural and remote areas of each country than in urban locations, as currently in Nigeria. Since most of the population resides in rural areas, it is most appropriate to concentrate these programs in such locations.

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Key words: stigma, HIV and AIDS, treatment, youth.

Introduction

Over a billion young people are living with HIV and AIDS worldwide, with 23.5 million found in sub-Saharan Africa [1]. The impact of stigma on youths has many consequences, including forced isolation, dropping out of school, and postponement of starting antiretroviral treatment, prescribed to HIV-positive patients. Such challenges may hinder the access to HIV treatment [2].

Globally, stigma is a major obstacle to effective HIV and AIDS prevention and care. Stigma, in the context of HIV and AIDS, is a unique factor compared to other infectious

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and communicable diseases. It tends to create a "hidden epidemic" based on socially-shared ignorance, fear, misinformation, and denial [3]. This is particularly more intense in sub-Saharan Africa, where a combination of inadequate health system is entangled in poor legal and ethical frameworks [4]. Issues concerning the impact of stigma are not yet addressed. Therefore, research studies are needed to thoroughly understand the consequences of stigma at all levels, and its effect on HIV prevention, treatment, and care, as it is directly related to different socio-cultural settings in sub-Saharan Africa [5].

The needs of youths are routinely disregarded while drafting strategies and policies on HIV and AIDS, and allocating finances. However, the challenges that many of these national programs face in a multi-diverse socio-cultural setting like sub-Saharan countries, include the problem of stigma.

Much has been written on the stigma and discrimination that surrounds HIV and AIDS in sub-Saharan Africa as well as difficulties in obtaining effective delivery of HIV testing and prevention efforts [6-9]. However, there has been little consideration about the role of larger community in shaping the attitudes of youths [7, 10, 11]. An understanding of factors associated with attitudes towards HIV and AIDS is essential to create a community-based innovative approaches and interventions, which aim to resolve the problem of stigma [12]. This review seeks to understand how community environment shapes HIV and AIDS attitudes among youths living these diseases in sub-Saharan African countries.

HIV and AIDS stigma is a complex concept that refers to discrediting, prejudice, and discrimination associated with persons perceived to have AIDS or HIV, their partners, friends, families, and communities [13]. Goffman defined stigma as an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society. HIV and AIDS stigma often reinforces existing social inequalities based on ethnicity, gender, race, sexuality, class, and culture. HIV has aggravated the stigma of sex work, poverty, drug use, homosexuality, and racial minority status. HIV and AIDS stigma is a problem in Africa and throughout the world, characterized by discrimination of those with the disease by their families, communities, governments, and healthcare professionals [14]. The victims may also face ostracism and rejection. Stigma surrounding HIV, commercial sex work, homosexuality, and drug use impede HIV prevention services to be provided in different settings [12]. While it is widely accepted that HIV prevention should be integrated into a broader health and community contexts, many places in communities, including schools, jails, businesses, prisons, and churches, have resisted incorporating frank discussions about HIV and AIDS.

Overall, HIV and AIDS stigma can negatively affect health and well- being of HIV-positive persons. For example, HIV-positive young individuals may delay visiting the doctor or not seek treatment at all due to real or perceived discrimination. A national study on HIV-positive young adults found that 36% of them experienced discrimination by healthcare providers, including 8% of those who had been denied medical services [15].

Dahourou *et al.* [16] and Eldredge *et al.* [17] reported social work practitioners to have knowledge about HIV transmission, prevention and care in the African context to counteract dangers of stigma caused by ignorance and misinformation. Stigma does not exist only in a person's actions but within a broader social and cultural frameworks that should be emphasized in programs that reduce stigma [15]. According to the study setting, accurate and up to date data on the impact of stigma on HIV treatment seeking behavior among the youth living with HIV and AIDS in Uganda are difficult to obtain, given the size and complexity of society, and its overtime statistical variations.

Material and methods

This critical review considered standard guidelines to conduct the research report analysis, including consolidated standards of qualitative content analysis and observational studies in epidemiology. Recommendations were used to conduct the meta-analysis, while other literature was used as a guide for data abstraction. Strategies for critical evaluation of studies on prognosis included validity, clinical importance, applicability, and generalizability. Respondents' characteristics of the study population comprised of youths between 18 and 24 years of age, living with HIV and AIDS. Research bias could include allocation (selection) bias (failure of randomization systematic differences in comparison groups), performance bias (systematic differences in interventions received by two groups), systematic differences in withdrawals from trial and detection (measurement) bias (failure of blinding systematic differences in outcomes assessment).

Search strategy

All original papers on HIV and AIDS stigma published between 1988 and 2019 in English language only were systematically searched. The search was conducted using the following key words: "Stigma", "Intervention", "Reduction", "Health education", "Behavior", "Attitude change", "HIV and AIDS", "Prejudice", "Health and seeking behavior", "HIV", and "Youths' treatment", which were combined at various times with "sub-Saharan Africa".

The search focused on Google Scholar, MEDLINE, PsycINFO, Science Citation Index, Social Science Citation Index, CINAHL, AIDSLINE, and POPLINE electronic databases. Additional searches were performed via journal search, particularly papers that specifically covered all aspects of HIV and AIDS research. Information was also obtained from organizational websites of the World Health Organization, the Joint United Nations Programs on HIV and AIDS, the National Centers for AIDS and STD Control, and the United National Child Care. In addition, a search

Table 1. Sample size of 1,454 HIV-infected persons in five countries in sub-Saharan Africa (source: Field Data, 2019)

Country	HIV-infected persons
Nigeria	Three hundred and fifty
Ghana	Three hundred and twenty-five
Kenya	Two hundred and eighteen
Tanzania	Three hundred and eight
Uganda	Two hundred and fifty-three
Total	One thousand four hundred and fifty-four

of published and unpublished literature, such as conference presentations with over 100 citations, was performed.

Criteria for inclusion

The main criteria for inclusion in this review were that the paper focused on: (1) assessment of stigma and discrimination; (2) stigma, particularly health-related stigma; (3) stigma reduction innovative approaches and interventions; and (4) cultural epidemiology of stigma in the African context. Using these criteria, we identified seven studies. We excluded the majority of articles that were studies directed at knowledge, attitude, and practices towards people living with HIV and AIDS, which provided no input on stigma measurement, literature review articles on stigma and discrimination in sub-Saharan Africa, including Ghana and anecdotal articles on stigma from people living with HIV and AIDS.

In addition, the criteria for inclusion in the review evaluated an innovative approach and intervention with various components to reduce stigma of HIV and AIDS or other sexual diseases related to HIV stigma, and the study design, a quasi-experimental or randomized experiment with at least a post-intervention test. Using these criteria, the research identified 20 innovation intervention studies and approaches that attempted to reduce HIV and AIDS stigma. Out of the 20 selected studies, only 12 published in peer-reviewed journals were evaluated.

Results

One of the studies reported a sample size of 1,454 HIV-infected persons in five countries in sub-Saharan Africa, with significantly less HIV stigma over time, as indicated in Table 1.

At the same time, those participants taking antiretroviral medications experienced significantly higher HIV stigma over time as compared to those not on antiretroviral therapy [18]. This findings contradicted with some of the authors' opinions that when clients enroll in ARV medication treatment, it signifies that they are experiencing fewer stigmas. This work provided caution to healthcare providers to alert new to antiretroviral treatment patients that they may experience more stigmas at different levels from their families and communities, when they learn they are taking antiretroviral medications [19].

Attitudes towards people living with HIV and AIDS

People with negative attitudes towards the youth living with HIV and AIDS in sub-Saharan Africa are the most common manifestations of HIV and AIDS stigma, which often lead to discrimination and disregard for others [20]. Therefore, the innovative intervention research aimed at increasing the acceptance and tolerance by reducing negative attitudes and promoting positive change in behavior [21]. All the seven studies attempted to change negative attitudes in general population towards people living with HIV and AIDS, especially youths.

Inadequate counseling services and ethics

The key informants reported that the youths' rights to privacy during counseling were not protected in some government hospitals. Therefore, the youths believed that the lack of privacy was a systemic problem, resulting from inadequate healthcare facilities and high numbers of patients [22, 23].

Negative experiences with healthcare providers can provide an inaccurate impression for youth, especially women. Various studies indicated that prior negative experiences in government healthcare system and having heard about other female sex workers' negative experiences, such as being labeled "promiscuous", discourage some female sex workers from attending antiretroviral treatment [24, 25]. Negative attitudes of doctors may also lead to inadequate or partial treatment of HIV and AIDS [26, 27].

The studies in developing countries emphasize the social and economic impact of HIV infection, mainly its effect on older grandparents and their role as caregivers of children orphaned as a result of parental HIV infection, and have ignored the prevalence of HIV infection in the youth and its impact on their lives [28]. A significant challenge to the success of achieving universal access to HIV prevention, treatment, care, and support by 2015 is HIV and AIDS stigma and discrimination [29, 30].

The results from eight studies focusing on the measurement of stigma and discrimination in Nigeria suggested that the reduction of stigma increased individual and community acceptance of people living with HIV and AIDS.

One significant fear influencing health-seeking behavior in sub-Saharan Africa was reflected in reports on social sanctions towards infected persons or those believed to be at risk of infection. Individuals would resist coming forward or exposing themselves to treatment due to fear of being identified with any behavior involving the risk of infection, which

result in despise, shamefulness, and fear of condemnation for being infected [31-33].

Lack of basic needs

The studies indicated that some youths were engaged in sex work for various reasons, such as basic daily needs like food and supporting their families. This lack of adequate food, in the face of counselors' emphasis on the importance of proper nutrition of people living with HIV and AIDS on antiretroviral therapy, makes some female sex workers reluctant to initiate antiretroviral therapy.

Programs for reducing stigma and trainings were evident throughout the world and Africa. However, it was hard to measure the effectiveness of these programs. Some studies indicated that various programs use multiple components to address stigma, including skills and capacity building, education and contact with HIV-positive persons on individual and community levels [31, 34].

The review found inter-related barriers at the family/social, healthcare system/programmatic, and individual levels. Major barriers included the fear of adverse consequences of disclosure of HIV status due to stigma and discrimination associated with HIV, sex work, and lack of family support. Others were negative experienced with healthcare providers, lack of adequate counseling services at government centers and by outreach workers of non-governmental organizations (NGOs), perceived biased treatment of female sex workers who were not referred by NGOs, lack of adequate knowledge about antiretroviral therapy, and pervading sense of fatalism [35].

Discussion

The findings of the present critical review provided a number of insights into the impact of HIV and AIDS fears of stigmatization on health seeking behavior. Evidences from the reviewed studies indicate that health seeking decisions were influenced by several factors, including suspicion about the quality and reliability of diagnosis and treatment, concerns about the monetary and time costs, and concerns about exposing oneself to social sanctions [33]. To avoid social reprimands, individuals take extraordinary measures to prevent exposure and identification. Consequently, fears of stigmatization present a powerful obstacle to individuals' willingness to discuss risky behaviors with others, respond appropriately to the appearance of HIV and AIDS symptoms, and seek healthcare whenever necessary [21, 28].

There is also the need to incorporate culturally sensitive modalities, which assure that target populations can respond to local understandings of key issues associated with HIV and AIDS stigmatization. This approach allows researchers to understand the cultural context, in which target populations live and negotiate.

We find that an attribute perspective is well-suited to understand the nature of HIV and AIDS fears of stigma and their impact on health seeking behavior in African countries. This understanding supports the development of interventions and education to target the content and activities that are most likely to be effective in promoting the desired change. The larger innovative intervention study, from which the data used was collected, has benefited from this research, and we hope other approaches would similarly be enhanced.

Some studies described the importance of diversity in African perspective, showing that communities were not homogeneous and community members were not all equal; even among the youth, there was significant diversity. Social relationships and power's dynamics inherent in this diversity would influence those who were most able to participate in HIV treatment [34].

The effect of stigma on public health innovative intervention was well explained. For many innovative interventions to achieve universal coverage, stigma reduction should be a major player in the design and implementation of HIV and AIDS prevention programs. With the introduction of new chewable antiretroviral drugs and HIV health provision, improved delivery services and prevention of HIV and AIDS amongst the youth, a significant proportion of research on community as well as individual stigma epidemiology are all needed, since the prospect of an HIV vaccine is still in the distant future [22].

In addition, proper counseling was not provided to some of the youths after coming to know their HIV status. Counseling may simply be perceived as threats because the youths who are engaged in sex work can become afraid when they hear harsh and threatening language; therefore, a person who is a counselor should speak politely and sensitively. Several studies have demonstrated how barriers can be tackled by creating effective measures to reduce stigma associated with HIV and AIDS and sex work at the family, societal and healthcare system levels. They include incorporating information about HIV regimens into targeted interventions among the HIV/AIDS-positive vulnerable youths, counselors' training at government hospitals and NGOs' outreach workers on treatment issues, improving facilities and staff levels at government centers to allow adequate time and privacy for counseling, and implementing government's mass media campaigns on antiretroviral therapy availability [34].

Conclusions

To address the issue of stigma in AIDS prevention, news media, home videos, radio jingles, etc., should all be involved to present de-stigmatization programs in schools, hospitals, churches, and religious centers [36]. The introduction of AIDS education can be integrated into school curriculum from the primary to university levels. Another way to address stigma can be the direct empowerment of stigmatized people, and involving them in the design and implementation of prevention programs, as recommended by Dahlui *et al.* [37]. Health education campaigns should integrate a change from fear to care of people living with HIV/AIDS, especially among healthcare personnel [38]. If we

are to address the challenge of HIV stigma and prevention of HIV and AIDS among the youth, designed programs targeting psycho-social experiences of risk behavior will play a tremendous role [34]. More and new innovative interventions, approaches, and techniques will continue to evolve, encompassing principles of youth development and being responsive to changes in social and biological factors, which substantially influence youths' health behaviors [39, 40].

Further research is needed to evaluate the role of culture, religion, and social structures, and their relationships to stigmatizing attitudes in various ethnic communities, which represent majority of countries in sub-Saharan Africa. Finally, this review might be biased since we were unable to examine studies published in languages other than English.

Conflict of interest

The authors have no conflict of interest.

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