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HIV Stigma among Women and Adolescent Girls in South Africa: Removing Barriers to Facilitate Prevention

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Abstract

HIV-related stigma is a global issue. Its perpetuation varies in magnitude across and within countries, and serves as a major barrier to HIV prevention efforts. Due to ignorance about the disease in sub-Saharan Africa, people living with HIV are often stigmatized, and as a result, experience dire consequences. In South Africa, women and adolescent girls are disproportionately infected by HIV. The stigma associated with HIV causes them to live in constant fear of discrimination, isolation, and violence from community members. The stigma also causes them to conceal their HIV status from family members, spouses, or partners, and thus, thwarts any chances of health seeking behavior that can improve upon their quality of life or prevent future transmissions. The stigma associated with HIV impacts women and adolescent girls in South Africa socially, economically and mentally. Given that women and adolescent girls are the population with the greatest HIV prevalence in South Africa, and given that prevention efforts cannot be as successful without addressing the issue of stigma among this group, deliberate commitment and an integrated approach from the government, healthcare professionals, public health officials, and communities are needed to stem the HIV tide in South Africa. These entities need to work together to create an environment where women and adolescent girls feel safe enough to disclose their HIV status and participate in prevention efforts. This article discusses HIV stigma among women and adolescent girls in South Africa. It presents some risk factors that predispose this population in South Africa to HIV, and highlights the social, economic and mental health effects of HIV-related stigma on them. The article further examines current efforts in South Africa to address HIV-related stigma among women and adolescent girls and proffers recommendations for eliminating stigma in order to pave way for effective national HIV prevention.

Keywords: HIV; HIV prevention; Stigma; Women; Adolescent girls; South Africa; Discrimination; Violence; People living with HIV.

Introduction

Sub-Saharan Africa has a disproportionate burden of the human immunodeficiency virus (HIV). Indeed, the region accounts for over 70 percent of the global burden of HIV infections. In sub-Saharan Africa, approximately 60 percent of all new annual HIV infections occur among women and adolescent girls, with South Africa bearing the greatest burden. Although the incidence of HIV infections in South Africa decreased by 49 percent and AIDS-related deaths decreased by 29 percent in 2010 [1,2], the country continues to have the highest number of people living with HIV. In 2017, statistics showed that in South Africa, 7.2 million people were living with HIV/AIDS [1], 270,000

had new HIV infections, and 110,000 died from AIDS-related illnesses [1]. Per the available literature, about 45 percent of all deaths in South Africa are AIDS-related [3]. When it comes to prevalence, HIV is highest among women - four times that of men [4]. Poverty, low socioeconomic status, intergenerational relationships with older men, gender inequality, trauma, abuse, women's unequal power in relationships, and gender-based violence (GBV) are among the factors responsible for the disparity in HIV prevalence among women and men [5], with GBV accounting for approximately 20–25 percent of all new HIV infections [6].

Women and adolescent girls living with HIV in South Africa experience stigma, which negatively impacts them socially, economically, and mentally. The fear of being ostracized socially and the reaction from society, family members and the community, often prevents women and adolescent girls from disclosing their HIV status. The repercussions of nondisclosure create a huge barrier to HIV prevention.

It has been over a decade since the first call to action was issued to reduce HIV infection among women in sub-Saharan Africa through addressing their HIV prevention [7]. To date, there has been some progress made in this area, however, much more still remains to be done. Given the fact that women and adolescent girls are the population with the greatest HIV prevalence in South Africa, and given the fact that prevention efforts will not be as successful without addressing the issue of stigma among this group, it is important for the government, policy makers, healthcare professionals, and communities to deliberately target this population in HIV prevention efforts as an important step to stemming the HIV tide in South Africa. According to the South Africa National AIDS Council, improving the prevention of HIV infection among adolescent girls and young women first will help the country to reach its HIV reduction targets [8]. This article discusses HIV stigma among women and adolescent girls in South Africa. It presents risk factors that predispose this population to HIV, and highlights social, economic and mental health effects of HIV-related stigma among these groups. The article further examines current efforts in South Africa to address HIV-related stigma among women and adolescent girls and provides recommendations for eliminating stigma in order to pave a way for effective HIV prevention. Eliminating stigma and discrimination, and recognizing women and adolescent girl's human rights are cornerstones of sustainable HIV prevention [9].

HIV Prevalence by Sex in South Africa

HIV continues to be the leading cause of death among women of reproductive age (15-49) worldwide. At present, about 51 percent of the 36.7 million people living with HIV globally are women. In 2017 alone, about 48 percent of the estimated 1.6 million new HIV infections in adults worldwide were among women [10]. That same year, the HIV incidence among young women aged 15–24 years was 42 percent higher than among young men in the same age group [10].

From the late 1990s to the early 2000s, political turmoil in South Africa and a long history of government denial about HIV, created a situation that allowed the disease to spread without restraint, claiming the lives of approximately 300,000 people [11]. Despite the eventual acknowledgement of the disease, and current gains in the reduction of AIDS-related mortalities in South Africa, about 5.7 million people are living with HIV, representing about 12 percent of the total population of the country (or nearly one in eight citizens) [3]. Significant variations in HIV prevalence exist between women and men in South Africa. The prevalence of the disease among adolescent girls and women is about four times greater than that of their male counterparts [12]. Young women between the ages of 15 and 24 accounted for 37 percent of new HIV infections in 2016 [12]. In 2017, HIV prevalence among adolescent girls and women aged 15-49 years was 26.3 percent compared to 14.8 percent among adolescent males and men within the same age range. Social and economic disparities, female disempowerment, and high rates of rape in South Africa are among the factors responsible for these statistics [3].

HIV Risk Factors among Women and Adolescent Girls in South Africa

Lack of education, poverty, cultural norms and practices supportive of male superiority and sexual entitlement, non-condom use, GBV, and the lack of access to prevention and treatment services are some of the factors that predispose women and adolescent girls in South Africa to HIV [13-15].

In a national study conducted among educators in South Africa, it was revealed that the higher one's educational level, the lower their HIV prevalence [16]. In another study conducted on HIV prevention knowledge, it was found that only 59 percent of young people in South Africa had comprehensive knowledge about how to prevent HIV [17]. In 2016, only 5 percent of schools in South Africa were providing comprehensive sex education [12]. This explains the paucity in HIV prevention knowledge, in addition to the issue of high school dropout rates, a shortage of trained teachers, and the resistance of parents to schools teaching sex education to their children [18]. While parental resistance is understandable, studies conducted by the United Nations Populations Fund found that there was a significant decrease in physical violence or sexual assault perpetrated by young men, and a lower proportion of young men engaging in transactional sex with a casual partner in schools where comprehensive sex education was taught [17].

There is a link between poverty and HIV. According to existing literature, different levels of poverty (individual, household, and community) and their related characteristics (low education levels, low marketable skills, lack of knowledge or information regarding the risk of infection and the lack of resources to act on this knowledge, lack of capacity to negotiate sex, and high population mobility) create fertile ground for HIV to flourish [19]. In a study conducted on poverty, knowledge of HIV and risky sexual behavior, Booysen found that risky sexual

behavior was higher among South African women from poorer households compared to those from more affluent households [20]. Booysen and Summerton [21] also found that poor women were less likely to be knowledgeable about HIV and were also more likely than their affluent counterparts to engage in risky sexual practices with a recent sexual partner. In his study, Nattrass [22] showed how destitution arising from high poverty and unemployment, can cause people to behave in ways they would otherwise not under more favorable circumstances. Still regarding the link between HIV and poverty, Kalichman et al. [23] found a positive correlation between the risk of HIV transmission and the lack of basic needs among South African women and adolescent girls. Hunter [24] also found that poor women in South Africa, were exposed to greater HIV risk through transactional sex and networking.

Cultural norms and practices supportive of male superiority and sexual entitlement have also predisposed women and adolescent girls to HIV infection in South Africa. The cultural and social systems in South Africa have strict rules regarding female sexuality, and gives women little to no control over their sexual lives [25]. The cultural norms have empowered men and have given them the right to control women in their relationships [26]. This imbalance in power creates disparities and allows men to maintain multiple concurrent partners outside the marriage and to refuse condom use [27]. This male attitude towards women, and the social acceptance of violence against women, contribute to the transmission of HIV among women and adolescent girls.

Gender inequity has implications for socioeconomic status. In South Africa, as in many other patriarchal societies, women are often dependent on men for financial support and sustenance. This state of dependency sometimes creates tension in the home, and on most occasions, results in violence [28]. Although accurate statistics are difficult to obtain, it has been reported that GBV is very common in South Africa. Studies report that between 25 and 40 percent of South African women and adolescent girls have experienced sexual and or physical violence in their lifetime, and a little under 50 percent have experienced economic abuse. The violence women and adolescent girls experience [29] serve as barriers to safer sexual practices and puts them at risk for HIV infection [30].

A study conducted by Luseno et al. [31] found that the fear of stigma among women in South Africa hinders the utilization of health care services. According to Shishana et al. [32] women who are part of marginalized and underserved groups—such as poor women with low levels of education, and those who engage in sex work to support themselves and their families—usually have greater limitations accessing appropriate health care services. Though efforts have been made to expand access to HIV treatment and care in South Africa, these efforts have failed to expressly address the issue of stigma and the needs of women and adolescent girls [33].

HIV-related Stigma and Prevention

Stigma is the extreme disapproval of a person or group of people based on certain characteristics that distinguish or make them undesirable by other members of a society. It is also a set of negative and often unfair beliefs that a group of people have about something [34].

HIV-related stigma is the negative beliefs, feelings, and attitudes towards people living with HIV/AIDS, their families, and people who work with them [35]. It causes discrimination and creates barriers that negatively impact HIV prevention.

The fear of HIV-related stigma, and the discrimination and potential violence it brings in its wake, undermines the ability of people living with HIV to seek treatment, or to participate in prevention efforts [36]. Oftentimes, people living with HIV avoid accessing care for the fear of having their status revealed [37]. With the absence of voluntary HIV disclosure, the health of populations will continue to be at risk.

Hospitals and HIV-related stigma

The way hospitals and clinics are set up and run in South Africa is not always conducive to protecting the privacy and HIV status of patients [38]. Doctors and nurses often attend to about 60 to 80 patients a day in overcrowded shared consultation rooms [38]. Often times, after an HIV positive diagnosis has been made, they shout out the information across the room filled with other patients to a colleague for recording without considering the fact that their actions could put patients at risk for stigma, embarrassment, and all the social ramifications associated with being HIV positive.

Special populations and HIV-related stigma

Due to stigma, female sex workers in South Africa do not often access treatment and care [4]. Despite the fact that the government of South Africa has a National Sex Worker HIV Plan that backs the provision of HIV services to sex workers, some organizations that provide such services are often harassed by the police due to the stigma associated with HIV [4]. Since HIV incidence is high among transgender women in South Africa and since they face constant discrimination from society, this population is often excluded from participating in HIV studies. The lack of transgender representation has resulted in limited knowledge about HIV transmission and acquisition vulnerabilities among partners of transgender people. The lack of information on transgender related HIV issues [4] therefore hinders the development of evidence-based HIV prevention interventions for transgender populations.

Consequences of HIV-related Stigma among Women and Adolescent Girls

Women and adolescent girls living with HIV in South Africa are often marginalized, discriminated against, and experience violence at the hands of their community [39]. The stigma associated with HIV has social, economic, and mental health effects on them.

Social

In South Africa, women and adolescent girls living with HIV are often shunned by their family and peers. Some are even abandoned by their partners because of their perceived

reduced capability to bear children. In South Africa, a woman's ability to have children essentially determines her worth in society. As this childbearing role becomes compromised by HIV, they are no longer 'needed". The fear of abandonment and the loss of respect in the community, prevent women from getting tested for HIV, and not disclosing their HIV status [40]. Additional consequences for women, arising from living with HIV, include social exclusion and the possibility of losing their homes and livelihoods.

Economic

Along with facing social rejection from their family members and peers, women who are living with HIV in South Africa experience hostility in educational and work settings [41]. In a survey conducted in Cape Town, about 43 percent of the people surveyed indicated that infected women should not be allowed to work with children and 41 percent stated that these women should have limitations placed on their freedoms [40]. The high levels of externalized stigma in both educational and work settings can contribute to low socioeconomic status due to discrimination. According to The AIDS Law Project, "The main source of complaints over the years has involved employer discrimination and HIV testing that is performed without regard to confidentiality." The South African Development Community and The Human Rights Monitor revealed that some companies in South Africa dismissed female workers because they had HIV. In other situations, they were denied promotion because of the thought that they could die soon. Women affected by workplace discrimination due to their HIV status are already marginalized, add discrimination to the situation and you have a recipe for mental ill health [42].

Mental health

HIV-related stigma negatively affects the mental health of people living with the infection. In South Africa, women and adolescent girls living with HIV are at high risk of low self-esteem, depression, and thoughts of self-harm [41]. A cross-sectional study conducted on HIV stigma and the mental health status of women and adolescent girls in Western Cape, in South Africa found that women who had experienced discrimination and bad treatment due to HIV stigma, presented with depressive symptoms, severe post-traumatic stress disorder (PTSD), and a lower quality of life [39]. Most often, the sharing of an HIV-positive diagnosis with partners elicits high levels of domestic violence against women and adolescent girls [40]. Thoughts or plans of leaving a violent partner is typically plagued with the fear of retribution, concern for the children, the fear of survival in the absence of other means of economic support, fear of social stigma, and the fear of being ostracized by family and friends [43].

HIV Prevention Efforts in South Africa

HIV treatment centers

In support of HIV prevention efforts, development partners like The Bill and Melinda Gates Foundations have provided South Africa with funds to increase its number of HIV/AIDS clinics and to educate the public on the importance of safe sex [40]. In tandem with this effort, the South African government, through domestic funds, has been sponsoring extensive HIV treatment programs for citizens (UNIAIDS, 2019). Nonetheless, national HIV reduction targets have not been attained as these efforts have not specifically targeted the issue of stigma among women and adolescent girls- the population most infected and vulnerable to the disease.

Even though HIV treatment centers are available in certain parts of South Africa, women are not taking advantage of these services because of the shame they feel and the fear of exposure. Stigma has prevented them from receiving HIV prevention medications such as antiretroviral drugs, which would otherwise help manage the disease, prevent future transmission, and improve upon their quality of life. Even women involved in HIV trials have discontinued participation because of the fear of being mistaken as having HIV [41].

Faith-based organizations

Faith-based organizations (FBO) have a tremendous impact on a large number of communities in South Africa. Some have provided care and support to people living with HIV and others have used religion as a tool to fight the stigma and discrimination associated with HIV [44]. From the pulpit, certain religious leaders have advised against stigma and the maltreatment of people living with HIV [44]. However, not everyone in the congregation is moved to action, as many see HIV infection as a punishment from God for immoral behavior. While some FBOs are speaking out against the hostility meted out to people living with HIV and stigma, a lot still remains to be done as their efforts can only go so far [44].

National HIV/AIDS policies and strategies

In May 2017, the South African National AIDS Council released the fourth National Strategic Plan (NSP) for HIV, Tuberculosis and Sexually Transmitted Infections Plan. The goal of the five-year plan (2017–2022) is to track progress towards eliminating HIV as a public health threat by the year 2030 [45], and to oversee the implementation of an HIV strategy for adolescent and young women and girls (AYWG). While the AYWG strategy is laudable, it does not expressly focus on the need to reduce or eliminate HIV-related stigma among this population.

Removing Barriers to HIV Prevention and the Way Forward

To facilitate the prevention of HIV in South Africa, a conscious effort needs to be made and targeted at reducing stigma, so that the populations most affected by HIV-women and adolescent girls - can freely disclose their status, participate in prevention efforts, and take precautions to prevent future transmission without the fear of discrimination, violence, or economic loss. Addressing HIV-related stigma will require among other things, creating health care provider awareness of HIV stigma, investing in educational anti-stigma interventions, humanizing HIV, involving people living with HIV in de-stigmatizing activities, and utilizing social workers.

Health care provider HIV stigma awareness

Studies show that HIV-related stigma and discrimination in health care settings contribute to keeping people away from accessing HIV prevention, care, and treatment services, and also prevents them from adopting key preventive behaviors [46]. There are three main causes of HIV-related stigma in health facilities: the lack of awareness among health care providers of what stigma looks like and its negative effects on patients, health care provider fear of contracting the disease, and the association of HIV with amoral behavior [46]. To combat HIV-related stigma, it is important for health facilities in South Africa to create an environment where health care providers acknowledge that stigma exists in their facilities, and as a result, develop strategies and action plans to build staff and management support for stigma-reduction and elimination [47]. In a study conducted in three public and private hospitals in New Delhi, India, hospital managers were initially unwilling to believe that stigma and discrimination were problems in their facilities. After the research team shared key findings, hospital managers and staff developed action plans to address hospital workers' misconceptions about HIV transmission, and to address their judgmental attitudes and differential practices toward HIV-positive patients [48]. Adopting this strategy will facilitate HIV reduction in South Africa and will facilitate the de-stigmatization of HIV services.

Educational anti HIV stigma interventions

To facilitate HIV prevention in South Africa, educational anti-stigma interventions need to be implemented with a focus on providing information about the stigmatized condition of people living with HIV, correcting misinformation and negative cultural beliefs and attitudes about the disease, and rectifying inaccurate stereotypes or myths [49]. These interventions may take several forms including national television and radio shows, or regular educational campaigns that discuss and provide information about the actions and behaviors that are stigmatizing, the consequences of stigma experienced by people living with HIV, and the steps that can be taken to eliminate HIV-related stigma, so as to promote prevention efforts. While educational anti-stigma interventions generally help to address public stigma of HIV, they have also been found to reduce self-stigma, improve stress management, and boost self-esteem [49].

Humanizing HIV

The stigma associated with HIV generally has a negative impact on the quality of life of HIV-positive people and on general prevention efforts. An additional way South Africa can combat HIV-related stigma is to focus on increasing the acceptance of HIV as another kind of disease. The government should make it a punishable offense for the media and other perpetrators who communicate negative and sensational stories about people living with HIV. This will help educate the media and other entities to better understand the reality of the consequences of their activities on people living with HIV - stigma, discrimination, and violence. Communities can also form anti-AIDS clubs and train members to provide care and support to people with HIV and help foster their acceptance within families and communities.

Involvement of people living with HIV in destigmatizing activities

As was done in Belarus, the South African government can provide people living with HIV with psychological support and legal advice to tackle internalized stigma (feelings of worthlessness, shame, and depression associated with an HIV diagnosis), and engage them in advocating for the implementation and enforcement of a rights-based campaign to raise awareness about HIV-related stigma [50].

Utilization of social workers

As part of their functions, social workers provide leadership and support in the mobilization of community response to HIV. In keeping with the tenets of their HIV Manifesto to promote social justice and to protect human rights among others, social workers can work with community members to eliminate misinformation and misunderstandings about HIV-related stigma. They can bring pressure to bear on the government of South Africa and organizations in the country to adhere to the principles of human rights and the dignity of people living with HIV in accordance with existing Human Rights conventions. They can also work to ensure that these entities respond compassionately to people living with HIV. Social workers can combat HIV-related stigmatization and the resultant discrimination by advocating for people living with HIV, including women and adolescent girls, to be given access to food, housing, education, and health care as well as the backing they need to exercise their rights as citizens regardless of their HIV status.

Conclusion

Research has shown that stigma and discrimination undermine HIV prevention efforts, in that, they make people afraid to disclose their HIV status, seek out HIV information and services to reduce their risk of infection, and to adopt safer behaviors. Thus, stigma, discrimination, and violence weaken the ability of individuals and communities to protect themselves from HIV.

Stigma and discrimination associated with HIV are among the most significant barriers to HIV prevention, treatment, care, and support in South Africa. Since women and adolescent girls in South Africa bear a disproportionate burden of HIV, it is only imperative that prevention efforts in this country target this population and focus on reducing and eventually eliminating stigma. This will encourage women and adolescent girls to disclose their HIV status and seek care without fear and anxiety and in the process, help to increase gains in national HIV prevention efforts.

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