

# HIV/AIDS Prevention: Reducing Social Stigma to Facilitate Prevention in the Developing World

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## Article Info

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## Abstract

An approach to preventing new HIV infections is the expectation that people living with the virus will disclose their status to their partners, healthcare providers, and family members. While this expectation would most logically contribute to reductions in new HIV infections, it is widely known that disclosure of status often results in problems for the person infected with the virus. Too often, status disclosure is not treated as confidential information and people become stigmatized, ostracized from society, and discriminated against. This is particularly true in developing countries where much is not known about the disease, and where being infected with HIV is an automatic sentence for social isolation. If strides are to be made towards reducing HIV incidence and prevalence in the developing world, then attitudes towards persons living with the disease have to change, so as to encourage free reporting and the seeking of appropriate medical care and counseling. This paper highlights the continued global burden and trends of HIV/AIDS, discusses the role, barriers, and effects of social stigma on HIV/AIDS prevention efforts, and proposes strategies for the reduction of stigma and other negative attitudes that inhibit HIV/AIDS prevention efforts in developing countries.

**Keywords:** HIV/AIDS; Stigma; Discrimination; Prevention; Developing countries; HIV counselling and testing; People living with HIV/AIDS.

## Introduction

Since 1981, the human immune-deficiency virus (HIV), which causes acquired immune deficiency syndrome (AIDS), has infected about 78 million people [1-3], and claimed the lives of 35 million people. Currently, 36.7 million people are living with HIV, the majority of which reside in developing countries [4]. While some countries have made considerable strides in slowing down the transmission of HIV, others have not been as successful. Given that there is no cure for HIV/AIDS, preventing new infections is a key global strategy that is reflected in the just expired Millennium Development Goal 6 and the newly launched Sustainable Development Goal target 3.3, which seeks to "by 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases" [5].

An approach to preventing new HIV infections is the expectation that people living with the virus will disclose their status to their partners, healthcare providers, and family members. While this expectation would most logically contribute to reductions in new HIV infections, it is widely known that disclosure of status often results in problems for the person infected with the virus. Too often, status disclosure is not treated as confidential information and people become stigmatized, ostracized from society, and discriminated against. This is particularly true in developing countries where much is not

known about the disease, and where being infected with HIV is an automatic sentence for social isolation. If strides are to be made towards reducing HIV incidence and prevalence in the developing world, then attitudes towards persons living with the disease have to change, so as to encourage free reporting and the seeking of appropriate medical care and counselling. This paper highlights the continued global burden and trends of HIV/AIDS, discusses the role, barriers, and effects of social stigma on HIV/AIDS prevention efforts, and proposes strategies for the reduction of stigma and other negative attitudes that inhibit HIV/AIDS prevention efforts in developing countries.

## Global HIV/AIDS Incidence and Prevalence

The human immune-deficiency virus causes AIDS. The virus is transmitted by having unprotected sex with infected persons, sharing infected needles, receiving infected blood and blood products, and mother to child transmission during pregnancy or breastfeeding. The virus attacks and compromises the body's immune system, specifically the CD4 cells (T cells), and reduces the body's ability to fend off infections and opportunistic diseases [6]. AIDS is diagnosed when an HIV positive person has a CD4 count less than 200 cells/mm<sup>3</sup>.

As of 2016, 36.7 million people of all ages were living with HIV/AIDS globally, and an estimated 10 million suffered from HIV-related illnesses worldwide [2]. The annual incidence of new HIV infections in 2016, was 1.8 million globally, 39% lower than in 2000 [7]. Over 95% of the new HIV infections occurred in developing countries, with about two-thirds in sub-Saharan Africa, where over 28 million people are living with HIV [8].

In 2015, Eastern and Southern Africa were the region's most affected by HIV in sub-Saharan Africa. These regions are home to about 6.2% of the world's population and accounted for over 50% of the total number of people living with HIV globally [9]. These regions had 960,000 new HIV infections, about 46% of the global total [3]. South Africa alone accounted for 40% of the region's new infections, while Ethiopia, Kenya, Malawi, Mozambique, Uganda, the United Republic of Tanzania, Zambia, and Zimbabwe accounted for 50% of the new infections in sub-Saharan Africa [3].

## HIV/AIDS and Social Stigma

Social stigma is extreme disapproval of a person or group of people based on certain characteristics that distinguish or make them undesirable by other members of society. It is also a set of negative and often unfair beliefs that a group of people have about something [10]. HIV-related stigmas are the negative beliefs, feelings, and attitudes towards people living with HIV/AIDS (PLWHA), their families and people who work with them [11]. These negative beliefs, feelings, and attitudes often reinforce existing social inequalities, cause discrimination, render people powerless, create greater differences, and diminish a person's social status and self-worth [12]. HIV-related stigma is the result of a lack of

understanding of the disease, negative media and social portrayal of the disease, the fact that AIDS is incurable, and prejudices caused by cultural beliefs [13].

While HIV-related stigma in developing countries has declined to some extent in the past few years, it continues to be a barrier to HIV prevention. Indeed, in 2016, the AIDS & Rights Alliance for Southern Africa (ARASA) described progress made towards HIV-related stigma as "inconsistent and uneven"[14]. Cultural beliefs about HIV create discrimination and discourage people from seeking counselling, getting tested, sharing their HIV positive status with loved ones, seeking care, and sticking to treatment regimens [15]. Studies conducted by the African Sex Worker Alliance in Kenya, South Africa, Uganda, and Zimbabwe, found that, sex workers experienced very high levels of stigma, and were for that reason, unwilling to disclose their occupation to healthcare providers [14]. Thus, stigma and discrimination are major barriers to HIV testing in this population.

### Social Stigma and HIV Prevention Efforts

Even though numerous efforts have been made at the global level to reduce the HIV/AIDS pandemic, many countries and regions continue to experience little or no change in their infection rates, and subsequent deaths [16,17]. In developing countries, especially those in Eastern and Southern Africa, large-scale HIV/AIDS prevention programs have focused on HIV education, counseling and testing, condom use, voluntary medical male circumcision, and antiretroviral treatment (ART). Nonetheless, these HIV/AIDS prevention efforts have not resulted in projected reductions in new infections, due in part to HIV-related stigma [18].

HIV-related stigma and discrimination create barriers, which negatively impact the ability of PLWHA to protect themselves and to stay healthy. The fear of stigma, discrimination, and potential violence, undermines their ability to access and adhere to treatment and prevention efforts such as condom use and needle sharing. HIV-related stigma causes PLWHA to develop low self-esteem and thus, resort to negative motivation for self-protection; they engage in risky sexual behavior, have multiple sexual encounters in an attempt to seek self-validation, or use alcohol or drugs. It also results in negative health behaviors including the unwillingness to seek voluntary testing, and obtaining appropriate treatment, care, and support [18].

In Southern and Eastern Africa, men who have sex with men, sex workers, transgender people, drug users, and key affected populations often experience increased levels of stigma and discrimination. Research shows that young men who have sex with men are disproportionately bullied at home, in schools, and in communities compared to their heterosexual counterparts [14]. The stigma associated with HIV/AIDS also causes people to lose their houses and jobs, and to be badly treated by some healthcare providers. It must be noted that, the extent to which people experience HIV-related stigma varies across countries and within communities.

HIV-related stigma discourages vulnerable populations

from seeking information and programs, for fear it will be taken to mean that they have HIV, are promiscuous, are unfaithful, or are members of populations associated with HIV, like people who inject drugs, sex workers, and gay men [11]. Consequently, people are less likely to inquire about their sexual partners HIV status, use clean needles, or access biomedical prevention options such as male circumcision and pre-exposure prophylaxis (PrEP). [11].

### **Practical Steps to Address Stigma and Promote HIV/AIDS Prevention**

Over three million people living with HIV/AIDS in developing countries now receive ART. However, close to seven million people in sub-Saharan Africa are still in need of ART and are awaiting access [19]. This gap in access to medical and diagnostic pathways contributes significantly to the continued challenges of reducing new HIV infections. Prevention is key, but it cannot be effective if stigma and discrimination impede people from seeking counselling and testing, and taking the deliberate steps needed to prevent potential transmission. If people are anxious about disclosing their status, they will not obtain the help they need.

The devaluation of identity and discrimination associated with HIV-related stigma does not occur naturally. Indeed, they are socially constructed by individuals and communities, who generate and perpetuate stigma as a response to their own fears [20]. Given that HIV-related stigma exists at various levels, a social-ecological framework can assist in our approach to better understand and establish appropriate interventions at both the micro and macro levels of human interactions. Practical steps to promote prevention efforts must be targeted at these levels. A simultaneous multi-level approach must be used. The Social-Ecological model of health purports that individual health behavior cannot effectively be addressed without taking into account the macro and environmental underpinnings of health [21]. With that in mind, to examine best practices in dealing with HIV-related stigma, a multi-level approach would help to inform prevention efforts. To further identify an in-depth understanding of how stigma and discrimination can be addressed for PLWHA, we also suggest that future research, using a community-based participatory research framework, be implemented to obtain stronger empirical evidence of how stigma and discrimination is experienced and what steps are necessary to be taken at both micro and macro levels, to help reduce personal and structural barriers to prevention.

#### **Individual Level**

At the individual level, PLWHA must be educated on how they can transmit HIV and what they can do prevent further transmission. They also need to be provided with information and given access to services that can protect them and their human rights when they feel that they have been betrayed by people they disclosed their status to. A study conducted in South Africa found that while some PLWHA experienced stigma through insults and arguments from family members during disagreements, they knew that disclosing the status

without their consent was a crime. In these instances, threatening to go to the police, or sometimes actually calling the police, allowed PLWHA to fight back and maintain their self-esteem [22].

#### **Community Level**

At the community level, social and structural interventions to change societal beliefs about PLWHA [23], should be implemented. Current research on HIV-related stigma suggests that interventions to reduce stigma in healthcare settings or in communities have primarily been directed at raising HIV/AIDS awareness [23,24]. Promoting antidiscrimination policies, and protecting the human rights of PLWHA [23,25]. But none of the interventions were specifically directed at the families of PLWHA. National governments in developing countries need to introduce and implement bold initiatives, and embark on campaigns that target families and communities, with the intent of educating and creating awareness on the need for them to be more supportive of their loved ones in the event that they test positive for HIV/AIDS. The link between stigma, negative behavior towards PLWHA, and potential increased infection should be highlighted.

Wohl et al. examined social stigma in their article "A youth-focused case management intervention to engage and retain young gay men of color in HIV care" [26]. At the social level, the authors explored some of the difficulties faced by PLWHA including stigma and isolation from community members, lack of social support and, the limited access to needed resources including transportation, mental health services, housing, and employment assistance. The treatment of HIV requires lifelong management of the disease, thus interventions are needed that can help these populations access and adhere to needed services. The authors concluded that structural barriers can have a direct effect on health care access. Given that there is a solid understanding of the structural barriers that PLWHA face, research should be conducted and aimed at methods of reducing some of these barriers, so treatment adherence can be optimal.

#### **Policy Level**

Mechanisms to eliminate anti-discriminatory practices against PLWHA should be introduced and enforced. In Ghana for example, the Commission on Human Rights and Administrative Justice, the Ghana AIDS Commission, and the Health Policy Project have developed a web-based mechanism that PLWHA can use to report discrimination at the workplace, and in health care, educational, and other settings. These reports are anonymous, and result in mediation, investigation, and legal resolution by human rights and legal organizations [27].

#### **Health Care Level**

The creation of awareness programs and the education of health workers to deliberately increase their knowledge and understanding of stigma and its detrimental effects on HIV/AIDS prevention efforts are essential. Stigma is already a pressing concern among PLWHA, and this concern can be

magnified when perpetuated by health care providers, ultimately affecting access to care, treatment adherence, and overall quality of life. Health workers' phobias and misconceptions about HIV and how it is transmitted must be dispelled and addressed, as the fear of acquiring HIV through everyday contact with infected persons, causes some providers to take unnecessary and often stigmatizing actions. The creation and implementation of an HIV/AIDS health care provider stigma instrument that is culturally sensitive, is one way of assessing HIV-related stigma amongst health care providers. Results from these assessments can be used to inform training, awareness creation, and education efforts to reduce stigma [28]. Research efforts in these aforementioned areas should focus on effectiveness, and the most effective training, awareness and education programs can then be modeled and duplicated in various settings. Efforts intended to increase awareness and education need to provide health workers with complete information about how HIV is and is not transmitted, and how treating PLWHA humanely can help with the prevention of potential new infections. The awareness creation efforts should also aim at getting health workers to separate persons living with HIV from the behaviors considered as improper or immoral.

#### **Program Level**

Programs that address negative perceptions and assumptions about HIV/AIDS are vital to confronting perceptions that promote stigmatizing attitudes toward PLWHA. Programs need to target and speak to the shame and blame directed at PLWHA.

#### **Research Level**

While numerous studies have been conducted on HIV-related stigma, and literature abounds on what PLWHA can do to stop HIV/AIDS transmission, there is a dearth of research on the perceptions and lived experiences of PLWHA on HIV-related stigma, and how discrimination and social isolation impact their role in HIV prevention efforts. If HIV/AIDS prevention is to be successful in developing countries, it is important that research be conducted with PLWHA as partners, to obtain their views and strategies on how best to address issues of stigma, discrimination and isolation, the three factors that current research tells us have such a negative impact on HIV/AIDS prevention efforts. Collaborating with PLWHA on examining stigma from their perspectives allows the researcher to collect narratives at the micro level of the social-ecological model and to use this information to inform prevention efforts designed at the individual level.

To begin to understand how to effect change regarding stigma, discrimination and isolation at the macro-environmental level, further research on policy implications at the community, healthcare, and program levels needs to be conducted. It is no surprise that policies at all of these levels can exacerbate stigma, discrimination and isolation for PLWHA. By focusing data collection efforts on PLWHA and their perceptions of structural barriers at the macro level, interventions and policy reviews will be specifically targeted at the direct and indirect forces that

perpetuate the stigma, discrimination, and isolation experienced by PLWHA. Additionally, current interventions and policies that focus on reducing HIV-related stigma in developing countries need to be assessed for their content, cultural sensitivity, and the extent to which they embody practices that inherently increase stigma related bias towards PLWHA.

Globally, prevention is vital in the fight against HIV/AIDS, but the stigma associated with the disease constricts prevention efforts and makes significant decreases in new HIV cases difficult to achieve, particularly in developing countries. Prevention efforts that are framed using the social ecological model may be one approach to addressing the multi-level antecedents that perpetuate the negative effects of stigma. As previously stated, stigma affects individual's self-image and ability to properly advocate for themselves, thereby limiting disclosure of their status to practitioners and even their partners. Allaying fears and myths about HIV/AIDS with family and community support will also serve to help reduce the deleterious impact of stigma. In developing countries where the use of prevention efforts do not seem to achieve the desired reduction in new cases of HIV, research and a strategic focus on reducing social stigma, isolation, discrimination, and other negative attitudes towards PLWHA may be the most appropriate next steps.

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