

HIV/AIDS-Related Stigma and Discrimination in Sub-Saharan Africa: A Review

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Abstract

HIV/AIDS-related stigma continues to be a global threat to HIV care, treatment and prevention especially in Sub-Saharan Africa. The aim of this narrative review was to examine the different context of HIV/AIDS-related stigma and discrimination, and its consequence in Sub-Saharan Africa. This review is significant as it will inform policy makers on HIV/AIDS to be able to combat HIV/AIDS-related stigma and discrimination as well as promote the rights of people living with HIV/AIDS. Detailed literature search was done using CINAHL, MEDLINE and EMBASE databases where relevant papers were selected. Also, relevant grey literature such as reports and newspapers were included in the review using the Google search engine. The review revealed that HIV/AIDS-related stigma and discrimination has resulted in loss of jobs and accommodation as well as difficulty in accessing healthcare and education among people living with HIV/AIDS. People living with HIV/AIDS have also suffered stigma and discrimination in the family and at church. Although strenuous efforts has been made to fight against HIV/AIDS-related stigma and discrimination in Sub-Saharan Africa, a lot more needs to be done. There is therefore the need to intensify educating people to see persons living with HIV/AIDS as 'normal' people. Governments should ensure that people living with HIV/AIDS have equal access to education, healthcare, housing and jobs. Also, the rights of people living with HIV/AIDS should be promoted.

Introduction

Globally, Human Immunodeficiency Virus (HIV)/Acquired Immunodeficiency Syndrome (AIDS) pandemic continues to be a threat to human livelihood and existence especially in Sub-Saharan Africa where the pandemic remains the largest in the world (Gibbs et al., 2012; Peltzer et al., 2011; Oramasionwu et al., 2011). Demmer (2010) and Julia et al. (2012) observed that HIV/AIDS continues to be a major cause of death in Sub-Saharan Africa with about 25 million People Living with HIV/AIDS (PLWHA). Although several factors have been implicated as a driving force of the pandemic, HIV/AIDS-related stigma is the single most important barrier to controlling the HIV/AIDS pandemic in Sub-Saharan Africa (Maughan-Brown, 2010; Peltzer, 2012; Mall et al., 2013; Boyes et al., 2013; Visser et al., 2009; Haber et al., 2011). This finding seems to posit the statement made by the United Nations Secretary-General Ban Ki-moon who argued that HIV/AIDS continues to devastate most communities mainly because of stigma (The Washington Times, 2008).

Stigma was described by Goffman (1963) as discreditable or undesirable attributes of some individuals or group of persons that makes them socially unacceptable in the eyes of the society. Stigma occurs when some members of the society are seen as people with a 'spoilt' identity which deviates from the normal or when a disease is linked to negative behaviour in the society (Goffman, 1963; Deaconet al., 2005). Several studies have found that HIV/AIDS-related stigma tends to be associated to negative behaviour such as sexual promiscuity which has resulted into HIV/AIDS victims seen as people with a 'spoilt' identity (Goffman, 1963; Deaconet al., 2005; Herek, 1999). Hence, the objective of this paper is to explore HIV/AIDS-related stigma and discrimination in Sub-Saharan Africa. This review will address the following research questions: 1) What are the forms of HIV/AIDS-related stigma and discrimination? 2) What makes HIV/AIDS-related stigma and discrimination pervasive? 3) what are the effects of HIV/AIDS-related stigma and discrimination? and 4) what efforts have been made to tackle HIV/AIDS-related stigma and discrimination? In addressing these questions, findings will be used to inform policy and decision making to help curb HIV/AIDS-related stigma and discrimination in Sub-Saharan Africa.

Methods

The review adopted a narrative approach rather than a systematic review. A detailed literature search using MEDLINE, CINAHL and EMBASE databases was done as they provide comprehensive literature on healthcare. Grey literature was also searched using the Google search engine, where relevant reports and newspapers were also included in the review. Also, relevant references from the selected papers were reviewed. The review included published literature that employed both quantitative and qualitative methods to get a broader scope of HIV/AIDS-related stigma and discrimination in Sub-Saharan Africa. The literature was searched using the following key words: human immunodeficiency virus, acquired immunodeficiency syndrome, HIV/AIDS, stigma, HIV/AIDS-related stigma and Sub-Saharan Africa were used.

The inclusion criteria for literature that were reviewed were studies that are cross-sectional, case-control, cohort and any other studies that focused on HIV/AIDS-related stigma and discrimination in Sub-Saharan Africa, and conducted in English language. All studies that did not meet the above criteria were excluded from the review.

Search Results

After a thorough literature search using the inclusion and exclusion criteria, a total of one hundred and sixty four (164) papers were retrieved. The papers retrieved were further scrutinized by going through their titles, abstracts and full text of the papers appropriately. Thirty (30) papers were included in the final review. Additionally, eleven (11) relevant references were obtained from scanning the thirty (30) papers included in the review. The search results on grey literature yielded one (1) relevant newspaper and four (4) reports. This produced a total of forty six (46) papers. Figure 1 shows a PRISMA diagram which shows a flow of the scientific literature results obtained.

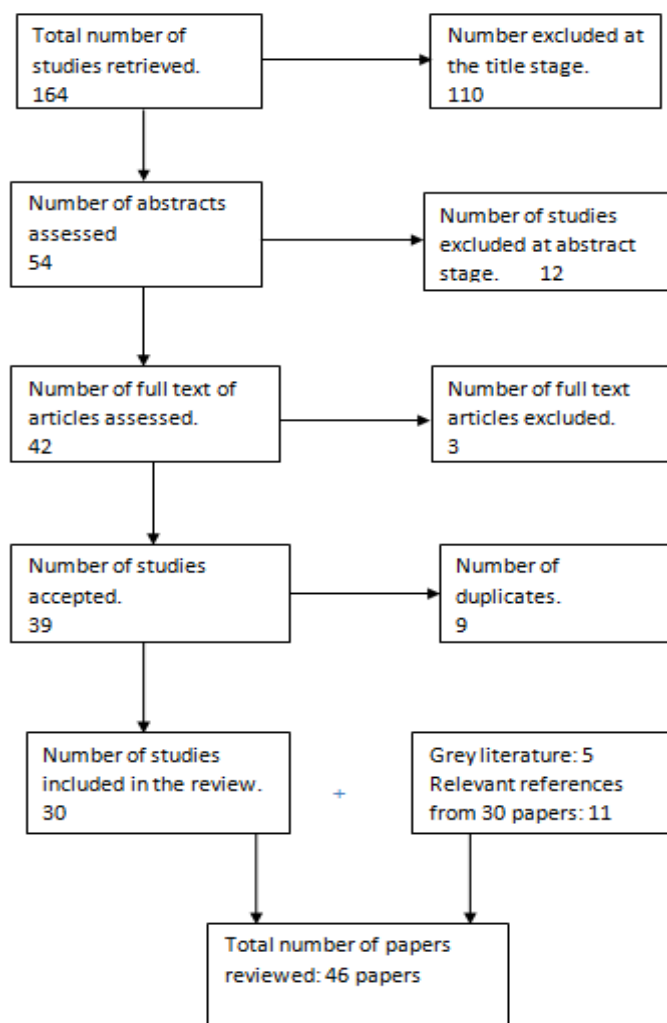


Figure 1: PRISMA diagram

Findings of Review

The data were extracted from the included studies and were analyzed thematically. This identified four themes from the included studies which include: 1) Forms of HIV/AIDS-related stigma and discrimination 2) The Pervasive nature of HIV/AIDS-related stigma and discrimination 3) Effects of HIV/AIDS-related stigma and discrimination and 4) Efforts made to tackle HIV/AIDS-related stigma and discrimination in Sub-Saharan Africa.

Discussion

Forms of HIV/AIDS-related Stigma and discrimination

Stigmatization of HIV/AIDS in Sub-Saharan Africa has been observed in various forms such as physical, moral and social stigma (Ogunmefun et al., 2011; Visser et al., 2008). Shisana and Simbayi (2002) found that in Cape town, South Africa physical stigma was evident as 18% of people did not want to sleep with PLWHA in the same room, 26% of the people were unwilling to share a meal with PLWHA and 6% of people did not want to talk to people they knew had AIDS. Although physical stigma of PLWHA is a major concern in Sub-Saharan Africa, Allanise et al. (2010) argue that what makes physical stigma even worse is the 'immoral' perception of PLWHA. Allanise et al. (2010) found that people do not want to associate with PLWHA because they are perceived as promiscuous, unfaithful to their partners and are being punished by God as a consequence of their 'immorality'. Moral stigma tends to be linked to physical stigma and is more likely to be reason for physical stigma. The other form of stigma is social stigma which has been associated with high risk groups such as sex workers and truck drivers who acquire HIV/AIDS as they are more likely to be promiscuous and unfaithful than other social groups (Visser et al., 2008). Researchers argue that social stigma does not thrive alone in communities as it is usually interlinked with moral and physical stigma (Visser et al., 2008).

Furthermore, HIV/AIDS-related stigma has also been expressed as internal or external stigma (Minrie et al., 2008). Internal stigma occurs when stigma is either felt or perceived by an HIV positive person and this makes him/her unwilling to seek treatment at health facilities as they perceive that societal attitudes towards PLWHA is that of stigma (Minrie et al., 2008). For example, a study by Dinesh et al. (2011) observed that because of internal stigma some HIV positive individuals prefer to be at home to receive home-based treatment for HIV/AIDS by caregivers rather than seeking treatment at health facilities. The Authors noted that although home-based care for HIV/AIDS has been found to be beneficial for PLWHA, it introduces external stigma to caregivers due to their association with PLWHA.

The Pervasive nature of HIV/AIDS-related stigma

Studies have shown that HIV/AIDS-related stigma is pervasive in most communities in Sub-Saharan Africa (Haber et al., 2011; The Washington Times, 2008; Campbell et al., 2005; Groenewald et al., 2005; Kalichman and Simbayi, 2004; Reddy and Frantz, 2011; Potgieter et al., 2012; Parry et al., 2009; Van et al., 2009; Daftary et al., 2007). The Researchers found that several factors have nurtured HIV/AIDS-related stigma to become pervasive. Reddy and Frantz (2011) observed that although most people had adequate knowledge on HIV/AIDS, some of them were ignorant of the mode of transmission of the disease and this tends to make the disease more likely pervasive. Additionally, Potgieter et al. (2012) and Parry et al. (2009) argue that although some individuals were aware of the mode of transmission of HIV/AIDS, they still perceive PLWHA to have acquired the disease through only unprotected sex. The Researchers noted that this perception is misleading and seems to worsen HIV/AIDS-related stigma as some victims of the disease acquired it through other routes other than sex.

Also, the physical impairments, loss of weight or disfigurement usually caused by HIV/AIDS is a major facilitator to the pervasive nature of HIV/AIDS (Van et al., 2009). Van et al. (2009) revealed that people tend to frown on people with such physical disfigurement as they perceive them to be people with HIV/AIDS. The incurable nature of the disease has also been implicated in the pervasive nature of HIV/AIDS-related stigma as PLWHA are more likely to suffer such stigma as they continue to live with the virus without a cure (Daftary et al., 2007).

Effects of HIV/AIDS-related Stigma and discrimination

In the light of the HIV/AIDS-related stigma, studies have found enormous effects of stigma on PLWHA in areas of health, education, employment, housing etc. which are major public health challenges that confront PLWHA (Ken, 2006). On the part of health, studies by Gilbert and Walker (2009) observed that some PLWHA are not able to access healthcare because of HIV/AIDS-related stigma. The Authors found that on account of HIV/AIDS-related stigma some families do not want to be identified with HIV/AIDS and as a result they do not allow family members who have been diagnosed with HIV/AIDS to seek healthcare at health facilities because of the fear of being tagged as an HIV/AIDS family. This often leads to imminent death for such victims because of their inability to access healthcare. Also, in some health facilities, health workers who were trained to provide special healthcare for PLWHA withdrew their services because of the external stigma they were challenged with (The Washington Times, 2008). This was because some of the health workers were labeled as HIV/AIDS victims and this resulted in their withdrawal of services. Evidence has also shown that some health facilities give priority treatment to patients not known to be HIV positive other than PLWHA because of the fear of contracting the disease when they come into contact with them (Minrie et al., 2008). For example, Minrie et al. (2008) found that an HIV/AIDS admitted patient was found crying because she had soiled herself with feces and was neglected by nurses.

Also, HIV/AIDS-related stigma is the single most influential barrier to VCT services for HIV/AIDS in Sub-Saharan Africa and this has resulted in low uptake of VCT services. The low uptake of VCT services for HIV/AIDS has left majority of individuals unaware of their HIV status and this poses a major problem for HIV/AIDS care, treatment and prevention (Mall et al., 2013; Meiberg et al., 2008). This often results in many people being diagnosed of HIV/AIDS for the first with complications of the disease making it difficult to treat. According to Heunis et al. (2011), HIV/AIDS-related stigma has coerced clients not to seek early treatment because of lack of confidentiality of VCT results. Heunis et al. (2011) revealed that some clients who tested positive for HIV were not given the opportunity to consent to who, how and when to disclose their HIV status to another person. This usually results in relatives or friends knowing the status of the HIV positive person and also marks the beginning of stigmatization from such friends/relatives. The lack of confidentiality of VCT results is in contrast to the World Health Organization call on all countries to ensure that VCT results are confidential (WHO, 2012).

The stigma associated with HIV/AIDS has also had untold effects in the area of education (Ann and Kitty, 2001; Ebersohn and Ferreira, 2011; Human Rights Watch, 2005). The Human Rights Watch (2005) observed that some children were denied access to education by their families on account of their HIV positive status. The families termed such children as 'evil' as they claim the disease brought shame and disgrace to the family. The families argued that it was better for such children to stay at home and die instead of publicly bringing shame and disgrace to the family by going to school (Human Rights Watch, 2005). Although some families allowed their children to go to school they dropped out as they were being called all sorts of names by their class mates because of their HIV positive status (Ann and Kitty, 2001; Human Rights Watch, 2005). Additionally, Ann and Kitty (2001) observed that some parents did not allow their children to attend schools that they were aware had enrolled students with HIV/AIDS. Similarly, some teachers were not willing to take up jobs or postings in schools that had HIV positive students (Li-Wei et al., 2010).

Furthermore, although some countries have chopped some success with educational campaigns against HIV/AIDS-related stigma through the media in the form of adverts, some parents did not allow their children to watch such adverts on television as they claim they were pornographic and tends to 'spoil' their children (Campbell et al., 2005).

The employment sector has also not been spared from the menace of HIV/AIDS-related stigma and discrimination. Some employers terminated the jobs of employees they found to be positive for HIV as well as refused to employ PLWHA (Holzemer et al., 2007). Holzemer et al. (2007) observed that employees with HIV/AIDS who did not have their jobs terminated suffered stigma from their co-workers in the form social isolation and ridicule. Collins et al. (2009) argue that the termination of jobs of some employees had resulted in food insecurity and also affected household livelihoods. The Authors noted that household heads who lost their jobs as a result of HIV/AIDS-related stigma found it very difficult to provide food and healthcare for their families as they no longer have any source of income.

The consequences of HIV/AIDS-related stigma do not only occur at individual level but has also been found to affect societal institutions such as the family, religion and marriage (Campbell et al., 2005; Campbell et al., 2011). A culture of denial exist among some families who had HIV positive individuals as such families hide victims from the public and denying them access to health due to HIV/AIDS associated stigma. Some community health workers were turned away by families who had HIV/AIDS victims because they did not want them to know they had PLWHA in their families (Campbell et al., 2005). Ken (2006) observed that some families because of HIV/AIDS-related stigma eject family members with HIV/AIDS and this compels victims to migrate to urban towns to struggle for survival and such victims who were women mostly end up as sex workers. Additionally, it was found that even some families reject their dead relatives who died from HIV/AIDS by refusing to accept their corpse at the healthcare facility in which the victim passed away (Campbell et al., 2005). Campbell et al. (2005) and Ken (2006) argue that behavioral change in attitude by families towards relatives living with HIV/AIDS is the most damaging part of HIV/AIDS-related stigma as such relatives need more support, love and care from their families at this crucial time instead of deserting them.

Although HIV/AIDS-related stigma has had negative consequences on the family, even marriage which is a basic foundation for the establishment of most families in Sub-Saharan Africa has also suffered from HIV/AIDS-related stigma (Campbell et al., 2007). Studies have shown that because of HIV/AIDS-related stigma persons who intend to get married are forced to do an HIV test before any marriage rites can be performed and those found positive were not allowed to marry when the other partner was negative (Campbell et al., 2007). This made it difficult for victims of HIV/AIDS to get married as some of them had to look for partners who were also positive for HIV/AIDS. This is inconsistent with the emphasis by the World Health Organization that HIV/AIDS counselling and testing services should be voluntary rather than a coercive one (WHO, 2012).

The role of Religion in Sub-Saharan Africa has been fundamental in tackling the HIV/AIDS pandemic (Krakauer and Newbery, 2007). Although studies by Krakauer and Newbery (2007) agree that churches have been influential in creating awareness on the HIV/AIDS pandemic, they have also been criticized for the moral

stigmatization of HIV/AIDS. The Authors argue that PLWHA are viewed by some churches as people who have refused to follow the teachings of the church. These churches regard PLWHA as individuals who have destroyed their bodies as a temple of God and are regarded as sinful (Campbell et al., 2011). The situation is even worse for PLWHA who have never been married as they are tagged as 'spoilt' individuals who may never get salvation from God as they have engaged in premarital sex (Campbell et al., 2011). The moral stigmatization of some churches have compelled some individuals to leave their own church and to worship in another church or stop their religion completely (Campbell et al., 2011).

Gender-related stigma has also been linked to PLWHA in Sub-Saharan Africa (Campbell et al., 2007; Okoror et al., 2007). Traditionally, women are expected to bear children, cook for the family and satisfy the sexual desires of their husbands (Okoror et al., 2007). Additionally, women are expected to maintain purity and stay faithful to their husbands and therefore those women who acquire HIV experience double stigma with a greater social disadvantage than their male counterparts (Campbell et al., 2007; Okoror et al., 2007). Okoror et al. (2007) and Iwelunmor et al. (2006) observed that women who disclose their HIV positive status to their partners are more likely to suffer accusation, physical violence or divorce from their partners as a result of HIV/AIDS-related stigma.

Also, some women living with HIV/AIDS are banned by their mothers from cooking meals for the family due to the stigma associated with HIV/AIDS (Okoror et al., 2007). Similarly, some people refuse to buy food from women caterers who are known to be HIV positive (Iwelunmor et al., 2006). Although HIV/AIDS-related stigma is higher among women than in men, Simbayi et al. (2007) and Strebel et al. (2006) found that men living with HIV/AIDS are more likely to suffer from internal stigma than women as they tend not to disclose their HIV status to their friends than women. The Authors argue that men tend not to disclose their status than women because of the fear of losing their jobs as they usually fall sick because of HIV/AIDS during work and owe it a responsibility to feed and shelter their families.

The Gay community or men who have sex with men in Sub-Saharan Africa are of no exception to HIV/AIDS-related stigma and discrimination. Men who have sex with men have lost their jobs and housing, refused employment or are unable to access treatment as a result of HIV/AIDS-related stigma (Tim et al., 2008; Bradley et al., 2012; Cloete et al., 2008). Studies have revealed that because men who have sex with other men have a higher prevalence of HIV/AIDS than the general population, most men who have sex with other men tend not to be given jobs or places to stay if they are found to be positive for HIV (Bradley et al., 2012; Cloete et al., 2008). Tim et al. (2008) also observed that most Gay men were harassed by healthcare workers as they sought treatment at health facilities as they were perceived as people who come to seek treatment for no other disease than HIV/AIDS. Some nurses at such health facilities made stigmatizing remarks such as we don't expect Gay men to suffer any medical condition apart from HIV/AIDS because they sleep around with men (Tim et al., 2008). Some healthcare workers showed disrespect to Gay men as they believed that the HIV/AIDS they acquired was a punishment from God as they argue that the anus was not created by God for sex (Tim et al., 2008). Persistent harassment by healthcare workers towards Gay men makes them afraid to seek healthcare and this explains why most Gay men often fall sick (Tim et al., 2008).

Efforts made to tackle HIV/AIDS-related Stigma and discrimination

Although HIV/AIDS-related stigma has had negative consequences in most communities in Sub-Saharan Africa, most governments, non-governmental organizations and churches have played a pivotal role in the fight against HIV/AIDS-related stigma and discrimination in Sub-Saharan Africa. The entrenchment of the rights of PLWHA in the constitution of some countries has helped to reduce the level of stigma associated with PLWHA (Yashmita, 2012). However, Yashmita (2012) argue that many PLWHA are not aware of their rights. Also, interventional measures such as education in schools, through the media as well as campaigns against HIV/AIDS-related stigma by various governments have chopped some successes in the fight against HIV/AIDS-related stigma (Hutchinson et al., 2007; Mantell et al., 2006). The introduction of antiretroviral drugs to PLWHA by most countries in Sub-Saharan Africa has played a major role in the reduction of HIV/AIDS-related stigma in the sub-region as it has reduced the number of PLWHA who fall ill (Gilbert and Walker, 2009). Also, it has been observed that some churches and non-governmental organizations have also been instrumental in the fight against HIV/AIDS-related stigma by providing care and support for PLWHA and also challenging stigmatizing ideas and practices among people (Campbell et al., 2011).

Conclusion

Although HIV/AIDS-related stigma and discrimination has declined all over the years in Sub-Saharan Africa, the stigma still remains high (Haber et al., 2011; Simbayi et al., 2007; Strebel et al., 2006; Ncama et al., 2008). It is therefore imperative for countries of Sub-Saharan Africa to put in much efforts to combat HIV/AIDS-related stigma in the sub-region (Scorgie et al., 2013; Forsyth et al., 2008). The way forward is to intensify education at national, regional and community levels that should be focussed at changing people's attitude towards PLWHA. People living with HIV/AIDS should not be seen as persons with a 'spoilt' identity. They should be allowed to enjoy equal access to healthcare, education, housing and employment like any other person. People living with

HIV/AIDS should be educated on their rights so as to be well informed and countries that have not entrenched the rights of PLWHA in their constitution should be encouraged to do so. Further research is recommended to holistically explore the consequences of HIV/AIDS-related stigma and discrimination. Further research should also be geared towards establishing measures to combat HIV/AIDS-related stigma and discrimination in Sub-Saharan Africa.

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