

Review Article

Stigma of People with HIV/AIDS in Sub-Saharan Africa: A Literature Review

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The aim of this literature review is to elucidate what is known about HIV/AIDS and stigma in Sub-Saharan Africa. Literature about HIV/AIDS and stigma in Sub-Saharan Africa was systematically searched in Pubmed, Medscape, and Psycinfo up to March 31, 2009. No starting date limit was specified. The material was analyzed using Gilmore and Somerville's (1994) four processes of stigmatizing responses: the definition of the problem HIV/AIDS, identification of people living with HIV/AIDS (PLWHA), linking HIV/AIDS to immorality and other negative characteristics, and finally behavioural consequences of stigma (distancing, isolation, discrimination in care). It was found that the cultural construction of HIV/AIDS, based on beliefs about contamination, sexuality, and religion, plays a crucial role and contributes to the strength of distancing reactions and discrimination in society. Stigma prevents the delivery of effective social and medical care (including taking antiretroviral therapy) and also enhances the number of HIV infections. More qualitative studies on HIV/AIDS stigma including stigma in health care institutions in Sub-Saharan Africa are recommended.

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1. Introduction

Although the current data show that the global HIV/AIDS epidemic is stabilizing, statistics still report an unacceptably high level of infection and progress is uneven in many countries [1]. In 2007, approximately 33 million people worldwide were infected with the human immunodeficiency virus (HIV) [1]. Sub-Saharan Africa remains the most affected region in the world and it is home to almost 67% of all people living with HIV (an estimated 22.5 million [1]). In 2007, an estimated 1.7 million adults and children in this region became newly infected, while 1.6 million died of acquired immune deficiency syndrome (AIDS).

People living with HIV/AIDS (PLWHA) face not only medical problems but also social problems associated with the disease. One of the barriers to reaching those who are at risk or infected with HIV/AIDS is stigma [2]. Stigma enhances secrecy and denial, which are also catalysts for HIV transmission [3]. Although the reaction to PLWHA varies, with some PLWHA receiving support which positively affects them, HIV/AIDS stigma negatively affects seeking HIV test-

ing, seeking care after diagnosis, quality of care given to HIV patients, and finally the negative perception and treatment of PLWHA by their communities and families, including partners [4, 5]. It isolates people from the community and affects the overall quality of life of HIV patients [2, 3, 6, 7].

Currently, there is an increasing number of research on HIV-related stigma in Sub-Saharan Africa. It is being increasingly acknowledged, however, that effective treatment and care strategies require an understanding of the cultural context [6, 8] in which stigma exists. The aim of this literature review is to elucidate what is known about HIV/AIDS stigma in Sub-Saharan Africa, the origins and contents of stigma, contributing factors and the gender dimension of stigma.

2. Methodology

The analyses in this review paper were based on Gilmore and Somerville's [9] classification of stigmatization in sexually-transmitted diseases, which for this paper was applied to the various factors that affect stigmatization of PLWHA.

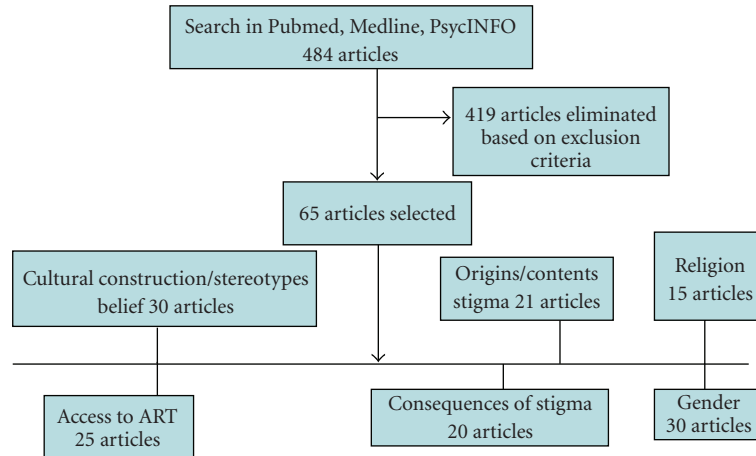


FIGURE 1

3. Materials

Literature about HIV/AIDS stigma in Sub-Saharan Africa was systematically searched in Pubmed, Medscape, and Psycinfo up to March 31, 2009. No starting date was specified.

A first search in Medline, PsycInfo and Pubmed with “HIV/AIDS”, “stigma” and “Africa” as key words gave 292 abstracts, of which 91 abstracts came from Medline, 57 from PsycInfo, and 144 from Pubmed; another search with “HIV/AIDS”, “discrimination” and “Africa” gave an additional 192 abstracts (Medline 73, PsycInfo 15, and Pubmed 104). A total of 484 abstracts were examined. From this list, papers relevant to the aim of this review were selected on the basis of their abstracts; uncertainties were reconciled through discussion with all the authors of this paper. The completeness of the search was checked by means of the reference lists of reviewed articles. Books or book chapters were included whenever applicable. Exclusion criteria included newspaper articles, campaign posters, articles not in the English language and articles not related to the topic. On the basis of this selection, 64 original articles were critically evaluated.

4. Outcome Selection

HIV stigma as a phenomenon was considered to be the major topic of the review and was not limited to any geographical region. Although HIV/AIDS stigma is a general phenomenon which affects PLWHA in all parts of the world, in this paper, we focused on an analysis of the factors contributing to stigma identified from empirical studies in Sub-Saharan Africa, books, theoretical, and review papers. They include cultural constructions, stereotypes and specific beliefs, access to and the role of antiretroviral therapy, religion, and gender.

5. Results and Discussion

Figure 1 shows the flow chart of the search results. A total of 64 articles were selected. Twenty of these articles were

theoretical papers, review papers and articles on stigma not limited to any geographical location while 45 articles were empirical studies from Sub-Saharan Africa. For the analysis of the contributing factors to HIV/AIDS stigma, 45 articles from empirical studies within Sub-Saharan Africa were used. In addition, books, theoretical papers and review papers were also used. Table 1 shows the method, study objective, study population and country of study of these papers; 21 articles addressed origin and contents of stigma, 30 articles addressed cultural constructions of HIV, stereotypes and specific beliefs, 25 articles addressed access to and the role of ART, 16 articles addressed religion, 30 articles addressed gender and 20 articles addressed consequences of stigma.

6. Origin and Content of Stigma

Etymologically, the concept of “stigma” derives from a Greek word referring to a tattoo mark. It generally has two meanings. One derived from Christianity and denotes bodily marks which resemble those of the crucifixion of Jesus Christ—they are attributed to divine favour. The second meaning is secular, namely marks of disgrace, discredit, or infamy [9]. Today, the term “stigma” is applied more to social disgrace than to any bodily signs [10]. Stigma is generally recognized as an “attribute that is deeply discrediting” that reduces the bearer “from a whole and usual person to a tainted, discounted one” [11]. Stigma is also used to set the affected persons or groups apart from the normalized social order (“us” against “them”) and this separation implies devaluation [2, 9, 12, 13]. HIV stigma is shaped not only by individual perceptions and interpretations of microlevel interactions but also by larger social and economic forces [6]. It is a social construct, which has significant impact on the life experiences of individuals both infected and affected by HIV [14]. Stigma includes prejudice and can lead to active discrimination directed toward persons either perceived to be or actually infected with HIV and the social groups and persons with whom they are associated [15]. Since not all stigmatizing attitudes result in overtly discriminatory

behaviors, Campbell et al. [6] described discrimination as negative behavior and stigmatization as any negative thoughts, feelings, or actions toward PLWHA irrespective of whether people are discriminated because they know that they are devalued. In other words, discrimination has to be acted out externally while stigmatization can be overt or constitute libel, slander, or defamation of persons who are stigmatized [9].

Stigma can be external or internal [3]. External stigma refers to the actual experience of discrimination [57]. Internal stigma (felt or imagined stigma) is the shame associated with HIV/AIDS and PLWHAs' fear of being discriminated against [2, 58]. Internal stigma is a powerful survival mechanism aimed at protecting oneself from external stigma and often results in thoughts or behavior such as the refusal or reluctance to disclose a positive HIV status, denial of HIV/AIDS and unwillingness to accept help [2, 7, 16, 17]. This collective public denial in societies is reflected by avoidance of mentioning any terminal illness including HIV/AIDS, a need to keep hope alive for therapeutic success, stigma attached to HIV/AIDS, and unwillingness to confront matters related to sexuality [17]. Many authors have theorized and produced models of stigmatization, but this paper will apply Gilmore and Somerville's [9] categorization of stigmatization in sexually transmitted diseases. They argued that any stigmatizing response has at least four processes [9].

- (1) *The problem.* The problem (in the context of this paper, HIV/AIDS) which Goffman [11] describes as the discredited attribute and Link and Phelan [59] describe in the component of conceptualizing stigma as distinguishing and labellizing, has to be such that the response in some way permits the stigmatizer to be spared, saved, or gives power to control the problem.
- (2) *Identification of the person or group who are targeted for stigmatization.* This means PLWHA must be recognizable and therefore have some identifying characteristics that can be used to recognise them correctly or erroneously, for example, loss of weight, skin rash, and so forth [2, 7, 8, 17–19, 60]. This process was also described by Link and Phelan [59] in the component of conceptualizing stigma as distinguishing and labellizing.
- (3) *Application of stigma to the target person.* Here specific persons are labelled with stigma. The stigma and the negative characteristics associated with it are perceived as belonging to them, for example, someone who is stigmatized is perceived as immoral [2, 6, 20]. This according to Link and Phelan [59] in the component of conceptualizing stigma relates to negative stereotyping.
- (4) *The outcome is usually a response to the stigmatized person such that they are distanced, disempowered or controlled by the stigmatizer.* In this process, there is a change in the relationship or interaction between stigmatizer and the stigmatized [6].

In this literature review these four processes of stigmatization will be illustrated in an analysis of the various factors that affect HIV/AIDS stigma.

7. Factors in HIV/AIDS Stigma

Everywhere HIV/AIDS has been accompanied by stigma and discrimination but stigma in Sub-Saharan Africa seems to be particularly common [2, 7, 55]. What happens to one person concerns the whole community [2, 3, 6, 7, 17, 21, 22, 61]. The communal life in itself poses a dilemma because, on the one hand, it can bring about stigmatization when PLWHA are not able to interact owing to fear of being exposed [2, 6, 13, 17, 21, 23, 48, 55], but, on the other hand, communal life also ensures help and care for sick people [2, 6, 7, 21, 22, 24]. It is important to understand how stigma is used by individuals and communities, in cultures where communal life is common, to produce and reproduce inequality [62]. Stigmatization is part of a conservative reassertion of power relations, poverty, or moral authority resting on the ability to control sexuality [6]. Because PLWHA are labelled as the "other" by the community, people try to secure the social structure, safety and solidarity by casting out offenders or reaffirming societal values [9]. PLWHA are assumed not to be able to contribute to the societal development [2]. For instance, some studies show that women will not disclose their HIV status to avoid being isolated from participating in the sociocultural aspect of food preparation since food is regarded as an expression of support and acceptance [21, 24], or people refuse to buy food from PLWHA [16]. Other studies show that family members of a person who died of HIV/AIDS or family members who live with PLWHA are stigmatized; therefore family members encourage PLWHA to remain silent to avoid social rejection [17, 22]. In some instances, receiving food assistance from the government also enhances a perception of difference from other members of the community since it is assumed that only PLWHA are offered such support in a community where almost everybody is poor and needs support [2, 57]. People from highly collectivist communities are more likely to be concerned with harmony and equality in the group [7]. We also need to further understand whether stigma is more or less likely to manifest itself in cultures with an extensive communal life and how stigma finds its origins in subcultural beliefs, religion, or individually conceived causal processes [6, 17, 63].

Factors that seem to mediate stigma include:

- (i) cultural constructions, stereotypes and specific beliefs,
- (ii) access to and the role of antiretroviral therapy,
- (iii) religion,
- (iv) gender.

8. Cultural Constructions of HIV, Stereotypes and Specific Beliefs

The association with specific sexual behavior that is considered socially unacceptable by many people contributes to the stigma associated with HIV infection [6, 17, 22, 25]. HIV/AIDS provides an example of how illness, despite the biological characteristics of its signs and symptoms, always carries a second reality expressed in cultural images and metaphors [8–10, 17, 19, 26, 61]. Campbell et al. argue that even when ART is available and the outcome of HIV/AIDS not always fatal, the link between HIV/AIDS and bad (sexual) behavior is still a concern for PLWHA because of shame and embarrassment [6]. The second and third processes (identification and linking to immorality) apply here. Fears associated with illness, disease and sex therefore need to be viewed in their broader social and cultural context [6, 64]. To illustrate the unacceptability associated with the disease, terms such as “a long illness” or “a short illness” are deemed culturally acceptable in the obituary of someone who dies from HIV/AIDS rather than mention of the real cause of death [2, 17, 20, 27, 61]. There is also reluctance to mention the name “AIDS” while the illness is ongoing [6, 19, 26]. This process can be a way of denying HIV/AIDS or simple avoidance of explicitness or specificity as a way of coping with the serious threat of HIV/AIDS [2, 6, 13, 17, 19, 23]. Since society acts strongly against threats to tangible assets such as life, safety, property or values, it tries to sanctify the problem to protect its self-identity or reduce the negative effect [9]. The fourth process (distancing, disempowerment or control) apply here. The practice of indirection has also been noted in areas outside HIV/AIDS, such as the use of coded language in relation to certain subjects in the presence of children [6, 17]. Furthermore, mentioning HIV/AIDS can be viewed as disrespectful to the deceased [6, 61]. In some cases, acknowledging the death of a relative as due to AIDS could put the family at risk of losing the financial benefits from insurance companies since some insurance companies may not pay out benefits resulting from death due to AIDS [61]. Yet not acknowledging the cause of death to insurance companies can be viewed as a moral hazard thereby complicating the rights of dead persons who are seen as vulnerable [61]. Furthermore, in a qualitative study in Zimbabwe, denial and miss-attributions of HIV/AIDS causes (e.g., witches, unhappy ancestors, etc.) were common [27]. Less than exact terms are also used by people, including health care professionals [27], to describe HIV/AIDS to avoid insensitivity to culturally sensitive issues but not necessarily denying HIV/AIDS: for example, health care professionals in Malawi calling it ELISA disease, immunosuppression, and so forth, or lay people calling it Kaliwondewonde (slim disease), Ntengano (the disease that leads to wife and husband dying together or one after the other) [61] or other indirect descriptions [6, 17, 27]. Denial is also a way of reinforcing that HIV/AIDS is a disease of others not of the self [28] and one of the ways people as individual, group or society respond to a frightening or intolerable situation [9]. This fits with the first and second processes.

HIV/AIDS is stigmatizing because it carries many symbolic associations with danger. Attribution of contagion, incurability, immorality and punishment for sinful acts is common in many societies [6, 9, 10, 16, 19, 22, 25]. In terms of the third process, any person diagnosed with HIV is perceived to be immoral. Quam [65] argues that beliefs about AIDS as a “polluted disease” reflect people’s negative evaluations of the routes through which HIV enters the body. Sexually-transmitted infections are considered to be agents of contamination or pollution in a study about HIV/AIDS prevention among African traditional healers [29]. This polluting quality of AIDS and fear of the disease are translated into stigmatizing responses such as avoidance and isolation which is where the fourth process applies (distancing).

Self-diagnosis and self-treatment remain widespread [26, 30] owing to stigmatization. The pursuit of different therapeutic options is sometimes a result of the problematic social complexity linked to AIDS [17]. Witches and witchcraft remain an option for self-diagnosis of illnesses [23, 26] as well as for diagnosis by traditional healers [6]. This fits with the first and second processes. Commonly, people say that HIV/AIDS hides behind witchcraft since it is more culturally acceptable and it avoids personal shame [27]. People prefer to claim that they are bewitched or have (normal) tuberculosis rather than accept that they have HIV/AIDS [6, 17, 31, 32].

Stigmatization is a stereotyping response to negatively perceived characteristics of a person or group [16]. The stereotyped individuals, the context of this paper, are PLWHA; they often look, act or live differently and do not fit into the societal norms [9]. As regards to the second process, identification of PLWHA, and the third process, linking HIV/AIDS to immoral behavior, the different languages used to describe PLWHA send clear messages [3, 19]. Examples are as follows: he is a walking corpse [3] or *Kakokoolo* (scarecrow), or *Kamuyoola* (was caught in a trap) in Uganda [31] and *ashawo* (prostitute) in Nigeria. An individual’s past social history may also be recalled to justify why they have AIDS [31]. PLWHA are seen as a reflection of evil and sin, leading to powerful stigma against those who have contracted the disease. In a study carried out in Tanzania, a distinction between “true” AIDS and “false” AIDS emerged, of which the former is more stigmatized and regarded as more hopeless than the latter, which is attributed to malice such as witchcraft [30]. Fear of stigma limits the efficacy of HIV-testing programs across Sub-Saharan Africa [33–35] because in most communities everyone knows sooner or later who visits test centers [31, 36]. The process of identification applies here. For some individuals, not knowing one’s HIV sero-status is far preferable for being tested. For example, a study carried out in Botswana on attitudes, practices and human right concerns of routine VCT showed that 33% of the respondents did not go for voluntary counseling and testing (VCT) because a positive HIV test result will force them to stop some of their sexual practices [56]. The belief is that it is better to suffer the disease quietly and hidden than to find out through HIV testing, because of the stigma

associated with receiving a positive test result, in addition to the feeling that “what you don’t know can’t harm you” [48].

9. Access to and the Role of Antiretroviral Therapy

Although access to antiretroviral therapy (ART) has increased more than tenfold in low- and middle-income countries including Sub-Saharan Africa in the last six years [66], reaching the potential beneficiaries has been difficult, as the PLWHA do not identify themselves to the medical professionals [37, 56]. Individuals who were not tested for HIV demonstrated significantly greater AIDS-related stigmas ascribing greater shame, guilt and social disapproval to PLWHA [38, 56]. Studies have shown that many Sub-Saharan Africans are reluctant to disclose their HIV status even when they have already gone for VCT; moreover, those who do disclose it are selective in choosing their audience [2, 6, 7, 13, 21, 39–41, 57]. In a study carried out in the Niger Delta, Nigeria, 23% of the PLWHA respondents had not disclosed their status, while of the 77% who had disclosed their status, 22.3% disclosed it to parents, 9.7% to siblings, 27.8% to pastors, 6.3% to friends, 10.4% to family members and 23.6% to sexual partners [42]. The first and second processes (HIV/AIDS as a problem and identification) apply here. Fears of stigmatization, of victimization, of confidants spreading the word, of accusation, of infidelity, and of abandonment were all noted to be barriers to disclosure. Similar findings resulted from a study carried out in Cape Town, South Africa which showed that nearly one in four participants never talked with a friend about their HIV status [16]. Yet a different study showed that respondents who personally knew someone infected with HIV or AIDS tended to report less stereotypical and less discriminatory attitudes, fewer feelings of discomfort and less intolerant attitudes [4]. Attempts to discuss HIV make many people withdraw or feel that the discussion should be discontinued. Some of them come up with questions about the very existence of HIV [6, 56]. Evidence also shows that noninfected people intentionally distance themselves from PLWHA [67].

A study carried out in Ghana showed that even though PLWHA regain their strength with ART and the physically devastating effect of HIV/AIDS is tempered, they still face psychological isolation and condemnation from their family, friends and society [43] because people around them are aware of their HIV status. This is linked to the first, second and fourth processes. Another problem PLWHA face is that combinations of health-seeking strategies make it difficult to know the effectiveness of ART [44]. Many stop taking ART when the symptoms are gone and resort to traditional medications. In a study in Tanzania, many people consult both traditional and medical facilities when faced with AIDS [30]. Traditional healers are accessible, affordable and culturally acceptable [44]. They are at the grass-roots level with sufferers and can provide psychosocial support [44].

ART has also been shown to be less effective when initiated in someone with advanced disease [68] so delay in care seeking should be avoided. Apart from the medical benefits, there are also psychosocial benefits associated with seeking treatment. PLWHA who opt for an ART program can take comfort from participating because they get counselling from professionals trained to handle the psychosocial problems [41, 45]. Ironically, widespread use of ART may decrease transmission concerns [2] and increase risky behaviors [69, 70]. Patients and their partners may believe that because their viral load is undetectable and they feel so much better, the virus is absent or dead and they are incapable of transmitting HIV to others [30, 69]. Their motivation to continue condom use or other risk reduction behaviors wanes [70].

10. Religion

In Sub-Saharan African, many people are religious [7, 17, 22, 28]. Religious institutions have been documented as playing both supportive and detrimental roles toward PLWHA [6, 7, 21, 23, 46]. Religious leaders have the possibility as any other leaders in position to be tempted to exercise power over others [3, 6]. One of the strategies used by some churches to regain their lost moral authority is vigorously linking sexual transgressions and AIDS with sin and immorality [46, 47]. The third process (linking to immorality) applies here. AIDS has been targeted by some religious groups in order to enhance their own beliefs, morality and ideology [9, 28]. This is because sexual activity is both biological and socially-constructed behavior which reflects and can challenge strong public and private religious, cultural and political values [25, 46, 71]. The religious approach warrants stigmatizing people as “saved” or “sinner”, “pure” or “impure”, “us” or “them”, and it strengthens the broader social stratifications within which stigma flourishes [3, 7, 9, 23, 25]. The fourth process applies here, where PLWHA are distanced, disempowered or controlled. In Zambia, churches sometimes impose mandatory HIV testing before allowing marriage and individuals with HIV have been excommunicated from churches because they were deemed “sinners” [6, 61]. It is also hard to find people openly critical of the religious authorities. At the same time, many people living with HIV/AIDS express faith and religion as important in coping with HIV. Religion gives people the opportunity to accept that they are wrong but through prayer subsequently to have hope that they are forgiven and will go to a better place after death [47]; this comfort is in addition to the care and support they get, which have increased [2, 7, 21, 23, 25, 49]. Such spiritual locus-of-control beliefs are important [2]. Consultative dialog between PLWHA and religious leaders is pivotal to a successful faith-based HIV intervention [25].

11. Gender Issues in HIV in Africa

Stigmatization has been linked with power [6, 9, 62]. In Sub-Saharan Africa, women are traditionally expected to bear

TABLE 1: Characteristics of the empirical studies used.

| Number | Author | Location number on reference list | Year of publication | Methods | Study objectives | Study population | Country |
|--------|-------------------|-----------------------------------|---------------------|--|---|------------------|---|
| 1 | Greeff et al. | [2] | 2008 | Qualitative research design focus group discussion | To increase understanding of disclosure as a circumstance that is affected by HIV/AIDS stigma and discrimination | 225 | Five African countries (Tanzania, Lesotho, South Africa, Swaziland, and Malawi) |
| 2 | Campbell et al. | [6] | 2007 | Qualitative research In-depth interview including focused group discussion | Study on complex interplay of psychological and social forces that drive HIV/AIDS stigma | 120 | South Africa |
| 3 | Neville and Rubin | [7] | 2007 | Semistructured focused group discussion | Identity of typical targets of disclosure of positive sero-status, commonly used avenues for disclosure, motivations for disclosure and nondisclosure of sero-status | 40 | Kenya |
| 4 | Strebel et al. | [13] | 2006 | Interview and focus group discussion | Construction of gender identities and roles, how women and men understand gender-based violence and what they believe about links between gender relations and HIV/AIDS risk | 78 | South Africa |
| 5 | Simbayi et al. | [16] | 2007 | Quantitative study | Examination of internalized AIDS stigmas among PLWHA | 1063 | South Africa |
| 6 | Wood and Lambert | [17] | 2008 | Participant observation, semistructured interview, focused group discussions | Description of family and community responses to HIV/AIDS epidemic: use of indirect communication | 152 | South Africa |
| 7 | Muula | [18] | 2005 | Theoretical review | What should HIV/AIDS be called in Malawi? | | Malawi |
| 8 | Uys et al. | [19] | 2005 | Focus group discussion | Identification of terminology used to talk about HIV/AIDS and PLWHA | 261 | Five African countries (Lesotho, South Africa, Malawi, Swaziland, and Tanzania) |
| 9 | Visser et al. | [20] | 2009 | Questionnaire | Assessment of stigmatizing attitudes among members of a community compared with perceived stigma within the community and the extent to which stigmatizing attitudes are affected by sociodemographic characteristics | 1077 | South Africa |
| 10 | Iwelunmor | [21] | 2006 | Focus group discussion | Family system responses to HIV and AIDS | 204 | South Africa |

TABLE 1: Continued.

| Number | Author | Location number on reference list | Year of publication | Methods | Study objectives | Study population | Country |
|--------|----------------------|-----------------------------------|---------------------|--|--|-------------------------|--------------|
| 11 | Ulasi et al. | [22] | 2009 | Questionnaire | Predictors of stigma and the perception of communities toward PLWHA | 104 | Ghana |
| 12 | Hartwig et al. | [23] | 2006 | Focused group discussion | A case study providing insights into how some local church leaders view HIV stigma, and changes some of them have made in their own church leadership behavior | 15 | Tanzania |
| 13 | Okoror et al. | [24] | 2007 | Focused group discussion | Role of food as an instrument in expressing and experiencing stigma used by HIV-positive women and their families | 249 | South Africa |
| 14 | Otolok-Tanga et al. | [25] | 2007 | Semistructured interview | Exploration of Uganda-based key decision-makers about the past, present and optimal future roles of faith-based organizations involved in HIV/AIDS work, including actions to promote or dissuade stigma and discrimination | 150 | Uganda |
| 15 | Chimwaza and Watkins | [26] | 2004 | Quantitative and interview | Focus on the caregivers' diagnoses of the illness of their patients, the type and duration of the care they provided, the support they received from relatives and other members of the community, and the extent to which caregiving was experienced as an emotional, physical and financial burden | 15 | Malawi |
| 16 | Duffy | [27] | 2005 | Focused group discussion, interview | Perspective on HIV-related stigma | 28 | Zimbabwe |
| 17 | Petros et al. | [28] | 2006 | Focus group discussion, interview | Exploring the concept and practice of "othering" in relation to HIV and AIDS today | 418 | South Africa |
| 18 | Kalichman et al. | [29] | 2005 | Questionnaire | Development of a brief measure of AIDS-related stigma that could be readily used in multiple settings and contexts | 1371 | South Africa |
| 19 | Plummer et al. | [30] | 2006 | Qualitative research (participant observation) | Examination of beliefs about general illness, STI and AIDS treatment practices | Participant observation | Tanzania |

TABLE 1: Continued.

| Number | Author | Location number on reference list | Year of publication | Methods | Study objectives | Study population | Country |
|--------|--------------------------|-----------------------------------|---------------------|---|---|------------------|--------------|
| 20 | Muyinda et al. | [31] | 1997 | Qualitative research (in-depth interview) | Knowledge, attitudes and practices of families caring for PLWHA in relation to stigma-related conditions | 127 | Uganda |
| 21 | Hatchett et al. | [32] | 2004 | Qualitative research (interview) | Exploration of traditional and modern health-seeking in Malawi | 46 | Malawi |
| 22 | Thorsen et al. | [33] | 2008 | Qualitative research (interview, nonparticipant observation) | Potential facilitation of stigmatization through inadvertent disclosure of HIV + status via PMTCT program components and attributes | 42 | Malawi |
| 23 | Daniel and Oladapo | [34] | 2006 | Quantitative study (questionnaire) | Assessment of acceptability of prenatal HIV screening among pregnant women attending primary healthcare centres in a suburban population | 333 | Nigeria |
| 24 | Hutchinson and Mahlalela | [35] | 2006 | Quantitative (survey data using questionnaire) | Examination of patterns and determinants of use of VCT services | 3374 | South Africa |
| 25 | Nyblade et al. | [36] | 2001 | Quantitative (questionnaire), laboratory and counselling data | Assessment of self-selection in those who chose to participate in VCT and those who chose not to participate in the start-up phase of a long-term VCT program | 10 950 | Uganda |
| 26 | Maedot et al. | [37] | 2007 | Case control study | Identification of factors that determine VCT uptake among pregnant women attending ANC services | 402 | Ethiopia |
| 27 | Kalichman and Simbayi | [38] | 2003 | Quantitative research (venue intercept study) | Examination of the relationship between HIV testing, history, attitudes toward testing and AIDS stigma | 500 | South Africa |
| 28 | Nachega et al. | [39] | 2005 | Quantitative research (questionnaire) | Investigation of knowledge, attitudes, beliefs and practices of PLWHA regarding HIV/AIDS and ART in an HIV outpatient clinic | 105 | South Africa |
| 29 | Turan et al. | [40] | 2008 | Qualitative research (in-depth interview) | How HIV-related fears may affect where women deliver and the difficulties maternity workers face caring for HIV-positive women with unknown HIV status | 37 | Kenya |
| 30 | Orner et al. | [41] | 2008 | Qualitative research (focused group discussion, in-depth interview) | Exploration of perceptions and experiences of PLWHA of reproductive age in relation to HIV/AIDS care and treatment | 8 | South Africa |

TABLE 1: Continued.

| Number | Author | Location number on reference list | Year of publication | Methods | Study objectives | Study population | Country |
|--------|--------------------------|-----------------------------------|---------------------|---|---|-----------------------------|--------------|
| 31 | Akani and Erhabor | [42] | 2006 | Quantitative research (questionnaire) | Evaluation of rate, patterns, barriers to HIV sero-status disclosure | 187 | Nigeria |
| 32 | Blackstock | [43] | 2005 | Narrative case study | Curing stigma—the limits of antiretroviral access | 1 | Ghana |
| 33 | Kayombo et al. | [44] | 2005 | Qualitative research (interview) | Role of traditional healers in supporting orphans, how they get the orphans, the basic needs they can provide, techniques used for psychosocial support and problems encountered when taking the orphans | 25 | Tanzania |
| 34 | Mshana et al. | [45] | 2006 | Qualitative research (focused group discussion, interview) | Identify and mitigate barriers to seek ART between the stages of testing for HIV and enrolling in the new government ART program | 18 | Tanzania |
| 35 | Campbell et al. | [46] | 2005 | Qualitative research (focused group discussion, interview) | Identification of forms taken by stigma and its effects; identification of material, symbolic and contexts associated with stigmatisation of PLWHA | 99 | South Africa |
| 36 | Thomas | [47] | 2006 | Qualitative research (interview, diaries) | Exploration of how illness, the daily and long-term duties of caring amongst a sample of households in the Caprivi region | 12 | Namibia |
| 37 | Skinner and Mfecane | [48] | 2004 | Qualitative research (focused group discussion, interviews) | | | South Africa |
| 38 | Amuyunzu-Nyamongo et al. | [49] | 2007 | Quantitative (survey) and qualitative (in-depth interview) | Examination of complex relationship between gender, poverty, susceptibility to HIV and vulnerability to AIDS through drawing on the lived experiences of infected women and exploring the coping strategies they adopt; how the specific conditions of informal settlements influence these challenges and support mechanisms | 390 (survey) 20 (interview) | Kenya |
| 39 | Mill | [50] | 2003 | Qualitative research (in-depth interview, focused group discussion) | Findings related to breaking the news of HIV infection to women and their maintenance of secrecy following diagnosis | 56 | Ghana |
| 40 | Antelman et al. | [51] | 2001 | Quantitative research | Examination of sociodemographic and behavioral factors predictive of an HIV-positive test result | 1078 | Tanzania |

TABLE 1: Continued.

| Number | Author | Location number on reference list | Year of publication | Methods | Study objectives | Study population | Country |
|--------|----------------------|-----------------------------------|---------------------|--|---|------------------|--------------|
| 41 | Maman et al. | [52] | 2001 | Qualitative research (interview) | Presentation of individual, relational and environmental factors that influence the decision to test for HIV-1 and to share test results with partners | 62 | Tanzania |
| 42 | Ndinya-Achola et al. | [53] | 1995 | Quantitative research | The right not to know HIV test result after being tested | 5274 | Kenya |
| 43 | Sanjobo et al. | [54] | 2008 | Qualitative research (interview, focus group discussion) | Exploration of patients' and health care professionals' perceived barriers to and facilitation of patients' adherence to ART | 72 | Zambia |
| 44 | Ncama et al. | [55] | 2008 | Quantitative research | Examination of characteristics related to social support and antiretroviral medication adherence | 149 | South Africa |
| 45 | Weiser et al. | [56] | 2006 | Quantitative research | Assessment of knowledge of and attitudes toward routine testing in Botswana with a focus on human rights concerns related to policy; factors associated with whether respondents had heard of routine testing and had positive attitudes toward the policy; the prevalence and correlations of HIV testing, barriers to and facilitation of testing and reported experiences of testing 11 months after introduction of routine testing | 1268 | Botswana |

children, cook for the family [24, 28] and submit to the sexual desires of their husbands [6, 13]. Gender inequality is one of the main influential factors in women's inability to protect themselves [6, 27, 49]. Many cultures consider ignorance of sexual matters as a sign of purity, making women reluctant to seek reproductive health information and services [6, 46, 72]. Several means of transmission of HIV have been recognized, but in Africa transmission by heterosexual contact is mostly understood to be the cause [6, 7, 13, 22, 33, 60]. People believe that infection must result from indecent sexual behavior [2, 6, 17, 19, 20, 28]. The third process applies here.

Society is more intolerant of females living with HIV/AIDS than of their male counterparts [13, 16, 27, 35]. A study carried out in Kenya shows that 56% of women are commonly viewed to be targets of stigma compared

with 12% of men [49]. Much of the social control over women's movements, voice and opportunities is based on the belief that they will become promiscuous if granted too much freedom and this could lead to contamination of the patriarchal lineage [27]. PLWHA have become scapegoats generally [9], but females experience an added intensity of this phenomenon, a double stigma with a bigger social disadvantage [6, 13, 27]. Women are frequently blamed as vectors of HIV transmission, although contrary to the factual process [3, 28, 31]. Most societies in Africa expect their women to be monogamous but expect men to have extramarital affairs [13, 23, 72] or to be polygamous [6, 13]. Yet a woman's monogamy does not protect her from the infection if her spouse has other sexual partners [72]. This gender aspect is even stronger in Sub-Saharan Africa because most women are dependent on their husbands for food,

shelter and clothing [13, 57]. In terms of all four processes, many women refrain from testing and (if positive) would rather conceal their status. A study carried out in Ghana showed that secrecy affected women's access to treatment, and financial and emotional support from families [50]. The main reasons for not disclosing HIV status were fear of stigma and divorce [49, 51], fear of losing confidentiality [51], women's low decision-making power, communication patterns between partners and male partners' attitude to voluntary counselling and testing (VCT) [52]. In line with the female's sex role she may not insist on condom use when a partner refuses which is important for prevention and spread of HIV infection [51, 72]. Studies have shown that women who share HIV test results with their partners may experience a range of reactions from support and understanding to accusations, discrimination, physical violence and abandonment [2, 7, 21, 24, 49, 52, 53] This relates to the fourth process which is distancing, disempowerment or control. Therefore, a woman exhibiting the independence needed to protect her health risks the condemnation from her family and of the community [3]. Although the majority of the studies show female stigmatization, a study carried out in South Africa [16] showed that men were more likely than women never to have discussed AIDS with friends, more likely to have been treated differently since testing, more likely to report experiencing internalized stigma, and more likely to have suffered loss of a place to stay or job owing to AIDS. Part of the explanation for this could be the fact that men are more likely to have been working before the sickness and are primarily responsible for providing shelter [13, 16].

12. Consequences of HIV/AIDS Stigma and Discrimination

Stigmatization can have many consequences for PLWHA and people affected by HIV/AIDS [6, 22, 47]. Some of the consequences of HIV/AIDS stigma include lower uptake of maternity health services by women, fear of health workers getting infected and less provision of health care workers' services because they take into account the HIV status of patients [37, 40, 45]. There is also a serious implication for prevention because people do not want to go for VCT [2, 27, 56] and even those people who go for testing do not disclose their HIV status to their sexual partners owing to HIV/AIDS stigma [53] and are more likely to engage in sexually-transmitted risk behaviors and this has implications for the spread of HIV/AIDS [9, 27]. Conversely, when PLWHA are shown compassion, they are likely to take protective precautions in sexual behavior [6] and be more open about their HIV status [2]. Some spouses end up knowing of their positive HIV long after their partners are dead because they were not informed [7]. Stigma also has ongoing effects on the adherence to ART by PLWHA thus affecting their quality of life and increasing complications [2, 6, 39, 54–56]. It also leads to collective public denial of HIV/AIDS, which does not help to reduce the HIV/AIDS infection and does not help in fighting stigma [6, 17, 46]. It worsens the stress PLWHA

live with, as they are forced to be silent about their status, which on its own is burdensome [2, 21, 41, 43] especially for people who need to keep their source of livelihood by keeping their jobs [2]. It affects access to social support networks either within PLWHA that will help their psychology, sharing of experiences [2, 6, 55] or from government that can offer them food supplements to improve their health or from their family as well as from their communities [21, 43, 46]. It hampers HIV-prevention and promotional efforts as people may not be willing to attend the educational programs aimed at reducing the spread of HIV/AIDS.

13. Conclusion

Although current literature shows that stigma in some countries, for instance, the Republic of South Africa, has started to decline over the years [13, 16], especially when it involves a close relative [33], it nevertheless is highly present [20, 22, 27, 31, 43, 55, 61]. This review was based on a systematic compilation and evaluation of literature on HIV/AIDS stigma in Sub-Saharan Africa. Detailed evaluation became possible owing to selected literature of sufficient quality and the number of publications available in Pubmed, Medscape and Psycinfo. At the same time, this implies a clear restriction. Papers on HIV/AIDS not related to stigma were not considered.

Despite the current progress of good prognostic health outcomes for HIV/AIDS, the Sub-Saharan African response still stands at a crossroads. In this paper, we contend that cultural constructions of HIV/AIDS, based on beliefs about contamination, sexuality and religion, play a crucial role and contribute to the strength of distancing reactions and discrimination in Sub-Saharan Africa by enhancing inequality. The public denial of HIV/AIDS is real and stems from a cultural undertone with a view which allows the pursuit of different treatment options, although denial on its own can be relative because it can be a way of coping with the disease while still acknowledging its existence. Denial can also be further enhanced when the PLWHA do not show some of the manifestations generally associated with HIV/AIDS by the community such as weight loss especially those on ART as people do not believe that they have HIV/AIDS even when they disclose their HIV status [2].

PLWHA experience stigma throughout their lifetime. Issues of stigma, discrimination and denial are still poorly understood and often marginalized within national and international programs and responses [27, 62]. Stigma prevents the delivery of effective social and medical care, enhances the number of HIV-infections and diminishes the public health effects of ART because PLWHA are not able to interact with their families and the communities which is supposed to make them feel complete and be a part of the society.

The identification of HIV patients poses a problem, because people try to hide the disease but perceivers assume that people have HIV if they are sicker than normal. Linking HIV/AIDS to immorality is common because of religious practices and a culture of serenity. This could be remedied by instituting programs that allow people to discuss sexuality

based on their cultural norms and beliefs during which some of the myths surrounding HIV/AIDS can be corrected. Putting people in touch with individual and collective strength is a key strategy to mobilizing them in such complex issues such as stigma [2, 6, 43, 46]. More qualitative studies are needed in Sub-Saharan Africa on HIV/AIDS for better understanding of stigma given that stigma regarding HIV/AIDS is rooted in local beliefs, religion and gender.

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