



REVIEW ARTICLE

Stigma Related to Fear and Shame Restricts Access to HIV Testing and Treatment in Tanzania

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Abstract

Background: Tanzania is one of 15 nations that share 75% of the HIV burden in sub-Saharan Africa, with a national prevalence of 5.3% and prevalence rates as high as 30% in special populations. Knowledge about HIV infection, testing, and treatment is low, especially in younger populations, suggesting a need for effective HIV educational programs. We sought to understand the impact of HIV-related stigma and gender roles in HIV education and knowledge in educational programs and explored methodologies that effectively incorporate culturally competent approaches to reduce stigma in HIV education programs.

Methods: Literature searches were conducted in multiple databases including the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Academic Search Complete, and the U.S. National Library of Medicine through the National Institutes of Health (Medline/PubMed). The search terms were structured to include all text of each article rather than restricting the search to titles or keywords. While these search criteria resulted in identification of 45 peer-reviewed articles, the inclusion criteria (HIV prevention, community education, HIV knowledge and stigma) led to the exclusion of all except 20 articles. Their findings are described here.

Results: Attitudes of blame, fear of people on antiretroviral therapy spreading the disease, and an acceptance of a positive HIV status as punishment for sin were identified as barriers to testing. Cultural norms/perceptions and gender power dynamics were key components in creating culturally competent models that empower women to be tested and

disclose their status. Community-level awareness and increased opportunities to interact with people living with HIV/AIDS were used successfully to reduce stigma among younger populations.

Conclusions: Community-based programs partnered with religious organizations were effective in disseminating HIV education and can be used as a strategy for reducing shame-based stigma based upon misconceptions and popular beliefs. Stigma can also be reduced by increasing HIV knowledge with an appropriate sociocultural framework. We propose targeting community and religious leaders using train-the-trainer models as a means to improve HIV education and reduce stigma, especially within high-risk populations.

Keywords

Cultural competence, Fear, Health care access, HIV education, Shame, Stigma, Sub-Saharan Africa, Tanzania

Introduction

Within sub-Saharan Africa, Tanzania, Zambia, and the Democratic Republic of Congo (DRC) are close neighbors geographically, yet they report widely different rates of HIV, with a much lower rate reported for DRC than for Zambia and Tanzania. We sought to evaluate what factors might contribute to the apparent discrepancy observed in testing and care in these three countries by investigating the literature that specifically pertained

to them. There was sufficient contrast in the findings between each of the countries that we separated the findings by country in three related review articles. Only publications that pertain directly to Tanzania rather than other regions of Africa were evaluated in the present review. Separate review articles specific to the literature concerning HIV rates in Zambia and the DRC were submitted simultaneously with this one.

Although the national prevalence rate of HIV in Tanzania is 5.3%, some districts within the country such as Njombe demonstrate prevalence rates as high as 14.8%. Special populations at high risk for contracting HIV such as injection drug users have rates as high as 30% [1]. Reports in the literature suggest that comprehensive knowledge about HIV infection, testing and treatment is low in Tanzania, especially in younger populations. These reports highlight the need for effective HIV educational programs, particularly ones that incorporate cultural sensitivity, remove gender bias, and reduce stigma [1].

This review synthesizes existing studies pertaining

to the impact of HIV-related stigma on prevention programs that focus on HIV education and knowledge in Tanzania. This foundation will provide an understanding of the current gaps regarding the impact of stigma and gender roles in HIV education programs. In addition, effective methodologies incorporated into culturally competent approaches that assist HIV programs in reducing stigma will be highlighted.

Methods

The literature review was completed between February and April of 2017 using comprehensive searches conducted in multiple databases including the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Academic Search Complete and the U.S. National Library of Medicine through the National Institutes of Health (Medline/PubMed). Because of the limited quantity of published manuscripts regarding HIV education programs in this region of Africa, no date limitations were set for the search period. The terms of interest, specific key words and combinations used in each of the databases are summarized in (Table 1).

Table 1: Keyword search conducted in identified search engines.

Terms required	Tanzania	Human Immunodeficiency Virus	Education, knowledge, stigma, prevention
Keywords and combinations	"Tanzania" AND	"HIV" AND	"Education" OR "Knowledge" OR "Stigma" OR "Prevention"
Location	Text	Text	Text

Table 2: Key points of the search results in Tanzania.

HIV/AIDS-Related Stigma	
Aggarwal, et al. [10]	Gaps in HIV knowledge. Participants interacting with PLWA were less likely to stigmatize others.
Agnarson, et al. [11]	Need to focus on stigma reduction with awareness and understand risky behaviors for individuals and on a community level.
Amuri, et al. [2]	1,130 men and 1,803 women interviewed. 58% "HIV/AIDS is punishment for sinning". People from the poorest households (without enough food in the last week) were more likely to believe HIV/AIDS is punishment for sinning.
Lyimo, et al. [8]	158 HIV-infected patients. Perceived stigma is primarily related to involuntary disclosure, whereas self-stigma is related to voluntary disclosure.
Maswanya, et al. [6]	20 qualitative interviews, college students. Fear of HIV/AIDS related stigma increasing stigma and isolation against them. Results further demonstrate that HIV/AIDS related stigma is still a very serious problem in Tanzania. Lack of HIV/AIDS related knowledge was one of the most important determinants of AIDS-related stigma.
Mhode M, et al. [7]	Participants had many forms of HIV-related stigma such as verbal, social, and perceived stigma, along with discrimination. Mistreatment by health care workers, blame and rejection by spouses, and workplace discrimination. Hiding HIV status as a result.
Roura, et al. [5]	Qualitative interviews and community activities: 91 community leaders, 77 ART clients and 16 health providers. Blaming attitudes present with stigma. Fear of ART users regaining health, increasing in sexual relations and "spread the disease". Fears provoked some leaders to suggest giving ART recipients drugs "for impotence", marking them "with a sign" and putting them "in isolation camps".
Roura, et al. [4]	As long as there are moral associations there will be stigma with HIV. Create an enabling environment for HIV status disclosure, treatment continuation, and safer sexual behaviors. Local leaders should be educated and empowered to address the blame-dimension of HIV stigma.
Cultural & Gender Roles	
Cawley, et al. [23]	Imbalanced gender-power dynamics. Understand the extent to which women felt able to control their HIV-related risk. "HIV prevention counselling based on a Western model of individual-level agency seems unlikely to make a significant contribution to sexual behavior change until there is greater recognition by counsellors of the ways in which power dynamics within many relationships influence behavior change". Culturally appropriate counseling strategies and messages.

Fehringer, et al. [25]	CP (concurrent sexual partnerships). Parents have encouraged CPs through silence when their daughters come home with money. "These results suggest that parents can influence their children's decision to engage in CPs". HIV interventions should address this by family communication, disease risks, and gender imbalances.
Kaufman, et al. [26]	Culture healing tea: Kikombe cha babu. 44.0% of people believe such treatments can cure HIV. Belief with decreased condom use (15.6%), no need to use condoms (94.9%), and no need to take antiretroviral therapy (81.7%).
Nyamhanga, et al. [24]	Qualitative case study focusses groups. Women with economic burden experienced more sexual violence. Married women experience a sexual risk of acquiring HIV from gender imbalance and cultural norms of masculine intra and extramarital sex.
Zou, et al. [3]	Self-administered survey for parishioners (n = 438) (Catholic, Lutheran, and Pentecostal churches). Shame-related HIV stigma is strongly associated with religious beliefs: HIV is a punishment from God (p < 0.01) or PLWHA have not followed their Bible (p < 0.001).
HIV Knowledge & Education	
Epsley, et al. [20]	Village AIDS committees (VAC). 100% of participants requesting further HIV training. There were increased HIV knowledge levels following short educational sessions.
Eustace, et al. [22]	34 stakeholders. There is a need to understand the family role for HIV/AIDS education in the community and for health providers.
Haile ZT, et al. [19]	10,299 women. Results showed only 46% of participants had adequate knowledge on MTCT and PMTCT of HIV.
Maswanya ES, et al. [6]	Fear of HIV and stigmatizing. "Results further demonstrate that HIV/AIDS related stigma is still a very serious problem in Tanzania. Lack of HIV/AIDS related knowledge and the life-threatening character of the disease were seen as the most important determinants of AIDS-related stigma".
South, et al. [18]	5,575 women, 3,886 men surveyed. HIV misconceptions were common: kissing (55% of women, 43% of men), or mosquito bites (42% of women, 34% of men). Odds of VCT use were lower among those with poor HIV knowledge. "Further HIV-related information, education and communication activities are urgently needed to improve VCT uptake in rural Tanzania".
Vaga, et al. [21]	HIV care and education cannot be a global model. There needs to be a socio-cultural context for training. In Tanzania quality care is considered with nurses' authority and personal engagement.
Yonah G, et al. [9]	Cross-sectional study, 270 HIV patients. Negative outcomes following disclosure. Need to increase health education and awareness for individuals and communities, and to increase disclosure.

The search terms were structured to include all text of each article rather than restricting the search to titles or keywords. These search criteria resulted in identification of 45 peer-reviewed articles. Those containing information specific to HIV testing programs, HIV knowledge, community education, and stigma in the respective regions identified were included for further review. Those articles containing information and/or terms relating to HIV management, antiretroviral therapy for HIV prevention, and those not available in English were excluded from review. Supplemental data sources for financial and demographic data were also obtained from a review of articles satisfying the search criteria on the inclusion list, including data from the World Health Organization, the United Nations Programme on HIV/AIDS, and AVERT. The inclusion criteria (HIV prevention, community education, HIV knowledge and stigma) led to the exclusion of all except 20 articles. Seven other supplemental data sources were identified that met criteria for inclusion in the review.

Results

A total of 20 studies were synthesized and categorized by topic for this review. The authors and main points extrapolated from each of the studies are explained in (Table 2).

HIV/AIDS-related stigma

Stigma can be a significant determinant of whether

an individual will obtain testing and/or treatment and may serve as a barrier when seeking health care. Common themes were identified implicating religious and community leaders as sources of shame for individuals with HIV [2-6]. Stigma also contributed significantly toward whether an individual would be willing to disclose a diagnosis of HIV [2-11]. Each of these will be examined in turn.

Punishment and shame: Religious organizations exist as a pillar of community in Tanzanian village establishment, provide a basis for stakeholder involvement in community health issues, and serve a vital role in disseminating important health information. However, data suggest that the same organizations can present a barrier to care when religious affiliations provide misinformation on disease transmission or are a source of stigma regarding the disease.

In particular, [2] found that religious misconceptions about the disease could increase stigma. For example, 58% of 2,933 men and women evaluated in their study believed that HIV/AIDS was a form of punishment for engaging in behaviors that were seen as improper or sinful. The most likely to believe these misconceptions were individuals who were the poorest and suffered from food insecurity [2]. Similar outcomes were documented in a study cohort of 438 subjects who belonged to Christian churches of Catholic, Lutheran, and Pentecostal denominations in Tanzania who were

surveyed to learn about religious beliefs influencing HIV-related stigma. HIV-related stigma and shame were strongly associated with beliefs that infection by HIV is a form of punishment for perceived sinful behavior thought to be contrary to biblical teachings ($p < 0.01$) [3].

Researchers have suggested that local leaders should be educated and empowered to specifically address this dimension of shame-induced stigma [4]. A lack of knowledge about HIV can lead to fear, which can increase stigma within a community. Interviews conducted with 91 community leaders, 16 health care providers, and 77 people living with HIV/AIDS (PLWHA) revealed that a source of fear within their communities was PLWHA on Anti-Retroviral Therapy (ART) who lack physical signs of the disease. This source of fear was perpetuated amongst local leaders, as some suggested marking HIV patients with a sign or placing them in isolation camps as a mechanism to protect the rest of the community [6] also highlighted that fear-related stigma and isolation toward people living with HIV was a current issue within Tanzanian communities, and that educating leaders and individuals on HIV disease, transmission and treatment will be an important step in reducing the fear, shame and stigma experienced by HIV-positive individuals in that region.

HIV status disclosure. Multiple issues can directly impact an individual's decision whether or not to disclose their HIV status to others. HIV status disclosure in Tanzania has been linked to discrimination, rejection, mistreatment by health care workers, and increased stigma [7-9]. Environments that are not conducive to status disclosure continue to perpetuate fear and stigma within the community.

Researchers have suggested that increasing HIV education and awareness on an individual and community level would promote testing and status disclosure [9]. For example, increasing the number of HIV education programs requiring participants to interact with a person living with HIV led to a reduction in HIV-related stigma [10]. Furthermore, interventions focused on stigma reduction should be designed in such a way as to increase awareness of the disease in communities and improve treatment for individuals with the disease [11]. Comprehensive and novel approaches that integrate community involvement and patient interaction should be the cornerstone of studies designed to reduce HIV-related stigma.

HIV/AIDS knowledge and education. Lack of HIV knowledge and disease misconceptions are often linked to poverty, stigma, and a higher burden of disease [12-14]. Increased HIV knowledge and education have been shown to help reduce the spread of disease in other countries within sub-Saharan Africa [15-17]. Studies focusing specifically on increasing HIV knowledge and

education in Tanzania have been limited, but those that have been conducted demonstrate the importance and overall impact of increasing knowledge about the disease [2,6,18-21].

Cultural competency

Sociocultural context for program implementation:

Increasing HIV knowledge to reduce stigma and increase testing cannot be implemented using a single globalized model, as sociocultural context should be adapted based on the area of interest and focus on culture-specific norms [21]. One of the key aspects about the quality of HIV care in Tanzania relates directly to the authority of nurses to educate patients and relate to them on a personal level [21]. The family structure has also been shown to play a major role in the overall ability of health care providers and nurses to understand the dynamics of patients living with HIV/AIDS and to improve HIV education and communication [22]. Cultural norms regarding the authority of primary health care providers, the mechanisms of disseminating HIV-related information, and the framework surrounding community involvement and support of HIV educational programs should be thoroughly assessed when collaborations are established for HIV program implementation.

Gender-power dynamics: The sociocultural context of gender-power dynamics or imbalances that exist within communities can directly and significantly impact care and treatment of HIV-positive individuals. Multiple studies have indicated that Western models are not optimal for promoting equitable and culturally relevant strategies for HIV education in Tanzania [23]. Confidential, culturally relevant HIV counseling has been successfully used to uncover the extent to which women feel they can control their risk of HIV infection [23]. Gender imbalances that exist for married women and/or parents condoning or encouraging high-risk sexual behaviors amongst their children can have significant influence regarding HIV risk behaviors, testing rates, and infection outcomes [24,25]. Women facing economic burdens are traditionally at a higher risk of experiencing sexual violence such as rape or incest, thus increasing their risk of HIV infection and transmission. Traditionally masculine cultural behaviors, including the allowance of a husband's participation in intra- and extramarital sexual activity, placed married women at a heightened risk for contracting HIV [24].

Parents were also observed to encourage multiple sexual partners for their daughters in exchange for silence and financial remuneration [25]. This parental reinforcement encouraged the high-risk behavior amongst young women and fostered acceptance of a non-monogamous lifestyle. These studies confirm the need for culturally competent interventions to address the role of birth and marital families in HIV education and risk reduction for HIV infection and transmission.

Traditional treatments: Traditional healers are a common source of care and treatment for individuals and families when clinics and health care professionals are not available. Some African populations use traditional African healing remedies and practices in an attempt to treat HIV. In a study performed by [26], 44% of Tanzanians strongly believed that traditional healing teas could cure HIV, while 80% believed that ART was not necessary if these types of alternate treatments were employed. Surprisingly, almost 95% of participants believed that an alternative form of treatment used in place of condoms was sufficient to reduce the spread of HIV. Although the data demonstrate that ART and condom use remain the most effective methods of treatment and reduction in HIV transmission, culturally sensitive interventions should be developed that respect cultural traditions and the role of traditional medicine in community public health.

Discussions

Tanzania is one 15 countries that contributes to the largest percentage of the global burden of HIV/AIDS (UNAIDS, 2014). Though the overall national prevalence is 5.3%, special populations that have rates as high as 30% often experience more stigma than the general populace [1]. This country remains a focal point for understanding how stigma presents a barrier to care and treatment of HIV patients, what role religious organizations play in influencing beliefs of shame, and the critical importance of creating culturally competent models of HIV testing and treatment.

This review sought to identify effective methodologies to incorporate into culturally competent approaches to assist HIV programs in reducing stigma and to better understand gender roles in HIV education. Community-level awareness and providing opportunities to interact with people living with HIV/AIDS were successful methods to reduce stigma. Partnering with religious organizations to educate communities was effective in disseminating information and proposed as a solution to reduce shame-based stigma from misconceptions and beliefs.

HIV/AIDS-related stigma was identified as a barrier to testing and care. Multiple studies concluded that shame-based stigma was present in Tanzania and was influenced by religious organizations. Because religious organizations are often the center of communities, they can be resources for providing information, but it is crucial to address the barriers of stigma that have been increased by them. Shame-induced stigma was documented as religious organizations spread the misconception that HIV/AIDS was a punishment for sin. The same organizations also impacted stigma from fear-based beliefs and misconceptions of the disease. These misconceptions were passed from community and religious leaders down through the members. HIV knowledge and education were limited, a finding

that highlight the need to increase HIV education programs alongside prevention and testing efforts. Clearly an understanding of cultural context and local gender power-dynamics was identified as an important consideration for organizations implementing HIV education and testing programs. Researchers suggested moving away from globalized models and moving toward adaptive models that incorporate cultural aspects of treatment and care. This is highlighted by the observations that women have a higher HIV prevalence than men in Tanzania, and that married women face additional barriers since many of them have little control over their own health decisions.

Looking ahead, we conclude that HIV programs must focus on ways to reduce stigma. Shame-based stigma from religious organizations, from fear, and from misconceptions needs to be researched further to identify culturally appropriate methodologies to decrease stigma and increase testing rates. Studies should seek to find novel interventions to empower women and improve testing through education. Working with key community and religious leaders is a vital part in implementing new HIV programs, along with addressing misconceptions and cultural beliefs.

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