



RESEARCH ARTICLE

Stigma Remains a Significant Barrier to HIV Knowledge and Treatment in Zambia

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Abstract

Background: Despite high HIV prevalence in Zambia, which lies within the heart of sub-Saharan Africa, early implementation of public policy and programs to effectively manage the burden of disease has insured consistently high testing rates. Zambian strategies to combat the HIV/AIDS crisis employ governmental support for HIV testing and public education and can serve as models for neighboring countries to advance the development of effective testing and treatment initiatives. Although these testing programs have proven highly successful, stigma and gaps in public knowledge continue to hamper access to treatment. Through this review of the current literature, we sought to better understand HIV-specific educational programs, the impact of HIV-related stigma, and the cultural components that influence patient care.

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 38 peer-reviewed articles, the inclusion criteria (HIV prevention, community education, HIV knowledge and stigma) led to the exclusion of all except 22 articles. Their findings are described here.

Results: In individuals who reported negative experiences with health workers, perceived HIV-related stigma was common. The fear of involuntary status disclosure while filling prescriptions for anti-retroviral medications led to higher levels of perceived stigma and treatment refusal.

Observation of stigma and bullying experienced by people living with HIV/AIDS in the educational system increased fear in both teachers and students.

Conclusions: Cultural and religious considerations were found to be important in stigma reduction. In sum, collaboration with key community leaders, church elders, and politicians were seen as vital in strengthening HIV programs. We propose using train-the-trainer models to empower teachers, particularly women, to become HIV educators and reduce stigma.

Keywords

Cultural competence, Health care access, HIV knowledge, HIV testing, Stigma, sub-Saharan Africa, Zambia

Introduction

Within sub-Saharan Africa, Zambia, Tanzania, 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 Zambia rather than other regions of Africa were evaluated in the present

Table 1: Keyword search conducted in identified search engines.

Terms required	Zambia	Human Immunodeficiency Virus	Education, knowledge, stigma, prevention
Key words and combinations	"Zambia" AND	"HIV" AND	"Education" OR "Knowledge" OR "Stigma" OR "Gender" OR "Culture" OR "Prevention"
Location	Text	Text	Text

review. Separate review articles specific to the literature concerning HIV in Tanzania and the DRC were submitted simultaneously with this one.

Zambia has a well-documented history of responding to the impact of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) and yet the country remains one of 15 countries that encompass 75% of the global burden of the disease, with a national prevalence rate of 13.3% [1,2]. The first National AIDS Control Program was established in 1986, with a primary focus of protecting the country's blood supply. After 1992, the organization transitioned toward recognizing and appreciating the need for the treatment of communicable diseases, including sexually transmitted infections like HIV/AIDS, and other comorbid infections affecting HIV-positive individuals such as tuberculosis. In 2002, the resulting National HIV/AIDS/Sexually-Transmitted Infection (STI)/Tuberculosis (TB) Council began implementing HIV/AIDS policies along with testing and educational programs [3]. Yet, despite national support of HIV/AIDS programs in Zambia, prevalence rates remained as high as 25% in 2015. In some regions, for example Chirundu, special populations such as sex workers have HIV rates as high as 73% [4,5].

We evaluated existing studies in the literature to highlight the issues pertaining to effectiveness of prevention programs focusing on HIV education and knowledge. This work will provide a foundation for public health professionals and community health workers to understand the current gaps in HIV education programs and suggest culturally competent approaches to consider with the impact of stigma and gender roles on education for future research in Zambia.

Methods

The search for relevant articles was conducted between January and March 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 number 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.

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 38 peer-reviewed articles. Those containing information specific to HIV prevention programs, community education, HIV knowledge, and stigma in the respective regions identified were selected for further in-depth 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 sources for 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 17 articles, 10 of which included aims pertaining to two or more of the key topics of interest and were used under multiple subheadings. Another three supplemental data sources were used to obtain HIV prevalence rates, epidemiological information, and regional data.

Results

A total of 17 studies were synthesized and categorized by topic for this review. The authors are listed, and the main points extrapolated from each of the studies are summarized in Table 2.

HIV/AIDS knowledge gaps

There are a very limited number of publications pertaining to HIV/AIDS knowledge in Zambia. Few researchers have published findings, though there is a strong association between increasing HIV knowledge and testing. Two of the primary studies examining this topic focused on special populations, college students and children. This suggests an immediate need for research to obtain a better understanding of HIV knowledge in Zambia.

Ngoma, et al. [6] conducted a study with a focus on HIV knowledge and behavior among 844 college students. The study contradicted the current literature around HIV knowledge and education being a form of prevention. The results identified a disconnect between HIV knowledge and behavior. Over 76% of students surveyed responded as knowing enough about HIV and transmission, yet 38% of them did not use a condom with their last sexual encounter and 10% reported never using a condom [6]. This study cannot be translated to the general population as it was conducted on college students, but it does raise questions around HIV knowledge and risk behavior. Further research is needed

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

HIV/AIDS-Related Stigma	
Parsons, Bond & Nixon [8]	Qualitative interviews. Common theme of internalized stigma. Negative experiences with health professionals made some patients want to die alone at home. Stigma experienced when getting ART, from health providers, community, and family. Stigma impacted willingness to get treated and employment.
Bond [9]	Two concerns of status disclosure explained: sharing with a select few to maintain moral integrity, social status, and professionalism; sharing with the public can be seen as dangerous and can create a new identity. These experiences need to be considered before new programs are implemented to raise status awareness.
Nozaki, et al. [10]	518 participants surveyed. 16% expressed a fear of stigma from taking ARVs at home/work.
Henning & Khanna [13]	Qualitative data. Fear of stigma, overburdened educators, and lack of agency support were common themes in educational interviews.
Robson & Sylvester [12]	30 out of 72 teachers reported knowing at least one child who had dropped out of school due to AIDS-related stigma. 26 teachers knew students who had been bullied and discriminated against because of HIV.
Hunleth [7]	Many child-led households where children provide care for adults on ART. 25 households analyzed with children ages 8-12 years. 16 had an HIV diagnosis, but low testing was suspected. Children rarely went to medical appointments and were unaware of HIV. Qualitative workshops found many children thought ART made people sick, and the silence around the illness was creating misconceptions instead of education and prevention.
Murray, et al. [11]	Qualitative study to understand why women do not get treatment (43 interviews). 70.2% of women refused treatment because of stigma. 46.8% do not have the information needed to get help (no blood tests, fear). 23.4% failed to accept their status. 75.8% had fear of husbands.
Cultural Gender Roles	
Menon [15]	Strategy: collaborate with local community influential leaders (church elders, politicians, headmen) to address cultural issues around HIV transmission. Empower women.
Henning, Chi & Khanna [14]	Gender norms, years of education, religion, adoption of HIV ed, and attitudes toward HIV were all associated with teacher self-efficacy for teaching students about HIV in classroom.
HIV Knowledge	
Hunleth [7]	Many child-led households with children providing care for adults on ART, but no knowledge of HIV. Qualitative workshops uncovered many children thought ART made people sick, and the silence around the illness they were caring for was creating misconceptions instead of education and prevention.
Ngoma, et al. [6]	Study conducted on special population, college students. 844 students surveyed first round: 76.1% knew enough about HIV, 38% felt no risk, 38% did not use a condom with last encounter, 26% occasionally use condom, 10% never use a condom. HIV test was not given, but this shows a disconnect between knowledge and risk behavior among college students.
HIV Education	
Henning & Khanna [13]	Qualitative data. Before programs are implemented it is important to understand educators perceptions of HIV.
Robson & Sylvester [12]	Zambia Free Basic Education policy. Increased number of teacher absences from HIV, and a decrease in the number of teachers over the last decade due to HIV-related deaths. Healthy teachers are overburdened by the number of students.
Henning, Chi & Khanna [14]	Create new strategies and ways to incorporate culture into the classroom environment to help teachers transition to HIV educators. There is a need for capacity building beyond what teachers do.

to identify levels of HIV knowledge among women and vulnerable populations to see if there is a difference in behavior risk.

Hunleth [7] was one of the first to qualitatively identify children as HIV caregivers in many Zambian communities. The interesting aspects uncovered in this study include the role of children caring for adults but having no knowledge of HIV [7]. The children did not know what HIV was and they thought Antiretroviral Therapy (ART) was the cause of the adult's illness rather than its treatment. This identified many opportunities within the care process to use as teachable moments to give the children age-appropriate HIV education and prevention.

HIV/AIDS-related stigma - negative experiences and silence

Stigma, both internal/perceived and external, can be triggered by a number of factors. Parsons, Bond & Nixon [8] conducted qualitative interviews to investigate HIV-related stigma in Zambia. The interviews had common themes of internalized stigma and negative experiences with health care professionals. Some participants stated that they would rather die alone at home rather than face stigma from negative interactions with health care providers again. Participants also reported experiencing stigma with getting antiretroviral prescriptions filled, from physicians, community members, and family. Stigma was found to impact employment status and

willingness to get tested [8]. These findings suggest a need for supportive and confidential care.

Further misconceptions identified by Hunleth [7] can lead to stigmatizing behaviors. As noted above, many of the children interviewed had misconceptions around ART and thought the medication was what made adults sick. The child caregivers would care for the sick adults at home but not attend medical appointments, allowing for silence around the disease and misinformation to continue [7]. Lack of knowledge and misunderstandings can perpetuate the issues embedded in stigma.

Fear of stigma hindering care

Stigma can impact numerous aspects of life, but researchers in Zambia found a common theme of fear of stigma hindering care. Bond [9] investigated fear of stigma with status disclosure and found that participants considered sharing an HIV status with the public to be dangerous [9]. Nozaki, et al. [10] surveyed over 500 participants and 16% of them expressed a fear of stigma surrounding the taking of antiretroviral medications in their own home or at work. Fears have been documented within public settings and in personal settings, such as a home environment [10]. Clearly, these studies show that fear of stigma could hinder testing and care.

Fear of stigma was also found to be a core barrier to care among women [11]. More than 70% of women interviewed stated they would refuse treatment because of stigma [11]. Almost one quarter of the women in the study refused to accept delivery of their HIV test results due to fear [11]. Over three quarters of the women expressed fear of their husbands when discussing HIV status [11]. This study clearly highlights the importance of future research addressing fear of stigma and barriers to care.

Impact of HIV on the Zambian educational system

As described previously, Zambia has led the way with several public health policies compared to other African nations. To give two examples, firstly the country established the National AIDS Control Program to protect the supply of blood collected for transfusion purposes before the first Zambian case of HIV/AIDS was documented. Secondly, Zambia, along with several other countries in Africa and elsewhere, has established a Free Basic Education (FBE) policy that allows children to have access to a free education that can facilitate spread of HIV knowledge and awareness [12]. Despite the existence of these and other government groups and policies, HIV/AIDS has become a heavy burden in Zambia and neighboring countries. Over the last 10 years, HIV/AIDS has increased the number of teacher absences while HIV-related deaths have decreased the number of teachers throughout the country [12]. Healthy teachers now feel overburdened by the number of students generated by the FBE policy and the reduced number of teachers [12].

This dynamic of having too few teachers for the number of students can negatively impact the quality of education a child will need to succeed in the future.

It is also important to consider the impact of HIV/AIDS on educational systems since schools can be used to implement HIV prevention and education programs. Henning & Khanna [13] recently conducted qualitative interviews to obtain a better understanding of the burden placed on the Zambian school system due to HIV/AIDS. Overall there was a fear of stigma, the teachers felt overburdened, and a lack of agency support was felt [13]. Robson & Sylvester [12] also investigated the impact of HIV/AIDS in schools. Over 40% of the teachers interviewed stated that they knew at least one child who had dropped out of school due to HIV-related stigma. Thirty-six percent of teachers knew students who had been bullied and discriminated against due to an HIV diagnosis [12]. Not only are the school systems losing teachers to HIV and experiencing increased burdens on the teachers that remain, but also students are dropping out from stigma and discrimination.

Suggestions for effective HIV education programs

It is important to understand educators' perceptions of HIV before implementing prevention or testing programs, since the programs will be affected if educators have a fear of stigma or feel overburdened [13]. Henning and colleagues have suggested that teachers be trained as HIV educators [14]. This dual role of teacher and HIV educator can help reduce stigma and misconceptions among teachers and students. An essential part of this transition would include incorporating culture and new strategies to increase capacity building for teachers to feel empowered [14]. It is evident that stigma reduction programs would need to start with teachers first and then children to break the cycle of fear and misconceptions surrounding the disease.

Cultural considerations

Cultural considerations are also vital components of program implementation. Henning, Chi & Khanna [14] suggested incorporating culture into the classroom, but they also analyzed the factors associated with teacher self-efficacy for educating students about HIV in the classroom. The results showed that gender norms, years of education, religious affiliation, and attitudes toward HIV were all associated with teacher self-efficacy [14]. Those factors should be considered within a cultural context for implementing programs. Menon [15] recommended strategic collaborations for implementing HIV programs. Influential community leaders, such as church elders, politicians, and headmen, were identified as potential collaborators to integrate culture with HIV programs [15]. An emphasis was also placed on the need to empower women and educate men within communities [15].

Discussions

Zambia initiated a National AIDS Control Program even before the first case was documented in the country. The current National HIV/AIDS/STI/TB Council has implemented a number of policies to promote HIV testing and adherence, yet HIV knowledge gaps and fear of stigma are hindering care in Zambia. HIV education programs addressing these issues are limited. During the course of this literature review, we found that integration of culture and traditional gender roles and reduction of HIV-related stigma were of paramount importance in the effectiveness of such HIV educational programs. There is a demonstrated need to improve education programs and reduce stigma in an effort to increase testing and adherence to reduce the spread of disease.

HIV-related stigma was documented, particularly when negative experiences with health care workers were observed. Misconceptions also contributed to stigma emerging in children and adults. Fear of stigma was highlighted as a key barrier to testing and care. One study in particular found that 70% of women sampled would refuse treatment due to fear of stigma [11]. This suggests an opportunity to work with health care professionals to reduce stigma. Professionals who work at hospitals and clinics are often the point of care contact for patients and have the ability to educate and influence personal views on stigma. Therefore, train-the-trainer models could be effective tools for empowering local health care workers and reducing stigma amongst patients.

The Zambian school system is another mechanism that could be utilized to improve HIV education and testing programs to reduce stigma. The number of teachers dying from HIV and using sick days for HIV-related illness has increased, creating a burden on the school system. Children have been bullied and/or dropped out of school due to HIV-related stigma, highlighting the need for stigma reduction programs. Researchers have suggested that HIV education should start with teachers who can then influence the children. Training teachers to become HIV educators would not only impact the education that children are receiving and reduce stigma among children, but it would likely also reduce stigma and improve treatment amongst teachers as well. Zambian policy on education makes a train-the-trainer model with teachers an effective tool to use to improve education. Additional collaborations with key community leaders, church elders, and politicians can help strength the effectiveness of HIV education programs to reduce stigma. Further studies are needed to identify core HIV knowledge gaps and assess the efficacy of stigma reduction programs such as those described here in improving HIV education and access to health care.

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References

- UNAIDS (2014) The Gap Report.
- WHO (2014) Prevalence of HIV among adults aged 15 to 49 estimates by country.
- National HIV/AIDS Council Zambia (2015) Historical background.
- <http://aidsinfo.unaids.org/>
- <http://www.avert.org/hiv-aids-sub-saharan-africa.htm>
- Ngoma MPS, Menon JA, Malungo J, Siziya S, Nkumbula T, et al. (2014) Appropriate HIV and AIDS interventions drawn from baseline knowledge attitude and behaviour surveys of university students. *Medical Journal of Zambia* 41: 109-114.
- Hunleth J (2013) "ARVs" as sickness and medicine: Examining children's knowledge and experience in the HIV era in urban zambia. *AIDS Care* 25: 763-766.
- Parsons JA, Bond VA, Nixon SA (2015) 'Are We Not Human?' stories of stigma, disability and hiv from lusaka, zambia and their implications for access to health services. *PLoS One* 10.
- Bond VA (2010) "It is not an easy decision on HIV, especially in Zambia": opting for silence, limited disclosure and implicit understanding to retain a wider identity. *AIDS Care* 22: 6-13.
- Nozaki I, Dube C, Kakimoto K, Yamada N, Simpungwe JB (2011) Social factors affecting ART adherence in rural settings in Zambia. *AIDS Care* 23: 831-838.
- Murray LK, Semrau K, McCurley E, Thea DM, Scott N (2009) Barriers to acceptance and adherence of antiretroviral therapy in urban zambian women: A qualitative study. *AIDS Care* 21: 78-86.
- Robson S, Sylvester KB (2008) Orphaned and vulnerable children in Zambia: The impact of the HIV/AIDS epidemic on basic education for children at risk. *Educational Research* 49: 259-272.
- Henning M, Khanna SK (2016) Overburden, Stigma, and Perceived Agency: Teachers as HIV prevention educators in urban zambia. *AIMS Public Health* 3: 265-273.
- Henning M, Chi C, Khanna SK (2011) Factors associated with school teachers' perceived needs and level of adoption of HIV prevention education in lusaka, zambia. *International Electronic Journal of Health Education* 14: 1-15.
- Menon JA (2014) Inter-linkages between culture and gender in HIV transmission in zambia. *Medical Journal of Zambia* 41: 100-106.