



RESEARCH ARTICLE

Overcoming Barriers to Improve HIV Education and Public Health Outcomes in the Democratic Republic of Congo

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Abstract

Background: Approximately 37 million people worldwide are infected with the Human Immunodeficiency Virus (HIV), with the majority located in sub-Saharan Africa. The relationship existing between HIV incidence and socioeconomic inequity confirms the critical need for programs promoting HIV education, prevention and treatment access. This literature review analyzed 36 sources with a specific focus on the Democratic Republic of Congo (DRC), whose critically low socioeconomic status and education rate have resulted in a drastically high HIV rates. Relationships between HIV testing and treatment and barriers to care were explored.

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 36 peer-reviewed articles, the inclusion criteria (HIV prevention, community education, HIV knowledge and stigma) led to the exclusion of all except 17 articles. Their findings are described here.

Results: Cultural and religious considerations were found to be vital when creating and implementing HIV education and testing programs. Partnerships encouraging active support from community-based spiritual leaders to implement HIV

educational programs were also key mechanisms to reach communities and individuals. Gender roles were highlighted as a key component for implementation of effective community trust-building and successful HIV education programs. The efficacy of added support by hospitals and clinics in rural areas to facilitate access to HIV testing and care for people living with HIV/AIDS (PLWHA) was discussed.

Conclusions: We highlighted the need for health care providers to provide a network of continued education for PLWHA in clinical settings during disclosure and throughout the course of treatment to increase retention in care and promote medication adherence for viral load suppression. Implementation of culturally-sensitive models that rely on community familiarity with HIV educators such as train-the-trainer were also proposed as efficacious tools for educating rural communities about HIV.

Keywords

Cultural competence, Democratic Republic of Congo, Health care access, HIV education, Prevention, Sub-Saharan Africa, Testing

Introduction

Within sub-Saharan Africa, the Democratic Republic of Congo (DRC), Tanzania, and Zambia are close neighbors geographically, yet they report widely dif-

ferent 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 DRC 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 Tanzania were submitted simultaneously with this one.

While the reported rates of HIV infection in DRC are low (1%), only a small percentage of the population has demonstrated detailed knowledge about HIV and the need to be tested and treated. This review of published works pertaining to HIV in DRC seeks to understand the root causes of this discrepancy. We found that poverty, lack of education and HIV-specific knowledge, stigma, and reduced access to antiretroviral treatments all contribute to the challenges faced in DRC.

Of the 79 million individuals residing in the DRC, more than 70% live below the poverty line, with only 46% having adequate access to basic health care services [1-3]. DRC also consistently scores toward the bottom of the Human Development Index scale (ranking 186 out of 187 countries in 2014), an indicator of socioeconomic development and potential [2]. A relative lack of general education may also contribute to the low level of HIV awareness in DRC. An average individual in DRC has an education level of 3.1 years, suggesting that institutional facilities are not a likely source for HIV education within these communities [2]. Although Congolese women are at a higher risk for contracting the disease than men because they are more likely to be victims of sexual crimes, estimates indicate that only 12.3% are knowledgeable of HIV transmission and prevention [4-6]. Finally, fewer than 25% of people living with HIV/AIDS (PLWHA) in the DRC have access to Antiretroviral Therapy (ART), demonstrating the need for both effective education programs to prevent HIV transmission and improved access to treatment [1].

Studies by Brewer [7] and others have shown that the incidence of HIV infection can be reduced through activities that heighten awareness, improve communication and reduce stigma about the disease [8,9]. We seek to identify what types of community-

and home-based HIV education programs have been implemented in the DRC and surrounding countries to mitigate the risk of new infections and to detect and treat those already infected [7,10]. Recommendations for improving HIV education through culturally competent models within the rural community and through local health care providers and community leaders in the DRC will be proposed.

Methods

The literature review was completed between September and October of 2015 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 starting 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 174 peer-reviewed articles, of which 28 were duplicates that were identified by multiple search engines. Of the 146 remaining articles, those containing information specific to HIV prevention programs, community education, HIV pre-test counseling and adult populations in the respective regions identified were included for further review. Those articles containing information and/or terms relating to HIV management, ART for HIV prevention, articles pertaining specifically to children 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 (WHO), the United Nations Programme on HIV/AIDS (UNAIDS), the United Nations Development Programme (UNDP), the United Kingdom Department for International Development, the Global Fund to Fight AIDS, Tuberculosis, and Malaria (Global Fund), and the International Federation of the Red Cross and Red Crescent Societies. The inclusion criteria (HIV prevention, community education, HIV knowledge and stigma) led to the exclusion of all except 22 data-driven articles. Fourteen other supplemental data sources

Table 1: Keyword search conducted in identified search engines.

Terms required	Democratic Republic of the Congo	Human Immunodeficiency Virus	Education
Keywords and combinations	"Democratic" AND "Republic" AND "Congo" OR "Central" AND "Africa" AND	"HIV" AND	"Education" OR "Program"
Location	Text	Text	Text

Table 2: Key points of the search results in Democratic Republic of Congo.

Access to Health Services	
Peters, et al. [12]	Poverty and access to healthcare in developing countries.
Collins [11]	Poverty and HIV link.
AVERTing HIV and AIDS [5]	Education and approaches to reduce stigma related to HIV on a global scale.
Ayiga [13]	Stigma reduces HIV testing/services. As education increases, stigma is reduced.
Maketa, et al. [14]	Lack of trust in health care workers, lack of information, negative rumors are all causes for not getting health care services.
Misconceptions, Cultural Beliefs, and Lack of HIV Knowledge	
Carlos, et al. [20]	Misconceptions: lack of knowledge, what HIV looks like, incorrect ways to contract the disease.
AVERTing HIV and AIDS [5]	Education and approaches to reduce stigma related to HIV on a global scale.
Hawkes, et al. [15]	Religious beliefs in the DRC impacting HIV. Cross-sectional study, 97% Christian and 7.4% tested positive. Higher rates among Catholic Christian subcategory, and decreased condom use with higher church attendance rates.
UNICEF [27]	DRC gender inequality and women having higher rates of HIV.
Dimbuene [21]	Relationship between parents' and adolescents' knowledge of HIV/AIDS transmission routes and prevention. Gender, communication, education gaps.
Neighborhood Education and Community Trust	
Ayiga, Namboozee [13]	Stigma reduces HIV testing/services. As education increases, stigma is reduced.
AVERTing HIV and AIDS [5]	Education and approaches to reduce stigma related to HIV on a global scale
MacIntyre, et al. [24]	Keys to understanding communities and building trust between NGOs and African communities to reduce rates of HIV/AIDS
Schirvel, et al. [17]	2 midwives provided community HIV education. Increased testing, return for care, and partner testing. Greatest impact seen in partner testing increase from 1-21%. HIV education can increase HIV testing.
Maketa, et al. [14]	Lack of trust in health care workers, lack of information, negative rumors are all causes for not getting health care services.
Kayeyi [8]	"HIV prevalence decreased substantially by increasing level of neighbourhood education."
Van der Borgh, et al. [9]	VCT; "Uptake of HIV testing can be actively influenced by educational or promotional activities."
Bewer [7]	"These findings suggest that knowledge of blood-borne HIV risk protects against HIV infection and that public education campaigns are important for spreading that knowledge."
Healthcare Approaches to Education and HIV Testing	
Vanden Driessche [18]	Health care provider education around HIV correlated with HIV testing: Important issues regarding HIV epidemiology and PEP remained poorly understood post-training. Mean post-training scores of clinic's HCWs were significantly correlated with the centre's HIV testing acceptance rates.
Vaz, et al. [25]	Health care provider roles and support to help parents with HIV disclose and educate their children
Parker, et al. [16]	Implementing a US-based prevention program in a low-resource community (DRC).

were identified that met criteria for inclusion in the review.

Results

A total of 22 studies were synthesized and categorized by topic for this literature review. The authors are listed, and the main points extrapolated from each of the studies are summarized in [Table 2](#).

Misconceptions and barriers to HIV education, care and management

A positive HIV diagnosis can negatively impact a multitude of personal and public aspects of an individual's life even under the best of circumstances. When substantial barriers to HIV education, care and management exist, the impact can be even more

devastating. Disease misconceptions and barriers to HIV care are often linked to poverty and stigma [5,11,12]. The level of poverty a person experiences can determine whether individuals have sufficient financial support to travel to a local clinic, cover the costs of care and continue treatment [11,12]. Psychosocial aspects such as isolation, discrimination, and fear also play critical roles in HIV education, care and management and can serve as barriers to care. This section will explore some common misconceptions and barriers to HIV transmission currently experienced in sub-Saharan Africa.

The effect of HIV education on individual's perceptions of HIV infection

HIV education is known to help prevent the spread

of HIV [7,8,13]. Individuals, particularly those in rural African regions, are confronted with a number of socioeconomic factors that influence their decisions to be tested and obtain treatment for HIV [5,11-14]. These issues may include access to appropriate health care, the cost of obtaining testing and treatment, and stigma and fear surrounding the disease that often stems from ignorance about HIV [13-16]. Individuals are less likely to be tested and learn their HIV status in regions where there is a lack of HIV education and stigma surrounding the disease is high [5,13,17]. Throughout sub-Saharan Africa, culturally-sensitive education and treatment programs designed to disseminate and implement widespread HIV education and screening are limited, allowing the perpetuation of fear, secrecy and stigma regarding HIV [7,9,13,17].

Perceptions toward HIV infection in rural community environments and cultural belief systems may also directly impact self-efficacy leading to stigma. Education programs seeking to improve awareness and understanding regarding the disease, and the mechanisms by which individuals can protect themselves and others, can reduce the degree of stigma that exists within communities [7,9,13,17]. Knowledge of the effects and impact of HIV is often the first step toward empowering an individual to get testing and treatment to mitigate the likelihood of transmitting the infection to others. Those with a positive disease diagnosis who are linked to a care team can be advised how they can protect others from contracting the disease and about the efficacy of ART to reduce viral load which further reduces the risk of transmission. HIV education can also assist PLWHA with more effectively managing the disease [18,19].

Stigma and fear in HIV testing and treatment

Stigma and fear of discrimination may directly influence a person's decision to seek health care for HIV testing and treatment [5]. In rural communities where the levels of HIV education are low, stigma is increased [5,13]. A person experiencing a higher degree of stigma is less likely to be tested for HIV. Educational levels are positively correlated to rates of HIV testing and negatively correlated to the degree of stigma experienced by individuals [13]. Lack of trust in health care workers and discrimination linked to stigma have been suggested as common fears among individuals that can contribute to reduced success of testing and treatment programs, particularly in the DRC [14].

Cultural beliefs and lack of HIV knowledge

Cultural beliefs and religious views can cause misconceptions about HIV [5,20]. [20] observed that among individuals studied in the DRC, a lack of HIV knowledge led to misconceptions about the physiologic presentation of HIV infection and modes of transmission. Further studies in the DRC conducted by Hawkes, et al. [15] identified that 97% of the participants who were tested for HIV identified themselves as Christians. Of

those, approximately 44% identified themselves as Catholic, with the remaining classifying themselves as non-Catholic Christian [15]. These Christian groups reported an increased frequency of church attendance and reduced rates of condom use, consistent with religious guidelines dissuading individuals from utilizing artificial methods of birth control [15]. HIV was detected in approximately 8% of Christians within these two groups, with Catholics more likely than non-Catholic Christians to test positive, indicating that religious practices can have a direct impact on HIV disease transmission and risk management [15].

Educational attainment and family roles in HIV education

Family and community are highly valued in many African cultures, and the roles of men and women remain well delineated in daily life [4,5]. In sub-Saharan Africa, HIV incidence and prevalence are statistically higher in women than in men primarily due to gender inequality, sexual crimes and domestic violence [4-6]. Educational levels were found to be significantly lower in Congolese women residing in rural communities, with only 12.3% demonstrating knowledge regarding HIV transmission and prevention [4]. Dimbuene [21] states that the level of communication regarding HIV transmission between adults and children in this region remains low. However, if such communication could be improved, particularly with children of sexual age, the risk of HIV transmission would likely decrease. Thus, educating women regarding HIV could empower families to reduce the incidence of new HIV infections.

The financial burden of HIV testing and treatment

Although many international HIV programs exist through governmental and private agencies such as the U.S. Centers for Disease Control and Prevention (CDC), U.S. National Institutes of Health (NIH), WHO, UNAIDS, and others to provide both financial and professional support to combat the spread of HIV in sub-Saharan Africa, significant complications remain regarding how to effectively screen large numbers of at-risk individuals. These often include a lack of clinical laboratory resources, an inadequate quantity of testing instruments and reagents and insufficient numbers of qualified personnel for testing and counseling of PLWHA, particularly in rural regions [18]. Also, as the incidence of HIV is reduced in other regions of Africa, the number of dollars committed by these programs to combat HIV spread likewise decreases [22].

The financial burden of HIV testing, and medical care can be exceptionally prohibitive to individuals residing in rural sub-Saharan Africa where the average annual incomes are extremely low. Severe poverty can also contribute to low levels of self-efficacy and empathy toward others, making efforts to educate individuals about HIV transmission more difficult [11,12,21]. Many government health agencies throughout Africa have

medication programs that provide PLWHA with ART medications at little to no cost following the initial diagnosis, but the financial burden of obtaining the diagnosis and treatment is often borne by the individual and can have a significant impact on decisions to get tested and follow through with treatment [5,14,22,23]. This financial burden can also directly impact families and communities because of the need for screening additional family members residing with the infected individual. These effects are compounded if the HIV-positive individual is a primary source of financial support for the family or within the community.

Mechanisms to improve HIV education, diagnosis and treatment

Regardless of socioeconomic status or poverty level, improving HIV knowledge through education will enable communities to promote the use of appropriate methods to prevent the spread of HIV and to decrease stigma regarding the disease [5,13]. We explore next how HIV education and community engagement can facilitate reductions in HIV incidence and prevalence in rural areas of sub-Saharan Africa.

Facilitating of community trust and enhancing HIV education

Before HIV-targeted education programs can be successfully implemented, service groups must establish an environment of trust and security that often can be facilitated through community and religious leaders. To accomplish this, respect for cultural and community identity must be demonstrated, so that the common goals existing among organizations and communities can be clearly identified and promoted once trust is established [24]. Because the social structure of many African communities remains male-dominated, organizations having key leaders who were male to initiate conversations regarding HIV education programs and facilitating trust-building were found to be more effective than those led by females [24]. Interestingly, the efficacy of HIV education and the degree of trust were higher in communities where females were trained to disseminate HIV information [24]. This was reinforced in a study by Schirvel, et al. [17] demonstrating that positive correlations existed between improved HIV education from sessions held by community midwives to discuss HIV, improved rates of testing and the frequency of return appointments. Most importantly, these educational programs led to a statistically significant increase in male partner testing from 1% to 21% in these Congolese communities, demonstrating that this is an effective model to reduce HIV transmission [17].

HIV education with community and government involvement to reduce HIV rates

Community educational programs and campaigns

are important ways to spread knowledge, particularly in increasing knowledge of HIV [7]. To better understand HIV perceptions regarding the quality of health care services and community-oriented interventions, eight focus groups were established in 2013 within the DRC. The focus groups expressed concern about the level of knowledge regarding HIV management at the community and government levels, indicating that key community leaders needed to be more involved and engaged in the health information being distributed to community members [14]. This was mirrored by other findings confirming that as HIV education levels and programs amongst communities rose, testing and knowledge increased, culminating in a decrease in HIV incidence and prevalence [8,9].

Health care approaches to HIV testing and education

Community-based HIV education programs are an effective way to improve HIV knowledge, promote disease prevention and reduce the risk of disease transmission. Health care provider education and training about HIV were positively correlated with HIV testing acceptance in clinics in the DRC [18]. By adding the support of hospitals and clinics involved in HIV testing and treatment, efforts toward disease management and prevention could be strengthened using a comprehensive and supportive approach on both an individual and community level. The roles of health care providers in clinical settings can provide support for patients through educating, testing and providing encouragement when disclosing their status [25]. The use of train-the-trainer models could help empower clinic employees to provide more effective education to patients to increase prevention efforts and HIV testing [25].

Another resource health care provider could utilize is a framework developed by the CDC to implement successful HIV programs in resource-limited rural communities. [16] explored an effective design to translate HIV educational material for resource-limited regions. The framework established five key steps for health care workers, including community assessment, selection of specific resources, then preparation, piloting and implementing the program [16]. Utilizing these steps, providers were able to assess what was culturally important to the population, to determine the level of HIV education in the patient population and how to choose and implement appropriate curricula from those available to achieve the maximum benefit.

Reducing stigma through community and clinical programs to improve HIV education and testing

The goal of improving HIV education within a community is to reduce fear and stigma so as to increase HIV screening and disease management. Stigma hinders HIV testing and education by placing a burden of

emotional shame onto individuals based on religious and sexual beliefs that can lead to isolation, secrecy and denial [26]. Discovering ways to recognize the types and root causes of stigma can assist in reducing or eliminating barriers to HIV testing and treatment in sub-populations where stigma exists, such as women living in communities infiltrated with gender inequality or men who have sex with men.

Discrimination, a form of stigma, has been associated with HIV testing and diagnosis. Discrimination experienced from family and/or community members, religious organizations, or even one's place of employment can hinder HIV education and testing within a community [14,26]. Functional assessment of current community practices, in addition to identifying the degrees of stigma and discrimination that exist within a community, can help clarify a path for improvement of HIV education to reduce levels of stigma and to improve HIV screening and management programs [8,9,25]. Improvement of HIV educational programs requires identification and critical evaluation of existing HIV testing and/or outreach programs, evaluation of screening criteria and requirements, and mapping out the linkage to and retention in medical care [5,9].

Needs assessments can further identify gaps in service for present programs and identify pathways toward implementation of services where none currently exist. Two specific areas that can be targeted for potential improvement are ongoing training sessions for staff delivering the educational programs and activity-driven community-based programs. Models such as train-the-trainer that promote exponential spread of information within communities can be adopted on multiple levels to improve teaching strategies and educational attainment among participants [5,9,18,25].

Discussions

Reductions in new HIV infections have been observed in more affluent regions throughout the world; however, the gap continues to widen in poverty-stricken areas. Regions such as sub-Saharan Africa often have poor health care options and suffer from high death rates. Socioeconomic factors and lack of access to adequate health care and treatment contribute significantly to the incidence and prevalence of HIV in these regions. There is a demonstrative need for programs facilitating community and individual HIV education, prevention and treatment in an effort to reduce stigma and reduce the spread of HIV. One of the hardest hit nations in sub-Saharan Africa is DRC, whose critically low socioeconomic status and education rate have led to drastically high HIV rates. Other factors such as lack of trust in the health care workers and stigma-related discrimination also contribute to the upsurge in HIV incidence.

Through this review, we have sought to identify possible alternatives for modulation and/or reduction

of HIV incidence and prevalence in DRC. Data are clear that increasing knowledge regarding HIV testing and treatment decreases misconceptions about the disease and improves disease outcomes [7-9]. Based on studies done evaluating programs to combat HIV infection in regions with similar socioeconomic status to DRC, we propose that programs designed to heighten individual and community awareness and that improve overall communication about the disease and reduce stigma may be effective in improving the continuum of care in this region. Because of the role of family and tribal affiliations in rural African communities, cultural considerations are vital when creating and implementing HIV education and infection management programs. Partnerships encouraging active program participation and support from community-based spiritual leaders to implement HIV educational programs are also a key mechanism to reach communities and individuals. Empowerment and education of families about the importance of HIV testing and care could be an impactful way to engage community support. These efforts would be further strengthened with the added support of hospitals and clinics in rural areas to facilitate access to HIV testing and care for positive patients. Health care providers in clinical settings need to provide a network of continued support and education for HIV-positive patients not only when disclosing a patient's status, but throughout the course of treatment. A model such as train-the-trainer can be an effective tool for educating rural communities about HIV education because of the cultural sensitivity and familiarity participants have with those providing the information.

Educational programs and community engagement that facilitate understanding of the role of individuals and community in reducing HIV incidence and prevalence can strongly impact an individual's decision to become educated about HIV, be screened and, if positive, obtain treatment. HIV education can empower individuals and communities while providing assistance in protecting themselves and others.

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