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## Chapter 3

# HIV/AIDS Program Planning in Kwazulu-Natal, South Africa: Addressing Gendered Stigma, Stereotypes, and Responsibilities

Emily I. Belanus

### Introduction

South Africa has been one of the most heavily targeted countries for HIV/AIDS intervention programs. Today, South Africa has the highest rate of HIV/AIDS infected persons in the world, with an estimated 6.1 million people living with the disease (Avert 2015). While HIV prevalence remains staggeringly high (17.9%) among the general South African population, it varies significantly between regions (Avert 2015). Of the nine provinces, Kwazulu-Natal (KZN) has the highest HIV infection rate in South Africa, affecting approximately 40% of the total population (Avert 2015) and 26.4% of Kwazulu-Natal's working-age population (Thurlow et al. 2009).

When analyzing this demographic context, gendered trends of infection are blatantly apparent. For instance, in 2012 HIV prevalence among women in South Africa was nearly twice that of men, and rates of new infections among young women aged 15–24 were more than four times greater than that of men in the same age range, accounting for nearly 25% of new infections in South Africa (Avert 2015). Recent studies indicate that HIV prevalence in the KZN province is concentrated in working-age Africans, especially younger females aged 20–34 years. Additionally, in a 2007 study conducted in KZN, 41% of women aged 15–49 years were HIV

infected, compared to 34% of men aged 15–54. The highest infection rates existed among 26-year-old women, affecting approximately 57.5% (Welz et al. 2007).

Despite the fact that the nation is home to the largest antiretroviral program in the world today, the epidemic continues to be rampant; there were approximately 240,000 deaths occurring from AIDS-related illnesses in 2012 (Avert 2015). While progress continues to be made, it is not at a fast enough rate to combat the hundreds of deaths occurring on a daily basis. This trend confirms that there are still significant areas for improvement in the fight against this epidemic in South Africa.

Given the unequal distribution of HIV infection rates as well as the socio-cultural and economic context of Kwazulu-Natal, this program proposal intends to (1) promote and celebrate women's self-empowerment, (2) increase awareness of the epidemic in the area while reducing AIDS-related stigma, and (3) reduce gender-based violence and gendered imbalances of power. If we wish to make any long-term, sustainable progress towards decreasing overall infection rates and increasing patient compliance, it is of utmost importance to address the gendered stigma and stereotypes associated with HIV and AIDS; without addressing the root of the epidemic, we cannot stunt its growth. Here, I propose a three-pronged HIV/AIDS intervention program in KZN. Focusing on the above goals, we will invest in gender equality through approaches that (1) increase economic opportunities for women, (2) increase educational opportunities for *both* young men and women, and (3) 'empower' men to "resist and challenge dominant social expectations of masculinity" (Leclerc-Madlala 2005). By utilizing anthropological and community-based research methods, we are confident that we will achieve our goals in a contextually appropriate manner. At the heart of anthropology is the drive to

understand the world through the perspective and realities of individuals and local populations. Therefore, every stage of the process is dependent upon the community's involvement.

One aspect that differentiates this project from the several others that have failed to gain success (e.g., Summertown HIV-Prevention Project and PEPFAR's ABC program) will be our substantial reliance upon anthropologists and anthropological methods of research to inform the design, implementation, and evaluation of the program. In order to effectively improve any humanitarian concern such as this, one must be fully informed on all aspects of the targeted population and be well versed in the sociocultural, political, economic, and historic context at hand. Given their formal training in ethnographic research and analysis, as well as the inclination towards culturally sensitive approaches, anthropologists will be of significant importance in all stages of the project. Not only will they help conduct the needs assessment with community-based participatory research methods and provide a cultural analysis to inform the design of the program, they will also be involved in all phases of evaluation, including the baseline survey, mid-term survey, and final survey.

### **Needs Assessment**

If there is one thing that experienced public health professionals have learned in their attempts to address HIV/AIDS, it is that intervention programs must be socially and culturally contextualized and include the perceptions of the beneficiaries (Needle et al. 2007; Jones 2009). For example, the universal ABC campaign (which stands for Abstinence, Be faithful, and Condom use), largely driven by George W. Bush's Emergency Plan for AIDS Relief (PEPFAR), has continuously failed time and time again despite its multibillion dollar efforts (Su 2010). The main reason for ABC's lack of success lies in the fact that the program takes a highly Westernized approach towards HIV prevention, espousing Eurocentric ideas about family

planning and sexual behavior that are not consistent with those of targeted communities. Because the ABC campaign has been applied in various countries in the same way, it overlooks crucial sociocultural factors, such as perceptions of sex and sexuality, gendered power dynamics and individual autonomy, and beliefs about illness and healing. It assumes that people live in a cultural vacuum, rather than a complex sociocultural reality shaped by local beliefs and health-seeking behaviors. According to Dr. Joe Lugalla, a professor of sociocultural, medical and development anthropology at the University of New Hampshire, the employment of blanket policies and campaigns is, "...the biggest mistake people make in this world. Programs must be contextualized. Factors that facilitate the spread of HIV vary by countries and by geographical areas. And therefore, having a universal strategy sometimes complicates things." (Lugalla 2015). That being said, if one wishes to design a successful HIV/AIDS intervention program in South Africa, specifically within the Kwazulu-Natal region, they must not only consider the unequal distribution of HIV/AIDS, but also the underlying factors that drive the epidemic.

In order to gain a comprehensive understanding of the social-cultural context at hand, we dispatched a team of anthropologists to conduct a six-month needs assessment in the field. While most programs rely heavily on quantitative data to inform the design of their projects, we drew on our researchers' anthropological expertise to gather information. Therefore, the research conducted focused on gathering qualitative, holistic data, as well as basic quantitative data. Methods utilized included participant observation, semi-structured interviews with key personnel (patients, clinicians, community health workers, peer educators, traditional leaders, and community and religious leaders as well as community-based organizations, civil organizations, NGOs, and the local and national government), focus group discussions, and community meetings. The anthropologists employed the "shared decision-making model," in which the

beneficiaries are included at all phases so that they may prioritize their own needs and desires and relay them to the researcher (Elwyn 2012). Through the use of these qualitatively focused methods, we were able to gather information that was culturally relevant and holistic in nature.

The quantitative data we gathered enriched our qualitative results. The use of measurable surveys and questionnaires helped us to (1) more clearly understand the emic and etic perspectives of the epidemic, (2) cement and numerically prove our findings from the qualitative research, and (3) provide ‘empirical’ statistics often required by donors and beneficiaries. Though some may argue that allocating six months to conduct a needs assessment is excessive given the rapid nature of the epidemic, we counter that the epidemic is tremendously complex and will not be eradicated overnight. Therefore, our primary goal was to create a fully informed, evidence-based program that focuses on the fundamental, yet often ignored, factors that perpetuate the epidemic.

At the end of the six-month data collection trip, the anthropologists returned to the US to begin the analysis phase. The quantitative data was analyzed using statistical analysis software, while the interviews and focus group discussions were transcribed, organized, and coded for proper analysis. Both emic and etic perspectives were applied to the data to investigate which conditions most heavily shape the lived realities of HIV/AIDS positive individuals and all others at risk of contracting the disease.

### **Cultural Background and Analysis**

In Kwazulu-Natal, “socio-cultural, ideological and violence-related factors” inform the dynamics of sexual negotiation and decision-making that exacerbate the epidemic (Varga 1997). More specifically, our research indicated that the most notable driving factors of the epidemic include gender-based sexual violence and coercion, poverty, the stigmatization of HIV/AIDS, and the overall low status of women, which presents several obstacles for sexual decision-

making, such as the ability to negotiate when, where, and how sex occurs (Varga 1997). This was further confirmed by Suzanne Leclerc-Madlala, the senior anthropologist at the United States Agency for International Development (USAID) and former Head of Anthropology at the University of KwaZulu-Natal. In a 2005 article titled, *Masculinity and AIDS in KwaZulu-Natal: A Treatise*, Leclerc-Madlala discusses the Zulu ideal of *amasoka*, a man who is popular among women. This concept encourages men to prove their masculinity through the engagement of multiple sexual partners, which is viewed as natural and often essential to the nature of manhood (Leclerc-Madlala et al. 2009) In accordance with our findings, this model of masculinity presents serious challenges to the effectiveness of prevention efforts, as it flies directly in the face of our suggestions to reduce one's number of sexual partners, and increase faithfulness and trust among sexual partners.

Further, we have found that in many Zulu communities, sexual domination is linked with notions of male control. In this context, a man proves his masculinity by demonstrating his ability to control 'his' women, whether it be his girlfriend(s), wife/wives, or daughters (Leclerc-Madlala et al. 2009). This may be exemplified through KZN's high prevalence of rape within South Africa, the country with the highest rate of rape in the world (Varga 1997). With rates of unemployment and income poverty much higher than the national average (one third of KZN's population lives below the \$2/day poverty line and two fifths of the workforce is unemployed); Thurlow 2009), many women in KZN depend on men for their livelihood. Given the high rates of poverty, coupled with gender-based violence and power imbalances, women in KZN are often in low-power positions that minimize their ability to negotiate safe sex practices.

Our research also revealed significant stigmatization of both the epidemic and condom use in Kwazulu-Natal (Varga 1997). While many women reported avoiding discussion about the

use of condoms for reasons such as fear of physical abuse or rejection, male participants often reported that condoms stripped them of their masculinity, and took away from the man's control of the sexual relation (Varga 1997). Relatedly, we found that requesting the use of a condom, even within relationships, was accompanied by stigmatizing and possibly the development of a perception that the woman may be accusing her partner of HIV infection or STDs, or even worse, that she herself is infected or unfaithful.

This stigma surrounding HIV and AIDS in KZN is severely limiting women's ability to openly discuss and negotiate safe sex practices as well as get treated after infection occurs. Over half of the female participants interviewed felt that AIDS-related issues were not appropriate for discussion with their sexual partner, even women who were in relationships (Varga 1997). This stigma is largely due to beliefs and perceptions surrounding transmission. In KZN, HIV is often perceived to be a disease transmitted solely through sexual intercourse (Boerjan 2013, 45). Interventions such as the ABC Campaign that focus exclusively on the sexual transmission of HIV have created a situation in which people are fearful of infection and link the transmission to promiscuous and deviant behavior. In a society where women are viewed as second-class citizens, men are hypersexualized, and sexual intercourse is a sensitive and private matter, HIV and AIDS have become clouded by stigma and denial.

### **Objectives and Methods**

As previously mentioned, our research indicated that the most notable driving factors of the epidemic includes economic poverty coupled with overall low-status of women and gendered power imbalances; lack of knowledge about HIV and AIDS and the consequential stigma associated with contracting the disease; and gender-based violence largely driven by the Zulu ideal of masculinity. In order to change the course of the epidemic in this region, we must



address these issues first and foremost. With this in mind, the proposed project intends to (1) promote and celebrate women's self-empowerment through increased economic opportunities, (2) expand awareness and understanding of the epidemic while reducing AIDS-related stigma, and (3) reduce gender-based violence and gendered imbalances of power through male involvement.

### *Economic Opportunities*

Given the high rates of poverty coupled with gendered power imbalances, a large number of women in KZN rely upon men for their livelihood. Oftentimes, this places women in low-power positions that minimize their ability to negotiate safe sex practices and protect themselves from HIV infection. In order to address this challenge, our proposed project intends to increase economic opportunities for women by expanding upon and creating new income-generating activities appropriate for the local context. Instead of creating opportunities for HIV positive women only, our project will include the provision of income-generating activities for all women, no matter their HIV status. By placing these economic opportunities at or nearby the CTCs (Care and Treatment Centers/Clinics) and allowing access for HIV positive patients as well as non-infected members of the community, the project will not only draw people to the clinic to get tested and adhere to their treatment regimens, but it will also greatly reduce the stigma of those who already attend these clinics. Furthermore, given the unemployment rates and gender imbalances in KZN, this approach will also work to empower women by decreasing their economic reliance on men. Encouraging women to rely upon themselves economically will enable them to hold more power in their relationships and negotiate sexual relations more equally, which will hopefully reduce the spread of HIV through sexual intercourse. It is of great

importance, however, to ensure that these income-generating activities are appropriate for the local context.

Though still in its developmental stage, we propose making a connection with a non-governmental, non-profit, and pro-poor organization that fosters sustainable income generation and social empowerment. One notable NGO, the Small Enterprise Foundation, provides low-interest loans to low-income persons living below or halfway below the global poverty line. The loans provide women (99% of their clients) with the baseline funds needed to create their own self-sustainable business (Thurlow 2009). Once women have received their loans, a program member will work with them to develop a sustainable financial plan. Given the local context and economy, we will encourage textile, clothing, footwear, and jewelry businesses. These ideas are only suggestions and may be subject to change as our study continues. Like all other aspects of our program, the beneficiaries will largely drive implementation. Therefore, the business initiatives must be dependent upon the women's own levels of interest and prior skills.

### *Educational Opportunities*

As our research indicated, the stigma surrounding HIV and AIDS in KZN has severely limited women's abilities to openly discuss and negotiate safe sex practices, as well as seek and adhere to treatment once infection has occurred. In order to combat this stigma and decrease gendered power imbalances, our program intends to work with the Ministry of Education in South Africa to further develop existing educational programs in the region, as well as create new, quality schools with wider enrollment for both boys and girls. In these schools, we will integrate HIV and AIDS knowledge into the curriculum starting at the elementary level so that children will learn about the disease in an educational, bias-free setting where they can gain knowledge and combat misconceptions at an early age. Considering the widespread belief that

HIV can only be contracted through sexual (often promiscuous or deviant) activity, there will be a strong focus on the many ways HIV can be transmitted, as well as methods of prevention and treatment. Not only will increased awareness of the epidemic decrease the stigma that surrounds it, but it will also make young women (and men) aware of their rights and abilities. According to Professor Lugalla (2015):

You need to make sure that they understand HIV/AIDS and they understand how it is spread. And ensure they understand the situation they occupy in society and become capable of designing their own means for employment and empowerment. You must send them to schools so they are employable and can compete equally in the job market. [...]

We must create a situation where awareness is increased and status increases both socially and materially.

Increased educational opportunities advance societies in more ways than one. As women gain greater access to formal education, not only will their knowledge expand but so too will their access to future employment in areas outside of the informal and domestic sectors. By increasing knowledge about HIV and AIDS and furthering opportunities for economic independence, we believe women will be able to escape their current fates as subordinate members of society and thus, reduce their vulnerability to HIV infection. This overlap of intended outcomes demonstrates the interconnected nature of our approach. However, without the approval and acceptance of the dominant sex, our success will be short-lived.

*Challenging Social Expectations of Masculinity*

Lastly, in order to reach our goal of decreasing gender dichotomy and gender-based violence in KZN, we must include men throughout all phases of the project. Understanding that men hold some of the most powerful positions in the national and local governments, organizations, and communities, and that men ultimately control much of society in KZN, "...the empowerment of women is a useless exercise if the other half of the equation—men—continue to disempower them" (Leclerc-Madlala et al. 2009). Furthermore, Lugalla (2015) states that including men in every intervention strategy is extremely important because:

...men are dominant in most societies in developing countries and in Africa. If we are able to change men so that their mentality is completely different in the way they perceive women and young girls, we can change the situation. If we can succeed in changing that mentality, we can change those dominant traditions and culture that marginalize women...

The Zulu ideal of masculinity, which links manhood with multiple sex partners and sexual dominance over women, presents several challenges to controlling and reducing the epidemic in KZN. As briefly mentioned in the above section, we will introduce sexual and gender-based violence awareness into school curriculums to shift the mindset of future generations. To shift mindsets among adult males today, we must include them in our efforts. We will look to other existing programs that are gaining success, such as Men as Partners, the HIV prevention program developed by EngenderHealth. According to the EngenderHealth website, "Through its groundbreaking work, this program works with men to play constructive roles in promoting gender equity and health in their families and communities" (EngenderHealth 2015).

Drawing upon their approaches, we intend to work with local male community leaders and government officials to develop a series of community-based workshops that are appropriate for the context. In these workshops, we will confront the dangerous ideal of masculinity in KZN by maintaining cultural sensitivity and responding to any and all concerns or opposing opinions. We will attempt to reframe the notion of *amasoka* and suggest that men think about the ramifications of controlling the women in their lives and lay out the many social and economic benefits to be had if women are given more freedoms. We will emphasize the fact that when women are marginalized, so too are men, their families, and the larger societies in which they live in. Furthermore, when women become more knowledgeable and educated, their children and family will become healthier and wealthier. Working with community leaders and health care providers, it will also be crucial to address the importance of safe sex practices, including the use of condoms. As previously mentioned, while women tend to avoid discussion about the use of condoms for fear of abuse or rejection, men often reported that the use of condoms stripped them of their masculinity. Linking new ideals of masculinity with safe sexual practices and healthy families and communities will help men understand that they have a key role to play in combatting the epidemic.

### **Conclusion**

While several other current and past projects have attempted to address the issue of HIV/AIDS in South Africa and specifically Kwazulu-Natal by increasing access to care and treatment or through universal, one-size fits all approaches, this project addresses individuals at the local context and the issues specific to this region. Utilizing anthropologists in all stages of the project, we will be able to address the underlying factors that perpetuate the epidemic. Furthermore, the project's dependence upon the community to inform the initial data collection,

design, and implementation will ensure that our efforts are culturally sensitive and accepted by the community. This aspect is of extreme importance because despite our best intentions, no project will be successful without the beneficiaries' approval.

We recognize that this project's implementation may not go smoothly or as expected. As previous failed programs have demonstrated (e.g., the Summertown HIV-Prevention Project), perceptions and stigma surrounding HIV are deeply engrained into the minds of many. While we intend to reach the next generation through education, it will be extremely difficult to challenge the dominant perceptions of those who have grown up in an environment that stigmatizes and shames the disease and those who have it. Therefore, it may be difficult to draw community members to the workshops, and those who attend may be accused of having the disease by association. It may also be challenging to obtain consent from community leaders to run the workshops, especially when community leaders in KZN are almost always older men.

By working with local health care-providers and researchers, however, we are optimistic that over time we will make progress. This optimism and hope for a better future in KZN is what drives the program. We understand that even if progress is slow, it is crucial; we refuse to sit back while thousands suffer from a disease that can be prevented with genuine effort and cultural sensitivity. As Ed Miliband, a left-wing British politician and self-identified feminist stated, "We do not have to accept the world as we find it. And we have a responsibility to leave our world a better place and never walk by on the other side of injustice" (Labour 2015).

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