HIV Activism in Dar es Salaam

A Case Study of Kimara Peer Educators and Health Promoters

Pictured: Director Pfirael Kiwia (left) with staff and volunteers at a Peer Education outreach session

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Introduction

In Dar es Salaam, Tanzania, the prevalence rate[2] of HIV[3] is 10%, a rate which has risen in recent years.[4] A big city harboring most of the country's urban poor, Dar has a prevalence rate congruent with patterns of HIV prevalence across the globe (Dyson 2003). As cities attract more and more people, crowded settlements on the fringes become larger and less habitable. Although places like Dar es Salaam are more vulnerable to disease outbreak, disease can now spread just as easily across the world as it can a neighborhood, "thanks to expanded air travel, new roads cutting through wilderness areas, and greatly increased trade" (Platt 1996, 7). Increased mobility, urbanization, increasing population density, and widening poverty have contributed to the spread of HIV (Platt 1996, 7-8).

The world's poor bear the greatest burden of disease in part because of their lack of access to nutritious food, clean water, sewage systems, adequate shelter, and education (Platt 1996). According to some scholars, the reasons that "HIV infection is linked to poverty [is] because of poor health care infrastructure, greater social density, social isolation leading to closed social networks, alcohol and drug abuse, and engaging in sex exchange for survival resources" (Kalichman et. al 2006, 1641). Regular healthcare for the poor is, in many ways, inaccessible.

Burdens of disease can also be analyzed along gender lines. Women often occupy the lower sectors of society, socially and economically. Women have less access to education and waged jobs in the public sphere, leading to dependence on male heads of households (Meeker and Meekers 1997). In this way, women disproportionately make up the poor in a population, and therefore suffer more disease than men. Also, women may be dependent on their husbands or fathers for good social standing. In many societies, a woman living alone can be socially isolated (Meeker and Meekers 1997, 45). Losing social connections—which in many cases provide informal health advice and care—can be detrimental to a woman's health and well-being. All of these factors add up to a systemic marginalization of women, placing them at "the bottom of the health pile" (Gilbert and Walker 2002).

How social marginalization affects health is logical; entrenched patriarchal systems, fixed gender roles, and limited economic independence all contribute to a low social standing, which leads to poorer health. Thus, according to this perspective, HIV would disproportionately affect

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[2] Prevalence rate can be defined as: the percentage of the population suffering from a disease at one point in time.
[3] HIV: Human Immuno-deficiency Virus
[4] ITV (Independent Television, Ltd.) Evening News Report, Tuesday March 13, 2007.

women. This has been corroborated in much of the research on HIV; "A particular theme of growing concern has been the disparity in HIV infection levels between men and women in many parts of Africa" (Luke 2007, 67). If women are carrying a greater burden of HIV in our communities, it is clear that initiatives fighting the spread of the virus will need to focus on the needs of women specifically.

Since the beginning of "the pandemic, HIV has cut across all demographic groups" (Platt 1996, 29). Although HIV is present to a greater degree among some groups, it is not the groups themselves that are somehow specially infected with the virus. For example, in the U.S., women with HIV can be labeled as drug users, prostitutes, and carriers of AIDS, just because they are infected with the virus (Bunting 1996).   In actuality, it is the social and cultural context in which they live that affects the spread, and their risk, of HIV infection. Although a relatively new disease, AIDS "is deeply embedded in social and economic structures long in place and that violence, poverty, and inequality are the fault lines along which HIV spreads" (Farmer 2002, xi).

Introduction to the Case Study

For this research project, I sought to understand the socio-cultural effects HIV/AIDS[5] has on women in Dar es Salaam, Tanzania. Public health initiatives in this country are under the influence of a specifically local, gendered societal structure. The focus of my research is a case study of Kimara Peer Educators, a grass roots organization located in a low-income neighborhood on the outskirts of Dar es Salaam. I believe that the story of one organization's activism can in many ways be more meaningful than a survey of public health programs in an area. In the same vein, the work that can be accomplished at the community level in many ways can be more effective and certainly more empowering for the community than a national initiative to fight HIV.

Therefore, in this paper, I aim to illustrate that, to fully understand the specific social and cultural implications of HIV in a certain community, activist organizations must be centered at the grassroots level. Furthermore, I argue that public health initiatives should also be centered at the grassroots level in order for programs to be community driven, and to ensure collective and effective community action and support.

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[5] AIDS: Acquired Immune Deficiency Syndrome

Methods

I used a combination of qualitative methods in an attempt to understand Kimara Peer Educators as an activist, grass-roots organization. The main method I used was participant-observation. I participated in the every-day activities of the staff in the organization, and observed the interactions that took place. During or after each visit, I recorded my observations and my interpretations of what I observed in a field journal. The journal also served as a space to reflect upon my experiences and pose further questions. After each entry, I attempted to critically reflect upon my position in my research as an outsider, as a woman, as a white person, etc. This critical reflexivity[6] helped me to understand the limitations of my research and also to accept that my contribution in return to Kimara Peer would be limited.

In addition to this participant research, I conducted three interviews at Kimara Peer: one with the Program Coordinator and one of the founders of Kimara Peer Educators,[7] the others with caregivers/counselors of Kimara Peer.[8] I recorded and transcribed these interviews, and took notes during each meeting as well. I presented and explained a consent form[9] at each interview, which was signed by both the interviewee and myself. Some of the recordings were of bad quality, so the notes and paraphrases I recorded are in some cases used as evidence in this paper.[10] Finally, I conducted one focus group discussion with the administrators, caregivers, and volunteer peer educators of Kimara Peer.[11] I compiled the questions that I had recorded in my field journal, grouped them appropriately by theme, and created a long set of questions. This discussion was conducted over two days, because of the number of questions, and the fullness of answers and other discussion. I recorded both sessions with a digital recorder, and I also took detailed notes. I typed these notes, and added information and quotes from the recordings as needed.[12]

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[6] Critical Reflexivity can be defined as: 'a process of conscious, self-conscious scrutiny of the self as researcher and of the research process' (England 1994). In other words, being reflexive means analyzing your own situation as if it were something you are studying. What is happening? What social relations are being enacted? Are they influencing the data? (Hay 2000, 22).

[7] See Appendix B for interview questions.

[8] See Appendix C for caregiver interview questions.

[9] See Appendix A for consent form.

[10] On 11 May 2007, a copy of the final paper and transcripts were given to Kimara Peer educators for affirmation of my analysis. A presentation of the research was also given exclusively to the organization on this date.

[11] See Appendix D for Discussion Group questions.

[12] The entirety of the discussion group recording was not transcribed because of the length of the recording, but also because it was spoken half in Swahili and translated by the English-Swahili speakers in the room.

Academic Framework

In order to effectively implement public health initiatives to fight HIV/AIDS, we must understand societal and cultural beliefs in a geographic context. This conviction comes from the convergence of three disciplines in which I have experience: geography, feminism, and public health.

The geographical discipline focuses on the importance of location, space, place, scale and networks to explain social interaction and human interaction with the environment. This paper relies on many of those concepts as explanatory tools for Kimara Peer's interactions within the community, and its connections outside the community.

Feminist ideology within geography is prominent. Feminism focuses on the importance of gender in social interaction and how social power—namely patriarchy—affects relationships, cultural beliefs, and daily interactions. In geography, feminism focuses on the voices of women and other marginalized groups, their experiences of place and location, and their perceptions of their environment.

Public health, then, can provide a meeting ground for these two theoretical disciplines. The field pays special attention to the social context of disease and health, and focuses on improving health through society-wide measures. This focus enables the synthesis of ideas of space, place, and location, and feminist ideas of gender inequality with concepts of disease as more than just a virus infecting a body. The common ground forged here can provide a forum for understanding why health status among impoverished and marginalized groups is relatively poor, and why healthcare is less accessible to these groups. As the "leading killer of migrant workers, the undereducated, and the poor...AIDS is more than simply a health issue: it is a development issue, an economic issue, and a human rights issue" (Platt 1996, 30).

Explaining the AIDS Epidemic: Literary Review
A Brief History

At the beginning of the AIDS epidemic, uncertainty and fear of the disease existed primarily because biomedical researchers did not understand it or how it spread. East-African physicians were the first to see the disease develop in humans, and contacted international health organizations, citing the emergence of a new, killer disease. Their calls for help were largely unanswered, until the same disease emerged in the United States. Here, AIDS was first identified

in the gay population, making it a 'disease of gay men'. This way of understanding disease is called "'risk grouping', [which] spurred the publication of a wide range of theories purporting to explain the epidemiology and origin of AIDS" (Farmer 2002, 2). Although an effective way to understand disease in some contexts, risk grouping in this case was problematic. Not only was this labeling discriminatory, but it also led the scholar and the lay person alike to think that HIV only affected certain groups. In the United States, these groups were initially homosexuals and Haitians (Farmer 2002). On the opposite side of the globe in Tanzania, HIV was "looked at in the beginning as a woman's disease" (Interview, P. Kiwia). Wherever AIDS was prevalent, this blame game was happening, and the blame was most commonly thrust upon the already marginalized groups in each society. For the U.S., risk grouping was clearly driven by dominant ideologies of racism and homophobia, and for Tanzania, gender inequality paved the way.

As time passed and the disease began to affect more groups—primarily the heterosexual population—risk grouping gave way to identifying individual risk behaviors. As Richard Parker (2001) states, the concept of risk behaviors at the individual scale came from western scientists and doctors with a "heavily biomedical emphasis and a largely individualistic bias" (164). In most cases, "these studies have aimed to collect quantifiable data ... the primary goal was to point the way for prevention policies and intervention programs designed to reduce behaviors associated with increased risk of HIV infection" (164). By focusing on individual behaviors, the discriminatory practice of risk grouping was no longer a big problem. It was—and in some cases still is— understood that individual sexual behavior change would be the answer to stopping the spread of HIV. To stop the spread of the disease all over the world, western societies thought that "prevention programs could be developed in order to persuade individuals to change their behaviors in ways that would ultimately reduce the risk of HIV infection" (Parker 2001, 164). Although this was medically and scientifically correct, this methodology was obviously not effective in every culture. Not unlike the different perceptions of health across culture, understandings of sexual customs, practices, and expression were in some cases radically different (Parker 2001). Clearly, a more "complex set of social structural, and cultural factors mediate the structure of risk in every population group, and that the dynamics of individual psychology cannot be expected to fully explain, let alone produce, changes in sexual conduct without taking these broader issues into account." (Parker 2001, 165) By the late 1980s, then, the collaboration of this individually-based HIV research made it apparent that something more complex than individual behavior needed to

be addressed in the scholarship on AIDS; a new narrative was necessary to explain the ways in which HIV was being spread.

The focus of HIV/AIDS research began to shift to "an adequate understanding of the social dimensions of HIV and AIDS." (Parker 2001, 166) Instead of looking at individual behavior, researchers began investigating the various cultural contexts within which sexual behavior occurs and trying to understand the various rules, meanings, and symbols that organize it. Apparently, "many of the key categories and classifications...that have typically been used in biomedicine to describe sexual behaviors... are in fact not relevant in all cultural contexts." (Parker 2001, 167) It became necessary to look at HIV transmission and the understandings of sex in different societies in depth, through the lens of socio-cultural influences on the spread of the disease. This perspective is still the focus of qualitative HIV/AIDS research and the foundation of culturally-based prevention and intervention programs.[13]

The Tanzanian Context

Tanganyika was a German colony from the 1880s until after World War I, when it became a British protectorate. After independence in 1961 and the union with Zanzibar in 1964, Tanzania became a socialist state under Julius K. Nyerere. Under the pressure of the largely capitalist world economy, in the mid-1980s the country made the switch to a liberalized, free-market economy.

As a unique nation on the continent of Africa, Tanzania fits some stereotypes of sub-Saharan Africa but not others. Tanzania does have a relatively high rate of HIV compared to the United States (7.2% compared to 1%) but a relatively low rate compared to Botswana (32%).[14] The idea of 'risk grouping' is no longer accepted, and therefore we cannot say that Tanzanians are somehow inherently more susceptible to HIV. On the contrary, it is by risky behaviors—or culturally based behaviors that become risky—that introduce and spread HIV in a population. Because of its particular cultural, historical, and social contexts, Tanzania has its own unique avenues of infection.

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[13] HIV/AIDS research has taken another path, which centers on structural inequalities or 'structural violence' (a term coined by Paul Farmer). This ideology focuses on political and economic factors that have created a social environment in which HIV is easily spread. For this paper, I will not discuss this because I am specifically studying the social and cultural effects of HIV and the experiences of stigma and AIDS within a small community, not at the many broader issues affecting the spread. However, this perspective should be taken into account in a more extensive review.

[14] World Health Organization. *Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections.* December, 2006.

Adolescent girls in Tanzania provide one example of a unique cultural avenue of HIV transmission. Many girls between the ages of 15 and 19 have male sexual partners who are much older than they are.[15] This age-asymmetry is accompanied in most relationships by economic asymmetry. For girls, these relationships provide many social and economic benefits. They can receive assistance for basic survival, secure a way to have longer-term opportunities (like jobs or schooling), and receive increased status among peers. Sometimes, a girl's parents will encourage her to form a relationship with an older man for these reasons. If a girl is in a relationship with an older man for economic gain, she may also have a younger boyfriend who represents a more serious relationship that may lead to marriage. The fact that young girls are having sexual relationships with older men who are already sexually active puts them at risk for being infected with HIV. Having relationships with two partners puts them at risk for being spreading the disease. This cultural situation for adolescent girls in Tanzania needs to be understood so that HIV intervention and prevention initiatives can be accordingly developed. (Luke 2003)

Widows and divorcees also provide an example of HIV transmission specific to Tanzania. Culturally, all women are expected to marry, and an unmarried woman is looked down upon. Because so much of a woman's identity rests on her marital status, many widowed women are unable to economically sustain themselves after the death of their spouse. As a widowed woman, Pfirael Kiwia has a personal understanding of the hardship and stigma that widows and divorcees experience:

> There are times when partners will go, and women will remain to suffer if they are not strong enough. We have seen widows going up and down. Women coming up very strong, and then when their partner dies, they end up becoming infected because, well, where do they go and what do they do? (Interview, P. Kiwia)

It is clear that women have limited options for living and gaining income after the death of a husband, and that prostitution becomes a common source of income. Also, divorced women have limited access to resources at the end of their marriage. Because women generally work in the home and not for wages, quantifiable contributions to the marriage are very few. The Law of Marriage Act of 1971 required that in case of divorce, the court "shall have regard to the customs of the community to which the parties belong." (Mtengeti-Migiro 1990, 525) This can prove difficult for women who worked in the home, because

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[15] Although this situation may not be unique to Tanzania, it is very common there, and it is not common on a global scale. Therefore, it is a unique avenue of infection in the country.

"although the domestic services rendered by a wife are traditionally appreciated, they have not been accepted as 'valuable'" in many communities (Mtengeti-Migiro 1990, 525). Because a woman's contribution to the household is not quantifiable by law, in the case of divorce she is left with almost nothing. The divorcee, like the widow, often turns to prostitution, with the concomitant risk of HIV/AIDS.

'Training Ourselves to Train Others': An Introduction to the Organization

Kimara Peer Educators began as a small NGO "in the low-income periphery area of the outer North-West Kinondoni Municipality, of Dar es Salaam, Tanzania." Established in 1992 and registered in 1996, the organization was founded by a small group of friends from Kimara—six women and two men. Each founder was either personally infected with the virus or had developed connections to the events surrounding HIV infection in their social networks (Interview, Kiwia). These men and women knew that their neighborhood was at risk of bearing a great burden of HIV and AIDS. Kimara fits the global pattern as a likely place for infectious disease, including HIV, to spread. The founders responded to the disease in their community by taking "up the mandate of reaching as close down as possible, [into] grass-roots communities who are least served and are likely to be infected with HIV and STIs due to ignorance, gender, stigma and discrimination, and poverty." The mission of the organization is to sustainably reduce the incidence of HIV/STI transmission and mitigate the impact of the epidemic through social and health services and community programs. Kimara Peer holds two visions. For the society, it envisions a community that is knowledgeable and responsible in HIV/AIDS issues. For itself, a sustainable organization with high quality service delivery, competence and able leadership. Employees at Kimara Peer say that "we train ourselves to train others."[16]

Now, Kimara Peer has eight to ten full time staff, and ten to twenty student and community volunteers. Despite its small size and grass roots focus, the organization reaches seventeen wards of the Kinondoni District by operating satellite offices that act as information centers in each community. Each satellite office, which also has its own peer education group, has different strengths in terms of services and community participation.

In the main office in Kimara, the organization provides a wide range of services. The Peer Education program uses dancing, skits, and speeches to disseminate information about HIV and

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[16] Kimara Peer Educators and Health Promoters" informational pamphlet; English version. Printed May, 2005.

AIDS into the community. The volunteer "performers" are primarily students from local high schools and universities. The Home-Based Care program allows people sick with AIDS to be cared for in the home. Special caregiver staff provide food and nutritional supplements, mosquito nets, blankets, etc. to the patients, and make referrals for all medication. An outgrowth of Home-Based Care is the Orphans and Vulnerable Children group that meets at Kimara Peer's main office once a week for information and group support concerning HIV/AIDS. The program also provides snacks and an opportunity for the children to play. Kimara Peer also hosts an adult Persons Living with HIV and AIDS (PLHA) therapy group once a month, which provides a place for people to support each other, share ideas, and encourage one another. This group also makes Batik cloth and sews shirts and other clothes to sell for income. These income generating activities allow PLHAs to continue participating in the community by making a little money for their families. Caregiver staff also provide Voluntary Counseling and Testing in the office, five days a week. Outside of the office setting, Kimara Peer is involved in research on stigma and gender and on the connections between HIV and diseases like tuberculosis and malaria. It also participates in capacity building and training with other organizations, including strategic planning and informational material production, like pamphlets. For such a small organization, the range of programs and services is wide, reaching far into the community. (Interview, Kiwia)

What's Happening in Kimara: The Status and Needs of the Community
Personal Empowerment, Social Change, and HIV Activism

In Kimara, in the early 90s, HIV was seen as a woman's disease. Although many ideas surrounding HIV have changed since then, the disease is still highly stigmatized, and "the stigma that is directed towards women who are HIV positive is stronger than what is directed to men" (Interview, Kiwia). Bearing that stigma, women in some cases accept the community feeling that they are at fault for bringing HIV into the community. Often, "women are scared to talk about it. Even if they are not really the one who brought the virus into the house, looking at it, women are saying we did it, because the community says we did it" (Interview, Kiwia). However, even among women who do not accept the general feeling of the community, few understand the complex social situations they live in. Even fewer would be willing to take action to change the situation in which they live, and that is something that Kimara Peer aims to change. The Coordinator of Kimara Peer believes that by targeting programs toward women, "we could cut down the rates of

infection for the general community" (Interview, Kiwia). The organization aims to change some of the flawed, but pervasive, local discourse on HIV/AIDS.

Kimara Peer not only targets adult women for their programs, but seeks to include girls to a greater degree as well. In its Orphans and Vulnerable Children group Kimara follows an unofficial policy by which girl applicants are admitted first to the program, and boy applicants, according to their level of need and hardship, after that. In "community meetings, we say we support orphans. But when we are really doing the program, when a girl comes, we pay more attention .... So we have some internal policy that we say, 'let's take the girls first'" (Interview, Kiwia). Kimara Peer understands the need to help girls to gain access and become involved in the program in order to gain information about HIV in the context of a complex social situation. For many women, low self-confidence makes it hard for them to participate in Kimara Peer's activist programs. The organization seeks to "help women understand that they have the capacity to be leaders in the whole process" (Interview, Kiwia). Kiwia sees the connection between a few strong women leaders and a community of empowered women. In her eyes, it is important to empower women in order to build a community in which women are validated members of society:

> There are very few women who are willing to take direct initiative on the whole [social] system. So, we need to help women to come up and understand the social complexities that are around within their communities, to help them to see that we don't need to talk about empowering women just because of HIV. But the whole system needs to look at women and say, we need to help women.
> (Interview, Kiwia)

Helping women and empowering women are very closely linked with HIV activism at Kimara Peer. The introduction of HIV into this community, and the disease's effect on women, has charged people like Pfirael Kiwia to work in the dual sphere of women's empowerment and HIV/AIDS activism. For HIV to decline in their community, change needs to happen on a grander scale than they are able to provide as a small organization. Not only people in Kimara but also the "whole system" must change in order for their goals to be accomplished. HIV is obviously a disease that is closely linked with social processes, and it will not go away without macro-level social change.

Silencing Women's Voices: Cultural Implications of Information Use

At the beginning, Kimara Peer's main focus was gathering information on HIV, absorbing it, and then distributing it into the community. But because of cultural rules, it seemed that women were not speaking up in community settings. At a meeting, "if women talk two or three times, men

say, 'this is bad'.... women were not talking in their communities." However, it wasn't for lack of information. Although it is culturally inappropriate for women to speak before men or speak more than men, "women and men have equal access to information—women may have a little less, but not much. The problem is how they use the information" (Interview, Kiwia). Thus, although HIV/AIDS information is available to both men and women, the ability of women to affirm, use, add to, or share this information is severely limited by cultural norms.

In the framework of public health, this concept is hard to understand. In many cases, women's lack of access to information limits their power to disseminate information (Platt 1996). But in the case of Kimara, the problem is the lack of social agency to use the information they have. Even if a woman knows her husband is cheating on her, and she knows she is at risk for HIV, and she understands what HIV is and how to prevent it, she does not have the agency to speak up to her husband. In Kimara, "culturally, women cannot say...it's done. I'm moving out. Because, where do you go to? All the property goes to the man. So they say, I will have to bear with it...all the time" (Interview, Kiwia). Here, it is apparent that women have a lack of socio-cultural tools that would enable them to talk about HIV/AIDS, because of the social dominance of men in their homes. Women's voices are therefore not heard in community settings or family decision-making situations. In the case of testing positive for HIV, "women have less chances of sharing the information in fear of being thrown out. Even if a new infection comes into the family, women are unable to act. 'What do I do?'" (Interview, Kiwia) In other words, women are unable to share this information with their spouses because of fear of being thrown out. This inability to share important information causes the silencing of women's voices in the context of HIV information, and perpetuates the problem:

> Men don't want to be seen as sinners, so they pass the blame to women. And based on gender lines, the women will just keep quiet because they are not equal. If they say anything, [the men] will just throw her out of the house with her own children. 'Just go away.' (Focus Group, PLHA Therapy Group)

This caregiver clarifies that it is large scale social factors inhibiting women from disseminating HIV/AIDS information, particularly concerning their own HIV status. Men's social power enables them to pass the blame of HIV onto women, and women's unequal status makes them unable to act. The socio-cultural situation in Kimara has systematically silenced women's voices in the context of HIV/AIDS.

Although women cannot initiate discussion of HIV in community settings or in their own homes, they are able to voice their opinions to a certain degree once the subject has already been brought up by others. As the primary occupants and workers in the home, women "have a big influence over prevention in their home. [But] women would normally find an entry point" (Focus Group, Prevention). An entry point into the discussion of topics around HIV and AIDS can happen in many ways. By "listening to the radio, there might be some information about condoms, or something. This will give them the opportunity to start discussions." (Focus Group, Prevention). The mass media, including advertisements on television or in newspapers, serve a big role in creating starting points for discussing HIV/AIDS issues, but social situations can also trigger discussion. If there is a death from HIV/AIDS in a community, discussion of the cause of death can help women to speak up and say, "'HIV is now an issue, *Baba*. We must know how to protect ourselves; we must know how to prevent it among ourselves. Look, this man is now gone. This *mzee* is now gone. It is a problem.'" (Focus Group, Prevention) By utilizing such entry points, women can have influence over the prevention of HIV in their home.

Kimara Peer's work in the community has uncovered the fact that women are ready to start talking about HIV in their community. They are utilizing the entry points available to them, and in general, they found that women are more open to sharing their problems than men. Within groups of just women, they are able to be open about the issues they see are affecting them:

> So, what it is based on is culture—culture and gender. Because, men feel that, because they are dominant in the house, they cannot be the cause of the infection. So usually, they can place the blame on women. They say, 'well, it's this wife who brought the disease into the family, and not me. But on the part of women, they are ready to share their problems, whatever problems they have.
> (Focus Group, PLHA Therapy Group)

If individual women are ready to start talking about HIV in their communities, they just need safe situations in which to do so.

The PLHA Therapy Group at Kimara Peer provides a safe situation for women living with HIV and AIDS in the Kimara neighborhood. When they get together every month, "in this particular group therapy, the number of women is many. [Because] also, women are more open. They are more willing to disclose their status than men" (Focus Group, PLHA Therapy Group). This group setting provides women with the opportunity to discuss their problems, support each other, gain confidence, and share solutions. For the Program Coordinator, this therapy group is important for the empowerment of women with HIV, and for women in general. With "ten or

fifteen women of my type in this community, things would change. Because, you believe in what you can do. And some women ... are cut off from thinking they can do things." (Interview, Kiwia). Because HIV is so closely intertwined with social and cultural issues, getting women to believe in themselves as social agents is imperative to reducing the spread of HIV. Additionally, many Kimara women are isolated. The Program Coordinator encourages women to get together in order to make some social change:

> Because, some women will not even spend even two hours outside of their homes. So you need to have a reason to meet. And when you meet, you need to have an agenda. And you need a person to lead you. And then slowly, you have a peer group. And you will meet to discuss issues, and then plan what you might do.
> (Interview, Kiwia)

In this group setting, women are able to voice their opinions, problems, and solutions concerning issues of concern to them. Here, their voices are not silenced.

The situation in Kimara makes clear the need for social change for information about HIV to effectively stop the spread of the disease. Entry points must be present in the mass media local leaders should encourage women to form groups. These methods can provide women with the social tools they previously lacked; it will enable them to speak up in about HIV and AIDS to inhibit the transmission of the virus, and stigma associated with it, in their communities.

Stigma and Discrimination: The Biggest Barrier to Reducing HIV Transmission in Kimara

The stigma associated with being HIV positive is still extremely strong in the Kimara neighborhood. Kimara Peer's biggest focus as an organization is stigma because of the huge impact it has on people. Stigma is really the main, underlying factor that drives so much of the fear and blame that accompanies HIV. Stigma is the reason people do not disclose their status to their partners and why women are subjected to greater discrimination for being HIV positive.

For people seeking HIV and AIDS services, the stigma is in many ways more hurtful than the disease itself:

> When the services were there, we had problems getting people to come and use them. 'You say you wanted this program but we do not see you coming out for this service. What is wrong?' This is where we found out that stigma was an issue. 'We don't want people to see us coming to your organization. They will say, like, confirm we are HIV positive. And if we test positive, we don't want to go for the medicine because they will see us at the clinic taking the ARVs and they will finger-point us. So that's why we don't want to come for that service.'
> (Interview, Kiwia)

For both men and women, disclosing a positive HIV status has serious negative social implications. Men hesitate to disclose their status "because they don't want to be seen as champions [players] to people in the community. They want people to feel that they are faithful to their spouses. But on the contrary, they are not" (Focus Group, PLHA Therapy Group). The fear of disclosure for men is linked to specific immoral connotations of infidelity, and HIV is a social marker for that infidelity in Kimara. Being perceived as a "champion" can cost a man the respect and friendship of other men in the community, especially elders and religious leaders.

Women have a similar, but gendered experience. Because HIV is transmitted by sexual contact and is a social marker for infidelity, "women fear to disclose their status to their husbands or family because they might be divorced right away, because she will be labeled as a prostitute." (Field Notes, Stigma Discussion) If the woman discloses her status first, whether she brought the virus to her husband or not, she will be blamed for bringing the disease into the family. The same is true for men, except that because they hold more social and economic power than women, they are not divorced or thrown out of the house. It is clear that both men and women fear disclosing their status, in fear of being socially cut off from their communities for being immoral people. People with HIV also risk being labeled sinners. Because the culture in Tanzania is very proper and religious, sexual contact outside of marriage is considered sinful. Having HIV confirms that, and labels one as a sinner. This is true in both the Muslim and Christian communities.

Although stigma affects all people with HIV/AIDS, women are exposed to stigma at a greater degree. First, they are more likely to get tested for HIV than men. Women are tested "when they visit ante-natal clinics, and they are given information about HIV and AIDS there" (Focus Group, PLHA Therapy Group). Healthcare providers provide HIV testing at pre-natal (or ante-natal) clinics in order to prevent the spread of HIV from mother to child. Although this enables women to learn their HIV status, gain information about the disease, and have access to counseling, this mode of prevention puts women in the position of testing positive first within their family, and therefore being blamed with getting and spreading the virus. Once they learn their status, women fear telling their husbands or families, but also do not want to spread HIV to their child. In many cases, "women will get the [ARV] medicine, but keep it secretly from their husband" (Focus Group, Prevention). Also, women who test positive for HIV in the clinic are advised not to breastfeed. However, infant formula is not available in the area, and the only

options are powdered milk or cow's milk. Breastfeeding is an important source of a baby's nutrition, and people will notice when a woman choosing not to do so. In some cases, people will assume that the "woman is working, if she is more wealthy, [and] the implications in the community are minimal" (Focus Group, Prevention). However, for poorer women who are not engaging in commodified work, "there will be many questions.'Why, why why?' And they will link it with HIV and then there will be stigma" (Focus Group, Prevention). Being an HIV positive mother is very visible to the community if she chooses to formula-feed her child. In this case, the safest decision for the child is the most stigmatizing for the mother.

The discrimination associated with stigma also affects women to a greater degree than it does men. If men disclose their status, it is still women who are blamed:

> A man can go and get an HIV test and be found positive. In that situation, the man would keep quiet and not tell his spouse. But the woman would go to the hospital because of her sickliness. And the doctors there may want to test her for HIV. And if found positive, the woman will go back to the house and disclose her status to the man. In this situation, then, the man can say, 'It is you who brought the virus into the house, not me.' But the actual person who brought it was the husband. And this is the most common situation.
> (Focus Group, PLHA Therapy Group)

If a woman is perceived to have transmitted HIV to her husband, he can call her a prostitute, kick her out of the house, divorce her, etc. (Field Notes, Stigma Discussion). Because women are economically and socially dependent on their relationships with men, this consequence is very severe. Men's social power and ability to place blame allows them to keep most of their social networks intact and preserve their place in society when they disclose a positive HIV status. However, women bear the burden of stigma, and the brunt of discrimination associated with HIV, because of their sex and precarious gender role in the community.

Although it is a greater burden for women, stigma is really the underlying problem for both men and women who have HIV/AIDS, creating an environment of fear and blame within the family and the community as a whole. Reducing this stigma can clearly help to alleviate the social exclusion associated with disclosure, and can therefore reduce HIV transmission in the community.

Cultural Understandings of Disease and Healthcare in Kimara

Although infectious disease is not uncommon in Tanzania or in Kimara, and people die of other, more deadly diseases, no disease is as stigmatized as HIV. Though cancer is also deadly,

"HIV is transmittable, but cancer is not; so there is a fear of HIV" (Focus Group, Health Perceptions). Even compared to other transmittable, deadly diseases like tuberculosis and cholera, HIV is different because "it is seen as a new disease, and also it is associated with sex, and other immoral things. And so, HIV is still seen as a disease that affects only specific groups of people" (Focus Group, Health Perceptions). Understanding how the community perceives HIV, and the specific cultural situations through which HIV is spread, is imperative for public health initiative to create intervention and prevention programs that will be effective in a certain culture. Because the staff at Kimara Peer have always been a part of the community, they understand the importance of addressing stigma as a problem, and therefore focus their research, services, and community education programs on stigma as a central issue.

In the same vein, it is a cultural trait in Kimara and Dar es Salaam that women specifically are the ones who seek healthcare services. Women take the burden of care for people in their household, and they are "the ones that naturally take care of the family. If there is someone sick in the house, they feel it is their duty to take care of that person" (Focus Group, PLHA Therapy Group). However, because they generally do not have economic resources themselves, they go to organizations that provide services for free, or at a reduced cost:

> Because women carry the burden of care, they come to get help and education from organizations like Kimara. They come to share experiences and to get help from each other. Also, women do not have the money, so they come look for help here [where services are free] because the men have the money.
> (Focus Group, PLHA Therapy Group)

By understanding this cultural characteristic, HIV prevention and intervention programs in this area could utilize women as a way to educate a community. Unique socio-cultural characteristics like this can vary even over a big city. Taking this into account illustrates how public heath initiatives can be more effectively created and implemented at the community level. Kimara Peer is an example of why working at the grassroots level is so important: community members as activists are truly able to understand the different cultural facets of community they work in and are therefore more able than cultural outsiders to effectively aid the needs of the Kimara neighborhood concerning issues of HIV and AIDS.

Placed at the Grassroots: The Geography of a Community-Based Organization
Placement and Safety: The Importance of Location for Kimara Peer Educators

The Kimara neighborhood is located on the periphery of the city of Dar es Salaam, the largest city in Tanzania. Most of the people living in Kimara are low-income, without running water or electricity. Many of the homes are clustered together and lack sanitation. The Kimara neighborhood fits global patterns for areas especially burdened by infectious disease, including HIV and AIDS.

The importance of location can also be understood in the physical placement of the office within the neighborhood. The Kimara Peer staff first located the office along the main road in order for their services to be accessible to all people in the area. However, at that time, the degree of stigma toward people with HIV was very high. When PLHAs "were coming for services, and the people saw that they were HIV positive, people would just shout and say, 'I see you are HIV positive!' from the main road" (Interview, Kiwia). On the main road, the organization was very visible, and the clients very vulnerable. The staff then moved the organization's office to a less visible location in the heart of the neighborhood. There, "people can just walk in, they are just going in and out, not exactly for our services, but they could be coming over this road for something else .... and it has been safer for everybody" (Interview, Kiwia). This location is imperative for the success of the organization, and the overall safety and satisfaction of the clients.

Driven by the Community—Kimara Peer Acting at the Grassroots

As a community organization working at the grassroots level, Kimara Peer has programs designed to be driven by the community. Instead of bringing in public health initiatives that have been used in other countries or even in other places in Tanzania, Kimara's initiatives are products that meet specific needs of the community that people have expressed to the organization. The founders began with HIV/AIDS information dissemination only. Soon people requested more than just information, "So we started the Home-Based Care program. And we went to their homes .... There is no way that we would jump and start something that the community doesn't need" (Interview, Kiwia). This way, the initiatives employed are guaranteed to be accepted and utilized by people in the neighborhood. Because the community members are the initial creators of the programs, they feel a sense of ownership. They feel that Kimara Peer is, in part, their own organization:

> Now, even community members invite us into their communities, telling us where we need to go to provide education. Now, it is more community driven. Now, people are giving their views and suggesting solutions. Some community members have contributed land and other things to aid Kimara Peer in their work. Through this, a few site offices have been created. This is very positive, and it reflects ownership that the community has to providing education and spreading awareness about HIV and AIDS. (Focus Group, Peer Education)

By facilitating a feeling of community ownership for their programs, Kimara Peer has made HIV and AIDS education something positive that is not only accepted but created by the community members themselves.

Currently, Kimara Peer is focusing most on the problem of stigma and discrimination that people living with HIV and AIDS experience in their daily lives. When people were not utilizing the available services at Kimara Peer, the staff asked why, and PLHAs in the community responded that stigma was preventing them from coming to the organization.

> Looking at it all, it is stigma. So now, we are addressing stigma to allow people to take up the services more, and to have an early diagnosis of the virus, so that the virus doesn't kill them. So we don't work from the abstract. We really work to answer what the community needs. (Interview, Kiwia)

Kimara Peer Educators is truly a grassroots organization, successfully working for the needs of the community.

Changing the Social Environment: The Successes of Kimara Peer Educators

In only 15 years of building their organization, Kimara Peer has seen significant change in the thoughts and actions of people in its community regarding HIV and AIDS. Kimara Peer has observed a change in reactions towards people living with HIV and AIDS in their neighborhood. Socially excluded before, they are now "given roles; they speak in meetings and nobody will shout at them, they are just normal people" (Interview, Kiwia). Elders especially, regardless of their HIV status, are being included and expressing their opinions in community settings. This change in the general community has prompted a change in the feelings of PLHAs themselves. Because direct stigma has subsided, "people are saying, 'Can you move back to the main road because it is closer, and we can just walk in.'" (Interview, Kiwia) Showing a reversal in attitude from when the organization was created, some PLHAs are now concerned with convenience instead of safety. Clearly, these people feel that stigma has been reduced a great deal in the neighborhood. Even

men, who have been reluctant to use the services at Kimara Peer, are coming to the organization for condoms. Even on Saturdays, "they will knock and say .... that they need the tools" (Focus Group, Prevention).

This change in attitude is noticeable at the community level as well. The peer educators, who perform skits and songs in public for HIV/AIDS education, were at first not well received by the community. People at first assumed that all of these educators had HIV:

> People said, they are doing this because they are HIV positive, and they did not want to talk to them. But after time, there was a change in the people's reactions. Now, people want peer educators to talk to them more on HIV. Now, even community members invite them into their communities, telling them where they need to go to provide more education. (Focus Group, Peer Education)

Now, community members not only tolerate the peer education programs, they invite them into their communities. This change enables community members to get tested and disclose their status without fear of being cut off by their families and friends. These transformations in attitude and action clearly illustrate the overall change in the social environment of the neighborhood, which Kimara Peer has played a powerful role in accomplishing.

Conclusion

For this research project, I sought to understand the socio-cultural effects HIV/AIDS has on women in Dar es Salaam through studying grassroots involvement in HIV/AIDS public health initiatives, as implemented under the influence of a strongly gendered societal structure. As a case study, I examined Kimara Peer Educators, the work it does, and the situation of its HIV-positive women clients. The story and analysis of one organization's activism can in many ways be more meaningful than a survey of all public health programs in an area. In the same vein, the work that can be accomplished at the community level can also be more effective and certainly more empowering for the community than a national initiative to fight HIV. In this paper, I intended to illustrate the importance of grassroots-centered, activist organizations and public health initiatives, and their role in understanding local socio-cultural characteristics and guaranteeing effective community action and support.

In Kimara, the social status of women is marginal, and their needs must be addressed by the community if HIV rates are to decline. Also, women need to empower each other in order to tackle the issues that affect them and create social change. Because of the greater degree of stigma

that women bear, and their cultural inferiority, women's voices are silenced when it comes to issues of HIV/AIDS in a community or household setting. As a community based and community driven organization, Kimara Peer Educators is addressing stigma as a major issue by implementing programs and providing a safe space for people to tackle the gendered social issues that are so closely intertwined with HIV and AIDS in their community.

By encouraging community member participation and ownership of initiatives, Kimara Peer is creating radical change in the social environment of the neighborhood. The work it is doing cannot be quantified, but it is changing individual attitudes and community understandings of the issues surrounding HIV and AIDS. More focus and funding should be directed towards creating and maintaining grass-roots, community driven organizations in order to ensure effective and appropriate implementation of HIV/AIDS prevention and intervention programs in Tanzania.

"Things have changed a lot, and we have done a lot in this community to make them change."
-Mama Kiwia

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3. Interview with Caregiver B, home-based caregiver and counselor at Kimara Peer Educators and Health Promoters. Conducted April 25, 2007, 11:30am.

4. Focus group with anonymous caregivers, peer educators, and employees at Kimara Peer. Sections conducted May 2 2007: Peer Education, PLHA Therapy Group, ARVs. Sections conducted May 3 2007: Prevention, Home-Based Care, Health Perceptions.

5. Field Notes. Sections include: Stigma Discussion, 29 March 2007; Q&A with PLHA Therapy Group, 13 April 2007; Peer Education Performance, 18 April 2007; Home-Based Care Visit, 19 April 2007.

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Appendix A: Interview and Focus Group Consent Form

Introduction
My name is Emily Gerteis and I am a university student from the United States currently studying at the University of Dar es Salaam. I am studying through the ACM (Associated Colleges of the Midwest) Program focusing on culture, society, and development in Africa.

Explanation of Research
As a part of this program I am conducting independent research on the social and cultural effects HIV/AIDS on women in Dar es Salaam. Specifically, I am studying NGO and government involvement in public health initiatives centered on HIV. By doing this research, I hope to better understand how gender inequality connects to issues of HIV/AIDS, and the disease's effects on society. Ultimately, I hope that my research will help to identify how HIV/AIDS initiatives in general can better serve women all over the world.

Informed Consent
Because it is my wish to conduct research in the most ethical way possible, I am asking that the interviewee or discussion group member read, understand, and sign this form. By signing this form, the interviewee will be giving consent to me to use all notes taken during this interview or discussion in my written research project. By signing this form, I promise to use the information given to me in the way it was intended by the interviewee, and to make sure that my written work is not in any way harmful or embarrassing to the interviewee. If the interviewee wishes to remain anonymous, I promise to keep all personal information confidential, and will not use any names or identifying characteristics in my written work.

If any of the information in my notes should be excluded before use in my written research, the interviewee is welcome to say so at the end of this interview or at any time after the interview (by using contact information below). If the research methods I am using are unsatisfactory to the interviewee, the contact information for my academic supervisors is listed below.

Academic Supervisors
Heather Brady: 0784-681924
Simeon Mesaki: 0713-407625

Researcher
Emily Gerteis: 0786-271676

I, _____, the interviewee or discussion member, consent to allowing the use of the

information from this conversation in the written work of Emily Gerteis.

X_____   Date _____ Anonymous? YES / NO

I, *Emily Gerteis*, the researcher, promise to use the information from this conversation in the most ethical way possible in my interpretations and written work.
X_____   Date _____

- -

I, _____, the interviewee or discussion member, consent to allowing the use of the

information from this conversation in the written work of Emily Gerteis.

X_____   Date _____ Anonymous? YES / NO

I, *Emily Gerteis*, the researcher, promise to use the information from this conversation in the most ethical way possible in my interpretations and written work.
X_____   Date _____

Appendix B: Interview Questions for Director of Kimara Peer Educators[17]

**If you don't understand something, or if you have any questions during the interview, feel free to ask.
-consent form

Background Questions
1. What is your official title in this organization?
2. Can you tell me a little about the history of this organization?
3. What is the mission and main goals of this organization?
4. What are your duties, day to day?
5. What do you think your role is in this organization? (informally)

Initiatives
1. What programs are you currently running within your organization?
2. Do you think that these programs are equally effective for men and women?
   - If not, who is favored? Why?
3. Are any of these programs specifically working for the needs of women?
   - If so, how are they different than a general program?
4. Are there national public health initiatives that you employ in your organization?
   - If so, could you tell me about one of them, and specifically how you implement it?

Successes and Needs
1. How are the programs that are employed at this organization working towards its mission?
2. Do you think that your organization has been successful in recent years? Can you explain how?
   a. If not, what needs to happen for your organization to be more successful?
3. In your opinion, should more HIV/AIDS initiatives be centered on the needs of women? Why or why not?
   a. If so, how can programs be adapted to center on the needs of women? Or, what do you think needs to be done in order to achieve this?

**Is there anything that I have missed that you think is important to talk about?
** Do you have any questions?

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[17] Transcript of this interview available upon request

Appendix C: Interview Questions for Caregivers at Kimara Peer Educators[18]

**If you don't understand something, or if you have any questions during the interview, feel free to ask.
-consent form

Background Questions
1. What is your official title at Kimara Peer?
2. What is the mission and main goals of this organization?
3. What are your duties, day to day?
4. What do you think your role is in this organization? (informally)

Gender Differences
1. Is there a gender difference in people who utilize the services at Kimara?
   a. If so, why do you think this exists?
   b. If so, has the gender difference affected how you practice the programs of the organization? How?
2. Do you target either men or women specifically to use the services you provide? Why?
   a. If so, how do you target them?

Initiatives
1. Do you think that the initiatives or programs at Kimara equally serve men and women?
   a. Why or why not?
   b. If not, who is favored?
2. What are some of the major needs of women using services in your organization?
   a. Do your services give aid to these needs?
   b. What are some of the things that Kimara Peer cannot provide that women need? What do the women say?
3. Do the women that you work with express any dissatisfaction with the programs available to them? Why or why not?
4. Do you think that women could in any way be better served in your organization? How?

**Is there anything that I have missed that you think is important to talk about?
** Do you have any questions?

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[18] Transcript of these interviews are confidential.

Appendix D: Questions for Focus Group[19]

PLHA Therapy Group
1. Why is the therapy group mostly women? Or, why aren't there very many men in the group?
2. What are the rules of the group?
3. It seems that the group is very independent. How does Kimara assist the group?
4. Is there anything else you think I should know about this topic?

ARVs
1. What kinds of subsidies is the government offering for ARVs?
    a. How much do they cost?
    b. How affordable are they for the average Tanzanian?
    c. Do men and women have equal access to ARV treatments? Why or why not?
        i. If not, is Kimara doing anything specifically to help those people get treatment?
2. The group leader talked about how some Tanzanians think that ARVs shouldn't be provided so that people sick with AIDS can be recognized. Can you talk more about that?
    a. Who holds this opinion? Is this opinion widespread?
    b. How is this opinion related to the stigma and discrimination that PLHAs experience?
    c. Is this opinion present within the government? Is there government policy regarding ARVs? If so, does/has this opinion affect(ed) that policy?
3. Do most of the PLHAs using services at Kimara take ARVs?
    a. If so, how do they access them?
    b. If not, what are they doing instead to keep their health?
4. Is there anything else you think I should know about this topic?

Prevention
1. What prevention techniques are most effective here in Tanzania? In Dar es Salaam?
2. How realistic is condom use in married couple situations? Are there cultural barriers?
3. Are women able to introduce prevention measures in sexual relationships?
    a. Married vs. non-married
4. What is the general opinion men have about condom use? Women?
    a. How do these opinions affect HIV transmission in general?
    b. How do these opinions affect women?
5. How culturally appropriate is formula feeding? Is formula affordable?
6. How much do vertical transmission medications cost? Are they affordable?
    a. Do women living with HIV/AIDS express interest in taking this medication? What do their husbands think?
    b. Are women able to access these medications if they want them?
7. Is there anything else you think I should know about this topic?

Community Education and Peer Educators
[Can I get one of the pamphlets they were passing out at the end? Is there one in English?]
1. How many of these community education performances happen every week/month?
    a. Where do they happen?
    b. Who are the actors/performers?
    c. Who creates the skits?
2. What are the different subjects of community education sessions? Or all they all the same?
    a. Are they generally well received?

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[19] Transcript of the Focus Group discussion is available upon request.

           i.   What are some of the positive reactions/outcomes you have witnessed?

          ii.   If not, what have been some of the negative reactions?

     b.   Do you think they are making a difference?

3. How long is training for Peer Educators?
   a. Who, generally, become peer educators? (what kinds of people)
   b. What is their commitment? Time and energy, etc.
4. Is there anything else you think I should know about this topic?

Home-Based Care
1. When we visited the woman in her home, can you remember how she qualified the help she got from Kimara Peer? (how Kimara helps her)
2. What happens during a normal home-based care visit?
   a. Is food always brought to the patients? Why is this important?
   b. Does Kimara Peer provide medicines for PLHA patients? (non-ARV medicines)
3. Are bio-medical types of treatment ever administered in Home Care visits?
4. Are most neighbors as welcoming as the ones we encountered?
   a. Are there negative responses to home-care? Who do they come from? Why?
   b. Are the levels of stigma higher in some areas more than others? Why?
5. Is there anything else you think I should know about this topic?

Understandings of Health
1. Can we talk generally about how HIV is perceived by the community in general? Why?
   a. What about people living with HIV/AIDS? How do they see it? Why?
2. How is HIV different than malaria? Than cancer?
3. Do Tanzanians fear getting sick in general? Why or why not?
4. Do people fear tuberculosis or cholera as much as they fear HIV?
   a. If not, why do you think there is a difference?
5. When someone is sick, what does a family usually do for the sick person?
   a. When someone is sick with HIV/AIDS, does the family treat the person the same?
      i. If not, how do they treat them differently?
      ii. Why do you think they are treated differently?
6. Is there anything else you think I should know about this topic?