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A comparison of HIV stigma and discrimination in five international sites: The influence of care and treatment resources in high prevalence settings

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Abstract

What accounts for differences in HIV stigma across different high prevalence settings? This study was designed to examine HIV stigma and discrimination in five high prevalence settings. Qualitative data were collected as part of the US National Institute of Mental Health (NIMH) Project Accept, a multi-site community randomized trial of community-based HIV voluntary counseling and testing. In-depth interviews were conducted with 655 participants in five sites, four in Sub-Saharan Africa and one in Southeast Asia. Interviews were conducted in the local languages by trained research staff. Data were audiotaped, transcribed, translated, coded and computerized for thematic data analysis. Participants described the stigmatizing attitudes and behaviors perpetuated against people living with HIV/AIDS (PLWHA). The factors that contribute to HIV stigma and discrimination include fear of

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transmission, fear of suffering and death, and the burden of caring for PLWHA. The family, access to antiretrovirals and other resources, and self-protective behaviors of PLWHA protected against HIV stigma and discrimination. Variation in the availability of health and socioeconomic resources designed to mitigate the impact of HIV/AIDS helps explain differences in HIV stigma and discrimination across the settings. Increasing access to treatment and care resources may function to lower HIV stigma, however providing services is not enough. We need effective strategies to reduce HIV stigma as treatment and care resources are scaled up in the settings that are most heavily impacted by the HIV epidemic.

Keywords

Sub-Saharan Africa; Thailand; HIV/AIDS; stigma; discrimination; Tanzania; Zimbabwe; South Africa

Introduction

When HIV was first discovered, it was identified and contained in specific sub-populations, and these early subgroups that were affected by HIV were easily identifiable and heavily stigmatized (Farmer, 1999; Herek & Glunt, 1988). Two decades later, the scope of the global HIV/AIDS epidemic is staggering. In some sub-Saharan African countries up to one in four individuals is living with HIV/AIDS (UNAIDS, 2008). Why does stigma persist in some settings where virtually everyone has been personally affected by HIV/AIDS, and what accounts for differences in HIV stigma across different high prevalence settings?

One of the earliest scholars to write about disease stigma was Erving Goffman (1963). Goffman suggested that people are stigmatized by others on the basis of being different, and this “deviance” results in “spoiled identity.” Singling people out as different devalues their social position. This early conceptualization of stigma focused on the social-psychological processes of being stigmatized and the consequences of stigma on social interactions (Mahajan, Sayles, Patel, Remien, Sawires, Ortiz, et al., 2008).

More recent research has described the social processes that define stigma, including labeling, discrediting and othering (Aggleton & Parker, 2002; Link & Phelan, 2001, 2006; Maluwa, Aggleton, & Parker, 2002). This research on stigma has also theorized about the broader structural conditions, such as socioeconomic and political conditions, that influence how HIV stigma is experienced and enacted (Castro & Farmer, 2005; Link & Phelan, 2001; Malcolm, Aggleton, Bronfman, Galvao, Mane, & Verrall, 1998; Ogden & Nyblade, 2005; Parker & Aggleton, 2003; Yang, Kleinman, Link, Phelan, Lee, & Good, 2007). Recognizing the influence of these structural determinants highlights the role of power in the perpetuation of stigma.

Describing the role of power as it relates to stigma leads to an understanding of discrimination as a consequence of stigma (Mahajan, et al., 2008). Deacon (2006) defines discrimination as acts that are meant to disadvantage people. While stigma may lead to discrimination it need not always result in discrimination. Distinguishing between stigma and discrimination is useful because it enables us to think about the negative consequences of stigma and to conceptualize responses to stigmatization more broadly (Deacon, 2006).

Research on HIV stigma has described the psychosocial experiences of PLWHA who have been stigmatized (Alonzo & Reynolds, 1995). Stigma has been shown to be associated with stress, depression, and lower perceived quality of life among PLWHA (Wingood, DiClemente, Mikhail, McCree, Davies, Hardin, et al., 2007; Simbayi, Kalichman, Strebel, Cloete, Henda,

& Mqeketo, 2007; Venable, Carey, Blair, & Littlewood, 2006). Some researchers also focused on how stigma affects HIV prevention and treatment efforts (Brown, Macintyre, & Trujillo, 2003; Ogden & Nyblade, 2005), including the use of condoms (Roth, Krishnan, & Bunch, 2001), HIV testing uptake (Fortenberry, McFarlane, Bleakley, Bull, Fishbein, Grimley et al., 2002; Obermeyer & Osborn, 2007), and uptake of prevention of mother to child transmission programs (Varga, Sherman, & Jones, 2006; Eide, Mhyre, Lindbaek, Sundby, Arimi, & Thior, 2006). Among those who agree to be tested, stigma has been identified as a factor contributing to the refusal to return for the results (Worthington & Myers, 2003) and low HIV disclosure rates (Derlega, Winstead, Greene, Servoich, & Elwood, 2002). Researchers have also described how stigma can negatively affect people's uptake of and adherence to antiretroviral therapy (ART) (Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Wolfe, Weiser, Bangsberg, Thior, Makhema, Dickinson et al., 2006; Sayles, Wong, Cunningham, 2006).

This paper aims to describe HIV stigma and discrimination in five international sites. We describe the expressions of stigma, the factors that contribute to stigma, and those that protect PLWHA from stigma. By comparing data across the sites we emerged with an understanding of HIV stigma and discrimination that is shaped by the availability of health and socioeconomic resources that are designed to mitigate the impact of HIV/AIDS on families.

Methods

The data for this study were collected prior to the launch of US National Institute of Mental Health (NIMH) Project Accept, a community randomized trial designed to measure the efficacy of a community-based model of voluntary HIV counseling and testing.

Study sites

NIMH Project Accept is being conducted in 48 communities in four countries, including 10 communities in Kisarawe, Tanzania, 14 in Chiang Mai, Thailand, 8 in Mutoko, Zimbabwe, and 16 in South Africa (8 in Vulindlela, KwaZulu-Natal, and 8 in Soweto, Gauteng). The study sites are all rural with the exception of Soweto, South Africa, which is a densely populated urban township of Johannesburg with just over 1 million inhabitants. The second site in South Africa, Vulindlela, is a sub-district within the KwaZulu-Natal midlands region. It is situated about 140 km from Durban, and has a total population of approximately 400,000. In Tanzania, the study site is located in Kisarawe, a rural district of approximately 100,000 people located 30 km northwest of Dar es Salaam. The Zimbabwe site is located in Mutoko, a rural district, with approximately 130,000 residents, located 150 km. from Harare. The only Asian site included in the trial is located in Chiang Mai Province, in Northern Thailand. The study communities are located in a mountainous area between 40-135 km from Chiang Mai City.

Table 1 provides a comparison of HIV related statistics for 2005-2006, the period of time in which these data were collected, in the four project countries (UNAIDS, 2007; WHO, UNAIDS, & UNICEF, 2007). The African sites are experiencing a generalized HIV epidemic, while the epidemic in Northern Thailand is concentrated among injecting drug users. The HIV prevalence among injecting drug users in the communities where this study is being conducted has been reported as high as 32% (Razak, Jittiwutikarn, Suriyanon, Vongchak, Srirak, Beyrer et al., 2003). Table 2 compares general health systems indicators across the countries (USAID, 2008).

Study sample

The data were collected using semi-structured interviews with a sample of community members who had previously been randomly selected for a baseline survey. To be eligible for the qualitative interviews participants had to be between 18-32 years, currently residing in the

study communities, and planning on remaining a resident for the next 2.5 years. To select participants for the qualitative interviews, we stratified the baseline survey sample into a combination of eight demographic categories according to gender, age (younger participants 18-24 years and older participants 25-32 years), and partner status (single or coupled). We felt it was important to have representation across these demographic categories because we anticipated that they would influence participants' experiences with HIV risk, HIV testing and HIV stigma. We randomly selected approximately two participants per demographic category in each of the African communities and one participant per category in each of the Thai communities because more Thai communities were included in the trial. In total, 655 participants were interviewed across all 5 sites at baseline including 109 in Soweto, 126 in Vulindlela, 159 in Tanzania, 117 in Thailand and 144 in Zimbabwe.

Participants will be interviewed four times throughout the study period at baseline and 6-months, 15-months and 30 months after the intervention launch. The data presented in this paper were drawn from the baseline qualitative, collected between January, 2005 and October, 2006. The qualitative assessment is designed to provide insight on changes in secondary study outcomes including HIV risk behaviors, HIV stigma, HIV testing behaviors and HIV related discussions.

Data collection methods

The in-depth interviews were semi-structured based on a standard field guide that was used across the four countries. The field guide outlined topics for discussion. Trained local interviewers conducted 30-60 minute in-depth interviews in the local language. The guide had questions to explore perceived, enacted and experienced HIV stigma and discrimination in the communities. We asked participants how they and members of their community feel about and treat PLWHA. For those individuals who knew someone with HIV/AIDS we asked them to provide details about how they learned of this individual's HIV diagnosis, how they felt about this person, and about their interactions with this individual. We did not ask participants to reveal their own HIV status; however, during the course of the interview six participants from Vulindlela, two participants from Soweto, one participant from Zimbabwe and one participant from Thailand disclosed that they were HIV positive. To the extent that these HIV positive participants were comfortable, the interviewers asked them about their experiences living with HIV in their communities, including the perceived attitudes and behaviors of people towards them.

Data processing and analysis

The interviews were audiotaped, transcribed and translated into English. Interviews were then computerized and coded in Atlas.ti. Thematic data analysis was conducted in two phases. In the first phase, the data were indexed by topics through the application of topical codes, also called descriptive codes in the literature (Miles & Huberman, 1994). Topical codes included general contextual information, HIV risk, HIV stigma, HIV testing and HIV related discussions. Within each topical code we had between four and 11 sub-codes. Our codebook included a detailed description of each code and sub-code, inclusion and exclusion criteria and examples of real text (MacQueen, McLellan, Kay & Milstein, 1998).

We trained coders at each site to conduct the topical coding. In the case of the data on stigma, often relevant information in the interview transcripts would appear within discussions about other topics such as HIV testing or HIV risk. Coders were trained to double code text with a stigma code in the event that this occurred. Each interviewer completed a coding certification process at the end of the training. To be certified each coder had to code two sample interviews. We compared their coding against coded templates created by the Qualitative Directors. If there were errors in the coding we provided the interviewers with additional coding training

and then had them repeat the certification process with another template. Ongoing quality of the coding was monitored during regular data merge cycles.

In the second phase of the analysis we developed interpretive codes to identify and analyze the themes that emerged within the topically coded data (Miles & Huberman, 1994; Ryan & Bernard, 2000). We developed coding definitions and rules for the interpretive codes, and then we coded the topical code reports with the interpretive codes. Example of interpretive codes that we applied included fear of transmission, fear of death, and family providing care and support. Three researchers applied the interpretive codes to the stigma data, each working independently on the data from different sites. We met regularly to talk about the coding and in that process further refined the interpretive code list. Data were synthesized and compared across the five sites by reviewing the interpretive code reports. We had two data analysis workshops with the Qualitative Directors to discuss and refine our understanding of the interpretively coded data. The study was approved by the South African, Tanzanian, Zimbabwean, Thai, and US-based institutional review boards representing each site.

Results

By comparing the data across the sites we identified interesting variations and commonalities in the expression of stigma and discrimination, the factors that contribute to stigma and discrimination, and the factors that protect PLWHA from stigma and discrimination.

Expressions of Stigma

When we asked participants how they feel about PLWHA, most participants initially described sympathetic or neutral attitudes. The sympathy that participants felt was usually associated with the suffering that they witnessed among PLWHA in their communities.

“I will only feel pity for them. [Why would you feel pity for an HIV positive person?] The nature of their illness and the suffering they will be going through. Some won't have people to care for them and their children will stop going to school.” (Older coupled female, Mutoko, Zimbabwe)

In Thailand and South Africa, participants made reference to anti-stigma media campaigns that communicated the importance of treating PLWHA respectfully and compassionately. Upon further probing and presentation of personal narratives, participants revealed less compassionate attitudes. Blame, othering, and disgust were the stigmatizing attitudes described most often by participants.

Stigmatizing Attitudes

Blame and Othering—There was an interesting connection in the data between the blame that people associated with getting infected with HIV/AIDS and the othering, or social distancing, that they described between themselves and PLWHA in their communities. The blame directed at PLWHA varied by site. In Tanzania and Zimbabwe, behaviors that led to HIV were often described as “*irresponsible*”, “*reckless*” and “*immoral*.” As a result, many individuals in these sites felt that PLWHA got what they deserved in terms of being punished for their reckless behavior. The blame was often accompanied by anger and resentment because of the demands that PLWHA placed on family members who were responsible for their care.

“They blame the patient that he or she was deliberately infected but now is burdening innocent people.” (Younger single male, Mutoko, Zimbabwe)

In Tanzania there was a contradiction in how participants perceived HIV risk and communicated associated blame. While many participants blamed PLWHA for getting infected, there were others who used the term “*ajali kazini*” (accident at work) to describe the

risk of getting infected. Associating HIV with an accident implied that there is an element of chance to getting infected. Like an accident, it can happen to anyone at any time, and there is little one can do to avoid the risk.

“Aaa, they just tell you that is an accident at work. [What do they mean by the word “ajali kazi”?] They mean that someone can die anywhere.” (Younger coupled female, Kisarawe, Tanzania)

Tanzanian participants who believed that everyone is at risk were more likely to perceive little difference between themselves and PLWHA.

“I believe human beings are not perfect, one may have done a mistake and when you laugh at your fellow today you may find yourself in that same position or situation tomorrow.” (Older single male, Kisarawe, Tanzania)

Some participants in South Africa expressed similar thoughts about ubiquitous risk for HIV, and as a result, feelings that PLWHA must be treated as they would want themselves to be treated if they became infected. These participants described little social distance between themselves and PLWHA.

“Why should I treat them bad while I might be next. I don't know maybe I am laughing at this person while I might have it.” (Younger coupled female, Soweto, South Africa)

Thai participants described pity and sympathy for most PLWHA, except those who continued to engage in risk behaviors that put other people at risk. There was also less tolerance for individuals who became infected through injecting drug use (IDU), and then continued to use drugs after diagnosis.

Disgust—Most participants described PLWHA in their communities who were at the end stages of the disease. Individuals who knew PLWHA often described the symptoms associated with AIDS in graphic detail. They were afraid and disgusted by the physical symptoms that they witnessed.

“Everyone who got infected must die. And it's the thing that is disgusting. Some got pimples and wounds, it made people disgust. People can't accept it. [But for some who don't have any symptoms?] They can live in the community and can go to everywhere.” (Older single female, Chiang Mai, Thailand)

Stigmatizing Behaviors

The blame, othering and disgust associated with HIV/AIDS often led to negative behaviors directed at PLWHA. The behaviors, or acts of discrimination, that were mentioned most often by participants included social isolation, gossip, and public shaming.

Social Isolation—Participants in all sites described the social isolation of PLWHA and their families. The isolation almost exclusively happened at the end stages of their illness when the physical deterioration of PLWHA was most acute, as this participant describes in Soweto:

“You start being sick, and then the neighbors pull away from you. They don't want to be involved and assist where they can.” (Younger single male, Soweto, South Africa)

In a few cases, the social isolation by the community was extended to the families of PLWHA.

“It is just discrimination because if they were to know that someone from that family was killed by HIV/ AIDS they will discriminate the whole family and even things such as cats and mice from that family they would say that they also have AIDS.” (Older single male, Soweto, South Africa)

The family of PLWHA sometimes isolated their infected family members within the home by providing them with separate bedding, utensils and in rare cases with separate living quarters.

“They feel that when you are HIV positive you are no longer like the others and you are not supposed to stay with the others. Just like in the past people with leprosy were isolated from the others. Right now HIV positive people are not necessarily chased away from home premises but they are isolated within the homestead.” (Younger single male, Mutoko, Zimbabwe)

In Thailand, participants described greater awareness and acceptance of PLWHA in their communities. In several interviews, participants talked about how in the past, HIV positive community members were socially isolated and not allowed to participate in social events such as funerals.

“When AIDS first came, they were afraid. But now it's like normal. In the past, if HIV infected persons went to a funeral, no one dared to eat with them because they were afraid. (Laugh) Now they're all like normal.” (Older single male, Chiang Mai, Thailand)

Gossip and Public Shaming—Gossip was described by participants in all sites. Community members speculated about who was infected with HIV, and how they may have become infected. Gossip was usually triggered by visible signs and symptoms of AIDS.

”Hay, you find that a person is now sick; he is on someone's back and is taken to the hospital. The people then with their curiosity come out, also those peep on the windows that a person has now been put on the wheelbarrow [on his way to the hospital]. This disease, aunties even the elderly people talk... Yes, yes, yes (laughter). You become the talk of the town.” (Older coupled male, Vulindlela, South Africa)

Most of the gossip did not occur in the presence of the PLWHA. However, a few of the Tanzanian and Zimbabwean participants described incidents of public shaming that they witnessed. In these examples, the PLWHA were verbally abused in public.

“When she passed them they would often tell her to her face, “You over-did it, no wonder you are suffering from HIV. You won't live long, you'll just die”, you see!” (Older single female, Kisarawe, Tanzania)

Contributing Factors—When analyzing the data across the five sites the factors that contributed to HIV stigma and discrimination emerged through the narratives of participants. Contributing factors are the underlying reasons that HIV stigma and discrimination are perpetuated in the communities.

Fear of Transmission from Casual Contact—Despite widespread and accurate knowledge of HIV transmission, participants in all sites described fear of transmission from casual contact. This fear led to the social isolation and neglect of PLWHA. This fear was most pronounced among participants from Zimbabwe and Tanzania.

“Ah it's scary. I fear to contract the virus by touching him maybe he will be having small wounds and may pass on the infection to me.” (Older coupled male, Mutoko, Zimbabwe)

There was some reference in the data from both South African sites to the role of media in educating people about HIV/AIDS transmission and reducing stigma, however, even in these sites there was still some fear associated casual contact.

“Because we are being taught about it everyday and people are growing and realizing everyday that they should treat a person with HIV like this... Yes there are those who

are still scared of it and saying things such as a person with HIV is very scary and I won't give him or her a hug.... (Older coupled female, Soweto, South Africa)

In Thailand, younger participants said they knew that HIV could not be transmitted through casual contact, and thus they had little fear of socializing with friends who may be HIV positive. They attributed fear of transmission from casual contact to older and less educated members of their community.

Fear of Suffering and Death—When recalling experiences with PLWHA in their communities, most participants focused on the physical deterioration of the infected community members, and described their symptoms in detail. Fear of the physical deterioration and death of PLWHA emerged from the African datasets, but was virtually absent from the Thai data.

“People in this community believe that people with AIDS are as good as dead and label them ‘dead people.’ They say such people are scary as they are already corpses.” (Older coupled male, Mutoko, Zimbabwe)

Within the African sites, there were differences in the perception of the inevitability of death for PLWHA. While HIV was described as a death sentence in Zimbabwe and Tanzania, death was not inevitable in the narratives from South Africa. Participants from these sites made reference to the role of treatment in keeping people alive.

“Being positive means I have the virus and I am going to live with it for the rest of my life. I would be scared (learning that I have HIV) because I know that I have it. Even though I know that when you find out that you have it, that doesn't mean that you are going to die at the same time. I heard when they talked about ARVs on the radio. They said they are now available. They say that they suppress the disease when you are too sick.” (Younger single female, Soweto)

Burden of Care and Support—Another factor that contributed to stigma and discrimination was the burden of caring for PLWHA. This burden was described most often by participants from Zimbabwe and Tanzania, where access to care and support resources were scarce. Participants in Zimbabwe talked about PLWHA as a drain on their communities.

“Right now those who are infected are not treated as fellow human beings. They are already declared dead, and regarded as useless as a grave. That is how they are treated... They mean that these people are no longer able to do anything useful. They say they are just waiting for the day of their death.” (Younger single male, Mutoko, Zimbabwe)

Caring for AIDS patients was usually the responsibility of family members. Family often felt unprepared to manage the health needs of their sick relatives and as a result these demands overwhelmed and burdened family members. Participants also acknowledged that often the families of HIV positive individuals are very poor, and the illness further strained the families' already limited resources.

“They won't have enough energy to go make a living, such as maybe fetch an axe or fetch charcoal. You see, they are already infected in their bodies, and you will find that they have really poor families. The family does not have any kind of help. If they are not helped with the disease, they might die of hunger before the disease even kills them.” (Older coupled male, Kisarawe, Tanzania)

Participants in Zimbabwe and Tanzania talked about the fear of learning their HIV positive status because of the burden that they knew their care would place on their family.

“If I hear that I am infected, I would kill myself. [Why would you want to kill yourself?] I will be lessening the burden to those who will take care of me because it's not easy bathing an HIV positive person.” (Older coupled male, Zimbabwe)

While participants in both sites in South Africa and Thailand also identified the family as an important source of care and support for PLWHA, participants in these sites also identified supplemental sources of care and support for PLWHA in the communities including, social grants, palliative care programs, and other community-based initiatives.

Protective Factors—Through the personal narratives of participants we identified people, resources and actions that protect HIV positive individuals from stigma and discrimination.

Family—The family played a role in both protecting against stigma and discrimination and being the source of stigma and discrimination in some cases. As we described earlier, there were examples of family members who isolated their HIV infected relatives within the home, and others who blamed HIV positive family members for becoming infected because of the burden that the disease placed on the family. However, more often participants referred to family members as a source of support and protection against stigma by others. Many participants made the distinction between their attitudes and behaviors towards someone in their family infected with HIV/AIDS and someone outside of their family. There was a deep sense of commitment to caring for family members infected with HIV in all of the sites.

“They may feel like discriminating them but they cannot do that to their own relatives. If you don't assist them you won't be doing yourself any good.” (Younger coupled male, Mutoko, Zimbabwe)

Family members also protected their HIV infected relatives from the stigmatizing behaviors and attitudes of others.

“So I didn't want people visiting her, I only wanted family members to be close to her. The other thing is that you can't trust a friend because they can be with you now and not be around when things are bad.” (Older coupled male, Soweto, South Africa)

Access to Antiretroviral Therapy (ART)—Very few participants in Zimbabwe and Tanzania knew people who were on ART, while participants in South Africa and Thailand made more reference to ART in their interviews. Thai and South African participants acknowledged that the drugs keep people healthy. As long as one looked physically healthy it was easy to conceal one's illness, and consequently avoid stigma and discrimination. This quote from a participant in South Africa demonstrates the perception that treatment is available in these sites and the belief that PLWHA who do not avail themselves of treatment services are unnecessarily burdening their family members with their care needs.

“Yes, when you are sick and bed ridden, messing yourself up [urinating and defecating on yourself] and everything else, unable to wake up and go to the toilet. It would have been you who did not take the treatment. It is the same thing as troubling your family members, because the treatment helps you to boost the soldiers [immune system] (...).” (Younger coupled female, Vulindlela, South Africa)

While taking ART could prevent PLWHA from stigma and discrimination, participants from South Africa also talked about the role of stigma in preventing people from accessing ART services.

“The person will go for a test and find out that he is positive, and be scared to go and collect them (ARVs) because they are usually scared. We are usually scared. We think it's too obvious because people look at us at the clinic... [Are you collecting the pills?]”

No, I do not collect pills. I am scared that people will look at me at the clinic.”(Younger single female, Vulindlela, South Africa)

Resources—Participants talked about other health services and socioeconomic resources that shielded PLWHA from stigma and discrimination. In South Africa and Thailand, participants mentioned social grants for PLWHA that provided funds for basic necessities like food, housing and medication. These grants help ease the burden on families caring for PLWHA.

“Yes, someone might have it, and does not have money to buy these food. The government helps with money so that a person can get a grant to buy those things that one can eat to strengthen their body.” (Younger coupled female, Vulindlela, South Africa)

However as we saw with ART, some South African participants talked about the stigma associated with accessing these social grants because they feared they would be identified as HIV positive when collecting the grants. There were other resources, including home-based care programs and peer education programs, which participants in South Africa and Thailand mentioned.

Financial resources that PLWHA were able to continue contributing to their households also helped to protect them from stigma and discrimination in the family, as described by this South African participant:

“My friend does not have a problem with her family since she is a breadwinner. She does not have parents. She is not staying with her brother, and she is taking care of her sister's children. So I would say she is doing everything in her family and they listen to her.” (Older coupled female, Vulindlela, South Africa)

Self-Protective Behaviors—We found examples of strategies that PLWHA use to protect themselves from stigma and discrimination. There were examples of PLWHA who isolated themselves to avoid the stigma and discrimination that they anticipated in their communities. This HIV positive participant from South Africa describes her fear of losing her life if she goes out publicly and others identify her as HIV positive,

“I do not believe I will be able to get out of my house to face them if many people know. Because perhaps when I am walking, even though you cannot see that I am HIV positive, that I am sick, but I may lose my life. (participant is silently crying).” (HIV positive, younger coupled female, Vulindlela, South Africa)

Some participants described PLWHA changing their behaviors to protect others from risk or from feelings of discomfort.

“I used to join dinner with my friend who was an HIV patient, but he told me to sit far away from him...I said that I was fine, but he said, ‘No you shouldn't do that. You must not eat with me if you love me’.” (Older single male, Chiang Mai, Thailand).

These strategies may reduce the PLWHA's exposure to stigma and discrimination, but they also led to other negative psychosocial outcomes for PLWHA, including loneliness and despair. In these narratives we recognize an internalization of stigma among PLWHA. The PLWHA identify themselves as different from others, and they took actions to protect others from the discomfort that this difference may create (Sayles, Hays, Sarkisian, Mahajan, Spritzer, & Cunningham, 2008).

Discussion

These qualitative data from participants in four countries illustrate the ways in which stigma and discrimination are expressed through attitudes and behaviors of community members. These data also highlight the factors that contribute to the stigmatizing attitudes and behaviors, as well as the factors that protect PLWHA from these negative experiences.

Through these individual reflections we begin to see differences across settings in the extent and types of HIV stigma and discrimination that exists. The differences in HIV stigma in these five sites reflect the differences in the resources available at each site to respond to the epidemic. As illustrated in Table 1, there is no clear association between HIV prevalence and resources spent by national governments on AIDS in these four countries. Table 2 summarizes differences in the strength of the health system across the four countries. The differences that we see through the country-level data is supported by the site specific data summarized in Table 3. Table 3 summarizes the baseline survey findings related to ART knowledge and perceptions of access from the five study communities (NIMH Project Accept, 2008). The lowest awareness of ART, knowledge of people on ART, and perception that ART is easily accessible were reported by participants in Tanzania and Zimbabwe.

The experience of caring for PLWHA without adequate external health and socioeconomic resources plays an important role in shaping attitudes and behaviors towards PLWHA. The blame that we found in the Zimbabwe data, for example, needs to be understood in that specific context where HIV prevalence is very high and there are very few resources available to families who have to care for PLWHA at the end stages of the disease. Families felt taxed by the burden of caring for PLWHA. In contrast, in settings like South Africa and Thailand, where there was a greater awareness of resources such as ART, social grants and other palliative care programs, there was less of a sense of burden and blame by community members. South African and Thai participants describe the specific ways in which these resources helped to shield PLWHA from stigma and discrimination. For example, access to ART helps PLWHA avoid the physical signs and symptoms of AIDS that often triggered stigma and discrimination, and access to social grants provide material support to families that can help ease the burden of caring for PLWHA.

This is not the first study to describe stigma across different contexts (Makoe, Greeff, Phetlu, Uys, Naidoo, Kohi, et al. 2008; Ogden & Nyblade, 2005; Dlamini, Kohi, Uys, Phetlu, Chirwa, Naidoo, et al., 2007). These prior studies provide information on how stigma and discrimination are expressed and how PLWHA cope with stigma in different settings, but they are limited in their analysis of the factors that contribute to and protect against stigma and discrimination across the settings. Studies carried out within the context of each of the four countries – Zimbabwe (Tarwireyi, 2005; Duffy, 2005), Thailand (Boer & Emons, 2003), South Africa (Campbell, Nair, Maimane, & Nicholson, 2007), Tanzania (Nyblade, MacQuarrie, Phillip, Kwesigabo, Mbwambo & Ndega, 2005) – have described how incomplete knowledge related to HIV transmission is related to HIV stigma (Boer & Emons, 2003; Ogden & Nyblade, 2005), how poor access to health related resources is associated with stigma, (Campbell, et al., 2007), and how blame and othering is a powerful expression of stigma in settings where communities feel overwhelmed in caring care for PLWHA (Duffy, 2005). Our study reinforces these associations, and the comparative nature of our study allows us to further explain variation in HIV stigma across different high prevalence settings.

The study is not without limitations. First, to allow for cross-site comparisons, we developed guides for the in-depth interviews that were semi-structured. The structure to the guides may have constrained the extent to which interviewers probed for emerging issues that were not covered on the guides. Second, we elicited a combination of perceived norms and actual

experiences related to HIV stigma. Interviewers were trained to elicit personal narratives from the participants when they self-disclosed as being HIV infected, or when they had first-hand experience interacting with PLWHA in their communities, however not all participants had these experiences. Third, all interview data were transcribed and translated into English for analysis. We felt the benefit of doing the cross-site analysis in English outweighed the cost of what we know can be lost in the translation process. In addition, we acknowledge that stigma may be perceived, expressed and experienced differently across the life course. Gaining an understanding of stigma across the life course would involve conducting similar data collection with other age groups in the communities. We identified examples of participants who expressed empathy towards PLWHA early in the interviews, but then later expressed less tolerant and supportive attitudes when narrating their own experiences with PLWHA. This discrepancy may reflect a positive reporting bias in our data, particularly in settings where there have been anti-stigma campaigns in the media. This discrepancy may also reflect the fact that our methods enabled us able to build rapport so that participants felt comfortable sharing less tolerant and supportive feelings. Finally, we had only 10 participants who self-disclosed as HIV positive in the interviews, thus we do not feel we have data to adequately represent the stigma experienced by HIV positive participants in these settings.

Despite these limitations, the opportunities that these data present to gain an in-depth understanding of HIV stigma and discrimination across five different settings are unprecedented. To our knowledge this is the first qualitative study of its kind to explore and compare HIV stigma among a demographically representative sample of community members within four countries. Considerable thought was given at the outset to how we can meaningfully explore similar experiences across very different settings. The interview guides were designed to be flexible enough for the qualitative teams to identify and pursue emerging themes at the sites, yet standard enough to allow us to compare data across the five sites. We used the multi-site trial design to implement a qualitative study that provides a rich understanding of our topics across these settings, and also provides critical input into the design, implementation and the evaluation of the overall study.

These data suggest that interventions designed to reduce stigma, in the absence of concurrent programs to scale up treatment and care services, may have limited impact. Similar arguments about the importance of access to ART in reducing HIV stigma have been made by others (Castro & Farmer, 2005; Wolfe, Weiser, Leiter, Steward, Percy-de Korte, Phaladze, et al., 2008). Fortunately, progress is being made globally to increase access to ART. As of December, 2007 there were 3 million people receiving ART in low and middle income countries (UNAIDS, 2008). While this represents a 45% increase from 2006, it is still estimated that 70% of those who need treatment are not receiving the medication (UNAIDS, 2008). Providing greater access to care and treatment resources, so that the families living in regions most affected by the HIV/AIDS epidemic are not left on their own to respond to the needs of their infected family members, may make the greatest difference in terms of reducing stigma and discrimination in these settings. At the same time, as we saw reflected in these data, providing the services is not enough. We need effective strategies to reduce HIV stigma as treatment and care resources are scaled up and rolled out in the settings that have been most heavily impacted by the HIV epidemic. To date we have limited information on what intervention approaches work to reduce HIV stigma (Brown, et al., 2003; Mahajan, et al., 2008). There is little evidence that the predominant HIV stigma reduction strategies that have been evaluated, including the provision of information at the individual level and through mass media campaigns, has led to significant and sustained changes (Mahajan, et al., 2008). There is a need to evaluate intervention strategies that target the structural determinants of stigma. Community-level interventions to mobilize PLWHA and community leaders in efforts to reduce stigma and discrimination are also important approaches that deserve more attention and study.

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Table 1
HIV/AIDS statistics for the NIMH Project Accept Sites

Country	HIV Prevalence (Adults 15-49) 2005	AIDS Deaths (Adults and Children) 2005	National Funds Spent by Government from Domestic Sources for AIDS 2005	ARV Coverage 2006
South Africa	18.8	320,000	\$446.50 Million US dollars	32%
Tanzania	6.5	140,000	\$45.00 Million US dollars	18%
Thailand	1.4	21,000	\$92.80 Million US dollars *	88%
Zimbabwe	20.1	180,000	\$12.10 Million US dollars	15%

* Only 2006 data available

Table 2
Health Systems Information for the NIMH Project Accept Sites (USAID, 2008)

Country	% expenditure on health financed by donors	% expenditure on health financed by households	Physician ratio per 1,000 people	Maternal Mortality Ratio per 100,000
South Africa	1%	11%	0.77	230
Tanzania	22%	36%	0.2	1,500
Thailand	0%	29%	0.37	44
Zimbabwe	7%	36%	0.16	1,100

Table 3

ART knowledge and perception of ART Access in NIMH Project Accept Sites

Site	Heard of ART	Know anyone taking ART	Perception that ART are easily available
Soweto, South Africa	72.5%	28.9%	20.8%
Vulindlela, South Africa	69.8%	27.3%	23.7%
Kisarawe, Tanzania	41.7%	9.6%	17.1%
Chiang Mai, Thailand	55.5%	40.5%	32.7%
Mutoko, Zimbabwe	28.3%	16.2%	9.9%