"I Have an Evil Child at My House": Stigma and HIV/AIDS Management in a South African Community

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We examined the social roots of stigma by means of a case study of HIV/AIDS management among young people in a South African community (drawing from interviews, focus groups, and fieldworker diaries). We highlight the web of representations that sustain stigma, the economic and political contexts within which these representations are constructed, and the way in which they flourish in the institutional contexts of HIV/AIDS interventions.

Stigma serves as an effective form of "social psychological policing" by punishing those who have breached unequal power relations of gender, generation, and ethnicity. We outline an agenda for participatory programs that promote critical thinking about stigma's social roots to stand alongside education and, where possible, legislation as an integral part of antistigma efforts. (*Am J Public Health.* 2005;95:808–815. doi:10.2105/AJPH.2003.037499)

Stigmatization of people living with AIDS is a key obstacle to HIV prevention and AIDS care. It is now generally accepted that efforts to reduce stigma should be an integrated part of all HIV/AIDS programming.[1] However, discussions of the form such efforts should take remain in their infancy. Here we discuss the social roots of stigma in the interest of contributing to debates about appropriate stigma reduction interventions, drawing on a case study of HIV/AIDS management among young people in South Africa.

The existing HIV/AIDS literature points to 3 antistigma strategies. The first is information-based awareness programs designed to reduce ignorance about people with AIDS. However, while ignorance often plays a key role in perpetuating stigma, providing people with factual information about the contagiousness of illnesses does not lead to widespread stigma reduction.[2] The second strategy is institution of legal safeguards making discrimination against people with AIDS a punishable offense. Antidiscrimination legislation has the potential to reduce the explicit and public stigmatization of such individuals.[3] However, manifestations of stigma are often too subtle to be immediately apparent, rooted within individual psyches, families, and communities and beyond the reach of the legal system. Thus, while education and legal safeguards may arguably be necessary conditions for fighting stigma, they are certainly not sufficient ones.

The third strategy—which we believe should go hand in hand with the first 2—involves participation of local community members in antistigma efforts. Our interest in this strategy informs the discussion provided here. Although community participation is repeatedly advocated, there is a lack of clarity regarding precisely *what* community members should participate in and *how* this participation should take place. Much work remains to be done in providing specific direction to calls for participatory initiatives, lest they result in nothing more than programs in which participants are encouraged to tell one another that stigma is a bad thing and that they should not contribute to it. Such didactic approaches are less likely to succeed than initiatives promoting debate and dialogue within a group of people, especially in marginalized communities where social obstacles may undermine attitude or behavior change. It is through such dialogue that a group may develop critical understandings of the social roots of health-damaging attitudes or behaviors, enhancing their awareness of the obstacles to change they will have to overcome and, ideally, leading to collective action to challenge such obstacles.[4]

What are the social roots of stigma? The theoretical literature emphasizes that stigma results not only from fear of physical contagion but also from fear of "symbolic contagion," a threat to both the health and well-being of individuals and to the well-being and legitimacy of the status quo. Whereas the form and content of stigma will vary from one context to another, various forms of stigma are united by the way in which they serve to support systems of social inequality and social difference and to reinforce the interests of powerful social actors seeking to legitimize their dominant status.[3] We examine the form taken by stigma in 1 small local community in the interest of understanding some of the ways in which stigmatization of people with AIDS is situated within other patterns of material and symbolic social exclusion. We conclude by discussing the implications of our findings for participatory strategies that challenge stigma.

CONCEPTUAL FRAMEWORK

Psychodynamic thinkers speak of the existence among humans of a universal unconscious fear of collapse and chaos.[5] People may cope by projecting their worst fears onto identifiable out-groups. This process of stigmatization or "othering" is thought to serve an "identity-protective" function by producing feelings of comfort and security and a sense of personal invulnerability to threats and dangers that might otherwise appear overwhelming.

Stigmatization is also argued to serve a "system-justifying" function.[6] The content of the psychological processes associated with "othering" may often reflect wider social interests. A study of representations of AIDS in Zambia highlighted how the stigmatization of women as vectors of AIDS, with men depicted as the "innocent parties," is part and parcel of a more general devaluing of women.[7] In another context, people with AIDS have been described as the symbolic markers of all that threatens to undermine American society and economic success.[8] In

a country where economic success is built on traditional values of self-discipline, self-control, and prosperity, HIV/AIDS (stereotypically associated with promiscuous sex, drug abuse, and poverty) can be seen as standing for everything that threatens the middle American way of life. HIV/AIDS is an "epidemic of signification" at the same time as it is a biomedical epidemic, and stigmatization of people with AIDS has been an important vehicle for affirming the status quo.[9]

The widespread stigmatization of sex in South Africa and President Mbeki's well-publicized refusal to acknowledge the extent of the AIDS problem have been linked to the president's project of postapartheid nation building and to his conception of the type of citizen best equipped to carry forward his vision of an "African Renaissance." The president makes a strong distinction between South Africa's wretched past and a bright new postapartheid future. AIDS, and its association with promiscuous and diseased sexuality, threatens to blur this distinction. Public discourses and silences around sexuality are embedded in "a wider matrix of moral anxiety, social instability and political contestation" characterizing the current historical moment in South Africa, where people battle with "the complexities and vulnerabilities of the drive to produce a newly democratic unified nation."[10]

More broadly, Africanist historians have found that policing of sexuality, stigmatization, and social inequalities are linked. They have shown how the teachings of the church (particularly Victorian sexuality as mediated by Christian missionaries) were combined with the construction and reconstruction of so-called "traditional African culture" to place limits on the sexuality of African women, preserving the patriarchal social relations that continue to dominate in South Africa, despite challenges and resistances.[11,12]

METHODOLOGY

We draw on a case study of a youth HIV prevention program run by an international body, the Christian Youth Alliance (CYA), in the South African community of Ekuthuleni, a periurban area near Durban in KwaZulu-Natal province. (Both the name of the community and that of the youth organization have been changed in line with the ethical principles of anonymity and confidentiality.) Sixteen percent of all KwaZulu-Natal adults aged 15 to 49 years are HIV positive,[13] as are 36% of women attending antenatal clinics.[14] Heterosexual sex is the most common mode of transmission, and levels of HIV among young people are particularly high.[4] Ekuthuleni is home to 20 000 people, some living in formal housing with road access and services, but many living in makeshift shacks with minimal access to water and electricity. Unemployment and poverty are rife. Although many residents are HIV positive or suffering from AIDS, levels of disclosure are minimal. Nearly all of our research informants reported that they were not aware of anyone in the community who they were sure was HIV positive.

Funded by overseas donors, the CYA has established a nongovernmental organization in Ekuthuleni that promotes peer education among young people, both in and out of school, in the context of an integrated approach, including support groups and individual counseling for people with AIDS. We examined how local community contexts facilitated or hindered the success of CYA's peer education program. An open-ended topic guide focused on informants' views of the South African political context; local community life; the causes of HIV transmission, the impact of AIDS on their community; the role of their particular peer group in contributing to HIV/AIDS management; and their views on peer education, participation, and partnerships as strategies for HIV prevention.

This case study took the form of 3-hour interviews conducted in 2003 with 44 people, 11 focus groups involving a total of 55 people, and fieldworker diaries. Informants included young people and peer educators both in and out of school, teachers, a school principal, community health workers, community leaders (traditional leaders, the local ward councillor, youth leaders, and members of the local development committee), CYA staff, a traditional healer, clinic nurses, parents, people with AIDS, church ministers, a government official, and representatives of a multinational company that employs local people.

Thematic content analyses were used in analyzing interviews.[15] Stigma emerged as a central topic, and the goal of the preliminary data analysis was to identify the forms taken by stigma and its effects on the CYA's work. A more detailed secondary analysis sought to identify the material, symbolic, and organizational contexts associated with stigmatization of people with AIDS.

FINDINGS

Forms of Stigma and Effects on the Christian Youth Alliance's Work

We found that stigma was rife. One anecdote after another referred to the vicious stigmatization of HIV-positive individuals of all ages. As reported by a youth worker: "Children are not comfortable to disclose [their HIV status] to their parents. Their mothers gossip, saying 'I have an evil child at my house who has contracted this disease.'" Family members sometimes hid away sick relatives, depriving them of health care or support. According to a community health worker, "Neighbors will tell me there is a sick person in the bedroom at the back of the house. But when I arrive the family denies having such a person. The families themselves prevent anyone from helping them."

Families sometimes disowned dead relatives, refusing to collect their bodies from the mortuary, for example. Amidst stories of rejection and prejudice, there were a few stories of care and compassion among family members. However, even in such families it was not uncommon for both the dying person and his or her family members never to refer to the fact that the person had AIDS, even when everyone was fully aware of the situation. One woman reported that, even after her sister's death, no one in the family had ever strayed from the "official story" that she had died of tuberculosis, despite everyone secretly being aware that she had died as a result of AIDS-related illnesses.

People with AIDS who did disclose to family members often did so in indirect ways. One man stated that his brother, 2 weeks before his death, wrote the family a letter disclosing his status rather than telling them face to face. When the man told mourners at the

funeral that his brother had died of AIDS, several friends and relatives berated him for "spoiling his brother's name."

Stigmatization by one's family members, at the very time one most needs their support, is often cited as the most hurtful and damaging form of stigma and the form that has the most negative effects on the HIV prevention struggle.[1] As one parent commented,

> We mothers and grannies play a key role in allowing HIV/AIDS to continue. Our refusal to disclose keeps the disease underground, and feeds into people denying the humanity of [people with AIDS] and their sense that they are no different to animals, with nothing to live for.

This stigmatization also served as a strong deterrent to young people seeking HIV/AIDS-related counseling.

One CYA worker reported that "there is fear of this place. Youth are scared to be seen entering our office that is known to be providing AIDS counseling. And the people who do come here are not from Ekuthuleni."

Other CYA workers reported that young people feared their parents would see them attending HIV prevention meetings and punish them. Many informants spoke of the way in which churches and schools also actively undermined HIV prevention efforts. According to a CYA worker,

> When we ask to talk about HIV in the churches they say we are encouraging the youth to sin. We recently called youth to attend a meeting on life skills [and had] a very poor turnout. Later we were told by youth that the minister said if they attended the workshop they would be demoted in the church.

Another CYA worker said "we sometimes use 'loveLife' brochures in schools, which have some sexual pictures in them. At one school the principal told us never to come again, that we were promoting pornography."

Symbolic Contexts of Stigma

What are the contexts that sustain the types of rejection and isolation of people with AIDS just outlined? We highlight 3 different aspects of context: the symbolic context (mapping out the wider field of social representations within which stigma is located); the economic, political, and local community contexts within which these representations are constructed; and the organizational context of efforts to address HIV/AIDS in Ekuthuleni.

Virtually every informant reported that stigma originated in the association between HIV/AIDS and sex. For example: "People know HIV/AIDS is here, but they won't talk about it because they believe if you have got AIDS you have got it through sex." Stigmatization of people with AIDS is supported by an associative network of symbolic links (sometimes logical and sometimes arbitrary) between such individuals and other negatively valued groups or attributes (in the very different context of the United States, a study of stigma highlighted the associative links between people with AIDS and homosexuality, death, drug use, and ethnic minorities).[16] In the following, we examine the web of representations within which stigma is located.

Many adults showed a strong unwillingness to acknowledge that their children were sexually active. When asked whether her son had ever told her he had girlfriends, one mother responded,

> Wow! Wow! He could never tell me that. Wow! There is no need for him to talk about that here. . . . I don't believe a parent must talk to their children about their love life. This is how I grew up. It wouldn't be right for me to know my children have relationships.

Such contexts exclude the possibility of parents providing a supportive environment for the promotion of safer sexual behavior by young people.

Some of the more frank adults in our sample wryly commented that this posturing by their peers was unconvincing, given that sexual activity among young people had been common for many years. According to one mother who was in her early 50s,

> In my time I could sleep with 7 men and only be infected with [a sexually transmitted disease]. I would go to the hospital or traditional healer and be cured in no time. The only difference now is that HIV has no cure. Nothing has changed in sexual behavior.

Denial of young people's sexual desire and relationships was particularly strong in the case of girls. Mothers refused to discuss sex in any way that resonated with their daughters' personal experiences of desires and relationships. They would darkly and indirectly allude to a link between sex, shame, and danger rather than accepting that their daughters were sexually active and teaching them how to protect themselves from sexually transmitted diseases and pregnancy.

According to one adolescent girl,

> Mother says that when you sleep with a boy you get a baby, he dumps you, and it's only afterwards that you regret that you ever slept with him. She says if you are a girl you must protect yourself against boys who will destroy your life.

Such denial of young girls' sexuality is related to what has been referred to as the wider "demonization of women" that the epidemic has provoked in sub-Saharan Africa.[17] In our interviews, many informants spoke of the way in which the weakness of women had fueled the epidemic. One of the church ministers stated, "The key to respect and good behavior is in the hands of women. A person who has the right to say no to sexual advances is a woman." Within such contexts, young women often had a particular investment in hiding their sexual activities. This made them less likely to seek out information about sexual health and to seek out or carry condoms. They often depicted sex as something that "just happened" to them, as something they did not expect and therefore did not prepare for.[18]

However, behind this public discourse is a thriving and dynamic world of young people's sexuality, away from the oversight of adults. In this world, many girls want and enjoy sex as often and as much as boys and adults. This counterstereotype emerged repeatedly in our interviews, and, not surprisingly, it was boys rather than girls who spoke of it. For example, according to one of the male youth informants: "Girls don't like trains that are not moving." Another stated: "Some girls say they don't want sex, but after an hour of kissing they always change their minds."

Another factor that supported stigmatization of HIV/AIDS was the link made by many between sex, sin, and immorality. The church was the main contributor of symbolic ammunition sustaining this link. According to one of the senior nurses, "If people reduce their sins God will cure their diseases. . . . It is

the devil that overpowers people [when they engage in wrongful sex]."

Similarly, in the words of a parent, "The Bible says the end of the world will come when we are struck down by incurable diseases. The Kingdom of God will come to destroy all the evil that is prevailing in this world. I always tell myself that AIDS shows us this time has come."

Part of the link between sex and sin that was widely lamented in the interviews was the sin of disrespect by young people for their elders.[19] According to one of the health volunteers: "God is angry with us. We have sinned so much, and we are living in bad times. This younger generation does not listen when they are told, they have no respect. He is punishing us for this."

Informants in all age groups spoke of young people as a "menace" needing to be controlled and disciplined. Aside from young people's engagement in sexual activity, informants frequently referred to their involvement in crime and drugs as further evidence of youthful bad behavior, proposing strong discipline as the solution. Informants frequently linked alleged "youth disrespect" with the political freedoms characterizing postapartheid society, stating that so-called "children's rights" contradicted the traditional culture. An out-of-school youth informant reported,

> Government policies on children's rights make it difficult for parents to discipline their children. What used to be called punishment is now called abuse, and a social worker can be called in. These "rights" contradict our traditional culture. . . . It is wrong that the threat of social workers should be allowed to disrupt the smooth running of the household.

Several informants spoke approvingly of the link between harsh discipline of young people and the so-called "African culture." The view of young people as "mad, bad, and deviant" was underpinned by parents' lack of confidence in their ability to control their offspring in general or, in particular, to talk to them about sex.

A number of informants spoke, sometimes in a self-denigrating way, of HIV/AIDS as a problem facing Black Africans. According to one father,

> The cause of the problem of HIV in this country is that we Black people don't behave ourselves. We have many girlfriends, that is what spreads AIDS all over. I have never heard that Whites, Indians or 'coloreds' [people of mixed race] have AIDS, yet AIDS infects many Black people.

The conceptual rationale underlying these informants' linking of HIV/AIDS with specific ethnic groups varied. Some informants referred to the spread of HIV/AIDS as the White regime's last gasp attempt to undermine Black opposition. A teacher spoke of members of the apartheid regime injecting Black political prisoners with the virus and then releasing them back into the community to infect others. Informants also spoke of the spread of HIV/AIDS as resulting from postapartheid White envy, with Whites infecting Blacks to "reduce the Black vote." Several people spoke of Whites spreading HIV/AIDS through the lubricant contained in condoms. One influential local leader spoke of how he had boiled a condom in water and taken the water to a medical laboratory for HIV testing. The water tested positive, he said.

What are the contexts within which this web of representations is constructed and sustained? We focus on this topic in the 2 sections to follow.

Economic, Political, and Local Community Contexts

General context of poverty and political disempowerment. Life in Ekuthuleni is characterized by high levels of poverty and political marginalization.[20] Many young people have little tertiary education, few skills, and poor job prospects. Some families are refugees from political violence in the surrounding areas and have suffered traumatic experiences. Many unemployed young men from poor families engage in crime, and informants spoke of drug abuse among young people as a serious problem.

Furthermore, young people have virtually no political representation and play no decisionmaking role in the local political or community development structures, and there were many stories of petty adult elites squashing young people's attempts to develop local initiatives. Youth representation on school councils was described as ineffectual by both students and teachers. Against this background, it was not surprising that many of the informants spoke of low morale among young people and a prevailing sense of apathy in regard to asserting their needs and rights.

Poor intergenerational communication. Informants reported that many young people have little support and guidance from their parents and that intergenerational communication is poor. Many young people spoke of their parents' failure to educate them about sex. According to one out-of-school youth: "Our parents have been shy to tell us the truth, they tell us children come from aeroplanes. This is a big mistake. They should have told us the truth. I got pregnant and I didn't know what had happened to me until my child was born."

Many parents refused to consider talking to their children about sex. A father of 10 told us that discussing condoms with his sons "would constitute pornography and only encourage them to have sex." A mother of 9 repeatedly insisted that it would be inappropriate to acknowledge that her children were sexually active outside of wedlock. Yet, 2 of her unmarried daughters (who lived with her) had their own children, and she herself had nursed a third unmarried daughter for the 18 months preceding her death from AIDS. Moreover, she spoke openly about the cause of her daughter's death.

Some women did speak of how important it was for mothers to be open with their children about sexual health. However, at different stages of their interviews, it became clear that they had not succeeded in doing so themselves. One who spoke at length about the importance of promoting intergenerational communication about sex later reported that she did not know whether her daughter had started menstruating and did not know how to broach the topic. Our sample did include parents who were more successful, however. One 41-year-old father of 5 praised the AIDS training his son was receiving at school. He also believed that young people received better guidance if their parents sat down and talked with them as opposed to disciplining them strongly. However, such parents appeared to be in the minority.

Community networks. Much has been written about the roles of "civic engagement" and local solidarity as key assets in poor

communities.[21] It is frequently argued that health promotional projects have the greatest chance of succeeding in united communities with dense local networks.[4,22] There are strongly supportive relationships and support systems among Ekuthuleni residents, including women's groups, prayer groups, gardening collectives formed to cultivate food for the sick and the unemployed, community health volunteers sharing their own meager incomes and food with destitute patients, and savings clubs run by housewives and pensioners.

These groups are a key element in the social fabric and economic survival of the local people. Yet, while they provide effective social support in a range of ways, these networks do not serve as potential resources for HIV prevention efforts among young people. Rather, they are usually adult dominated, and they tend to have a narrow focus. Furthermore, to date there has been no effective community leadership to take up the challenge of mobilizing these small, dispersed, and fragmented networks in the pursuit of other goals (such as initiatives to reduce stigma).

The solidarity that does exist in Ekuthuleni is mostly that among micro-networks of older women united by their commitment to "respectability." According to social identity theory,[23] human beings have a fundamental need for positive self-esteem and often seek to achieve this need through making favorable comparisons between themselves and others. Two types of "social competition" form the basis of these comparisons: objective competition (competition for material resources such as money) and subjective competition (competition for symbolic resources such as respect or recognition). Sex and alcohol use constitute 2 key ways in which a person's respectability might be compromised.[24,25]

In the context of poverty and disempowerment, many people lack access to the conventional social advantages of a highly materialistic society (e.g., expensive clothing and cars) and thus to those objective resources that might boost their self-esteem. Symbolic resources—such as respectability—come to constitute valuable currency in individuals' efforts to enhance their self-esteem. In the case of many Ekuthuleni residents, openly expressed stigmatization of people with AIDS has become a way of asserting claims to respectability.

AIDS-Related Institutional Contexts

Many of the informants commented regretfully on the shortcomings of government services aimed at HIV prevention and AIDS care. Lack of national government leadership and services went hand in hand with a lack of local leadership and inadequate or nonexistent local services. According to a health worker,

> I don't see the government having any care for [people with AIDS]. Here there is no proper hospital treatment, people can't afford medication for opportunistic infections, there are delays in grants . . . until patients are dead—the money arrives too late to help them eat and get tablets to survive—so far I haven't heard of 1 who was still alive when the grant [government grant for people in the later stages of AIDS] came through.

Both the school principal and the clinic director expressed bewilderment in the face of frequent media publicity highlighting the availability of government funds for HIV/AIDS management, stating that such resources had never materialized at schools or clinics of which they were aware. Informants also remarked on the poor networking between local health professionals involved in caring for people with AIDS (another symptom of the failure of local leadership and local coordination of networks and services). In the words of a community health worker,

> There are so many people that need us. This is a frustrating job. When we complain or make suggestions, we don't get any response from the hospital. The lines of communication are very poor. Social work referrals are even worse. Sometimes I have to hide from my patients in the street because the response from the social workers has been so slow I no longer know what to say to them.

The lack of adequate government leadership, resources, and infrastructure went hand in hand with lack of action in Ekuthuleni schools. The school principal who participated in the present study, who was head of the local school in which the CYA had instituted its most extensive peer educator program, repeatedly referred in glowing terms to the positive contribution the CYA was making to young people in the local community and how the school found its support invaluable, because there was so little aid from the government.

The principal also insisted that despite his compassion for affected pupils, he did not have the resources or time to take any action in relation to AIDS (while informally estimating that up to 50% of his pupils might be HIV positive). He stated that the school could not address a problem of this magnitude without counseling and welfare backup: "If the 14 schools in this area were to take up this problem we would need a clinic, a psychologist, and a social worker to back us up." This seems like a reasonable requirement given that such an effort would involve more than 7000 pupils, many infected or affected by AIDS.

Lack of resources was often identified as a cause of loss of hope among people with AIDS. A support worker reported that "we visit people with AIDS in their homes and offer emotional support through counseling. But you find people expecting more from us because they are sick and don't have anything to eat. How can you motivate people to live positively if they are hungry?"

The CYA's work is further complicated by the dual leadership system that prevails in Ekuthuleni, with hereditary traditional chiefs existing side by side with municipal councillors elected according to political party affiliations (in this case, the African National Congress). According to CYA workers, the councillors tended to have a relatively progressive attitude toward women and sexuality that appealed to many young people. Traditional leaders tended to be more conservative, highly critical of sexually active young people, and supportive of the "policing" of young people's sexuality, particularly that of young women, through practices such as virginity testing.[26,27]

CYA employees stated that they had to take care not to offend either of these constituencies, usually through working with different sets of leaders on different occasions. For example, they might work with traditional leaders in setting up HIV/AIDS events on the more traditional Heritage Day, and they might work with councillors in setting up other types of HIV/AIDS activities on holidays such as June 16, which celebrates South Africa's history of radical political protest.

DISCUSSION

In unequal societies, social dynamics are often inherently conservative, and a series of multilevel symbolic, material, and institutional dynamics are in place that ensure that inequalities are perpetuated even in the face of challenges or resistance.[28,29] Foucault's work highlights the way in which power hierarchies are policed not only by *overt* systems of power and government (inherent in laws and police forces, for example) but also by *covert* systems of power: the internal "psychological policing" through which people at all levels of the social hierarchy are socialized to voluntarily behave in ways that support the status quo.[30] Integrating our Ekuthuleni findings with this theoretical frame, we argue that stigmatization is 1 form of covert psychological policing whereby those who breach power relations of gender, generation, or ethnicity are disciplined and punished. Stigmatization of people with AIDS serves as a mechanism for highlighting the literally fatal consequences that face young people or women who step out of line, for example.

High levels of HIV/AIDS among youth expose the previously hidden ways in which many young people in general, and young women in particular, have resisted adult attempts to control their sexuality (with such control playing a key role in the perpetuation of male and adult authority). They have done so through their active participation in a thriving sexual subculture.[10] In many ways, this subculture is a positive element in Ekuthuleni, part of young persons' assertion of energy and creativity in a community where they tend to be marginalized at best and denigrated at worst. Some of the excitement and mystique of this world comes from the fact that many aspects of young people's sexual relations take place away from the eyes of adults and are shrouded in secrecy. Yet, the secret nature of young people's participation in this world—secret not only from adults but often, in the case of girls, from each other—places it beyond the reach of the best-intentioned (and almost always adult-orchestrated) HIV prevention efforts.

The nature of this world also places it out of the reach of adults, such as parents. Many parents are particularly ill placed to contribute to the fight against HIV because of their (often well-founded) fear that their children are more worldly wise than they are in regard to much of the new way of life in South Africa. Their refusal or downright unwillingness to talk about AIDS is part and parcel of their attempt to maintain what they believe is their "traditional" or "cultural" right to dominance over young people.

Many authors have pointed to the important role the church has played in sanctioning and sustaining unequal relationships between men and women and between adults and young people, postulating a strong link between the moral order of the church and the sexuality of its members. The very public nature of the HIV/AIDS epidemic brings the church face to face with the dramatic contradictions between (1) its teachings that sex should take place only within the context of a faithful marriage and (2) the epidemic's very public and assertive evidence of the church's failure to reinforce these teachings. By implication, the existence of the HIV/AIDS epidemic highlights the loss of the church's moral authority. One of the strategies now being used by representatives of many churches to regain this lost moral authority is that of vigorously linking sexual transgressions and AIDS with sin, immorality, and, sometimes, even the end of the world.

In a similar way, the existence of the epidemic—drawing attention to the sexual activity of large numbers of people who are not located within monogamous marriages—highlights the lack of influence of traditional chiefs and the traditional leadership system over the sexuality of many women and young people. Supporters of traditional systems of authority seek to reassert this influence by reinstating old-fashioned practices such as virginity testing, rewarding girls who pass this test with "goods" ranging from enhanced social status to virginity certificates. In short, stigmatization of people with AIDS is part and parcel of a conservative reassertion of power relations of gender and generation and a public reinforcement of social institutions whose moral authority rested on their ability to control the sexuality of women and young people (or to at least be seen as controlling this sexuality at the level of rhetoric, if not at the level of reality, in the pre-AIDS days when it was easier for sexual "transgressors" to be discreet about their activities).

Stigmatization also serves as 1 aspect of a vicious reassertion of the racial and economic marginalization of many Black South Africans. At the symbolic level, the close link that several of our informants made between HIV/AIDS and Black African people both draws on and feeds back into negative stereotypes of Black people that have a long history in South Africa. At the material and political levels, stigmatization of people with AIDS dramatically undermines the likelihood that they or their families will stand up openly and challenge inadequate levels of social recognition and support in a society that often fails to acknowledge even their existence, let alone their needs and rights.

Much has been written about the way in which AIDS undermines the economic well-being of both sufferers and their families.[31,32] In the absence of appropriate medical and welfare treatment and support, people with AIDS and their families become trapped in a downward economic spiral that has extremely negative consequences for individual families and communities and threatens to undermine many of the development gains of recent years; examples are the negative effects of AIDS on life expectancies, which had previously been rising, and on the material well-being and morale of communities.[33]

IMPLICATIONS FOR INTERVENTION

Although the strategies of education and legislation are vital elements in the fight against stigma, they will not be adequate on their own. Communities need to be mobilized to engage in critical thinking about the wider webs of representation and practice that feed into stigmatization of people with AIDS. Arguments that provision of free and accessible medical treatment to people with AIDS will contribute to the end of stigma are increasingly common.[34] We have no doubt that a key facet of the fear and denial surrounding HIV/AIDS in many of the poorer countries where the disease flourishes is linked to its

currently incurable status in the case of those who do not have access to drugs. However, we believe that even after treatment is available and HIV/AIDS is no longer fatal, the link between HIV/AIDS and "bad behavior" (i.e., sexual behavior) will still exist in ways that associate the disease with shame and embarrassment. In the absence of initiatives to tackle root social causes, the potential impact of treatment on stigma will be reduced.

Paulo Freire argued that marginalized groups are most likely to improve their circumstances in projects that simultaneously work to challenge the social conditions that contribute to their exclusion.[35,36] Writing in the context of HIV/AIDS among more confident and articulate groups residing in wealthier countries (e.g., gay men in San Francisco and Australia), researchers have pointed to the positive role of collective action by members of stigmatized groups.[5] These groups have often organized themselves in a strong and assertive way to improve their access to health services and challenge those who seek to discriminate against them.

In South Africa, the Treatment Action Campaign (TAC) has opened up the exciting possibility of collective action by people with AIDS, engaging in many high-profile actions highlighting the ways in which people's lives are blighted by various forms of interpersonal stigma and institutional discrimination.[37] CYA workers in Ekuthuleni were aware of the existence of the TAC and had invited individual TAC speakers to address local meetings on different occasions. However, much work remains to be done to extend the reach of this high-profile organization in South Africa and to mobilize collective action by people in the marginalized communities (such as Ekuthuleni) within which many of the country's people with AIDS reside.

Furthermore, the necessary support must be in place if people are to be expected to disclose their HIV status even to 1 close friend or family member, let alone stand on public platforms asserting their rights and needs. Freire would contend that a key stage in doing the necessary groundwork would be development of critical thinking about the social roots of the problem of stigma and about the social obstacles standing in the way of its solution.

We agree with Freire and argue that an important first step toward mobilizing people with AIDS would involve initiatives that work toward facilitating the participation of local community groups in critical thinking programs. Such programs would aim to expose, confront, and resist the webs of signification and practice that sustain stigma and undermine the confidence of communities and individuals who might otherwise challenge it. Our case study suggests that, in contexts such as Ekuthuleni, programs could include critical thinking about the marginalization of young people and women, denial of young people's sexuality, and, more particularly, denial of the sexual activities of women. Programs might also seek to generate critical thinking about the ways in which social institutions such as the church, the family, and the traditional leadership system do or do not contribute to these forms of marginalization and denial, which are so undermining of effective HIV prevention and the humane treatment and care of people with AIDS.

Such critical thinking might also seek to challenge the fictional notion that young people of the current generation are necessarily more sexually active than those of earlier generations. It might seek as well to deconstruct and challenge the distinction between "good" and "bad" behavior and, particularly, the invariable association of sex outside faithful marriage with "bad" behavior. Finally, it might highlight the possibility that sexual activity need not "destroy" a young woman's life if she is discreet and protects her sexual health.

Our case study highlights the gap between rhetoric and reality in terms of the way in which people often seek to give the impression that they or other family members are sexually inactive or HIV/AIDS free when, behind this curtain of social desirability, the truth might be very different. It also highlights the way in which the conventions of what constitutes social desirability may often both feed on and perpetuate unequal power relations between young and old, men and women, Black and White, and rich and poor. Community participation has a key role to play in promoting forms of critical consciousness that both expose and challenge the unequal social relations drawn on and sustained by stigma. As such, it should stand alongside education and legislation as a powerful weapon against stigma. ■

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This article was accepted July 27, 2004.

Contributors

C. Campbell conceptualized and designed the study, analyzed the data, and wrote the article. C.A. Foulis established and maintained the partnership between the researchers and the study community and managed the data collection. S. Maimane and Z. Sibiya conducted the fieldwork and kept detailed fieldworker diaries. All of the authors engaged in discussions of every aspect of the research.

Acknowledgments

We are grateful to Mpume Nzama and colleagues at the Christian Youth Alliance and to Eleanor Preston-Whyte and Debbie Heustice from the Centre for HIV/AIDS Networking for enabling this research. We also wish to thank the Atlantic Philanthropies and the Carnegie Corporation of New York, whose grants made this study possible.

Note. The views expressed in this article are those of the authors alone and do not necessarily reflect the views of the Christian Youth Alliance, the Centre for HIV/AIDS Networking, or the funding agencies.

References

1. *Stigma and AIDS in Africa: Setting an Operational Research Agenda.* Dar es Salaam, Tanzania: Joint United Nations Programme on HIV/AIDS; 2001.

2. Hayes R, Vaughan C. Stigma directed toward chronic illness is resistant to change through education and exposure. *Psychol Rep.* 2002;90:1161–1173.

3. Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med.* 2003;57:13–24.

4. Campbell C. *Letting Them Die: Why HIV/AIDS Prevention Programmes Fail.* Bloomington, Ind: Indiana University Press; 2003.

5. Joffe H. *Risk and the Other.* Cambridge, England: Cambridge University Press; 1999.

6. Jost J, Banaji M. The role of stereotyping in system-justification and the production of false consciousness. *Br J Soc Psychol.* 1994;33:1–27.

7. Joffe H, Begetta N. Social representations of AIDS

among Zambian adolescents. *J Health Psychol.* 2003;8: 616–631.

8. Crawford R. The boundaries of the self and the unhealthy other: reflections on health, culture and AIDS. *Soc Sci Med.* 1994;38:1347–1365.

9. Treichler P. AIDS, homophobia and biomedical discourse. In: Crimp D, ed. *AIDS: Cultural Analysis/ Cultural Activism.* Cambridge, Mass: MIT Press; 1988: 164–182.

10. Posel D. "Getting the nation talking about sex": reflections on the politics of sexuality and "nation-building" in post-apartheid South Africa. *Afr Aff.* In press.

11. Gaitskell D. "Wailing for purity": purity unions, African mothers and adolescent daughters, 1912–1940. In: Marks S, Rathbone R, eds. *Industrialisation and Social Change in South Africa: African Class Formation, Culture and Consciousness, 1870–1930.* Harlow, England: Longman; 1982:338–357.

12. Marks S. Patriotism, patriarchy and purity: Natal and the politics of Zulu ethnic consciousness. In: Vail L, ed. *The Creation of Tribalism in Southern Africa.* Berkeley, Calif: University of California Press; 1989: 226–247.

13. Shisana O. *Nelson Mandela/HSRC Study of HIV/ AIDS: South African National HIV Prevalence, Behavioral Risks and Mass Media.* Cape Town, South Africa: Human Sciences Research Council; 2002.

14. South African Department of Health. Summary report: National HIV and syphilis antenatal seroprevalence survey in South Africa, 2002. Available at: http://www.doh.gov.za/aids/index.html. Accessed December 1, 2002.

15. Flick U. *An Introduction to Qualitative Research.* 2nd ed. London, England: Sage Publications; 2002.

16. Pryor J, Reeder G. Collective and individual representations of HIV/AIDS stigma. In: Pryor J, Reeder G, eds. *The Social Psychology of HIV Infection.* London, England: Lawrence Erlbaum Associates; 1993: 263–286.

17. Leclerc-Madlala S. On the virgin cleansing myth: gendered bodies, AIDS and ethnomedicine. *Afr J AIDS Res.* 2002;1:87–95.

18. MacPhail C, Campbell C. 'I think condoms are good but, aai, I hate those things': condom use among adolescents and young people in a southern African township. *Soc Sci Med.* 2001;52:1613–1627.

19. Campbell C. Intergenerational conflict in township families: transforming notions of "respect" and changing power relations. *S Afr J Gerontol.* 1994;3:150–159.

20. Campbell C, Foulis CA, Maimane S, Sibiya Z. *Supporting Youth: Broadening the Approach to HIV/ AIDS Prevention Programmes.* Durban, South Africa: Centre for HIV/AIDS Networking; 2004.

21. Moser C. The asset vulnerability framework: reassessing urban poverty reduction strategies. *World Dev.* 1998;26:1–19.

22. Baum F. Social capital: is it good for your health? Issues for a public health agenda [editorial]. *J Epidemiol Community Health.* 1999;53:195–196.

23. Hogg M, Abrams D. *Social Identifications.* Oxford, England: Blackwell; 1988.

24. Campbell C. The social identity of township youth (part 1): an extension of social identity theory. *S Afr J Psychol.* 1995;25:150–159.

25. Campbell C. The social identity of township youth (part 2): social identity theory and gender. *S Afr J Psychol.* 1995;25:160–167.

26. Scorgie F. Virginity testing and the politics of sexual responsibility: implications for AIDS intervention. *Afr Stud.* 2002;61:55–75.

27. Geisler G. "Women are women *or* how to please your husband": initiation ceremonies and the politics of "tradition" in southern Africa. In: Goddard V, ed. *Gender, Agency and Change: Anthropological Perspectives.* London, England: Routledge; 2000:203–229.

28. Bourdieu P. The forms of capital. In: Richardson J, ed. *Handbook of Theory and Research for the Sociology of Education.* New York, NY: Greenwood Press; 1986: 241–248.

29. Bourdieu P. *Distinction: A Social Critique of the Judgement of Taste.* Cambridge, England: Cambridge University Press; 1984.

30. Rose N. *Governing the Soul: The Shaping of the Private Self.* New York, NY: Routledge; 1991.

31. Barnett T, Whiteside A. *AIDS in the 21st Century: Disease and Globalisation.* New York, NY: Palgrave Macmillan; 2002.

32. Nattrass N. *The Moral Economy of AIDS in South Africa.* Cambridge, England: Cambridge University Press; 2004.

33. Nnko S, Chiduo B, Wilson F, Msuya W, Mwaluko G. Tanzania: AIDS care—learning from experience. *Rev Afr Political Economy.* 2000;86:547–557.

34. Cameron E. Speech to the Second Annual Conference of People Living with AIDS, Durban, South Africa, 10 March 2000. Available at: http://www.tac.org.za. Accessed September 20, 2003.

35. Freire P. *The Pedagogy of the Oppressed.* London, England: Penguin Books; 1993.

36. Freire P. *Education for Critical Consciousness.* New York, NY: Continuum; 1993.

37. Treatment Action Campaign. About TAC. Available at: http://www.tac.org.za. Accessed September 20, 2003.