

Factors Related to HIV Disclosure in 2 South African Communities

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Disclosure of HIV status is an essential part of behavior modification and access and adherence to treatment in people infected with HIV.

We conducted interviews in 2 South African communities of similar ethnic mix but with very different rates of disclosure of HIV status and found that disclosure was the catalyst for access to a variety of important and often essential resources. In the community with high rates of disclosure of HIV infection, disclosure led to greater access to formal institutional support and opportunities to take positive leadership roles in the community.

Our findings highlight the prominence of wider sociopolitical contexts for disclosure decisionmaking and the need for HIV interventions to increase levels of disclosure of HIV infection. (*Am J Public Health*. 2007;97:1775–1781. doi:10.2105/AJPH.2005.082511)

The sheer scale of the HIV/AIDS epidemic in sub-Saharan Africa has finally led to an expanded global response. South Africa, a nation in which more than 5 million people are estimated to be infected with HIV/AIDS,¹ has established large-scale prevention and treatment programs. However, the uptake and effectiveness of many of these interventions remain suboptimal and are only having a marginal impact on the trajectory of the epidemic.¹

We believe that effective public policy can be fostered through an understanding of the issues surrounding the disclosure of HIV infection and of the environments that enable disclosure at the individual and community levels.

There is increasing recognition that voluntary testing and counseling are important first steps for the modification of behaviors required to reduce the incidence of HIV infection. For example, a study in South Africa found that knowing someone infected with HIV was positively associated with condom use at last sexual contact and negatively associated with multiple and casual sexual partners.² Further, in Thailand it was found that those with histories of contact with people living with HIV/AIDS were more tolerant of the disease in general as well as of those infected.³ However, community benefits such as the reduced incidence of HIV infection and reductions in stigma and discrimination cannot be realized without disclosure by HIV-positive individuals.

At the individual level, disclosure of HIV infection can enable the activation of family or community support networks and reduce morbidity through better psychosocial management of the illness. Disclosure is also fundamental to the management of HIV infection; it has become an entry criterion for many treatment programs in resource-constrained settings and is crucial to adherence to complex treatment regimens in which treatment “buddies” and support can be accessed. For example, HIV-positive people have reported that they sometimes skip doses of their prescribed medications because they cannot take them without being observed doing so.⁴

Access to other forms of care such as home-based care, nongovernmental organization (NGO) support, and specific social grants also depend on the disclosure of HIV status. From a health policy perspective, then, effective response across all levels centers on the creation of an enabling environment for disclosure of HIV infection.

Although there are clear benefits to increased rates of disclosure of HIV infection at the individual and community levels, levels of disclosure remain low, especially in developing countries.⁵ Dominant explanations for this issue focus on the role of stigma. Stigma is a social construction that dramatically affects the lives and experiences of individuals living with HIV infection, as well as their partners, families, and friends.⁶

Disclosure of HIV infection can be an extremely difficult process because it makes one vulnerable to the perceived stigma of friends, family, or the community.⁷ Stigma thus makes HIV-positive individuals reluctant to become identified and seek appropriate care, which ultimately results in a lack of access to important sources of family and social support.⁸ The decision to disclose HIV status is therefore presented as the outcome of a calculation of the immediate benefits and risks of such an action.

However, traditional definitions underplay the role of stigma as a social and political construction that facilitates the domination of certain social groupings, especially in the context of competition for scarce resources.⁹ This conceptualization of stigma introduces the wider social, cultural, and economic environment as another determinant in decisions related to disclosure of HIV infection.

Despite the plethora of explanatory theories related to disclosure of HIV infection, empirical evidence of the actual strategies individuals use to negotiate and counter the fear of rejection and isolation is scarce. Most studies examining disclosure have been conducted in Western contexts.^{4,10,11}

There is a dearth of research on the complex process of disclosure of HIV infection in sub-Saharan African nations, especially when the prevalence rates in the region one considers. We could find no analytic studies from Africa that attempted to identify the determinants of HIV disclosure.

As increasing numbers of Africans test positive for HIV, an understanding of the disclosure process is essential to effective public policy and programming. Describing and analyzing the decisionmaking process before disclosure of HIV infection, as well as the event itself within the wider sociopolitical context, is an essential step in designing effective interventions that will facilitate increases in disclosure rates.

We describe the realities of disclosure of HIV infection in 2 South African communities

of similar ethnic mix but with very different overall levels of HIV disclosure. We sought to discern key factors that would encourage greater disclosure in both communities and have the potential for policy implications at the national and regional levels.

SETTING

Our research took place in 2 South African communities: Mbekweni in the Western Cape and Umzimkhulu in KwaZulu-Natal (formerly Eastern Cape). The communities were geographically diverse in that 1 was urban and 1 was rural, and they are located in different provinces. However, culturally they were similar in that the majority of the populations in both communities were of Xhosa ethnic origin. Although cultural and behavioral norms were similar in both communities, the rate of disclosure of HIV infection in Mbekweni was recently found to be as high as 70%, whereas in Umzimkhulu, the rate was only 30%. The disclosure rates were from the cohort of 308 HIV-positive pregnant women participating in the evaluation of a national prevention of Mother-To-Child Transmission (PMTCT) trial program. The women were closely followed from the birth of the infant to 9 months postdelivery; 140 women came from Mbekweni, and 168 from Umzimkhulu.¹²

Mbekweni lies in the district of Paarl, a urban commercial farming area in the Western Cape that, despite its relative wealth, has high levels of socioeconomic inequality.¹³ In many ways, the community provides a microcosm for the reality of inequality characterized by most of South Africa: immense wealth and privilege alongside vast and segregated poverty.

The African residents of Mbekweni township are an ethnic minority in Paarl and represent the poorest residents in the district. The District Antenatal Survey of the Provincial Department of Health shows that the HIV prevalence in the district as a whole increased from 4.5% in 2000 to 15% in 2004.¹³ The HIV statistics for Mbekweni are unknown but are undoubtedly much higher than in the district as a whole.

Umzimkhulu lies in one of the poorest rural areas of South Africa, formerly known

as the Transkei in KwaZulu-Natal. Employment levels are very low, with about 12% of residents in the municipality employed. There is a marked dependency on governmental services, pensions, and community members who work outside the area and send remittances home; 38% of households report no income at all. The antenatal HIV prevalence rate is very high: 28% of pregnant mothers are infected.¹⁴

There was also a broad contextual difference between the 2 communities in the availability of formal support. Although individuals in both communities depended heavily on government grants, those in Mbekweni could approach a wide variety of NGOs in times of crisis. These included World Vision, the Mbekweni Community Health Project, and various community centers and faith-based organizations. No similar institutional support was available in Umzimkhulu.

METHODS

Our initial aim was to build on the knowledge gained from a cohort of women who had participated in the PMTCT study. The PMTCT study examined the dynamics of responding to the unique impact of HIV/AIDS-related “shocks” such as caring for ill family members, coping with the loss of a productive household member, taking in orphaned children, and the experience of being abandoned or rejected by family members and loved ones because of HIV/AIDS disclosure. Because many of the women within the PMTCT study had not yet experienced these shocks, we used additional sources to help recruit additional respondents for sampling. In Mbekweni these sources included community health workers, a fieldworker from the PMTCT study, and 2 local NGOs that support households caring for AIDS orphans. In Umzimkhulu, local fieldworkers employed by the PMTCT study located potential respondents.

Respondents were approached by phone or in person and asked if they were interested in participating in a study looking at the experiences of households “going through difficult times.” If they agreed, they were subsequently introduced to the researchers and given oral and written explanations of the study. They were told of their right to end

interviews, as well as their right to confidentiality. At this point, written informed consent was obtained.

A total of 25 HIV/AIDS-affected adults from 18 households were interviewed between February and April 2005. Fourteen respondents came from Mbekweni, and 11 came from Umzimkhulu. Sixteen respondents stated that they were HIV positive, and an additional 3 respondents were likely positive (1 man stated that he had refused testing even though his wife tested positive, and 2 women stated that they were HIV negative even though local contacts identified them as HIV positive and both had been widowed by husbands who had died of AIDS). Although disclosure of HIV infection was not initially intended as a key research question, it immediately became clear that disclosure was a critical issue in the effective responses undertaken by the HIV-positive women interviewed. Subsequently, questions surrounding experiences of disclosure were included in the interview guide and detailed data were collected.

The respondents were overwhelmingly women (88%) because of the sampling frame, although when male household members were present, they were also interviewed; the vast majority of individuals (88%) in both communities resided in households headed by women; and only 1 HIV-positive respondent still lived with her husband. The average age of HIV-positive respondents was 31 years. The majority of respondents (76%) in both communities were unemployed, subsisting mainly from governmental assistance in the form of grants and support from NGOs; 2 women held full-time jobs.

Ten key informants were also interviewed; these informants included health care professionals, counselors, educators, and local NGO workers. The interviews were semistructured and lasted between 1 and 2 hours. The interviews were conducted by 2 experienced researchers, 1 of whom was fluent in the dominant local language, Xhosa. Neither researcher had been previously employed by the PMTCT study, and neither was a permanent resident in either local community. Thematic analyses were used to identify key themes within the interviews. We identify respondents using

numbers or pseudonyms to protect their privacy.

RESULTS

Negotiating and Managing Disclosure

The nature of disclosure of HIV infection is processual and fluid and is not necessarily unilinear, sequential, or with 1 inevitable outcome. Possible steps of the process include undergoing a cost–benefit analysis immediately upon discovery of HIV-positive status, responding to pressure from the health system (to disclose HIV status in order to access treatment and care), sounding or feeling out potential reactions to disclosure from family members or loved ones, full disclosure to closest friends and family, full but passive public disclosure (admitting to those who ask), and active disclosure (as part of activism and to support others).

For all our respondents, disclosure of HIV infection was not a 1-time event but was experienced as a process. Within this fluid process, we found that respondents were actively engaged in managing the process. For some this entailed disclosure to some family

members but not to others. As a respondent from Umzimkhulu put it:

The first person he disclosed to was his eldest sister. He also disclosed to his mother right away, and although she was devastated, she accepted the news. Sipho's brothers do not know of his status because he does not want to worry them. He thinks they need to concentrate on their own lives, and he admits that he also does not have the courage to tell them. He said that he would never disclose to his father because he thinks that his father would talk about his problems to other people and even ridicule him about it.

For others, HIV management necessitated disclosure of HIV infection only to those who worked in the health care system or those who would offer some support. Other studies have shown that HIV-positive people expend considerable energy trying to manage information and manipulate their environments appropriately so as to maintain the appearance of being uninfected.¹⁰

Our respondents used various tactics in order to maintain relationships, while simultaneously “feeling out” the impact an HIV-positive status would have on their relationships (see the box on this page). In terms of

intimate relationships, this reflects the uncertainty about how a partner will react to news about the diagnosis, including potential fears about violence, loss of economic security, rejection, or abandonment.

Some of these concerns may be particularly important for women, who may depend on the support of male partners for their livelihood as well as their children's (however, more research is required into the inherently gendered experiences of disclosure in the African context).

Further, HIV-positive people identified alternative methods to avoid having to disclose HIV status to partners on their own, as evidenced by comments from a translator for a respondent from Mbekweni:

Indeed, she told her husband she was going to the clinic because she thought she was pregnant. She was trying to find a way to draw him to the clinic (she was not actually pregnant). She wanted someone else to tell him that she is positive, not her.

In another case, the respondent had asked her partner to be tested, but he told her that he had been to the clinic and that his results were subsequently lost. She believed that he was “probably in the same boat” as she was and was also afraid to disclose his HIV status. At the time of the interview, she was planning to take him to the clinic so that they could both be tested and that she could then act surprised about her positive status outcome.

Thus, for some of the respondents, the active management of HIV disclosure represented an area of control over their management of the disease, in that they were able to make decisions on disclosure to chosen family members, friends, and health professionals.

Outcomes of Disclosure

Disclosure can have both positive and negative consequences. The subsequent sections highlight some of these issues and outcomes. The majority of respondents cited a degree of fear of rejection by loved ones as a possible consequence of the disclosure of their HIV infection. However, in this sample there were no reports of violence because of disclosure of HIV-positive status. Of the 16 respondents who disclosed their HIV-positive status to partners, 6 reported that they had experienced negative outcomes. A translator for 1 respondent from Mbekweni explained the woman's experience:

Negotiating HIV Disclosure to Children

Bongi (Umzimkhulu) is a 40-year-old woman living near Umzimkhulu, KwaZulu-Natal. In 2003, while at the hospital to give birth to her baby, she was tested for HIV and discovered that she was HIV positive. Her newborn daughter also tested positive upon her birth and only lived for 3 months. Bongi has never been formally employed and currently lives in a government house. Her livelihood consists of support from her brother who lives in Johannesburg and her informal selling of goods in the community.

Her living daughter, 17, is not aware that Bongi is HIV positive. Her daughter has bad asthma, and Bongi is afraid that if she discloses her infection to her daughter, the daughter might get sick. Bongi is also concerned that her daughter will worry too much about her or be devastated by the news. However, she is still grappling with the decision and is hopeful that one day she will be able to disclose her situation to her daughter. Recently, as a way of testing her daughter's reaction, she told her daughter she was HIV positive. Almost immediately, she took back the comment and told her that she was joking. To her surprise, her daughter said that even if it were true, it would be okay because there were many other people who were positive and it was just like any other disease.

Interestingly, although Bongi does not discuss her own status, she does talk to her daughter about HIV/AIDS. She tells her that “you can love someone but you don't have to have sex with them.” She also tells her daughter that if she has unprotected sex, she will get pregnant or will get AIDS.

Bongi's story highlights the complexity of HIV disclosure and the process of negotiation that women undergo in making decisions about disclosure. Although Bongi would like to disclose her infection status to her daughter, she does not feel ready to do so, even though she thinks that her daughter likely would be supportive. Nevertheless, Bongi is acutely aware of how important it is to speak with her child about the risks of HIV/AIDS, especially as she is a young woman and particularly vulnerable.

She disclosed her status to her boyfriend at the time, but he immediately abandoned her. She has seen him since, and he is very sick. She encourages him to get tested, but he is in denial and won't. He tells her that people who get HIV/AIDS are "whores."

Although some women experienced rejection and abandonment from partners upon disclosure, in all cases in which rejection or abandonment occurred, other relatives, neighbors, friends, or local organizations were supportive. The majority of women stated that by disclosing their HIV status to either loved ones or professionals, they were able to receive both material and emotional support. As Tumi, a single woman living in Mbekweni, stated: "When you yourself are open you can access the relevant people in order to help you access resources." Ziyekela, a respondent in Umzimkhulu, claimed that her overall support had actually improved. She "gets more support now from her mother and her sister-in-law" than she did before.

Consistently, family members were the most supportive in terms of providing material services and emotional support. This has important implications because satisfaction with social support has been found to buffer the effect of HIV-related physical symptoms on depressive symptomatology. Furthermore, people infected with HIV who are integrated into social networks have higher levels of psychological well-being than those who are not.¹⁵

Perceptions of social support are also positively associated with the percentage of friends, family, and sexual partners to whom the diagnosis has been disclosed.¹⁶ This source of support was essential to the well-being of all our respondents; the 1 respondent who was not receiving family support was the worst off psychologically and materially. The vast majority who were receiving support felt that they were supported well by their loved ones.

Of the 16 respondents in Mbekweni and Umzimkhulu who disclosed their HIV-positive status, 15 stated that they were receiving either material or emotional support from family members. In the only case in which all family members had abandoned the respondent on HIV disclosure, neighbors had been filling in the support gap through child care and food sharing.

Of family members, female members were consistently identified most often in terms of providing support. A translator for a respondent from Mbekweni described one woman's responses as such:

She has a sister-in-law here in Mbekweni who is very helpful. If she needs paraffin oil or anything, she will help her. She is also very supportive emotionally.

She also told her sister who is now looking after her child, but she only did this when she became very ill. Her sister was very supportive and accepted it right away. Immediately after she disclosed, her sister said she would take her baby to make life easier for her.

Disclosing HIV infection to family members consistently allowed HIV-positive people and their families to maintain their livelihoods. Respondents reported being taken in by family members, receiving cash and other goods, and receiving payment for services they otherwise could not afford. In other cases, neighbors had bolstered family resources or had filled in the chasm left by household and extended family members who reacted negatively to the disclosure:

She has a neighbor who used to live nearby but who has now moved to Worcester and is very supportive. She comes to visit her and she says that she knows if she ever needed help, this woman would be there for her.

"Freedom" and the Unburdening Effect of Disclosure

Nearly all respondents experienced a period of struggle before their disclosure of HIV infection and had taken a period of time (up to a few years) to disclose their HIV status to those closest to them. One respondent stated that, "when you haven't disclosed, you are always worried." The daily reality of keeping their HIV status a secret was a very difficult and onerous process. However, all the respondents eventually disclosed their HIV status to at least 1 member of their family, a partner, or a friend.

Because the knowledge of HIV infection is encumbering to an individual, the experience of disclosure often represents a release of this "weight." Two of the women used the word "freedom" when describing how they felt once they had disclosed their HIV status; 1 respondent stated, "If you are open, you are free." Neliswa, a respondent from Mbekweni, told her

sister about her status after a month. Before she told her, she was very stressed out and depressed and lost weight even though she was pregnant at the time. After Neliswa told her sister, she said she felt "free."

For others, not only did the events of disclosure to family members unburden them, but also by disclosing their HIV status to other HIV-positive people, they were able to join a community in which people were going through similarly difficult experiences. As a translator for one respondent from Mbekweni put it:

She is a member of the Catholic church support group. When she began attending, she says that she was very depressed but that when she went and spoke with the other women she felt "lighter."

This correlates with Paxton's description of the paradox of coming out openly as an HIV-positive person: by facing AIDS-related stigma, one finds psychological release—liberation from the burden of secrecy and shame: "the very thing that seems the most dangerous to do, openly confronting stigma and facing possible discrimination and rejection, ultimately can be the most liberating."¹⁷(p565)

Holding back one's feelings results in stress, which negatively affects physical health, and negative emotional reactions, including depression and HIV-related worries, are inversely related to disclosure.¹⁶ For our respondents, the process of unburdening oneself of this weight allowed both the release of psychological stress and the potential for positive life changes and social support.

Responses in the 2 Communities

When we compared the individual responses to HIV/AIDS-related "shocks" in the 2 communities, 1 of the major differences we found was in the sources of support. In Umzimkhulu, support generally come from family, friends, and neighbors. Although these sources were equally important in Mbekweni, women in this community also identified key sources of institutional support in the form of NGOs, hospitals, and government grants. The women in this community accessed a wider variety of safety nets and were more aware of different sources of support within their communities. The importance of these institutions was consistently

identified. A translator from one respondent from Mbekweni spoke of this importance:

At the hospital, even right away she was very open about her status. She learned early that in order to get support for her child she had to be open and willing to talk about her problems. After they were born, she literally had no means of taking care of them [her twins]. She told the doctors that she didn't even have enough money to take them home from the hospital. The doctors then helped her to access the grants; they started the ball rolling. It was a quick process, only taking 2 months. If she had not gotten this support she would have left them at the hospital.

A key example of the diversity of institutional support came in the form of local support groups for those affected by HIV/AIDS. In Mbekweni, of the 10 respondents who disclosed their positive HIV status, 9 were attending support groups. Support groups were easily accessible and were successful in mitigating some of the psychosocial effects of an HIV-positive diagnosis. As a translator for a respondent from Mbekweni put it:

She does think it was helpful in that it provided her with emotional support and an opportunity to speak with others about her problems. She felt even better when she went to the Roman Catholic Church support group. It was helpful to see that others were going through the same things as she was. This made it a lot better.

Support groups are an essential component of positive living with HIV/AIDS. However, this was a resource that either did not exist or was not accessed by those who had disclosed their HIV status in the Umzimkhulu community. Not one woman was attending a support group in the region, and we did not come across any key informants who identified the existence of one, although the prevalence of HIV infection is significantly higher in this community.

A translator for a key informant from Umzimkhulu described the need as such:

She feels that this could be solved if groups could be formed. These groups would be a place where people would be able to talk about the disease. This would help those who have problems and have nobody to talk to.

Thus, although respondents in both communities were able to access support from

The Story of an "Expert Patient"

One of our most memorable key informant interviews occurred at Rietvlei hospital in the Umzimkhulu district when we interviewed Sisanda, a young woman who was working as a counselor at the local HIV treatment clinic. After only a few minutes of speaking with us about her role at the clinic, she disclosed her HIV-positive status. The following is her story.

When Sisanda first found out she was positive, she "just knew that it was something she had to accept." She also knew right away that it was something she wanted to learn more about, and upon learning about the disease, she decided that "there was life after being diagnosed HIV positive." She felt that "there were things that she could do," and she began with disclosing her HIV status. Now, she has disclosed her HIV status to many people because she likes to tell them that "there is hope," that one "can live with HIV—there is life after HIV." This was her main motivation: to help others who were in a similar situation.

In Sisanda's case, knowing her own status made her very sensitive to others. She found that some other health workers can speak harshly to people, but she knows that people living with HIV must support each other. She has received special training for counselors who are HIV positive, and she works with the clinic by monitoring for any ill treatment of people living with HIV/AIDS that may occur. In such cases, she is trained to approach the staff member to improve sensitivity and professionalism at hospitals and treatment clinics.

This program providing special training for HIV-positive counselors and those involved is called Expert Patients, and Sisanda is proud that she is able to contribute to the healthy lives of other people like herself who are also living with the disease.

family, friends, and neighbors, those in Mbekweni were also able to use formal institutional support through local NGOs and governmental social services.

Empowerment and Community Involvement

Another important difference between the communities was the greater opportunities available for HIV-positive people in Mbekweni to take a positive leadership role and to act as a role model for others (see the box on this page). Further, by publicly acknowledging their HIV status, they were able to become actively involved in their communities and to lend support to other HIV-positive individuals and their affected families.

At the most basic level, community involvement entailed lending informal support to those who approached them. As a translator for a respondent from Umzimkhulu explained on behalf of the respondent:

She does support others when she is approached. Someone will come to her and tell her about their status and she will tell them, "You can live with HIV and be healthy." When there are people in the community who are sick, she can tell and she will go and refer

them to places where they can receive help. For those who are open, she will tell them about her experiences. She tells them, "There is help; your life is not over."

A respondent in Mbekweni found that being open about her status allowed her to directly challenge discrimination in the community. This woman said, "When I became open about my status, people did treat me differently, but I tell them that "if you are not tested you don't know your HIV status."

Furthermore, respondents themselves benefited from being in contact with others who were HIV positive, and this mitigated their own psychological impact at the time of their diagnosis. As 1 respondent explained, "Other people who were also positive came to visit me and would tell me that I would be okay. At this time it helped a lot because I really had no hope."

In Mbekweni there were formal avenues for community involvement such as NGOs like the Mothers-to-Mothers program, church support groups, and the Treatment Action Campaign, an organization of AIDS activists fighting for equal and improved access to antiretroviral therapies. Programs like this did not exist in Umzimkhulu.

Ultimately, disclosure of HIV infection opens the door to a dynamic response encompassing community involvement and the support of other HIV-positive individuals and their families and enabling a platform for public disclosure and the eradication of stigma.

HIV-positive individuals have remained a largely underutilized resource on the HIV/AIDS prevention and mitigation landscape. This human capital holds great potential, as in the case of Umzimkhulu—a resource-poor community in desperate need of HIV services directed and managed by other HIV-positive individuals.

Beyond the impact on the greater community, involvement can also build the morale of people living with HIV/AIDS and can provide them with a sense of purpose; speaking out about their experiences with HIV/AIDS enables many individuals to reassert control over their lives and reclaim personal dignity and pride.⁷ This is a benefit that has been channeled in Mbekweni but has yet to be engendered in Umzimkhulu.

CONCLUSIONS

We sought to describe the process and consequences of disclosure of HIV infection in 2 South African communities. For our respondents in both urban and rural communities, the process of disclosure of their HIV status to family, loved ones, and professionals had important implications for how they were able to respond to the impacts of HIV/AIDS on their lives and livelihoods.

Successful disclosure of HIV infection was often seen as a way for HIV-positive persons to regain the freedom that their HIV-positive status had taken away from them. Those who had family support were better able to manage their situation, both financially and emotionally.

Disclosure also offered HIV-positive persons the opportunity to become involved in the local HIV community and to foster important social and material resources. Disclosure was the catalyst for access to a variety of important and often-essential resources required to respond effectively to the impact of HIV/AIDS-related “shocks.”

We also sought to compare the consequences of disclosure in 2 communities with differing rates of disclosure. A behaviorist model has dominated previous research and

subsequent policy prescriptions concerning HIV stigma and disclosure. This model gives preeminence to the stated attitudes and beliefs of individuals to explain important behaviors such as the disclosure of HIV infection. In this paradigm, eminence is given to the social exclusion, fear, and distress caused by both perceived and real stigma and discrimination.¹⁷

The process of deciding whether to disclose one’s HIV status is conceptualized predominantly in terms of individuals undergoing a cost–benefit analysis of preconceived risk. Our study suggests that this is only a partial explanation for how individuals make decisions regarding HIV disclosure.

We found that many of the experiences surrounding disclosure of HIV infection in the 2 communities were not entirely dissimilar; individuals in Mbekweni and Umzimkhulu both found it difficult to disclose their HIV status, went through periods of negotiation and management, and did not encounter dissimilar rates of stigma or rejection from loved ones.

This does not explain the vast difference in the prevalence of disclosure of HIV infection between the 2 communities that were otherwise similar in terms of ethnicity and culture. We found the major difference when comparing the process of disclosure in the 2 South African settings to be in the broader social and political contexts within which disclosure was considered.

The social-political activism in the form of civil society movements surrounding HIV/AIDS in Mbekweni has fostered the transformation of the stigma and marginalization previously associated with HIV/AIDS into new forms of belonging and, perhaps ultimately, citizenship in the HIV-positive community.¹⁸ Social movements such as the Treatment Action Campaign have created a “moral economy” based on altruism, affiliation, and care.

Our study design made it difficult to assign the different social and political contexts of disclosure between the communities as a causal factor for the much higher rates of disclosure of HIV infection. However, this and other studies have shown that HIV-positive people rationally carry out an internal cost–benefit analysis of their potential disclosure. Decisions about disclosure are ultimately influenced not only by considerations

that reflect the impact of stigma⁴ but also by the perceived positive outcome.

When individuals are able to gain or protect their current livelihoods, they are more likely to disclose their HIV status.¹⁹ Our study synthesizes the cost–benefit and moral economy approaches; we believe that the 2 are not mutually exclusive. The presence of social-political activism improves the rational potential benefits of disclosure; better support services can lead to higher rates of disclosure.

Rachel Jewkes recently stated that “if the focus shifts, we could provide positive role-modeling in care and support, and in doing so, shift the discourse from the negative . . . to the empowering.”^{20(p431)} We begin this process with the call for the creation of an enabling, resource-rich environment for individuals seeking to disclose their HIV infection, forming a virtuous cycle; in such a situation, individuals are more likely to disclose their HIV status, thus offering personal and community benefits and further perpetuating disclosure and its benefits at all levels of society. ■

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Contributors

A. Norman worked on the methodological framework, carried out the fieldwork, analyzed the data, and wrote the article. M. Chopra originated the study with S. Kadiyala, supervised aspects of its implementation, and contributed to the analysis and writing. S. Kadiyala worked on the methodological framework, analyzed the data, and provided comment on drafts.

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Human Participant Protection

The ethics review board, University of Calgary, Calgary, Alberta, and the University of Western Cape, Bellville, South Africa, approved this study.

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