Suffering, Shame, and Silence: The Stigma of HIV/AIDS

Lynne Duffy, BScN, MEd, PhD

HIV/AIDS, especially in the context of poverty, results in considerable suffering. The issues surrounding prevention, transmission, and mitigation are complex, but one very important concept sustaining the epidemic is stigma. This article examines the meaning of stigma in the literature and through the experience of people living in a high-prevalence area. An ethnographic study in rural Zimbabwe, where approximately one third of adults are infected, revealed how stigma, suffering, shame, and silence are mutually supporting concepts that challenge health promotion efforts. For a reduction in HIV/AIDS morbidity and mortality rates, there is a need to understand and act on contextual issues such as stigma with increased political and social commitment at local, national, and international levels. Nurses and other health care professionals need to be involved to ensure public policy and local interventions are aimed at enhancing supportive environments and reducing suffering.

Key words: gender, health promotion, HIV/AIDS, poverty, social justice, stigma, suffering

In Zimbabwe, with a population of approximately 12 million and one of the highest global rates of HIV, it was estimated at the end of 2001 that 33.7% of adults (aged 15-49 years) were infected, and there were 780,000 AIDS-related orphans (UNAIDS/UNICEF/WHO, 2002). During 2001 and 2002, an ethnographic study in rural Zimbabwe examined factors that facilitate or hinder women’s ability to prevent HIV (Duffy, 2002). Key participants included a core group of 11 women recruited through purposive sampling (Table 1). As well, 17 key informants (Table 2) and four focus groups (Table 3) added to the depth and richness of the data. Although gender inequality emerged through the narratives as the main influencing factor for women’s inability to protect themselves, serious issues around the stigmatization of the disease were revealed and significantly added to the complexity surrounding HIV transmission and AIDS care. The last few years have seen an intensified focus on stigma related to HIV/AIDS, most notably through UNAIDS and World AIDS Day. Yet visible change has remained slow, affirming the enduring strength of stigmatization.

This article offers a perspective on HIV/AIDS-related stigma through the voices of the study participants who are immersed in the epidemic on a daily and lifelong basis. The Ministry of Health in Zimbabwe recognized that HIV/AIDS is no longer merely a medical problem but a social and economic one that affects the whole country and its future. A 1999 HIV/AIDS policy document stressed that the crisis required a focus on and analysis of gender, cultural norms, and human-rights issues, as well as the need to create supportive environments for dealing with all aspects of the epidemic (Ministry of Health, 1999). We are reminded that “any epidemic sustains itself largely because of the social organization that supports its propagation, not simply because of the biological characteristics of the causative agent” (Basset & Mhloyi, 1991, p. 144).

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Stigma

For several decades, stigmatization has been recognized as a major influence in treatment and care of ill persons and groups for the reason that it strongly relates to the way persons are viewed within their communities. More recently, it has been linked to HIV prevention by social science researchers building on the work of Irving Goffman. Goffman (1963) was a pioneer in examining the relationship of stigma to disease processes. He wrote that *stigma* was originally a Greek term and referred to “bodily signs designed to expose something unusual and bad about the moral status of the signifier” (p. 1). Goffman noted that when people are marked as different, it means they are “thus reduced in our minds from a whole and usual person to a tainted, discounted one” (p. 3). Because the stigmatized person is thus seen as “not quite human,” as substandard, it is easier to discriminate, resulting in reduced opportunities for that person (p. 5).

Kleinman (1988) wrote, “Diseases that stamp very powerful cultural meanings into the sick person stig-
matize in the same way as Hester Prynne’s scarlet letter, the yellow Star of David sewn to the sleeve of a Nazi concentration camp victim” (p. 159). He stressed that the disfigurations or markings of a disease stigmatize “because they break cultural conventions about what is acceptable appearance and behaviour, while invoking other cultural categories—of what is ugly, feared, alien, or inhuman” (p. 159). Kleinman further explained that stigmatizing can also be related to moral and religious beliefs in which a person is considered sinful or evil. Such labels help define the social group by projecting its negative values on the other who is labeled defective or depraved (p. 159). People in Zimbabwe who are in the advanced stages of HIV disease exhibit shared physical symptoms (e.g., hair and skin changes, wasting), often from the opportunistic infections that occur, and they are quickly labeled as AIDS sufferers. Most people in the study said they could recognize someone who had HIV or AIDS, with little differentiation between the stages of HIV disease. It is believed that 90% of HIV transmission in Zimbabwe occurs through heterosexual contact (UNIFEM, 2000). The physical manifestations of advanced disease are therefore considered clear indications of immoral behavior and can mark someone to be avoided or ill treated. As well, groups linked to high HIV prevalence, such as commercial sex workers, are stigmatized even if they are not infected.

The issue of HIV/AIDS stigma as an important public health concern was reflected in the 2002-2003 theme for the UNAIDS campaign: Stigma and Discrimination. A 2001 National Institutes of Health conference held in the United States titled “Stigma and Global Health: Developing a Research Agenda” attempted to consolidate understanding of stigma and disease. The public response to HIV/AIDS affects how people view themselves. Goffman (1963) called this their “social identity” (p. 2). Kleinman (1988) noted that the stigmatization process usually begins with the community’s response to the person, but eventually the person “comes to expect such reactions, to anticipate them before they occur and even when they don’t occur” (p. 160). Kleinman described another process important to those working in health care where many people “feel shame, not because of the cultural meaning of illness, but rather in response to the reactions of family and especially health professionals” (p. 160).

### Table 3. Four Focus Groups

<table>
<thead>
<tr>
<th>ID #</th>
<th>Name/Pseudonym</th>
<th>Occupation</th>
<th>Age</th>
<th>Sex</th>
<th>Marital Status</th>
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<tr>
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<td>Farmer/HIV+</td>
<td>30</td>
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Suffering and Shame

A diagnosis of AIDS brings with it considerable physical and emotional suffering, especially in a context of limited treatment that includes no access to antiretroviral medications unless one is wealthy. That is the reality in Zimbabwe, because the health care system has experienced serious deterioration amidst increasing economic and political chaos. With no cure and with care and mitigation of symptoms constrained within a climate of increasing poverty and disappearing health care resources, misery is increasing. The further emotional trauma created through stigmatization only intensifies the suffering.

When participants in the ethnographic study (Duffy, 2002) were asked how people with AIDS are treated, there seemed to be an understanding that they should be seen as normal. However, reality suggests that fear, suspicion, and victim blaming are still very common. A village health worker noted that treatment of people living with AIDS very much depends on individual families. “But mostly they are ill-treated,” she said. “Nobody likes to associate or share anything with an AIDS patient. In most cases they are considered repugnant or repulsive.” One woman whose son was HIV-positive said, “People will run away,” and “The person remains alone with their problem.” They are given separate eating utensils and towels, any leftover food is thrown away (instead of being shared with others), and people tend to clap hands when greeting instead of the very important handshaking that is the norm in this culture.

Nurses see many AIDS patients and their visitors and have observed negative interactions. One nurse reported, “They are treated differently, they isolate them, they don’t take care of them, they don’t even socialize with them or listen to their problems. . . . ‘Serves you right, why did you acquire it?’” Several participants told how HIV is so strongly associated with promiscuity that the terms are nearly interchangeable. “People in the society that are promiscuous are generally rejected.” Therefore, once labeled an AIDS patient, one is forced to accept personal responsibility for the illness that then implies little care and support from others. Being HIV-positive carries a strong sense of shame, with the disgrace also felt by the family. Even if the family does provide good care, the true diagnosis is rarely, if ever, mentioned.

Silence

The stigma, discrimination, and resulting isolation means that people do not easily, if ever, disclose their diagnosis. One study participant who is HIV positive stressed that “telling everybody is not easy. People would start to dislike you and would classify you under prostitutes. Nobody would respect you for you would be an AIDS person.” The 7 women in the study who were living with HIV told only one or two people; those who they trusted to accept them unconditionally and maintain confidentiality. One said she would be laughed at if she spoke openly. “People would have found jokes (about me) for months. They would talk bad about me.” Others in a focus group explained why they had been secretive about their status. “Let’s say people would know that I am HIV positive. If we go to a funeral they would not like to sit next to me or share anything with me. Even eating from the same bowl, they would refuse.” Two others reported, “Let’s say you go to the river to bathe, everybody would stop washing and bathing until you finish,” and “You would be an outcast in the society. Nobody would love you.”

It appears that the stigma associated with AIDS is more serious for women, who already experience considerable silence. Men’s promiscuity is more easily accepted or at least tolerated. Women, on the other hand, are expected to remain faithful to their husbands. It appears that much of the social control over women’s movement, voice, and opportunity is based on the belief that they will become promiscuous if granted too much freedom and this could lead to contaminating the paternal lineage. When they (or their husbands) are recognized as having AIDS, women are often blamed for the infection as they have been blamed throughout history in relation to other sexually transmitted diseases (Morrison & Guruge, 1997; Schoepf, 1995). With an AIDS diagnosis, women may be sent away or ostracized by both in-laws and family of origin, even though such women most likely contracted the infection from their husbands (Meursing & Sibindi, 1995).
women are not accused of promiscuity, the disease is thought to be related to bewitching or other evil spirits. Whatever the cause, women are not only in danger through isolation and neglect or through dangerous exorcising rituals. Wives are expected to care for their ill spouses, and after the husband’s death they are often left to care for their own terminal illness with very limited resources.

Denial and Secrecy

It is not surprising that with the degree of stigmatization there is a corresponding level of denial and secrecy that supports the silence. Everyone at some point is affected by the epidemic, yet many are still not able or willing to openly discuss it. People search for every possible reason to explain the high morbidity and mortality that is tearing apart families and communities. A teacher talked about the death of her brother, who she admitted had AIDS. However, 5 years later she is still searching for another cause, something supernatural. She recalled a time when he began to make a partial recovery: “So I said to myself, these doctors are used by the devil. Look, he is up now and about.” Even though she could see he was not back to normal, “In my mind I dismissed what that doctor had said about him being HIV-positive.” Another participant pointed out that many believe AIDS is not a real disease; that “God wants us to die. . . .”

As people started hearing about AIDS, they were convinced that everyone was going to get sick and that, as another teacher related, “The whole community would be wiped out.” Since that did not happen, she said people stopped worrying about it. When they see a promiscuous woman who is still alive after many of her partners have died, “It means it is not AIDS; there is something else that is killing these men. . . . So we start looking for the unknown but we don’t want to deal with what is before us.”

The subject of HIV/AIDS is avoided at all levels of Zimbabwean society. Female nurses in the focus group talked about how even the government is in denial while supposedly supporting interventions. When high-level cabinet ministers showed clear signs of AIDS, their deaths were reported as caused by a long illness or malaria. “When it started, people said there is nothing like AIDS. It was an American way of discouraging sex. No one was taking it seriously,” reported one male nurse. Another added that even if people admit AIDS exists, they think they are personally immune. “It won’t affect me, it’s over there, and we are always pointing fingers.” He explained that the denial is abetted because of the tradition of going to N’angas (traditional healers) to find out the cause of an illness. The diagnosis of unhappy ancestors or bewitching feeds into the denial while providing psychological comfort. The spirit mediums will say, “Ah, it is not a virus, it’s because the spirits are not happy.”

A male nurses’ focus group discussed the decreasing rates in Uganda where the government encouraged openness about diagnoses even at funerals. All agreed this would not happen here. “You can’t say somebody has HIV at a grave, you can’t do that. If you do, you destroy the whole family one way or another. If you say that, they will shun the children, they will shun the wife and everybody. It’s a no-go area.”

Nurses and other health care providers contribute to the level of denial. One woman who is HIV positive wondered about her status, but staff told her she was looking healthy so did not have HIV. It took several years for symptoms to appear, and then she was tested. Doctors are asked by nurses not to write the diagnosis on the chart or the death certificate, because this causes problems for families and affects insurance. Instead, the term RVI, for retroviral illness, is used. The Dutch medical superintendent stressed, “It’s like there is a huge denial and passive attitude to the whole problem, where I expected that some people would stand up and try to fight. But it’s not really like that.” He described what happens when he attempts to give a correct diagnosis to someone: “People suddenly change the subject completely. . . . They ask, ‘Doctor, did you already give malaria tablets, did you do this?’ and they just avoid it.” He added, “So the denial is not just with the patients themselves, it’s throughout the whole society. Even in official reports they don’t expect you, or they don’t want you, to write down the correct diagnosis.”
People are said to be talking about the problem, but not openly. The use of various terms like TB2 (second-level treatment of tuberculosis), whole-body illness, home-based care, and various indigenous names adds to the denial. The two N’angas in the study said they never told a patient directly, because it would not be accepted. Even with advanced symptoms, a female healer said, “You don’t tell her [the patient] that she has it.” The other N’anga explained his approach to diagnosis while tracing a line on his carpet and moving his hands around the imaginary hakata pieces (items thrown and then read for a diagnosis and cause of illness) to demonstrate the twisted route he takes. The hospital counselor said that it is easy to talk about malaria or tuberculosis, “but with AIDS, we feel we should not mention it. When it comes to HIV, it’s [called] a ‘long illness.’”

**Implications for Health Promotion**

Stigmatization resulting in silence, secrecy, and denial not only affects care and treatment, it has serious implications for prevention that is critical in a disease with such a long subclinical phase. Most people in Zimbabwe do not want to be tested, and this feeds into their personal denial. Instead of beginning to care for their health, which could prolong life, they continue unhealthy practices that include putting partners at risk. Nurses and others in the study stressed that AIDS must be brought into the open so that stigma would be removed.

Webb (1997) wrote that “community responses to AIDS can be investigated by examining attitudes towards people with AIDS” (p. 165). Positions found in this type of research “have been classified into three groups: kill, isolate . . . and care” (p. 165). These viewpoints will certainly affect a community’s approach to the illness and the resulting level of suffering of its members. They also influence how health care providers treat those infected and where their energy is focused regarding prevention. Looking at the failure of many prevention programs in Africa and considering the fairly high level of awareness, Webb recommended further study on “the links between personal knowledge, stigma, and behavioural change” (p. 195). A 1994 report from the Center for Strategic and International Studies “emphasized once again the fact that the main barriers to effective strategies against the epidemic are stigmatization and discrimination” (Bell, 1997, p. 192). A longtime advocate for AIDS prevention and care in Zimbabwe stressed that “Most important is to reduce the stigma and discrimination attached to HIV/AIDS, so that those affected can openly seek the support they need” (Jackson, 2002, p. 211). She related many stories of individual and family rejection resulting from “fear, confusion, shame, anger or blame; these feelings and attitudes need to be understood and changed” (p. 211).

This study in Zimbabwe (Duffy, 2002) showed considerable discrimination toward and suffering of women in this rural area related to economic and sociocultural inequality and oppression. Poor women are already overrepresented in the AIDS crisis, and stigmatization adds to their suffering in ways that are hardly imaginable. Being female means they have limited voices, yet “suffering tends to make people inarticulate, and in this sense the voicelessness of suffering often resembles the quiet retreat of people who live with chronic pain. . . . [This withdrawal is] constructed in response to an environment where effective help and concern have all but vanished” (Morris, 1997, p. 28). It seems a vicious circle. Stigmatization leads to greater suffering resulting in lack of voice, while silence allows the stigma to gain more influence.

Nurses can be catalysts for change in communities in which long-established practices of silence and denial exist. Change, especially in traditional societies, is usually slow and requires great sensitivity to the problems caused by too much directness. Meanwhile, establishing open and trusting relationships with regard to HIV and ensuring confidentiality will go far in giving people permission to begin talking about the issues and to be tested without fear of reprisal, reprimand, or labeling.

Nurses need to continue working within a primary health care framework and to distinguish this from the more limited practice of primary care. This will encourage not only health promotion over cure but will work toward building stronger communities and multisectoral collaboration. It is critical that HIV prevention be integrated within an overall development framework that respects and builds on the strengths of individual cultures. It is also important
that health promotion messages do not further stigmatize particular groups, as happened with commercial sex workers and truck drivers.

High school students in the study offered hope that their adult lives will be different from their parents’. They appear more open to challenging tradition that so seriously affects the health of the community, especially the women. This openness needs to be nurtured with early, appropriate, and relevant learning regarding HIV, AIDS, and gender issues in the schools. School-based peer education programs have worked well and need more support. However, many young people are forced to abandon their formal education because of the financial and care implications of AIDS in the family, requiring innovative out-of-school programs to be a priority as well. Zimbabwe’s increasing number of orphans are especially vulnerable to sexual abuse. Development of nurturing and safe community-based orphan care is critical.

The serious implications of the epidemic and the fact that everyone in high-prevalence areas is impacted in some way require that HIV become a topic of everyday life, supported with broad collaboration from all sectors of the community and beyond.

**Barriers or Bridges?**

It is relatively easy to talk about stigma and suffering in communities of Africa, Asia, Latin America, and in our own minority groups in Europe and North America. Action is more difficult. Most of us are removed from the level of poverty and suffering that exists in areas of high HIV prevalence. Under the Western medical model, Lock (1997) charged that “efforts to reduce suffering have habitually focused on control and repair of individual bodies. The social origins of suffering and distress, including poverty and discrimination . . . are set aside” (p. 210). Strong words from Farmer (1997) challenge us to examine poverty, suffering, and silence:

> The poor are not only most likely to suffer; they are also more likely to have their suffering silenced. A wall between the rich and poor is being built, so that poverty does not annoy the powerful and the poor are obliged to die in the silence of history (p. 280).

Are stigma and resulting discrimination the reasons why so little seems to be done about finding a vaccine, about funding antiretrovirals for developing countries, or about finding methods of prevention that are controlled by women and that reflect the realities of their lives? Stephen Lewis (2004), the United Nations special envoy on AIDS in Africa, gave a speech to the Rotary Club in Toronto. In his powerful style, he challenged us again by asking how this situation was allowed to happen:

> There seems to be these historical moments, these historical periods when moral resolve either freezes or evaporates . . . The excruciating truth is that the pandemic need not have come to this. If the African leadership, early on, had not been consumed by denial and fear; if the industrialized nations, early on, had made resources available; if the world had been energized around the pandemic as it has been around Afghanistan, Iraq, and terrorism . . then millions of people would still be alive today, and millions of others would have a fighting chance of prolonging life.

Kofi Annan (2003), the secretary general of the United Nations strongly expressed the importance of speaking openly and the danger of building walls:

> No progress will be made by being timid, refusing to face unpleasant facts, or prejudging our fellow human beings—still less by stigmatizing people living with HIV/AIDS. Let no one imagine that we can protect ourselves by building barriers between “us” and “them.” In the ruthless world of AIDS, there is no us and them. And in the world, silence is death.

All over the world, the AIDS epidemic is having a profound impact in many ways, both positive and negative:

> It triggers the best when individuals group together in solidarity to combat government, community, and individual denial, and to offer support and care to people living with HIV and AIDS. It brings out the worst when individuals are stigmatized and discriminated against by
their loved ones, their family, and their communities, and discriminated against individually as well as institutionally (UNAIDS, 2003).

HIV/AIDS is the most insidious disease faced in this century. The issues are complex, but we must not allow this to sustain our apparent apathy. Urgently needed are global, multilevel, and justice-based approaches that address the many underlying causes. This includes challenging stigma, silence, poverty, and inequality. Nurses and other health professionals can play an important role in building bridges between governments and local people that enhance understanding of the contextual issues of people’s lives. Tearing down walls of misunderstanding, fear, stigma, and discrimination must be part of any health promotion effort, while building supportive environments that eliminate unnecessary suffering from AIDS.

References


