Changing the Course of AIDS

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Changing the Course of AIDS: Peer Education in South Africa and Its Lessons for the Global Crisis.


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In South Africa, one in three women between the ages of twenty-five and twenty-nine and one in five men in their thirties are infected with HIV. South Africa is not alone in facing these levels of HIV infection; many other sub-Saharan African countries face similar or even higher prevalence rates. In developed countries AIDS is largely contained as a problem of marginal groups with specific factors rendering them vulnerable. In developing countries, such as India and China, the epidemic threatens to go on the march, as it is doing in the transitional economies of Eastern Europe and Russia. The epidemic is still globalizing, and its impact continues to unfold.

As the epidemic has taken on global dimensions, there has been dramatic progress in treatment but little in the prevention of HIV infection. In a 2007 World AIDS Day editorial entitled “HIV Treatment Proceeds as Prevention Research Confounds,” the editors of *PLoS Medicine* argued that “interrupting HIV transmission remains one of the world’s greatest scientific challenges.” The acknowledgment is to be welcomed, but we
should also understand that the vision of prevention that the PLoS Medicine editors put forward is one rooted in a biomedical paradigm: prevention as technical fixes—a vaccine, microbicidal gels, circumcision, or condoms—that can be used to prevent infection. This largely ignores the human processes of responding to AIDS. The challenge involved in prevention is really the challenge of profound shifts in both individual and social behavior.

This is true for many other health-related problems, not just HIV/AIDS. The developed world may be able to shrug off its marginal AIDS problem, but problems of diet, lifestyle, obesity, smoking, and alcohol present endemic or epidemic challenges that significantly detract from well-being. Some of these concerns are as much problems of affluence as of poverty. No matter what one’s social position, health-related problems such as obesity, addiction, and lack of exercise can be changed only when individuals recognize the implications of ingrained habits.

Examining the practice of peer educators helps us understand this difficult quest for behavioral change. What workplace peer educators in South Africa can teach us about changing beliefs and behavior around HIV/AIDS can help us better understand challenges in responding to other behaviors that detract from health and well-being. This concluding chapter draws together what we have learned into a three-part model of peer-led behavioral change that incorporates social space, social leadership, and social action.

Social Space

Drawing and expanding on Erving Goffman’s dramatic model of social interaction, we have identified three sites of human interaction related to HIV/AIDS (and quite possibly to much else): (1) front-stage space, where formal performances are typically given; (2) backstage space, where informal interventions can be made within the daily lives of peers; and (3) liminal space, where peer educator and peer slip away momentarily from the constraints of social order.

Front-stage performances are the easiest type of interaction to initiate. Modeled on the classroom lesson, the church sermon, and public speeches, these performances, whether by a socially distant expert or a peer before
an audience, present information on HIV and AIDS but provide no guarantee that anything will change because such performances are largely unconnected to the lives of the audience. Most mass media communications on HIV/AIDS operate along similar principles. This does not mean that front-stage presentations on HIV/AIDS are not of value; they are, and they can be improved. In isolation, however, they are unlikely to reshape beliefs and behavior.

Focusing on front-stage spaces also ignores a vast hinterland of social interaction. Away from the staccato volleys of AIDS facts delivered through formal educational interventions there are countless moments when the same information can be woven into the routines of everyday life: at work, at leisure, at worship, or at the bus stop—anywhere. When peer educators operate in backstage spaces they contextualize factual information so that those they educate can relate this information to their beliefs, concerns, and actions.

Although backstage spaces may exclude the most obvious social divisions, it is fanciful to think that these spaces are tension free. Far from it: In these seemingly more private spaces, tension is rife. This is as true for the supposedly intimate space of the family as it is for local communities, church congregations, work, or other peer settings. The hope that informal activity by peer educators need only clarify what has not been grasped when presented from a front-stage platform is wildly optimistic. Sometimes it can, and peer educators need to be constantly watchful for such teachable moments. But, more often, the tight social order in backstage space makes open discussion difficult and behavioral change hazardous. This is not only because HIV/AIDS is a difficult issue to address, but because the multiple lines of division in backstage space are well entrenched and there are no institutionalized processes for their (re)negotiation. Bringing in any new issue, beyond the trivial, threatens already accommodated worldviews and positions.

Paul Farmer’s study (1990, 1994, 1999) of the construction of a cultural model of AIDS in a Haitian village during the 1980s argues that it took approximately five years for the generation of a consensual schema of understanding. The difficulty that peer educators have in operating in their own backstage spaces would indicate that in South Africa we are still far from a consensual cultural model of AIDS. One explanation for Farmer’s rapid timeline is that he overweighted the degree of consensus
and underestimated the significance of variations that he identifies in
the model (1999, 175–177). Alternatively, and not incompatibly, we can
acknowledge the point made by anthropologists that the exact dynam-
ics of the AIDS epidemic and how it is understood will vary by location
(Preston-Whyte 1995; Schoepf 2001; Setel 1999). A Haitian village is not
South Africa, nor should South Africa be seen as a unitary entity.

Perhaps the most illustrative contrast to the difficulty South African
peer educators have in working in backstage space is the achievements of
peer education in urban gay communities. In cities across the globe, gay
male communities were particularly vulnerable to HIV infection when it
first spread beyond its African origins in the late 1970s and early 1980s.
Penetrative anal sex is an efficient route for HIV infection, extensive sex-
ual networks linked many in these communities, and condoms, given their
then-primary contraceptive function, were not part of the gay scene. As the
first sites of response to AIDS, urban gay communities are credited with
considerable success in changing sexual behavior and lowering infection
rates (Kippax et al. 1993). The STOP AIDS project in San Francisco in the
1980s utilized peer education within a community-based response (Wohl-
feiler 1997). Arvind Singhal and Everett Rogers (2003, 210) argue that the
main lesson of STOP AIDS in San Francisco was, “customizing the design
and delivery of a communication program on the basis of the characteris-
tics of an intended audience segment [i.e., peer education].”

A randomized, controlled intervention, using peer communication
among homosexual men in eight small U.S. cities found that “population-
level risk behavior decreased significantly in the intervention cities com-
pared with the controlled cities” (Kelly et al. 1997, 1500). The authors
concluded that, “Popular and well-liked members of a community who
systematically endorse and recommend risk-reduction behaviour can in-
fluence the sexual-risk practices of others in their social networks. Natural
styles of communication, such as conversations, brought about population-
level changes in risk behaviour” (1500)” Susan Kippax et al. (1993) found
that the best predictors of behavioral change among gay men, along with
knowledge of HIV transmission and educational level, were the correlated
variables of residence and attachment to the gay community: something
that would promote access by and to peers.

The tangible success of peer education programs among urban gay com-
munities has been much more difficult to replicate elsewhere. As discussed
in Chapter 1, what peer educators do has been poorly understood. Given what we now know about the activity of South African workplace peer educators, we can suggest why peer education among gay men in Sydney, London, San Francisco, and other cities across the world has been so effective.

The first thing to note is that the backstage social space of gay communities was less complex and less divided than that of the social spaces in which South African workers live, love, and labor. There is, obviously, only one gender within gay communities, and strongly gendered roles are rarely re-created within same-sex relationships (Bolton 1992). Additionally, these gay communities were, in comparison to wider society, also highly homogeneous along lines of race, education, and economic status (McKusick et al. 1990). High education and economic status are regarded as a factor supporting behavioral change, but this is not the point being made here. Rather, it is the similarity of community members around these characteristics that is being highlighted.

Of course, gay communities are not entirely homogeneous. For example, as Ralph Bolton (1992, 154) notes, “the gay community is divided between separatists and integrationists [with respect to straight society]” something that, through perspectives on promiscuity, sets up tensions over strategies to counter HIV transmission. However, overall, it is plausible to argue that the gay community of San Francisco is less complex than the situation of a Xhosa migrant worker employed on a mine in the North West Province, whose girlfriend lives in a nearby informal settlement, while his wife remains a thousand kilometers away in the Eastern Cape. Additionally, Graham, Bill, and Paul in San Francisco may have, by virtue of their education and economic status, less need to defend particular positions in backstage space in the face of AIDS than Isaac, Lydia, and Tandi in South Africa.

The realities of these complex divisions and tensions over HIV/AIDS backstage means that peer educators, in South Africa at least, have emphasized slipping out of order into temporary and liminal spaces to effect change. Here, peer educator and peer can talk honestly and, as is often necessary, strategize about changes in peers’ lives that stand a chance of success in the mist of everyday encounters. The need to step back into order armed with tricks, lies, and deceit reflects the difficulty of changing behavior when it comes to HIV/AIDS in South Africa. While change may be particularly hard when it comes to “this disease,” other behavior linked to
poor health—such as eating, smoking, and drinking—are also powerful human experiences that are entangled within social relationships and social positions. Slipping out of order is a pivotal step in how peer educators seek to turn behavior around AIDS. It is likely to provide a similar function for other health concerns around the globe.

A second difference between urban gay communities and those of black workers and their families in South Africa is how HIV/AIDS relates to front-stage divisions. Many homosexual men made a conscious choice to move to gay centers from more heterogeneous—and less tolerant—communities. This allowed gays to create a sense of collective identity directly linked to sexuality. Such a collective identity was then openly expressed in public, front-stage encounters; for example, when a gay group lobbied a city council or otherwise discussed the AIDS crisis. This openly expressed collective identity supported the efforts of peer education in gay communities.

As we have seen, however, in South Africa there is no collective identity or set of shared beliefs about HIV/AIDS aligned to major social divisions. The salient collective identities involved in front-stage encounters between workers and management, or between workers’ communities and the state, have nothing to do with sexuality. In South African workplaces, unions have struggled to respond to HIV/AIDS beyond what can be packaged into the existing framework of collective bargaining around wages, benefits, and working conditions. Questions of sexuality are largely confined, and controlled, backstage. Peer educators seeking to intervene around HIV/AIDS are unable to align their messages with wider community identities. Again, this may not be so different from other problems of wellness. For example, those concerned about alcohol must not work only against powerful commercial interests but also a widespread acceptance of alcohol as an essential and desirable part of social life. Such challenges demand, if they are to be successfully tackled, a much broader approach than peer educators alone can mount.

Social Leadership

One of the many things we learn from exploring the work of peer educators is the difference between authority and social leadership. Those in authority, such as company managers, are obeyed—at least in the letter—because
disobedience is sanctioned. However progressive a workplace might be, this social fact undergirds the functioning of all organizations. As we saw in Chapter 4, managers and AIDS experts have limited effectiveness when they try to promote behavior change among the workforce not only because of linguistic and cultural barriers but also because they are authority figures. In workplace relationships, characterized by unequal power, the risk and reality is that, should their policies and practices around HIV/AIDS be ineffective, these “emperors” will not be told that they wear no clothes. When it comes to educating employees on matters of personal behavior, they will be “leaders” without followers.

Peer educators are therefore asked to perform leadership roles. Depending on whether peer educator programs are conceived and designed as vertical or horizontal communication processes, this can take very different forms. If peer educators are viewed as conduits in a vertical transmission stream through which AIDS experts get their messages down to target populations, then the leadership roles peer educators are being asked to perform are, at best, compromised, at worst, a sham. They are being told both what to do and how to define success. There is little room for genuine leadership. Indeed, with this model of peer education in place, it is easy to see why South African workers might accuse peer educators of being pawns of management. However genuine, they are being asked to be the AIDS “boss boys” (i.e., Africans promoted into supervisory positions within apartheid workplaces to control the black workforce) and girls of management.

In practice most company programs incorporate a great deal of leeway for an alternative, horizontal model of peer education—even if this is the result of neglect as much as design. Peer educators may attempt to push packaged messages, but they will only be successful if dialogue is centered on the beliefs and concerns of peers. It is in achieving these forms of discourse that the linguistic and sociocultural access of peer educators is so vital. It is also central to their role as social leaders in promoting and supporting change in attitudes and behavior over HIV/AIDS. Such changes need to be brought about within the worldviews of their peers: a horizontal process of insider contestation over explanation and behavior. But we should not underestimate the difficulty of horizontal communication—a theme throughout this book. Sensing the potential of peer education, some argue that it should be used to develop a Freireian “critical consciousnesses”
among peers who will challenge existing norms and conceive alternative ways of being (Campbell and MacPhail 2002). Such aspirations are to be welcomed, but first we need to understand the social environment of peer educators before demanding that they so dramatically reconstruct their (and our) world.

Beyond the training of peer educators, the role of experts in horizontal communication strategies is to understand the debates peer educators are engaging in and channel appropriate knowledge, resources, and skills to support them. To use a metaphor: those responsible for peer education programs need to see themselves not as generals in command of an army but as the logistics corps maintaining supply lines that keep peer educators equipped, motivated, and able to conduct their work. Maintaining these supply lines requires, of course, a vertical channel of communication, but this is not one of command and control; rather, it is a line of contact enabling peer educators to explain what is happening backstage. Such a process allows a genuine partnership between companies and peer educators.

What we have seen is that achieving shifts in belief and behavior around HIV/AIDS is extremely difficult. Peer educators face open challenges and more subtle resistance. When confronted with either, as we saw in Chapter 5, they try to slip past these barriers. In practice, they support behavioral change without directly challenging the wider set of social and cultural relationships. Such behavior is not specific to peer education. Professional counselors do this on a formal basis around a wide range of issues. Indeed, all of us have had “quiet words” with family, friends, or colleagues or responded to requests to share a problem under circumstances similar to what I have described in this book as “slipping out of order.”

It is the multiplicity of perspectives held within everyday social spaces which prevents peer educators from engaging in more open and more aggressive activity or tempers the effectiveness of bold, but likely

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1. Paulo Freire (1921–1997), a Brazilian educationalist, promoted a critical theory of education that opposed the idea of students being empty vessels to be filled with facts and argued that the teacher-learner relationship should be one of reciprocity.

2. There may be occasions when slipping out of order is not supportive. The soliciting of a bribe by a traffic cop involves a careful process requiring privacy and confidentiality. Here, however, the intention is not to assist the motorist who has violated a traffic regulation but to “solve” the problem the motorist has as a result of this violation with an easier solution from which the corrupt policeman benefits.
counterproductive, attempts to openly dominate backstage spaces with their message. Peer educators know that work colleagues and community members can easily desert them, psychologically if not physically, for others promoting alternative, more attractive explanations of AIDS. The social leadership peer educators display at the worksite or community level needs to be matched by similarly committed leadership from those in diverse positions of social and political authority. As we saw in Chapter 6, high-level leadership in all social institutions—including unions, churches, and traditional healers—needs to speak with one voice if such escape routes are to be closed. The failure of leadership in South Africa to date reveals the importance of this united voice. The same charge could well be leveled elsewhere when it comes to AIDS as well as many other problems that require an individual to bring about change within social settings.

Social Action

The question of what social action can be taken in response to HIV/AIDS is important, and will remain so as long as medical science has no cure for this disease. A key theme of this book has been to distinguish processes of collective action from individual behavioral change. This dichotomy of action repertoires is a perennial concern for those seeking to bring about change. The balance of what peer educators are doing in response to HIV/AIDS focuses on changing the individual. That does not mean that their work is not a form of social action.

Of course, the response to HIV/AIDS must include classic collective mobilization. The Treatment Action Campaign (TAC) has certainly proved this. Through widespread mobilization TAC pressurized the South African state to provide antiretroviral drugs. This approach worked not because it is a universally applicable model but because there was a “quick fix”—antiretroviral drugs—available. It also worked because TAC was able to mobilize a constituency (HIV-positive people and a range of allies such as unions) along existing front-stage divisions—that of the state and the population—using demonstrations, legal action, and the media. It did this while having to make minimal headway in backstage spaces. Indeed, we have learned that getting people to take antiretroviral drugs is a different problem—which often requires backstage change. The point that we should draw from this
example is that confronting AIDS will require a range of social action. And if this is true of AIDS, it will be true of other health concerns.

Achieving individual change is almost certainly harder than achieving collective change when it comes to HIV/AIDS. It is difficult to encourage individual behavioral change not only because of what is at stake—sex, pleasure, power, comfort, elation, escape—but also because these behaviors are deeply embedded in complex social relationships. Many of those working toward the prevention of HIV infection believe that behavior cannot be changed by individuals away from group norms. Vera Paiva (1995, 112) argues that unless “socially constructed prejudices and fears” are broken down by members of a community, then “calls for individual responsibility are a waste of time.” Based on this perception, a number of academic activists and practitioners have stressed that behavioral change programs must be integrated into community responses to the disease (Altman 1994; Kippax et al. 1993; Paiva 2000; Wohlfeiler 1997). Typically, this means involving the community by bringing people together in focus groups, workshops, or town hall meetings.

Involving communities in any response to HIV/AIDS is critical, but we need to question how to best accomplish this activity. What this book has demonstrated is that communities are not composed of individuals who share the same beliefs and customs even if they have the same skin color or ethnic background. To imagine a community as a cohesive group of people who, when brought together to listen to experts, will leave the room united in a different set of social relationships is fanciful. As we have seen, such performances win polite applause that may hearten the speaker but accomplish little else in daily lives. Because peer educators don’t organize town hall meetings, or march, or carry placards and shout slogans, peer education may not look like community participation. Yet the heart of peer education is individual change rooted in a clear sense of community and social relationships. To dismiss peer education because it doesn’t conform to our stereotypical understanding of social action (drawn heavily from the model and images of collective mobilization and public demands) is to narrow our understanding of social action. To do so discards an important way in which the collective and individual approaches to bringing about behavioral change can be integrated.

Peer educators are well aware of how socioeconomic conditions structure and constrain individuals’ sexual behavior, but they have little power
to do much about this. Given the failure of higher echelons of social leadership to respond to the epidemic, peer educators’ efforts have been focused on spheres of activity that they believe they can influence: changing individuals’ behavior within current contexts. In doing this they are acutely aware of how socially established norms inhibit their activity. Yet, their response has not been to throw up their hands in despair because they believe no one can change until everyone has changed. In practice rather than theory, they are seeking to negotiate ways around the difficulties encountered in backstage space. In doing so, their quest provides us with another form of social action in the fight against AIDS.

**What Would Success Sound Like?**

As peer educators continue to exercise leadership and engage in their version of social action, their companies and society are constantly trying to assess their effectiveness, evaluate their accomplishments, and define their “success” or “failure.” Thus, the final question we must address is: For peer educators, what is success, how does one define the impact of a peer education program?

In reflecting on this question, it should be clear that peer educators are not—by themselves—going to turn the AIDS epidemic in South Africa or elsewhere. Nonetheless, they can make a major contribution—if they are properly understood and supported.

Any unified model of HIV transmission needs, within each particular context, to (1) account for the socioeconomic conditions that frame human relationships and sexual networks, (2) acknowledge the importance of sexuality to the human condition, and (3) grasp the cultural understandings of HIV/AIDS that exist within the population. Successfully slowing the rate of HIV transmission requires the use of such a model along with feasible methods of achieving behavioral change. In South Africa, and probably elsewhere, this will involve, among other things, reforming the migrant labor system, validating sex and sexuality, and aligning folk and scientific understandings of HIV and AIDS. Alongside such a program, there remains a need for comprehensive interventions around treatment, care, and support.

The contribution that peer educators can bring to this huge enterprise is quite simple: They can get people to talk. Their primary mission is not to
make speeches, lectures, or presentations, but to listen and talk with other individuals. By participation in conversations with their peers, they generate other conversations, conversations that in turn generate further conversations that they will never hear. It is easy to underestimate the value of this fundamental human activity, especially when in search of the one quick fix that will “cure” a crisis. When those who want a silver bullet rush to evaluate interventions they typically hand out questionnaires and seek “better” responses to questions. They want to know if more condoms have been used, whether testing and treatment is up, or infection rates down. What this account of peer education has demonstrated is that such approaches to measuring the success of interventions miss the very foundation on which success rests. When it comes to behavioral change, talking to each other comes before anything else, and, beyond trivial superficialities, talking is not easy.

Instead of giving up or pursuing ever-diminishing returns by repeating previously ineffective communication strategies, the peer educators described in this book have pushed ahead. To do this, they have had to lower expectations. Instead of trying to find that elusive magic bullet that stops the epidemic in its tracks, they have engaged in tiny acts of resistance. They sow seeds of doubt as to whether a sexual partner can be trusted, offer information, suggest a trick that will make sex safer, silence a whisper, befriend an HIV-positive colleague and thus challenge the stigma of HIV/AIDS, help one person find the courage to test, let someone cry. All this is possible only because they have done the most important thing of all: listened before speaking.

Conversations that allow people to speak about AIDS aloud in intimate social spaces are critical to normalizing the epidemic. And normalization is the greatest challenge in bringing this epidemic to an end. Only if we can normalize AIDS can individuals change behavior without recourse to lies, tricks, deceit, or open defiance of those closest to them. Peer educators need to initiate and maintain conversations that will reconfigure the contours of backstage space and permit discussion on HIV/AIDS.

Peer educators are ahead of most of us in confronting AIDS. We should acknowledge their commitment and their contribution. But we should not put them on a pedestal. If we are to normalize the epidemic, then the peer educators that we have met in this book are but outriders of a much larger force. In a normalized epidemic we will all be peer educators.