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Overcoming AIDS Stigma : Creating Safe Communicative Spaces.

● Arvind Singhal

"HIV/AIDS is like a huge rock in society. Only if everyone in society keeps breaking the rock into smaller pieces will it eventually become dust".

Sommai Punnyakamo (2001, p. 25), a Buddhist monk who counsels people with AIDS in Mae Chan District of Northern Thailand.

In 1996, Govind Singh, a 25-year-old migrant worker left the village of Churcher in the Indian State of Uttar Pradesh to find employment in Mumbai. Like many of his fellow migrant workers, he slept with commercial sex workers. In 1999, when he began to feel tired and lose weight, he went to Mumbai's Laksh Deep Hospital for a check-up. He was HIV-positive. Govind Singh's fellow migrant workers, many of whom belonged to Churcher, wrote home to their kin that Singh had AIDS and "nobody should touch, talk with, or see him" (Mishra, 2000, p. 40). Too weak to work, when Singh returned to his village in April, 2000, seeking shelter and care, he was shunned by his neighbors and family members, including his wife. Villagers dragged Singh into a *gote,* an enclosure for cattle and goats. His captivity became a center of attraction for Churcher's villagers, who peeped into the *gote,* teasing him about his promiscuity. Twice a day, the villagers threw food into his cold, wet, foul-smelling enclosure. As his condition worsened, Singh lay on the floor, and was often stepped on by the animals.

On July 5, 2000, Singh was found dead, and given a hurried cremation at a site outside of the village. Since his death, Singh's wife, Devaki, and their two young children have become social outcastes in Churcher. Govind Singh was not the only victim of the AIDS epidemic and of anti-AIDS stigma in Churcher. In 2001, two other returned migrant workers, both HIV-positive, met the same fate (Mishra, 2000). AIDS patients, and their families, represent India's new class of "untouchables".

Deaths like Govind Singh's, and others reported in India, South Africa, and in other nations are extreme manifestations of the stigma attached to people living with HIV/AIDS. In every nation, and among the members of every culture, the stigmatization of people living with HIV and AIDS is a severe problem. Perhaps no illness in the history of humankind has encountered such strong stigma as has HIV/AIDS, with the possible exception of leprosy in Biblical times. The stigma associated with HIV/AIDS has interfered with gathering accurate information about the extent of infection, it is a barrier to prevention programs, it inhibits effective testing and counseling, and in many cases stigma interferes with effective treatment and care.

The purpose of this article is to analyze (1) the nature of stigma associated with HIV/AIDS, and (2) the role of safe communicative "spaces" in overcoming stigma.

AIDS and Stigma

The term "stigma" goes back to the days of Greek civilization when it referred to a tattoo mark branded on an individual's skin for a wrong-doing (Crawford, 1996). The physical mark publicly identified the blemished individual as one to be avoided. So stigma is prejudice and discrimination against a set of people who are regarded by others as being "flawed, incapable, morally degenerate, or undesirable", and who are treated in a negative way. Prejudice is an attitude, while discrimination is overt behavior. The two usually go together. A stigmatized person is one who possesses "an undesired difference" from members of mainstream society, which leads society to discredit them (Goffman, 1963). A person with leprosy, AIDS, or some disability may be stigmatized. The stigma may be obvious (for example, a missing arm), or the marker may be less obvious (for example, being gay). Being identified with AIDS, transforms a person from discreditable (for instance, secretly gay) to discredited (publicly gay) (Herek & Glunt, 1988).

Through an accident of history, AIDS became a disease of already-stigmatized groups. In the initial era of the epidemic in most countries,

HIV infection began to spread through sexual networks of gay men, commercial sex workers, and/or intravenous drug users. These marginalized groups were already heavily stigmatized by society, and this prejudice carried over, and was strengthened, by such individuals becoming identified as carriers of HIV. This "double stigma" of AIDS stemmed from identification of AIDS as a serious illness, and from the identification of AIDS with already-stigmatized groups (Herek & Glunt, 1988).

Another important reason for the stigma of AIDS, which is based in large part on ignorance of the means of transmission, is a common fear that by associating with people living with AIDS, individuals might put themselves at risk. Such fear of infection, even among people who know and understand the actual means of transmission, may be based on an irrational reaction. The lethal nature of HIV/AIDS undoubtedly raises the level of fear.

Providing only knowledge about the means of virus transmission, social psychologists of prejudice found, is seldom sufficient to change such strongly-held attitudes as stigma. Prejudice and discrimination are emotional matters, and are not based on facts alone. In Colombia, a 2001 national health survey revealed that 60 percent of women had positive attitudes toward PWAs. However, 85 percent strongly felt that HIV-positive people should not have sex (even with protection). Interventions to overcome the stigma of AIDS must attack emotionally-based, strongly-held attitudes and behaviors. HIV/AIDS is a disease of ignorance and intolerance. HIV-positive people are often defined by the public as "the other," and treated accordingly as an out-group. The death of Govind Singh in India, described at the top of this article, shows how the villagers defined Singh as the "other", as not one of "us", leading to his death.

Many nations have launched communication efforts seeking to decrease the stigma of HIV and AIDS. Although useful lessons have been learned, few of these anti-stigma programs have been successful. Anti-HIV stigma remains a major problem throughout the world, and in some nations, like India, it is extremely serious. In other nations, the stigma of

HIV/AIDS decreased somewhat, especially when safe communicative spaces were created.

Safe Communicative Spaces

A safe communicative space is one in which interactants feel comfortable to listen, talk, and dialogue. It is a space in which they can be who they are, without fear of being marked, judged, or ridiculed. What might be some ways in which safe communicative spaces can be created to address, and perhaps even overcome, AIDS-related stigma? Consider the following examples.

Pink Triangle Malaysia (PTM), a non-governmental organization, operates an innovative outreach program targeted at injecting drug users (IDUs) in Chow Kit, a poor red-light community in Kuala Lumpur, Malysia's capital city. PTM creatively uses space to reduce stigma and prejudice (UNAIDS, 1999). A culturally-sensitive research protocol to assess the clients' needs, prior to launching the PTM Program, pointed to the importance of creating an Ikhlas ("sincere") Community Center (ICC), a "safe space" where the IDUs would feel comfortable about dropping in. The Ikhlas Community Center provides meals to IDUs, medical care and treatment, referrals to hospitals and drug treatment centers, counseling and psychological support, access to condoms and other risk-reduction services, and referrals to job placements. Clean bathroom and toilet facilities are also provided so that drug users can bathe, wash their clothes, and maintain their hygiene.

The IDUs participate in running these ICC activities: They cook and clean, serve as outreach workers and volunteer counselors, and carry out administrative work. This involvement helps them take ownership of the *Ikhlas* project, and builds their self-esteem. The IDUs of the ICC now routinely liaise with volunteer groups from hospitals, nursing schools, the corporate sector, and colleges, and thus feel more accepted by the general community. Their active involvement also makes the Pink Triangle Malaysia's Ikhlas program highly cost-effective and effective.

The *Ikhlas* program represents a non-stigmatized, non-judgmental space for IDUs in Malaysia, a country where drug use, according to the local law, is punishable by death. However, the humane environment created by ICC is palpable enough that law enforcement authorities look the other way. As such, the Ikhlas Community Center achieves harm reduction, rather than seeking to eliminate injection drug use.

The principle of harm reduction is also the basis of several Dutch initiatives that create safe, comfortable communicative spaces for commercial sex work, legalized in the Netherlands in 2000 (Kapila & Pye, 1992). Many local municipalities have established *gedoogzones,* streets where soliciting is allowed during predetermined hours. The city of Utrecht has an *afwerplek*, a special car park with parking bays divided by high-fences, where commercial sex work is transacted. Many Dutch towns established *huiskamers* ("living rooms"), where counseling, care, and assistance are available to CSWs. Utrecht's Huiskamer Aanloop Prostitutes Foundation established a mobile caravan-style *huiskamer,* which is parked in local gedoogzones during permitted hours. CSWs stop by to rest, take a shower, to buy condoms, receive counseling, and for medical care (Kapila & Pye, 1992). This mobile *huiskamer* is an example of creating a mobile "comfortable space" for those at risk for HIV. The Dutch projects, much like the *Ikhlas* in Malaysia, are respectful of people's lifestyles, non-judgmental, and create comfortable spaces where people can take responsibility (and refuge) for their personal decisions.

PATH (Program for Alternative Technology in Health) created youth-friendly drugstores in Thailand and Cambodia. Studies indicated that 40 percent of young men seeking health products view pharmacies as the access point for buying condoms and STD treatment. Pharmacies in Thailand averaged as many as 50 youthful clients at a drugstore per day. PATH's strategy in creating "friendly drugstores" involves training Thai pharmacists to interact with young people in a compassionate, nonjudgmental manner, and to refer them, if needed, to appropriate clinical services.

In India, the use of barber shops to stimulate discussion about AIDS demonstrates the strategic use of space in addressing the taboos associated with AIDS. Many Indian men are too embarrassed to buy condoms at a drugstore or to talk freely about sex with health counselors or with family members. But one place in which they feel comfortable about "letting their hair down" is at the barber shop. The Indian State of Tamil Nadu trained barbers to be its frontline soldiers in the fight against the AIDS epidemic. In the poorer and blue-collar areas of Chennai, Tamil Nadu's capital city, men often have their hair and beard trimmed before frequenting a commercial sex worker. Now they pick up a free condom on their way out of the barbershop. Participating barber shops in Tamil Nadu provide free subsidized condoms to their clients; some barbers offer a premium "pleasure pack" at subsidized rates, from which they earn a 25 percent commission.

Mr. Mani, a local barber, cuts hair and dispenses advise on safer sex, which represents a new dimension in his 20-year old career: He starts by talking to a client about his family and children. Slowly, he gets to women, HIV/AIDS, and condoms. The barber program was launched in 1995 in Tamil Nadu, and within a year recruited 5,000 barbers who receive AIDS training on Tuesdays, their day off. The barbers are not paid to be HIV/AIDS promoters, but they appear to take considerable pride in their new responsibility.

Over the centuries, India's barbers have been regarded as traditional healers, confidantes, advisors, and matchmakers. In rural areas, the barber's wife is often a *dai*, a traditional birth attendant, a low-status but highly respected role in an Indian community. "To get the king's ear, tell his barber", goes a popular saying. Reinforcing the image of barbers as healers, the local trade group is called the Tamil Nadu Medical Barber Association.

Although HIV/AIDS may be taboo in a society like India, there are special places like barber shops where this topic can be discussed openly. Women's beauty parlors and gay bars may represent other spaces where discourse about HIV/AIDS can take place comfortably.

Virtual Spaces

Comfortable spaces can also be created virtually, for instance, through telephone help-lines. AIDS help-lines abound throughout the world, some directed at the general public, while others are targeted to gays, injection drug users, CSWs, and other groups. Some telephone help-lines are managed by professionals such as the Italian Telefono Verde AIDS, which employs trained physicians and psychologists, while others such as AIDS-Linien in Denmark is staffed by volunteers (Kapila & Pye, 1992).

In New Delhi, India, a telephone help line called TARSHI (Talking About Reproductive and Sexual Health Issues) provides AIDS-related and sexuality information, counseling, and referrals in both Hindi and English to Indian men and women of all ages, castes, and socioeconomic classes. Of the 30,000 calls received since its inception in 1996, 80 percent of the calls were from men, and about 70 percent of the callers were in the 15 to 30 age group (Chandiramini, 1998). The anonymity and confidentiality of telephonic communication, as well as the nonjudgmental attitude of trained telephone counselors, makes it possible for people to feel "virtually" comfortable in discussing their concerns. Callers often begin with a question on one topic, for instance, masturbation, but then move to related issues like genital size, premature ejaculation, sexual relations with multiple partners, and HIV/AIDS (Chandiramini, 1998). *These callers are moving on the continuum from less taboo towards highly taboo topics.*

Disque Saude is a telephone hotline operated by the Brazilian Ministry of Health. The Director of Disque Saude, Ellen Lita Ayer, told us in 2001 that the hotline received 8,000 calls per day, about 3 million per year. Some 50 percent of the calls concern HIV/AIDS, and another 20 percent deal with STDs. The 145 telephone operators are mainly medical and dental students in Brasilia, who work five hours per day. Disque Saude will double its size in 2002. A popular television show, *"Lacos de Familia"* (Family Links), which frequently deals with health problems, placed the hotline's telephone number at the bottom of the television screen. When

this tie-in with Disque Saude first happened, a major increase in the number of calls promptly occurred. The callers only use their first names, and the anonymity thus provided helps overcome the stigma of HIV/AIDS that may prevent individuals from seeking information from other sources.

Anonymous information gleaned by counselors at TARSHI and Disque Saude represents a goldmine of data for understanding prevailing cultural beliefs about sexuality and HIV/AIDS, including levels of ignorance and misconceptions. For instance, when talking about HIV and AIDS, male callers to TARSHI often say: "I can't understand how the virus can get *into* my body? After all semen comes out of my body. Nothing flows into it!" Only a virtually-created comfortable space through telephone help-lines allow for such candid discussion. The most widespread misunderstandings suggest needed messages for HIV/AIDS prevention.

In sum, telephone help-lines provide a confidential, accessible, sympathetic, non-judgmental, and non-embarrassing virtual space for discussion of HIV/AIDS issues. Telephone help-lines are highly relevant for callers, as their individualized needs can be served. Further, callers take the initiative, so they are more likely to follow the advice that is provided. As a bonus, telephone help-lines are an invaluable source of collecting data about the general public's perceptions of AIDS, including their feedback on specific intervention programs (Kapila & Pye, 1992).

Conclusions

AIDS is a disease of ignorance and intolerance, as well as a biological illness. When the mass media profile AIDS as a disease of gays, injecting drug users, and commercial sex workers, it perpetuates stigma. Fear, prejudice, injustice, and stigma are every bit as dangerous, if not more, than the biological virus. An HIV-positive Brazilian writer, Herb Daniel, said: "Prejudice kills during life, causing civilian death....[such a death] is worse than real death" (quoted in Daniel & Parker, 1993, p. 131). Further, taboos surrounding HIVAIDS often prevent recognition, discussion, and acceptance of safer sex practices, and serve as a barrier to testing, counseling, treatment, and care. Stigma is one of the major barriers to effective communication about AIDS.

Safe communicative spaces can help preserve the civil rights and personal dignity of those afflicted or affected by AIDS. They can spur compassion for those living with AIDS. They can open channels of communication, where none existed. Communication practitioners, public health interventionists, and social change activists must consider the creation of safe communicative spaces, both physical and virtual.

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* This article draws upon Singhal and Rogers (2003).

Convergence, Networking and Development

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The main aim of this paper is to enable the NGOs, Churches and other related organisation to make use of the emerging Information Communication Technology (ICT) for the social development of people. Social development could be broadly understood as a process in which people are engaged in order to improve their standard living; to liberate themselves from oppressive forces; to address and solve new socio-cultural and political issues that emerge from new contexts and to lead their communities into a promising future. Development of a particular community is an ongoing process that can influence and can be influenced by other social processes such as urbanisation, communication revolution and industrialisation. I use ICT to refer to a wide range of converging technologies, particularly to computer and microprocessor technology through which diverse forms of information, communication and entertainment (ICE) could be made available to individuals and to communities.

Before understanding the relationship between convergence, networking and development, I wish to refer to a few perspectives that relate ICT to development. Hamelink (1) identifies two major perspectives in this area which are: Utopian (Optimistic) and Dystopian (Pessimistic) perspectives. For him those who support Utopian perspective highlight the positive development that is brought about by the information technology. Those who support Dystopian perspective argue that the ICT deployment will simply reinforce historical trends toward economic disparities, inequality in political power and gaps between knowledge disfranchised.

Utopian Perspective:

This perspective refers the present time as "ICE age", "media saturated age", "new civilisation", "information revolution", "knowledge society" and "age of infotainment". It derives its image from a techno-centric perspective(2) that is characterised by an emphasis on the historical