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NOTE FROM THE EDITOR

This special issue of the journal is dedicated to the theme of 'Communication and Social Change.' Within this broad classification, I have selected the subject of HIV/AIDS, a pandemic that has become a major medical and social issue all over the world. According to a recent report of UNAIDS, this epidemic continues its devastating march across large parts of the globe bringing with it more infections, suffering and death. The articles in this issue deal with (a) HIV/AIDS and ways to protect vulnerable populations such as commercial sex workers, and (b) destigmatizing the disease as well as infected persons. The stigma attached to AIDS rivals leprosy, a disease with a long history of stigma in human societies. Communication and other intervention strategies are particularly useful in these areas and the authors of the three articles in this volume provide useful pointers to development support communicators, social workers, development planners and policy makers.

I wish to thank the expert readers for giving their time generously to reading and critiquing all the submissions.

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Communication Strategies to Overcome AIDS Stigma

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The purpose of this article is to analyze the nature of stigma associated with HIV/AIDS, and suggest certain communication strategies for overcoming stigma. We argue that communication strategies can help reduce stigma by (1) breaking the silence about AIDS, and by (2) moving the discussion of HIV/AIDS from the personal-private to the public-policy sphere. Through mass-mediated and interpersonal discussion about HIV/AIDS, individuals and communities can be moved on the continuum from a high degree of stigma toward lessened stigma.

"Living with HIV is like dying every minute. People kill you by their looks....by their words." (Personal conversation with one of the authors and a person living with AIDS in India).

"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 living with AIDS in Mae Chan District of Northern Thailand.)

At an International Conference on HIV/AIDS and African Children held at a mid-western U.S. university in 2002, a participant shared the plight of a fourth grade student in a Soweto school, on the outskirts of Johannesburg. The student, an AIDS orphan who lived

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with her grandmother, tearfully asked the teacher: "Why are my friends laughing at me? Is it because my parents died of AIDS?" Sadly, society stigmatizes those afflicted with AIDS and those affected by it, including orphaned children.

By mid-2003, 26 million people had died of AIDS and over 42 million people were HIV-positive. Some 15 million of the world's children have lost one or both parents to AIDS. Countries in sub-Saharan Africa are especially badly hit, although AIDS is a pandemic, spanning the globe and cutting across geographical boundaries (Singhal & Rogers, 2003). In Zimbabwe, 45 percent of children under the age of five are HIV-positive, and the epidemic has shortened life expectancy by 22 years. A 15-year-old in Botswana or South Africa has a one in two chance of dying with AIDS. AIDS deaths are so widespread in South Africa that small children now play a new game called "Funerals".

Disturbingly, this global AIDS pandemic has spawned what some refer to as the world's new class of "untouchables": People living with HIV and AIDS (PLWHAs) throughout the world face social marginalization, alienation, and victimization. All too often, their human rights are violated. As an example, consider the case of Govind Singh in India.

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 a Mumbai clinic 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. 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).

Govind Singh's death and other similar cases are extreme manifestations of the stigma attached to people living with HIV/AIDS. Perhaps no illness in the history of humankind has encountered such strong stigma as has HIV/AIDS, with the possible exception of leprosy. The stigma associated with HIV/AIDS interferes with gathering accurate information about the extent of infection, represents a barrier to prevention programs, inhibits effective testing and counseling, and interferes with effective treatment and care.

The purpose of this article is to analyze the nature of stigma associated with HIV/AIDS, and to suggest certain communication strategies for overcoming stigma. We argue that communication strategies can help reduce stigma by (1) breaking the silence about AIDS, and by (2) moving the discussion of HIV/AIDS from the personal-private to the public-policy sphere.

Stigma and AIDS

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 (Singhal & Rogers, 2003). Prejudice is an attitude, while discrimination is overt behavior. The two usually go together. Stigmatized persons possess "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, privately gay) to discredited (publicly gay) (Herek & Glunt, 1988).

Most past research on HIV-related stigma has focused on the stigmatizing attitudes of individuals, rather than as a social process (Crandall & Moriarty, 1995). So stigma has been studied through self-reported attitudes and hypothetical behaviors (Herdt, 2001; Herek & Capitanio, 1999), as if it were primarily an individual attribute. Some recent studies look at the stigmatic experiences of people living with AIDS, the forms of stigma encountered, stigma within the workplace, and how stigma hinders participation in HIV/AIDS programs (Malcolm et al., 1998; Nyblade et al., 2003; UNAIDS, 2000).

In every nation, and among the members of every culture, the stigmatization of people living with HIV and AIDS is a severe problem[ii], although its nature and severity vary greatly by context. Stigmatization occurs in various forms – from instilling fear and shame on those infected and affected by HIV, to social alienation and ostracization, to human rights violations, to coercive government policies and laws (Malcolm et al, 1998).

Silence Rules, Fear Reigns

HIV-related stigma is closely associated with sex and death – topics that are taboo (Singhal & Rogers, 2003). Talking about sex and sexuality, or death and dying, is uncomfortable, difficult, and laced with moral tones. In this "silent" backdrop, dominant groups exercise power over stigmatized groups to marginalize or ostracize them from the wider community (Gilmore & Somerville, 1994). Stigma is used to legitimize and perpetuate inequalities based on gender, age, sexual orientation, class, race, or ethnicity (Nyblade et al., 2003). HIV-infected individuals thus experience fear, doom, and isolation. Infected individuals (and the affected family) feel unsafe, ostracized, and alienated. To avoid being stigmatized, people are reluctant to undergo HIV-testing, or even if tested, they prefer to hide their status (especially if it is positive). They fear the consequences of disclosing one's status.

Fear operates at another level. Even for people who know and understand the actual means of transmission, the fear of coming in contact with an HIV-infected individual may spur an irrational reaction. The lethal nature of HIV/AIDS undoubtedly raises the level of irrational fear. For instance, in the United States, in the months after Magic Johnson disclosed his HIV-positive status and retired from the Los Angeles Lakers in November, 1991, he regularly came to each

of the team's practice sessions, hoping to continue his relationship with his former teammates. They let him know that he was unwelcome. Magic was forced to shoot baskets by himself on another court. Sometime later, when Magic announced that he was considering a return to professional basketball, various players around the National Basketball Association publicly stated that they would refuse to play (Crawford, 1996). Karl Malone of the Utah Jazz was particularly outspoken, announcing that Magic's opponents might be at risk if they came in contact with his sweat.

The language and metaphors used to depict AIDS elevate levels of fear associated with the disease, further legitimizing HIV-related stigma (Malcolm et al., 1998). Common AIDS metaphors include "AIDS as death," "AIDS as punishment," "AIDS as crime" (making a distinction between the "innocent" and "guilty"), "AIDS as war," "AIDS as otherness," and "AIDS as shame" (Sontag, 1991). Use of such language reinforces AIDS-related fear, avoidance, and ostracization.

So, communication strategies to address stigma must necessarily be geared to breaking the silence on AIDS, and to the creation of "safe" communicative spaces, where fear and avoidance can be countered by trust and cooperation.

Human Rights Violations, Private-Public Delineations

AIDS disqualifies people from being regarded as whole, intact individuals (Alonzo & Reynolds, 1995; Herdt, 2001; Taylor, 2001). 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[iii], 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). Moreover, these "double-stigmatized" individuals were blamed for the problems of the group, shifting the blame from public spheres of action to the private. Such stigma-based violations greatly impede the notion of "personhood" in communities and "citizenship" in states (Herdt, 2001).

For instance, the gay community in the United States was often blamed for starting the epidemic. Members of the Christian Right and other political conservatives in the U.S. proposed quarantine, reinstating state sodomy laws, and eliminating the civil rights of HIV-infected gays to protect them from discrimination (Herek & Capitanio, 1999). A Gallup poll conducted in the mid-1980s showed that 50 percent of Americans agreed that "most people with AIDS have only themselves to blame". Those who contract AIDS through behavior that is controllable (for example, through commercial sex work or sharing needles) are perceived as "guilty" and hence assigned more blame, receive less sympathy, and face more anger, than those who are perceived as "innocent victims" (for example, individuals infected while receiving a blood transfusion) (Wiener, 1993). AIDS-related stigma would have been far less if the epidemic were first identified, for instance, among straight, heterosexual individuals, hemophiliacs, or children.

When people in societies discriminate, coercive government policies may follow. By 1990, some 104 countries had enacted HIV-related legislation, including policies ranging from compulsory detention and restriction of movement of certain groups, to regulations ensuring the confidentiality of persons with HIV (Malcolm et al., 1998). In 1991, some 40 countries required proof of HIV-negative status before allowing foreign visitors to enter. Foreigners have been blamed for the spread of HIV in many countries, particularly Africans, for instance, who were attending universities in India, the former USSR, and in parts of Europe (Malcolm et al., 1998).

So, communication strategies to address stigma must necessarily uphold the civil liberties of those infected and affected by HIV, and move the discourse from private to public spheres of action, where individual choice can be negotiated with collective civic responsibility. Such actions can occur only through public and workplace policies on AIDS-related stigma and discrimination.

Communication Strategies to Overcome Stigma

Here we investigate the role of communication strategies in reducing stigma by (1) breaking the silence about AIDS, and (2) by moving the discussion of HIV/AIDS from the personal-private to the public-policy sphere. Through mass-mediated and interpersonal discussion about

HIV/AIDS, individuals and communities can be moved on the continuum from a high degree of stigma toward lessened stigma.

Strategies for Breaking the Silence. As we noted previously, AIDS is clearly a taboo topic, one which is so sensitive that it usually cannot be discussed openly. Because HIV/AIDS deals with sexual intercourse, morality, and death, it is treated by many people in hushed tones. If HIV/AIDS were completely taboo in a society, of course, there could be no communication of any kind about this issue, no effective intervention programs, and no testing and counseling. In reality, the topic of HIV/AIDS lies somewhere on the continuum from relatively highly taboo to relatively less taboo. In most nations, HIV/AIDS is closer to the highly taboo end.

The communication challenge is how to move the issue of HIV and AIDS from the taboo end toward the less taboo end of the continuum. Only by making a topic less taboo, can silence be broken at the individual, community, and national level. It is only through spurring private, public, policy, and media discussion that the issue of AIDS can become increasingly non-taboo and thus destigmatized (Habermas, 1989). Therefore, communication activities are really at the heart of overcoming stigma about AIDS. Following are some promising ways to break the silence on AIDS.

Making the Untalkable Talkable by Harnessing Symbols. One strategy for coping with a taboo topic is to represent it with a symbol, the red ribbon in the case of AIDS. To millions of people in today's world, the red ribbon is AIDS. Given that the virus is so small as to be invisible to the naked eye, and that most PLWHAs do not show outwardly evident symptoms of infection for many years, a widely recognizable symbol for AIDS is a key to giving greater visibility to the epidemic.

Symbols such as the red ribbon "speak" despite their inanimate nature, breaking the silence on AIDS. Symbols like the red ribbon can be further modeled through the mass media to break the silence on AIDS. In 2001, two of the present authors were invited to an informal meeting in Johannesburg with creative writers and producers who were planning an AIDS television drama series. The discussion centered on how funerals in South Africa, which typically are attended by hundreds of people, were usually silent about AIDS as the cause of death. How could this silence be broken by the television series? Many ingenious suggestions flew around the room. One individual suggested that the AIDS red ribbon should be displayed on the coffin of a young protagonist who dies of AIDS. Another television

scriptwriter suggested that a wreath be placed on the coffin by a family elder with a large red ribbon in its center. Another person suggested that while the coffin was being lowered into the grave, a moment of great poignancy, the father of the dead person would hand out red ribbon pins to those present. The emotional impacts of such media depiction result from the use of a symbol to break the silence.

Another example of mass-mediated modeling to address AIDS stigma occurred in South Africa in 2003, when Kami, a five-year-old, mustard-colored, bear-like Muppet, joined the cast of "Takalani Sesame", South Africa's version of "Sesame Street". Kami, who sports a mop of brown hair and dons a beaded blue vest, is HIV-positive (Singhal & Howard, in press). Her parents died when Kami was young; so Kami is also an AIDS orphan. Through Kami, the Muppet, three-to seven-year-olds (and their families) in South Africa are learning about HIV prevention, care, and support. Kami's name is derived from the Tswana word "acceptance". In a world where HIV-positive children are often stigmatized, demonized, and victimized, Kami symbolizes the message of hope, possibility, and compassion.

Overcoming Vulnerability by Creating "Safe" Spaces. Another way to address stigma is to create "safe" non-judgmental communicative spaces for PLWHAs. 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, the nation'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 (Singhal & Rogers, 2003). 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. T IDUs of the ICC now routinely liaise with volunteer groups from hospitals, nursing schools, the corporate sector, and colleges, and th feel more accepted by the general community. Their active involvement also makes the Pink Triangle Malaysia's Ikhlas progra highly effective.

The Ikhlas program represents a safe, 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.

"Safe" spaces for dialogue 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 oth are targeted to gays, injection drug users, commercial sex workers (CSW), and other groups. 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 may oft begin with a question on one topic, for instance, masturbation, but th move to related issues like genital size, premature ejaculation, sexua relations with multiple partners, and HIV/AIDS (Chandiramini, 199

Reducing Alienation through Care and Support Programs[iv]. common finding from investigations of stigma interventions is that programs that foster direct contact with people living with HIV and AIDS are somewhat more effective than those that do not (Nyblade al., 2003). Where HIV/AIDS is widespread and health workers have considerable contact with PLWHAs, discrimination is less and stign is reduced. For instance, a study of over 800 general practitioners in Australia showed that their direct contact with people living with HIV/AIDS significantly reduced their fear and prejudice (Bermingh & Kippax, 1998). Another study of some 400 health workers in Peru found that caring for an AIDS patient greatly reduces fear (Malcolm al., 1998).

Similarly, home-based care programs for AIDS patients mad HIV/AIDS more visible in the community, and over a period of time

reduced stigma and discrimination, as evidenced by the experience of Tateni Home Care Services in Mamelodi, South Africa. Tateni Home Care Services was started by a group of retired nurses in Mamelodi, the black township of 1.5 million people just west of Pretoria, the capital of South Africa. In response to the growing need for care and support among local AIDS patients, Tateni developed a home-based care policy and training materials in cooperation with local health authorities (Singhal & Rogers, 2003). Tateni's credo is based on the values of empathy, acceptance, and the removal of discrimination against those infected with HIV/AIDS.

Strategies for Moving the AIDS Discourse from the Private to the Public. In addition to breaking the silence, discourse about HIV/AIDS needs to move from the personal sphere to the family, community, public, and policy sphere (Habermas, 1989; Singhal & Rogers, 2003). Following are illustrations of how this movement can happen.

Humanizing HIV/AIDS through Disclosure. As more and more people disclose the fact that they are HIV-positive, the tabooness of the infection lessens. When former Zambian President Dr. Kenneth Kaunda, a highly-respected African statesman, disclosed that his son died of AIDS, it humanized the AIDS epidemic in Zambia.

It is important to humanize stigmatized individuals, who are, or become, well-known public figures: Nkosi Johnson in South Africa, Ryan White and Magic Johnson in the United States, and singer Philly Lutaaya in Uganda (Singhal & Rogers, 2003). These courageous figures help set the media agenda for the issue of AIDS, but they do much more. They show that people living with HIV/AIDS are individuals just like everyone else. They are children, women, and men; gay and straight; wealthy and poor; famous athletes, movie stars, and ordinary people. In their public appearances, these "poster people" for the epidemic stress that they want to be treated the same as everyone else. They want to pursue an education, earn a living, maintain their health, and help others.

Grieving Publicly: The AIDS Quilt. The AIDS Quilt represents another example of how the AIDS discourse moves from the private to the public sphere. When Cleve Jones started the quilt in San Francisco in 1986 to honor his friend Marvin Feldman, who died of AIDS, it was a symbol of personal grieving. As the idea of honoring the dead spread to other grieving individuals in other locations, the panels began to be sewn into vast quilts, representing a move toward public grieving. For

several years, the quilts were displayed on football fields at multiple U.S. locations. In 1996, all the quilts were sown together and displayed on the Washington Mall by AIDS activists and grieving relatives. The Quilt had grown to 40,000 panels, large enough to cove 26 football fields (Holland, 2001). Collectively, the quilt is an enormous canvas of those who have died of AIDS. It poignantly represents the growth of the epidemic.

Symbolically, the ever-growing Quilt moved the issue of AID from a space of personal to public grieving, reducing the stigma associated with AIDS deaths. The Quilt helps break down the "social distance" between the dead and the alive: Those watching the Quilt say they feel "similar"to the PLWHAs and that"AIDS is their problem" (Knaus & Austin, 1998). Through the AIDS quilt, relatives and friends do not grieve alone. A sense of collective efficacy was built among grievers to cope with their loss.

The Quilt does not discriminate. It honors individuals of different color, sexual orientations, socio-economic status, age groups and gender (Hawkins, 1993). The Quilt also serves as a highly visual and permanent symbol of the devastating effects of AIDS, becoming a tool of media and public advocacy to mobilize political will and resources to combat the disease.

AIDS Policies and Anti-Stigma Campaigns. Anti-stigma campaigns can also stimulate the public-policy discourse on HIV/AIDS (Singhal & Rogers, 2003). Confronting stigma means that communication campaigns must also be designed to reduce prejudice against gays, injecting drug users, and commercial sex workers.

When Mechai Viravaidya was a cabinet minister in Thailand in charge of the National AIDS Control Program, he drank Coke out of the same glass as an HIV-positive child. This act helped show that using common utensils was not a means of HIV transmission. Mechai's much-publicized action also showed that he accepted HIV-positive people on a personal basis. Actress Elizabeth Taylor has been a tireless spokesperson and fundraiser for HIV/AIDS programs and research in the United States. Taylor was a personal friend of actor Rock Hudson, who died of AIDS in 1985. Karunanidhi, the former Chief Minister of Tamil Nadu State in India, held hands with children living with HIV/AIDS in a human chain on World AIDS Day in the late-1990s. This symbolic act of acceptance communicated an important message against stigma.

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 so, 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.

AIDS stigma evokes negative reactions -- denial, shame, fear, anger, prejudice, and discrimination – which manifest themselves in interpersonal and group relationships. Hence, communication strategies need to be at the heart of all efforts to overcome the stigma of HIV and AIDS. Communication strategies can break the silence on AIDS by making the untalkable talkable (through the strategic use of symbols such as AIDS ribbons), and lead to the creation of "safe" communicative spaces (such as the Ikhlas Community Centers), where fear and avoidance can be countered by trust and cooperation. Communication strategies can also move the discussion of HIV/AIDS from the personal-private to the public-policy sphere, thus gradually overcoming tabooness. Public figures like Magic Johnson and Ryan White in the United States helped lessen the stigma with which the public viewed HIV-positive people. The AIDS Memorial Quilt Project, which began in San Francisco in 1986, reminds the public that people who died from AIDS were former friends, brothers, sisters, sons, daughters, parents, and lovers.

The stigmatized nature of HIV/AIDS in most societies is an important barrier to effective program interventions, and wearing down the mountains of stigma requires repeated efforts over dozens of years. In many African countries, HIV-positive mothers continue to breastfeed because if they stop, everyone will know why. An Indian wife, who knows that she will be rejected by her husband and his family if she tests HIV-positive, is highly unlikely to seek a blood test. So AIDS stigma contributes to new infections. Eventually, stigma kills people.

As an HIV-positive person in India said to us: "Stigma is more virulent than the virus. It is the relational virus."

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