The Persistence of the AIDS Stigma in North America

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The Acquired Immunodeficiency Syndrome (AIDS) pandemic is one of the biggest contemporary global health concerns. Although the majority of cases are in Africa, the prevalence of AIDS grows steadily within the populations of Canada and the United States. As such, AIDS is not simply a disease, but an illness in which social and psychological contexts greatly influence the experience of those afflicted. AIDS is essentially a disease with triple stigma: it is a terminal disease, it is associated with other stigmatized groups, and it is most commonly sexually transmitted, which implies responsibility on the part of the individual. A stigma is an undesirable characteristic that, according to others who do not have it (the majority), reduces the status of individuals who possess it and marks them as deviant (Brown et al., 2003). This allows the majority to define and reaffirm their identity by discrediting and demeaning those who have AIDS. This process of "othering" is the most common form of discrimination experienced by People Living with HIV or AIDS (PLHA); however, AIDS stigma includes all types of prejudice and stigma related to HIV and AIDS (Brown et al., 2003). It is these three aspects, the fear or uncertainty, the other associated stigmas, and the tendency to hold individuals responsible for their disease, which account for the persistence of AIDS stigma in North American society.

Historical Perspective

The stigma of certain diseases and the discrimination and exclusion of people who had those diseases were not new phenomena and did not pertain exclusively to AIDS. In the early 19th century, hospitals in Canada and the United States used moral worthiness as the criteria to determine the admission of patients. They denied medical treatment to patients with venereal diseases, whom they deemed immoral and undeserving (Lloyd, 1988). Individuals with cholera were ostracized and condemned as "intemperate, lazy, and vice ridden" (Valdiserri, 2002). Hospitals also refused admittance to contagious, chronically ill, and incurable patients, which included those with smallpox and tuberculosis (Lloyd, 1988). Even substantiation of Louis Pasteur's Germ Theory, which posited the role of microscopic pathogens in causing disease, did not halt the persistence of prejudice (Davison et al., 2002; Valdiserri, 2002).

Scientists discovered that the disease originated from a virus that migrated from chimpanzees and mutated into the human immunodeficiency virus-1 (HIV-1) to infect humans. However, the emergence of AIDS was not entirely a virological event - human behaviour, namely changes to sexual mores and intravenous drug use, enhanced pathogenicity (Washer, 2004). Since such underlying factors were perceived to be controllable, PLHA were blamed and held personally responsible for the disease. Prejudice was especially focused due to the association of the disease with marginalized social groups, in particular gay men and intravenous drug users.

During the initial years of the epidemic when little was known about the cause and transmission of the disease, the fear of AIDS virtually bordered on hysteria (Conrad & Kern, 1990). After more than two decades since the onset of the epidemic, there remains much to learn about both the biological mechanisms and the social impact of AIDS. The uncertainty that surrounds AIDS is closely related to fear and the overestimation of the risk of casual contact in the transmission of the disease (Herek et al., 2002). AIDS stigma is one way of coping with fear, and allows for the externalization of evil and badness (Aaronovitch, 2003). Misconceptions about casual social contact are pervasive. Exaggerated and irrational fears manifests in a phenomenon called magical contagion, where people believe that contact with objects touched by a person with AIDS will result in HIV contagion (Herek et al., 2002).

Is AIDS Unique?

Nonetheless, this fear of AIDS did not derive solely from the infectious and deadly nature of the disease. The outbreak of Severe Acute Respiratory Syndrome (SARS) in 2003 caused widespread panic. People wore masks, used hand sanitizer compulsively, shunned Asian stores and communities, and quarantined individuals suspected of infection. To some extent, however, the fear of SARS was justified. The novelty of SARS meant that there was no cure, and alarmed even the experts in the field. SARS was also fairly communicable, and infected many in a short period of time. Yet, unlike AIDS, the fear of SARS was temporary and dissipated shortly after the last patient recovered. Perhaps this was due to the development of a vaccines, but some believed that the previous experience

from AIDS was only reason for the exaggerated fear because it allowed the public to conceptualize SARS on the same scale. Along with the uncertainty and fear, other associated stigmas rendered AIDS not simply a disease that attacked physiological systems, but an illness that involved social and psychological phenomena, and contributed to the continuation of the othering of PLHA (Conrad, 1990).

AIDS And Associated Stigmas

Although the first cases of AIDS appeared in North America in 1981, there was little coverage in the press until 1983 because the majority of those inflicted were men who had sex with other men and drug users, which therefore did not concern average citizens (Washer, 2004). Association with these marginalized groups provoked intense, value-laden reactions in response to PLHA (Valdiserri, 2002). Allen (2002) argued that the use of the plague metaphor "contributed to the normalization of an ideological dichotomy between alien, less than human 'others'...and everyone else...during the initial stages of the moral panic..." In fact, the early designation of the disease was Gay Related Immune Deficiency Syndrome (GRID) (Conrad, 1990). Healthy individuals used othering to establish exclusion barriers in attempt to protect the social order (Ungar, 1998). The general population (i.e. those who were not PLHA) successfully extricated from the negative connotations of the disease and shifted the blame of AIDS onto the "other people." They sought reassurance from the irrational notion that the differences between the "others" and the "us" sufficiently rendered AIDS as "nothing more than a hypothetical threat" (Washer, 2004).

Even when AIDS spread to groups that had no attached stigma, the hostility resisted correction (Smithurst, 1990). The Canadian government initially refused to allocate any money from the federal budget for education and prevention of AIDS because they were afraid to be seen as condoning homosexuality and extramarital sexual activity (Edginton, 1989). Since such behaviours are regarded as "moral weaknesses" on the part of the PLHA, the government did not act to curb the AIDS stigma.

Attribution Of AIDS

Attribution theory describes how people perceive others' behaviour and situation, which determines their reactions and attitudes toward those individuals (Myers & Spencer, 2004). The behaviour and condition of others can either be attributed to internal influences (i.e. motives and

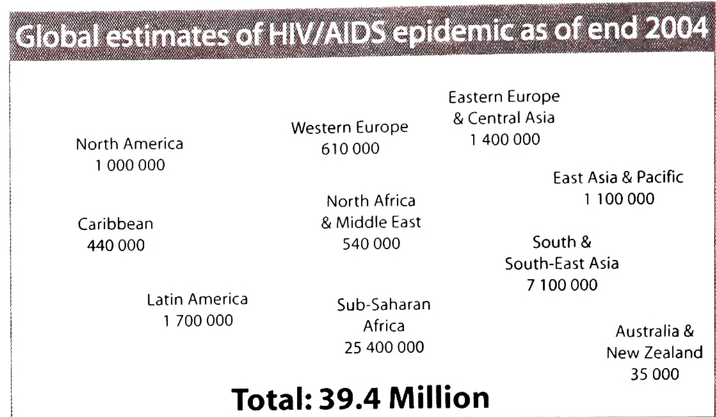

Figure 1: *Global estimates of HIV/AIDS epidemic as of end 2004 (www.unaids.org)*

disposition) or external influences (i.e. the situation). Unfortunately, people often commit the fundamental attribution error, which is the tendency for observers to underestimate situational influences and overestimate dispositional influences, in their evaluation of others (Myers & Spencer, 2004). As a result, individuals are held more personally responsible for outcomes in situations where they are perceived to have control. If the outcome is negative, the person receives more blame, but less sympathy, pity, and offers of help (Cobb & de Charbert, 2002). With HIV and AIDS, those infected or have the disease attract increased anger and decreased empathy because the public consider their illness a product of personal decisions.

Fear And Uncertainty Of AIDS

The fear of AIDS breeds prejudice. One man is reported to have advised other PLHA over the radio against revealing their seropositive status: "...say absolutely nothing. It will ruin your career, and your family life, and it will destroy your friendships" (Smithurst, 1990). The public considers the high level of consumption of healthcare resources by PLHA an economic burden that the rest of society do not want and should not have to tolerate. This implies that PLHA cannot be productive individuals and the services and resources they require would be better spent on healthy members of society (Silvers, 2001).

In 1991, public opinion overwhelmingly favoured coercive policies that demanded quarantine of PLHA, mandatory testing of individuals in high-risk groups, and disclosure of disease status (Herek et al., 2002). Such punitive policies disguise the violation of human rights of PLHA under pretences of protecting the health of the public (Herek et al., 2002).

Consequences Of AIDS Stigma

While overt and violent displays are rare, subliminal forms of discrimination can spread and reinforce AIDS stigma. People who do not experience AIDS stigma and othering often have no interest in advocating for those who do because they are afraid that the stigma would extend to include them and they would lose their identity with the "us" group. PLHA themselves may internalize such negative attitudes that have profound impact on self-perceptions and self-efficacy (Myers & Spencer, 2004). PLHA begin to attribute personal blame for their disease and see themselves as inferior. This self-fulfilling prophecy, in which they conform to the misconceptions and stereotypes created by the mainstream of society who are not HIV-positive or have AIDS, can lead to increased risky behaviour like multiple sexual encounters and alcohol/ drug use in order to seek self-validation (Valdiserri, 2002). AIDS stigma can also affect people indirectly associated with HIV and AIDS. Family, friends, and even healthcare workers of PLHA often experience secondary stigma where they are subjected to the same kind of prejudice and exclusion as those who have the disease (Brown et al., 2003). It is not surprising that AIDS stigma is currently evident even among health care professionals.

Despite superior medical expertise and experience, health care professionals are not wholly immune to the apprehension and stereotypical beliefs when treating patients with AIDS. Some healthcare workers, including physicians and dentists, refuse to care for and treat PLHA (Brown et al., 2003). Hospital workers in San Francisco who were ordered to attend to a patient with AIDS wore masks, gowns, and goggles for "protection" (Conrad & Kern, 1990). Some physicians who are willing to treat PLHA still make assumptions regarding sexual orientation based on patients' AIDS disease status. The effects of AIDS stigma generate shame and embarrassment for patients, who would be more averse to disclosing information that potentially valuable in deducing an accurate diagnosis. Scientific knowledge and mastery of clinical skills do not provide sufficiently effective preparation. Lack of respect toward patients with AIDS exposes the negative attitudes, fears, and anxieties that arise from ignorance. Neither specialty nor previous experience influence whether or not healthcare professionals discriminate against patients with AIDS, or the extent to which othering occurs. As a result, patients often receive less empathy from reluctant caregivers.

In addition to treating the physical ailments, physicians, nurses, and other healthcare workers must administer to the emotional and psychological distress of patients who receive a diagnosis for HIV or AIDS. The attitudes and beliefs regarding PLHA determine the ability and effectiveness in which the needs of the patients are met. If the actions of physicians and nurses reinforce the AIDS stigma, discrimination and othering of PLHA will persist while the quality and accessibility to adequate health care for these patients will deteriorate.

Conclusion

With increased visibility and prevalence of HIV and AIDS in populations who are neither homosexual nor intravenous drug users, one may have expected the abolishment of AIDS stigma. However, this is not the case. The ambiguity of the disease and lack of a cure maintains an environment of fear and ignorance, which allows discrimination to thrive. Despite increased tolerance, and even the legalization of same-sex marriages in Canada, the stigmas of homosexuality and intravenous drug are still associated with AIDS and bring negative connotations to the disease. Responsibility of AIDS is therefore attributed to the afflicted individuals, and they are denied sympathy and pity for their suffering. These prejudices, fears, and misconceptions contribute to the persistence of stigma, and must be overcome before comprehensive and effective management of AIDS can be attained. M