Conceptual and Practical Approaches to HIV/AIDS: The Brazilian Experience

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Introduction

Within the field of social psychology, modern cognitive theory argues that people use conceptual frameworks to classify their experiences (McDavid and Harari, 1974/1980). Yet these frameworks are limited: their translation into social practices is imperfect and can lead to negative outcomes. In this paper I show how conceptual frameworks have limited the understanding of the course of the HIV/AIDS epidemic in Brazil, and thus failed to address properly its related problems. Health education, to be an efficient response, must be part of broad health promotion programs that target all conditions that lead to the infection and the disease.

Historically, encouraging individual behavioral change has been used to address health problems. Unless a health promotion approach addressing social problems alongside individual problems is employed, there is little hope to change the course of the HIV/AIDS epidemic. It is important to note, however, that although the role of health education as a concept is by definition restricted, pointing only to individual behavioral changes, this does not mean that schools play a limited role. For instance, the concept of "health promoting schools" has envisioned them as ideal sites to target the health problems related to the individual child and to social aspects that lead to the disease. Finally, I provide recommendations for educators, primarily based upon building more symbolic resources intended to amplify peoples' visions and actions.

The Case of Brazil and the Need for a Health Promotion Approach

Conceptual frameworks are influenced by cultural, social, economic and political forces. They often lack necessary information which leads to stereotypes and prejudices (McDavid and Harari, 1974/1980). As a result, risk groups for HIV/AIDS have not been properly identified in Brazil. Although women have been particularly at risk due to their gender subordination and biological vulnerability, recognizing women as a group at risk is a recent development. Studies on reproductive tract infections have exposed the vulnerable position of women, pointing to problems that preceded the epidemic. In the beginning of the epidemic, homosexuals were thought to belong to a group of greater risk. For this reason, I will start by discussing how this perception unfolded in Brazil.

In Brazil, the lack of a self-identified homosexual community delayed the response to HIV/AIDS related illnesses. Instead of a defined community, however, we see a spectrum of sexual identities and practices. For social scientists and educators, the problem of addressing HIV/AIDS lies not only in the many taboos surrounding sexuality, but also in the difficulty of establishing categories related to sexual identities and behaviors. In the homosexual world in particular, where these identities and

practices tend to be more secret and marginal, the confusion is exacerbated. Thus, the complexity may not be grasped completely in self-reported sexual identifies nor in accounts of sexual behaviors. For instance, Lago, (1999) studying self-reported definitions of bisexual men in Brazil, argues that there is no basic sexual activity criterion for identifying them. He states that among bisexuals, identification is related more significantly to homosexual attraction rather than equivalent to homosexual practice.

Comparing Brazil to other countries, Parker (1993) contends that the epidemic in Brazil received less attention than that given to the epidemic in the United States and Central Africa because Brazil was dissimilar in epidemiological features, social and cultural forces, and reactions. According to Parker, international epidemiologists look in two directions to map HIV transmission--one through male homosexuality and drug injection, and the second through heterosexual relations and transfusions with contaminated blood. These directions only narrowly apply to Brazil because male homosexuality and bisexuality practices occur differently from those in the United States in that there is no identified gay community in Brazil, and because blood contamination has been related more to social and political forces than to the lack of economic resources. Moreover, Daniel (1993), discussing the problem of using an imported epidemiological model for identifying HIV cases in Brazil, says in regard to homosexuality among Brazilian men: " (...) men that have sexual relations, occasionally or frequently, with other men continue to consider themselves 'men' both 'heterosexual' and 'macho', playing an active role in sexual relationships" (p. 37).

The difficulty with concepts also emerged in defining risk groups. For example, even though more men than women in Brazil are considered to be in risk groups that have acquired AIDS, such as homosexual men (41.9%) and bisexual men (19.5%) (Peixinho et al., 1990), women are recognized increasingly as a group at risk for HIV infection and for developing AIDS. Indeed, some argue that women face a greater risk than men of acquiring the disease due to the following: the social approval of male bisexualism given that men continue to exhibit "macho" behaviors, the neglect of women's sexuality with the exception of prostitutes, the delay of biomedicine to accurately diagnose HIV/AIDS among women before the terminal stage of the disease, and the inferior status of women--particularly those from poor classes (Guimarães, 1994). Aside from these sociocultural conditions that place women, particularly the poor, at a disadvantage, women are also at a biological disadvantage as they are two to three times more likely than men to acquire the disease (Royce et al., 1997).

That the medical system represents women in one of two ways--either as prostitutes or as "family women" (Barbosa, 1993)--has led to an incorrect mapping of the AIDS epidemic. Although epidemiologists have considered Brazilian female prostitutes to have been at risk since 1985, this recognition has not happened vis-à-vis family women who were also at risk (Guimarães, 1994). Koifman, Quinhões, Monteiro, Rodrigues and Koifman (1991) studying AIDS cases during the 1980s among adult women from the municipality of Rio de Janeiro found an even higher percentage of the disease among family women than among prostitutes. This higher incidence of HIV infection in family women relates to their companions who are bisexual, but who define themselves as macho and heterosexual. Many family women do not know of their partners'

homosexual behaviors until physicians reveal to these women that they are infected with the disease (Amaral, 1999). As pointed out by Lago (1999), male bisexual practices are marked by secrecy. Indeed, in Koifman's et al. study, the group of women with the highest percentage of AIDS were housewives (33.9%), domestic workers (14.4%) and prostitutes (6.7%). Interestingly, these categories of women are replicated among HIV infected women themselves creating a discriminatory marker. According to Knauth (1999), Brazilian HIV infected family women distinguish themselves from the "other" women by believing that while they are infected due to their roles as wives, the latter women are infected because they engaged in health-compromising behavior, actively searching the disease.

The epidemiological data of HIV/AIDS is not promising for young women. Pimenta (1997) contrasts data of the United Nations Program for AIDS which found that 40% of the new incidence affects women ranging from 15 to 25 years old with Brazilian data estimating that it is affecting mostly those from 15 to 39 years old. Aside from gender differences, the HIV/AIDS infection is reported to appear mainly among the young, those between the ages of 15 and 24. Considering this age group and using estimates from a health and demographic survey (Macro International Inc., 1997) this means that almost 32 million young Brazilian people could be at risk. However, it is the poor youth, and even more likely, street youth, who are particularly at risk. Almost a decade ago, Luna (1991) cited evidence showing that there was HIV infection among more than one third (245) of the 700 abandoned Brazilian youths that belong to FUNABEM (Fundação Nacional do Bem-Estar do Menor) and FEEM (Fundação Estadual de Educação ao Menor).

It is important to stress that beyond the issue of risk groups, the very same social conditions that lead to the spread of HIV are closely associated with other conditions associated with previously known reproductive tract infections. The likelihood of contracting HIV increases when the person has other reproductive tract infections (Amaral, 1999), particularly for women. The fact that HIV/AIDS epidemic emerged in the midst of a pattern of neglect of reproductive tract infections in Brazil and elsewhere (Faúndes & Tanaka, 1992) shows that there has been a fertile terrain for social and health problem to escalate. Thus, one can assume if the older problems of reproductive tract infections had been better addressed, the devastating problems generated by HIV infection could at least have been attenuated. Wasserheit and Holmes (1992) provide a detailed account of reproductive tract infections and social neglect. These authors state that they have been overlooked worldwide because of: the false assumptions that these infections are not serious, not life-threatening, very complex, costly to care for, and are present mainly among the promiscuous adult population. The values and attitudes associated with these infections are taboo and donor agencies have a policy of providing only preventive care and not focusing on how curative care of reproductive tract infections can prevent other infections and diminish prevalence. In addition, there is gender division of the delivery of health care services. Usually AIDS and sexual transmitted diseases services target only men and family planning and maternal-child health clinics target only women. Meanwhile society continues its permissive tolerance of male promiscuity and perpetuates the low status of women, which may prevent them from controlling their sexual encounters. All of this means that priority is not given to

diseases that affect more women than men as is the case with reproductive tract infections, thus placing responsibility on women to avoid infection and pregnancy.

Not Only Health Education but Health Promotion is Needed

According to Candeias (1997), the meaning of health education and health promotion that specialists generally accept is that delineated by Green and Kreuter. Green and Kreuter (1991) define health education as: "Any planned combination of learning experiences designed to predispose, enable and reinforce voluntary behavior conducive to health in individuals" (p. 432). These authors state that health promotion is broader and involves: "Any planned combination of educational, political, regulatory, and organizational supports for actions and conditions of living conducive to health of individuals, groups, or communities " (p. 432). Thus, in the case of HIV/AIDS, health education cannot fulfill completely its promise, nor should it be expected to, if coordinated actions related to health promotion, which include education and environmental supports, are not in place. Candeias (1997) explains that environmental supports encompass not only social, political, economical, organizational and regulatory circumstances related to human behavior, but also all political actions related to health.

At times, however, health education and health promotion have been used interchangeably in the developing world (Candeias, 1997). The concept of health education is more limited than that of health promotion because it only addresses individual behavioral changes. Although social change is part of the health promotion conceptualization, in practice health promotion has historically concentrated more on individual behavior changes (Sousa, 2000). Nevertheless, this does not mean that health education cannot be linked to health promotion. In fact, Minkler (1989) argues that health education should move to health promotion in order to tackle both the individual and the social levels. Still, the concept of 'health promotion schools' implies that schools should promote strategies targeted to reduce disease and promote health by allied changes in both the individual and social levels. According to St. Leger (1999), this means that the schools' traditional focus, which was either health behavioral change or health maintenance, now also encompasses advocacy, empowerment and support.

Educational interventions emphasize that the transmission of HIV/AIDS is associated with actions such as sexual intercourse, blood transfusions, the injection and use of other skin-piercing instruments, organ and semen donation, perinatal transmission, and with the delivery of vaccines. However, less stressed in educational interventions are the non-behavioral problems affecting the transmission of the disease. These stem from an economic base (no money to buy condoms and health care, no efficient blood screening), occupation (prostitution, blood donation to get money) and environmental isolation (lack of family support and lack of access to school and/or work). These non-behavioral problems are exactly the issues health promotion should address.

It is often assumed that health education can protect health status if people learn to avoid the behaviors leading to the spread of HIV infection. However, people need to have sufficient material and symbolic resources to avoid the health compromising behaviors. Material resources refer to: condoms in the case of sexual intercourse, disinfected piercing instruments in the use of drugs or other activities, decontaminated blood in blood products and transfusions, decontaminated organs and semen, use of

drugs to both prevent vertical transmission and health related complications, and better access to vaccines. Symbolic resources refer to access to information as well as the understanding of cultural values and norms. In other words, symbolic resources provide a shared cultural understanding of current events, affectivity, social norms and social ties. People and institutions provide these resources. The three main institutions--family, school and work--can generate both material and symbolic resources to prevent and treat health problems. These institutions can act in alliance with each other, in the way that health clinics and neighborhood associations do to promote health.

In a world divided between rich and poor nations, this epidemic has increased rapidly among the majority of the poor living in the developing world. As the link between HIV/AIDS and poverty is reported increasingly, the lack of both material and symbolic resources is crucial. The fact that the epidemic is growing among the poor can be seen in extreme cases such as South Africa where one fifth of its population is already infected (VEJA, 2000) and is considered pandemic. Daniel (1991) says: "It is inevitable that AIDS claims the largest number of people from this majority of the poor, mainly because they have no access to resources-whether material or symbolic: not only no hospital, but also no education or information to help them cope with the disease" (p. 545). It is also apparent that these poor conditions undermine average survival after diagnoses. In the last decade, Brazil embraced the political strategy to distribute freely drugs for HIV/AIDS patients to help their survival (VEJA, 2000). Before this policy, the average survival after diagnosis was reported to be only 5.1 months, less than half as long as the average in countries such as the United States, Spain, Italy, Australia, and England (Chequer et al., 1992).

Yet many people are either abandoned entirely, or helped only by institutions that are ill-prepared to cope with the problem. The lack of health education can be crucial. In fact, the HIV/AIDS scientific advances that should increase the compliance to the drug usage are not always known. Porto and Vargas (2000) applying questionnaires to 168 women in a poor community in Rio de Janeiro found that 77 percent of this population were not aware of the preventive measures to avoid the vertical transmission of HIV from the mother to the infant. Moreover, essential knowledge about the disease and its transmission is lacking among the most in need. Silva and Sousa (2000) interviewing 65 poor women in a public health clinic who studied only until the 8th Grade, found that only four of them had well-rounded knowledge related to HIV/AIDS.

It is important to note that not all material and symbolic resources available in any society are conducive to enhancing the health of individuals and groups. An extreme example is one related to street youths' symbolic resources. Luna (1991) studying 103 Brazilian street youths, states that their reports indicate that they engage in high-risk sexual activity not only for money, but also as a rite of passage for men (homosexual or bisexual experimentation and sexual intercourse), as birth control for women (anal intercourse) and for both sexes, as a means to get affection.

Moreover, it is possible that material resources are available but symbolic resources may enter in competition with them. Avoiding pregnancy is one of these situations where women may resort to the symbolic role of becoming a mother. In a fascinating study, Kanuth (1999) explains that it is primarily through motherhood that HIV infected poor

Brazilian women can hold on to their status as women and to their social identity threatened by the disease. Of course, these women's choice to have the child despite infection could be seen as part of their right to lead a gratifying life.

Considering all the complexities imposed by HIV/AIDS and by society at large, it is hoped that neither health education nor health promotion becomes prescriptive. Health education must provide people with a multitude of symbolic resources so that they can decide how to avoid infection and improve their health status. It is also expected that health promotion programs will be inclusive, providing as many material and symbolic resources as possible for people to choose from. Perhaps then this comprehensive approach, designed to go beyond the individual level will be capable of addressing the social problems that contribute to the spread of HIV/AIDS such as the causal relationship between poverty, ignorance and infection.

Some Challenges of the HIV/AIDS Epidemic that Educators can Address

Some challenges with regard to the HIV/AIDS epidemic are left for all of us if we are to build societies based on health promotion approaches. The initial recommendations for educators relate to building and providing more symbolic resources. First, educators should study and discuss with the population the symbolic contents related to HIV/AIDS and to the experience of death. This means addressing the psychological factors of people dealing directly or indirectly with family members who died or will die. Thus, a task can be for educators to try teaching hope for children who have experienced the death of their parents from AIDS. Another difficult task that educators can embrace is to encourage and give practical advice to parents who will die of AIDS and leave their children as orphans (with or without the infection). Educators should also study and address other symbolic issues related to the identification and explanation of cultural issues and problems. This may mean examining the specific ways in which individuals and institutions deal with a health problem, comparing hegemonic health models with popular health models. Third, educators can contribute by studying and discussing social patterns that do not apply only to the HIV/AIDS epidemic.

Health promotion should focus on reducing and eliminating discrimination. WHO (1997) recognizes the need for school policies to avoid discriminating against students and teachers with HIV/AIDS. But there are other noninfectious diseases and social differences that continue to generate discrimination. The need for policies to reduce and eliminate discrimination against HIV infected people is the responsibility of all institutions. Without social solidarity and tolerance, the challenges of this epidemic will continue even if a cure is found because the challenges do not lie only with HIV/AIDS related problems, but with the way we have organized our societies in discriminating, hierarchical models. An effort in this direction is the remarkable work by Lopes-Júnior (2000) in the Brazilian Northeast who has been investing in social networks of students and teachers to disseminate values of tolerance, the recognition of human rights and the need to build a culture that values individual rights and respects individual history.

The last recommendation for educators and the most difficult to achieve is not to focus only on building symbolic resources since social action is pressing. For instance, I interviewed a woman in a public health clinic who told me she was cured of AIDS

because the hospital gave her leave. She did not have a home, a family or a job. It is possible that the hospital did not have the resources to keep her or that they did not evaluate a real need. It is also accurate that the concept of home care is regaining status among the middle and upper classes. Yet how should an ill and poor woman without any resources proceed? To this woman, unfortunately, simply leaving the hospital made her think she had been cured. Promoting health demands actively searching socially appropriate alternatives, so that flagrant situations of social neglect and exclusion such as this will be less likely to occur.

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