Moral Hopelessness and HIV/AIDS Global Paralysis

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No disease ever in history, other than the plague of the 14th century, has caused such serious psychological and emotional distress, affecting families and communities as the AIDS pandemic. The United Nations AIDS Program (UNAIDS) and the World Health Organization (WHO) now estimate the number of people living with HIV/AIDS today is 40 million. More than 25 million people have died of AIDS since 1981. At the end of 2007, women accounted for 48% of all adults living with HIV worldwide, and for 59% of those in sub-Saharan Africa. Young people (under 25 years old) account for half of all new HIV infections worldwide and about 6,000 become infected with HIV everyday (UNAIDS/WHO, 2007). Most of the infected (22.5 million) live in Africa, a continent home to only 10% of the world's population, but shouldering over 70% of all cases and 95% of all orphans according to the UNAIDS/WHO report.

About 2.5 million adults and children became infected with the Human Immunodeficiency Virus (HIV) in 2007 alone. Furthermore, an estimated 33.2 million people worldwide are living with HIV/AIDS. The year also saw 2.1 million AIDS-related deaths despite recent improvements in access to antiretroviral treatment. The purpose of this paper is to highlight the problem of indifference in the approach to the disease by the world community and how this ambivalence has turned a controllable problem into a lethal one. It argues that the scale in numbers of the sufferers, the helplessness faced by their governments in instituting meaningful care, and the desperation of the victims, has created a state of moral hopelessness. Moral hopelessness, as defined in this paper, is a situation of total individual and collective surrender that is pervasive. The Beck Hopelessness Scale conceptualizes hopelessness as an individual's negative expectancies regarding the future (Beck, 1988). This paper provides a unique perspective that questions the conventional thinking surrounding the issue of HIV/AIDS and provides a direction that includes a new disease definition and approach.

HIV/AIDS has taken different faces since it was first identified in 1981 in the USA by the scientists at the Center for Disease Control and Prevention (CDC). Following a series of similar reports from the University of California Los Angeles Medical Center of a rare illness that had

occurred among five homosexual men (Gottlieb, 2001; Oppong & Kalipeni, 2004), the CDC decided to act. At the time, it was thought that the disease was limited to certain high-risk groups, including gay men, hemophiliacs and injecting drug users (IDU) (Gottlieb, 2001).

In 1984, research in Central Africa revealed that the disease affected men and women equally and for epidemiologists studying the disease in 1986, it became clear that this disease had become a particular brewing danger to the developing world, especially in Central and East Africa (Oppong & Kalipeni, 2004). Later in 1986, WHO declared HIV/AIDS to be a pandemic and a serious mortal problem. It is now over twenty years in this declared "campaign" against this menace and researchers, patients and afflicted families are still asking: "Why"? Why is it that more than 40 million people are now living with the disease with millions more dead? It is apparent that knowledge of the disease was there even in the mid-1980s. This knowledge was utilized by affluent nations for the good of their citizens; for the poor however, the opposite is true. This has created a reality of moral hopelessness.

This paper argues that the egalitarian principles that have usually promoted fairness and equity might have been ignored in addressing the HIV pandemic. Soon after the WHO announcement of the HIV global epidemic, rich nations initiated drastic mechanisms and programs to alleviate the problem and this was reflected in a dramatic plummeting of the numbers of those infected. This was the case for the United States. Elsewhere however, particularly for governments of poor nations that had neither the funds nor the infrastructure required to deliver the appropriate response, many were left in a state of debased moral hopelessness.

Emile Durkheim, a 19th century French sociologist, introduced the concept of anomie in his book, *The Division of Labor in Society*, published in 1893 (Calhoun, 2007). Durkheim used anomie to describe a condition of moral recklessness that was occurring in society. There was a breakdown of rules and regulations, and people's moral responsibility and accountability to one another was lacking. Anomie, simply defined, is a state where norms (expectations on behaviors) are confused, unclear or not present. It is normlessness or moral recklessness (Lemert, 1993). Today nations operate under a universal system of rules (norms) and conventions (treaties) that guide human activities and decisions. A good example is the Universal Declaration of Human Rights. If for some reason those established rules, having been sanctioned by nations of the free world, fail to protect those under their protection (the powerless), a situation of anomie is created. This is the situation in which people with HIV virus often find themselves.

There is a collective anomie on a grand scale surrounding the issue of HIV/AIDS. Developing nations are undergoing episodic moral hopelessness, defined as the state of desperation, defeat and confusion that puts them in a "coiled up", "given up" mode. It is a situation of despair sustained by the hope that rich nations will one day have the conviction to come to their aid. It is a state of "total surrender." The parallel between anomie and moral hopelessness is that the former creates chaos, the latter, desperation. The mood today for most people in the developing world and their governments in reaction to this calamity is despair, and their response as pietism, devoted now to burying their dead and the observance of "final rites." Plainly speaking, the HIV/AIDS problem has gone beyond these countries' ability and capability, thus creating this moral hopelessness. The public health infrastructure of most of these countries has been choked to capacity through many centuries of battling endemic ailments such as kwashiorkor, malaria, typhoid, cholera, dysentery and others. The emergence of HIV/AIDS in the 1980's not only sent shockwaves through an already fatigued system, it created

a paralysis far greater than imagined. Faced with no choice at all, many nations have desperately watched their life expectancies drop to a decade's low.

HIV as a Human Rights Issue

Fifty-nine years after the Declaration of Human Rights, the world still has not reached a practical consensus on making AIDS a binding human rights issue. Article 25 of the Universal Declaration of Human Rights underscored clearly the social and economic rights of all persons:

> Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

This paper argues that despite proclamations by the United Nations regarding what are acceptable basic rights, there is little progress in the quest for social and economic rights for all individuals. The right to health and medical care has not been given a serious consideration, particularly in the treatment of the poor. The epidemiology of HIV/AIDS in sub-Saharan Africa is fundamentally different from the rest of the world, and unfortunately corresponds with the economic deprivation of the region. Sub-Saharan Africa contains about 10% of the world's population, yet accounts for over two-thirds of the more than 40 million people living with HIV. It accounts for 70% of incidents of HIV infections, 80% of AIDS deaths and 90% of AIDS orphans (UNAIDS/WHO, 2007). One can argue that this is not an accidental phenomenon. It is a direct product of the indifference to this problem by affluent nations that has created this hopelessness. These devastating social, demographic, and economic consequences and the severity of HIV/AIDS are very unique to sub-Saharan Africa and, to some extent, the Caribbean. Consequently, they require unique responses (De Cock, Mbori-Ngacha & Marum, 2002). Even in the backyards of the industrialized world, for example in the U.S., AIDS is killing more people living in poverty from communities of color and minority populations compared to other demographic groups. By 1995 for example, over half a million people in the United States had been diagnosed with AIDS. In 1992, blacks were only 12% of the U.S. population, but 30% of AIDS cases. Latinos were 9% of the population, but 17% of AIDS cases. Blacks and Latinos together accounted for 46% of AIDS cases and 54% of deaths from AIDS (Schneider, 1998). Obviously there is no known and scientifically established genetic predisposition of the disease to minorities. The current situation is primarily a product of access or lack of access to knowledge and preventive care.

The global response to this problem has been abysmal. Since the earliest days of the problem, there has been an exclusionary, hands-off approach by the West to the problem of HIV/AIDS in Africa, a trend which Bayer (1991) defines as "HIV exceptionalism." By contrast with Africa, the AIDS incidence and mortality rates in the industrialized world have fallen, and pediatric HIV disease has completely been eliminated largely through antiretroviral (ARV) drugs (De Cock et al, 2002). Globally, however, ARV remains beyond the reach of the majority of people with HIV/AIDS. Of the 6 million people worldwide who needed ARV in 2003, fewer than 8% were receiving them (Galvao, 2005). Ironically, major international forums of the UN have identified and recognized HIV/AIDS treatment as a human rights issue. Yet, no major, legally binding mandates have been instituted or imposed to any country. Both the United States and Great Britain still bar the entry of people proclaimed to be HIV positive. At the 57th Session

of the Commission on Human Rights in April 2001, the United Nations High Commissioner approved a resolution that made access to treatment a basic human right. In 2003, UNAIDS reaffirmed the relevance of human rights to HIV/AIDS by establishing a Global Reference Group on HIV/AIDS and Human Rights (P. 1111). These covenants or treaties are of little significance when governments cannot implement them. A suffering orphan, widowed mother, or young father is left immobile without strong legal and political advocates. These highlights of the indifference are the pivot points to this paper. The hopelessness and despair borne by the victims of this disease is horrendous, yet, the world has not embraced this problem as one of the greatest threats facing mankind today.

HIV/AIDS as a Public Health Issue

The US Surgeon General under Franklin D. Roosevelt, Thomas Parran, published "Shadow on the Land" in 1937, a book outlining his plan to combat syphilis. He thought at the time that public efforts to combat the disease had been "scattered, sporadic, and inadequate." His public health program included promotion of case detection, testing (including premarital and antinatal testing), treatment, contact investigation, and public education. His intrinsic vision was to demystify syphilis, fight it with the necessary resources, and define it as a public heath rather than a moral problem (Parram, 1937). This paper argues that the HIV/AIDS issue has not been defined and addressed as an infectious disease emergency as was successfully done for syphilis. The overriding premise is that how an issue is defined strongly influences public perception. Susan Robbins (2007) has called this phenomenon a "paradigm of definition": a socially constructed phenomenon debased of its external reality and inherent essence, but by an act of mind. The public health approaches during that period which targeted testing and follow-up investigation typical of tuberculosis and sexually transmitted disease control, were deemed inappropriate for HIV/AIDS and were codified in a confidentiality lingo. Focusing primarily on informed consent and counseling, as was the case before, (although important) restricted testing for HIV. This type of "surveillance" or "caution" implicitly perpetuated the stigma and isolation associated with HIV/AIDS. Many infected people were not readily willing to participate in voluntary testing because stigma was heightened in these implicit legal controls. It is this kind of illusive lack of public health approach that might have contributed to the moral hopelessness situation we see today.

Conclusion and Implications for Social Work

The reality is that HIV/AIDS has devastated our world. Over 40 million people presently living with AIDS is a worrisome statistic. By 2010, Ethiopia, Nigeria, China, India and Russia with 40% of the world's population will add 50 to 75 million infections (UNAIDS, 2005). Social workers will have to respond in a unique and aggressive way. The worried, the ill, the dying, and the bereaved occupy social workers' caseloads and continue to touch them personally. Innocent children, young mothers and the families of intravenous drug users are becoming infected and dying (Leary, 1989; Williams, 1989). Orphaned children with AIDS languish in inner-city hospitals; gay men die; elderly parents grieve for sons, daughters, and grandsons. Governments in poverty and conflict-stricken countries have no muscle to fight the epidemic. This state of hopelessness calls for an invigorated collective will of social workers in the tradition of the pioneers in the profession who bent backwards to meet the challenges of the time. The history of social work and the profession's innovations during the Progressive Era and the New Deal under the leadership of Jane Addams, Lillian Wald, Florence Kelley, Harry Hopkins,

and Frances Perkins resulted in the creation of settlement houses, playgrounds, child labor laws, visiting nurses, maternal health clinics, social security, and labor legislation (Shernoff, 1990). HIV/AIDS is the defining issue of the day and it will require unique individuals and perspectives in dealing with it. There is an urgent need for visionary leaders in the rank of our pioneers to demand that resourceful governments respond fast and appropriately to this dreadful pandemic.

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