HIV: HOW SCIENCE SHAPED THE ETHICS

by Gayle E. Woloschak

Abstract. AIDS is a debilitating and fatal disease that was first identified as an infectious disease syndrome in the 1970s. The discovery of a nearly universally fatal infectious and rapidly spreading disease in the post-antibiotics era created apprehension in the medical community and alarm in the general population. Questions about how patients should be handled in medical and nonmedical settings resulted in the ostracizing of many AIDS patients and inappropriate patient management. Scientific investigation into modes of disease transmission and control helped to shape the management of AIDS patient care in such a way that ethical and protective practices could be developed. In this article I discuss some of the ethical questions that were addressed by appropriate scientific inquiry.

Keywords: Acquired Immune Deficiency Syndrome (AIDS); AIDS and ethics; AIDS and scientific inquiry; ethics and decision-making in AIDS patients; Human Immunodeficiency Virus (HIV).

HIV AND AIDS: A PRIMER

The Human Immunodeficiency Virus (HIV) has been established as the cause of Acquired Immunodeficiency Syndrome (AIDS). The virus is an obligate intracellular parasite with nine different genes and is a member of the Lentivirus genus of the Retrovirus gene family—that is, it is a virus that carries RNA as its genome and upon entry into a cell converts the RNA into DNA using a combination of cellular and viral proteins (Finzi and Siliciano 1998). HIV infects several different cell types, but the most prominent cell in humans is the T-helper lymphocyte, a cell important in

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the generation of immune responses to infection. The infection and eventual death of T-helper lymphocytes results in a drastically depressed immune response that leads to the eventual development of immunodeficiency and full-blown AIDS (McMichael and Rowland-Jones 2001; Woloschak et al. 1997).

HIV progresses into AIDS, but HIV is not synonymous with AIDS. Many people can be infected with HIV for decades before developing symptoms associated with AIDS. Generally AIDS is diagnosed based on presence of the HIV virus in conjunction with symptoms of immunodeficiency, Kaposi's sarcoma, and/or other problems. HIV infection generally causes the immunodeficiency (AIDS) that leads to susceptibility to infection; it is usually these secondary infections that cause death in AIDS patients.

Two major strains of the virus have been identified (HIV-1 and -2) with several groups found in each strain. HIV-2 is considered to be less pathogenic and progresses to AIDS more slowly than HIV-1, but among HIV-2–infected people who develop AIDS, brain disease is much more common.

HIV is a model virus for maintaining maximal mutability while retaining functional and replicative fitness. The degree of genetic diversity of HIV in a single infected person is greater than the worldwide diversity of the Influenza A virus during the height of an epidemic. This genetic diversity has led to difficulties associated with treatment, including drug resistance and resistance to vaccine development (Nabel 2001; Nabel and Sullivan 2000). One concern among scientists is what this continued unchecked diversity in HIV can lead to as the next step in disease progression. Can it lead to altered patterns of transmission of the virus, to new types of cells being infected, to a new host range for the virus, and so on?

AIDS and Science

Prior to the discovery that HIV caused AIDS, numerous reports in the popular press attributed AIDS to a variety of causes. Many blamed alcohol and drug abuse, the gay lifestyle, or the bathhouse scene in San Francisco; there were even reports that AIDS was the result of a biowarfare experiment gone awry and spreading throughout the American population. Eventually, scientific research established that AIDS was caused by a virus, and this created new panic in the general population. Typical methods of transmission of viruses had a range of possible routes of transmission. Table 1 lists common modes of transmission for typical viruses that influenced the thinking of scientists and the general population when scientific research was being done to establish the route(s) of transmission of HIV. Clearly, containment of the virus and proposed methods of control depended on the method of transmission. In addition, ethical handling of AIDS patients should be determined by the actual mode of transmission of the virus and not by imagined fears of contamination that were not based on sound scientific reasoning and logic. Table 2 provides a list of questions that could be addressed ethically once the general mode of transmission of HIV was identified. In the absence of this information, the medical community and the population at large assumed that any and all known means of transmission of viruses could be in operation for HIV (as listed in Table 1), and therefore any form of containment was acceptable—from seclusion of AIDS patients in isolated groups to widespread use of mosquito repellants to avoiding all contact with AIDS patients for fear of respiratory or contact spread of the disease.

Eventually, scientific research from a large number of different groups around the world established that HIV was spread through infection through three different routes: (1) across mucosal surfaces (predominantly sexual and oral), (2) by injection/transfusion, and (3) by childbirth. In

Table 1. Modes of Transmission of Common Viruses

Mode of Transmission	Virus
Respiratory	Influenza
Contact	Rhinovirus (cold), Smallpox
Ingestion	Hepatitis (contaminated food/water)
Animal reservoir	Rabies
Close person-to-person contact	Herpes
Borne by insects	Encephalitis

Table 2. Questions Determined by a Scientific Understanding of How HIV was Transmitted

- How should patients be treated in the clinic?
- Is containment needed to protect the general population?
- Are insect/animal vectors (such as mosquitoes) a possible source of infection?
- How should contaminated materials (needles, blood) be handled?
- How should people living with those with HIV protect themselves (glassware, meals, etc.)?
- How can lab workers doing studies with HIV protect themselves?
- What personal practices are risky (unprotected sex, shared needles), and which are not?
- What medical practices (untested blood for transfusion, natural birthing) are risky, and which are not?
- Are there risks for unborn babies?

addition, intensive research established the parameters required for transmission via each method. For example, while kissing could serve as a possible method of spread of the virus, this required open sores in the mouth and prolonged periods of exposure. Surgical C-section procedures for childbirth greatly reduced the infection rate for children, and breast-feeding of the baby (an oral means of infection) was not recommended for HIV-infected mothers. The restriction of the use of infected needles and promotion of safety precautions regarding sexual activity also contributed significantly to a slowing of the AIDS epidemic.

Many other effective and ethical responses to the AIDS epidemic were established on the basis of information obtained by scientific investigation. The fact that HIV transmission is known to occur in intimate contexts led to childhood sex education and the eventual reduction of risks for transmission. Concerted effort against the stigma of having AIDS was now possible since isolation could no longer be rationalized as a means to prevent virus infection; while much work still needs to be done in this regard, working against the stigma has led to an improved quality of life for those living with HIV and those most vulnerable to infection and has also increased the response to the epidemic itself. People living with HIV have been included in decision-making processes, eventually leading to increased accountability of medical workers and scientists in the response to the AIDS epidemic. Scientific knowledge has also contributed to the development of methods for safe handling of the virus, thus providing safe practices and reassurance to laboratory and medical workers. The development of diagnostic tests for AIDS and its progression have resulted in more rapid and effective treatment strategies and a general prolongation of a high quality of life.

HIV Ethics Today

The global impact of HIV/AIDS has been most strongly felt in sub-Saharan Africa where it is estimated that 25.3 million people are currently living with AIDS and where 75 percent of the world's AIDS-associated deaths occur. Seven African nations have HIV infection rates of over 20 percent. It is estimated that if such an infection rate were to occur in the United States, health management and insurance systems would collapse. The problem of sub-Saharan Africa is complicated by the fact that the use of drugs has resulted in reductions of AIDS mortalities for HIV-infected people in the United States, but such drugs are rarely available in Africa because of their high costs. It is expected that AIDS will wipe out decades of gains in life expectancy in sub-Saharan Africa, with the predominant affected population being young, mobile, productive, active members of the workforce (Piot et al. 2001; Haynes 1993). How can science drive the ethics in the problems associated with AIDS in the world, particularly nations of Africa so drastically affected by HIV?

Clearly, much scientific effort is being spent on the development of an AIDS vaccine. Such an accomplishment could once again provide a means for science to resolve the ethical dilemma facing the world, especially related to the high incidence of AIDS in Africa and the paucity of approaches for disease control there (Piot et al. 2001; Haynes 1993). Nevertheless, many hurdles exist for the development of a vaccine for HIV including the lack of a strategy to address the genetic diversity found among HIV isolates, the failure to identify HIV molecules that induce long-lasting immunity, and the lack of information regarding what is needed to induce immune protection to HIV in humans or even in animal models (Weiss 2001). While some of this information may come forth as more scientific research is conducted, some of these problems may require decades for resolution. Until science leads to the development of a vaccine or cost-effective treatment options, it is likely that economic considerations rather than scientific information will drive the ethical concerns about AIDS in the global community.

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