AIDS and Health Care Deficiencies

Anselm L. Strauss, Shizuko Fagerhaugh, Barbara Suczek and Carolyn Wiener

AIDS is having a substantial impact on health services. The increasing number of those suffering from Acquired Immune Deficiency Syndrome (AIDS) is greatly taxing the capacities of public hospitals and clinics, especially in cities like New York and San Francisco. AIDS has even affected traditional procedures in medical science. The normal sequence of steps through which treatment drugs reach the public – screening by the Federal Drug Administration (FDA) and then carefully controlled clinical trials – has partly been altered by AIDS activists, who have created a powerful national lobby bent on changing certain features of the health care system. AIDS has heightened tensions around certain moral dilemmas associated with current health care policy by raising issues of personal responsibility for illness and public responsibility for preventing and treating certain illnesses. AIDS also highlights several grave deficiencies in the health care system.

This essay will explore both the moral issues and the preventive/treatment ones, as well as the systemic deficiencies beginning with a discussion of the implications of chronic illness – for AIDS is now recognized as a chronic illness, although still a deadly one. Then the discussion will turn to AIDS in relation to broader health issues. AIDS needs to be thought of not as a uniquely different, late-twentieth century disease, but as a belonging to a broader category. Activists recognize this in part when they talk about the usefulness or political necessity for "mainstreaming" (getting AIDS into political alignment with health issues in general). We offer here a more comprehensive framework for understanding AIDS in relation to several important health issues.

Chronic illnesses are the prevalent contemporary type of disease. The prevalence of this type of illness is due partly to antibiotics that have greatly decreased the rate of acute illness, and partly to Americans' improved nutrition and to medical treatments that have resulted in longer lives (though ones prone to more chronicity in the later years). Some chronic illnesses (cardiac disease, lung cancer) are also associated with certain life styles; while still others are known or suspected to be associated with inadequate regulation of substances (like some conditions of industrial work and urban air pollution).

Moral and Economic Issues

Moral and economic debates swirl around all of these sources of long-term illness. Our aging population, for example, raises the costs of medical care, especially when the ill are in their last months and years, for then frequent and intensive hospital care is added to other costs of treatment. This being so, the argument has been made that limits be placed on spending for the very old or the hopelessly ill – the money would be better spent on lowering the nation's deplorable rate of infant mortality or at least spent on
improving the health of younger citizens. Not so long ago, when the matter of rationing medical treatment for the very old was broached publicly by a governor of Colorado, it roused highly indignant responses on humanitarian moral grounds. There are also the moral issues that have come in the train of medical technology's ability to keep brain-damaged individuals alive. The costs of maintaining these socially dead, but biologically alive, people are frightful, but so are the ethical dilemmas of such situations. Increasing numbers of middle-aged children, especially the daughters, of the very old are faced with giving domestic and nursing care to their sick and sometimes senile or Alzheimer-stricken parents, while forced to expend sorely needed personal resources.

Urging "personal responsibility" is absurd and ethically dishonest when applied to the economically deprived.

All of this is accompanied by considerable feelings of guilt and moral anguish when it finally becomes necessary to resort to nursing home placement. (In fact, it is entirely possible that a generation or two from now these same children will elect not to live so long, so sick, but be part of a general movement to extend a growing custom of requesting "no heroics during my last days or hours." If the elderly are able to fend for themselves, they may have to use up all their savings before they die or until the government finally picks up payment for nursing home care. At the opposite end of the age scale, some premature children, who are saved in intensive care nursery units, will suffer from long-term disabilities incurring familial costs for corrective care; but also because "worst case" infants are often not allowed to die, moral dilemmas are created for hospital staffs, parents and society at large.

Aside from the moral issues resulting from improved medical technology and care, there are also the issues associated with personal and societal responsibility. Passionate arguments have been made for holding individuals responsible for their own condition since life-styles contribute to such illnesses as heart disease and lung cancer, and to the worsening of illnesses such as diabetes and asthma. This version of ethics is countered by, or supplemented with, pointing a finger at a society that has not instituted adequate preventive measures, including extensive and determined educational efforts.

Another line of moral argument faults society for actually causing or increasing the rate of certain illnesses. The state of air pollution in many cities is not only disgraceful but physically harmful; industrial accidents that result in disabilities could be avoided or their numbers lessened by stricter regulation. Lack of access to quality medical care, or any care at all, for many Americans, especially the poor, reflects upon the country's social system and its skewed values. So does the relatively low rate of medical insurance that contributes to lack of access. Personal responsibility, it is argued, is an absurd and ethically dishonest concept to apply to economically deprived Americans. Should the nation's terrible record for child mortality be attributed to failures of personal responsibility? And what about the homeless— at least the involuntarily homeless—are they to be held responsible for their all too evident sicknesses?

The moral issues and dilemmas associated with contemporary (mostly chronic) illness are complex and varied. Bioethicists address mostly the more obvious pertaining to matters of death that have come in the train of effective medical technology and have yet to plumb the depths of their subject by looking at the entire trajectory of chronic illness, the living with it as well as the dying from it. Consider pain for instance. The conflicts between patients and hospital staffs over what constitutes pain relief reflect not just differences over medical care but they raise questions that are deeply moral. One sees this in extremis when dying patients are denied sufficient pain medication because of staff ideologies about addiction ("They will become addicted").

Deficiencies in Health Care

There are several grave deficiencies in the American health care system. Not all are evident enough to attract much attention or public debate, but all are associated with the prevalence of chronic illness. Areas of deficiency include: 1) home care; 2) difficulties of managing new phases of illness (brought about through increased medical knowledge and improved technology); and 3) inequities in gaining access to health care. The third, well recognized and debated, issue will be discussed specifically in connection with two sub-issues concerning discrimination in our health care system against the homeless and against drug addicts (AIDS aside).

These deficiencies in the health care system are largely due to traditional assumptions about what kinds of illnesses are most important to manage. The evolution of our hospitals and clinics was for many years