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AIDS and the Challenge of a Plague

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Introduction

Throughout history, the psychosocial consequences of the plagues which have beset humanity have been predictable. These outbreaks of disease threatened the sense of control underlying most forms of social organization. The potential threat was profound, particularly when the existing social order, the theological bases, the feudal system, or the assumed biomedical-technological preeminence of a society appeared powerless to provide the protection implicitly promised. Because the cause was seen most often to originate from infected "others" (some stigmatized and easily identifiable subgroup), the sense of risk or threat was further increased, leading to fear, anxiety, hysteria and scapegoating, and intensifying the need for more stringent "control" measures.

By examining the historical parallels and similarities of society's responses to past plagues and its response to the present day scourge of AIDS, we can learn how fear and prejudice affect the providing of empathy and mercy. This added understanding may facilitate a more compassionate response by caretakers and the nonafflicted public to the victims of this terrible disease and minimize the fear and discrimination subverting the drafting of more effective public health policy.

Sontag (1978) has written graphically of the metaphorical uses of illness. Terminal diseases can be seen as morally, if not literally, contagious and experienced as a supernatural punishment for immoral behavior, a symptom of

demonic possession, or a reason to blame the victim. Western culture has a long history of reacting this way to outbreaks of illness that can not be treated.

Historical Overview

Plagues have beset the Eastern and Western world at least from the times of the Egyptian pharaohs in the second century B.C. (McNeil, 1976). The first pandemic, Justinian's plague, led to the death of a quarter of the population. With accompanying diseases, social disruption and wars, the population in many parts of Europe fell by half between the sixth and eighth century. Moslem religious leaders at the time saw the plague as sent by God as a mercy and martyrdom for the faithful, and a direct invitation to Paradise (Simpson, 1988). For the infidel, it was merely a horrid death with no consequent benefit.

The Black Death

A well-documented example of a plague was the "Black Death," or the Bubonic Plague, which decimated one third of the world's population. Peaking about 1350 and lasting for about 60 years, its origins are unknown. In an early outbreak, Tartars, besieging a city, used catapults to lob the corpses of victims over the citadel walls, leading to the spread of the plague to the Christians within.

Science was helpless to prevent or treat the epidemic because it was unaware that transmission was through fleas from the brown rat. In fact, anyone who had any unprotected contact with the body or clothing of a plague-afflicted person had a high probability of contracting the disease, and died within one to five days.

Attribution

Religion in the East first saw the "Black Death" as an expression of the just wrath of God; this belief spread to the West where it was viewed as a punishment for wrongdoers, for sexual excesses, and as a punishment God inflicted on whom He willed, clemency being granted to the faithful (Fulton and Owen, 1988).

Others believed the plague was caused by the influence of the stars. This started with the unbelievers who came to Italy and crossed the Alps to France, Spain and Germany. Jews, hated because they were money lenders, were quickly made the scapegoats, and were blamed for poisoning the water and spreading the pestilence. Quickly rounded up, they were attacked and killed, often burned alive. In fact, the reason they survived the plague was because of their superior health habits.

The Response of Society

Society's response to plagues was individualistic, with the exception of some monastic orders and medical schools. Among the first to care for the victims, entire monastery populations and medical school staffs consequently perished. In many towns, timid priests and physicians withdrew, leaving the exercise of their ministry to the more daring. Fox (1988) documented how the medical profession responded with remarkable continuity to the threat of contagion. Many physicians treated most of the patients who sought their help, though they frequently charged higher fees. These physicians ended up being ostracized by their peers. Other physicians fled from the cities, as was common in times of plague. Galen left Rome in the second century A.D.; Sydenham fled from London in the seventeenth; and some leaders of the profession in Philadelphia and New York left during outbreaks of yellow fever in the eighteenth, and cholera in the nineteenth centuries. Many doctors who did not flee reportedly refused to visit patients who were acutely ill and told surgeons "who had lower status" to treat the ill in their own locales (Fox, 1988:6).

The population at large reacted to the plague by abandoning the sick, so that many died alone. In the belief that God was punishing city dwellers, huge portions of the population fled from the city. Others totally ignored the situation by shutting themselves up in their houses. Some attempted to cope with the situation by carousing and making merry, satisfying the appetite in every way possible, and laughing at what befell others. Suggestions for remedies abounded and included daily lovemaking or no lovemaking, prayer, superstitious rituals, starvation or overeating. Groups of flagellants appeared in different parts of Europe and beat themselves and others in acts of propitiation and atonement, so as to allay the wrath of God.

Meanwhile, many of the afflicted breathed their last in the open street, and others made their deaths known to their neighbors by the stench of their rotting bodies. In one year, 100,000 died in the city of Florence alone. In Siena, where 100,000 also died, the entire city was said to be stupefied by seeing the pain.

Aftermath

When the pestilence ended, those who survived gave themselves over to pleasures, glad to be alive. Afterward, many ignorant, incompetent and corrupt men were hired to replace the skilled officials who had died, because the offices had to be filled and the government kept running at all costs. The church was no better off. Decimated by the plague and anxious to keep huge monasteries in existence, it admitted, professed, and ordained poorly educated men and

professed illiterate and even retarded men and women. Complaints then arose against political and administrative corruption, the increase and prevalence of crime, the lightness of mind and looseness of morals, the high prices, the profiteering, industrial and farm strikes, the extravagance, the indolence or refusal to go to work, and the cry for reform gradually became widespread. As a result of the Black Death there was a universal upheaval and transformation of society.

The plague was seen as a watershed between a Middle Ages marked by hope and optimism (and some would say a degeneration of family life and morals), and a new epoch in medieval society that witnessed the growth of institutions founded solidly on deep human needs, and more compassionate care of the sick (Helgelund, 1984). Even national peace temporarily increased as the kings of France and England, the pope, and the Italian republics renounced their extensive political and military activities because the plague had made the raising of armies difficult.

AIDS as a Plague

The Plague Mentality

Despite outstanding medical advances, a pandemic has developed over the last decade which has infected over two and a half million Americans, and inhabitants of over eighty-five other countries (Fulton and Owen, 1988). In some cities, such as New York, autopsies have found one in seven infected (Lambert, 1990). Gallo, instrumental in first isolating the AIDS virus, recently wrote: "AIDS is a modern plague: the first great pandemic of the second half of the 20th century" (1989:47). A disease which physically afflicts mostly socially stigmatized groups, it affects all of humanity psychosocially.

We twentieth-century humans initially have responded to this epidemic as our ancestors in the Middle Ages did when dealing with plagues. The same fears (however irrational) of contracting a terrifying illness, the despair of a terminal prognosis, the resulting anger at oneself, someone else, or God, the projection of blame onto others, and the ostracizing of stigmatized populations are some of the compelling issues which confront society. Extremely destructive stereotypes and deep-seated prejudices about homosexuals, IV drug users and prostitutes have allowed the general population to be detached and unempathetic (Foster, 1988).

With AIDS, scapegoating is encountered on a societal level as well as in individual care. For example, the early inadequate funding of research betrayed the popular perception that since the population most afflicted by AIDS was gay people, AIDS was "their" problem and not "ours" (Gebbie, 1989). Stigmatization of gay men has resulted in an atmosphere in which even a medical journal

published editorial remarks by a minister suggesting that AIDS may be the divine punishment of "a transgression of universal and natural moral law" (Selby, 1985:275). A physician recently described homosexuality as "a psychobiological perversion" and argued for mandatory testing for HIV (Tanay, 1988). Although public opinion about AIDS exists today in a context of little personal experience with the epidemic, 82 percent of the general public believe that the disease is a threat to them (Katz, et al., 1987), and attitudes are heavily weighted by a belief that the disease is a punishment for deviant behavior (Nichols, 1984).

Fear is the initial reaction in both laypersons and health care providers, with its level similar to the societal reaction to leprosy in premedieval Europe, syphilis epidemics in the late fourteenth century, or the Bubonic Plague. Although education about AIDS (as much as we know today) should result in a better understanding of AIDS, phobic blocks—both in the practitioner and the patient—preclude this transition from occurring. These phobias can focus on death and dying, premature death, having a protracted wasting state culminating in death, contracting a new infectious disease that has no cure or vaccination and which can extend to family members or friends, disfigurement, diminished life qualities (loss of mental capacity, body control, ability to generate income) and/or a phobia of social isolation (Bartnof, 1988). Fear is a normal human emotional reaction to contagion and death, but phobias are not.

Almost daily, the news media reports incidents or issues involving the disease in response to the public's growing awareness and concern. These concerns include the risk which infected children pose to classmates, the advertisement of condoms on television, the distribution of free needles to drug addicts, and the legal and civil propriety of identifying seropositive persons in official records. Still other news reports tell of persons with AIDS who have lost their jobs, homes, medical insurance, or the support of families and friends. Documented are disapproval of, or prejudice against, homosexuality, including homosexual lifestyles; abhorrence of persons who use drugs, who prostitute, and who are prisoners.

Anxiety within the Medical Professions

In 1984, Ostrow wrote: "We physicians have come to hysterical, emotional, and sometimes irrational reactions to anxiety about AIDS, and to further anxieties produced by our responses to AIDS" (1984:95). By 1987, the American Medical Association (AMA) had to mandate that "a physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence solely because the patient is seropositive.... The tradition of the AMA, since its organization in 1847, is that: 'when an epidemic prevails, a physician must continue his labors without regard to the risk to his

own health. That tradition must be maintained" (AMA, 1988:263). However, fear of contagion still induces physicians to refuse to treat persons with AIDS (Annas, 1988), and uncomfortableness with sexuality still leads to the avoidance by physicians of obtaining a sexual history as part of the medical history. Only 11 percent of nurses polled were willing to work with persons with AIDS and 60 percent feared HIV infection (Douglas and Kalam, 1985). The authors commented: "These studies and others show that getting AIDS from a patient is a frightening possibility for many health professionals" (Douglas and Kalam, 1985:3481). Health professionals must become more aware of their attitudes about the care of AIDS patients and come to terms with their fear of contagion. "Unless educational and psychiatric resources are developed to facilitate these goals, patient care will suffer and the level of emotional stress of hospital staff may prove overwhelming" (Wallack, 1989:510).

Impact on Persons with AIDS

Facing a fatal and mysterious illness such as AIDS is a horrendous task and facing the same circumstances as a member of a stigmatized group is even worse. The public's reactions to AIDS have become sources of significant psychological distress for persons with AIDS and others at risk (Siegel, 1986). Our culture has not yet understood how isolation affects our capacity as individuals or as a community to care for its members. Despite the fact that AIDS is not generally contagious, its victims may be shunned as if they were lepers, denied the rights of employment, armed service, or the sacrament. There have been many treatment ramifications. People are not coming forward to be tested, nor supplying names of sexual contacts, because of the fear of stigmatization and discrimination. Many AIDS patients are being severely isolated because of the social stigma attached to AIDS (Salisbury, 1986). Funding and treatment decisions for the patient have been subtly influenced by prejudice. Turmoil has been created for families who are faced with the knowledge that a family member belongs to a stigmatized group. Worse yet, this prejudice can be incorporated by the person with AIDS, and one can spend the last days of one's life tormented by self-blame and self-hatred, remorse, and a feeling that one deserves retribution (Krajeski, 1984).

The Future of the AIDS Epidemic

Today, persons with AIDS cannot be offered reassurance against discrimination, because a substantial number of Americans still display outright hostility. Public health education alone is not enough to prevent this, and perhaps

only legal mandates can prevent discrimination and encourage public health and other health workers to care more appropriately for people infected with AIDS (Blendon and Donelan, 1988).

The future of the AIDS epidemic will depend on many variables, including our ability as world societies and individuals in those societies to take responsibility for ourselves and others, not only in preventing people from getting infected with the virus, but in caring for those who are ill. Currently, we are almost immobilized from providing support and care for the seriously ill and dying persons with AIDS. Our abilities and willingness to discover and apply therapeutic and preventive agents to combat the disease must not be encumbered by the stigma against it or the tendency toward any irrational or biased fear of contagion. The current tragic dilemma of choosing between the duty to protect patients versus the obligation to protect the health of society will need to be resolved. Society at large has a challenge to become so creative in its thinking that it can accept with new insight the person with AIDS who needs our care. The AIDS patient, sick and certain to die too soon, has a similar challenge to accept dying as a process of moving toward a completion of one's life.

If we can meet these and other challenges of AIDS, responding appropriately to its medical, social, psychological, and spiritual crises, true social progress can result. The epidemic is bound to have a lasting impact on our society. It can influence current biomedical research and medical therapeutics, affect our cultural mores, our attitudes about death and dying, and many of our basic assumptions about the primacy of technology as a solution to problems.

Conclusion

Although epidemics are first and foremost medical phenomena, they are also extraordinary catalysts for societal change (Valdiserri, 1988). If America can meet the challenges of AIDS, overcoming the "plague" mentality and responding appropriately to its medical, psychological, and social crises, true social progress can result.

In The Plague, Camus (1946) demonstrated how a dreaded disease, as horrible as it was, gave the community of Oran an opportunity to transcend its petty existence. Through the townsfolks' honesty in the face of terror, their compassionate moral choices, and finally, their commitment to their fellow men and women, they achieved a new awareness of the meaning of life and of love (Broadsley, 1988). The havoc wrought by our modern-day plague is forcing our culture to also redefine its values, behaviors and ethics. Although there is no formal quarantine system in the United States, we do have intense, informal pressure which isolates people with AIDS from the support normally granted to those with handicaps, illness or terminal disease. Camus insists that love

demands a total surrender to the service of others in the face of a terrible, widespread disease.

In America, there are now signs that the importance of community services for AIDS is beginning to be recognized. In the major cities, men and women are creating humane educational, support, and treatment programs to serve the needs of seropositive, ARC and AIDS patients and their loved ones. Slowly, policies based on love, rather than the Plague mentality of fear, are helping AIDS sufferers. The challenge of the Plague can be met!

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