

AIDS: A View from the Trenches

Margaret C.Heagarty

PROLOGUE: *In 1991 there will have been 270,000 diagnosed cases of AIDS nationwide and 174,000 AIDS patients will still be alive, according to Public Health Service estimates. Their medical care will cost some \$8 billion to \$16 billion that year alone. Already, the burden of the epidemic on the health care system is substantial in some parts of the country.*

In this personal essay physician Margaret C.Heagarty describes what the AIDS epidemic has meant to her hospital in the heart of Harlem. The New York area has the highest proportion of intravenous drug users and children with AIDS of any area in the country. Indeed, almost half of the children diagnosed with AIDS nationwide reside in the New York area. Impoverished AIDS patients, especially intravenous drug users and their children, have special health problems and require longer hospitalizations than other AIDS patients, often because they have no place else to go. Moreover, says Heagarty, municipal hospitals like Harlem Hospital must absorb much of the huge cost—\$800 per day and perhaps \$60,000 per year per patient—of caring for these medically indigent patients. Inevitably, Heagarty says, the cost of caring for AIDS patients reduces resources available for health care for the rest of the poor population.

With the projected increases in the number of drug addicts and their children with AIDS, New York City's health care system may soon be overwhelmed, Heagarty predicts. She makes an urgent plea for reinforcements—for federal funds for the direct medical care of AIDS patients and for facilities that can provide compassionate care and shelter for AIDS patients outside of the hospital.

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Sometime in 1982 one of my faculty presented me with the case of an infant with severe growth failure and recurrent pneumonia. The child's mother, an intravenous drug user, had similar symptoms. This little girl was the first of what has become an avalanche of infants and children with acquired immune deficiency syndrome at Harlem Hospital Center.

With projections of 270,000 cumulative cases of AIDS nationwide and 174,000 patients living by 1991, health policy analysts are now struggling to define the effects of this epidemic on the nation's health care delivery system. As the director of pediatrics of Harlem Hospital, my view of this matter is personal, based on my experience in treating adults and children with this disease at a public general hospital in an urban, disadvantaged community. Although what I describe has the biases of that perspective, it may be useful to those who lack this experience but have the power to help deal with this medical disaster.

Public hospitals are and always have been the endangered species of the nation's health care delivery system. By tradition and charter, this group of institutions, administered by city or county government, provides care for all citizens regardless of social or economic class. Usually located in a poor area of the city, the typical municipal or county hospital has the air of a medical "Hill Street Blues"—underfinanced, besieged, crisis oriented, and engaged in a never-ending battle with the diseases of poverty.

In recent years the country's entire health care delivery system has been forced to change its methods of operation. A number of factors—chief among them the rising cost of medical care, a physician surplus, and increases in malpractice claims—have provoked significant changes in government's view of health care regulation, in the structure and governance of hospitals, in individual physicians' modes of practice, and in the economics of medical care. A whole new vocabulary has emerged: "competition," "market share," "allocation of scarce resources," "cost shifting," and "prepaid case managed care."

Unfortunately, these changes offer public general hospitals small comfort. Within the marketplace of medical care, only these hospitals are expected, as they always have been, to provide care for the large population in this country that has no health insurance and no money. Since Mother Teresa of Calcutta is a rare commodity, these hospitals must continue to scramble for money to provide care for medically indigent patients. Some of their funds derive from Medicaid and Medicare, but substantial amounts must come from local government through taxes. And in these Gramm-Rudman days, local governments, particularly in older cities with shrinking tax bases, are less able or willing to continue to bail out these hospitals.

In the midst of these fundamental shifts in the medical care system and in health care financing, the AIDS virus appeared in Harlem. At first it was seen as almost a medical curiosity—the occasional adult homosexual or drug addict hospitalized with a rare malignancy or with an unusual but serious infection. But now, several years later, the problem of AIDS in homosexual men has been widely, even dramatically described in print and on television. The images of gifted, middle-class men suffering slow and painful deaths have surely been imprinted on the national consciousness.

However, the even grimmer reality of lower-socioeconomic-class drug addicts and their children with AIDS has not been portrayed with the same detail or sympathy. Since 1979 about 7,000 people with AIDS have been

identified in New York State, 90 percent of whom reside, or resided, in New York City. (More than 50 percent of these patients have already died.) In contrast to San Francisco, where 90 percent of AIDS patients are homosexual or bisexual men, in New York City only about 55 percent of AIDS patients have a history of homosexual activity. About 35 percent are heterosexuals who either are intravenous drug addicts or who have had sexual contact with addicts. The remaining 10 percent include children, both those with transfusion-related disease and those from other risk categories. Moreover, the number of drug addicts with AIDS is increasing steadily. Whereas 32 percent of the first 2,000 AIDS patients in New York City had a history of drug abuse or contact with drug abuse, 37 percent of the most recent 2,000 patients come from that population.¹

Because so many of the adults infected with the AIDS virus in New York are heterosexual, the New York metropolitan area has the dubious distinction of having more children with AIDS than any other area of the country. Of the 350 or so children in the nation with AIDS, 141 reside in the New York area. Most of them have parents who either have AIDS or are intravenous drug users who presumably have been infected by the virus. The current assumption is that these children have been infected by their mothers, although the precise method of viral transmission has not been established. While AIDS is always fatal, it seems to attack children with particular violence, usually killing them within two years. Nearly 70 percent of the children who have been diagnosed with AIDS to date are already dead; by contrast, 50 percent of the adults with AIDS are still alive.

Poor AIDS patients and their families must rely on public hospitals for their medical care. When they come to us, we ask them to tell us about their lives; sometimes, if or when they trust us, they do.

For some, drug addiction is a way of dealing with the distress of serious mental illness. One of our patients, a woman in her 30s who has used intravenous drugs for at least 10 years, almost certainly has a serious psychiatric disorder. She has two adolescent children, an 18-year-old daughter who has followed her mother to life on the streets and a 16-year-old son who was recently admitted to the hospital's adolescent ward for a drug overdose. The woman is infected with the AIDS virus. She is also pregnant. At birth the baby may also be infected with the virus. After the delivery the woman will live in a two-room apartment in Harlem with her mother, her adolescent son, and her new baby.

One child, a three-year-old named Sally, has been on our wards for several months. She has been sickly since she was a baby. Finally, about a year ago, her pediatrician hospitalized her because of growth failure and repeated bouts of pneumonia. This little girl has AIDS, and both parents show serologic evidence of the infection. Both parents also have long histories of intravenous drug use, although both have been enrolled in methadone maintenance programs for some years. Neither of the couple is employed. The mother probably has clinical AIDS. Over the past year she has lost 50 pounds and has had recurrent pneumonias. Recently, she has resumed her drug habit, and her husband is drinking heavily. Despite their drug problems these parents obviously love their emaciated, sad daughter. For hours every day they sit by the child's bed, watching her grow sicker and,



I suppose, contemplating the possibility of their own deaths from AIDS.

Children with AIDS are brought to this and the city's other public hospitals more and more frequently. At Harlem Hospital only 1 child was admitted with AIDS in 1982; in 1985, 35 children with AIDS were admitted. Many of these children are hospitalized for weeks or months, either because they are severely ill or because there is no one to care for them and no place for them to go.

Jane was first admitted to the hospital at six months of age because her weight was that of a two-month-old. She was a pale, listless infant who struggled to breathe because of severe lung infections. Her mother is an intravenous drug user who 18 months earlier had delivered another baby who never left the nursery and who died of AIDS at the age of five months. The mother almost certainly also has AIDS, but we never managed to get her to see an internist often enough to confirm the diagnosis. Over the course of 10 months Jane was hospitalized several times. Her maternal grandmother took care of her when she was out of the hospital. When Jane finally died from repeated infections, the nurses on the ward took up a collection so that the family could buy clothes in which to bury her.

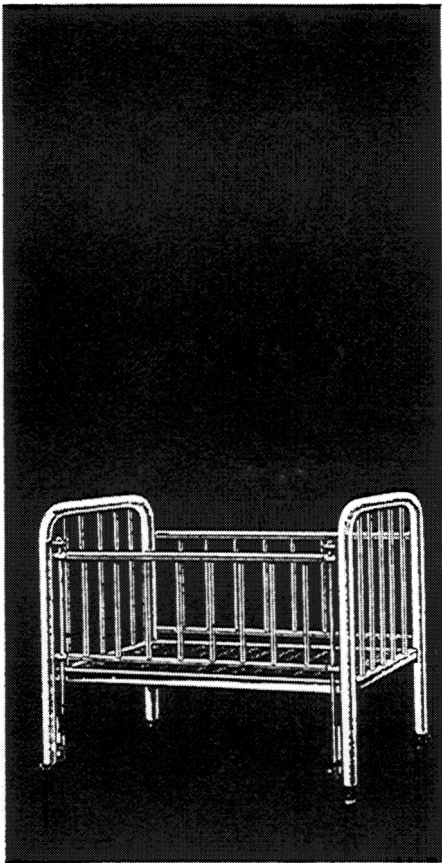
I understand that with my limited narrative ability, I risk producing melodrama rather than tragedy—or worse, that these descriptions may be dismissed as the ruminations of yet another “bleeding heart” or “knee-jerk liberal.” Let me be clear, the poor have about the same proportion of virtue and vice, of good and not so good, as other social groups. These impoverished drug addicts and their families are usually socially disorganized, poorly educated, unemployed, and without adequate housing. They are often antisocial, rude, and angry. They can be infuriating when they don't take care of themselves, don't follow our instructions, and fail to return to the clinic on schedule or take their medicines. But they can also be tender, courageous, and appreciative. Whatever they are, we, as representatives of the health profession and in some sense of the general society, must provide them with the best and most humane medical care we can.

However, the medical care system for the poor of New York City has been all but overwhelmed by AIDS. As the number of patients with AIDS has increased, we have learned that AIDS will tax not only our stamina but also the economic and human resources of the entire community.

In March 1985 about 135 AIDS patients were hospitalized in New York City's 11 public, acute-care hospitals. By that fall the number had jumped to 239. By the end of 1986 the number of hospitalized AIDS patients is projected to reach 385, and by 1989 there may be as many as 650 AIDS patients in this city's municipal hospitals at any one time.

Given the complex, invariably fatal nature of this disease, the economic cost of caring for AIDS patients is very high. Moreover, the difficulty and expense of managing this disease rise considerably for impoverished patients, whose underlying health was poor before they contracted the disease.

Because of the special medical, social, and emotional problems of the poor population, the average hospital stay for AIDS patients in New York City is more than twice that of AIDS patients in San Francisco. In New York City public hospitals, the cost of caring for an AIDS patient is estimated at \$800 a day, compared with \$500 a day for non-AIDS patients. The cost of drugs for AIDS patients is twice that for more typical patients. Adult AIDS patients require 40 percent more nursing time, and more than twice the nursing effort is necessary for children with AIDS.



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Nationwide, the cost of hospital care for each AIDS patient is estimated at between \$20,000 and \$60,000 per year. For New York City, with its disproportionate number of intravenous drug users and children with AIDS, the cost estimates at the higher end are probably the most accurate. For 1986 New York City has allocated about \$62.5 million dollars from its general revenue budget to cover the cost of hospital care for AIDS patients and about \$3 million for public health education and laboratory support.² By 1991 an estimated 7,500 New York residents will have AIDS, and the number of hospital beds they occupy and the total hospital treatment costs they will consume are expected to be more than double what they are today.³

Economic statistics are insufficient to describe the medical and human requirements of AIDS patients or the problems of those who care for them. Five years into this epidemic, I continue to have what I have come to recognize as “Whaddaya mean” conversations. One day last winter I stormed into the hospital pharmacist’s office saying, “Whaddaya mean we don’t have any cough syrup?” She answered, “Yesterday I had to order antibiotics that cost \$175,000 for the AIDS patients and I couldn’t order cough syrup at the same time. We have a cash flow problem.” This trivial example (after all, cough syrup isn’t exactly a lifesaving drug, and we did get a supply within a short time) illustrates an important and little recognized cost of AIDS. The epidemic not only affects patients with the virus, it also detracts from the provision of care for the larger poor population. In a time of scarce resources, the cost of caring for AIDS patients inevitably reduces the resources available for other aspects of health care for the poor.

Or, “Whaddaya mean we don’t have any cribs left?” Within the past 8 to 12 months the number of inpatients in this pediatric department has increased dramatically, both directly and indirectly because of AIDS. At Harlem Hospital we now care for between 35 and 40 infants and children with AIDS; on average about 8 or 10 of these children are so ill as to require what is often a prolonged hospitalization. Pediatric wards are appropriate places for very sick children, but they are terrible places for well infants and children. Unfortunately, at any one time an additional 30 or so infants and children with AIDS are housed on the pediatric service, often for weeks or months, because we can’t find them homes.

Infants and children of drug-addicted parents often need foster care placement until their parents can provide safe homes for them, and over the years an elaborate foster home system has developed for this group of children. Recently, however, foster parents have become reluctant to take children whom they suspect may develop AIDS—in fact, they usually will not take them. To many foster parents, all children of drug-addicted parents are seen as possible AIDS victims. Moreover, children who do have AIDS or its milder version, AIDS-related complex (ARC), simply cannot be placed. If the projected increases in the number of children and intravenous drug users with AIDS are at all accurate, poor children whose only homes are hospitals may soon crowd out others who need hospital care because of acute illness.

This problem is not limited to the pediatric service. Adult AIDS patients, especially drug addicts, often stay in hospital longer than medically necessary simply because they have no place to go and no one to care for them. In their zeal to reduce the costs of medical care, insurance companies

and government agencies sometimes refuse to pay for these lengthy hospitalizations. Hospital administrators trying to balance the books become agitated with these financial losses and push physicians and social workers to get the AIDS patients out of the hospital. Where shall we send them?

Another, less tangible cost of AIDS is the stress and fatigue of those in the trenches of medical care. With the medical advances of the past half century, physicians, nurses, and other health professionals are seldom forced to deal with the death of children and young adults. But now, almost weekly, physicians here must give a patient or his or her family a diagnosis of AIDS and must then cope with their rage and despair. The pediatricians of my department must care for what seems to be an ever-increasing number of critically ill children with AIDS. The nurses and aides who come to love these children grieve visibly when they die.

I don't mean to canonize these workers. Society has a right to expect them to care for everyone without regard to his or her disease, income, or social class. But the physicians, nurses, social workers, aides, and technicians who physically care for AIDS patients, give them their medicine, change the infants' diapers, cuddle and play with children, and bathe and feed them must be counted in the ledger of the casualties of the AIDS epidemic.

Public general hospitals are among the most stressful arenas of American medicine. Characteristically, these hospitals care for the community's sickest patients with fewer resources and staff. The AIDS epidemic has stretched the endurance of an already highly stressed group of health professionals. If the projected huge increases in the numbers of AIDS patients have any validity, and we have every reason to think they do, reinforcements are urgently needed.

From my admittedly biased perspective, the form of these reinforcements seems obvious. First, the country must find a way to pay for the direct medical care of AIDS patients. Our society has yet to decide what to do about citizens who lack private or government medical insurance. Public hospitals are expected to provide free care for the medically indigent, but many areas of this country do not have such facilities.

When a natural catastrophe strikes an area of the country, the nation as a whole responds with sympathy, with both public and private contributions. The AIDS epidemic should be considered just such a natural catastrophe demanding similar responses. To date the public has responded to the epidemic with a series of benefits, but the funds required for the care of AIDS patients are beyond the scope of private philanthropy. Similarly, despite efforts under way to marshal needed financial resources, state and local funds are not and will not be sufficient in communities with large numbers of AIDS patients.

The federal government must acknowledge and deal with AIDS. One approach would be to make all patients immediately eligible for Medicare upon the diagnosis of AIDS. It now takes two years for a patient with a serious chronic disease to become eligible for Medicare, and because most AIDS patients die within two years, federal funds for direct medical care for these patients have not been available. Moreover, under the recently instituted prospective payment system, Medicare and insurance companies now reimburse hospitals for patient care on the basis of disease classifications



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known as diagnosis-related groups, or DRGs. DRG categories define the allowable length of hospital stay for each type of diagnosis. These diagnostic categories, however, predate the AIDS epidemic and thus do not reflect the intensity or duration of hospitalization necessary for AIDS patients. As a result, under the prospective payment system, hospitals are forced to absorb the additional, and legitimate, costs of the care of AIDS patients. Without some form of government remedy, hospitals in the private sector may tend to discourage, if not deny, care for AIDS patients in their facilities, leaving the burden to an already underfinanced and overburdened public sector.

Even funds for the direct medical care of this group of unfortunate people, while essential, will not be sufficient. AIDS patients, particularly those who are poor and perhaps without homes or families, must be provided with shelter, food, and support. In New York and other cities that can anticipate a dramatic increase in the number of poor AIDS patients, a massive and coordinated effort is urgently needed to establish facilities in which patients can find compassion and care outside the hospital.

The fundamental question is whether the citizens and leaders of this country are willing to pay for the research to understand this disease and the medical care essential for those it attacks. We, as a national community, must respond to this disaster as we have to other calamities. To do less would make a mockery of our traditions and values. ■

NOTES:

1. New York City Department of Health, Sept. 1986.
2. New York City Health and Hospitals Corporation, 1986.
3. Institute of Medicine, National Academy of Sciences, *Confronting AIDS: Directions for Public Health, Health Care, and Research* (Washington, D.C.: National Academy Press, 1986), 161.