Cite this article as:
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Lessons from the past: responding to the AIDS crisis
Health Affairs 8, no.3 (1989):16-32
doi: 10.1377/hlthaff.8.3.16

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LESSONS FROM THE PAST: RESPONDING TO THE AIDS CRISIS

by David Mechanic and Linda H. Aiken

Prologue: As the acquired immunodeficiency syndrome (AIDS) insinuates its way into American culture, the nation approaches the dubious milestone of 100,000 reported AIDS cases—over half the reported cases worldwide. Increasingly, those affected most harshly by AIDS and human immunodeficiency virus (HIV) infection are poor, members of minority groups, and children. These Americans typically live in communities that lack the social supports and cohesiveness undergirding successful community-based responses to AIDS in the gay communities of San Francisco and other cities. “The disease distribution of AIDS increasingly reflects the social stratification of American society,” David Mechanic and Linda Aiken write. “The changing configuration of AIDS . . . , if not approached carefully, could overwhelm our mental health capacities, social services, and public hospitals, and destroy the fragile structures we have been working so hard to develop.” In this article, Mechanic and Aiken propose a series of lessons to apply to AIDS from long-term care for the severely mentally ill, long-term care for the elderly, and terminal care for people with cancer. “These issues may come together differently in AIDS,” the authors write, “but it would be a grave error to neglect previous lessons of relevance.” Mechanic, who received his doctorate in sociology from Stanford University, has been director of Rutgers University’s Institute for Health, Health Care Policy, and Aging Research since 1981. He is also Rene Dubos Professor of Behavioral Sciences at Rutgers. Aiken, a nurse, holds a doctorate in sociology and demography from the University of Texas at Austin. She is Trustee Professor of Nursing and Sociology at the University of Pennsylvania and is associate director of the Leonard Davis Institute of Health Economics there. She was formerly a vice-president of The Robert Wood Johnson Foundation. Both Mechanic and Aiken have done extensive research in approaches to care for the population groups from which the lessons in this article are taken—pursuits from which their current work on AIDS has evolved.
The tragic and threatening consequences of the epidemic of acquired immunodeficiency syndrome (AIDS) to date illustrate in miniature what lies ahead for the delivery of health services in this country. Estimates of the number of Americans infected by the human immunodeficiency virus (HIV) vary from one to one and a half million in the absence of reliable data, but we can be sure that the number is large and increasing. Recent evidence suggests that almost all those infected with HIV will eventually develop AIDS or HIV-related illnesses and die prematurely. Even with concerted public health and educational interventions, those already infected and those likely to become so will pose massive problems to our service delivery systems. The issue is no longer simply a question of the cost of care, but the threat that AIDS will overwhelm and disrupt our capacity to provide health services. The challenge of AIDS provides an opportunity to restructure our rich health resources to respond not only to the desperate needs of people with AIDS, but also to the need for a broader range of services for millions of Americans with other serious, chronic, and disabling diseases.

An emerging response to AIDS. Formal service structures organized to meet the needs of people with AIDS have been slow to emerge. In the early years of the epidemic, self-help and volunteer programs, organized by the gay communities in many of the large cities where the epidemic began, compensated for the absence of formal services. Since then, the epidemic has taken root in the most vulnerable, alienated, and impoverished subgroups of our population who typically lack the education, social resources, and group structures to develop the self-help initiatives that have been a central resource for gay persons with AIDS. As of May 1989, blacks and Hispanics were estimated to account for 27 and 15 percent, respectively, of all AIDS cases, greatly in excess of their proportional representation in the population. These may be overestimates, biased by the way cases are reported by private physicians and public clinics, but the fact remains that AIDS is an increasing burden among minorities and the poor. Many of these patients rely almost exclusively on publicly sponsored health services, which were overburdened in most communities even before the AIDS epidemic.

The growing prevalence of HIV infection and AIDS in the intravenous (IV) drug-using population, which now accounts for the majority of HIV-infected people in New York/New Jersey, greatly compounds the difficulties of mobilizing necessary service responses. Serum surveys reveal that 50 percent or more of the IV drug users in New York City have antibodies to HIV. The ghetto areas, where IV drug users typically live, lack the resources that helped contain the epidemic in gay communities and that energized the types of community care exemplified by San
Francisco, with its organized local networks of response, its development of hospice care, and its creative inpatient hospital AIDS unit. IV drug users with HIV infection are predominantly a disadvantaged minority population, highly demoralized and stigmatized. In addition, they may confront a hostile and unsympathetic community who see them as a source of criminal activity and victimization. As Samuel Friedman and his colleagues note:

Minority communities bear a disproportionate burden of crime by drug users seeking money for drugs, and a disproportionate loss of access to neighborhood facilities that are taken over by drug users. Thus, many blacks and Hispanics are unfriendly to drug users or to any proposals that seem to offer aid to drug users. One indicator of this attitude is a poster that was plastered on many lamp posts in Harlem in 1986. It says: “When will all the junkies die so the rest of us can go on living?”; on many occasions, we have seen approving graffiti added to these posters.

As the epidemic penetrates the drug user community, it increasingly involves the sexual partners and infants of these users. In the larger picture, a group of increasing importance is children with AIDS. More than 1,600 pediatric cases have been reported, with 618 cases reported between June 1988 and May 1989. Over three-quarters of children with AIDS have become infected as a result of the drug culture.

Plans for accommodating the future service needs of patients with AIDS are developing slowly amid financial and institutional uncertainty. The requirement for large new resources will add to the tensions of devising a realistic and humane system to care for patients who have the multiple stigmas of AIDS, disadvantage, minority status, drug use, and sometimes mental illness as well.

New York hospitals are already reeling under the increasing number of AIDS patients and the myriad problems associated with the drug culture. The excess hospital capacity there of a few years ago has been replaced by a shortage. A spot survey in October 1987 documented that all eleven municipal hospitals and thirty-four voluntary hospitals had occupancy rates of over 90 percent; seventeen were at or above 100 percent occupancy. Twenty-two hospitals either had requested or were on diversion status for emergencies. A core question is how to facilitate access for persons with AIDS and HIV-related illness to the services required, with the most cost-effective use of resources.

AIDS has unique aspects, but in a remarkable range of areas it confronts us with service challenges and policy dilemmas common to issues that policymakers and the health care system have been addressing for some time. These issues may come together differently in AIDS, but it would be a grave error to neglect previous lessons of relevance. Relevant
areas include long-term care of the severely mentally ill; long-term care of the elderly; and service innovations in terminal care for cancer.

Lessons From Care For The Severely Mentally Ill

The severely mentally ill (especially those with chronic schizophrenia, many of whom depend upon public-sector services) share many of the characteristics of IV drug users with AIDS. They are disproportionately members of minority groups, impoverished, unable to work, and behave in ways that sometimes frighten or disgust the public. Moreover, many are difficult to work with, do not respond well to treatment, and may show little appreciation for efforts on their behalf. Their social behavior may disrupt treatment settings and offend staff, making caretakers angry and resentful. Successful community adaptation requires a coordinated range of medical, psychosocial, rehabilitation, housing, and income support services. Providing such integrated care is difficult in the American health care context in which services are fragmented and decentralized.

A number of controlled clinical trials and other experiments in community care for the chronically mentally ill show that an appropriately organized care management system that combines aggressive psychiatric community care with training in psychosocial skills and assistance in housing, social needs, and attaining entitlements can provide care comparable or superior to that achieved by good, conventional inpatient care and aftercare. Patients in these experimental programs, in comparison to patients in more conventional care settings, suffer less frequent relapses, use less hospital care, demonstrate higher levels of function, and report a better subjective quality of life. There is lack of agreement as to whether such organized systems of care are less expensive than conventional care. The debate over costs is, in part, complicated by the reality that “conventional care” often amounts to benign neglect. However, cost/benefit analysis has confirmed that, for the resources invested, aggressive community treatment programs for the seriously mentally ill achieve outcomes that are superior to those from conventional approaches that rely almost exclusively on institutional care.

The evidence is overwhelming that organizing and financing the necessary care for the chronically mentally ill requires consolidating the benefits of entitlement programs for which these patients are eligible, such as Medicaid and Medicare, Supplemental Security Income (SSI) and disability, welfare, and housing subsidies. Over time, the mental health system has become more skillful in garnering these benefits on behalf of clients, although many barriers and delays persist and the quality of efforts varies widely. The problems are complicated by the fact that these
benefits are provided by varying levels of government and categorical programs, and it requires a strong, responsible, and expert managerial capacity to overcome the organizational impediments expeditiously. Demonstrations are now in place in nine large cities to learn how care management might be better organized to improve care for the chronically mentally ill. These public-sector models for the mentally ill probably fit the emerging needs of people with AIDS in many communities better than the San Francisco model, which gains its strength in large part from the cohesiveness and skill resources of the gay community.

**Eligibility and timing of entitlements.** Key issues in respect to any entitlement program are eligibility and timing. Many mentally ill patients face long waiting periods to become eligible and to work their way through the bureaucratic processes required to gain benefits. The delay is often harmful, but the duration of need is typically long, thus justifying persistence. In contrast, the interval between an AIDS diagnosis and death is comparatively short, and required waiting periods and processing delays may make entitlements irrelevant. Each of the entitlement programs, in addition, has requirements that make it difficult for AIDS patients to receive timely benefits. Disability insurance and SSI are premised on total, irreversible disability and require a waiting period to establish eligibility. AIDS typically involves a trajectory of severe acute episodes followed by periods in which a range of ordinary activities, including work, may be possible.

There is a need to examine existing eligibility criteria to assess how barriers can be reduced for AIDS patients to receive timely services, and to examine what additional programs might assist the private sector in maintaining employment and health insurance benefits for those who must leave the work force. In an innovative program, Michigan has agreed to pay insurance premiums of patients with AIDS who have to terminate employment. The state estimates considerable Medicaid savings by extending the group insurance of ex-workers as allowable under federal law. The current requirement that Medicaid beneficiaries must meet income and savings limitations means that people with AIDS who are not covered by private insurance must exhaust their personal assets to qualify, which then leaves them vulnerable to loss of housing and other supports necessary to maintain independence.

**Case management.** Case management is vaguely perceived as a solution to many of our health care system’s ills. It is advocated as a strategy to reduce fragmentation of services, to improve clinical outcomes, to contain health care costs, and even to solve the nation’s hospital nursing shortage. The concept of case management has a long tradition in social work, in which caseworkers assess clients’ needs and mobilize necessary
services on their behalf. Typically, in the case of the severely mentally ill, case managers have limited training and experience, are poorly paid, have little control over medical and community resources, and have excessive caseloads. Often case managers experience conflict between the needs of their clients for service and their employing organization’s desire to minimize expenditures. Job turnover and attrition are high. By itself, case management is a weak intervention, and the case management model rarely fulfills expectations. Experience in mental health suggests that if case management is to be effective, it must be included in a broader organizational structure that clearly defines responsibility for care and that has in place a range of services to be deployed when needed.  

Many efforts are now under way to build community systems of care for chronic patients that take case management responsibility on a longitudinal basis, that plan and provide a broad range of medical and social services, and that bring together varying streams of public and private funding to manage care across a range of needs. Financing mechanisms that partially capitate the case management agency provide opportunities for balancing inpatient care, psychiatric outpatient treatment, and a variety of social, rehabilitation, and habilitation services. More ambitious capitation plans are in varying stages of development in some states and cities, including Philadelphia, Rochester (New York), and Rhode Island. However, we have too little experience with mental health capitation to extrapolate to financing schemes for AIDS, which must make provision for more intensive medical need and requirements for inpatient care. A significant risk in AIDS financing is the neglect of mental health need because of acute medical needs. Yet, services directed to psychological well-being may substantially reduce distress, enhance function, and limit deterioration in the quality of life. Although the evidence remains uncertain, effective psychological services and interventions could support a higher level of immune function.  

In sum, systems of managed care now emerging for the chronically mentally ill have organizational characteristics likely to be of crucial importance in developing a broad response to AIDS care. These include arrangements for organizing and coordinating the necessary spectrum of care; case management strategies as part of a broader organizational approach; links with social security and housing agencies; financing that consolidates federal, state, and other funds; and innovative financing strategies. Building on these experiences and the existing research base will prevent false starts in addressing AIDS care.  

Relationship of AIDS and mental illness. We should be alert to interconnections between care for severe mental illness and services for people with AIDS. In recent years, approximately 8 to 9 percent of residents in
state and county mental hospitals had joint diagnoses of mental illness and drug abuse, although data are not available specifically on IV drug abuse. There is mounting concern within public psychiatric hospitals about how to reorganize inpatient care in response to increased numbers of HIV-positive patients. We have no good information about the proportion of psychiatric patients in general hospitals, in outpatient settings, or on the streets who fit this dual diagnostic picture and may already be infected, but the numbers are possibly substantial among younger, sexually active mental patients. New reports of substantial HIV infection rates among the homeless, many of whom have histories of mental illness, are consistent with this scenario.

The public mental health system is highly fragile, and struggling to develop viable systems of care in a context of severe fragmentation and underfinancing. The large numbers of homeless mentally ill in many cities are the most visible evidence of unmet need. Patients seeking treatment, especially for drug abuse, far exceed our capacity to respond. Of the more than 1.2 million IV drug users in the United States, fewer than 250,000 are estimated to be in treatment at any one time. The waiting period for such treatment is more than six months in some cities. The service demands associated with the growing AIDS epidemic among mentally ill persons will exacerbate these problems.

AIDS will affect the capacity of existing systems of care and the internal operation of our hospitals, nursing homes, correctional institutions, and clinics. People with AIDS will become more prevalent in all such institutional settings. Problems of controlling infection and providing appropriate care will increase. The necessity in some communities to mix patients with AIDS with others such as the mentally ill and the elderly in mental hospitals and nursing homes also will require careful management of fear and stigma and will add to the risks of demoralization of staff who already feel overburdened.

Lessons From Lone-Term Care For The Elderly

While the systems of care for the chronically mentally ill suggest some coordination problems and financing strategies pertinent to AIDS care, long-term care of the elderly provides another view and highlights issues of home versus hospital care, community social supports and informal care, and financing. In the individual case of all but the most severely incapacitated elderly, home care is less costly than nursing home care. Yet, policymakers have been cautious in extending home care benefits because such benefits attract many more clients eligible for care than enter nursing homes, resulting in increased aggregate costs. Most frail
elderly with reduced functioning manage to keep living in the community with assistance from relatives and other informal care. Often the loss of a spouse or the breakdown of informal supports precipitates nursing home admission. Other major reasons for admission include incontinence and disorientation associated with significant dementia. Another concern in extending community care is the fear of undermining informal supports; however, existing demonstrations indicate that while some substitute for informal services occurs, most community care is a complement to informal care and not an expensive replacement.

Organization of care. A major challenge in long-term care of the elderly is to target successfully those elderly at greatest risk of institutionalization within the community. This has been extremely difficult to achieve because such patients are a small minority within a much larger group of elderly with significant needs, and many factors other than disability explain nursing home referral. AIDS patients, in contrast, are more obviously in crisis as they develop complicated opportunistic infections, and thus targeting is probably more easily achieved. However, people with AIDS are more likely to be admitted to hospitals than to nursing homes. Few nursing homes to date have shown much interest in becoming providers of AIDS care. In the case of AIDS care, demonstrating the cost-effectiveness of expanded community-based services depends primarily upon reducing hospital care. The substantial differences across communities in average costs of AIDS care are primarily due to the wide variation in numbers of admissions and length of hospital stays. San Francisco’s low average costs have been achieved in large part through the availability of community services.

Successfully organizing care depends on our capacity to identify needs as patients move through the illness trajectory and to target those at varying stages who most urgently require various medical, mental health, and social services. Needs will depend not only on levels of morbidity and disability but also on the strengths of existing social networks, the capacities and commitment of informal caretakers, and the particular burdens that illness manifestations put on these helping networks. Cognitive impairment and dementia in persons with AIDS is particularly pertinent since loss of judgmental capacity puts these patients at additional risk and places more profound burdens on caretakers. Attention must be focused not only on patients but on dedicated caregivers, put at risk because of the stress of their role. Mechanisms such as respite care and social support groups for caretakers need development.

AIDS-related dementia poses a number of challenges for the existing services system. Nursing homes have become a setting for care for many elderly and some younger people with mental illness and cognitive
impairment, but concerns persist about the availability and quality of mental health services in nursing homes. A high proportion of nursing home residents have serious mental, behavioral, or emotional disorders. Nursing homes currently account for almost 30 percent of total national expenditures for the care of the mentally ill—more than state, county, and other public mental hospitals combined. However, there is a general consensus that the mental health needs of persons in nursing homes are not effectively addressed. Few nursing homes provide any mental health services, and those that do often lack the expertise to do so effectively. The Omnibus Budget Reconciliation Act (OBRA) of 1987 required for the first time that nursing home residents with psychiatric diagnoses receive active psychiatric treatment. The extent to which these provisions will improve care for patients with dementia is unknown, and many fear that the shortage of alternative placements for those not receiving active treatment will result in diminished care for some patients.

The debate over the pros and cons of establishing dedicated Alzheimer’s units in nursing homes is almost identical to the debate over establishing dedicated AIDS units in hospitals. On the positive side, advocates of dementia units argue that staff in a dedicated unit would be more motivated because they chose to work there. The quality of care might improve because the staff would be more experienced. Also, other patients would be spared the disruptive consequences of scattering demented patients throughout an institution. On the negative side, specialized units tend to be expensive, the isolation of dementia patients could hasten their decline, labeling associated with a unit could have a negative impact on expectations, and staff recruitment might be a problem. The limited information currently available on dedicated Alzheimer’s units, however, does suggest positive results for staff and patients.

Social health maintenance organizations (SHMOs), now being evaluated through a Health Care Financing Administration (HCFA) demonstration, provide one possible model for meeting the varied needs of persons with AIDS. As with managed care more generally, the intent is to provide a broader spectrum of relevant services within the context of medical organizations and health financing approaches, which allows control over aggregate expenditures but makes possible trade-offs among different types of services needed by the patient. It will be necessary to examine these newly emerging models in light of the AIDS epidemic and the complex medical and psychosocial needs of people with AIDS.

Financing. As the prevalence of AIDS escalates, we must take a longer view of how we can finance the necessary care within the likely constraints emerging in the health care system overall. Under these constraints, emphasis is likely to be given to medical crises while neglecting
psychological support and interventions that limit disability and sustain function. If the mental health sector is to play its vital part in the care of AIDS, financing must be facilitative. Achieving such a financial framework, identifying the role of private insurance and public subsidy, and delineating case management and triage functions are large challenges.\textsuperscript{30}

Costs of care depend on the prevalence of the disease, the expected life span from the point of diagnosis, the available treatment technologies and how they are applied, and the settings of care. Costs could change substantially with new medical treatments or with medical advances that slow the disease and extend expected longevity. Treatment for AIDS patients will vary, but the real issue involves the quality of care and how the cost burdens will be distributed. Given the geographic concentration of AIDS, the burden now falls disproportionately on a few localities, greatly straining the economic position of the institutions that care for many AIDS patients.\textsuperscript{31} These problems will soon mount, and there is a need to assess how these costs can most fairly be distributed. The San Francisco experience indicates that the costs of care can be much reduced by avoiding the use of life-extending technologies such as respirators, from which AIDS patients often cannot be weaned, and making use of community and home services and hospice care.\textsuperscript{32} In the case of hospice, both the San Francisco AIDS experience and the care of patients with terminal cancer make a strong case for its extension.

### Lessons From Terminal Care For Cancer Patients

Cancer has been for several decades the most dreaded disease of high prevalence. Although the stigma of cancer appears to have declined significantly in recent decades, it shares significant commonalities with AIDS. In some cancers, death occurs relatively quickly, with increasing decline in function and high levels of pain and psychological distress. The use of aversive treatment protocols, including chemotherapy and radiation therapy, often results in a range of secondary problems and diminishes the quality of life. A major challenge is to balance radical approaches to treatment that may extend life against the noxious consequences of treatment itself. Researchers increasingly attempt to measure “quality life years” and related concepts to capture treatment dilemmas associated with radical but unproven therapeutic approaches.\textsuperscript{33}

In state-of-the-art cancer care, patients usually will reach the terminal phase in a clinical cancer center where significant efforts are typically made to control symptoms and extend life.\textsuperscript{34} This pattern of care is expensive, and its value is controversial.\textsuperscript{35} In the past decade, hospice care, which began as a voluntary social movement, has gained wide acceptance
and has received official recognition through coverage in Medicare and other insurance programs.

The role of hospice care. The policy debate over hospice care has focused on issues of the quality of life in terminal care, the appropriate control of pain, and the costs of care. Clearly, the role of hospice in AIDS care will become an issue of mounting importance, and decisions will have to be made about the development of additional hospice care, the value of integrated or dedicated hospice units for AIDS patients, and financing. These policy questions transcend the care issues, since in localities with high AIDS prevalence, AIDS patients occupy increasing proportions of hospital bed capacity. Moreover, the financing of AIDS care is in a state of chaos, with many AIDS patients occupying beds in hospitals because of the unavailability of alternative care sites. This is evident in the differences in average length-of-stay of thirty days in some New York City public hospitals to seven days at San Francisco General with its continuum of community-based services. The question also remains, How will existing facilities and non-AIDS patients in hospices and nursing homes accept people with AIDS?

The National Hospice Study is the most extensive examination of the structure and content of terminal care in varying settings, the use of medical technology, costs, and secondary effects on the primary significant other of the cancer patient. In this national study, care was contrasted in clinical cancer centers, hospital-based hospices, and home-based hospices. The study, which could not randomize patients and thus encompasses some selection effects, demonstrated little difference in quality of life or satisfaction in varying settings, but large differences in the use of technology and cost. In general, home-based hospice care was least expensive, clinical centers most costly. The clinical centers used more advanced expensive technologies but with little advantage over hospital-based hospices. Home-based hospices were somewhat less successful in pain maintenance, but least costly. The financial advantage of hospice over clinical center care was dependent on the longevity of the cancer patient and the length of the hospital stay. The study showed persuasively that providing the choice of hospice care for those patients who preferred it was a viable and cost-effective policy option.

Implications for AIDS care. The role of hospice, home care, and other community alternatives to inpatient hospital care is of crucial importance to planning for the future service needs of varying types of AIDS patients. These approaches may fit some subgroups much better than others. For instance, the National Hospice Study included only patients who had a dedicated informal caretaker who assumed many burdens, and it seems clear that many people with AIDS may lack such support. We will have
to face the challenge of developing diverse options fitted to the varying clinical trajectories, sociocultural characteristics, and community features characteristic of the population of people with AIDS.

Hospice care for people with AIDS may differ in fundamental ways from the approach in terminal cancer care because the opportunistic infections that often cause death among AIDS patients can be treated well into the terminal phases. AIDS patients seek continued state-of-the-art treatment even when their debilitated general condition requires the symptomatic and supportive care offered by hospices. Thus, AIDS hospices may have to include more aggressive medical treatment regimens than are typically found in hospice programs.

Access To Care

The policy debate on financing AIDS services will take place in the complex context of budgetary constraints and unequal access to medical care. In recent years, only two-fifths of the poor have been covered by Medicaid, and the population without either public or private health insurance now numbers between thirty-one and thirty-seven million people. These trends burden many with low incomes, minority groups, single-parent families, and children.

An unattractive feature of the impending debate that must be addressed involves societal conceptions of personal worth or, in the context of the traditional debate, the worthiness of competing populations. A major barrier to addressing many AIDS policy issues are unspoken beliefs about the lack of “deservingness” of major subgroups, particularly the IV drug user. In the aggregate, blacks and Hispanics, among whom IV drug use is concentrated, have higher mortality than whites. The Secretary’s Task Force estimates that in 1979–1981, among blacks up to age seventy, 59,942 of an annual total of 138,635 deaths would not have occurred if blacks had the same age and sex-specific death rate as the nonminority population. This results in an “excess death” ratio of 42.5 percent. These “excess deaths” occur for a variety of medical and social reasons, including differential access to care.

More pertinent to our discussion is the issue of survival with cancer, which is probably more closely linked to access to care and the quality of care received than to overall mortality. Compared with whites, blacks have less chance of surviving cancer for five years, 38 percent versus 50 percent. Poorer survival is particularly large in cancers for which five-year survival rates are reasonably high, and for which early effective intervention probably makes some difference. The size of the black/white differences in five-year survival may be exaggerated because blacks
may come into care later than whites, and staging in many instances is an uncertain process. Comparable findings are already evident in AIDS care. Minority group members survive for shorter periods than whites after diagnosis. This may result from a variety of factors including comorbidity, poor nutrition and fitness, or lack of access to care, but all ultimately relate to social causes. The disease distribution of AIDS increasingly reflects the social stratification of American society.

Oppportunities In AIDS Care

Both the Presidential Commission on the HIV Epidemic and the Institute of Medicine of the National Academy of Sciences have criticized our slow and limited mobilization in the face of the AIDS crisis, and have urged substantial new commitments to almost every aspect of the attack on AIDS. It is too early to estimate the response to these efforts, but it seems evident that the failure to contain, AIDS and respond in a humane way to the desperate needs of people with HIV-related illnesses will further fragment our society and threaten important civil liberties and antidiscriminatory activity.

More specific to the health care system, the AIDS crisis offers an opportunity to mobilize our creative talents to improve the quality of care. It offers a potential challenge to reorganize inpatient hospital care in a more balanced and comprehensive way, to redress the imbalance between curing and caring services, and to revitalize nursing roles and services to meet future needs. Our health care system has responded poorly to long-term care needs and is marked by overspecialization, fragmentation, cost escalation, service gaps, and poor coordination. It faces a large and immediate crisis in nursing and recruitment of nursing students. While one might guess that AIDS might deter nurses from hospital practice, it is instructive to learn that the dedicated AIDS unit at San Francisco General Hospital has a waiting list of nurses seeking employment at the same time that the city seems to face a nursing shortage; hospitals across the country are beginning to report similar successes. Explanations may include the innovative nursing care practice model characterizing San Francisco’s system of integrated inpatient/community care used for AIDS patients.

An Agenda For The Future

The changing configuration of AIDS and related service needs, if not approached carefully, could overwhelm our mental health capacities, social services, and public hospitals, and destroy the fragile structures we
have been working so hard to develop. Poor planning and little readiness will be far more costly in the long run than a responsive and humane approach. The review of service and policy issues related to AIDS suggests critical areas that should be central on our agenda for services research and development. We summarize these below.

Guarantee insurance coverage. An urgent issue is the need for mechanisms to ensure that persons with AIDS and HIV-related disease are covered by either private or public health insurance. The efforts of Michigan to pay premiums of persons with AIDS to retain private group coverage when they can no longer remain employed suggest the innovative possibilities. Alternatively, when private insurance is not an option, we need to examine how to extend eligibility in public programs in ways that are expeditious and do not compound the adversities these patients already face. We have noted various barriers in disability policy to the attainment of timely benefits and believe it necessary that new pathways to eligibility be developed not only to ensure humane care but also to prevent compounding the disabilities of AIDS with such social disabilities as poverty and loss of housing.

Build an integrated care structure. Core to our discussion has been the need for care structures that (1) make clear the lines of responsibility for AIDS care and (2) consolidate resources and funds in ways that facilitate access to a wide range of service settings. Such structures must include alternative case management models as a major feature and interdisciplinary treatment teams with the expertise to address the varied problems faced by persons with AIDS. Efforts should be made to use continuous treatment teams to ensure continuity of care.

Use resources wisely. As in the broader area of chronic care, we need to examine financing reforms that use resources in the most appropriate settings by the most appropriate providers. Whether SHMOs or some other type of integrated service provide the best alternative remains to be seen, but it is clear we must move expeditiously to address such questions. In doing so, we cannot neglect considering carefully the minimally needed mental health benefits that must be part of any comprehensive response to AIDS or any other chronic disease.

Include housing options. One of the most serious errors in community mental health planning was the neglect of housing needs. We must avoid repeating this disastrous experience and plan for housing as part of the necessary AIDS treatment continuum. Already, a growing number of homeless persons have AIDS. A sensible AIDS policy must include a range of residential care options consistent with the medical and social circumstances of AIDS patients.

Modify existing service settings. As we noted, hospices are one poten-
tial setting for AIDS management, as are nursing homes. Neither has been used widely, nor is it clear that their current service mix appropriately fits the needs of persons with AIDS. Careful attention should be given to examining varying services needed by AIDS patients at different stages of their illnesses and the concordance between such needs and the types of services available in hospices and nursing homes. We have already noted that people with AIDS may desire and require more aggressive medical management than is usually available in these facilities. Concurrently, we require careful examination of whether financial mechanisms and regulations as they affect hospice and nursing home care appropriately fit the circumstances of the AIDS patient.

Finally, in all types of facilities, including hospitals, we must examine how appropriate care—especially nursing care—can best be delivered to persons with AIDS. We should be working on nursing care models that are effective and attractive for both patients and nurses. If approached wisely, AIDS care can serve as a catalyst for addressing many current and emerging problems of chronic disease care in our society.

NOTES


32. Scitovsky et al., “Medical Care Costs of Patients with AIDS in San Francisco.”


41. Mor, *Hospice Care Systems*.


44. National Cancer Institute, *Cancer Control Objectives for the Nation*.


