Chapter 2

THE PROVISION OF CARE TO PEOPLE WITH AIDS IN SAN FRANCISCO: PAST, PRESENT, AND FUTURE

Karen Allen

History of San Francisco's Response to AIDS

In late 1981 and early 1982, when cases of Pneumocystis carinii pneumonia (PCP) and Kaposi's sarcoma (KS) began showing up unusually frequently in San Francisco's gay community, most people who were aware of the incidence of these "opportunistic infections" denied that there was a problem. By late 1982, members of the gay male community, comprising about 10 percent of the city's population, started realizing that AIDS was a disease requiring serious attention (T. O'Connor, 1987, pers. comm.). While the city, state, and federal governments failed to recognize the urgency of the epidemic, these men began lobbying for local funding (Leishman, 1985). At this time, when little was known about transmission of the virus, volunteer efforts helped to disseminate information and care for those in need (Christen, 1987, pers. comm.).

The strong political and financial organization of the gay community, in a city that is uniquely open to alternative lifestyles, was largely responsible for the effective initial response to AIDS by the city of San Francisco. Political pressure led Mayor Dianne Feinstein to recognize early in the development of the epidemic that the city would be faced with an enormous health care burden. In November 1982, a city budget surplus helped make it feasible for Feinstein to authorize $180,447 for the first locally-funded AIDS services (Office of Mayor, 1985). Evaluation of home and hospice care programs which could help keep people out of the hospital and thereby reduce costs was one of the first city-sponsored efforts (Christen, 1987, pers. comm.). In March 1983 the AIDS Task Force was established to enable the mayors of cities across the country to share information on efforts to deal with the disease. The AIDS Activity Office, also established in 1983, assists the Director of Health in the San Francisco Department of Public Health (SFDPH) in coordinating city-funded AIDS activities (SFDPH, 1985). An integrated network of advisory groups informs the Director of Health and the Mayor of community needs and the effectiveness of the city's services (SFDPH, 1985). SFDPH currently subsidizes most AIDS programs and services in San Francisco.

More than 100 programs dealing directly with AIDS are presently located in San Francisco. Most have changed form over time and all are in a constant state of transition, as the development of the epidemic places ever-increasing demands on them. This paper is intended to provide an overview of the major AIDS-related health care services currently available in the city. The first question I address is: how is San Francisco meeting the needs of people with AIDS? To answer this question I

identify the primary requirements of AIDS patients and discuss the principal programs that have emerged to address these needs. Second, in what ways must these services expand in order to cope with the demands of the rapidly growing epidemic? I highlight issues affecting the expansion of the AIDS programs. My goal is to examine the adequacy of San Francisco's existing AIDS-related health care system and of the city's planned expansion of these services in the near future.

Past Studies

SFDPH (1985) describes AIDS-related programs and services subsidized by the City of San Francisco. SFDPH (1986) outlines the issues and priorities for city-funded programs for 1987-88. It represents the city's first officially compiled and adopted short-term plan to cope with the AIDS epidemic and is continually being updated (Barnes, 1987, pers. comm.).

Background: The Primary Needs of People with AIDS

Through the course of the disease, a person with AIDS requires various levels of care. A person infected with the HIV virus may never develop ARC or AIDS. If an opportunistic infection invades his body, however, he is diagnosed as having AIDS. Generally an individual feels healthy until the immune system is sufficiently weakened that a rare infection such as PCP or KS can develop, requiring special tests for diagnosis, often administered in a hospital (Davidson, 1987, pers. comm.). From this point to death, an AIDS patient needs a great amount of emotional support. Financial aid is also often necessary, since many people with AIDS are forced to leave work due to the weakened immune system. Once a hospitalized person with AIDS no longer requires the "acute care" available at a hospital, he may require "intermediate care." This describes 24-hour skilled nursing and rehabilitation at a residence facility, and is frequently used when a patient is too debilitated to care for himself at home, but not ill enough to need acute hospital care. Most people with AIDS prefer to remain at home, and may then desire home care services. Health monitoring and regular check-up examinations are also necessary. A person with AIDS needs to be respected and listened to by health care providers so that he can retain his individuality and dignity. This sense of self-worth and control over his life can aid in the healing process. AIDS patients need to be informed about all aspects of the disease and made aware of the variety of options for care, so they can seek the kinds of help that meet their needs.

Methodology

In the section entitled Services for People with AIDS, programs are discussed in the following order: acute care, outpatient clinical care, intermediate care, home care, and counseling. Information regarding the nature of the service and its history of growth, derived mainly from interviews with health professionals, is presented on each type. Also discussed is the patient load on each service and plans for and limits to expansion of each program.

Quarterly morbidity (number of new cases) and mortality (number of deaths) statistics for San Francisco, taken from July 1981 through December 1986 were collected from the Bureau of Communicable Disease Control (BDC). By subtracting mortality from morbidity, the net increase in the number of living AIDS patients was determined. This value is added to the previous AIDS population to establish the current number of people with AIDS living in the city. Projections for the number of people expected to be ill with the disease by June of 1987, 1988, and 1992 are also presented.

In the Discussion, I comment on the current lack of planning for AIDS in 1992. Opinions of health workers and people with AIDS and ARC on the adequacy of San Francisco's AIDS-related health care system are presented, along with ideas for a more equitable distribution of the burden among hospitals in the city and between cities in the region. Since the availability of care depends largely upon funding levels, the evaluation of programs is further expressed in terms of the sufficiency of governmental subsidies. Recommendations for ways in which the city can continue to reduce AIDS-related health care costs while effectively responding to the epidemic are presented in conclusion.

Services for People with AIDS

Approximately 10 percent of all AIDS patients in San Francisco are hospitalized at any one time (SFDPH, 1986). All hospitals in the city now provide inpatient care to persons with AIDS or ARC, although some are more involved than others. San Francisco General Hospital (SFGH) treats about one-third of the 100 AIDS patients currently in San Francisco hospitals, while Kaiser cares for about 15 percent (Shilts, 1987). The city's 12 community hospitals treat most of the remaining 50 percent of AIDS patients requiring acute care, while private hospitals assume a smaller role in this care delivery. SFGH maintains the best AIDS unit in the world (Baloff, 1987, pers. comm.).

In June 1983, SFGH opened Ward 5B, a 12-bed AIDS unit of single-bed rooms providing "comprehensive care" for the acutely ill. The needs provided for in the unit include a variety of medical and social services, physical therapy, primary nursing care, and emotional support. KS and PCP are the most common causes for hospital admittance; inpatients sick with PCP receive IV treatments. Prior to establishment of the ward, AIDS patients were assigned to private rooms in other parts of the hospital, as is currently done for overflow. The average daily census of AIDS inpatients averaged 19 for fiscal year 1984-1985; in January 1986 the unit was moved to Ward 5A and expanded to 20 beds. The hospital currently averages 30 AIDS patients, so that there are always 10-20 on a waiting list to get into Ward 5A. SFGH is considering taking 24 AIDS patients in the special unit sometime this year (Cloniger, 1987, pers. comm.). The hospital is licensed to fill 582 beds, but does not have the funding or staff to fill more than the 480-490 beds now occupied (Baloff, 1987, pers. comm.).

SFGH is also the city's major provider of outpatient services. The AIDS Outpatient Clinic (Ward 86) opened in August 1983, initially serving 300 patients per month. Ward 86 operates much

like a doctor's office. It offers comprehensive medical care, including evaluation, diagnosis, treatment, and follow-up care. Various procedures, which elsewhere might require a hospital admission, are performed on an outpatient basis, thereby helping to reduce costs. In October 1986, 1,700 patients with AIDS or ARC were monitored there (SFDPH, 1986). This growth rate of over 500 percent in three years indicates that outpatient services are helping to keep people out of the hospital. The clinic currently has 1,500 patient encounters per month, including repeat visits, and generally has a crowded waiting room (Molaghan, 1987, pers. comm.). Administrators predict a doubling of the number of patient contacts to 3,000 per month sometime this year. SFGH has no current plans to expand its outpatient facility to help cope with the growing demand. Physical space is limited and, without increased city funding, facilities cannot be expanded (Baloff, 1987, pers. comm.).

Garden Sullivan Hospital supplies most of the intermediate care available in San Francisco. Its facilities for AIDS patients have grown from four beds in the 1985-1986 fiscal year to a ten-bed unit, licensed to serve "acute-rehabilitation" needs (SFDPH, 1986). The unit averages six patients with AIDS or ARC per day, all suffering from diarrhea, dementia, dehydration, and other losses of function that require 24-hour care (SFDPH, 1986). Since the number of patients requiring intermediate care is increasing, the need for more facilities of this kind is growing (Baloff, 1987, pers. comm.).

In early 1984, a large part of the patient load of Hospice of San Francisco, an organization providing home and hospice care to terminally ill patients, was composed of people with AIDS. In July, city officials requested that Hospice begin a program directed strictly toward the care of AIDS patients. In October, the AIDS Home Care and Hospice Program began services to 18 patients. The organization supplies health monitoring and nursing in the home, enabling AIDS patients to remain in a comfortable environment for as long as possible. Social workers provide psychological, legal, and financial support, while attendants and volunteers offer assistance with daily living and emotional counseling. Hospice helps the AIDS patient deal with the grief, anxiety, and fear caused by the prospect of an early death (Bell, 1987, pers. comm.).

About half the people with AIDS in San Francisco die at home while in the Hospice program. Since establishment, the caseload has steadily grown to 63. Nurses currently carry a full load of patients and the waiting list usually consists of about 30 people who are taken in order of need. The program may increase its patient load by July 1987, but this expansion will address only a part of the growing need for home care services (H. O'Connor, 1987, pers. comm.).

Hospice plans to broaden its program to include a 15-bed inpatient facility. This Coming Home Hospice, scheduled to open March 2, 1987, will be the first Hospice intermediate care project designed specifically for people with AIDS. Like other intermediate care facilities, it will offer 24-hour nursing, but in addition will implement the Hospice philosophy of care. The agency is already looking for a larger facility to house at least 50 beds, to alleviate further the great need for intermediate care in the city. Consolidation of services into one location is expected to keep costs down (Bell, 1987, pers. comm.).

The Shanti Project began its support services to people with life-threatening illnesses in 1974. Not until early 1983 did the organization become a contracted agency with the City of San Francisco, f ocusing entirely on the needs of AIDS patients and their support network of family and friends. The Shanti Project provides counseling to AIDS patients at home and at SFGH's Ward 5A and Ward 86. Its philosophy of care is to remain open and non-judgmental, and to make the last days of the individual as comfortable and life-affirming as possible (Davidson, 1987, pers. comm.). Shanti's focus on the psychological preparation for death led to a negative reaction among some AIDS and ARC patients, but the organization serves an important function for most people with AIDS (Lopez, 1987, pers. comm.).

Shanti now serves about 1,500 clients per month, relying mainly on its volunteer base of 480 people. All volunteers are currently working their maximum of eight hours per week. About one-third of those cared for have AIDS, while the rest are family members and friends. People with ARC are not given priority unless they have a prognosis of six months or less remaining to live (Davidson, 1987, pers. comm.). In addition to support services, the agency offers low income housing to people with AIDS, charging clients 25 percent of their monthly incomes for rent. This year, local funding represents about one-third of Shanti's revenues (Davidson, 1987, pers. comm.).

Numbers of People Alive with AIDS

Table 1 shows the numbers of people alive with AIDS in San Francisco at the end of March, June, September, and December for 1981 through 1986, noted by the first, second, third, and fourth quarter rows, respectively. These figures give a gross indication of the demand for health care services. At the end of December 1986, the city had at least 1,152 people with AIDS (BDC, 1986). Projections by city health planners estimate that by June 1987, there will be at least 1,226 people alive with the disease and by June 1988, 1,449 patients (SFDPH, 1986). Members of the mayor's AIDS Task Force predict that by 1992 there will be 5,000 AIDS patients in San Francisco. These predictions represent conservative estimates, as cases and deaths attributable to AIDS are probably under-reported (Shilts, 1987). Also, the development of new drugs to treat the HIV virus is expected to keep people with AIDS alive longer (Barnes, 1987, pers. comm.). The numbers of people with ARC are not included in the table, yet they represent a large fraction of those requiring care, especially outpatient and psychological support (see Harris, 1987 for additional discussion of AIDS and ARC projections). The estimates for 1992 represent over four times the number of people alive with AIDS at the end of 1986, and will require expansion of AIDS-related services of a similar magnitude.

Quarter	1981[1]	1982[1]	1983[1]	1984[1]	1985[1]	1986[1]	1987[2]	1988[2]	1992[3]
1st	—	24	126	294	556	846	—	—	—
2nd	—	40	159	341	619	930	1,226	1,449	5,000
3rd	13	55	193	417	698	1,049	—	—	—
4th	18	83	227	467	761	1,152	—	—	—

Table 1. Actual and Projected Numbers of People Alive with AIDS, San Francisco, 1981-92
Sources: [1]Bureau of Communicable Disease Control, 1986
[2]SFDPH, 1986
[3]Shilts, 1987

Discussion

Despite these alarming projections for 1992, plans to expand existing services do not extend beyond 1988. The data in Table 1 suggest that 500 AIDS patients will need hospital care in 1992 (Shilts, 1987). Consequently, five times the number of hospital beds currently utilized by AIDS inpatients in the city will be necessary. Outpatient services will have to expand their staffs and facilities beyond this five-fold increase, since additional ARC patients will continue to rely heavily on clinical care. Although the actual amount of growth in all types of services necessary to care adequately for 5,000 people with AIDS is difficult to determine, some attempt to estimate future needs ought to be made now. Unofficial projections by the SFDPH and the mayor's budget office indicate that the city will need to spend 7.5 percent of its 1991 general fund on AIDS programs, assuming AIDS spending grows proportionately with the expected number of cases; this would amount to $70 million. San Francisco devoted 1.9 percent of its 1986 general fund to AIDS services, totaling $13 million (Rosenheim, 1987).

SFGH will not be able to continue to handle such a high proportion of the city's AIDS cases as the numbers requiring inpatient care rise (Shilts, 1987). SFGH will not refuse service to any AIDS patient, but as a public hospital, it must continue to serve the health care needs of the rest of the community (Baloff, 1987, pers. comm.). Private hospital involvement in the delivery of services to AIDS patients must increase. SFDPH is currently negotiating with private hospitals to encourage participation in the provision of acute care to AIDS patients. Overall, they seem to be cooperating, and realize that they will have to start sharing more of the burden of AIDS cases (Barnes, 1987, pers. comm.).

Many health care providers feel that San Francisco should be the site of a regional hospital devoted strictly to the demands of persons with AIDS. The state has already funded the initial architectural plans for an infectious disease lab located at SFGH, devoted solely to AIDS clinical research, but continued funding will be necessary for its completion (Baloff, 1987, pers. comm.). Additional funding for the lab was promised to the city but was deleted from the 1987-88 budget. In 1986, the state released a plan to cope with the health care demands of the epidemic; the proposal was criticized highly by the city. It contained no indication of how certain regions might work together to care for AIDS patients, a step the city feels is essential. Since 15 percent of the AIDS patients who receive treatment in San Francisco come from outside of the county, a great need exists to educate physicians from other areas so that they can treat their own patients (Barnes, 1987, pers. comm.).

The city is aware of the spectrum of care necessary for people with AIDS and has allocated money to each of these areas; therefore, many of the major needs of AIDS-afflicted individuals, especially gay and bisexual men, are being addressed (Christen, 1987, pers. comm.). San Francisco's mobilization of outpatient and home care services has kept inpatient care and consequent costs to a minimum (Winkelstein, 1986). A patient in the hospital may spend $900-$1,000 per day for 24-hour care, while at home he may spend only $420 per day for 24-hour home care services (H. O'Connor, 1987, pers. comm.). Dr. Philip Lee, president of San Francisco's Health Commission, estimated that the total cost of in-hospital treatment falls between $25,000 and $32,000 per AIDS patient in San Francisco, as compared to $143,000 per patient in other parts of the country (Lee, 1985). The availability of outpatient clinics, home health care, and other support services in San Francisco allows patients to remain out of the hospital longer than in other cities (Lee, 1985).

Although the variety of needs is being addressed in a highly economical manner, all of the AIDS-related health care providers and people with ARC and AIDS I interviewed agree that current funding from the SFDPH is insufficient to meet the needs of people with AIDS. Most can appreciate, however, the constraints of limited resources and feel that the money available is being spent wisely. Short-range plans to expand AIDS programs generally call for delivering current services to more people; this approach seems to be the best way to address the worsening epidemic under expected future budget constraints.

The city obviously will not be able to carry the entire financial burden of the epidemic, but can continue to partially finance AIDS organizations. In 1986, 74 percent of the operational funds of San Francisco's AIDS programs were provided by the city, while state and federal grants each contributed 13 percent to these services (Rosenheim, 1987). City officials feel that state funding for AIDS services is inadequate. The billion-dollar budget surplus that the governor claims he must have in case of an emergency is not being spent (Barnes, 1987, pers. comm.). Is the AIDS epidemic not cause enough to spend some of this money?

Recommendations

Opinions vary on how the city should respond to the growing needs of people with AIDS. Expansion of existing services will require the state and federal governments to assume a larger role; to accomplish this, lobbying by local officials must increase. Current efforts directed toward keeping people out of the hospital, thereby reducing costs and maintaining a high quality of life, must continue. An awareness of options on the part of doctors can help in these efforts. For instance, an oral treatment for PCP that can be taken at home is now available, thereby making the in-hospital IV treatment unnecessary for some (Lopez, 1987, pers. comm.). If a patient has contracted a disease such as PCP in the past, there seems little reason for hospitilization for a second diagnosis if he feels confident of his condition. The expansion of intermediate and home care services can also help reduce the need for hospitalization.

The need for an awareness of the mental health aspects of AIDS is growing. Physicians, in addition to having knowledge in their special fields of expertise, ought to be aware of other factors that affect a person's well-being, such as nutrition and psychological health, and be able to direct patients to others who can help in these areas (T. O'Connor, 1987, pers. comm.). There is a great need for health professionals to be informed about the disease, to have a genuine concern and desire to treat those with AIDS, and to offer a sense of hope to their patients (Barnes, 1987, pers. comm.). The person with AIDS has a responsibility for his own treatment and must explore the options for care. Many people with AIDS and ARC are exploring alternative therapies, outside of the traditional Western approach to medicine, and realizing the importance of nutrition and exercise in remaining healthy (T. O'Connor, 1987, pers. comm.). While there is no vaccine to stop the spread of the HIV virus, we all can help those infected by offering comfort and emotional support.

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