Case management of persons with acquired immunodeficiency syndrome in San Francisco

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The acquired immunodeficiency syndrome (AIDS) epidemic represents a growing challenge for the health care system and for case management models applied to persons with AIDS. The experience of San Francisco highlights some of the issues involved in developing a case management system appropriate to the needs of persons with AIDS, as well as providers, and payers. Dramatic growth in the size and complexity of the AIDS caseload and the involvement of public, health maintenance organization, and community providers has required the increasing formalization and centralization of case management roles. Persistent questions about the definition and goals of case management complicate development of these services.

Introduction

It is estimated that between 1.0 and 1.5 million individuals are infected with the human immunodeficiency virus (HIV) in the United States, with the majority likely to develop acquired immunodeficiency syndrome (AIDS) in the next decade. By mid-1988 over 57,000 cases of AIDS had been reported to the Centers for Disease Control (CDC). More than one-half of the individuals diagnosed have died, and thousands more are afflicted with AIDS-related complex (ARC). By 1991, more than 270,000 individuals will have been diagnosed with AIDS and 179,000 will have died from the disease. It is projected that in 1991 alone, 145,000 persons with AIDS will require medical attention, and 54,000 will die during that time (Centers for Disease Control, 1988).

Nationally, 64 percent of all AIDS cases are reported among homosexual or bisexual males who are not IV (intravenous) drug users; 18 percent among heterosexual IV drug users; 7 percent among homosexual males who are also IV drug users; 4 percent among heterosexual partners of those in high-risk groups; 2 percent among recipients of blood or blood products; 1 percent among persons with hemophilia, and 3 percent of undetermined cause (Centers for Disease Control, 1988). The number of cases of AIDS in children is growing steadily; in early March 1988, this totaled 865. Although homosexual or bisexual males continue to account for the largest number of cases nationwide, the disease is spreading most rapidly among IV drug users, blacks, hispanics, women, and children.

AIDS cases have been reported in each of the 50 States plus Puerto Rico and other territories. The burden has been greatest in eight States, with New York, California, Florida, Texas, New Jersey, Illinois, Pennsylvania, and Massachusetts each reporting 1,000 or more cases. Most major metropolitan areas have now experienced the impact of the epidemic, most notably New York, San Francisco, and Los Angeles.

Although New York has many more total cases, no city has been as affected by the disease as San Francisco in terms of the burden of AIDS relative to its total population (Table 1). The response of the city and county of San Francisco to the local AIDS epidemic has been described in some detail elsewhere (Arno, 1986; Arno and Hughes, 1987; Silverman, 1987). As early as 1981, the San Francisco Department of Public Health (DPH) began to coordinate efforts to plan and develop services to respond to the health care needs of growing numbers of persons with AIDS (PWA's) in the city, most of whom were (and are) homosexual/bisexual males. In early 1982, DPH was provided local tax funds by the board of supervisors for the support of AIDS prevention activities and community psychosocial support services. In late 1982, a multidisciplinary

Table 1

Actual and projected AIDS cases by fiscal year: San Francisco

Fiscal year ending June 30	Cumulative cases	Number alive
	Actual number	
1980	0	0
1981	10	9
1982	63	45
1983	253	172
1984	634	355
1985	1,371	680
1986	2,353	1,031
1987	3,648	1,500
	Projected range	
1988	5,152-5,281	1,814-2,660
1989	6,536-6,983	1,954-3,201
1990	7,947-8,957	2,074-3,811
1991	9,386-11,258	2,178-4,522
1992	10,854-13,934	2,276-5,348
1993	12,349-17,022	2,383-6,288

NOTES: The difference between "cumulative cases" and "number alive" for a given year equals the cumulative number of deaths at the end of that fiscal year. AIDS is acquired immunodeficiency syndrome.

SOURCE: City and County of San Francisco, Department of Public Health. *AIDS in San Francisco, 1987-88.* Report to the Health Commission, Mar. 1988.

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AIDS outpatient clinic was established at San Francisco General Hospital (SFGH) to provide screening, diagnosis, treatment, followup, education, and counseling services. The first inpatient AIDS ward in the United States was opened at SFGH in 1983. Over the last 6 years the city has provided a substantial level of funding for a wide range of medical and social services for PWA's (City and County of San Francisco, 1988). Following is a list of available health and supportive services:

- AIDS screening/outpatient services, including dedicated clinics.
- General acute care resources at public and private hospitals.
- Skilled/intermediate nursing care.
- Residential care.
- Home health assessment/care.
- Attendant care.
- Hospice care.
- Practical support for daily living.
- Emotional support/counseling.
- Professional counseling and hospital advocacy.
- Mental health support.
- Telephone information and referral.
- Social service/financial entitlement.
- Emergency housing.
- Long-term housing.
- Substance abuse services.
- Food support.
- Foster care supplements.
- Social service advocacy.
- Practical support services.[1]

In addition, private physicians in fee-for-service practice, community hospitals, the Kaiser Hospital, and the Permanente Medical Group have become increasingly involved in the care of PWA's. What came to be known as the "San Francisco model" was developed through strong public sector leadership, exemplary medical care, a highly mobilized gay community providing volunteer services, psychosocial support and advocacy, and an early commitment to outpatient, home, and community-based services rather than inpatient hospital care (Arno and Hughes, 1987).

Emergence of case management

The response to the AIDS epidemic of both the public and private sectors in San Francisco has generated a range of medical, social, psychological, housing, and other services to meet the needs of PWA's. Considerable State and local resources have been directed toward development of a continuum of services appropriate to the complex character of the disease, which has significant and multiple acute and chronic dimensions. Somewhat paradoxically, the success of San Francisco in developing a range of services to address this complex of AIDS care needs has produced a new set of problems for planners and program managers, namely, how to manage the care of PWA's across providers in appropriate, responsive, and cost-effective ways (Morrison, 1988). This need to better manage the delivery of health and social services is exacerbated by two other characteristics of AIDS: (1) the likelihood of precipitous changes in physical and emotional status throughout the course of the illness, resulting in frequent changes in care needs; and (2) the increased incidence of neurological and psychosocial problems, further broadening the range and complexity of care needs. Like many communities that have had to confront the AIDS epidemic, San Francisco has devoted increased attention to development of case management services for PWA's in order to plan and monitor care throughout the course of the illness (Benjamin, 1988).

The current system

Case management refers to a set of support activities designed to complement various direct services provided to persons in need, especially the chronically ill. Although there exists considerable variation in definitions, models, and goals associated with case management (Spitz, 1987), these support activities generally are intended to reduce inappropriate use of inpatient hospital care, improve continuity of care, and enhance the client's quality of life in the community (Franklin et al., 1987).

Despite the widespread equation of case management with the "San Francisco model" of AIDS care, the emergence of formal case management as a public policy priority in San Francisco has been a relatively recent development. A brief examination of the role of case management within the local service network suggests at least three phases in the formalization and centralization of these support services. The definitions of "formalization" and "centralization" in this context will become clearer as these phases are discussed.

The first phase: 1982-85

As suggested earlier, the most striking feature of the period between 1982 and 1985 was the development of a continuum of medical and social services for PWA's, in the form of public services (e.g., inpatient and outpatient care), private sector care provided through public contracting (e.g., home health and hospice care), or volunteer services subsidized by public funds (e.g., housing, practical support/homemaker, food, information, and referral). During this period, case management as a set of activities was relatively informal and decentralized. Case assessment, planning, and monitoring were done by dedicated professionals and community volunteers as PWA's moved from agency to agency. In the early years of the epidemic, hospital discharge planning at SFGH, where more than one-half of the AIDS population received acute care, was a central (and the most formal) part of this informal case management network. More generally, when a PWA moved from one organization to another for

[1]City and county of San Francisco, 1988.

care, case management responsibilities were assumed by professionals in that organization. To the extent that these responsibilities were centralized at all, this occurred through a physician with a large AIDS caseload and/or a volunteer with the time and expertise to share this role. No single case manager was assigned to follow the patient throughout his or her illness and to plan and facilitate access to needed services.

For several years this relatively informal and decentralized system generally proved successful in San Francisco for a variety of reasons. First, the sheer number and variety of medical, social, and other support services available to PWA's reduced the likelihood that many persons would "fall through the cracks," however informal the case management might be. Second, a cadre of medical and social service professionals dedicated to AIDS care emerged rapidly in the city, and this group shared a philosophy regarding the importance of home- and community-based services and the need to help PWA's negotiate this network of services. Third, a large number of volunteers (many drawn from the local gay community) filled roles as case advocates when increasingly overworked professionals could not. Fourth, a relatively enlightened political and public health leadership took advantage of the city's then-sound fiscal situation and allocated funds to public and nonpublic AIDS providers so that the first three conditions were reinforced. Fifth, because DPH administers a full range of public health, medical, and long-term care services, it has been able in some important ways to coordinate care within the public sector and with the private sector. Sixth, DPH is governed by a broadly representative health commission that enhances public participation in policies and programs of the department. Seventh, the city itself is small and compact, so that, despite the growing AIDS caseload, there was a small number of core providers (among them, SFGH, Shanti, the Visiting Nurse Association and Hospice of San Francisco, the San Francisco AIDS Foundation, and the AIDS Health Project) that offered services to most PWA's and were well known to one another, thus facilitating informal planning and management across agencies over time. Finally, the number of AIDS cases, although large relative to other communities, did not overwhelm the service system in the early years so that informal and decentralized strategies could succeed.

The second phase: 1985-86

This system of case management worked well until the number of PWA's began to increase rapidly in 1985-86, at which point more formal but still relatively decentralized variants began to develop. In 1986 various observers began questioning whether the pool of volunteers on which the San Francisco model depended could be sustained (Arno, 1986; Lee, 1987; Jenna, 1987) and whether dedicated professionals could continue to coordinate and manage care as an adjunct to their direct service responsibilities. As more community hospitals, including the Kaiser hospital, physicians, home care agencies, and other providers, became involved with AIDS care, informal approaches to case coordination became much more difficult. Growth in the number of intravenous drug users and homeless among persons with AIDS (although still small proportionally), along with the expanded number of cases with central nervous system involvement, increased the complexity of the (mainly white, homosexual/bisexual male) caseload in the city and demanded more experienced and less episodic attention to the service needs of PWA's than was available from volunteers. The result has been an increased need to formalize and coordinate the case management efforts of individual provider agencies and to plan for a more centralized system of communitywide AIDS case management in the future.

The third phase: 1986-present

The case of SFGH, which currently provides excellent care to about one-third of the inpatient and outpatient PWA's in the city, illustrates both the strengths and limits of current case management efforts. The highly esteemed designated inpatient unit and outpatient clinic at SFGH have developed a significant capacity for hospital discharge planning and followup for PWA's. Multidisciplinary discharge planning at SFGH begins at the point of inpatient admission or earlier (i.e., in the outpatient clinic). The public health department has helped established formal agreements between the public hospital and other community care providers to facilitate coordinated care outside the hospital. Weekly case conferences at SFGH involving many community providers and volunteers have enhanced case planning and coordination. Because the hospital currently utilizes 40 or more acute care beds for AIDS patients and provides 2,000 outpatient visits per month, however, sustained case management activities must be limited primarily to the acute episode and its immediate aftermath, rather than to the entire period of illness. Although this hospital and post-hospital period may well be the most difficult for many PWA's, for most it represents 10 percent or less of the duration of the illness. Because even excellent hospital discharge planning is circumscribed in its scope and impact, therefore, these activities need to be articulated with a broader system of case management.

Kaiser Permanente, the largest health maintenance organization in the region, currently enrolls nearly one-third of PWA's in San Francisco. At the same time that Kaiser has become a major provider of AIDS care, it has sought to avoid designation as carrier of choice for PWA's and the adverse selection that might follow from favorable publicity. Kaiser does not provide an expanded service package for AIDS, although it does flag catastrophic cases and provide "out-of-contract" services where those will reduce hospital use. Case management services are

offered to PWA's and persons with severe ARC. Because the Kaiser service package is limited (e.g., home care services are not covered) case managers focus upon locating resources, including local programs and Medi-Cal (Medicaid), that will pay for and/or provide needed services to plan members. As at SFGH, case management attention has been given primarily to hospital discharge activities, especially to arranging referrals to nonplan providers.

One of the goals of case management at SFGH, at Kaiser, and at the community hospitals is to reduce the utilization of inpatient care through the planning and coordination of care provided outside the hospital. In addition to those enrolled in the Kaiser health plan, over one-third of San Francisco's AIDS population is covered by private insurance during at least part of their illness. Blue Cross, Prudential, Aetna, and other third-party insurers share an interest in limiting hospital use and managing medical care to reduce costs. Most insurers have established mechanisms for flagging catastrophic cases and for offering case management to these potentially costly enrollees, and AIDS tends to be included in this general process. Like Kaiser, these insurers will pursue those home and community-based alternatives acceptable to the client and considered to have cost-saving potential; however, care for which reimbursement is provided tends to be limited to skilled medical services. Few insurers in California are planning to develop AIDS-specific case management efforts outside their broader mechanisms for addressing catastrophic illness.

Next steps

By most indications, the next stage in the evolution of case management in San Francisco will be the development of centralized case management that attempts to bridge those services provided by single agencies, organizations, and individuals. The availability in the last 2 years of State and Federal funding to support case management initiatives has reinforced local efforts at formalization and encouraged trends toward more centralization. The Department of Public Health in San Francisco received a demonstration grant in 1986 from the Office of AIDS (California Department of Health Services) to provide home care and case management services to a small number of PWA's. The success of this modest initiative, which placed more emphasis on service subsidies and data collection than case management, has led the city to apply for more substantial funding from the State to support development of a centralized case management system; that proposal is still pending. At the State level, the California Department of Health Services is seeking a Home and Community-Based Waiver for Medi-Cal-eligible PWA's, and strong provisions for local, centralized case management are included in that pending application. Both initiatives have stimulated planning for new approaches to case assessment, coordination, and monitoring.

The case management program for which additional funding has been sought from the State Office of AIDS is designed to establish a case management capacity in the city DPH that is expected to serve PWA's referred from SFGH, district health centers, community hospitals (including Kaiser), physicians in private practice, community and government agencies, family members and friends, and self-referrals. The proposed program will initially support two case management teams, each of which will follow 40 AIDS/ARC patients from the time of initial inpatient admission (or referral) through the course of the illness. Directed by a public health nurse with assistance from a medical social worker, the team will be responsible for conducting initial and ongoing needs assessment and ensuring access to appropriate services.

Conclusion

The experience of San Francisco in organizing and managing the delivery of AIDS care leaves various questions unanswered regarding case management system design and financing. The AIDS provider community in San Francisco remains split on the merits of centralized case management. In a relatively small city with relatively abundant services and strong provider networks, decentralized case management can claim considerable success. The centralization of case management under DPH, moreover, may require the adjustment of established interagency linkages at some administrative cost to participants. On the other hand, centralized case management may be essential in those communities where similar resource and collaborative conditions do not exist. Although San Francisco has embraced what has come to be known as a "brokering model" of case management, under which case management involves gaining access to and coordinating existing services, communities with fewer available AIDS services have adopted a "direct service" model (Wright, Sklebar, and Heiman, 1987), in which case managers not only plan for care but directly provide those services not otherwise available to PWA's. In the latter model, caseloads must necessarily be smaller than in the brokering model, case management costs are likely to be higher, pressures to ration care will be greater, and the need for centralized administration more obvious.

Considerable debate continues regarding another design issue: who should perform case management functions? Although everyone endorses a team approach in principle, participants differ in terms of their commitment to medical versus social case management models (usually in the form of nurse versus social worker) and in terms of the extent of professional training needed (i.e., bachelor or masters level). Arguments on both sides usually involve the types of services that should be emphasized and the cost of staffing a case management system. An additional issue concerns the scope of case management and, specifically, whether case managers can reasonably be expected to foster interagency

coordination in areas where that is rare (e.g., psychosocial and mental health with medical care). Under some circumstances, professionals trained to manage the care of individual PWA's will confront the need to alter institutional relationships in order to be successful. Such change may only result from the efforts of institutional leadership, not case managers.

Case management in San Francisco and many other communities has been designed primarily to address the needs of the largest subpopulation of PWA's in those locales, i.e., homosexual and bisexual men. It is likely that case management approaches will have to be adapted to different AIDS populations, because a system designed for gay, white males is unlikely to be appropriate for minority, male and female intravenous drug users (IVDU) with children who also are infected. At the least, we know that the latter population is not accompanied by the network of volunteers and specialized services established by gay organizations in various communities and that various behavioral problems associated with drug use make planning and monitoring care more difficult. Demonstration and waiver programs in New Jersey, New York, and a few cities with large numbers of IVDU-AIDS cases may cast light on the elements of case management appropriate to this AIDS population.

Special state-funded initiatives and prospective Medicaid waivers currently represent the primary sources of funding for case management services.[2] Payment for case management continues to be provided only under exceptional circumstances, and more established and routine sources of funding may be needed if case management is to play a significant role in AIDS care. Case management has succeeded in San Francisco because many of the services needed by PWA's were available for case managers to coordinate. Without additional funding for such services, and most significantly long-term care services, case management becomes an empty gesture. As the number of AIDS cases grows and the fiscal burden of AIDS care on governments (especially local ones) increases, it is important also to recognize that funding for indirect services like case management are likely to be reduced before that for "harder," direct services. In the absence of a clear understanding of what case management is and which goals it serves (Spitz, 1987), the price of such policy choices will be difficult to assess.

The literature on case management for the chronically ill elderly, the mentally ill, and others needing a wide range of medical, social, and support services, raises serious questions regarding the capacity of case management to reduce inpatient hospital utilization or to reduce costs (Capitman, Haskins, and Bernstein, 1986; Kemper et al., 1986; Spitz, 1987; Franklin et al., 1987). In many cities where AIDS lengths of stay are twice (or more) those of San Francisco, planners remain hopeful nonetheless that the introduction of case management will reduce dependence on inpatient care through the coordinated use of outpatient, home, and community services. Although many factors besides case management explain the shorter length of stay in San Francisco (Scitovsky, Cline, and Lee, 1986; Arno and Hughes, 1987), there remains reason to believe that in other communities, AIDS may prove the exception to prior findings on the limited impact of case management by demonstrating that these services can shorten hospital stays and thus reduce the overall costs of caring for persons with AIDS.

[2]The Robert Wood Johnson Foundation and the Health Resources and Services Administration (Public Health Service) also provide demonstration funds for AIDS case management in selected cities.

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