

New AIDS Grant For S.F. General

AIDS research funds at San Francisco General Hospital will increase by \$3.7 million as a result of a grant approved this week from the federal government's National Institutes of Health.

Dr. Paul Volberding, director of AIDS activities at San Francisco General — already one of the nation's leading centers for research into basic biology of the disease and patient care — said the money will go for the study of how the human immunodeficiency virus responsible for AIDS infects patients, and why patients fail to develop immunity to it. The answers may be vital to the discovery of drugs or vaccines that will be effective against AIDS.

The grant also will help support research at the University of California at San Francisco Medical Center and the San Francisco Veterans Administration Hospital.

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The AIDS Resource Program is a program of information, education and training, technical assistance, and policy research and analysis linking communities nationwide in the fight against AIDS.
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The Clinical Spectrum of the Acquired Immunodeficiency Syndrome: Implications for Comprehensive Patient Care

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The clinical spectrum of the acquired immunodeficiency syndrome (AIDS) is broad and presents unique challenges to the health care system. Among the challenges are the unusual presentations, unexpected complications, psychosocial sequelae, and poor outcome of patients with the syndrome. From our experience with hundreds of patients at the San Francisco General Hospital, we propose a system for optimal care for patients with AIDS that requires a high degree of planning and commitment by hospitals and health care providers. In this model, rigid subspecialization is avoided, outpatient care is stressed, and community involvement is solicited. In these ways we can hope to improve the care of patients with AIDS and learn lessons that should be important in other illnesses as well.

MEDICAL PROVIDERS and the health care system face a unique set of demands created by the acquired immunodeficiency syndrome (AIDS). The overriding concern, however, is to deliver the best possible patient care. This duty has been a complicated process, reflecting the complex nature of the disease.

This article discusses the clinical spectrum of AIDS from the clinician's perspective by presenting three typical case histories. The organization of systems for the delivery of optimal care is addressed, first in general terms, and then specifically, using the San Francisco General Hospital as a model.

Case Histories

The following cases have been chosen to illustrate the clinical spectrum of AIDS. They are typical rather than unusual cases and include Patient 1 with severe, debilitating AIDS-related complex, Patient 2 with Kaposi's sarcoma alone, and Patient 3 with complex AIDS involving multiple malignancies and opportunistic infections.

PATIENT 1

A 27-year-old homosexual man who used intravenous stimulants was well until December 1982, when he was first hospitalized. At the time he had diffuse lymphadenopathy; an 11.3-kg

weight loss; severe, constant bilateral headaches; and oral candidiasis. His erythrocyte sedimentation rate was 111 mm/h, total leukocyte count was 2.5×10^3 cells/mm³, and hematocrit was 30.3%. A cervical lymph node biopsy sample showed reactive hyperplasia. Findings of a complete neurologic evaluation were normal. The patient regularly missed follow-up clinic visits but was seen in the emergency room of the San Francisco General Hospital in October 1983 with cough, shortness of breath, temperatures above 39.4° C, drenching sweats, and severe fatigue. The patient refused full evaluation and left the hospital against medical advice.

He was next hospitalized in December 1983, again with pulmonary symptoms, recurrent severe oral candidiasis, and staphylococcal folliculitis. His erythrocyte sedimentation rate was 120 mm/h, his hematocrit was 28%, and he had severe lymphopenia. Pulmonary findings included a normal chest radiograph and pulmonary gallium scan; the pulmonary diffusing capacity was 77%. Bronchoscopic samples showed cytomegalovirus by culture, without *Pneumocystis carinii*. The patient again was poorly compliant but was rehospitalized in June 1984. At that time, in addition to all previous symptoms, he complained of hemoptysis. A small area of distal herpetic esophagitis was found that was successfully treated with intravenous acyclovir. After this hospitalization, the persistence of his disabling symptoms prompted the attending staff to recommend that, despite the absence of a definite diagnosis of AIDS, the patient be accepted into a low-cost housing program operated jointly by the City of San Francisco and the Shanti Project.

In July 1984, a bone marrow biopsy sample showed rare acid-fast bacilli that were later shown to be *Mycobacterium avium-intracellulare*. Thus, after 19 months of disabling AIDS-related symptoms, a diagnosis of AIDS was established. An abdominal computed tomographic (CT) scan showed extensive intra-abdominal lymphadenopathy. The patient, however, refused fine-needle aspiration of these nodes.

In October 1984, he was again hospitalized with severe abdominal pain, nausea, and vomiting, in addition to all previous symptoms. A fine-needle aspirate of an abdominal lymph node showed acid-fast bacilli, and the patient was discharged on a four-drug regimen of isoniazid, ethambutol, ansamycin (rifamycin), and clofazimine. Two weeks later he complained of severe headaches. He had not taken any of the prescribed antibiotics. A CT scan of the head showed no focal lesions but did show moderate cortical atrophy. The patient refused lumbar puncture and left the hospital against medical advice.

The patient was last hospitalized with status epilepticus in September 1984. A lumbar puncture sample showed 21 leukocytes, all monocytes. Cultures were negative for viruses, bacteria, and fungi. Despite control of his seizures, his condition deteriorated rapidly and he died after 21 months of continued

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Illness. Postmortem examination documented extensive intra-abdominal lymphadenopathy with disseminated *M. avium-intracellulare* infection. Microscopic examination of the central nervous system showed an extensive, unsuspected central nervous system lymphoma with necrosis.

PATIENT 2

A 36-year-old homosexual man, a native of San Francisco, had been employed as an office worker. He was in excellent health until March 1982, when he noted bilateral axillary lymphadenopathy. He remained asymptomatic but in May 1982 observed several purplish nonpainful skin nodules. Biopsy showed them to be Kaposi's sarcoma.

In August 1982 the patient began to receive chemotherapy with vinblastine, 5 to 8 mg weekly. He had no alopecia, nausea, or vomiting during therapy but complained only of mild fatigue on the day after drug administration and of wrist arthralgias. His skin lesions gradually regressed in size, and in April 1984, after 23 months of weekly therapy, a complete tumor response was documented. Therapy was thus decreased to a biweekly schedule. Currently, 35 months after initial diagnosis, he remains without evidence of Kaposi's sarcoma. He is clinically asymptomatic and has been free of all infectious diseases.

PATIENT 3

A 39-year-old homosexual man, who had been trained as a classical musician, was in excellent health until 1981, when he noted generalized lymphadenopathy, high fevers, and nightly drenching sweats. These symptoms continued and in March 1983 he developed disseminated herpes zoster. The herpes zoster resolved without complications, but in June 1983 he was again hospitalized because of ongoing temperatures of over 40°C, a 13.6-kg weight loss, nightly drenching sweats, severe nonproductive cough, and progressing lymphadenopathy. A biopsy sample of an axillary lymph node revealed mixed-cellularity Hodgkin's disease, stage IV-B, with involvement of bone marrow, spleen, liver, and mediastinum.

In August 1983 the patient began combination chemotherapy (mechlorethamine, vincristine, procarbazine, prednisone, and doxorubicin, bleomycin, vinblastine, dacarbazine [MOPP/ABVD]) at another medical center. This therapy was complicated by recurring, severe pancytopenia and fevers requiring multiple hospitalizations. In March 1984 the patient was again evaluated for severe constitutional symptoms and dyspnea. A bronchoscopic examination was positive for *P. carinii* pneumonia. Skin lesions were noted and proved to be Kaposi's sarcoma. His Hodgkin's disease was in clinical remission.

In July 1984, he was hospitalized with oral bleeding, severe headache, dyspnea, and diarrhea. Physical findings included extensive Kaposi's sarcoma, particularly on the face. His leukocyte count was 1000/mm³ and his platelet count was 14 000/mm³. Sputum induction showed recurrent pneumocystis pneumonia. He was treated initially with trimethoprim/sulfamethoxazole, but after 5 days of clinical deterioration, the treatment was changed to intravenous pentamidine. Despite this change, the patient's pulmonary symptoms, chest radiographic signs, and arterial blood pressures deteriorated, and 10 days after admission he died of respiratory failure. A postmortem examination was refused.

Discussion

Clearly, three brief case reports cannot capture the full clinical range of a disease as complex as AIDS. Nevertheless, from them, one can begin to appreciate the frequent frustrations that face the clinician dealing with this disease. From our experience with hundreds of patients in our clinic, we make the following general statements about AIDS and describe some guidelines for providing comprehensive care for these patients.

THE CLINICAL SPECTRUM

In dealing with AIDS, medical providers and health care systems face an extremely variable epidemic disease. Although most persons infected with the virus that causes the syndrome are asymptomatic (1-6), others develop a rapidly progressing and fatal disease (4-6). Variability is still the rule when subsets of patients are studied. The AIDS-related complex, for example, ranges from a minor illness to one that causes severe disability, even death (4, 6-9). In AIDS itself, most patients have a rapid deterioration leading to death within 2 years (10), but the spectrum of the disease is broad and some groups of patients with Kaposi's sarcoma have an excellent prognosis for a 3- to 5-year survival (11, 12).

THERAPY

Therapy for AIDS-related diseases is complicated by three central issues. First, clinicians, even specialists, have had little direct experience with these diseases. Second, in treating AIDS, conventional therapies often cause unexpectedly frequent or severe toxicities. Finally, the underlying immunodeficiency makes both malignancies and infections more resistant to conventional therapy.

Kaposi's sarcoma demonstrates each of these issues clearly. Clinicians in the United States had rarely seen Kaposi's sarcoma before AIDS and thus had little information available to help in planning therapy (12, 13). Conventional cytotoxic drugs have resulted in unexpectedly severe myelosuppression. Some evidence, in fact, suggests that chemotherapy further damages the immune system, increasing the risk of opportunistic infections.

Clinicians treating opportunistic infections face similar difficulties. In pneumocystis pneumonia, a longer course of antibiotic therapy appears necessary compared with that required for the pneumonia in populations without AIDS (14, 15). Also, both commonly used drugs for this pneumonia, trimethoprim/sulfamethoxazole and pentamidine, are much more toxic when used in patients with AIDS (16, 17).

PSYCHOSOCIAL PROBLEMS

Patients with AIDS and the AIDS-related complex typically are young adults who were previously in good health and who are ill-prepared to face a life-threatening disease (18, 19). In this respect, patients with AIDS are similar to young adults who have cancer. There are differences, however. With AIDS, in addition to facing a terminal disease requiring frequent and prolonged hospitalizations, the patient encounters a hostile and fearful society. Instances of rejection by family, friends, employers, and landlords are frequent, even in cities like San Francisco where major public education has occurred.

Although disabling symptoms are seen less commonly in patients with the AIDS-related complex than in those with diagnosed AIDS, they do occur, and when they do, patients with the AIDS-related complex may not share the same access to services provided for patients with AIDS as defined by the Centers for Disease Control. Patients with AIDS are, by law, presumed disabled and entitled to benefits, whereas these benefits are much more

difficult to obtain for a person disabled by the related complex. Because AIDS-related symptoms can persist for months or years, patients become frustrated when no specific diagnosis or prognosis for their disabling illness can be given. These debilitated patients occasionally express relief when a diagnosis of AIDS is finally established.

MEDICAL SPECIALTY BOUNDARIES

Because of its complexity, AIDS frequently exposes shortcomings in systems of contemporary subspecialized medicine. Infections in AIDS-related malignancies are common, difficult to treat, and often fatal. Similarly, in patients who present with opportunistic infections, malignancies often appear and again can complicate management of the infection. In both AIDS-related malignancies and infections, the presenting signs and symptoms are frequently atypical, which adds to the difficulty in making the correct diagnosis. For example, pulmonary Kaposi's sarcoma is often complicated by intercurrent opportunistic infections (20), but even in the absence of infections pulmonary Kaposi's sarcoma can be difficult to distinguish from *P. carinii* pneumonia (21). The care of patients with AIDS therefore requires clinicians who are extremely competent specialists in a carefully planned, multidisciplinary medical care system.

Guidelines for Optimal Care

A model system for the care of patients with AIDS has been developed that recognizes the many difficulties involved. This model equally emphasizes multidisciplinary medical and psychosocial care. Any effective system must recognize the complexities in both areas and have staff and facilities able to provide necessary services. A third component is the integration of inpatient and outpatient functions.

MULTIDISCIPLINARY MEDICAL CARE

The care of patients requires several medical specialists, including oncologists and infectious disease experts. Also important are specialists in those organ systems that are particularly affected by the disease. These specialists may include pulmonary physicians, neurologists, neurosurgeons; dermatologists, ophthalmologists, radiation therapists and many more.

Whereas most medical centers have specialists in each of these areas, patient access and communication between these services may be a problem. Unless these specialists are familiar with AIDS and are readily available, care will be compromised. For this reason, multidisciplinary AIDS clinics are strongly recommended. In such clinics, most clinical problems can be addressed, reducing miscommunication and improving patient convenience and compliance. Also, larger multidisciplinary clinics are capable of providing more complex outpatient management (for example, medications by central line); substantial cost-savings may be realized by the clinics, by limiting the necessity for expensive inpatient care.

MULTIDISCIPLINARY PSYCHOSOCIAL CARE

Psychosocial problems are common and often severe in

patients with AIDS (18, 19), and financial difficulties can also be expected. For these reasons, it is recommended that multidisciplinary AIDS clinics should include, at a minimum, representatives from psychiatry and medical social work. Community organizations, which can provide extremely important services, should be invited to participate as an integral part of clinic structures.

INTEGRATION OF INPATIENT AND OUTPATIENT CARE

Outpatient management must be the desired goal of care, both to allow the patient as much time as possible at home and to reduce overall costs. Approaching this goal, however, will result in an increase in the severity of disease in outpatients. Although this emphasis on outpatient management will limit the need for hospitalizing patients, those patients who require hospitalization will be extremely ill.

Complex outpatient management requires rigorous planning and close integration with inpatient services. Patients leaving the hospital may require immediate care from several community agencies as well as frequent outpatient clinic visits. Management plans such as these must be cautiously designed and instituted before the patient is discharged from the hospital, and they must be carefully monitored after the patient is discharged. Otherwise, frequent and avoidable readmissions will occur. Maximal cooperation and communication between outpatient and inpatient staff is facilitated by integrated AIDS clinics and inpatient units.

San Francisco General Hospital: A Model System

The San Francisco General Hospital is a large public hospital owned by the City and County of San Francisco and staffed by the University of California, San Francisco. In January 1983, a multidisciplinary AIDS outpatient clinic opened with attending staff from the medical oncology and infectious disease divisions. From the first, this clinic also included medical social workers and representatives from community support agencies. Also in 1983, the first AIDS inpatient unit in the country was formed at the hospital. Patients with AIDS are admitted to this unit under the care of general medical service teams composed of attending staff, medical housestaff, and medical students.

The AIDS clinic includes six physicians, three nurse practitioners, and an extensive psychosocial, nursing, and research support staff. The clinic is open Monday through Friday and sees all categories of patients, from the "worried well" through those who are dying. Currently, one half-day clinic is devoted to AIDS screening and another to patients with the AIDS-related complex. Two general AIDS clinics are jointly staffed by oncologists and infectious disease specialists. Finally, two separate clinics concentrate on patients whose predominant problem is cancer or infectious disease. These clinics are staffed by physicians with the appropriate subspecialty. Extensive staff overlap among these clinics permits patients to be moved between clinics with minimal disruption of care. Furthermore, cooperation in patient management promotes the development of consistent

philosophies of care.

The AIDS inpatient unit at the hospital opened in July 1983 to ensure comprehensive and sensitive patient care by a centralized nursing staff who have volunteered for this service. Although there was serious concern that such a unit could increase the isolation and stigmatization of AIDS, this has not happened; instead, the opposite has occurred and the AIDS inpatient unit is widely perceived as a near-ideal place in which to be treated—both because of its state-of-the-art medical care and its expert nursing. Several factors have contributed to this success. First, the nursing staff was all volunteer, in that they chose to work with patients with AIDS. Second, no barriers were erected to isolate the unit from the rest of the hospital. Finally, the gay community was invited to participate in the unit's development, thus increasing open communication and a sense of mutual trust.

The nursing staff of the AIDS clinic and inpatient unit has rapidly become expert in AIDS-related medical and psychosocial issues. Patients in both areas have immediate access to current information about AIDS and about available community services. Patients newly diagnosed with the syndrome are offered intense education about their disease and what they can anticipate during their clinical course. Crisis intervention can be delivered immediately after identification of emotional problems. Because much of the counseling is done by nursing and psychosocial support staff, burdens on housestaff are somewhat lessened. A final benefit is the management of media access to patients. Medical and nursing staff are able to help ensure that the message relayed by the media concerning AIDS is accurate and educational rather than sensational and alarmist.

San Francisco Community Services

The contribution of the San Francisco community agencies cannot be overstated. The Shanti project provides volunteer counselors for every newly diagnosed patient with AIDS in the city. Staff members work in the AIDS outpatient clinic and on the AIDS inpatient unit at the San Francisco General Hospital, coordinating patient access to these services. The Shanti Project also has organized an ongoing series of support groups for patients and their friends. Finally, and perhaps uniquely, it has cooperated with the City and County of San Francisco to make low-cost housing available to people with AIDS. The city leases units to Shanti Project, which then manages them. Patients in these units are monitored regularly by Shanti and additional assistance is provided by community agencies, if required. The centralization of housing facilitates the provision of these services. Furthermore, because patients live together in these residences, networks providing extensive support are established, which often decreases the need for inpatient acute hospital services.

The San Francisco AIDS Foundation provides a telephone hotline and physician referral lists. The foundation staff includes medical social workers who provide financial and social assistance to people with AIDS, and the foundation also operates a free food bank, again for pa-

tients with diagnosed AIDS. Probably the most important function of the AIDS Foundation is professional and public education. The foundation has sponsored many community forums for discussion of issues relating to AIDS therapy, sexual risk-reduction, and AIDS virus antibody testing.

The Hospice of San Francisco and the Visiting Nurse Association cooperate to deliver complete in-home nursing and attendant care for patients with terminal illnesses. Because of the large number of patients with AIDS in San Francisco, specific services for these patients have been made available by these agencies. Because agencies can deliver complex in-home care, the need for acute hospitalizations is reduced, and patients who choose to do so may die at home.

People with AIDS Alliance is a network of patients with diagnosed AIDS. This organization provides a broad spectrum of educational and recreational programs for persons with AIDS and has organized retreats and support groups. The organization has worked to make the professional and general public aware of the need to see persons with AIDS not as victims but rather as vital members of a community.

Exporting the San Francisco General Hospital Model

Although the system of health care described works extremely well in our community and facility, we realize that not all elements of the system will be possible or desirable in other settings. Some factors will limit the application of this system, including the number of patients seen and the resources available. Because the start-up costs for establishing a multidisciplinary AIDS service are considerable, there must be a large number of patients with AIDS. Hospitals caring for small numbers of patients may be able to incorporate required services effectively into existing systems. Where patients with AIDS are more numerous, coordinated services producing fewer and briefer hospitalizations may be cost-saving.

A second factor limiting the provision of dedicated services in hospitals is the fear—sometimes stated openly, other times covertly—that hospitals providing coordinated AIDS services will be seen by the public as "AIDS hospitals." In the case of private facilities, the concern is that this label may discourage referral of patients with other illnesses and result in major financial losses.

It is a challenge for hospitals to provide comprehensive, sensitive care for patients with AIDS. The system of care should not increase the suffering of the patients. Whereas not every hospital can be expected to make a commitment to provide comprehensive care, more should be encouraged to do so. All hospitals caring for patients must recognize and address the clinical variability of the manifestations, the multisystem nature of the disease, the intensity and complexity of therapy, and the profound psychosocial consequences of the disease.

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Bobbie Wilson 4/18/86

1. called upon daily to answer questions about what's going on w/ AIDS services
2. It's not a problem, but it's difficult to absorb with given staff secy, admin, clinical -- not area that gets funded
2. money, hundreds used 86 run, what kind of ^{other} services are needed? everything what's latest in AIDS care? what to ^{see} hospital unit, not not so interested in administ, politics
3. medical people
4. 2 Europe/International
 - (1) U.S.
NY
 - (3) just about every state



10
24

34,125

40% / week

program responsibilities

AAII

secretarial responsibilities

~~SRA III~~
(epidemiology)

Tasks

Program Coordinator

- (1) Responds to all visitor requests (2) arranges appts, tours, in with City and County (3) puts together packets forwarded ^{agencies, SFGH, and UCSF} to visitors needs; (4) ^{community agencies} meets them, follows through w/visit (5) ^{conference} package (6) Education's Training Sessions

AIDS File (Newsletters)

- (7) ^{need at} understands UCSF policies, programs, resources as well as AIDS activities (8) understands DPH/SFGH (9) understands AIDS service delivery system

visitors

program

Don't track

(7) conference

Sept

one

people

- (8) setting up AIDS contacts for visitors



What about position?

Don't necessarily need Admin Analyst

~~PAA + PAA~~

Program Coordinator, AIDS Services, SFCH

~~30%~~

Program Assistant

50% - PAA

Two positions

Clinical

administ

Faculty

~~RW Admin~~
Analyst
9
~~PAA~~
Admin
Nurse

10

AIDS

Questions for Community Agency Directors
re: AIDS Resource Program

1. What is your biggest problem related to requests for

- information
- education & training
- technical assistance

from people from communities outside SF?

2. What is the largest category of requests (by volume)?

3. What is the largest category of people seeking:

- information
- education & training
- technical assistance?

1. Can you identify the most common areas, geographically, in terms of requests for information?

5. What types of information do you get requests for most often?

6. What types of requests for education & training? ^{most often}

7. What types of requests for technical assistance? ^{most often}

8. What funding sources presently support your activities in:

Information
Education & training
Technical assistance?

9. Is the ^{current} support adequate to respond to requests from communities outside SF?

10. If not, how much more do you need?

11. Are you presently included

in program development or
fund raising in:

information
education & training
technical assistance?

12. Is it a priority for future?

13. How can the AIDS Resource
Program help?

14. How will (SF AIDS Foundation)
use #10, CCC?

Obtain name of Fiscal person
contact →

We will initiate purchases
orders/ → Accounting office → sends
with agencies → out

IX transfer (purchase order)

for year
Accounting office will purchase order along with
with need invoice

✓

Purchase what

15. What else can AIDS Resource Program
use do?