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The AIDS Challenge: A Psychosocial Perspective

Madelyn S. Plotkin, ACSW,* and Margaret Dietz Domanski, ACSW*

The Psychosocial Challenge

The acquired immunodeficiency syndrome (AIDS) is a multifaceted physiological, social, and emotional illness that challenges and taxes the health care professional's scientific and personal resources. The unique social and emotional situations that AIDS patients face make it imperative for health care providers to look at, through, and beyond the presenting physiological symptoms. Dr. Robert H. Moser, Executive Vice President Emeritus of the American College of Physicians, states that he "can recall no issue in [his] lifetime that has been more emotionally charged, intellectually challenging and downright frightening than the acquired [immunodeficiency] syndrome" (1). To deal with these challenges and to attain comprehensive care for persons with AIDS, health care practitioners must examine both physiological and psychosocial components of this disease (2,3).

Obstacles to successful treatment of the physiological and psychosocial sequelae of AIDS include:

1. The social stigma, isolation, and prejudice attached to the members of high-risk populations with or without the disease (bisexuals, homosexuals, intravenous dmg abusers, etc) (4,5).
2. Discrimination against those with disease, along with the general population's irrational fear of AIDS as "the unknown plague" (1,4,6). As Levine (7) reports:

   In addition to the epidemic of disease, there is a second, potentially even more damaging epidemic. The New Republic calls this phenomenon AFRAIDS...It is the [unfounded] fear of contracting AIDS through water fountains, handshakes, dishes, schoolrooms, workplaces, or casual contact with an AIDS patient, with someone who knows an AIDS patient, or even with someone in a risk group—usually a homosexual man.

3. Inadequate funding by government and private insurance programs to cover the costs of health care (1,8,9).
4. The hesitancy or resistance among some health care providers to work with this particular patient population. As stated by Volberding and Abrams (10) of San Francisco General Hospital:

   Historically physicians have tacitly accepted an occupational risk of exposure to fatal infectious disease. In fact, much of the prestige and respect accorded to physicians can be directly traced to public regard for the physician's willingness to assume increased personal risk. Only the current generation of physicians, trained after the development of effective antibiotics, has never confronted this potential occupational risk.

Without good staff education, the American Hospital Association predicts that staff concerns about AIDS will rise as the number of AIDS patients increases (11).

AIDS is a complex issue. It is a disease that results in progressive physical and emotional deterioration of its victims. The physical and psychosocial pathogenesis of AIDS is illustrated in Figs 1 through 3. Fig 1 illustrates the clinical course of infection with the human immunodeficiency virus; Fig 2 illustrates the psychosocial problems that coincide with physiological symptomatology over the natural history of the disease; and Fig 3 demonstrates how patient access problems to health care providers exacerbate and compound across the continuum of AIDS (12). The existence and/or exacerbation of psychosocial symptoms across the natural history of chronic diseases is not unique to AIDS. Rather, the lack of personal, societal, and professional resources available to patients and health care providers hinders the latter's effectiveness in intervention efforts. As the AIDS patients' psychosocial, financial, and health care needs multiply, accessible services and agencies to address these demands diminish and/or close (4,12,13). The challenge to health care professionals is how to most effectively meet the complexity of problems faced by persons with AIDS. "The disease and its sequelae are overwhelmingly physically debilitating. The transition from being a young, active, vigorous person to being a debilitated, symptom wracked, possibly dying person...requires a massive adjustment" (2). The importance of utilizing a broad spectrum, multidisciplinary team in helping persons with AIDS can make this transition smoother.

Assumptions in Psychosocial Care

To ensure comprehensive patient care, several assumptions can be made. These assumptions, which serve as a basis for patient assessment, intervention, and treatment program design, include:

1. AIDS is a progressive, debilitating, terminal disease through the course of its natural history (Fig 1).
2. Disease progression, from the asymptomatic carrier through the terminal event, compounds and exacerbates social, emotional, and economic problems (Fig 2) (2,3,6,12).
3. Prevention of the disease and public education are crucial to control.

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4. Education of the person with AIDS, his/her significant others (ie, family, friends, colleagues, peers), and health care staff is vital to effective patient care management (2,4,6,14).

5. The care of persons with AIDS can become highly stressful to both medical and ancillary staffs (1,2,5,11,15).

**The Multidisciplinary Challenge**

The most productive means for combating this multifaceted disease is through engaging the wide base of professional resources already within hospital systems. Internal resources can be productively mobilized to meet the demands of unmitigated care. When instituted at the onset of care, a multidisciplinary team approach can most effectively and efficiently handle the broad-spectrum aspects of caring for AIDS patients. Team composition most often represents staff trained and certified to fulfill the following care needs: education about disease transmission, medical care, mental health care, nutritional support, patient education, peer support, rehabilitation, social and environmental concerns, and spiritual care.
Meeting the Challenge

To function most efficaciously on behalf of patient care, the designated interdisciplinary team members are advised to:

1. Engage the patient and significant others in education, treatment, and planning from diagnosis through the terminal event. These activities can occur in a one-on-one or group format, depending on everyone's needs (2,5,16).

2. Actively involve the patient and significant others in talking with the health care team about the disease, treatment recommendations, and process of care. Always ask for questions as a means to engage the patient (17).

3. Communicate regularly with team members on patient management plans and the personal stresses inherent in intensive work with AIDS patients and their significant others (15-17).

In meeting the complex psychosocial needs of persons with AIDS, medical and ancillary staffs are most effective if they have addressed the following characteristics of each AIDS patient: ongoing understanding and acceptance of diagnosis,
## Case Report

A 36-year-old homosexual, white male came to the Infectious Diseases clinic at Henry Ford Hospital four months after a confirmed diagnosis of AIDS. He had lived in Texas for 15 years to "hide" his homosexuality from his family, but had returned to his parents' home after learning he had AIDS. At presentation, the patient faced the following psychosocial problems:

1. Informing his family of his lifestyle and the diagnosis and prognosis of AIDS.
2. Dealing with drug abuse (cocaine, intravenous amphetamines, and marijuana).
3. No income or medical insurance as a result of losing his job because of his diagnosis.
4. A low threshold for stress and anxiety exhibited by chemical dependency, crying spells, and temper outbursts.

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### Fig 3

- **Patient resource access problems along the natural history of human immunodeficiency virus (HIV) disease.**
To assist the patient and his family in coping with these problems, both hospital and community resources were employed. The Infectious Diseases physician and hospital social worker met with the patient and his family in a group meeting. The physician addressed the patient's direct medical course, and the social worker addressed issues regarding the patient's adjustment to his changing life-style, diagnosis, and prognosis. The patient's family was tearful upon learning of the diagnosis, yet suspected he had AIDS due to his weight loss, lack of energy, and behavioral changes. Throughout later medical appointments, the physician and social worker met with the patient and his family to discuss his progress and to educate them about treatment and disease transmission and to provide counseling on adjustment to his illness.

Other members of the health care team assisting in patient care included 1) clinic and floor nurses, who addressed the patient's direct care needs, teaching, and reassurance; 2) the psychiatrist, who assessed the patient's behavioral changes (agitation and anxiety) and monitored his medications; 3) the chemical dependency program, which addressed the patient's polysubstance abuse problem; 4) the pharmacy, which evaluated the various pharmaceutical combinations utilized; 5) dietary personnel, who counseled the patient on nutrition; and 6) occupational/physical therapists, who taught the patient about energy conservation, strengthening, transfer techniques (ability to move self from one surface to another, ie, bed to chair), and home safety. The social worker, who coordinated the health care team's efforts, also helped address the patient's financial and medical insurance needs, ongoing counseling needs (for both patient and family), and discharge planning.

Community linkages further maximized the patient's functioning and independence. The Social Security Administration and the Department of Social Services provided financial assistance and medical insurance. (Problems had developed when the patient earned more than $300/month on Social Security and became ineligible for Department of Social Services medical insurance. He then had to pay for medical care, which was exorbitant.) The Wellness Networks, Inc, provided therapy through their AIDS support group and companionship through the buddy system. The Home Care Department informed the patient about instruction at home regarding medication schedules and home infusion therapy. This was available on an extremely time-limited basis and for teaching only.

The outcome of this multidisciplinary, collaborative effort was positive. The patient's family was able to accept his homosexuality and diagnosis of AIDS and became actively involved in his care. The patient's coping mechanisms were reinforced, and he seemed to have an improved sense of self. Through the implementation of financial support benefits and medical insurance, the patient developed a sense of financial independence and became more active in decisions regarding his care. As a whole, this comprehensive care enabled the patient and his family to actively participate in treatment planning and decision-making.

This situation exemplifies how early, multidisciplinary intervention with the patient and his/her significant others will make it more likely that 1) patients receive comprehensive care, 2) treatment goals designed by the medical team are met, 3) patient compliance is improved, 4) the patient and significant others have greater involvement in the decision-making process, and 5) prompt identification and timely intervention of risk management issues help to influence better quality of care.

Conclusion

To fulfill the insidious psychosocial demands of treating persons with AIDS, health care providers must be creative problem-solvers. Caregivers must look beyond traditional professional roles to become enablers, advocates, listeners, and compassionate providers. The multidisciplinary team allows for creativity, collaboration, and psychological strength to both providers and their patients. The challenge to all health care professionals in meeting the multiple care needs of persons with AIDS is eloquently summarized by Dr. Molly Cook (18):

The scientific and logistical challenges posed by the AIDS epidemic are enormous. . . . The disease raises for providers and laypersons alike images of pestilence and physical destruction, perhaps more intensely than any other illness of the modern era. Our response will mark us as either technicians or healers.

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