Coping With Grief in Response to Caring for Persons With AIDS

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AIDS has or will affect virtually every professional health care provider. Occupational therapists are in a key position to identify and intervene with the social and occupational changes and losses commonly experienced by this patient population. Suggestions are provided to assist occupational therapists in helping patients with AIDS maintain meaning in their lives. Strategies to help occupational therapists prevent burnout resulting from the emotional stress related to caring for patients with AIDS are suggested as well.

The AIDS epidemic affects every sector of the health care provision system and, consequently, affects every member of the health care provision team, personally, professionally, or both. As members of the helping professions, we must continually prepare ourselves to provide optimal care. This ongoing preparation and provision of services requires us to familiarize ourselves with the current research findings on AIDS, to understand the needs of persons with AIDS, and to examine our own feelings and responses to this patient population.

Description and Incidence of AIDS

AIDS is the most severe disease state of a continuum of illnesses related to infection by the retrovirus HIV (Flaskerud, 1989). It is a life-threatening condition characterized by a serious impairment of the cell-mediated branch of the immune system, which leaves the person defenseless against infections and certain forms of malignancies. The two diseases most commonly found in AIDS patients are Pneumocystis carinii pneumonia, a lung infection caused by a parasite, and Kaposi sarcoma, a rare form of cancer of the blood vessels. Although now known cure exists for AIDS, experimental treatments with some antiviral agents have proven to prolong patients' lives. Nevertheless, the mortality rate of AIDS patients is 100% (Flaskerud, 1989).

No other disease in our lifetime has had such a global effect. The statistics are staggering. In New York City, AIDS is the number one killer of men between 24 and 44 years of age and of women 25 to 29 years of age (Kloser, 1987). Nationwide, 47% of persons with AIDS are 30 to 39 years of age, 21% are aged 20 to 29 years, and 21% are aged 40 to 49 years. Of the 99,936 cumulative cases reported as of June 30, 1989, 98,255 are adults, and 91% of these are men. Of the 1,681 children (under 13 years of age) with AIDS, 55% are boys (Centers for Disease Control, 1989a). By 1993, it is estimated that, without treatment, 365,000 AIDS cases will be diagnosed in the United States (A. Fauci, personal communication, March 22, 1989). This prediction is based on the estimation that 1.5 to 2 million Americans have already been infected with the virus and that the incubation period is approximately 7 years (Selwyn, 1986).

HIV transmission is well documented: It results from the exchange of body fluids, specifically blood and semen. Since the onset of the AIDS epidemic, five groups have been identified as being at risk: (a) sexually active homosexual and bisexual men with multiple sex partners, (b) present or past users of intravenous drugs, (c) patients who have been transfused with blood or blood products, (d) heterosexual partners of persons with AIDS or of persons infected...
with HIV, and (e) persons with hemophilia (Popkin, Madden, Laurich, & Sherlock, 1983). The highest risk behaviors are those associated with homosexual and bisexual men and intravenous drug users (Leibowitz, 1989). AIDS from intravenous drug use accounts for most of the AIDS cases in heterosexual men, women, and children (Centers for Disease Control, 1989b). The only high-risk group that is now protected from AIDS is blood transfusion recipients. This is the result of the effective screening (enzyme-linked immunosorbent assay [ELISA] and Western blot assay) of donors’ blood. This safeguard, however, is only as effective as the diligence and consistency with which the tests are conducted.

As virulent as HIV is, it is not transmitted by casual contact such as shaking hands, hugging, or sharing articles. Additionally, although the virus has been isolated in tears, saliva, and sweat, there is no documentation of its transmission through contact with these fluids. These facts must be accepted and understood by the public and by health professionals to eliminate irrational fears. If beliefs are not based on fact, or if individuals are skeptical, then incongruence between verbal and nonverbal behaviors is probable. Health professionals must exercise self-protection, however, and the need to do so can be explained to patients without making them feel alienated (Denton, 1987).

This article focuses on insights the occupational therapists may gain by examining the losses encountered by persons with AIDS and on the challenges that occupational therapists must face in assisting those with AIDS to live as productively and fully as possible.

The Patient’s Response to AIDS

Feelings of Personal Loss

As soon as a person is diagnosed with AIDS, AIDS-related complex, or seroconversion, he or she contemplates multiple losses. The person recognizes immediately, for example, that the disease is fatal. Many may have already experienced the death of family members, friends, or lovers due to AIDS. Almost equally disturbing is the anticipation of a progressively disabling condition in which physical and cognitive abilities deteriorate. Many persons have said that in the initial stage of the diagnosis, they felt they were on an emotional roller coaster, because they felt fine sometimes and fearful of incapacity and a horrible death at other times.

Interventions at the initial stage focus on helping the patient use effective coping mechanisms and maintain a productive life. An important part of the occupational therapy assessment is to ascertain what is important to the patient at that point in his or her life (Pizzi, 1989). The therapist may ask, What, in the patient’s opinion, makes his or her life most meaningful?

We have found in our experience that the vast majority of persons with AIDS want to continue to lead productive lives that provide satisfaction and enhance self-esteem. Work helps to foster feelings of normalcy and productivity, and patients typically continue to work in their chosen field until they are no longer able to do so. Disclosure of the diagnosis of AIDS to co-workers varies depending largely on the person’s sense of trust and support in his or her workplace.

For many patients, the perception of being in control, or of at least having the ability to influence a particular outcome, facilitates the ability to cope. Conversely, high levels of anxiety or uncertainty prevent effective coping. Unless the patient abdicates responsibility, he or she can be supported in making decisions about socialization, work, activities, and interests that provide normalcy in his or her life.

Altered Social Roles

Other social roles of persons with AIDS may also be affected. As mentioned, the disease usually affects those in the most active years of their lives. The patients may experience discrimination within or rejection from their family or the larger social system when the cause of the disease is evident. The rejection and consequential estrangement and isolation make the fulfillment of the social roles of friend, lover, family member, and colleague difficult, if not impossible, to maintain. Identity and self-esteem can be affected markedly by the changes that occur in stamina, appearance, and psychosocial and cognitive functioning. The vibrance typically associated with the young and middle adult years is challenged by the possibility of repeated infections, neurological impairment, and apathy.

Several studies have documented the effects of the changes in relationships with family, significant others, and, sometimes, caregivers. Rubinow (1984), a psychiatrist caring for AIDS patients at the National Institutes of Health, reported that AIDS patients had to deal with a loss of social support manifested by the abandonment by family and friends. This loss took place at a time when the need for support from loved ones was essential. Deuchar (1984) showed that in addition to being rejected by society because of membership in the gay community, the AIDS patient may experience nonspecific and obvious rejection from professional and nonprofessional hospital staff. Durham and Hatcher (1984), in working with AIDS patients in critical care units, observed that each of these patients lacked support systems. The researchers concluded that this resulted from the pa-
tient's "having maintained a life-style that alienated his family or having been unsuccessful in establishing an enduring, meaningful relationship with another person" (p. 302). They also noted that, once a diagnosis of AIDS was confirmed, the patients experienced more fragmentation in support systems because of the stigma and fears associated with the disease. Christ and Wiener (1985) wrote that one of the main worries of the AIDS patient was fear of social abandonment and of isolation, not only from society and from work colleagues, but also from friends and family members.

**Threatened Employment**

Many AIDS patients fear a loss of work. This anticipated loss might involve the fear of discrimination in the workplace due to the moral judgments of the employer and co-workers. Loss of work is also feared because of expected physical limitations or cognitive impairment and the anticipated financial ramifications of anticipated sick leave. Most AIDS patients experience episodes of general malaise and fatigue. Because of the alterations in the immune system, susceptibility to various infections is increased. The most pronounced cognitive changes are forgetfulness and decreased concentration.

The threat of loss of work is real—Persons with AIDS have been fired, despite the protection guaranteed by both the Federal Rehabilitation Act of 1973 and state statutes (Gostin, 1989). The loss of a job not only alters income and financial independence but also affects the availability of health insurance, which is imperative to cover health care costs. Unemployment is also damaging to self-esteem; social norms and expectations dictate fulfillment of the role of worker during the young and middle adult years. Although better work protection is available today as a result of battles against discrimination, a recent survey (Blending & Donelan, 1988) found that 25% of those people polled indicated they would refuse to work with someone with AIDS. Additionally, 25% believed that an employer should have the right to fire a person with AIDS (Blending and Donelan, 1988).

**The Occupational Therapist's Response to AIDS**

In view of the devastating effects AIDS has on relationships, the occupational therapist has an important role in helping patients develop a new social network, solidify an existing network, or maintain a sense of belonging to a network. The therapist must always consider, however, the physical and cognitive limitations imposed by the disease. Another role of the therapist is to help patients express their grief over social losses (i.e., rejection by family members or significant others). For many patients, the quality of life becomes richer as they focus on giving and receiving all that is possible each day.

Regardless of the quality of care that is provided, occupational therapists and other health care providers will lose many patients as a result of the 100% mortality rate associated with AIDS. Consequently, they may experience grief reactions similar to those faced by the patients. These reactions can be manifested through depression, avoidance, anger, or feelings of helplessness and guilt, as well as various somatic complaints.

Because of the disease's high mortality rate and because it affects primarily young people in the most productive phase of life, therapists may face various stressors that require intervention. One stressor is the conflict created by providing services to someone who will eventually die, and the resulting contradiction between the professional responsibility for restoring function, occupational role, and relationships (i.e., helper versus fatalist). Therapists may feel ineffective at making a difference in the patient's care. In addition, complications may arise as therapists attempt to cope with their own values, professional ethics, and irrational fears regarding the infectious nature of AIDS.

Another stressor for occupational therapists is bereavement overload caused by exposure to several terminally ill patients over a short period of time and grief for their deaths or marked disability. To maintain effectiveness, therapists must develop ways to prevent professional burnout. One strategy is a weekly support group run by a mental health professional. Such a group can facilitate the exploration and expression of feelings about caring for persons with AIDS, their families, and significant others. Through sharing, caregivers realize that they have similar concerns about the effect of their work, not only on themselves but also on their families. When a death occurs, the group can provide a place to express grief and receive support.

Another strategy for reducing burnout is the use of multidisciplinary team meetings. Such meetings provide important feedback to each member of the health care team, making clear how each discipline can contribute to the patients' care. This reduces duplication of services and role conflicts. Members of the health care team also use these meetings to provide support for one another and to facilitate communication between disciplines. Close collaboration among disciplines not only leads to better care of patients but also helps caregivers cope with the detrimental effects of grief associated with providing care to persons with AIDS.
Summary

The AIDS epidemic will affect every area of the health care provision system for the foreseeable future. AIDS affects many aspects of the lives of those with the disease, particularly their social roles, relationships, and work. The Occupational therapist’s role is to help the person with AIDS cope with the many restrictions imposed by the disease, while finding ways to continue with a productive life. Grief reactions are common among health care professionals who treat AIDS patients. Occupational therapists must use effective measures to cope with their own emotional responses and to implement specific activities to reduce stress and prevent burnout.

References


