Psychosocial Occupational Therapy Intervention With AIDS Patients

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The role of psychosocial occupational therapy with AIDS patients is explored. The clinical picture is defined, information regarding the transmission, incidence, diagnosis, and treatment is presented, and the impact of the illness on the developmental life cycle is described. The occupational behavior framework is used to guide evaluation and intervention and case examples are provided. Finally, fears and issues affecting therapists working with these patients are explored.

The World Health Organization, in November 1983, acknowledged acquired immune deficiency syndrome (AIDS) as a worldwide problem. Accurate reporting has been carried out in the United States since 1981, and as of March 1, 1988, 54,233 cases have been reported to the Centers for Disease Control in Atlanta (Gable, Barnard, Norko, & O’Connell, 1986; Centers for Disease Control, Atlanta, personal communication, March 1988).

AIDS is a complex disease process characterized by a collapse of the body's natural immune system. A virus, now labeled human immunodeficiency virus (HIV), has recently been discovered by investigators as being linked with AIDS (New York State Department of Health, 1987).

Most AIDS cases are found in metropolitan areas; yet cases have been reported in all 50 states (and in all ethnic groups). AIDS occurs most frequently among male homosexuals and bisexuals and intravenous drug users. However, it is also seen in the female sexual partners of men with AIDS or at risk for AIDS, children who acquired AIDS at birth from infected mothers, and persons with hemophilia who received transfusions of infected blood or blood products. Most persons with AIDS are in their early twenties to midforties—an age group that does not expect to develop a terminal illness (Christ & Wiener, 1985; New York State Department of Health, 1987).

AIDS is not an easily transmissible disease. Evidence to date indicates that the virus is spread only through blood-to-blood and semen-to-blood contact. Although it was originally feared that the virus could be contracted through casual methods, evidence indicates that the disease cannot be transmitted through casual contact such as sneezing, coughing, or sharing household items with a person with AIDS (New York State Department of Health, 1987; Ungvarsiki, 1985).

Presently, there is no definitive test to diagnose AIDS; nor is there a vaccine or a cure. However, a blood test has been developed that detects antibodies to the HIV. Some people infected with the virus have no symptoms at all, whereas others may develop mild or temporary symptoms that disappear a few days or weeks after exposure. About 20% of those infected with the virus have developed the severe and fatal form of the disease. The incubation period for AIDS ranges from a few weeks to many years (New York State Department of Health, 1987).

Because AIDS is a severe immune defect, persons with AIDS are open to a number of opportunistic diseases. About 85% have one or both of two rare diseases: pneumocystis carinii pneumonia, an infection of the lungs, and Kaposi's sarcoma, a rare type of cancer occurring on the skin or in the mouth. A variety of antiviral drugs are showing some promise of killing...
or inhibiting the HIV, but most treatment is presently aimed at specific opportunistic infections or cancers (New York State Department of Health, 1987).

Another syndrome associated with the HIV is AIDS-related complex (ARC). The symptoms categorized as ARC are associated with the HIV but are not components of the Centers for Disease Control’s definition for AIDS. Some of the symptoms seen with ARC are continued fever, swollen lymph glands, bouts of diarrhea, and thrush. Persons with ARC may die of their infections without ever developing full-blown AIDS (New York State Department of Health, 1987).

**Effect of AIDS on Life Roles and Tasks**

Patients with AIDS require a massive adjustment upon diagnosis of the syndrome. They are suddenly faced with the issue of contagion and must worry about transmitting the disease to others, and dealing with the responses and fears of lovers, parents and other family members, co-workers, and the public. They must also be concerned about protecting themselves from opportunistic diseases. During the first 100 days after the diagnosis the AIDS patient is vulnerable to reactive psychiatric symptoms, such as depression, anxiety, and preoccupation with the illness. This vulnerability to AIDS-related distress is at least as serious and widespread among ARC patients as it is among AIDS patients. In a comparative study of gay men with AIDS \( n = 89 \), gay men with ARC \( n = 39 \), and gay men with no physical symptoms \( n = 149 \), ARC patients scored at least as high as, if not higher than AIDS patients on multiple parameters of both general and AIDS-specific distress. This is believed to be secondary to the persistent uncertainty about developing AIDS (Holland & Tross, 1985).

Other issues may require adjustment: The patients may not have resolved issues regarding their homosexuality or drug abuse. Additionally, because the public is ambivalent about the illness and the major high-risk populations who contract it, AIDS patients tend to be denied some of the psychological benefits of the sick role that other terminally ill patients receive. For example, because of the fear of contagion, AIDS patients are often isolated and have difficulty obtaining benefits, employment, and care. Moreover, public fear and anxiety about homosexuality and drug addiction can contribute to a social rejection of the patient (Christ & Wiener, 1985).

AIDS patients also need to cope with declining function in physical, psychosocial, and cognitive functioning. General physical problems include weight loss, progressive weakness, and decreased endurance. Denton (1987) cited evidence that 40% of AIDS patients manifest neurological impairment such as paraparesis, sensory neurological impairment, peripheral neuropathies, and dysphagia. Additionally, recent studies indicate that the HIV directly affects the central nervous system and may cause psychiatric symptoms such as dysphoric mood, apathy, impaired concentration and memory, and anxiety, before other signs of immune deficiency, cognitive impairment, or neurological abnormalities emerge. For example, patients with AIDS who had been relatively well adjusted and had no psychiatric history developed depression, major affective disorder, and psychosis before acquiring other medical AIDS/ARC-associated conditions (Perry & Jacobsen, 1986).

Because this disease usually strikes persons in their early to middle adulthood, it has a huge impact on the developmental tasks of this period. Overall, the young adult (25–45 years old) is expected to enter new roles at work, home, and in society and develop the values, attitudes, and interests attributed to these roles (Christ & Wiener, 1985; Murray & Zentner, 1979).

In family relationships, the young adult is expected to be independent of the parents' direct care although he or she may receive some indirect assistance. Work becomes a major focus and the young adult is expected to choose an occupation that will provide a livelihood for him- or herself and possibly for dependents. Much time and energy is focused on this process, and work becomes a central part of the adult self-concept. Leisure is now viewed as a time of earned recreation and relaxation from work and often takes the form of exercise, sports, and hobbies (Murray & Zentner, 1979).

During young adulthood, a person has reached his or her optimum mental and motor functioning. Thinking and learning are objective, realistic, and problem-centered, and the person can cognitively combine or integrate steps in addition to considering alternatives and synthesizing information. Emotionally, the young adult is in Erikson's (as discussed by Murray & Zentner, 1979) developmental crisis of intimacy versus self-isolation in which he or she will form an intense commitment to another person, cause, or institution or become withdrawn, lonely, or self-centered. Sexuality is powerful, and there is a need to find adequate and satisfying sexual experiences (Murray & Zentner, 1979).

Patients diagnosed with AIDS or ARC are suddenly thrown to a much later developmental period without adequate opportunity to master the life tasks for young adulthood. At a time when the young adult is expected to be independent from his or her parents and establish an occupation, he or she is now facing less financial independence with increased depen-
Physiologically, the patient with AIDS is often very weak and ill at a time when he or she should be functioning at peak efficiency. Cognitively, the thought processes can be severely disabled if there is any neurological manifestation of the illness. Emotionally, the patient may not have the energy or opportunity to seek and form intimate relationships and may feel isolated and lonely and withdrawn. Although sexuality is usually powerful at this stage, the person with AIDS may have a very weakened sexual drive or may experience guilt or conflictual feelings about practicing sexual intercourse since it is a major method for transmitting the disease.

All of these changes interrupt every facet of life for the young adult with AIDS/ARC. The young adult is forced into a developmental period usually experienced by persons who are 20-40 years older, he or she has to face retirement from work, separation and/or the loss of intimate relationships, and decreased physiological and mental functioning.

Despite the alarming facts regarding the disease, studies have shown that patients with AIDS are surviving for significant periods of time after diagnosis. A study of 178 patients conducted in Britain between 1982 and 1985 showed that three quarters of the patients died up to 28 months after diagnosis. With the development of the new drug AZT these time periods are increasing (Guiles & Allen, 1987). Patients will therefore often survive for a considerable length of time after diagnosis and will often be well enough to live outside of the hospital with varying amounts of assistance (Guiles & Allen, 1987).

Because the syndrome has such a debilitiating effect on the patient's ability to perform the physical and psychosocial aspects of work, leisure, social interaction, and self-care and because the patient needs to cope with these changes for 2 or more years, occupational therapy intervention is of great benefit.

Occupational Therapy Intervention

My review of the occupational therapy literature revealed that only three articles on AIDS have been published (Caestle, 1986; Denton, 1987; Guiles & Allen, 1987). I incorporated the information from these articles with literature from other allied health professions on AIDS. During the review I also found that the occupational behavior model, which had previously been incorporated with terminally ill patients, can be used in the treatment of patients with AIDS.

Principles of Occupational Behavior

Kielhofner defines occupation as "the purposeful use of time by humans to fulfill their own internal urges toward exploring and mastering their environment that at the same time fulfills the requirements of the social group to which they belong and personal needs for self-maintenance" (Kielhofner, 1980, p. 659). Through the course of normal development people explore their environment and make choices. However, terminal illness disrupts this process. The ability to control and master life situations ceases and life goals may be abandoned. Temporal adjustment to a shortened life span and to the present, with its problems, may be difficult. Physical, psychosocial, and cognitive disabilities can limit a person's ability to explore and master his or her environment. This is especially a problem for patients with AIDS since most are in the early to middle adult period of their life, and have chosen or are beginning to choose an occupation and have formed or are beginning to form enduring relationships. The younger ones among them are still solidifying their identity. Additionally, not only may they be partially or completely unable to fulfill the requirements of their social group, they may be shunned by members of society, not only for their serious illness, but also because their illness labels them as people having a different sexual orientation or having an addiction.

For example, A., a 35-year-old homosexual man, 2 years after he had received a diagnosis of AIDS, was severely emaciated, had peripheral neuropathy, and was confined to a wheelchair. He was enrolled in a weekly outpatient support group for persons with AIDS, which was co-led by a psychiatric resident and an occupational therapist. Because of generalized muscle weakness, he did not have the strength and endurance to care for any of his needs and required a 24-hour home health aide. This man, who had been a stand-up comedian until 4 years earlier, now stayed home all day, limiting his activities to watching television, and he had become very depressed. He was shunned by the members of his family, who were hurt and angry after learning about his homosexuality at the time of diagnosis. Many of his friends had died of complications from AIDS. This man was no longer able to explore and master his environment and he was shunned by or lost contact with his small social group.
Evaluation and Treatment—Occupational Behavior Model

Evaluation. In the evaluation phase the occupational therapist formally assesses role performance and addresses treatment to those areas in which the patient prefers to remain in control. The patient’s present skills and deficits (both physical and psychosocial) are evaluated in the areas of work, leisure, activities of daily living and with an emphasis on the areas the patient wants to maintain or improve. If there is severe weakness, the patient may want to build up his or her strength and endurance in order to carry out specific activities. If the patient is depressed, he or she may want to work toward improving his or her psychosocial functioning to return to the highest level of functioning possible.

Evaluation should also address the three subsystems (volitional, habituation, and performance) outlined in the occupational behavior model. Because of the disabilities that result from the physical, neurological, and psychological opportunistic diseases, the components of the three subsystems may undergo extreme changes (Kielhofner & Burke, 1980).

In the volitional subsystem, the therapist would evaluate the patient’s personal causation (image of him- or herself as a competent or incompetent person), valued goals, and interests. With the disruption in accomplishing or maintaining specific developmental milestones, such as financial independence, the patient may experience a negative change in his or her sense of competence and goals and interests. In the habitual subsystem, the therapist would assess the patient’s habits and internalized roles. Habits and roles that have been incorporated into daily life may now be difficult to accomplish. For example, independent self-care habits could be limited by a physical disability that resulted from an opportunistic illness, or a patient may no longer be able to fulfill selected life roles such as a worker role. Finally, in the performance subsystem, the therapist would assess the patient’s present skills. The motoric, psychosocial, cognitive, and sensory aspects of the skills could be dysfunctional. For instance, limited motor ability could affect a person’s ability to complete a self-care task. After a thorough evaluation, the next aspect would be to assist the patient in setting concrete, measurable goals that reflect the time constraints imposed by a terminal illness (Pizzi, 1984).

Treatment. Despite the severe life changes imposed by a terminal illness, occupation, as the tool of the occupational therapist, can enhance the quality of life for AIDS patients by assisting them to develop skills, set priorities, maximize occupational roles, and gain a sense of mastery and competence over the present environment, the self, and the disease process (Pizzi, 1984). For example, A., because his cognitive functioning and speech were still intact, was encouraged to tell his comedy routines into a tape recorder. A. enlisted the help of a friend to write down the jokes, hoping to get them printed for fellow comedians or possibly published. In this way, he was able to enhance skills that had been abandoned, maximize his role as a comedian, and gain a sense of mastery over his goals, his environment, and the disease.

More specifically, the occupational behavior frame of reference (Kielhofner, 1980; Kielhofner & Burke, 1980) can be incorporated into the treatment of the AIDS population, as it would be with any other population, through assisting the patient to move through a process that begins with exploration and leads to competency and achievement in physical, cognitive, and psychosocial tasks (Kielhofner, 1980). This method allows for trial and error, which is essential for developing problem-solving and decision-making skills (Tigges & Sherman, 1983). This process also addresses the three subsystems through assisting the patient in acquiring skills, forming roles and habits, and developing interests, goals, and a positive sense of personal causation. I have incorporated Kielhofner’s (1980) framework with the case study described below.

Another patient, G., a 28-year-old, single, white, heterosexual woman, with no prior psychiatric history, was admitted to an inpatient psychiatric unit for adults with acute problems with a 1-week history of labile and elated affect, grandiose delusions, auditory hallucinations, agitation, hyperactivity, sexual preoccupation, and numerous spending sprees. Prior to admission the patient had been living with her boyfriend in an apartment and had been working as a pharmacist in a major metropolitan hospital. The patient’s condition was initially diagnosed as bipolar affective disorder—manic phase, and she was treated with a variety of medications, including lithium, none of which had positive effects. As the patient continued in treatment, she began to develop fevers and weight loss in addition to psychosis and disorientation. Although initial medical tests were nonconclusive, later tests showed pneumocystis carinii pneumonia. At this time the patient’s boyfriend acknowledged he was bisexual and had probably transmitted the HIV to her.

After her mania subsided, G. began to regress physically, cognitively, and psychosocially. She had been very attractive, but now she began to lose weight and was unable to consistently tend to her grooming and hygiene needs. Although her periods of regression were increasing, she did have lucid periods in which she would become quite depressed about her situation. One look in the mirror would intensify her...
depression. Her clothes had become much too large for her, her hair had lost its style, and she no longer continued her routine of applying makeup and manicuring her nails. Since she stated a desire to become more feminine again, a goal was set to increase her independence in self-care and grooming.

It had been quite a few months since she had tended to these needs, and in the interim she had lost some of the cognitive skills (judgment and sequencing) necessary to carry out these tasks. Therefore the process began with exploration and experimentation with different kinds of makeup, nail products, and hair styles. Although she required relearning and assistance initially, G. was able to become more competent with practice. A visit to the hospital thrift shop was arranged where G. purchased appropriate clothing. Eventually G. was able to carry out these tasks independently and continued to do so as long as her cognitive ability permitted. Although her health continued to slowly decline, she was able to master a goal that was important to her.

**Issues for Therapists Working With AIDS Patients**

Working with persons with AIDS can raise many fears and concerns in the occupational therapist. The fear of contagion, although unwarranted, presently appears to be the most widespread and persistent issue for several reasons.

First, there has been an unrealistic desire for absolute proof of absence of risk. Secondly, it remains difficult to believe that a virus capable of causing a cruel and fatal disease is not easily transmitted. Thirdly, because the HIV has been isolated from other bodily fluids, such as saliva, tears, and urine, there is concern that contact with these fluids can lead to infection. However, the evidence to date is that only blood and semen are involved in the transmission of the virus. Finally, there has been an overemphasis on isolated and unusual cases of HIV transmission in health care workers. On further inspection of these cases, it has been documented that blood-to-blood contact was involved ("AIDS: Health Prevention," 1987; Friedland & Klein, 1987). Infection control procedures for the therapist include hand washing after all contacts with the patient and the use of sterile equipment and materials during contact with blood or bodily fluids. Infection control for equipment consists of cleaning the equipment with a 9:1 solution of water and household bleach (Denton, 1987).

Several other fears and issues, in addition to the fear of contagion, can influence the therapist's relationship with the patient with AIDS. One is fear of the unknown. To counteract the tendency to treat the person with AIDS as the "other" (Dunkel & Hatfield, 1986), the patient must be recognized as an individual and not as a member of a stereotyped group (Denton, 1987). Another issue is fear of dying. Working with a young person with a terminal illness evokes unresolved feelings regarding one's own mortality. Working with AIDS patients can also raise issues regarding a fear of homosexuality (homophobia). Prior to being diagnosed with AIDS, a person's sexual preference may not have been known or not have been an issue. The AIDS label associates a person with having a same-sex preference or as being an IV drug user, and this raises questions regarding one's own beliefs and values. Therapists can also overidentify with the patient and have difficulty maintaining an objective point of view or may take on a magical belief of omnipotence. The therapist could also experience anger because of feelings of helplessness, fear, and guilt in treating a terminally ill patient. This can result in blaming the patient for having a disease that defies traditional treatment (Dunkel & Hatfield, 1986). Education regarding AIDS, peer support groups, and ongoing supervision can facilitate a therapist's ability to recognize these issues and deal with them in an appropriate, productive manner. These forums can also enable the therapist to ventilate other fears and concerns associated with this challenging population.

**Summary**

AIDS has been identified as a worldwide problem and a highly debilitating and fatal disease. The epidemiology and clinical picture of AIDS has been described.
The disease usually strikes persons in their early twenties to middle forties and greatly influences and interrupts the regular developmental tasks of this period. With occupational therapy's focus on promoting independence in developmental tasks, the role of our profession is emerging as a vital one.

Occupational therapy evaluation and intervention, using the occupational behavior frame of reference (Kielhofner, 1980; Kielhofner & Burke, 1980), can be applied to the AIDS population. In evaluation, the therapist formally assesses role performance via the three subsystems with an emphasis on those areas in which the patient wants to remain in control. Once realistic goals are established, the therapist addresses intervention by assisting the patient to move through a process of exploration to competency to achievement in physical, cognitive, and psychosocial tasks. This process was highlighted in this article with case examples that focused on psychosocial intervention. Working with persons with AIDS also raises many issues and concerns for the therapist. These issues were addressed, and realistic methods to explore these issues were provided.

With all of the physical, psychosocial, and cognitive aspects of the AIDS illness, working with the AIDS population can be a vital role for occupational therapy. However, before successfully assuming this role, occupational therapists need to become knowledgeable about the medical and psychological aspects of the illness, explore the application of occupational therapy theories and treatment with this population, and address the many fears and concerns in working with patients with AIDS. Through application of their knowledge occupational therapists can demonstrate the value of their services for this very challenging population.

References


