AIDS: Guidelines for Occupational Therapy Intervention

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Key Words: acquired immunodeficiency syndrome • immunologic diseases • occupational therapy services

Acquired immune deficiency syndrome (AIDS) is currently considered the nation's number one health problem. More than 30,000 persons have been diagnosed with this disease to date, and 40,000 new cases are anticipated for the next 2 years. This paper reviews the current facts regarding AIDS, including its modes of transmission and clinical symptomatology. Guidelines for occupational therapy assessment and treatment are presented, including general precautions and recommended intervention strategies.

AIDS and Its Transmission

AIDS was first described in 1981 as a virulent condition characterized by immunosuppression against disease. Those afflicted become susceptible to a variety of rare opportunistic infections not typically deleterious to the immune-competent person (Gong, 1985). The two diseases most commonly associated with AIDS are pneumocystis carinii pneumonia, a lung infection caused by a parasite, and Kaposi's sarcoma, a rare form of cancer or tumor of the blood vessel walls (Langone, 1985).

AIDS is caused by a human retrovirus, human T-lymphotrophic virus, isolate III (HTLV-III) (Langone, 1985). The virus was renamed human immunodeficiency virus (HIV) at the International Conference on AIDS in Paris, July 1986. It is carried in the blood by attaching itself to T-lymphocytes (white blood cells) and may be transferred to semen (Langone). The virus has been isolated in tears, saliva, and sweat; but the concentrations in these fluids are minute in comparison with those in the blood and semen and therefore are less likely to be capable of transmission (Gosnell & Seligmann, 1985). The AIDS virus is transmitted through blood and semen during intimate sexual contact or via blood alone during transfusions, sharing of needles by IV drug users, or from mother to infant prenatally. Transfusion recipients are less likely to contract AIDS now that all blood products are screened for its presence (Gosnell & Seligmann). Earlier it was believed that sexual transmission of the HIV occurred exclusively by male-to-male or male-to-female routes. Recent evidence
such as fungus, parasites, and other opportunistic agents (see Table 1).

As of March 1987, there have been approximately 32,000 diagnosed cases of AIDS and approximately 19,000 known deaths in the U.S. alone (Center for Disease Control, 1987). AIDS has been identified primarily in five main high-risk groups (see Table 2).

AIDS is a difficult disease to contract for someone not engaging in a high-risk behavior (Langone, 1985; Sande, 1986). The virus grows rapidly within the body, but once exposed to air it dies (Langone). It can be destroyed by common cleansers such as bleach and soap. It is not transmissible via casual contact (i.e., touch). No siblings of children with AIDS have been diagnosed with the disease, nor have health care workers contracted AIDS, except those who themselves were in high-risk groups or those few who accidentally stuck themselves with needles from infected blood samples ("Update," 1985; Gosnell & Seligmann, 1985; Sande, 1986).

Symptoms

Adults who develop AIDS typically exhibit a cluster of symptoms, which may include prolonged fever, lymphadenopathy, night sweats, prolonged diarrhea, unexplained or unplanned weight loss, fungal infections and persistent cough (Fauci, 1983).

Infants who develop AIDS via teratogenesis usually show symptoms by 3 months of age, which commonly include failure to thrive, hepatospleno-

megaly and chronic lung infection. They may appear chronically ill with persistent diarrhea, otitis media, and rashes. One third of these infants are also small for gestational age (Shannon & Ammann, 1985).

Persons diagnosed with AIDS manifest physical and psychosocial dysfunctions familiar to practicing occupational therapists. The fact that AIDS can cause these deficits to occur may be less understood. Also, the hysteria often associated with a contagious disease may interfere with knowledge acquisition or inhibit therapists from viewing these patients in the typical function–dysfunction perspective rather than from a solely diagnostic perspective.

Recent evidence (Langone, 1985) shows that up to 40% of all persons with AIDS manifest some neurological impairment. The results of post mortem studies demonstrate brain atrophy, demyelination of the cord, and encephalitis and meningitis (Langone; Perry & Jacobsen, 1986). Originally these neurological complications were thought to be related to the presence of opportunistic infections that had infiltrated the central nervous system. New evidence appears to suggest that the HIV itself may be capable of attacking T-cells in the brain, or glial cells which support neurons and provide the brain with nourishment. Macrophages which devour bacteria may also be targets for the AIDS virus (Langone; Perry & Jacobsen).

The literature includes reports of neuromotor and psychosocial complications in persons with AIDS (Anders, 1986; Bass, 1984; Beckman, 1986; Dilley, 1985; Goldstick & Mandybur, 1985; Hoffman, 1984; Kermani & Drobb, 1984; Lipkin, 1985; Ochitill, Perl, Dilley, & Volberding, 1984; Snider, Simpson & Nelson, 1983). These complications include spinal cord degeneration resulting in paraparesis, progressive weakness, decreased endurance, sensory-perceptual changes, peripheral neuropathies, dysphagia, and progressive multifocal leukoencephalopathies.

Table 1

<table>
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<tr>
<th>Opportunistic Infections Frequently Accompanying AIDS</th>
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<tr>
<td><strong>A. Protozoal/Parasitic</strong></td>
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<tr>
<td>2. Toxoplasmosis (cyst transmitted via cat feces)</td>
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<tr>
<td>3. Cryptosporidium (causes diarrhea)</td>
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<td>4. Strongyloidosis pneumonia (worm)</td>
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<tr>
<td><strong>B. Fungal</strong></td>
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<tr>
<td>2. Candidiasis or thrush (most common orally or in the esophagus, may cause dysphagia)</td>
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<tr>
<td>3. Histoplasmosis (lungs)</td>
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<tr>
<td><strong>C. Viral</strong></td>
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<tr>
<td>2. Herpes (anal, genital, encephalitis)</td>
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<tr>
<td>3. Varicella zoster (shingles)</td>
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<td>4. Epstein-Barr virus (typically causes mononucleosis)</td>
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Note: CNS = central nervous system. G1 = gastrointestinal.

Table 2

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<th>Incidence of AIDS in High-Risk Groups</th>
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<tr>
<td>1. Homosexual/bisexual men = 73%</td>
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<td>2. Intravenous drug users = 17%</td>
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<td>3. Hemophiliacs = 1%</td>
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<td>4. Transfusion-related cases = 2%</td>
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<td>5. Miscellaneous = 7%</td>
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<tr>
<td>(a) Female sex partners of persons with AIDS or of intravenous drug users</td>
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<tr>
<td>(b) Female sex partners of persons with AIDS or of intravenous drug users</td>
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<tr>
<td>(c) Infants and children who contracted AIDS prenatally</td>
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<tr>
<td>(d) Persons born in other countries whose contact with AIDS is unknown</td>
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<tr>
<td>(e) Persons who claim not to be in any of the high-risk groups</td>
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Note. The data in this table were obtained in a volunteer training workshop sponsored by the New Orleans AIDS Task Force, October 1986.
ganic brain syndrome, major depressive and adjustment disorders, and gross cognitive deficits have also been described.

In addition, acute episodes of hypochondriases, diffuse anxiety reactions, panic and phobic attacks, and psychosomatic disturbances have been reported in the “worried well” population (Perry & Jacobsen, 1986; Morin, Charles, & Malyon, 1984). These problems develop in people who are in high-risk groups and have potential for developing AIDS but currently do not have any of its symptoms.

Responding to the Challenge of AIDS

Burke states that “our response to new frontiers depends on our own ability to change” (1984, p. 26). With AIDS the changes may need to occur partially in our attitudes, beliefs, and value systems regarding sexuality and morality which may clash or conflict with those of the patient group. Recognizing the person with AIDS as an individual, rather than as a member of a stereotyped group, may enhance the quantity and quality of the patient-therapist interaction while potentially challenging firmly established beliefs or value systems. In addition, health care professionals who care for persons with AIDS may experience helplessness or hopelessness caused by a disease which most often ends in death. To be successful in these new frontiers therapists must learn to identify and manage the stress associated with these treatment challenges and the feelings the disease evokes.

Persons with AIDS cannot benefit from occupational therapy services until those providing the services take responsibility for educating themselves, their peers, and their students about this condition. Siebert emphasized this point by stating, “Keeping current is essential if the profession is to adapt to and adopt change, when it will benefit patient care” (1985, p. 29).

Occupational Therapy Intervention

The disabilities that result from AIDS (cancer, hemiplegia, adjustment reactions, cognitive disorders, etc.) do not require a change in occupational therapy intervention approaches. There are precautions to adhere to, observations to be made, assessments to complete, and treatment plans and goals to be devised. As with other patient groups, therapists working with AIDS patients may be more effective if they use the “whole person” concept to address the psychosocial, physical, and environmental factors influencing function.

The following five guidelines are derived from my clinical consultations and volunteer experiences with persons with AIDS and from a review of the literature. They are intended to facilitate the implementation of occupational therapy services for persons with AIDS and AIDS-related disorders.

1. Education

As previously discussed, education is crucial in allaying fears, in correcting misinterpretations of the disease, and in making intervention plausible. It includes educating ourselves by keeping current with research findings and medical advancements, educating our peers formally and informally, and ensuring that AIDS is addressed in the occupational therapy curriculum.

2. Precautions

Precautionary measures may be helpful when dealing with the clinical manifestations of AIDS or AIDS-related conditions. For the patient who is weak, fatigues easily, or has reduced endurance, energy conservation or work simplification techniques may be indicated or evaluation and treatment sessions may be kept brief. For the disoriented patient the therapist can use reality orientation techniques, speak slowly, repeating when necessary, or use visual cues and sensory input. If a patient displays anger, the anger is validated and the patient is helped to identify its cause and manage it, so that it is not inappropriately displaced. Potential intervention strategies may be derived from these observations and precautions.

A few environmental precautions can make intervention more comfortable for both patient and therapist. Gowns and gloves are not necessary unless there will be contact with the patient’s blood or blood products. However, good hand washing before and after patient contact is an essential part of any infection control program (“Recommendations,” 1985). Because some hospitals have strict infection control policies regarding persons with AIDS, the therapist who is required to don these articles could reduce the patient’s feelings of alienation by explaining why they are being worn. Masks are necessary only if the patient has active tuberculosis or if the therapist is recovering from or developing a cold or flu. Common illnesses or opportunistic infections could be life threatening to the person with AIDS. Again, the patient may feel less alienated if the reason for wearing a mask is explained as a life-protecting measure.

The therapeutic materials and activities need to be carefully selected and implemented to avoid the transmission of airborne or moisture-reproduced foreign microbes into the already immune-compromised individual. Equipment such as raised toilet seats, goniometers, dynamometers, Dycem, and other devices may be effectively cleaned with a 9:1 solution of water and household bleach. Dishes and utensils used in cooking activities need only be cleaned in hot
soapy water and air dried before being used by other persons. Pregnant therapists should avoid direct contact with bodily secretions such as diarrhea, vomitus, or urine, especially in home care activities of daily living. Because not all the members of the health care team are usually present during home treatment sessions, the therapist may need to help personally with cleaning up the patient. Under these circumstances gowns and gloves are necessary, particularly for therapists who are pregnant, to avoid potential harm to the fetus (Lusby, Martin, & Schietinger, 1986).

3. Evaluation

Individual hospitals have begun to develop evaluation and treatment protocols primarily intended to enumerate infection control procedures or to ensure a thorough assessment of the AIDS patient. Because persons with AIDS manifest many of the performance deficits commonly seen in occupational therapy practice, an evaluation can be completed by using a combination of observation and standardized assessment measures. Evaluation tools currently used in physical and psychosocial dysfunction are also appropriate for persons with AIDS but they may vary according to the patient's level of wellness and treatment status (inpatient, outpatient, homebound, or hospice care). Tools may also vary according to the patient's primary presenting problems (i.e., psychosocial versus physical disability) and the severity of the disabling conditions seen upon referral. Because of the debilitating physical impairments, as well as the cognitive and psychosocial manifestations often associated with AIDS and AIDS-related conditions, it is recommended that all performance components of the patient be explored during assessment. The person who is adjusting to receiving positive HIV test results may have different assessment needs than the patient who is bedridden and physically compromised.

Other issues frequently identified during assessment include the patient's need to face his or her own mortality, changing body image, and current or potential loss of independence.

4. Treatment

AIDS patients span a wide spectrum of ill health. Treatment depends on factors such as the phase of illness the person is in (before onset of the disease, early stage, late stage), the support systems available to help carry out treatment programs, and the logistics of the treatment program. It is recommended that occupational therapy services be tailored to the particular needs of the patient and his or her disease state. A three-phase system is presented as a guide for intervention (see Table 3).

<table>
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<th>Table 3</th>
<th>Suggested Treatment Phases and Intervention Strategies</th>
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| A. Phase 1: Pre-AIDS | 1. Stress management  
2. Education  
3. Group intervention (activity/verbal combination)  
4. Creative self-expression  
5. Vocational/leisure assessment |
| B. Phase 2: Early- to Mid-Stage Disease | 1. Standardized assessment (physical and psychosocial where applicable)  
2. Therapeutic crafts  
3. ADL intervention  
4. Adaptive equipment  
5. Cognitive remediation  
6. Energy conservation/work simplification  
7. Facilitation techniques such as PNF, NDT, etc.  
8. Mobility training  
9. Dysphagia intervention  
10. Pain management  
11. Self-ranging  
12. Leisure/play activities  
13. Orthotic fabrication  
14. Discharge planning/home assessment  
15. Consultation  
16. Vocational planning/adaptation |
| C. Phase 3: End-Stage Disease | 1. Discharge planning continued  
2. Consultation (assistive devices, positioning, ADL, etc.)  
3. Family, support system training  
4. Reality orientation/sensory retraining  
5. Creative self-expression/therapeutic crafts/leisure interests |

Note. PNF = Proprioceptive neuromuscular facilitation. NDT = neurodevelopmental treatment.

Phase 1 or pre-AIDS intervention strategies are geared primarily toward educating and supporting persons at high risk for the disease. These persons may show acute psychiatric symptoms because of their potential for contracting AIDS. Secondarily, these interventions are aimed at persons suffering from adjustment reactions to the fact that their friends, lovers, or relatives have been diagnosed with AIDS or have died from it. This group may also include individuals who have positive HIV test results indicating they have antibodies to the AIDS virus and therefore may be carriers of the disease but who show no signs or symptoms of AIDS. (It is a common mistake to include persons who have tested positive into the same diagnostic category as those with full spectrum AIDS.) This group may also include those who have AIDS-related complex (ARC), a cluster of symptoms often including fungal and viral infections, night sweats, fever, and lymphadenopathy but excluding Kaposi's sarcoma or pneumocystis pneumonia. Some of these individuals will progress to full spectrum AIDS whereas others will not (Gong, 1985). Worden and Weisman's study (1984) of newly diagnosed cancer patients showed that those receiving early psychosocial intervention had lower levels of emo-
tional distress than did the control subjects and that they also had reduced levels of denial. Reducing levels of denial may be tantamount to altering high-risk behaviors of persons who have potential to contract or transmit AIDS. Reducing distress may allow patients to continue productive lives by establishing adaptive coping behaviors.

Treatment in Phase 2 or early- to mid-stage disease uses aggressive intervention strategies typical in both acute care and rehabilitation settings. Maintaining function, preventing deformities, increasing mobility, and providing expressive outlets are all potential goals of treatment in this phase. Discharge planning in this phase may include assessing the need for adaptive equipment; training support systems provided by family, friends, and significant others; doing work simplification techniques; and providing referrals to community support services or home health care. Carefully selected therapeutic crafts and leisure activities may also be important in fostering and maintaining feelings of self-worth, productivity, and competence. Finally, activities which provide opportunities to nurture (e.g., carefully planned activities involving plants or pets) may be particularly relevant for patients experiencing feelings of isolation and dependence.

Phase 3 or end-stage treatment is centered on the maintenance of function and interests. Patients are given opportunities to make choices, become oriented in reality or be involved in activities which may foster the expression of feelings about death. This may include a verbal life review, the discussion of fears, regrets, or plans regarding death, or the use of artistic media (e.g., collage, decoupage, or painting) that allow these themes to be explored. Activities are selected with the individual's particular needs in mind, and if possible, mutually agreed upon. Allowing the patient to make choices may also mean respecting his or her desire to discontinue therapy and instead arrange occasional contacts as a measure against feelings of abandonment. Discharge planning in this phase may include arranging for hospice care.

5. Consultation
Consultation rather than direct service may be helpful to patients who need simple assistive devices to maintain functional independence. For example, built-up pens, utensils, or brushes may enable patients to write and maintain self-care independence; book holders or prism glasses can foster reading and leisure time activities in the patients; reachers may allow patients easier access to personal belongings; and an inflatable shampoo basin may allow bedridden persons to be cared for more easily. Consultation services may also entail training support or family members in positioning, mobility, and simple exercise regimens or in identifying the need for involvement by other team members.

Summary
Therapists treating the person with AIDS need to become knowledgeable about the disease, its modes of transmission, its high-risk groups, and the precautions that are necessary for health care workers. Such knowledge, although important in treating any diagnostic category of patients, is particularly important in the treatment of AIDS patients because of the contagious nature of this disease and the fear and emotions it evokes. Persons with AIDS encompass a broad illness–wellness spectrum, and intervention depends upon where in the spectrum the patient is. The use of physical as well as psychosocial assessments is advocated for evaluating the person with AIDS because of the multiple AIDS-related neuromotor and neuropsychiatric deficits that have been reported in the literature. Besides assessment, occupational therapy services for persons with AIDS may include direct service and consultation.

Acknowledgment
This article is dedicated to my good friend Arthur who helped me realize the importance of occupational therapy for persons with AIDS.

References


