A Day Treatment Program for Persons With AIDS

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This paper describes the Village Nursing Home's day treatment program for persons with AIDS, with an emphasis on the role of occupational therapy and the outcomes of occupational therapy interventions. The clients' demographics are included, and a general program philosophy of clients' empowerment is discussed. The health promotion framework and the use of holistic modalities address the spiritual aspect of the individual and how occupational therapy and spirituality might interconnect.

The Village Nursing Home in New York, New York, developed a project to focus on the needs of persons with AIDS. As a result, a three-part plan of action was created to meet these needs. Part 1 entailed the establishment of the AIDS day treatment program, which has been operating since August 1988 under a mental health license and has been serving persons who have both AIDS and a psychiatric disorder. Part 2 entailed the development of a home care program to serve persons with AIDS. Part 3 entailed the opening of a nursing home for persons with AIDS.

The AIDS day treatment program was conceived to provide direct services and a caring environment for persons with AIDS who cannot return to work, require supervision, or need a social support network. Additionally, the program provides the clients' caregivers (spouses or significant others, friends, families) with respite. Adult day care has existed for the elderly and for persons with psychiatric disorders, but it is relatively new for persons with AIDS. Persons with AIDS and elderly persons both experience loss of physical independence, pain, impaired memory and judgment, anxiety and depression, loss of and changes in roles, loss of self-esteem, loss of loved ones, and loss of community. These problems are further compounded for AIDS patients because they must confront these complications of aging without the accompanying chronology. Studies of adult day-care programs have shown significant results regarding the ability of these programs to enhance clients' quality of life by reducing isolation, maintaining and improving activities of daily living skills, improving health status and feelings of well-being, and decreasing the rate of institutionalization (Harder, Gornick, & Burt, 1986).

The holistic approach of the Village Nursing Home's AIDS day treatment program addresses the emotional, psychological, social, physical, spiritual, and environmental needs of the individual and group to establish the highest functioning community possible within the program and to support the highest functioning of the individual.

Program Overview

Many of the clients in the AIDS day treatment program have housing and homelessness problems or have lived in unsupportive environments. Their conditions have included the following psychiatric diagnoses: (a) history of bipolar illness, personality disorder, or schizophrenia; (b) depression or anxiety in response to a diagnosis of AIDS; and (c) AIDS dementia complex, often resulting from opportunistic infections in the central nervous system. The program's population is approximately 10 men to each woman, with the total number of clients ranging between 100 and 125.
The cause of HIV transmission in this population is due mainly to sexual contact (55%-65%), with the remaining cause being a history of intravenous drug use. Most clients have varying degrees of cachexia, skin and gastrointestinal symptoms, respiratory impairment, neurological involvement, and impaired ambulation and endurance. The clients are referred to the day treatment program by hospitals, clinics, private physicians, other health care professionals, or other clients, and some have walked in off the street. Before admission to the program, the client must have a medical diagnosis from a primary care physician that states the presence of AIDS or AIDS-related complex and a psychiatric disorder. The program is staffed by an occupational therapist, a program director, a medical director (psychiatrist), an infectious disease physician, two nurses, an art therapist, a music therapist, a social worker, a coordinator of volunteers, an operations manager, a dietitian, a substance abuse counselor, an office manager, and an assistant. Volunteer clergy provide pastoral counseling. A psychotherapist from outside the facility leads a staff support group twice per month. Role overlap among disciplines is constant. In this setting, the total multidisciplinary effort is greater than the sum of its parts. Were the staff to remain within their traditional professional roles, there would be large gaps in programming and many unmet needs.

Program Philosophy

The philosophy of the day treatment program and the occupational therapy program is that AIDS is a chronic disease that requires medical and psychiatric attention, rehabilitation (including expressive arts therapies and holistic modalities), psychotherapeutic intervention (including substance abuse counseling), nutritional counseling, and pastoral care. The clients who attend the day program benefit from a milieu that supports their empowerment and facilitates their self-care abilities beyond the usual activities of daily living (e.g., washing, dressing, grooming), to also include self-healing. The incorporation of self-healing into the domain of self-care acknowledges that the spiritual and attitudinal facets of the individual are major forces in the healing process, while noting that healing may not always mean survival. Empowerment and self-healing result from the clients’ ability to self-actualize and to discover and respond to their own inner truths. In intense moments of self-revelation, for example, the individual commonly experiences a reduction in or a new perception of pain and a sense of relief in experiencing a self-truth (Ferguson, 1980). For some clients at the day treatment program, empowerment may be a new experience. Although many clients have learned to be “good” patients by becoming passive, the day treatment program encourages them to reclaim their power to direct their own lives. For example, clients can

- Make informed decisions regarding medications and dosages with awareness of drug interactions and adverse reactions.
- Choose to enroll in substance abuse detoxification programs.
- Work with a lawyer to establish a living will or last will and testament, thereby addressing unfinished business and easing the transition for self, family, and friends.
- Use meditation and visualization techniques to control pain, reduce stress, increase coping mechanisms, and facilitate physical and attitudinal healing.

The Occupational Therapist’s Role

Health Promotion Groups

While providing traditional occupational therapy services to treat the loss of physical and cognitive function, the occupational therapist at the day treatment program also acts as an agent of change, as depicted in the literature as an educator, an indirect service provider, and a program planner (Grossman, 1977; Laukaran, 1977). The occupational therapist fulfills this role by helping to create a fertile internal and external environment for change. At the day treatment program, the therapist’s primary focus is to provide health education and health promotion activities that (a) support clients physically, emotionally, and spiritually; (b) facilitate adaptive behavior; and (c) act as a catalyst for change where there is receptivity and motivation.

Occupational therapy is interested in wellness. Activities with this objective include educational classes that are taught by the therapist or by guest teachers. For example, 20 clients complaining of severe, constant itching; reddened, dry skin; and sores that became infected and were difficult to heal attended a skin care class. This class focused on the use of nontoxic natural and herbal remedies, including salves and baths. A general instruction section followed, as well as a question-and-answer session and an experiential component in which clients gave one another cleansing facials. This was followed at a later date by a workshop in which the clients made salves for themselves.

Another health promotion class addressed nutrition and emphasized the use of unprocessed foods and foods free of preservatives and chemicals, the use of herbal teas to decrease caffeine intake, and the reduction of sugar in the diet. This class was given by a clinical nutritionist who volunteered her time.
clients and staff members received copies of dietary information. A nutritionist was hired recently to oversee the clients' general nutrition. Although caloric intake is crucial to persons with AIDS, calories must be worthwhile and not devoid of nutrients. For example, although sugar is high in calories, it offers little in the way of nutrients and causes the loss of chromium and other minerals from the body. Chromium is necessary for correcting the amino acid balance in the body (Badgley, 1986). Food served in the day treatment program tries to incorporate this information while acknowledging that dietary habits are difficult to change, even for those who are motivated. Whenever possible, the occupational therapist has provided the clients with information about holistic alternatives for maintaining health, because the clients are already overstressed by high doses of medications, such as zidovudine (AZT), which has multiple adverse reactions. The program's medical staff has been interested in this information and supportive of its use.

**Spirituality and Holistic Modalities**

Occupational therapists examine motivation and attitudes and their direct effect on quality of life. Motivation can be defined as that which moves or prompts a person to act in a certain way. Spirit, the force behind motivation, is a crucial aspect of the person and an important one to reach in the healing process. Spirituality and occupational therapy interconnect when we define spirit as the life force within us that tells us who we really are. Occupational therapists can stimulate, or inspire, the client toward self-actualization and insight by teaching or providing opportunities for learning self-healing techniques. Within this framework, the inner spirit is the source. Motivation, or a lack of it, may be indicative of the client's desire to live. In the day treatment program, the occupational therapist teaches the clients the use of visualization and guided imagery to evoke their self-knowledge to help with pain or anxiety reduction, problem solving, or overall relaxation. Additionally, the occupational therapist, who is also trained in holistic healing, provides supervision as needed to volunteers licensed in massage; certified in yoga instruction; and trained in movement and exercise, therapeutic touch, and other modalities that deal with the electromagnetic field. The occupational therapist and the volunteer coordinator determine the level of competence and professionalism of these volunteers. Licensed volunteers can document their treatment sessions with a client in the client's chart. To receive a particular treatment, a client may request the service or a staff member can make a referral.

One client, C.R., showed severe weight loss, decreased appetite, decreased endurance, and a sunken posture. He had a grayish complexion, and he isolated himself on days when he felt particularly fatigued. The occupational therapist recommended an appointment with the massage therapist who, with C.R., decided on a full body massage lasting 1½ hours. After two massages on different occasions and a myofascial release session with the occupational therapist, C.R. returned to the program with more color in his complexion, a more upright posture, and a greater sense of vitality and well-being. He also actively participated in programming and in helping to set up the tables and chairs for lunch. He commented that although he did not know how the massage and myofascial work helped him physically, he did feel very positive about the prolonged attention and touching (Montague, 1986; Older, 1982).

**Occupational Therapy Assessment and Intervention**

An initial occupational therapy assessment of the client, in the form of an interview, covers the following:

1. Activities of daily living, including food shopping, meal preparation, and diet.
2. Overall feelings and facts regarding past and present health status.
3. Social environment (e.g., Is there a support network? Are there any involved caregivers, or is the client isolated?).
4. Pain or other problems or concerns that keep the client from performing desired activities.
5. Assessment of strength, coordination, sensation, ambulation, and cognition, as indicated.
6. Time management, including activities engaged in for enjoyment.
7. Substance abuse issues and, if applicable, how they are handled.
8. Work history and how the worker role has changed since the onset of AIDS.

The following are examples of interventions used as a result of this assessment:

- J.M., who has progressive multifocal leukoencephalopathy and who appears much like a person with advanced multiple sclerosis, was given adapted eating utensils that enabled him to feed himself, after months of being fed at home.
- A.G., who lives alone, is ambulatory with decreased endurance, was previously suicidal, is isolated, and was unable to shop or prepare meals. He consumed milkshakes, cakes, and soft drinks when he was at home. The occupational therapist referred him for a home attendant to decrease his isolation and increase the availability of adequate nutrition.
• M.W. complained of severe headaches. He received medications from his psychiatrist and was referred to occupational therapy for pain management. The client learned a basic relaxation and visualization method to physically reduce tension. He began working with this technique on his own, with positive results.

• W.R. had chronic sinus swelling. He learned to apply pressure to specific areas on his face, head, and neck, which improved his nasal breathing.

• A support group led by the occupational therapist addresses time management issues with an emphasis on what people do during their day that makes them feel good. Most clients reveal that when they are not at the day treatment program, they are often in a clinic or hospital waiting room, in line at a welfare agency, or at home watching television. The quality of activity is often not as rewarding as it could be. This group discussion is geared toward a stimulation of the clients’ interests and a discovery of ways in which they can pursue these interests.

• Several clients concerned about what they could do to remain well were referred by the occupational therapist to acupuncture clinics that accept third-party payment. One client in particular experienced significant relief in lower extremity pain due to peripheral neuropathy.

• E.D., who was frail, underweight, and wheelchair-bound due to wasting syndrome, was evaluated for mobility by the occupational therapist. After 2 weeks, he was able to use a walker independently at the day treatment program and at home.

Additional Observations

Several additional observations have come from this program. First, since the beginning of this program, the staff has felt a sense of urgency, based in part on the desire to meet clients’ needs and to provide the missing link (e.g., change in medication or diet, provision of a walker) that will improve the client’s quality of life immediately and in some cases increase life expectancy. This urgency was unexpected before the opening of the day treatment program, but evolved as it became clear that the basic survival needs of persons entering the program were not being met.

Second, several clients have stated that AIDS is not the worst thing that has ever happened to them, and that, in fact, having AIDS has afforded them adequate housing, food, clothing, and medical care for the first time in a long while. Third, it has become evident that clients vary in their outlooks. Whereas some clients may feel hopeless or angry when confronted with options to maintain or improve their strength or health, others are interested in making changes in order to live. Often a person will fluctuate between these two attitudes. A critical role of the day treatment program, therefore, has been to gently guide each person in the direction of self-love and healing.

References


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