



## Wilma L. West Library Resource Notes

### Pandemic: Part 3. Occupational Therapy and HIV/AIDS

March 2003

This is the third and last Resource Note, for now, on Acquired Immunodeficiency Syndrome (AIDS) and HIV infection. This third part will look at the attitude and knowledge of OT personnel for treating patients/clients with HIV/AIDS, educational or training preparation, and occupational therapy intervention or practice. All the references in this list are from **OT SEARCH** and are part of the collection of The Wilma L. West Library, housed in the American Occupational Therapy Foundation.

Attitude, Ethical Care and Legal Issues

Mattimore, C., Levison, L. & Bear, L. (1988). AIDS: occupational therapists and registered nurses attitudes and anxieties. *Journal of Occupational Therapy Students*, 3, 34-46.

Acquired Immune Deficiency Syndrome (AIDS) is a rapidly increasing concern to health professionals. With limited knowledge of transmittance of AIDS there is a need for education within the health field. The fear of AIDS is in direct proportion to the general education and knowledge about the disease. People who know the least are the most afraid (Smithson, 1987). If we fear AIDS through ignorance and misinformation, this will show in our quality of care. The reason for this study is to explore the attitudes of Registered Nurses (RNs) and Occupational Therapists (OTs) in regards to treating patients with AIDS. It is therefore hoped that this information will facilitate approaches to diminish fear and anxiety surrounding AIDS and increase the quality of care to these patients.

Dickinson, E. (1989). Establishing a code of practice for staff in contact with HIV sero-positive patients. *The British Journal of Occupational Therapy*, 52, 433-434.

Atchison, B.J., Beard, B.J. & Lester, L.B. (1990). Occupational therapy personnel and AIDS: attitudes, knowledge, and fears. *The American Journal of Occupational Therapy*, 44, 212-217.

This study explored the attitudes, knowledge, and fears of occupational therapists and certified occupational therapy assistants regarding AIDS and HIV. The 119 respondents' scores related to knowledge and fear revealed that many had significant fears about AIDS which in turn may inhibit their willingness to care for persons with AIDS. The respondents also indicated a need for specific information about the condition, including current research data and information on infection control.

Cornblatt, M.S., Ayres, M.J. & Kolodner, E.L. (1990). A legal perspective on AIDS. *The American Journal of Occupational Therapy*, 44, 244-246.

AIDS presents difficult and unprecedented legal problems. Because modern law requires that persons with disabilities illnesses be integrated into the mainstream of society, past responses to those with communicable diseases are no longer acceptable. Laws dealing with AIDS patients will have to evolve gradually and build upon commonsense solutions to problems.

Hansen, R.A. (1990). The ethics of caring for patients with HIV or AIDS. *The American Journal of Occupational Therapy*, 44, 239-242.

Health care professionals encounter many ethical issues in the care of persons who are HIV positive or who have been diagnosed as having AIDS. Such issues include the allocation of scarce resources for research and health care; the use of various methods of disease control, including mandatory testing, forced isolation, informing of sexual partners, and education, and the determination of the responsibility to treat infected patients. These issues are presented as a stimulus to readers to examine their own attitudes regarding HIV and AIDS. The usefulness and limitations of occupational therapy's professional code in resolving ethical dilemmas are discussed, followed by the description of a process that can be used to analyze and solve these dilemmas.

Peloquin, S.M. (1990). AIDS: toward a compassionate response. *The American Journal of Occupational Therapy*, 44, 271-278.

AIDS evokes powerful feelings, often manifestations of fear, among health care providers. To effectively treat patients with AIDS, occupational therapists must acknowledge and reconcile their personal feelings. One way to formulate a compassionate response to patients is to understand the meanings that we give to AIDS, meanings that shape our interpersonal behaviors. Restricted meanings--that the disease constitutes death, sin, crime, war, or community division--place the person with AIDS at risk for compromised care. Recognizing the limitations of these meanings can free therapists to find other meanings that inspire compassion.

Pizzi, M. (1990). Nationally Speaking: The transformation of HIV Infection and AIDS in occupational therapy: Beginning the conversation. *The American Journal of Occupational Therapy*, 44, 199-203.

A choice confronts us. Shall we, as we feel our foundations shaking, withdraw in panic? Frightened by the loss of our familiar mooring places, shall we become paralyzed and cover our inaction and apathy? If we do those things, we will have surrendered our chance to participate in the forming of the future. We will have forfeited the distinction characteristic of human beings--namely, to influence our evolution through our own awareness.

Pizzi, M. (1990). The transformation of HIV infection and AIDS in occupational therapy: beginning the conversation. *Occupational Therapy in Health Care*, 7(2/3/4), 45-53.

HIV infection and AIDS can be transformed through an attitude change and a change in thinking about levels of productivity and function of people diagnosed with HIV. This change in thinking demands that people with HIV/AIDS is viewed as vital, functional, productive and contributing

members of society and the world. This article focuses on transforming HIV/AIDS through an examination of personal and professional transformation. It is through personal and professional transformation that the transformation of HIV/AIDS will occur. New ways of thinking about HIV/AIDS are explored. Present and future possibilities for therapeutic interventions are discussed. Transformation of HIV/AIDS will occur through empowerment of each other as human beings.

Valentin, C. (1990). Results of the Survey of OTS Treating AIDS Patients. *World Federation of Occupational Therapists: Bulletin*, 21, 47-51.

Mazor, T. & Schenker, I. (1993). AIDS in Israel - a challenge for occupational therapists. *World Federation of Occupational Therapists: Bulletin*, 28, 19-23.

The Acquired Immune Deficiency Syndrome (AIDS) creates new responsibilities and difficulties for occupational therapists in Israel. Since the first reports on people with AIDS (PWA) in 1981, AIDS has become the most serious pandemic of this century. With 260 AIDS cases and 5,000-8,000 HIV infected in Israel, there is an urgent need for Israeli OTs to become more knowledgeable about this disease, be aware of their role in the care for PWA, and be unbiased toward the infected.

Falk-Kessler, J., Barnowski, C. & Salvant, S. (1994). Mandatory HIV testing and occupational therapists. *The American Journal of Occupational Therapy*, 48, 27-37.

**OBJECTIVES.** As the prevalence of human immunodeficiency virus (HIV) increases, so does the prevalence of HIV-positive health care workers. This study explored what effect this will have on occupational therapy service provision. Attitudes and policies of 118 occupational therapy administrators were examined in relation to mandatory testing for HIV, attitudes on treating

HIV-positive patients, working with HIV-positive staff members and students, and use of Centers for Disease Control's guidelines on universal precautions.

**METHODS.** A stratified sample of 200 occupational therapy administrators, drawn proportionally from all occupational therapy fieldwork centers, was sent questionnaires. The respondents (N = 118) were asked questions reflecting policy and attitude regarding HIV-positive staff members, students, and patients and mandatory testing. Descriptive statistics and chi square analyses were computed to examine variances related to policy, ethics, and attitudes.

**RESULTS.** Few occupational therapy departments have policies regarding HIV-positive health care workers or students. Those policies in place involve disability discrimination acts and using universal precautions. More than one third of the respondents support mandatory testing of all health care workers and notifying patients if their occupational therapist is HIV-positive. A large minority of respondents would either refuse to hire or train an HIV-positive therapist or student, or would restrict patient care responsibilities.

**CONCLUSIONS.** Although most occupational therapy administrators adhere to CDC guidelines and anti-discrimination policies, some concern and fear was expressed regarding HIV transmission through occupational therapy practice. This may result in administrative decisions regarding work and training responsibilities that are unnecessarily restrictive, such as limiting all patient care responsibilities.

Helfer, P.S. (1994). Legal issues of AIDS and persons with developmental disabilities. *Developmental Disabilities Special Interest Section Newsletter*, 17(2), 1-3.

McNelis, D.N. & McNelis, T. (1994). AIDS and the person with mental retardation: critical issues for practice. *Developmental Disabilities Special Interest Section Newsletter*, 17(1), 5-6.

Strax, T.E. (1994). Ethical Issues of Treating Patients with Aids in a Rehabilitation Setting. *American Journal of Physical Medicine and Rehabilitation*, 73, 293-295.

Human Immunodeficiency Virus (HIV) is frightening and fatal. The great fear of acquiring HIV magnifies ethical issues concerning patients and health care workers. Practitioners in the field of rehabilitation medicine will become increasingly aware of these issues, because at least 50% of patients with HIV-related illnesses develop neurological disorders. Many will need physical, emotional, social, psychological or vocational restoration. This article explores some of the ethical issues related to Acquired Immune Deficiency Syndrome (AIDS) rehabilitation, including confidentiality, risk of exposure to infected patients or infected health care workers, treatment of patients and the rights of patients and health care workers.

Lang, G.B. (1995). Knowledge about AIDS and attitudes towards persons with AIDS: implications for occupational therapy. *Work: A Journal of Prevention, Assessment & Rehabilitation*, 5, 301-310.

Persons with acquired immunodeficiency syndrome (AIDS) are frequent users of healthcare services, and their care presents a critical challenge to the healthcare profession. With an estimated one million persons in the United States believed to be infected, occupational therapy practitioners will see increasing numbers of referrals to provide services to persons with AIDS. Like other healthcare professionals, occupational therapy practitioners have expressed inaccurate knowledge about AIDS and negative attitudes towards persons with AIDS, both affecting the therapeutic relationship, and possibly leading to suboptimal clinical care. This paper summarizes research that measures healthcare professionals' knowledge and attitudes about AIDS. It also explores the effectiveness of educational programs aimed at increasing knowledge about AIDS and modifying attitudes towards persons with AIDS. Further research is proposed in the occupational therapy field to assist in the development of educational programs addressing these important AIDS issues.

## EDUCATION

Vincent, T.A. & Schkade, J.K. (1990). Knowledge and attitude of occupational therapy students regarding AIDS. *The American Journal of Occupational Therapy*, 44, 205-210.

In this pilot study, knowledge regarding AIDS was tested in 36 occupational therapy students and 33 education students. Also measured were the students' attitudes toward AIDS patients and the resulting health care controversies. An analysis of the results revealed no significant differences in knowledge between the two groups. Attitudinal differences between the two groups, however, were significant for two items. Implications for occupational therapy curricula are discussed.

Alverio-Girot, C. E. (1992). A comparison of the levels of awareness of the acquired immunodeficiency syndrome between students in the occupational therapy professional program at the University of Puerto Rico and at Texas Woman's University. Guaynabo, PR: The University of Phoenix, Puerto Rico Campus. (Master's thesis)

The purpose of this study was to determine if there were any significant differences in the level of awareness between the students of the bachelors programs in occupational therapy at The University of Puerto Rico and students of the same program in a university in Texas, regarding the acquired immunodeficiency syndrome prior to taking the formal AIDS courses offered by the educational program. The study sample includes thirty-six junior level occupational therapy students of the Denton Campus of Texas Woman's University and thirty-two sophomore level occupational therapy students of the University of Puerto Rico, Medical Science Campus. Both groups are comparable since they are the complete universe sample within their level and they have not taken any formal educational AIDS related course in the occupational therapy curriculum.

A questionnaire of three parts and a total of 61 questions was administered to gather the data.

Donohue, M.V. & McCreedy, P. (1992). Supervision processes for students and staff who treat persons with AIDS. *Occupational Therapy in Health Care*, 8(2/3), 197-213.

Supervision of students and staff working with persons who have AIDS is a challenging process under constant revision as new policy and research about AIDS unfolds. A systematic process with a structured schema for supervision is proposed in this article to facilitate the application of well known supervisory processes to an area of treatment which is still developing.

Kloor, K. (1993). *National Survey of HIV/AIDS-Related Curricula in Programs of Occupational Therapy*. Fort Collins, CO: Colorado State University. (Research Project)

AIDS has or will affect virtually every provider of health care. The purpose of this study was to determine the quantity of HIV/AIDS-related curricula occurring in programs of occupational therapy across this nation, in light of the rising incidence of the AIDS population. A survey was distributed

to the program directors of all accredited technical, undergraduate, and graduate programs in the United State. Of the 137 surveys mailed, 95 were returned, yielding a 69% response rate. Results of the study indicated graduate and undergraduate programs devoted an average of 6 classroom hours to this topic while technical programs averaged 3 classroom hours. A significant

finding revealed the majority of program directors feel there is no need for further HIV/AIDS-related curricula in their respective programs.

Rugg, S. (1994). 'Positive Preparation': educational input on HIV/AIDS in British occupational therapy schools. *The British Journal of Occupational Therapy*, 57, 76-78.

This article presents the results of a national postal survey to determine the type and amount of educational input on HIV/AIDS received by British occupational therapy students. All respondents (18/25 courses 75%) indicated that they currently provided such input, with an average of 11.9 hours of course time being devoted to it. The majority of presenters were occupational therapists, although colleagues from many other backgrounds were also involved. Much of the material was considered in small group settings, with the content being balanced among a range of subjects. The article concludes that most British occupational therapy students are 'positively prepared' to work with clients with HIV/AIDS.

DeGraff, M.S. & Bennett, D. (1995). Survey of HIV/AIDS-related curricula in programs of occupational therapy. *Occupational Therapy in Health Care*, 9(4), 3-20.

AIDS has affected or will affect virtually every provider of health care. The purpose of this study was to determine the quantity of HIV/AIDS-related curricula in programs of occupational therapy across the United States. A survey was distributed to the program directors of all accredited technical, undergraduate, and graduate programs in the United States. Of the 137 surveys mailed, 95 were returned, yielding a 69% response rate. Results of the survey indicated that graduate and undergraduate professional programs devoted an average of six classroom hours to this topic while technical programs averaged three classroom hours, with the majority of program directors indicating there is no need for further HIV/AIDS-related curricula in their respective programs.

Shaw, A. (1996). Prepare yourself to treat people with AIDS. *The Journal of Occupational Therapy Students*, 17-20.

This article discusses the etiology and transmission of acquired immunodeficiency syndrome (AIDS) and the physical and psychosocial needs of persons with AIDS. As occupational therapists and occupational therapy students, we each have a responsibility to educate ourselves about this disease and how we can help those infected. Persons with AIDS can benefit from our services as we work with them to make their lives as meaningful as possible.

Balogun, J.A., Kaplan, M.T. & Miller, T.M. (1998). The effect of professional education on the knowledge and attitudes of physical therapist and occupational therapist students about acquired immunodeficiency syndrome. *Physical Therapy*, 78, 1073-82.

**BACKGROUND AND PURPOSE:** Anxiety and fear about caring for people with acquired immunodeficiency syndrome (AIDS) are concerns expressed by students in health care professions. This study was designed to evaluate the influence of education offered to physical therapist (PT) and occupational therapist (OT) students on their knowledge, attitudes, and willingness to provide services to people with AIDS.

**SUBJECTS AND METHODS:** Twenty-six undergraduate PT students and 23 undergraduate OT students completed a questionnaire at the beginning of their professional education program, following a 5-hour AIDS education seminar, and shortly before their graduation. The questionnaire consisted of 3 subscales designed to evaluate the respondents' knowledge, attitudes, and willingness to treat people with AIDS.

**RESULTS:** At the time of graduation, the students in both disciplines showed improvement in knowledge about AIDS (14.3% for PT students and 13.8% for OT students) and more positive attitudes toward people with AIDS (7.4% for PT students and 5% for OT students). In both disciplines, the students' willingness to provide services for people with AIDS remained unchanged following the AIDS education seminar and at the end of the professional education program.

**CONCLUSION AND DISCUSSION:** The professional education offered to the cohort of students in this study appeared to be beneficial in improving their knowledge and attitudes toward people with AIDS, but it did not affect their willingness to work with this patient group.

### Occupational Therapy Models

Clark, F.A. & Jackson, J. (1989). The application of the occupational science negative heuristic in the treatment of persons with human immunodeficiency infection. *Occupational Therapy in Health Care*, 6(4), 69-91.

The knowledge that one is infected with the human immunodeficiency virus (HIV) inevitably generates psychological fragility. Fear of disfiguring physical symptoms, loss of occupational role and financial status, rejection and social ostracism, and of death itself may be overwhelming. In this paper, we extracted themes from the negative heuristic of occupational science in order to conceptualize occupational therapy programming that would meet the needs of persons in various stages of HIV infection. A blueprint for programming that flowed from the themes of symbolism, control, temporal rhythms, wellness through occupation, occupational role, and environment is presented.

Pizzi, M. (1990). The Model of Human Occupation and adults with HIV Infection and AIDS. *The American Journal of Occupational Therapy*, 44, 257-264.

HIV infection affects all aspects of a person's occupational functioning. This article examines the application of the Model of Human Occupation (Kielhofner & Burke, 1980) to adults with HIV. An occupational therapy assessment battery based on the model is introduced. Given the physical, psychosocial, and environmental needs of persons with HIV, the assessment must be comprehensive to fully evaluate the effect of HIV on occupational behaviors. Goal planning and treatment follow the assessment process. A case example illustrates the integration of the Model of Human Occupation with clinical practice.

#### Clinical Care and Treatment

Johnson, C.D. & Glickel, S.Z. (1989). AIDS and the hand therapist. *Journal of Hand Therapy*, 2, 157-163.

For the near future, at least, the hand therapist may expect to treat an increasing number of patients with AIDS, sometimes unknowingly. This paper is based upon the authors' experience in a hand center located in a hospital designated as a State AIDS Center. The goals of the article are to provide background information about the epidemiology and pathogenesis of AIDS, to describe some of the authors' clinical experiences, and to present precaution guidelines and the Center's treatment protocol for treating patients with a confirmed or presumptive diagnosis of AIDS. The patients on whom this paper is based were referred for therapy during treatment for resistant hand infections. A poor response to medical treatment and prolonged healing time were observed, possibly due to the decreased number and function of helper T lymphocytes characteristic of AIDS patients. Infection control for the AIDS virus, precautions for hand therapists based on current knowledge of the HIV virus and on current hospital guidelines and protecting the AIDS patient from secondary infections are discussed. A treatment protocol designed to meet the needs of this patient group is included. Special considerations include lengthy immobilization, fragile wounds, and the patient's compromised immune response.

Bonck, J. & MacRae, A. (1990). Adult day care for people with Human Immunodeficiency Virus. *Occupational Therapy in Health Care*, 7(2/3/4), 195-212.

The human immunodeficiency virus (HIV) adult day care (ADC) center is an important component in the continuum of care for the HIV ill client, providing therapeutic advantages to the client and administrative advantages to the community as it copes with the growing HIV epidemic. THE HIV ADC center was designed using several models of adult day programs for developmental, psychosocial, geriatric and neuropsychiatric treatment. The HIV ADC client is typically in a non-acute phase of a chronic disability resulting from some combination of primary

HIV pathology and secondary illnesses associated with the Acquired Immune Deficiency Syndrome (AIDS) and is in need of some level of rehabilitation. This article describes occupational therapy intervention focused on maintaining, restoring, or adapting functional skills, with special attention to the daily activities most affected by cognitive/perceptual dysfunction.

Edson, M. (1990). St. Francis Center: one organization responds to AIDS. *Occupational Therapy in Health Care*, 7(2/3/4), 185-194.

The St Francis Center in Washington, DC was founded in 1975 to provide support and guidance for individuals and organizations facing life-threatening illness and bereavement. The Center began seeing clients who were living with AIDS since 1983, and has expanded all of its services to include components specifically designed for people living with AIDS and organizations serving people with AIDS. This article describes the origins of the Center and reveals how the organization grew to meet the challenges of AIDS. The Center can be seen as an organizational model for other pre-existing institutions. Brief case studies demonstrate the activities and techniques of the Center's counseling, training, and volunteer support programs as they help people with AIDS, their families and service organizations.

Schindler, V.J. (1990). AIDS in a correctional setting. *Occupational Therapy in Health Care*, 7(2/3/4), 171-183.

This article will provide current, relevant information on human immuno-deficiency virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) in the correctional setting. Issues pertinent to the correctional setting, such as HIV testing and confidentiality, transmission of the HIV virus in the correctional setting and HIV related education will be explored. An occupational therapy program, outlining two separate programs for (1) those who are HIV positive and those who are diagnosed with AIDS and (2) those at risk for contracting the virus, will be described.

Galantino, M.L. (1990). Pain management and neuromuscular reeducation for the HIV patient. *Occupational Therapy in Health Care*, 7(2/3/4), 161-170.

As a multisystem chronic illness, two areas come to the forefront for management by the rehabilitation specialist. Pain and neuromuscular deficits may be a result of direct insult by the human immunodeficiency virus (HIV) or opportunistic infections affecting functional abilities. A brief overview of pathologic findings reveals that the types of pain experienced is based upon the disease processes that are occurring secondary to HIV. The management of pain and resultant functional changes depends on the source, symptoms and signs of pain. Physical and Occupational therapists are key health care professionals to conduct pain assessments and evaluate functional impairment to better employ non-invasive techniques for management of HIV complications. This article presents various modalities and modes of therapeutic intervention to enhance full participation of the person with HIV in activities of daily living.

Johnson, J.A. & Pizzi, M. (Eds.) (1990). *Productive living strategies for people with AIDS*. New York, NY: Haworth Press, Inc.

O'Connell, P.G. (1990). AIDS: a medical rehabilitation perspective. *Occupational Therapy in Health Care*, 7(2/3/4), 19-43.

This chapter gives a concise overview of the Acquired Immunodeficiency Syndrome (AIDS), with special emphasis on clinical aspects relevant to rehabilitation professionals. AIDS is a

novel form of an acquired immune deficit now known to be caused by the recently recognized Human

Immunodeficiency Virus (HIV). Symptoms result from the direct effects of the virus on the immune system and the nervous system, which appear to be the primary targets. Much of the morbidity and mortality, however, is caused by opportunistic infections which occur in patients unable to mobilize the appropriate immune defenses against them. Characteristic, but previously rare, neoplasms occur due to failure of immune regulation. Improved medical care, however, has changed AIDS from a rapidly fatal disease to one where survival may be prolonged. The rehabilitation setting, the physical disability caused by AIDS, along with the psychosocial and economic impact of the disease on the patient have become...

O'Rourke, G.C. (1990). Case Report: The HIV-positive intravenous drug abuser. *The American Journal of Occupational Therapy*, 44, 280-283.

Gutterman, L. (1990). A day treatment program for persons with AIDS. *The American Journal of Occupational Therapy*, 44, 234-237.

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.

Weinstein, B.D. (1990). Assessing the Impact of HIV Disease. *The American Journal of Occupational Therapy*, 44, 220-226.

This article presents a definition of HIV disease as a four-stage process. The Sickness Impact Profile (SIP) (Bergner, Bobbitt, Carter, & Gilson, 1981) was used to measure behavioral dysfunction in a sample of 15 persons with Stage 3 or Stage 4 (symptomatic) HIV disease. The areas of work, leisure, cognitive behavior, and emotional behavior were found to be, on the average, most affected by HIV disease. A diagnosis of AIDS does not affect the severity of dysfunction. Functional deficits that are experienced for longer periods of time affect several behavioral categories on the SIP as well as on the overall SIP score.

Galantino, M.L. (Ed.). (1992). *Clinical assessment and treatment of HIV: Rehabilitation of a chronic disease*. Thorofare, NJ: Charles B. Slack, Inc.

Galantino, M.L. & Pizzi, M. (1992). Occupational and physical therapy for persons with HIV disease and their caregivers. *Occupational Therapy Practice*, 4(1), 22-31.

Marcil, W.M. & Tigges, K.N. (Eds.). (1992). *The person with AIDS: a personal and professional perspective*. Thorofare, NJ: SLACK, Inc.

Edianus, G. (1993). AIDS/Drug Abuse. *World Federation of Occupational Therapists: Bulletin*, 28, 39-42.

Saleh, G. & Akrouk, W. (1993). Recognizing AIDS in Jordan. *World Federation of Occupational Therapists: Bulletin*, 28, 36-38.

Err, C. (1993). Quel Est L'Impact de L'Infection au VIH Sur le Travail de L'Ergothérapeute? World Federation of Occupational Therapists: Bulletin, 28, 31-35.

Dans cet article, l'auteur s'interroge sur les risques, les modes de prevention, l'approche et les attitudes a avoir envers les personnes contaminees par le HIV.

Malta Association of Occupational Therapists. (1993). HIV/AIDS and substance abuse: the Malta situation. World Federation of Occupational Therapists: Bulletin, 28, 10-18.

Pizzi, M. (1993). HIV infection and AIDS: an update for occupational therapists. Physical Disabilities Special Interest Section Newsletter, 16(3), 2-4.

Snyder, C. (1993). AIDS: awareness, assistance, and acceptance. Journal of Occupational Therapy Students, 7, 49-54.

Occupational therapy definitely has a role in the evaluation and treatment of acquired immunodeficiency syndrome (AIDS) patients. The article begins with a summary of the physical, psychosocial, and environmental considerations that must be made when treating an AIDS patient. The assessments used in the evaluation of AIDS patients are discussed. Next, the article focuses on the categories of AIDS patients, and on general treatment strategies. There is an example of the treatment of an intravenous drug abuser with AIDS. Finally, the roles of occupational therapists in AIDS education and prevention are discussed.

Cripps, S., Spencer, M. & Clark, A. (1994). Providing care to meet complex needs: a cross-sectional approach. Occupational Therapy International, 1, 203-208.

This is a case study of a young man with a mild intellectual disability and schizophrenia, who as a result of engaging in high-risk behavior acquired HIV and subsequently developed AIDS dementia. This resulted in a crisis of care that could not be resolved by traditional diagnostic based clinical services. A care package was developed by the authors that focused on the young man's needs, while embracing the principles of harm minimization and the least restrictive environment. The authors argue that it is only through the development of a cross-sectional approach based on the needs of the individual that the needs of people with complex care issues can be met.

Noack, J.E. (1995). Dementia programming in occupational therapy: implications for HIV-1-associated dementia patient inclusion. A Literature Review. Houston, TX: Texas Woman's University.

This paper will examine past and present occupational therapy programming for patients with dementia resulting from Alzheimer's disease and will explore the inclusion of HIV-1-associated dementia patients in treatment programs utilizing appropriate frames of reference for this population.

Bedell, G. (1998). Finding balance: The daily lives of urban gay men with HIV/AIDS. New York, New York: New York University. (Dissertation)

This study explored what daily life was like for eight gay men with HIV/AIDS living alone in New York City. Information about their daily life experiences was collected and analyzed using

qualitative research methods. Data was collected using in-depth interviews and observations of the participants' home environments. This data was recorded and stored in a field log which included interview transcripts, field notes and analytic memos. Constant-comparison and thematic analysis was used to identify categories and themes from the data that elucidated the participants' individual and shared daily life experiences. Four major themes and one overarching meta theme, "It's About Finding Balance in My Life," emerged from data analysis. The participants described the importance of having adequate financial resources and social supports. They also had to reconstruct their daily activities and routines due to HIV/AIDS-related factors. Work and the redefinition of work had a significant influence on the participants' lives. Activities that involved sharing something of themselves to others had become important such as establishing intimate relationships, doing creative projects, or helping sick friends or others in the community. Daily life entailed dealing with vast amounts of symptoms, treatments, side-effects, information, and services. Dealing with fears, uncertainties, loss, and stigma was clearly a part of living with HIV/AIDS as well. The participants described some common and diverse experiences in their lives related to being gay men with HIV/AIDS such as disclosing their sexual orientation and HIV status, coming to terms with HIV/AIDS, caring for sick friends or lovers, and attending many funerals and memorial services. There were numerous examples of their attempts to find balance in their lives. This was illustrated by paying attention to physical and emotional signs of health and illness, modifying activities and life goals, managing resources, letting others help, and rethinking what they needed or wanted to do on a daily basis. The implications these findings have for consumers and health professionals were discussed in relation to service delivery, and assisting individuals with HIV/AIDS and other chronic illness with finding and maintaining balance in their lives.

NOTE: Bedell's study was published in *The American Journal of Occupational Therapy*, vol. 54, Number 2, 197-206, 2000.

Murphy, N., Messina, W., Getter, E., Gutterman, L., Martin, T., Rincon, P. & Zimmerman, J. (1999). The Village AIDS Day Treatment Program: a model of interdisciplinary and interdependent care. *The American Journal of Occupational Therapy*, 53, 561-565.

This article describes the Village AIDS Day Treatment Program, a program for people living with HIV/AIDS that provides health care by using a full range of interdependent services. Opened in 1988, this program was the first of its kind in the country. It has provided leadership in developing a model of care that addresses the full spectrum of health care--promotion, prevention, maintenance and treatment. Along with describing the program and its services, this article includes the program's history and its influencing philosophies.

Perfetto, C. & Como, C. (1999). Adults with HIV/AIDS in the community and occupational therapy. Bay Shore, NY: Touro College. (Mater's Thesis)

AIDS is a diagnosis that affects millions of people each year. It does not discriminate against race, religion, age group, or gender. When diagnosed with AIDS, a patient goes through stages of denial to acceptance that affects their family, friends, job and the individual as a whole. These stages if not resolved, can worsen the patient's condition, leading to secondary diagnoses and complications which can eventually lead to death. Occupational therapists can provide rehabilitation to assist the patient while going through these difficult stages, helping the patient maximize their ability to be independent in caring for themselves and their families to achieve the highest quality of life possible. Secondary complications and diagnosis that usually follow a

primary diagnosis of AIDS can have an effect on a patient's activities of daily living, leisure abilities and work status. Secondary diagnosis often seen in connection with AIDS include dementia, peripheral neuropathies, pneumonia, HIV encephalopathy, Kaposi's sarcoma, severe wasting (slim disease), Non-Hodgkin's lymphoma, tuberculosis, toxoplasmosis, thrombocytopenia nephrotic syndrome, herpes simplex viral infections, and lymphocytopenia. Complications may include problems with vision, sensation, range of motion, strength, skin breakdown, edema, cognition, and difficulties with oromotor control. The combination of any of these secondary complications can lead to a breakdown in the patient's ability to physically and mentally function in their everyday roles. The psychological and psychosocial implications of being diagnosed with AIDS can have a negative impact on a patient's recovery due to the inevitable onset of stress and depression that the patient experiences. Psychological implications can include feelings of inferiority, loss of previous life, loss of previous goals, fear of what the future holds, fear of dying. Psychosocial implications include fear of rejection by family, friends, intimate partners, co-workers, and employers. These issues can create stress and depression which can have a negative effect on the immune system. Psychological and psychosocial issues should be dealt with through appropriate outlets in order to decrease the impact of stress on the body. Due to the implications of what a diagnosis of AIDS means, a given patient can experience dysfunction in every area of their lives. Occupational therapists are trained to look at patients' needs from a holistic approach in order to improve functional capabilities in their everyday roles. An occupational therapist has a knowledge base that encompasses the treatment of physical, neurological, psychological, and social limitations which can be accomplished on an individual or group basis in order to improve function. Our focus will be on the negative effects that develop due to the illness and impact the life style of person's with AIDS.

George, K., DiJiacomo, R., Neely-Aurandt, J., Dworak, P. & Holm, MB. (2000). Patterns of referral and intervention for persons with AIDS. *Occupational Therapy in Health Care*, 13(2), 25-39.

**Objective:** This study identified reasons practitioners receive occupational therapy (OT) referrals for persons with AIDS (PWAs). Frequency of OT interventions and perceived priorities of PWAs at each Center for Disease Control and Prevention (CDC) stage of the disease's progression were examined.

**Method.** Surveys were sent to practitioners (N=47) listed with AOTA having current or past work experience with PWAs. Twenty of the returned questionnaires were usable for analysis.

Frequencies, ANOVAs, and weighted rank order statistics were used to bring meaning to the data. **Results.** Significantly more referrals for OT services were received for PWAs in Stages 3 and 4 of the disease than Stages 1 and 2 ( $F=43.99$ ,  $df=3$ ,  $p<.001$ ). Referrals for early stages of the disease focused on role status and play/leisure activities. In the latter stages, referrals for cognitive/perceptual skills, adaptive equipment, and caregiver training were more frequent. Frequency of interventions used by practitioners tended to mirror referral patterns, as did the perceived priorities of the PWA.

**Conclusion.** Reasons for referral and the interventions used with PWAs throughout the stages of the AIDS/HIV disease were similar to the perceived priorities of PWAs receiving services from OT

practitioners, and reflected the typical symptoms experienced by PWAs receiving services from OT practitioners, and reflected the typical symptoms experienced by PWAs at each CDC stage.

Yallop, S. (2000). Identity issues for people living with HIV/AIDS: Humans with potential or sexual victims? *The British Journal of Occupational Therapy*, 63, 419-424.

Sexuality issues are important to consider within the practice of occupational therapy. This is especially so when working with people with the human immunodeficiency virus and the acquired immune deficiency syndrome (HIV/AIDS), where issues related to sexuality are both relevant and present. Recent advances in HIV medications have improved the health and life expectancy for many people living with HIV/AIDS (PLWHA). This has been not only a medical and biological change, but also one that has had dramatic impact on the psychosocial issues, including those related to sexuality, relevant for PLWHA. This shift in HIV context prompted the creation of a new occupational therapy service for PLWHA - Positive Employment Support (PES). This paper describes data from a focus group held with PES clients, conducted to evaluate the client responses to PES and to direct future service provision. While the focus group provided the expected data about client responses to PES, it also provided rich data about the impact of the shifting HIV/AIDS context on notions of sexuality and identity. This paper explores these ideas and the resulting implications for occupational therapists, especially those working within the field of HIV/AIDS.

### Burnout

Piemme, J.A. & Bolle, J.L. (1990). Coping with grief in response to caring for persons with AIDS. *The American Journal of Occupational Therapy*, 44, 266-269.

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 therapist 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.

Hooley, L. (1997). Circumventing burnout in AIDS care. *The American Journal of Occupational Therapy*, 51, 759-766.

Previous studies have determined that health care providers who specialize in AIDS care are particularly susceptible to work-related stress and resulting burnout. This qualitative study derived themes from interviews with three occupational therapists in order to examine these findings. Ultimately, stress and burnout were not dominant themes in the interviews. Instead, the prominent themes were loss; death and dying; boundaries, connecting, and empathy; education; and coping strategies. An accepting attitude toward diversity coupled with the use of both individual and institutional stress management techniques modulated stress and prevented burnout among the study participants.

### Patient Education

Slady, K. (1990). Brief or New: teaching safe sex practices to psychiatric patients. *The American Journal of Occupational Therapy*, 44, 284-285.

Bedell, G. (1994). *HIV/AIDS: a consumer guide for daily living*. Rockville, MD: American Occupational Therapy Association, Inc.

This information guide is intended to be used by people with HIV/AIDS and their caregivers, in collaboration with their occupational therapist. Occupational therapists support and help people achieve as much independence as possible in necessary and desired life-activities. The term

occupational refers to any meaningful activity that a person engages in to develop, grow, learn, adapt, sustain life, and achieve need satisfaction and self-actualization.

Schindler, V.P. & Ferguson, S. (1995). Brief or New: An education program on Acquired Immunodeficiency Syndrome for patients with mental illness. *The American Journal of Occupational Therapy*, 49, 359-361.

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