



**Wilma L. West Library Resource Notes**

**Pandemic: Part 2. Occupational Therapy and HIV/AIDS**

**February 2003**

In preparing the second Resource Note (RN), which addresses HIV/AIDS, I came to the conclusion that it was going to have to be done in three parts. The first part addressed the global spread and impact of HIV Infection and AIDS. Part 2 looks briefly at the early published literature, special populations, and the holistic approach of occupational therapy practitioners. The third part will look at the attitude and knowledge of OT personnel for treating patients/clients with HIV/AIDS, educational preparation, and occupational therapy intervention or practice.

These references were compiled from **OT SEARCH**, the bibliographic database, and a joint program of the American Occupational Therapy Foundation and the American Occupational Therapy Association. I used the main subject headings ACQUIRED IMMUNODEFICIENCY SYNDROME AND HIV INFECTIONS. Due to the large number of references retrieved, I deleted most references that did not have an author abstract, OT Week articles, and conference or proceeding abstracts. Within the groups, references are arranged chronologically from the earliest to the most recent, as a means to show the profession's attention to this social issue, as it has unfolded.

The earliest reference in OT SEARCH on this topic is an April 1987 article:

Giles, G.M. & Allen, M.E. (1987). AIDS, ARC and the Occupational Therapist. *The British Journal of Occupational Therapy*, 50, 120-123.

This paper suggests precautions to be taken around individuals infected with the human immunodeficiency virus (HIV). Infection control and health risks are discussed, which are of relevance to the occupational therapist in the hospital and in a domiciliary setting. The importance of safe sex for the total population is emphasized. Counseling issues are discussed briefly.

In June and September, respectively, of the same year, an article appeared in *The American Journal of Occupational Therapy*, and an issue of the *Physical Disabilities Special Interest Section Newsletter* was devoted to the topic.

Denton, R. (1987). AIDS guidelines for occupational therapy intervention. *The American Journal of Occupational Therapy*, 41, 427-432.

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.

Gordon, L. (1987). An Occupational Therapy Protocol for the AIDS Patient. *Physical Disabilities Special Interest Section Newsletter*, 10(3), 4-5.

Person-Karell, B. (1987). The role of the occupational therapist in an AIDS clinic: case reviews. *Physical Disabilities Special Interest Section Newsletter*, 10(3), 3-4.

Denton, R. (1987). The role of hospice with the AIDS patient. *Physical Disabilities Special Interest Section Newsletter*, 10(3), 2, 6.

Denton, R. (1987). An overview of acquired immune deficiency syndrome (AIDS). *Physical Disabilities Special Interest Section Newsletter*, 10(3), 2.

Bonck, J. (1987). The neurological sequelae of AIDS: treatment Issues for occupational therapy. *Physical Disabilities Special Interest Section Newsletter*, 10(3), 1, 6-7.

Ten years later, Matthew Molineux referred to the above July 1987 article.

Molineux, M. (1997). HIV/AIDS: a new service continuum for occupational therapy. *The British Journal of Occupational Therapy*, 60, 194-198.

The first cases of what is now known as AIDS were reported in the USA in June 1981. The first article on occupational therapy for people with HIV/AIDS was published 6 years later in July 1987. Since that time, much has been written about the work of occupational therapists with people affected by HIV or AIDS. This article presents some of the material published on this area of work, and suggests that occupational therapy has much more to offer this group of people than is described in the literature. A new continuum of service provision is outlined and discussed. This includes practice that falls outside what might be considered the traditional role of occupational therapists. Although this article is specific to HIV/AIDS, many of the issues raised are applicable to other areas of practice.

The most recent articles in OT SEARCH, as of February 19, are two 2001 articles:

Braveman, B.H. (2001). Development of a community-based return to work program for people with AIDS. *Occupational Therapy in Health Care*, 13(3/4). 113-131.

This article overviews the needs assessment and program development process conducted by an occupational therapist in partnership with a community-based agency. The resulting work rehabilitation program for persons living with HIV/AIDS and based on the Model of Human Occupation is utilized as a case example to illustrate the process. The needs assessment of the target population, the processes of organizational and environmental assessment and the resulting program design and program evaluation are discussed. © 2001 by The Haworth Press, Inc. All rights reserved.

Braveman, B. & Helfrich, C.A. (2001). Occupational identity: Exploring the narratives of three men living with AIDS. *Journal of Occupational Science*, 8, 25-31.

The relationship between occupation and identity has received increased attention in recent years. This article explores the usefulness of the construct of occupational identity as measured by the Occupational Performance History Interview (OPHI-II) in understanding the evolving narratives of three men living with AIDS who participated in a vocational rehabilitation program. The narratives of the three men are described and the impact of AIDS and an attempt to return to work on each individual's occupational identity is discussed. Narrative slopes are presented for each of the three men. Directions for future research are suggested.

I did, however, find this 2002 article in MEDLINE/PubMed.

Phillips I. (2002). Occupational therapy students explore an area for future practice in HIV/AIDS community wellness. *AIDS Patient Care and STDS*, 16, 147-9.

Participating in community wellness projects is one way occupational therapy students at Winston-Salem State University (WSSU), Occupational Therapy Program in North Carolina are learning to expand occupational therapy into the community. In a fieldwork experience, 13 juniors are assigned to a community HIV/AIDS project to increase community awareness and prevention of the spread of HIV/AIDS. The project is implemented in conjunction with HOPE (HIV Outreach Programs and Education), STEP ONE, and the Samaritan Ministries. The students' efforts culminate in an HIV/AIDS Rally. Student learning is grouped into categories of planning, implementation, and follow up. This experience resulted in students working as volunteers for HOPE; students collaborating together on a research project to determine the extent University students understand how to prevent the spread of HIV; and students considering a WSSU campus-based HIV/AIDS awareness activity during October 2001 AIDS Awareness Month.

OTA has had two official papers on occupational services for persons with HIV/AIDS over the years, though there is not one in the current group of "Official Documents of the American Occupational Therapy Association, Inc."

The Representative Assembly adopted the first in 1989 - American Occupational Therapy Association, Commission on Practice. (1989). Position Paper: Human Immunodeficiency Virus. *The American Journal of Occupational Therapy*, 43, 803-804.

In 1996, the Representative Assembly rescinded the 1989 Position Paper and replaced it with American Occupational Therapy Association, Commission on Practice. (1996). Position Paper: providing services for persons With HIV/AIDS and their caregivers. *The American Journal of Occupational Therapy*, 50, 853-854. In 2002, the Representative Assembly rescinded the 1996 Position Paper.

In the "Pandemic" Resource Note, one highlighted issue was the increasing number of women who are HIV positive or have AIDS; so, I wanted to be sure to retrieve articles from OT SEARCH that spoke to this aspect of the HIV/AIDS pandemic.

Wood, W. & Aull, M.R. (1990). Women and AIDS: implications for occupational therapists. *Occupational Therapy in Health Care*, 7(2/3/4), 151-160.

This article examines the special issues which confront women with AIDS. The population of women with AIDS is described and differences in the course of the disease between women and men are briefly explored. The psychosocial responses of women with AIDS are reviewed

with respect to considerations of stigma, informational needs, economic impact, psychological responses and social supports. Lastly, the role of occupational therapy is described as it relates to enabling and empowering women with AIDS to perform daily activities and role obligations and to achieve terminal occupational goals.

Pizzi, M. (1992). Women, HIV Infection, and AIDS: tapestries of life, death, and empowerment. *The American Journal of Occupational Therapy*, 46, 1021-1027.

Women, the minority population in the human immunodeficiency virus (HIV) pandemic, are fast becoming one of the highest subgroups to be infected and affected by the disease. In the United States most of these women are black or Hispanic, poor and urban dwellers, and addicted to drugs. This paper discusses the physical, psychological, and social manifestations of HIV disease in women, such as diminished activity tolerance, neurologic or cognitive changes, occupational and social role imbalance, and stigma and discrimination, and describes the sociocultural aspects of women's lives for assessment and treatment of women with HIV. Health promotion, education, and AIDS prevention and wellness programming are emphasized as strategies toward facilitation of self-empowerment for women with HIV disease. These health promotion and wellness strategies include learning of new and adaptation of current roles; learning strategies for self-care that include care for one's physical, psychosocial, spiritual, and sexual health; and learning and developing action plans toward healthy living and self-empowerment.

Herzberg, G.L. (1996). Positive Parenting. *OT Practice*, 1(12), 21-26.

Reaching into the community, an OT finds an unexpected-but rewarding--setting for her skills: an agency that serves mothers with HIV or AIDS

Barrett, H.R. (1997). Women, occupation and health in rural Africa: adaptation to a changing socioeconomic climate. *Journal of Occupational Science: Australia*, 4, 93-105.

Over the last ten to fifteen years socioeconomic conditions in sub-Saharan Africa have declined. Economic crisis has resulted in the adoption of International Monetary Fund and World Bank sponsored economic structural adjustment policies by most African governments. These highly criticized policies have had limited economic success and are often blamed for stagnant and even deteriorating human development indicators and declining living standards. At the same time families and communities are coping with the increasing morbidity and mortality and social issues associated with HIV/AIDS. These changing socioeconomic conditions have particular implications for vulnerable groups, such as poor rural women and their families. Using empirical material collected by the author in Southern and Western Africa, the paper examines the triple workload borne by rural African women. Their roles as biological and social reproducers as well as economic providers are described and the links between these occupations and personal and family health are explored. The extra burden imposed by recent socioeconomic changes, in particular poverty and HIV/AIDS is examined. The desire and need for children are explained and the demands of poverty on rural women are explored. The evidence indicates that deteriorating socioeconomic conditions in sub-Saharan families are adversely affecting the lives and health of rural African women and their families. Poverty and the shadow of HIV/AIDS have serious implications for rural African women, for whom access to labor and income is now critical to family well-being and survival in many parts of rural Africa. The international community must recognize the changing and varied occupational roles that rural women now

perform and should be prepared to respond to the needs and challenges that African women will face as the new millennium approaches

A related topic, of course, is HIV infection or AIDS in the pediatric population.

Anderson, J., Hinojosa, J., Bedell, G. & Kaplan, MT. (1990). Occupational therapy for children with perinatal HIV infection. *The American Journal of Occupational Therapy*, 44, 249-255.

This article discusses occupational therapy for children with perinatal HIV infection and their caregivers. An interdisciplinary early intervention and preschool program serving these children is described. Current medical and neurological research is reviewed to serve as a basis for occupational therapy intervention. Therapeutic approaches that integrate physical, neurological, developmental, and psychosocial needs are presented.

Kaplan, M. (1990). Psychosocial issues of children and families with HIV/AIDS. *Occupational Therapy in Health Care*, 7(2/3/4), 139-149.

The complex psychosocial issues for families who have a child diagnosed with HIV infection present a series of unique challenges for all health care providers. All members of the interdisciplinary team must be knowledgeable about these factors in providing all aspects of care to the child within the context of the family unit. Fear and secrecy are at the core of all persons living with HIV and AIDS, and health care providers must respond with compassion, empathy and sensitivity. The issues that will be discussed address the multiple factors that most frequently impact on a family's ability to function following their child's diagnosis of HIV infection or clinical AIDS and through the bereavement process. Concerns related to school attendance and the use of community services will be highlighted.

Pizzi, M. & Hinds-Harris, M. (1990). Infants and children with HIV Infection: perspectives in occupational and physical therapy. *Occupational Therapy in Health Care*, 7(2/3/4), 103-123.

Infants and children with human immunodeficiency virus (HIV) infection are a rapidly growing population that can be viewed in the category 'at risk.' These children and their families require rehabilitation services to facilitate adaptive responses to HIV infection. This article addresses the clinical manifestations of HIV infection and normal growth and development. The impact of HIV on growth and development is presented through a description of clinical interventions that highlight basic clinical need areas of children with HIV and their families. A rehabilitation classification system is introduced as a means to identify rehabilitation needs of children with HIV.

Johnson, C.B. (1993). Developmental issues: children infected with the Human Immunodeficiency Virus. *Infants and Young Children*, 6(1), 1-10.

Treatment of children infected with the human immunodeficiency virus (HIV) poses a number of complex neurologic, developmental, emotional, familial, and educational challenges. These multidimensional factors need to be considered when one is thinking about the effect of HIV infection on the developing child. The article reviews the present state of knowledge regarding the epidemiology and clinical manifestations of HIV infection in children and the developmental course seen in these children. Psychologic and familial issues are discussed. Treatment and intervention that influence the neurodevelopmental course are described.

Kelly, L. (1994). Developmental patterns in Zimbabwean children with HIV+ serology: a guide to planning a service delivery model. *The British Journal of Occupational Therapy*, 57, 121-123.

The sequelae of AIDS are presenting a worldwide challenge, both in numbers and in the presentation of symptoms, and more children are being affected. Seventy-five children ranging from one month to 4 years were assessed on the Gesell Developmental Schedules in a paediatric clinic for follow-up of children with HIV+ serology in Zimbabwe. When children are deficient in their developmental milestones, it is of concern to their parents. Therapists are involved in the stimulation, adaptation and remediation of the deficits and problems encountered. Combining the parents' concerns with the child's needs can be a challenge with children who, in the long run, will face death. Four patterns emerged which required different levels of intervention. The levels may be described in a graded sequence that increases with disability, beginning with no developmental delay, then increasing from mild to moderate to severe developmental delay. Handicapping conditions vary within this framework. Within the severe category, there are children who have a range of neurological deficits, including dystonia, hypotonia and tongue thrust. Intervention requires strategies that use a variety of techniques, dependent on the presentation of symptoms. The level of illness in the parents must also be taken into account because they too may need intervention. Intervention strategies are outlined according to the pattern of delay.

Lesar, S. & Maldonado, Y.A. (1994). Infants and young children with HIV infection: service delivery considerations for family support. *Infants and Young Children*, 6(4), 70-81.

Children diagnosed with the human immunodeficiency virus (HIV) are a new challenge and often go without needed supports and resources. This article presents findings from a study that examined the relationships of family functioning, stress, and social support of caregivers who are parenting infants and young children with HIV infection. A family adaptational model is suggested that integrates the concepts of stress, coping, and ecological systems for understanding the impact of an HIV-infected child on family adaptation and functioning. Service delivery considerations for family support are discussed in terms of their relationships to social support, adequacy of resources, and coping behaviors.

Parks R.A. (1994). Occupational therapy with children who are HIV positive. *Developmental Disabilities Special Interest Section Newsletter*, 17(1), 5-6.

Rogers, L.A. (1994). Annotated bibliography: developmental and functional status of children with HIV or AIDS. *Physical & Occupational Therapy in Pediatrics*, 14(2), 67-77.

As an increasing number of infants with HIV infection survive, occupational and physical therapists must become familiar with the associated sequelae. They estimated that 10,000 to 20,000 children in the United States are infected with the HIV virus. This annotated bibliography contains an overview of current writings regarding pediatric AIDS particular to cognitive-perceptual and neurodevelopmental status of interest to occupational therapists and physical therapists. The first articles were written by pediatricians and neurologists who looked at the neurological deficits that children with AIDS or HIV present. The last few articles were written by occupational therapists and an educator regarding the functional implications of assessing and treating these children. Also addressed by these authors are the psychosocial implications of AIDS for the family system.

Sherwen, L.N. (1994). Pediatric HIV infection: implications for provision of care. *Developmental Disabilities Special Interest Section Newsletter*, 17(1), 1-4.

Schaaf, R.C., Sherwen, L.N. & Youngblood, N. (1997). An interdisciplinary, environmentally-based model of care for children with HIV infection and their caregivers. *Physical & Occupational Therapy in Pediatrics*, 17(3), 63-85.

In this paper we describe a home-based, interdisciplinary, environmentally-based model of intervention with children with human immunodeficiency virus (HIV) and their caregivers. The environmental perspective is focused on the animate and inanimate environments of the child and caregiver as the major agent of change. Following a detailed assessment of the supports and constraints of environments, the stress level and coping strategies of the caregiver, and the skills and capacities of the child, an interdisciplinary team meeting is held to summarize the data and make suggestions for intervention. The interdisciplinary team then develops an intervention plan, which is shaped and guided by interactions and feedback with the caregiver. Effectiveness of the intervention is measured by specific outcomes reflecting enhanced competence in the caregiver and child as well as cost effectiveness. We anticipate that a program based on this model will address the need for cost effective, culturally relevant services for the increasing population of children and families infected with and affected by HIV.

Parks, R.A., Oakley, F. & Fonseca, M. (1998). BRIEF OR NEW: Play development in children with HIV infection: a pilot study. *The American Journal of Occupational Therapy*, 52, 672-675.

As occupational therapy practitioners treat the whole person, not only the medical diagnosis, I wanted to pull together a few references with a more holistic bent.

Schindler, V.J. (1988). Psychosocial occupational therapy intervention with AIDS patients. *The American Journal of Occupational Therapy*, 42, 507-512.

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.

Okoneski, D. (1990). Gay grief: issues of love, loss, and loneliness. *Occupational Therapy in Health Care*, 7(2/3/4), 213-226.

This article is intended to provide an overview of the special needs for individuals who are gay and bereaved. Also included is a personal account from a lover whose partner died of AIDS. The intent of this article is to increase the level of understanding and sensitivity of practitioners who will be assisting persons affected by Human Immunodeficiency Virus (HIV)

Pizzi, M. (1990). Occupational therapy: Creating possibilities for adults with Human Immunodeficiency Virus Infection, AIDS related complex, and Acquired Immunodeficiency Syndrome. *Occupational Therapy in Health Care*, 7(2/3/4), 125-137.

Occupational therapists prevent dysfunction and maintain and restore function for people with HIV/AIDS in the areas of work, self-care, and play/leisure. These occupational areas are assessed and treated from psychosocial, physical and environment perspectives. This article examines occupational therapy assessment and treatment for people with HIV/AIDS with the primary focus on adaptive equipment, energy conservation, habits and time management and work.

Scaffa, M.E. & Davis, D.A. (1990). Cultural Considerations in the Treatment of Persons with AIDS. *Occupational Therapy in Health Care*, 7(2/3/4), 69-85.

The impact of AIDS has been most notable in three subpopulations in the United States: the gay community, intravenous drug users and minority groups, particularly Blacks and Hispanics. Little information is available on the cultural considerations which are relevant in the treatment of these individuals. This article describes basic principles of cross-cultural analysis, explores individual aspects of AIDS in these populations and discusses the implications for health care providers.

Presti, H.L. (1990). AIDS: the spiritual challenge. *Occupational Therapy in Health Care*, 7(2/3/4), 87-102.

Three primary spiritual aspects of HIV and AIDS are guilt, perceived experiential losses, and the search for meaning. The founding theoretical principles of occupational therapy, including moral treatment, are combined with spiritual components in this paper. The meaning of occupation and activities are discussed. Emphasis is placed on hope and its effects on restoration of health in relation to maximum functioning of the immune system. Occupational therapy combined with reaching spiritual well-being, which contributes to the quality of life, are seen as methods by which optimum health is achieved.

Waterbury, M., Williams, J. & Pizzi, M. (1990). Personal perspectives. *Occupational Therapy in Health Care*, 7(2/3/4), 9-17.

This article focuses on the personal stories, in their own words, of those affected by the human immunodeficiency virus (HIV). HIV does not discriminate, as is noted by the diversity of these personal perspectives. The authors hope that the reader will understand the many complex and varied issues that need to be addressed on an individual basis in assessment and treatment of people with HIV. There are no stereotypes on people with HIV. There are only human beings requiring dignified and respectful care and support.

Williams, J.K. (1990). Values and life goals: clinical interventions for people with AIDS. *Occupational Therapy in Health Care*, 7(2/3/4), 55-67.

This article will address the development of strategies and therapeutic interventions which may be used to help PWAs (people with AID) cope with the illness and assist them in the reevaluation of life goals and changes in values from those of the living to those of the dying. Clinical interventions designed to empower PWAs to take control of their lives and to play an active part in their medical care are outlined.

Valentin, C. (1993). SIDA et Ergotherapie a Domicile. *World Federation of Occupational Therapists: Bulletin*, 28, 24-30.

The main goal in treating AIDS patients is to maintain the best quality of life as long as possible. Therefore, as OTs, we used the Kielhofner approach to establish the priorities, the habits, as described by M. Pizzi (1990a; 1990b).

Bedell, G. (2000). Daily life for eight urban gay men with HIV/AIDS. *The American Journal of Occupational Therapy*, 54, 197-206.

**OBJECTIVE.** The purpose of this qualitative research study was to gain an understanding of the daily life experiences of eight gay men with HIV/AIDS living alone in New York City.

**METHOD.** The participants ranged in age from 25 to 50 years. Data were primarily collected using in-depth personal interviews in 1996 followed by telephone interviews 1 year later.

Constant-comparison and thematic analyses were used to identify themes and subthemes.

**RESULTS.** Two broad themes with related subthemes were generated from the data. "A Reasonably Stable Base" represented the emotional, physical, and environmental foundation that preexisted or was created as a consequence of living with HIV/AIDS. This theme played a particularly important role in the participants' lives, especially during periods of emotional and physical instability. "Finding and Maintaining Balance" was a second theme that illustrated strategies used for managing and readjusting daily routines, goals, and priorities, as well as how the participants experienced this readjustment process.

**CONCLUSIONS.** All of the participants developed their own daily living strategies that were comparable to intervention methods provided in occupational therapy such as energy conservation and work simplification. The findings suggest that occupational therapy practitioners could potentially assist urban gay men with HIV/AIDS with finding and maintaining stability and balance in their lives.

You might also add the 1997 Molineux and two 2001 Braveman articles to this group.

Resource Note created by Mary Binderman, MLS, Director of Information Resources, American Occupational Therapy Foundation, Bethesda, MD. February 26, 2003.