The Experiences of Women with AIDS Who Have Received Occupational Therapy in a Home Care Setting

by

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THE EXPERIENCES OF WOMEN WITH AIDS
WHO HAVE RECEIVED
OCCUPATIONAL THERAPY INTERVENTION
IN A HOME HEALTH CARE SETTING

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DISSERTATION: THE EXPERIENCES OF WOMEN WITH AIDS
WHO HAVE RECEIVED
OCCUPATIONAL THERAPY INTERVENTION
IN A HOME HEALTH CARE SETTING

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Signed: March 19, 2002

Ruth A. M. Meyers
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DEDICATION

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Acquired Immune Deficiency Syndrome (AIDS) is a complex, multifaceted disease that has dramatically affected the health care delivery systems of the world in the years since its identification in 1981. The progressive degeneration of the human immune system that is caused by infection with the human immunodeficiency virus (HIV) results in the manifestation of a broad range of specific diseases, as well as severe immunodeficiency which leaves the affected individual vulnerable to generalized infections and cancer. Recent advances in medical care have resulted in prolongation of life expectancy for many adults in the United States so that the number of years of survival anticipated after infection with HIV is now unknown. (CDC, Feb. 1997). The multiplicity of problems experienced by persons with AIDS, while now occurring over an extended trajectory, continue to compromise independent living as the immune system erodes. These concomitant problems include physical symptoms such as pain, fatigue and weight loss, social isolation and conflict, and cognitive changes such as memory problems or dementia (Hench, 1990; O'Connell 1991; O'Dell, 1991; Powell-Cope, 1990).

Need For The Study
It has been estimated that 10-25% of persons with AIDS in the United States will need long term health care (Oakland, 1993). Health care provided in the home may be 40-87% less costly than that provided in the hospital (Atchison, 1997), or other in-patient facilities and is increasingly relied upon as a viable service delivery alternative (Oakland, 1993). The unique characteristics of the setting must be considered when examining home-based intervention. Burger (1990), in a discussion of the factors influencing ethical decision-making in the home care setting, cautions health care providers to consider the entire social setting of the client when planning for intervention. She suggests that health care providers consider not only the individuals right to autonomy, but the context in which that right exists. The implication is that there is a broader definition of patient/client that must include the individuals in, and the characteristics of, the home setting and that there are factors inherent in the situation that affect intervention. These concepts are consistent with occupational therapy's concern for the social environment and social interaction activities of our clients (Mosey, 1981, 1996; Punwar, 1994). The context in which the clients live, and the roles and responsibilities that are a part of that context must be examined. Home care services provide an opportunity to observe these influences as the client (Head & Patterson, 1997; Rogers, Holm & Stone, 1997) experiences them.

Nearly 135,000 adolescent and adult women had been reported diagnosed with AIDS in the United States as of June 2001 (CDC, 2001), see APPENDIX A for a graphic presentation of these figures. This figure is over 300% greater than that reported in 1985 and represents an ominous upward trend; women are the
most rapidly increasing group of newly infected individuals (CDC, 1997). Women account for approximately 24 percent of the total number of cases in the United States, and 35% of the adults infected since 1995. AIDS is the leading cause of death among young women in 9 large American cities, and the fourth leading cause of death among women aged 15-24 (O’Leary & Jemmot, 1996). The CDC case definition of AIDS did not include any female-specific conditions until 1992 (CDC, 1992), a fact that negatively effected women’s access to AIDS specific health care prior to that (Hanna, 1995, Rose, 1993). Although the number of women with HIV/AIDS is increasing at a rate disproportionate to that of men, women’s unique issues have not received a comparable proportion of the research and treatment attention (Hanna, 1995, Rose, 1993; Sabo & Carwein, 1994; Williams, Shahryarinejad, Andrews, Alcubes, 1997).

Occupational therapy intervention strategies for individuals with HIV/AIDS were first proposed by Denton (1987). His seminal work, urging the involvement of the profession in the development of rehabilitative approaches to the treatment of individuals dealing with the effects of HIV-infection, was based on two observations. The first is the history of the profession, which he characterized as continually adapting to the changing health care needs of society, as exemplified by the AIDS epidemic. The second was his perception that the functional or performance problems that persons with AIDS have are similar to those of other types of chronic and terminally ill clients that occupational therapists have traditionally treated. Thus the profession should be capable and is suitable to serve this population. These two elements, Denton (1987) reasoned,
provided both the rationale for occupational therapy intervention and the experiential base necessary to succeed. Fundamental to this is the development of a substantive body of knowledge that elucidates the nature of the illness, its functional manifestations within the individual client, and the attitudes, beliefs and values, which are related to HIV/AIDS. Denton (1987), as well as a number of other authors in the field (Denton et al 1987; Pizzi, Ed. 1990; Schindler, 1988), have emphasized the complexity of both this disease process and its sociocultural ramifications; a combination which inevitably requires the most organized response feasible from the professional health care provider. Denton’s work was based on his personal and clinical experience, but included no research data.

The majority of occupational therapists are employed in settings most often associated with the provision of health care to persons with chronic illness (AOTA, 1997). Twenty-four percent of occupational therapists who have graduated within the previous five years work in home health care treatment settings (Steib, 1996) which are often the venue for treating individuals with chronic conditions. Individuals diagnosed with HIV/AIDS, now a chronic condition, are therefore an inevitable part of the rehabilitation caseload. The primary focus of occupational therapy intervention, as described by the profession’s national organization, is helping clients to assume the roles and functions that are important to them in the home setting (AOTA, 1995a).

The emerging discipline of occupational science (Zemke & Clark, 1996) has focused the attention of occupational therapists on broadening our understanding of occupation. Occupation has been defined by Punwar (1994) as:
the process by which one is engage in goal directed activity. An essential element to this goal-directed activity is the context in which it occurs (AOTA, 1995, Mosey, 1981, 1986; Zemke & Clark, 1996). Understanding what the occupations of women are, the meanings they attach to them, and the purposefulness of the activities through which they are demonstrated is more complex than simply describing the ability to perform household chores or carry out requirements of commonly defined roles. Women have a unique way of evolving and defining their occupations and their meaning. These meanings may prove very different from what other people, invested in the same occupations, may envision (Clark & Larson, 1993).

Women with HIV/AIDS experience a radical assault to their functional abilities which occupational therapists are particularly well prepared to help manage. Focusing on improving the quality of life of persons with disabilities is a fundamental element of the profession of occupational therapy (Yerxa, 1991). In order to know what activities or abilities should be the focus of interventions the therapist must know both what is meaningful to the client and how to communicate with the client in a way that elicits this important information.

Problem Statement

It is the intention of this researcher to describe the experiences of women living with AIDS in their homes, and to explore the nature and effectiveness of occupational therapy interventions, which they received at home. The researcher
sought to describe the effect of those interventions in helping women with AIDS engage in those life role activities which are important to them.

The research questions of concern are:

A) What are the experiences of a small group of women with AIDS who have received occupational therapy in a home care setting?

B) How do these women describe the effect of occupational therapy on their experience of living with AIDS?

C) How has occupational therapy affected their ability to engage in activities that are important to them?

It is important to understand the nature of the challenges and opportunities for providing service that the AIDS epidemic poses for occupational therapists. Understanding how individuals make meaning out of their lives when an occupational therapist helps them achieve that meaningfulness is potentially an important contribution to the professional literature. The researcher in this study, using a qualitative research design, interviewed a small group of women with HIV/AIDS who have received occupational therapy services in home health care.

The unique constellation of problems experienced by women with AIDS, the impact of that illness upon their ability to engage in important functional activities, and their experiences with occupational therapy is described. No published data have been located regarding occupational therapy intervention with women with AIDS in the home health setting. These findings could have
implications for guiding the development of future practice by providing vital information not presently available.

**Definitions**

The following definitions are presented to clarify for the reader several important terms that are meaningful in this study. These definitions will help the reader to understand both the context of the study and the profession of occupational therapy as they are being examined in this research.

**Occupational Therapy:** The art and science of utilizing purposeful activities, based on selected theories, to collaborate with a client who is limited by physical, psychological or developmental injury or illness to help that individual to acquire the necessary skills, attitudes or behavior to function at their maximum feasible level. A primary focus of this process is the performance of life tasks and roles. (Hopkins & Smith, 1993; Mosey 1981).

**Occupational Therapist:** An individual who has been certified by the National Board for Certification of Occupational Therapy (NBCOT) to practice occupational therapy as a Registered Occupational Therapist, having completed the educational and experiential requirements and passed a national certification examination.

**Home Health Care:** Services provided by health care professionals in an individual’s place of residence on a per visit or per hour basis to patients or clients who have or are at risk of an injury, an illness, or a disabling condition or who are
terminally ill and require short-term or long-term intervention by health care professionals. These services may include dental, medical, nursing, occupational therapy, physical therapy, speech-language pathology, audiology, social work, pediatric services and nutrition counseling services and may be provided directly or through contract with another organization or individual. (Joint Commission on the Accreditation of Health Care Organizations, 1992).

Researcher Stance

My first personal experience with AIDS occurred in 1982 when my brother's former college classmate died as a result of complications of Kaposi's Sarcoma. The news of the death of this young man I had spoken to only a year previously was shocking and ominous in its mystery. By early 1988 I had followed the course of the epidemic in the popular press, drawn to it by a mixture of apprehension and fascination, feeling somehow connected to this plague as it spread among members of my generation, but witnessing from a distance as I worked as a private occupational therapy practitioner in a small upstate New York community. As I sat through what was to be the first of countless memorial services following the AIDS-related death of a long-time friend, I listened to his words as they were read, urging that we remember his life with action, that we become involved in fighting this disease. Observing from a distance no longer seemed acceptable.

I began to work at the AIDS Treatment Center of a large medical center soon after my friend's death; having convinced the medical director that what the center really needed was an occupational therapist. I was uncertain about what I
could do, but I was sure that this was where I should be. Ten years of clinical experience since that time have taught me that occupational therapy has a significant role in the treatment of people who have this disease, and that the challenges are more than offset by the enhancements afforded to the quality of life for clients.

It has been my observation that women do not seem to have the same experience as men relative to living with HIV / AIDS. The men I have worked with, while being involved and concerned for family and friends, have been primarily focused on sustaining their own health. The focus of my work with men with HIV/AIDS nearly always was concerned with improving their personal situations. Women, on the other hand, seem to have evolved a way of being that differs from men: they may take care of themselves, but first they care for others. Understanding this, and understanding how women choose what to focus their energy on is important if we are to help them achieve their maximum potential, and accomplish their goals.

Almost from the beginning of my work with individuals with AIDS I noticed differences not only in how men and women dealt with their illness, but also in how they were handled by health care providers. My earliest recollection is of an incident with Millie, a young mother with pneumocystis carinii pneumonia (PCP). Millie was hospitalized for a three-week course of treatment in late August. She was soon labeled ‘non-compliant’ when she left the hospital after permission for a weekend leave was denied. Millie needed to buy her children their new school clothes. The male physician in charge declared that Millie’s
treatment was more important than her family and threatened to deny future treatment if she left without permission. Millie did leave and was reprimanded severely when she attempted to return. I never saw a male patient request a modification of a treatment plan to accommodate his personal responsibilities outside the hospital.

A more current example is that of Bonnie. This young, HIV-infected mother of four was initially not taking her anti-viral medications. She said she was too busy caring for her children. “It's just another thing to have to handle; to worry about .. it's just too much”, she complained. When she was encouraged to finally see that medication and better self-care could be a way of achieving her goals (e.g. keeping her children with her and avoiding the need for foster care or other negative choices) she began to change her behavior and comply with the medical regimen.

Scenarios similar to Millie's and Bonnie's have been repeated many times over the years I have spent with women with AIDS; women made health care choices that were often based on their responsibilities to, or care for, others.

Two additional stories further illustrate the concepts presented above:

Theresa

I first met Theresa, a 30-year-old mother of two, when she was hospitalized for a severe case of cat-scratch-fever, which had been exacerbated by her HIV positive status. She had been HIV positive for 2 years, and had AIDS-defining illnesses for approximately 1 year. She left the hospital in mid-treatment after her husband visited and said he needed to have her come home to