The Transformation of HIV Infection and AIDS in Occupational Therapy: Beginning the Conversation

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 distinctive characteristic of human beings—namely, to influence our evolution through our own awareness. (May, 1975, p. 488)

In her book *The Aquarian Conspiracy*, Ferguson (1980) stated, "Anything that disrupts the old order of our lives has the potential for triggering a transformation, a movement toward greater maturity, openness, strength" (p. 73). HIV has altered forever the ways in which we think about and act on life and living. Through an examination of HIV as an opportunity and possibility for personal and professional transformation, we can "influence our evolution through our own awareness."

HIV has had a profound effect on the ways in which communities, societies, and the world cope with life's unknowns. HIV has provided us with a choice. As occupational therapists, we must choose either to remain threatened, fearful, and disempowered by the disease and its medical and social sequelae, or to take action, to strengthen our personal and professional character, values, and integrity; and to become role models in health care. The choice we make today will influence who we become tomorrow.

The conversation I am beginning is one grounded in several of my own beliefs. I believe that

1. Human beings have the power and ability to change and transform anything into possibility.

2. Engagement in occupation is transformational.

3. Occupational therapists influence the state of health of the people they serve through their own self-awareness and their knowledge of the art and science of occupation.

4. Occupational therapists have a responsibility and opportunity to transform the ways in which health care is provided.

5. Human beings deserve dignified and respectful care provided in accordance with their individual choices and values.

6. Open and honest communication amongst ourselves and our patients is essential.

Personal Transformation

In the HIV pandemic, fear often prevails, and it disempowers persons with HIV, their caregivers, and the people who serve them. Personal fear requires transformation—Once this begins, societal and global fear can be transformed.

I believe that fear is a response to something uncommunicated and often unacknowledged, something perceived as threatening and confrontational, and something that is unfamiliar and that demands adaptation; all of these characteristics seize a person's control. HIV confronts us because it forces us to examine our personal values concerning homosexuality and bisexuality, intravenous drug use, and our own mortality. The fear of contagion is linked to the fear of one's own mortality. As Frank (1958) said, "Man is always faced with the threat of obliteration, and this is probably the root of anxiety all humans feel. . . . Man must construct a meaningful world out of his environment" (p. 215). We must examine these personal fears and values to transform our thinking about HIV.

HIV may make some persons uncomfortable because it challenges their vision of the ideal self, "the person I would like to be or feel I ought to be" (Frank, 1958, p. 218). If we maintain a vision of who we ought to be, then we limit our ability to grow, to learn, and to discover. Too often, we feel others ought to be a certain way. If we believe that certain types of people or behaviors are bad and wrong, it will affect our interaction.
with them. An acknowledgment of who the patient is rather than of who the patient ought to be can be powerfully transformative.

In patient-therapist interactions, we bring who we are, including our values, beliefs, and cultural differences, into the interaction. Our expectations, judgments, or values and attitudes about homosexuality and bisexuality, intravenous drug use, and racial minorities affect our interactions. "From the fact that each of us constructs a world based on his expectancies, it follows that, to the extent we can influence another person's expectancies, we can affect how he feels, thinks, behaves" (Frank, 1958, p. 216). We can change our focus from illness to wellness through respectful and dignified relationships with persons with HIV and their caregivers. We need to treat caregivers (and patients) as equal partners in our caring relationships. We are there to support them, not judge them.

I offer an example of how a new occupational therapist approached her fears of the unfamiliar when given an opportunity to work with a young homosexual man with HIV. Her conflict was not with the illness, but with her sexual orientation. She walked into his room and sat down near his bed, lowered the bed rails, and offered a cheerful but tenuous greeting. The patient detected her tenuousness. Having become familiar with people's varied reactions to his illness, he asked if she was frightened by HIV. She replied that she was not, but she realized that she was being affected by her lack of knowledge about homosexuality. She expressed concern that this patient was feeling stigmatized because she was not communicating with him about this matter, and she explained that she came from an environment that was not open about cultural differences. She replied in a straightforward manner that she had asked if she was frightened by HIV, an acknowledgment of her personal and professional character and integrity, and of what was needed to provide that service. In this case, what was needed and what was provided were honest communication and conversation about each other's personal, social, and cultural values. We often can learn much about ourselves from our patients if we are authentic and honest. Personal transformation is the beginning of the development of honest, authentic, caring relationships.

Professional Transformation

I suggest there is a need for transformation in occupational therapy before there can be a universal acknowledgment of the power of occupation in the lives of persons with HIV infection and AIDS. Our profession needs to focus on the art and science of occupation—the examination of occupation in assessment, the use of occupation in treatment, and the scientific study of occupation. Occupation and adaptation, the tools of occupational therapists, can make the difference in a person's quality of living and creation of meaning in the world.

The primary focus of HIV management has been on HIV pathology and medical symptoms because of the urgency to find a vaccine and cure. The social and psychological aspects of HIV have been given greater emphasis only recently. Even with this new emphasis, HIV management has not necessarily included therapy, particularly occupational therapy, services. My commitment is that there be universal acknowledgment of the need for occupational therapy services for persons with HIV and AIDS. Such services would not be aligned with the medical model of care but rather would incorporate medical information into a holistic model of care—one that emphasizes occupation.

Occupational therapists do not focus on pathology, but rather on productivity, function, and wellness within the value system and on the occupational choices of human beings. Our professional values are grounded in the art and science of occupation. Our clinical reasoning and problem solving are based on thinking in terms of systems and on the integration of the psychosocial, physical, and environmental aspects of care combined with the universal modality of human touch.

Transformation in the profession, with regard to the HIV pandemic, can occur through an acknowledgment of our history, particularly that which is grounded in Moral Treatment, and a commitment to the fundamental principle of occupational therapy. The purpose of Moral Treatment was to restore patients to improved function and productivity (Bing, 1981). Such occupations as music, literature, physical exercise, and particularly, work, were used to develop skills. It was believed that the social environment in which the person was treated should resemble that of a family unit, which incorporated a spiritual dimension. Caregivers used approaches of kindness and consideration, viewed patients as having the ability to change, and emphasized a positive prognosis and a strong therapeutic relationship (Bing, 1981). Given the social isolation and loss of family, friends, and loved ones resulting from the stigma surrounding HIV, the use of these basic principles of care, which are more aligned with systems thinking than with reductionist thinking, can strengthen the integrity, mind, and will of persons with HIV and their caregivers.

Occupational therapy can become the role model for the creation of safe and secure environments in which persons with HIV can live, work, and function. We need only to believe in the abilities and inherent power of people to change, in the power of occupation, and in the power of ourselves as the catalyst for transformation.

Using systems thinking and committing to the fundamental principles of occupational therapy, as we involve ourselves proactively with persons with HIV, we can strengthen our personal and professional character and integrity and realize the ultimate responsibility of human being to human being.

Yerxa (1967) contributed to this conversation on transformation:

Philosophically we do not see man as a "thing" but as a being whose choices allow him to discover and determine his own Being. Our media, our emphasis upon the...
Transformation of HIV and AIDS

Thus far in our conversation, I have talked about the transformation of HIV and AIDS. Personal and professional transformation can make a powerful difference in the lives of persons with HIV and their caregivers. Through our personal and professional transformation will come the transformation of HIV. We must also acknowledge, however, other possibilities for transformation, particularly regarding the disease itself.

HIV is now considered a chronic disease, not a terminal disease. The increased life span of persons with HIV infection, especially with the advent of life-sustaining drugs, is transforming HIV from a terminal disease to a chronic disease. This includes the many long-term survivors of HIV infection. In her analysis of neuroimmunomodulation, Farber (1989) cited a study that investigated personal attitudes of long-term survivors. Among their attitudes and behaviors cited were realistic expectations (e.g., accepting the disease but believing in life), a fighting spirit, a willingness to modify their life styles, assertiveness, attention to personal needs, open and honest communication, assumption of responsibility for personal health, and contributions to others (Solomon, Temoshak, O’Leary, & Zich, 1987). Occupational therapists can facilitate these attitudes and behaviors to improve the quality of life for persons with chronic HIV infection.

Positive and supportive attitudes of occupational therapists can positively influence the state of health of persons with HIV. Persons with HIV are devastated physically, psychologically, and spiritually and most likely have encountered prejudice and discrimination before and after their diagnosis of HIV. We have an opportunity to support people with HIV through nonjudgmental, positive approaches to life and living and to use our power as a catalyst for transformation. We can provide hope and meaning to patients through adaptation, occupation, and a positive spirit without providing false hope for a cure.

Stereotypes should be avoided. Human beings often have a preexisting interpretation of each other, of situations, and of how things ought to be. In caring for patients with HIV infection, therapists must avoid any preexisting interpretations of what gay persons should look like or what their interests should be, how an intravenous drug user usually responds to others, or even what a person with HIV infection should present clinically. Stereotyping is much like judging others, and it creates boxes, or categories, in which patients are placed. Patients, as well, may have a stereotype of who we are as health care providers, on the basis of their positive and negative experiences with the health care system. Transformation begins when we see each other as unique and with a special contribution to make. The inclusion of life-style and subcultural (e.g., homosexual, bisexual, intravenous drug user) needs in our HIV assessments and treatments shows our respect for the person’s individuality.

No one person or group of persons is to blame for HIV. HIV does not discriminate—people do. The discoverers of HIV, Gallo and Montagnier (1988), believed that the virus had existed in small, isolated groups of people in central Africa or elsewhere for years. Because these groups had little contact with the outside world, HIV stayed within the groups. As the way of life changed in central Africa, however, the pattern of transmission most likely was affected. Migration from remote areas to urban centers increased, sexual mores changed, and blood transfusions became more common (Gallo & Montagnier, 1988). “Once a pool of infected people had been established, transport networks and the generalized exchange of blood products would have carried it to every corner of the world” (p. 47). The reality is that HIV is here and must be dealt with.

Human touch is important and necessary. Universal precautions to benefit the patient and ourselves have been implemented worldwide (U.S. Department of Health and Human Services, 1988). It is vital that we give ourselves and our patients and their caregivers permission to experience connectedness through touch. It is feasible, without gloves, to hug, hold, and touch HIV-infected persons when precautions are unnecessary (e.g., when the therapist is not at risk for exposure to blood and body fluids). Huss (1977) stated:

Touching involves risk. If we are not in tune with ourselves and the one we touch, it may be inappropriate. However, non-touch may be just as devastating at a time when words are insufficient or cannot be processed appropriately because of disintegration of the individual. (p. 16)

A view of AIDS as a conversation. A shift in thinking, or a transformation, can occur most easily when we think of AIDS in terms of a conversation, that is, not something that simply is a certain way but, rather, something that can be altered by the way in which we speak or think about it. We as occupational therapists can transform the conversation called AIDS through our personal and professional transformation and through our commitment to the conversation called the art and science of occupational therapy.

The Future

Future vaccines and strategies will alter the course of the HIV pandemic and increase the number of long-term survivors. Recent research has demonstrated the effectiveness of an HIV vaccine in monkeys, which is "the first truly promising step toward creating a human AIDS vaccine" (Specter, 1989, pp. 1, 12). Until there is a cure, knowledge and education are the best strategies to combat this disease.

Occupational therapy is on the forefront of transforming the conver...
sation about HIV and AIDS. Our belief in occupation and in the possibilities for human beings for productive living will support us. Questions for us to examine, given the possibilities for HIV-infected children and adults living long and full lives, include the following:

1. What will the role of occupational therapy be for the chronic HIV patient throughout a normal life span? How can occupational therapy be effective in developing normalized occupational roles such as student, player, and friend for HIV-infected children who reach adulthood?

2. What are the current and future mental health problems of persons with HIV and their caregivers and what will occupational therapy's role be in meeting the current and future needs of this population?

3. What will the clinical picture be of children with HIV, on permanent drug treatments, who become workers in society? Will special adaptations be needed? What will be the special mental health problems of these children, if any, related directly to the stigma of HIV infection? Will occupational therapy be needed to make a difference?

4. How can occupational therapists develop adaptive environments along the developmental continuum to promote adaptive occupational behaviors for long-term survivors of HIV?

5. Can occupational therapy be a vital service in industries that have HIV-infected persons who wish to maintain their worker roles? How can occupational therapy promote continued productivity and well-being in the workplace despite the stigma and chronic illness that disrupts habits, roles, and skills?

6. How can occupational therapy make a significant contribution in minority communities in which the prevalence of HIV is increasing? What program development skills can we offer?

7. What types of creative wellness programs can occupational therapists develop for children and adults with HIV and their caregivers?

8. What role will occupational therapy play in developing family-centered care for adults and children with HIV infection or AIDS?

9. What role will occupational therapy play in addressing the special needs of women affected by HIV (i.e., women who themselves have HIV infection or who are caring for others with HIV infection)? What occupational therapy services are necessary to support the development and maintenance of these occupational roles?

These are a few of the many questions occupational therapists are going to face. We can begin our transformation now or allow the fear of risk taking to stop us.

We are all afraid—for our confidence, for the future, for the world. That is the nature of human imagination. Yet every man, every civilization, has gone forward because of its engagement with what it has set itself to do. The personal commitment of a man to his skills, the intellectual commitment and the emotional commitment working together, has made the Ascent of Man. (Bronowski, 1973, p. 432)

Regarding the AIDS epidemic, by aligning with this personal, intellectual, and emotional commitment, occupational therapy will make a difference on a societal and global level. It is our opportunity for transformation. ▲

Acknowledgments

I acknowledge all of the authors as well as the following reviewers for their contributions to this issue: Carolyn Baum, David Clark, Florence Clark, Helen Cohen, Mary Donohue, Janie Eddy, Shereen Farber, Jacqueline Jones, Ellen Kolodner, Deborah Labovitz, Ruth Levine, Karen Lohmann, Susan Merrill, Frances Oakley, Susanne Pickering, Marjorie Scafa, Kathleen Barker Schwartz, Anne Hiller Scott, Steven Stanhope, and Roy Swift. I am especially grateful to Elaine Viseltear for her unwavering commitment to making this issue possible. I am also particularly grateful for the contributions of Rick Denumeg, whose AJOT article (July 1987, pp. 427-432) really began the conversation on AIDS in occupational therapy. Thank you all for sharing in the vision that I have for occupational therapy.

This special issue is dedicated to the memory of our patients, friends, and colleagues who have taken a different journey and to those living with HIV. Their courage and their contributions to our lives will always be remembered.

References


Related Readings


