Daily Life for Eight Urban Gay Men With HIV/AIDS

Gary Bedell

Key Words: activities of daily living • chronic disease • qualitative method

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 daily lives.


Acquired immunodeficiency syndrome (AIDS) is one of today's leading health concerns. As of September 1998, there were more than 270,000 reported cases of persons living with AIDS in the United States (Centers for Disease Control and Prevention, 1999). AIDS is the final stage of the clinical spectrum of human immunodeficiency virus (HIV) disease, which is classified on the basis of the amount and clustering of symptoms and laboratory test findings. An AIDS diagnosis includes having a seropositive HIV antibody test and a CD4 (T-cell) count of less than 200 or one of the opportunistic infections associated with immune suppression such as Pneumocystis carinii pneumonia, Kaposi's sarcoma, Mycobacterium Avium complex, and toxoplasmosis (AIDS Medical Glossary, 1997).

Persons living with HIV/AIDS may have any of a number of psychosocial, physical, and cognitive problems that limit the type and amount of activities that they want and are able to do (Bedell, 1994; Dillon, 1993; O’Dell, Levinson & Riggs, 1993a). Chronic psychological stress...
may result from the unpredictable course of the illness, the constantly changing and often conflicting information available regarding effective treatment, societal stigma, financial hardships, and dealing with the bureaucratic red tape that often accompanies a multitude of health care and social services (Baumgartner, 1985; Black, 1994; Hayes, Chauncey, & Tobey, 1990; McConnaughy, 1994).

Men who are gay currently constitute approximately 66% of all reported cases of AIDS in the United States (Centers for Disease Control and Prevention, 1999) and may experience unique circumstances related to living with AIDS. Frequently, they “come out,” or identify themselves as gay, for the first time to friends, family, or coworkers after they have received a positive result on the HIV antibody test (Delaney & Goldblum, 1987; Grossman, 1993). Added to the fear and anxiety related to having a potentially deadly or debilitating disease, they may fear rejection from their loved ones and discrimination at the workplace and in the community (Grossman, 1993; Kurdek & Siesky, 1990; National Commission on AIDS, 1991; Saunders, 1989; Sonntag, 1988).

While young, gay men often hide their sexual orientation from their family and friends. This pattern of secrecy, due to fear of rejection, unresolved feelings of guilt or shame, or estranged relationships, can continue throughout their adult lives. As a result, friends, frequently other men who are gay, become primary caregivers during periods of illness (Hayes, Chauncey, & Tobey, 1990; Wolfe, 1992; Zich & Temoshek, 1987). In addition, many men who are gay have suffered multiple losses of friends or lovers dying from AIDS-related illnesses. These losses and the accompanying grief have an ongoing impact on the structure and nature of the support networks that have emerged among men who are gay and who are living with or affected by HIV/AIDS (Cody, 1995; O’Brien, 1992; Wolfe, 1992).

Occupational therapy practitioners working with persons with HIV/AIDS address psychosocial, physical, and cognitive performance component problems such as depression, fatigue, pain, poor motor control, and memory loss; difficulties in particular performance areas such as basic and instrumental activities of daily living, leisure pursuits, and work transition; and issues and problems associated with performance contexts such as necessary modifications of the physical environment at home and reasonable accommodations at the workplace (American Occupational Therapy Association, 1996; Bedell, 1994; Denton, 1987; Guiles & Allen, 1987; Marcil & Tigges, 1992; McCready, Personius, & Bedell, 1990; Pizzi & Johnson, 1990; Schindler, 1988). Although literature exists that describes occupational therapy intervention for persons with HIV/AIDS, there has been limited research conducted in occupational therapy that has described the reported experiences of men who are gay and other individuals living with HIV/AIDS. This information can provide insight into the type of services that may be important in their lives and the factors to be considered when providing these services.

The purpose of the current research was to gain understanding about the daily life experiences of eight gay men with HIV/AIDS living alone in New York City. Information was obtained about their daily activities and routines and their experiences and perspectives that was deemed important related to living with HIV/AIDS.

Method

Participants

PURposive sampling and networking were used to recruit participants for this study (Bogdan & Biklen, 1982; Lincoln & Guba, 1985). Colleagues and acquaintances were asked to provide information about the study to persons with HIV/AIDS who could then contact the researcher if interested in participating in or finding out additional details. As an additional recruitment procedure, a flyer with a description of the study was posted at eight facilities that provide services for persons with HIV/AIDS. All recruitment and informed-consent procedures were approved by the researcher’s University Committee On Activities Involving Human Subjects.

Eight gay men with HIV/AIDS, residing in New York City, between 25 and 50 years of age, participated in this study. Six participants had been diagnosed with AIDS for 2 or more years. Two participants were HIV positive, but had not yet developed AIDS. Of these two men, one was employed full-time, and the other was looking for employment while receiving public assistance. Three participants with AIDS were involved with part-time, freelance, paid work. The other three were not engaged in paid work; two of these men were receiving public assistance. Six of the participants were white; two were African American. The level of education acquired ranged from one year of college to the completion of a doctorate. Consistent with the selection criteria, all participants lived alone at the time of the study and reported that they had prior or current difficulty with doing one or more daily activities. A few required assistance for basic activities of daily living such as toileting, bathing, and dressing during hospitalization or at home following an extensive illness period. It was most common, however, for the participants to receive assistance for instrumental activities of daily living such as meal preparation, cleaning, laundry, grocery shopping, transportation, and running errands in the community.

Data Collection

IN-depth interviewing (Bogdan & Biklen, 1982; Ely, Anzul, Friedman, Garner, & Steinmetz, 1991; Seidman, 1991; Spradley, 1979) was used as the primary data collection method. Each participant was interviewed twice, and each interview was audiotaped and then transcribed verbatim. The initially proposed duration of 1 hr per interview
was extended to 2 hrs in all but two interviews. All participants were interviewed in their homes except for one person who preferred to be interviewed in a neighbor’s home. The initial data collection lasted 7 months, from April to October 1996. Follow-up telephone interviews with six of the men were conducted in October 1997. Two men had died before these follow-up interviews could be performed.

An initial interview guide (see Appendix) with open-ended questions was used to elicit information about the participants’ daily life experiences. The first interview typically began with a general question to the participants: “Please tell me about some of the things you do during the day.” Based on the participants’ responses, additional information was explored about specific activities, the importance of these activities, and other factors that had an impact on performing daily life activities. From this process, more questions arose.

Field notes were used to describe observations and thoughts about the interview, the interaction, the participants’ home and community environments, and any new questions or speculations about the focus of the study (Bogdan & Biklen, 1982; Ely et al., 1991; Lofland & Lofland, 1984). The questions in the subsequent interviews were derived from analyzing prior interviews and field notes.

Data Analysis

The process of data analysis coincided with and followed data collection. Constant-comparative analysis was the primary procedure used (Bogdan & Biklen, 1982; Strauss, 1987; Strauss & Corbin, 1990). The data collected were reviewed for the purpose of searching for “certain words, phrases, patterns of behavior, subjects’ way of thinking, and events [that appeared to] repeat and stand out” (Bogdan & Biklen, 1982, p. 156). Each time one of these units of data emerged, it was given a label called a coding category. To maintain these data in a systematic way, a computerized modification of the “Cut-Up-and-Put-in-Folders Approach” was used (Bogdan & Biklen, 1982, pp. 166–169). Units of data were cut from the interview transcript and pasted into separate data files labeled by coding category using WordPerfect 6.1©.

Patterns in the data emerged by analyzing the information in each coding category and by linking the data from different coding categories. For example, based on combined information from the coding categories of stigma and clinical, it became apparent that all participants believed that specific AIDS-related symptoms, results from various measures of HIV/AIDS disease progression, and responses to new drugs or therapies could often have a major impact on how they were perceived by others, as well as how they viewed themselves.

The final phase of the analysis, thematic analysis, resulted in the development of themes—statements of meaning that emerged in the data and reflected common experiences, perspectives, and ways of living (Ely et al., 1991; Ely, Vinz, Downing, & Anzul, 1997). For example, the theme “Not Letting the Clinical Aspects of AIDS Define Me” was developed through further analysis and linking of the previously identified pattern with another pattern that reflected how the participants managed on a daily basis in spite of symptoms.

Four procedures were used to establish trustworthiness. Peer debriefing involved a bimonthly meeting with three other doctoral candidates who examined portions of the data, discussed the emerging categories and themes, and assisted with methodological concerns. Participant checking entailed having the research participants clarify and elaborate on the emergent research findings. Triangulation entailed searching for data that corroborated and provided support for the findings. Negative case analysis, searching for information that was in discordant with the findings, was used to modify initial interpretations (Ely et al., 1991; Guba, 1981; Lincoln & Guba, 1985).

Results

Two broad themes were generated from the data. The first theme, “a reasonably stable base,” encompasses subthemes that reflect how the participants used and viewed their resources from home and the community. The second theme, “finding and maintaining balance,” includes subthemes that illustrate the strategies that were used for managing and readjusting daily routines, goals, and priorities, as well as how the participants experienced this readjustment process.

A Reasonably Stable Base

All of the participants reported that they had relatively secure environmental supports and resources that they believed allowed them to more fully address their health-related needs and pursue their necessary and desired activities. Most described themselves as feeling fortunate or blessed in comparison to other persons with and without HIV/AIDS. Although there were expressed difficulties associated with dealing with health insurance companies and obtaining public assistance, all but two participants downplayed the amount of effort required and frustration experienced to obtain these resources. A reasonably stable base was the emotional, physical, and environmental foundation that previously existed or was created as a consequence of living with HIV/AIDS and that played a particularly important role, especially during periods of emotional and physical instability.

Home is my safe place. Home was the place where the participants felt most safe and in control. It was the place where they were able to be themselves, make their own rules, and to do whatever they needed or wanted to do, given personal or environmental constraints:
Home is my safe place, from all the madness of the world. I know that when I come here, I'm going to be safe, and I can have everything I want. I can do whatever I want in my house. That's what a home should be. Diana Ross had a song called 'It's My House and I Live Here.' "There's my chair. I put it there. There's a welcome mat at the door." A lot of people don't have that. And when people can't control anything in their environment, then usually they want to and try to control other people and other things.

Home was a haven where the participants could escape or return to after a day of waiting in physicians' offices or dealing with other people's attitudes, impatience, or ignorance. They controlled who came to visit, and where, when, and for how long. Although the participants still had to deal with AIDS-related activities in their homes, such as medication regimens and contacting insurance or public service agencies, many of these activities often could be done according to their own daily schedules and physical and emotional states.

The phone is my lifeline. Speaking on the telephone was a regular and important part of the participants' daily life at home. They were able to connect to significant others, obtain needed services and information, and perform many activities such as ordering food, managing bills, and engaging in work-related tasks. The telephone was used most frequently during times of convalescence from AIDS-related illnesses at home or in the hospital to connect with significant people in their lives:

My phone bill now is running me close to $100 a month. Since I'm not working, since I'm home, you know, the phone is my lifeline...And when I was sick, I was constantly on the phone. My family and friends were calling me a lot, checking up on me.

Consistent with the perception that home provided security and comfort, many of the participants believed that when speaking on the telephone at home, they had greater control over who they spoke with and the length and content of conversations. Many of them reported screening their calls by listening to the caller's voice on the answering machine or not picking up the phone when feeling sad or disconnected.

Location makes a difference. The participants believed that where they lived had an effect on the services they received, the amount of time and effort required to obtain these services, and their sense of community:

Manhattan is a wonderful place. I have access to a full complement of medical services and social activities. When I was very sick after getting out of the hospital, and I didn't really want to bother my friends, I was able to order Chinese, Mexican, or Indian food, or a burger and fries. I even could have ordered groceries delivered from the A&P.

The participants who lived furthest from Manhattan, where many AIDS-related services and gay organizations are located, experienced more anxiety and fear about disclosing their HIV status and sexual orientation:

I don't go around telling the world that I'm gay. A few neighbors may know. There's also a great deal of AIDS in this community that no one knows about. People in this community either lie about the disease, or, because they receive their services in Manhattan, people in this community tend not to be aware of it. But it's like you tell them you have AIDS and everything, like, changes. Or might change. It's like, I'm still the same person. But they have all these misconceptions. And in this community, and I think outside of Manhattan, there's a lot of "Only dirty people get AIDS." You know?

People I feel I can lean on. Emotional and practical support was obtained in varying degrees from friends, family, boyfriends, therapists, and support groups. The meaning placed on this support also varied. The knowledge that friends and family were nearby, or one phone call away, was comforting. Although some participants described conflicts with certain friends and family members, all described talking to or being with at least one family member or friend as an important source of support and a regular activity in their lives. Some participants described being closer to their families now, or having fewer—but closer—friends:

Resource number one is—family and friends. People I feel I can emotionally and in a very practical way lean on. A day does not go by that I don't talk with these people. And I talk very openly. And try to listen as well. And they have responded.

My lover is very important to me. In the middle of all my personal madness, he can be a solid rock for me to kind of hang onto. And I do hang onto him sometimes. Sometimes I hang onto him too much. But, he allows it to happen.

The participants in intimate relationships received the most consistent and intensive emotional support. Friends and family members were mentioned as equally important for emotional and practical support. All of the participants had come out to their families as gay men, and all but one had disclosed their HIV status to them as well.

Support groups offered important informational support, as well as an outlet to share feelings and fears. Because support group members had similar experiences, the participants felt more comfortable sharing certain emotions and circumstances with them than with family and friends, whom they wanted to protect from their own negative emotions:

When you're diagnosed with this disease, you realize that you have also created an enormous burden on others. I have a sister who's like, Everything is fine! I'm fine! And she's got broad shoulders. She's a wonderful woman. That's why I belong to the support group, because I go there and feel, Aaaah! And I can tear my hair, and we all understand each other. There are a few people there who are very important to me. They're not friends. You know, there's that distance. We just get together to unburden on each other. And we have this sort of agreement that we listen. And that's a very important concept.

The extent of loss and grief experienced by the participants furthered the significance of having people to lean on. Although many of the men developed new platonic and intimate relationships, descriptions of these relationships were often placed within the context of discussions about other friends or lovers who had died as a consequence of AIDS:

I'm talking about 50 or 60 people who have died, and I always feel that it's a part of my past that dies with them. There's nobody alive today who I was friends with during the 1970s. You can't suffer these kind of losses and not be tremendously affected by them.
Finding and Maintaining Balance

The word balance was used by many of the participants without any prompting from the researcher. Balance was described as the act of orchestrating or developing strategies to manage daily and weekly activities, as well as the resultant experience of being able to perform one's necessary and desired activities without, with, or in spite of symptoms:

There are all sorts of things that I've implemented in my day-to-day lifestyle that bring balance and are an indication that I'm in enough balance to do them. Doing yoga, meditating, breathing exercises, working out at the gym, riding my bike, and just being active. And keeping things together, keeping my apartment reasonably clean, and definitely preparing my own food is a source of and indication of balance for me also.

The participants had to balance personal and environmental resources, activities, health-related information and regimens, as well as multiple life priorities and plans. Finding and maintaining balance seemed to be facilitated by having a reasonably stable base, but as the following themes suggest, also involved a great deal of work.

Redefining work. All participants described the importance of job or career-related work in their lives. The choice to change or stop working was important and affected how they viewed themselves and what they did on a daily basis. Work clearly had broader implications than just paid employment for the participants:

The freelance work is something I feel I have to do, and there are times that I don't want to. But the money is nice, and I feel like it's part of staying alive. It gives me something to do that is productive, and I feel a certain amount of pride in the work that I do.

Some participants had left their jobs due to AIDS-related illnesses and the belief that they were going to die in the very near future. The prospect that they could now live longer lives due to improved treatment paradoxically created anxiety and the need for additional support and coping strategies. This shift in thinking about living versus dying was closely tied to working and the broader question: “What am I going to do for a living?”:

And this year for the first time, I missed working. I missed the structure. I missed getting up in the morning. I missed interacting socially with people. I missed the stimulation. So that does create a lot of problems. But there must be something else outside of working! You know, I read this article where AIDS is going to create a chronic disease. I’ve been working for years to get ready to die, and now I’m going to live? What am I going to do with the rest of my life, now that I’m not working? I mean, how much tinkering can I do?

Four of the participants reported that there were insurmountable obstacles or disincentives to returning to work. All of these men feared that they would lose certain benefits such as public assistance, disability payments, Medicaid, or housing if they returned to paid employment. The perception was that the current system did not allow persons to gradually return to work without forfeiting all benefits. Work-related decisions involved a cost-benefit analysis that resulted in all participants but one leaving their full-time employment, none returning to employment, and three participants working on a part-time freelance basis. Other reported constraints for returning to employment included not wanting to be set up for failure or be a burden to others, as well as fear of bias-related incidents at the workplace.

Several of the participants were engaged in a process of reframing how they viewed work. This process entailed a restructuring of plans and schedules to account for the time that work had filled and the emotional needs that work had fulfilled. The sense of “work” extended to other meaningful activities that required more than the usual amount of time and effort to do during the day, e.g., managing one’s health care regimen, filling out insurance forms, caring for sick friends, volunteer work, community activities, creative projects, and socializing or connecting on a more-or-less intimate basis with others.

Personal-reflective work was another important aspect of daily life that assisted the participants with emotions and issues related to occupying their time with meaningful activities given the sporadic nature of HIV/AIDS and uncertainties about the future. This personal “work” either was formal and associated with specific spiritual and religious teachings, or was an informal practice that had become an increasingly important part of the participants’ everyday lives. This work also appeared to provoke or be the result of personal awakenings and transformations:

There’s a question that’s in the air these days: “Have you done the work?” And I think that means, Do you know who you are? And are you learning how to share who you are with other people in a way that doesn’t require that they give something back? I try to share more of myself with people than I used to. And to spend more time with myself looking inward, which is something I wouldn’t have done if I didn’t have AIDS, because there was no reason to. I felt like just the process of getting older would make me wiser, but now I might not get a whole lot older, so I’m looking for the wisdom around me. I seek it out, because I think that’s what we take with us when we go.

Not letting the clinical aspect of AIDS define me. The participants emphasized that it was important to avoid allowing the clinical aspects of AIDS to take control of their daily lives and define how they viewed themselves, or others viewed them, as individuals. Taking medications, for example, had become a routine activity that required a significant amount of time and planning throughout each day for the participants with AIDS. “You do what you have to do and hope for the best,” was an attitude described that often assisted the participants to cope with managing their medication regimens and the overall clinical aspects of AIDS. However, as the following quote illustrates, the number of medications, often experimental in nature, the possible side effects of these, and the unpredictability of symptoms, all had a major impact on their daily lives:

The clinical aspect of AIDS, if I let it, can define who I am as a human being. Because I’m currently taking something like 50 pills a day. And that may just seem like an idle statistic to someone who is not taking 50 pills a day. My answer to that is, “Try it.” And see how that controls your day. Every eight hours you have to take X amount of pills. The midday dosage, the one at 3:00 is a problem for me. Either I forget, or
I’m somewhere else. When you travel, it almost means a separate case for medication. Because there are so many different bottles. You’ve got to be careful not to run out. And I have no idea in terms of liver, kidney, and stomach and whatever what this constant massive dosing of chemicals does to my body. The doctors can’t really tell me, either.

Particular attitudes and strategies were incorporated into the participants’ daily lives to address the clinical aspects of AIDS. These approaches to daily living will be highlighted in the final theme.

**Living by a tentative plan.** Change in health status, whether gradual or abrupt, had forced the participants to modify their activities, routines, plans, and goals:

I kind of do deal with what’s happening now. And I make a plan, but I know the plan may be totally turned upside down by something that comes down the pike.

In the participants with AIDS, an increase in the number and severity of AIDS-related symptoms resulted in an increase in the amount or intensity of the modifications necessary. The more the participants perceived themselves to be in control of their symptoms, the more they were able to modify their daily lives without the assistance of others. Modification of activities and routines were necessary mainly due to physical fatigue and emotional exhaustion. The following three guiding principles assisted the participants with decisions about how to regulate the amount and type of activities they were able and wanted to do.

**Being careful with resources** included devising ways to access, budget, and allocate personal and environmental resources. Most often, however, the participants described strategies used to conserve their physical energy throughout the day and for longer periods of time:

Sometimes you just get real tired real fast. So, pacing yourself is very important in this illness, because you have a package of energy every day. You sort of have to really use it right, time management. Sometimes I cook in the morning, and then I’ll freeze food. Because I’m much more productive in the morning. And sometimes by the time it’s 6:00 in the evening, I can’t be bothered. So you learn yourself. I use a lot of frozen vegetables. I’ll do salads. And stuff that I can stick in the broiler for like 3 minutes and take it out again. Or microwavable stuff. And I do really easy meal planning.

I remember there was a period where I was like, God, this might be the way it is from now on. I am just not getting my strength back very quickly. But then gradually it started to come back, and I felt better. And I wanted to go out and run laps, but I was careful because I realized that, to really steadily build things, strength, I needed to take it slow. And so I resumed, doing yoga every day, and much lighter activity and exercise, but made sure that it was really consistent and steady and at the level I was ready for.

**Listening to the body** entailed paying attention to and monitoring energy levels, AIDS-related symptoms, and emotional states for planning, initiating, and completing activities:

I try to remain flexible so that I can respond to my body’s needs on a day-to-day basis. Some days, I’ll get up at the regular time and start doing my things, but if I’m tired, I’ll go back to bed for an hour. How I feel physically and emotionally guides how I might need to modify my behavior... And there was a time when I felt very strongly that I should ignore these signs and carry on. I don’t anymore. Now I listen to my body.

**Changing the “should” philosophy** involved attempts to avoid having their own egos or others’ expectations, or their perceptions of these, influence their decisions:

Physical weakness forced me to change the “should” philosophy. But I think the main motive for change was [that] I realized a lot of things that had been extremely important to me didn’t matter. Being successful at work. Being able to press 20 more times at the gym. Being at this party. Didn’t matter. You know, it seemed very superficial, silly.

Living by a tentative plan also required ongoing modification of short-term and long-term goals and plans. These adjustments were more common for the men with AIDS than for the two men who were HIV seropositive:

So a lot of what you deal with has to do with how you live your life. It tends to be a day at a time. A week at a time. I live my life between my birthday and Christmas, which are very important dates for me. So I live it in monthly chunks. And the illness is a variable that factors in on a different level every day. So I live by my calendar. And it actually fills up pretty fast. Part of the activity is structured, but you gotta leave some leeway. I usually plan one large thing in a day.

I have stopped thinking on a long-term basis. And to have a project, that really projects you into the future. Life’s too uncertain. I’ve just kind of stopped that. I just finished a large project for work, that I did want to finish. I took two trips recently. But they’re short-term projects. I made plans to go away just 3 weeks ago. I mean, your tickets are bought on an airline, and you can’t go because you’re sick. And it’s not fair to my friends. So I don’t make long-term projects. Personal projects, yes. I want to be able to deal better with my emotions and the emotions of other people who are close to me. And I want to clean out this apartment!

Finally, living by a tentative plan meant that one never knew if or when one would require the assistance from others to perform necessary and desired activities. This was by far the most difficult aspect or prospect of living with AIDS. As a group, the participants were resourceful and valued their independence and personal freedom. Requiring assistance for daily activities from lovers, friends, family members, or home health aides was feared and avoided to the greatest extent possible:

It won’t be an easy transaction to make to let someone help. It’s like you give up control. To ask someone into your life in a real intimate way is when the reality hits. To have somebody come over to take care of you, to feed you or whatever, will be very difficult. I have no idea how I will handle that when the time comes. Probably not very easily.

**Discussion**

This study focused on the daily lives of eight gay men with HIV/AIDS living alone in New York City. The participants had access to vast amounts of resources and services that are similar to what is reported in other literature that describes the needs of educated middle-class white gay men with HIV/AIDS in large cities in the United States (Burkett, 1995; Siegal & Raveis, 1997). Therefore, the findings may not be applicable to other persons with HIV/AIDS who may have inadequate resources, or different ways of accessing or using resources (Burkett, 1995; Lather & Smithies, 1997; Mor, Fleishman, Dresser, & Piette., 1992; Siegal & Raveis, 1997; Verghese, 1994). Persons with different life circumstances than the participants in this study may use...
Physical fatigue and emotional exhaustion were the two most common clinical symptoms that influenced daily life for all of the participants, but less so for the two men who were HIV seropositive but did not have AIDS. These symptoms have been described in other literature as often being the most chronic and disabling for persons with HIV/AIDS, who otherwise do not have other impairments or illnesses, because they may hinder the performance of instrumental activities of daily living, participation in paid employment, and community integration (O’Dell, Levinson, & Riggs, 1996; Soucy, 1997). To accurately measure the disabling impact of fatigue, O’Dell and colleagues (1996) noted that these higher level functional aspects of daily life need to be addressed in the evaluation process by rehabilitation professionals.

Taking medications also had a major impact on the daily lives of the men with AIDS. Smith (1992) reported that, along with walking and vigorous physical activity, taking medications was one of the most frequently cited activities for which persons with AIDS living in New York City (n = 60) required assistance. Although taking medications is often described as an instrumental activity of daily living (Health Canada, 1998; Hurley & Ungvars, 1994), the amount of time and effort spent each day on taking medications for the participants in this study suggests that this activity may be a basic activity of daily living for persons with AIDS.

Leaving full-time paid employment and returning-to-work were important issues for the participants; these issues often were tied to the broader existential issue of focusing on living a longer life rather than preparing for death. From a developmental perspective, leaving or returning to work are considered to be major life stressors for all individuals (Moos, 1986), but especially for persons with HIV/AIDS who may be at the beginning or the peak of their careers, and who are facing the irony of losing necessary financial and health benefits if they resume working (Health Canada, 1998; Mobilizing Talent and Skills, 1999a, 1999b).

Variations of the theme “Finding and Maintaining Balance” are reported in other research about living with HIV/AIDS (Barroso, 1997; Cowles & Rodgers, 1997; Gaskins & Brown, 1992; Wilson, Hutchinson, & Holzemer, 1997) and other chronic illnesses (Corbin & Strauss, 1988; Strauss, 1984). The participants in this study attempted to find and maintain balance to manage the three lines of work that were described by Strauss and Corbin (1990) in their research with persons with chronic illness. Illness work involved following diagnostic and treatment regimens, preventing and dealing with crises, and controlling symptoms. Everyday work entailed the performance of basic and instrumental activities of daily living. Biographical work, similar to the personal-reflective work described in the current study, included an integration of past, present, and anticipated future conceptions of one’s self and one’s life roles. For example, when the participants with AIDS in the current study experienced multiple or severe symptoms, they were more involved with illness work, which then decreased the time spent on or changed the focus of everyday and biographical work. Unlike the current study, Strauss and Corbin (1990) did not focus on the importance that persons placed on being able to manage these aspects of work. However, similar to the current study, they broadened the concept of “work” to include other necessary and meaningful tasks that require more than the usual effort to do during the day.

Other researchers have identified particular strategies that persons with HIV/AIDS use to achieve balance in their lives (Barroso, 1997; Reeves, Merriam, & Courtenay, 1999; Wilson et al., 1997). For example, Reeves et al. (1999) depicted balance as a coping strategy that involved the juggling between work and play activities, as well as between two seemingly opposing ways of living—not wanting to be ruled by HIV/AIDS while not wanting to neglect one’s treatment regimen.

Wilson et al. (1997) reported that persons with AIDS used body listening as a method to assist with decisions about the effectiveness of various treatments and identified independence in daily activities as the most tangible indicator of their quality of lives. Being able to independently perform typical or planned daily activities was also an indicator of finding or maintaining balance for the participants in the current study, yet body listening was used in a more comprehensive way to make decisions about what and how much to do in their daily lives.

Barroso (1997) identified a number of ways that persons reconstruct their lives and find health within the context of living with AIDS. One important finding that was similar to the current study was the importance that persons placed on keeping to a daily routine, especially if they were not currently employed. This had the effect of alleviating the stress associated with uncertainty. However, another perspective was reflected in the current study as was indicated by the remark made by one participant, “What am I going to do with the rest of my life, now that I’m not working. I mean, how much tinkering can I do?” Apparently, some of the men did not have faith in the long-term benefits of maintaining a daily routine without the prospect of also being employed or having paid work.

Implications for Occupational Therapy Practice
The concept of balance has been described in relationship to the core philosophy of occupational therapy (Christiansen, 1996; Kielhofner, 1977; Meyer, 1922; Wilcock, 1998). The participants in this study attempted to find and maintain balance by developing ways to manage on a daily basis to do many of the things they wanted and needed to do in spite of their symptoms and health-related regimens. They had to pace themselves, manage...
personal and environmental resources, and modify their daily activities, routines, goals, and plans. These strategies are similar to interventions used by occupational therapy practitioners, such as work simplification, energy conservation, time management, goal-setting, activity planning, and organizational and memory strategies (Bedell, 1994; Denton, 1987; Health Canada, 1998; Neistadt & Crepeau, 1998). The findings suggest that these types of interventions may be effective for persons with HIV/AIDS, but this topic was not investigated in this study.

The pervasiveness of the physical and emotional fatigue experienced by the participants and its influence on instrumental activities of daily living and work activities suggests that a fruitful area of research would be to determine the effectiveness of occupational therapy methods (e.g., energy conservation, work simplification) that address fatigue and its impact on daily life activities. This research could measure the change in the level or amount of fatigue as well as the quality and quantity of necessary and desired activities performed as a result of these occupational therapy methods. Measurement would have to take into account the episodic nature of HIV/AIDS and include a range of relevant daily life activities that require minimal to maximal energy expenditure.

The importance placed on home and the frequency with which the participants used the telephone to connect with others need to be considered by practitioners working in home health care or in clinical settings where there are numerous infringements on privacy, personal control, and connecting with significant others. The emotional and physical scaffolding provided to the participants by their friends, families, and lovers must be considered as well. Although the needs and perspectives of these significant people were not investigated in this study, collaboration with them may offer additional insights and other service provision options.

Due to the importance placed on work by participants in this study and the fact that persons with HIV/AIDS are living longer lives (Cadman, 1997; Centers for Disease Control and Prevention, 1999), professionals must become more involved with helping persons with HIV/AIDS return to or enter the workforce. This involvement will entail providing guidelines about necessary accommodations and services to allow access and optimum participation in the workplace and community as mandated under the Americans with Disabilities Act (1990). Professionals also should consider options such as independent entrepreneurial work when assisting urban gay men and possibly others with HIV/AIDS who are interested in working for pay. Such options are important, given the value placed on personal autonomy by the participants and that the only men in this study who had left full-time employment and were involved with paid work were working on a freelance basis.

Furthermore, there is a need for professionals and consumers alike to encourage policy planners in government agencies (e.g., the Social Security Administration) to rethink policies and procedures and collaborate more to reduce the financial disincentives for resuming or beginning paid employment. This change may involve a gradual reduction in public assistance commensurate with finances earned through paid work while at the same time allowing persons to resume receiving prior levels of public assistance if and when they are unable to work (Mobilizing Talent and Skills, 1999a, 1999b).

To fully address the needs of urban gay men with HIV/AIDS in practice, occupational therapy practitioners must consider the issues and particular circumstances with which they and others with HIV/AIDS are confronted. All people, practitioners included, have unique experiences or views in relation to personal identity, independence, and meaningful activities and relationships in their daily lives. The impact that these experiences and views may have on the nature and effectiveness of therapeutic relationships that develop in practice must also be considered (All & Fried, 1994; Bailey, 1996; Crepeau, 1998; Jackson, 1995; Walsh & Crepeau, 1998; Weitz, 1991; Wolfe, 1992).

Finally, it was apparent from this current study and a review of the literature that many persons with HIV/AIDS and chronic illnesses experience positive transformations and somehow find a deeper sense of meaning and purpose in their lives (Belcher, Dettmore, & Holzemer, 1989; Fine, 1991; Kleinman, 1988; Miller, 1989; Weitz, 1991; Wong-Wylie, & Jevne, 1997). Further inquiry into the personal-reflective work engaged in by persons with HIV/AIDS, as well as the relationships and experiences that they describe as having life-affirming qualities, may shed light on how or whether occupational therapy practitioners can actually assist them with experiencing this transformative process in their lives. The occupational therapy literature on this topic may offer additional insights (Christiansen, 1997; Peloquin, 1997; Sharrott, 1983; Spencer, Davidson, & White, 1997).
2. What activities are most important to you and why?
   (Changes; meaning; other aspects of life.)
3. Tell me about some of the people in your life who are important to you and why?
   (Identify persons who can provide emotional support or assistance if person becomes upset or physically ill; changes; meaning.)
4. Tell me more about yourself.
   (Life goals, perspectives, attitudes, experiences; changes; meaning; related to being gay.)
5. What are the most significant events that have happened in your life?
   (Changes; meaning; related to living with AIDS, being gay.)
6. What is daily life like for you?
   (Changes; meaning: How do they manage?)
7. What do you think influences the decisions you make and what you do on a daily basis?
   (Helps and hinders; specific resources, availability, and utility; specific problems and needs; how addressed?)
8. What advice can you give to other people living with HIV/AIDS?
   (To family, friends, service providers.)
9. Is there anything else you would like to discuss?

References


Cowles, K. V., & Rodgers, B. L. (1997). Struggling to keep on top: Meeting the everyday challenges of AIDS. *Qualitative Health Research, 7*, 98–120.


Mental health issues of long-term survivors of HIV disease (pp. 23–31). New York: NYU AIDS/SIDA Mental Hygiene Project.


