Resident and Staff Perceptions of Barriers to Independence and Employment in Supportive Living Settings for Persons With AIDS

Amy Paul-Ward, Gary Kielhofner, Brent Braveman, Mara Levin

The purpose of this study was to identify perceived barriers to independent community living and employment among clients and staff members in a transitional living facility for persons with AIDS. This qualitative study used focus groups to collect these perceptions from staff members (N = 21) and clients (N = 16). Whereas staff identified both systemic and personal barriers, clients only identified systemic barriers. These findings suggest that both clients and staff recognize the types of environmental barriers to participation that have been identified by disability scholars. The findings also underscore a consequential gap between clients’ exclusive emphasis on environmental barriers and staff emphasis on clients’ personal barriers that impact upon participation.


Introduction

Over the past 20 years, the epidemiology of HIV/AIDS has changed dramatically. It has shifted from a disease affecting predominantly gay men to one affecting individuals of both genders from largely minority populations. This population is also characterized by histories of mental illness and substance abuse, low economic status, limited education, and limited work experience (e.g., Centers for Disease Control and Prevention [CDC], 2000; Karon, Fleming, Steketee, & De Cock, 2001; Kates, Sorian, Crowley, & Summers, 2002; Orenstein, 2002).

With the advancement of drug therapies, AIDS mortality has dramatically declined. However, increasing numbers of persons are living with the disabling aspects of the disease and numerous associated conditions continue that pose challenges to occupational participation (George, DiJiacomo, Neely-Aurant, Dworak, & Holm, 2000; Kielhofner et al., 2004; McReynolds & Garske, 2001; Sankar & Luborsky, 2003). Many people with HIV/AIDS struggle to overcome significant challenges that affect their abilities to live independently and return to the workforce.

Facilities that have served people with AIDS over the past decade are finding it necessary to reorganize their programs. For most, this means shifting from a hospice-based model to a transitional living, rehabilitation model. Instead of offering palliative care, these facilities now seek to enable residents to live, work, and participate in the community.

Through Enabling Self-Determination (ESD), a federally funded project at the University of Illinois at Chicago, we have been working collaboratively with supportive living facilities to develop and test a new model of service. This participatory action research (PAR) project recognizes the importance of input and collaboration from clients and facility staff for achieving the program goals.

Focus groups were initially employed to identify potential barriers related to independent community living and employment. We sought the perspectives of clients living in these facilities, as well as the staff whose jobs are to help clients achieve these goals. This paper presents findings from the focus groups that elicited perceived barriers by both clients and staff in the facilities. We discuss these
findings in the context of the disability studies and professional theoretical contexts that guide the project.

**Theoretical Contexts**

The ESD project combines the social model of disability, a fundamental framework within disability studies, with an occupational therapy theory, the Model of Human Occupation (MOHO). The social model of disability views disability as a consequence of interaction between the person and his or her social environment (Charlton, 1998; Fine & Asch, 1988; Hahn, 1985; Longmore, 1995; Oliver, 1990, 1996). MOHO also places a strong focus on person–environment interactions (Kielhofner, 2002). Both models underscore: (a) how barriers at the community or societal level can impose disability on the individual and (b) that eliminating these barriers and creating proactive policies can reduce disability. MOHO also includes a consideration of how personal factors including motivation, lifestyle, and impairment experiences can affect participation.

**Methods**

This qualitative study used focus groups to gather data. Ethical approval of the study was obtained from the Institutional Review Board at the University of Illinois at Chicago. The focus group participants were recruited from clients and staff at three transitional living facilities in greater Chicago.

**Focus Groups: Data Collection and Analysis**

Focus groups are commonly used to explore perceptions and attitudes regarding topics of interest to both the participants and the researchers (Bernard, 1994; Krueger & Casey, 2000; Morgan & Spanish, 1984; Nabors, Ramos, & Weist, 2001). In a focus group, the researcher creates a permissive environment that offers participants the opportunity to share their perceptions and views without the need for overall group agreement (Krueger & Casey). Multiple discussions involving similar types of participants allow the researcher to identify common themes, trends, and patterns (Krueger & Casey, 2000). Focus groups are increasingly used for obtaining data for the development and evaluation of community-based service programs (Heary & Hennessy, 2002; Hildebrandt, 1999; Ivanoff, 2002; Poindexter, Lane, & Boyer, 2002).

Each focus group was conducted in the supportive living facility and was moderated by the first author. All of the participants gave informed consent. Participants were informed prior to the start of each group that their participation in the focus groups was voluntary. They were also informed that the discussion would be audiotaped, and permission to do so was explicitly obtained from each participant. Demographics of staff participants are in Table 1 and those of client participants are in Table 2.

Every session began with a general introduction regarding the purpose of the study, why the individuals were being asked to participate, an overview of the topics to be discussed, and why we were interested in their thoughts on these topics. Each session lasted between 60–90 min.

All of the tapes were transcribed verbatim. Data analysis included content analysis of the transcripts based on the identification of relevant themes both within and across client and staff groups. Analysis of the data was an interactive process that included identification of themes, discussion and refinement of these themes among the project personnel who included peer client mentors who were paid project staff, and selected member checking to assure faithfulness of the themes to the constituents’ perspectives.

**Findings**

Clients and staff identified both systemic barriers (social, cultural, political, and economic factors) and personal barriers (e.g., lack of motivation, initiative, or ability to sustain effort to address a problem or undertake an activity). As illustrated in Table 3, clients almost exclusively identified environmental barriers whereas staff, who agreed with clients’ perceptions of these barriers, also emphasized personal barriers. In the following sections these perceived barriers are discussed. In order to protect confidentiality, pseudonyms are used for all participants.

**Clients’ Perceptions of Independent Living Barriers**

One of the major barriers to returning to independent living for clients was the lack of affordable low-income housing. As James explained:

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<th>Table 2. Client Demographics</th>
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... there’s not enough subsidized houses. ... If you get an income of $600, say, from the government once a month, you can’t afford to pay rent, light, and gas. ... You can’t do that unless you have someone to get you subsidized housing where you’re paying a third of what your income is. ... Other than that you’re just out there.

Clients also identified the complexities associated with working with community-based agencies as a barrier to independent living. Several clients described their frustration when, after working with an agency over a period of time, they learned that they did not meet the agency’s requirements for eligibility. John describes a particularly frustrating aspect of eligibility for some programs:

Your qualifications sometimes just completely cut you out of a service if you don’t have an AIDS diagnosis. And that’s a real problem for people in the HIV community. ... HIV in itself is not [perceived as] a handicap to any [agency].

Further illustrating this point, Isabel shared her experience with the group:

I was disappointed when I went to Agency A and to Agency B to apply for myself to get in. ... Because I never had blood down below 600 or 700 T cells, I’m not eligible for the program. Because I never had been diagnosed with AIDS, you know. So I got disappointed. I stopped trying to find housing with agencies that have to deal with HIV because then what happens is everyone is going to tell me the same thing.

Clients also expressed concerns about their ability to cover all of their living expenses on their limited incomes. Of particular concern for many is the possibility that after moving into an apartment, their health may falter resulting in the inability to work and, thereby, cover living expenses. As Marcus explains:

With HIV you never know when you’re going to be able to work or not, and if you’re not in some type of government-funded program or something, a landlord doesn’t want to hear nothing about what you’re going through. All they want is rent.

AIDS-related stigma also posed considerable concern for clients. Carla expressed the need to “know how to not get labeled” when looking for a subsidized apartment in the community. The desire for confidentiality stems from the recognition that many people are still unknowledgeable and therefore fearful about HIV transmission, resulting in discrimination. Desmond summed the feelings of many clients:

I want to be an ordinary person. ... I accept the disease, but we still have to see folks out there who don’t know nothing about the disease and I don’t want to live in a place that’s labeled for just AIDS.

Clients also talked about the lack of available information regarding which community organizations have housing programs for people with HIV/AIDS. As part of this discussion, Marcus expressed his frustration that housing agencies “do not advertise the fact that they have resources for people with HIV to find housing.” Clients stressed the need to have accessible information about housing programs and housing advocates for community placement.

A few clients identified a tendency for the transitional living facility to create complacency in clients. Dan explained this barrier in the following way:

I could see how it would be easy for someone to just become complacent after a while here, and just become dependent, like having the meals prepared every day.

In summary, then, clients’ perceptions of barriers to independent living focused on their contexts.

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Table 3. Client and Staff Perception of Barriers to Independent Living and Employment

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<thead>
<tr>
<th>Client Perceptions of Barriers</th>
<th>Staff Perceptions of Barriers</th>
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<tr>
<td><strong>Independent Living</strong></td>
<td><strong>Employment</strong></td>
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<tr>
<td><strong>Systemic Barriers</strong></td>
<td><strong>Independent Living</strong></td>
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<tr>
<td>• Lack of affordable low-income housing</td>
<td>• Lack of affordable housing</td>
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<td>• Lack of resources to cover expenses if one becomes ill and unable to work</td>
<td>• Lack of health insurance in light of unpredictable health</td>
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<tr>
<td>• AIDS-related stigma and discrimination</td>
<td>• Low income in terms of meeting basic needs</td>
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<tr>
<td>• Lack of available information for working with community-based agencies</td>
<td>• Stigma/Discrimination</td>
</tr>
<tr>
<td>• Institutional tendency to create dependence on agency staff</td>
<td>• Mental health</td>
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<tr>
<td><strong>Personal Barriers</strong></td>
<td><strong>Employment</strong></td>
</tr>
<tr>
<td>• Lack of realism/flexibility in planning</td>
<td>• Lack of motivation, insight, and responsibility</td>
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<tr>
<td>• Fears of being alone</td>
<td>• Limited skills and training</td>
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<tr>
<td>• Vulnerability of relapse to substance abuse</td>
<td>• Difficulty with coping and problem solving</td>
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Clients’ Perceptions of Employment Barriers

Many clients noted that there were few available jobs for them. They noted that employers were reluctant to hire them because of their level of education, skills, and training. Moreover, most clients saw their AIDS diagnosis and other factors in their background as negative incentives for potential employers. For instance, Greg, who in addition to his illness has little work experience, a poor credit history, and unpaid student loans, expected that most employers would not find him a desirable employee.

Clients also perceived that employers would have difficulty with the gaps in their employment histories. Joseph, who has not worked regularly for several years, stated that he is constantly worried that “the question is gonna come up, in the interview: ‘What about this gap in your work history, this gap of time?’” For Clint, the concern was how to address the fact that he had a good job for 21 years and has not had steady employment after he left that position. He was concerned that he might have to discuss his health which, he expected, potential employers would receive negatively. Thus, he like many others would rather not disclose his diagnosis.

For a considerable number of clients, there was also concern that no employer would want to accommodate their fluctuating health and functional status such as the varying energy levels many clients experienced. As Joanne stated, “. . . I have more bad days than good days. How are you supposed to accommodate both, on a job? That’s my issue.” Another concern was that no employer would want to take on the cost of their medication. For instance, it was Julian’s belief that:

When they find out you are HIV-positive, insurance is not going to deal with that. You are not going to be able to get insurance in their company with $2–3,000 worth of medicine every month. It ain’t happening. . . . That’s the biggest problem I see about working.

Clients also identified several interrelated resource barriers, namely Social Security benefits, disability benefits, and health insurance. The rules and procedures surrounding these benefits are complex. Not surprisingly, in the course of discussing their perceptions of systemic barriers, many clients reported misinformation regarding the regulations governing benefits and returning to work. Nonetheless, their incorrect beliefs about rules and regulations that governed their eligibility for various benefits did constitute perceived barriers for them.

The majority of clients acknowledged the concern that obtaining employment would eliminate their ability to receive federal and public benefits. For many clients, this concern focused on what would happen if their health status changed and they could no longer work. For example, Steve noted:

The problem I find about working is health care. As long as I’m on Social Security I have medical care, but when I start working the medical care ceases and you have to have a mighty good job to pay for this medicine that you get . . . that’s the biggest problem that I see about working in general.

Clients also worried about whether they would be worse off financially if they worked. For instance, Robert, explained, “I knew early on, early on that underemployment is sometimes as bad a curse as no employment. I probably would live on less money than if I were completely on disability.”

Staff Perceptions of Barriers to Independent Living

Like clients, staff members identified the limited availability of low-income housing as a barrier to independent living. According to Dennis, “Everyone is competing for a limited amount of low-income housing, including the elderly and the disabled.” Staff members also identified the difficulties that clients may have in covering all of their everyday expenditures. For example, they noted clients may not be able to pay rent and utilities and have enough money left for food, clothing, and other lifestyle choices (e.g., having cable television and a phone).

Although some staff felt that clients sometimes needed to be more realistic about what they could afford, most recognized genuine dilemmas of living on such a limited budget. As Kevin explained, it’s important to “understand it from the [client’s] standpoint because if I get sick and have diarrhea and can’t leave the house for the next 2 weeks, my cable’s important to me.”

Nonetheless, staff members did identify and emphasize individual barriers to independent living. For instance, staff members pointed out that clients may not always explore the full range of housing options, including living with roommates. They felt that clients needed to have a more pragmatic view of their housing options in light of their limited income and the reality of subsidized housing.

Staff members also identified isolation as a barrier. They felt that the fear of being alone with health problems was a significant barrier for people returning to independent living. One of the benefits of transitional living was the built-in support network for clients that was especially important for clients who struggled with addiction and/or mental health problems. As Kevin observed, “. . . to leave a house like this and live on one’s own means losing community.”
Staff in two groups identified sobriety as a major challenge for drug addicted clients. As Dan noted:

Seventy-five percent or more of our residents are recovering and working hard and building clean and sober time. But it doesn’t take much of a crisis to really challenge a person to hang on to their sober time and not self-medicate to feel better.

**Staff Perceptions of Barriers to Employment**

Staff members identified stigma and discrimination as a major barrier facing their clients as they seek employment opportunities. Kevin explained that many people are afraid not only that they wouldn’t be hired, but also of the perceived consequences of being discovered by coworkers as being HIV-positive or having a mental illness. Staff members also recognized that benefits were a primary barrier to working. Specifically, staff members were concerned about the complexities associated with participation in Social Security, Medicare, and Medicaid programs. Like clients, they expressed frustration with trying to keep up with the changing requirements for obtaining benefits and the difficulties associated with working with bureaucracies where workers were notorious for giving out incorrect information.

Staff understood their clients’ fears of being removed from these programs upon returning to work. As Dennis noted:

I think clients are really afraid that they’re gonna lose their benefits. I’m sure you’ve heard about that over and over and over again . . . but that’s the problem. . . . One really needs to understand the program.

He went on to note that many clients were wary because of what they have heard from others about the difficulties of getting back into these programs if they get sick and can no longer work. However, although acknowledging that there were systemic reasons for the prevalence of misinformation about the complex bureaucracies and rules governing various types of eligibility for benefits, staff members also felt that clients could take more responsibility for seeking out and learning appropriate information.

Staff members also uniformly felt that clients faced significant personal barriers to obtaining work and maintaining employment. They identified clients’ lack of motivation and their sense of entitlement (that they should be able to receive benefits and not have to worry about work) as barriers. Staff members also identified concerns about clients’ lack of insight and limited ability to problem solve and cope with stress as factors that would compromise their employability. Staff members also saw lack of education and training, and lack of life skills as personal barriers to clients achieving employment.

**Discussion**

The findings from this study indicate that both clients and staff members recognize the types of environmental barriers to participation that have been identified in disability studies. The findings also underscore that there is a gap between the perceptions of service providers and clients regarding the factors influencing participation. That is, whereas clients emphasized environmental barriers to independence and employment, staff saw a combination of environmental and personal barriers. Staff members tended to emphasize insufficient motivation and personal responsibility as a significant issue. They also identified underlying personal problems related to mental illness, substance abuse, lack of education or training, and lack of life skills as the greatest barriers to accomplishing independence and employment.

There was also a difference in how some issues are framed by clients versus staff members. Where clients saw an unwillingness of employers to find them desirable, staff saw the need for clients to seek out and receive more training and to learn how to communicate more effectively about their circumstances. Where clients perceived a systemic lack of information, staff saw possibilities for clients to take additional responsibility for getting information.

The gap between client and staff perceptions of barriers replicates much of the contemporary tension between the perspectives of the social model of disability studies and the traditional rehabilitation approaches as identified by Kielhofner (2005) in this issue. Disability studies authors have criticized rehabilitation professionals for attributing disability to personal failing where social obstacles are really to blame. Although rehabilitation professions have been mostly silent on the issue, one suspects that they, like the staff members in these transitional living facilities, may feel that the exclusive focus on social issues may be overstated.

How, then, is one to read this gap between staff and clients? Are clients insufficiently motivated and prepared for the realistic demands of society? Are staff unfairly blaming the victims of social oppression for their plight? Is disagreement with the client’s version of barriers a failure to include the client as active participant in the identification and treatment of the problem? Would failure to challenge clients about perceived personal barriers in intervention be an abdication of responsibility by service providers?

That none of these questions resonate with clear answers is vexing. However, even more cogent is the fact that these questions play out in just about every client’s story in our ongoing ESD project.

It would be premature to suggest that we have resolved the tension. Nonetheless, recognizing and addressing this gap in perceived barriers has been critical
for the development and implementation of services for these clients. Importantly, this disconnect in perspective, when not openly acknowledged, serves to limit the effectiveness of the therapeutic relationship and the outcomes of therapeutic interventions.

Based on the social model of disability and the Model of Human Occupation, we have developed and implemented services that seek to bridge clients’ and staff members’ perceptions. For example, we have sought to address both clients’ perceived need for better information and the staffs’ members’ perceived need to improve clients’ communication and problem-solving skills. Ultimately, by developing resources to combat lack of information and improving clients’ abilities to navigate systems and communicate with individuals in the various agencies regarding their immediate and long-term needs, we hope to show positive outcomes for clients in the areas of both successful independent living and employment. Moreover, as clients develop not only skills but also an increasing sense of efficacy, what seemed insurmountable obstacles appear more manageable. In the end, theoretical models such as the social model of disability and rehabilitation models such as the Model of Human Occupation can find common ground and offer complementary perspectives.

Acknowledgments

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References


