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Developing a Community-Based Definition of Needs for Persons Living with Chronic HIV

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Abstract

With the advent of antiretroviral therapy, HIV has become a chronic illness for those who have access to the medication. But unlike our understanding of acute disease experience which can be grasped within parameters defined by categories of medical diagnosis and treatment, understanding the experience of chronic illness requires that we expand our analytic frame to include variables and perspectives created by the beliefs, behaviors, context, and culture of the participants. Drawing on focus groups conducted among African American, Hispanic, and white people with HIV in Detroit, Michigan, we show that expressions of needs related to the lived experience of HIV vary among racial and ethnic groups and between genders, resulting in an experientially distinct set of needs.

Keywords

HIV; community-based needs; stigma; ethnicity; gender; focus groups; Detroit

For people with access to the new therapies, HIV has been transformed into a chronic condition with all the associated issues of living and coping with a chronic illness (Pequegnat and Stover 1999). Studies of the chronic illness experience of people with HIV have, with few exceptions (e.g., Farmer 1991), focused on white men who have sex with men (e.g., Brauhn 1999; Ezzy 1998) Unlike our understanding of acute disease experience, which can be grasped within parameters defined by categories of medical diagnosis and treatment, understanding the experience of chronic illness requires that we expand our analytic frame to include variables and perspectives created by the beliefs, behaviors, context, and culture of the participants (Corbin and Strauss 1988; Luborsky 1995; Roth and Conrad 1987; Scheer and Luborsky 1991). It is the daily experience of living with a chronic illness that generates the needs people identify as much as those related to the clinical features of the disease.

Social scientists following the United States epidemic have emphasized that the nature of the HIV illness experience depends on the social and cultural location of the patient (Diaz 1998; Davies 1997). These social and cultural differences extend beyond the domain of beliefs to inform actual care practices and thus may affect medical outcomes. An example of this is the case of HIV+ women who tend to be diagnosed later, have more clinical symptoms than men with similar plasma HIV loads (Farzadegan 1998), receive antiretrovirals later, and die sooner (Sowell 1998) than men. HIV+ African Americans receive antiretroviral therapy at lower rates than HIV+ whites (Stolberg 2002). Variations in experience give rise to different needs that, if unmet, manifest themselves in differential clinical outcomes.

Background

Finding a useful and valid way to identify a culturally informed understanding of the needs associated with living with HIV remains a trenchant problem for public health agencies at this juncture in the HIV pandemic. HIV service delivery systems are modeled on community-based long-term care services designed to meet the needs of the elderly chronically ill (Crystal, Merzel, and Kurland 1990). Similarly, HIV agencies conduct needs assessment to facilitate the rational and efficient delivery of appropriate services to meet assessed needs. That the research on need has been closely tied to the structure of the preexisting service system was, in part, a result of the ad hoc crisis nature of the emergence of HIV services and, in part, reflected vested professional and political interests that helped structure, and are structured by, the service delivery system. Thus, much of the early research on HIV-related needs is based on expert opinion or surveys that match the needs of people living with HIV with available services using normatively defined social groups or risk categories.[1]

Understanding chronic illness requires that we attend to variables and perspectives derived from and created by cultural and individual beliefs, behaviors, and contexts of those suffering from the disease (Corbin and Strauss 1988; Luborsky 1995; Roth and Conrad 1987; Scheer and Luborsky 1991). Chronic illness becomes integrated into one’s life and simultaneously restructures that life to meet the demands of coping with the illness. Thus, characteristics of an individual’s life setting and identity influence the experience of illness. People reorganize their daily priorities and routines to accommodate limitations created by diminished physical abilities, restructure their social relationships to address rejection due to HIV stigma, and rethink their lives and future goals due to the terminal nature of their disease.

Conversely, the nature of an individual’s social and cultural context structures the experience of an illness through such features as access to services and sources of support. The chronic illness orientation differs from the approach to understanding the HIV experience that organizes people into research categories defined by risk-group status or by

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[1] See Flynn (1994), Gellert et al. (1993), and Garrison (1989) on the needs of HIV children and adolescents; Rotherman-Borsu (1991) on homeless HIV+ persons; Williams (1992) on women’s needs; Kelly (1993) and Klines (1991) on the needs of informal caregivers; and Jimenez and Jimenez (1992) on the special needs of Hispanics. Cochran and Mays (1991) urge researchers and clinicians to focus on the diversity in the patient population and on the specific patient context to understand HIV needs. Only 5 out of 36 studies reviewed addressed the possibility of the broader conceptualization of need implicit in the chronic frame by basing their assessment of need on open-ended interviews with people living with HIV (PWH) (Florence, Lutzen, and Alexius 1994; McGrath et al. 1993).

severity of HIV infection. The lack of correspondence between the risk category in which individuals are placed and their experience of HIV has been extensively argued by anthropologists such as Glick-Schiller, Crystral, and Lewellen (1994), who have demonstrated that risk-group membership cannot reliably be linked to socially or culturally meaningful categories of experience.

Attention to how a person with HIV discusses daily life with the disease provides insight into how various social and cultural contexts in which people find themselves can work to shape the trajectory and impact of the disease. As we will show, expressions of needs related to the lived experience of HIV vary among racial and ethnic groups and between genders, resulting in experientially distinct sets of needs. The variations in meaning and experience reported here have their basis not in the pathophysiology of the disease, but rather in the diverse nature of the history and institutions that structure the illness experience among different groups.

With the advent of antiretroviral therapy (ART), research on the needs of people living with HIV moved away from the narrow view of immediate functional limitations caused by the disease. Prior to becoming a chronic illness, the living needs HIV/AIDS created converged around coping with a severe, highly debilitating disease. This has changed with ART. The needs themselves are different. For example, the need for nutrition and primary care that are tied to HIV-wasting syndrome appear less frequently in research findings than needs such as housing or transportation associated with the sequelae of living with an incurable chronic illness. And the needs are more diverse. Convergence remains, however, in the shared experience produced by the stigmatizing nature of HIV, which creates a set of needs common to all sufferers.

Valid working concepts to guide the process of identifying, assessing, and providing for the needs of persons living with HIV remain elusive. While some studies are available that report on needs, few were developed with adequate attention to defining needs in terms salient to the categories of belief and everyday community life of persons with HIV[2] The standard needs assessment approach does not capture the broader experience of what is required to cope with HIV disease.

“Living while dying” (Sankar 1991) is a useful concept to guide research and programs developed from studies of practices and experiences of persons with chronic fatal conditions and their caregivers. It examines the day-to-day experiences that become suffused with meaning, such simple actions as meals or the telling of family stories. This concept shifts our analytic focus from the tasks and treatments related to physical care of the person to the wider realm of the daily concerns, activities, and social interactions that constitute the

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[2] In many cases, professionals were interviewed concerning patient needs. For example, Linsk and Marder (1992) interviewed social workers concerning PLWH community service needs and Kunzel and Kind (1992) surveyed physicians about pediatric HIV needs. Similarly, medical record reviews were the basis for identifying patient needs (Barnes et al. 1993). Hurley and Ungvarski (1994) identified the psychosocial needs of women with HIV by adopting rather than questioning traditional social categories, such as PLWH, women, or people with cognitive impairments. Yet surveys of 128 adults with HIV led Lamping et al. (1992) to caution that needs varied within as well as between the PLWH’s age and class status. One useful strategy has been to bring together members of the community to describe their experiences and concerns. Indyk et al. (1993) describe how a women’s HIV support group can be used to identify needs.

experiential contexts of human life in the face of dire adversity. A major contribution of that work was to identify the salience of affected individuals' attention to preserving and extending their social relationships; to affirm basic cultural ideals that make the person's life meaningful; and to fix their place in the heritage and memory of the surrounding community of family, friends, and neighbors. The construct marks an important shift away from a perspective narrowly restricted to the physical and social processes of dying and separation. The concept of living while dying contributes to public health by providing an orientation within which we can design programs that are attuned to the perceived needs, barriers, and goals of those living with and assisting in the care of persons with AIDS.

Methodology

Design and Sample

As part of a larger survey to assess the unmet needs of people living with HIV in the city of Detroit, we conducted nine focus groups between 1994 and 1995 with HIV+ adults to address HIV-generated needs. An important impetus was to identify needs not addressed by the Ryan White HIV Care Act, which was designed to meet the community-care needs of people with HIV. The Detroit Health Department specified nine populations for inclusion in the survey. Four groups coincided with those defined by the Health Services Research Administration (HRSA) as special at-risk populations: white men who have sex with men (WMSM), African American men who have sex with men (AAMSM), women, and intravenous drug users. (Note, we have retained the use of public health research-defined risk category labels to enhance the comparability of these data even as we share the widespread recognition of several limitations to the concept of HI V-risk category. Most prominent among these limitations is the lack of meaningful overlap between an individual's self perception [e.g., a wife] and the risk category label [e.g., sexual partner] [Glick-Schiller, Crystal, and Lewellen 1994].

To better represent the actual range of the universe of populations at risk within the study area, the health department expanded the study to include the homeless, recent ex-offenders, physically or developmentally impaired (two groups representing this category were those individuals with cognitive disabilities and those with hearing impairments), and first- or second-generation linguistic minorities (this category was represented by Hispanics). To ascertain HIV status, volunteers were asked to produce a recent (within one month) prescription for an HIV treatment medication. This method was deemed to be a valid, nonintrusive assessment of HIV status.

Recruitment

Intense and protracted outreach efforts recruited 238 volunteers for the survey, of whom 52 agreed to participate in the focus groups. Survey volunteers received $10 and focus group volunteers an additional $20. To recruit these volunteers, we employed a combination of targeted sampling directed at specific community and service sites, snowball sampling, and list sampling utilized with the guidance of professional informants. Targeted sampling (Walters and Biernacki 1988) combined with snowball sampling was used to recruit the intravenous drug users, white and African American MSM, and women. Agencies that served people affected by HIV were contacted and asked to recommend people to serve as interviewers and recruiters. These people were trained in recruitment and interviewing techniques. Street-level outreach staff were used to contact people engaged in high-risk activities, such as sex industry workers.

List sampling, combined with the use of professional informants (Lee 1991), was used to recruit populations who were not geographically grouped: the hearing impaired, cognitively impaired, ex-offenders, and Hispanics (recruited at an assisted-living facility). A combination of street ethnography and list sampling was used to recruit the homeless. The sample is described in Table 1.

Focus Groups Procedures

A focus group approach (Agar and MacDonald 1995) was selected in light of the goals and the study population. It enabled us to elicit spontaneous and relatively unstructured responses to open-ended questions about needs and to obtain community-based definitions and evaluations of needs. The focus group approach allowed us to move beyond the limits of the structured, fixed response format to identify the range and variation in community definitions of need. In this way, we elicited topics of importance to participants that had not been anticipated in the design of the protocol or structure of the focus group.

Four to nine participants volunteered for each focus group. Each session lasted for 90 to 120 minutes. Focus groups were conducted in community centers, local churches, a homeless shelter, an assisted-living facility for the developmentally or cognitively impaired, and in the conference rooms of case-management agencies. They were facilitated by an ethnographer and by the person who was responsible for community outreach and data collection for the survey.

The sessions began with a brief informal visiting period, followed by the facilitator introducing two discussion topics: “Tell us about the needs you have resulting from your being HIV+” and “Which of these needs do you feel is unmet?” Group members in turn shared their opinions or experiences, and discussion among participants was encouraged. When the group discussion topics and time were completed, the facilitator thanked the participants for their help and the meeting ended. A court recorder made a verbatim transcript of each session that provided a detailed record of the group discussion.

Analysis

Interpreting qualitative significance required that we employ two standards for evaluating content and theme analyses (Luborsky 1994a): frequency of statements and direct statements of salience or meaning. In the content analysis, most frequently mentioned or coded categories were deemed important. Frequency was viewed as indirectly marking importance or salience. In the thematic analysis, direct statements of the importance of a value or belief were used to judge significance. It was the explicit statement by participants in the social and cultural group under study that provided the index of significance. For example, assertions that “creating a legacy” was an important need were taken as significant despite the few numbers of such statements in the sample. Vague quantifiers such as “some” or "most" were avoided in favor of specific counts and statements as the basis for determining the significance of data.

Topics

First, using a method developed by Luborsky (1994a), we identified each separate topic in a speaker's statement within each focus group. A topic is a distinct, complete idea. Its beginning and end are marked, and the content is summarized succinctly to create the individual topics. The topics of each individual speaker were identified and coded. We then aggregated the topics within each group. In total, there were 1,111 topics. The aggregate list constituted a free-list format of all possible replies. These were rank ordered according to the frequency of appearance in each individual focus group data set. These data provided direct expressions of informants' own words on their own beliefs, ideas, and concerns.

Second, the topics in each free list were sorted into piles by the staff, working as a team, to group together the individual items into groups of shared content. The main topic categories were then grouped into larger domains. These codes were developed in one focus group and applied to each subsequent group and expanded or adjusted as needed. On completion, the entire list of topics was recoded using the final domain list.

To guard against possible over representation by any one group due to the number of participants (e.g., the African American MSM group had nine participants with the number of topics per person ranging from 46 to 89 for a total of 268 topics, or under representation due to restricted discussion, (e.g., the cognitively impaired group had only 67 topics, with 4 to 18 topics per participant), we calculated the proportional representation of each domain for each focus group (see Table 2). Further, we grouped the sample by gender, ethnicity, and sexual orientation, and determined the percent of each domain within these aggregate groupings.

Themes

Next, using sociolinguistic discourse and content analytic techniques we identified major themes—shared scripts for living with the social consequences of HIV—and evaluative clauses that expressed fundamental moral and cultural orientations. The goal was to identify contents, concerns, idioms of speech, shared guiding moral perspectives, and conflicts. Open focus group discussions can be a valuable data source because they tap arenas of experience, meaning, and attention that are inadequately captured or missed by standardized assessments or direct questions.

Findings

Results are presented in two sections. We first describe the range of individual topics or concerns identified by focus group participants. Second, we turn to the analysis of recurrent themes. These two analytic steps provide a complete description of the universe of perceived needs and the themes that are most salient from the participants' perspective.

Perceived Needs in Living With HIV: Range of Topics Provided by Focus Groups

We started each focus group by asking participants to tell us their particular HIV-related needs. Summaries of responses to this question indicated that the concerns participants raised were not limited to fundamental necessities of daily existence. Much of the discussion did not focus on medical or social service delivery definitions of need. Rather volunteers discussed a more sociocultural, existential need that related to how they coped with and adjusted to a terminal and highly stigmatized illness. Analysis of the flow of conversations in the groups showed that after discussants first identified basic functional needs, they quickly moved to discuss their experience and the sociocultural value-based needs arising from having to make sense of and manage a life as a person with HIV. Analysis revealed six main domains: coping with HIV; the social consequences of being HIV+; making sense of being HIV+; nonhealth-related needs, health-related needs, and HIV risk.

Coping

Coping covers the expressed needs for specific skills or services to help an individual deal with being HIV+. Coping and social consequences of being HIV+ were mentioned at least once by the most participants (88.5%). Needs associated with coping accounted for the largest proportion of needs in two groups (cognitively impaired and homeless), although different groups identified different needs for coping. For example, the homeless and substance users requested services to help provide the skills to cope. They also made specific requests, especially for a 24-hour hotline for people who were having a difficult time coping. The availability of on-demand support 24 hours a day was linked to the fear of dying voiced in all groups. “I can cope pretty well except in the middle of the night.”

> If we had a motivational speaker, this would help us to cope with these things in a much more positive way, because people don’t understand that being HIV+ and by being new, this was something that we had to go day by day developing our own coping skills. There was none. There was none, no coping skills. Where am I going to get the coping skills to deal with this? There is none (African American, women’s group).

> It’s things like this that we need that I know the city could help us with. Motivational speakers, that would help a lot because the mind with this disease, you could be feeling great and then it hits you, “Oh, yeah, I’m HIV” (African American, women’s group).

Participants explicitly expressed the need for social contact or activities to help cope with the extreme isolation of many individuals. In part this isolation was self-imposed due to shame from HIV stigma or from depression accompanying ill health and fear of death. In part the isolation stemmed from rejection by family and friends. The need for social contact was not mentioned in the women’s, Hispanic, hearing-impaired, or cognitively impaired groups.

> Really a lot of people are saying to me that they need something to occupy time. They’re unemployed. They’re not in school. They’re just there. They just exist. They’re not living, so when they said they need activities, they want something that’s going to get them out of the house and take their minds off the illness. So

> anything would be better than what they're already doing, because they're like that plant there, they're just there. Nobody comes to look at them. They don't get any attention, and that eats you up more than anything. That gives you time to get depressed. You worry, you cry, and you're down. Your morale is gone, so they have activities to keep them going, you know, group activities, sole activities. It's something to occupy their time is what I'm talking about to be a problem (African American MSM group member).

If we group the participants by sexual orientation, the need for help in coping represents the only substantial difference between people with a gay/lesbian orientation and those who do not self-identify as such (see Table 3). This suggests that the challenges of coping with HIV may differ depending on one's sexual orientation.

The need for help in coping meant different things in the various groups. White MSM and Hispanic groups each identified the need for emotional support in coping with the disease, the need for more support groups, and the need for support for people caring for those with HIV. In other groups, participants referred primarily to the need for professional support for coping.

> It would be nice if my family would come over and visit me, but they won't come to my house. I have to go there, and like when I do go, though, you know, my father'll slip me $20 or something, which is helpful, but that's not what I need from the family (white MSM group member).

The church and religion are included in this domain. Participants in each group where it was mentioned complained about the hostile treatment they had received from the church. While noting the need for spiritual support, participants in these groups were unanimous in noting its lack.

> It's very dehumanizing to have to go and beg for food, you know; and then they want to ask you, "Can I see your food stamp card?" What is the problem? And I don't feel like I should have to tell everybody that I have AIDS to get a box of food, you know. You have to go to these churches, and if you don't tell them, they only give you one box, and you can't come back next month because you didn't tell them why, and then they look at you and the next thing you know, they come out with rubber gloves on, you know. And when they do know, it's like they're whispering, they're looking, pointing. You want to just hide in the corner, and sometimes you feel it's better off not to even go. (white MSM group member).

Social Consequences of Being HIV+

Focus group participants struggled with the stigma and hostile treatment they regularly received as a result of being HIV+. Most important in this domain was the rejection and denigration individuals experienced in daily life. The general need they expressed clearly and forcefully was "to be treated like a human being." Social consequences was the most frequently mentioned topic for four of the nine focus groups (WMSM, women, hearing impaired, and intravenous drug users). Social consequences of being HIV+ is salient to MSM and to whites—every member of these groups mentioned this topic. In addition, MSM made significantly more references to social consequences (an average of 7.8 mentions per respondent) than others (an average of 2.9 per non-MSM-identified respondent,) (race F = 5.829, p = .005; orientation F = 11.132, p = .002).

> I talked to my mom right before she asked me to leave. The way she put it, she put it like this. She don't feel like the rest of the family being able to handle me being there, but she still—I was like, "Mom, I need you one day because I am going to get sick." She tried to give me that pep talk and she said, You going to be around, you going to be okay" (AAMSM group member).

The day-to-day, petty humiliations also figured prominently in these discussions.

> Once a month we have a covered dish in our group. Everybody brings something in for dinner, and my coworker always has to know what I've made because she will not eat it. (WMSM group member).

Confidentiality is seen as a protection from HIV stigma.

> I find my confidentiality has been breached by going to a doctor's office and you fill out this thing that then it has, "Do you have so-and-so?" And this does not even go to the doctor. This is the receptionist that gets this back, and I'm like what business is it of hers? So I don't fill it out. So when I was given my paper back and it was the date and time and all the blood work and whatever is on there, and down at the bottom where somebody—where I wouldn't have noticed it, it had "HIV positive" on there (African American, women's group).

Making Sense of HIV

Participants struggled with "Why have I become HIV+?"; "What does it mean?", "Why me?" Included in this domain are stories of the diagnosis and the meaning of having contracted HIV. This domain accounted for more than 20 percent of all topics in every group except the ex-offenders and the homeless. If we organize the focus group participants by gender, we find a significant difference between men and women. Making sense of HIV appeared to be a male issue—64 percent of the male participants made at least one reference to this topic as compared to 31 percent of the women (chi square = 4.39, F = 2.942, p = .093) (See Table 4). When women searched for meaning in their infection their approach was different from that taken by men. In general, they sought to frame their disease in a positive manner. For example, one African American woman said it was "God's wake-up call," allowing her to make a break from her drug addiction and "take control of my life." Men tended to struggle with the injustice of their diagnosis, "I didn't do anything wrong."

Nonhealth-Related Needs

Included in this domain are the needs focus group participants attributed to their being HIV +. These included housing—both problems with housing discrimination and homelessness—transportation, help paying bills, help paying for insurance, accommodations at work, money for food, and financial help in general. More specific needs such as cosmetics that did not interact with antiretroviral medications, sufficient toilet paper, and the generalized distress of "a whole lot of help" were mentioned. Nonhealth-related needs were mentioned by 92 percent of the male participants but by only 54 percent of the women (chi square = 10.08, F

= 3.659, p = .062). Among males, it was particularly a topic for MSM— 95 percent of them mentioned it, compared to 75 percent of non-MSM (F = 12.134, p = .001)

This was a particularly salient domain for the white MSM's group. Many of their needs were associated with changes in their lifestyle caused by loss of active employment. For example, they needed help paying bills, a need shared only with the hearing-impaired group, also exclusively white MSM. When white MSM referred to transportation problems, they meant problems paying for car insurance; in other groups, this referred to the need for bus fare.

> I've had a problem with kind of the budget, and really, it's almost—I think the electricity is so expensive, and I use a lot of heat because my body gets the chills, and I use a lot of heat, apparently. I guess I can pay for gas. That's no problem. But car insurance and normal expenses—really, I pay, you know, car insurance. I paid it last week and it was way overdue and I hadn't been able to pay for it and I kind of put it off because I didn't feel that—sometimes, I don't feel very responsible in paying my bills because I don't want my electric bills to get cut off, and I have to pay those kinds of things. SSI checks are not enough to buy food and personal things. It's not enough, and I'm afraid that with the car insurance problem—I was driving without insurance, and I couldn't pay the bill (while MSM group member).

In the African American MSM group needs were also related to lifestyle problems caused by loss of employment, but they represented a smaller percentage of the total topics than for either the white MSM or hearing-impaired groups.

For participants in the ex-offender and homeless groups, finding adequate housing outweighed concern with disease. In fact, this domain accounted for almost 40 percent of all topics for ex-offenders. Women needed HIV-related services that addressed their health problems. They also identified a need for women-only support groups because potential benefit offered by mixed groups was thwarted because men were seeking sexual liaisons and "hitting on them."

> I agree with the support groups for women and women with children because you can't touch base in a big, open support group that has men and women. They're not looking at the aspect of you having HIV. They're looking at the aspect of "since you got it and I got it, let's get together." It creates stress because that's the last thing you're thinking about is lying down in the bed, of all things, with a man, you know (African American in women's group).

In the substance-user group some participants worried about the impact their disease would have on their family, which was already strained by participants' addiction, and how children would cope after their death. Participants also identified the need for improved case management and for funerals. The need was not for more case management, but for oversight of existing agencies. In particular, participants in the African American MSM's group felt agencies were improperly run, that money for clients was being misappropriated, and that staff behaved inappropriately. Discussion of the need for information about funerals and for financial support for a decent funeral was spread evenly across the substance user, white MSM, ex-offender, Hispanic, and cognitively impaired groups.

Health Needs

Health-related needs included finding physicians with expertise in HIV, access to clinics, nutrition, treatment for depression, information about HIV, relationships with health care professionals, and dental care. The specific needs differed by group. Substance users cited the need for basic HIV care and treatment for depression, as well as treatment for substance abuse which was also a significant topic for ex-offenders. In contrast, the hearing-impaired group sought sign interpreters to assist in communication with health care professionals.

> When people speak, we don't get that information. The hearing people can hear that and can learn from that, and they can find out from other people whether or not there's good options or bad options available, and how to live with HIV and being sero-positive, and what you can do, any information about that, and also the option to express our emotions and our feelings and to get feedback from someone, and to have someone say, "Oh, yeah, I've learned to do something else. You can use this other method to take care of yourself better" (white male, hearing-impaired group).

The Need to Reduce HIV Risk

Participants said they found meaning in having HIV because they were now in the position to educate others, especially the young, to avoid risk factors. This sentiment was most frequently voiced in the white MSM group, but it was the dominant topic mentioned by white women.

Themes

There was considerable variation across the focus groups in the proportion represented by a topic within a specific focus group's discussions, but some groups stood out in mentioning certain topics. For MSM, health, nonhealth needs, and the social consequences of living with HIV were particularly salient topics. For white participants, risk and the social consequences of having HIV were important topics. For men, nonhealth-related needs and the need to make sense of the disease were important. Topics related to the need for help in coping with HIV were most prevalent in the homeless and cognitively impaired groups. (See Table 5).

Talk of perceived needs only partially characterizes the focus group discussions. Focus group participants rarely limited their comments to functional need and regularly progressed into the existential need to "be treated like a human being" and "to have a sense of my own worth restored." Thus, the relatively prosaic purpose of the focus groups—to identify the unmet needs of people living with HIV—became a framework for people's consideration of the knowledge, skills, beliefs, emotions, and relationships needed to exist in a stigmatized status and, in some cases, to change or challenge that status. Specific service needs carried far less emotional valence and occupied much less talk than discussion of how and what participants needed to live with HIV

Several explicitly stated themes (Luborsky 1994a) marked this type of talk. Key themes were self-esteem, responsibility for care, and discrimination. These themes were shared across more than one and in some cases all focus groups (see Table 6). The differences in expression of the themes that emerged were associated with gender and ethnic identities.

The groupings were not consistent: gender sometimes marked the difference; other times the difference was distinguished by ethnicity or race and, in one case, disability status.

Self-Esteem

Restoring self-esteem was a major theme in all groups, with the substance user and homeless groups explicitly identifying low self-esteem as a major problem of being HIV+.

For African American men the theme of restoring self-esteem ran through every focus group in which they participated. Suggestions to accomplish this drew on the deep-seated values associated with work in American culture, both paid and volunteer. Employment as a vehicle for self-esteem can present a dilemma, however. Many participants felt racial discrimination had created lifelong difficulties in gaining equal access to employment; thus, the desire for training and a job as a vehicle for self-esteem was marked by conflicting associations. Work is a source of self-esteem because it is both associated with respected adult status—something that is threatened by the stigma of HIV—and it implies responsibility, another value.

> I want some kind of—what are we going to do. I have to have a job, and I got to have a dream. These bills coming, it's some kind of—and I never knew what—no sell-esteem. I didn't even know it, but oops, there it is (African American male, ex-offender group).

Some resolved the conflict between wanting productive labor and their feelings that it had been denied them through discrimination by advocating volunteer work. Volunteer work can fulfill the work ethic—it provides both productive labor and responsibility for others, a central aspect of adult identity. Volunteer work was also characterized as a means to create an enduring legacy by contributing to the well-being of others and enhancing the self-esteem.

> I've been looking for work to do. I want to help other people with this virus. I went to Children's Hospital to sign up for volunteer services. All I want to do for myself, before I leave this world—I don't have to go with the virus. I don't know how I'm going to go—all I want to do is leave my name on something, to say I did something, that I helped somebody else. I don't feel ashamed. If a person can't deal with me with HIV, they can keep walking (African American male, cognitively impaired group).

This statement reveals a sense of both social and spiritual isolation. Robert Murphy (1987:227), writing about the experience of living with a progressive fatal illness that produces disabilities, described this as a situation where one "feels riven from within and from without." It also reveals a desire to invest or contribute to the welfare of others, perhaps future generations, and to leave a mark after one's passing.

Focus group participants actively sought ways to break or disrupt the stigmatizing impact of HIV. Public education was one of the most prominent strategies. Significantly, participants relied on education not only to reduce the condemnation of others through increased empathy and compassion, but also to enhance the speaker's ability to cope with the stigma through improved understanding. African Americans and Hispanics shared the belief that education would help reduce the stigma. In particular, African Americans and Hispanics stated that adequate information for the public and, in particular, their relatives and friends would eliminate the stigma. They were unswerving in affirming the power of education to change people's attitude toward HIV and remove the stigma.

> Everything revolves around the educational part of it. Learning about the disease itself is educational at the same time. It's helping not only us dealing with ourselves, but we can also help somebody else, and that's the part I guess I get the enjoyment out of, because there's no enjoyment in having what I have, but learning to live with it is the educational part. If we all get the education and experience with it, it will be so much better for everybody. So that's it (member, African American MSM group).

For white MSM, education was not a major strategy to reduce stigma, which for them was strongly mixed with the humiliation of loss of class status and the necessity to accept welfare and charity. Public education could not have addressed this problem. White MSM discussed education primarily as a means to learn more about the disease and, hopefully, "control" its impact on them.

> The case manager gave me the information, and I have the attitude, just give me a direction, I want to completely empower myself, and if I'm talking to the people, I'm getting as much information directly, because I always have lots and lots of questions. "How does this work? How does that work?" (member, white MSM group)

Criticism of the ineptness, uncaring behavior, and negative attitudes of physicians appeared frequently in discussions. Physicians and occasionally other health care personnel, such as x-ray technicians, became concrete and localized sources of stigma. Their response to breaking the stigma differed significantly from those of African Americans. Instead of seeking to educate others about the disease, white MSM told of asserting their status vis-á-vis their physicians. Stories of standing up to, changing, or "firing" one's physician, reestablish their status as empowered middle-class men. These acts redressed some of the perceived loss of class status and strengthen self-esteem by asserting control.

> I've fired four doctors since the beginning. My first doctor told me—I found out—I had to go on AZT right away, and I asked him what are my chances, and he says, "The AZT usually works for two years and then most people die." It took me a while through counseling to get through that, and then when I did find this self-empowerment, I fired him, and I've fired four doctors since. I've had to fire them because of many different reasons, not being able to get in to sec them when I need to see them; not answering my questions, I had to fire one; one that when I asked him, "Can I live to be 100 with this?" and he said, "No." So I fired him, because I need to know that—I mean at least that there is going to be hope that they are coming up with things that might work.... So I fire them so I'm in control (member, white MSM group).

The actions illustrated by the patient above may be counterproductive; they may hinder provision of the kinds of care to manage chronic illness. The frequent change of doctors truncates the long-term relationship with a physician that can improve effective individualized care. A lesson from the policy perspective, however, is that we must be alert to overly simplistic conclusions derived from defining a need out of context to other needs and requirements. Here, the desirability of enhancing patient choice of providers (familiar to acute care and short-term treatment models) must be situated within information about the kinds of complex and lengthy care required for chronic illnesses. Finally, the example poses a more challenging value dilemma: in light of immanent disability and death, what is the ethical foundation for choosing a paradigm of care rooted in the medical model of effective treatment outcomes as opposed to comfort of a patient who is struggling to “live while dying” (Sankar 1991)?

Responsibility for HIV

Participants in all focus groups protested against the popular notion that they were responsible for having acquired the disease. “We didn’t bring the disease on ourselves. It just happened” (African American male, ex-offender group). But this sense that they were not responsible for acquiring the disease was not interpreted to include being exempt from the moral duty of self-care. Participants strongly endorsed the value of individual responsibility for self-care.

> But as far as myself with the virus, I just look at it like as long as you can keep your mind strong—and the healing power of the mind is really, really great because it’s, you know, real powerful, a lot more powerful than people realize. If you keep a positive attitude about it and say, “This is something that I can overcome and not let it get me down,” I think you’ll grow a lot farther and you will stay healthier longer than if you get depressed and say, “I’m going to die.” I keep a positive outlook. I’ve always been a fighter, and this is something I still have another good 10, 12 years coming. So I don’t really let myself get depressed about it too much (male, Hispanic group).

Ethnic differences appeared in attribution of responsibility to others for caring and providing support to people with HIV. These centered on who else is responsible for the care of the sick person. All ethnic groups expressed the sentiment that families should be the primary care givers. Where the groups differed was in government’s role. Whites and African Americans said the government “should” take care of people with HIV, they being innocent victims in a national tragedy.

Hispanics also believed the government was responsible for their care, but they characterized this care as their right to care, based not on moral innocence but on the legal rights of citizens.

> Don’t be afraid to pick up the phone and fight for your rights, because the funding and the money for it is there. If it’s there, it’s yours. Don’t be afraid to come and say, “I’m in need. I need it.” If I don’t make a lot of noise, they’re not going to give me what I want. The more noise you make, the more you’re going to get. Don’t be afraid to fight for your rights. They’re there (Hispanic woman).

Hispanics extended their expression of a formal obligation to care to the church, which they said had a moral duty to care.

> I mean, these leaders (of the church) have to start, you know, coming through. They have to start saving these lives and stop looking at their own conscience and look at the conscience of others (Hispanic male).

Whites, especially MSM, and African Americans discussed the significance of spirituality in coping, but most had written off the institutional church as a source of support.

> So a lot of us have been—it's a scary place to go because they are so judgmental. I don't go to church. I believe in Jesus Christ. That's my faith, and I don't need to go to church or a priest to confess my sins (member, white MSM group).

Discrimination

In various ways, all groups expressed a strong sense that they were discriminated against because they had HIV. Each group also identified other sources of discrimination. For white MSM, this discrimination took the form of homophobia. Hispanics and African Americans stated that white MSM received preferential treatment and better access to HIV benefits than any other group with HIV. Hearing-impaired, white MSM also shared this suspicion and resentment. They linked their experience to being a disabled person more than a MSM. In this respect, they depicted themselves as disadvantaged compared to white MSM who were not hearing impaired.

> Well, really, in the first place, the world or the society is very unaccepting of the MSM community, of people with HIV, and of people who are deaf. So we've got all three of these, and that's a heavy burden, and I feel. I mean, I've got all of these three strikes against us, so that's a lot for us to bear, and because I'm not a hearing person, there are some people who may be have HIV but they're hearing and they can get services, but it exacerbates the pain when you can't access services because you can't hear. I feel like I am just fully handicapped because of the three. Being deaf, I could handle. Being MSM, I could handle. But with HIV, it's so debilitating. There are many people who really will not accept me (member, hearing-impaired group).

Discussion

This paper has argued that the needs of people living with HIV cannot be understood if solely limited to a narrow functional definition of need as the "existence of a necessity or want." Rather need, in the case of people with HIV, must be understood as a "condition marked by the lack of something requisite," namely treatment as a human being (Luborsky 1994b).

This argument is based on focus group data that has some limitations. First, as Agar and MacDonald (1995) have noted, focus group data are structured by the dynamics of the group. Some topics were salient to individual groups because of the influence of specific participants. We do not discount the role of individual life-specific experience reflected in focus group membership. Just as the nature of being a person with HIV in the community structured the ways of making sense, the immediate experience reflected in focus group membership created a shared context of mutual understanding that permitted and facilitated disclosure and discussion. Knowing that others “shared where they were coming from,” allowed participants to explore their experience and its significance and go beyond the immediate purpose of the group: the identification of needs. No doubt specific group dynamics colored what was discussed in each group. Still, striking similarities appeared across the focus groups in the proportion represented by each domain, as well as themes expressed by different ethnic groups.

Second, although we conducted content and thematic analyses, we were not able to probe in depth the various topics raised or collect individual narratives typically used as data in a thematic analysis because of the focus group format.

Third, the participants do not constitute a representative sample of persons with HIV. But, as Luborsky and Rubinstein (1995) have argued, when seeking to understand communities of cultural meanings, a statistically representative sample of the entire population is not the only appropriate concern for research.

Finally, we do note that findings for particular ethnic or gender groups are not generalizable to the non-HIV population, and differences here between African Americans and whites may be more reflective of entrenched social class and inequities of life conditions. The proportion of total topics represented by each domain differed across the groups for all but the social consequences of being HIV+ and the risk of acquiring HIV. Risk represented a distinct but relatively minor domain in each group. Social consequences represented a significant domain in each group. This also suggests an emergent commonality to the HIV experience; namely, the overwhelming need to cope with the experience of stigma.

The role of context in differentiating the experience emerges if we examine the domain making sense of HIV. Here we see variation related to lived experience. For men, African American MSM in particular, making sense of why they contracted the disease was an essential aspect of coping with the disease. For women, adequate and appropriate health care was far more significant than for men. For white MSM and the hearing impaired (also white MSM), the domain of nonhealth-related needs was dominated by the need to maintain their middle-class identity by paying bills. For Hispanics, the domain of nonhealth-related needs was also important, but for them it referred to securing adequate housing.

Coping with stigma was a dominant theme for all groups, except those with overwhelming immediate needs: the homeless and ex-offenders. HIV thus represents a variant in our’ understanding of the chronic illness experience. Chronicity continues to structure the illness experience, as seen in the topic domains specific to the conditions that defined people’s daily lives. That is, preexisting social structural and historical conditions shaped the definition of these needs, their solution, and implications for their remaining unmet. Yet the stigmatizing nature of HIV determines the social consequences of the disease; thus, framing the nature of that experience.

Related to the theme of breaking a stigmatized identity, self-esteem is emphasized throughout participants’ discussions. Ethnic variation occurs, but it is in how to restore self-esteem or in the location of responsibility for care.

Few needs were directly attributed to the behaviors or status used to define the risk group to which participants were assigned. Instead, the factors that structured an individual’s lived experience—gender, ethnicity, sexual orientation, class—also structured the illness experience and the needs it created. Thus, public health surveys designed to identify service delivery may not adequately capture the relevant phenomena for study.

Conclusion

To argue that participants in these focus groups do not primarily experience HIV-created need as materially or physically based is not to deny the existence or significance of such needs. Rather, it is to reorient the concept of need to encompass an appreciation for the salience of living with a chronic illness that is highly stigmatizing. Studies of chronic illness have established a strong research tradition, documenting the significance of nonmaterial factors in the experience of disease. Like anything of significance in life, but especially so in issues that threaten the very continuance of a life, we are driven to make sense of the situation or event. This sense making or interpretation is a fundamental aspect of culture and one of the basic dimensions along which cultures differ. An individual’s experience of a terminal and highly stigmatized illness can no more be reduced to the material conditions it generates, such as loss of income or reduced functional ability, than old age can be understood by an analysis of functional status. In chronic illness, the meaning and experience of the illness affect not only accommodation to the disease but, in some cases, the progress of the disease itself.

This is not to say that interpretation alone explains the illness experience, but rather that there is a dynamic relationship between the underlying physical condition, the material circumstances produced by the illness, and the interpretation of the illness and the patient’s experience of that illness. In the case of HIV, the role of meaning to those afflicted and those who constitute the potential care-giving network is especially significant. The stigma both stops people with HIV from seeking care and, when they do, it frustrates their ability to have their needs met.

To move away from the narrow functional conception of need as deriving directly from the biological dysfunction and therefore relatively fixed, varying only with severity of the dysfunction, we have suggested the concept of living while dying. Living while dying directs attention to the process of sense making and accommodation that are at the core of living with a terminal illness. A terminal illness is not about dying, but about living in the face of death. Key to this process is the maintenance of on going social relationships, enactment of and adherence to basic cultural values, and fixing one’s place for posterity. In this framework, participants’ focus on need as the absence of something requisite is readily apprehensible (Sankar 1991).

The two constructions of need represented here in different research approaches need not and should not be separate. Indeed, failure to appreciate the existential aspect of HIV-related need leads to considerable dissatisfaction with the service delivery system, as the participants in these focus groups amply demonstrated. From the perspective of people with HIV, the system had failed to address their main need: to control and reduce the threats to their humanity. Individuals' attention to monitoring and managing threats to their adult personhood comprise a large arena of engagement in living with disability and disease (Luborsky 1994b). Service delivery agencies and the policies that guide them must acknowledge the need of people with HIV to have their humanity recognized and sustained in the face of stigma. Until they do, they cannot truly help individuals live while dying.

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Table 1

Sample Description

Focus Group	Number of Participants	Race/Ethnicity/Gender	Average # of Mentions per Participants
White men who have sex with men (WMSM)	4	White men	76.5
African American men who have sex with men (AAMSM)	9	African American men	26
Women	6	1 white woman 5 African American women	22
Intravenous drug users (IDU)	4	3 African American men 1 African American woman	48.5
Homeless person	5	4 African American men 1 white woman	22
Hispanics	5	1 Hispanic woman 4 Hispanic men	22
Cognitively impaired person	7	5 African American men 1 African American woman 1 white woman	17
Exoffenders	7	3 African American women 1 white woman 3 African American men	12
Hearing-impaired person	5	5 white men	23

Table 2

Proportion of Domains Represented within each Focus Group

Focus Group	Coping	Social Consequences	Nonhealth- Related Needs	Health	Making Sense	Risk
WMSM	.24	.34	.24	.10	.07	.02
AAMSM	.20	.22	.30	.15	.13	.00
Women	.28	.34	.04	.33	.01	.00
IDU	.20	.25	.25	.16	.04	.11
Homeless	.38	.14	.25	.03	.21	.00
Hispanic	.21	.23	.29	.11	.13	.03
Cognitively impaired	.40	.25	.07	.10	.01	.16
Exoffenders	.27	.11	.38	.00	.14	.10
Hearing impaired	.13	.29	.25	.19	.10	.04

Table 3

Proportion of Domains by Sexual Orientation

Sexual Orientation	Coping	Social Consequences	Nonhealth-Related Needs	Health	Making Sense	Risk
Straight	.29	.21	.23	.11	.09	.07
Gay	.21	.28	.26	.13	.10	.02

Table 4

Proportion of Domains by Gender

Gender	Coping	Social Consequences	Nonhealth-Related Needs	Health	Making Sense	Risk
Male	.25	.25	.26	.11	.11	.03
Female	.25	.25	.18	.19	.05	.09

Table 5

Proportion of Domains Within Each Ethnic Group

Ethnic Group	Coping	Social Consequences	Nonhealth-Related Needs	Health	Making Sense	Risk
White	.21	.31	.24	.12	.07	.05
Black	.27	.22	.24	.13	.11	.04
Hispanic	.23	.21	.29	.10	.14	.03

Table 6

Focus Group Themes

Theme	**WMSM**	**HI**	**AAMSM**	**W**		**SU**		**HO**			**CI**			**EX**		**H**	
	WM	WM	AAM	AA	W	AAM	AAW	AAM	HM	WM	AAW	AAM	WW	AAM	AAW	HW	HM
Self-esteem						x	x	x		x							
Fire MD	x																
Help others, feel useful			x	x				x			x						x
Get job			x	x		x	x	x									
Responsible for self- care			x	x		x											
Self-reliance		x	x											x	x		x
Personal cleanliness			x														
Empowerment	x															x	x
Control	x																
Educate to reduce stigma		x		x			x				x						
Educate to manage HIV			x	x			x										
HIV blessing	x												x		x		
Legacy												x					
Discrimination																	
Homophobia	x																
System unfair			x	x	x	x											
WGM get better treatment		x				x								x			x
Responsibility																	
Government responsibility		x	x			x											
Church responsibility																x	
Not responsible for HIV			x	x													

Focus Group Abbreviations

SU Substance users

HO Homeless

AAMSM African American men who have sex with men

WMSM	White men who have sex with men
EX	Ex-offenders
W	Women
H	Hispanic
HI	Hearing impaired
CI	Cognitively impaired