Negotiating Risk: Knowledge and Use of HIV Prevention by Persons With Serious Mental Illness Living in Supportive Housing

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Abstract

As a population, persons with serious mental illness (SMI) have an elevated risk for HIV infection. However, relatively little is known about how the risk of HIV has affected their lives, how persons with SMI evaluate their HIV risk, and what preventive measures they undertake. Furthermore, relatively little is known about community-based HIV prevention for persons with SMI as most interventions have been restricted to clinical settings. This report presents findings on the HIV-related experiences of persons with SMI living in supportive housing programs, one possible setting for implementing community-based HIV prevention with this population. The qualitative investigation interviewed 41 men and women living in five supportive housing programs. In-depth, qualitative interviews elicited discussion of research participants' (a) experiences with HIV, (b) knowledge about HIV and HIV prevention, (c) assessments of their own risk, (d) descriptions of how they apply their prevention knowledge, and (e) reports of barriers for HIV prevention. Research participants describe social networks that have substantial contact with persons affected by HIV. However, contrary to some expectations of persons with SMI, research participants report using HIV prevention knowledge in negotiating their risk of contracting HIV. The implications of these findings are discussed in terms of their relevance for implementing community-based HIV prevention for persons with SMI.

Individuals diagnosed with serious mental illness are disproportionately affected by HIV. In the general US population, the rate of HIV infection is less than 1% (UNAIDS, 2002). However, several studies document markedly elevated rates of HIV infection among persons with serious mental illness, with estimates ranging from 4 to 23% (e.g., Carey et al., 2004; Empfield et al., 1993; Rosenberg et al., 2003). The reported estimates of HIV infection rates among individuals dually-diagnosed with SMI and substance use disorders are even higher (e.g., McKinnon, Cournos, & Herman, 2001; Ramrakha, Caspi, Dickson, Moffitt, & Paul, 2000; Silberstein et al., 1994). The scale of this problem has become significant enough to mobilize responses from

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policy makers in public health and mental health fields (Center for Disease Control [CDC], 1999; Cournos & McKinnon, 1997; National Institutes of Health [NIH], 1997).

The term "serious mental illness" (SMI) is a broad term that refers to a range of psychiatric disorders, including schizophrenia, bipolar disorder, and major depression, that can persist over time and have profound effects on a person's behavior, thinking, emotions, and relationships (Carey, Carey, & Kalichman, 1997; Rosenberg et al., 2003). The designation of "serious" or "severe" refers to more extreme and persistent disturbances in everyday activities (e.g., social or occupational functioning). The term is also associated with higher levels of intervention that are almost universally delivered, coordinated, or funded through public sector health care (e.g., inpatient ward, outpatient clinic, day hospital, supportive housing, supported employment). Thus, a description of an individual having SMI suggests particular diagnoses and symptoms, as well as an individual's socioeconomic status and health care options (Kloos, 2005). The term "serious mental illness" is used widely in research and practice, but persons with diagnoses covered by this term have a wide range of symptoms, abilities, and life situations.

Risk Factors for Contracting HIV

An emerging body of research is beginning to examine the personal and environmental factors that place persons with SMI at greater risk for HIV infection (Carey et al., 1997; Meade & Sikkema, 2004). Despite myths to the contrary, many adults with SMI are sexually active. A review of 44 studies of adults with SMI recruited from outpatient clinics, inpatient wards, and day hospitals documents a weighted mean of 57% of the samples had been sexually active in the past 6–12 months, with a range of 42–74% (Meade & Sikkema, 2004). People with diagnoses of schizophrenia and in depressive crises represent the lower range of sexual activity reported in these studies (i.e., 42–44%), while persons with manic disorders represent the higher end of the range. Furthermore, a weighted mean of the samples included in Meade and Sikkema's review suggests that 29% have had a sexually transmitted disease during their lifetime. These studies describe a high proportion of persons with SMI engaging in risky sexual practices, including unprotected intercourse, sex with multiple partners, sex while intoxicated, sex trade, and sex with high-risk partners (e.g., Carey et al., 2004; Cournos et al., 1994; Kalichman, Sikkema, Kelly, & Bulto, 1995; Otto-Salaj, Heckman, Stevenson, & Kelly, 1998; Ramrakha et al., 2000; Rosenberg et al., 2003).

These higher rates of risk behavior for HIV infection among adults with SMI are likely strongly affected by social factors associated with their psychiatric disability. The majority of persons with SMI live in poor, inner-city neighborhoods with high rates of drug use, STDs, and HIV (Carling, 1995; Wong & Solomon, 2002). Typically, they are socioeconomically disadvantaged, have transient living situations, and have small social support networks (e.g., Caton et al., 1995; Goldberg, Rollins, & Lehman, 2003; Hall & Nelson, 1996; Nelson, Lord, & Ochocka, 2001; Newman, 1994). Persons who have SMI and are also homeless have particularly high rates of HIV infection (e.g., Levounis, Galanter, Dermatis, Hamowy, & DeLeon, 2002; Meyer et al., 1993; Susser et al., 1998), and individuals living in urban settings appear to be at greater risk than those in rural areas (Brunette et al., 1999). These factors likely place persons with SMI in more at-risk situations than persons who are not comparatively disadvantaged. Furthermore, persons with SMI who lack resources may experience significant pressure to trade sex for money or goods (Butterfield et al., 2003; Carey et al., 2004; Goodman & Fallot, 1998). Similarly, a substantial proportion of individuals with SMI encounter high-risk situations, including sexual coercion, when relationships are connected with access to material resources (e.g., Otto-Salaj et al., 1998). HIV risk behavior among adults with SMI appears to be influenced by factors from multiple domains, including psychiatric illness, substance use, living conditions, and social relationships.

HIV Risk Reduction for Persons with SMI

Compared to other populations with elevated levels of risk for HIV infection (e.g., gay men, IV drug users, sex workers), there have been relatively few interventions tailored for persons with SMI, or specific subgroups of persons with SMI. The primary strategy has been cognitive-behavioral, small group interventions that develop individual competencies (e.g., condom use, sexual assertiveness and negotiation, problem solving) to reduce sexual risk behavior (e.g., Carey et al., 2004; Otto-Salaj, Kelly, Stevenson, Hoffman, & Kalichman, 2000; Susser et al., 1998). However, intervention effects have been modest, tend to diminish over time, and are almost always delivered in clinical settings (e.g., Meade & Sikkema, 2004). Surprisingly, community-level HIV prevention interventions and targeted public health messages have not been used widely with persons who have SMI, or even particular subgroups of persons with SMI, although they have been successfully implemented among other populations judged to be "at risk" (e.g., CDC, 1999; Meade & Sikkema, 2004; Winett et al., 1995). Thus, HIV prevention strategies for persons with SMI appear to have been limited in modality and setting.

Perhaps a restricted range of HIV prevention for persons with SMI can be attributed to the challenges of developing interventions for this heterogeneous "population." The symptoms and abilities of individuals with SMI can vary widely. Persons with severe major depression, manic-depressive disorder, or schizophrenia spectrum disorders have different clusters of symptoms. Furthermore, the symptoms of individuals with the same diagnoses vary in their intensity and vary over time (e.g., Carpenter & Strauss, 1991; Cohen, Slomkowski, & Robins, 1999). Similarly, there is a wide range in functioning within this group—those who live independently, those who need minimal structure of a supportive housing program, those living in programs with on-site staff support, and those in long-term institutions (e.g., DeSisto, Harding, & McCormick, 1999). The variety of needs, abilities, and living situations can make it difficult to tailor interventions that are relevant for all subgroups of this population.

Alternatively, the range of HIV prevention for this population may be restricted, in part, because of limited views about the capabilities of persons with SMI. Stigma about mental health problems is widely held in Western countries and the negative stereotypes are widely overgeneralized (Corrigan & Penn, 1999). Corrigan and Penn's research on media representations of serious mental health problems suggests three thematic categories: (a) persons with SMI should be feared and thus excluded (e.g., the homicidal maniac); (b) they are child-like, irresponsible, and need care from others (e.g., the innocent, child-like man who can't make good decisions for himself); (c) they are rebellious free spirits who do not accept the norms of community living. Any of these stereotypes may cast doubt on the advisability or utility of particular approaches to HIV prevention for persons with SMI. Indeed, research has documented how stigmatizing views about mental health problems are also held by well-trained mental health professionals (Keane, 1990; Mirabi, Weinman, Magnetti, & Kepler, 1985). Clinicians have been found to underestimate the capability and willingness of persons with SMI to care for their own well-being (Chinman et al., 1999; Davidson et al., 1999; Salzer, Rappaport, & Segre, 2001; Sarason, Levine, Goldenberg, Cherlin, & Bennet, 1966). However, contrary to these expectations, several studies suggest that condom use is unrelated to psychiatric diagnosis (e.g., Kelly et al., 1995; Levounis et al., 2002; McDermott, Sautter, Winstead, & Quirk, 1994; Susser et al., 1995). Similarly, of three studies examining the accuracy of HIV risk assessment by persons with SMI, two found that individuals who engaged in sexual risk behaviors *correctly* perceived themselves at higher risk for HIV (Carey, Carey, Weinhardt, & Gordon, 1997; Otto-Salaj et al., 1998; Weinhardt, Carey, & Carey, 1998). The overwhelming majority of HIV prevention studies with individuals with SMI have been done in treatment institutions—inpatient (30%), outpatient clinics (55%), day hospitals (11%)—although the majority of persons with SMI live in community rather than institutional settings (Meade & Sikkema, 2004). When combined with the record of limited HIV prevention for

persons with SMI, these data suggest that mental health professionals who underestimate the cognitive and behavior change capabilities of persons with SMI may not consider particular interventions a worthwhile use of resources.

Finally, the paucity of community-based HIV interventions may be due to prevailing views of persons with SMI that emphasizes their deficits rather than their abilities. Most of the studies cited above have focused on documenting risk factors but few, if any, have described potential protective factors. Relatively little has been documented about the contexts in which HIV risk is negotiated for persons with SMI. For example, how are persons with SMI affected by the risk of HIV; what knowledge and what myths do they have about HIV; what do they already do to protect themselves? To improve outcomes, interventions must be developed that take into greater account the risk situations, the types of relationships typically encountered by particular groups of persons with SMI, and their current competencies. We need to know more about what specific groups of persons with SMI are doing to negotiate their risk and to protect themselves. Finally, we need to know about settings that are viable for implementing community based intervention and allow persons with SMI to use and develop their own preventive practice in supportive environments.

This study was designed to investigate the contextual factors of how persons with SMI living in supportive housing understand and negotiate their risks for contracting HIV. The research seeks to identify community-based settings where HIV prevention can be promoted for persons with SMI. It uses a qualitative, semistructured interview to elicit conversation about (a) how HIV/AIDS has affected their lives (e.g., death of loved ones, changes in behavior, changes in relationships), (b) their HIV knowledge, (c) their efforts to protect themselves, and (d) their assessments of personal risk for contracting HIV. This study is part of a program of research that is investigating the feasibility of an integrated skills and community norm change for persons with SMI living in supportive housing. The study addresses several gaps in the literature about HIV prevention for persons with SMI. First, it focuses on a particular community-based setting that has been neglected as a potential site of HIV prevention for persons with SMI, those living in supportive housing. Second, it goes beyond a deficits focus to document potential strengths and protective factors upon which interventions can be built. Third, it considers whether HIV interventions used with other populations might be relevant for this group in this setting. Fourth, it examines the unique needs of this subpopulation and the development of tailored interventions.

METHODS

Sample

The sample is comprised of 41 interviews with persons recruited from five supportive housing programs, two in New York City and three in a moderate-sized Connecticut city. Each program serves persons diagnosed with SMI, the primary eligibility criterion for program entry, and provides an apartment in a larger building with on-site staff to offer case management and programming support (e.g., educational presentations, social events). Residents demonstrate a level of independence in self-care, responsibility for their rehabilitation, and an ability to participate in group activities in order to be admitted to the programs. The Connecticut programs were designed for persons with SMI who had been homeless and had cooccurring substance abuse. The New York programs also serve persons with histories of homelessness and substance abuse problems, although these were not program entry criteria. Residents participated in the regular activities of their settings (e.g., social events, house maintenance, group therapy) and community (e.g., employment, AA meetings), as well as their outpatient mental health services. Supportive housing program staff members encourage residents to be increasingly independent in activities and expect residents to take responsibility for their health

and program participation, using limited staff support as needed (e.g., skills training, counseling, dispensing medication).

A total of 43 individuals were recruited from an invitation made to all residents in each of the five programs. The interviews of two individuals were not included in the analyses because of language (e.g., English as a second language) or cognitive difficulties. Additionally, we did not recruit five persons from the total sample whom setting staff indicated had psychiatric or personal crises at the time of the interviews. Thus, the sample used in the following analyses was 41 of 98 residents (42% of the total five-setting population). We aimed to create a stratified sample, and successfully recruited between seven and nine persons from each setting. Program staff's review of records indicates that none of the participants had a legal status or current level of functioning that would suggest an inability to give informed consent, which was confirmed by research staff assessment of the informed consent process.

Although the samples within each setting were not random, the distribution of the overall sample on several demographic indicators is remarkably balanced. The average age was 40 years old, with a range from 22 to 61. Grouped by decade, the distribution is nearly symmetrical: 20s – four persons, 30s – eight persons, 40s – eight persons, 50s – four persons, and 60s – one person. The sample was fairly balanced in terms of gender: 19 women and 22 men. Similarly, the self-identified ethnicities of participants are roughly balanced: African American – 40%, White – 40%, and Other (Latino, Native American, Mixed) – 20%. The most significant variation in the sample was length of stay (LOS) in the supportive housing. Roughly half of the participants ($n = 19$) had a LOS of 12 months or less; about one-quarter lived at the residence between 12 and 48 months ($n = 11$), and one-quarter for greater than 48 months. Most of the participants with LOS greater than 48 months were from one program. These lengths of stays are generally representative of the range of supportive housing programs (Corporation for Supportive Housing, 1999). In terms of diagnostic categories, nearly all of the participants reported primary psychiatric disabilities (38/41): Schizophrenia spectrum diagnoses (34%, $n = 14$), Bipolar (29%, $n = 12$), Major Depression (15%, $n = 6$), and Other (15%, $n = 6$). The majority of the sample reported substance abuse problems (61%, $n = 25$).

Consistent with previous studies (Carey et al., 1997; Gift, Wynne, & Harder, 1988; Grassi, Pavanati, Cardelli, Ferri, & Peron, 1999), a substantial portion of participants in this sample reported that they were currently sexually active (17/41) in an ongoing relationship at the time of the interviews. We suspect that these data underestimate sexual activity in that no instances of recent unexpected or casual sexual encounters were reported.

Protocol

The IRB-approved interview protocol used a semistructured format with specific, open-ended questions in six broad domains: (a) Understanding of HIV/AIDS, (b) Conversations with Others about HIV/AIDS, (c) Self-Assessment of HIV Risk, (d) HIV Prevention Practice, (e) Perspectives on Changing Risk Behavior, and (f) Health Promotion in their Setting. Introductory questions for each section (e.g., *What do you do to protect yourself*?) were accompanied by probe questions in the event that the initial question did not elicit a significant response from a research participant (e.g., *How do you feel about using condoms? Who initiates condom use? Who can you talk to about protecting yourself?*).

Procedure

The open-ended nature of the interview allowed for research participants to share information that they thought was most relevant given the open-ended probes. Interviewers moved on to different probe questions and domains when they judged that the information for a particular domain had been exhausted. Masters level clinical psychology students and postdoctoral

fellows conducted the interviews in residents' apartments or in confidential rooms at the supportive housing programs. The duration of interviews ranged from 30 min to 120 min, with a mode of 50 min. All interviews were tape recorded and transcribed verbatim.

Analyses

Identifying Themes—As the initial step of the analysis, the lead author and three of the interviewers independently identified thematic structures unique to a subset of five transcripts. Using a grounded theory approach to qualitative data analysis (Glaser & Strauss, 1967), each transcript was systematically read to identify thematic categories emerging from the text. Analyses emphasized within-case understanding of each interview using that research participant's understandings of experience (i.e., an emic approach). A strategy of open coding (Strauss & Corbin, 1990) was used to propose thematic categories for each of the five interviews. These four readers independently constructed a list of codes for each interview. Triangulation of coding categories was used to reach consensus about appropriate themes and to discuss terminology and definitions. If consensus could not be reached on thematic material, the theme was not included as a coding category. After themes were proposed for each of the first five interviews, cross-case comparisons were used to compare coding frameworks across these participants to begin creating unified thematic categories (i.e., an etic approach). To strive for a relatively parsimonious coding framework, thematic categories were reduced through an iterative, constant comparative method (Glaser & Strauss, 1967) of re-reading and discussing the interviews to refine the coding categories.

Creating a Thematic Structure—With an emerging consensus of thematic categories, the four readers began to propose a structure of relationships among interview themes. Thematic structures were initially generated for each interview and then compared between interviews to propose an overarching structure. Root categories were created that could organize thematic categories already identified into branches of a tree structure. After 12 interviews, the working structure of themes was applied to additional sets of transcripts and reviewed in consensus discussions. This iterative process was repeated until analytic saturation was achieved. That is, readers refined the coding framework until (a) no new thematic information or thematic relationships were identified in transcripts or (b) coders reached consensus on codes to include and their structural relationships. Analytic saturation was achieved after 20 interviews.

Establishing the Credibility of the Thematic Structure—Once the coding system was established, the thematic structure was used to re-code all of the interview transcripts using NUD*IST 4 qualitative data analysis software. Rules for inclusion of particular coding categories were formulated and refined. After all of the interviews were re-coded, a *Data Audit* was conducted for each interview and for each thematic category; both coding and text excerpts were examined. Those codes that had fewer text excerpts than expected were investigated to account for why particular interviews were not included. When no coding was included, readers conducted a *Negative Case Analysis*; the identified transcripts were reread to explain their lack of coding for a thematic category and to search the text for possible missed coding. The last phase of coding, a *Construct Check*, was used to examine the text excerpts of each coding category for consistency with construct definitions to guard against conceptual drift. The end product of the thematic analyses was the creation of a set of themes clustered by relevance into a tree structure. The thematic structure was constructed without using the framework of the probe questions, rather they were patterns identified by a close reading of the interviews. The thematic tree structure constitutes the data set used to investigate interview questions.

Using the Qualitative Database to Answer Research Questions—The last step in the analyses was to establish answers to the interview questions and evaluate their empirical

support in the data set. These analyses sought to answer (a) descriptive questions about participants' experiences with HIV and prevention and (b) summative questions about their reported behavior by searching for patterns of results in the thematic structure data. These analytic questions were based upon the probe questions constructed for the interview. In the case of formative, descriptive questions (e.g., *what interactions did persons with SMI have with persons who had HIV?*), all text identified by the thematic coding framework was examined for consistency across individuals. Where appropriate, subcoding was developed for finer description of variation in research participants' experience. Substantive conclusions were tested by searching for *disconfirming* evidence. That is, readers examined all of the relevant thematic material again looking for cases that challenged conclusions or disproved them (Miles & Huberman, 1994). When conclusions were challenged by the data, either questions were revised and a new process of testing was started, or the conclusion was dropped. For summative questions about reported behavior (e.g., *how prevalent were reports of condom use?*), the coded text of interviews followed a similar process to find empirical evidence relevant to the question. Interviews without coded material were re-examined to ensure that no material was missed. The readers assessed both fidelity to the construct and instances of contradiction within individual interviews and across interviews. As analyses proceeded, a few additional thematic categories were created as new questions emerged from the findings. Readers applied the same process for defining categories, systematically re-coding all transcripts, and searching for disconfirming evidence.

RESULTS

The results are organized into four major sections. First, descriptive analyses document how HIV/AIDS has affected their lives (e.g., death of loved ones, changes in behavior, changes in relationships) and the contexts of their encounters with HIV. Second, we examine research participants' knowledge of facts about HIV and prevention methods. Third, we examine how research participants assess their current risk for contracting HIV and what they are doing to protect themselves. Finally, we investigate how participants respond to barriers they encounter in HIV prevention.

Experience with HIV/AIDS

More than two-thirds of the sample (29/41) reported an interaction with someone believed to have HIV, most commonly with a friend or family member (25/41). About one-third of the sample reported knowing two or more people who had contracted HIV ($n = 13$). Although the protocol did not inquire about HIV status, two participants reported that they were HIV positive.

Personal Encounters with HIV

Participants described their encounters with HIV as occurring in three different kinds of settings: (a) long-standing social networks of friends or family ($n = 25$), (b) "the streets" during periods of homelessness ($n = 8$), and (c) institutional settings such as a hospital or jail ($n = 15$). While contact with someone believed to have HIV was prevalent in this sample, the intimacy of these contacts varied. Three levels of intimacy were identified in the analyses: (a) witnessing the effects of AIDS, (b) encounters with HIV risk, and (c) depersonalized reports about persons affected by HIV/AIDS.

Witnessing AIDS—Participants who had long-standing relationships with a person who had contracted HIV often described their interactions in terms that made them a witness to the effects of AIDS. That is, the character of their descriptions took the form of a testimony to a person's suffering:

When I saw all the medicines he had to take, it was just overwhelming. … And I went through him having the thrush and the night sweats and things like that … And just his fears of no one being there for him. INTERVIEW 23 (59–82)

Nearly 40% of research participants (*n* = 16) described being present for instances of suffering and human vulnerability. Not surprisingly, research participants presented these interactions typically as having a profound effect on them. In a few cases, people described the interaction in the manner of a tribute to the individual and how that person coped:

One of my friends, his name was JD, he passed away. He was very frank and open about having AIDS. You know, he could have prevented it, you know … I happened to be in the hospital with him the day he died. … He tried to advocate other people about it before he passed. You know, he went out of his way to do that. He was like, "Don't make the same mistakes I made. Don't do this. Don't do that." … I was really, really proud of him. INTERVIEW 14 (70–99)

Not all instances of witnessing were based in longstanding relationships. Several participants witnessed suffering as a result of meeting individuals in institutional circumstances (e.g., jail, treatment setting).

I remember the first time I ran across somebody that had full-blown AIDS and I was still naïve 'cause I didn't know none of the things that I know now about it. I was locked up in jail and this guy was my cellmate. He was in my cell for like three months. And I remember all the signs. The ashiness of the skin, the brittleness of the hair, the stomach is pot bellied, his legs were like pencils. I remember seeing little, little like eruptions on the skin all over himself. … I remember the look in his eyes—like he was terrified, like he was scared. I never forget that look. And I ran across his nephew and I asked his nephew how was his uncle doing … and he told me "Man, don't you know, he died. He got AIDS." And then I thought, "Damn he could've at least told me." INTERVIEW 17 (14–103)

After this account, the participant related three additional stories about encountering other people who had died of AIDS. Clearly, HIV and AIDS have had a "face" and emotional impact on the lives of a significant portion of this sample.

Encounters with HIV Risk—In a second group (*n* = 9), participants also described emotionally involving experiences, but at a lower level of intimacy. These experiences range from confronting one's own vulnerability for contracting HIV through conversations with persons who had developed AIDS symptoms. These accounts typically focused on a desire to get more information to protect oneself from HIV infection:

I found out (my roommate) was HIV positive. She told me herself which was good. And she told me what to do and what not to do. She was very cautious and everything. I always asked her questions and she told me she got it from sharing a needle and it got worse because her former fiance was diagnosed with ′ it and he had it worse than she did. So they were still having unprotected sex so she would get even worse. … Well I was kinda scared because she would always tell me the precautions and I was always thinking we're female and we're still in the stage of still having our period but I don't know if you can get it if she takes a bath first and then doesn't wash the tub and I might have a cut under my foot. INTERVIEW 10 (73–117)

Accounts grouped into this category typically were accompanied by a confession of the fear participants experienced in coming "close" to HIV/AIDS.

Recounting Reports From a Distance—The last group of experiences with HIV can be described as interactions with low levels of intimacy. This group includes observations of

acquaintances purported to have HIV (*n* = 4) and those that received brief reports about a person who died of AIDS (*n* = 7). The nature of these descriptions is typically restricted to accounts of "facts" about who had HIV, when someone was seen, or how they looked:

> I went into the hospital one day to get some medication for myself. He was in his wheel chair now and the only way I recognized him was his braid. … And he seen me. … I said, "How you doing, man?" … He said, "Man, you can see man. Look at me." And I didn't have to ask him anything. I knew right then and there what was … even the pharmacist looked at me and shook his head like this, you know what I'm saying. And that was right before Thanksgiving. And he died right after Thanksgiving, he did. INTERVIEW 12 (62–105)

These reports keep an emotional and physical distance from persons who have HIV. These reports describe mundane details of how someone contracted HIV or how one's appearance had changed. Personal reactions by research participants were minimal, if present at all. Each of these types of experiences have their own implications for intervention, which is discussed below.

Knowledge About HIV

Sources of HIV Information—Given the amount of experience with HIV reported in this sample, perhaps it is not surprising that exposure to HIV information was widespread. Every participant described encountering some type of HIV information in their daily lives. This included advertising in magazines and billboards, television shows, one-time speakers at treatment settings, and a few didactic courses. Participants appear to have absorbed these messages as evidenced by the widespread use of public health prevention language in describing their personal practices (e.g., "use clean needles," "use protection" for sex). However, the nature of research participants' participation in formal HIV prevention education was limited. Slightly more than half of the sample reported receiving HIV-related education as part of their health care or housing program. Furthermore, the majority of these sessions appeared to be brief, one-time, overviews about HIV and AIDS that did not provide a framework to support changes in practices.

Knowledge About Etiology and Course of HIV—All research participants had basic knowledge about how HIV is contracted: unprotected sex, "dirty" needles, and other contact with blood or semen. Although we did not test them on their knowledge, most offered a correct description of AIDS symptoms when we asked "What is AIDS?." However, research participants had many questions about the details of HIV transmission and whether particular practices were risky (e.g., sharing a toothbrush). Nearly three-quarters of the participants (*n* = 30) indicated interest in learning more about how they can protect themselves. Contrary to stereotypes of persons with SMI, people in this sample had both a substantial interest and a basic knowledge that may be helpful for implementing new prevention programs.

Knowledge of HIV Prevention

Given the broad exposure to HIV/AIDS reported in this sample, the next analyses investigate the depth and detail of participants' knowledge of HIV prevention methods. First, we present how mainstream prevention messages had been absorbed. Second, we examine whether knowledge of prevention methods reflected methods endorsed by public health policy. Third, we consider how research participants report applying their knowledge of prevention.

Knowledge of HIV Prevention Methods

All participants were able to present examples of HIV prevention that were consistent with public health standards. For instance, when asked, *"How can people protect themselves from*

exposure to HIV?," every participant spontaneously identified barrier methods: male and female condoms, dental dams, and protected/safe sex. We are struck by the ubiquity of the condom response, which was offered by 38 of the 41 research participants; the three who did not spontaneously mention condoms specifically cited "protected" or "safe" sex as a means of prevention. Clearly, they had been exposed to messages about the necessity of barrier methods of HIV prevention.

An awareness of the need for HIV prevention related to drug use behaviors was also widespread, cited by over two-thirds of our sample (*n* = 29). For example, 12 identified having and using one's own needles as a means of prevention, 10 advised using clean needles as a means to prevent the spread of HIV, and six stated that avoiding IV drug use altogether was an effective way to prevent infection. Furthermore, a considerable number of participants also indicated that any drug or alcohol use, not just IV injection, can have a disinhibiting effect, which could lead to reckless behavior when it comes to HIV transmission:

> *Interviewer*: How do you feel about using condoms?
>
> *Research Participant*: I think its okay. … But a lot of times I'm not protected because (of) what I'm doing at that time. I'm usually on crack and I'm out there and if there is not a condom there I just go ahead and you know do it. It's being very at risk, you know. INTERVIEW 8(59–64)

The third most frequent category of preventive strategies identified in interviews was sexual partner relationships. For example, two out of five participants indicated that abstinence from sexual activity prevents the spread of HIV, while about a third stated that monogamy is a means to prevent transmission. Knowledge of one's partner was seen as a key to the negotiation of HIV risk:

> It also makes me think more about who I wanna have sex with. I don't just do it with just anybody anymore. I mean, I used to like doing it a lot, but I used to get used a lot and now this way, you know, it's nice to think about it for a minute and say, no, I'd rather not have sex with this person because it's just too much trouble. INTERVIEW 11(470–475)

While knowledge of one's partner or limiting the number of partners is not enough to prevent the spread of HIV, these data suggest an awareness of harm reduction principles among a substantial portion of the sample that might help introduce other interventions.

Idiosyncratic Views of HIV Prevention

While these results are encouraging for planning HIV preventive interventions, not all of participants' responses conform to HIV prevention standards. We characterize these responses as idiosyncratic because they appear to deviate from prevention norms in a personal manner.

Nearly a third of research participants (*n* = 13) include idiosyncratic methods of HIV prevention in response to interview questions. However, these idiosyncratic responses constituted only 13% of the total number of examples generated by the sample (23/177). Idiosyncratic prevention strategies included avoiding thin female partners whose lack of body mass may indicate disease progression, adopting a lesbian sexual orientation, only having sexual contact with individuals who are more educated, engaging in positive or religious-oriented thinking, and avoiding any contact with body fluids of other people:

> I don't drink from anybody's cup. It might be my daughters or my grandbaby's. Not my grandbaby. My grandbaby spits in his cup. So I wouldn't drink from his cup …. Not even my daughter's. 'Cause she's young and she doesn't protect herself. INTERVIEW 10 (287–291)

While these prevention methods are not those promoted in public health policy, we note that most were not particularly bizarre in that they each touch on culturally- and/or historically-endorsed means to protect oneself (e.g., avoiding colds by not sharing cups).

Further analyses of idiosyncratic beliefs about HIV revealed a greater number of participants who report idiosyncratic views of HIV transmission ($n = 20$) than HIV prevention methods ($n = 13$). This distinction suggests that participants think differently about HIV risks and the methods they use to protect themselves. They appear to include additional information in their evaluation of transmission risks. Two major patterns emerged from our analyses: (a) emotion-based responses and (b) history-based responses.

Emotion-Based Idiosyncratic Responses—Several participants were quite direct about connecting their fear of AIDS with fear of its transmission, and thus overgeneralizing the possibility of transmission. These responses were full of feeling, if vague in specifics:

> AIDS is catchy. If you get next to a person who [has] AIDS and you don't know about it, it can happen. INTERVIEW 5 (79, 80)

> That's a highly deadly disease out and I don't want to discuss it. I don't want to hear it. Because there are a lot of people out there dying from that. And it's sad. So you know I just try to avoid it. I just hope they find a cure for it one day. INTERVIEW 9 (157–161)

A few cited sensational cases where motivations of revenge were a key to HIV transmission:

> People that have AIDS, they just have this fixation that they wanna share it with everyone else … I'm from New York and we lived upstate for a while, my wife and I and kids and we had one guy up there who was just passing it around to everyone that he could. I thought he really should have been convicted of murder because several people died from that. … In his mind it was like, well, I have it. Okay. I think everybody else should experience it also. INTERVIEW 14 (106–116)

It appears that in these interviews, morally objectionable behavior became conflated with the gravity of the disease itself, and was seen to be much more prevalent in the minds of the interviewees. This might be indicative of a more general phenomenon in which focusing on high-profile but statistically rare sources of transmission obscures more realistic approaches to assessing risk and protecting oneself.

While these responses may appear to be the product of a delusional mindset, they can also (and perhaps more parsimoniously) be attributed to the fear of AIDS and its consequences. One woman articulated this tension between fear and rationality:

> *Interviewer*: What do you want to know?

> *Research Participant*: I guess how to keep myself protected. I can't say I really don't fear being around people with AIDS. But being that I was incarcerated too, there were a lot of women in there that were infected and used to have nosebleeds and things like that. … so just how to protect myself but not be in hysteria. INTERVIEW 23 (49–55)

History-Based Idiosyncratic Responses—These responses wove information that was once valid into current perceptions of risk that are not. For example, while gay communities in the U.S. were most affected by HIV at the outset of the epidemic, it has since spread far beyond this group. However, several of the interviewees continue to see those with alternative sexual orientations as embodying a particularly salient risk ($n = 7$). It is interesting to note that in this case gay individuals have been grouped with lesbians since lesbians have never been

identified as a high-risk group. This may be an example where cultural factors (e.g., homophobia) have an impact on HIV-related attitudes.

Responses offered by four African American participants highlight the issue of distrust in scientific and governmental agencies in some minority communities. Mild examples acknowledge flaws in the public health system:

> I know [blood transfusions] are a lot safer than they used to be, but I know because you know the need for blood is so great sometimes that they can't wait as long as they need to test again. INTERVIEW 23 (235–238)

More extreme examples of distrust of "the system" came from two interviewees who said that AIDS was created by the government. One believed that the government was waiting for more "undesirables" to be killed before making a cure available.

Contrary to some expectations for persons with SMI, these fear-based or history-based transmission perceptions are remarkably similar to those of general populations (Kalichman, 2003; Ostrow, 1999). Although beyond the scope of this analysis, the more idiosyncratic responses cannot simply be attributed to individual paranoia or delusions.

Negotiating Self-Assessed Risk for Contracting HIV

In addition to documenting basic prevention knowledge and experiences with HIV/AIDS, we designed the study to investigate how persons with SMI apply their knowledge of HIV prevention in their own personal practices. We asked those who had not already contracted HIV ($n = 39$) to rate their own risk for HIV infection on a scale from 1 to 10; this provided a metric that was culturally familiar and useful for comparing research participants' perceptions. Respondents' self-risk-assessments were placed in two categories: (a) "lower perceived risk" (4 and below a scale of 1–10) and (b) "higher perceived risk" (5 or above on a scale of 1–10). Second, we classified each participant's reported behavior as "lower" or "higher risk" according to public health standards. Finally, the participants' reported behavior risk categories were compared with their perceived risk for contracting HIV infection to create four categories of risk negotiation: (a) lower risk behavior/low perceived risk; (b) lower risk behavior/high perceived risk; (c) higher risk behavior/low perceived risk; (d) higher risk behavior/high perceived risk.

Lower Risk Behavior/Low Perceived Risk

A third of the sample's self-assessment of low-risk matched their low-risk prevention behavior ($n = 13$). This group of respondents had accurate prevention knowledge and reported implementing this knowledge into consistent practice (i.e., condom use or abstinence). These included consistent condom use, using a strategy of sexual abstinence, and abstinence from drugs, particularly IV drug use. These participants were generally adamant about the importance of consistent use whether their partner wanted to use them or not:

> Well, [condoms don't] bother me. So, if the guy really cares for me, he has to use it. No glove, no love, like they say. INTERVIEW 10 (302, 303)

Some respondents reported wearing condoms in the context of monogamous relationships, particularly when their partners were engaging in risky behaviors. A woman married for 11 years reported:

> "[I tell him] if you want it, you have to wear a condom …. I like to use a condom because I want to be protected with him and his drugs …." INTERVIEW 21 (374, 454, 455)

Regardless of the reason for decreased risk, these respondents appeared to be aware of which behaviors and situations placed them at risk and reported implementing practices to decrease their risk for HIV infection.

Lower Risk Behavior/High Perceived Risk

About a quarter of the sample considered themselves to be at higher risk than their reported behavior suggested (*n* = 11). This group expressed higher levels of anxiety and concern about HIV than the rest of the sample and appeared to base their risk assessment on concern about the seriousness of HIV, rather than on their prevention practices. For example,

> I'd say [I have a risk of] a 10 [out of 10], because I don't want to lose my health. It's really important. Especially at my age, I'm gonna be 49. I've been lucky so far. So I don't want to take any risks. INTERVIEW 29 (120–123)

This group had a greater level of fear about their past and about what could happen in the future. Overall, members of this group appear to need reassurance that their prevention practice is sound, information on how to know if you have HIV, and skills to help them negotiate safely entering into sexual relationships when they decide they are ready.

A majority of participants from these two "lower risk behavior" groupings (15 of 24) reported using sexual abstinence to protect themselves from HIV. Many appeared to view abstinence as part of a harm reduction strategy. For example, one man stated:

> "Usually I try to stay abstinent. When I do have sex, I use a condom every time." INTERVIEW 11 (303, 304)

Abstinence appears to be a strategy that many had learned from substance abuse treatment and now apply to other areas of life:

> … being abstinent from drugs changed my whole life around. I don't frequent the same people … I don't have to indulge the things that go along with drug use. Getting high, arguing with people, having [unprotected] sex, you know. INTERVIEW 17 (521–528)

The vast majority of participants in the "lower risk" categories (20/24) reported that they had not used IV drugs in the recent past, if at all.

Higher Risk Behavior/Low Perceived Risk

This group (*n* = 6) had a more troubling mismatch between behavior and perceived risk. This group appears to be at an elevated level of risk for contracting HIV in that they did not acknowledge their HIV risk,

> "God created the woman to be the man's companion … so that's what we're supposed to do. … It ain't gonna hurt you." INTERVIEW 27 (256–260)

Participants from this group were also at higher risk because they rely on prevention practices that are not considered sound by public health standards:

> I don't use [condoms]. I never use them because I always know my mate very well. … it would be an insult to say you gotta get a test. And they'll tell somebody what they'll believe. … So you just go get checked [yourself]. INTERVIEW 16 (431–437)

In sum, interventions for people in this risk category would appear to need to focus on assessment of one's own risk for contracting HIV and motivation to implement their prevention knowledge.

Higher Risk Behavior/High Perceived Risk

Nearly a quarter of the overall sample (*n* = 9) assessed their own risk as high and reported similar behavior. Almost all of the participants in the higher risk category reported inconsistent condom use. For the most part, these respondents appeared to have knowledge of sound prevention practices, though they did not implement their prevention knowledge consistently:

> Yeah, I'm very worried. I mean, God knows, for one day I might … You know, I see some cute little girl and all my knowledge about [HIV prevention] goes out the window. INTERVIEW 15 (454–456)

Drug use was acknowledged as contributing to higher risk related to HIV. One woman trying to stay off crack reported that she needed to avoid drugs

> "so it doesn't leave me with risky behavior and stupidity, because there is a lot more than HIV out there … crimes. And I could end up dead in the middle of the road." INTERVIEW 8 (367–369)

Several participants indicated that they did not use condoms with their partners, even when they suspected that the partner was engaging in risky behavior:

> I don't feel he's as safe as I am … because I know him. If he was cheating I guess I would know it. He'd go out there and find someone else off the street. It's more of a chance to catch the HIV. INTERVIEW 4 (74–177)

Despite these concerns, this participant also said that she did not use condoms when having sex with him. As noted earlier, these participants expressed concern that their behavior put them at increased risk for contracting HIV and knew of the potential consequences of not protecting themselves. They appear to be blocked in applying their knowledge to changing their behavior.

Barriers to Prevention

In reflecting on their risk negotiation, research participants discussed two primary challenges to use of HIV prevention methods: a dislike of condom use and expected transitions from the structure of supportive housing to more independent living. While men made the majority of the complaints (24/33), and were identified by women as the major source of resistance to condom use, women were a sizable minority of the total responses (9/33) indicating that they, too, felt that condoms were an impediment to sexual encounters.

When asked about surmounting barriers to condom use, two-thirds of research participants indicated that they believed that holding the line against unsafe sexual activity, even in the face of rejection, is the primary way to continue to protect oneself. However, they did not report many alternatives short of outright rejection of sexual partners who propose unsafe sex. One-quarter of the sample (*n* = 10) suggested negotiating with the partner about condom use. Five participants advocated that individuals have condoms on hand and two suggested strategies to make the use of condoms more sexually provocative.

Even among those who were insistent about condom use, it appears that interpersonal factors can overcome their resolve; these participants reported capitulating under pressure from their condom-refusing partners. These factors include one's intuition about the partner's relative risk, their history together, and the attractiveness/persuasiveness of the partner. For this woman, their history and her partner's persuasiveness undid her resolve:

> Well I kept asking him [to use a condom], you know. But I kept having sex with him anyway. And I would keep asking him to wear it on but, he wouldn't. You know. He said it was like taking a shower with a raincoat. So, he wouldn't do it. You know. And

> I really liked him so I didn't really say anything. But then, um, he broke up with me. INTERVIEW 6 (374–379)

Although none of the interviews identified emotional issues as barriers to condom use, they appear to be involved in all the instances of resolve being undone. These data suggest strongly that interventions addressing barriers need to integrate emotional processing interventions along with skill building.

A sizable portion of the sample reported that the structure and focus of the supportive housing programs have helped them exercise personal care to a greater extent than in their recent past. They explicitly connected their efforts to improve their mental health with overall efforts to improve health. When asked about what they did to protect themselves from HIV prevention, they included it as a part of an overall health strategy. However, over a third of the sample ($n = 14$) were not certain that they could follow through on these strategies to promote their health and well-being if they left the structure of the programs. Many of them also expressed a desire to live in independently and to live "safer" than before, although they were not sure of their ability to stay clean of drugs and avoid risky situations for HIV and STDs:

> I have gone out there a few months ago and went back to old ways and had some unprotected sex, so I'm nervous about it. INTERVIEW 8 (203–206)

For these individuals, the structure of the programs are helpful in fostering attitudes and support for making health behavior changes, such as HIV prevention. However, some residents appear to be challenged in their anticipated transition from the supports of this structure (e.g., peers, staff, predictable environment) to living on their own.

DISCUSSION

This study represents the first steps toward building a base of knowledge about how persons with SMI living in community-based settings understand their HIV risks and what they do to protect themselves from infection. The ecological perspective of this research varies from other studies of HIV prevention among persons with SMI in that it did not only focus on risk factors and deficits, but also considered whether research participants know and use HIV prevention methods in negotiating their HIV risk. The findings document numerous instances of how individuals in this subgroup of persons with SMI, those living in supportive housing, have competencies on which to build. There was widespread knowledge of basic HIV prevention messages throughout the sample and substantial interest in learning more about how to protect themselves. Community-based HIV prevention not only seems feasible for some persons with SMI, but appears to have already made some impact, even if it has been by virtue of universal-type prevention strategies for general populations (e.g., public service announcements). Our conclusion is that despite the multiple stressors and disadvantages that these research participants have encountered, they have participated in the public discourse about HIV prevention. These provide encouraging starting points upon which to build more systematic interventions for persons with SMI living in community settings.

The findings document HIV prevention needs, challenges, and opportunities that are unique considerations for persons with SMI. Unlike interventions developed for other groups of persons identified with elevated risk for contracting HIV, interventions for those with serious mental illness need to take into account pervasive stigma about the capabilities of persons with serious mental illness. Contrary to the stereotypes of persons with SMI psychiatric diagnoses, we found little evidence of cognitive limitations in this sample that might restrict learning from public health messages about preventing HIV transmission, learning skills, or persuading peers to use these skills as part of a community norm change intervention. All participants had basic knowledge about what HIV is, how it is transmitted, and how to protect oneself. Rather, the data suggest that emotional, motivational, and structural limitations in implementing

prevention knowledge appear to be larger consideration than cognitive factors. Overgeneralized low expectations for the capabilities of persons with serious mental illness may limit the amount and type of HIV prevention methods used with this population. Interventions to persuade mental health professionals and program administrators of the feasibility of HIV prevention in their settings may be necessary to advance a broader array of interventions for this population.

Given the structure of the housing programs and the supports that facilitate making changes in health behavior, these settings offer unique advantages for engaging persons with SMI to learn about and to practice HIV prevention in supportive contexts. However, particular attention is needed to promote the use of prevention skills outside of program structures. A third of the participants articulated concern about being able to apply their strategies for HIV prevention once they leave the housing program; this was articulated without a direct question in the protocol, suggesting that there may be others who share this concern. Research participants described examples of how this had been a problem during time away from the program. Their anticipation of the transition indicates both a need for a targeted intervention but also an opportunity that may be well received. For example, this might include the development of integrated mental health, substance use, and behavioral health interventions that incorporate HIV risk reduction in a manner similar to how dual diagnosis approaches integrate mental health and substance abuse interventions (Drake et al., 2001). Supportive housing may provide a better context for implementing and carrying through these types of interventions than clinical settings.

The findings also document how participants' experiences with HIV and prevention efforts have meaningful similarities to other populations. Many challenges discussed by research participants have been described for other populations. For example, like some gay communities, persons in this sample report a relatively high rate of interaction with persons who had HIV and who suffered from AIDS. More than two-thirds of the sample knew at least one person infected with HIV and a substantial number had witnessed AIDS suffering. These experiences appear to motivate them to be concerned about what they can do to protect themselves. Second, research participants live in supportive housing because of their low-income (i.e., a criteria of admission) and disenfranchisement in society. Like many IV drug users, persons in this sample have multiple needs that can have an impact on their HIV risk (e.g., experiences with homelessness, poverty, drug use) that need to be taken into account for intervention efforts. Third, research participants also faced challenges in applying particular HIV prevention strategies that have been documented in the broader HIV literature. Several articulated interpersonal barriers around negotiation of condom use and how their resolve to practice safe sex can be overcome in particular situations, particularly for women with few resources or social status. A few described instances of sexual coercion. These data suggest that HIV interventions developed for other populations facing similar problems in living could be implemented to a greater extent than has been to this date for persons with SMI.

A range of approaches to intervention may be needed based upon persons' prior experiences with HIV. This sample had a significant amount of variation in the level of intimacy that persons had with HIV experiences. Persons who "*witnessed*" suffering from AIDS acquired vibrant images about the effects of the disease. Interventions with these individuals may need to allow for processing of these experiences to allow for effective learning of health promotion skills. In contrast, few persons who experienced the less intimate "*confronting their own HIV risk*" as the result of personal interaction connected their stories to health promotion practices, as did those who "*witnessed*" AIDS suffering. Interventions for persons with these experiences may need to accommodate both fear-based motivations for learning about HIV prevention skills and health promotion interests. Finally, a last category of participants was less emotionally engaged about HIV in their accounts. These data cannot explain why these

descriptions appear to be less personal or emotionally engaged (e.g., individual differences in expression, psychiatric symptoms, psychological defenses), but interventions for them will likely need to take into account that some intervention practices, particularly ones designed for those bearing witness to AIDS, may overwhelm persons with SMI who are less emotionally engaged with the subject of HIV and HIV risk. It seems quite likely that variation in intimacy of HIV experiences and emotional reactions to these experiences need to be considered in developing interventions that are both comprehensive and engaging for persons with SMI.

One promising alternative prevention strategy may be to embed integrated interventions into "host" settings that can help facilitate learning of skills, assist emotional processing, and provide interpersonal support for implementation of prevention knowledge. Supportive housing for people with SMI may offer such an opportunity to structure a prolonged intervention with supportive resources to work through prevention barriers. These settings appear to be in a position to capitalize on individuals' desire to make changes in their lives (e.g., sobriety, recovery from SMI, work, independent living). Even research participants who reported high-risk HIV-related behavior talked about making some changes to care for themselves. These settings may provide an opportunity to step back from intimate relationships and think through how one wants to practice HIV prevention within their current or future relationships. The support of fellow residents and staff is a promising resource to help residents consistently use prevention methods.

While the data suggest that persons in this sample were more aware, capable, and active in using HIV prevention efforts than has been previously documented, the study has several limitations. The generalizability of the findings to a broader population of persons with SMI is not known. First, persons with SMI living in supportive housing represent a subgroup of persons with SMI, investigations in other types of settings are needed, as well as replication in supportive housing programs. Second, generalizability of the findings is somewhat limited in that the study was conducted in two high-HIV prevalence urban areas. The level of exposure to HIV experiences and information is likely lower in many areas. Third, self-selection of participants requires a significant caveat on generalizations. Because of federal restrictions on obtaining personal health information of persons not interested in participating in the research, not much is known about the 45 persons who did not participate in the study except that met the admissions criteria of the settings (e.g., diagnosis of serious mental illness, adequate level of functioning for the structure of the setting). Therefore, the results are of limited utility for establishing the proportion of persons with SMI that have specific types of experiences with HIV or percentage of persons with SMI who accurately assess their risk status. Rather, the findings are more helpful in documenting diversity within this sample, suggesting diversity in the population, and for challenging assumptions about the limited capabilities of all persons with SMI to participate in HIV prevention (Kloos, 2005). Further research is needed to establish whether the patterns of results identified in this study are useful dimensions for HIV prevention in other settings. In the absence of other systematic data, these findings offer a starting point for planning HIV interventions that build upon the prevention practices of persons with SMI.

In conclusion, due to their life circumstances individuals with SMI have increased risk of contracting HIV. Many persons with SMI need HIV prevention programs that will help augment their ability to protect themselves from HIV infection. The findings document that a substantial number of persons in these settings already engage in their own HIV prevention informed by public health messages. We suggest, however, that specialized HIV prevention integrated into mental health care is needed which goes beyond education about risks and prevention methods and allows for processing of emotional material and addressing motivational challenges to implementing HIV prevention within the context of supportive settings. This study's findings suggest that supportive housing programs can provide opportunities for development and implementation of interventions that both enhance

prevention knowledge and promote motivation for making the life changes needed for consistent HIV prevention. Although often overlooked, the findings also suggest that community-based interventions are feasible, promising, and appropriate means of HIV preventive interventions for persons with SMI.

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