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Factors Influencing The Delivery of HIV-Related Services to Severely Mentally Ill Individuals: The Provider's Perspective

Monica Biradavolu,

American University, Department of Sociology

Yujiang Jia,

Washington DC HIV/AIDS, Hepatitis, STD and TB Administration

Keenan Withers, and

National Institutes of Health, National Institute of Mental Health

Suad Kapetanovic

National Institutes of Health, National Institute of Mental Health

University of Southern California Keck School of Medicine, Department of Psychiatry and The Behavioral Sciences

Abstract

Objective—Individuals with severe mental illnesses (SMI) are disproportionately vulnerable to HIV infection, but not consistently engaged in HIV-related services. To understand factors influencing implementation of HIV-related services to individuals with SMI, we conducted series of focus groups with multidisciplinary clinicians and staff serving individuals with SMI at outpatient, emergency, acute inpatient and chronic inpatient level of care.

Method—Six focus groups with 30 participants were conducted, audiotaped and transcribed. Our qualitative analysis drew on Grounded Theory. Utilizing nVivo Version 9, coding was conducted by the first and senior authors, inter-rater reliability verified by running Coding Comparison queries.

Results—The providers' narratives highlighted 1) patient-related factors, 2) stigma and 3) administrative factors as themes particularly relevant to the delivery of HIV-related services to individuals with SMI. The reported relevance of these factors ranged across levels of care, from creating multiple barriers in the outpatient care, to relatively seamless and effective delivery of full continuum of HIV-related services in the chronic inpatient environment, where adequate structural support is provided.

Conclusion—Providers' narratives suggest that effective delivery of HIV-related services for individuals with SMI requires sustained structural support that is coordinated across levels of

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psychiatric care, and tailored to individual patients' needs. The narratives also suggest that such support is currently not available.

Keywords

severe mental illness; HIV risk; HIV testing; continuum of psychiatric care

Introduction

Most adults with severe mental illnesses (SMI) are sexually active, and some evidence suggests that they might be highly vulnerable to HIV infection [1-3]. With advancement of effective antiretroviral therapy (ART), HIV testing, early diagnosis and linkage with care, the life expectancy of asymptomatic HIV-infected (HIV+) individuals is approaching that of the general population [4]. Yet, the reported lifetime prevalence of HIV testing among individuals with SMI ranges from 11% to 89% [3], and there is a lack of evidence-based strategies to engage them in HIV-testing and care [5]. This renders individuals with SMI and comorbid HIV disproportionately vulnerable to late HIV diagnosis, under-treatment and related morbidity and mortality. [6]

The revised Centers for Disease Control and Prevention guidelines recommend HIV screening for patients in all health-care settings, on an opt-out basis, and annual screening for persons at high risk for HIV infection [7]. While individuals with SMI should be routinely screened for HIV, one recent literature review identified a lack of evidence base that would inform innovative strategies to optimize their psychiatric, behavioral, and medical outcomes [5]. To develop such evidence base, it is important to understand the factors that influence effective implementation of HIV-related services to this highly vulnerable population. With that objective in mind, we conducted focus groups with clinical providers caring for individuals with SMI in Washington DC. We explored the providers' experiences, attitudes and beliefs about providing HIV-related services to individuals with SMI.

Materials and Methods

"Factors influencing provider decision to implement HIV-related services in DC psychiatric facilities" was a qualitative study which aimed to identify key provider attitudes, beliefs and experiences regarding factors influencing the delivery of HIV-related services in facilities caring for individuals with SMI. The Institutional Review Board of American University approved the study protocol. Written informed consent was obtained from each study participant prior to enrollment. Data were de-identified once merged into the study database.

Participant Recruitment

With approval from the DC Department of Behavioral Health and DC HIV/AIDS, Hepatitis, STD and TB Administration, we contacted organizations serving individuals with SMI in DC; and solicited voluntary participation from their providers and staff.

Focus Groups

The 90-minute focus groups enquired about the overall context of care and treatment needs of individuals with SMI, including the profile and life context, the current protocols for linkage with HIV care, the perceived gaps in providing HIV-related services, and the individual and structural factors that influence provision of HIV-related services. The focus groups were facilitated by a sociologist experienced in conducting focus groups.

Participants were informed that interviews would be audio-recorded prior to providing consent. Recordings were transcribed, pseudonyms used in place of actual names, and other identifying features removed.

Qualitative Data Analysis and Interpretation

Our qualitative analysis drew on Grounded Theory [8], which allows including both a priori codes and codes generated iteratively; utilizing nVivo Version 9 (QSR International Pty Ltd.). Six analytic strategies were used as identified by Miles and Huberman: 1) coding data from transcripts to identify emerging themes; 2) recording reflections; 3) sorting and sifting through data to identify similar phrases, relationships, patterns, themes and common sequences; 4) seeking commonalities and differences; 5) elaborating on a small set of generalizations; and 6) confronting these generalizations with a formalized body of knowledge [9]. Coding was conducted by the first author and the senior author; inter-rater reliability verified by running Coding Comparison queries on nVivo 9.

Results

Focus Group Participants

Six focus groups were conducted with a total of 30 participants: 9 registered nurses, 6 physicians (3 infectious disease specialists and 3 psychiatrists), 6 clinical supervisors, 2 case managers, 2 nurse practitioners, 2 social workers, 1 program specialist, 1 project director, and 1 pharmacist. Although the participants were interviewed in the clinical venues where they currently practice, they had practiced at other levels of care in their careers, and were encouraged to share those experiences as well.

Participant Facilities

The participants were currently practicing in 8 community-based agencies, clinics, and health centers that serve individuals with SMI or provide mental health assessments, medication, counseling and community support; 1 acute inpatient psychiatric unit of a DC government hospital; 1 chronic public psychiatric facility serving patients who require long-term intensive inpatient care; and 1 free-standing psychiatric emergency department.

Qualitative Data

Here, we report on three major themes that, in the providers' view, describe three factors that affect the delivery of HIV-related services to SMI individuals: a) Patient-related factors, b) Stigma, and c) Administrative factors. During our qualitative data analysis, one of the key patterns observed across themes was that providers' perceptions about the relevant import of these three factors varied by the level of care where they currently practiced. To illustrate

this pattern, we highlight the distinction between different levels of care throughout the presentation. Figure 1 provides the visual overview of the providers' experiences and views by levels of care.

a) Patient-Related Factors

Many characteristics of patients with SMI complicate the delivery of HIV-related services, including poor insight, impaired judgment, transiency/homelessness, sexual vulnerability, inadequate support, frequent incarcerations, high rates of substance abuse and medical comorbidities. We present the data on patient-related factors in relation to three elements of HIV treatment cascade: testing, prevention and retention in care.

HIV Testing—With regards to when, how, and even whether to administer HIV testing for patients with SMI, **emergency providers** argued that most patients with SMI do not have the mental capacity needed to consent or opt out of testing at the time of active psychiatric emergency; that, if found to be HIV+, they would not be able process the information. Some emergency providers opined that a patient's psychiatric condition may worsen if they find out they are HIV+, or if they are put through the stress of HIV testing. The following quote from one emergency care provider captures the provider's dilemma on HIV testing:

“How do you tell someone in a psychiatric emergency that they are HIV-positive? They are in a crisis already!”

Inadequate support post-discharge was a chief concern among **acute inpatient** providers, as in the following quote:

“We do test them on our unit. If they test HIV-positive, we get an infectious disease consult and initiate ART. We also make referrals for outpatient HIV care. The real problem is what happens after they leave the hospital and are back in the community without adequate support to maintain their adherence, doctor appointments etc.”

Acute inpatient providers expressed patient safety concerns as well, as in this quote:

“We had a woman with bipolar disorder who tested HIV-positive while on the unit and, for days after was telling everyone ‘I have HIV’ ... how is that going to affect her safety, her support system after discharge?”

By contrast, providers at the **chronic inpatient** facility, where opt-out HIV testing is routinely done during intake, did not voice major concerns about the complications or logistics of testing. Sometimes HIV-testing is not feasible during the intake if patients are acutely psychotic or non-cooperative, but eventually the testing gets done, usually after the patient's psychiatric condition has stabilized. The testing and its results do not seem to result in significant psychiatric complications. This quote highlights the routine nature of HIV testing at a chronic inpatient facility:

“For the last 4-5 years now, it's part of the routine labs that we do; routine admission, the package. We do the HIV, Hepatitis B and C, and syphilis.”

Moreover, since **chronic inpatient** providers worry less about patients leaving their care, they can administer testing at a pace based on the patient's mental status:

“... once they have become stabilized psychiatrically, then they may go ahead and allow blood draw or any other kind of exam. So sometimes, it's a matter of giving them time and letting the psych medications work on them.”

The importance of testing in a comfortable environment that took into account the patients' individual needs was also highlighted by **outpatient** providers, who do not conduct HIV testing on-site, but do collaborate with certified testing agencies in the community, and counsel clients to get HIV tested. Still, they thought that testing rates would improve if the procedure could be conducted at their site:

“Many consumers would be comfortable doing it here but wouldn't necessarily go someplace else to do it.”

HIV Prevention—HIV prevention options are also complicated for individuals with SMI. One **outpatient provider** argued how transactional sex puts women with SMI at higher risk:

“Sex is a commodity for our folks who are really desperate. (Sex) can be a source of food, income or housing. (Many women with SMI) are exchanging sex for a place to stay. So whether you call it prostitution or survival or whatever, there's lots of sex going on, I think.”

Although providers consider HIV prevention to be critical, there are challenges to conducting HIV prevention work. The following quote from a **chronic inpatient provider** about an ongoing controversy among staff highlights the challenges of condom promotion amongst populations with SMI:

“We know that sex is not allowed between patients. But do they do it? Probably yes. (...) There is a working group in progress right now investigating the possibility of us making condoms available. There is a move toward allowing condoms, but we haven't worked out the details yet. (...) There are some individuals more vulnerable here than others. There are issues in terms of consensual sex. Some individuals in care here report every day they have been raped. (...) Right now in the working group, we're talking about separating the notion of providing condoms from having sex. (...) If we can (make) that distinction, then it will be easier for us to get to this road of allowing condoms for our individuals in care.”

Retention in HIV Care—Retention of patients with SMI in HIV care is more challenging in the **outpatient** setting than it is in the **chronic inpatient** setting. The **outpatient providers** highlighted the transiency of populations with SMI as one critical consideration that they have to deal with:

“We get all sorts of people from all different places... We have clients who work a circuit. So, the weather here last night was what – 20 degrees – so it's too cold for some of them. They're down in Florida right now. When the weather gets warmer, they will come back here, probably around June....”

Another outpatient provider concurred:

“There are people who in the winter will adhere more to their substance abuse treatment, or HIV or psychiatric medications (...) because they need to do certain things to stay in shelters and when the weather gets warm enough and they don’t mind sleeping out in the parks, then they will go back. You have to build that momentum in the few months that you have or else you will lose them in the summer months.”

Chronic inpatient providers find that engaging patients with SMI in HIV care may be a challenge in the early days of their hospitalization. This sometimes requires stabilization of their psychiatric condition, often on an involuntary, court-ordered basis. There is a difference between getting patients started on psychiatric medications compared with non-psychiatric medications, with the former proceeding with greater speed because it can be court-mandated, while the “medical medications” such as ART, have consent requirements:

“It is a little faster to do involuntary (court-ordered) medication with psychiatric meds. Not so much involuntary with anything medical. For example, if we get a case already known to have HIV and they have already been on ART, when they come here if they refuse everything, the move is the quickest when it comes to the psychiatric meds. But there is a delay in getting any ART (...), because of the consent issue.”

Overall, **chronic inpatient** providers shared very positive experiences with integrated care, especially with their long-term inpatients, who, over time, do get engaged in HIV care with very good medical outcomes:

“(If patients are found to be HIV+), they are immediately sent to an infectious disease clinic, so they can get genotyping (...). Once they’re back (on our unit), we follow the ID doc’s recommendation and administer ART every day. When the patients are compliant, we find very good results. Their viral loads and CD4 counts are great (...) as long as they’re here.”

For the same reasons highlighted by the inpatient providers, the **outpatient providers** believed that integration of mental health with HIV and other medical care would be very beneficial to their SMI clients. **Outpatient providers** emphasized the importance of prioritizing competing individual client needs and setting realistic goals through a personalized approach. Often that means assistance with finding appropriate housing arrangements or stabilizing their mental illness before they can meaningfully engage in HIV-related services:

“In the homeless clinic, our issues are a lot more complicated. We’re trying to get individuals off the streets, out of the shelters and into stabilized environments. And so, (...) when they first walk in through the door, we are trying to figure out – what’s THE most important thing this person needs right this instant. Sometimes it is that they need housing, sometimes it is that they need insurance, sometimes they really just need 3 square meals a day and we have to figure out where to send them to get those meals. HIV medication and adherence is way down on the list for a lot of our clients.”

b) Stigma

Provision of HIV services to individuals with SMI is further complicated by the dual stigma against both HIV and mental illness, which manifests itself in particular ways, most visibly in HIV treatment adherence. An **outpatient provider** described a scenario of an individual with SMI and HIV in a homeless shelter:

“Stigma is also an issue in the shelters. You’re taking all these medications and people around you want to know what you’ve got that you have to take all those pills. (...) There is a specific atmosphere when it comes to HIV in the shelters. Part of that is lack of knowledge. Part of it is mental health issues in people who are paranoid and feel that bugs are everywhere, that they are going to get HIV by just looking at the person. (...) If I am in the shelter and my biggest priority is that I don’t know where my next meal is going to come from, I don’t want to have to be trying to hide medications at the same time I am trying to figure out where am I going to eat... will I have enough food to take my medications with. are people looking at me funny... it keeps going farther and farther and farther down the list... until you can get some of these other issues addressed.”

c) Administrative Factors

Outpatient providers consistently brought up certain administrative requirements that, in their view, affect their ability to offer HIV-related services. Consider this quote:

“You have to make a certain amount of face-to-face time per day or else you can’t be billed. Your job isn’t supported. So at my last job if I didn’t have 5 hours of face-to-face time with my clients, my salary wouldn’t be paid. So the people who are hard to reach, (...) who are most in need, those you cannot find, that aren’t quite ready to commit, you don’t have the time to go out and do (the outreach).”

Outpatient providers stressed that a typical individual with SMI has multiple medical and psychosocial needs, including medical co-morbidities, substance abuse, unstable housing, or frequent incarcerations. They report spending a substantial amount of their work hours on inter-agency coordination on behalf of their SMI clients. The result is a severe fragmentation of care:

“Depending upon the level of acuity, which for our clients is very high, an individual client needs to be hooked up with 5, 6, 7, 8 different agencies.”

Emergency care providers, however, did not find the fragmentation of care problematic for achieving their clinical objectives. There was a prevailing attitude that the need for knowing a patient’s HIV status is outweighed by the need to attend to their immediate psychiatric symptoms. Furthermore, they believed HIV testing was time-consuming and would create staff burden; and unnecessary because there are designated HIV-testing facilities in the community.

Several **outpatient** providers voiced concerns about discrepancies between the administrative agenda of the local health administration and the clinical, patient-centered agenda of the personnel “in the trenches”. The providers acknowledged the need to track

staff performance and measure patient outcomes but complained that the current paperwork requirements were not helpful:

“It takes time and energy for us in the trenches to establish rapport and make people love us. And then we go to these meetings and the administration officials say, ‘We need you to fill out this 32-item scale here and if they are a homeless person, we need you do it every 3 months, then we need this one done every 2 months etc’. Those things take time, and when someone misses an appointment, or you can’t rely on them to come in every 3 months to get the paperwork done, then it becomes (a barrier). I understand the need for some kind of ability to gauge whether we are working or not. But I think the scale should be about how many times that person is coming in to see me. If 2 years ago they were coming in once a year and now I have them coming every 2 weeks to every week to see me, then I think something I am doing is working. (...)”

Discussion

The providers’ narratives suggest that delivery of HIV-related services to individuals with SMI is influenced by a combination of patient-level and structural factors. Providers from all settings agreed that individuals with SMI are a very challenging population, not only because their mental illness can undermine their judgment and decision-making, but also because of their multiple competing psychosocial and medical needs. Outpatient environment is where these patient-related factors interact with administrative barriers (e.g., counterproductive billing or paperwork policies) and social stigma. Crucially, the experiences shared by chronic inpatient providers demonstrate that SMI-specific clinical challenges can be overcome, and that all elements of the HIV treatment cascade, from screening to sustained engagement in care, can be implemented safely and effectively when the necessary support is provided. That support includes integration of medical and psychiatric care, and often requires clinical stabilization of acute mental illness, skilled nursing support, and continuous and persistent adherence monitoring.

Focus groups are ideally suited to reveal the range of experiences and to learn about differences among categories of interviewees relevant to the study [10]. Indeed, our focus groups revealed that providers’ perceptions of the relative import of certain patient-related and structural factors differed across levels of care. (Figure 1) It seems reasonable to hypothesize that improved coordination of HIV-related services for individuals with SMI across all levels of psychiatric care would result in improved HIV and mental health outcomes. The goal of such coordination would be to sustain optimal structural support that is adaptable to specific needs and life circumstances of individual patients with SMI as they move along the continuum of care.

It appears critical to create policy environment that would optimize coordination across levels of care. For example, fragmentation of care could be minimized by creating “one-stop shop” medical homes that specialize in providing integrated primary medical care, psychiatric care and intensive case management services to individuals with SMI. Within such model of care, HIV testing and related services could be routinely integrated into

clinical lab protocols within the agency environment the patients are already familiar and comfortable with. Building more flexibility into case-manager positions (e.g., lighter case-loads, less rigid billing procedures) may improve outreach to some of the most vulnerable patients with SMI and their retention in care. Soliciting input from agency personnel in the development of outcome measures may improve the clinical salience of these measures and facilitate development of more patient-centered care plans while minimizing the paperwork burden. The process of transition of patients with comorbid SMI and HIV from one level of care to another may need to be closely overseen by a designated case manager familiar with the individual patients' unique circumstances and needs. In homeless shelters, where HIV+ individuals with SMI often struggle to remain ART-adherent in the face of stigma and other competing needs, it may be critical to train staff to assist these clients with problem-solving in an individualized, confidential manner.

This study has limitations. Although participant recruitment from different levels of care provided broad range of experiences, the purposive sampling may have biased the results. The results of this DC-focused study may not generalize to other US urban centers. Our study focused on providers only, thus not providing the perspective of SMI individuals.

In conclusion, the key for meaningful and safe implementation of HIV-related services to SMI individuals may be in understanding how significance of SMI patient-related and structural factors varies across levels care. These qualitative data may inform future research aimed at developing specific structural interventions to optimize the delivery of HIV-related services to individuals with SMI.

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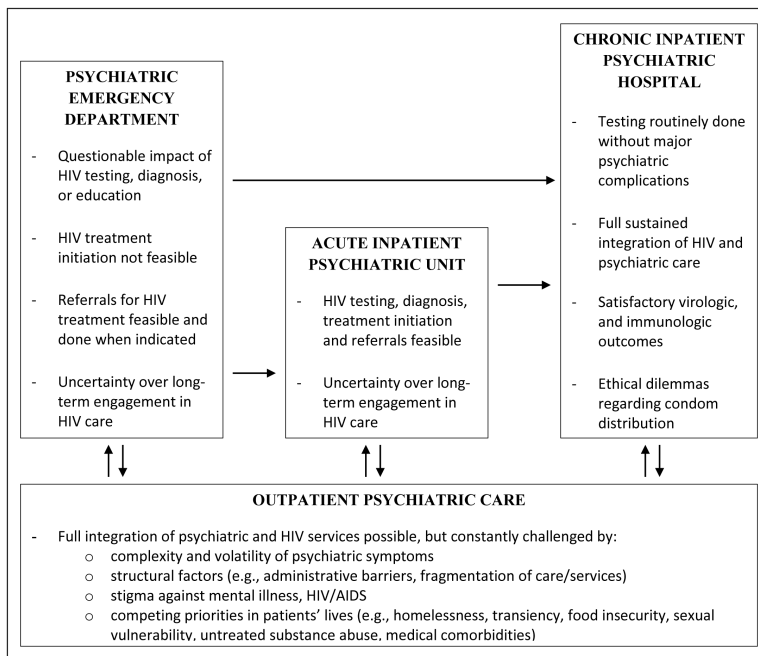


Figure 1. Providers experiences with provision of HIV-related services to patients with SMI across continuum of psychiatric care
 Patients with SMI move through levels of care depending on the severity of their mental illness. As the least restrictive level of care, outpatient care is considered suitable for individuals with SMI who are not gravely disabled or immediate danger to self or others. However, this level of care poses multiple challenges to effective delivery of HIV-related services. For this reason, providers from acute psychiatric inpatient unit and psychiatric emergency department view efforts to provide HIV testing and linkage with HIV care as mostly futile. Paradoxically, the most severely impaired individuals who require long-term stay in a chronic psychiatric facility, are best served when it comes to HIV testing and linkage with long-term, effective HIV care; an exception is the issue of condom distribution, which some providers find ethically and medico-legally disputable. (Arrows indicate possible directions of patient movement between levels of care)