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SEVERE MENTAL ILLNESS

There is a higher prevalence of HIV among people who live with severe mental illness than in the general population, which suggests that these people may be at increased risk for HIV infection. This issue of PERSPECTIVES explores the reasons for this elevated prevalence, including how sexual and drug use behaviors may be influenced by these mental health conditions. In addition, PERSPECTIVES discusses the role social settings and sexual networks play in elevating HIV risk for this group. The Implications for Counseling section highlights the significant yet limited role of HIV test counselors in serving this population, and offers strategies for conducting successful sessions.

Research Update

People with severe mental illness make up about 2.6 percent of the U.S. population. These individuals live with psychiatric disorders that cause a serious and continuing impact on their daily lives. Among the challenges people with severe mental illness face is an extremely high HIV prevalence—estimated at 3.1 percent, or eight times the national average. HIV prevalence estimates from some studies are even higher, with the highest reaching 23 percent.

While the topic of HIV and serious mental illness has been relatively under-studied, researchers offer a number of theories to explain this heightened prevalence. People with severe mental illness are more likely than others to engage in sexual and injection practices that transmit HIV. Reasons for this may include lack of knowledge about HIV transmission and prevention, a lack of motivation to engage in safer practices, or a lack of the behavioral skills to engage in prevention practices. However, elevated rates of HIV risk behaviors do not fully explain elevated HIV prevalence. Even among people with severe mental illness who engage in the same level of risk behaviors as others, HIV prevalence is still twice that of the general population. This suggests that aspects of life besides behavior, such as membership in a high-prevalence sexual network, increase risk for contracting HIV.

Despite high prevalence rates, many individuals with severe mental illness have not been tested for HIV. One study of 150 people, half of whom had a recent experience of homelessness, found that half of the participants who engaged in HIV risk behaviors had not been tested in the past year. Specifically, people with psychotic disorders were less likely to have tested, possibly due to their providers’ misconception that people with schizophrenia do not have sex. Psychiatric symptoms and the medications used to treat them may also have a blunting effect on a client’s perceptions of pain, physical ailments, and the need for medical attention, perhaps including the need to test for HIV.

The Spectrum of Mental Illness

The impact of a mental illness on a person’s life can range from relatively mild to quite disabling. Part of what determines the severity of this impact is the type of condition itself and its characteristic symptoms. For example, a disorder such as schizophrenia usually involves a history of hallucinations (the perception of something, such as a voice or a person, that does not actually exist), or delusions (a fixed, false belief, such as the belief that one is president). Because of these severe symptoms, and because psychosocial impairment is a central part of the diagnosis of the disorder, schizophrenia impairs daily life more than a disorder that results in moderate anxiety in social situations.
Within a given disorder, symptoms also vary in type, frequency, and intensity—and therefore impact. Some illnesses, like depression, may be described as “mild,” “moderate,” or “severe,” depending on how a given individual’s symptoms present themselves. This means that the symptoms and the effect of these symptoms on a person’s ability to function define the severity of his or her condition beyond the fact that he or she is simply diagnosed with a depressive disorder. Many diagnoses share overlapping symptoms, and the ways that symptoms manifest are influenced by culture, gender, age, and race.

Definitions of severe mental illness vary, sometimes making it difficult to compare information across studies. Researchers generally describe severe mental illness as a range of major psychiatric disorders that persist over time and cause extensive disability. Disturbances in feeling and thinking caused by these disorders often impair social and work functioning. Many individuals with severe mental illness experience frequent hospitalizations and require treatment with psychotropic medications in order to function. While treatment and supportive interventions enable a number of people to work and to relate better to others, life with severe mental illness often involves unemployment, recurrent homelessness, poverty, and unstable relationships, resulting in an increased vulnerability to HIV infection.

These kinds of impairments occur most frequently in schizophrenia-related disorders, bipolar disorder (which is also called “manic-depressive disorder”), and major depression. Together, these three disorders make up the bulk of severe mental illness diagnoses. Some sources also include anxiety disorders, such as posttraumatic stress disorder. People with schizophrenia and people with mood disorders are estimated to be 1.8 times and 3.8 times as likely respectively to be HIV-positive as are members of the population as a whole.

### Estimating HIV Prevalence

Historically, much research on HIV and severe mental illness has focused on small studies of subjects in treatment at mental health hospitals and clinics in New York City. Studies refer to HIV prevalence rates of 3 percent to 23 percent, with the highest rates of HIV occurring among people who are also homeless or diagnosed with a substance use disorder.

In 2001, a prevalence study of participants in both inpatient and outpatient mental health treatment in four states tested 931 people for HIV. Researchers found an HIV prevalence rate of 3.1 percent, eight times the estimated HIV rate among the U.S. population. The authors also noted that, unlike the general population—in which the male-to-female ratio of HIV infection is five to one—in this group, the ratio was nearly equal: four to three.

The national prevalence of HIV among people with severe mental illness may be higher than the estimate above. The study did not involve any of the 10 largest U.S. cities, where HIV infection is more widespread, and where prevalence would be expected to be greater. However, the findings do indicate that, even in areas with low general prevalence, people living with severe mental illness have elevated rates of HIV infection.

### Behavior and Mental Illness

A greater frequency of HIV risk behaviors among people with severe mental illness may partially explain this elevated HIV prevalence. A 2005 review of 32 studies found that people living with severe mental illness were more likely than others to have multiple sexual partners, to trade sex for money, drugs, or other goods, and to inject drugs.

According to the review, 51 percent to 74 percent of severely mentally ill participants were sexually active. Approximately half of these sexually active participants had multiple partners and never used condoms. One quarter of participants also reported a history of sex trade, and over half of these had traded sex in the past year. Sex trade was notably more common among homeless and indigent participants. Twenty-nine percent of participants reported ever having had a sexually transmitted disease (STD), with 8 percent reporting an STD in the last year. While national prevalence rates of STDs are difficult to estimate, the presence of STDs—particularly if untreated—could contribute to the high prevalence of HIV.

Serious mental illness also has a number of cognitive, behavioral, and social consequences that may account for this increased HIV risk. Some studies indicate that people with severe mental illness possess HIV knowledge similar to that of the general public; other studies suggest that people with serious mental illness have less accurate knowledge of HIV transmission and prevention. Further, it may be that some aspects of a psychiatric disorder (such as impulsivity or lack of self-care) make it difficult for individuals to implement prevention strategies even when they know how to protect themselves.

Psychiatric conditions may also indirectly increase the likelihood of HIV transmission. Symptoms can impair judgment, decrease motivation to change behavior, and undermine behavioral skills aimed at minimizing transmission. In some cases, the very characteristics of the diagnosis may be closely related to an HIV-related risk behavior. For example, one symptom...
of bipolar disorder is engaging in sexual activity despite a strong likelihood of negative consequences. Depressed or anxious people may use sex or drugs to “self-medicate,” that is, to help themselves feel their symptoms less acutely. Certainly risk behaviors may also be associated with the severity of symptoms; in one study, patients with more severe psychiatric symptoms were three times more likely to have multiple sexual partners than those with milder symptoms. In addition, negotiating safer sexual and substance-using behaviors requires complex social skills—the very skills that people with severe mental illness often lack.

As is true for many people affected by HIV, HIV prevention may also be perceived as a lower priority than dealing with stressors such as poverty, homelessness, stigma, and interpersonal problems. Structural interventions—programs such as supportive housing that directly change the environment in which people live in order to indirectly support their health and well-being—can be useful with this population.

Substance Use

Dual diagnosis—the occurrence of substance use disorders in people with mental illness—is more the norm than the exception. A study conducted by the U.S. Substance Abuse and Mental Health Services Administration reported that 21 percent of adults with severe mental illness were dependent on or abused drugs, compared to 8 percent of adults without severe mental illness. Since substance use can be associated with HIV risk behaviors, the higher rate of substance use may partially explain the elevated rates of HIV among people with severe mental illness. In support of this idea, one study of 152 people with severe mental illness found the highest rates of HIV, hepatitis C virus, and STDs among participants with both a substance use disorder and another psychiatric diagnosis. However, the cause and effect relationship between substance abuse and severe mental illness is complicated and not well understood. Some studies have reported that people with severe mental illness were more than five times as likely to have injected drugs in recent years than both control group members and the general population. Needle sharing was common among those who had ever injected. According to the same review, however, none of the following factors—drug of choice, duration of use, quantity of use, or frequency of use—was related to whether or not a participant used condoms during sex.

Sexual Behavior

A 2006 study indicates that people with severe mental illness engage in sexual activity earlier in relationships, and have less satisfying, less intimate, and much briefer sexual relationships. This may not be surprising, since psychiatric illnesses and the medications used to treat them often impair social and sexual functioning. For example, certain illnesses and medications decrease sexual desire. Others cause impotence, premature ejaculation, or an inability to orgasm (although newer medications may cause fewer of these side effects).

A 2006 study found that sexual dysfunction among people with severe mental illness was associated with a higher likelihood of being sexually active. It may be that sexual dysfunction leads to briefer, less satisfying sexual relationships that might result in a greater number of partners. Circumstances may also make sexual dysfunction irrelevant to HIV risk. People with severe mental illness who are also poor and homeless may engage in survival sex trade despite sexual dysfunction. Coerced sex, reported by 20 percent of participants with severe mental illness in one study, also may occur regardless of...
sexual dysfunction. Severe mental illness may also limit people’s access to sexual partners, leading some people with severe mental illness to “take what they can get.” A scarcity of potential sex partners may likewise lead some people with severe mental illness to compromise on their commitments to risk reduction.53

Social Settings and Sexual Networks

The settings in which people with severe mental illness live and receive care and their social and sexual networks may also increase HIV risk behaviors. For example, inpatient mental health care settings are usually not conducive to safer sex, since condoms are rarely available and since encounters may be prohibited and therefore rushed and secretive. These conditions also reduce the possibilities for negotiating safer sex.4,51

Outside of the hospital setting, people with severe mental illness often live and receive care in areas with high prevalence rates of HIV, other STDs, drug use and drug injection, and sex work.4,52 Concentrating services in these areas may expose mental health clients to social influences that encourage or reinforce HIV risk behaviors.53 It also increases the likelihood of contact with an HIV-positive sex or injection partner.4

Research suggests that many people with severe mental illness meet their sexual partners “at the clinic,” suggesting the role of closed sexual networks in high prevalence rates.53 A “sexual network” is a group of people that is connected through sexual contact. When people with severe mental illness meet sexual partners mostly in clinics or on hospital wards, their sexual networks are more limited and interconnected, allowing a rapid spread of HIV within the group.4,53 Such closed networks could explain why people with severe mental illness have higher HIV prevalence rates than the general population, even with the same degree of HIV risk behavior and even in small, nonmetropolitan areas with low general prevalence rates.5 In addition, research suggests that people with severe mental illness are more likely than others to have multiple sexual partners. Thus, it is possible that concurrent sexual and needle-sharing relationships—those that involve multiple relationships at the same time during a given period—may be a factor in elevated HIV prevalence.16

Conclusion

People with severe mental illness are clearly at increased risk for contracting HIV. Research has highlighted a number of possible reasons for increased prevalence in this group, including sexual and injection behaviors, the impact of dual diagnosis, and membership in a high-prevalence sexual network. Still, the complex relationships between these factors and HIV infection are not yet well understood. Both test counseling and other prevention interventions have a role to play in helping reduce risk in this population, as do interventions outside the counseling session that address the social and sexual relationships of people living with severe mental illness.

References

Implications for Counseling

While most HIV test counselors are not trained as mental health professionals, at some point they are likely to encounter individuals with either severe or milder forms of mental illness. The counselor’s task is to notice ways that the client’s mental health issues may both impede the counseling session and hinder the client’s risk reduction abilities. Because mental illness can have a substantial effect on communication, it may be useful for counselors to emphasize some client-centered counseling tools (such as reflection, repetition, and process comments) while using others (such as open-ended questions) less often.

Assessing the Client

Sometimes it will be obvious that clients have a mental illness, as when testing takes place in a psychiatric setting. More often, however, the counselor may suspect that the client has a mental illness because of other factors. These include disclosure of the client’s mental illness by other staff; the client’s self-disclosure; or something about the client’s presentation, such as bizarre clothing combinations, pacing or body tremors, or speech that indicates a disturbed thought process.

When counselors suspect that a client may have a mental illness, or when the client discloses a mental illness, counselors should not be afraid to talk about it and its relationship to preventing HIV infection. While some individuals with serious mental illnesses may feel shame or stigma in discussing their diagnoses, others do not. As long as questions are asked in a respectful manner, many clients will be relieved to discuss their problems with someone who is nonjudgmental. If a client with a severe mental illness is not in care, the counselor can refer the client to mental health care services.

Even when a client does not disclose a mental health diagnosis, a counselor can help the client make connections between certain feelings, thoughts, and behaviors (such as those that may indicate anxiety or depression) and HIV risk. In some cases, this may lead to a referral for further counseling. For example, a counselor might say: “It sounds like when you felt really sad and scared last month you didn’t care if you lived or died, and that’s when you had a lot of unprotected sex. So there are really two things that we’re talking about: keeping you safe from HIV, and, if you want, getting you some support so that you feel less sad and scared.”

Counselors are always aware that substances can directly (as with shared needle use) or indirectly (for example, by lowering inhibitions) affect HIV risk. Because of the high co-occurrence of substance abuse and severe mental illness, counselors should be especially alert for the impact of substances on behavior in this population.

Consent and Safety Issues

When a counselor suspects a client is living with mental illness, the counselor should also seek to determine the client’s ability to engage in the session, give informed consent, and to understand the client’s HIV-related risks and prevention skills. Assessment, however, should stop short of diagnosis, as this lies outside the scope of the HIV test counselor’s role.

The informed consent process can serve not only to confirm that the client understands and agrees to counseling and testing, but also can help indicate the client’s ability to engage in the session. To assess informed consent, a counselor might first ask a client why he or she is coming in to test and then briefly describe the testing process. The counselor might follow this by asking the client to restate in his or her own words the process and outcomes of testing. Some clients with severe mental illness may, despite having just heard this information, offer unusual or bizarre responses that could indicate an inability to give consent. Since many individuals, even those without severe mental illness, may have inaccurate information about HIV, the counselor might first respond by going over the information again, expressing the ideas as simply as possible. If a client is still unable to give informed consent, the counselor should follow the agency’s guidelines for such situations, including seeking supervisory help.

Client-centered counselors have skills that help their clients feel comfortable and safe in the session. At the same time, counselors must also consider their own safety. Many clients with serious mental illness may behave in unusual ways, some of which are distracting but harmless. However, if a counselor feels that a client presents a real threat, the counselor should take steps to promote safety. It is helpful if the counselor has already become familiar with his or her agency’s safety procedures before an incident arises. In addition, the counselor can alert a supervisor or colleague to stay close, and can sit nearer to the

A Counselor’s Perspective

“With every client—but especially with clients with mental illness—it’s important to remember the goals of the session and to have realistic expectations about the ground you can cover.”
Keeping the Session Focused

It can be challenging to maintain a clear focus on HIV risk and prevention during sessions with clients whose mental health symptoms disrupt the flow of communication. Some clients may hear voices, address someone not in the room, describe fears that a government agency is trying to infect them, or simply have extreme difficulty understanding information. Other clients, for example, those who are severely depressed, may simply be unresponsive to the counselor.

Certain client-centered counseling techniques make it more likely that the counselor and a client with serious mental illness will communicate more effectively. Counselors can review the structure of the session early, letting the client know what to expect. Counselors can then refer back to the description of that structure as necessary in order to refocus discussion on HIV-related behavior and prevention.

All counseling statements should be as simple and clear as possible. Some of the active listening techniques of client-centered counseling are more useful—and others are less useful—depending on the client’s symptoms. For example, many counselors successfully use open-ended questions during sessions. With seriously mentally ill clients, however, questions that require the client to use his or her imagination may be too unstructured. Direct questions or statements that describe real situations are best. For example, “Tell me about…” or “When was the last time…” are more concrete than “what if” questions.

When a client’s thinking is disorganized, certain client-centered counseling tools may be especially helpful. Summarizing, paraphrasing, and making process comments can help focus the session. For example: “I apologize for interrupting. I think we are going off the topic of HIV. Let’s go back to something you said earlier, about what brought you in.” Or ask a direct, closed-ended question relating to HIV: “When was the last time you had sex?” Repeating just a few of the client’s words and mirroring his or her language can help keep the session on track. Checking in with clients throughout the session about the client’s understanding of the discussion can also help the client avoid feeling overwhelmed.

With clients who are highly anxious, it may be helpful to discuss whether this is the best time to test. In these cases, counselors must assess even more fully than usual the client’s outside support in case the test result is HIV-positive. Clients who are visibly anxious may benefit from the technique of third-personing: they may be reassured when they hear that many clients feel anxious when they come in for testing.

Another way for a counselor to continue assessing a client’s capacity and pursue the prevention goals of the session is to ask the client what he or she would be willing to do to lower the risk of HIV infection. If the client’s answer contains inaccurate information about how to reduce HIV risk, the counselor can provide correct risk reduction information. Counselors should keep in mind that, for many seriously mentally ill clients, negotiating safer sex with a partner may not be possible. Educating the client in simple terms about the hierarchy of risk and talking about, for example, performing oral sex on a partner rather than having anal or vaginal intercourse may be helpful.

Limited Role and Use of Referrals

It is not the role of an HIV test counselor to diagnose or treat psychiatric conditions. Counselors with less experience with people with serious mental illness may feel overwhelmed by interactions with some clients. In these cases, it is good to make use of supervision, consultation, and peer support, as well as to maintain realistic expectations of the session.

Understanding and accepting the limitations of their role can help counselors feel more comfortable working with clients with mental illness. For example, a counselor might say: “I’m not knowledgeable (or skilled) in that area. I’d be happy to give you a referral to someone who can help you with that.” It is helpful when counselors appreciate what they are offering clients simply by sitting with them and being available to help them take small, manageable steps to reduce their HIV risks.

The ability to effectively use referrals is an important aspect of a counselor’s limited role. The brief time a counselor can spend with a client may highlight important issues that cannot be adequately addressed in the session. Mentally ill clients may have an assortment of immediate needs such as housing, food, primary care, clothing, and substance abuse services including needle exchange and crisis counseling. Supervision, consultation with
colleagues, and research (for example, searching the Internet) can all provide counselors with resources that can help clients.

Many referral agencies have eligibility criteria. Counselors should contact these agencies to define the services they offer and how clients may be referred to them. This ensures that counselors are familiar with community resources, and ensures that referrals are current.

Case Study

Carlton is a 36-year-old gay man who tests every three months. His clothes are stained, and though it is a warm day, he wears multiple layers of clothing and a stocking cap. Carlton speaks softly and rapidly, and sometimes it is difficult for his counselor, Jonah, to hear what he is saying. Sometimes he seems to be talking to himself, while looking from side to side. He is very anxious about germs and reveals in the session that at times he takes care of himself by wearing a protective mask and latex gloves while on the bus. Carlton is fidgety and gestures with his hands as his anxiety increases. Carlton’s only risk for HIV is performing oral sex on other men in adult bookstores.

Counseling Intervention

“The HIV risks with oral sex are very low so it sounds to me like you are taking good care of yourself,” Jonah remarks after filling out the Client Information Form.

“My mouth bleeds,” Carlton explains. “I brush hard and it bleeds. I have to brush out the semen.” His voice rises. “That’s where the virus is and I have to brush hard to get it all out.” He pulls back his lips with his fingers, revealing gums that are red and raw.

Jonah realizes that Carlton has some misinformation about how to prevent HIV, but he also suspects from Carlton’s intensity and presentation that Carlton may be mentally ill. Jonah feels somewhat uncomfortable, since he has no mental health training and because there is only one other counselor at the site.

Jonah takes a deep breath and thinks about what he has to work with: his own empathy and a few key facts. If Carlton is accurately describing his HIV risk behaviors, then the client seems to be at low risk for HIV. His profound anxiety about HIV, however, is prompting him to brush his teeth in a way that might, in fact, increase his risk by opening up cuts in his gums. Jonah says, “You know, coming in to test is scary for a lot of people and sometimes it takes a lot of courage.”

Carlton nods, and Jonah continues. “It’s great that you are trying to take care of yourself by protecting your mouth. Keeping your mouth clean is important to your health and can also help you prevent HIV. But brushing so hard that your mouth bleeds can actually make it easier for the virus to get into your body by opening up cuts in his gums. Jonah says, “You know, coming in to test is scary for a lot of people and sometimes it takes a lot of courage.”

Carlton nods, and Jonah continues. “It’s great that you are trying to take care of yourself by protecting your mouth. Keeping your mouth clean is important to your health and can also help you prevent HIV. But brushing so hard that your mouth bleeds can actually make it easier for the virus to get into your body by opening up cuts. There are a couple of other things that you can do instead. The first thing is to brush more softly. You can also have the other guy use a condom so that none of the semen gets in your mouth.

Do either of those things sound like something that you could do?”

Carlton is silent, but taps his foot and looks around the room.

Jonah tries a different approach, and when he says, “For some clients, all this information can be overwhelming,” Carlton nods again.

“I think if we figure out a better way for you to protect yourself, some of this might be less scary,” Jonah says, and explains the options of brushing more softly and of using condoms again. Carlton says that he could try brushing more softly but he’s worried that it won’t kill all of the virus.

Jonah explains that brushing doesn’t really kill the virus and Carlton starts to cry.

Jonah realizes that he is feeling anxious too. He says: “I wish there was something I could say that would help you feel less scared because in general, oral sex is unlikely to transmit HIV, especially if you aren’t brushing so hard. But I know that sometimes it can feel scary anyway. Who do you talk to when things feel really scary?” Carlton replies that he talks to his friend Bill, or sometimes his case manager.

When Carlton’s results are in, Jonah shares the HIV-negative result with him and asks him if he has any questions. Carlton shows him a sore in his mouth and asks him what he should do about it. Jonah says: “That looks painful. You said you have MediCal, right? Here’s the number of a couple of dentists close to here that could help you with that. Also, you said your case manager knows that you come in to test. You might want to talk to her tomorrow and let her know what happened and that it felt kind of scary.” As Jonah speaks, he realizes that he could use some support too, since he’s not sure he was able to help Carlton. He decides to bring up the session in group supervision next week.
Test Yourself

Review Questions
1. Severe mental illness usually includes which of the following disorders? a) major depressive disorder, bipolar disorder, and schizophrenia; b) major depressive disorder, schizophrenia, and substance use disorders; c) schizophrenia, bipolar disorder, and substance use disorders; d) bipolar disorder, major depressive disorder, and substance use disorders.

2. True or False: The high number of HIV-positive individuals with serious mental illness is completely explained by a heightened degree of HIV-related risk behavior among this group.

3. True or False. HIV prevalence among people with severe mental illness is estimated to be eight times the HIV prevalence of the general population.

4. Which of the following is not a factor that may contribute to increased HIV risk behavior among people with severe mental illness? a) psychiatric symptoms that impair judgment; b) self-medication; c) coerced sex; d) asexuality of people with mental illness.

5. True or False. Treatment of severe mental illness may cause sexual dysfunction.

6. True or False. After an HIV test counselor diagnoses a client with mental illness, the counselor should discuss a treatment plan.

Discussion Questions
1. What experiences have you had counseling people with severe mental illness? How do these experiences influence your approach to meeting new clients living with severe mental illness?

2. What sources of strength and resilience related to HIV prevention have you seen or can you imagine seeing among people with severe mental illness?

3. How might you ensure informed consent when you are working with clients whose mental health symptoms seem to be interfering with their understanding of the risks and benefits of HIV counseling and testing?

4. Many people with severe mental illness have multiple social service needs. How do you help prioritize a client’s needs when the client has a mental illness, uses substances, and needs housing?

5. In your setting, what kinds of referrals are available for clients with severe mental illness?

Answers to Review Questions
1. a, b and c. Substance use disorders are often associated with severe mental illness, but are not themselves severe mental illnesses.

2. False.

3. True.

4. d.

5. True.

6. False. HIV test counseling does not include the diagnosis of clients or treatment planning. Counselors should refer clients to treatment professionals.