HIV testing among individuals with a severe mental illness: review, suggestions for research, and clinical implications

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Background. The prevalence of human immunodeficiency virus (HIV) is elevated among individuals with a severe mental illness (SMI). Because of the benefits of HIV testing, it is important for individuals with SMI to have routine access to testing. The goals of this review are: to summarize knowledge about HIV testing prevalence, correlates, and interventions among individuals with an SMI; to identify research needs; and to discuss clinical implications of the studies reviewed.

Method. Literature searches were conducted using PsycINFO, PubMed, and Medline. Additional articles were obtained from reference lists of relevant articles.

Results. Fewer than one-half of individuals with an SMI have been tested for HIV in the past year. Engaging in sex or drug risk behavior was the only consistent correlate of HIV testing. Interventions for promoting HIV testing among individuals with an SMI have not been well developed or evaluated.

Conclusions. Research on HIV testing among individuals with an SMI is needed. Mental health settings may be opportune venues for HIV testing, even though providers face ethical challenges when implementing testing programs in these settings.

Introduction

The prevalence of human immunodeficiency virus (HIV) infection is believed to be elevated among individuals with a severe mental illness (SMI; McKinnon *et al.* 2002); thus, it is important for individuals with an SMI be tested for HIV, which confers both individual and public health benefits. Individuals who test positive will benefit from medical care; the public benefits because antiretroviral therapy reduces infectiousness and knowledge of infection status motivates risk reduction (Weinhardt *et al.* 1999; Marks *et al.* 2005). In this article, we summarize knowledge regarding sexual risk behavior and HIV prevalence among individuals with an SMI, review the prevalence and correlates of HIV testing in this population, suggest directions for research on testing, and discuss the clinical implications of the research reviewed.

Sexual risk behavior and HIV prevalence among individuals with an SMI

The majority of adults with an SMI are sexually active, and those that are sexually active engage in high rates of sexual risk behavior. Reviews of the literature have found that 54% to 74% of adults with an SMI were sexually active in the last year (Carey *et al.* 1997; Meade & Sikkema, 2005*a*). Among sexually active patients, 43% had multiple partners and 46% had not used a condom in the past year; lifetime sex trading was reported by 22%, and 33% reported a history of sexually transmitted diseases (STDs), rates much higher than those found in the general population (Meade & Sikkema, 2005*a*).

There are many possible causes of the high rates of sexual risk behavior among individuals with an SMI. Sexual risk behavior has been related to: (*a*) psychiatric symptoms or diagnosis (e.g. Carey *et al.* 2004; Meade & Sikkema, 2007); (*b*) factors associated with SMI, such as lack of planning, inaccurate assessment of risk, and poor communication skills (e.g. Gordon *et al.* 1999); (*c*) lack of information (e.g. Strauss *et al.* 2006); (*d*) lack of motivation to engage in safer sexual

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Table 1. *HIV testing prevalence among individuals with a severe mental illness*

Authors	Participants (n)	Gender	Primary diagnoses	Substance use	Setting	Time-frame for testing	% HIV tested
Blumberg & Dickey (2003)	1834	Not reported	Major depression, bipolar, or schizo-affective disorder	Not reported	National survey of non-institutionalized adults	Past 12 months	17.6%
						Lifetime	46.5%
Desai & Rosenheck (2004)	5890	61% male	Major depression, schizophrenia, other psychoses, personality disorder, bipolar disorder, and anxiety disorder	42.8% Reported alcohol abuse; 38.4% reported drug abuse	Homeless adults recruited through outreach and enrolled in intensive case management	Past 3 months	38%
Desai et al. (2007)	487	100% male	Schizophrenia, bipolar disorder, major depression with psychotic features, or psychosis not otherwise specified	Not reported	Out-patient settings (VA medical center and two state mental health centers)	Lifetime	58.1%
Goldberg (2004)	170	65% male	Schizophrenia	Not reported	Out-patient	Lifetime	69.4%
Goldberg et al. (2005)	200	48% male	Schizophrenia spectrum disorder or major mood disorder	25% Used alcohol, past month; 11% used drugs, past month	Out-patient	Lifetime	59.5%
Grassi et al. (1999)	91	65% male	Schizophrenia	43% Reported using drugs in the past 10 years	In-patient and out-patient psychiatric facilities in Italy	Lifetime	36.7%
Katz et al. (1994)	54	74% male	Schizophrenia or bipolar disorder	About one-third had a drug problem	Out-patient	Lifetime	61%
Kelly et al. (1992)	60	53% male	Schizophrenia, affective disorder, or severe borderline personality	In past month, 54% used alcohol, 12% used marijuana, 5% used crack, 7% used illicit pills, and 2% used intravenous drugs	Out-patient	Lifetime	33%
Knox et al. (1994)	120	54% male	Schizophrenia, major depressive disorder, schizo-affective disorder, bipolar disorder, mood disorder not further specified, dysthymia, and paranoid personality disorder	One-third had a substance-use disorder	In-patient and partial hospitalization	Past 12 months	47%
						Lifetime	64%
Levounis et al. (2002)	104	100% male	Psychotic disorder, depressive disorder, or bipolar disorder	100% Co-occurring substance-use disorder	Therapeutic community for homeless, chemically addicted men with a mental illness	Lifetime	89%
Meade & Sikkema (2005b)	150	54% male	Schizophrenia, schizo-affective disorder, bipolar disorder, major depressive disorder, posttraumatic stress disorder	47% Had a co-occurring substance-use disorder	Community mental health center, intensive out-patient program, supportive housing programs, and a crisis/respite center	Past 12 months	41%
						Lifetime	81%
Miller & Finnerty (1996)	44	100% women	Schizophrenia and schizo-affective disorder	78% Reported drug use during pregnancy	In-patient and out-patient psychiatric facilities	Lifetime	10.9%

Study	N	Gender	Diagnosis	Substance use	Setting	Time frame	%
Pirl *et al.* (2005)	655	70% male (in subset of patients on whom additional information was obtained)	Schizophrenia and bipolar disorder (in subset of patients on whom additional information was obtained)	Not reported	State psychiatric hospital	While hospitalized	9.5%
Thompson *et al.* (1997)	145	60% male	Schizophrenia, bipolar disorder, and depression	58% Reported ever using illegal drugs	In-patient and out-patient psychiatric facilities in Melbourne, Australia	Lifetime	34.5%
Walkup *et al.* (2000)	300	64% male	Schizophrenia or schizo-affective disorder	52% Reported alcohol abuse; 54% reported drug abuse	In-patient	Past 6 months	17%
Weinhardt *et al.* (1998)	61	100% female	Schizophrenia, schizo-affective disorder, bipolar disorder, major depressive disorder, other psychotic disorders, and pervasive developmental disorder	31% Had been in drug or alcohol treatment	Out-patient clinics and day treatment programs	Lifetime	56%

HIV, Human immunodeficiency virus; VA, Veterans Affairs.

behaviors (e.g. Otto-Salaj *et al.* 1998); and (*e*) lack of safer sex skills (e.g. Kalichman *et al.* 2005; Meade & Sikkema, 2005*a*). In addition, (*f*) the consequences of mental illness (e.g. poverty, homelessness) may lead to insufficient money to purchase condoms and no privacy for safer sex negotiation (Carey *et al.* 1997; McKinnon *et al.* 2002). SMI also leads to periods of hospitalization, which make it difficult to form long-term sexual relationships, and to acquire condoms while hospitalized (McKinnon *et al.* 2002), and SMI may lead to a lack of social support, which has been associated with sexual risk behavior among individuals with an SMI (e.g. Randolph *et al.* 2007). Finally, variables that are associated with both SMI and sexual risk behavior, such as (*g*) childhood sexual abuse (Meade & Sikkema, 2007) and (*h*) substance use (e.g. Weinhardt *et al.* 2002; Carey *et al.* 2004; Meade & Weiss, 2007), may lead to increased sexual risk behavior.

The prevalence of HIV is higher among individuals with an SMI than among individuals in the general population, with rates ranging from 4% to 23% (Cournos & McKinnon, 1997). These rates are much higher than the 0.43% HIV prevalence rate found in the general population (McQuillan *et al.* 2006). The high rates of HIV in individuals with SMI may be, in part, driven by individuals who are dually diagnosed with a substance-use disorder (Himelhoch *et al.* 2007; Parry *et al.* 2007). Among the dually diagnosed, HIV prevalence ranged from 6% to 23% (Meade & Weiss, 2007).

Method

To obtain articles for this review, searches were conducted with PsycINFO, PubMed and Medline (using the keywords 'mental* ill*' and 'HIV test*') and by perusing reference lists of published articles. To be included in the review, studies had to: (*a*) be published in a peer-reviewed journal; (*b*) include individuals with an SMI; and (*c*) report on HIV testing (i.e. prevalence, correlates, interventions). All articles published through 2007 that met inclusion criteria were included in the review (*n* = 18).

Results

HIV testing rates

Studies investigating HIV testing rates among individuals with an SMI indicate that the percentage of individuals who have been tested in the past year ranged from 17% to 47% (see Table 1); lifetime prevalence of testing ranged from 11% to 89%. Pirl *et al.* (2005) reported that 10% of patients in a state

psychiatric hospital were tested during a single hospitalization.

In one study that compared HIV testing rates among individuals with and without SMI, adults with major depression, bipolar disorder, or schizo-affective disorder were more likely than individuals without a disorder to have been ever tested for HIV (46% *v.* 31%), to have been tested for HIV in the past 12 months (18% *v.* 10%), and to expect to be tested for HIV in the next 12 months (14% *v.* 7%) (Blumberg & Dickey, 2003). However, in another study, women with schizophrenia or schizo-affective disorders were less likely than women without an SMI to ever be tested for HIV (11% *v.* 67%; Miller & Finnerty, 1996). Most adults with an SMI who report ever being tested for HIV were tested for HIV more than once, with 30% reporting two lifetime tests, 21% reporting three tests, and 35% reporting ⩾four HIV tests (Meade & Sikkema, 2005*b*).

HIV testing correlates

Several studies have investigated HIV testing correlates. Among various sociodemographic characteristics, only homelessness has been consistently associated with being tested for HIV (Desai & Rosenheck, 2004; Meade & Sikkema, 2005*b*). Characteristics such as age, education, and race/ethnicity have not been consistently associated with testing uptake, although these findings are based on only a few studies (Walkup *et al.* 2000; Desai & Rosenheck, 2004, Goldberg, 2004, Meade & Sikkema, 2005*b*, Desai *et al.* 2007).

The relation between testing and psychiatric symptoms also has been investigated. Meade & Sikkema (2005*b*) found that being tested for HIV was associated with having a non-psychotic disorder as the primary diagnosis and having borderline personality disorder. In an Australian sample, Thompson *et al.* (1997) found that individuals diagnosed with bipolar disorder were less likely to be tested than individuals diagnosed with schizophrenia. Some studies have found that more psychiatric distress or more severe symptoms and more psychiatric hospitalizations were associated with testing (e.g. Thompson *et al.* 1997; Desai & Rosenheck, 2004), but Desai *et al.* (2007) found that having fewer psychiatric symptoms was associated with testing, and Walkup *et al.* (2000) found that being voluntarily admitted to in-patient hospitalization, a proxy for less severe symptoms, was associated with being tested.

The number and types of services used are also associated with testing. Receiving services at an urban (*versus* suburban) mental health center (Goldberg *et al.* 2005), using a greater number of treatment services (Meade & Sikkema, 2005*b*) and recently using health services (Desai & Rosenheck, 2004) were associated with being tested.

More social support is associated with being tested for HIV (Meade & Sikkema, 2005*b*); being in an intimate relationship, which could be an indication of greater social support, also was associated with HIV testing (Walkup *et al.* 2000). In addition, having a stronger therapeutic alliance with the primary clinician (construed here as a type of social support) has also been associated with HIV testing among individuals with an SMI (Desai *et al.* 2007). Motivational variables related to testing include having more concerns about contracting HIV and knowing someone who has acquired immune deficiency syndrome (AIDS) or who died of AIDS (Knox *et al.* 1994; Desai & Rosenheck, 2004).

Individuals who engage in risk behaviors are more likely to be tested for HIV. Those with drug problems or a history of injection drug use (Thompson *et al.* 1997; Walkup *et al.* 2000; Desai *et al.* 2007) were more likely to be tested for HIV, although there appears to be no relation between alcohol problems and HIV testing (Walkup *et al.* 2000). More sexual risk behavior is also associated with HIV testing among SMI, with those who had unprotected sex, engaged in recent sexual risk behavior, exchanged sex, or ever been diagnosed with an STD more likely to be tested for HIV (Knox *et al.* 1994; Thompson *et al.* 1997; Weinhardt *et al.* 1998; Goldberg *et al.* 2005; Desai *et al.* 2007). Meade & Sikkema (2005*b*) found that individuals who had engaged in any sexual or drug-use risk behavior were more likely to have been tested (55% *v.* 24%).

Reasons for testing (and declining testing)

Research suggests several reasons why individuals get tested. In one study, adults with an SMI who were tested were more likely than adults without SMI to report they simply wanted to know their HIV status; in contrast, adults without SMI were more likely to get tested because of insurance, employment, military, immigration, pregnancy, or hospitalization (Blumberg & Dickey, 2003). An Australian study found that individuals with an SMI reported being tested for HIV because they requested it, because they were raped, or for a medical reason (e.g. pregnancy, illness, overdose, blood-borne infection; Thompson *et al.* 1997).

To our knowledge, there has not been investigation of the reasons that people with an SMI choose not to be tested. Among the general population, people decline testing for many reasons; for example, some have been tested previously whereas others believe they are not at risk for HIV (Carey *et al.* in press). Sometimes people fear the results (Simon *et al.* 1996; Centers for Disease Control and Prevention, 2003*a*); others may

be reluctant to be tested because of misgivings about provider sensitivity or subsequent stigma (Mimiaga *et al.* 2007). Research is needed to determine if such reasons are barriers to people living with an SMI.

Returning for test results

Among the general population, test return rates are poor; in contrast, 89–96% of people with an SMI return for their results (Desai & Rosenheck, 2004; Desai *et al.* 2007); however, only 50% of adults with an SMI reported receiving post-test counseling (Desai *et al.* 2007). Returning for results was associated with more education, not having a disability, having been tested previously, not having an STD, having fewer drug problems, and having previously received HIV test results (Desai & Rosenheck, 2004).

Interventions to promote testing among individuals with an SMI

Few interventions have been designed to promote testing among individuals with an SMI. In the most well-described intervention to date, Rosenberg *et al.* (2004) developed the 'Screen, Test, Immunize, Reduce risk, and Refer' (STIRR) intervention. With this program, infectious disease specialists traveled to mental health centers and met with administration and staff to encourage support of the project. Next, a nurse provided HIV and hepatitis testing, pre- and post-test counseling, hepatitis immunization, and referrals for individuals who were HIV positive. At one mental health center, 136 out of 173 (79%) patients were tested for HIV. At a second mental health center, 65 out of 99 (66%) dually diagnosed patients were tested (Rosenberg *et al.* 2004). Although there was no comparison group, the percentage of patients in the program who were tested for HIV was higher than the 17% to 47% of patients who reported recently being tested for HIV in other studies (Walkup *et al.* 2000; Blumberg & Dickey, 2003; Desai & Rosenheck, 2004; Meade & Sikkema, 2005*b*). Meyer (2003) reported that 78% of patients in a state psychiatric hospital were tested for HIV after initiation of a voluntary hepatitis and HIV screening program, but the program was neither well described nor compared with a control condition.

Conclusions

Studies reported that 17% to 47% of individuals with an SMI were recently tested for HIV, and that 11% to 89% were ever tested for HIV. The variability in estimates reflects variability in many study features including sample size, dates of investigation, sampling (e.g. in-patients *v.* out-patients), and policies at the centers from which participants were recruited. Despite these methodological variations, the range of findings indicates that routine HIV testing is not yet a standard practice in most mental health settings.

Studies investigating correlates of testing among individuals with an SMI have reported mixed findings. There was no clear association between HIV testing and either demographic or psychiatric variables; however, many of these findings were based on only one or two studies. The lack of an association between psychiatric symptoms and HIV testing was unanticipated; we expected that individuals with greater distress would be less able to provide informed consent, and would be less likely to be tested for HIV. In a vignette study, clinicians were reluctant to test for HIV if a patient was impaired, even if the patient had a history of risk behavior (Walkup *et al.* 2002). The association between testing and psychiatric symptoms or level of functioning merits investigation; it may be important to tailor HIV testing interventions to different levels of functioning.

Engaging in more HIV risk behavior was associated with HIV testing. Thus, among individuals with an SMI, those who are most in need of an HIV test are being tested. Individuals who engage in HIV risk behaviors may be more concerned about their HIV risk, and therefore seek testing. Clinicians most likely refer patients who report HIV risk behaviors for HIV testing. Although only one study investigated the clinician/patient relationship and HIV testing, a stronger therapeutic alliance was associated with a greater likelihood of testing (Desai *et al.* 2007), which suggests that therapists could be a valuable resource to encourage their patients to get tested for HIV.

We located only one well-described intervention to encourage HIV testing among individuals with an SMI (the STIRR program; Rosenberg *et al.* 2004). Testing rates for individuals at mental health centers that participated in the intervention were higher than testing rates in other studies; however, because the study employed a post-test only design, firm conclusions cannot be drawn about the efficacy of the intervention.

There are several limitations to this review. First, most of the findings presented in this article were based on only a few studies. More research is needed before firm conclusions about HIV testing rates and correlates can be drawn. Second, because there are few studies, we could not explore the impact of characteristics of study samples or methodology on findings. Finally, the majority of studies reported in this article were conducted in the US; findings may differ in other countries, where HIV rates, SMI or HIV stigma, and access to HIV testing may differ.

Research needs

HIV testing among individuals with an SMI deserves further study. First, studies investigating the prevalence of HIV testing among individuals with an SMI should determine the overall prevalence of HIV testing as well as the prevalence among individuals engaging in risk behavior (e.g. Meade & Sikkema, 2005*b*). Second, it is important to know the timing of HIV diagnosis among individuals with an SMI (Cournos & McKinnon, 1997). Research has found that a large percentage of individuals are diagnosed late in the course of HIV infection (Centers for Disease Control and Prevention, 2003*b*). Early diagnosis of HIV allows for earlier entry into care, and facilitates risk reduction. It is important to know if individuals with an SMI are diagnosed later than other individuals. Third, research might explore individual (e.g. low risk awareness) and structural (e.g. logistic, policy) barriers to testing, in order to inform intervention development.

Fourth, studies to encourage HIV testing among individuals with an SMI who engage in HIV behavior are needed. To date, no randomized controlled trials (RCTs) to increase HIV testing rates among individuals with an SMI have been conducted. Interventions focusing on service barriers could evaluate the STIRR intervention in an RCT. Alternatively, if attitudinal barriers were targeted, HIV testing interventions that have been efficacious with individuals without an SMI could be adapted and implemented with individuals with an SMI (e.g. Carey *et al*. in press).

Finally, the impact of HIV diagnosis on an individual with an SMI merits study. One reason for trying to increase HIV testing uptake is that individuals infected with HIV reduce their sexual risk behavior (Weinhardt *et al*. 1999; Marks *et al*. 2005). Given the cognitive and social impairments characteristic of SMI (e.g. social skill deficits), research might determine whether HIV diagnosis in individuals with an SMI results in changes in sexual risk behavior. If not, further intervention may be needed to provide individuals with an SMI who are HIV positive with the information, motivation, skills, and other support they need to adopt safer sexual practices.

Clinical implications

To promote the overall health of adults with an SMI, it is important that individuals with an SMI who engage in HIV risk behaviors are tested for HIV. Psychiatric settings may be an opportune venue for HIV testing, for several reasons. First, this is where patients can be found, reducing the need for additional transportation or appointments. Second, mental health clinicians can provide pre- and post-test counseling that is tailored for individuals with an SMI, which other HIV testing sites may be less able to provide (Satriano *et al*. 2007). Third, therapists can encourage HIV testing, address patients' barriers to testing, and allay concerns about testing, confidentiality, and stigma.

Unfortunately, many mental health settings do not encourage HIV testing. In a survey of psychiatric units in hospitals, 53% reported that they encouraged only a few patients to get tested, and 17% reported encouraging almost no patients to get tested (Walkup *et al*. 1998). Among out-patient mental health centers in New York state, only 22% provided pre- and post-test counseling, only 16% offered testing on-site, and 13% did not have a procedure to refer patients to other sites for testing (Satriano *et al*. 2007).

Although providers usually agree that HIV-related services are important (Satriano *et al*. 2007), there are many barriers to providing HIV services, including lack of training, discomfort with the topic, and competing priorities (Solomon *et al*. 2007). Clinicians may be uncomfortable delivering risk-reduction counseling, or obtaining consent for or administering HIV tests. Patients may be uncomfortable talking about HIV as well. Additionally, because of resource constraints, HIV testing and counseling in mental health settings might take time away from the provision of mental health services.

To reduce barriers to HIV testing in mental health settings, therapists should be provided with training around HIV testing and prevention. Fortunately, the Centers for Disease Control support technical assistance and training programs. In addition, recent advances have led to the development of rapid HIV testing, which is easy to administer, does not require a venipuncture, can be administered by non-medical personnel, and provides results within 20 min, eliminating the need to return for test results.

There are several ethical and legal challenges associated with HIV testing of individuals with an SMI. First, there may be limited benefits if individuals learn they are HIV positive, because some doctors delay the prescription of antiretroviral medication for individuals with an SMI (Fairfield *et al*. 1999; Bogart *et al*. 2000). This delay in prescribing medication may be due to concerns about interactions among medications, or concerns about HIV-medication adherence (Fairfield *et al*. 1999).

Second, even if HIV-infected individuals are prescribed medication, they may not benefit, because individuals with a mental illness often have difficulty adhering to antiretroviral medication (e.g. Tucker *et al*. 2003). Interventions to increase adherence to antiretroviral medications are needed (Simoni *et al*. 2003; Uldall *et al*. 2004).

Third, some individuals, because of their mental illness, may not be able to provide informed consent for HIV testing. The laws requiring informed consent for HIV testing for individuals with mental disabilities differ from state to state, and often the need for testing without consent is decided on an individual basis (Haimowitz, 1996).

Fourth, the ethical and legal issues associated with testing are complex. Clinicians must balance confidentiality with the duty to warn (particularly if patients are infected and sexually active in an in-patient setting; see Odunsi, 2007). Such issues require knowledge of state law, and use of clinical judgment (Haimowitz, 1996).

In conclusion, individuals with an SMI are at elevated risk for HIV but many have never been tested. Research on testing should include individuals with an SMI, and interventions to promote testing should be evaluated in RCTs. Mental health settings may be opportune venues to test individuals with an SMI for HIV even though clinicians in these settings will face a number of barriers and ethical challenges. These challenges indicate the need for research, continuing professional education, and the commitment of additional resources to this neglected component of comprehensive health care.

Acknowledgements

Declaration of Interest

None.

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