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Primary and secondary HIV prevention among persons with severe mental illness: recent findings

Andréa L. Hobkirk, PhD¹, Sheri L. Towe, PhD², Ryan Lion³, and Christina S. Meade^{4,*}

Andréa L. Hobkirk: Andrea.Hobkirk@duke.edu; Sheri L. Towe: Sheri.Towe@duke.edu; Ryan Lion: Ryan.Lion@duke.edu

¹Duke University School of Medicine, Department of Psychiatry & Behavioral Sciences, Box 90519, Durham, NC, 27708, Phone: 919-613-5061, Fax: 919-681-7748

²Duke University School of Medicine, Department of Psychiatry & Behavioral Sciences, Box 90519, Durham, NC, 27708, Phone: 919-668-4030, Fax: 919-681-7748

³Duke University, Duke Global Health Institute, 310 Trent Drive, Trent Hall, Durham, NC, 27708, Phone: 919-613-5061, Fax: 919-681-7748

⁴Duke University School of Medicine, Department of Psychiatry & Behavioral Sciences, Box 90519, Durham, NC, 27708, Phone: 919-613-6549, Fax: 919-681-7748

Abstract

Persons with severe mental illness (SMI) have been disproportionately affected by the HIV epidemic, with higher rates of HIV prevalence and morbidity than the general population. Recent research has advanced our understanding of the complex factors that influence primary and secondary HIV prevention for those with SMI. Sex risk in this population is associated with socioeconomic factors (e.g., low income, history of verbal violence) and other health risk behaviors (e.g., substance use, no prior HIV testing). Several interventions are effective at reducing risk behavior, and reviews highlight the need for more well-controlled studies that assess long-term outcomes. Recent research has elucidated barriers that interfere with HIV treatment for SMI populations, including individual (e.g., apathy, substance use), social (e.g., stigma), and system factors (e.g., transportation, clinic wait times). Interventions that coordinate HIV care for individuals with SMI show promise as cost-effective methods for improving medication adherence and quality of life.

Keywords

HIV; AIDS; Serious Mental Illness; Sex Risk; Prevention

Introduction

Severe mental illness (SMI) describes the presence of a chronic psychiatric disorder that results in substantial functional impairment and typically includes the diagnoses of psychotic

*Corresponding Author: Duke University School of Medicine, Department of Psychiatry & Behavioral Sciences, Box 90519, Durham, NC, 27708, Phone: 919-613-6549, Fax: 919-681-7748, Christina.Meade@duke.edu.

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disorders, bipolar disorder, and recurrent major depressive disorder. Persons with SMI have been disproportionately affected by the HIV/AIDS epidemic. The prevalence rate of HIV among adults with SMI ranges from 2% to 6% in rural and large metropolitan sites in the U.S., respectively [1, 2], which is significantly higher than the estimated HIV prevalence of 0.5% in the general U.S. population [3]. Recent evidence suggests that the risk of HIV infection may increase as the severity of psychiatric illness increases. In a U.S. multisite study, the prevalence of HIV among persons with SMI was 5.9% in psychiatric inpatient units, 5.1% in intensive outpatient case management programs, and 3.9% in community mental health centers [2]. International studies have found even higher rates of HIV among persons with SMI, ranging from 11% to 27% in African countries where the national HIV prevalence tends to be higher than the U.S. [4].

Although there is some research to suggest that HIV risk behavior is the direct result of psychiatric symptoms (e.g., hypersexuality during manic episodes) [5, 6], growing evidence suggests that HIV transmission risk in SMI populations is much more complex and often occurs as an indirect consequence of multiple individual, social, and system factors [7–11]. Factors such as a history of homelessness, experience of sexual violence, early sexual debut, drug or alcohol use during sex, and lifetime illicit drug use, which are disproportionately common among persons with SMI, increase risk of HIV infection. This review discusses recent findings from empirical studies and review articles on primary and secondary prevention of HIV in SMI populations, emphasizing new data from 2012 to 2015.

Primary HIV Prevention

Sex risk among persons with SMI

In the general U.S. population, 80–95% of adults report a lifetime history of sexual activity, and self-reported sex risk behavior varies greatly depending on the sample surveyed: 13% to 60% report multiple sex partners in the past year, 42 to 62% report using a condom with a non-regular partner, and 36–70% report prior HIV testing [12–17]. Although research shows that a lower proportion of individuals with SMI are sexually active compared to the general population, those with SMI who are sexually active tend to engage in higher rates of sex risk behavior [8, 18]. Sex risk behavior among individuals with SMI has been related to a number of factors including psychiatric severity, high rates of substance-related sexual activity, and sex trade influenced by financial instability. Several recent studies have explored the rates of sexual activity and risk among persons with SMI globally.

In a survey of 102 patients from a Nigerian psychiatric hospital, the majority of those who reported a lifetime history of sexual activity also reported engagement in HIV risk behaviors, which included inconsistent condom use, having multiple partners, and sex trading [7]. Additionally, these researchers found that alcohol use was associated with HIV risk behavior, while demographic factors were not. In a national Brazilian sample of nearly 2,500 participants from inpatient psychiatric hospitals and community mental health clinics, half of whom had an SMI diagnosis, 60% of participants were sexually active in the past 6 months [11]. As with the Nigerian sample, high rates of HIV risk behaviors were reported among those who were sexually active, including 30% sex trading, 82% inconsistent condom use, and 26% multiple partners in the past 6 months. Additionally, only 33%

reported prior testing for HIV and 31% stated that they did not perceive themselves as being at risk for HIV infection. These studies provide further support that HIV risk behavior prevalence is high among sexually active persons with SMI; however, the study designs were cross-sectional and did not assess other potentially relevant psychosocial and contextual factors.

Recent research has contributed to the extensive literature assessing the correlates of sex risk behavior for men and women with SMI. Understanding the factors that drive risk behavior among persons with SMI may elucidate potential points of intervention. Emerging results emphasize the important role of social determinants, as well as how individual characteristics and behaviors that frequently co-occur with SMI may contribute to HIV risk. In the Brazilian cohort described above, multivariate analyses assessed factors associated with recent unprotected sex [11]. For men, unprotected sex in last 6 months was associated with being married, low income, living with children or a partner, depression or anxiety, and lifetime cigarette smoking. For women, unprotected sex in the last 6 months was associated with being less than 40 years old, being married, living with children or a partner, no previous HIV testing, self-reported sex under the influence of alcohol or drugs, lifetime verbal violence, and lifetime cigarette smoking. The Indiana Mental Health Services and HIV-Risk Study found that better global functioning reported in patient medical records was associated with a higher number of sex partners in the past 3 months, along with more permissive attitudes about sex and higher reported importance of sexual relationships [8]. After controlling for marital status, having a greater sense of control over the future and more permissive attitudes toward sex were related to more sex partners. Together these findings suggest that sex risk behavior is influenced by a complex set of factors, most of which are common targets of intervention (e.g., substance use, sexual violence). Typically, being married and living with children is indicative of being in a current, ongoing relationship, and thus unprotected sex in this context is not traditionally thought of as an HIV risk behavior; however, more accurate risk estimates may be gained from better understanding the rates and characteristics of extramarital sex for those in committed relationships and the sex risk behavior of their partners.

Sex risk reduction interventions

A variety of social, cognitive, and behavioral sex risk reduction interventions for persons with SMI have been developed over the past two decades, with considerable heterogeneity in the methodology and outcomes used. While most include components common to generalized sex risk reduction interventions [19–21], others have been tailored more specifically to meet the psychological and interpersonal needs of SMI populations. Interventions have implemented strategies such as repeating content to accommodate poor attendance or cognitive impairment, modeling effective behaviors to facilitate learning, and utilizing group practice exercises and role-plays to increase interpersonal effectiveness [22–30]. Specifically, to target deficits in interpersonal effectiveness, interventions have included assertiveness and negotiation skills training, as well as skills for managing partner reactions and removing oneself from dangerous situations [22]. Some interventions focus on identifying behavioral and psychological triggers for risk behavior and then developing

personal problem-solving strategies to maintain safety in the future [22, 24, 25, 27, 28, 31, 32].

Two reviews evaluated the effectiveness of these interventions for improving sex risk behavior, knowledge, and attitudes [19, 20]. The number of intervention sessions was quite variable, ranging from 3 to 15. While the majority of studies demonstrated effectiveness in decreasing sex risk behavior through condom use and fewer sex partners, no study saw effects lasting longer than 6 months post-intervention. Studies including other components, such as motivational enhancement and peer advocacy, showed mixed effectiveness.

In addition to highlighting the efficacy of these interventions, Pandor and colleagues also describe the methodological limitations, including selection bias, no randomization to interventions, lack of data on confounds between study groups, not blinding assessors to condition, no assessment of treatment fidelity, and small sample sizes [20]. Both review papers identified several potential moderators of treatment success, such as gender and psychiatric diagnosis. However, many studies did not analyze data by these factors, and those that did were underpowered to detect effects. These reviews suggest that behavioral interventions are effective at reducing HIV risk behavior for persons with SMI, at least on a short-term scale, and they highlight the need for continued evaluation of these interventions with more rigorous methodology and an emphasis on developing interventions that can produce longer-lasting effects.

HIV testing

Another integral component of HIV prevention is the early detection of HIV infection through regular testing, especially for high-risk individuals. In the U.S., HIV testing rates among individuals with SMI have been higher than the general population since the 1990s, and a recent study using data from over 21,000 respondents in the 2007 National Health Interview Survey shows that this trend continues [33, 34]. The self-reported rates of ever being tested for HIV were higher among those with schizophrenia (64.3%) and bipolar disorder (63.4%) than those with depression or anxiety (46.5%) or no mental illness (34.7%); however, the authors point out that these numbers do not represent an increase in testing over the last decade, suggesting that there is still a need to improve testing rates among persons with SMI [34]. Increasing the accessibility of HIV testing and willingness to receive HIV testing has the potential to improve primary and secondary HIV prevention for individuals with SMI. A large randomized clinical trial (Project Accept) confirmed the efficacy of an HIV testing intervention in 10 rural communities in Tanzania, Zimbabwe, and Thailand [35]. The intervention included community mobilization activities, mobile HIV counseling and testing, and post-test support services in the community, including mental health services. Although this intervention was not tailored specifically to SMI populations, it can serve as a model for increasing HIV testing uptake and repeat testing, as well as linking individuals living with mental health disorders to care after receiving an HIV diagnosis. In addition, community-based interventions have the potential to reduce stigma around HIV status, which facilitates HIV testing, linkage to care, and treatment adherence [36].

Secondary HIV Prevention

HIV healthcare utilization

Individuals living with SMI in the U.S. have mortality rates two to three times higher than the general population, mostly due to undertreated physical illness [37]. Reasons for this disparity are multifaceted and include individual factors (e.g., health behaviors, medication induced weight gain, functional limitations) and social determinants (e.g., poverty, neighborhood, social supports) that contribute to poor health and reduced access to quality care, including HIV care. A recent review of the overall healthcare quality for individuals living with SMI in the U.S. revealed that antiretroviral therapy (ART) was less often prescribed for persons with SMI compared to the general population; however there was not a disparity for CD4 count and viral load monitoring [38]. Disparities in general and HIV-specific medical treatment for individuals living with SMI are global problems. A Canadian study found that homeless individuals with SMI had lower utilization of primary care and specialist care in the past month compared to their non-SMI counterparts [39]. High usage of specialized care was associated with a recent history of psychiatric hospitalizations and current major depression; however, having a blood-borne infectious disease, like HIV or hepatitis C, was associated with lower odds of high specialist care utilization. A South African study found that distance and cost of transportation were the greatest barriers to retaining individuals with co-occurring HIV and SMI in ART (43%), followed by work or school conflicts (15%) and confusion about follow-up (13%) [40].

Qualitative research has revealed that issues related to mental illness are common barriers to consistent HIV care. A U.S. study of HIV-infected individuals from treatment clinics explored facilitators of and barriers to ART adherence and retention in treatment [41]. Retention in care and adherence were impacted by a complex array of both individual (stigma, social support) and environmental factors (unprofessional medical staff, late prescription refills, and limited clinic hours and appointment availability). In particular, patients reported that periods of active mental illness were often accompanied by apathy about their health care, resulting in missed appointments and poor ART adherence. In a second U.S. study, mental health was described as a barrier to engaging in HIV care among individuals who were identified as particularly vulnerable to suboptimal engagement, including African immigrants, recently released prisoners, young men who have sex with men, and transgender women [42]. In a third study of program directors at HIV testing sites in New York, perceived barriers to HIV care were related to the healthcare system (e.g., inaccessibility, long wait times, and disrespectful or rude clinic staff), social dynamics (stigma), and individual risk factors (mental illness, homelessness, substance use) [43]. Participants described their personal experiences with overcoming these barriers, such as using a team approach with patient navigators and care coordinators, building trusting relationships, employing patient advocates, improving confidentiality, reducing stigma, decreasing wait times, and providing immediate mental health service.

Adherence to HIV care

Disproportionately more individuals with SMI are not prescribed or are non-adherent to ART, which can result in compromised immune function, HIV-related morbidity and

mortality, increased rates of HIV transmission, and a higher likelihood of drug resistant mutation of the virus [44]. In a review, McGinty and colleagues found that the rate of ART receipt for persons with SMI in the U.S. (ranging from 51%–83% across studies) was below the recommended guidelines (85%) [38]. A similar trend has been noted in low and middle-income countries, where ART has traditionally been denied to persons with SMI. Two studies of SMI and adherence highlight the efforts in African countries to integrate HIV and mental health care [45, 46]. In a medical record review of 100 HIV-positive patients admitted to psychiatric units in South Africa, 63% of patients did not attend a 6-month follow up visit at a referral HIV clinic [45]. There was no difference in SMI diagnoses (mood or psychotic disorder) for those who did and did not attend the follow-up care visit; however those who did not attend the follow-up visit were more likely to be readmitted to a psychiatric facility over the 6 month follow-up period. A second study of 773 patients who enrolled in ART in Uganda found that SMI was predictive of discontinuing HIV care within the first 6 months [46]. However, if they remained in treatment past 6 months, patients with SMI were no more likely to drop-out thereafter. In a re-analysis of this data, however, the effect of SMI on treatment retention was largely driven by being on efavirenz [47]. Efavirenz-based ART regimens have been found to cause psychiatric symptoms, such as psychosis, depression, and anxiety [48]. In the Uganda sample, efavirenz treatment resulted in a 6-fold higher risk of disruption in HIV care for patients with SMI [47]. Such findings highlight the complicated interaction of SMI and HIV, and how these factors may impact treatment engagement and outcomes.

Integrated HIV and SMI treatment

Given the complex relationship between SMI and HIV, interventions must be tailored for individuals with co-occurring HIV and SMI for effective secondary HIV prevention. The Preventing AIDS through Health for HIV Positive persons (PATH+) intervention was a randomized controlled trial designed to improve HIV care among 238 individuals with SMI [49]. Participants in the intervention group were assigned to advanced practice nurses who coordinated medical and mental health care and provided in-home services at least once a week for 1 year. A unique aspect of the intervention was the cascade model, which calibrated the intensity of care based on outcomes criteria, such as HIV and psychiatric medication adherence. Control participants received treatment as usual, and completed research assessments and blood draws, but no other study activities. In addition to improving retention and adherence to ART medication [50], the intervention also significantly reduced viral load and improved mental quality of life compared to the control group [49]. Wu and colleagues conducted a cost analysis of this intervention using CD4 cell count improvements as a measure of benefit [51]. Among the intervention group, participants whose baseline CD4 count was < 50 cells/mL saw the most benefit, with an average increase of 264 cells/mL over the 12 month intervention period. The increase resulted in an estimated savings of \$267,802. In the treatment-as-usual condition, participants with CD4 cell counts between 50 and 199, saved the most, \$77,291 per year. It is important to note that a full cost-analysis of this intervention could not be conducted since the intervention staff was also responsible for research-related duties. These findings suggest that coordinating mental health and HIV care has the potential to improve HIV medication adherence and has an overall financial benefit.

Conclusions

While disparities in HIV risk and HIV treatment continue to affect individuals living with SMI, recent attention to these issues has resulted in advances for both primary and secondary HIV prevention. Researchers are asking important questions about financial, social, and medical resources and incorporating these factors into their conceptualizations. The age of “big data” has provided the opportunity to assess for overarching trends across a variety of individuals using datasets with thousands of participants (e.g., Yehia, 2015; Peixoto, 2014). In addition, qualitative research has provided insight into individuals’ dynamic, personal experiences, (e.g., Holtzman, 2015; Ramien, 2015; Bauman, 2014), which can fill gaps in our of understanding in a way that cannot be obtained with quantitative data alone. This research points to several future directions.

The rates of sex risk behavior among individuals with SMI continue to be high. Research has shown that psychiatric symptoms are often not the direct cause of sex risk behavior; instead, indirect socioeconomic factors like financial instability and partner violence [11] and individual characteristics such as substance use and attitudes toward sex [8, 10] may drive sex risk behavior. There are a number of effective interventions to reduce sex risk among this population in the short term, but research assessing sustained effects is needed [19, 20]. Future studies could better assess the effectiveness of these interventions by implementing more rigorous randomized clinical trials. Pandor and colleagues (2015) outline specific recommendations for future studies, including randomizing participants to intervention arms, controlling for group confounds at baseline, and ensuring intervention integrity. Although difficult to implement, blinding assessors to group assignment and participants to the research question can help to reduce biases in the outcome.

Additional intervention components that bring skills training to real-world situations through the use of mobile devices may help to improve the generalizability and sustainability of sex risk interventions. For example, GPS mobile applications that send reminders about negotiation skills in high-risk locations could provide a unique opportunity for improving outcomes. Incorporating maintenance planning and offering “booster” sessions, where participants can review their skills or troubleshoot unexpected barriers into the interventions could also promote sustained benefits. The content of interventions could also be improved by adding components to facilitate access to resources such as housing, since poor socioeconomic conditions are known to contribute to morbidity and mortality for those with SMI [52]. Understanding the sociocultural context is particularly important when implementing interventions within regions where HIV-burden is high and resources are low, such as many countries in Africa.

Recent evaluations have suggested that persons with SMI are equally likely, or more likely, to receive preventative care for HIV [52]. The rates of HIV testing have been consistently higher among individuals with SMI than among the general population, but a large proportion are still unaware of their HIV status. Knowing one’s HIV status is an important step in reducing HIV transmission among this vulnerable population, since learning of a positive HIV status is associated with reductions in sex risk behavior and linkage to care is associated with reduced viral load and lower rates of HIV transmission risk [53].

Community based interventions, such as Project Accept, could be tailored for SMI populations to increase testing rates and encourage repeat testing [35]. Outreach at mental health and substance abuse clinics, as well as homeless shelters could increase access to SMI populations.

Reducing disparities in access to HIV care for individuals with SMI should continue to be a priority for researchers, healthcare providers, and policy makers. Currently, there are no clear guidelines for clinicians when treating comorbid HIV and SMI, and there is a need for protocols rooted in evidence-based research [54]. In general, HIV-positive individuals with SMI are prescribed ART less often than their non-SMI counterparts [38]. The reasons for this are likely complex. Providers may be hesitant to prescribe ART medication to patients with SMI due to concerns that they will be poorly adherent, increasing the likelihood of developing ART resistance. These issues point to the need for further research examining the neurobehavioral effects of comorbid HIV and SMI, and how ART and psychotropic medications contribute to treatment outcomes. Ideally, this research will translate into improved monitoring and treatment outcomes, and will inform integrated care for those with HIV and SMI.

Improving attendance to HIV care appointments and ART adherence for those with SMI should also remain a priority area. The PATH+ intervention found that patient navigators, like advanced practice nurses, are a cost-effective method of improving outcomes for individuals with comorbid HIV and SMI [49, 51]. International research has shown a similar need for integrated care, given the high burden of co-occurring HIV and SMI in some resource-limited settings. Because stigma is especially relevant to both HIV and SMI care, decreasing stigma around these conditions may increase willingness to present for treatment, ease the burden of taking medication in public, and improve communication about the transmission of HIV and access to treatment for both HIV and SMI. One recent study found that exposure to vignettes portraying SMI and addiction as treatable conditions resulted in less desire for social distance from persons with SMI or addiction and less willingness to discriminate against individuals with these conditions [55]. Using innovative methods to change the public's attitude toward SMI and HIV could help to close the gap in treatment.

In conclusion, recent research shows advances in prevention and treatment for individuals with HIV and SMI, and highlights where gaps in access to care continue to exist. Broadening our focus to the complex and unique cultural, social, and individual factors that influence HIV transmission and treatment for individuals with SMI has led to effective interventions for reducing HIV risk behavior and improving HIV care. Continued research using more rigorous methodology to test these methods is warranted. In addition, translational research aimed at understanding the complex neurobehavioral outcomes of individuals with HIV and SMI has the potential to inform better integrated treatments for these common comorbidities.

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