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Stigma, substance use and sexual risk behaviors among HIV-infected men who have sex with men: A qualitative study

E. Jennifer Edelman ^{a,b,*}, Christopher A. Cole ^{b,c}, Wanda Richardson ^d, Nicholas Boshnack ^c, Heidi Jenkins ^d, Marjorie S. Rosenthal ^{e,f}

^a Department of Internal Medicine, Yale University School of Medicine, New Haven, CT, United States

^b Center for Interdisciplinary Research on AIDS, Yale University School of Public Health, New Haven, CT, United States

^c AIDS Project New Haven, New Haven, CT, United States

^d STD Control Program, Connecticut State Department of Public Health, Hartford, CT, United States

^e Department of Pediatrics, Yale University School of Medicine, New Haven, CT, United States

^f Robert Wood Johnson Foundation Clinical Scholars Program, Yale University School of Medicine, New Haven, CT, United States

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ABSTRACT

Background. Public health HIV-service providers, including Medical Case Managers (case managers) and Disease Intervention Specialists (DIS) have a key role to play in identifying and addressing clients' complex mental health needs and substance use which contribute to sexual risk behaviors, yet their understanding and its consensus with HIV-infected men who have sex with men (MSM) have not been well characterized.

Methods. Together with an AIDS Service Organization and the Connecticut State Department of Public Health in 2011–2012, we conducted a focus group of case managers (n = 14) and interviewed DIS (n = 7) and HIV-infected MSM (n = 17) in Connecticut. We used the constant comparison method, grounded theory, and a community-based participatory approach to guide analysis.

Results. We identified three themes characterizing public health HIV-service providers' and MSM's perspectives regarding factors contributing to substance use and sexual risk behaviors in the context of HIV infection: 1) While both MSM and providers described a co-occurrence of HIV, stigma, substance use, and sexual risk behaviors, only MSM identified a causal relationship between these factors; 2) MSM and providers both described varying levels of self-efficacy in readiness to decrease substance use and sexual risk behaviors among MSM; both identified the social network as the key barrier to overcome; 3) Providers described how the co-occurrence of HIV, stigma and sexual risk behaviors leads to multi-faceted client needs for which they lacked sufficient training and collaboration.

Conclusions. Provider education, skills-based training, and interventions targeting social networks may decrease sexual risk behaviors among HIV-infected MSM.

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1. Introduction

Globally, men who have sex with men (MSM) are disproportionately impacted by HIV (Baral et al., 2007; Baral et al., 2014; Beyrer et al., 2012; Centers for Disease Control and Prevention, 2008a, 2010, 2012) explained, in part, by sexual risk behaviors (Crepaz et al., 2009; Durham et al., 2013; Mattson et al., 2014) in the context of substance use by HIV-infected MSM (Beyrer et al., 2012; Colfax et al., 2004; Mayer et al., 2010; Morin et al., 2005; Weinhardt et al., 2004). While effective behavioral interventions to address sexual risk behaviors among HIV-infected MSM exist (Collins et al., 2010; Crepaz et al., 2014; Johnson et al., 2008), efforts to optimize their implementation are needed. Conceptual models, such as that described by Baral and colleagues (Baral et al., 2013), highlight the importance of considering multi-level factors which contribute to the HIV epidemic and may be addressed in HIV prevention efforts (Fig. 1).

As they represent both community and individual-levels, understanding perspectives and experiences of HIV service providers and HIV-infected MSM regarding the role of stigma and substance use in sexual risk behaviors represent an important next step. Prior studies have identified suboptimal HIV provider practices and comfort with addressing substance use and sexual risk behaviors (Flickinger et al., 2013; Laws et al., 2011; Metsch et al., 2008; Ray et al., 2013). Few studies examines providers' perceptions of stigma and substance use's role in promoting sexual risk behaviors among HIV-infected MSM, particularly among providers well positioned to intervene: Medical Case Managers

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^{*} Corresponding author at: Yale School of Medicine, General Internal Medicine, PO Box 208025, New Haven, CT 06520-8088, United States.

E-mail address: ejennifer.edelman@yale.edu (E.J. Edelman).



Fig. 1. Model for Factors Impacting Health and HIV Transmission among HIV-Infected MSM*. *adapted from Baral S, Logie CH, Grosso A, Wirtz AL, Beyrer C. Modified social ecological model: a tool to guide the assessment of the risks and risk contexts of HIV epidemics. BMC Public Health. 2013;13:482.

(case managers) and Disease Intervention Specialists (DIS), public health authorities who provide partner services (Centers for Disease Control and Prevention, 2008b; Rapp et al., 2014). Despite the complexity surrounding HIV, stigma, and substance use, no studies have incorporated community-based participatory research (CBPR) principles (Cashman et al., 2008; Israel et al., 1998; Minkler, 2005) to address these questions. Through CBPR, members of the community impacted by the issues of concern may be involved in all stages of the research process, including development and framing of the research questions, data collection and analysis, and dissemination. Thus, CBPR promotes development of unique and relevant research questions to the community of interest and optimizes the validity of research findings, particularly those focused on sensitive topics (Cashman et al., 2008; Horowitz et al., 2009).

Therefore, our aims were to characterize the perspectives and experiences regarding the role of stigma and substance use in sexual risk behaviors among HIV-infected MSM, case managers, and DIS, and compare and contrast findings across these groups. We also aimed to identify multi-level opportunities to address substance use and sexual risk behaviors among HIV-infected MSM to ultimately improve their health and enhance HIV prevention efforts.

2. Methods

2.1. Study overview

In 2011, we created *Project C.O.A.C.H.*: *Counseling Others about Contacts and Exposures with HIV*, a collaboration between academic researchers, an AIDS-service organization (ASO), and the Connecticut State Department of Public Health (CT DPH) (Cole et al., 2013; Edelman et al., 2013; Edelman et al., 2014). Our approach was grounded in CBPR principles, whereby members of the community affected by the topic under investigation are directly involved in all stages of the project with the goal of translating the findings into action (Agency for Healthcare Research and Quality, 2009; Cashman et al., 2008; Israel et al., 1998; Minkler, 2005). Our research team was diverse in terms of age, gender, race, occupation, sexual orientation and HIV status and included an equitable partnership, involving all partners throughout

the research process. We used two qualitative methods to address our research questions: we conducted a focus group with case managers and face-to-face interviews with DIS and HIV-infected MSM (Curry et al., 2009).

2.2. Study design and sampling

To examine perspectives regarding factors contributing to sexual risk behaviors among HIV-infected MSM from multiple perspectives (Curry et al., 2009), we conducted a focus group (Morgan, 1996) with Ryan White-funded medical case managers working in New Haven, CT, a medium-sized urban center who were recruited during a regularly occurring monthly meeting. Next, we completed in-depth in-person interviews (Britten, 1995) with all CT-based DIS, excluding one who was part of the research team. We recruited a purposeful sample (Curry et al., 2009) of MSM until we reached thematic saturation using flyers and face-to-face techniques to achieve a diverse sample, including individuals receiving services from an ASO; a lesbian, gay, bisexual and transgender-focused health center; and an addiction treatment center located in three different cities (Table 1) (Curry et al., 2009). Human Investigation Committees at Yale University School of Medicine and CT State DPH approved the protocol. After receiving an information sheet outlining the study's goals, anticipated risks and benefits and alternatives to participation, all participants provided verbal informed consent and the study was HIPPA compliant. Case managers and DIS were provided a meal and MSM were reimbursed with a \$25 gift card for participating.

2.3. Data collection

The focus group and interview guides were developed by those with academic expertise and with lived experience in HIV, partner notification, MSM, social services, qualitative research and CBPR. The case managers participated in a focus group, which was led by one research team member, the Executive Director (ED) of the partnering ASO (CC), with co-facilitation by a health care provider with training in HIV clinical care and health services research (EJE). We chose to use a focus group for data collection with the case managers given feasibility and with

Public health	HIV-service	nrovider	characteristics
i ublic ficaluli	1110-3010100	provider	characteristics

Characteristic	Medical case managers, $n = 14$	Disease intervention specialists, $n = 7$
Male gender, %(n)	28% (4)	43% (3)
Age, years, mean (SD) ^a	40 (12)	49 (9)
Race, %(n)		
White	71% (10)	43% (3)
Black	29% (4)	57% (4)
Ethnicity, %(n)		
Hispanic	21% (3)	14% (1)
Education, %(n)		
Bachelor's Degree and/or post-graduate Studies	79% (11)	71% (5)
Years employed in current role, mean (SD) Location of employment, % (n)	5 (5)	15 (6)
Hospital-based clinic	14% (2)	n/a
Community health center	14% (2)	n/a
Community-based organization	78% (11)	n/a
Average weekly case load , mean (SD)	31 (19)	11 (5)

Notes: SD = standard deviation

the expectation that the group dynamic would help generate unique insights about shared experiences (Curry et al., 2009). The DIS and MSM each participated in face-to-face, in-depth interviews; we chose to use in-depth interviews due privacy concerns and our goal of eliciting data on individual experiences (Curry et al., 2009). We sought to optimize data validity by matching characteristics of study participants and research team members based on, sexual orientation and HIV status. Thus, interviews of the DIS were conducted by the health care provider (EJE) and those of MSM by the ASO's ED (CC) (Adamson and Donovan, 2002; Cashman et al., 2008; Curry et al., 2009; Rhodes, 1994). Both of these individuals (EJE and CC) participated in an inperson training session on qualitative data collection prior to initiating data collection and received ongoing supervision and feedback during the data collection phase by the team's qualitative expert (MSR) (Rosenthal et al., 2009). The focus group and interviews were conducted between January 2011 and March 2012, using "grand tour" questions (i.e. open ended questions intended to stimulate discussion) followed by "probes" (i.e. prompts) (Box 1) (Edelman et al., 2014) after the interviewers introduced themselves and stated their professional roles (if not already known by the participant). These guides were piloted and refined prior to use with the study participants (Edelman et al., 2014). All participants completed a brief demographic survey. The focus

Box 1

	Example focus	aroup and	interview	auide	arand	tour of	questions
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Providers (medical case managers and disease intervention specialists) Clients (men who have sex with men)	 To get started, can you tell me generally about your experiences working as medical case manager? Can you tell me about your experiences when interviewing individuals from different risk groups? Here are some examples: heterosexuals; people who use drugs; men who have sex with men; HIV-positive clients; clients living in poverty; currently or recently incarcerated What kinds of trainings or support do you have to work with different populations? How do your personal beliefs or experiences impact your work? To get started, can you tell me how HIV has impacted your relationships, if at all? What kinds of experiences have you had or heard others having when talking to their partners about potentially being more date JUD
	 exposed to HIV? What makes it easy or hard to notify partners of a potential exposure to HIV?

group and interviews were audio-taped, professionally transcribed, reviewed for accuracy, and identifying information was removed prior to analysis (Curry et al., 2009). The focus group lasted approximately two hours, while each interview was approximately one hour in duration.

2.4. Analysis

Our three-person multidisciplinary analysis team adhered to CBPR principles by including research team members with expertise that was both academic and lived, including the two interviewers (CC and EJE) and a health services researcher with CBPR and qualitative methods expertise (MSR) (Rosenthal et al., 2009). These three individuals, who were most directly involved with the data collection and analysis, did not have regular interaction with the study participants. Some of the participating MCMs and clients, however, were employed or received services at the ASO where CC was the ED (Cole et al., 2013). We used the constant comparative method and grounded theory, in which our code structure and subsequent themes were generated iteratively based on participants' quotes (Curry et al., 2009). To organize data and facilitate retrieval, we used qualitative analysis software (AtlasTi version 6.2, Berlin, Germany) and selected quotations from codes relating to sexual risk behaviors, as well as stigma and substance use.

2.5. Development of recommendations

Consistent with CBPR (Horowitz et al., 2009), we aimed to translate our research findings into action. We thus developed our dissemination plan and recommendations iteratively and in collaboration with various stakeholders. A summary of recommendations relevant to this analysis are presented in the results.

3. Results

All participants who consented, completed the study. For this analysis, we only included those MSM who were HIV-infected. Our analytic sample included 14 case managers, 7 DIS and 17 HIV-infected MSM (Tables 2 and 3). Case managers were predominantly white (71%), non-Hispanic (79%) women (72%), with a mean age of 40 years. DIS were mostly black (57%), non-Hispanic (86%) women (57%) with a mean age of 49 years. Case managers had been in their current role for a mean of 5 years and had average weekly case load of 31 clients; DIS, in contrast, had been in their role for a mean of 15 years and had an average weekly case load of 11 clients. The MSM were predominantly black (76%), non-Hispanic (82%) had a mean age of 46 years and had been diagnosed with HIV a median of 15 years prior to the study.

Table 2

Client (HIV-infected MSM) Characteristics

Characteristic	MSM, n = 17
Male gender, % (n)	100 (17)
Age, years, mean (SD)	46 (7)
Race, % (n)	
White	24 (4)
Black	76 (13)
Ethnicity, % (n)	
Hispanic	18 (3)
Education, % (n)	
Some high school	24 (4)
High school graduate or GED	41 (7)
Some college, associate's or technical degree	18 (3)
College graduate	6(1)
Any post-graduate studies	12 (2)
Sexual Identity, % (n)	
Heterosexual	6(1)
Homosexual or gay	71 (12)
Bisexual	24 (4)
Years diagnosed with HIV, median (range)	15 (3-30)

Notes: age data was missing for 4 participants; race data was missing for 1 participant; SD = standard deviation

We identified three themes characterizing public health HIV-service providers' and MSM's perspectives regarding factors contributing to sexual risk behaviors in the context of HIV infection: 1) While both MSM and providers described a co-occurrence of HIV, stigma, substance use and sexual risk behaviors, only MSM identified a causal relationship between these factors; 2) both MSM and providers described varying levels of self-efficacy in readiness to decrease substance use and sexual risk behaviors among MSM; both identified the social network as the key barrier to overcome; 3) providers described how the cooccurrence of HIV, stigma and sexual risk behaviors leads to multifaceted client needs for which they lacked sufficient training and collaboration (Fig. 1).

3.1. Theme 1: While both MSM and providers described a co-occurrence of HIV, stigma, substance use and sexual risk behaviors, only MSM identified a causal relationship between these factors

Providers described co-existence of stigma, substance use and sexual risk behaviors, but did not identify the causal link between these factors. MSM, in contrast, described substance use as a coping strategy for managing their HIV diagnosis, self-perceived stigma, and depression; they described substance use as a way to facilitate social connectedness, through sexual risk behaviors and otherwise.

This provider reflected on the social connectedness garnered from substance use among HIV-infected individuals but did not link this to behaviors that might lead to HIV:

A lot of them [HIV-infected individuals with substance use] find, aside from the support system that they get from different agencies, they are alone. Once they make that decision [to stop their substance use], really aside from agencies that are willing to help them, they don't have those family members or friends... they figure, "If I make the change, hey, I'm alone."- Case Manager

On the other hand, this MSM explicitly linked his HIV diagnosis to suicidality, social isolation, and subsequent substance use:

I've always thought about [suicide]. Always thinking of a way to do it... I'm scared to do anything because I'd rather be here and try to deal with it. And my way of dealing with it is isolate myself, just stay to myself. And that's what I've meant to do after the shock of finding out I have HIV. I start[ed] isolating myself... I think that's when my alcohol problem and drug problem accelerated.-MSM Also making an argument for causation, this MSM described how his HIV diagnosis increased his need for external validation through substance use and sex:

I think that because I knew that I had AIDS, I was HIV +, I thought that maybe someone could look at me and tell, from the outside, so I had to make myself feel, like, desirable, in a flipped crazy way, and part of doing that was that I had to make sure that I was drunk before I even went out... Once I found out I was HIV, that made me, believe it or not, even more reckless... It made me even more sexually reckless and sexually irresponsible than I had ever been in my entire life.-MSM

3.2. Theme 2: MSM and providers both described varying levels of selfefficacy in readiness to decrease substance use and sexual risk behaviors among MSM; both identified the social network as the key barrier to overcome.

For example, this provider described how, for a client who was contemplating stopping using substances, the social environment and potential social isolation were barriers:

Or the issue of wanting to do it [stop using substances], but not having the supportive network from where they're from, because they might be the first ones to step out and try to do something different. And then they'll get the discouragement of, "Well why you trying to do that? Who you trying to become? You think you're better than us now?"... And then that fear of failure.-Case Manager

On the other hand, this MSM described his self-efficacy as he reported how maintenance of his recovery was dependent on avoiding his previous social network:

I only been infected with HIV for 5–4 years? 3, 4, 5 years? And I think about it sometime because I get depressed about it. . . and sometimes I want to get out there and just go start using drugs. . .but it's just being around certain people. . . So I'm trying to stay away from them.-MSM

This provider described a self-efficacy and commitment to getting his client out of his social environment and into treatment:

I had a client it took me days to get him into help [with his substance use]. We went got his medicine – it was like 6 months since he took his medicine. See, I'm not going to give up on them. If I got to take him 60 times.... I try to get them away from their neighborhood... just to move him away from that area because it's a trigger to them. Anybody who uses drugs, it's a trigger...-Case Manager

 Table 3

 Improving Case Managers and DIS Effectiveness to Address Stigma, Substance Use and Sexual Risk Behaviors

Identified Barrier	Recommendation
Variable understanding and skills at	Provider training on effective behavioral
addressing both sexual risk	interventions for sexual risk reduction
behaviors and substance use	and substance use
Complex social, mental health and	Multi-pronged and comprehensive
medical client needs	treatment approaches
Unhealthy social networks	Peer- and network-based interventions to promote new social networks and interventions designed to reduce stigma and change social norms surrounding substance use within existing social networks
Inconsistent communication across	Multi-disciplinary, cross-institutional
organizations	quarterly meetings
Variable provider adoption of stages of change model to behavior change	Provider training to apply stages of change theory to promoting change in substance use and sexual risk behaviors

3.3. Theme 3: Providers described how the co-occurrence of HIV, stigma and sexual risk behaviors leads to multi-faceted client needs for which they lacked sufficient training and collaboration.

Providers described how by considering the multiple factors that inform a client's readiness to change sexual risk behaviors, providers may be better positioned to effect change.

This provider described how, in order to facilitate change, it is important to assess a client's comprehensive needs:

We try to remember that they might come in for one thing, but what they need is something else. We might be making referrals to ... comprehensive risk counseling services, if they're high risk behavior, and they've got all kinds of issues, maybe they're suicidal, maybe not, but maybe they're so depressed, their self-esteem is really lousy...-DIS

This provider described how a lack of training in the multi-faceted problems of clients, specifically substance use and sexual risk behaviors, may lead providers to misunderstand MSM and their sexual risk behaviors; accordingly, this provider advocated for training in substance use:

I think with the frustration that we get from a bad interview [to discuss partners], if we can understand why they're doing different things, I think it would kind of relieve us a little bit as to maybe they're just not ready... we can be taught in a sense to understand that it's not personal, and that this person can't stop doing drugs, that's why he has unprotected sex, or, and stuff like that. We haven't really done [any trainings regarding drug use].-DIS

This provider described how a "dually diagnosed" client, one with substance use and mental health issues, can create an especially frustrating situation when there is lack of collaboration among case managers and clinicians:

I don't know if that colleague on the other side, when they're getting ready to discharge, are they going to call me? Even though you ask, "Please call me so we can work on a plan to get him into inpatient," it doesn't always work. So when they are dually diagnosed, those are the more complicated.-Case Manager

3.4. Actionable items for improving case managers and DIS effectiveness at addressing stigma, substance use and sexual risk behaviors

In response to the themes and ideas that emerged, we list specific recommendations for action (Table 3). These recommendations are likely to involve multi-step processes with ongoing evaluation and refinement.

4. Discussion

In this qualitative study of three key groups – MSM, case managers and DIS - we found that HIV-infected MSM perceived stigma, isolation, and substance use as critical factors contributing to sexual risk behaviors. Yet many HIV-service providers, while acknowledging the cooccurrence of these factors, did not perceive that the factors were both causal of sexual risk behaviors and a response to a HIV diagnosis. Both HIV-infected MSM and providers described varying levels of efficacy among HIV-infected MSM to change their substance use and sexual risk behaviors and viewed the MSM's social network as a barrier to achieving change. Finally, our study found that providers described the importance of training and inter-professional collaboration designed to address multi-faceted clients' needs. To our knowledge, prior studies have neither applied gualitative methods with CBPR principles to examine factors contributing to sexual risk behaviors among HIVinfected MSM nor, despite their unique position to facilitate treatment, examined the perspectives of case managers or DIS. Our findings demonstrate opportunities for addressing the needs of HIV-infected MSM across multiple levels (Fig. 1).

Our finding that sexual risk behaviors occurs in the context of complex negative psychosocial experiences is consistent with prior work (Herrick et al., 2013; Mosack et al., 2005; Stall et al., 2003; Wade Taylor et al., 2013). Our findings extend these data by demonstrating that providers inconsistently described how substance use and sexual risk behaviors may be a coping mechanism for feelings of stigma, social isolation and depression in response to living with HIV. This identified gap in understanding may serve as a place in which to begin training for providers. Further, while previous literature demonstrates that knowledge of an HIV diagnosis is associated with decreased risk behaviors (Marks et al., 2005), our study provides evidence that the initial period after diagnosis may warrant special attention.

In addition, our study demonstrates the relevance of the *Stages of Change* model (Prochaska et al., 1992), for addressing substance use and sexual risk behaviors. Stages of change research demonstrates that to understand where on a cycle the client is, and to understand

the work it might take to get them to the next step in the cycle, relieves the provider of a sense of helplessness and facilitates movement along the curve and are likely to be more successful (Prochaska et al., 1992). Training public health HIV-service providers in Stages of Change may facilitate their work with the complicated lives of HIV-infected MSM by giving them a greater understanding of the difficulties of behavior change, which may, in turn, reduce their judgment of clients and optimize their level of engagement with challenging clients.

Importantly, providers identified existing social networks as a key barrier to behavior change. While social networks may serve as a buffer to perceived stigma and other stress related to being of a marginalized group (e.g. MSM, HIV-infected) (Wong et al., 2014), social network structures may play a key role in normalizing substance use and sexual risk behaviors (Latkin et al., 2010). Existing data demonstrating efficacy of social network-based interventions for addressing behavior change (Hoffman et al., 2013; Tobin et al., 2011), provide support for use of such interventions to target substance use and sexual risk behaviors among HIV-infected MSM (Tieu et al., 2015).

Among participating providers, we found variability in self-perceived skills for addressing substance use and sexual risk behaviors and promoting behavior change. While one provider articulated the necessity of matching their approach to the client's needs – acknowledging a key principle to promoting effective behavior change (Pearson et al., 2012) - others appeared less well prepared. A recent meta-analysis indicates that case management is effective at promoting increased linkage and retention in substance abuse treatment services, but that it does not lead to substantial improvements in substance use, physical and mental health and risk behaviors. Our findings that providers were variable in their knowledge and self-efficacy in comprehensively managing HIV-infected MSM may, in part, explain these findings (Rapp et al., 2014). Furthermore, given ongoing initiatives to expand the role of DIS to promote retention in care of HIV-infected individuals (Centers for Disease Control and Prevention, 2013), efforts to promote more comprehensive training around issues such as substance use are likely to become increasingly relevant. Our data indicate that provider trainings on complexities involved in sexual risk behaviors and how to deliver effective behavioral interventions are warranted (Johnson et al., 2008; Sullivan et al., 2011). Additional community and network-focused opportunities for addressing substance use and sexual risk behaviors among HIV-infected MSM emerged from our data (Table 3). It will be important that any provider-focused initiatives, however, consider variability in case loads, experience, training, and staff turnover given existing differences among case managers and DIS.

Our study has limitations. Participants were recruited from three metropolitan areas within a single state. That we employed rigorous qualitative methods using CBPR-principles improves the likelihood that these findings may apply to other medium-sized metropolitan areas (Cashman et al., 2008). The majority of MSM in our sample had been living with HIV for a median of 15 years and were engaged in services, which may not reflect perspectives of individuals newly diagnosed or not in care. Lastly, we did not routinely document field notes or review transcripts or a summary of these findings with study participants (i.e. participant confirmation) from this analysis as it was not feasible. We were otherwise consistent with the consolidated criteria for reporting qualitative research (COREQ) guidelines and believe that the multi-disciplinary nature of our research team optimizes the validity of our reported findings (Edelman et al., 2014).

4.1. Conclusions

Perspectives among HIV-infected MSM, case managers and DIS on the causal relationships leading to HIV-risk behaviors differ, yet there is recognition of a need to meet multi-faceted needs through increased training and collaboration. Strategies to optimize how case managers and DIS understand and intervene upon stigma, substance use and sexual risk behaviors among HIV-infected MSM has potential to help prevent ongoing HIV transmission.

Disclosures

The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Yale Center for Clinical Investigation, the Department of Veterans Affairs, the Connecticut State Department of Public Health, or the National Institute on Drug Abuse. An earlier version of this work was presented as an oral abstract at the 38th National Annual Association for Medical Education and Research in Substance Abuse, November 6th, 2014, San Francisco, CA.

Conflicts of interest

The authors have no conflicts of interest to disclose.

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