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**A mixed method study on correlates of HIV-related stigma among gay and bisexual men in the southern United States**

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## **Abstract**

Societal prejudice against people living with HIV infection is a formidable public health challenge that can negatively impact health and well-being. We recruited a multiethnic sample of 129 gay and bisexual men living with HIV who completed a brief survey; a subset of participants completed semi-structured qualitative interviews to contextualize the data. In bivariate analyses, stigma was positively and significantly correlated with depression ( $r = .402, p < 0.001$ ) and negatively correlated with social support ( $r = -.482, p < 0.001$ ). Qualitative interview results captured the mental suffering caused by stigma and coping strategies the men had developed. Although some of the coping strategies reduced the likelihood of experiencing acts of stigmatization, they also exacerbated the psychological stress of living with a stigmatized disease and limited the potential for social support. Our results highlight the need to scale up stigma-reduction programs, particularly those that can bolster social support networks.

*Keywords:* bisexual, gay, HIV-related stigma, mixed method, men who have sex with men, United States

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HIV is a major global public health issue. In the United States alone, it is estimated that more than 1.2 million people are living with HIV, with 67% of these cases in men who have sex with men (MSM). The area with the highest estimated number of people living with HIV (PLWH) is the southern United States, which at the end of 2014 accounted for 50.4% of all estimated new diagnoses (Centers for Disease Prevention and Control, 2015).

Since the beginning of the epidemic, HIV has been associated with stigma, described as, “a process of devaluation of people either living with, or associated with, HIV and AIDS” (Smit et al., 2012, p. 405). Recent Joint United Nations Programme on HIV/AIDS (UNAIDS, 2015) data have indicated that in 35% of countries with available data, more than 50% of people reported having discriminatory attitudes toward PLWH. While the level of societal stigma connected with HIV has decreased since the early epidemic, it continues to pose a serious challenge for HIV prevention and care efforts (Chenard, 2007; Smit et al., 2012; UNAIDS, 2015).

The notion of minority stress (Meyer, 2003) can help to better understand the societal prejudice against PLWH and its implications. It is a model that explains how stigma and prejudice create a stressful social environment that lead to mental health problems. Meyer (2003) defined minority stress as, “excess stress to which individuals from stigmatized social categories are exposed as a result of their social, often a minority position” (Meyer, 2003, p. 676). HIV-related stigma is often conceptualized as a form of minority stress that is exacerbated by social rejection from families and religious institutions (Emlet, 2007; Garcia et al., 2016) and influences a range of negative health outcomes in PLWH (Pulerwitz, Michaelis, Weiss, Brown, & Mahendra, 2010), including mental health outcomes (Courtenay-Quirk, Wolitski, Parsons, & Gomez, 2006).

Researchers have not examined to any significant degree HIV-related stigma in MSM in general, as noted, for example, by Dowshen, Binns and Garofalo (2009), Hatzenbuehler, O’Cleirigh, Mayer, Mimiaga, and Safren (2011), and Smit et al. (2012). Even fewer have examined how HIV-related stigma is experienced by MSM with HIV infection (Courtenay-Quirk et al., 2006). Our own search of the literature and a recently published literature review of HIV-related stigma in communities of gay men identified only a handful of qualitative and mixed-methods studies on this topic. The studies that have been conducted have demonstrated significant associations with mental health problems and social isolation. In quantitative studies, HIV-related stigma in MSM has been found to be associated with post-traumatic stress disorder symptoms (Bogart et al., 2011), anxiety (Courtenay-Quirk et al., 2006; Hatzenbuehler et al., 2011), depression (Bogart et al., 2011; Courtenay-Quirk et al., 2006; Dowshen et al., 2009; Hatzenbuehler et al., 2011), and self-esteem (Dowshen et al. 2009). Additionally, cross-sectional studies have identified an association with loneliness (Courtenay-Quirk et al., 2006), quality of life (Slater et al., 2013), and social support (Burnham et al., 2016; Dowshen et al., 2009). There has been some investigation of whether there are other potential correlates of HIV-related stigma (see literature review by Smit et al., 2012), but research into a potential link with behaviors such as alcohol use is limited and results are equivocal (Courtney-Quirk et al., 2006; Galvan, Davis, Banks, & Bing, 2008; Liao et al., 2014; Radcliffe et al., 2010).

Findings from a few U.S.-based qualitative studies of gay, bisexual, and other MSM indicated that HIV-related stigma intersects with social rejection. Among Black MSM, rejection from families and religious institutions was reported as a common HIV-related stigma experience, which in turn affected men’s self-care behaviors, such as medication adherence and sexual practices (Garcia et al. 2016). In striving for normalcy, the participants in Chenard’s (2007) study attempted to avoid social rejection by deliberately limiting their

social contacts to other PLWH and HIV-related environments. A third qualitative study showed that romantic and sexual rejection was a unifying reality experienced by most of the gay participants. Enacted HIV-related stigma had made many men closeted about their serostatus, a behavior that “required substantial effort, in particular continuous management of stigmatizing information, and appeared to be psychologically taxing” (Berg & Ross, 2014, p. 196). Indeed, the Seropositive Urban Men’s Study, which collected qualitative and quantitative data up to 1998, found that HIV-related stigma influenced gay, bisexual, and other men’s psychological experiences with HIV infection through, for example, the loss of formal and informal relationships (Courtenay-Quirk et al., 2006).

While a growing number of quantitative studies have described how the societal stigma associated with HIV posed a psychological challenge to MSM with HIV infection, knowledge about its association with factors such as social support and alcohol use has been sparse. An investigation into these links is important because the pervasiveness of HIV-related stigma theoretically disrupts social relationships (Lakey & Cohen, 2000), and alcohol use could form a maladaptive coping strategy, which is associated with sexual risk behaviors (Radcliffe et al., 2010). Further, few mixed method and qualitative studies that provide context to previous quantitative findings of stigma and psychosocial health outcomes in MSM exist. The objectives of our mixed method study were to examine whether HIV-related stigma was associated with psychosocial variables in MSM with HIV as well as how MSM with HIV experienced and coped with HIV-related stigma.

## **Methods**

This was a concurrent mixed method study involving quantitative survey data and qualitative interview data. Figure 1 illustrates the steps in the study. We selected this design because of its potential to expand the dimensions of the research topic as well as increase comprehensiveness and validity of findings and methodological rigor (Chow, Quine, & Li,

2010). The study was approved by the Institutional Review Board at the University of Texas.

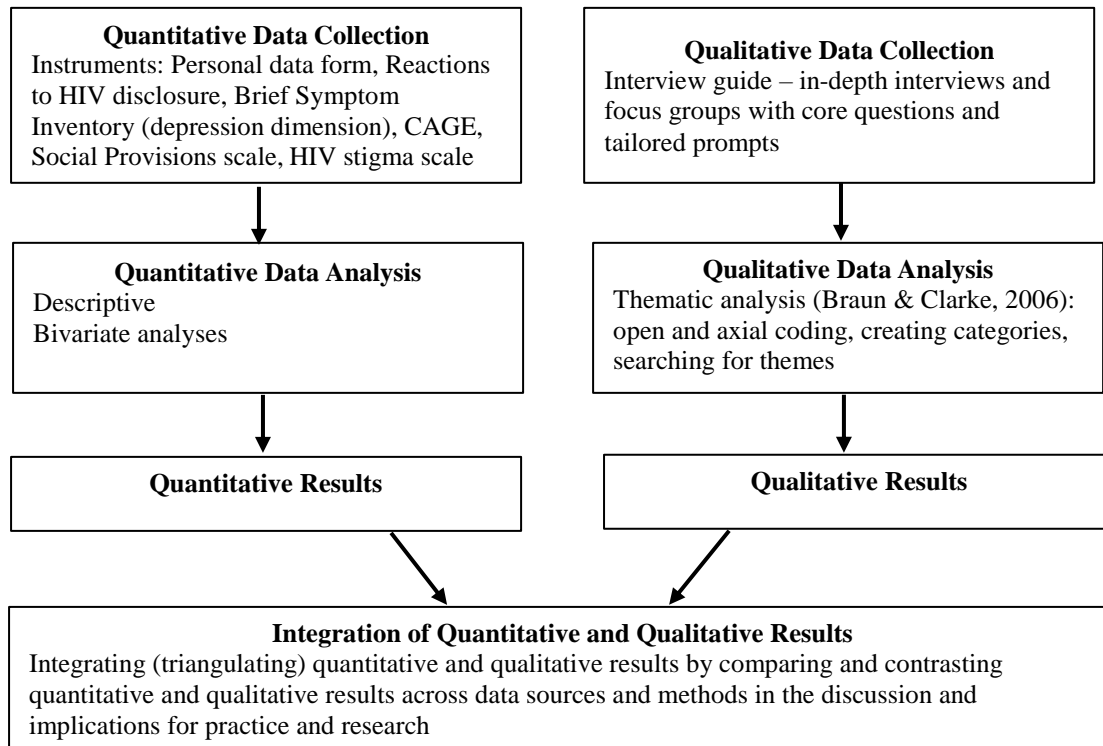


Figure 1. Illustration of steps conducted in this concurrent mixed method study.

### Sampling and Data Collection

We recruited MSM with a diagnosis of HIV infection through a community-based organization (CBO) that addressed psychosocial concerns related to HIV in a large city in the southern United States. We used non-probability, purposive sampling techniques: the CBO invited participation to both the survey and the in-person interviews through its membership base, and participants were asked to endorse the study to eligible persons in their social networks. Inclusion criteria for participants in our study were being male, 18 years of age or older, infected with HIV, and identifying as gay, bisexual, or an MSM. All recruitment and data collection took place during spring 2013.

Eligible participants were asked to complete a short survey and invited to participate in an individual or group interview (focus group). They all received a written explanation of the content of the research (interview participants also received an oral explanation) and

needed to indicate, by checking a box, that they understood the nature and purpose of the research and consented to take part. Participants did not receive any recompense, but we provided refreshments for interview and focus group participants.

*Survey.* Eligible men were invited to complete the brief, self-administered survey online or on paper (2 modes were available to support choice and convenience). It took about 6-8 minutes to complete. With regard to the online survey, we neither collected Internet Protocol (IP)-addresses nor used cookies. The link to the online survey was posted on the Webpage of the CBO.

The survey included standard sociodemographic variables, including age, year of HIV diagnosis, sexual orientation, education, relationship status, and race/ethnicity. The last four of these variables offered multiple response options, including the option *other* with a request that the respondent specified his answer. Participants were also asked to indicate recency of having experienced five situations related to HIV disclosure. The answer options ranged from *in the last week* to *a long time ago or never*. These indications of experienced societal HIV-related stigma were developed from the Consumer's Experience of Stigma Questionnaire (Stutterheim, Bos, & Schaalma, 2008), with exploratory factor analysis results showing that it can distinguish disclosure concerns from other stigma perceptions and experiences (EMIS Network, 2013).

We included four scales: (a) Depression was measured with the depression dimension of the Brief Symptom Inventory (Derogatis & Melisaratos, 1983) and consisted of six items with good internal consistency in our study ( $\alpha = .87$ ). Response options to the feeling items were rated on a Likert scale ranging from *not at all* (0) to *extremely* (3). A higher rating and total score indicated the intensity of distress during the past 7 days (Derogatis & Melisaratos, 1983). (b) Participants' alcohol dependency was measured with the CAGE four-item *yes/no* response scale. Two or more *yes* answers indicated alcohol dependence. It is an

efficient (can be completed in less than 1 minute), reliability- and validity-tested instrument for assessing alcohol dependency, and it has been successfully applied in male gay and bisexual samples (Ewing, 1984; Shields & Caruso, 2004). Shields and Caruso (2004) found that the scale's median internal consistency reliability across 22 samples was .74, which was the same as for our sample. (c) We used the reliability- and validity-tested 12-items Social Provisions Scale (Cutrona & Russel, 1987) to measure perceived social support in the dimensions of attachment, social integration, and reliable alliance. Each of these three dimensions consisted of four items. Respondents were asked to indicate on a four-point scale the extent to which each statement described their current social network, with responses from *strongly disagree* (1) to *strongly agree* (4). A higher score indicated a greater degree of perceived support (theoretical range 1-4). Overall, the scale showed good internal consistency with our sample ( $\alpha = .89$ ). (d) The fourth and final scale we used was the recently revised HIV Stigma Scale. This 10-item scale had good internal consistency and validity (Wright, Naar-King, Lam, Templin, & Frey, 2007), and showed good internal consistency in our sample ( $\alpha = .83$ ). Answer options were on a five-point scale from *strongly agree* to *strongly disagree*, with a scale range from 1-5.

*Interviews and focus groups.* Face-to-face interviews and focus groups were conducted in a building that offered the participants anonymity and privacy. Interviews and focus groups were tape recorded in English by one investigator who had experience in qualitative HIV-related research. The interview guide used to structure the interviews and focus groups included a set of 10 open-ended questions to elicit the experiences, perspectives, and life contexts of the participants in their own terms and words. Interviews and focus groups explored experiences with HIV status disclosure and meanings and norms concerning perceived social stigma and social environments for PLWH. The interviewer used prompts to clarify vague or unclear responses and to elicit more complete narratives



regarding stigma. Core questions did not differ between the individual interview and focus group formats. However, in both formats, follow-up questions and prompts unfolded organically from the participants' responses. In the focus groups, the researcher elicited information about community norms and variability; in the interviews, prompts sought more detailed narratives of individual experiences. Sample questions included the following: *In your experience, what are some situations, reactions or behaviors that indicate social HIV-related stigma? Can you tell me about a time when you believe that you experienced social stigma because of having HIV? How did you experience that situation? How did you deal with that situation? In your view, what do you think are some of the ways that social HIV-related stigma affects people like you who live with HIV?*

### **Analyses**

*Survey.* For quantitative data, we used SPSS<sup>®</sup> 22.0 statistical software to perform analyses. Descriptive statistics (counts, percentages, means) were performed to provide sociodemographic, health, and experiential profiles of study participants. We tested the association between HIV-related stigma and the set of selected variables using bivariate correlation. Analyses were two-tailed with significance set at  $\alpha < 0.01$ .

*Interviews and focus groups.* For qualitative data, interviews were transcribed verbatim, making a data corpus of 127,500 transcribed words. In accordance with our interest in HIV-related stigma, we restricted this corpus to all instances across the data with relevance to HIV-related stigma, which we identified by reading and re-reading the transcripts. Restriction of the dataset was a necessary analysis step that sharpened and organized the data such that coding could be developed (Boyatzis, 1998; Patton, 2002).

We used manual thematic analysis, as outlined by Braun and Clarke (2006), because of its ability to provide a detailed account of data, and offer a lens on experience (Boyatzis, 1998) and compatibility with the constructionist paradigm (Braun & Clarke, 2006). Thematic

analysis is defined as, “a method for identifying, analyzing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 82). The thematic analysis entailed recursive rounds of coding and searching for themes. First, we used open and axial coding, which entailed conceptualizing and categorizing the data before we reassembled it into groupings or categories on the basis of relationships identified in the data. Then, we searched for themes by looking for repeated patterns, responses, or meaning across the entire data set that captured central themes of the data in relation to our overall research question (Braun & Clarke, 2006). The process was largely data-driven but we also used *a priori* codes derived from the survey (particularly related to social support and depression) to seek out evidence from the qualitative data. This involved creating a pre-set list of relevant codes that was used throughout the analysis process (Patton, 2002). To ensure reliability as well as to promote discussions toward consensual categories and themes, all transcripts were analyzed by two of the authors (the third author reviewed the preliminary results and provided suggestions for refinement of the results).

While we analyzed qualitative data separately from the quantitative data, in the final stage of the research, we compared and incorporated the two sets of results (see Figure 1). Integration of data across sources and methods is desirable in mixed method research analyses because cross verification from several sources serves as validation of the phenomena being studied (Chow et al., 2010).

## **Results**

### **Participant Characteristics**

The full sample included 129 community-recruited men, of whom 20 volunteered for a face-to-face interview or focus group. As shown in Table 1, the 129 participants ranged in age from 21 to 67 years (mean = 45). On average, they had lived with an HIV diagnosis for 12 years (range = < 1 year to 30 years). The majority had graduate degrees (77%), identified

as gay or homosexual (89%), and were either dating or single (63%). About three quarters identified as White and 20% identified as Latino or African American. A few respondents selected the response option *other* for some of the sociodemographic answer options and most of them did not specify answers in the space provided for specification. However, for sexual orientation, one person listed *questioning*; for relationship status, one person wrote “in transition, partnership to be determined.”

The subsample of men who participated in a qualitative interview or focus group ( $n = 20$ ) were between 33 and 66 years of age (mean = 51) and, on average, had lived with an HIV diagnosis for 18 years (range = 3-30 years). Most had some college education (55%), identified as gay or homosexual (80%), and were either dating or single (70%). About half identified as White while five participants were Latino and four were African American. Bivariate analyses showed that, compared to men who did not participate in an interview or focus group, this subsample was statistically older, had lived with an HIV diagnosis for a longer time, and had a somewhat lower education level ( $p < 0.01$ ). They were also more ethnically diverse ( $p < 0.01$ ). There was no statistical difference between the two groups concerning sexual orientation and relationship status.

Table 1

*Sociodemographic Description of the Study Participants (n = 129)*

	Interviewees (n = 20) n (%)	Non-interviewees (n = 109) n (%)	Full sample (n = 129) n (%)
Age (median, range)	50 (33-66)	45 (21-67)	46 (21-67)
Years lived with HIV diagnosis	16 (3-30)	10 (0-30)	12 (0-30)
Education			
High school graduate or less	6 (30)	5 (6)	11 (9)
Trade/vocational school	3 (15)	5 (6)	8 (6)
Some college	4 (20)	29 (27)	33 (26)
Graduate degree	4 (20)	39 (36)	43 (33)
College graduate	3 (15)	31 (28)	34 (26)
Sexual orientation			
Gay or homosexual	16 (80)	99 (91)	115 (89)
Bisexual	3 (15)	8 (7)	11 (9)
Other	1 (5)	2 (2)	3 (2)
Relationship status			
Have a primary partner	6 (30)	37 (34)	43 (33)
Dating	2 (10)	10 (9)	12 (9)
Single	12 (60)	57 (52)	69 (54)
Other	0	5 (6)	5 (4)
Race/Ethnicity			
White	11 (55)	89 (81)	100 (77)
Latino	5 (25)	13 (12)	18 (14)
African American	4 (20)	3 (3)	7 (5)
Asian American	0	1 (1)	1 (1)
Native American	0	1 (1)	1 (1)
Mixed race / ethnicity	0	1 (1)	1 (1)
Other	0	1 (1)	1 (1)

**Survey Results**

*Descriptive results.* The survey asked participants about experiences with various situations related to HIV disclosure (Table 2). About three quarters (73%) of the participants explained that in the previous year, they had avoided telling others that they lived with HIV. The great majority of them had in the previous year been treated less favorably by others when they learned that the participant had HIV. Additionally, in the previous year, as many as three quarters (75%) had been shunned or avoided sexually because of their HIV status, and 39% stated that they had been shunned or avoided socially. On the other hand, the

participants almost always said that friends were supportive and understanding when they learned about the HIV status.

Table 2

*Description of Experiences With HIV Disclosure*

	N (%)				
	In the last week	In the last month	In the last 6 months	In the last year	A long time ago or never
I have avoided telling others that I have HIV	21 (16.4%)	16 (12.5%)	23 (18.0%)	33 (25.8%)	35 (27.3%)
I have been treated less favorably by others when they have learned that I have HIV	11 (8.5%)	13 (10.1%)	13 (10.1%)	46 (35.7%)	46 (35.7%)
I have been shunned or avoided sexually when it was known that I have HIV	13 (10.2%)	12 (9.4%)	19 (15.0%)	51 (40.2%)	32 (25.2%)
I have been shunned or avoided socially when it was known that I have HIV	3 (2.3%)	8 (6.3%)	9 (7.0%)	29 (22.7%)	79 (61.7%)
Friends who learned that I have HIV were supportive and understanding	36 (28.3%)	17 (13.4%)	17 (13.4%)	50 (39.4%)	7 (5.5%)

The responses to the CAGE questions showed that about 40% of participants evidenced alcohol dependency. The mean score was 0.38 ( $SD = 0.49$ ). The averages and standard deviations for the other scales were: Brief Symptom Inventory Depression score = 0.77 ( $SD = 0.62$ ), Social Provisions Scale score = 3.23 ( $SD = 0.53$ ), HIV Stigma scale = 2.69 ( $SD = 0.84$ ).

*Bivariate correlation results.* As shown by the bivariate correlation analysis results in Table 3, neither sociodemographic characteristics nor alcohol dependence were significantly associated with HIV-related stigma (all  $p \geq .12$ ). However, there was a positive association between HIV-related stigma and depression: Men with a higher HIV-related stigma score evidenced more depression symptoms ( $r = .402$ ). Additionally, there was a negative association between HIV-related stigma and social support: Men with a higher HIV-related stigma score perceived they had less social support ( $r = -.482$ ).

Table 3

*Bivariate Correlations Between HIV-related Stigma and Psychosocial, Health, and Demographic Characteristics<sup>a</sup>*

Variables	<i>r</i>	<i>p</i> -value
Age	.079	.37
Years lived with HIV diagnosis	-.041	.65
Identify as gay	-.137	.12
Race/Ethnicity	-.139	.12
Have a primary partner	-.116	.19
Higher education	-.079	.37
Alcohol dependency	.120	.18
Depression	.402	***
Social support	-.482	***

*Note.* \*\*\*  $p < .001$ ;  $a = n$  ranges from 125 to 129 due to occasional missing data.

### **Interview Results**

Thirteen men chose to contribute their views in an individual interview while seven men participated in a focus group (there was 1 focus group with 4 men and 1 with 3 men). The interviews lasted from 35 to 97 minutes with an average duration of 57 minutes.

The overarching theme of our qualitative analysis, how gay and bisexual men experience and cope with HIV-related stigma, was comprised of the following basic and organizing sub-themes: (a) stigma (enacted stigma) is subtle yet mentally damaging, (b) fear of disclosure, and (c) importance of professional and informal support (detailed below). Essentially, the men's narratives portrayed a strong conviction of HIV being a socially stigmatized disease. This sense of stigma led to fears of status disclosure, which in turn generated a range of coping strategies through concealing behaviors, including social self-quarantine. In their own right and collectively, stigma, concealment, and social isolation caused the respondents considerable mental distress. However, social support functioned as a buffer, reduced the distress, and enhanced the men's quality of life.

In the following, to illustrate themes, we provide representative quotes from participants (accompanied by pseudonym and age of participant). To increase readability, we

have deleted repeated words and word fillers (e.g., um, hmm, eh) from participants' quotes, and we use ellipses to indicate places where we have skipped portions of a quote. Otherwise, we present the quotes verbatim.

*Stigma is subtle yet mentally damaging.* Almost all the participants expressed an awareness of HIV-related stigma operating largely in subtle ways, yet causing mental harm to those living with the disease. They explained: "A lot of it now is a lot more subtle. There's so many little ways that you still have stigma associated with HIV" (Daniel, 61); "Perhaps it's not as much as it was before, but there is still a very subtle stigma" (James, 57); and "I don't know what they are afraid of. They're well educated, they are knowledgeable about the disease, and still, underlying, there's this subtle stigmatization" (Matthew, 32). Throughout the interviews, it became clear that subtle stigma took many forms, such as whispers and looks, cautioning not to reveal HIV status, refusal to join basketball games, declination to share cigarettes and drinks, provision of plastic tableware at social functions, and rejection from friends and potential (sexual and romantic) partners. For example, Charles (45) said: "I did have an experience or two, you relay to folks that you have HIV and then they don't ever call you again."

The emotional impact of stigma included feelings of sadness, worthlessness, alienation, and depression: "My brothers treated me very differently, such as they purchased plastic or Rubbermaid plates and bowls and spoons and forks and I had to use a different restroom and so forth and so on. And I felt very alienated" (David, 33); "I've heard so much of the negative side that it finally started affecting me, and I started to feel dirty, unclean, and not fit to be around other human beings" (Christopher, 49); and "I cry. It makes me sad ... it makes me feel worthless. Makes me feel like a piece of fecal matter" (Geoff, 49).

*Fear of disclosure.* Most apparent in the narratives was the respondents' pre-emptive coping strategy toward HIV-related stigma through non-disclosure of their HIV-infection

status. To varying extents, all informants exercised caution in disclosing their HIV status. The general caution applied to acquaintances, family members, potential sexual partners, friends, and work relations alike. James (57) put it simply: “I wouldn’t dare to tell anybody outside my circle of HIV’ers that I am HIV positive – I wouldn’t dare!”, while Randy (51), who participated in the same focus group, later said: “The disease itself is being so demonized by society that we are so scared, we’re so afraid to tell.” Christopher (49) offered this clarification: “You’re afraid to tell somebody you’re HIV because you usually have a tendency to lose friendship, you lose relatives, family...because they push you away.” Even those who had lived with HIV for many years, such as Tony (52), feared disclosure: “To this day it [HIV] is a very difficult thing to talk about. I mean, I was afraid that I would be refused, rejected by others if I tell them.” Overwhelmingly, the men avoided and feared disclosure due to concerns of people’s negative reactions (i.e., stigma). For many, like Richard (55), disclosure to family members was particularly distressing:

It’s fear of rejection. Fear of humiliation. It took everything I had to tell my step-sister...I just fear the reaction that might come from them, you know?... So I don’t tell anyone, like my brothers for instance. And by God’s honest truth, I don’t know how they would react. And I am scared to find out.

These quotes clearly portray the men’s mental distress from concealment and expectations of rejections linked to HIV.

At the same time, several of the men revealed a personal awareness of the mental toll of concealment:

I’m pretending that I’m not positive: at work, in the theatre... It’s hard to keep that a secret. It’s not easy. It would be so much easier if we could just have that conversation... Wiping away stigma, which it seems like it’s the big elephant, is half the cure, because it’s huge, it has to be because we keep it such a secret. That can’t be



good for us inside. That can't be healthy for us... carrying that is pretty nerveing.

(Mark, 48)

Additionally, the men understood that openness about HIV would help them deal better and overcome the adverse effects:

When I first discovered it, I went through a lot of stress, and it would have been less if I would've talked about it more, but since I kept it in, it was more stressful. It took a longer time to get over that hump. (William, 53)

I mean, if you open talk about it [HIV], because even though it's hurting and it's killing you inside, if you talk about it, the person you're going to talk to, they may understand of what you're going through, but if you keep all bundled up, it's going to kill you. (Joseph, 52)

*Importance of professional and informal support.* While fearing stigma from status disclosure, many of the informants expressed the value of support gained from being open about living with HIV, even if it were just with a counselor or therapist. As William (53) stated: "That's what makes it better, when we talk about it...Once I started talking about it, it eases the pain. I mean, it may not take away the situation, but it'll ease your pain." Social support was described as an essential response to stigma. Many had at some point(s) seen a therapist or counselor, several mentioned that their physicians had provided both emotional and informational support, while others highlighted the benefits of peer-mentors, friends who lived with HIV, positive men's programs, and support groups. For example, four of the informants asserted: "the support group is fantastic" (James, 57); "Then I started going to support groups – that helped a lot" (Geoff, 49), "Once I found a group [with people] that had the same problem, going through the same dilemmas I'm going through, it became a whole lot easier" (William, 53); and "I go to this day center [name of center] and that program has helped me out a lot. And I feel comfortable there because everyone there, as the client, is all

HIV or AIDS... That's my support group" (Richard, 55). In fact, some of the men realized that the only way they could get support around living with HIV was by talking about it with somebody else. David (33) explained: "In the beginning, I felt an obligation to tell my family because how else would they help me or support me if they don't know what's going on?"

The rewards of disclosing were a sense of closeness with those who could provide support and reduced distress. As two of the respondents said: "Talking about it helps. Talking about it helps because it helps relieve pressure and stress that builds up" (Richard, 55); and

It does help me to talk about it, when I do open up and talk about it. Because then I kind of reason with the thought process of, "Why I am really ashamed?" It's mainly my fear of being rejected and looked down upon. (George, 56)

Overall, the interviews showed that talking about HIV – and stigma – allowed for various forms of professional and informal support, which in turn reduced mental distress and enhanced the men's quality of life.

### **Discussion**

In this mixed method study, which concerned the relationship of psychosocial variables with HIV-related stigma, the main salient result was the strong association between HIV-related stigma and psychosocial health. First, our study was congruent with research showing that HIV-related stigma was significantly associated with greater symptoms of depression among PLWH (Logie & Gadalla, 2009), including MSM (Bogart et al., 2011; Courtenay-Quirk et al. 2006; Dowshen et al., 2009; Hatzenbuehler et al., 2011). A meta-analysis of the overall strength and direction of health correlates of stigma toward PLWH concluded that while the magnitude of the associations varied across studies, the positive relationship between HIV-related stigma and depression was consistent (Logie & Gadalla, 2009). A recent and unique study, because of its prospective design, confirmed the causal direction of this association, showing that HIV-related stigma experiences predicted greater

symptoms of depression in MSM (Hatzenbuehler et al., 2011). To our knowledge, there has been no empirical literature on the amount or degree of enacted stigma and its impact on mental health outcomes, but the qualitative results of our study suggest that even subtle stigma affects people's psychological well-being. In contrast to overt acts of stigmatization, our respondents characterized subtle stigma as being hard to notice and indirect, yet evident through, for example, disapproving looks, gossip, rejection, disrespectful treatment, and avoidance and distancing behaviors. Most participants described a variety of society's negative attitudes and reactions to PLWH, illustrating the ongoing challenges these individuals experienced when dealing with HIV-related stigma that is often understated but nonetheless psychologically and emotionally damaging.

Second, both our quantitative and qualitative results drew attention to the association between low perceived social support and higher HIV-related stigma in MSM. This finding was in agreement with previous studies (Burnham et al., 2016; Dowshen et al., 2009). Research has found that social support (having emotionally validating, supportive relationships with friends, family, and others) enhanced quality of life by providing a buffer against stressful life events, such as HIV-related stigma, and reduced the psychological and physiological consequences of adverse life events (Salovey, Rothman, Detweiler, & Steward, 2000; Slater et al., 2013). Similar to respondents in Chenard's (2007) research, several of the men interviewed in our study described how social support functioned as protection against prejudice related to HIV and helped them cope more effectively. More often, however, the participants described HIV-related stigma enacted by family members and other gay and bisexual men, the very individuals they relied on for support, thus negatively affecting future reliance on these and other people for support. Social ostracization, one expression of stigma, prevented them from acquiring social support that would have been conducive to their psychological well-being (Dowshen et al., 2009). Albeit limited, other literature has indicated

that social support was protective in the adjustment to living with an HIV diagnosis (Galvan et al., 2008). Theoretically, positive self-appraisals from others promote the development of a buffer and strong coping skills when faced with life stressors. Social support theory, for example, has proposed that social support serves to protect individuals against the negative effects of stressful situations by leading them to interpret life challenges less negatively (Lakey & Cohen, 2000).

Our qualitative data extend our quantitative findings by pointing to how HIV-related stigma created a fear of HIV status disclosure. The quantitative results revealed that a large majority of the respondents at some point had avoided telling others that they lived with HIV. Similar to findings by Berg and Ross (2014), the most frequently raised concern in the interviews was the possibility of rejection, usually socially by friends and family or sexually by potential partners, following disclosure of HIV status. Indeed, the quantitative data showed that most respondents had been treated less favorably by others when they learned that the participant had HIV, been shunned or avoided sexually, and almost 40% had also been shunned or avoided socially. The qualitative results indicated the harm caused to the men's mental health, as stigma experiences left them feeling worthless and depressed.

Importantly, in continuation of the above discussion, the respondents also developed coping strategies such as preemptive avoidance of rejection by nondisclosure of status. In a qualitative study of gay men, hiding the socially devalued HIV-infection status was referred to as "the second closet" (Berg & Ross, 2014, p. 186). But while offering instant self-protection, hiding one's serostatus required continuous self-censoring and was mentally taxing. The coping strategy of self-quarantine with avoidance of particular social spaces, scenes, and activities led to social isolation and loss of intimacy. Social isolation and lower levels of emotional support have been found to be associated with HIV-related stigma. While Galvan et al. (2008) quantitatively showed that perceived social support from friends was

associated with HIV-related stigma, mixed method studies by Emlet (2007) and Courtenay-Quirk et al. (2006) found that many PLWH experienced loss of formal and informal relationships following an HIV diagnosis, which brought loneliness and social isolation. Moreover, meta-analyses have shown that social ill health was negative in itself and strongly linked to mental health in sexual minority populations (Meyer, 2003). At the same time, our respondents acknowledged that disclosure could function as a coping strategy against stigma by facilitating socially supportive relationships. This finding resonated with results from a qualitative study of 20 gay men living with HIV, which revealed the use of serostatus disclosure as a main route to an affirming social support system (Chenard, 2007). Data from our informants replicated some of this literature by describing how, for these men, taking advantage of existing, and creating and maintaining new, supportive contacts provided an important source of social support.

It is important to stress that service providers, researchers, and others must realize that HIV is still very much a stigmatized condition and that many PLWH struggle to cope with the social challenges imposed by the illness. Strong and supportive social networks are essential for handling HIV-related stigma. Preliminary research has indicated that there are several promising ways to bolster social support, such as peer-to-peer work, where a person with HIV provides coaching, support, and education to other PLWH (Berg et al., 2015). Some of our interview participants indicated benefits of community involvement, such as volunteerism and activism, on social support, social connection, mastery, and psychological well-being. In fact, Ramirez-Valles and Brown (2003) documented that gay men with HIV infection who became involved in community-level HIV-related activities not only created social connections and a sense of belonging, but also an increase in self-esteem. Similarly, in a randomized study, Heckman et al. (2006) found that adult PLWH who received an immediate coping improvement group intervention reported fewer psychological symptoms,

lower levels of life-stressor burden, and increased coping self-efficacy.

Stigma-reduction programs should include discussions of the benefits and strategies of disclosure. Our findings also reinforce the need for HIV care practitioners and service providers to be aware of and, when indicated, screen for depression in their patients living with HIV. While it is important to continue to develop and offer psychosocial interventions, social support, and resiliency training to persons who struggle with stigma, it is also imperative to challenge the prejudice of the perpetrators of stigma and continue to work toward elimination of the societal views that perpetuate HIV-related stigma. By normalizing and facilitating comfortable discussions about HIV, disclosure of HIV-infection status becomes easier; more people will come out about living with HIV; and there will be less stigma. Future longitudinal rather than cross-sectional studies are needed to elucidate not only the interrelationship between HIV-related stigma and psychosocial variables, but also effective interventions. Further qualitative research can clarify contextual pathways and the feasibility of prevention programs. Finally, the relationship between HIV-related stigma and other psychosocial variables, such as anxiety, substance use, and quality of life, warrants further research.

### **Strengths and Limitations**

The mixed method design of our study was a significant strength. By examining both quantitative and qualitative data regarding HIV-related stigma we could investigate convergence, concurrent triangulation, and offer a more complete understanding of the relationships between HIV-related stigma and psychosocial health that would be available based on only one strand of data (Chow et al., 2010). Our study sample was diverse with regard to race/ethnicity, age, years having lived with HIV, and education. We used validity tested scales with good internal consistency. With regard to the ethical aspects of the study, we assured privacy and safety for all study participants, who were all older than 18 years.

Participation was voluntarily, and no volunteer was excluded based on ethnicity, socio-economic status, first language, or similar variables. All data collected were kept confidential.

The results of our study should nonetheless be interpreted considering their limitations. This was a convenience sample of MSM living with HIV from an urban CBO in the southern United States. The sub-sample of men who provided qualitative data was more ethnically diverse than the men who only provided quantitative data; they were also somewhat older, had lived with an HIV diagnosis longer, and had lower education levels. The design precluded assertions about causality and the participants may not have been representative of all MSM living with HIV in the region. However, it can be argued that these men – all recruited through a local CBO engaged in HIV-prevention activities – were more open than others about their HIV status, given they had at least disclosed to persons associated with the CBO, and were, therefore, less affected by stigma. Thus, our results may underestimate the negative correlates of stigma. On the other hand, the qualitative interviews were conducted in person, and there was the possibility that some participants' responses were biased due to social desirability.

### **Conclusion**

Our study confirmed that HIV-related stigma takes many forms, and that even subtle stigma is related to depression and low social support. Qualitative interviews yielded additional valuable insights about the mental suffering caused by stigma, as well as the coping strategies the participants developed. The coping strategy of serostatus disclosure avoidance reduced the likelihood that PLWH would experience acts of stigmatization, but it also limited illness-related social support. The results highlight the need for a scaling up of stigma-reduction initiatives, particularly those that can bolster social support networks.

## References

- Berg, R. C., Gamst, A., Said, M., Aas, K. B., Songe, S. H., Fangen, K., & Rysstad, O. (2015). True user involvement by people living with HIV is possible: Description of a user-driven HIV clinic in Norway. *Journal of the Association of Nurses in AIDS Care*, 26(6), 732-742. doi:10.1016/j.jana.2015.07.002
- Berg, R. C., & Ross, M. W. (2014). The second closet: A qualitative study of HIV stigma among seropositive gay men in a southern U.S. city. *International Journal of Sexual Health*, 26, 186-199. doi:10.1080/19317611.2013.853720
- Bogart, L. M., Wagner, G. J., Galvan, F. H., Landrine, H., Klein, D. J., & Sticklor, L. A. (2011). Perceived discrimination and mental health symptoms among Black men with HIV. *Cultural Diversity & Ethnic Minority Psychology*, 17(3), 295-302. doi:10.1037/a0024056
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. London, UK: Sage.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi:10.1191/1478088706qp063oa
- Burnham, K. E., Cruess, D. G., Kalichman, M. O., Grebler, T., Cherry, C., & Kalichman, S. C. (2016). Trauma symptoms, internalized stigma, social support, and sexual risk behavior among HIV-positive gay and bisexual MSM who have sought sex partners online. *AIDS Care*, 28(3), 347-353. doi:10.1080/09540121.2015.1096894
- Centers for Disease Prevention and Control. (2015). *HIV surveillance report 2014; vol. 26*. Retrieved from <http://www.cdc.gov/hiv/library/reports/surveillance/>
- Chenard, C. (2007). The impact of stigma on the self-care behaviors of HIV-positive gay men striving for normalcy. *Journal of the Association of Nurses in AIDS Care*, 18(3), 23-32. doi:10.1016/j.jana.2007.03.005



- Chow, M. Y., Quine, S., & Li, M. (2010). The benefits of using a mixed methods approach—quantitative with qualitative—to identify client satisfaction and unmet needs in an HIV healthcare centre. *AIDS Care*, 22(4), 491-498. doi:10.1080/09540120903214371
- Courtenay-Quirk, C., Wolitski, R. J., Parsons, J. T., & Gomez, C. A. (2006). Is HIV/AIDS dividing the gay community? Perceptions of HIV-positive men who have sex with men. *AIDS Education and Prevention*, 18, 56-67. doi:10.1521/aeap.2006.18.1.56
- Cutrona, C. E., & Russell, D. (1987). The provisions of social relationships and adaptation to stress. In W. H. Jones & D. Perlman (Eds.), *Advances in personal relationships* (Vol. 1, pp. 37-67). Greenwich, CT: JAI Press.
- Derogatis, L., & Melisaratos, N. (1983). The Brief Symptom Inventory: An introductory report. *Psychological Medicine*, 13, 595-605.
- Dowshen, N., Binns, H. J., & Garofalo, R. (2009). Experiences of HIV-related stigma among young men who have sex with men. *AIDS Patient Care and STDs*, 23(5), 371-376. doi:10.1089/apc.2008.0256
- EMIS Network. (2013). *EMIS 2010: The European Men-Who-Have-Sex-With-Men Internet Survey. Findings from 38 countries*. Stockholm: European Centre for Disease Prevention and Control.
- Emler, C. (2007). Experiences of stigma in older adults living with HIV/AIDS: A mixed-methods analysis. *AIDS Patient Care and STDs*, 21(10), 740-752. doi:10.1089/apc.2008.0256
- Ewing, J. A. (1984). Detecting alcoholism: The CAGE questionnaire. *Journal of the American Medical Association*, 252(14), 1905-1907. doi:10.1001/jama.1984.03350140051025
- Galvan, F. H., Davis, E. M., Banks, D., & Bing, E. G. (2008). HIV stigma and social support among African Americans. *AIDS Patient Care and STDs*, 22(5), 423-436.

doi:10.1089/apc.2007.0169

Garcia, J., Parker, C., Parker, R. G., Wilson, P. A., Philbin, M., & Hirsch, J. S. (2016).

Psychosocial implications of homophobia and HIV stigma in social support networks: Insights for high-impact HIV prevention among Black men who have sex with men. *Health Education & Behavior*, 43(2), 217-225. doi:10.1177/1090198115599398

Hatzenbuehler, M. L., O'Cleirigh, C., Mayer, K. H., Mimiaga, M. J., & Safren, S. A. (2011).

Prospective associations between HIV-related stigma, transmission risk behaviors, and adverse mental health outcomes in men who have sex with men. *Annals of Behavioral Medicine*, 42(2), 227-234. doi:10.1007/s12160-011-9275-z

Heckman, T. G., Barcikowski, R., Ogles, B., Suhr, J., Carlson, B., Holroyd, K., & Garske, J.

(2006). A telephone-delivered coping improvement group intervention for middle-aged and older adults living with HIV/AIDS. *Annals of Behavioral Medicine*, 32(1), 27-38. doi:10.1207/s15324796abm3201\_4

Joint United Nations Programme on HIV/AIDS. (2015). *On the fast-track to end AIDS by 2030. Focus on location and population*. Retrieved from

[http://www.unaids.org/sites/default/files/media\\_asset/WAD2015\\_report\\_en\\_part01.pdf](http://www.unaids.org/sites/default/files/media_asset/WAD2015_report_en_part01.pdf)

Lakey, B., & Cohen, S. (2000). Social support theory and measurement. In S. Cohen, L. G.

Underwood, & B. H. Gootlieb (Eds.). *Social support measurement and intervention: A guide for health and social scientists* (pp. 29-52). Oxford, UK: Oxford University Press.

Liao, M., Kang, D., Tao, X., Bouey, J. H., Aliyo, M. H., Qian, Y., ... Jia, Y. (2014). Alcohol use, stigmatizing/discriminatory attitudes, and HIV high-risk sexual behaviors among men who have sex with men in China. *Biomedical Research International*, 143738.

doi:10.1155/2014/143738

- Logie, C., & Gadalla, T. M. (2009). Meta-analysis of health and demographic correlates of stigma towards people living with HIV. *AIDS Care, 21*(6), 742-753.  
doi:10.1080/09540120802511877
- Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin, 129*, 674-697. doi:10.1080/09540120802511877
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA.: Sage.
- Pulerwitz, J., Michaelis, A., Weiss, E., Brown, L., & Mahendra, V. (2010). Reducing HIV-related stigma: Lessons learned from Horizons research and programs. *Public Health Reports, 125*, 272-281.
- Radcliffe, J., Doty, N., Hawkins, L. A., Gaskins, C. S., Beidas, R., & Rudy, B. J. (2010). Stigma and sexual health risk in HIV-positive African American young men who have sex with men. *AIDS Patient Care and STDs, 24*(8), 493-499.  
doi:10.1089/apc.2010.0020
- Ramirez-Valles, J., & Brown, A. U. (2003). Latinos' community involvement in HIV/AIDS: Organizational and individual perspectives on volunteering. *AIDS Education and Prevention, 15*(Suppl. A), 90-104. doi:10.1521/aeap.15.1.5.90.23606
- Salovey, P., Rothman, A., Detweiler, J., & Steward, W. (2000). Emotional states and physical health. *American Psychologist, 55*(1), 110-121. doi:10.1037/0003-066X.55.1.110
- Shields, A. L., & Caruso, J. C. (2004). A reliability induction and reliability generalization study of the CAGE questionnaire. *Educational and Psychological Measurement, 64*(2), 254-270. doi:10.1177/0013164403261814
- Slater, L. Z., Moneyham, L., Vance, D. E., Raper, J. L., Mugavero, M. J., & Childs, G.

(2013). Support, stigma, health, coping, and quality of life in older gay men with HIV. *Journal of the Association of Nurses in AIDS Care*, 24(1), 38-49.

doi:10.1016/j.jana.2012.02.006

Smit, P. J., Brady, M., Carter, M., Fernandes, R., Lamore, L., Meulbroek, M., ... Thompson,

M. (2012). HIV-related stigma within communities of gay men: A literature review.

*AIDS Care*, 24(3-4), 405-412. doi:10.1080/09540121.2011.613910

Stutterheim, S. E., Bos, A. E. R., & Schaalma, H. P. (2008). *HIV-related stigma in the Netherlands*. Retrieved from

[https://www.researchgate.net/publication/237233881\\_HIV-](https://www.researchgate.net/publication/237233881_HIV-Related_Stigma_in_the_Netherlands)

[Related\\_Stigma\\_in\\_the\\_Netherlands](https://www.researchgate.net/publication/237233881_HIV-Related_Stigma_in_the_Netherlands)

Wright, K., Naar-King, S., Lam, P., Templin, T., & Frey, M. (2007). Stigma scale revised:

Reliability and validity of a brief measure of stigma for HIV+ youth. *Journal of*

*Adolescent Health*, 40(1), 96-98. doi:10.1016/j.jadohealth.2006.08.001

### **Key Considerations**

- HIV-infected individuals' perceptions and experiences demonstrate that HIV is a socially stigmatized disease.
- HIV stigma is positively linked to depression in individuals living with HIV.
- HIV stigma is negatively linked to social support and may exacerbate social ill health.
- More stigma-reduction programs for individuals living with HIV are needed.