

## THE SECOND CLOSET: A QUALITATIVE STUDY OF HIV STIGMA AMONG SEROPOSITIVE GAY MEN IN A SOUTHERN U.S. CITY

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**ABSTRACT.** *Objectives:* Stigma connected with HIV/AIDS has decreased considerably since the early epidemic yet affects those living with HIV in many ways. Little research, particularly qualitative research, concerning HIV stigma from the perspective of gay men has emerged. The present qualitative study aimed to fill this evidence gap by examining how HIV stigma is perceived and experienced by gay men who have become HIV-infected and how they respond to this stigma. *Methods:* Thematic analysis of 19 gay men's narratives identified six main themes. *Results:* Encountering HIV stigmatization was common and was linked to the physical stigmata identifying respondents as HIV-positive. Overwhelmingly, they found stigmatization to be most intensely felt within gay communities. One profound theme was internalized HIV stigma, referring to respondents' internalized negative feelings about their HIV status. A related theme was the closeted nature of HIV. Lastly, regarding how the men dealt with the HIV diagnosis and experiences of HIV stigma, a theme of adaptation became clear. *Conclusions:* Although exploratory, the results can serve as a beginning framework for understanding and assisting seropositive gay men who experience HIV stigma. The findings are important because it is realistic to expect that in a climate in which HIV has become increasingly invisible and closeted and in which infections are on the rise, gay and bisexual men will be increasingly affected and infected by HIV.

**KEYWORDS.** Gay, HIV stigma, qualitative research, United States

### INTRODUCTION

HIV is one of the most severe health threats in the world (UNAIDS, 2012). In the United States alone, it is estimated that more than 1.1 million people are living with HIV, with 52% of these cases being among men who have sex with men (MSM; Centers for Disease Control and Prevention [CDC], 2012). The area with the highest HIV rate is the South (20.9 per 100,000). And of the states in the South, Texas has the greatest number of cumulative AIDS cases. These are primarily located in metropolitan areas, where an estimated 68,140 MSM live

with HIV (CDC, 2012; Texas Department of State Health Services, 2013).

Sadly, HIV is a disease that since the beginning of the epidemic has been associated with social stigma. According to Canadian sociologist Ervin Goffman (1963), one of the earliest scholars to theorize stigma, it is any personal attribute, real or perceived, that conveys a negative social identity, thus devaluing the person's social position. Specific to HIV, the Joint United Nations Program on HIV/AIDS describes stigma as "a process of devaluation of people either living with, or associated with, HIV and AIDS" (UNAIDS, 2003, p.1). The

Received 1 May 2013; revised 2 October 2013; accepted 5 October 2013.

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subsequent discrimination is described as the “unfair and unjust treatment of an individual based on his or her real or perceived HIV status” (UNAIDS, 2003, p. 1). It is unique from gender- and race-based stigma because HIV-positive serostatus most often can be concealed. As an exception, lipodystrophy, a process of fat redistribution due to HIV therapy that results in distinctive body shape changes, signifies HIV socially (Persson, 2005). Although these kinds of changes have almost disappeared as a result of medical advances, Persson (2005) writes that among her 19 seropositive gay informants, lipodystrophy challenged their control over their HIV status in social situations. In effect, this visibility of illness moved their serostatus from a private and personal experience into a “public spectacle” (Persson, 2005, p. 239).

Researchers believe that the level of stigma connected with HIV has decreased considerably since the early epidemic yet continues to pose a serious challenge for HIV prevention and care efforts (Chenard, 2007; Herek, Capitanio, & Widaman, 2002; Lee, Kochman, & Sikkema, 2002; Parker & Aggleton, 2003). Some label the HIV stigma as the most important social and psychological issue of the HIV experience (e.g., Moneyham et al., 1996), while others (e.g., UNAIDS, 2006) underscore that it is one of the greatest barriers to the provision of treatment, care, and support to HIV-positive people, exacerbating the already heavy burden this group experiences. HIV stigma can harm those living with HIV in many ways, perhaps most detrimentally through poorer mental health (Simbayi et al., 2007; Teti, Bowleg, & Lloyd, 2010). In multivariate analyses conducted by Venable, Carey, Blair, and Littlewood (2006), depression, serostatus disclosure, and poor HIV medication adherence were independent correlates of stigma-related experiences among HIV-positive study participants.

Studies suggest that seropositive gay men are particularly affected by HIV stigma because they are seen as having self-inflicted HIV by engaging in sexual behaviors of a socially unacceptable nature (Herek & Capitanio, 1999; Nepal & Ross, 2010). A mixed-

methods study on the effects of HIV stigma on seropositive MSM revealed that it was linked to increased levels of depressive symptoms, anxiety, and loneliness, a history of suicidal ideation, and using avoidant coping strategies (Courtenay-Quirk, Wolitski, Parsons, & Gomez, 2006). While responses to HIV stigma may include a variety of stigma management strategies, Chenard (2007), who analyzed interviews with 20 HIV-positive gay men, observed that gay men managed stigma threats by use of strategies within a continuum from preemptive disclosure to hiding.

With the notable exceptions mentioned, little research concerning HIV stigma from the perspective of gay men has emerged, as noted by, for example, Courtenay-Quirk and colleagues (2006). In particular, there is an evidence gap with regards to how HIV stigma is perceived and experienced by gay men who have become HIV-infected and how they respond to this stigma. Given that stigma is rooted in the concept of deviance and social norms, the perceptions and experiences of stigma likely differ among social groups (Herek & Capitanio, 1999). In-depth explorations of how HIV stigma presents itself and how it is perceived and handled by gay men are therefore meaningful and can also improve understanding of how to create programs to mitigate HIV stigma's harmful effects. Additionally, such research is a crucial effort in the ongoing facilitation of medical support and maximization of the quality of life for seropositive gay men.

## METHODS

The overarching aim of this formative qualitative study was to supplement the quantitative data from other studies with gay men's narratives of living with HIV to understand how they perceived, experienced, and responded to HIV stigma. The study was approved by the institutional review board at the authors' institution.

### Sampling and Data Collection

HIV-positive participants were men drawn from a community-based organization (CBO),

which addresses psychosocial concerns related to HIV, in a large city in the Southern United States. Participants were recruited through non-probability, purposive sampling techniques, including snowballing, the CBO inviting participation through its membership base, and participants being asked to endorse the study to eligible participants in their social networks. Inclusion criteria for participants in this study were being male, 18 years of age or older, and HIV-positive, and identifying as gay or bisexual.

Potential participants were asked to participate in an individual or group interview. They were free to choose, as both were considered appropriate formats for providing detailed insight of HIV stigma and because serostatus can be a highly sensitive subject. Participants were not financially compensated, although refreshments were provided. All participants received an oral and written explanation of the content of the project and were asked to read and consent to a consent form. Prior to starting the focus group or interview, participants also completed a brief, self-administered questionnaire, which assessed demographics.

Interviews were conducted with men during the spring of 2012 in an anonymous building in a residential area, which offered the participants full privacy. Eleven men chose to contribute their views in a focus-group discussion (FGD). The three FGDs lasted 65 min to 115 min (average time of 98 min). Each of the eight in-depth interviews lasted 35 min to 84 min, with an average duration of 61 min. All FGDs and interviews were conducted in English and were led by the first author, who has experience in qualitative research and working with HIV-positive individuals. An interview guide was used to structure the individual interviews and FGDs. It included: (a) a set of open-ended questions to elicit input regarding experiences with serostatus disclosure, situations of HIV stigma, and perceptions of the social environment for seropositive individuals; and (b) prompts to facilitate discussion and further details regarding stigma. Examples of core stimulus questions are, "What are your experiences with HIV stigma?" and "How do you see HIV stigma manifested in your commu-

nities?" Core questions asked of participants did not differ between the individual interview and focus-group formats, but in both formats, prompts and follow-up questions evolved organically from the responses of participants. Further, prompts in the FGDs provided more information about community norms and variability, while prompts in the interviews elicited more detailed narratives of individual experiences and perceptions of HIV stigma. The first author engaged in active self-reflection to recognize when data saturation had begun (Marshall, 1996; after about 17 conversations); this also involved recognizing when she was less awash in description and more awash in thoughts of emerging themes.

### Analysis

We followed the analytic phases of thematic analysis as outlined by Braun and Clarke (2006). First, we familiarized ourselves with the data. Orthographic transcriptions were carried out from the audio-taped interviews and focus groups, capturing the verbatim account of all verbal utterances. The data corpus (i.e., all data collected) constituted more than 112,000 transcribed words from 19 data items (interviews and FGDs) as well as field notes taken immediately after each data collection activity. Given our interest in HIV stigma, the corpus was restricted to the data set identified by this analytic interest and consisted of all instances across the data corpus with relevance to HIV stigma. The set was identified by reading and re-reading the transcripts. Second, we generated initial codes by canvassing the data set and systematically demarcating interesting features of the data. Our collating of data relevant to each code kept some of the surrounding data such that context was maintained.

Next, we searched for themes. Thematic analysis is defined as "a method for identifying, analysing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79). We applied thematic analysis because of its ability to provide a detailed and complex account of data, offer a lens on experience, and allow one to go deeper into the data and interpret aspects

of the research topic (Boyatzis, 1998). The approach was suitable for our research also because it is compatible with the constructionist paradigm (Braun & Clarke, 2006).

The process of searching themes involved looking for repeated patterns, responses, or meaning across the entire data set that captured something seemingly important in relation to our overall research question (Braun & Clarke, 2006). It was a data-driven and inductive process, meaning that the identified themes were strongly linked to the data themselves (Patton, 2002; Ryan & Bernard, 2003). Specifically, the process of inducing themes was based on open coding using analysis of words (word repetitions, key terms, keywords in contexts; Ryan & Bernard, 2003). That is, we paged through the texts (corpus) multiple times, noted words and synonyms that the informants used often—because repetition is one of the easiest ways to identify important ideas—identified key words, and systematically searched for all instances of the word or phrase (Ryan & Bernard, 2003). Bernard (2000) refers to this as the ocular scan method.

We collated codes into potential themes and gathered all data of relevance to each potential theme. The process involved refocusing the analysis at the broader level of themes, by which we sorted the codes into potential themes and considered how different codes combined to form a larger theme. It was a recursive process of constant moving back and forth between the data set, coded excerpts, and the preliminary analysis. As suggested by Braun and Clarke (2006), we reviewed themes and checked that data within themes cohered meaningfully and themes were distinctive. We compared and discussed the results of the analyses until we agreed on a final version of codes. In generating clear names for each theme, we attempted to identify the essence of each theme. Lastly, once we had organized the data to show patterns in the content, the analytic process progressed to interpretation, whereby we attempted to theorize the significance of the themes and their broader meanings (Patton, 2002), while linking them to previous literature. An abbreviated form of respondent validation

was performed whereby two participants read through our findings. They offered agreement and no suggestions for changes.

## RESULTS

### Participant Characteristics

The sample included 19 men. Their ages ranged from 32 to 66 years, with an average age of 48 years old. While 2 men had lived with an HIV diagnosis for less than a year, 2 had been diagnosed 26 years before the study. The average number of years living with an HIV diagnosis was 13. Three quarters of the participants were White and 5 men identified as Latino. All self-identified as gay. Eight men reported they were single, 8 had a partner (6 lived with their partner), 2 were dating, and 1 responded that he was in a transition phase with regards to relationships. All but 1 of the participants had at least some college, with 42% stating that they were college graduates. We did not systematically collect data about family arrangements, but 2 participants revealed that they lived with their parents (2 had a roommate).

### Themes

The analysis identified six themes of how gay seropositive men residing in a large, Southern U.S. city perceived, experienced, and responded to HIV stigma. These themes were: stigmata, encountered HIV stigmatization, HIV stigmatization within gay communities, internalized HIV stigma, the second closet, and adaptation to HIV diagnosis and stigma. All quotes are accompanied by the name (pseudonym) and age of the participant.

### *Stigmata*

A first theme of HIV stigma was the idea of stigmata—visible marks and signs that designated individuals as HIV-positive. Throughout the interviews, the respondents talked about three stigmata of HIV: “the HIV look,” medications, and gayness. First, HIV

stigma manifested through the physical stigmata of “the HIV look” because, as William (age 45) said, “A lot of people have a look associated with HIV.” However, we noted that the informants confessed this look was less frequently observed in the last few years and only a few of the older men expressed personally having recently felt stigmatized on the basis of their HIV-related appearance. According to Persson (2005), visible physical changes, particularly lipodystrophy, that can present due to HIV or its medications are generally considered unattractive and especially stigmatizing. In the minds of the respondents, the HIV look inscribed a stigmatized disease on the body positive.

Second, and relatedly, HIV medication was a forceful mark of HIV, as the following comment reveals: “I really don’t know if I would take medication to live if it is going to make me look different, or look odd” (Ethan, age 45). Antiretroviral therapies were constant and powerful mementos of the disease. Ethan remarked how taking HIV medications was a big step for a lot of people: “There’s this big fear about, ‘oh meds, I’m going to have to go on meds’” because it was attached to stigma. As Jacob (age 32) clearly voiced: “There’s not only the stigma of finding out they’re HIV but also the stigma of meds.”

Third, HIV stigma was bound up with pre-existing stigmatizing attributes of male gayness. The following comment from Peter (age 32) captured this point: “I think very much of it [stigma] is it’s still considered a gay disease . . . there’s association tied to the disease with gay people.” Several respondents mentioned that they encountered an expectation that being gay meant being HIV-positive, like Kevin (age 45) who said: “When I came out as a gay male to my mom, one of her first questions was ‘aren’t you scared of AIDS?’” The conflation of one stigma with the other created a costigmatization of male homosexuality and seropositivity, which in the research literature often is referred to as double stigma (Grossman, 1991) or layers of stigma (Herek, 1999). We return to this issue indirectly in the context of the theme of the HIV closet.

### ***Encountered HIV stigmatization***

One of the questions asked was how the participants saw HIV stigma manifested in their own gay and larger communities. Although several respondents expressed a belief that HIV was less taboo today than it used to be—“I think that stigma has gotten better in many ways” (Daniel, age 53)—the men’s narratives portrayed a wide range of stigma expressions, ranging from subtle to blatant discriminatory behaviors due to their HIV-positive status.

Almost all interviewees expressed a strong perception that HIV stigma was subtle. It included gossip behind people’s back, warnings not to date individuals who were believed to be HIV-positive, requests not to talk about HIV in public settings such as at parties, avoidance behavior such as testing for HIV outside of one’s own city, and a general judgment of HIV-positive people as being morally deficient. The following quotations provide a few illustrations: “There are many instances over the years where I have learned that there is that stigma, people who do that talking behind people’s backs, you know, ‘oh don’t date him, he’s positive’” (Luis, age 37); “The rumor mill is vicious online and also wherever your social groups are, and if you come out as positive to one person, that can be circulated very quickly” (Jacob, age 32); and “A good friend of mine, he told me he went to [city] to get tested because he did not want to walk into any of the clinics here because he didn’t want to be seen going into that clinic” (Liam, age 49). Subtle stigma was perceived to exist also on a structural level with system obstruction, particularly in regards to insurance. A number of men spontaneously described how having public insurance was better than private insurance coverage.

Relatedly, respondents’ narratives revealed an understanding of HIV stigma being (re)generated through a vociferous silence concerning HIV, which was perceived as sustaining a discourse of subtle stigma. This silence was perceptible at most levels of society, including the structural level such as in health care settings. For example, in one of the focus groups, Tristan (age 45) observed: “You can

go into any of the clinics and they have other educational stuff, but nothing on HIV." Daniel (age 53) continued: "I think most lobbies are being sanitized. I've been seeing that, where there's nothing about HIV in the lobby area." The participants found there was a silent stigma at the societal level with limited to no coverage of HIV in the print and electronic press. At the community level, few open conversations about HIV took place. Adam (age 50) lamented: "Nobody on the street talks about HIV anymore, nobody. And I think a lot of that is the stereotype and the stigma." Nowhere was the silent HIV stigma as pronounced as in the African American and Latino communities and among religious groups. According to some interviewees, in the African American communities, HIV was a sign of weakness, and in the Latin communities, it showed a lack of masculinity. James (age 50) described: "The African American community and how they respond to HIV is through a lot of silence and denial, and same thing with the Latino community."

Stigma experiences were not always subtle. At the other end of the spectrum, stigma of HIV was blatantly apparent from rejection, threats to personal well-being, verbal harassment, and job discrimination including loss of employment. Patent stigma was evident in the stories of Jacob (age 32), who had encountered violation of confidentiality regarding seropositivity from his physician, and Liam (age 49) who had faced public harassment in a grocery store: "This one guy came up to me and said 'you fag,' da-da-da, and started, 'I heard that you had that gay disease.' And da-da-da and he is just going on and on and on. I'd never met this person in my life!" Lucas (age 39) had lost advancement opportunities due to stigma: "I know the only reason why I didn't get that work is because I'm HIV." The most commonly mentioned manifestation of HIV stigma was sexual rejection, which we address in the next section on stigma in gay communities.

### ***HIV stigmatization within gay communities***

Our analysis revealed that, overwhelmingly, the men found stigmatization to be most

intensely felt within their own gay communities. Sheldon (age 61) explained the stigma in the gay community this way: "I would say that gay people who are HIV-negative have a much bigger issue with people with HIV than the straight population does. Gay people who don't have HIV are really downright nasty about it." In fact, the stigma attached to HIV was perceived as dividing gay men into separate HIV-negative versus HIV-positive cohorts. Sheldon continued: "In the gay community, there's a real deep chasm for a lot of people between people who are HIV-positive and people who are HIV-negative. It's the Grand Canyon of gay culture." Additionally, the cohort effect was noticeable as a generational disconnect in that older gay men were perceived as being more concerned about HIV and its stigma than were younger men.

The stigmatization and division between gay men were particularly noticeable with respect to dating and were encountered online more than in any other arena. As Matt (age 51) put it: "If you don't have a little complex about being HIV-positive, go on the dating sites and you'll get one real quick!" The stigmatization extended into sexual situations. Indeed, almost every interviewee had experienced rejection by potential sexual partners due to having HIV, as evident in the following comments: "I've gotten rejected sexually. Usually it's online, and a few times it's face to face" (Daniel, age 53); "And people will put on there, 'you must be HIV-negative.' And that hurts, to read that" (William, age 45). There was an agreement that HIV was perceived as the anti-Viagra for many gay men. In the words of Liam (age 49): "It's a total mood-killer . . . Just talking about HIV or AIDS is the anti-Viagra."

The ignorance regarding HIV mentioned earlier extended to potential sex partners. Much of the stigmatization the participants had experienced from potential sex partners could be attributed to an unreasonable fear on the part of HIV-negative men, who failed to understand issues such as likelihood of infectiousness according to viral load. Yet the stigmatization they encountered within gay communities meant that a few of the interviewees avoided dating altogether and others dated seroselectively, seeking out only other seropositive partners for sex.

Jacob (age 32) explained: "In terms of dating, for a while, I was very clear that I only dated other positive guys until I met my current partner." This statement concurs with Kevin (age 45) who said: "I always seek out other people who are positive, so I don't have to go through the disclosure of it."

### *Internalized serostigma*

One of the most profound themes that we identified was internalized HIV stigma, spontaneously expressed by almost all participants and referring to the HIV-positive person's internalized negative attitudes and feelings about their own HIV status. Similar to internalized homonegativity (Malyon, 1981), self-stigmatization imposed from external situations appeared to develop through a process of introjections in which negative views of HIV-positive people were taken in and incorporated into the individual's self-representation. For example, Matt (age 51) said: "Although I've accepted it [HIV diagnosis] now, I still . . . I've been suicidal, I've done crazy things, I've gotten heavily into drugs, alcohol, you name it, all to try to dull that stigma that was amplifying inside myself, feeling it from externally, but then internalizing it." Similarly, Ethan (age 45) stated: "I've been around for a while and I know that when it first came out it was a bad disease, it was a dirty disease, and so I think because that is the way I was brought into it I can't help but to think that still."

The participants thought many HIV-positive people had varying internalized levels of HIV stigma and acknowledged struggling with such internalized serostigma themselves: "Internalized stigma is to me the thing that I've had to overcome," Roger (age 66) said. This participant, and others like him, described having feelings of shame, guilt, and lack of self-worth, and feeling damaged because of being HIV infected. James (age 50), who had lived with HIV for 24 years, explained: "Even today, no matter how I might improve my physical status through diet and exercise and vitamins and walking and blah, blah, blah, I can't quite shake the feel-

ing that I'm still damaged goods. Less than. Less than perfect."

Psychologists Mohr and Fassinger (2006) wrote that the psychological health of members of stigmatized groups is related to the ways in which they evaluate and react to their devalued collective identities. Among men in our sample, HIV stigmatization was commonly directed inward and became intrinsic to their self-concept, negatively influencing gay men's well-being. Not only did serostigma internalization affect their psychological health, but men's cognitions and behavior changed accordingly. Specifically, some participants appeared to internalize serostigma such that they anticipated rejection in various forms due to their positive status. Kevin (age 45) said: "That fear of people rejecting me, fear of people judging me because I have HIV, and I think sometimes I probably misinterpret people's attitudes and that I am placing, I am sort of, am placing my own stigma on to them, thinking they are stigmatizing me whereas I'm probably just stigmatizing myself." A few participants remarked that they avoided dating, relationships, and opportunities for intimacy, because, as Ethan (age 45) explained: "That [fear of rejection] may even be a contributing factor to me being single. It is a little bit in there, 'oh, why even go there?'"

### *The second closet*

As could be expected given the parallel between internalized homonegativity and internalized serostigma, the closeted nature of HIV emerged as a weighty theme that characterized men's situations of living with HIV in a Southern U.S. city. Searching for contradictory data showed that not all informants were closeted about their serostatus, like William (age 45) who was at the opposite end of the spectrum: "If it comes up, I have no issue whatsoever telling anyone my status." Yet, the significance of this theme is striking, as we did not ask men about it directly; rather, it emerged organically throughout the course of the interviews. Tellingly, most participants used the closet metaphor, as this 45-year-old: "It [HIV] is still kind of in the closet

here, and that is kind of how I feel about my status, it is in the closet" (Ethan).

Many participants described how they and people they knew, for fear of ramifications devised strategies of hiding their seropositivity, made easier by the fact that the disease is concealable or a hidden stigma (Goffman, 1963). In one vivid account from Kevin (age 45): "When I finally disclosed to him, he said, 'oh good, now I don't have to hide everything in my house,' and I was like 'what?' and he said, 'oh, every time before you came over, I would put away anything, magazines, that are related to HIV, pill bottles.' He said, 'I would completely clean the house out, and make sure nothing was out that said I was positive.'" A certain level of self-spectatoring helped to keep HIV hidden, as did self-censoring of information and behavior. Jerome (age 63) explained: "I've had cancer, non-Hodgkin's lymphoma, and my lymphoma was Burkitt's lymphoma, which is AIDS-related, it's HIV-related . . . and I self-censored that. I would tell people I have non-Hodgkin's lymphoma, but I wouldn't tell a soul, you know, certainly nobody at work—everybody at work knew that I had cancer, that I had non-Hodgkin's lymphoma, but I didn't tell it was Burkitt's because they might think it's—they could go on the Internet and find that out and see that it's HIV-related." Hiding their socially devalued seropositivity from others offered instant self-protection and allowed them to pass as nondeviant.

Whereas concealment was a rational self-protection strategy, being closeted required continuous self-censoring and was psychologically taxing. Some of the men expressed that coming out of the second closet would be emotionally cathartic. In the words of Ethan (age 45), who had been HIV-positive for 8 years: "I would just like to just come out of the closet and just say 'I am positive.' For me. That would benefit me . . . It's just like coming out all over again, [but] it would just be a big relief." Asked what might prompt that process, Ethan replied, "It would be having a partner who understands and I feel complete with, or possibly just from being exhausted of hiding it . . . I think after years and years of hiding it."

(Lack of) serostatus disclosure was an important subtheme of the HIV closet, with fear of potential discrimination and rejection as the expressed reason: "I would never be open with my family about it [HIV diagnosis]. And the reason for that is that I don't wish to get the judgment and disdain from my father and my stepmother that I would get. I've already seen them treat my stepsister miserably because of her seroconversion" (Sheldon, age 61). The most frequently mentioned group of people to whom the participants would not disclose was employers. Jerome (age 63) remarked: "I haven't told a soul at work . . . I don't want anybody at work to know." Daniel (age 53) continued: "I was worried at [organization] too. I was in a double closet on HIV and being gay."

Although no clear pattern was discernible (we did not ask about symptomatology), it seemed that those respondents with increased symptomatology and who had lived with HIV for a longer period of time more readily disclosed their HIV status, which was possibly linked to a lessening of internalized stigma due to increased time dealing with HIV-related issues. According to Matt (age 51), who had lived with HIV for 14 years: "My family knows [that I am HIV-positive]. They didn't know for years, and there were health issues that kind of pushed me to tell them . . . it was an opportunity to come clean and tell them that part." Nonetheless, disclosing their serostatus was difficult for many, as one participant observed: "We are coming out of a second closet. And we're in pain still from the first closet and we get this trauma coming out of the second one" (Daniel, age 53).

### *Adaptation to HIV diagnosis and stigma*

In response to questions about how they dealt with receiving an HIV diagnosis and with experiences of HIV stigma, a theme of adaptation became clear. There was a narrative story of adjustment for many of those who had dealt with HIV for a longer period of time. For most, it seemed the adjustment approximated a grief process, characterized in particular by



the emotions of denial, anger, depression, and for a few, eventual acceptance, which typically took years. In the words of Kevin (age 45): "It is a grief process. You're grieving the loss of all this life you thought you were going to have." The gay male respondents often reported having feelings of shock and denial during the first stages. Denial was characterized by a refusal to accept the reality of the situation: "I'm one of those guilty ones that was HIV[-positive] for many, many years, that was in total denial because it wasn't affecting me, it didn't affect me. At the beginning, when I wouldn't talk about my HIV, I think a lot of it was the guilt" (Liam, age 49). Likewise, Kevin (age 45) stated: "I immediately started having those, you know, all this, 'oh, it's not true, this isn't really happening to me.' I was angry at myself!"

Frequently, people were catapulted from denial into a period with depressive symptoms and suicidal ideation. Elijah (age 34) said: "I just thought of suicide. I didn't deal with it [HIV diagnosis]. I put it on the back burner." In the experience of Matt (age 51): "There were times when I did crazy things to hurt myself and thought about death—very serious about doing things. I could have continued down that path because a lot of people do. A lot of people kill themselves. Or kill themselves indirectly, through drug addiction and abuse." Although we did not specifically inquire about suicide, of the 19 interviewees, 5 stated that they had contemplated suicide following their diagnosis and several others noted that their partners and friends had attempted suicide after receiving an HIV diagnosis. With depression, the seropositive men had begun to understand the certainty of the situation. Therapy, in the initial phase and sometimes ongoing for years, was used by the majority as an aid in the adaptation process. Additionally, accessing a gay doctor and becoming advocates with the capacity to resist stigma situations functioned as proactive strategies of handling the HIV diagnosis and its stigma. The following quotations provide a few illustrations of such adaptations: "I went to therapy. I got a therapist and she was very helpful and that was probably after a year of knowing" (William, age 45). "I also have a therapist who I

see. And I'm very open with her about it [HIV] and she's every supportive" (Sheldon, age 61). "I'm an advocate. I want to break the stigma. I want people to understand what it's like living with AIDS" (Liam, age 49). Finally, Matt (age 51) noted: "Kind of how I think we all need to deal with our internal stigma is to become advocates."

At the same time, the HIV diagnosis was a life-changing event, which a few turned into self-empowerment. The empowered self is described by one respondent: "I say to myself 'thank you HIV, you gave me life' . . . HIV gave me life. It gave me a perspective on my life. It saved my life. You can ask anyone who knows me, I was a wild boy. It saved my life" (William, age 45). Largely, the process of self-acceptance moved from the shame of living with a socially discrediting identity to engagement in an internal change process, which leads to self-acceptance and, for a few, to self-empowerment.

## DISCUSSION

In considering the findings and the discussion, the reader should keep in mind our social constructionist framework and that the researchers are White, seronegative, and able-bodied. However, both younger and older, male and female subjectivities are present. The limitations of our study include its comparatively small size, although data saturation was reached, and the fact that the respondents were all gay and predominantly White. Our results may be less relevant to younger ethnic minorities and rural gay/bisexual men. The HIV-positive gay men in this study were a convenience sample that consisted of those willing to collaborate on a study of HIV stigma, and it is likely that they are not representative of all gay HIV-positive men in the Southern United States, particularly those who feel most stigmatized and closeted about their HIV status. This study can only be taken to be suggestive and not conclusive, but despite the potential contextual limitations, our data provide a rich view into the HIV stigma perceptions, experiences, and responses for this sample of gay HIV-positive men.

The study purpose was to provide, through thematic analysis of semistructured interviews and focus groups, an account of how HIV stigma presents itself, how it is perceived and handled by gay men with HIV/AIDS in the Southern United States, one of the epicenters of HIV infections in the country. In analyzing these men's narratives, it became clear that there were six main themes. A premise of the study was that stigma is rooted in the concept of deviance and cultural norms, and indeed, one of the stigmas of HIV revealed by the participants was male homosexuality. Historically, the disease has been linked to subgroups of people who already experienced social marginalization, in particular gay men (Herek & Capitanio, 1999). We found that in men's perspectives, large segments of the public do not distinguish between identity and behavior; thus, gay and HIV have become conflated, such that people's perceptions of HIV are largely indistinguishable from their perceptions of male homosexuality. But the disease also manifested with the physical stigmata of HIV medications and lipodystrophy, which Persson (2005) writes about. Although such images have almost disappeared as a result of medical advances (fewer pills and side effects), the visibility of the disease has the capacity to accentuate stereotypes and to perpetuate stigma. Possibly, fewer medications with even fewer stigmatizing side effects can help reduce stigmatizing attitudes.

Inevitably, the interviewees' stories revealed that there is significant stigma still attached to HIV, as found in similar studies (Nepal & Ross, 2010; Teti et al., 2010). In the present study, it seemed ignorance may lie at the root of stigma and contribute to its regeneration, in particular through an ongoing social invisibility of HIV experienced at the institutional, community, and interpersonal levels. The men described encountering both subtle and overt stigmatization from people in their social milieu and from society's institutions through, for example, violation of confidentiality regarding their HIV status. Stigmatization was particularly observed from African American and Latino communities. This may not be unique to our sample, as research by Diaz (2006) re-

veals. Diaz, who examined the presence of HIV stigma among seronegative Latino MSM, concluded that more than half of the respondents thought HIV-positive gay men were personally responsible for their seroconversion and were more promiscuous than them.

Indeed, these qualitative data illustrate the ways in which gay seropositive men perceive that stigma is expressed, not just through attitudes and behaviors of members of the larger society, but specifically through those of the gay communities. HIV, most interviewees observed, was enveloped by silence and avoidance within the very communities where it is most prevalent. There was limited public dialogue of what HIV and the stigma meant not just for the men affected but also for gay communities altogether. There was silence on HIV between lovers, between parents and their children, media and its readers, policymakers and their constituents, which not only strengthened the status-quo stigma, but promoted ignorance. The finding that HIV stigmatization is intensely felt within gay communities and seems to have divided gay men according to serostatus supports quantitative research that has located stigmatization of HIV-positive gay men within communities of gay men (Dowshen, Binns, & Garofalo, 2009) and documented a growing division between seronegative and seropositive MSM (Courtenay-Quirk et al., 2006; Smit et al., 2012).

In addition, sexual rejection due to having HIV was a unifying reality experienced by the majority of those interviewed. Keeping the theme of internalized stigma in mind, it is quite likely that such situations affected the men's self-esteem and self-confidence. Overall, the findings demonstrate that HIV stigmatization influences gay men's psychological experiences with HIV infection and negatively impacts their well-being. However, although romantic and sexual rejection was painful, there was understanding as to the seroselective gay dating culture. In fact, finding a seroconcordant sexual partner served to alleviate concerns regarding the potentially negative consequences of revealing their seropositive status, essential for those who internalized serostigma and avoided

disclosure. We found evidence that the empirically documented (in the present study and other studies; e.g., Cobb & De Chabert, 2002; Herek et al., 2002) social repudiation and lack of knowledge surrounding HIV had led to internalized HIV stigma among many of the gay men in our sample, in line with Goffman's (1963) thesis regarding stigma. Likely, internalized serostigma developed as the men directed negative cultural values about HIV inward, thereby assuming a "spoiled identity" characterized by shame, self-accusations, and feeling "dirty." Like Goffman, Foucault (1982) emphasized the importance of the power of discourses on self-identity. Importantly, he noted the ways in which external persons, often those with authority, shape self-definitions through a "policing" process and that the self internalizes the policers' terms of reference through self-surveillance. According to Foucault, self-identity results from the various discourses available for learning about the self and how this knowledge is taken up by the self and used to produce a truth about the self.

The second closet was a main theme in this study. Given the range of firsthand and secondhand stigma experiences, and the simultaneous experience of social and intrapersonal stigma, it is understandable why retreating into an HIV closet became a rational option, motivated by self-protection, in the lives of men who learn that they are infected with HIV. Yet being closeted required substantial effort, in particular continuous management of stigmatizing information, and appeared to be psychologically taxing. Such closetedness unfortunately also reproduces the hegemonic status quo of HIV as a shameful disease, and those who bear the greatest burden become entangled in perpetuating the social avoidance surrounding serostigma. Research indicates that serostatus disclosure can help build individuals' comfort about living with HIV and the stigmatization that often comes with it. Like Chenard (2007), Makoae and colleagues (2008) found some evidence that HIV disclosure facilitated stigma coping and helped resolve contradictions between self-appraisals and reflected appraisals. Similar to our findings, in a sample of

HIV-positive men and women, Lee et al. (2002) found that most felt some degree of embarrassment about being seropositive and experienced difficulties in disclosing their status to others.

With the theme of adaptation, we described how HIV and its stigma may be experienced differently across the life course, as a trajectory that approximated a grief process. From denial and shame, many interviewees moved to engagement in a process of internal change, occasionally facilitated by activism, which ultimately led to acceptance. According to Ramirez-Valles and Brown (2003), despite the obstacle of stigma, HIV-positive gay men who become involved in community-level HIV-related activities discovered a sense of self-esteem and empowerment. Through activism, HIV-positive people can work toward simultaneously reducing intrapersonal stigma and societal views that perpetuate HIV stigma. Further, as also suggested by others (Lee et al., 2002), HIV support groups may be helpful to lessen internalized serostigma.

Our results firmly support a scaling up of stigma-reduction initiatives to increase awareness of and counter stigmatization of HIV-positive gay men, particularly within gay communities. The men's narratives imply that improving knowledge about HIV transmission, HIV infectiousness, and understanding about living with HIV could help resolve some of the stigma that exists due to lack of awareness and understanding. This could be attempted through, for example, HIV awareness efforts that reach out to a diverse public. Such programs may help counter some subtler forms of HIV-related stigma, but for more institutionalized stigmatization, explicit antidiscrimination legislation in areas such as housing, health care, and employment may be needed, as proposed by Parker and Aggleton (2003). Addressing structural issues is essential to mitigating stigma. Practically, structural relations that produce stigma, such as legislation, involve individuals in positions of power and influence; thus, approaches must involve such key persons. Therefore, community members at all levels, like policymakers, health care personnel, people working with faith-based organizations,

and people living with HIV must be integral members of all efforts addressing HIV-related stigma. A useful starting point would be open conversations, debates, and discourses that can begin to overcome the culture of silence surrounding HIV that breeds ignorance, perpetuates inequalities in relationships, and promotes stigma.

In conclusion, the present in-depth exploration advances the literature by showing how HIV stigma is perceived, experienced, and responded to in the daily lives of gay men. Our results are based on the findings of a single study in a Southern U.S. city, and their relevance in other contexts needs to be tested. It is important to follow up these findings with additional qualitative and quantitative research to better understand questions such as the experiences of HIV stigma in rural settings and among ethnic minorities. A central focus of intervention research is advancing effective strategies for lowering stigmatization at the societal level. Although exploratory, the results outlined here can serve as a beginning framework for understanding and assisting seropositive gay men who experience HIV stigma. Additionally, the results can be helpful for therapists, case managers, and others who work with HIV-positive men. The knowledge presented here is especially important because it is realistic to expect that in a social climate in which HIV is becoming increasingly invisible and closeted, and in which infections are on the rise, gay and bisexual men will be increasingly affected and infected by HIV.

#### ACKNOWLEDGEMENTS

The authors report no real or perceived vested interests that relate to this article (including relationships with pharmaceutical companies, biomedical device manufacturers, grantors, or other entities whose products or services are related to topics covered in this manuscript) that could be construed as a conflict of interest. The manuscript has not been published elsewhere and has not been submitted simultaneously for publication elsewhere. The study has received institutional review

board approval. We are indebted to the men who volunteered their time and perspectives. We also gratefully extend our thanks to LIVE Consortium, the community-based organization that collaborated with us on this project.

#### FUNDING

The study was underwritten by the generous contribution of Charles Gulick in loving memory of Allen Anthony Huff.

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