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## Perceived and experienced stigma among people living with HIV: Examining the role of prior stigmatization on reasons for and against future disclosures

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### ABSTRACT

HIV remains a significant health concern entering the fourth decade of the epidemic [Centers for Disease Control and Prevention. 2014. *HIV basics*. Retrieved from <http://www.cdc.gov/hiv/basics/index.html>], and people living with HIV continue to grapple with stigma. This study uses Leary and Schreindorfer's [1998. The stigmatization of HIV and AIDS: Rubbing salt in the wound. In V. J. Derlega & A. P. Barbee (Eds.), *HIV and social interaction* (pp. 12–29). Thousand Oaks, CA: Sage] conceptualization of stigma to explore prior stigmatization on reasons for and against future disclosures. We interviewed HIV+ individuals ( $N=59$ ) and used a combination of deductive and inductive coding to analyze participants' responses. Deductive codes consisted of four stigma characteristics (pose a threat to others' health and safety, deviate from group standards, create negative emotional reactions in others, and failure to contribute), experiences of feeling stigmatized due to HIV status (yes or no), and the degree to which HIV stigma was a concern (major, minor, or no concern). Inductive coding identified examples of perceived and experienced stigma and stigma concerns on future disclosure decision-making. Practical implications discuss individual, institutional, and societal stigma-reduction interventions and programs.

### ARTICLE HISTORY

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### KEYWORDS

HIV/AIDS; stigma; perceived stigma; experienced stigma; disclosure; disclosure decision-making

The number of individuals 13 years or older living with HIV in the United States exceeds 1.1 million (Centers for Disease Control and Prevention [CDC], 2014). HIV is now categorized as a treatable chronic illness in the United States in part because people have access to highly active antiretroviral and other therapies (HAART). People living with HIV (PLWH) not only manage living with a chronic condition but also grapple with stigma. Although knowledge of HIV has increased, HIV stigma still persists after more than 30 years. The Kaiser Family Foundation (KFF, 2011) reported that some United States adults feel discomfort about interacting with HIV+ individuals. For example, 18% say they would be uncomfortable working with someone HIV+. Besides stigma-related

contact, perceptions that individuals with HIV are responsible for their infection remain (Herek, Capitano, & Widaman, 2002) with an association of HIV and AIDS<sup>1</sup> with specific behaviors and groups such as homosexual, bisexual, and injection drug using communities (Herek et al., 2002; Leary & Schreindorfer, 1998). Moreover, 29% agree that “it is people’s own fault if they get HIV” (KFF, 2011).

The negative consequences of HIV stigma are well documented (see Greene, Derlega, Yep, & Petronio, 2003; Mahajan et al., 2008). HIV stigma is associated with inhibiting early detection and treatment, poorer medication adherence, engaging in risky sexual behaviors, nondisclosure of HIV status, limited social support, and increased risk of depression. The present study focuses on how prior stigmatization influences reasons for and against future disclosure of HIV status to social network members. We begin with a review of literature on conceptualization of stigma broadly and HIV stigma specifically.

### **Conceptualization of stigma and HIV stigma**

Goffman (1963) is credited with early conceptualizations of stigma and defined stigma as “an attribute that is deeply discrediting” and a mark that reduces the bearer “from a whole and usual person to a tainted, discounted one” (p. 3). Goffman held that stigma arises from one of three sources: abominations of the body, blemishes of individual character, and tribal identities/group affiliations. In the case of HIV, stigma can be attached to multiple characteristics across all three sources, and subsequent theorists have advanced Goffman’s work in ways that have further enhanced theorizing regarding HIV stigma.

Leary and Schreindorfer (1998) extended the definition of stigma for use in health contexts and suggest that stigma exists to the extent that a person’s identifying traits or characteristics lead to avoidance, rejection, or ostracization from others. According to Leary and Schreindorfer (1998) reconceptualization, there are four stigma characteristics: pose a threat to others’ health and safety, deviate from group standards, create negative emotional reactions in others, and failure to contribute. For example, HIV’s status as communicable and presently incurable but treatable contributes to the construction of PLWH as representing a health threat to others. In this case, fears about contagion and the desire to avoid infection can result in the further stigmatization of PLWH (Herek et al., 2002; KFF, 2011). Negative assumptions exist about groups that have been disproportionately affected by HIV. These assumptions, for example, include that the person contracted HIV due to immoral behaviors such as intravenous drug use or deviant sexual acts. Not only does HIV evoke fear and anger for the reasons described above, but it may also make others uncomfortable (Herek et al., 2002). In more advanced stages, AIDS may become progressively more visible to others through physical manifestations that may be unsettling for others including Kaposi’s sarcoma, emaciation, hair loss, and disfigurement.

### **Public perception**

Since the epidemic emerged in 1981 to the present, HIV has been met with high levels of societal hostility. For example, a nationwide phone survey conducted in 1999 in the United States reported that a majority of Americans supported mandatory testing for people at risk for HIV (Herek et al., 2002). At least one in five persons surveyed said they

“feared” PLWH, and one in six admitted to feelings of “disgust” (Herek et al., 2002). Almost half felt that PLWH are responsible for having their illness, and about a quarter reported that PLWH “got what they deserve” (Herek et al., 2002).

Beyond the overall negative perceptions of HIV, there is also considerable misunderstanding among the United States public about how HIV is transmitted. Most people understood that HIV could be transmitted from unprotected sex and/or sharing needles with a PLWH. However, many people believed that HIV was transmitted by casual contact. A nationwide phone survey conducted in 1999 found 50% believed that it could be transmitted by sharing a glass with someone who was HIV+ and 50% believed that HIV was transmitted by a PLWH sneezing or coughing on them (Herek et al., 2002). Thus, people who believe that HIV can be spread through casual social contact may be more likely to fear such contact with PLWH. In the era of HAART, the public also seems unsure how to view HIV (KFF, 2011). A nationwide phone survey conducted in 2011 by the KFF revealed while almost all Americans now believe it is possible for PLWH to lead healthy, productive lives (87% yes) the public is divided on whether HIV should be perceived as a manageable chronic disease, similar to diabetes or high blood pressure (48% agree, 48% disagree).

Unlike other health conditions, HIV meets all four of Leary and Schreindorfer’s (1998) stigma characteristics. A meta-analysis comparing attitudes toward PLWH versus people with leukemia suggested that participants viewed PLWH as more responsible for their health status, more dangerous, more deserving of infection, and tended to avoid them (Skelton, 2006). In Crawford’s (1996) meta-analysis of health professionals’ and students’ attitudes, stigma towards PLWH was higher than stigma toward people with other conditions (i.e. cancer, herpes).

### **Types of stigma**

PLWH contend with two main types of stigma: perceived and experienced stigma (Phillips, Moneyham, & Tavakoli, 2011). *Perceived stigma* refers to real or imagined fear of societal attitudes regarding a particular condition and a concern that these attitudes could result in acts of discrimination directed at individuals with that condition. PLWH may perceive that another is fearful of contagion through casual contact (e.g. Lexas et al., 2006). They may also recognize that someone pities or blames them for their illness or assigns guilt and punishment for their disease. In addition, PLWH may have an awareness of potential social rejection, as well as denial or limitation of opportunities (in community, housing, workplace, and healthcare settings) due to HIV status.

*Experienced stigma* refers to discriminatory behavior or acts directed at individuals because of specific attributes or conditions. For PLWH, these experiences may include denial of rights to health, education, and employment (e.g. Nyblade, 2006). PLWH may also experience being treated differently (e.g. Greene & Faulkner, 2002) and being excluded by family and community (e.g. Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006). In addition, PLWH may be victims of physical and verbal abuse (e.g. Nyblade, 2006; Swendeman et al., 2006). Greene et al. (2003) reported that participants either knew of instances in which people were beaten in response to disclosing HIV infection or feared/experienced this violence themselves.

## Consequences of stigma

PLWH today are living longer and must manage the effect of perceived and experienced stigma on their physical and mental health (Herek et al., 2002). HIV stigma discourages people from seeking HIV education, prevention, testing, and treatment. For example, HIV stigma has been associated with lower levels of HIV testing and knowledge of risk reduction (e.g. Nyblade, 2006), thus presenting barriers to HIV prevention. Fear of disclosure associated with purchasing and taking medicine may also negatively affect medication adherence for PLWH (e.g. Vanable, Carey, Blair, & Littlewood, 2006). Consequently, HIV stigma may lead to delayed diagnosis and treatment and can also present a barrier for PLWH accessing and retention in healthcare services. These physical health consequences of HIV stigma are compounded by mental health outcomes.

PLWH have increased risk for mental health issues. For example, HIV stigma is associated with depression, lack of self-efficacy, and increased psychological distress (e.g. Vanable et al., 2006). Psychological distress is important to consider because it is associated with poor coping, disease progression, and quality of life outcomes among PLWH, as well as perceived lack of support among PLWH (e.g. Catz, Gore-Felton, & McClure, 2002). Thus, HIV stigma may lead to negative psychological outcomes that may, in turn, contribute to decline in physical health discussed previously. These physical and mental correlates of HIV stigma underscore the need to disclose HIV status in order to gain access to social support and potentially buffer the negative consequences of HIV stigma.

## Disclosure and HIV

PLWH not only have to adapt to life with a chronic condition but also cope with stigma. Members of a stigmatized group may attempt to manage stigma via three communication strategies (Link, Mirotznik, & Cullen, 1991): avoidance, nondisclosure, or disclosure. Avoidance involves strategically trying not to talk about something or not to disclose information on a particular topic to another. Through topic avoidance, relational partners protect themselves or their partners as well as maintain their privacy. Nondisclosure may imply the absence of disclosure, or the opposite of disclosure, it can also be conceptualized as a decision “to preserve a more tightly controlled privacy boundary” (Greene et al., 2003, p. 55). Self-disclosure refers to an interaction between at least two individuals where one intends to deliberately divulge something personal to another. PLWH may avoid interacting with anyone except for those who would accept their diagnosis, attempt to conceal their positive status to evade negative reactions, or share their status with others in order to reap benefits. Stigma is thus a crucial feature in HIV disclosure.

Faced with psychosocial and physical issues, PLWH can benefit from disclosing their status in order to gain access to social support (e.g. Greene et al., 2003). Social support is particularly important because it not only enables PLWH to better cope with health concerns but also buffers stress, anxiety, and depression that can result from stigmatization (e.g., Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003). In addition, concealing a stigmatized condition has been associated with substantial psychological and social costs including increased stress, poor mental health outcomes, strained social interactions, and social isolation.

Despite possible benefits, there are a number of potential risks associated with HIV disclosure which PLWH must take into consideration. Some of the risks of disclosing an HIV + status include negative emotional responses, inability to control information, relationship termination, increased stigma, and fear of rejection (see Catz et al., 2002; Derlega, Winstead, Greene, Serovich, & Elwood, 2002; Greene et al., 2003). Consequently, HIV disclosure represents a dilemma because PLWH must risk stigmatizing reactions in order to gain the social support necessary to deal with stigmatizing reactions. PLWH are likely to consider benefits and costs associated with being stigmatized and rejected by others. Simultaneously, HIV nondisclosure reduces the risks associated with being stigmatized and rejected but it also increases the risks of harmful effects associated with concealing a stigmatized condition. For PLWH, it is important to consider the overall benefits and costs associated with disclosure and nondisclosure for self, others, and relationships and make decisions about whether or not to disclose. Based on the research described above the following research questions are proposed:

RQ1: How do PLWH perceive that others view HIV in the twenty-first century?

RQ2: How do PLWH describe past or present stigma-related experiences?

RQ3: How is prior stigmatization associated with future disclosure decisions?

## Method

### Participants

Participants ( $N = 59$ ) were clients of a large AIDS Service Organization (ASO) in a northeastern state. The sample included 29 males and 30 females ranging in age from 20 to 64 ( $M = 47.02$ ,  $SD = 10.32$ ). Individuals self-identified as heterosexual ( $n = 43$ ) and Lesbian, Gay, Bisexual, and Transgender (LGBT) ( $n = 16$ ). Level of education was distributed across three groupings: did not complete high school ( $n = 19$ ), diploma or General Education Diploma (GED) ( $n = 22$ ), and completed more than high school ( $n = 18$ ). Case managers provided clients' health-related information including current CD4 level and viral load,<sup>2</sup> as well as length as an ASO client. Individuals ranged from 1 to 31 years post HIV diagnosis ( $M = 12$  years,  $SD = 8.19$ ). Most individuals acquired HIV through sexual contact ( $n = 47$ ); the rest contracted HIV through IV drug use ( $n = 6$ ), either through IV drug use or unprotected sex ( $n = 2$ ), rape or sexual assault ( $n = 1$ ), prenatally ( $n = 1$ ), or were "unsure" how they acquired HIV ( $n = 2$ ).

### Procedure and measures

Four graduate students conducted and tape-recorded semi-structured interviews<sup>3</sup> at one of two ASO locations.<sup>4</sup> Interviews ranged from 20 to 72 minutes ( $M = 42.11$ ,  $SD = 15.52$ ), generating 11–36 ( $M = 22.32$ ,  $SD = 6.44$ ) pages of transcribed text. Participants received a \$35 VISA gift card for participation. The procedures were approved by a University Institutional Review Board.

Interviewers followed a guide but were able to explore topical trajectories in the conversation that strayed from the guide when appropriate. The interview guide consisted of three main questions: (1) How do you think others view HIV in the twenty-first century? (2) Can you describe an example of a time when you felt stigmatized? (3)

Presently, how much is stigma a concern in your life? Follow-up questions based on participants' responses included: How much do you worry about telling people your HIV status, and how confident are you in your ability to tell someone that you are HIV+?

## **Analyses**

To address research questions, we used a combination of deductive/directed and inductive/conventional coding (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). Unit of analysis selected was the sentence or thought unit. We began with deductive/directed coding defined as analysis starting with a theory or relevant research findings as guidance for initial codes. This included a structured categorization matrix consisting of the four stigma characteristics proposed by Leary and Schreindorfer (1998) (presence or absence), experiences of feeling stigmatized due to HIV status (presence or absence), and the degree to which HIV stigma was a concern (major, minor, or no concern). This process allowed us to examine changes in stigma-related perceptions, experiences, and concerns by coding participants' responses according to theoretically driven categories in extant research. Krippendorff's alpha was calculated to assess intercoder reliability on 10% of data in common for training purposes (category agreement exceeded .8 for all codes).<sup>5</sup>

Given how participants' stigma-related perceptions, experiences, and concerns differed, we additionally used inductive/conventional coding to categorize examples present within participants' responses. Coders next immersed themselves in a line-by-line reading/re-reading of participants' responses to become familiar with the data; then, they conducted open and axial coding (Strauss & Corbin, 1998). Open coding is an interpretive process designed to examine, compare, and categorize qualitative data to develop thematic concepts. Axial coding involves searching for similar data sequences to foster connections between emerging thematic concepts. Concepts and topics were identified by coders during the open coding phase and then combined to create overarching categories or themes that were reflected in the axial coding phase. This process revealed three categories of perceived stigma (RQ1), two categories of experienced stigma, and seven categories of stigma concerns (RQ3).

## **Results**

Data are organized by research question. Each section is labeled according to deductive category (perceived stigma, experienced stigma, and stigma concerns). Next, inductive, emergent themes within participants' responses are described, with illustrative quotes and relevant participant demographics (race, sexual orientation, and sex) to provide insight into participants' experiences; parenthetical numbers refer to participant ID.

### ***Perceived stigma***

RQ1 asked how PLWH perceive that others view HIV today, focusing on the awareness of current societal attitudes toward PLWH. Three of the four stigma characteristics proposed by Leary and Schreindorfer (1998) are present in these data, with public ignorance emerging as an additional category.

### **Threat to others**

Participants believed that others viewed HIV as a contagious condition that poses a threat to the health and safety of others. An African-American heterosexual female summarized public perception as, “Others see us as contaminated, where they don’t want to touch [us]” (05). Participants compared the public’s reaction to HIV to other historically stigmatized conditions that resulted in isolating marked others from society in order to protect public good. A multiracial heterosexual male said, “I think a lot of people think we [are] lepers” (37).

Several participants highlighted the irrational fear of infection based on casual contact despite extensive education and public awareness campaigns. An African-American heterosexual female shared, “Some people still have that theory, ‘OMG, if you breathe on me or touch me, I GOT it!’” (18). Another African-American heterosexual female echoed inaccuracies about close proximity and sharing personal belongings: “You can’t be around this [HIV+] person or you can’t eat off of this person’s plate” (16). Participants perceived that others still feel at risk from simply being in the same room as a PLWH.

Participants acknowledged the communicability of HIV as the reason for evoking negative emotional reactions. An African-American homosexual male explained, “It’s still scary to them, for their own reasons, like not wanting to contract it” (47). Other participants expressed information about transmission as a way to reduce fear. An African-American heterosexual male described, “Others view HIV like it’s contagious. Which it is, but you know, as long as you have safe sex and be cautious about what you doing, it’s ok” (40). In summary, participants viewed HIV as evoking fear and avoidance among the public due to the potential spread of disease.

### **Responsibility**

HIV is not only stigmatized because of perceived threat to others but also because of association with groups that were stigmatized prior to the epidemic. Participants perceived that others associated HIV with behaviors regarded as deviant or morally wrong. An African-American heterosexual female described public perceptions of HIV as “a dirty disease where you catch it from homosexual contact or mainly drug use” (05). Those who contracted HIV through sexual activity or drug use are considered to be “deserving” because they willingly engaged in high risk behavior that violated some form of societal standards. A Caucasian heterosexual male said, “I think the people’s first thoughts are that you’re gay. Some people think that you deserve it” (31). An African-American homosexual male echoed this perception and said, “Others look at it as something that you brought on yourself” (46). Ultimately, participants viewed some others as presently being unsympathetic and judgmental due to PLWH’s association with previously stigmatized groups.

### **Public ignorance**

The final category of perceived stigma is public ignorance where participants perceived that others are misinformed and in need of education about HIV. Participants noted that society at large fails to make a distinction between HIV (a virus) and AIDS (a clinical syndrome). An African-American heterosexual female expressed frustration about the public’s ignorance of proper medical terms: “I say majority of people today are very stereotypical and judgmental because a person has HIV. They don’t say the person has HIV, they

say the person has AIDS” (07). In addition to the inaccurate use of terms, participants identified slang phrases such as those reported by a male, heterosexual, multiracial participant: “You hear people talk about ‘Oh, he got *the package*’ or, excuse the expression, ‘He got *that mess*.’ Oh, he got AIDS, but he doesn’t have AIDS, he has HIV” (37). In summary, participants expressed frustration about public ignorance regarding disease classification, terminology, and progression.

Participants also described public associations between HIV and death or physical deterioration. An African-American heterosexual female said, “I think they see it as a death sentence. But now you can live with HIV” (04). Another African-American heterosexual female described challenging inaccurate perceptions, “A lot of people aren’t educated with it to realize that you live a long time” (02). Ultimately, participants were frustrated with people viewing HIV as a terminal illness, leading to desire to educate others.

Participants had observed others identifying a person as HIV+ based on the presence of appearance cues such as weight loss. For example an African-American homosexual male described, “The stereotype is you’re thin, you’re wastin’ away” (12). An African-American heterosexual female shared, “They see somebody that don’t look well. They talkin’ ‘bout, ‘Oh, know what they got.’ They put a stigma on how people with HIV supposed to look” (02). Thus, participants identified physical appearance cues that activated others’ stereotypes about PLWH.

Participants acknowledged that information about HIV is widely available, but people still do not understand the disease. An African-American heterosexual female expressed,

Stigma is huge. But again, it’s because of their own ignorance, and they’re still in the past and have not read up on the new stuff. ‘Cause there is information out there, but they just goin’ on what they hear. They don’t take time to read, they just need more education. But half of ‘em don’t want it. (14)

An African-American homosexual female said, “People are not knowledgeable on this disease. They’re left behind. They don’t read up on it, they don’t study nothin’, they don’t get into it to find out nothin’” (23). PLWH viewed others’ knowledge as being stuck in the past while advances continue.

### **Experienced stigma**

Beyond perceptions of societal attitudes that form PLWH’s perceived stigma, RQ2 asks about PLWH’s (past or present) stigma-related experiences or receiving discriminatory behaviors based on HIV status. Participants’ responses revealed experienced stigma primarily in the form of rejection and avoidance at both the institutional and interpersonal levels.

#### **Institutional level**

PLWH described experiencing discrimination at the institutional level including health-care and workplace settings. An African-American homosexual male described an unsatisfactory healthcare encounter with a dentist,

On the [dental] application, I put that I had HIV, and they left me on the table for like two hours, trying to come up with some reason why they couldn’t do anything. They finally said

“We need blood work from your doctor and we can’t touch you until we get it.” So I know what to make of that, ‘cause it took you two hours to figure out I need blood work? (35)

An African-American homosexual male shared a disrespectful interaction with a psychiatrist,

When I first got diagnosed, I saw a psychiatrist and I told her my status and she kind of was taken aback, and then she said I’ll treat you, but she made up a story that I was missing my appointments. (39)

Participants reported that some healthcare personnel came up with excuses for making them wait and some even discontinued treating them as patients.

Participants also experienced workplace stigma. A Hispanic homosexual male shared, “I’m afraid it [HIV status] is going to affect whether they’re [employers] going to give me hours or they’re afraid I’m going to be on the premises and affect the other employees” (30). Many participants were currently not working, in part, based on prior perceived and experienced workplace stigma. The association between HIV and stigmatized behaviors is clear where participants reported negative experiences in healthcare and workplace institutions.

### *Interpersonal level*

PLWH also reported being stigmatized primarily in family and romantic partner interactions. A multiracial heterosexual male explained hurtful treatment from his mother:

When I ate I had to use a plastic fork, plastic spoon, paper cups. I was hurt by that. And this was my mother! But if my mother acts like that, what do you think other people will act like? (37)

An African-American homosexual female expressed upsetting treatment from her siblings, “When my older sister gave me that plastic plate and forks and started wiping down everything I touch with bleach, it was a hurtin’ situation, it was like painful. Because that’s family, man, and you do this to me?” (23). Participants’ responses demonstrate that knowledge about HIV and a close personal relationship do not always override others’ misperceptions about contracting HIV.

Besides family, a number of participants shared stories of rejection from potential romantic partners. An African-American homosexual male described a disappointing online exchange:

I met this person online, and I didn’t mention my status. We met for lunch and had a great lunch, and engaging conversation, the whole piece. I thought to myself, “Oh well, you know I need to say something.” And instead of waiting until our next meeting or whatever, I emailed, you know, and he emailed me back, “Thanks, but no thanks, ‘cause I can’t deal with that. Think you’re a nice person” or whatever. I think I was more crushed at that moment than I was the day I was diagnosed. (35)

Another African-American homosexual male shared a similar frustrating face-to-face interaction that resulted in relationship termination:

There was a guy who I was interested in. I really liked him. When I sat down and told him about my situation, he looked at me and patted me on my head and says “Oh, and you are so nice lookin’ too.” He made it seem like I was gonna be dying within two weeks. I didn’t see or deal with him any more after that. (32)

Some participants avoided intimate relationships in order to protect themselves against this type of rejection. An African-American heterosexual female explained,

When it comes close to being intimate, and when I do tell, and we sit down and talk. I have a pamphlet for him to see. Then it's like, "Oh, we'll talk, I'll call you." And I never get the call any more. So it hurts. (05)

Participants reported being treated differently which, in turn, increased social strain and decreased access to potential social support necessary to deal with stigmatizing reactions.

### **Stigma concerns**

RQ3 addresses the role of prior stigmatization on future disclosure decisions. Participants indicated the degree to which HIV stigma was a concern (major, minor, or no concern). For those individuals who indicated stigma concerns, future disclosure decisions emerged as an additional area of distress. Participants' responses revealed that the decision to disclose their HIV status represents an ongoing attempt to manage stigma, to exercise control over it, and to minimize anticipated harm. For PLWH, reasons for disclosure must be significant enough to risk experiencing stigmatizing responses. However, when anticipated stigmatizing responses outweigh potential gain then nondisclosure is more likely to occur.

### **Reasons for disclosure**

Beyond findings for perceived and experienced stigma, PLWH's reasons for disclosure can be categorized as self, other, and relationship-focused (see Derlega et al., 2002).

**Self-focused.** Findings suggest PLWH may decide to disclose their status based on motivations for fulfilling personal needs: acceptance and catharsis.

**Acceptance.** Acceptance includes coming to terms with identity. After diagnosis, PLWH may integrate aspects of their former self with current aspects of their diagnosis. Higher levels of acceptance enabled participants to take the risk of disclosing despite the acknowledged possibility of encountering stigma. An African-American homosexual male shared,

I am the type of person if you are going to accept me, you are going to accept me. If you are going to judge me, I don't need you. If you can't accept the fact that I am cool with where I am and who I am and what I am dealing with and be supportive of me, who cares what you think? (41)

Participants emphasized the importance of PLWH coming to terms with who they are. An African-American heterosexual female shared:

Because I'm a stronger individual and I know who I am. And I have to accept who I am and if I want to tell someone about me, that's who I am, that's something I have, so I'm not going to leave a part of me out. They can't accept me as a complete package so I don't need them. (36)

Once PLWH had integrated HIV into their identities, they were better able to handle potentially stigmatizing responses. Acceptance served as a buffer from stigma by making it less threatening to disclose, yet it also decreased the availability of social support if participants had reduced social network size due to disapproving and judgmental others.

*Catharsis.* Another self-focused reason for disclosure is catharsis, the process of releasing, and thereby providing relief from, strong or repressed emotions. An African-American homosexual male described the benefits of disclosing as, “I feel like a burden is lifted when I express myself. Getting it out and saying it helps me” (47). An African-American heterosexual female expressed similar advantages of sharing her status with others, “It really doesn’t help you to hold it in because holding it in hurts me more than letting it out. Because then I’m stuck with all these emotions” (14). Participants highlighted the rewards of disclosure in releasing pent up feelings. Bottling up emotions was generally perceived as more costly than potentially stigmatizing reactions to sharing HIV status.

*Other-focused.* Besides self-focused motivations, PLWH also consider how their disclosure affects others. PLWH may disclose and risk experiencing stigmatizing responses if sharing is relevant to others or has the opportunity to educate others.

*Relevance to others.* The first other-focused reason for disclosure is relevance to others, or how the disclosure target may be affected by the disclosure. For example, the disclosure target may be at risk for contracting the communicable condition or may be asked to serve as guardian for a child. A Hispanic homosexual male expressed a sense of duty to share status to potential romantic partners,

I don’t want to do the same thing to them that happened to me. Where it is like they didn’t tell me and they infected me. I don’t want to put anyone else’s life at risk. I am very open right away. I am like, “Look, this is my status.” (30)

Some participants shared with potential or past partners out of obligation due to HIV being transmitted through sexual contact. Preserving others’ health and wellness was perceived as more important than potentially stigmatizing reactions, such as reactions from potential partners described earlier.

*Desire to educate others.* Besides relevance to others, the second other-focused reason for disclosure is desire to educate others. PLWH may disclose to educate others. An African-American homosexual female expressed, “I want other people to know. Especially I want my family to be safe. Because I have young family members, males that are coming out gay and I just want them to be aware” (17). This participant felt obligated to serve as a role model about the importance of safe sex practices. Other participants described disclosure as a means of advocating for themselves and others. A Caucasian homosexual male explained, “I’m okay with it because I’m doing it for a reason: to either advocate for myself or for other [HIV+] people” (31). The ability to help others avoid contracting HIV and challenge negative misperceptions sometimes outweighed potentially stigmatized responses.

*Relationship-focused.* Besides self- and other-related reasons for sharing, PLWH take the relationship into account when processing stigma and disclosure decisions. Participants described willingness to share their HIV status after careful evaluation of the disclosure target. A Hispanic heterosexual male explained, “It depends on the person. What kind of person they are, kind of character they are, how they carry themselves. If they need to know or they don’t need to know” (42). Participants made estimates about the likely reaction of a receiver before deciding whether to share the information. In addition,

participants expressed a willingness to disclose if the relationship with the disclosure target was characterized as significant and long-term. A Caucasian heterosexual male shared,

I don't disclose it [HIV status] until I get to the point where I am feeling where that relationship might go a little bit farther or whatever. Sometimes it works and sometimes it backfires, but I am going to tell them regardless, regardless of what the outcome is. (41)

Thus, assessment of characteristics of and relationship with the target influence disclosure decision-making. PLWH make disclosure decisions so they can protect themselves by depending on people they have a close/supportive relationship with and trust.

### *Reasons against disclosure*

Next, we explore stigma-related reasons that PLWH are motivated to maintain privacy. Unlike the reasons for disclosure, reasons for nondisclosure in these data were based only on fulfilling personal needs: right to privacy and anticipated response.

*Right to privacy.* Participants recognized the right to protect their personal information and sometimes chose not to share, and this tendency was especially pronounced outside of potential sexual relationships. An African-American homosexual male shared, "It is really my right to tell, and unless I'm being intimate with somebody, I don't have to disclose that [HIV status]" (33). Depending on the relevance of the information to others, self-protective reasons to avoid stigma leading to nondisclosure may triumph.

Participants also expressed concern about losing control over who knows about their HIV status. An African-American heterosexual female reported, "Sometimes you don't want to tell because you don't know if that person is going to tell someone else" (15). Another African-American heterosexual female expressed regret in sharing status with a particular person because she lost control over whom and how many others knew:

I just wish my mom hadn't told her, because my sister has a big mouth. I feel like what goes on with you is your business and even if your family member knows, it does not give them a right to put your business out. And my sister did that, and she hurt me. (06)

This participant felt injured by her family violating her right to privacy. Nondisclosure or selective disclosure enabled participants to gain some control by informing only appropriate targets. Due to perceived stigma described previously, participants reported concern about the degree to which their information was safe with the target.

*Negative anticipated response.* Anticipated response refers to the discloser's assessment of how the target might react to the shared information. Based on experienced stigma, PLWH may employ nondisclosure or selective disclosure. An African-American heterosexual female expressed fear of relationship change and possible termination, "It's kind of nerve racking because you don't know what people's feelings are when they hear the news. Or eventually will they come around or will they be distant?" (16). For this participant, being excluded by family and community was a concern when deciding whether to disclose. An African-American homosexual male shared a similar sentiment, "I didn't know how they would take it. Would they still wanna be around me or talk to me?"

(12). Previous stigma experiences and fear of future stigmatizing reactions acted as a deterrent to disclosure, and participants sometimes thought the target would respond badly.

One way that PLWH assessed the likelihood of a positive or negative reaction was through the use of indirect disclosure strategies. Some participants described using indirect disclosure strategies such as hinting, testing reactions, and incremental disclosure to maximize protection and avoid risk. An African-American heterosexual female described considering telling as,

It's hard to figure out how they are going to react to it. There are a lot of people I want to tell but sometimes I don't because I don't know what their reaction is. I don't tell them without feeling them out first. (15)

This participant emphasized assessing target emotions and knowledge about HIV/PLWH prior to disclosure to minimize negative reactions. Hypothetical situations may act as a means to gauge the target's likely response. An African-American heterosexual male explained, "Before I tell them, I do a test on them. I ask certain questions and see what their response would be to that" (11). For this participant, initial target reactions guided whether or not to tell. An African-American homosexual male emphasized the importance of listening to gain insight into target's likely reaction: "If you just listen to people sometime, you know how they'll react. You know how they'll react when they'll speak of someone else who's HIV+, and they don't know that that's me" (33). Participants reported using indirect disclosure strategies due the stigma surrounding HIV. By gauging disclosure targets' impressions of HIV, PLWH were able to decide whether or not to disclose in order to avoid or minimize stigmatizing reactions.

## Discussion

This study explored the role of perceived (RQ1) and experienced (RQ2) stigma and how this affected PLWH's future disclosure decision-making (RQ3). Participant interviews revealed that HIV stigma still persists. PLWH's perceptions about how society currently views HIV correspond with three of four of Leary and Schreindorfer (1998) stigma characteristics: pose a threat to others' health and safety, deviate from group standards, and create negative emotional reactions in others. Although HIV remains a communicable disease, inaccurate beliefs about transmission via casual contact are foundational to some remaining forms of stigma. Negative assumptions persist about groups that have been disproportionately affected by HIV such as intravenous drug users and homosexuals. The majority of participants in the present study contracted HIV from heterosexual sex. For non-drug using, heterosexuals in particular, these associations evoke fear, anger, and disgust in others who continue to view HIV in a stereotypic manner. In addition, participants report public ignorance regarding disease classification and progression. PLWH emphasize the need for education about HIV as a chronic condition rather than a "death sentence," the distinction between HIV and AIDS, and available treatment.

Beyond perceived stigma, participants described experiencing stigma (in the past and present) at the institutional and interpersonal levels. PLWH reported denial of rights to healthcare and employment consistent with previous research (e.g. Nyblade, 2006). Participants also noted being treated differently by various family members and rejected by

potential romantic partners. Moreover, participants reported romantic relationship termination and withdrawal from dating altogether.

The study sample provided the opportunity to compare and contrast heterosexual and LGBT participants' stigma perceptions and experiences. Most themes including threat to others, evoking fear in others, and rejection by social network members transcended sexual orientation. This may be attributed to the current state of HIV knowledge (stigma-related issues that are universal as the epidemic enters its fourth decade) and mistaken concerns that remain about how HIV is transmitted (KFF, 2011). The few areas where sexual orientation differences were apparent included the institutional level and desire to educate others. Specifically, individuals who identified as homosexual shared examples of experienced stigma in healthcare and workplace settings. Some homosexual participants also expressed the need to disclose their status to make other aware of transmission risks (especially friends and family). Some participants revealed contracting HIV through unprotected sex and wanting to prevent others from having the same thing happen to them. The older generation felt a sense of responsibility to protect and forewarn the younger generation of friends and family who were preparing to engage in initial sexual encounters.

The influence of perceived and experienced stigma was apparent in participants' reflecting on disclosure decision-making. PLWH identified several motivations for disclosure, organized into self-, other-, relationship-focused categories (see Derlega et al., 2002). Differences may exist between our study and previous research because we focus on the impact of stigma and not on disclosure reasons broadly. Previous research described two main reasons PLWH disclose that are self-focused: catharsis and seeking help. In our data, these categories partially represented the data. Participants reported catharsis and acceptance but not seeking help as self-focused reasons for disclosure. Other-focused categories (duty to inform, labeled as relevance to others, Greene, 2009, and desire to educate others) are consistent with previous research. Prior research identified three reasons PLWH disclose that are relationship-focused: testing others' reactions, close relationships, and common experiences or similarity. In our data, only one category was consistently reported, close/supportive relationships. We labeled this relational quality because participants' responses focused more on relationship evaluation than establishing relationships. We have noted various reasons for disclosure that may outweigh potential stigmatizing reactions. These factors emphasize self, other, and relationship reasons for future disclosure.

Unlike previous research, participants only identified self-focused reasons for nondisclosure and did not report other- or relationship-focused reasons. Self-focused reasons included right to privacy and fear of rejection (labeled as negative anticipated response, Greene, 2009), and are consistent with previous research (Derlega et al., 2002). The focus on stigma in the present study may highlight self-protective factors rather than other or relationship motivations for nondisclosure. PLWH often will not disclose their HIV status if they anticipate a negative response or if they are unsure about the target's response. HIV stigma may influence PLWH's decisions to disclose information about their infection; they also may wish to maintain their privacy (Derlega et al., 2002; Greene et al., 2003). Thus, perceived and experienced stigma played a central role in disclosure decisions. Self, other, and relationship reasons for disclosure were juxtaposed with

self-protective nondisclosure reasons when deciding whether or not to reveal an HIV diagnosis.

### ***Implications for disclosure decision-making***

There are a number of theoretical frameworks that can be applied to understand how stigma influences the process of disclosure. Petronio's (2002) communication privacy management theory (CPM) describes how people control potential risk to self, others, and relationships when making disclosure decisions. Individuals regulate disclosure of private information in their relationships to attain a balance between disclosure and privacy, and between intimacy and autonomy. CPM may be useful in determining the way the many PLWH navigate making decisions about whom, when, and how they should give access to their health information. Individuals erect a metaphoric boundary to protect themselves and reduce their chances of being stigmatized and losing face. The risks associated with disclosing HIV status are tremendous, perhaps leading to more rigid boundaries (little or no disclosure). PLWH must deal with the consequences of disclosing to others about their HIV status. However, there are also consequences of protecting HIV status by avoiding non-accepting others or restricting the level and amount of disclosure.

Scholars have focused additional attention on developing models that identify and quantify factors influencing disclosure decisions. These models (e.g., Disclosure Decision-Making Model [DD-MM], Greene, 2009) examine the process of coming to the decision to disclose or conceal private information to particular recipients. The DD-MM is particularly relevant to this study because it fully incorporates the assessment of the health information component of disclosure decision-making or focuses on what is being shared. For example, the first of the five health information components is the stigma associated with the health diagnosis. Consistent with the DD-MM in the present study, perceived and experienced stigma decreased intentions to disclose. In addition, stigma effects were influenced by assessment of the receiver and discloser efficacy.

Participants mentioned selective disclosure after a careful evaluation of the potential disclosure recipient including anticipated response and relational quality. PLWH's reported likelihood of stigmatized reactions such as being treated differently and/or experiencing sexual and personal rejection as deterrents to disclosure. However, if the relationship with the potential recipient was characterized as significant, long-term, and trustworthy, participants expressed greater willingness of risking being stigmatized and thus disclosing.

Participants' description of indirect disclosure strategy enactment supported the DD-MM's proposition that both confidence and skills are necessary to disclose health information and may mitigate the negative effects of stigma on intentions to disclose. Participants described utilizing strategies such as incremental disclosure to maximize protection from stigmatized reactions. Participants emphasized how being able to gauge recipients' responses empowered the discloser and made them feel more in control of the disclosure interaction. These feelings increased disclosure efficacy and subsequently intentions to disclose. If the recipient seemed accepting and the discloser anticipated a positive reaction then disclosure was likely, but if the recipient seemed judgmental and the discloser anticipated a negative reaction then nondisclosure was likely.

## **Practical implications**

Stigma remains a challenge for PLWH, one that generally inhibits disclosure. Individual, institutional, and societal level interventions are three possible ways to combat stigma challenges. At the individual level, PLWH can express their personal stigma experiences in narrative or story form through writing. Researchers have found that verbally discussing or writing about traumatic or upsetting life experiences, such as an HIV diagnosis or responses, is associated with fewer physician visits and less immune dysfunction (Pennebaker, Kiecolt-Glaser, & Glaser, 1988). Expression of distressing information in narrative form may accomplish catharsis without risking exposure to negative recipient reactions.

At the institutional level, healthcare personnel can assist PLWH with identifying stigma concerns, making effective disclosure decisions (weighing possibility of stigmatizing reactions versus benefits of disclosure), and learning communication skills to minimize stigmatizing reactions. Healthcare personnel may develop programs (or incorporate the information into social support groups) to help individuals with difficult decisions about disclosure. Such an intervention could help PLWH to assess the risks and benefits of sharing their HIV+ status with a particular disclosure target, focus on strategies for sharing, and identify and prepare for potential reactions from the target (see Greene, Carpenter, Catona, & Magsamen-Conrad, 2013). Being familiar with a number of strategies and thinking through a backup/contingency plan is particularly useful if PLWH are unsure of and/or expect stigmatizing reactions. Specific discussion of both stigma and disclosure problems may be useful.

There may also be a need to tailor interventions to demographic groups that may face different stigma-related issues. This study identified issues unique to sexual orientation, although not on all facets. For example, participants who identified as homosexual shared examples of experienced stigma in healthcare and workplace settings. There may be a need for disclosure practice exercises/modules that focus on sharing HIV status with healthcare providers and workplace professionals as the disclosure target to think through appropriate disclosure strategies that minimize stigmatizing responses as well as prepare for possible follow-up questions. Healthcare workers should continue to be sensitive to differences in willingness to disclose and possible sexual orientation differences. Patient diversity, in this case sexual orientation, emphasizes the need for additional training modules for healthcare workers that focus on stigma considerations unique to specific groups. These modules could be added to medical school curricula for residents as well as continuing medical education credit opportunities for practicing providers. Provider education should, at a minimum, focus on examples of behaviors that patients report to be stigmatizing.

At the societal level, specific campaigns portraying how HIV affects social networks and what types of support social networks can provide might be useful in reducing this stigma and labeling. In addition to learning about provision of helpful types of social support, campaigns can educate family, friends, and co-workers more broadly about responding to disclosure of HIV status in an appropriate and sensitive manner.

The four characteristics proposed by Leary and Schreindorfer (1998) could be targets for stigma-reduction campaigns. These campaigns should focus on changing beliefs about PLWH posing a threat to others' health and safety, deviating from group standards, creating negative emotional reactions in others, and failing to contribute. More messages

with positive portrayals of people with HIV doing ordinary tasks might serve to reduce stigma and increase likelihood of disclosing. For example, the CDC (2012) launched the “Let’s Stop HIV Together” campaign, which is aimed at reducing HIV stigma. In the ads, PLWH join their friends and family to show that PLWH are people living active and productive lives. Such campaigns portraying how HIV affects families and the support families can provide might be useful in reducing this stigma. More messages with positive portrayals of PLWH might serve to reduce stigma, increase likelihood of disclosing, and reduce family members’ fears of and misinformation about contracting HIV through casual contact.

### **Limitations**

The present study has some limitations. We asked patients to recall stigma related to their HIV status. The average participant had been living with HIV for a number of years, and there may be some distortion in their recall about the experience. Participants who indicated stigma was a major or minor concern were prompted about disclosure issues. These concerns might be different from what a PLWH would have generated without follow-up. The sampling strategy underrepresented PLWH not using ASOs, and ASOs often provide programs to assist with stigma management, as well as access to a network of similar others. Finally, participants were recruited from a large metropolitan area and a mid-sized city including some suburbs, and perceived and experienced stigma, in addition to reasons for and against disclosure, may be very different for PLWH in rural areas or in smaller cities.

### **Future research**

This study addressed HIV stigma and the connection to disclosure of an HIV diagnosis. However, disclosure is not a onetime event, rather it is an ongoing interaction where people may modify, change, or reframe previous interactions. It would be worthwhile to examine ongoing disclosure decision-making because HIV is considered a chronic illness and see if there are more or less stigmatized reactions across time as PLWH adjust and develop coping mechanisms. This would include longitudinal studies of disclosure and relationships, in addition to examining historical changes in public perceptions of HIV.

This study examined disclosure decision-making by generating a list of reasons for and against disclosure from the discloser’s perspective. Future research should explore whether the target advises the discloser to reveal or conceal to others, as well as the self-, other-, and relationship-related reasons for recommending further disclosure or nondisclosure. There are few studies of dyads interacting in the health disclosure context. This type of study would also test the notion of courtesy stigma that suggests targets may co-own not just the information of the discloser’s stigmatized condition but its negative consequences as well (Goffman, 1963). Self-protective reasons such as avoiding negative reactions may emerge as the main reason for recommending nondisclosure.

This study highlights the stigma and disclosure experiences of heterosexuals living with HIV, under-reported in the HIV literature. The reports of different reasons for/against future disclosure by sexual orientation were clear for experienced stigma at the

institutional level and desire to educate others. At present, however, the conclusions are not definitive and warrant added consideration. There is a need for expanded exploration of sexual orientation and unique features of coping with HIV stigma via avoidance, non-disclosure, and disclosure.

## Notes

1. Based on the United Nations AIDS Terminology Guide's (2011) recommendation to avoid confusion between HIV (a virus) and AIDS (a clinical syndrome), the term HIV was used throughout the manuscript. HIV stands for human immunodeficiency virus, the virus that causes AIDS. Having HIV does not mean a person has AIDS. Participants in the present study were HIV+. AIDS stands for Acquired immunodeficiency syndrome, a disease that results in a weak immune system and increases the risk of getting certain infections and cancers (CDC, 2014).
2. A CD4 count is a lab test that measures the number of CD4 cells in a sample of your blood. It is an important indicator of how well an immune system is working. Normal CD4 counts range from 500–1200 cells/mm<sup>3</sup> in adults/adolescents. A CD4 count of fewer than 200 cells/mm<sup>3</sup> is one of the qualifications for a diagnosis of stage 3 infection (AIDS) (CDC, 2014). Study participants' CD4 counts ranged from undetectable to 1267 ( $M = 561$ ,  $SD = 279$ ), viral load from undetectable to 9730 ( $M = 555$ ,  $SD = 1641$ ), suggesting a reasonably healthy sample with some physically distressed participants.
3. Each interviewer received extensive training (minimum two practice interviews with feedback). Consistency was assessed by comparing interview length across interviewers, monitoring adherence to the interview guide by comparing interviewer audio recordings and the order and manner interview questions were asked, and making note of interviewee comments. Three interviewers were White women; one was an African-American man. Based on review of transcripts, we combined data for analysis.
4. This study was conducted in two of 10 largest New Jersey cities for PLWH; in addition, these two cities rank high for percentage of the population below poverty level, suggesting an economically disadvantaged sample.
5. Three undergraduate coders blind to the research questions received training prior to deductive/directed coding. The training sessions included weekly group discussions about the meanings and nuances of the coded variables.

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