

Experiences of Social Stigma and Implications For Healthcare Among a Diverse Population of HIV Positive Adults

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ABSTRACT *Stigma profoundly affects the lives of people with HIV/AIDS. Fear of being identified as having HIV or AIDS may discourage a person from getting tested, from accessing medical services and medications, and from disclosing their HIV status to family and friends. In the present study, we use focus groups to identify the most salient domains of stigma and the coping strategies that may be common to a group of diverse, low-income women and men living with HIV in Los Angeles, CA (n=48). We also explore the impact of stigma on health and healthcare among HIV positive persons in our sample. Results indicate that the most salient domains of stigma include: blame and stereotypes of HIV, fear of contagion, disclosure of a stigmatized role, and renegotiating social contracts. We use the analysis to develop a framework where stigma is viewed as a social process composed of the struggle for both internal change (self-acceptance) and reintegration into the community. We discuss implications of HIV-related stigma for the mental and physical health of HIV-positive women and men and suggestions for possible interventions to address stigma in the healthcare setting.*

KEYWORDS *HIV, AIDS, Stigma, Healthcare, Gender, Minority, Framework, Qualitative*

INTRODUCTION

Stigma profoundly affects the lives of individuals living with HIV/AIDS and those at risk of HIV infection. Fear of being identified as having HIV or AIDS may discourage a person from getting tested, from accessing medical services and medications, and from disclosing their HIV status to family and friends.¹⁻⁶ Studies of HIV-positive adults in the USA have demonstrated a relationship between stigma and multiple health-related outcomes, including poor antiretroviral therapy adherence, health-related quality of life, and increased HIV symptoms and depression.^{1,7-10} Although valuable theoretical models of stigma exist in the social science literature,¹¹⁻¹⁶ our understanding of the mechanisms of *how* and *why* stigma may affect health and healthcare and what can be done to mitigate the impact of stigma on the health and quality of life of HIV-positive persons remains limited.^{13,17,18} Thus, we aim to contextualize the theory of stigma within the everyday lives and experiences of persons living with HIV and to gain a better

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understanding of stigma's relevance and impact on physical, emotional, and mental health and healthcare for these individuals.

Link and Phelan¹² provide a useful definition of HIV-related stigma that serves as the foundation for the work in the present study. In this conceptualization, the following five components converge to produce stigma: (1) identification and labeling of human differences, (2) dominant cultural beliefs that link the labeled person to undesirable characteristics, creating negative stereotypes, (3) categorization of labeled persons to separate "us" versus "them," (4) labeled persons experiencing status loss and discrimination, leading to unequal outcomes, and (5) access to social, economic, and political power by the dominant group allowing for the full execution of disapproval, rejection, exclusion, and discrimination against the labeled group. As emphasized in this definition, grounding research in the cultural context and social inequities in which stigma is rooted is a critical component of any study of HIV-related stigma.

HIV in the USA has increasingly become a disease of poverty and as such affects already marginalized populations who face inequities on the basis of race/ethnicity, gender, sexual orientation, and substance abuse.¹⁹⁻²¹ In the present study, we identify the most salient domains of stigma and the coping strategies that may be common to a group of diverse, low-income women and men living with HIV in Los Angeles, CA ($n=48$) who face multiple inequities based on class, race, gender, and sexuality. We also examine the impact of stigma on health and healthcare among HIV-positive persons in our sample. This study builds on our findings and the existing literature to develop a novel framework that views stigma as a social and psychological process in which HIV-positive individuals struggle for internal change and reintegration into the community and to direct future work in identifying targets for interventions to mitigate stigma within the healthcare setting.

MATERIALS AND METHODS

Study Design

Qualitative research methods are particularly suited for exploring experiences of HIV-related stigma in a population of HIV-positive adults living in Los Angeles. In contrast to more confirmatory qualitative approaches, such as classic content analysis, our goal was to engage in a generative process to discover key domains of HIV-related stigma as experienced in the social and cultural context of participants' lives. We use focus groups to explore experiences and perceptions of stigma in a diverse group of women and men living with HIV. We systematically identify the most salient domains of stigma from the narratives of our participants and explore how they are linked together to build a framework to understand HIV-related stigma.

Participant Recruitment

Focus group participants were recruited from five community-based HIV outreach and support organizations and from two HIV specialty clinics in the city of Los Angeles. Partnering with both community organizations and clinical sites allowed us to include individuals in our study who access the healthcare system and those who may not. The inclusion criteria were as follows: age over 18 years, diagnosis of HIV or AIDS, English or Spanish speaking, and ability to provide informed consent. HIV-positive women and men were recruited for the study through fliers posted at community organizations and clinic sites. Organization and clinic staff also referred interested clients to the study. Potential subjects were screened, and if eligible, they

were invited to sign up for one of the group discussions. We intentionally recruited from sites that serve primarily minority women and men, many of whom have limited education and income, to explore the perceptions and experiences of stigma among HIV-positive persons who may also be marginalized by race/ethnicity, gender, sexual orientation, poverty, or some combination of these factors.

Data Collection

We chose focus groups to discuss the potentially sensitive topic of HIV-related stigma, as they offer participants a safe environment to share experiences and ideas in the company of others who have a central element of their experience in common (i.e., HIV disease). The setting of focus groups promotes synergy, where group dynamics may stimulate thinking and lead to contributions that may not occur in one-on-one interviews. Finally, less direct methods of obtaining qualitative data such as focus groups are recommended to elicit responses that reflect the social and cultural realities of the lives of the participants.²²

The goals of the focus groups were to generate ideas and real-life examples of the perceptions and experiences of HIV-related stigma, and to explore how this stigma may affect the health and healthcare of HIV-positive people. We developed a focus group script based on a broad review of the literature on stigma and both qualitative and quantitative studies of stigma specific to HIV-infection. Open-ended questions were used to guide each discussion. If key concepts/content areas were not generated by the group, standard probes were used to elicit further information. We focused on identifying mutable factors that define or contribute to HIV-related stigma in women and men because these factors may be amenable to intervention in future studies.

We conducted seven focus groups in October and November 2005 in Los Angeles: four comprised of HIV-positive women and three of HIV-positive men. Each focus group consisted of approximately six to eight participants, for a total sample of 48 participants. Groups were gender specific because individuals may be more comfortable discussing sensitive topics such as stigma in same-sex groups, and this stratification allows us to understand how stigma may differ by gender. Focus groups were not specific to race or ethnicity. A trained bilingual female moderator conducted the female focus groups, and a trained African American man moderated the male focus groups. Focus groups lasted approximately 90 min, were audio taped, independently transcribed, and checked for accuracy. At the end of the focus group, each participant completed a brief self-administered sociodemographic survey. Information collected included gender, age, race/ethnicity, primary language, education, and income. Participants received a \$20 stipend for participation.

Data Analysis

To identify key domains of stigma in our sample of HIV-positive women and men, we used an exploratory pile-sorting technique described by Lincoln and Guba.²³ This technique is similar to the free pile-sorting methods used by cognitive anthropologists²⁴ and affinity grouping methods used by psychologists,^{25,26} and it has been used successfully by one of the authors in the past.²⁷ These methods involve aggregating similar ideas or items into piles based on their mutual affinity and then identifying and labeling the overarching domains of the groups. First, two investigators read each focus group transcript to uncover core statements that represented key constructs of participants' experiences of HIV-related stigma. This involved extracting the most salient ideas from the 300 pages of the seven focus group transcripts and resulted in a core group of approximately 500 core statements

that reflect participants' diversity of experiences. We then printed these core statements on small slips of paper and labeled the informant identification number on the back of each statement. Two investigators (JNS and JSS) together sorted the statements into piles that formed broad general categories. All investigators then reviewed all of the statements in the general category piles and decided whether they belong in the existing piles or a new pile representing a new domain of HIV-related stigma. After multiple iterations of free pile-sorting, all investigators reached consensus on key domains and themes. To understand how the key domains were organized into a framework, the investigators examined quotes and discussion where participants linked separate domains and themes together as they described experiences of HIV-related stigma.

RESULTS

Participant sociodemographic characteristics are displayed in Table 1. All participants resided in the city of Los Angeles. Fifty-four percent of the participants were female, and over half of all participants were between the ages of 35–49. The majority of participants were minorities: 56% were African American, 21% were Latino/a, 15% were white, and 8% self-identified a race/ethnicity other than those mentioned. Overall, the sample was of low socioeconomic status: over 70% reported a high school education or less, 50% reported having been homeless in the past, and the median household income for the group was \$870 per month.

TABLE 1. Focus group participant characteristics (n=48)

Participant characteristic	Number (%)
Gender	
Male	22 (46)
Female	26 (54)
Age	
18–34 years old	9 (19)
35–49 years old	23 (48)
50+ years old	16 (33)
Race/ethnicity	
White	7 (15)
Latino/a	10 (21)
Black	27 (56)
Other	4 (8)
Primary language	
English	38 (79)
Spanish	10 (21)
Ever homeless	
Yes	24 (50)
No	24 (50)
Education	
Less than high school	18 (38)
High school diploma or GED	16 (34)
Finished Vocational school	3 (7)
College degree	10 (21)
Graduate/professional degree	1 (0)
Median household income per month	\$870

Domains of Stigma

Through our analysis of the focus group data, we identified four key domains of HIV-related stigma in our sample: (1) confronting blame and stereotypes of HIV, (2) encountering ‘fear of contagion,’ (3) negotiating disclosure of a stigmatized role, and (4) renegotiating social contracts. These domains of stigma are described below.

Confronting Blame and Stereotypes of HIV

Starting at the time of diagnosis, our participants described feeling blamed for their HIV infection by others, which is often compounded by their own internal self-judgment and feelings of shame for having contracted HIV. In the context of blame, friends, family, medical professionals, and even total strangers assume the right to ask participants what they have done to become infected, no matter how painful or personal such a question may be. In other words, it becomes important for those in an HIV positive person’s social network to differentiate *how* someone is infected with HIV. This sets the stage for a type of *innocence discourse*,²⁸ which categorizes people based on how they were infected. As one participant explains, “I really resent that there is an ‘A’ list and a ‘B’ list.... If I tell them that I got it from a transfusion, then I’m the victim, but if I got it from having sex then I have scarlet letters on my chest.” Participants explain that the “innocent victims” of HIV are described as being children and those who contract HIV from blood transfusions, needle sticks, or rape. Those who contracted HIV through consensual sexual activity or drug use are considered to be deserving of HIV because of their “bad” or “high-risk” behavior.

Participants in several focus groups emphasized that having HIV “should be no different than having cancer.” However, the vast majority of men and women in our study report that, in reality, having HIV is markedly different from having other life-threatening diseases such as cancer or diabetes. Participants explain that this is because, for most diseases, the attention of others is directed to the comfort and well-being of the sick person, whereas with HIV, their attention is often focused on “assigning blame” based on how the disease was contracted.

The blame associated with how a person contracts HIV is pervasive and re-enforced by community stereotypes. These stereotypes differ significantly for men and women. One woman in our study explains:

Our stigmas you know, it is different for women, and it’s assumed if a woman is HIV-positive she was a sloppy whore...She either shot drugs or she was a slut, and there’s just no other way.

These stereotypes are extremely powerful and are often internalized. As one woman explains, “You end up believing you are damaged goods...Just knowing you have it, that is what makes you sick, and the more you sit there and think about it, the sicker you get.” Women in the study also describe strategies for avoiding the label of promiscuity that comes with having HIV. One young woman reports, “I didn’t want to be a statistic saying oh well she got pregnant at 19 and now she’s just, you know, whoring around with anybody down the street. I want it to be known that I got it by being raped, so don’t even put me into that category with everybody else.” This participant’s desire to separate herself from the blame and stereotypes of HIV is so strong that she routinely brings up the trauma of rape to avoid blame and being labeled as promiscuous and a drug user. In this context, gendered stereotypes of HIV may lead a woman to emphasize her role as victim, which in turn serves to re-enforce the stereotypes she is trying to avoid. In addition, this

process may result in further isolation from other women living with HIV who are not labeled “innocent victims” and may be a potential source of social support.

Whereas stereotypes of women with HIV focus on promiscuity, stereotypes of HIV-positive men center on homosexuality. In the words of one heterosexual man, “My whole stigma thing was that it was straight up a gay disease. You got it, man, you must have screwed some dude. That is all they could see, and I never did that.” As reflected in this comment, homosexual men are also a stigmatized group, which further compounds the stigma of HIV. One male participant explains:

First we face the stigma of being gay and we have to come out, if we choose to come out. Then we have to face the stigma of being HIV-positive, which involves another coming-out process...we have newly diagnosed people that have not come out as gay men and they are facing the double whammy of being both gay and HIV-positive. I think that is a difficult situation.

Several male participants in each focus group also report facing stigma within their own gay community. They describe encountering fear, ignorance, and the attitude that “HIV is from another generation” from HIV negative peers who do not perceive themselves to be at risk. One participant explains, “I am amazed because I was standing in a group of gay men in a bar, and they were all negative, talking about HIV and how they wouldn’t deal with anyone being HIV, didn’t want to touch them, and I am standing there as part of the group. I finally had to say ‘how can you assume that of the six people talking in this group that not at least one of us is HIV positive?’ I was devastated, and I left.”

In addition to gender and sexual orientation, race presents another opportunity for marginalization, adding to the layers of stigma described by our participants. We found a wide range of opinions about the role of race in the experience of stigma. One African-American male stated, “I experience violence and discrimination because I am Black, not because I have HIV.” Another African American male participant seemed to experience marginalization based on HIV status more acutely than that of race, explaining that “Being an ethnic minority in the gay community seems like a piece of cake compared to what HIV status is now.” Whereas perspectives on race varied within our sample, it was readily apparent from participant narratives that stereotypes and blame for HIV infection were frequently intensified by coexisting marginalization on account of gender, sexual orientation, and race among other factors.

Encountering Fear of Contagion

In addition to blame and stereotypes, HIV-positive women and men must also negotiate fears about spreading a communicable disease such as HIV. We have named this domain of stigma “fear of contagion,” which involves an irrational fear of infection through casual contact that poses no significant transmission risk. This is to be distinguished from fears of infection through sexual contact, the most common mode of HIV transmission in the USA. A participant fear of infecting others through casual contact was a frequently mentioned theme in the setting of relationships with loved ones. In three of the four female focus groups, women expressed a fear of “contaminating” their children through sharing utensils or food, a bathroom, or through affectionate parenting behavior such as kissing and hugging. Participants’ fears of infecting their children often undermined the parent-child bond of physical affection and introduced fear of contagion into everyday activities of the family such as cooking and sharing meals.

Both the community and loved ones fear of being infected through casual contact with HIV-positive participants was also a frequently mentioned theme. One man described a disappointing and hurtful experience with a close friend:

My best friend is a very intelligent black woman and she knows my status. I had spit in her eye by accident about two weeks ago and she said, "I have a confession to make, I thought you gave me HIV, so I called the health department to find out if I could get it through you spitting in my eye." And she knows how to get it and how you can't, but she was so traumatized... she literally thought that there was HIV in her eye. The stigma of the fear that "you are going to give me HIV".... For that to come across from her, my best friend...

This story demonstrates that knowledge about HIV and a close personal relationship do not always eliminate people's irrational fears of contracting HIV. Our participants describe fear of contagion surfacing in unpredictable circumstances and serving as a painful reminder of the stigma that they encounter on an ongoing basis.

Negotiating Disclosure of a Stigmatized Role

A myriad of questions arise when a person is diagnosed with HIV. How will I tell others about my illness? What will my friends, family, and community think? Will I be able to keep my job? How will I get the medical care I need? Negotiating the disclosure of this stigmatized role is the first challenge. Our participants' experiences ranged from keeping HIV infection a secret from everyone to full disclosure to almost anyone. The majority of the participants who keep their HIV a secret describe fear of rejection and of being "labeled" as the reasons for not sharing their HIV status. For some, the fear of being rejected is so intense that they choose not to be involved in any intimate relationships. One woman states, "I am still messed up inside, it is still that stigma, that pain. You can't tell anybody. They are not going to accept you. Even thinking about a boyfriend, I say forget about it. I don't want to date."

Difficulties in negotiating the workplace environment were also mentioned by participants in each focus group. Several participants described disclosure in the workplace as a "no-win" situation. In this context, one must weigh the risks and possible negative impact of disclosure (e.g., losing the job or healthcare coverage) with the stress of maintaining secrecy about having HIV. Some participants describe being upfront and disclosing their HIV status to employers and coworkers. Whereas a few found the workplace to be a supportive place after disclosure, many others report experiences ranging from frank discrimination to subtle remarks and stigmatizing behaviors that ultimately led them to file for disability or resign. Those who chose not to disclose lived in constant fear of their colleagues finding out about their HIV. They struggled to find excuses for missing work because of multiple doctor appointments or frequent episodes of illness. In several instances, it appeared that employers did not know what to make of multiple absences and eventually reached the conclusion that the participant was an unreliable employee. One man described his experience keeping his HIV a secret in the workplace as follows:

I regret not telling my employer because I would need to be at the school at 7 AM to lead physical education activities with the kids.... I would have terrible diarrhea every morning after I started on the HIV meds and I just couldn't get there. Over time it began to look like I had an attendance problem, and I never explained to my boss what was really going on...I eventually ended up quitting.

Whereas the majority of the women and men in this study have disclosed to a small group of family and friends, only a few have reached a point of being completely open about having HIV. These individuals appear to have achieved a level of self-acceptance and resilience that enables them to take the risk of disclosing despite the possibility of encountering stigma. Some participants reported that this type of full disclosure can lead to a sense of empowerment and a desire to become an activist and advocate for others with HIV in the community. As one female participant explains,

What I did was I empowered myself by disclosing. I went on TV, radio talk shows, and magazines.... I just went public with my whole life and I felt like a sense of freedom and I gained my power. I am comfortable with the facts and I am very realistic that I have this virus in my body.... Right now there is no way I can get rid of it, so therefore I must learn to live with it. I am going to live in this world whether you like me or not. This is my world.

Renegotiating Social Contracts

The decision “to tell or not to tell” lays the groundwork for re-establishing connections (*social contracts*) with support systems, particularly with family and friends. Participants describe searching for “safe” environments, which are supportive and accepting of their HIV status. In contrast, “unsafe” environments involve judgmental and unsupportive people and often lead to withdrawal and social isolation. One man who has not found a support system expresses his desperate loneliness, saying, “It is like a physical pain. Sometimes I cry out at night wanting to connect to somebody.”

However, when HIV-positive women and men are successful in reconnecting with family and friends, it is immediately recognized as a very meaningful and powerful experience. The support of loved ones is no longer “taken for granted” the way that it may have been in the past but is instead met with gratitude and appreciation. One male participant shared his experiences:

We always get together on the Fourth of July for barbecue and I was put in charge of watching my nieces and nephews in the little wading pool. Nothing was said. No parameters were set and it was just sort of like Uncle J is going to be in charge of the kids in the pool. I didn't say to my family what that felt [like] to me that they were that okay with me being there with their kids, that they trusted me. But I don't know that I could do that with kids from the street. What would happen if I had to go to a parent of one of the playmates and say listen, I have HIV and I am going to be one of the adults supervising your kids on some school outing? I burn off brain cells trying to imagine all that...

It also becomes apparent from this participant's story that even people who have found acceptance among close family and friends continue to struggle with how they can engage with their community as an HIV-positive person.

Participants who have been successful in *renegotiating social contracts* speak of reaching a new view of themselves and the meaning of their HIV-infection. Stories of personal agency, prevailing through much adversity, and a sense of empowerment and “championing” others in the community are characteristic of individuals who have successfully reintegrated back into the community as a person living with HIV. Many participants describe how a reprioritization occurs in which emphasis

and attention are placed on the core relationships that bring meaning to life. Participants in our study speak of “thinking with a clear head” or “seeing things with a sober mind” as they place importance on connecting with loved ones and contributing to their community in meaningful ways. This often results in strengthening bonds with children, partners, and close family members or friends and learning to be an advocate for others who share in the struggle of living with HIV. For some, this clarity and connection to loved ones truly transform their lives. They view HIV as both a deadly disease and a motivator of positive change in their lives.

Stigma Within the Healthcare System

In all seven focus groups, HIV-positive women and men reported experiencing stigma in the healthcare setting. The implication is that participants must negotiate *blame and stereotypes, fear of contagion, disclosure, and social contracts* in the context of the medical community in addition to other areas of their life. Some women and men in our sample describe the HIV specialty clinic as the only place where it is safe to be open about their illness. Others avoid accessing care altogether for fear of being labeled by providers or being “outed” if they are seen at an HIV clinic. Early negative experiences with the healthcare system may also result in delaying or forgoing medical care for their HIV disease. One participant described such experiences as follows:

If you are new to this virus and you are looking for some help, and you go to that window and Andre gives you a snotty attitude, you are going to turn around and walk back out of that clinic...

When people do access medical care, often they do not disclose their HIV status to medical professionals other than their primary HIV physician because of fears of being stigmatized by medical staff. This response in turn has the potential to compromise the medical care they receive. As one participant explained:

Of course stigma has affected my health care because I was reluctant to want to share about my medical problems with any doctor [other than] ... my HIV doctor. My HIV doctor is not always available in emergency cases. Sometimes I have to go to just any emergency hospital and I am reluctant to share my status. Therefore, I put myself at risk because I can't tell [them] I am taking HIV medications.

HIV-positive individuals also report that, on occasion, they perceive that they receive inferior medical care because of their diagnosis. One female participant described her experiences in the emergency room as follows:

In the ER they don't want to be bothered with you, and they will tell you anything to send you back to your own physician instead of taking care of the problem there.... I get boils under my arms and sometimes they're real painful, and I've had them for a while, so I know when they are ready to ... bust. But I had doctors turn me away: “I don't think it's ready, check back in a couple of days with your physician....” When I get boils now I don't even bother going; I put hot water on them and try to fix it myself....

In contrast, HIV specialty care was one of the few “safe” places described by participants. Experiences of stigma—in the form of disparaging comments, refusal

to provide care, or provision of inferior care—were reported to be less common in the care provided by HIV experts. As one person explained:

When you go to an HIV clinic, ... their whole concentration [is] on how they can give the best care to any patient who comes in with AIDS. What I have found is that they are compassionate and genuinely concerned as [people].... if you go to a regular clinic or doctor's office you may not get those same needs met ... They don't really dig in and want to help you because they still have their stigmas, their fears, their stereotypes going on that interfere with giving the best care.

Perhaps most troublesome to many of the participants were perceptions of fear of contagion within the medical community—people who are expected to be the most informed and educated about the disease and its transmission risks. Many men and women expressed outrage and disbelief at being treated as if they were “contaminated” by healthcare providers. One participant described his experience with nursing staff putting on a mask and double gloves to take his blood pressure during a recent hospitalization. It takes only a few such experiences with healthcare providers for a person to become overly sensitive to provider behavior and perceive fear of contagion. Under these conditions, even good intentions can be construed as stigmatizing if they are not viewed as a part of the established provider routine. For example, one female participant perceived the basic universal precaution of cleaning hands after examining a patient as stigmatizing:

Everybody came through and they touched my stomach, and they were cool about it. But this one resident, as she was walking out she hits the hand sanitizer, and it was like [she was thinking] “ugh”.... So that was like a real subtle stigma. There's a lot of things like that, real subtle reminders that you are different than others.

Finally, participants believed that the physical changes that often result from HIV infection or the use of antiretroviral therapy contribute to the stigma of their disease. Wasting syndrome and the disfiguring lesions of Kaposi's Sarcoma identified people as having AIDS in the beginning of the epidemic, abnormalities of fat distribution (known in the medical community as lipoatrophy and lipodystrophy), including sunken cheeks, “potbellies” or “pregnant-looking” abdomens, and fat deposition in the neck known as “buffalo humps” give away chronic HIV infection in the era of highly active antiretroviral therapy (HAART).

One of the things now about HIV, because of the meds, is that you can tell by looking. One of the side effects is lipodystrophy/lipoatrophy and so it sort of shows. The stigma is right there. You don't have [the] ... question of disclosing or not. It is a huge fear.... One of my goals is to prevent that. I don't want that part of me to show because then I feel like you have no choice [of whether to disclose].

Lipodystrophy/lipoatrophy was one of the most distressing aspects of living with HIV for many of our participants, and it had the potential to influence their decision to start or to stop taking antiretroviral therapy. Many participants stated they believe there is a lack of understanding on the part of the medical providers regarding the effect of these physical changes on an HIV-positive person's emotional and mental health and quality of life.

DISCUSSION

Through exploring the experiences of a diverse group of HIV-positive men and women, we identify the salient domains of HIV-related stigma encountered by our participants in the context of their daily lives. The narratives of the study participants demonstrate that *blame and stereotypes of HIV* and *fear of contagion* are key domains of stigma that have a powerful impact on an individual's internal world, including self-esteem and self-acceptance. Our results also reveal that *negotiating disclosure* and *social contracts* play an integral role in a person's ability to find social support while living with HIV. These findings inform a novel framework that views stigma as a social and psychological process in which HIV-positive individuals struggle for internal change (self-acceptance) and reintegration into the community (see Figure 1).

In this study, we find stigma manifests in the tensions that exist between the cultural norms and attitudes about HIV/AIDS and the implications of these cultural narratives for individuals living with HIV/AIDS. This process begins as a person confronts two domains of stigma that arise from cultural beliefs about HIV: *blame and stereotypes* and *fear of contagion*. Individuals are seen as 'contaminated' and linked to the stereotypes of promiscuity, drug use, and homosexuality that characterizes HIV. The result is a 'spoiled identity' as described by Goffman¹¹ and manifests by status loss and social exclusion. Participants in our study describe a range of strategies for coping with this stigma that eventually leads them to one of two general categories: denial/social isolation or internal change and self-acceptance. This is represented as a branch point within the framework. Almost all participants in our study described some period of time when they were in denial of their HIV-infection, withdrew from family and loved ones, and lived in relative isolation with little social support. Whereas some continued on this path, many others described engaging in a process of internal change characterized by forgiveness and self-acceptance.

As individuals begin to negotiate their internal worlds, they must also confront the challenge of reintegrating into relationships and the community as an HIV-positive person. The process of reintegration is captured in the second two domains of stigma: *negotiating disclosure of a stigmatized role* and *renegotiating social contracts*. The

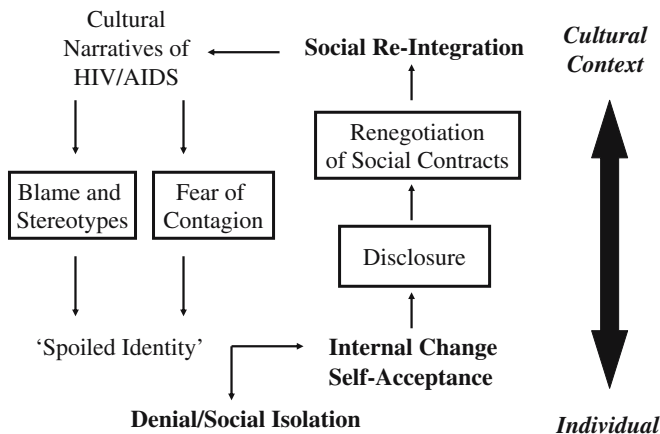


FIGURE 1. Framework of HIV-related stigma including four key domains: blame and stereotypes, fear of contagion, disclosure, and renegotiation of social contracts.

participants in our study varied greatly in the number of persons they disclosed to; however, the majority viewed disclosure as the first step in re-establishing relationships and gaining social support now that they are living with HIV. We learned that some individuals confront stigma with openness about their illness, often becoming advocates and activists in their community with the goal of changing the cultural narratives and beliefs that shape stigma. Others choose to live in silence, keeping their HIV status private and forgoing the search for support and acceptance. Understanding stigma within this framework reveals that what HIV-positive individuals desire most is support in the process of renegotiating relationships with loved ones and reintegration into the community.

A recent review by Parker and Aggleton¹³ highlights the need for context-specific studies to better understand the social processes that shape stigma as experienced by persons living with HIV/AIDS. There has been some notable work in this area,² and our findings complement the work of Ware et al.,^{29–31} who described loneliness, exclusion, and social marginalization as consequences of stigma in a sample of HIV-positive illegal drug users. Our results build on this work by demonstrating how the desire for connection and reintegration into relationships and the community is a powerful theme in the lives of persons living with HIV and may contribute to an individual's resilience in confronting and overcoming the stigma of their illness. We also contextualize the work of Link and Phelan by explicitly identifying the mechanisms by which stigma may lead to unequal outcomes for HIV-positive individuals. We describe how the consequences of stigma such as poor social support, fear of disclosure, and fear of medication related physical changes often become important barriers to HIV treatment and may lead to poor health outcomes in our sample of women and minority participants living with HIV.

Our results suggest several possible changes that may be made to address stigma within the healthcare system. An important first step is for all providers to create "safe" and supportive environments and to become familiar with the concerns of HIV-positive individuals within both healthcare and the broader social environment. For example, clearly emphasizing to each new patient that the use of gloves and other universal precautions is a standard of care for all patients in the clinic—regardless of HIV status—may help to eliminate perceptions of provider stigma based on such behavior. In addition, efforts by providers to find ways to engage close friends and family in a support system for each patient can help to facilitate reintegration into family and community.

Our findings also suggest that interventions that empower HIV-positive individuals to better understand how stigma may impact decisions about healthcare, and to engage in the process of reintegration may be effective in mitigating some of the negative impact of HIV-related stigma. Negotiating the stigma of HIV on a daily basis can be an overwhelming and painful experience; however, our participants described feeling empowered and inspired by sharing their experiences in the safe and supportive environment that emerged in each of our focus groups. Thus, a group-based setting may be a meaningful way to deliver interventions to reduce stigma, as it may reduce isolation and encourage learning and support from peers. Our framework describing the process of stigma and the resilience afforded by reintegration into one's community may be used to develop interventions that are tailored to the unique cultural context of persons living with HIV. For example, results from this study could be used to develop an intervention for HIV-positive minority women in Los Angeles that addresses how stigma may negatively impact retention in care and antiretroviral therapy adherence. It will also be important to

explore in future work whether such an approach could be effective among communities facing stigma in the developing world.

There are several limitations of this study because of small sample size, selection bias, and convenience sampling strategies. Despite our efforts to recruit a wide range of participants, the men and women who agreed to participate may differ in significant ways from those who chose not to participate. In addition, if an individual were not seeking medical care or support services, she or he may not have had the opportunity to be recruited into the study. The sample may be biased toward people with positive experiences in HIV clinics and community organizations. The goal of this study was to explore stigma among HIV-positive people who may also be marginalized by race/ethnicity, gender, sexual orientation, poverty, or some combination of these factors. Thus, we intentionally recruited from urban community sites and clinics that serve primarily minority women and men, many of whom have limited education and income. We did not attempt to recruit a representative sample, and HIV-related stigma experiences may differ for those with higher-income, more education, or living in rural areas.

CONCLUSIONS

Study participants emphasized that HIV has devastating effects on all aspects of health and expressed a desire for medical providers to consider the complex interplay between emotional and social well-being and physical health. A medical provider's understanding of the daily struggle of living with HIV—which extends beyond the familiar biomedical markers such as CD4 cell count and viral load—is believed to be of critical importance to maintaining health and survival among people living with HIV. Just as participants struggle to be treated with compassion and respect in their families and communities, a parallel process occurs in the healthcare system. When asked how the “medical system” could be improved, many participants said that they would like to be listened to, taken seriously, and seen as more than simply their disease. As articulated by one focus group participant, “They could become more sensitive to our needs—not just thinking of us as numbers, not just seeing us as a patient, but seeing us as a whole person. When you treat a person for HIV, it is their life.”

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