Published in final edited form as:

Qual Health Res. 2011 September ; 21(9): 1205–1219. doi:10.1177/1049732311405684.

Felt and Enacted Stigma Among HIV/HCV-Coinfected Adults: The Impact of Stigma Layering

Helen-Maria Lekas¹, Karolynn Siegel¹, and Jason Leider²

¹Columbia University, Mailman School of Public Health, New York, NY, 10032, USA

²Network HIV Services, North Bronx Health Care Network, Bronx, NY, 10461, USA

Abstract

The realization that many persons with HIV/AIDS are subjected to multiple layers of stigmatization because they belong to socially deviant and disenfranchised groups (e.g., injection drug users, racial/ethnic and sexual minorities) accounts for an increasing interest in the phenomenon of stigma layering. The stigma associated with HCV has also been conceptualized as layered. However, researchers have overlooked the fact that HCV adds a layer to the HIV stigma and vice versa. Qualitative interviews with 132 HIV/HCV coinfecting patients were analyzed to explore how they experience the two layers of stigma. Most participants hierarchically ordered the stigmas associated with each disease and regarded HIV as the more stigmatizing of the two. A small number perceived HIV and HCV as equally stigmatizing. The impact of the hierarchical and non-hierarchical ordering of the two stigmas on coinfecting patients' felt and enacted stigmatization is explored and implications for interventions are discussed.

Keywords

addiction/substance use; hepatitis C; HIV/AIDS; marginalized populations; stigma

Despite treatment advances that have transformed HIV/AIDS into a less deadly, more manageable, chronic disease, it remains highly stigmatizing and contributes to the social marginalization of those infected, thus undermining their mental and physical well-being (Logie & Gadalla, 2009; Ware, Wyatt & Tugenberg, 2006). In the US, public education campaigns and programs aimed at destigmatizing HIV/AIDS notwithstanding, the uninfected continue to harbor misconceptions about the disease and irrational fears of contagion, as well as blame those infected for acquiring HIV through socially- and morally-irresponsible sexual and drug-using behaviors (Brodie, Hamel, Deane & Gutierrez, 2006). In attempting to account for the persistent nature of HIV stigma, researchers have focused on the co-occurrence of multiple stigmas assigned to the social groups typically infected with the disease, a phenomenon that has been called stigma layering (Reidpath & Chan, 2005).

Corresponding Author: Helen-Maria Lekas, Columbia University, Mailman School of Public Health, 722 West 168th Street, 9th floor Room 908, New York, NY, 10032, USA, hl11@columbia.edu.

Declaration of Conflicting Interests

The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.

More than a decade ago, Novick (1997) referred to the “peculiarly stigma-sensitive epidemiology of HIV” (p. 54) and suggested that most persons who became infected had been exposed to stigma and discrimination prior to their HIV diagnosis because of their being homosexual, bisexual, racial/ethnic minorities, poor, drug users or sex workers. An HIV positive diagnosis conferred on these social groups one more stigmatizing attribute that justified further disenfranchising and “layering upon them more disdain and punishment.” (Novick, 1997, p. 60) The recognition that persons living with HIV/AIDS (PLWHA) confront multiple stigmas because of their sexual and racial/ethnic minority status, low socioeconomic status, and engagement in drug use and sex work that systematically relegate them to the margins of society underlies the recent research on the layering of HIV stigma. Recognition of the layered nature of HIV stigma has also prompted researchers to revisit the ways it has been conceptualized (Parker & Aggleton, 2003).

A characteristic of the stigma literature, including the one on HIV stigma, is the lack of a clear definition of the concept (Link & Phelan, 2001). Researchers tend to assume either the dictionary’s definition as a mark of shame or discredit, or a version of Goffman’s definition of stigma as an “undesirable difference” that undermines a person’s identity (Goffman, 1963). Moreover, although Goffman understood stigma as the outcome of the “relationship between attribute and stereotype” (Goffman, 1963, p. 4), most researchers do not use his language of relationships and instead view stigma as an individual attribute by default socially undesirable. Therefore, researchers tend to disregard the role of others, individuals or social groups, in linking an attribute to a negative stereotype and actively discriminating against its carriers (Link & Phelan, 2001). This conceptualization obscures the delineation between sources and targets of stigmatization, and fails to differentiate between felt and enacted stigma. It also prohibits the realization that the sources and the targets of stigmatization are socially situated, that enacted stigma is a means of producing and reproducing the existing social hierarchies, and that resisting or negotiating the experience of felt stigma is a means of challenging these hierarchies (Parker & Aggleton, 2003). The distinction between felt and enacted stigma that enables the targets of stigmatization to provide a situated account of their experience of having multiple stigmatizing statuses, although essential for understanding stigma layering, has been largely overlooked. In this analysis, we use the terms of “enacted stigma” to refer to “episodes of discrimination against” those with a stigmatizing attribute, and “felt stigma” to refer to the shame associated with having this attribute and/or “the fear of encountering enacted stigma” (Scambler, 2004, p. 33). Below, we organize the literature on HIV- and HCV-stigma layering using the concepts of felt and enacted stigma.

A few researchers measured the stigmatizing attitudes of the public and health care providers toward PLWHA, and tried to disentangle the extent of stigma evoked by their HIV status from the stigma evoked by other discrediting statuses, such as injecting drug use, bisexuality, sex work, and mental illness that often accompany those infected (Chan, Stoové, Sringernyung & Reidpath, 2008; Reidpath & Chan, 2005; Walkup, Cramer & Yeras, 2004). Walkup and colleagues (2004) using vignettes to control for the two statuses of HIV and severe mental illness demonstrated that undergraduate college students had less stigmatizing attitudes (expressed in terms of social distancing) toward PLWHA compared to those with severe mental illness. The vignette depicting a person diagnosed with both conditions

elicited the highest stigmatization, thus leading to the conclusion that the layering of the two stigmas had an additive effect on the students' stigmatizing reactions. Similarly, vignettes of injecting drug users (IDU) elicited the strongest stigmatization from nursing students in Thailand followed by vignettes of persons with AIDS (AIDS), and finally of those engaging in commercial sex (CS) (Chan et al., 2008). The researchers concluded that "the double stigma of IDU and AIDS was far more stigmatizing than the double stigma of AIDS and CS or AIDS on its own," and called for future studies to explore "the relevant impact of co-stigmas" (Chan et al., 2008, p. 154) on the public's discrediting reactions and the lives of PLWHA. Both studies addressed tendencies of the uninfected to enact stigma through social distancing. Therefore, their finding that multiple stigma layers had an additive effect on enacted stigma cannot be automatically applied to felt stigma.

Recently, researchers have endeavored to measure PLWHA's felt stigma elicited by different stigmatizing statuses, and used the concept of HIV stigma layering to interpret their findings. Most analyzed how racial/ethnic minority status and gender interface with HIV stigma and indicated that how PLWHA perceived and felt about stigma differed by these two variables (Bogart et al., 2007; Rao, Pryor, Gaddist & Mayer, 2008; Wolitski, Pals, Kidder, Courtenay-Quirk, & Holtgrave, 2008). Rao and colleagues (2008) found that Black PLWHA endorsed as most salient the items on the HIV Stigma Scale that referred to being socially discriminated and morally judged, whereas their White counterparts endorsed items related to interpersonal rejection and concealment of their HIV status. In interpreting these race-related differences in stigma experiences, the researchers referred to the multiple stigmas confronting Black PLWHA as a result of racial and social class discrimination. Wolitski and colleagues (2008) indicated that homelessness and low educational attainment, characteristics that also confer stigma, along with female gender heightened the sense of shame and fear of being discriminated of PLWHA, a finding the researchers linked to HIV stigma layering. Bogart and her colleagues (2007) in a qualitative study of PLWHA and their families concluded that being a woman, of a racial/ethnic minority background, a man who has sex with men, or an injection drug user "compounded" a person's felt stigma. The researchers also used the concept of "multiple layers of HIV stigma," to account for their participants' varied stigma experiences. Similarly, in our study of African American, Puerto Rican and White women living with HIV/AIDS we found that participants from the first two groups associated their feelings of shame to society's stereotypical view of PLWHA as non-White, and feared being discriminated by society. White participants felt ashamed for being outliers in their own racial community and in the HIV community, and feared being discriminated by these two communities (Authors, 2006). In the same study, women across racial/ethnic groups agreed that society tended to blame and discriminate them more than men for engaging in the same sexual and drug-using risk behaviors. This realization, however, did not always intensify the women's felt stigma.

The studies above revealed that having multiple stigmatizing statuses influenced a persons' exposure to enacted stigma and shaped his or her experiences of felt stigma. We propose, however, that assuming an additive or compounding effect on the felt stigma experienced by persons exposed to multiple layers of stigma might be premature or even misleading. A recent literature review on HIV stigma layering confirmed that the stigmas of female gender, racial/ethnic minority status and young age account for why "AIDS-related stigma is

experienced differently by people with additional stigmatized identities” (Henkel, Brown & Kalichman, 2008, p. 1596), and emphasized the need to better understand stigma layering.

Coinfection with hepatitis C virus (HCV) is another socially-devalued characteristic common among persons infected with HIV that has been overlooked in studies on HIV stigma. In the United States, approximately 33% of persons infected with HIV are also infected with HCV (Sulkowski, 2008), and among HIV-infected injection drug users this rate ranges from 50 to 90% (CDC, 2004). Although HCV infection is typically the result of injecting drug use, a highly-stigmatizing behavior that has been defined as one of the layers of HIV stigma, there is very limited research on the two stigmas associated with being HIV/HCV-coinfected. We found only one qualitative pilot study of six gay-identified coinfecting men in the UK who reported that, in the gay community, HCV is more stigmatizing than HIV because of its association with injecting drugs (Owen, 2008). HIV as a factor that might “compound” the HCV stigma was also mentioned in a recent literature review on HCV stigma, where the author recognized that the stigmas of both diseases are shaped by their association with “devalued social groups” (Butt, 2008, p. 712)

The impact of HCV stigma both on those infected and the attitudes of health care practitioners who treat this population has been the focus of several studies. Persons with HCV have identified stigma as a significant challenge that undermined their quality of life (Strauss & Teixeira 2006), mental well-being and adjustment to their illness (Crockett & Gifford, 2004; Golden et al., 2006). At the root of HCV stigma is its association with injecting drug use (Conrad et al., 2006; Crockett & Gifford, 2004; Golden et al., 2006). Golden and colleagues (2006) indicated that in a clinic sample awaiting treatment for HCV in Ireland, the highest stigma scores were reported by patients whose infection was attributed to injecting drugs, whereas the lowest scores were reported by those with an unknown aetiology. The researchers attributed the heightened sense of stigma of those infected through drug use to the “double stigma of an infectious disease associated with behavior perceived as socially deviant” (Golden et al., 2006, p. 3196). Qualitative data from HCV-infected persons in Australia also suggested that their feelings of stigma stemmed from the association of the disease to injecting drug use (Conrad et al., 2006). In this same study, an additional source of stigma was the fear of contagion, stemming from the lack of understanding of the disease among both the public and those infected. Similarly, an HCV-infected sample of women in Australia linked their feelings of shame and sense of being tainted to their concerns about HCV transmission (both casual and sexual), and witnessing their families’ and partners’ “conspicuous fear of contracting the virus” (Crockett & Gifford, 2004, p. 124). Perceiving their health care providers as lacking an understanding of the disease further eroded these women’s own understanding of their HCV and sense of self.

A recent literature review revealed that HCV-infected persons attributed their experiences of felt and enacted stigma to their health care providers’ negative views of injection drug use and lack of understanding both of this behavior and of the disease (Paterson, Backmund, Hirsch, & Yim, 2007). Reviewers hinted at the phenomenon of HCV stigma layering by stating that, “hepatitis C-related stigma is multifaceted”, complicated by the stigmas of, “illicit drug use, poverty, ethnicity, homelessness, and prostitution,” and identified the lack of research on how HCV stigma differs by these negative attributes as a major limitation of

the literature (Paterson et al., 2007, p. 369). Coinfection with HIV, another disease with layered stigma, is a conspicuous omission from this list of discrediting statuses that effect HCV-related felt and enacted stigma.

In this article, we explored the impact of the layered stigmas of HIV and HCV on the experiences of felt and enacted stigma among former and current injecting drug users coinfecting with both diseases. Most participants' accounts revealed an interaction effect between the two diseases' stigmas and fewer, an additive effect. With this analysis on how persons contend with the stigmas of being HIV/HCV-coinfecting, we intend to contribute to our understanding of the phenomenon of stigma layering as experienced by socially-situated targets of stigmatization.

Methods

Sample

The present analysis is based on in-depth interview data from 132 HIV/HCV-coinfecting men and women participating in a New York City-based qualitative study about their adaptation to living with these two serious chronic illnesses. To be eligible for study participation, a person had to meet the following criteria: (a) be a current or past injecting drug user; (b) be both HIV-infected and have chronic hepatitis C and have been notified of these results by a health care provider; (c) not have chronic hepatitis B infection; (d) be at least 18 years of age; (e) be African American or Puerto Rican, born in the US or Puerto Rico. This last criterion was imposed to reflect: first, the coinfection epidemic that has afflicted predominantly African American and Hispanic injection drug users (Strader, 2005), and second, the racial/ethnic make-up of the patient population in the two AIDS clinics that served as the study's recruitment sites where 93% of the coinfecting patients were African American and Puerto Rican (representing 75% of the Hispanic patients).

The participants ranged in age from 30 to 69, with a mean age of 49.9 years. The majority were men (69% versus 31% women) and Puerto Rican (64% and 36% African American). Eighty-nine percent of participants identified as completely heterosexual. The sample was quite socioeconomically disadvantaged reflecting their long engagement with injecting drug use. Forty-three percent had not graduated from high school, 80% were not working, and approximately half (49%) earned less than \$10,000 annually. Eighty-eight percent indicated that they had not injected drugs in the past year. In terms of their health status, more than half (53%) had an AIDS diagnosis and 77% were on HIV treatment at the time of interview. More than one quarter (27%) had been on HCV therapy at least once since their diagnosis, and 11% were diagnosed with liver cirrhosis.

Recruitment

To identify and enroll eligible cases two case identifiers, staff members of the two large public AIDS clinics collaborating with the study, every week reviewed the medical records of patients scheduled for upcoming clinic appointments. On the day of their appointment, potentially eligible patients were approached in the waiting area by the case identifier and asked to come to a private office. This process ensured that identified patients would not be

recognized by others in the waiting room as prospective study participants, and therefore as HCV infected. In the office, the case identifier explained the purpose of the study and pre-screened the patients to ensure they were aware of their coinfecting status. Interested patients were directed to the study's private office where a study interviewer provided further information about the study and screened for eligibility. Those eligible and wishing to participate scheduled an appointment with the interviewer. The Institutional Review Boards of the authors' university and the two AIDS clinics approved the study and its procedures.

Data Collection

All data were collected from July 2004 to March 2006 by three women interviewers, two Latina and one White non-Hispanic—the last is also the first author. More than one third of the Puerto Rican participants (38.8%) were interviewed in Spanish. The interviews took place in a private office dedicated to the study and located in each AIDS clinic, thus increasing convenience and facilitating participation.

The interview consisted of two sessions (each lasting approximately 2 hours) that most participants (89%) elected to complete on the same day with a break for lunch. Prior to the interview, participants read and signed the informed consent and HIPAA forms. Next, the interviewer administered a brief questionnaire that elicited standard sociodemographic and health data, including information on sexual risk behavior, current and past drug/alcohol use and experience with HIV and/or HCV treatment. The session continued with participants completing a small set of battery of self-administered measures assessing psychological distress and well-being, quality of life and coping strategies. Following completion of these measures, the remainder of the interview (150–170 minutes) was dedicated to the qualitative interview. Participants received a \$25 honorarium per session (\$50 for completing the full interview) and were reimbursed for all transportation and child care costs.

An interview guide was used to direct the qualitative interview. The guide focused primarily on the adaptational challenges facing patients coinfecting with two serious and contagious diseases, and the coping strategies they employ. Based on preliminary data analysis, the investigators identified the participants' extensive lack of knowledge regarding HCV and its treatment, reluctance to discuss the impact of being HCV infected on their health, and rich and complicated experience as long-term injecting drug users. These insights resulted in revising the guide to better elicit data on all these three areas of the participants' lives. The main domains covered in the guide were the following: symptom interpretation and management, treatment decision-making and adherence, becoming informed about each disease and its modes of transmission, disclosure of each status, experiences of felt and enacted stigma related to HIV and/or HCV, contending with the impact of their coinfection on their wellbeing and quality of life and satisfaction with medical and social services.

To elicit data on felt and enacted stigma and their impact on a participant's identity, if these issues did not emerge organically during the interview, we asked the following questions separately for each disease: (a) What beliefs and opinions do you think that people who are not HIV or HCV positive have about those who are? (b) Do you ever feel that people who are not HIV or HCV positive judge you in any way for being HIV or HCV positive? (c) Was there ever a time when you felt that people reacted to you or treated you differently because

you're HIV or HCV positive? (d) Has how you feel about yourself changed in any way as a result of being HIV or HCV positive? Stigma experiences were discussed throughout the interview and we estimated that they lasted approximately 15 to 25 minutes. The present analysis is based primarily on data related to these stigma questions, supplemented by insights from the whole interview.

Qualitative Data Analysis

All qualitative interviews were audio-recorded and transcribed verbatim for analysis. To define codes for organizing the data, the investigators (first and second authors) read approximately half of the transcripts multiple times to become familiar with the content of the interviews including participants' interpretations of the challenges of coinfection covered in the guide and any unanticipated issues that emerged in their accounts. While reading the transcripts, it became apparent that the construction of a coding scheme was impeded by the type of accounts participants provided. Specifically, their accounts of contending with both diseases tended to be exceptionally fragmented and meandering (i.e., non-linear). When the interview raised issues participants had not previously thought about, many would initially provide a short and simple response, but later in the interview, they would return to these same issues and provide a more comprehensive response. In this manner, the participant compared the two diseases and discussed their differences and similarities throughout the interview. Three participant characteristics appear to have fostered this response style: first, their lack of knowledge regarding HCV in comparison to HIV; second, their ambivalence toward contending with being coinfecting; and third, their long-term drug use that contributed to disjointed cognitive patterns. Consequently, the investigators recognized that coding the transcripts and extracting blocks of text under specific codes and subcodes would over-fragment the data, compromising their interpretation. Therefore, a decision was made to develop analytic profiles for each case that would allow for a more comprehensive and complete presentation of the data.

The first and second authors each read a different set of 25 interviews and independently decided on the main domains that should be included in the analytic profile. Next, the authors discussed and jointly defined these domains that closely reflected the interview guide domains. They decided that under each domain the relevant data would be extracted and a summary of these data composed. All profiles were finally constructed by four researchers: two were interviewers for the study, and thus intimately familiar with the data, and two were previously uninvolved with the study and provided a fresh perspective on the data. The first author trained these four researchers in the creation of the profiles, and ensured quality control through random checking of profiles, training meetings to discuss the data and process, and periodically assigning to all four researchers the same case thus assessing reliability of the profiles. The creation of each profile began with reading the whole interview transcript, then synthesizing and organizing all the relevant data under the main domains addressed in the interview. Second, based on the data excerpted that substantiated their observations and inferences about different aspects of each domain, the researchers wrote interpretative summaries for each domain in every profile. Constructing these summaries and identifying data to support their interpretations promoted the analysis by leading to further decisions about creating or splitting a domain or analytically linking

various domains. For instance, the domain of disclosure was divided into two domains: disclosure to family and friends that was analytically linked to the stigma domain, and disclosure to sexual and drug-using partners analytically linked to the risk behavior domain. The following findings are based primarily on the data under the “stigma” domain supplemented by data under the “disclosure to family and friends” domain. After completion of all profiles, the first and second authors identified analytic patterns across all cases.

Findings

The primary finding was that most participants compared the stigmas from the two diseases, hierarchically ordered them and perceived their HIV as more stigmatizing than their HCV status. Some participants diverged from this pattern and viewed HIV and HCV as equally stigmatizing.

HIV Is More Stigmatizing Than HCV

Most participants reported experiencing some felt stigma for being HCV infected associated with the disease’s contagious nature. However, their feelings of stigmatization because of their HIV status were more intense and far-reaching for several reasons. Specifically, the societal stereotypes associated with an HIV-infected person, the perception of HIV as a deadly disease, and the enacted HIV stigma participants had experienced resulted in their viewing the HIV stigma as more pervasive and detrimental to their well-being and lives compared to the HCV stigma.

Societal features of HIV, embodied features of HCV

Participants discussed extensively the highly-derogatory stereotypes society has constructed for persons with HIV/AIDS and the public’s conviction that infected individuals are drug users, sex workers, homosexuals, or sexually promiscuous. All these behaviors, participants claimed, are viewed by society as illegal or morally reprehensible and undesirable. Therefore, persons with HIV are classified as blameworthy, undeserving of compassion, and targets of unrelenting stigmatization. Many participants internalized these stereotypes, and attributed their feelings of shame, worthlessness and being tainted primarily to their HIV status. The association of HIV with drug use and the “street life” was especially salient for most participants and significant given that the sample consisted exclusively of long-term injecting drug users who typify this stereotype. A 51-year old Puerto Rican man associated his intense feelings of stigma with the HIV-related stereotypes:

Already like if you are HIV, already you cannot make more children, meaning, it has like a , a stigma more, a little bit more, . . . it [HIV] has a stigma that for me is too strong. . . . Well, I have heard some say that you are homosexual, they have it because they are homosexual, like he has it because like, or, because he is an addict, or that one because, she got [HIV] because she was having too many men or something like that, or [had sex with] women [sex workers]; those are the comments.

This participant contended that, in contrast to HIV, society does not have a negative stereotype for persons with HCV, “. . . [there is no] mention [by the public], no, you know,

about the hepatitis C.” In discussing the stigma related to HCV, he focused on this disease’s modes of transmission, and expressed concern about infecting his family, but denied feeling ashamed:

No, no, no [I don’t feel ashamed for my HCV]. [It’s] Not that. With my grandchildren, is that I am more careful with the hepatitis C when I cut myself or something, right away I get nervous, like, you know I, I am the one that cooks at home, sometimes I help my daughter. . . . With the hepatitis C, I am more afraid than with the HIV. Because I don’t want to infect someone dear to me like, you know, the, at least HIV [is transmitted through] use of intravenous, breast-feeding, give blood, or something, and, or sexual relations, . . . and I have been told that the virus from hepatitis C lives, lives longer outside than the HIV, well, sometimes, I, I worry a lot about my family.

In comparing others’ attitudes toward the two diseases, he suggested that HCV does not carry the same opprobrium as HIV: “[For an HIV-positive person, others will say] he has the monster, you know, he has these and that, you know, like, ‘Be careful.’ This is not said to a person with hepatitis.” Other participants also indicated that the disparaging term “monster” is reserved solely for HIV. This supported their belief that HCV is less stigmatizing, and justified their feeling less or no shame for being HCV positive. The term “monster” was used in the stigma accounts of both African American and Puerto Rican participants including those who were interviewed in Spanish, suggesting that this demeaning term or “illness slur” (Authors, 2006) is not culturally specific. For instance, a 53-year old African American woman who claimed that the HIV-related stigma is stronger than the HCV, referred to the same term when describing her experience of vicarious stigmatization:

I had a conversation with a lady that didn’t know that I was HIV positive. And everything that came out of her mouth was negative about a person with the virus. “Oh they nasty, um, they probably was crack heads. Or, they’re living with that monster.” And all the time she was saying it, I was just gritting my teeth. Gritting my teeth. And finally, when she finished just saying what she had to say, I said, “You know what, well I’m one of those persons.”

She viewed HCV as a biological agent that caused a physical illness that, unlike HIV, did not carry any negative connotations about the infected person’s character. This difference between the two diseases also accounted for why her HIV serostatus undermined her mental well-being and self-worth, whereas she considered HCV as a disease she can manage:

The hepatitis C, I can deal with. . . . Because to me, I’m living, that hepatitis C as a, just, just a fungus. Or a bacteria. Where, the HIV virus is more in depth. You know, as far as, um, the disease itself. Because it just takes a toll on your mentally, [choked up] physically. Um, it just turns your whole life around. You know, because, I mean, there are so many aspects of your life. Who wants, no one accepts rejection. . . . I know I’m worthy. I’m a worthy person, but sometimes I feel worthless [because of my HIV status].

Many participants shared the belief expressed above that becoming infected with HIV damaged their sense of self, primarily because it implied a moral failing. “Garbage,” “piece

of trash,” “nobody,” and “outcast” were terms used to describe how they felt as a result of internalized HIV stigma, and very infrequently HCV stigma. In an attempt to salvage their discredited self, several participants tried to differentiate themselves from the stereotypical PLWHA. Specifically, those who indicated that they got infected through injecting drug use emphasized that they did not routinely share their needles and other drug use paraphernalia, frequent shooting galleries or were not sexually promiscuous and attributed their infection to exceptional circumstances. Those who claimed to have become sexually infected with HIV highlighted their infrequent drug use. These accounts of how participants became infected designed to decrease the moral blemish on their character were provided primarily for HIV not HCV. For instance, a 54-year old African American woman who did not fear any rejection for having HCV because she agreed with society that it is “no big deal” explained to her family that she became infected with HIV sexually, thus proving a less blameworthy account:

I guess it’s because of how you may develop [HIV], but they [her family] know that I was not, no, um, IV drug user, so there was, there’s no need for them to um, uh, to, to withdraw from me the way they do. Um, I told them it was unsafe sex; I have no reason to lie about it. . . . That’s why I keep it to myself about HIV because people are out of their mind. They are very, you know, it’s like I’m a piece of trash because I have HIV.

In contrast to HIV, most participants discussed HCV as just another illness instead of a moral failing. Perceiving HCV as a physical illness normalized it to some extent, and decreased or even eliminated participants’ felt stigma. For instance, a 41-year old African American woman indicated that having hepatitis C is less likely to evoke rejection and might even elicit compassion from others because it is viewed as a true illness:

[Others think about those with HIV] that they is a freak, oh they think they must be bad. You know like they not know the deal . . . you would have to have sex with like a trick, or you were going to have an affair with somebody you know, or you know it’s ‘less they get high. You know and I know that I’m a good person, but everybody don’t. . . . I think people have different opinions about people who have hep C, because you know that’s uh that’s not like uh catching AIDS. It’s, they’re maybe more compassionate there, they are more, you know, more interaction, rather than when they are finding out you have AIDS. . . . So you have, people don’t have to look at the homosexuals like, y’all brought these diseases to you, you know. But see, like the hep C, it’s like a, a, a genuine disease.

In the following quote, a 50 year-old Puerto Rican man [240] defined hepatitis C as a “malfunction of the liver,” and referred to the numerous ways the disease can be transmitted when explaining why HCV elicits less “harsh” reactions than HIV:

It’s not as harsh as, as HIV, um, but from my experience, it hasn’t been as harsh. I guess they figure you get hepatitis from—most people are not that educated on hepatitis, like I wasn’t. Uh, so you think hepatitis is just a malfunction of the liver, or you know, you got it in the hospital, or you got cut, or, you know, um, but HIV has been associated with gay people and drug users. . . . No [others do not look down upon those with HCV].

Claiming that HCV is a “genuine disease,” or “a malfunction of the liver” called attention to its physical (i.e., embodied) instead of its social features, thus deflecting social stigmatization. In addition, referring to the multiple ways in which HCV can be transmitted, and emphasizing the blameless ways of acquiring the disease (e.g., nosocomially or through a wound) divorced the disease from its association with discrediting sexual and drug-using behaviors, thus further decreasing its stigmatizing potency. Therefore, conceptualizing HCV as a physical illness that can be transmitted in a variety of ways seemed to diminish its stigma, especially in comparison to HIV, and assuage participants’ feelings of shame. As a 40 year-old Puerto Rican man explained, HCV is in the lower ranks of the stigma hierarchy, “...because nobody talks about it. Because it’s, it’s not up there. It’s a vaccine, something you catch from fish or tainted meat, you know, nobody knows.”

HIV is perceived as more deadly than HCV and therefore more stigmatizing

The hierarchical ordering of the two stigmas was also influenced by the participants’ and the public’s perceptions of the mortality and associated dread of each disease. Several participants viewed HIV as a more deadly disease than hepatitis C and thus, felt more stigmatized for being HIV positive. Some just evoked the severity of HIV, whereas others focused on the potentially curable nature of HCV when discussing the stigma conferred by having each disease. For instance, the belief that HCV is curable minimized the stigma a 49 year-old Puerto Rican man felt for having this disease. His HIV serostatus made him feel like an “outcast,” whereas his HCV serostatus was far less distressing:

I’m more, I was more focused on the virus, on the HIV virus, the hepatitis C didn’t really bother me too much because after speaking to the doctors, the doctor explained to me that you know with treatment you know if I get treatment it’s a 50–50 chance that you know we get rid of that all together and the virus I never heard that about the virus. The virus is here, it’s here, it’s here, it ain’t going nowhere. I can never suppress it, bring it under submission, you know.

This participant, similar to others who perceived HIV as the more stigmatizing illness of the two, used the term “virus” only for HIV not HCV.

Another participant, a 57 year-old African American man who clearly perceived his HCV as less stigmatizing than his HIV highlighted the fact that the public is well aware that HIV is a fatal disease. Although he was recently told by his medical provider that he had to undergo treatment for his HCV, he continued to perceive it as a less severe disease:

[People with HCV are not rejected] No, not like people who have HIV, no. Well, I think, because people, they, they think they know a little more about HIV and the outcome is death, of course and they don’t see hep C probably like I do, as something that can kill you, you know. . . . [Why he did not disclose his HCV to his family] I haven’t really spoken about it because I never really took it that serious, you know. Until here recently and um, and I still don’t look at hep C as being as serious as HIV, you know.

The impact of HIV hygienic degradation rituals on HCV felt stigma

The third reason why most participants regarded their HIV as more stigmatizing than their HCV was their exposure to interpersonal everyday acts of discrimination after disclosing their HIV diagnosis to family and friends. Specifically, the majority of participants were diagnosed with HIV several years prior to their HCV diagnosis. Thus, many had disclosed their HIV status to friends and family and contended with HIV stigmatization prior to even confronting the prospect of HCV stigma. Moreover, many had disclosed their HIV status to others in the early to mid 90's, some even in the 80's, when the disease was highly fatal, poorly understood and elicited intensely fearful and stigmatizing reactions. The most frequent form of enacted stigmatization consisted of what we have called "hygienic degradation rituals" (Authors, 2006), that is, the adoption by uninfected persons of excessive often gratuitous precautions to avoid becoming infected with HIV through casual contact with the person that has the disease. Many participants indicated that their families viewed them as vectors of HIV infection and engaged in these hurtful hygienic rituals. Designating particular plates and utensils for the participants' sole use, constantly disinfecting the bathrooms, refraining from kissing them, and even barring participants from interacting with the family's children were experienced as degradation rituals. In many cases, exposure to such rituals resulted in intense HIV felt stigma, anticipation of being subjected to similar HCV degradation rituals, concealment of their HCV status and therefore, generated some HCV felt stigma. For example, a 33 year-old Puerto Rican woman referred to her family's unfounded fears of infecting her son with HIV, when describing her feelings of shame and decision to conceal her HCV serostatus from her relatives:

[When I told them about my HIV status] I was told to leave the house, not to touch anything. [You were living with them?] No, I went to visit my son, and they told me not to, you know, come any more and not to touch my son, and two months later they moved to Puerto Rico.

This earlier experience of enacted HIV stigma, she explained, contributed to her resolve to conceal her HCV status to avoid a similar form of rejection:

They [siblings] don't want me around 'cause they have kids and they're ignorant. They said they don't want their kids, you know, for me, you know, to touch their kids or it [HIV] could be contagious or whatever. . . . [I have not told anybody about my HCV status] because you know, they, they would not accept me at all, you know, if I was to say that [I also have HCV], that would have been even worst. Why? Because they, you know, they know that it's not something; you can catch that [HCV] by, you know, like sharing stuff or whatever, you know? Not like HIV that it has to be, you know, through intercourse or sharing needles.

She concluded that these discriminatory experiences had made her feel highly stigmatized and resulted in her social withdrawal, "I feel like I don't belong and I just, that's what I do, I just isolate and stay home away from people."

A 49 year-old African American woman also suggested that the intense rejection by her son because of his irrational fears of becoming HIV infected informed her decision not to disclose her HCV status, and accounted for her feeling some HCV-related stigma. Eighteen

years after disclosing her HIV status to her son, his childhood's fears of becoming HIV infected through casual contact persist:

He was scared of it [HIV]. Just like I thought. He no longer hugged me or kissed me and always— “Mom wash your hands,” and he wouldn't let me fix his food. It made me feel bad but I understood. . . . Whatever I cook, he's going to eat it. He loves my cooking. What I mean like, you know how you serve your man or you serve the people? He don't want me to serve him. Yeah, and I'm quite sure I brought him literature. We had talked about it, but he's still afraid.

Her disclosure of her HIV status to her family was an attempt to gauge their fears of contagion and protect herself from her relatives' degradation rituals:

[I told them about the HIV] Because I visit them. I'm in they household. You either want me there or you don't. You understand 'cause I don't want to be served on paper plates and all that stuff. I want to know where you at with me. Not where I'm at with you. You understand so either— either they going to shy away and treat me different— that means that part of the family— I don't mess with.

She also explained that she has concealed her HCV status from her family because of its contagious nature, “No [I haven't told my family about the HCV] 'cause they know that hepatitis C is very contagious, right?”

Although most degradation rituals were enacted by family, some participants reported being subjected to such rituals by close friends - an equally hurtful and distressing experience. A 42 year-old Puerto Rican man attributed his decision to end a friendship to being treated in a manner that exaggerated his contagious status. This experience convinced him to conceal his HCV status from other friends:

[I did not tell them about my HCV] Because, they're—again, they're going to think they're going to catch something from me breathing on them or something. Yeah, [I felt] that I would be rejected by them, yeah. I had a friend that actually, he found out I was [HIV] positive, I went to his house, and every time I went there, he would have a special glass just for me, and that really like, it tore me up and I just stopped being friends with him because of that. Oh, yeah, we spoke on it. It was just, I guess he wasn't educated enough on the, you know, about the HIV, that it was, that's just the way he thought, that you catch it by touching, by eating with someone's fork or drinking out of someone's glass. So, that caused us not to become friends. We just broke up our friendship.

As the quotations above revealed, the HIV-related degradation rituals participants experienced resulted in their regarding HIV as more stigmatizing than HCV. However, these same degrading experiences partly generated their HCV felt stigma and accounted for their decision to conceal their HCV status. This decision, as we discussed next, was associated with the perception of HCV as a highly-contagious disease.

Perception of HCV as a contagious disease

Accounts of HCV stigma tended to focus on the multiple modes of transmission of this disease and the fears of contagion participants and others harbored. The participants' illness

representation of hepatitis C as a highly contagious disease that can be passed on through casual contact constituted the primary source of HCV-related felt stigma. In addition to the degrading rituals related to their HIV, two other factors amplified participants' concern about being contagious and fears of being treated by others as untouchable: the public's ignorance about HCV, and the participants' own ignorance about the disease.

The public's ignorance about HCV

Participants believed that most people do not know how HCV is transmitted and therefore are inclined to excessively fear the disease and ostracize those infected. The terms "uneducated" and "ignorant" were repeatedly used to describe the public's lack of knowledge about HCV that caused its fearful and stigmatizing attitude. "A lot of people fear the unknown," as one participant said when accounting for the stigma attached to hepatitis C. A 52 year-old Puerto Rican man referred to this notion of being seen as a vector of HCV infection, and his anticipation of discriminatory reactions from others as follows:

Well, there I would say that the majority of the people think that the person who has hepatitis C is a danger; that's the first one. If they are aware that you have that kind of illness, what they do is that they exaggerate everything. If you go to eat in someone's home and they know you have that, the first thing is that they separate the plate and separate the spoon, no kisses on the lips and be very carefully, you know.

As the following quotation from a 54 year-old Puerto Rican man suggests, the participants' worry that their HCV seropositive status raises other peoples' anxiety about becoming infected and result in rejection was not unfounded:

They don't want to eat from the same bottle or drink from the same bottle or eat from the same spoon . . . well anybody gets sick, that I, that I noticed, okay? People are very cold. I noticed it. I, uh, the majority of the people. If they're told, maybe, five or ten percent that don't feel that way. . . . Uh, yeah [I have been treated differently because of my HCV], uh, what do you call it, the, yes. My, my wife's, my, my common law wife's mother tell, telling my wife. I got offended because she was telling my, my wife, "Oh, don't eat from the same plate. Keep his plates, spoon, and cup separate."

The participants' ignorance about HCV—The second factor that increased participants' apprehension about the highly-contagious nature of HCV and their feelings of stigma was their own lack of information and understanding of this disease which became apparent throughout the interviews. Numerous participants believed that HCV could be transmitted through sharing kitchen utensils or the toilet, by kissing, eating unclean food, drinking contaminated water, even touching or breathing into somebody's face. Some participants confused the modes of transmission of hepatitis A and B with those of C, and this heightened their sense of being contagious. These misconceptions about how easily HCV can be transmitted accounted for their acute concern about infecting others through casual contact, their descriptions of themselves as potential vectors of infection, and their acts of self stigmatization and self exile. For instance, a 51 year-old Puerto Rican woman in

discussing her fear of infecting her grandchildren with HCV confessed that she did not know much about this disease and saw it as a form of cancer:

I just try to be more careful, being I'm around my grandkids, you understand? Well, I take care of my body. I take care of any cuts that I have, you know, and I try to take care of myself individually, so that way I don't pass it on, I'm around my grandkids so much. . . . I don't know too much about Hep C, if, you know, like the HIV, that you lose weight. I know it's like if you have cancer. And I have. My son had leukemia. I have a friend now that's in the hospital with cancer.

A 53 year-old African American woman who speculated that she became infected with HCV from “using drugs...or eating off other people's utensils” included “dirt, germs, and bacterias” that enter one's body “through the mouth” as possible modes of transmission. She believed HCV is very contagious, “Because if the germ is spread, in, in and on the utensil, if somebody else already had it, and then, you using the utensil, I mean, I feel that it's easy to get.” Her belief that HCV is transmitted through casually resulted in extensive disinfecting practices:

I'm in my house by myself but, but I have, I am in the habit of, when I go to use my bathroom in the morning, and when I get up I pray it with a disinfectant. When I get through using it, I spray it with a disinfectant. And clean it. You know. And, I just got in the habit with that. When I go visit my daughter I always keep tissues or wipes and, I will wipe the toilet off behind me. Because, she has four boys, I mean, three boys and a little girl. . . . me and the boys use the bathroom. . . . I had to look out for those three children.

The description of herself as a “Fanatic when it comes to Clorox,” and concealment of her HCV status from relatives to avoid being subjected to disinfecting rituals reveal that she has internalized the HCV stigma:

[I have not told my relatives] 'cause, because, due to the fact that, hepatitis C is more, uh, I mean, a germ and a bacteria that's picked up off of things. And then if I go to their house, and eat, you know, wondering when I leave, what are they doing, I mean, if they're running to get Clorox, to wash this down, to do that, because see, I, experienced that with members of my family [for my HIV status].

HCV and HIV are Equally Stigmatizing Because They Imply Drug Use

Although the majority of participants hierarchically ordered the stigmas of the two diseases, some claimed that both HIV and HCV are associated with drug use and socially marginalized groups, and therefore are equally stigmatizing. The same social stereotypes that exist for HIV and contribute to its discrediting nature were also perceived as relevant to the HCV disease. Participants believed that others blamed them for becoming infected with both diseases through their own illegal and irresponsible drug-using and sexually promiscuous behavior. For instance, a 56 year-old Puerto Rican woman attributed the intense stigma of both diseases to their preventable nature and the illegal and morally discrediting behaviors associated with becoming infected. Her clear differentiation between those blameless individuals who acquired HIV through no fault of their own and the

blameworthy who became infected through their own actions indicated her internalization of society's stereotypes:

Oh, a lot believe that, unless they were infected [with HIV] through transfusion or by a, um, a husband that was not very honest, the ones that are, that don't fit those categories, are dirty, are junkies, they pretty much, you know, deserve whatever they get, because they, they didn't take, they weren't very responsible with their lives or their family. So, I don't think they have too much sympathy for that population. Because HIV is something that could have been avoided, had, had the person been more responsible. . . . [I feel judged for being HIV infected] Because it's an illness that could have been avoided. . . . [How do others judge] Me? Oh, even worse, because I'm a woman. I didn't get it through homosexuality, I got it through drug use. Those, no one forced me to use drugs. This was a choice I made. And then everything that goes with being a female drug abuser. If you have to support yourself, and even if you have a partner, you still have to bring in some money, because drugs are very expensive. You know, what you have to do to get the money. You have to steal, you have to prostitute yourself, you have to, um, cheat, lie, everything that's bad, you have to do.

Similarly, for HCV she referred to its preventable nature and poor choices that lead to infection and elicit negative judgments and reactions:

A lot of people believe it [HCV] comes from our drinking, just drinking.

The mainstream, you know, population, you know, every time you have hepatitis C, they either think it's um, hepatitis, you know, what's the one with the yellow eyes? Jaundice. They either think it's jaundice, which comes, in most cases in the Bronx, from IV drug use, you know. Or they, if they don't believe that you got it that way, then they think right away, well, cirrhosis of the liver, don't people that drink get that? . . . Yes [I think those with hepatitis C are looked down upon], just like HIV. Because, because they feel people have choices, and, and this is proof that you've made bad choices. If you were infected through a transmission, then you did it to yourself.

A 46 year-old Puerto Rican man also claimed that both diseases are equally stigmatizing because of their association with drug use and the accompanying lifestyle. He indicated that both HIV and HCV connote "dirt" and something "foul." At the time of the interview, he remained an active heroin user and had not disclosed either serostatus to his adult son:

They [uninfected people] might think it's dirty [an HIV+ person]. . . . I guess the same thing [for HCV]. Dirty. Foul [an HCV+ person]. Because they don't have it [HCV], and so they think that they're better than, than the ones who do have it. [I have not told my son about either disease] it's because of the dr—I never showed him drugs, or anything like that. You know, he was raised up without knowing that stuff, so for him to think that I was using, maybe he does know, maybe he doesn't. I don't, I don't know.

The concern mentioned above that by revealing to his son his HIV and HCV serostatuses the participant implicitly confessed to long-term drug use and the accompanying lifestyle was a

theme in several of the participants' stigma accounts. It often shaped their decision to conceal these diseases from their family thus intensifying their sense of shame. Indeed, the association between drug use and particularly being HCV seropositive was so salient for some of these participants that it determined their disclosure patterns. For instance, they were more likely to disclose their HCV to their drug-using friends and acquaintances because they perceived them as likely to also be infected or at least understanding. As a 49 year-old African American woman stated, "[I told my closest friends about my hepatitis C] Because they, the majority of them was in a drug life. They not anymore and stuff. I don't talk about my drug life. But they might have hepatitis C but not HIV." In contrast, those who moved away from their drug-using networks refrained from disclosing their HCV for fear of being discredited as drug users. A 45 year-old Puerto Rican man explained that he has not disclosed his HCV status to any of his current friends because they live a different lifestyle:

No [I have not told them]. I mean all the friends now that I have don't do drugs. They're occasional drinkers; it's, it's an entirely different lifestyle from what I had. Here [in the past], dope fiends, crack heads, non-working, to [in the present] people that are working, professionals, teachers.

After coming out of jail, he told some of his drug-using peers about his HIV status, further evidence that he was not concerned about being rejected by those who had shared the same lifestyle:

When I ran into them [people I used drugs with] I found out some of them aren't even alive any more and the ones that are alive, I told them, "Listen yo, you, are you [HIV] positive? Because I'm positive." Some of them are, some of them aren't, or the ones that aren't, are saying that they're not.

Discussion

This analysis revealed the multifaceted ways in which HIV/HCV-coinfected patients contended with having two stigmatizing diseases. Moreover, the participants' accounts of their perceptions and experiences of one disease's stigma in the presence of the other disease's stigma highlighted three themes that can inform the conceptualization of stigma. First, the value of distinguishing between what Goffman called "abominations of the body" and "blemishes of individual character" (Goffman, 1963, p. 4) for understanding the types and intensity of stigmas conferred by illnesses. Second, the importance of identifying the variety of ways in which enacted stigma has an impact on felt stigma, and allowing for targets of stigmatization to resist and/or negotiate feelings of stigma. Third, the significance of recognizing that the multiple layers of stigma do not have by default an additive or compounding effect on how people experience their multiple stigmatizing statuses. Instead, layers of stigma can interact in ways that mitigate a person's felt stigma and lessen his or her exposure to enacted stigma.

Participants compared the stigmas conferred by each disease and overwhelmingly perceived HIV as more stigmatizing than HCV. This hierarchical ordering of the two stigmas was associated with several factors including their conceptualization of their HIV serostatus as a

moral and social blemish on their character and their HCV serostatus as a physical blemish. Participants attributed the stigmatizing potency of HIV and their feelings of shame and self-loathing to the stereotypical depiction of PLWHA as members of the socially-despised groups of drug users, sex workers and homosexuals that are blamed for becoming infected through deviant behaviors. In contrast, their discussions of HCV-related stigma focused on the embodied and contagious nature of the disease and emphasized the multiple ways it can be transmitted. By representing hepatitis C as a disease that, apart from injecting drug use, can also be transmitted through innocuous everyday behaviors (e.g., sharing kitchen utensils or the toilet, consuming contaminated food or water), participants detached it from the deviant behavior of injecting drugs, thus promoting its normalization. Conceptualizing HCV as a “genuine disease,” or “a malfunction of the liver” underscored its physical instead of its social feature, thus rendering it less stigmatizing than HIV. This finding that the interaction of the two diseases’ stigmas severed the association of becoming HCV infected from the illegal and socially-reprehensible behavior of injecting drugs is entirely novel. Moreover, this process of perceiving the HCV stigma in the context of the HIV stigma and vice versa explains why this study’s coinfecting sample attributed their HCV felt stigma primarily to its contagious nature, unlike the HCV- mono-infected samples of other studies that unequivocally identified the stereotypical perception that all HCV-infected persons are drug users as the primary source of their felt stigma and exposure to enacted stigma (Conrad et al., 2006; Crocket & Gifford, 2004; Golden et al., 2006; Harris, 2009).

In explaining why they feel more stigmatized for having HIV than HCV, participants also referred to their own and the public’s perception of the former as a more deadly disease than the latter. As articulated in the HIV stigma literature, association of the disease with death challenges the public’s existential denial of death, thus creating a reason for scapegoating and stigmatizing those infected (Gilmore & Somerville, 1994; Herek, 1999). Although treatment advances have dramatically lowered the mortality rates of HIV and rendered it a more manageable chronic illness, its representation as a fatal illness persisted among our coinfecting participants and contributed to their HIV felt stigma. Participants indicated that HIV continues to connote death, elicit dread and thus, confer stigma. To substantiate the lethal nature of HIV, some emphasized its incurable nature and others, by comparison, referred to the curable or simply less serious nature of the HCV disease. Conceptualizing HCV as potentially curable and less lethal than HIV increased the latter disease’s stigmatizing potential. This finding highlights that the interface between the two diseases’ representations that resulted in the participants’ perception of HIV as incurable reproduced its image as a highly-fatal disease and intensified its stigmatizing potency. Therefore, when designing interventions to de-stigmatize HIV or HCV, it is important to recognize that the perception of how fatal each disease is might differ among the HIV-mono-infected, the HCV-mono-infected and the HIV/HCV-coinfecting populations.

The third reason why participants regarded the HIV stigma as more detrimental to their lives, sense of self, and well-being than the HCV stigma was their exposure to interpersonal enacted stigmatization. Specifically, the demeaning rituals of excessive disinfection and segregation participants had been subjected to in the 80’s and 90’s after disclosing their HIV serostatus fostered the perception of themselves as tainted and vectors of HIV infection, thus producing their feelings of profound shame and self-loathing. Based on their exposure to the

HIV-related hygienic degradation rituals, many participants anticipated subjection to similar HCV-related rituals. Their perception of HCV as a highly-contagious disease and one that can be casually transmitted amplified their fears of exposure to degradation rituals and partly accounted for their HCV felt stigma. To protect themselves from exposure to such rituals, many participants concealed their HCV status, at times socially isolating and engaging in self-stigmatizing practices, thus worsening their feelings of shame. The result of this emphasis on the infectious nature of HCV by comparison decreased the salience of the infectious nature of HIV. In the participants' accounts, infectivity was not the most prominent feature of the HIV disease, nor was it discussed as the primary reason for their HIV felt stigma. Therefore, contending with two stigmatizing infectious diseases might increase or diminish the relative salience of each disease's infectious nature, thus changing the reason why carriers of multiple stigmatizing attributes experience stigma. In this sample, amplifying the infectious nature of HCV vis-à-vis HIV made contagiousness the primary source of HCV stigma.

In addition to the anticipated HCV degradation rituals, participants ascribed their feelings of HCV-related shame and fear of rejection to the casual ways in which this disease can be transmitted. Moreover, their perception of the public as ignorant about HCV, and their own ignorance about the disease intensified their felt stigma and fear of infecting others and being ostracized. The finding that the participants' and the public's lack of HCV knowledge contributes to feelings of shame and anxiety about infecting others has been corroborated by studies on HCV-mono-infected populations (Conrad et al., 2006; Crocket & Gifford, 2004).

Our analysis of the interface between the HIV- and HCV-related stigmas and its impact on felt stigma and exposure to enacted stigma revealed how individuals contend with having multiple stigmatizing attributes, and has the potential to further our understanding of stigma layering. Although researchers on HIV stigma layering have recognized that PLWHA "juggled a number of stigmatizing attributes and/or identities" (Ware et al., 2006, p. 908), they have not identified the factors that influence this juggling act nor its outcomes. Similarly, researchers have identified the existence of HCV stigma layering and highlighted the significance of examining, "the experience of stigmatization among those who are hepatitis C positive and have various attributes common to other stigmatized groups" (Paterson et al., 2007, p. 371), but they have not addressed how individuals perceive and manage multiple stigmas. The fact that HCV adds another layer to the HIV stigma and vice versa has been largely overlooked in the stigma layering literature. Moreover, researchers that have used the concept of stigma layering assumed an additive or compounding effect on the stigma experiences of the carriers of multiple stigmatizing attributes. The ways, however, most participants contended with the stigmas of two highly-discrediting, infectious and behaviorally-acquired diseases, suggested an interactive effect with multifaceted outcomes instead of an additive effect on felt stigma.

In our study, most participants hierarchically ordered the two stigmas and although they perceived HIV as more stigmatizing than HCV they also minimized the HIV's contagiousness, thus decreasing the overall felt stigma associated with their coinfecting status. Similarly, although they attributed their HCV felt stigma to the disease's highly-contagious nature they effectively severed the association of HCV from the discrediting

behavior of injecting drug use, deflecting the blame of acquiring this disease through their own behavior, thus lessening the overall felt stigma associated to their coinfecting status. In their discussions of how the HIV degradation rituals shaped their anticipation of similar HCV rituals, participants indicated how earlier experiences of enacted stigma because of one discrediting attribute has a formative effect on the management and felt stigma associated with a subsequent discrediting attribute. Therefore, future research on stigma layering will benefit from a comprehensive examination of how prior exposure to different forms of enacted stigmatization such as racism, sexism, and classism, shape individuals' experiences of HIV and HCV felt stigma and disclosure.

Although most coinfecting patients hierarchically ordered the two stigmas and regarded HIV as the more stigmatizing disease, some did not differentiate between the two stigmas and focused instead on their similarities. According to these participants, the feature shared by HIV and HCV and the common source of their stigmatizing property was that both diseases are behaviorally acquired through injecting drug use, a deviant and highly stigmatizing behavior that renders them blameworthy for becoming coinfecting. In their stigma accounts, these participants discussed extensively their long-term drug use and expressed intense feelings of guilt, regret and shame about the deleterious effects of their drug-using lifestyle on their families and own lives. Their strong feelings of stigma and self-loathing were based on their having internalized society's accusations of the drug-using lifestyle. These findings revealed that conceptualizing both diseases as the outcome of the same socially-despised behavior (i.e., injecting drug use) prevented any differentiation between the stigmatizing potency of the two serostatuses, thus excluding the possibility of negotiating or resisting the stigmatizing potency of each disease's features and associated stereotypes. Homogenizing the source and intensity of the HIV and HCV stigmas seemed to result in participants experiencing the sum of the addition of two equally-potent stigmas, thus increasing their overall felt stigma for being coinfecting. For these participants, the two stigmas of HIV and HCV had a compounding effect.

Some limitations related to this study's sample must be addressed. All the participants were former or current injecting drug users, belonged to a racial/ethnic minority group, and overwhelmingly were socioeconomically disadvantaged. The lack of a subset of coinfecting White non-Hispanic, economically stable, non drug users limited our ability to engage in comparisons that might have elicited insights on how participants contended with the additional layers of stigma that stemmed from their race/ethnicity, social class and drug-using status. However, despite having both men and women in the sample, female gender only sporadically emerged as a status contributing another layer of stigma. In accounting for this lack of gender difference and considering the relative homogeneity of the sample, we proposed that the salience of the stigmas associated with the two diseases that are contagious, acquired behaviorally and serious might account for their overriding all other stigmatizing statuses. As PLWHA live longer and contend with other comorbidities, such as cancer, diabetes, or heart disease, that confer varied degrees of stigma, researchers will be able to examine how patients contend with the impact of different combinations of stigmatizing comorbidities on their felt and enacted stigma.

This analysis on how coinfecting patients perceived, felt about and managed having two stigmatizing diseases has important implications for intervention design. For instance, campaigns focusing on de-stigmatizing injection drug use will have a more beneficial effect on coinfecting individuals who attribute both HIV and HCV stigmas to this behavior. In contrast, individuals who associate HIV stigma to its disparaging impact on their character and HCV stigma to its embodied and contagious nature will benefit less from an intervention combating exclusively the opprobrium of IDU and will require a program addressing misconceptions and concerns about the HCV's highly-infectious nature. As Reidpath & Chan (2005, p. 431) conclude, "there needs to be an understanding of the layering of (HIV) stigma so that informed policies and interventions can be developed that will address the entire experience of stigma." As the two epidemics of HIV and HCV continue to intersect and the population of coinfecting increases, it becomes imperative to understand how they perceive, order and contend with the two stigmas.

In this article, we also endeavored to enhance the conceptualization of the phenomenon of stigma layering by substantiating that individuals contending with multiple stigmatizing attributes actively engage in negotiating and even resisting the multiple layers of stigma. By comparing and hierarchically ordering the two diseases' stigmas, most participants influenced the intensity and source of each disease's stigma, thus diminishing the stigma of being coinfecting. Therefore, we propose that the concept of stigma layering must be revisited and expanded to allow for the exploration of whether the multiple layers of stigmas conferred on individuals or groups have an interactive or compounding effect on their felt and enacted stigma.

Acknowledgments

We thank our Research Assistant Louise Enten as well as Ivette Estrada and Mabel Bolivar-Rodriguez for their invaluable contributions to the study.

Funding

The authors disclosed receipt of the following financial support for the research and/or authorship of this article: This article is based on work support by funds provided by the National Institute of Drug Abuse [DA017005], Karolynn Siegel, Ph.D., Principal Investigator.

References

- Bogart LM, Cowgill BU, Kennedy D, Ryan G, Murphy DA, Elijah J, Schuster MA. HIV-related stigma among people with HIV and their families: A qualitative analysis. *AIDS and Behavior*. 2007; 12:244–254. [PubMed: 17458691]
- Bogart LM, Wagner GJ, Galvan FH, Klein DJ. Longitudinal relationships between antiretroviral treatment adherence and discrimination due to HIV-serostatus, race, and sexual orientation among African-American men with HIV. *Annals of Behavioral Medicine*. 2010; 40:184–190. [PubMed: 20552416]
- Brodie, M.; Hamel, E.; Deane, C.; Gutierrez, C. Attitudes about stigma and discrimination related to HIV/AIDS. Kaiser Public Opinion Spotlight. Aug. 2006 Retrieved from http://www.kff.org/spotlight/hivstigma/upload/Spotlight_Aug06_Stigma.pdf
- Capitiano JP, Herek GM. AIDS-related stigma and attitudes towards injecting drug users among Black and White Americans. *American Behavioral Scientist*. 1999; 42:1148–1161.
- Centers for Disease Control and Prevention. Treating opportunistic infections among HIV-infected adults and adolescents: recommendations from CDC, the National Institutes of Health, and the HIV

- Medicine Association/Infectious Diseases Society of America. Morbidity and Mortality Weekly Report. 2004; 53:51–53.
- Chan KY, Stooze MA, Sringeruayang L, Reidpath DD. Stigmatization of AIDS patients: disentangling Thai nursing students' attitudes towards HIV/AIDS, drug use, and commercial sex. *AIDS and Behavior*. 2008; 12:146–157. [PubMed: 17364148]
- Conrad S, Garrett LE, Cooksley WGE, Dunne MP, Macdonald GA. Living with chronic hepatitis C means 'you just don't have a normal life any more.'. *Chronic Illness*. 2006; 2:121–131. [PubMed: 17175655]
- Crockett B, Gifford SM. Eyes wide shut: Narratives of women living with hepatitis C in Australia. *Women & Health*. 2004; 39:117–137. [PubMed: 15691088]
- Gilmore N, Somerville MA. Stigmatization, scapegoating and discrimination in sexually transmitted diseases: Overcoming 'them' and 'us'. *Social Science of Medicine*. 1994; 39:1339–1358.
- Goffman, E. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice Hall; 1963.
- Golden J, Conroy RM, O'Dwyer AM, Golden D, Hardouin J-B. Illness-related stigma, mood and adjustment to illness in persons with hepatitis C. *Social Science & Medicine*. 2006; 63:3188–3198. [PubMed: 17010490]
- Harris M. *Injecting, Infection, Illness: Abjection and Hepatitis C Stigma*. Body & Society. 2009; 15:33–52.
- Henkel KE, Brown K, Kalichman SC. AIDS-related stigma in individuals with other stigmatized identities in the USA: A review of layered stigmas. *Social and Personality Psychology Compass*. 2008; 2:1586–1599.
- Herek GM. AIDS and stigma. *American Behavioral Scientist*. 1999; 42:1106–1116.
- Herek GM, Capitanio JP, Widaman KF. HIV-related stigma and knowledge in the United States: prevalence and trends, 1991–1999. *American Journal of Public Health*. 2002; 92:371–376. [PubMed: 11867313]
- Lekas H-M, Siegel K, Schrimshaw EW. Continuities and discontinuities in the experiences of felt and enacted stigma among women with HIV/AIDS. *Qualitative Health Research*. 1996; 16:1165–1190. [PubMed: 17038751]
- Link BG, Phelan JC. Conceptualizing stigma. *Annual Review of Sociology*. 2001; 27:363–385.
- Logie C, Gadalla TM. Meta-analysis of health and demographic correlates of stigma towards people living with HIV. *AIDS Care*. 2009; 21:742–753. [PubMed: 19806490]
- Mawar N, Sahay S, Pandit A, Mahajan U. The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma & discrimination & future needs. *Indian Journal of Medical Research*. 2005; 122:471–484. Retrieved from <http://ezproxy.cul.columbia.edu/login?url=http://proquest.umi.com/pqdweb?did=1012477071&Fmt=7&clientId=15403&RQT=309&VName=PQD>. [PubMed: 16517997]
- Mill JE, Edwards N, Jackson RC, MacLean L, Chaw-Kant J. Stigmatization as a social control mechanism for persons living with HIV and AIDS. *Qualitative Health Research*. 2010; 20:1469–1483. [PubMed: 20663937]
- Novick A. Stigma and AIDS: Three layers of damage. *Journal of the Gay and Lesbian Medical Association*. 1997; 1:53–60.
- Owen G. An 'elephant in the room'? Stigma and hepatitis C transmission among HIV-positive 'serosorting' gay men. *Culture, Health & Sexuality*. 2008; 10:601–610.
- Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science & Medicine*. 2003; 57:13–24. [PubMed: 12753813]
- Paterson BL, Backmund M, Hirsch G, Yim C. The depiction of stigmatization research about hepatitis C. *International Journal of Drug Policy*. 2007; 18:364–373. [PubMed: 17854724]
- Rao D, Pryor JB, Gaddist BW, Mayer R. Stigma, secrecy, and discrimination: ethnic/racial differences in the concerns of people living with HIV/AIDS. *AIDS and Behavior*. 2008; 12:265–271. [PubMed: 17588146]
- Reidpath DD, Chan KY. A method for the quantitative analysis of the layering of HIV-related stigma. *AIDS Care*. 2005; 17:425–432. [PubMed: 16036227]

- Scambler G. Re-framing stigma: Felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. *Social Theory & Health*. 2004; 2:29–46.
- Shelton JN, Alegre JM, Son D. Social stigma and disadvantage: Current themes and future prospects. *Journal of Social Issues*. 2010; 66:618–633.
- Siegel K, Lune H, Meyer I. Stigma management among gay/bisexual men with HIV/AIDS. *Qualitative Sociology*. 1998; 21:3–24.
- Strauss E, Teixeira MCD. Quality of life in hepatitis C. *Liver International*. 2006; 26:755–765. [PubMed: 16911456]
- Sulkowski MS, Thomas DL. Hepatitis C in the HIV-infected person. *Annals of Internal Medicine*. 2003; 138:197–207. [PubMed: 12558359]
- Taylor B. HIV, stigma and health: Integration of theoretical concepts and the lived experiences of individuals. *Journal of Advanced Nursing*. 2001; 35:792–798. [PubMed: 11529982]
- Walkup J, Cramer LJ, Yeras J. How is stigmatization affected by the “layering” of stigmatized conditions such as serious mental illness and HIV? *Psychological Reports*. 2004; 95:771–779. [PubMed: 15666906]
- Ware NC, Wyatt MA, Tugenberg T. Social relationships, stigma, and adherence to antiretroviral therapy for HIV/AIDS. *AIDS Care*. 2006; 18:904–910. [PubMed: 17012079]
- Wolitski RJ, Pals SL, Kidder DP, Courtenay-Quirk C, Holtgrave DR. The effects of HIV stigma on health, disclosure of HIV status, and risk behavior of homeless and unstably housed persons living with HIV. *AIDS and Behavior*. 2008; 13:1222–1232. [PubMed: 18770023]

Biographies

Helen-Maria Lekas, PhD is an assistant professor at the Mailman School of Public Health of Columbia University.

Karolynn Siegel, PhD is a professor at the Mailman School of Public Health of Columbia University and Director of the Center for the Psychosocial Study of Health & Illness.

Jason Leider, MD, PhD is the Director of Adult HIV Services of the North Bronx Health Care Network and Associate Director of the Network’s HIV Services.