Published in final edited form as:

AIDS Care. 2018 July ; 30(7): 871–878. doi:10.1080/09540121.2018.1441971.

The Experience and Management of HIV Stigma among HIV-negative Adults in Heterosexual Serodiscordant Relationships in New York City

Karolynn Siegel^{a,*}, Étienne Meunier^a, and Helen-Maria Lekas^{a,b}

^aDepartment of Sociomedical Sciences, Columbia University Mailman School of Public Health, New York, USA

^bNathan Kline Institute for Psychiatric Research, Orangeburg, New York

Abstract

Despite treatment advances that improve the health and life expectancy of HIV-positive people and contribute to prevent HIV transmission, HIV stigma is still frequently experienced by HIV-infected individuals and those close to them. This study investigated the experiences of HIV-related stigma by HIV-negative adults in serodiscordant heterosexual relationships and their strategies to manage it. In-depth interviews were conducted in New York City with 56 men and 44 women who had been in a relationship for at least six months with an HIV-positive partner of the opposite sex. Those who had disclosed the HIV status of their partner to their family or friends experienced four main types of stigmatizing behaviours: distancing (avoidance of the participant or his/her partner for fear of infection), depreciation of the partner (being told their partner is not worthy of them), violation of privacy (people spreading the information that the partner is HIV positive), or accusations (being told that it is wrong to be in a relationship with an HIV-positive person or to try to conceive a child with one). Participants described four main ways of managing actual or anticipated stigma: secrecy (not disclosing the HIV status of their partner to anyone), avoidance (breaking ties with people who held stigmatizing views), seeking outside support (obtaining help from HIV-related organizations or their partner's family or friends), or education (informing family or friends about HIV treatment and prevention). Findings show that HIV-related stigma is frequently experienced by HIV-negative people in serodiscordant relationships but can be managed. Offering support to serodiscordant couples can improve the quality of life of HIV-positive people and their HIV-negative partners and can help reduce HIV stigma.

*Columbia University Mailman School of Public Health, 722 West 168th Street, 9th Floor, New York, New York, 10032

Conflict of Interest

The authors declare that they have no conflict of interest.

Compliance with Ethical Standards

All procedures performed in this study involving human subjects were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its latter amendments or comparable ethical standards.

Informed Consent

Informed consent was obtained from all individual participants included in the study.

Keywords

serodiscordant couples; HIV stigma; stigma management strategies; heterosexual couples; reproductive desires

Introduction

Antiretroviral treatments for HIV can increase the life expectancy of HIV-positive people (Trickey et al., 2017) and prevent transmission of the virus between sex partners (Rodger et al., 2016) and to a child during pregnancy (Little et al., 2017). As a result, researchers have suggested that the number of HIV serodiscordant couples is increasing (Mendelsohn et al., 2015) and that many of them strive to live their relationship as if both partners were HIV negative, including making long-term goals and conceiving children (Hughes, 2017). Nevertheless, HIV-related stigma is still widespread (Florum-Smith & De Santis, 2012) and often based on the enduring belief that HIV is a highly contagious and fatal disease.

HIV stigma affects not only HIV-positive people but also those who are close to them. Stigmatizing behaviour towards HIV-positive people often involves distancing based on fears of contagion. People may avoid infected individuals or refrain from touching them or sharing objects like dishes, utensils, furniture, or toilet seats (Bogart et al., 2008; Sayles, Ryan, Silver, Sarkisian, & Cunningham, 2007). Another common stigmatizing behaviour is depreciation—attributing HIV infection to personality flaws (e.g., imprudence or irresponsibility) or to engagement in socially and morally disapproved behaviours (e.g., intravenous drug use, prostitution, promiscuous sex, homosexual sex, etc.) (Bogart et al., 2008; Sayles et al., 2007). “Courtesy stigma” refers to the extension of stigmatization to people who associate with those who carry the stigmatized status (Goffman, 1974). Such associates may be blamed for supporting the stigmatized or presumed to share their moral weaknesses (Smith, Zhu, & Quesnell, 2016). Caretakers and family members of HIV-positive people often experience courtesy stigma; for instance, people may avoid them for fear that they may also be infected and highly contagious (Bogart et al., 2008).

The consequences of stigma on HIV-positive individuals’ psychological and physical health have been well documented (Florum-Smith & De Santis, 2012; Talley & Bettencourt, 2010) and often culminate in poor engagement in care and adherence to treatment (Walcott, Kempf, Merlin, & Turan, 2016). HIV-positive people can also reconsider their reproductive desires because of stigma as they fear accusations of being selfish and endangering the health of an innocent child (Craft, Delaney, Bautista, & Serovich, 2007). Surveys have found that stigma also has a negative impact on the well-being of HIV-negative partners in heterosexual serodiscordant relationships (Liu, Xu, Lin, Shi, & Chen, 2013; Yu, Chan, & Zhang, 2016), but little is known about the nature and mechanisms of these deleterious effects.

There are different strategies to protect oneself from stigmatization such as: maintaining secrecy about the stigmatized characteristic, avoiding people or situations that can be or have been stigmatizing, or educating people to correct their misconceptions about the stigmatized condition (Smith et al., 2016). HIV-positive people and those close to them have the choice

of keeping their condition secret to avoid stigma or to disclose it, which could result in support or stigmatization. There have been numerous studies about HIV-infected individuals' decisions and strategies of disclosure to their partners, family, friends, and healthcare providers (for a review, see Bairan et al., 2007). However, little is known about the experiences of disclosure of HIV-negative people in serodiscordant relationships (Mendelsohn et al., 2015). In a recent qualitative study of Black African men and women in serodiscordant relationships in England, about half of the HIV-negative partners had not disclosed the HIV status of their partners to anyone and the majority of those who did faced negative reactions such as insults, rejection, or being told to end the relationship (Bourne, Owuor, & Dodds, 2017). When HIV-negative partners in serodiscordant relationships fear negative reactions from their family or friends, they may elect to seek support within their HIV-positive partners' network or HIV community organizations or events (Talley & Bettencourt, 2010).

To address gaps in the literature, this article describes the experiences of stigma of HIV-negative partners in heterosexual serodiscordant relationships and their strategies to manage stigma and find support for their relationship and, when applicable, their reproductive desires.

Methods

The sample for this paper is drawn from a larger study of reproductive desires of HIV-affected couples. Between 2009 and 2012, interviews were conducted with both members of heterosexual couples in which one or both partners were seropositive. Couples had to have been together for at least six months, be aware of their partner's HIV status, be fluent in English, and live in the New York City metropolitan area. Both members of the couple were at least 18 years of age and the female partner had to be no more than 45 years old. Participants were recruited through advertisements in local newspapers, clinics, and community-based organizations. Data were gathered through a computer-assisted self-interview, an interviewer-administered questionnaire, and an in-depth interview. The in-depth interviews covered an array of topics including the participant's reproductive history and goals and their experiences or anticipations of HIV stigma. Both members of each couple completed the study separately but at the same time. Recruitment, eligibility criteria, and data collection procedures were described in greater detail in another publication (Siegel, Meunier, Tocco, & Lekas, 2017). All study procedures were approved by the Institutional Review Board at Columbia University Medical Center and informed consent was obtained from all study participants.

Recorded interviews were transcribed verbatim for analysis. The interviewer prepared an analytic profile summarizing the material relevant to the study aims including substantiating interview excerpts, a method we have further described elsewhere (Lekas, Siegel, & Leider, 2011). One of these aims was to investigate disclosure about their partner's HIV status to family or friends and the support or discouragement they had received or anticipated about being in an HIV-serodiscordant relationship and (if relevant) the desire to have a child together. In this paper, findings relating to that aim for the HIV-negative participants are reported. The authors first used a descriptive coding technique (Saldaña, 2015) to identify

the different experiences of stigma and management strategies related by the 100 HIV-negative participants. Then, we organized the coded excerpts into the different types of experiences and strategies described below.

Results

Participants' characteristics are displayed in Table 1. Male participants were between 19 and 64 years old (mean: 41.6) and female participants between 18 and 45 (mean: 33.3). Fifty-seven percent were Black, 30% Hispanic, 5% White, 1% Native American, and 7% identified with more than one race/ethnicity. Sixty-one percent had no more than a high school degree, 39% were employed, and 52% made less than \$10,000 a year, reflecting the low socioeconomic status of the sample. Almost two thirds (66%) were married or engaged to their partners and more than half had been in their current relationship for four or more years. Three quarters of the sample had previously had children, but only 21 participants had done so with their current (HIV-positive) partner. However, 54% responded that they would like to conceive with their current partner.

Forms of stigma experienced

About half of the participants had told at least some family members or close friends about their partner's HIV status and many of those described stigma-related experiences. Table 2 shows participants' quotes regarding different types of stigmatizing behaviour.

Distancing—Some participants reported that, after they disclosed that their partner was seropositive, family or friends seemed to try to avoid physical contact or sharing dishes or utensils with the couple (quote 1). In a few cases, participants said that their family or friends avoided physical contact with them because they assumed that they had inevitably been infected and were extremely contagious (quote 2). In the most extreme cases (quote 3), people seemed to have ended all forms of contact with participants upon learning their partners were seropositive.

Depreciation—Many participants reported that their family or friends tried to discourage them from pursuing the relationship with their HIV-positive partner. Participants were told that their partners were dangerous because they could infect them or that being seropositive was reflective of negative character traits or involvement in socially disapproved behaviours. Some family or friends presumed that the partner was intentionally trying to harm the participant (quote 4). Family or friends also expressed that a relationship with an HIV-positive partner was not worth fighting for and, instead of supporting the participants to address any relationship issues, they advised them to leave their partner and find an HIV-negative one (quotes 5 and 6).

Violation of privacy—After they disclosed being in a serodiscordant relationship, many participants said family or friends shared that information with others without their consent, and even distorted the facts, by saying that the participant or their children were also infected (quotes 7 and 8). This experience of being outed and exposed to malicious rumours resulted in participants feeling betrayed by people they had trusted enough to confide in and feeling a loss of control over their privacy.

Accusation—Some participants said their family or friends had very strong moral stances against HIV-positive people and disapproved of the participant having a seropositive partner. By doing so, participants were seen as acting immorally because they were supporting a person family or friends believed had sinned and should be shunned (quote 9).

Whether the participants shared their reproductive desires with others or not, their family or friends often expressed that the couple should not have children, assuming an offspring would inevitably be born infected, and/or that the infected partner would not survive long enough to raise the child. Those who had conceived with their partners or contemplated doing so reported feeling accused of endangering the child's life (quote 10). Participants were also disconcerted that others felt entitled to give their unsolicited opinions about the couple's reproductive decisions.

Ways of managing actual or anticipated stigma

Participants who had not disclosed being in a serodiscordant relationship often refrained from doing so because they worried that they would experience the forms of stigmatization and disapproval described above. Whether they had experienced or only anticipated it, participants had different strategies to manage HIV stigma; these are described below with relevant quotes in Table 3.

Secrecy—Many participants chose not to disclose being in a serodiscordant relationship to anyone. They had various reasons for doing so. For instance, some participants simply felt no need to disclose this information to anyone and preferred secrecy than risking being degraded or rejected. This was particularly true among participants who had never had a child with an HIV-positive partner and had no desire for any more children (quote 11). Participants who were hoping to conceive with their current partner felt a greater need to disclose in order to obtain support from family or friends (quote 12). Participants recognized that trying to keep their partner's status secret was a burden on the relationship (quote 13) and on their relations with family or friends (quote 14).

Avoidance—Some participants preferred to avoid people who they anticipated would stigmatize their HIV-positive partner or the couple. Rather than challenging, or tolerating others' demeaning attitude, they chose to stay away from people who held irrational fears towards HIV-positive people (quote 15). Some participants were willing to alienate themselves from people who had expressed lack of understanding of HIV as an illness, and therefore, most likely would disapprove of their relationship or their plans to have a child with their partner (quote 16).

Outside support—Participants, some who had disclosed and some who had concealed the serostatus of their partner, sought support outside their immediate network because they anticipated no help from their family or friends. Many partners had been seropositive for a long time and had been able to find support within their own family and friends. Several participants who did not feel supported by their own families found support with their partners' (quotes 17 and 18).

Many participants also found support in HIV-related community-based organizations and support groups. In these settings, they acquired information on how to protect themselves or their future children from HIV, but also felt personally accepted and encouraged to be in a serodiscordant relationship (quote 19). Some also joined their partners in advocacy events such as AIDS Walk New York. Feeling part of a community allowed them to stand up to stigmatization (quote 20).

Education—Many participants chose to educate their family or friends about HIV in an effort to get them to reconsider their stigmatizing notions and accept the relationship. They explained that fears of contagion were often unjustified, that HIV transmission could be efficiently prevented, and that treatment allowed HIV-positive people to live long and healthy lives (quote 21). In time, family or friends may gradually became more understanding and accepting of the serodiscordant relationship. For those who wanted to conceive with their partners, the next step was then to educate family or friends about safer conception methods. They used online and print resources to educate family or friends (quote 22).

Discussion

Although several studies have looked at the experiences of stigma of HIV-positive people, few have focused on their HIV-negative partners. We found that HIV-negative men and women in heterosexual serodiscordant relationships can experience several forms of stigma after telling family or friends that their partner is seropositive. As observed in other studies, stigmatizing behaviours were often grounded in irrational fears of contagion (Bogart et al., 2008; Sayles et al., 2007), what we have called “hygienic degradation acts” (Lekas, Siegel, & Schrimshaw, 2006), as family or friends avoided physical contact with HIV-positive partners or refused to handle objects that had been used by them without excessive cleaning or disinfecting. These degrading and distancing reactions sometimes also extended to the HIV-negative participant whom they presumed had become infected by the partner. Given that the study was conducted in New York City, an epicentre of the HIV epidemic and the site of numerous HIV educational interventions and programs, the lack of knowledge about the transmission of the virus and the extent of irrational fears of contagion are noteworthy.

Studies had also found that family or friends sometimes advised HIV-negative people to end a relationship with a serodiscordant partner (Bourne et al., 2017). Participants in our study also reported getting such advice, not simply because their family or friends worried that the participant would get infected, but also because they perceived HIV infection to be emblematic of being morally and socially irresponsible and believed HIV-positive people were not worthy partners. Because participants chose to be in an intimate relationship with an HIV-positive partner, family or friends could also accuse them of disrupting the moral order by supporting rather than shunning the stigmatized. Such accusations became more severe if the couple entertained the idea of conceiving a child, as family or friends assumed that the couple would inevitably give birth to an infected child.

Many studies have documented the ill effects of stigma on HIV-positive people’s mental and physiological health (Florom-Smith & De Santis, 2012; Talley & Bettencourt, 2010).

Similarly, we found that some of the ways in which HIV-negative participants tried to avoid or cope with stigmatization also had psychological consequences. Some participants who chose secrecy were burdened by the hyper vigilance necessary to keep a secret and expressed being distraught by their inability to seek support from family or friends. Others alienated themselves from family or friends they found or anticipated to be unsupportive. Those who were considering having a child with their current seemed more affected by this lack of support than those who did not want any children. HIV stigma can discourage HIV-positive people from having children (Craft et al., 2007) and, as our study suggests, it could also affect HIV-negative partners' reproductive desires. This study was cross-sectional and with people who were currently in an ongoing relationship, but it is likely that the discouragement HIV-negative individuals receive about being in a relationship or having children with an HIV-positive partner can may cause strain and sometimes lead to ending the relationship.

However, we also found that many HIV-negative participants were able to manage stigma effectively. They challenged the stigmatizing attitudes of family or friends by educating them about the disease and about treatment and prevention options. For this goal, they shared informational online and/or print material with family or friends. As reported in a review of studies of HIV-affected couples (Talley & Bettencourt, 2010), some of our participants benefitted from HIV-related services and organizations, where they could obtain information about HIV, but also find supportive people. HIV-related services and programs targeted at HIV-negative partners of HIV-positive people should be supported where they already exist or implemented where they do not.

The findings are important as supporting serodiscordant couples can be beneficial in the fight against HIV/AIDS and against HIV-related stigma. Being in a long-term relationship and feeling supported in their reproductive goals contributes to HIV-positive people's feeling of normalcy (Hughes, 2017) and, as we found in another study, often encourages them to adhere to healthy behaviour, such as staying engaged in care and adhering to treatment (Siegel et al., 2017). Further, the possibility of serodiscordant partners to remain together and even conceive children while avoiding infection to the HIV-negative partner and the child proves that HIV is an illness that can be managed and that irrational fears of contagion—on which most HIV stigmatization are grounded—are unwarranted. Thus, promoting the notion that HIV transmission can be effectively prevented in serodiscordant couples and during conception could be powerful in fighting HIV stigma.

Findings should be interpreted in light of some limitations. Participants were in relationships in which both partners were willing to come to our institution to talk about their experiences in an HIV-affected relationship. As such, the sample is biased towards individuals who are comfortable discussing personal and potentially sensitive issues. Further, recruitment was limited to the New York City metropolitan area where HIV is prevalent and HIV-related resources accessible, but experiences of stigma might be different in other areas. Data were also collected before pre-exposure prophylaxis (PrEP) became widely available and it is possible that, as knowledge about biomedical prevention methods become more widespread, attitudes towards HIV-positive people and serodiscordant relationships become more accepting.

Acknowledgments

This work was supported in part by a grant from the National Institute of Child Health and Human Development from the National Institutes of Health [HD058338].

References

- Bairan A, Taylor GAJ, Blake BJ, Akers T, Sowell R, Mendiola R. A model of HIV disclosure: disclosure and types of social relationships. *Journal of the American Academy of Nurse Practitioners*. 2007; 19:242–250. <https://doi.org/10.1111/j.1745-7599.2007.00221.x>. [PubMed: 17489957]
- Bogart LM, Cowgill BO, 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*. 2008; 12:244–254. <https://doi.org/10.1007/s10461-007-9231-x>. [PubMed: 17458691]
- Bourne, A., Owuor, J., Dodds, C. Intimacy, Support and Social Connectivity: Experiences of HIV Serodiscordant Relationships Among Black African People Living in England. In: Persson, A., Hughes, SD., editors. *Cross-Cultural Perspectives on Couples with Mixed HIV Status: Beyond Positive/Negative*. Springer International Publishing; 2017. p. 111-124. https://doi.org/10.1007/978-3-319-42725-6_10
- Craft SM, Delaney RO, Bautista DT, Serovich JM. Pregnancy Decisions Among Women with HIV. *AIDS and Behavior*. 2007; 11:927–935. <https://doi.org/10.1007/s10461-007-9219-6>. [PubMed: 17323122]
- Florum-Smith AL, De Santis JP. Exploring the Concept of HIV-Related Stigma. *Nursing Forum*. 2012; 47:153–165. <https://doi.org/10.1111/j.1744-6198.2011.00235.x>. [PubMed: 22861652]
- Goffman, E. *Stigma: notes on the management of spoiled identity*. New York: J. Aronson; 1974.
- Hughes, SD. HIV Serodiscordant Couples and the Discourse of Normality: Reconciling the Biomedical and the Social in Porto Alegre, Brazil. In: Persson, A., Hughes, SD., editors. *Cross-Cultural Perspectives on Couples with Mixed HIV Status: Beyond Positive/Negative*. Springer International Publishing; 2017. p. 55-69. https://doi.org/10.1007/978-3-319-42725-6_5
- Lekas HM, Siegel K, Leider J. Felt and enacted stigma among HIV/HCV-coinfected adults: the impact of stigma layering. *Qualitative Health Research*. 2011; 21:1205–1219. <https://doi.org/10.1177/1049732311405684>. [PubMed: 21498828]
- Lekas HM, Siegel K, Schrimshaw EW. Continuities and discontinuities in the experiences of felt and enacted stigma among women with HIV/AIDS. *Qualitative Health Research*. 2006; 16:1165–1190. <https://doi.org/10.1177/1049732306292284>. [PubMed: 17038751]
- Little KM, Taylor AW, Borkowf CB, Mendoza MCB, Lampe MA, Weidle PJ, Nesheim SR. Perinatal Antiretroviral Exposure and Prevented Mother-to-child HIV Infections in the Era of Antiretroviral Prophylaxis in the United States, 1994–2010. *The Pediatric Infectious Disease Journal*. 2017; 36:66–71. <https://doi.org/10.1097/INF.0000000000001355>. [PubMed: 27749662]
- Liu H, Xu Y, Lin X, Shi J, Chen S. Associations between Perceived HIV Stigma and Quality of Life at the Dyadic Level: The Actor-Partner Interdependence Model. *PLOS ONE*. 2013; 8:e55680. <https://doi.org/10.1371/journal.pone.0055680>. [PubMed: 23383343]
- Mendelsohn JB, Calzavara L, Daftary A, Mitra S, Pidutti J, Allman D, Myers T. A scoping review and thematic analysis of social and behavioural research among HIV-serodiscordant couples in high-income settings. *BMC Public Health*. 2015; 15:241. <https://doi.org/10.1186/s12889-015-1488-9>. [PubMed: 25885027]
- Rodger AJ, Cambiano V, Bruun T, Vernazza P, Collins S, van Lunzen J, Lundgren J. Sexual Activity Without Condoms and Risk of HIV Transmission in Serodifferent Couples When the HIV-Positive Partner Is Using Suppressive Antiretroviral Therapy. *JAMA*. 2016; 316:171–181. <https://doi.org/10.1001/jama.2016.5148>. [PubMed: 27404185]
- Saldaña, J. *The Coding Manual for Qualitative Researchers*. SAGE; 2015.
- Sayles JN, Ryan GW, Silver JS, Sarkisian CA, Cunningham WE. Experiences of social stigma and implications for healthcare among a diverse population of HIV positive adults. *Journal of Urban*

- Health: Bulletin of the New York Academy of Medicine. 2007; 84:814–828. <https://doi.org/10.1007/s11524-007-9220-4>. [PubMed: 17786561]
- Siegel, K., Meunier, É., Tocco, JU., Lekas, H-M. Reproductive Desires and Considerations of HIV-Positive Men in Heterosexual Relationships in New York City. *AIDS and Behavior*. 2017. <https://doi.org/10.1007/s10461-017-1864-9>
- Smith, RA., Zhu, X., Quesnell, M. Stigma and Health/Risk Communication. *Oxford Encyclopedia of Communication* Oxford University Press; USA: 2016. Jun 9. Retrieved from <http://communication.oxfordre.com/view/10.1093/acrefore/9780190228613.001.0001/acrefore-9780190228613-e-96>
- Talley AE, Bettencourt BA. A relationship-oriented model of HIV-related stigma derived from a review of the HIV-affected couples literature. *AIDS and Behavior*. 2010; 14:72–86. <https://doi.org/10.1007/s10461-008-9493-y>. [PubMed: 19037718]
- Trickey A, May MT, Vehreschild JJ, Obel N, Gill MJ, Crane HM, May MT. Survival of HIV-positive patients starting antiretroviral therapy between 1996 and 2013: a collaborative analysis of cohort studies. *The Lancet HIV*. 2017; 4:e349–e356. [https://doi.org/10.1016/S2352-3018\(17\)30066-8](https://doi.org/10.1016/S2352-3018(17)30066-8). [PubMed: 28501495]
- Walcott M, Kempf MC, Merlin JS, Turan JM. Structural community factors and sub-optimal engagement in HIV care among low-income women in the Deep South of the USA. *Culture, Health & Sexuality*. 2016; 18:682–694. <https://doi.org/10.1080/13691058.2015.1110255>.
- Yu NX, Chan CLW, Zhang J. Dyadic Effects of Stigma and Discrimination on Distress in Chinese HIV Discordant Couples. *AIDS Education and Prevention*. 2016; 28:277–286. <https://doi.org/10.1521/aeap.2016.28.4.277>. [PubMed: 27427923]

Table 1

Participants' characteristics.

	n	%
Sex		
Male	56	56%
Female	44	44%
Age (mean/s.d.)		
Male	41.6	9.6
Female	33.3	9.0
Race/Ethnicity		
Black/African American	57	57%
Hispanic/Latino	30	30%
Native American	1	1%
White/Caucasian	5	5%
More than one race	7	7%
Highest Education Level		
Less than High School	24	24%
High School/GED	37	37%
Technical degree/some college/Associate's degree	34	34%
Bachelor's degree or higher	5	5%
Main source of income (n=99)		
Employment/business	39	39%
Public assistance	39	39%
Unemployment benefits	8	8%
Spouse/partner	6	6%
Other	7	7%
Personal Income		
<\$5,000	39	39%
\$5,000–\$9,999	13	13%
\$10,000–\$14,999	17	17%
\$15,000–\$24,999	16	16%
\$25,000–\$49,999	13	13%
>\$50,000	2	2%
Living Situation		
Owned apartment/house	9	9%
Rented apartment/house	69	69%
Room/hotel paid by welfare	8	8%
Specialized AIDS housing	8	8%
Temporary housing (shelter, friends, relatives)	6	6%
Type of relationship with main partner (n=94)		
Married	38	40%
Engaged	24	26%

	n	%
Boyfriend/Girlfriend	21	22%
Other	11	12%
Duration of Sexual Involvement (n=94)		
Less than a year	11	12%
1–3 years	35	37%
4–6years	24	26%
7–10 years	9	10%
>10 years	15	16%
Number of biological children (mean/SD)	1.98	2.19
Previously had children	75	75%
Previously had children with current partner	21	21%
Not counting adoption, would you like to have a child with your main partner in the future? (Yes) (n=93)	50	54%

Table 2

Forms of stigma experienced by HIV-negative adults after disclosing being in a relationship with an HIV-positive partner.

Distancing

1. After my sister found out, ...she started acting, like, funny ...and cleaning this and cleaning that.... like the spoons. She started buying plastic spoons as opposed to ...using her serving spoons; plastic cups, you know? And she started buying the cover things for the toilet, buying a lot of more bleach than she should have. (Female, 39 years old, Hispanic)

2. At one time, ...I was very skinny and they thought I had it, you know? And I had to drink out of my own cup. I had to have my own plate, you know, my own spoon. (Male, 47 years old, Hispanic)

3. I told her [participant's sister] my wife is HIV positive. She got mad and got upset.... "Ah," she goes, "why didn't you tell me this before, earlier?" ...She says, "Well, you should have told us before! Why didn't you tell me before?" ...And she hung up. I never – nothing from her no more.... So I think that I lost them. I lost everybody. (Male, 52 years old, Native American)

Depreciation

4. They treat him like he's little or nothing.... That he's out to, like, harm me and stuff like that; like he's set up part of a scheme to get at me or something. (Female, 33 years old, Black)

5. I went through a big thing with my family, "Why are you getting so bent out of shape? Why are you crying over that woman? She has HIV and you don't. You can always find you another woman." ...Why am I making a big thing over it? "This girl got HIV. You can always find you somebody else!" ...Those type of comments. (Male, 44 years old, Black)

6. Yeah, my family, ...they were always telling me I could do better than to be wasting my time on a sick person. (Female, 30 years old, Hispanic)

Violation of privacy

7. The first time I ever told my best friend, she acted like she was cool about it, and then, the next day, told her mom.... She [friend's mother] came to the house to fight. Like, it got crazy.... She started telling the whole neighborhood how he gave me AIDS, ...and said [to participant's mother], "You need to get your daughter tested." Like, "Do something!" (Female, 19 years old, Hispanic)

8. Rumor started going around in the neighborhood [that participant was HIV positive].... I don't like people talking about me and I tried talking to everybody one on one, real calm, you know? ...And that's how they all found out, eventually, she [partner] was HIV positive. I had to tell them the truth, you know.... About a week later, rumors are still going around that, "This kid [participant's child] got the monster, he's sick." (Male, 26 years old, White)

Accusation

9. My family, they feel that, you know, being spiritual the way they are, it's a curse from God. And right now as far as they concerned, I'm interrupting God's business. That woman's supposed to be to herself as far as they concerned. She should be by herself and that's how, you know, they feel, my family. (Male, 30 years old, Black)

10. I've heard from my friends, I've heard, "Oh, you're a baby killer." You know, "Why would you do that to a child? Why would you bring a child into the world?" You know, "So the baby can be sick? Oh, that's crazy!" I've heard everything. (Female, 42 years old, Black)

Table 3

Strategies for coping with actual or anticipated HIV stigma by HIV-negative adults in serodiscordant relationships.

Secrecy

11. Nobody don't know nothing.... I believe that's our business, you know, and that nobody else needs to know. For what? To go spread the news? No!... That's news for them to go and spread it out. I don't need that. (Male, 52 years old, Black)

12. Well, matter of fact, it is difficult 'cause I can't tell my mother about the situation [trying to conceive with her HIV-positive partner]. That bothers me that I can't tell her.... 'Cause I don't have the support that I need. He got his sister's support and everything, and I don't have nobody 'cause I can't tell nobody. (Female, 24 years old, Black)

13. Just not being able to tell anybody, that you have to choose wisely who you tell and who not to tell. I would say that would be the hardest thing [about being in a serodiscordant relationship]. (Male, 23 years old, Black)

14. I'm affected to the point to, where it is, there's not a day that don't go by when I have to deal with what [partner] has.... It places a lot of limitations on us.... You have to make up excuses and stuff. It does affect us.... It has affected my ability to socialize like I like,... because, to have to lie and to hide his medication and stuff like that, you know what I'm saying? (Female, 40 years old, Black)

Avoidance

15. I know a lot of people are closed-minded, and they'll try and get disrespectful about it. So I don't open that door. You know, because I give respect [and] I would like to have it as well, you know? If I'm around people that I know for a fact won't give it to me, then I won't be around those people.... I don't bother with them. (Male, 43 years old, Black)

16. If you can't accept it, and you can't understand it, and you haven't done your research on it, then we should not be friends and we should not be speaking until you do that research and understand what it's about.... And if I choose to have a baby, and bring a baby into this world, then that is my decision. (Female, 34 years old, Hispanic)

Outside support (from partner's family)

17. When we talk [with her partner's mother], she asks me, "Are you taking precautions?"... She's a nice person. His [partner's family] probably would support me [if they decided to conceive] because they know about his situation.... But my family, now I don't know so much.... Those who know, I don't think they will. (Female, 30 years old, Black)

18. All her family know.... They love me more because I'm with her.... But I know that my family's very judgmental. I'm like the black sheep of my family. [If we had a child,] they'd be judgmental about it.... Her family love her.... They'd love a baby just as much. (Male, 46 years old, Black)

Outside support (HIV-related services and community)

19. This program that we go to, it's mixed with HIV [-positive] and negative people.... I feel more comfortable with the people [in the program] because they know more.... You hang out with [people outside the program], well, "Oh girl, it's nasty!" I don't want to hear that. I want something to benefit me. So, I hang around with people who can inspire me more than just trying to put you down for whatever the case is. (Female, 24 years old, Hispanic)

20. Like the other day,... HIV Awareness Day.... It's full of people. We have the police blocking streets as we cross. So people are noticing. ... I see a lot of the looks but it doesn't faze me. I'm gonna hold my head higher because you wanna look, you know, like it's something wrong with us. It's not something wrong with us, it's something wrong with you because you choose to stay close-minded, you chose to stay blind. (Male, 36 years old, Black)

Education

21. Well, I told him [participant's son], HIV is, you know, it's not the end of life and the only way you catch HIV is through sexual or blood transmitted diseases or intravenous drug use.... I said other than that there has been no other studies saying that if somebody breathes on you or somebody spits in your face or anything like that, that you won't contract HIV.... 'Cause he had a whole bunch of different information whereas, "Oh, if somebody touch you, cough on you, you get sick." (Male, 42 years old, Black Hispanic)

22. I believe, at first, they [participant's family] were just kind of worried.... I sent them to TheBody.com and that's been a huge resource. His doctor... told me about that site. And, you know, it's my go-to thing whenever I have a question.... My brother was a little upset, like, he was a little scared about it. But,... he just researches anytime he doesn't understand something. So once he did some research, he, you know, figured out that it's not something to worry about. (Female, 25 years old, White)