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HIV stigma and social capital in women living with HIV

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Abstract

Women living with HIV (WLWH) continue to experience HIV-related stigma. Social capital is one resource that could mitigate HIV stigma. Our cross-sectional study examined associations between social capital and HIV-related stigma in 135 WLWH in the San Francisco Bay Area. The mean age of study participants was 48 years; 60% were African American; 29% had less than a high school education; and 19% were employed. Age was significantly associated with perceived HIV stigma (p = .001), but total social capital was not. Women with lower Value of Life social capital scores had significantly higher total stigma scores (p = .010) and higher Negative Self-image stigma scores (p = .001). Women who felt less valued in their social worlds may have been more likely to perceive HIV stigma, which could have negative health consequences. This work begins to elucidate the possible relationships between social capital and perceived HIV stigma.

Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

The contents of this article are solely the views of the authors and do not necessarily represent the official views of the National Institutes of Health or of UCSF.

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Kevwords

HIV; social capital; stigma; women

Since HIV was first identified more than 30 years ago, people living with the disease have experienced stigma from an array of people and institutions. This has been, and continues to be, the case in the United States and around the world (Earnshaw, Lang, Lippitt, Jin, & Chaudoir, 2015; Herek, Saha, & Burack, 2013; Turan et al., 2011). HIV stigma has a range of consequences, from emotional (e.g., verbal abuse, shunning), to physical (e.g., beatings, expulsion from the home), to financial (e.g., firing someone from a job). Stigma can also have direct impacts on the health of people living with HIV (PLWH), as it may act as a barrier to testing (Bokhour, Solomon, Knapp, Asch, & Gifford, 2009; Leblanc, Flores, & Barroso, 2016; Turan, Miller, Bukusi, Sande, & Cohen, 2008), to accessing care (Bauman et al., 2013; Turan et al., 2008), and/or to understanding and adhering to treatment regimens (Brion et al., 2011; San Francisco Department of Public Health, 2013; Sweeney, Mitzel, & Vanable, 2015). The U.S. Office of National AIDS Policy has identified reducing HIV stigma as an important step in reducing HIV disparities and inequalities in health outcomes (The White House, 2015).

Women, who currently account for approximately 23% of PLWH in the United States (Centers for Disease Control and Prevention, 2016), may be particularly vulnerable to HIV-related stigma. Many women living with HIV (WLWH) are women of color living in poverty, already marginalized not only for their gender, but also for their race, social class, and/or sexual and substance use risk behaviors. The various social worlds in which they live, and the social capital that they have within those social worlds, may provide support as they deal with the illness. Conversely, those same social worlds could be sources of stigma. Because of the complexity of stigma processes, it is important to have a more nuanced understanding of the social situations in which stigma occurs in order to address it more effectively. Therefore, the purpose of our study was to examine the relationship between HIV-related stigma and social capital in a sample of WLWH.

Background

Although stigma is a concept that has been studied in many domains over the years, it is often not clearly understood. In the early 1960s, Goffman (1963) provided the pioneering social science definition of stigma as "an attribute that is deeply discrediting," but he added that "it should be seen that a language of relationships, not attributes is really needed" (p. 3). Goffman emphasized that an attribute was deemed "deeply discrediting" only through social interaction, and was thereby socially constructed by people, their social networks, and the larger social worlds in which they lived. Link and Phelan (2001) went beyond Goffman, proposing a theory of stigma as a set of interrelated components that were "entirely contingent on access to social, economic, and political power" (p. 367). Parker and Aggleton (2003) built on this work, describing stigma as an ongoing dialectical process that served to reproduce the power inequalities discussed by Link and Phelan (2001). They proposed that, "Stigma and stigmatization function, quite literally, at the point of intersection between

culture, power and difference" (Parker & Aggleton, 2003, p. 17). In explicitly pointing to the dynamics of power and differentiation, Parker and Aggleton (2003) saw power differentials as a cause of stigma rather than just a necessary presence in which stigma and discrimination occurred. Further, they specifically acknowledged the interaction between multiple inequalities based on, for example, race, ethnicity, and gender (Parker & Aggleton, 2003).

Internalized stigma is an important issue for PLWH. In his work on mental illness, Link (1987) explained that being diagnosed with a stigmatized condition can have significant negative impacts, including devaluing oneself, having low self-esteem, and creating defenses that lead to isolation. Labels such as "mental patient" or "HIV-infected", when applied to oneself, may cause individuals to stigmatize themselves. A number of authors have applied the idea of internalized stigma to the experiences of PLWH (Cuca, Bukusi, Onono, & Turan, 2012; Earnshaw & Chaudoir, 2009; Lekas, Siegel, & Leider, 2011).

Similar to concepts of stigma, social capital is also based on relationships between individuals and groups. Bourdieu (1985) defined social capital as the resources that a person can potentially call upon, based on her/his interactions and relationships with other group members. Within those relationships, however, individuals are also responsible for maintaining the integrity of the social group, including by "expelling or excommunicating... [or] embarrassing individuals" (Bourdieu, 1985, p. 251). Portes (1998) described the functions of social capital more specifically: "(a) as a source of social control; (b) as a source of family support; (c) as a source of benefits through extrafamilial networks" (p. 9). Similarly, Coleman (1988) suggested that these norms and the capacity for sanctions were important aspects of networks, serving both positive and negative functions. Social capital and other forms of capital – economic and cultural – were, in fact, seen to be convertible into one another (Bourdieu, 1985), suggesting that economic, cultural, and social forms of capital were indicators of power, and that accumulated resources of social capital could be seen as a form of greater power of one individual or group over another.

These theories are useful for examining the potential relationship between social capital and stigma for WLWH. Social controls work to define both acceptable and unacceptable behaviors for group members. The threat of sanctions can limit behaviors that put women at risk for HIV, such as sex and alcohol and drug use, but they may also limit disclosure of HIV status. For WLWH, lower levels of social capital or power within their social networks could lead to sanctions such as stigma and exclusion. Conversely, social capital may function as social support for WLWH, potentially outweighing social controls.

Pescosolido, Martin, Lang, and Olafsdottir (2008) proposed the Framework Integrating Normative Influences on Stigma (FINIS), which can be tailored for different health-related stigmatizing conditions to help identify areas that should be examined for their impact in a particular context. Explaining that "stigma lies at the interface of community and individual factors" (Pescosolido et al., 2008, p. 433), the authors identified some of the micro-, meso-, and macro-level contextual issues that take place in communities and among individuals, and which make the stigma process more or less likely to occur. At the micro-level are factors such as the individual's social characteristics (e.g., age, race, class) and disease characteristics (e.g., course of the disease, concealment of the disease). At the meso-level,

Pescosolido et al. (2008) discussed the role of social networks, finding conflicting empirical evidence. In some cases, social networks offer increased social support if a member needs help; in other cases social networks have lower tolerance for people who are or become different from them, making stigmatization of a group member more likely if s/he discloses something such as HIV. Many theorists have built on the idea of social networks by examining the social capital that is created within them.

In a study of 619 people in a South African community, Chiu et al. (2008) found that various factors of social capital predicted stigmatizing attitudes. People with a greater sense of empowerment and more education were less likely to have stigmatizing attitudes toward PLWH. People with a greater sense of trust and safety in their neighborhoods were less likely to perceive stigmatizing attitudes in their communities. Sivaram et al. (2009) found that community members in India who perceived themselves as having greater social capital – through participation in groups, collective action, reciprocity among community members, and trust in providers – had less stigmatizing attitudes toward PLWH.

To date, research on social capital and HIV stigma has mainly examined the stigmatizing attitudes that uninfected people feel toward PLWH. The purpose of our paper, however, was to begin exploration of the relationship between social capital and the stigma that PLWH have experienced due to their HIV status. An understanding of this relationship could provide innovative strategies to address HIV-related stigma and its negative health and social consequences. We hypothesized that WLWH with higher levels of social capital would perceive less HIV-related stigma.

Methods

The data and analyses presented here were part of a larger longitudinal study to validate a self-management instrument for WLWH (Okonsky et al., 2015; Webel, Asher, et al., 2012). For the analysis presented here, data were collected using convenience sampling in the San Francisco Bay Area in California, USA, from October 2010 to February 2011.

Human Subject Protections

The institutional review board of the University of California, San Francisco reviewed and approved the study. Women who were interested in the study received an explanation of the purpose and activities of the study, including information regarding assurance of confidentiality; because participants were recruited directly from HIV-related organizations and because interviews were conducted face-to-face, participants were not anonymous. Those who agreed to participate signed an informed consent form and then completed a self-report questionnaire on paper. Investigators were present to answer any questions. Upon completion of the questionnaire, participants received a \$25 cash gift card.

Sample

Women were recruited from three HIV sites in the San Francisco Bay Area, including two women's HIV clinics and one women's AIDS services organization. At the two clinics, investigators were present in the waiting rooms during the clinic hours specified for HIV-infected women and invited all women to participate. At the AIDS services organization,

flyers were posted in advance, and those who were interested went to the organization on a specified date to complete the questionnaire. Women were eligible to participate if they had HIV infection, were 21 years of age or older, self-identified as female, and were fluent in English. After completing the informed consent process, participants completed the survey booklet on paper, which took approximately 45–60 minutes. Research assistants then entered the data into an electronic database. The final sample included 135 women who completed the self-report survey instrument.

Independent Variables

Socio-demographics—We collected information about age, race/ethnicity, marital status, parental status, employment status, and education and annual income (as proxies for class), and year of HIV diagnosis.

Social capital—Social capital was assessed using the Social Capital Scale (Onyx & Bullen, 2000). This 36-item instrument measures an individual's perceptions of social capital in eight domains: participation in the local community (e.g., Do you help out a local group as a volunteer?); social agency (e.g., If you disagree with what everyone else agreed on, would you feel free to speak out?); feelings of trust and safety (e.g., Do you agree that most people can be trusted?); neighborhood connections (e.g., Can you get help from friends when you need it?); family and friend connections (e.g., How many people did you talk to yesterday?); tolerance of diversity (e.g., Do you think that diversity makes life in your area better?); value of life (e.g., Do you feel valued by society?); and work connections. In addition, one general factor measures overall social capital. Because we expected low levels of employment in this sample, the five items related to employment were not included in the instrument. This shorter 31-item instrument has been validated in PLWH (Webel, Asher, et al., 2012). Participants responded to each item on a 4-point response scale tailored to the particular item (e.g. No = 1, Yes = 4). Factor scores and the total social capital score are calculated by summing responses and dividing by the number of items, for a range of 1-to-4. Cronbach's alpha reliability coefficient was 0.90 for the total score in this sample.

Disclosure—The women were asked whether they had disclosed their HIV status to anyone and, if *yes*, *to whom*. This included husband/wife/partner, children, relatives, neighbors, friends, church community, work colleagues, and other members of the community. Because they were recruited from HIV service organizations/clinics, the women were not asked about disclosure to health care providers.

Outcome Variables

Perceived stigma—The Perceived Stigma Scale (Berger, Ferrans, & Lashley, 2001) is a 40-item instrument examining the experiences, feelings, and opinions of PLWH since diagnosis. Participants responded to each item on a 4-point scale (*strongly disagree* to *strongly agree*) and responses were summed to generate a total score (possible range = 0–120), and four factor scores: personalized stigma (e.g., *I have lost friends by telling them I have HIV*; possible range = 18–72); disclosure concerns (e.g., *I work hard to keep my HIV a secret*; possible range = 10–40); negative self-image (e.g., *Having HIV makes me feel that I'm a bad person*; possible range = 13–52); and concern with public attitudes (e.g., *Most*

people believe that a person who has HIV is dirty, possible range = 20–80). Cronbach's alpha reliability coefficient was 0.96 for the total score in this sample.

Analysis

Study data were entered into a Research Electronic Data Capture (REDCap) system, then exported into Stata 11 for cleaning, scoring, and analysis. Multivariate linear regression analysis was used to examine the relationship between variables that were a priori considered to be relevant to HIV-related stigma based on the FINIS model, including the concepts of social capital (Total Social Capital), social characteristics (age and race, and income and education as proxies for class), and disease characteristics (disclosure, years since diagnosis). Subsequent analyses examined a priori relationships between specific social capital and marginalization factors and stigma factors in order to pinpoint which aspects of social capital should be targeted.

Results

The mean age of the 135 study participants was 48.2 years \pm 8.9 (Table 1). Most participants were African American/Black (60%) and single (66%). Almost one third of the participants (29%) had less than a high school education, while another third (30%) had 2 years of college or an associate/technical school degree. Mean annual income for participants was \$14,619 (\pm \$16,733; median = \$10,140), and only 19.3% of participants were currently employed. One-hundred participants had permanent housing (74%). Of the 135 women, most had been pregnant at some point in their lives and 29.6% had been pregnant when they were first diagnosed with HIV. Although most had been pregnant, only 37% currently had children living with them. Mean perceived stigma overall among participants was 51.5 on the scale of 0 to 120. Women who were pregnant when diagnosed with HIV had Total Stigma scores 14 points higher than women who had not been pregnant when they were diagnosed (95% CI 1.8, 26.4, p = .03). The mean social capital score was 2.58 \pm .59 on a scale of 0–4. Of the study participants, 117 (88.6%) had told at least one person of their HIV status.

In a multiple regression model for total perceived stigma (Table 2), age was significantly associated to stigma (F = 1.85, p = .05, $R^2 = .23$). Women who were older were significantly less likely to perceive experiences of stigma related to their HIV status than were younger women (beta = -1.08, 95% Confidence Interval [CI] -1.73, -.45, p = .001). For each additional year of age, women's total stigma scores declined by a little more than one point, showing that stigma experiences for women in their 20s, 30s, 40s and on could be significantly different. Total stigma scores for Asian/Pacific Islander women tended to be substantially higher than for White women (22.8 points, p = .07). While total stigma scores for African American, Hispanic, and Native American women were higher than for White women, the differences were not significant, and when these categories were combined into one "other" category because of the small numbers, differences between White, African American, and other minority races were not significant. In this model, total social capital, annual income, education, disclosure, and years since HIV diagnosis were not significantly predictive of total stigma.

To further probe the relationship between social capital and stigma, we developed a second model using the Value of Life factor from the Social Capital Scale, as it was significantly associated with stigma in bivariate analysis (p = 0.004); this model provided greater explanation (F = 2.50, p = .008, $R^2 = .29$). Women who had lower scores on the Value of Life factor had significantly higher total stigma scores (p = .010), suggesting that women who did not feel valued by society were also more likely to perceive experiences of stigma related to their HIV status. As in the first model, younger women and Asian/Pacific Islander women were more likely to perceive experiences of HIV stigma compared to older women and women of other races. We also examined the relationship between the Value of Life factor of social capital, and the Negative Self-Image factor of stigma (Table 3). Again, there was a significant relationship between value of life and negative self-image, controlling for other variables (F = 3.21, p = .002, $R^2 = .25$). Women with lower scores on the Value of Life factor of the social capital scale perceived significantly greater internalized stigma (negative self-image) than did women with higher scores (p = .001; data not shown).

Discussion and Conclusions

In this analysis of WLWH, those with less social capital perceived more HIV-related stigma, although the relationship was not significant. When the Value of Life factor of the Social Capital Scale was examined in greater detail, however, significant associations were found with both total stigma and with the Negative Self-image factor of the stigma scale. These results indicated that women who felt less valued in their social worlds, who were marginalized or lacked a valued social identity, might be more likely to perceive HIV stigma, including internalized stigma. Studies have shown the importance of having a valued social identity, such as mother, for some HIV-infected women (Barnes & Murphy, 2009; Bedimo-Rung, Clark, Dumestre, Rice, & Kissinger, 2005; Webel & Higgins, 2012). Although the majority of the participants had ever had children, many fewer had children currently living with them, either because the children were grown, or possibly because of the involvement of Child Protective Services. In either case, not having children at home may have resulted in a less substantial mother role for participants. For the women in this sample – who were largely poor, unemployed, and of color – not feeling valued by society could have lead to internalization of some of these negative opinions into their views of themselves. Internalized stigma has been shown to be associated with poor mental health outcomes, such as depression. In a study of 408 PLWH in Thailand, depression was found to be significantly associated with HIV stigma (Li, Lee, Thammawijaya, Jiraphongsa, & Rotheram-Borus, 2009). Vyavaharkar et al. (2010) similarly found that, of 340 African American women living with HIV, internalized stigma was significantly associated with depression.

In the models that we tested, education and annual income, as proxies for social class, did not contribute significantly to the explained variance in perceived stigma. While being of Asian/Pacific Islander descent was associated with greater perceived HIV stigma, this may have been an anomaly due to the small sample of such participants. When combined with other small sample groups (Hispanic/Latino and Native American/Indian), Asian/Pacific Islanders and other minorities had perceived stigma, but this was not significant. Prior research, however, has identified disclosure and stigma as substantial issues for people of

Asian descent due to cultural norms (Kang, Rapkin, & DeAlmeida, 2006), and further exploration of this may be warranted.

In all of the models examined, age contributed significantly to the variance in stigma. Younger women were more likely to perceive social stigma, including negative self-image, than were older women. It may be that younger people, many of whom are developing identities, are more conscious of and concerned with other people's opinions of them. Other research, however, has suggested that older PLWH may experience more stigma (Solomon, 1996). In a study of 88 PLWH, Emlet (2006) found no difference in total HIV-related stigma between adults older and younger than 50, but significant differences in terms of sub-factors. Younger PLWH were more concerned about losing jobs, while older people disclosed their HIV status to fewer people. Differences in definitions of older and younger have made it difficult to compare results of prior studies, suggesting that further research in this area may be important.

There were several limitations to this study, including the use of a convenience sample. In addition, the lack of longitudinal data limits the results to associations and does not allow us to determine possible causal effects of social capital on stigma. In addition, although we theoretically presupposed that social capital could serve as a form of power within networks, we did not have a true measure of social power. However, in our review of the literature, we did not find an operationalized measure of social power appropriate for a study of health. The measure of social capital, although previously used and validated in populations of PLWH, has more of a focus on measuring social capital at a community level, rather than solely at the individual level. Further, this instrument did not take into consideration the fact that all people inhabit multiple social worlds and not only may have different degrees of social capital in each world, but also may or may not have "bridging capital" to be used outside of their own social worlds (Putnam, 2001). WLWH may, for example, have social capital within networks of other WLWH, but less social capital in their neighborhoods, or even in the cities in which they live. Therefore, better instruments to measure the nuances of social capital are needed.

Although the overall hypothesis in our study was not supported, further analysis identified a significant association between the Value of Life factor of the Social Capital Scale and both Total Stigma and Negative Self-image. Although some research has examined social capital in PLWH (Webel, Phillips, et al., 2012), its distinct relationship to HIV stigma in WLWH has not yet been studied. Young WLWH who do not feel valued by society, and who may lack a valued social identity, may be more likely to perceive HIV-related stigma, which could lead to increased morbidity and mortality.

A woman's various social networks may be important sources of empowerment and support that can reduce HIV-related stigma and its distal effects, such as depression. Many WLWH experience social isolation brought on by their own fears of stigma, negative self-image, or through active exclusion by others (Emlet, 2006; Sandelowski, Lambe, & Barroso, 2004). However, women who are able to create new social networks for themselves or involve themselves in supportive social worlds (e.g., support groups, supportive communities,

women's groups) may be better equipped to avoid or deal with HIV-related stigma, particularly internalized stigma.

These findings have implications for research and practice. Future research should consider the importance of a valued social identity in models examining predictors of stigma. Further, efforts by policymakers and practitioners to empower women may help WLWH deal with stigma. For example, employment programs help women financially and also provide a valued social identity – worker – and may be key to providing women with economic and social capital, which may reduce the health and stigma effects of HIV. In addition, health care providers are part of the social context of women's lives and, therefore, it can be useful for them to be aware of these factors to identify women who may be more likely to experience HIV stigma and related mental health issues such as depression. Practitioners can encourage women to become involved in their communities and link them to employment programs and other services; similarly, clinics can serve as networks of support for WLWH and can help organize support groups.

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Key Considerations

 Women living with HIV who lack social capital and social support may experience greater HIV-related stigma, which can affect their abilities to access and adhere to care.

- Social capital interventions for women could diminish perceived stigma toward women living with HIV.
- Holistic approaches to providing care for women, especially women who test and enter HIV care during pregnancy, must include methods to address stigma and increase social capital.
- Clinicians can create clinical environments that are not stigmatizing for women living with HIV.

Table 1

Demographic, Health, and Stigma Characteristics of Study Participants at Baseline (n = 135)

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Characteristic	Mean \pm SD (or) # (%)
Age, years, mean \pm <i>SD</i> , median	48.2 ± 8.9 (range: $22 - 71$)
Race/Ethnicity	
Asian/Pacific Islander	5 (3.9%)
African American/Black	78 (60.5%)
Hispanic/Latina	9 (7.0%)
Native American/Indian	7 (5.4%)
White (non-Hispanic)	22 (17.1%)
Other	8 (6.2%)
Marital Status	
Single (never married)	85 (65.9%)
Married or Domestic Partnership	18 (14.0%)
Separated or Divorced	18 (14.0%)
Widowed	6 (4.7%)
Other	2 (1.6%)
Education	
11 th grade or less	37 (29.1%)
High school or GED	52 (41.0%)
2-year college/AA degree/Tech school	28 (22.1%)
College or higher	10 (7.9%)
Works for pay (yes)	26 (19.3%)
Annual income	\$14,620 ± \$16,733
Currently on Antiretroviral Therapy (yes)	96 (73.9%)
Ever been pregnant (yes)	109 (80.7%)
Pregnant when diagnosed with HIV (yes)	32 (29.6%)
Have children (yes)	89 (82.4%)
Have children living with you (yes)	30 (37.0%)
Stigma	
Total stigma score (possible range 40-160)	91.46 ± 25.84
Personalize stigma (possible range 16-66)	38.29 ± 13.59
Disclosure concerns (possible range 10-40)	25.30 ± 7.16
Negative self-image (possible range 13-52)	28.35 ± 8.33
Concern with public attitudes (possible range 20-80)	45.70 ± 13.59

Social Capital (range 1-4)

Characteristic Mean $\pm SD$ (or) # (%) Total social capital $2.58\pm.59$ Value of life $2.80 \pm .96$ Social agency $2.75\pm.72$ $2.22\pm.84$ Participation in the local community Feelings of trust and safety $2.36\pm.80$ Neighborhood connections $2.54\pm.80$ Family and friends connections $2.75\pm.85$ Tolerance of diversity $2.97\pm.98$

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Note. GED = graduate equivalency degree; SD = standard deviation; AA = associate degree.

Table 2

Relationship Between Total Social Capital, Marginalization, and Total Perceived Stigma

Model 1	β	95% Confidence Interval	p-value	F(df)	Adjusted R ²
Age	-1.08	-1.73,45	.001		
Race					
White	(ref)				
Asian/Pacific Islander	22.85	-1.89, 47.58	070.		
African American/Black	3.58	-10.96, 18.13	.625		
Hispanic/Latina	12.26	-15.73, 40.25	.386		
Native American/Indian	3.82	-21.05, 28.69	.760		
Other	-8.15	-32.27, 15.96	.503		
Annual Income	00007	0004, .0002	889.		
Education					
11th grade or less	(ref)				
High school or GED	5.61	-7.99, 19.20	.414		
Any college or higher	6.31	-7.85, 20.47	.378		
Disclosed to anyone (yes)	-1.05	-19.02, 16.93	806:		
Years since HIV diagnosis	.45	30, 1.20	.234		
Perceived Social Capital	-4.11	-12.75, 4.54	.347		
Constant	139.46	99.44, 179.48	<.001	1.85 (12,75)	.11

Note. df= degrees of freedom; GED = graduate equivalency degree.

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Table 3

Relationship Between Value of Life, Marginalization, and Total Perceived Stigma

Model 2	β	95% Confidence Interval	p-value	F (df)	Adjusted R ²
Age	-1.12	-1.73,51	.001		
Race					
White	(ref)				
Asian/Pacific Islander	24.20	0.51, 47.89	.045		
African American/Black	5.89	-8.20, 19.98	.407		
Hispanic/Latina	12.76	-14.10,39.62	.347		
Native American/Indian	5.41	-18.51, 29.33	.654		
Other	-5.13	-28.48, 18.21	.663		
Annual Income	00003	0003, .0003	.840		
Education					
11th grade or less	(ref)				
High school or GED	4.34	-8.78, 17.45	.512		
Any college or higher	5.48	-8.15, 19.11	.426		
Disclosed to anyone (yes)	.10	-17.16, 17.35	.991		
Years since HIV diagnosis	.50	22, 1.22	.167		
Value of Life	-6.95	-12.22, 1.69	.010		
Constant	146.55	110.33, 182.77	<.0001	2.50 (12,75)	.17

Note. df= degrees of freedom; GED = graduate equivalency degree.

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