



Published in final edited form as:

Health Psychol. 2006 July ; 25(4): 501–509.

Predictors of HIV-related Stigma among Young People Living with HIV

Dallas Swendeman, M.P.H., Mary Jane Rotheram-Borus, Ph.D., Scott Comulada, M.S., Robert Weiss, Ph.D., and Maria Elena Ramos, M.S.

UCLA AIDS Institute and the Center for HIV Identification, Prevention, and Treatment Services (CHIPTS)

Abstract

Enacted and perceived HIV-stigma was examined among substance using young people living with HIV (YPLH) in Los Angeles, San Francisco, and New York City (N = 147). Almost all YPLH (89%) reported perceived stigma and 31% report enacted experiences in the past three months; 64% reported experiences during their lifetime. The HIV-stigma questions were characterized by factors of avoidance, social rejections, abuse and shame. In multivariate models enacted stigma was associated with gay/bisexual identity, symptomatic HIV or AIDS, and bartering sex. Perceived stigma was associated with female gender, symptomatic HIV or AIDS, bartering sex, lower injection drug use, and fewer friends and family knowing serostatus. Gay/bisexual YPLH who were also HIV symptomatic or AIDS diagnosed experienced more HIV-stigma than their heterosexual peers.

Keywords

Stigma; HIV; AIDS; Youth

Introduction

HIV-stigma has been increasingly recognized as a key factor impeding HIV identification, prevention, and treatment efforts (Chesney & Smith, 1999; UNAIDS, 2000). Although HIV-stigma has decreased since the early epidemic, it continues to be a significant problem (Herek, Capitanio, & Widaman, 2002; Lentine et al., 2000). However, there is still relatively little empirical research on HIV-stigma among people living with HIV (PLH).

Most of the theoretical and empirical work on stigma and discrimination among stigmatized persons has focused on the experiences and perceptions of stigma (e.g., discrimination, prejudice, violence, etc.) and their negative sequelae (i.e., emotional distress), based on conceptualizations of stigma as a stressor (see Miller & Kaiser, 2001). The link between emotional distress and stigmatizing events, as well as support for the hypothesis that discriminating events cause distress, has been documented in empirical studies on gender and race/ethnicity based stigma (Landrine, Klonoff, Gibbs, Manning, Lund, 1995; Landrine & Klonoff, 1996; Swin, 2001). Several empirical studies among PLH have documented the

Address all correspondence/reprint requests to: Dallas Swendeman, M.P.H. Center for Community Health 10920 Wilshire Blvd., Suite 350 Los Angeles, CA 90024 (310) 794-6144 e-mail: dswendeman@mednet.ucla.edu.

Publisher's Disclaimer: The following manuscript is the final accepted manuscript. It has not been subjected to the final copyediting, fact-checking, and proofreading required for formal publication. It is not the definitive, publisher-authenticated version. The American Psychological Association and its Council of Editors disclaim any responsibility or liabilities for errors or omissions of this manuscript version, any version derived from this manuscript by NIH, or other third parties. The published version is available at <http://www.apa.org/journals/hea/>

association between HIV-stigma and depression (Lee, Kochman, Sikkema, 2002; Lichtenstein, Laska, & Claire, 2002; Crandall & Coleman, 2002; Laryea & Gien, 1993; Berger, Ferrans, & Lashley, 2001), as well as anxiety, alienation, social conflict, and poor social support (Berger et al., 2001). Because HIV-positive serostatus is often not evident, managing social relationships and serostatus disclosure to avoid stigma and discrimination has been suggested as an added source of stigma induced stress among PLH (Alonzo & Reynolds, 1995; Chesney & Smith, 1999; Crandall & Coleman, 2002; Scambler, 1998), distinguishing HIV-stigma from non-concealable gender and race/ethnicity based stigma.

Considering the negative impact that stigma and discrimination may have on stigmatized persons it may be useful to conceptualize stigma as an outcome (Weiner, Perry, & Magnusson, 1988). This may be particularly relevant for HIV-stigma because HIV serostatus can often be concealed until later stages of infection. The ability to conceal serostatus highlights the issue of knowledge and attribution of HIV serostatus and subsequent enactments and perceptions of HIV-stigma, raising questions about the factors that are likely to predict experiences and perceptions of HIV-stigma among PLH.

Predictors of HIV-Stigma

HIV/AIDS is highly stigmatized as a result of several key characteristics of the epidemic (Alonzo & Reynolds, 1995; Herek, 1999): 1) the means of transmission are negatively sanctioned social behaviors, including male-to-male sex, injection drug use, bartering sex, and having high numbers of sex partners (Crawford, 1996; Díaz & Ayala, 2001; Novick, 1997); 2) transmission behaviors are typically perceived to be voluntary and avoidable, implying that infected persons are responsible for their illness (e.g., victim blaming), reinforced by religious beliefs about HIV/AIDS and transmission behaviors; 3) HIV is contagious and risk of contagion is frequently overestimated by those at low risk for infection (see Herek, Widaman, Capitanio, 2005); 4) AIDS is considered an unalterable and fatal disease, although this has been mitigated by advances in antiretroviral therapies (HAART); and 5) HIV infection is concealable until disease advances and becomes apparent to others through AIDS symptoms, use of complex HAART regimens, or HAART side effects.

Layered Stigma—Groups with high rates of infection are often also stigmatized based on race/ethnicity, sexual orientation or behaviors, poverty, or substance use (Díaz & Ayala, 2001; Parker & Aggleton, 2003). For example, urban youth who use drugs or exhibit high risk sexual behaviors (similar to youth recruited for this study) experience stigma related to those behaviors (Flom et al., 2001). HIV-stigma is hypothesized to further stigmatize those with traits or behaviors that are deemed to be undesirable and are also associated with the epidemic through “symbolic” stigma (Herek, 1999). Symbolic stigma “involves a synergy between the stigma attached to AIDS as an illness and the stigma attached to the groups linked to AIDS in popular perceptions” (Herek et al., 2005). Thus, it has been suggested that various “stigmas” may “layer” onto HIV-stigma and result in differential expression towards unpopular groups associated with increased risk or rates of HIV infection (Novick, 1997).

Survey and experimental social psychological research among the uninfected supports the layering hypothesis for HIV-stigma, documenting that stigmatizing attitudes around HIV are disproportionately held toward gay or bisexual men (Crandall, Glor & Britt, 1997; Herek & Capitanio, 1999) and injection drug users (Capitanio & Herek, 1999). It has also been suggested that African-American or Latina women living in poverty, who have high rates of HIV infection among women, experience increased stigma due to associations with bartering sex, drug use, poverty, gender and ethnicity (Bunting, 1996). No empirical research that we are aware of to date has reported the effect of multiple sources of stigma on reports of HIV-stigma among PLH. Therefore, one set of hypotheses in the present study posit that factors associated with

the HIV epidemic through layered stigma will be reflected in higher reports of HIV-stigma among PLH, including sexual orientation, injection drug use, bartering sex, race/ethnic minority status, poverty, and gender.

Awareness of HIV-infection—HIV-stigma perceptions and experiences are likely to increase as PLH advance towards AIDS disease (Alonzo & Reynolds, 1995). When HIV infection manifests through AIDS symptoms or HAART use and side effects, concealing HIV status becomes more challenging, particularly from those who are familiar with the signs and symptoms of HIV infection and HAART use (whom Goffman refers to as the “wise”; 1963). PLH may seek acceptance and support dependent on openness about serostatus rather than continuing the increasingly difficult task of serostatus concealment, yet this may also present opportunities for stigmatizing reactions (Alonzo & Reynolds, 1995; Chesney & Smith, 1999). Therefore, another set of hypotheses in this study posit that higher reports of HIV-stigma among PLH will be associated with awareness of HIV status, through advancing HIV disease, HAART use, or openness about serostatus.

Moderators—Stigmatizing attitudes around HIV have been found to vary based upon the attributes of both the potential enactors of stigma and the stigmatized, shaped by variations in the epidemiology and social construction of HIV/AIDS. African-Americans' stigmatizing attitudes about HIV/AIDS have been found to be more strongly associated with having negative attitudes towards IDUs than towards gay persons; Caucasians were more likely to stigmatize on the basis of sexual orientation, not drug use (Capitanio & Herek, 1999). This suggests that African American PLH may experience more HIV-stigma if they are IDUs, while Caucasian PLH may experience more HIV-stigma if they are gay/bisexual. Similar attitudes may be internalized by PLH and manifest through variations in perceptions or fears of HIV stigma based on their ethnicity, sexual orientation, or risk behaviors. Evidence for this trend manifesting among PLH has been observed through ethnic variations in patterns of serostatus disclosure (Petрак, Doyle, Smith, Skinner, & Hedge, 2001), reflecting similar variations in sexual identity disclosure among gay/bisexual men (Kennamer, Honnold, Bradford, & Hendricks, 2000); higher levels of gay related stigma among African Americans is hypothesized to result in lower rates of disclosure. Therefore, this study also tests hypotheses that ethnicity moderates the impact of other hypothesized predictors of HIV-stigma, specifically, sexual identity, injection drug use, and the proportion of the PLH's social network that is aware of serostatus.

Poor women of color may also experience more HIV-stigma related to bartering sex or drug use, compared to men or Caucasian women (Bunting, 1996). Therefore we also hypothesize that ethnicity moderates the potential impact of gender, bartering sex or having high numbers of sex partners, drug use, and poverty on reports of HIV-stigma.

Gay and bisexual men may be more sensitive to signs and symptoms of HIV infection, and in some settings they may have more fears of infection that would lead to stigmatizing reactions toward their peers living with HIV/AIDS (Rinken, 2002). Gay and bisexual PLH are expected to experience more HIV-stigma if they are also HIV symptomatic or have AIDS through more frequent interactions with the “wise”, and/or through the layering effects of symbolic stigma. Thus, sexual orientation is hypothesized to moderate the impact of HIV disease progression on reports of HIV stigma in this study.

Enacted and Perceived Stigma

Much of the previous research on stigma uses a broad and vague concept of stigma. More recent work distinguishes between *enacted* stigma (actual experiences of stigma and discrimination) and felt or *perceived* stigma (a stigmatized person's fear or anticipation of

discrimination and rejection, and internal sense of shame) (Scambler, 1998). Perceived or felt stigma may lead people to shape their behaviors to avoid enacted stigma, but in so doing they may also limit opportunities for support and treatment or otherwise disrupt their lives (Scambler, 1998). This paper examines rates and predictors of both enacted and perceived stigma as distinct outcomes.

Recent research has also begun to elucidate more subtle dimensions of HIV-stigma. An exploratory factor analysis of an extensive HIV-stigma measure for PLH identified four factors: personalized stigma (i.e., social rejection), disclosure concerns, negative self-image (i.e., internalized shame), and concern with public attitudes about people with HIV (Berger et al., 2001). Another study comparing the effects of the stigma associated with AIDS and cancer examined four dimensions of illness stigma (social rejection, internalized shame, social isolation, and financial insecurity), finding differential correlates for the different dimensions (Fife & Wright, 2000). This paper also examines sub-dimensions of HIV-stigma, identified in the measures used in this study, as distinct outcomes.

Methods

Participants

Young people living with HIV (YPLH) aged 16 to 29 (median = 23 years) were recruited to participate in a secondary HIV-prevention intervention trial from 1999 to 2002 from over 20 HIV/AIDS clinical care sites, social service agencies, street outreach programs, and through community announcements and advertisements in Los Angeles, New York City, and San Francisco (see Rotheram-Borus et al., 2004 for details). Among the 253 YPLH recruited to participate in the study, 72% (n = 184) were eligible based on the study's requirement to intervene with high-risk YPLH, identified by self-report of at least five occasions of substance use during the past three months. Due to the convenient recruitment strategy, only 23 refusals could be documented. Of the 184 substance-using YPLH enrolled in the study, 83% (n = 152) completed the assessment three months after baseline when the HIV-related stigma measures were first administered; the stigma measures were excluded from the baseline interview to reduce the heavy assessment burden. Five electronic interview files were damaged, allowing 147 interviews usable for these analyses.

YPLH provided informed consent. Parental consent was also obtained if a youth was under 18 years of age and the parent knew the young person's HIV status. A \$25 incentive was paid to each person to participate in the 2-hour interviews. Links to appropriate medical care were provided prior to study enrollment if the person did not have a medical provider.

Procedures

Data was collected by a team of ethnically diverse interviewers using a combination of orally administered computer-assisted protocol interviews (CAPI) on laptop computers and audio computer-assisted self-interview (ACASI) for sensitive information, such as substance use and sexual behaviors. Interviewer training included intensive review of research ethics, emergency procedures, abuse reporting, psychosocial and substance use assessment, and repeated modeling and practice of the assessment. All interviews were audiotaped and 20% were randomly selected and reviewed for quality assurance; 93% demonstrated high consistency with protocol in multiple dimensions. Lifetime information was collected at baseline and updated with data from the 3-month follow to correspond to the stigma assessment.

Measures

Intervention attendance—Since this data is from an intervention trial the potential confounding of intervention participation on stigma reports were controlled for in multivariate

analyses. Participants were categorized as receiving intervention sessions before the 3-month interview (1) or not (0).

Enacted Stigma—Experiences of HIV-related stigma were assessed by 11 yes (1) or no (0) items adapted from those reported by Sowell and colleagues (1997). Items included being hassled or threatened, physically abused, or losing a friend “because you are HIV+” (Table 1). Two items with low rates (‘denied medical treatment’ and ‘lost a job’) were excluded from Table 1. Enacted stigma was assessed for lifetime and past three months. Dichotomous responses were used to enhance reliability of response and to reduce assessment burden.

Perceived Stigma—Recent feelings and fears of HIV-related stigma were measured by seven items, also adapted from those asked by Sowell et al. (1997), asking how often the respondent felt blamed or ashamed, avoided, or feared losing family or friends “because you are HIV+” during the past three months (Table 2). Responses were given using a four-point Likert response scale ranging from ‘not at all’ (1) to ‘often’ (4).

Demographic factors—Background factors hypothesized to predict HIV-stigma include gender, ethnicity, and sexual orientation. Financial status was based on self-reports as poor/very poor (1) versus have the necessities/comfortable (0).

HIV Risk Behaviors—Lifetime frequency of injection drug use and number of sexual partners measures were log transformed to account for skewed distributions. Bartering sex (“ever traded sex for money, drugs, food, or a place to stay”) was assessed for lifetime through a yes (1) or no (0) question. Since sex partner identifying information was not assessed, lifetime number of sex partners was not updated with data from the 3-month follow up; recent partners may have also been reported as lifetime partners in the baseline assessment.

HIV/AIDS progression—Respondents self-reported their current HIV disease status as having AIDS (2), being symptomatic (1), or asymptomatic (0). Time since first testing HIV positive, measured in years, was also assessed.

HAART use—Respondents were classified as having ever used HAART (1) or not (0).

Serostatus awareness—The proportion of a respondent's social network that knows serostatus was assessed with a stem question (“About how many people know you are HIV positive?”) applied to two domains (family and friends), collected in the baseline assessment. A four-point Likert scale response scored none (1) to all (4) was used for each domain. Scores were summed across the two domains to derive a general score (range 2–8). Size of YPLH network was approximated by the number of “close friends and confidants” that youth reported.

Statistical methods

Separate factor analyses were performed on lifetime enacted and recent perceived HIV-related stigma items to confirm item groupings based on conceptual considerations from the literature review. Enacted stigma experiences reported for the three months prior to the assessment were rare and not analyzed further (Table 1). Principal component analyses were used to extract initial factors, followed by Varimax rotation. Factors with eigenvalues greater than one were retained except for one instance where the fourth factor of lifetime enacted stigma contained one item, “denied medical treatment.” The enacted stigma item for “lost a job” had low loadings across all factors (.31 and less); the factor analysis was rerun after removal of the item.

Regressions were performed to examine the relationship of each stigma factor, referred to as a dimension hereafter, with the hypothesized predictors. Due to the marginally low number of

items in each factor we considered the analyses of these dimensions to be exploratory. Therefore, we also examined all of the items represented in the dimension taken as a whole for lifetime enacted and perceived stigma respectively, referred to hereafter as the overall measures. Lifetime enacted stigma items (yes or no responses) were treated as repeated measurements within each dimension and overall, and analyzed by logistic regression models that included a random effect for each person. Recent perceived stigma items (Likert scale responses) were summed within each dimension as well as across all items and analyzed by linear regression.

Univariate analyses were conducted to identify significant predictors to include in the final multivariate models. The number of observations available for this analysis limited the number of predictors that could be included in final multivariate models. In order to identify a single set of predictors that could be used for all of the enacted and perceived stigma models, and thus allow comparisons across models, predictors that were significant in univariate analyses for more than two of the eight domains (i.e., the six sub-dimensions and two overall measures) were included in the final models with two exceptions. Sexual orientation was included as a predictor based on significant discussion in the literature, and intervention attendance was included to control for potential confounding effects of intervention activities. Parameter estimates in the univariate analyses were similar for HIV symptomatic and AIDS, and for gay and bisexual categories. These categories were collapsed and both HIV disease status and sexual orientation were assessed as dichotomous variables in the final models.

Analyses were conducted to test the hypothesized moderator effects for each enacted and perceived stigma outcome. Each model contained a hypothesized predictor, moderator, and two-way interaction between the predictor and moderator. Significant two-way interactions indicated moderating effects. Two interactions were also tested among self-identified gay or bisexual men ($n = 101$): ethnicity by HIV disease progression and ethnicity by the proportion of friends and family knowing HIV serostatus; the model for the second interaction with ethnicity also included effects for the size of social network and an intervention effect for ethnicity by size of social network to adjust for the proportion.

Participants with and without 3-month follow up data were compared on sociodemographic measures and other hypothesized correlates of HIV-stigma. No statistically significant differences were found. However, participants with 3-month follow up data trended towards being less likely to report clinical level of emotional distress (76% vs. 91%; Chi-square = 3.51, $df = 1$, $p = .06$). All analyses were performed using SAS version 8.01 (SAS Institute Inc., Cary, NC). Random-effect logistic regressions were fit in the SAS Macro Glimmix.

Results

Sociodemographic profiles

The final age range of participants ($n = 147$) was from 16 to 29 years (median = 23). Most participants were male (79%), gay or bisexual (74%), and ethnic minorities (44% Hispanic, 24.5% African-American, 24.5% Caucasian, and 7% were other ethnicities). More than half (56%) graduated from high school or had a GED certificate. Most participants had manifest HIV disease; 39.5% were HIV symptomatic and 26.5% were diagnosed with AIDS.

Rates of enacted and Perceived HIV-stigma

Reports of lifetime enacted and recent perceptions of HIV-stigma are shown in Tables 1 and 2, respectively, except for two enacted items. Seven percent of YPLH ($n = 10$) reported losing a job during their lifetime because they were HIV+; one respondent reported losing a job due to HIV status for the prior three months (0.6%). Five percent of YPLH ($n =$

7) reported being denied medical treatment in their lifetime, 3 percent ($n = 4$) for the past three months. The rates of past 3 month enacted stigma are quite low (less than 5% for all but two items) and were not analyzed in the factor analyses or as outcomes in univariate and multivariate analyses.

Factor analyses

Factor loadings are shown in the last three columns of Tables 1 and 2. Three factors, accounting for 61% of the total variance, were retained from the analysis of lifetime enacted HIV-stigma to create the following dimensions: *avoidance*, *abuse*, and *social rejection* ($\alpha = .71, .59, \text{ and } .53$). Three factors, accounting for 75% of the total variance, were retained from the analysis of recent perceived HIV-stigma to create the following dimensions: *avoidance*, *social rejection*, and *shame* ($\alpha = .83, .67, \text{ and } .69$).

Lifetime enacted HIV-stigma

Univariate results are reported below. Odds ratios (OR) and 95% confidence intervals (C.I.) for univariate results are reported for significant measures that were not included in the final multivariate models. Odds ratios for significant measures included in the final multivariate models did not change direction and are only reported in the final models.

All four enacted stigma outcome measures were positively associated with lifetime sex bartering. Avoidance, abuse, and overall stigma were positively associated with having symptomatic HIV or AIDS. Avoidance, social rejection, and overall enacted stigma were associated with an increase in the log frequency of injected drug use and a higher proportion of friends and family knowing the participant's HIV serostatus, adjusted for size of social network. Social rejection and overall enacted stigma were associated with an increase in the log frequency of injected drug use, and identification as gay or bisexual.

Enacted avoidance HIV-stigma was associated with an increase in the log number of lifetime sex partners (OR = 1.24, 95% CI = 1.05 to 1.46, $p < .01$) and self-reported poverty (very poor/poor vs. having necessities/being comfortable; OR = 3.37, 95% CI = 1.35 to 8.41, $p < .01$). Overall enacted stigma was also associated with an increase in the log number of lifetime sex partners (OR = 1.12, 95% CI = 1.02 to 1.22, $p = .01$). Odds ratios were not significant across any enacted stigma outcome for intervention condition, age, gender, ethnicity, years since first testing HIV positive, and HAART use.

Recent perceived HIV-stigma

Univariate results are reported below. Parameter estimates (B) and standard errors (SE) for univariate results are included for significant measures not included in the final models. Estimates for significant measures included in the final models did not change direction.

Social rejection, shame, and overall perceived stigma were associated with female gender and a lower log frequency of injection drug use. Higher levels of avoidance, shame, and overall perceived stigma were associated with having symptomatic HIV or AIDS. Social rejection and overall perceived stigma were associated with a lower proportion of friends and family knowing HIV serostatus, adjusted for size of social network. Higher levels of perceived avoidance were associated with lifetime sex bartering. Higher levels of shame were associated with non-attendance to intervention ($B = -1.07, SE = .54, p = .05$). Age, financial status, sexual orientation, number of lifetime sexual partners, years since first testing HIV positive, and HAART use were not associated with any perceived stigma outcomes.

A test of ethnic differences was significant for perceived social rejection ($F = 6.56, df = 2, 144, p < .01$). Blacks reported higher levels of perceived social rejection than Whites ($B = 1.54, SE$

= .43, $p < .01$, reference group is White) and Hispanics; differences between Hispanics and Whites were not significant ($B = .48$, $SE = .37$, $p = .20$). A test of ethnic differences for overall perceived stigma was not significant ($F = 2.63$, $df = 2, 140$, $p = .08$), but Blacks reported higher levels of overall perceived stigma than whites ($B = 2.33$, $SE = 1.07$, $p = .03$); other differences were not significant.

Moderators

The sexual orientation by disease progression interaction was significant in the model for lifetime enacted avoidance ($F = 3.95$, $df = 1$, $p = .05$). No other interactions were significant. Among self-identified gay or bisexual YPLH the odds of avoidance enacted stigma were higher for those who were HIV symptomatic or AIDS-diagnosed, ($OR = 10.1$, 95% C.I. = 2.7 to 38.8, $p < .01$); among self-identified heterosexuals the odds of avoidance enacted stigma were similar for those HIV symptomatic or AIDS-diagnosed compared to asymptomatic ($OR = .9$, 95% C.I. = .1 to 6.4, $p = .95$). This sexual orientation by disease progression interaction was added to the multivariate model for avoidance enacted stigma. Odds ratios comparing symptomatic or AIDS-diagnosed individuals to asymptomatic individuals remained similar to the univariate results for both self-identified gay or bisexual individuals ($OR=16.7$, 95% C.I. = 3.7 to 75.2, $p < .01$) and self-identified heterosexual individuals ($OR=.7$, 95% C.I. = .07 to 7.7, $p = .79$); models without interactions are reported in Table 3.

Final multivariate models

Results for final models are shown in Tables 3 and 4. The coefficient of determination (R^2), the fraction of variability in the outcome variable explained by the regression model, is shown for perceived stigma models in Table 4.

Higher odds of enacted avoidance and overall enacted HIV-stigma were associated with self-identification as being gay or bisexual and with being HIV symptomatic or diagnosed with AIDS. Avoidance stigma was also associated with female gender. Enacted abuse HIV-stigma was also associated with being HIV symptomatic or diagnosed with AIDS and with having bartered sex.

Higher levels of perceived social rejection, shame, and overall perceived stigma were associated with female gender and a lower proportion of friends and family that knew the participant's HIV serostatus. Higher levels of avoidance, shame, and overall perceived stigma were associated with symptomatic HIV or AIDS. Avoidance and Overall perceived HIV-stigma were also associated with having bartered sex. Social rejection and overall stigma were associated with lower log frequency of lifetime injected drug use. Perceived shame was also associated with having a smaller social network.

Discussion

Through a set of diverse recruitment strategies, a sample of YPLH was recruited with a sociodemographic profile similar to that reported for HIV infected youth nationally. Most were gay or bisexual males (74% vs. 60% nationally) and of ethnic minority heritage (75% vs. 60% nationally), and few early adolescents were identified (CDC, 2002). The sample also had a high proportion of HIV symptomatic and AIDS diagnosed YPLH, reflecting the delayed identification of YPLH nationally, often only after symptoms of infection appear (Rotheram-Borus, O'Keefe, Kracker, & Foo, 2000). However, this convenience sample was selected based on recent substance use and may not be representative of or generalizable to all YPLH in the United States. Many YPLH do not engage in substance use and sexual risk behaviors after learning that they are HIV positive (Rotheram-Borus et al., 2001) and they may experience

less HIV-stigma than their more risky peers. In addition, PLH with high levels of perceived or feared HIV-stigma may be less likely to participate in this or any voluntary research study.

Another limitation of this study is the timing of the assessments. The primary goal of the research study was to assess the efficacy of a secondary prevention intervention (see Rotheram-Borus et al., 2004). The stigma measures were first administered at the three month follow-up interview in order to reduce the already heavy assessment burden incurred by collecting both lifetime and recent information in the baseline interview. Some participants received intervention sessions prior to the administration of the stigma measures. The intervention may have impacted reports of stigma, particularly perceived stigma. We attempted to control for these potential confounding effects in the multivariate models.

Almost all YPLH (89%) reported perceived stigma in the past three months compared to only 31% reporting recent enacted experiences and 64% reporting enacted HIV-stigma during their lifetime. HIV-stigma does not need to be enacted for PLH to be affected by fears and perceptions of HIV-stigma and related discrimination. The higher levels of perceived stigma compared to enacted stigma are consistent across the two dimensions that are shared in the enacted and perceived stigma measures, avoidance and social rejection. However, a limitation of this study is that the enacted and perceived stigma measures are not directly comparable. Direct translation of questions from enacted to perceived domains is problematic in terms of meaning and interpretation; responses are innately different for questions regarding perceptions versus events. The measures are also relatively brief compared to others currently available (see Berger et al., 2001; Fife & Wright, 2000) and may not capture the variety of stigma experiences and perceptions faced by PLH. They were also not tested for validity and reliability. However, slightly modified versions of the seven perceived stigma items were used in another study and found to have good construct validity and reliability; the alpha coefficient for the nine-item scale used was .84 for PLH respondents (Wight, Aneshensel, Murphy, Miller-Martinez, & Beals, 2005).

This research should be considered exploratory, particularly the analyses of HIV-stigma sub-dimensions, which had a marginally acceptable number of items to be considered for factor analysis. In addition, the enacted stigma questions sought to capture the diversity of stigma experiences but did not capture an accumulation of stigma experiences. Considering the increasingly recognized importance of HIV-related stigma for prevention and treatment efforts, psychometrically valid and reliable measures for HIV and illness stigma are needed (see Berger et al., 2001; Fife & Wright, 2000). Brief measures are of particular importance to encourage assessment of stigma in studies whose primary focus is not stigma (i.e., intervention studies), and to keep the assessment burden low for research participants. However, even the results obtained with these brief measures point to the importance of examining different dimensions of stigma (i.e., avoidance, rejection, shame, abuse) as distinct outcomes.

This study supports the call to “resocialize” conceptualizations of HIV-stigma through consideration of the social ecological factors that feed upon, reinforce, and cross-cut stigma resulting from HIV/AIDS and other existing sources such as racism, gender and economic inequalities, and other forms of “structural violence” (Link & Phelan, 2001; Parker & Aggleton, 2003; Castro & Farmer, 2005). This study documents the effect that “layering” of stigmas has on the experiences and perceptions of HIV-stigma among PLH. Gay/bisexual identity predicted enacted HIV-stigma (avoidance dimension and the overall measure), supporting the hypothesis around the “layered” or “double” that gay PLH experience (Novick, 1997; Crandall et al., 1997; Herek & Capitanio, 1999). Gay/bisexual identity did not predict perceived stigma, suggesting that the gay/bisexual YPLH in this study have not significantly internalized feelings of blame for their HIV infection nor do they have fears and perceptions of HIV-stigma. By contrast, bartering sex predicted enacted abuse stigma as well as perceived stigma (avoidance

dimension and the overall measure). YPLH who barter sex are likely to be among the most marginalized and powerless persons in the study, which is reflected in higher levels perceived avoidance and enacted abuse.

Injection drug use did not predict enacted stigma and, importantly, was associated with lower shame and overall perceived stigma. This counterintuitive finding should be explored in future research but we suggest two possible explanations. IDUs may have greater fears of stigmatization related to their drug use rather than their HIV status, reflecting what Goffman (1963) referred to as a “master status” in a hierarchy of potentially stigmatizing traits or identities. IDUs concerns over stigma related to their drug use may result in lower concerns around HIV-stigma, reflected in lower reports of perceived HIV stigma. Alternatively, IDUs may have developed mechanisms for coping with stigma related to their drug use that translates to their ability to cope with enacted stigma and mitigate perceived or internalized HIV-stigma.

Similar explanations may account for the lack of statistically significant associations between ethnicity and HIV-stigma. African American ethnicity was associated with perceived overall and social rejection HIV-stigma in univariate models but the association did not hold in multivariate models. Although ethnicity and poverty status did not meet our criteria for inclusion in the final multivariate models, we compared the final models presented in Tables 3 and 4 with models that also included ethnicity and poverty as predictors. Neither predictor was significant for any stigma outcome and none of the other predictors changed direction of association or statistical significance except for the association between gender and enacted avoidance stigma (OR=.18, 95% C.I. = .03 to 1.03).

The lack of significant findings for ethnicity and poverty, as opposed to gay/bisexual identity and bartering sex, suggests that stigmas that are likely to layer onto HIV-stigma are those that are associated with what are considered to be voluntary behaviors that facilitate attributions of blame for the stigmatized trait (Weiner et al., 1988). The sample size in this study may have also limited the ability to detect differences based on ethnicity or poverty, and also precluded testing moderating effects within subsamples of women, or heterosexual men, or injection drug users.

HIV disease progression predicted both enacted (avoidance, abuse, and overall) and perceived HIV-stigma (avoidance, shame, and overall). These findings support the hypotheses that PLH awareness of advancing HIV disease and others awareness of serostatus through manifest HIV infection results in increased perceptions and experiences of HIV-stigma. Gay/bisexual YPLH who were symptomatic or AIDS-diagnosed had higher odds of reporting enacted avoidance and overall enacted HIV-stigma compared to their heterosexual peers, which further supports the layering hypothesis for gay/bisexual PLH. This finding might also lend support for the suggestion that men who have sex with men may be more sensitive to signs and symptoms of HIV infection and, in some settings, may have more fears of infection that would lead to stigmatizing reactions toward their peers living with HIV/AIDS (Rinken, 2002). This should be examined more in future research and has implications for interventions that might attempt to reduce HIV-stigma and increase serostatus disclosure in sexual encounters.

A high proportion of family and friends knowing a PLH serostatus was not associated with enacted stigma but was associated with lower perceived stigma. This is not surprising since we would expect people with high levels of perceived stigma to generally be more closeted about their serostatus and vice versa. Perceived HIV-stigma very likely influences YPLH to limit others' awareness of their HIV serostatus, including decreased disclosure. This may result in both self-protective (e.g., limiting opportunities for stigmatizing and discriminating events and reactions), and detrimental outcomes (e.g., limiting social support and receipt of appropriate care and services, increased risk of HIV transmission, etc.). Supporting YPLH in

making informed and well-planned decisions about serostatus disclosure may help maximize the benefits of those decisions for both YPLH and society.

Males report less perceived HIV-stigma than females in three of the four multivariate models. Females tend to have higher levels of depression and anxiety than males, and therefore may be more likely to have fears and anxiety regarding their HIV status. Young women living with HIV would appear to benefit from targeted interventions that help them cope with their own feelings and fears about their HIV infection, which may be exacerbated by higher rates of emotional distress. The YPLH in this study have high levels of emotional distress (see Rotheram-Borus et al., 2004). Depressed persons make global, stable, and internal attributions about negative events. Emotional distress may color perceptions and result in increased perceived stigma and reports of enacted stigma (Sechrist, Swim, & Mark, 2003). The results indicating higher rates of perceived stigma compared to enacted experiences support this idea. The impact that stigma likely has on emotional distress is not contested. However, some degree of reciprocal causation, which can not be accounted for in this relatively small cross-sectional study, should be acknowledged and examined in future research.

Conceptualizing stigma as a form of stress that impacts emotional distress highlights the importance of examining styles of coping with HIV infection in relation to HIV-stigma (Miller & Kaiser, 2001; Scambler, 1998). Similarly, serostatus disclosure may be considered a crucial form of coping with HIV infection and is likely to be heavily impacted by stigma experiences and fears. Social support is another factor that should be examined in relation to HIV-stigma; PLH with high levels of prior stigma experiences or current fears and perceptions may isolate themselves from social support networks in order to prevent stigmatizing events. Future research using longitudinal data should examine how HIV-stigma may predict or mediate outcomes such as emotional distress, coping styles, social support, serostatus disclosure, and sexual risk behaviors.

Acknowledgements

This study was supported by Grant R01 DA-07903 from the National Institute on Drug Abuse (NIDA) to the second author.

References

- Alonzo AA, Reynolds NR. Stigma, HIV and AIDS—an exploration and elaboration of a stigma trajectory. *Social Science & Medicine* 1995;41(3):303–315. [PubMed: 7481925]
- Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health* 2001;24(6):518–529. [PubMed: 11746080]
- Bunting SM. Sources of stigma associated with women with HIV. *Advances in Nursing Science* 1996;19(2):64–73. [PubMed: 8939289]
- Capitanio JP, Herek GM. AIDS-related stigma and attitudes toward injecting drug users among black and white Americans. *American Behavioral Scientist* 1999;42(7):11482–1161.
- Castro A, Farmer P. Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti. *American Journal of Public Health* 2005;95(1):53–59. [PubMed: 15623859]
- Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report 2002;14. 2002. Available at: <http://www.cdc.gov/hiv/stats/hasr1402.htm>. Accessed on April 7, 2004
- Chesney MA, Smith AW. Critical delays in HIV testing and care: the potential role of stigma. *The American Behavioral Scientist* 1999;42(7):1162–1174.
- Crandall CS, Coleman R. AIDS-related stigmatization and the disruption of social relationships. *Journal of Social and Personal Relationships* 2002;9(2):163–177.
- Crandall CS, Glor J, Britt TW. AIDS-related stigmatization: Instrumental and symbolic attitudes. *Journal of Applied Social Psychology* 1997;27(2):95–123.

- Crawford AM. Stigma associated with AIDS: A meta-analysis. *Journal of Applied Social Psychology* 1996;26:398–416.
- Díaz R, Ayala G. The impact of homophobia, poverty and racism on the mental health of Latino gay and bisexual men: Findings from a probability sample in three U.S. cities. *American Journal of Public Health* 2001;91(6):927–932. [PubMed: 11392936]
- Fife BL, Wright ER. The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health & Social Behavior* 2000;41(1):50–68. [PubMed: 10750322]
- Flom PL, Friedman SR, Kottiri BJ, Neaigus A, Curtis R, Des Jarlais DC, Sandoval M, Zenilman JM. Stigmatized drug use, sexual partner concurrency, and other sex risk network and behavior characteristic of 18- to 24-year-old youth in a high-risk neighborhood. *Sexually Transmitted Diseases* 2001;28(10):598–607. [PubMed: 11689758]
- Goffman, E. *Stigma: Notes on the management of spoiled identity*. Simon & Shuster; New York: 1963.
- Herek GM. AIDS and stigma. *The American Behavioral Scientist* 1999;42(7):1106–1116.
- Herek GM, Capitanio JP. AIDS stigma and sexual prejudice. *The American Behavioral Scientist* 1999;42(7):1130–1147.
- 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(3):371–377. [PubMed: 11867313]
- Herek GM, Widaman KF, Capitanio JP. When sex equals AIDS: Symbolic stigma and heterosexual adults' inaccurate beliefs about sexual transmission of AIDS. *Social Problems* 2005;52(1):15–37.
- Kennamer JD, Honnold J, Bradford J, Hendricks M. Differences in disclosure of sexuality among African American and white gay/bisexual men: Implications for HIV/AIDS prevention. *AIDS Education and Prevention* 2000;12(6):519–531. [PubMed: 11220504]
- Landrine H, Klonoff EA. The schedule of racist events: A measure of racial discrimination and a study of its negative physical and mental health consequences. *Journal of Black Psychology* 1996;22:144–168.
- Landrine H, Klonoff EA, Gibbs J, Manning V, Lund M. Physical and psychiatric correlates of gender discrimination: An application of the schedule of sexist incidents. *Psychology of Women Quarterly* 1995;19:473–492.
- Laryea M, Gien L. The impact of HIV-positive diagnosis on the individual. Part 1: Stigma, rejection, and loneliness. *Clinical Nursing Research* 1993;2:245–266. [PubMed: 8401240]
- Lee RS, Kochman A, Sikkema KJ. Internalized stigma among people living with HIV-AIDS. *AIDS and Behavior* 2002;6(4):309–319.
- Lentine DA, Hersey JC, Iannacchione VG, Laird GH, McClamroch K, Thalji L. HIV-related knowledge and stigma—United States, 2000. *MMWR* 2000;49(47):1062–1064. [PubMed: 11186610]
- Lichtenstein B, Laska MK, Clair JM. Chronic sorrow in the HIV positive patient: Issues of race, gender, and social support. *AIDS Patient Care STDs* 2002;16(1):27–38. [PubMed: 11839216]
- Link BG, Phelan JC. Conceptualizing Stigma. *Annual Review of Sociology* 2001;23:363–385.
- Miller CT, Kaiser CR. A theoretical perspective on coping with stigma. *Journal of Social Issues* 2001;57:73–92.
- Novick A. Stigma and AIDS: Three layers of damage. *Journal of the Gay and Lesbian Medical Association* 1997;1:53–60.
- Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science and Medicine* 2003;57:13–24. [PubMed: 12753813]
- Petrak JA, Doyle AM, Smith A, Skinner C, Hedge B. Factors associated with self-disclosure of HIV serostatus to significant others. *British Journal of Health Psychology* 2001;6:69–79. [PubMed: 14596739]
- Rinken, S. Utilization of psychosocial PHA support services by British and Spanish men who have sex with men (MSM): the problem of information control; Poster #7894 presented at the *International Conference on AIDS*; Jul 7-12, 2002; 2002. Abstract no. ThPeE7894
- Rotheram-Borus MJ, O'Keefe Z, Kracker R, Foo H-H. Prevention of HIV among adolescents. *Prevention Science* 2000;1(1):15–30. [PubMed: 11507791]

- Rotheram-Borus MJ, Lee MB, Murphy DA, Futterman D, Duan N, Birnbaum JM, Lightfoot M. Efficacy of a preventive intervention for youth living with HIV. *American Journal of Public Health* 2001;91:400–405. [PubMed: 11236404]
- Rotheram-Borus MJ, Swendeman D, Comulada WS, Weiss RE, Lee M, Lightfoot M. Prevention for Substance-Using HIV-Positive Young People: Telephone and In-Person Delivery. *JAIDS Journal of Acquired Immune Deficiency Syndromes* Jan October;2004 37(Suppl 2):S68–S77.
- Scambler G. Stigma and disease: Changing paradigms. *Lancet* 1998;352(9133):1054–1055. [PubMed: 9759769]
- Sechrist GB, Swim JK, Mark MM. Mood as information in making attributions to discrimination. *Personality and Social Psychology Bulletin* 2003;29(4):524–534. [PubMed: 15273005]
- Sowell RB, Lowenstein A, Moneyham L, Demi A, Mizuno Y, Seals BF. Resources, stigma, and patterns of disclosure in rural women with HIV infection. *Public Health Nursing* 1997;14(5):302–312. [PubMed: 9342922]
- Swim JK. Everyday sexism: Evidence for its incidence, nature, and psychological impact from three daily diary studies. *Journal of Social Issues* 2001;57:31–53.
- UNAIDS. UNAIDS Best Practice Collection. UNAIDS; Geneva, Switzerland: 2000. HIV and AIDS-related stigmatization, discrimination and denial: Forms, contexts, and determinants; p. 00.16E
- Weiner B, Perry RP, Magnusson J. An attributional analysis of reactions to stigmas. *Journal of Personality and Social Psychology* 1988;55:738–748. [PubMed: 2974883]
- Wight RG, Aneshensel CS, Murphy DA, Miller-Martinez D, Beals KP. Perceived HIV stigma in AIDS caregiving dyads. *Social Science and Medicine*. 2005In press

Summary statistics for lifetime and recent enacted HIV-stigma (n = 147) and factor loadings for lifetime enacted HIV-stigma items after Varimax rotation.

Table 1

	Lifetime		Recent		Lifetime factors			Social Rejection
	%	n	%	n	Avoidance	Abuse		
Avoidance Dimension								
Someone refused to eat with you	12	17	3	4	.80	.09	.02	
Someone refused to hug you	18	26	5	7	.76	.17	.21	
Had children kept away from you	17	25	3	4	.69	-.21	.31	
Had to move	10	14	3	5	.54	.48	.03	
% yes to any avoidance item	29	43	8	12				
Abuse Dimension								
Beaten up	4	6	1	2	-.02	.86	-.04	
Hassled or verbally threatened	15	22	5	7	.13	.77	.25	
% yes to either abuse item	15	22	6	9				
Social Rejection Dimension								
Lost a friend	15	22	5	7	.20	-.12	.79	
Heard AIDS joke	46	68	20	29	-.01	.15	.74	
Shut out by a family member	20	30	9	13	.28	.24	.52	
% yes to any rejection item	54	80	25	37				
Overall Enacted HIV-stigma*	64	94	31	46				

Note. Items above represent stem question followed by "because you are HIV-positive"; responses were yes/no.

* Overall enacted stigma represents a yes response to any item from any dimension.

Table 2
 Summary statistics for perceived HIV-stigma (n = 147) and factor loadings after Varimax rotation.

	%	n	Mean	SD	Avoidance	Factors Social Rejection	Shame
Avoidance Dimension *	59	86	3.7	1.8			
Felt others were uncomfortable	57	83	2.0	1.0	.90	.06	.17
Felt people avoided you	46	68	1.7	.9	.89	.19	.13
Social Rejection Dimension *	64	94	3.9	2.0			
Feared family rejection	46	62	1.9	1.2	-.04	.88	.21
Feared losing friends	52	77	2.0	1.1	.34	.77	-.01
Shame Dimension *	73	107	5.8	2.5			
Felt blamed by others	33	49	.8	.8	.01	-.11	.83
Thought HIV was punishment	51	75	2.1	1.2	.26	.36	.69
Felt ashamed	63	93	2.2	1.1	.28	.41	.64
Overall Perceived HIV-Stigma *	89	131	13.4	4.8			

Note. Items above represent stem question followed by "because you are HIV-positive". Rate statistics represent 'rarely' or higher responses versus 'not at all', during the prior three months.

* Rates statistics for dimensions represent a 'rarely' or higher response to any item in the dimension; . overall perceived stigma represents a 'rarely' or higher response to any item in any dimension

Table 3

Odds ratios (OR) and confidence intervals (95% CI) from random-intercept logistic regression of whether or not stigma item was enacted within each dimension and overall. A random effect is included for each person.

Covariate	Avoidance			Abuse			Social rejection			Overall		
	OR	95%	C.I.	OR	95%	C.I.	OR	95%	C.I.	OR	95%	C.I.
Intervention received												
Yes	.28	.07	1.14	.74	.11	5.02	.86	.42	1.78	.73	.39	1.38
No	1.00	-	-	1.00	-	-	1.00	-	-	1.00	-	-
Gender												
Male	.17	.03	.93*	.13	.01	1.28	.95	.38	2.40	.54	.24	1.20
Female	1.00	-	-	1.00	-	-	1.00	-	-	1.00	-	-
Sexual orientation												
Gay / Bisexual	6.40	1.21	33.89*	2.83	.30	27.04	1.52	.64	3.61	2.19	1.02	4.72*
Heterosexual	1.00	-	-	1.00	-	-	1.00	-	-	1.00	-	-
Disease progression												
Symptomatic, AIDS	7.77	2.21	27.26*	7.21	1.11	46.92*	1.15	.62	2.12	1.84	1.06	3.17*
Asymptomatic	1.00	-	-	1.00	-	-	1.00	-	-	1.00	-	-
Bartered sex												
Yes	2.56	.78	8.36	6.74	1.18	38.54*	1.37	.72	2.59	1.70	.98	2.95
No	1.00	-	-	1.00	-	-	1.00	-	-	1.00	-	-
Log freq injected drugs												
Friends & family that know serostatus	1.08	.95	1.24	1.06	.87	1.28	1.05	.97	1.14	1.05	.98	1.12
Proportion												
Size of social network	1.08	.80	1.46	1.03	.68	1.55	1.12	.95	1.32	1.09	.95	1.26
Size of social network	.95	.89	1.02	1.01	.97	1.04	1.00	.98	1.01	1.00	.98	1.01

Note. Overall enacted stigma represents sum of all items from the three dimensions.

* p < .05

Table 4
Parameter estimates (B), standard errors (SE), and coefficients of determination (R^2) from linear regression of perceived stigma dimension sums and overall perceived stigma sum.

Covariate	Avoidance		Social rejection		Shame		Overall	
	B	SE	B	SE	B	SE	B	SE
Intervention received								
Yes	.191	.368	.118	.375	-.342	.487	.010	.935
No	0	-	0	-	0	-	0	-
Gender								
Male	-.360	.465	-1.263	.474*	-1.533	.614*	-3.166	1.181*
Female	0	-	0	-	0	-	0	-
Sexual orientation								
Gay / Bisexual	.211	.430	.278	.439	.687	.569	1.152	1.094
Heterosexual	0	-	0	-	0	-	0	-
Disease progression								
Symptomatic, AIDS	.624	.321*	.558	.327	1.532	.424*	2.669	.816*
Asymptomatic	0	-	0	-	0	-	0	-
Bartered sex								
Yes	.880	.329*	.505	.335	.260	.435	1.623	.836*
No	0	-	0	-	0	-	0	-
Log freq injected drugs								
Friends & family that know serostatus	-.072	.045	-.091	.045*	-.107	.059	-.276	.113*
Proportion								
Size of social network	.095	.086	-.411	.088*	-.198	.114*	-.521	.219*
R^2	.001	.009	-.008	.009	-.024	.011*	-.031	.022
	.10		.26		.18		.21	

Note. Overall perceived stigma represents sum of all items from the three dimensions.

* $p < .05$