Experiences of HIV-Related Stigma Among Young Men Who Have Sex with Men

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Abstract

Young men who have sex with men (MSM) represent an increasing number of new HIV infections in many communities. Many individuals still hold beliefs that may lead to discrimination against HIV-positive individuals. HIV stigma is associated with negative health and psychosocial outcomes and may lead to greater challenges for this marginalized population. This study describes stigma experienced by HIV-positive young MSM, explores its relationship to psychosocial measures, and tests the hypothesis that stigma scores will be higher in those diagnosed less than 1 year ago versus more than 1 year. From August 2004 to September 2005 young MSM completed a questionnaire including demographic information and psychosocial measures. Descriptive and bivariate analyses of association were used to interpret data from the total stigma scale and four subscales: personalized stigma (PS), public attitudes (PA), negative self-image (NSI), and disclosure concerns (DC). Index scores were calculated by standardizing each subscale for direct comparisons. The 42 participants were: mean 21.3 years; 45% black, 24% Hispanic, 26% white; 14% transgender; and 50% diagnosed HIV-positive less than 1 year. Participants reported HIV-related stigma across all domains with mean index subscale scores: PS 0.57, PA 0.61, NSI 0.63, DC 0.75 indicating that disclosure concerns were prevalent in comparison to other forms of HIV-related stigma. Stigma scores correlated with depression, social support, self-esteem, and romantic loneliness. Stigma scores did not differ for those diagnosed less than 1 year ago versus more than 1 year ago. Providers should address HIV-related stigma concerns, particularly disclosure, throughout the trajectory of the illness when caring for HIV-positive young MSM as a factor affecting health outcomes and psychosocial functioning.

Introduction

STIGMA EXPERIENCED BY people living with HIV has been well documented by numerous previous studies.^{1–3} HIV-related stigma has been problematic for people living with HIV since the beginning of the epidemic and has been associated with several health outcomes including HIV testing and health care seeking behaviors, psychosocial functioning, and sexual risk behaviors. Studies have documented that stigma and shame associated with HIV represent a significant barrier to screening for the disease.⁴ For example, one study reported that over half of men who had not been tested for HIV cited fear of negative social consequences as an important reason for not getting tested and over 40% of high risk men in another study indicated that name-based reporting of HIV test results would lead them to defer testing.^{5,6} HIV-related stigma and discrimination have also been identified as barriers to seeking appropriate healthcare for people living with HIV.^{7,8} In a study of HIV-positive adolescents, half of participants reported

skipping medication doses to avoid disclosure of HIV status to friends and family.⁹ Other authors have clearly linked experience of HIV stigma with increased rates of depression.^{10,11}

While attitudes toward people living with HIV have seemed to improve over the past few decades, a recent Kaiser Family Foundation report showed that many people still hold beliefs that may stigmatize or lead to discrimination against HIV-positive individuals.¹² Other recent studies indicate that HIV-related stigma remains a significant problem across many groups of people living with HIV/AIDS including older adults, women, lesbian, gay and bisexual (LGB) individuals, and ethnic minorities.^{11,13–15}

Conceptually, HIV-related stigma has been described across a variety of separate domains including: disclosure concerns, negative self image, public attitudes, and personalized stigma.¹⁶ These domains have been used to better describe how stigma is experienced by individuals and how it may be operationalized as a basis for intervention or treatment. Instruments to measure HIV-related stigma have been

developed and validated by correlation with other psychosocial measures including self-esteem, social support and depression.^{16,17} However, stigma experienced by those living with HIV/AIDS varies greatly among individuals and different populations. For example, one study measured and explored the relative importance of different domains of stigma experienced by older people living with HIV/AIDS revealing that concern about disclosure of HIV status was most troubling for this population.¹⁴ Another study of women living with HIV showed that levels of stigma were highly correlated with depression.¹¹ Among African Americans living with HIV factors including increased social support from friends and higher educational level predicted lower perceived HIV-related stigma.¹³

To date, there is little published literature on HIV/AIDS-related stigma experienced by young men who have sex with men (MSM); a demographic group representing a significant portion of those already living with HIV/AIDS and recent Centers for Disease Control data suggest represent an increasing number of new HIV infections in many communities.¹⁸ HIV-positive young MSM are among the most marginalized and at-risk groups in our society and may experience multiple layers of stigma due to their sexual orientation, gender identity, and/or race/ethnicity in addition to their HIV status.

Not only is there little information about how young MSM experience HIV-related stigma, but it is also unclear if and how the experience of HIV-related stigma changes over time. While the trajectory of stigma over time has been described for other chronic diseases, few data have addressed these changes in the context of HIV/AIDS. One qualitative study developed a framework of perceived HIV/AIDS related stigma including the following four phases throughout the disease course: at risk, diagnosis, latent, and manifest.¹⁹ However, this conceptual model was developed prior to the widespread availability of highly active antiretroviral therapy (HAART) and increased survival rates of people living with HIV in the United States. With improved access to care and availability of HAART with fewer side effects, the latent phase of disease, when an individual is relatively healthy with no obvious physical signs of disease, may last for up to 20 years or more.²⁰ In fact, as the paradigm of HIV disease has shifted more toward that of a chronic rather than a fatal illness, the concept of HAART optimism or treatment optimism has emerged, which may impact the way youth view HIV and may decrease perceptions of stigma.²¹

With regards to stigma experienced throughout different phases of the illness, the first year after diagnosis has been described as a key adjustment period by multiple studies and in one study of adults living with HIV those retained in care during this time reported decreased stigma.^{22–24} Another recent study of adults attending an urban HIV clinic found a negative correlation between HIV-related stigma and the number of years since HIV diagnosis.²⁵ A better understanding of the trajectory of HIV/AIDS related stigma experienced by young MSM may help to target interventions and clinical practices for this population.

In this exploratory study we have three specific aims: (1) to describe the HIV-related stigma experienced by an ethnically diverse group of young MSM, including several transgender youth; (2) to explore the relationship between stigma and several measures of psychosocial functioning in this unique population; and (3) to examine whether experiences of stigma

will change over time following diagnosis. We hypothesize that individuals diagnosed more than one year ago would have lower stigma scale scores than young MSM diagnosed less than 1 year ago.

Methods

Study participation

A diverse, cross-sectional, community-based sample of 310 ethnically diverse young MSM in Chicago participated in the Project Q study. Participants were aged 16–24 and were recruited consecutively from August 2004 to September 2005 through various avenues including flyers, e-mails, and snow-ball sampling. Participants received \$30 for completing the 90-minute computer-based survey. The Institutional Review Boards of Children's Memorial Hospital and Howard Brown Health Center approved all aspects of the study prior to recruitment. A more detailed description of the Project Q study procedures has been published elsewhere.²⁶ Among those young MSM completing the overall survey, those participants who self-identified as HIV positive and who completed the Berger HIV stigma scale comprised the final study population for this analysis ($n = 42$).

Measures

Demographics and HIV status. Demographic measures included age, self-reported race/ethnicity, sexual orientation, gender identity, housing status, and socioeconomic status. Participants were asked if they had ever been told they were HIV positive by a health care provider and, if so, when they were diagnosed.

HIV-related stigma. The Berger HIV Stigma Scale is a 40-item instrument previously validated with an adolescent population.^{16,17} Each question with a four-point Likert scale response option was scored from 1–4 giving total possible scores of 40–160, with higher scores indicating greater stigma. The instrument includes four subscales: (1) personalized stigma (PS), which measures the consequences of others knowing about one's HIV status including loss of friends, avoidance of others; (2) disclosure concerns (DC) measuring issues related to disclosing or hiding HIV status from others; (3) negative self-image (NSI) measuring shame, guilt, and self-worth; and (4) public attitudes (PA) measuring participants' perceptions of what others think about those living with HIV/AIDS. In addition, all 40-items on the scale were used to compute a total stigma score (TSS). Total and subscale stigma scores were analyzed for reliability giving the following Cronbach α for each: TSS (0.94), DC (0.79), PS (0.93), NSI (0.84), and PA (0.91).

Depression. The Brief Symptom Inventory-18 is a 18-item measure commonly used to screen for psychological distress and psychiatric disorders in medical and community populations.^{27,28} Responses were recorded on a five-point scale from "not at all" to "extremely"; higher scores indicate greater distress. The reported coefficient α for the inventory is 0.89 and with our sample 0.94.

Self-esteem. The Rosenberg Self-Esteem (RSE) Scale is a 10-item global measure of self-esteem using responses on a four-point scale from "strongly disagree" to "strongly agree."²⁹ Higher scores indicate lower self-esteem. The coefficient α of

this scale, widely used in adolescents is reported to be greater than 0.7 and was 0.87 in our population.

Loneliness. The Social and Emotional Loneliness Scale for Adults (SELSA) is a multidimensional measure of emotional and social loneliness and connectedness.³⁰ A 12-item Romantic Loneliness subscale and a 11-item Social Loneliness subscale with responses recorded on a 7-point scale from “very strongly disagree” to “very strongly agree” were used to assess loneliness among our study population with higher scores indicating increased loneliness. The coefficient α for SELSA reported in the literature and in our study are 0.89 and 0.79, respectively.

Social support. The Multidimensional Scale of Perceived Social Support (MSPSS) is a 12-item measure of participants’ perceived social support from family, friends and significant others.³¹ Responses were recorded on a seven-point scale from “very strongly disagree” to “very strongly agree.” Higher scores indicated higher perceived social support. The coefficient α reported in previous studies and in our study were 0.93 and 0.91, respectively.

Statistical analysis

Statistical analyses were conducted using SPSS, version 12.0 (SPSS, Inc., Chicago, IL). Significance was set at $p < 0.05$.

We first examined frequencies of demographic data and reported HIV-positive status. Scores were calculated for all of the above measures. In order to examine the relative importance of each of the four domains of HIV-related stigma, index scores were calculated for each subscale of the HIV Stigma Scale by taking the actual score and dividing by the total possible score for that domain. This computation standardized each subscale to allow for direct comparisons of their importance. Index scores for each subscale were then tested for normality. The disclosure concerns subscale was not normally distributed so nonparametric, Whitney-Mann tests were used for comparison with the disclosure concerns subscale scores. Pearson correlation coefficients were calculated for the total stigma score and each Berger HIV Stigma Scale subscale index score compared to each of the above psychosocial measures. In order to examine the hypothesized relationship between stigma and time since HIV diagnosis, a t test was used to compare total stigma scores and subscale scores among those diagnosed less than one year ago versus those diagnosed more than 1 year ago.

Results

Demographics

Forty-two young MSM self-identified as HIV positive and completed the Stigma Scale and psychosocial measures (Table 1). The mean age of participants was 21.3 years with 33% under the age of 20. The sample was ethnically diverse: 26% white, 25% black, 24% Latino, and 5% other/multiracial. Fourteen percent of the young MSM participants identified as male to female (MTF) transgender individuals.

Descriptive statistics of stigma

The mean total stigma scale score was 102.5 with a standard deviation of 22.7. Mean subscale index scores indicate that this

TABLE 1. DEMOGRAPHICS

	Number of participants	Percent (n = 42)
Gender/sexual orientation		
Male born (MSM)	36	85.7
Male born (female identified)	6	14.3
Race/ethnicity		
White	11	26.2
Black	19	45.2
Latino	10	23.8
Other	2	4.8
Age		
16–20	14	33.3
21–24	28	66.7
Housing status		
No permanent address	3	7.1
Group Home	1	2.4
Other	38	90.5

MSM, men who have sex with men.

sample of young MSM experienced greater stigma related to disclosure concerns relative to other types of stigma (Fig. 1). There were no statistically significant differences of stigma total or subscale scores when analyzed by race/ethnicity, gender identity, or age group.

Psychosocial measures

Total stigma scale scores were significantly, positively correlated with depression (BSI), social support (MSPSS) and self-esteem (RSE) with Pearson correlation coefficients all greater than 0.3 (Table 2). While the total stigma score was not significantly correlated with the social loneliness subscale, romantic loneliness was correlated with the disclosure concerns stigma subscale.

Stigma trajectory

Of the 42 subjects, 40 reported a time since diagnosis and were included in the following analysis. Half of young MSM participants reported being diagnosed 1 year or less before taking the survey. While the mean total stigma score (TSS) and each stigma domain’s subscale scores were all higher for those diagnosed within the last year, these differences were not statistically significant (Table 3).

FIG. 1. Index scores on four HIV-related stigma subscales.

TABLE 2. CORRELATIONS BETWEEN STIGMA SCALES AND PSYCHOSOCIAL VARIABLES

	PA	NSI	DC	PS	BSI	PSS	RSE	S-Ro
Total stigma (TS)	0.954 ^a	0.921 ^a	0.833 ^a	0.885 ^a	0.356 ^b	−0.316 ^b	0.335 ^b	−0.273
Public attitudes (PA)		0.861 ^a	0.728 ^a	0.890 ^a	0.367 ^b	−0.272	0.310 ^b	−0.194
Negative self-image (NSI)			0.740 ^a	0.738 ^a	0.385 ^b	−0.338 ^b	0.479 ^a	−0.164
Disclosure concerns (DC)				0.561 ^a	0.214	−0.284	0.205	−0.326 ^b
Personalized stigma (PS)					0.324 ^b	−0.236	0.224	−0.228
Brief Symptoms Inventory (BSI)						−0.036	0.602 ^a	0.065
Multidimensional Scale of Perceived Social Support (PSS)							−0.444 ^a	0.416 ^a
Rosenberg Self-Esteem (RSE)								−0.259
Loneliness—Romantic (S-Ro)								

^aCorrelation is significant at the 0.01 level (2-tailed).

^bCorrelation is significant at the 0.05 level (2-tailed).

Discussion

To our knowledge, these data are among the first to describe the HIV-related stigma experienced by young MSM and to document an association between stigma and other psychosocial factors related to HIV (i.e., psychological distress, lower self-esteem, loneliness) for this population. We found levels of reported HIV-related stigma similar to previous studies with other populations.¹⁴ We also report no significant differences in levels of experienced stigma based upon age, race, or gender identity.

Our results are also consistent with the associations between stigma scale scores and psychosocial measures such as depression and self-esteem reported in other populations.^{11,17} While we did not find any significant association between total stigma scores and overall social and emotional loneliness measures, there was a notable correlation between HIV-related disclosure concerns and the romantic loneliness subscale score. This may suggest that HIV-positive young MSM who have fears about disclosing their status are less able or willing to seek out and find romantic partners. Alternatively, these youth may also be more likely to be socially isolated, and thus have less access to partners who they feel they can trust with disclosure of their HIV-positive serostatus.

Our data show that while the most recently diagnosed HIV-positive young MSM consistently reported higher levels of stigma on all scales and subscales when compared to those diagnosed more than a year ago, these differences did not attain statistical significance. Due to our relatively small sample size, we should use caution with the interpretation of this finding, since there may in fact be some changes in the experience of stigma over time not captured by these data. In either case, these data suggest that the perceptions of HIV-related stigma do not simply disappear with time.

There are several limitations that should be considered when interpreting the findings of this study. Since the data we collected are cross-sectional we cannot draw any conclusions about causality. For example, we cannot determine whether concerns about disclosing HIV status leads to romantic loneliness or whether those HIV-positive young MSM who are romantically lonely at baseline experience more stigma related to disclosure of their HIV-positive serostatus. Because the data are not longitudinal we cannot draw conclusions about how individuals may experience stigma over time. Participants were drawn from one urban geographic area where economic and health care resources and social networking opportunities for HIV-positive young MSM may be different than other areas and therefore our findings may not represent the experiences of HIV-positive young MSM in other parts of the United States or those living in other countries. Our sample may also not be representative of all HIV-positive young MSM since we only recruited those who were comfortable enough to self-identify as such on a confidential computer-assisted survey. HIV-positive young MSM unwilling to self-disclose their diagnosis as part of research participation may experience different, in all likelihood greater, HIV-related stigma than our study population.

While our data showed no significant difference in stigma scores based on race, age or gender identification our sample size was limited. We did not report or analyze the data by socioeconomic status or examine stigma in the context of other risk behaviors, which should likely be considered for future studies. Despite these limitations, these data are among the first to describe HIV-related stigma in an ethnically-diverse sample of HIV-positive young MSM, a population with increasing rates of HIV infection in the United States.

Similar to other people living with HIV/AIDS, this diverse group of young MSM reported considerable levels of stigma

TABLE 3. COMPARISON OF MEANS OF STIGMA TOTAL AND SUBSCALE BY TIME SINCE DIAGNOSIS

	Time since diagnosis	n	Mean	SD	t	p value (2-tailed)
Total stigma	< 1 yr	20	106.4	21.0	0.901	0.374
	≥ 1 yr	20	99.8	25.2		
Personalized stigma	< 1 yr	20	41.0	12.2	0.088	0.930
	≥ 1 yr	20	40.7	12.8		
Negative self-image	< 1 yr	20	34.6	7.6	1.463	0.152
	≥ 1 yr	20	30.8	8.8		
Public attitudes	< 1 yr	20	50.5	11.5	0.866	0.392
	≥ 1 yr	20	47.1	12.9		
Disclosure concerns	< 1 yr	20			$z = -1.13^a$	0.260
	≥ 1 yr	20				

^aMann-Whitney *U* test.
SD, standard deviation.

which was positively correlated with depression and self-esteem. Despite reports of HAART optimism and the paradigm shift of HIV from a fatal to a chronic disease among many HIV-positive young MSM, our data suggest that there was no difference between levels of stigma reported before versus after 1 year of living with HIV. Future longitudinal rather than cross-sectional studies may be needed to elucidate how individuals experience HIV-related stigma over time which may lead to more effective counseling and interventions regarding HIV related stigma among young MSM. However, these findings reinforce the importance of regularly addressing stigma in the clinical setting. Providers should include psychosocial screening and counseling related to stigma that is culturally and age appropriate at all visits. New interventions should be directed to helping HIV-positive young MSM deal with their experience of stigma in order to overcome social and health care access barriers. Given the prominence of disclosure concerns reported by our subjects, we suggest that interventions specifically address the process of disclosing one's HIV status in a variety of settings. These data also speak to the continued need for education of the general public about HIV/AIDS to prevent the discrimination that these vulnerable youth may face.

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Author Disclosure Statement

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