

HIV Stigma Study in the Deep South: <u>Descriptive Findings</u>

August 2017 http://southernaidsstrategy.org Susan S. Reif, Research Associate susan.reif@duke.edu Elena Wilson, Research Assistant Elena.wilson@duke.edu Carolyn McAllaster, Clinical Professor of Law mcallaster@law.duke.edu





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EXECUTIVE SUMMARY |

Overview:

The US Deep South has disproportionately high rates of HIV diagnoses and HIV-related deaths in comparison to other US regions.¹⁻³ HIV-related stigma and discrimination have been implicated as contributing to the greater impact of HIV in the Deep South along with poverty, racial inequalities, and less access to adequate HIV care and prevention. Previous research has found HIV-related stigma to predict negative outcomes such as higher HIV risk behavior and lower HIV medication adherence.^{4,5} However, few studies have documented the level and types of HIV-related stigma in the Deep South and investigated the relationship between HIV-related stigma and health outcomes.

This study documented HIV-related stigma in the Deep South by recruiting individuals receiving care at HIV medical care facilities and social services organizations to complete a survey about their HIV stigma experiences and perceptions and their health status and use of health care. The survey included existing and tested scales such as the Berger HIV Stigma Scale.⁶ The survey was administered to 201 individuals living with HIV in 4 Deep South states (AL, MS, NC, SC) in 2016-2017.

Results:

The findings from the participant surveys show high levels of stigma experiences and perceptions among individuals living with HIV in the Deep South. For example, for stigma

Nearly one-third (31%) answered yes to the item "Have you been told not to share your food or utensils with family because of your HIV?" experiences, nearly one-third (31%) answered yes to the item "Have you been told not to share your food or utensils with family because of your HIV?" and 1 in 4 said they had been insulted because of their HIV status in the last 3 months. Perceptions regarding the existence of HIV-related stigma were also quite high, as 62% agreed with the statement "Most people are uncomfortable or afraid to be around someone with

HIV" and 61% agreed that ""Most people with HIV are rejected when others learn they have HIV." Survey participants also reported considerable fear about the consequences of revealing their HIV status. For instance, nearly half of participants (48.2%) agreed with the statement "It is easier to avoid friendships than worry about telling that I have HIV," and nearly two-thirds of participants (65%) agreed that "I worry that people may judge me when they learn I have HIV". These expectations of difficulties following disclosure were significantly associated with whether individuals disclosed their HIV status to family or friends. Relatively high levels of internalized HIV-related stigma were also found. For example, 36% percent agreed that "I feel guilty because I have HIV" and a majority of participants (56.4%) disagreed with the statement "I never feel ashamed of having HIV." Statistical analysis revealed that a history of higher levels of stigma experiences was associated with having higher internalized stigma.

Data for some of the HIV-related stigma questions included in this stigma survey were compared to responses to the same questions that were part of a Harvard study of HIV-related

stigma in Massachusetts (MA) conducted approximately 8 years ago. The findings regarding stigma experiences between the Deep South and MA study were fairly similar except the item "I have avoided telling others outside my immediate family that I have HIV," as nearly two-thirds (65%) of the Deep South respondents agreed with this statement, whereas 50% of the MA participants agreed with this statement. It is possible that because the Deep South sample appear to have disclosed their HIV status less often, they had fewer opportunities to experience HIV-related stigma.

Poorer overall health, lower social support, depression, and heavy alcohol use were associated with reporting higher overall HIV stigma (as measured by the Berger HIV Stigma Scale) and higher internalized stigma. Higher internalized stigma was also associated with illicit substance

use. Individuals with higher internalized stigma were more likely to have missed a medical appointment in the last 6 months, to report poorer medication adherence, and to not have an undetectable viral load. In addition, individuals reporting more stigma experiences (such as having been insulted because of HIV status) reported poorer medication adherence. Additional research is planned to assess how mental health and substance use, which have been consistently related to medication adherence in

Individuals with higher <u>internalized stigma</u> were more likely to have missed a medical appointment in the last 6 months, to report poorer medication adherence, and to not have an undetectable viral load.

previous research, and stigma may work together to negatively influence medication adherence.

Conclusions:

Study findings indicate that individuals living with HIV in the Deep South who completed the survey experienced considerable HIV-related stigma and that this stigma, particularly when internalized, was associated with negative health outcomes including poorer medication adherence and lower viral load. These findings add to the growing evidence of the need to address stigma to improve the well-being of individuals living with HIV and to reduce HIV transmission. Adapting existing stigma reduction interventions and/or creating new stigma reduction strategies that are suited to the culture of the Deep South and providing enough resources for these programs to be implemented will be critical to adequately addressing HIV in the Deep South.

INTRODUCTION |

The US South has been disproportionately affected by HIV; this region has consistently had the highest HIV and AIDS diagnosis rates and has the highest proportion of individuals living with HIV of any US region.^{1,3,7} The South and particularly the Deep South has the highest death rates associated with HIV.² A number of factors have been identified to contribute to the Southern HIV epidemic including poverty, racial inequalities, incarceration, gaps in access to health care, and HIV-related stigma.^{1,8-15} HIV-related stigma and discrimination are widespread in the US and have been consistently associated with negative HIV outcomes including increased HIV risk behavior and poorer adherence to medical care visits and medication adherence.^{4,16} Several studies have found HIV-related stigma to be particularly high in the US South.^{14,15,17} However, previous studies in the South have not examined the prevalence of multiple dimensions of stigma and their association with health outcomes.

Stigma can exist in several different forms including experienced/enacted stigma, which is the occurrence of a specific act of discrimination such as a breach of confidentiality or insult to a person living with HIV/AIDS (PLWHA) about the disease. Perceived stigma is the individual's thoughts about and observation of stigma toward individuals living with HIV by the community,¹⁸ and internalized stigma has been defined as "the degree to which PLWHA endorse the negative beliefs and feelings associated with HIV/AIDS about themselves".¹⁹ Another form of stigma, anticipated stigma, refers to the fear of the negative outcomes of an individual's HIV status being known or the expected consequences if an individual tests positive for HIV.^{18,19} Experiences with these various types of stigma may affect decisions regarding participation in health care and disclosure of HIV status.

Forms of Stigma

-At a Glance:

- **1. Experienced/enacted stigma**: occurrence of a specific act of discrimination or insult...to a person living with HIV/AIDS about HIV.
- 2. Perceived stigma: the person's thoughts about and observations of community stigma towards PLWHA.
- Internalized stigma: the degree to which PLWHA endorse the negative beliefs and feelings associated with HIV/AIDS about themselves.
- Anticipated stigma: the fear of the negative outcomes of an individual's HIV status being known or the expected consequences of a positive HIV test.

This study describes different forms of stigma experienced by individuals living with HIV in the US Deep South and examines how stigma relates to participant characteristics and health care participation including missed medical appointments and medication adherence. This information is essential to determining means to reduce stigma and its negative consequences on the health of individuals living with and highly vulnerable to HIV disease in the South.

METHODS |

Surveys regarding HIV-related stigma and health outcomes were completed by 201 individuals living with HIV in 4 Deep South states: Alabama, Mississippi, South Carolina and North Carolina. Individuals were recruited to participate in the survey primarily through Infectious Diseases Clinics (64%). Study staff were present at the clinics to ask all HIV-positive individuals present in the clinic that day if they were interested in completing a HIV stigma survey. In addition, individuals were recruited through partnerships with AIDS Services Organizations. At these ASOs, study staff were present for HIV support groups, at an HIV housing program, and at a substance use treatment program for individuals living with HIV to identify individuals interested in participating in the survey. Participants were provided with \$5 as compensation for completing the survey.

The stigma survey included questions from standardized stigma scales including the Berger HIV stigma scale.⁶ The Berger HIV Stigma Scale has been shown to be both valid and reliable and has 4 dimensions, including negative self-image related stigma (which measures internalized stigma), concern about public attitudes, concerns about HIV status disclosure and the anticipated consequences if HIV is disclosed, and personalized stigma, which is what someone believes will happen if others know of their HIV status, such as "I lost friends by telling them I have HIV."²⁰ Response categories are "strongly agree", "agree", "disagree", and "strongly disagree." In addition, items from other stigma scales were used in the survey, including the verbal abuse subsection of the HIV/AIDS Stigma Instrument (HASI-P) by Holzemer and colleagues²¹ and the enacted stigma subscale of the stigma scale developed by Steward and Colleagues.²² Questions from a Harvard study of HIV-related stigma conducted in Massachusetts (MA) were also included to measure HIV-related stigma and to allow comparisons between participants in the Deep South and MA.²³ Social support was measured using the MOS social support scale and information about depressive symptoms was measured with the PHQ-9 depression scale.^{24,25} We also measured substance use with an alcohol use scale,²⁶ a question regarding heavy drinking (5 or more drinks for men and 4 for women)²⁷ and a validated question regarding drug use.²⁸ The survey also included questions about missed HIV medical appointments, viral load, and HIV medication adherence scales. Although most participants reported having a viral load test done in the year of survey, 15 percent did not provide information regarding date of test so it is not feasible to determine how recently these participants had their viral load tested. Self-reported medication adherence was assessed using a visual analog scale²⁹ which has been successfully used in previous adherence studies and the CASE Study Adherence Index.³⁰ The survey also included guestions regarding disclosure of HIV status to partners, family and friends.

Descriptive statistics were used to examine participant characteristics and stigma experiences. Bivariate statistics, including t-tests, chi-square tests, linear regression, and negative binomial regression, were calculated to examine relationships between participant characteristics and different types of HIV-related stigma. Bivariate analyses were also used to examine the relationship of HIV-related stigma with outcomes including missing a medical appointment in the last 6 months, adherence to HIV medications and undetectable viral load. Missing data on items in the HIV stigma scale were addressed by assigning a total HIV stigma score as the average of the answered items if more than 75% of items were answered. This method was used to address missing data for the HIV stigma subscales as well as the PHQ-9 score and social support scale score.

RESULTS |

Survey respondents were mostly African American (81%, 15% Caucasian) and 53% were male (Table 1). Just over one-third (37%) identified as gay, lesbian, or bisexual. Nearly one-third of participants reported being disabled and 18% had less than a high school education. Ten percent of participants were aged 18-24 and 76% were aged 35 and older. Nearly one-quarter of participants (24%) had a PHQ-9 score that qualified them as having a probable diagnosis of depression and 35% had used illicit substances in the previous year. Thirty-one percent of respondents reporting missing a medical appointment in the last six months and 64% reported HIV medication adherence of 95% or greater.

Disclosure of HIV Status (Table 2):

HIV status disclosure was reported very differently depending on with whom the participant was sharing their status. Disclosure to primary sexual partners was reported by 63.5% of participants (18.7% stated that this question "does not apply"). Disclosure to other sexual partners was less prevalent, as 45.5% said they disclosed to all sexual partners (25.9% said the question did not apply to them). Twelve percent of participants said they had not disclosed to any close family and 61% said they had disclosed to all close family. Just under one-third (31.4%) said they had disclosed to no extended family, while 37.7% had disclosed to all extended family. Nearly half (46%) said they had disclosed to some friends, 29.9% to all friends and 18.5% had disclosed to no friends.

Stigma:

Study findings regarding stigma are presented by type of stigma including experiences of stigma, perceptions of stigma in the community, internalized stigma, and anticipated stigma.

Experienced Stigma:

When asked about specific stigma experiences, respondents reported that they had been insulted because of their HIV status (25% of participants), told that they were "to blame for your HIV status" (23%), and told that "God is punishing me" (24%) at least once or twice in the last 3 months. Approximately one third of participants said they had been told "not to share your food or utensils with family because of your HIV." Approximately 1 in 5 participants reported that their confidentiality had ever been breached by a health care worker. Threats of

violence due to HIV were less common, as 8% reported experiencing this in the last 3 months. Only 13% of participants reported that they had been treated differently in church because of HIV, however, 52% stated that they were "not at all" comfortable discussing their HIV status at

Fifty-two (52%) [of participants] stated that they were "not at all" comfortable discussing their HIV status at church. church. This discomfort may have led to participants being less likely to disclose their status in church, thereby lessening their chance of experiencing discrimination.

Several items on the HIV Stigma Scale measure concerns about HIV negatively affecting social interaction and relationships. Results of these scale questions included that one-third of participants reported that they agreed or strongly agreed that "as a rule, telling others that I have HIV has been a mistake" and 25% agreed or strongly agreed that "people who know I have HIV tend to ignore my good points" (Table 3). In addition, 42% of respondents agreed or strongly agreed that "I have been hurt by how people treated me after learning I have HIV"; and nearly one-third (32%) agreed or strongly agreed that "some people avoid touching me if they know I have HIV."

Perception of community stigma: Responses to survey items that addressed how participants saw HIV-related stigma in their communities showed that participants believe their communities to have high levels of stigma. For example, 58.4% of participants agreed or strongly agreed that "Most people believe a person who has HIV is dirty", 60.7% agreed or strongly agreed that "Most people with HIV are rejected when others learn they have HIV" and 61.6% agreed or strongly agreed that "Most people that "Most people are uncomfortable or afraid to be around someone with HIV."

Anticipated/Disclosure stigma:

Responses among participants showed that they greatly anticipated stigma from others regarding their HIV status and were cautious about disclosing their status for fear of experiencing stigma. Nearly half of participants (48.2%) agreed or strongly agreed that "It is easier to avoid friendships than worry about telling that I have HIV," and 55% agreed or strongly agreed that "Since learning I have HIV, I worry about people discriminating against me." Sixty-five percent agreed or strongly agreed that "I worry that people may judge me when they learn I have HIV" and 78.7% agreed or strongly agreed that "I am very careful whom I tell that I have HIV."

Internalized Stigma:

Participants were less likely to report high internalized stigma, [where they believe negative thoughts associated with HIV about themselves] than other forms of stigma, including perceived stigma and anticipated stigma. Nonetheless, at least 20% of participants agreed or strongly agreed with the internalized stigma statements included in the HIV Stigma Scale. For example, 28% agreed that "having HIV makes me feel unclean," and 32% agreed that "people's attitudes about HIV make me feel worse about myself." Thirty-six percent agreed that "I feel guilty because I have HIV." A majority of participants, 56.4%, strongly disagreed or disagreed that "I never feel ashamed of having HIV."

Comparison of Findings from Deep South Sample to Massachusetts Sample: (Table 4)

Questions from a Harvard Stigma Study (2007/2008; n=137) conducted in Massachusetts (MA) were included in the Deep South stigma study survey in order to examine regional differences in stigma experiences. The MA and Deep South samples had similar characteristics regarding

gender, sexual orientation, age, and education. However, there were substantial differences by race/ethnicity, as the Harvard sample was 31% African American, 34% White, 14% other, and 24% Hispanic/Latino. In contrast, the Deep South sample was 81% African American, 15% White, 4% other and 6.5% Hispanic/Latino. The Deep South study was conducted nearly a decade after the Harvard study so changes in stigma may have occurred over time.

No substantial differences were found between the Deep South and MA participants regarding perceptions of HIV-related stigma in the community. For example, 77% of the MA sample and 75% of the Deep South sample agreed or strongly agreed that "Many people think that if you have HIV today, it's your own fault." For the questionnaire item, "Many people think that people living with HIV don't care if they infect other people," 46% of the MA participants and 51% of the Deep South participants agreed with the statement.

When asked about medical care experiences, 71% of the MA participants and 77% of the Deep South participants agreed that "I have been treated with kindness and sympathy by dentists, doctors and other medical providers when they learned that I have HIV." Other experiences of stigma did not differ remarkably between the two samples. For example, 76% of the MA sample and 76% of the Deep South sample agreed that "I have been treated fairly by most people who know I have HIV." However, responses were quite different between the two samples for the item "I have avoided telling others outside my immediate family that I have HIV." Hole of the MA respondents agreed with this statement, whereas nearly two-thirds (65%) of Deep South agreed with this statement. Since fewer participants in the Deep South shared their HIV status with others, they may have had less opportunity to experience stigma than they would have had if they disclosed their status.

Participants in both the MA and Deep South studies were asked about their level of concern before HIV testing that they "might be treated badly" if they tested positive for HIV. Nearly half (48%) of Deep South participants reported "A lot" of concern about being treated badly as compared to 39% of MA participants. When asked how much their level of concern affected their decision to get tested, 37% of the Deep South participants reported that their concerned affected their decision "a lot" as compared to 32% of MA participants.

Other types of stigmas:

Survey respondents were asked about whether they had experienced stigma for reasons other than HIV, including stigma related to mental health, substance use, race, sexual orientation, poverty, and history of incarceration. Sixty-two percent of participants reported experiencing another type of stigma. Of those who reported they had experienced stigma for other reasons, the average number of stigma types reported was 2.6. Stigma based on race was the most commonly reported, as over one-third (35%) of participants stated that they experienced this stigma. In addition, one-third (32%) experienced stigma due to sexual orientation, 26% reported stigma related to mental health issues, nearly one-quarter reported substance use stigma (23%) and poverty-related stigma (24%), and 19% reported stigma due to incarceration.

Relationships between HIV-related stigma and participant characteristics: (Table 5)

Demographics:

Gender, age, and educational level were not associated with HIV-related stigma (including total HIV Stigma Scale score and subscales). Nonwhite race was associated with a lower level of stigma as measured by the total Stigma Scale score; this relationship also existed for all subscales except for the internalized stigma scale. Reporting being "straight" as a sexual orientation was associated with lower levels of stigma related to HIV disclosure. No differences in levels of stigma were found comparing those living in rural vs urban areas or when looking at different states of residence.

Social Support:

Bivariate analysis of the relationship between HIV-related stigma and social support, which was measured by the MOS social support index, indicated that having a greater total HIV Stigma

...having a <u>greater</u> total HIV Stigma Scale score was associated with reporting <u>less</u> social support. Scale score was associated with reporting less social support. This relationship with social support held true for all stigma subscales except for stigma associated with disclosure of HIV status.

Mental Health and Substance Use:

Having a probable diagnosis of depression was associated with a higher HIV stigma, as measured by the total HIV Stigma Scale score and subscales scores except for stigma related to HIV disclosure. Higher internalized stigma had the strongest relationship with depression (p<.001). Illicit substance use and heavy alcohol use in the past year were also associated with greater internalized HIV stigma.

Health Outcomes:

Poorer self-reported overall health was associated with a higher total HIV Stigma Scale score. Poorer health was also associated with higher reported stigma on all stigma subscales except for the subscale measuring concerns regarding public attitudes about HIV. Participants reporting greater internalized stigma also reported being more likely to have missed a medical appointment in the last 6 months, having poorer medication adherence, and not having an undetectable viral load. No other forms of stigma were associated with missed appointments and undetectable viral load. However, higher levels of stigma, as measured by the total HIV Stigma Scale score, and more experienced HIV stigma, as measured by the Stewart and Holzemer stigma scales, were associated with poorer medication adherence.

HIV Disclosure:

Reported disclosure of HIV status to friends, partners, close family or extended family was not associated with total HIV Stigma Scale score or with the HIV stigma Scale subscales except for the disclosure stigma scale. Higher levels of disclosure stigma (which includes items regarding concerns about stigma if HIV status is revealed) were associated with lower levels of disclosure to friends, close family, and extended family but not to sexual partners.

Internalized Stigma:

We also explored the relationships of stigma experiences with the HIV Stigma Scale's internalized stigma subscale to look at associations between having greater stigmatizing experiences and having higher internalized stigma. Higher internalized stigma score was strongly related to greater stigma scores on both the Holzemer HASI-P scale (which measures stigma experiences in the last 3 months) and the Stewart enacted stigma experience scale, which measures lifetime stigma experiences (p < >001).

DISCUSSION |

Results from the HIV stigma study conducted among individuals living with HIV in the Deep South indicate substantial HIV-related stigma in the region. Individuals living with HIV in the Deep South reported high levels of stigma and discrimination experiences along with significant

Results from the HIV stigma study...in the Deep South indicate substantial HIV-related stigma in the region.

perceptions of community HIV stigma, anticipated/disclosure related stigma, and internalized stigma. Greater anticipated stigma around disclosure of HIV status (expecting to experience stigma if HIV status was revealed) related significantly to whether participants had disclosed their HIV status to friends, close family members, and extended family. Expectations of stigma did not affect whether participants disclosed to sexual partners. How frequently and to whom individuals disclose their HIV status may affect the experiences of stigma following disclosure, as those participants who had not disclosed their status may have had less opportunity for stigmatizing experiences, whether from family, sexual partners or in the greater community. This lack of disclosure among participants is significant; since many participants did not disclose their status frequently or widely among their social and community circles, measurements of stigma experiences may be reported as lower in this sample than among individuals who have

For a majority of participants (62%), stigma was multi-layered, as they reported experiencing at least one other type of stigma. disclosed more widely. For a majority of participants (62%), stigma was multi-layered, as they reported experiencing at least one other type of stigma. The most commonly reported types of stigma were related to race and sexual orientation.

Comparisons of responses regarding stigma perceptions and experiences between the Deep South participants and participants in a study in Massachusetts (MA) identified relatively similar responses on most stigma questions. However, responses differed considerably for the item "I have avoided telling others outside my immediate family that I have HIV," as nearly two-thirds (65%) of the Deep South respondents agreed with this statement, whereas 50% of the MA participants agreed with this statement. It is feasible that because the Deep South sample appear to have disclosed their HIV status less often, they had less opportunity for HIV stigmarelated experiences. In addition, a higher proportion of the Deep South sample reported concerns about stigma before being tested for HIV compared to the MA sample. When comparing the samples from different locations, it is important to note that the Harvard study participants completed the survey approximately 8 years before the Deep South participants. Thus, it is unclear whether the MA respondents would answer differently in the present day, as stigma may have lessened over time. Two previous studies compared HIV-related stigma between US regions, one among African American adolescents and the other a community based sample, and identified higher stigma in the South.^{14,15} Additional research is needed to further examine regional differences in stigma experiences and perceptions among individuals living with HIV and to examine the impact of regional differences in stigma on health outcomes.

Internalized stigma was found to be associated with a more extensive history of stigma experiences, such as being told to use different utensils than the rest of one's family or being insulted because of HIV status. These findings suggest these negative experiences related to HIV resulted in greater feelings of internalized stigma among participants. Study findings also indicated that greater HIV-related stigma was associated with less social support, having a probable diagnosis of depression, and poorer self-reported overall health among individuals living with HIV in the Deep South. These findings showed similar results to previous studies that found a co-occurrence of these negative factors, which may lead to lower quality of life and poorer health outcomes.^{22,31-33}

Study findings also indicated that participants reporting greater internalized stigma were more likely to have used illicit substances in the last 6 months, to have missed a medial appointment in last 6 months, and to not have an undetectable viral load. In addition, higher internalized stigma and greater lifetime stigma experience were significantly related to poorer HIV medication adherence. More complex multivariable analyses are planned to examine the interwoven and independent effects of internalized stigma, depression, and social support on missed medical appointments and HIV medication adherence.

The findings of this study must be taken in the context of the study's limitations including the cross-sectional design, which does not allow for us to draw conclusions regarding the direction of relationships between stigma and participant health outcomes since they were measured at the same time rather than stigma being measured at an earlier time than the HIV outcomes. Missing data for viral load (28%) limited our ability to explore the relationship between stigma and viral load for all participants. Participants' lack of knowledge about their viral load status also raises the concern that more education may be needed to ensure that PLWH in the Deep South, even those in regular medical care, are aware of their disease status. In addition, because this was a sample primarily of individuals participating in medical and/or social service care, the findings may not be generalizable to individuals not in care or attending care more sporadically. Furthermore, the age of participants was older than what is found in the general population of individuals living with HIV thus limiting the ability to assume similar experiences and results for younger individuals living with HIV. More research is needed to assess stigma levels among a younger population in the Deep South in order to generate culture and ageappropriate interventions that are designed to alleviate this HIV-related stigma and related negative health behaviors.

CONCLUSIONS |

Despite the study limitations, the findings from the stigma study provide evidence of high levels of multiple dimensions of stigma including experienced, perceived, anticipated, and internalized stigma among individuals living with HIV in the Deep South. HIV-related stigma, particularly internalized stigma, was found to be associated with negative health care outcomes, which has implications for quality of life, mortality, and the spread of HIV disease. These findings signal a critical need to address HIV-related stigma to improve the health outcomes of those living with HIV in the Deep South. Addressing the negative consequences of

These findings signal a critical need to address HIV-related stigma to improve the health outcomes of those living with HIV in the Deep South. stigma has the potential to improve the lives of individuals living with HIV as well as to stem the spread of the disease by increasing undetectable HIV viral load rates. There are innovative interventions that have shown effectiveness in reducing stigma, particularly at an individual level, that can be implemented or adapted for use to address stigma

among PLWH in the Deep South.^{34,35} Attention and adequate resources are needed to adapt these existing interventions and/or to create new and effective interventions that are appropriate for the culture in the Deep South in order to decrease HIV-related stigma and its negative impact.

TABLE 1: PARTICIPANT CHARACTERISTICS (n=201)

Characteristic	Proportion
Female	.45
Male	.53
Transgender	.02
African American	.81
Caucasian	.15
Other Race	.04
Hispanic/Latino	.065
18-24	.096
25-34	.14
35-45	.24
45 and over	.52
Heterosexual	.59
Gay/Lesbian/Bisexual/Uncertain	.41
Disabled	.32
Employed	.34
Less than High School Education	.18
Completed high school	.29
Alabama	.18
Mississippi	.16
North Carolina	.31
South Carolina	.35
Ever told had AIDS diagnosis	.20
PHQ-9 score indicates major depression	.24
Illicit substance use in the past year	.35
Heavy Drinking*	.17
Missed Medical Appointment in Past 6 Months	.31
HIV Medication Adherence >=95%	.64
Viral load undetectable	.81
No information provided for viral load	.28

*more than 5 drinks for men/4 for women monthly or more on average

	All	Some	None	Does Not Apply
Primary Partner	63.5	10.2	8.6	18.7
Other Partners	45.5	15.3	13.2	25.9
Children	40.2	3.8	15.2	40.8
Medical Providers	85.5	8.8	3.1	2.6
Close Family	61.3	22.0	12.0	4.7
Extended Family	37.7	22.5	31.4	8.4
Friends	29.6	46.6	18.5	5.3

TABLE 2: HIV STATUS DISCLOSURES (%)

TABLE 3: HIV STIGMA SCALE FINDINGS (%)

Statement	Strongly Agree	Agree	Disagree	Strongly Disagree
In many areas of my life, no one knows I have HIV	30.0	33.7	21.9	14.4
I feel I'm not as good a person as others because I have HIV	8.5	12.2	33.3	46.0
Having HIV makes me feel unclean	9.3	19.1	29.9	41.8
Having HIV in my body is disgusting to me	11.3	17.0	27.3	44.3
People's attitudes about HIV make me feel worse about myself	13.5	18.5	26.0	38.0
I feel guilty because I have HIV	11.9	23.9	26.9	37.8
I never feel ashamed of having HIV	21.3	22.3	29.3	27.1
It is easier to avoid friendships than worry about telling that I have HIV	19.3	28.9	27.3	24.6
Having HIV makes me feel that I'm a bad person	9.9	10.9	33.9	45.3
Since learning I have HIV, I feel set apart and isolated from the world	13.0	20.1	27.1	39.1
I work hard to keep my HIV a secret	20.9	21.4	32.6	25.1
As a rule, telling others that I have HIV has been a mistake	11.2	21.8	37.4	29.6
People who know I have HIV tend to ignore my good points	8.2	17.0	41.8	33.0
People seem afraid of me once they learn I have HIV	11.0	15.0	39.5	26.5
Since learning I have HIV, I worry about people discriminating against me	22.0	33.0	25.1	19.9
I worry that people may judge me when they learn I have HIV	26.7	38.7	16.2	18.3
People with HIV lose their jobs when employers learn their status	16.4	32.8	33.3	17.5
I regret having told some people that I have HIV	18.8	32.3	25.3	23.7
Some people close to me are afraid others will reject them if it becomes known that I have HIV	16.7	23.1	31.7	28.5
I am very careful whom I tell that I have HIV	46.6	32.1	9.8	11.4

Telling someone I have HIV is risky	39.9	28.2	18.1	13.8
I have told people close to me to keep my HIV a secret	28.1	26.0	26.5	19.5
People with HIV are treated like outcasts	24.7	36.3	26.8	12.1
Most people believe a person who has HIV is dirty	21.6	36.8	27.4	14.2
Most people think a person with HIV is disgusting	17.6	34.6	27.1	20.7
Most people with HIV are rejected when others learn they have HIV	21.3	39.4	26.1	13.3
Some people who know have grown more distant	9.5	25.5	31.5	27.5
Most people are uncomfortable or afraid to be around someone with HIV	23.7	37.9	25.3	13.2
I never feel the need to hide the fact that I have HIV	18.5	17.4	38.0	26.1
I have been hurt by how people treated me after learning I have HIV	18.3	23.3	29.4	28.9
I worry that people who know I have HIV will tell others	29.6	32.3	21.7	16.4
Some people avoid touching me if they know I have HIV	15.0	17.2	37.8	30.0
People I care about stopped calling after learning I have HIV	10.6	13.8	41.5	34.0
People have told me HIV is what I deserve for how I lived	11.1	17.4	44.2	27.4
People don't want me around their children once they know I have HIV	9.1	21.1	38.3	31.4
People have physically backed away from me because of HIV	11.6	22.2	31.8	35.5
Some people act as though it is my fault I have HIV	13.9	29.4	32.1	24.6
I have stopped socializing with people due to their reactions to my HIV status	14.3	23.6	33.5	28.6
I have lost friends by telling them I have HIV	12.1	17.6	39.6	30.8
People look for flaws in your character if they know you have HIV	22.2	36.5	25.9	15.3

TABLE 4: COMPARISON OF STIGMA QUESTIONS BETWEENDEEP SOUTH AND HARVARD PARTICIPANTS

Item	Deep South: % Strongly Agree/Somewhat Agree	Harvard: % Strongly Agree/Somewhat Agree
When I disclosed my HIV status to family and friends, I received support, comfort, and assistance	76	79
I have been shunned or avoided when people learned that I have HIV.	50	59
I have been treated fairly by most people who know I have HIV	76	76
I have had difficulty finding a medical provider when it was known that I have HIV	17	15
I have been treated with kindness and sympathy by dentists, doctors and other medical providers when they learned that I have HIV	77	71
Coworkers and supervisors at work were supportive and accommodating when they learned that I have HIV	51	68
Many people think that if you have HIV today, it's your own fault	75	77
I have worried that others will view me unfavorably because I have HIV	65	75
I have avoided telling other outside my immediate family that I have HIV	65	50
Many people think that people living with HIV don't care if they infect other people	51	46

TABLE 5: BIVARIATE RELATIONSHIP OF HIV STIGMA SCALE AND PARTICIPANT CHARACTERISTICS

Variable	Total Stigma Score	Negative self-image scale	Disclosure stigma	Public Attitudes	Personalized
Gender	.32	02	1.11	.58	29
Black/African America	-2.31*	-1.78	-2.09*	-2.93**	-2.83*
Age 18-30	.76	.98	1.02	.88	.11
"Straight"	-1.52	-1.33	-2.20*	-1.33	61
Education – high school only	.91	.58	14	.74	.19
Poor self-rated health	2.85**	2.80**	2.51*	1.48	2.54*
Social Support	2.24*	2.14*	1.84	2.12*	2.74*
Depression	3.27**	3.46**	1.52	2.17*	3.36**
Disabled	.52	.0020	69	.37	1.16
Illicit drug use past year	1.70	2.25*	1.05	1.17	1.94
Heavy Alcohol Use^	2.11*	2.41*	1.58	1.74	1.69
Percent Medication Adherence	4.75*	5.61**	1.37	2.84	3.85*
Missed medical appointment in last 6 months	1.50	2.04*	1.06	1.60	1.27
Viral load undetectable	-1.47	-2.12*	084	69	-1.53

^more than 5 drinks for men/4 for women monthly or more on average

*p<.05

**p<.01

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