

Experiences of stigma and health care engagement among Black MSM newly diagnosed with HIV/STI

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Abstract Rates of HIV/STI transmission among Black men who have sex with men (BMSM) are alarmingly high and demand urgent public health attention. Stigma related concerns are a key barrier to accessing health care and prevention tools, yet limited research has been focused in this area. Experiences of stigma related to health care were evaluated among 151 BMSM residing in the Atlanta, GA area, both prior to and post HIV or STI diagnosis in a longitudinal study (data collected from 2014 to 2016). Findings demonstrated that inadequate health care engagement is associated with post-diagnosis anticipated stigma ($b = -0.38$, $SE = 0.17$, $p \leq .05$). Pre-diagnosis prejudice is a predictor of post-diagnosis enacted ($b = 0.39$, $SE = 0.14$, $p < .01$), anticipated ($b = .28$, $SE = 0.14$, $p < .05$), and internalized ($b = .22$, $SE = 0.06$, $p < .001$) stigmas. This study is the first of its kind to assess experiences of stigma among BMSM during a critical time (i.e., before and after diagnosis) for HIV/STI prevention and treatment. Results provide a novel understanding of how stigma unfolds over-time and provide direction for stigma intervention development.

Keywords Stigma · HIV/STI · Black men who have sex with men

Introduction

Rates of HIV/STI diagnoses among Black men who have sex with men (BMSM) have been, and continue to be, alarmingly high, and therefore, require immediate attention and action (CDC, 2016). The observed rates of HIV/STI among BMSM, however, will not decline without considerable targeted changes to the current HIV/STI prevention landscape. Matthews et al. estimates that, by age 40, approximately 60% of BMSM will be living with HIV (Garofalo et al., 2016; Koblin et al., 2013; Matthews et al., 2016). In the southern US, in particular, HIV/STI transmission among BMSM is a public health crisis and remains under-prioritized in health care initiatives.

Engagement in health care services for BMSM is a critical component of slowing the HIV/STI epidemics observed among BMSM (CDC, 2016; Millett et al., 2012; Millett et al., 2006). Our inability to achieve sufficient rates of routine HIV/STI testing and treatment among BMSM continues to drive HIV/STI epidemics among this population. Suboptimal engagement in health care is the Achilles' heel of HIV/STI prevention, and currently our most effective forms of prevention [i.e., pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP)] are entirely dependent on consistent engagement in health care systems. Attenuating the multiple barriers to health care engagement must be a top public health priority.

In order to adequately respond to the HIV/STI epidemics among BMSM, the socio-ecological environment wherein transmission occurs, must be comprehensively understood (Baral et al., 2013; Sullivan et al., 2014, 2015).

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Stigma and its relationship to health care engagement is one such area in need of further investigation. Earnshaw and Chaudoir (2009) proposed the HIV Stigma Framework in order to conceptualize how stigma affects health outcomes for both people at-risk for and living with HIV/STI. This framework proposes that experiencing stigma [i.e. enacted stigma (experiencing mistreatment), anticipated stigma (expectation of future mistreatment), and internalized stigma (personal endorsement of stereotypes and prejudice)] can affect health-related outcomes, such as an individual's likelihood of accessing medical care. Experiences of stigma are considered *stigma mechanisms* that result from possessing a socially devalued characteristic (such as HIV or STI diagnoses). Further, stigma mechanisms manifest through the existence of stigma drivers [i.e., prejudice (negative feelings), stereotypes (negative group-based beliefs), and discrimination (endorsing mistreatment of stigmatized groups)]. Stigma drivers are social beliefs that serve to identify and describe socially devalued characteristics. This framework provides guidance on how stigma impacts health outcomes such as engagement in health care, but has yet to be tested in a longitudinal model.

The need to better understand stigma as a barrier that impacts health care access is evident in the literature. The word 'stigma' is frequently observed in scholarly work as a catch-all phrase that fails to capture important dimensions of stigma, such as, type, source, and attribution (Dowshen et al., 2009; Turan et al., 2017b; Vanable et al., 2006). This shortcoming is of concern as recent work has demonstrated the importance of type of stigma as an explanatory factor in health outcomes, and notably, the strength of these relationships has varied by stigma type (Golub & Gamarel, 2013; Quinn et al., 2017; Turan et al., 2017a). This work, however, has primarily focused on health related outcomes (e.g., HIV viral load, medication adherence) with health care engagement serving, presumably, as the mediating variable between stigma and health outcomes. Experiences of stigmas and health care engagement has been rarely studied.

For the current study, stigma mechanisms were used to predict health care engagement among BMSM newly diagnosed with HIV or STI. BMSM were categorized into two groups: those who were adequately or inadequately (defined below) engaged in health care. Specifically, HIV and STI prejudice, stereotypes, and discrimination were assessed prior to HIV or STI diagnosis, and experiences of enacted, anticipated, and internalized stigma were assessed longitudinally at multiple time points post diagnosis. Three separate models were tested, one model for each stigma mechanism (internalized, enacted, and anticipated). Based on HIV Stigma Framework, it was hypothesized that health care engagement would be negatively associated with experiencing stigma mechanisms and drivers.

Methods

Participants and procedures

Participants were recruited using online advertisements (e.g., dating apps, craigslist, BGClive.com), as well as in-field, active recruitment at gay-identified bars, clubs, parks, and sex parties. Potential participants were described details related to the study, including that they would be asked to partake in a survey assessment and complete biological testing for HIV, syphilis, chlamydia, and gonorrhea. Participants were followed in a yearlong longitudinal study that included monthly assessments focused on stigma measures and HIV/STI-related health care engagement. Participants completed 14 audio computer assisted self-interview (ACASI) assessments in total; 1 prior to diagnosis, 1 one-week post-diagnosis, and 12 monthly assessments post-diagnosis for 1 year.

Participants included 151 BMSM residing in the Atlanta, GA metropolitan area. All participants provided written informed consent. As part of a larger longitudinal study (Eaton et al., 2017), 351 BMSM were tested for HIV and 271 BMSM were tested for STI at 4 time points over 1 year. From these study testing procedures, 50 participants were newly diagnosed with HIV (50/351, 13.5%) and 101 were newly diagnosed with gonorrhea, chlamydia and/or syphilis (101/271, 37%). Participants testing positive for either HIV or STI enrolled into the current year-long study, and enrollment occurred between 2014 and 2016. Participants who did not test positive for HIV or STIs were referred to other available studies.

The research site is primarily focused on community outreach and provides linkage to health care providers for ongoing HIV/STI treatment. Due to the need to link participants not only to immediate treatment but also to ongoing, long-term care, project staff worked with each participant to identify and coordinate HIV/STI-related health care with a local health department, clinic, or private practice provider that best suited the needs of the participant. Using existing relationships with numerous treatment providers, project staff coordinated the linkage to the initial treatment appointment with participant and the provider.

Measures

Stigma drivers: prejudice, stereotypes, and discrimination

Stigma drivers were measured using multiple items for each construct and were based on adapted measures (Earnshaw & Chaudoir, 2009; Earnshaw et al., 2013). Prejudice (i.e., negative feelings) towards people with HIV or STI was assessed using a total of six items. Three items

focused on HIV and these items were then repeated for STIs [e.g., People who are HIV positive make me feel uncomfortable (Cronbach's $\alpha = .93$)]. Likewise, stereotypes (i.e., group-based beliefs about stigmatized persons) towards people living with HIV or STI were assessed using a total of six items. Three items focused on HIV and these items were then repeated for STIs [e.g., Most people who are HIV positive sleep around a lot (Cronbach's $\alpha = .86$)]. Finally, discrimination (i.e., behavioral expression of prejudice and/or stereotypes) was measured using six items; three were focused on HIV and repeated for STIs [e.g., If a friend of mine got HIV I would continue being friends with him/her (Cronbach's $\alpha = .73$)]. Response sets to measures included a 6-point Likert scale ranging from 1 = *Strongly Disagree* to 6 = *Strongly Agree*.

Stigma mechanisms: enacted, anticipated, and internalized stigmas

Participants were asked to report whether they had been mistreated in the past month due to their HIV/STI diagnosis (three items) and if they had been mistreated by health care providers in the prior month (three items). In total, six items were used for this composite scale [e.g., Do you think you have been ignored by people close to you due to your HIV (STI) diagnosis?]. All six items from the enacted stigma score were repeated for anticipated stigma score, however, the timeframe was focused on the coming month. Response set included, *Yes* (coded as 1) or *No* (coded as 0) and responses were summed to create a composite number of events for both enacted and anticipated stigmas. Finally, four items focused on HIV/STI internalized stigma [e.g., I feel ashamed of having been diagnosed with HIV (a STI)] (Earnshaw & Chaudoir, 2009; Earnshaw et al., 2013). Response sets to this measure included a 6-point Likert scale ranging from 1 = *Strongly Disagree* to 6 = *Strongly Agree* (Cronbach's $\alpha = .80$).

Consistent with Earnshaw and Chaudoir (2009) and to address multicollinearity, one scale for each stigma mechanism and driver was created. Responses to prejudice, stereotypes, discrimination, and internalized stigma scales were averaged, and reported instances of anticipated and enacted stigmas were summed.

Socio-demographic data

Participants reported their age, education, income, employment status, sexual orientation, and health care coverage information.

Confirmed engagement in HIV/STI related health care

Attendance to health care appointments was confirmed through appointment documentation (e.g., doctor's note, prescription information, insurance print-outs). Participants who tested HIV positive and attended at least three appointments at least 3 months apart over the course of the 1-year follow-up (1st appointment for linkage, and 2nd and 3rd appointments for ongoing care) were described as adequately engaged in care (Mugavero et al., 2013). Likewise, participants who tested STI positive and attended two or more STI treatment/testing appointments that were at least 3 months apart over the course of the 1-year follow-up (1st appointment for linkage, 2nd appointment for routine HIV/STI testing) were described as adequately engaged in care (CDC, 2015). The remaining participants were described as inadequately engaged in care.

Data analysis

Three primary models for each stigma mechanism (i.e., enacted, anticipated, and internalized stigmas) were investigated. Correlational analyses were used to investigate the relationships between the three stigmas. For modeling analyses, time was centered at the first follow-up assessment, and in each model a random intercept was estimated. Models predicting enacted stigma and anticipated stigma were analyzed through multi-level modeling in PROC GLIMMIX SAS version 9.4. In each model, a negative binomial distribution with a log function was employed. Laplace approximation was used as the estimation method for its accuracy under a variety of conditions. The model predicting internalized stigma was analyzed with multi-level modeling through PROC MIXED in SAS version 9.4. To examine whether each stigma mechanism changed over time and as a function of whether participants were engaged in care, stigma was predicted at each month from time, health care engagement, and the interaction between time and health care engagement. Further, stereotypes, prejudice, and discrimination (assessed prior to diagnosis) were included in the models, as well as their interactions with time (Fitzmaurice et al., 2011). Finally, diagnosis (HIV vs. STI), as well as its interaction with time, was included in the models.

In sensitivity analyses, it was determined the relationships between stigmas and health care engagement did not significantly differ for individuals testing HIV positive versus testing STI positive, and therefore, models were run for all participants simultaneously. These analyses were completed by testing the interaction effect of diagnosis, health care engagement, and time. The three-way interac-

Table 1 Sociodemographic variables among BMSM adequately and inadequately engaged in health care

Variable	Inadequate engagement <i>n</i> = 67		Adequate engagement <i>n</i> = 84		<i>t</i> (df)	
	M	SD	M	SD		
Age	26.55	7.54	26.34	5.32	.20 (150)	
Education	1.88	1.11	2.12	0.87	1.47 (151)	
		N	%	N	%	X²
Income						
< \$20,000		48	71.6	53	61.6	1.68 (1)
> \$21,000		19	28.4	33	38.4	
Currently employed (yes)		43	64.2	52	60.5	.22 (1)
Sexual orientation						
Same gender loving		35	53.0	38	44.2	2.87 (2)
Bisexual		26	39.4	34	39.5	
Heterosexual		5	7.6	14	16.3	
Sexual orientation openness						
Open		31	46.3	43	50.0	2.46 (2)
Sometimes open		34	50.7	36	41.9	
Not open		2	3.0	7	8.1	
Without health coverage in past 2 years (yes)		34	50.7	50	58.8	.99 (1)
Has regular physician (yes)		28	41.8	39	45.9	.25 (1)
Talked with doctor about sexual health (yes)		30	44.8	38	44.7	.01 (1)
Where health care is received						
Emergency room		23	34.3	26	30.6	2.52 (4)
Community health Care Center		7	10.4	13	15.3	
Private clinic		29	43.3	36	42.4	
Hospital outpatient		7	10.4	6	7.1	
Other		1	1.5	4	4.7	
Depressive symptoms \geq 10		21	31.3	26	30.6	.01 (1)

*** $p < .001$; ** $p < .01$; * $p < .05$

tion between HIV/STI diagnosis, engagement, and time was not significant for any model.

Results

Of the 151 participants, 84 (56%) met the definition of being adequately engaged in care. There were no significant differences in age ($M = 26.34$, $SD = 6.30$), education [$M = 2.01$ (average = some college), $SD = .99$], income (< \$21,000, 66.2%), sexual orientation (same gender loving/gay, 47%), or depressive symptoms ($M = 8.65$, $SD = 6.10$) on engagement in health care (Table 1).

Analyses examining the relationships between the three types of stigmas demonstrated significant correlation between enacted and anticipated stigmas ($r = .554^{**}$).

Correlations between enacted stigma or anticipated stigma and internalized stigma were, however, non-significant (Table 2).

Enacted stigma and health care engagement

Experiences of enacted stigma did not vary by engagement in care [$b = -0.22$, $SE = 0.17$, $t(1269) = -1.30$, $p = .20$]. There was no difference in the change of enacted stigma over time as a function of whether participants were engaged in care [$b = -0.01$, $SE = 0.01$, $t(1269) < 0.01$, $p = .99$ (see Fig. 1)]. As for stigma drivers (all assessed prior to diagnosis), prejudice [$b = 0.39$, $SE = 0.14$, $t(1269) = 2.71$, $p = .007$] and discrimination [$b = -0.90$, $SE = 0.42$, $t(1269) = -2.12$, $p = .034$] were both significant predictors of enacted stigma. Finally, there was a

Table 2 Correlation matrix for enacted, anticipated, and internalized stigmas at first post-diagnosis follow-up assessment

	1. Enacted stigma	2. Anticipated stigma	3. Internalized stigma
1. Enacted stigma	–		
2. Anticipated stigma	.554**	–	
3. Internalized stigma	.06	.12	–

** $p < .01$

significant random intercept ($\tau = 3.18$, $SE = 0.66$, $z = 4.80$, $p < .0001$) indicating that there was significant variance in enacted stigma across participants at the first follow-up assessment. Fixed effects estimates from all models are reported in Table 3. The relationships between health care engagement and stigma mechanisms are depicted in Fig. 1.

Anticipated stigma and health care engagement

Participants inadequately engaged in care reported more instances of anticipated stigma [$b = -0.38$, $SE = 0.17$, $t(1268) = -2.19$, $p = .029$] than participants adequately engaged in care. We observed a significant effect of time [$b = -0.05$, $SE = 0.01$, $t(1268) = -4.25$, $p < .0001$], such that participants experienced a decrease in anticipated stigma over time. Prejudice [$b = .28$, $SE = 0.14$, $t(1268) = 2.00$, $p = .045$] and discrimination [$b = -0.10$, $SE = 0.41$, $t(1268) = -2.24$, $p = .016$] were significant predictors of anticipated stigma. There was no difference in the change of anticipated stigma over time as a function of whether participants were engaged in care [$b = 0.01$, $SE = 0.01$, $t(1268) < 0.01$, $p = .99$]. Finally, there was a significant random intercept ($\tau = 3.16$, $SE = 0.60$, $z = 5.26$, $p < .0001$) indicating that there was significant variance in anticipated stigma across participants at the first follow-up assessment.

Internalized stigma and health care engagement

Internalized stigma was not related to engagement in health care [$b = -0.02$, $SE = 0.08$, $t(1270) = -0.25$, $p = .80$]. We did observe a significant effect of time [$b = -0.05$, $SE = 0.01$, $t(1270) = -7.69$, $p < .0001$], such that participants experienced a decrease in internalized stigma over time. Prejudice was a significant predictor of internalized stigma [$b = .22$, $SE = 0.06$, $t(1270) = 3.33$, $p < .001$]. There was no difference in the change of internalized stigma over time as a function of whether participants were engaged in care [$b = -0.01$, $SE = 0.005$, $t(1270) = -0.20$, $p = .84$]. There was a significant random intercept ($\tau = 0.83$, $SE = 0.10$, $z = 7.90$, $p < .0001$) indicating that there was significant variance in internalized stigma across participants at the first follow-up assessment.

Discussion

The impact of stigma on engagement in health care among BMSM is a novel priority area of research (Cahill et al., 2017; Quinn et al., 2017). This study is the first of its kind to evaluate, in a longitudinal approach, how stigma related to health care and health statuses unfolds during a critical time for health care engagement among BMSM (Goodreau et al., 2017; Villarosa, 2017). Findings offer new insight into this time period and guidance for next steps when addressing stigma.

Rarely does research on stigma focus on multiple forms of stigma, however, these findings demonstrate important distinctions between observed stigmas. Anticipated stigma was reported at a significantly higher rate among BMSM not engaged in care, while this relationship did not exist when examining enacted and internalized stigmas. Anticipated stigma is unique in its focus on the perception that *one will be mistreated* in the future (Golub & Gamarel, 2013), as opposed to prior instances of mistreatment and one's personal endorsement of negative beliefs. It's noteworthy that individuals can experience prior mistreatment (enacted) or harbor negative self-beliefs (internalized) yet doing so does not necessarily impact accessing care, and what remains important is the belief that these experiences will continue in the future. The variability in findings may speak to the resiliency in BMSM to have had negative prior experiences (McNair et al., 2017), but be able to seek out and continue in care regardless.

Remarkably, anticipated stigma dissipated over time (similar to internalized stigma), but remained elevated for individuals not adequately engaged in health care. This finding is likely influenced by the proximity to diagnosis and subsequent processing of a stigmatized health status or confronting an altered identity (Alonzo & Reynolds, 1995). The dissipation is consistent with prior work (Holzemer et al., 2009) and has implications for timing of intervention work. Additionally, it's also possible that even minimal engagement in health care results in reductions in anticipated and internalized stigmas as these forms of stigma dissipated over time even for participants inadequately engaged in care.

With the strong emphasis on TasP (Cohen et al., 2011), and the documented benefits of starting antiretroviral

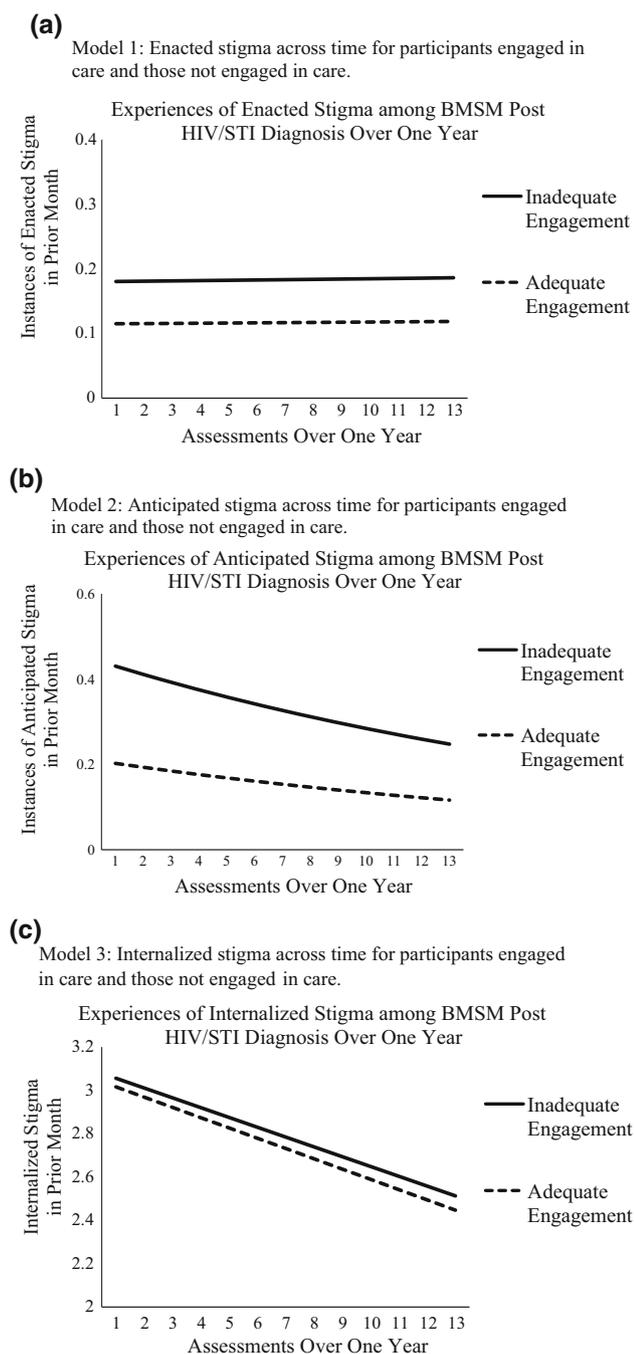


Fig. 1 Models depicting the relationships between experiences of stigma and health care engagements. **a** Model 1: enacted stigma across time for participants engaged in care and those not engaged in care. **b** Model 2: anticipated stigma across time for participants engaged in care and those not engaged in care. **c** Model 3: internalized stigma across time for participants engaged in care and those not engaged in care. *Note* for all models, time was centered at the first follow-up assessment and model included random intercept. PROC GLIMMIX SAS 9.4 was used with a Laplace approximation. Diagnosis, time, and the interaction between diagnosis and time were included in the models

Table 3 Fixed effects estimates for the models predicting enacted, anticipated, and internalized stigma models

Variable	Fixed Effects Estimate	SE
Model 1 enacted stigma		
Intercept	- 1.94***	0.22
Time	0.003	0.01
Diagnosis	0.30	.019
Diagnosis × time	0.003	0.01
Stereotypes	0.02	0.16
Stereotypes × time	- 0.0003	0.01
Prejudice	0.39**	0.14
Prejudice × time	- 0.003	0.01
Discrimination	- 0.90*	0.42
Discrimination × time	0.02	0.02
Engaged in care	- 0.22	0.17
Engaged in care × time	- 0.0001	0.01
Model 2 anticipated stigma		
Intercept	- 1.22***	0.20
Time	- 0.05***	0.01
Diagnosis	0.73***	0.18
Diagnosis × time	- 0.01	0.01
Stereotypes	0.01	0.15
Stereotypes × time	0.004	0.008
Prejudice	0.28*	0.14
Prejudice × time	0.006	0.008
Discrimination	- 0.10*	0.41
Discrimination × time	0.02	0.02
Engaged in care	- 0.38*	0.17
Engaged in care × time	0.00002	0.01
Model 3 internalized stigma		
Intercept	3.04***	0.09
Time	- 0.05***	0.01
Diagnosis	- 0.03	0.09
Diagnosis × time	- 0.01*	0.01
Stereotypes	0.06	0.07
Stereotypes × time	0.01*	0.03
Prejudice	0.22***	0.06
Prejudice × time	- 0.01**	0.004
Discrimination	0.13	0.21
Discrimination × time	- 0.01	0.01
Engaged in care	- 0.02	0.08
Engaged in care × time	- 0.001	0.01

*** $p < .001$; ** $p < .01$; * $p < .05$

treatment early (Group et al., 2015; Lifson et al., 2017) and timely STI treatment (CDC, 2010), public health messaging has promoted immediate engagement in health care. Although the benefits of a treatment-centric approach must not be understated, this strategy does not accommodate for meeting the needs of persons who are processing emotional

barriers to care. This study is the first to demonstrate that, among BMSM, the immediate time period following diagnosis may pose challenges for treatment related interventions, or may require interventions wherein treatment is a secondary focus and more holistic approaches to care are a primary focus (e.g., negotiating disclosure and its impact on interpersonal relationships (Alonzo & Reynolds, 1995), and addressing how a change in health status may disrupt one's daily life (Scambler, 2009)).

The results of the present study suggest that pre-diagnosis stigma drivers, specifically prejudice, impact post-diagnosis stigma mechanisms. Prejudice is considered the emotional component of stigma drivers [which is distinct from the cognitive (stereotypes) and behavioral (discrimination) components]. The different stigma drivers are considered distinct psychological processes and are expected to differentially impact outcomes (Earnshaw & Chaudoir, 2009; Link & Phelan, 2006). Given that prejudice emerged as the only pre-diagnosis measure to predict all post-diagnosis experiences of stigma, targeting the emotional component of stigma should be prioritized. It is unknown exactly how prejudice impacts stigma mechanisms, however, it is possible that negative emotions affect one's interpretation of whether mistreatment occurred and the attribution of mistreatment. For example, someone with higher levels of HIV/STI related prejudice might be more likely to attribute experiences of mistreatment to their HIV/STI diagnosis than individuals with lower levels of prejudice.

The association of HIV/STI transmission with "improper or immoral behavior" (Nyblade et al., 2009) has perpetually stymied health care engagement, resulting in steady or increasing HIV/STI rates. The cycle of stigma preventing health care access, which exacerbates transmission rates, must be broken by greater awareness of stereotypes, prejudice, and discrimination. In order to break this cycle, health care infrastructure (inclusive, in part, of staff training, advertising of services, logistical aspects of accessing care etc.) must be reconceptualized to address the gap between our most vulnerable patients and receipt of comprehensive health care. In work by Calabrese et al., (Calabrese et al., 2017) the authors make the strong case for routinization of addressing sexual health in medical settings as a way to address stigma and improve health care engagement. This approach could incorporate brief assessments of stigma, and be used as a marker for individuals potentially at-risk for falling out of care.

Limitations

The results of the study must be interpreted in light of their limitations. First, some measures in the study relied on self-reported information which may be prone to social desirability bias. Further, constructs were assessed repeatedly and, therefore, may be prone to response bias. Third, data come from individuals residing in and around the Atlanta metro area and may or may not be generalizable to individuals outside of the study target area. Likewise, most participants reported incomes < \$20,000, which may further limit generalizability to broader communities of BMSM. Fourth, prior STI testing and treatment history were not included in the current study, and therefore, it is unknown how this history may have affected experiences of stigma in the current study. Finally, although effects were detected, the small sample size impacts power and reproducibility of results.

Conclusions

In this study, we examined multiple experiences of stigma over the span of 1-year by way of the HIV Stigma Framework; importantly, we found that anticipated stigma operates separately from enacted and internalized stigma for BMSM. Based on these findings, the mechanisms through which multiple types of stigma affect the health of BMSM related to their health care engagement differ based on type of stigma (e.g., enacted, anticipated, internalized). Given the unique experiences and overall heightened risk for HIV/STIs among BMSM, research needs to continue disentangling the complexities of stigma for this increasingly vulnerable population. These findings further expand the empirical base related to stigma's role in accessing and engaging with the health care system for BMSM.

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Compliance with ethical standards

Conflict of interest Lisa A. Eaton, Valerie A. Earnshaw, Jessica L. Maksut, Katherine R. Thorson, Ryan J. Watson, and Jose A. Bauermeister declare that they have no conflict of interest.

Human and animal rights and Informed consent All procedures were in accordance with the ethical standards of the institutional research committees and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

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