



Original Reports

Mixed evidence for the relationship between HIV stigma and Pain in two studies of people with HIV in Florida

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ABSTRACT

Previous work suggests that HIV stigma is associated with greater pain severity. We sought to characterize this relationship by examining intersectional identities that tend to be stigmatized (i.e., gender; sexual orientation) in two cross-sectional studies of people with HIV (PWH). In Study 1 ($N = 840$), participants responded to the Enacted Stigma Scale and the Brief Pain Inventory. We found a significant positive association between HIV stigma and pain severity (and between sexual orientation and pain severity), but no interaction effects. In Study 2 ($N = 309$), participants responded to Internalized Stigma Scale and the Brief Pain Inventory. We did not find a relationship between HIV stigma and pain severity but conceptually replicated the relationship between sexual orientation and pain severity. Results may be due to a small sample size in Study 2, or because the relationship between HIV stigma and pain is specific to enacted stigma (i.e., overt acts of stigma; Study 1) rather than internalized stigma (i.e., an intrapersonal aspect of stigma; Study 2).

Perspective: Among people with HIV (PWH), there is a positive relationship between enacted stigma and pain. This relationship between stigma and pain should be studied among other intersectional groups including gay men and women of color. PWH should be provided with supportive care for both physical and psychosocial symptoms.

Introduction

Experiencing stigma can have dramatic effects on health behaviors¹, including how we assess and feel pain. In one classic social psychology experiment, participants were randomized to a social rejection condition and excluded from playing ball toss with others. Those in the rejection condition (compared to those who were allowed to play in the social inclusion condition) reported more social distress in the game and greater pain thermal pain sensitivity during testing after completion². Social rejection can occur in various forms, including stigma. Stigma is the process through which an individual is viewed to possess negative, undesirable attributes³. Pain is a common health concern exacerbated by stigma^{4,5} and is a fundamental source of health inequalities in the

United States⁶. Stigma may be associated with identities such as race, ethnicity, and gender. Researchers observed that women in a stigma condition reported lower pain tolerance, suggesting that stigma related to gender increases pain sensitivity⁷.

Besides gender, stigma regarding sexual orientation can have adverse health outcomes⁸. Sex and gender diverse individuals experience stigma-related stress, which elevates poor health outcomes like mental health⁹ and physical illness⁶. Social rejection due to sexual orientation increases distress¹⁰. Data from a large sample ($N > 60,000$) in which those who identified as lesbian, gay, and bisexual reported greater pain symptoms compared to those who identified as heterosexual¹¹.

Another form of stigma is HIV-related stigma¹². Internalized HIV

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stigma can increase shame and guilt¹³, increase negative thoughts about oneself¹⁴, cause adherence difficulties¹, and cause a decrease in disclosures of HIV status and health to social networks¹⁵. PWH who report more stigma-related experiences self-report more physical and cognitive impairments¹. HIV-stigma has also been found to be related to lower CD4 counts, an indicator of immune system functioning¹⁶.

HIV stigma and pain

For PWH, pain tends to be a common occurrence¹⁷, and estimates suggest that 39–85% of PWH experience chronic pain¹⁸. This association between stigma and physical pain warrants additional confirmatory and exploratory research because the relationship between HIV stigma and pain has primarily been observed in women. An initial focus on women is expected because women tend to report experiencing greater HIV stigma^{19,20}, social rejection,²¹ and chronic pain²² compared to men. However, men (especially non-cisgender, non-heterosexual men, and men who have sex with men) may also experience stigma, and it is unclear whether men who experience HIV stigma also report increased pain severity. Additionally, no studies have yet explored how sexual orientation may influence the relationship between HIV stigma and pain. Members of the LGBQ community are frequent targets of stigma, and living with HIV may exacerbate these experiences. Examining group differences in the relationship between HIV stigma and pain may inform tailored interventions to reduce the impact of HIV stigma on pain in understudied groups (e.g., LGBQ populations).

Current studies

We aimed to test the relationship between HIV stigma and pain in PWH in Florida using data from two cross-sectional studies. Recently, there has been a call in the behavioral sciences for conceptual replication studies to better generalize findings by using different methods, tools, and populations.²³ Therefore, we used data from two separate cross-sectional studies of similar, yet distinct populations of PWH who completed different measures of HIV stigma (i.e., enacted and internalized). One sample from the Florida Cohort Study assessed factors that impact healthcare accessibility among PWH, and the MAPLE cohort oversampled PWH who use cannabis. We hypothesized that (1) Women, compared to men, with HIV who experience HIV stigma would report greater pain severity. (2) Those who identify as LGBQ and experience HIV stigma would report greater pain severity.

Study 1 Method

Participants

Participants were recruited from recruited from a network of community-based clinics and organizations as well as county health departments throughout Florida and a total of 932 people with HIV were enrolled from 2015 to 2018. After excluding participants who did not complete measures of the focal variables (e.g., stigma, pain; $n=92$), our analytic sample comprised 840 cisgender PWH (278 women).

Procedure

This study was approved by the authors' IRB informed consent was obtained from participants. The study methods and degree of patient and public involvement have been previously published²⁴. The sample was recruited for the Florida Cohort Study, an investigation examining determinants of health outcomes for people with HIV in Florida (Gainesville, Lake City, Tampa, Orlando, Miami, Sanford, and Ft. Lauderdale). A pre-screening recruitment system was introduced to increase the number of Latine participants aged 60 and older to better align with demographics of PWH in Florida²⁴. All participants recruited responded to demographic questions, then completed the Enacted Stigma Scale²⁵

and the Brief Pain Inventory²⁶.

Measures

Demographics

Participants reported their age, gender, sexual orientation, ethnicity, relationship status, and time since HIV diagnosis. Gender (0="Men"; 1="Women,") and sexual orientation (0="LGBQ"; 1="Heterosexual") were dichotomized.

Herek HIV Stigma Scale

Participants completed the 10-item HIV Enacted Stigma Scale (e.g., "Someone insulted or verbally abused me because I have HIV") with endpoints 0 ("Never") to 3 ("3 or more times")²⁵. A mean composite was created ($\alpha=.89$) with higher mean scores indicating higher enacted stigma.

Brief Pain Inventory

Participants reported their pain via one question: "Have you had pain other than minor everyday kinds of pain in the past 24 h?"²⁷. This item was dummy coded (0="No"; 1="Yes"). If participants responded "Yes," they were asked four follow-up questions: "Rate your pain at its..." (1) "...Worst," (2) "...Least," (3) "...Average," and (4) "...Right now," with response options on a scale from 0 ("No Pain") to 10 ("As bad as you can imagine"). A mean composite of the four items was created, for those that responded that they were in pain ($\alpha=.83$).

Analysis plan

Using a binary logistic regression, we first regressed experiences of pain ("pain other than minor everyday kinds of pain in the past 24 h") on age, gender, and sexual orientation in Step 1. In Step 2, we added stigma. In Step 3 we included interaction terms (gender x enacted stigma; sexual orientation x enacted stigma). Next, using linear regression we regressed self-reported pain severity (among those who reported clinically relevant pain) on age, gender, and sexual orientation in Step 1. In Step 2, we again added stigma, and in Step 3 we included interaction terms.

Study 1 results

Descriptive statistics

Sample characteristics

The mean age of participants was 46.0 years old ($SD=11.18$) and the number of years since HIV diagnosis was 21.6 years ($SD=9.4$). The sample comprised 32.1% White, 57.9% Black, 0.7% Native American, 0.6% Asian, 4.6% Multiracial, and 4.1% otherwise identified individuals. Half the sample (51.9%) identified as heterosexual, whereas 37.2% identified as gay or lesbian, 9.4% identified as bisexual, 0.5% identified as asexual, and 1.1% identified as other. Approximately half of the sample comprised never married or single individuals (55.8%), whereas 8.0% reported being married, 14.9% reported being divorced, 3.8% were widowed, 6.0% were separated, and 11.6% were living with a long-term partner.

Stigma

The mean enacted stigma score was 0.39 ($SD=0.59$). There were no gender, $t(838)=-0.53$, $p=.60$, 95% CI [-0.11, 0.06], or sexual orientation, $t(867)=-1.44$, $p=.15$, 95% CI [-0.02, 0.14], differences in experiences of enacted stigma (see Table 1).

Pain

Approximately 46.7% ($n=392$) of participants reported experiencing more than minor pain. Men and women did not differ in their reporting of pain: $\chi^2(1)=1.47$, $p=.22$, Cramer's $V=.04$ (Men_{yes}=45.2%; Women_{yes}=49.6%), nor did heterosexual and LGBQ individuals, $\chi^2(1)=3.03$, p

Table 2

Regressing pain and pain severity on age, gender, sexual orientation, and stigma in two studies of people with HIV in Florida.

Model		Coefficients				Confidence Intervals	
		UnstandardizedB	SE	β (ExpB)	Sig	95% LL	95% UL
Study 1: Pain Experience (Logistic Regression)							
1	Age	.02	.01	1.03	<.001***	1.01	1.04
	Gender	.13	.18	1.14	.48	.80	1.62
	Sexual Orientation	.12	.17	1.13	.49	.80	1.58
2	Enacted Stigma	.56	.13	1.75	<.001***	1.36	2.24
Study 1: Pain Severity (Linear Regression)							
1	Age	.02	.01	.08	.14	−.003	.04
	Gender	.20	.25	.04	.42	−.29	.68
	Sexual Orientation	.88	.24	.20	<.001***	.40	1.35
2	Enacted Stigma	.41	.16	.12	.012*	.09	.73
Study 2: Pain Experience (Logistic Regression)							
1	Age	.02	.01	1.02	.11	1.00	1.04
	Gender	.00	.27	1.00	.99	.59	1.69
	Sexual Orientation	.03	.30	1.03	.92	.57	1.86
2	Internalized Stigma	.21	.12	1.23	.097	.96	1.57
Study 2: Pain Severity (Linear Regression)							
1	Age	.33	.02	−.20	.055	−.001	.067
	Gender	.44	.35	.12	.20	−.24	1.12
	Sexual Orientation	−.80	.40	−.20	.048*	−1.59	−.01
2	Internalized Stigma	−.08	.15	.05	.58	−.38	.22

Note: ***: $p < .001$; **: $p < .01$; *: $p < .05$. β is for the linear regression, and Exp (β), represents the logistic regressions.**Table 3**

Bivariate correlations between age, stigma, and pain severity in two studies of people with HIV in Florida.

Study 1				
		1	2	3
1.	Stigma	–		
2.	Pain Severity	.12*	–	
3.	Age	–.02	.10**	–
Study 2				
		1	2	3
1.	Pain Severity	–		
2.	Stigma	–.13	–	
3.	Age	.27**	–.25**	–

Berger Internalized HIV Stigma Scale. Participants completed the 10-item Internalized HIV Stigma Scale (e.g., “I feel that I am not as good a person as others because I have HIV”) with endpoints 1 (“Strongly Disagree”) to 5 (“Strongly Agree”) ²⁹. A mean composite was created ($\alpha=.85$) with higher mean scores indicating greater internalized HIV stigma.

Brief Pain Inventory. Participants reported their pain via the same method described in Study 1 ($\alpha=.83$) ³².

Analysis plan. Using a binary logistic, we again regressed experiences of pain (“pain other than minor everyday kinds of pain in the past 24 h”) on age, gender, and sexual orientation as predictor variables in Step 1. In Step 2, we added internalized stigma. In Step 3, we included interaction terms (gender x internalized stigma; sexual orientation x internalized stigma). Using linear regression, we then regressed self-reported pain severity (among those who reported pain) on age, gender, and sexual orientation in Step 1. Then in Step 2, we added internalized stigma and in Step 3, we included interaction terms.

Study 2 Results

Descriptive statistics

Sample characteristics

The mean age of participants was 49.9 years old ($SD=11.90$) and the number of years since HIV diagnosis was 20.3 years ($SD=9.88$). The

sample comprised 25.2% White, 71.5% Black, 0.6% Native American, 1.0% Asian, and 1.6% otherwise identified individuals. More than half of the sample (67.3%) identified as heterosexual, whereas 19.7% identified as gay or lesbian, 10.0% identified as bisexual, 0.6% identified as asexual, and 2.3% identified as other. Most of the sample comprised never married or single individuals (54.0%), whereas 11.3% were married, 12.0% reported being divorced, 6.5% were widowed, 5.8% were separated, and 10.4% were living with a long-term partner.

Stigma

The mean internalized stigma score was 2.67 ($SD=2.60$). We observed no gender differences in stigma, $t(302)=0.90$, $p=.92$, 95% CI [-0.21, 0.23; see Table 1], but those in the LGBQ community ($M=2.86$, $SD=.93$) did report more stigma compared to heterosexual individuals ($M=2.58$, $SD=1.01$), $t(302)=-2.31$, $p=.02$, 95% CI [-0.51, -0.41; see Table 1].

Pain

Approximately, 57.9% ($n=179$) participants reported more than minor pain. Men and women did not differ in their reporting of pain: $\chi^2(1)=.007$, $p=.93$, Cramer's $V=.005$, $Men_{yes}=57.7\%$; $Women_{yes}=58.2\%$, nor did heterosexual and LGBQ individuals, $\chi^2(1)=.04$, $p=.84$, Cramer's $V=.01$ ($Heterosexual_{yes}=57.8\%$; $LGBQ_{yes}=56.6$). Of those who experienced pain (responded yes to the binary pain question), the mean pain severity was 6.30 ($SD=1.88$). Similar to Study 1, there was a gender difference, $t(128)=-2.68$, $p=.008$, 95% CI [-1.51, -0.22], Cohen's $d=.47$, such that women ($M=6.74$, $SD=1.81$), compared to men ($M=5.87$, $SD=1.86$) reported higher pain severity. Effects of sexual orientation were also apparent, such that those who were heterosexual ($M=6.71$, $SD=1.82$) experienced greater pain severity compared to those in the LGBQ community ($M=5.41$, $SD=1.66$), $t(127)=3.77$, $p<.001$, 95% CI [0.61, 1.97], Cohen's $d=.72$ (see Table 1).

Experiencing pain

As in Study 1, we conducted a hierarchical binary logistic regression to assess the effects of (Step 1) age, gender, and sexual orientation, (Step 2) internalized stigma, and (Step 3) the interactions between internalized stigma and key variables (i.e., gender; sexual orientation) on experiencing pain. The interaction terms in the third step were not significant and were dropped from the model, leaving the model with

the main effects, which was statistically significant, $\chi^2(3)=1.85$, $p < .60$ (see Table 2).

Pain severity

Next, among those who reported experiencing pain, we assessed pain severity. We conducted a linear regression to assess the effects of (Step 1) age, gender, and sexual orientation, (Step 2) HIV internalized stigma ($\beta=-0.05$), and (Step 3) the interactions between internalized stigma and key variables (i.e., gender; sexual orientation) on pain severity. The interaction terms in the third step were not significant and thus were dropped from the model. The first step with the main effects (internalized stigma, age, gender, and sexual orientation) was significant, $R=.35$, $R^2=.11$, $p=.002$. However, the only variable that was associated with pain severity was sexual orientation, unstandardized $B=.20$, $b=.88$, $p<.001$, 95% CI [.40, 1.35], such that heterosexual individuals were more likely to report more pain (Table 2).

General discussion

In response to mixed evidence for an association between stigma and pain and a call in the behavioral sciences for conceptual replication studies²³, we used data from two separate cross-sectional studies of similar populations of PWH that used two different measures of stigma to test the association between HIV stigma and pain. We identified mixed evidence for a unique relationship between HIV stigma—measured by the Enacted Stigma Scale in Study 1 and Berger Internalized HIV Stigma Scale in Study 2—and pain (measured via the Brief Pain Inventory).

In Study 1, we observed a bivariate correlation between experiences of enacted HIV stigma and pain severity. There were no gender or sexual orientation differences in enacted stigma scores or reporting of pain but, women and those who were heterosexual did report more severe pain than did men and those who were LGBTQ. In Study 1 logistic regression models, individuals scoring higher on HIV enacted stigma were more likely to experience pain, but gender and sexual orientation were not associated with pain when in the model together (with age). We also found no interaction effects between gender or sexual orientation and enacted HIV stigma on pain. These findings extend previous research on the pain symptoms of PWH^{29,30}. Interestingly, both enacted stigma and sexual orientation was associated with pain severity in our linear regression.

In Study 2, we found no bivariate correlation between reports of internal HIV stigma and pain severity. There were no gender differences in internalized stigma (but those in the LGBTQ community did report more internalized stigma). There were no gender or sexual orientation differences in reporting of pain, but women and those who were heterosexual did report more severe pain than did men and those who were LGBTQ. In our Study 2 logistic regression models, individuals scoring higher on HIV internal stigma were not more likely to experience pain, and again, gender and sexual orientation were not associated with pain when in the model together (with age). Despite not conceptually replicating the effect of enacted stigma on pain using the internalized stigma measure, sexual orientation was associated with pain severity in our Study 2 linear regression.

This finding was counter to our hypotheses. Previous studies have indicated that sexual and gender diverse individuals have increased risk of physical health conditions³¹ and experience worst health-related quality of life³² compared to their counterparts. Although our findings do not comport well with this literature, instead suggesting there could be heightened risks for pain among heterosexual individuals, it is important to note that both Studies 1 and 2 comprise samples of PWH. Subgroups of PWH experience different likelihoods of outcomes like depression³³, health disparities³⁴, and now, perhaps pain. The finding that heterosexual PWH experience more pain than their LGBTQ counterparts may warrant further investigation (e.g., among heterosexual

women with HIV).

We might not have conceptually replicated findings across studies for a few reasons. First, in Study 1, we had a large sample ($N=840$), which provided adequate power to detect the small relationship between enacted stigma and pain. In Study 2, the sample was smaller ($N=309$). The effect size in Study 1 was small ($\beta=-.12$), so it is possible that our Study 2 was not sufficiently powered to detect such an effect. Second, we did not examine comorbidities, and these may contribute to differences between study findings. Third, the type of stigma measure used may have played a role. For example, from research in other domains we know that both enacted and internalized HIV stigma are related to lower quality of life, but that enacted stigma is directly correlated with lower quality of life, whereas the relationship between internalized stigma and quality of life was mediated by social identity³⁵. It could be the case that there is a direct relationship between enacted stigma and pain and perhaps an indirect relationship between internalized stigma and pain. We found a significant relationship between enacted stigma and pain, but not internalized stigma, possibly because experiencing pain is so closely related to feelings of rejection from others. This inconsistency suggests the importance of replication in health research—both exact and conceptual. These conceptual replications highlight the fact that measurement of HIV stigma arguably lacks a uniform framework³⁵. Future work should aim to understand the ontogeny of the stigma that PWH experience.

Future directions

Previous work has documented that stigma predicts adverse health outcomes and lower qualities of life^{35–37}. Moreover, in a descriptive study that focused on the different predictors that explain pain levels associated with lower quality of life, one significant variable was experience with complicated social relationships³⁸. While we did not directly measure downstream quality of life, we conceptually replicated the first part of this descriptive finding that complex relationships leading to adverse health outcomes by observing a significant, albeit small, relationship between enacted stigma and pain in Study 1. If both stigma and subsequent pain are arguably related to quality of life, results from Study 1 (i.e., that enacted HIV stigma is related to pain) may provide useful information for understanding the quality of life among PWH. Besides the physical symptoms that interfere with everyday life, managing pain symptoms and the myriad of health complications can decrease quality of life³⁸. If stigma is associated with experiencing pain, future interventionists might create stigma-related programs for healthcare professionals and PWH that could help reduce stigma and its association with pain experiences, thereby improving quality of life.

Moreover, the relationship between stigma and pain has significant implications for pain management and interventions. The precise management of pain and chronic pain in PWH needs to address the various factors that could lead to pain³⁶. Stigma could be one consideration. In Study 1, we observed no interaction effects for gender or sexual orientation. Therefore, our results tentatively have general applications to multiple groups of PWH. However, when designing novel interventions targeting pain, understanding how those with HIV experience enacted stigma and from whom is important. That is, being judged by a romantic partner compared to a health care provider could lead to different reactions and therefore need specific intervention considerations.

Although living with a chronic illness can increase pain, PWH are at risk of also experiencing a stigma related to experiencing pain and pain management³⁸. Patients who express pain or have a substance use disorder are at risk of being judged by various healthcare professionals. Based on the increased risk of experiencing various forms of stigma throughout treatment, future research should begin to implement a form of health care and pain management that is de-stigmatizing.

Future directions and limitations

The research here provides evidence of our social systems' physical manifestations, but we only examined enacted and internalized stigma. Other types of HIV stigma including anticipated stigma (perceived stigma) should also be examined to fully assess the relationship between stigma and pain among PWH. Moreover, other forms of stigma, like those related to sexual and gender identity, should be examined to fully understand the relationship between stigma and pain. Depending on the individual, stigma associated with gender or sexual orientation might be stronger than the stigma associated with HIV. Moreover, future studies might consider the changing climate surrounding media exposure (e.g., U=U campaigns) and social support of certain groups with HIV, which may have an impact on internalized stigma.

We assessed different groups of people (e.g., men compared to women; LGBTQ compared to heterosexual individuals), however, there are many intersectional groups that we did not assess due to statistical power³⁹. For instance, gay men of color or gay women of color might experience an exacerbated effect of stigma on pain. This intersectionality has been observed in other studies—different members of minoritized groups with HIV experience a greater likelihood of depression³³ and other health disparities³⁴. Specifically, transgender men and women are understudied groups at high risk for experiencing stigma. However, there were only 17 transgender people in Study 1 and only 4 transgender women in Study 2. Several participants skipped some stigma and pain questions, so statistical comparisons were not conducted. As can be seen in descriptive summary of Table 1, enacted stigma and pain severity scores among the transgender individuals in Study 1 look lower than among cisgender counterparts, but due to low sample size, statistical comparisons were not conducted. In Study 2,

internalized stigma scores seemed similar to cisgender scores provided, and pain severity scores looked lower, but again, statistical analysis could not be conducted.

Additionally, health-related stigma may also be an area of fruitful future research. For example, PWH might experience chronic pain, and may have to navigate the feelings of stigma concerning their pain management along with HIV stigma. Researchers and clinicians might consider incorporating stigma measures into their research and practices, with the end-goal of improving pain management. Moreover, we did not assess whether our participants were currently dealing with other chronic or acute issues that may be related to pain. Other limitations in this study are the assessment of pain and HIV progression. This includes the etiology, site, maintenance, and cause of pain the type of medication administered, and any substance use. We assessed pain using the Brief Pain Inventory (BPI). Typically, the BPI includes a pain mannequin for indicating the location of painful areas, and a section regarding current pain treatment approaches and perceived efficacy, as well as some questions regarding pain interference. However, these measures were not included in the BPI in both studies. Future research should begin to understand other comorbidities of HIV and their relation to pain. Similarly, we did not have access to viral suppression data. This is an essential factor to consider in future research because stigma is related to lower odds of being virally suppressed⁴⁰.

Finally, in Study 2, our participants were enrolled in a cannabis study and used cannabis which could have influenced our results as well. PWH have reported using cannabis to mitigate pain⁴¹. Indeed, more than a quarter of people with HIV report using cannabis to treat symptoms like muscle pain, nerve pain, and depression⁴², suggesting cannabis use among PWH may function to alleviate pain. Thus, PWH in Study 2 could be treating pain with cannabis, and future research should test the interaction between cannabis use and stigma.

Disclosures

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CRediT authorship contribution statement

James Moran was involved in conceptualization, methodology, software, formal analysis, writing – original draft. Miranda Arnold was responsible for software, validation, formal analysis, data curation, writing – review & editing, visualization. Robert Cook was involved in conceptualization, conducted the investigation, provided validation, resources, data curation, supervision, project administration, and funding. Was involved in writing – original draft, writing – review & editing. Jeff Boissoneault, was involved in conceptualization, writing – original draft, writing – review & editing. Deepthi S. Varma was involved in conceptualization, writing – review & editing. Yan Wang was involved in conceptualization, writing – review & editing. Liana S. E. Hone was supervised conceptualization, methodology, software, validation, formal analysis, data curation, visualization; and provided resources, supervision, project administration, and funding.

Declaration of Generative AI and AI-assisted technologies in the writing process

No AI was used during the preparation of this work.

Declaration of Competing Interest

Authors declare that they have no conflict of interest

Data Availability

Data are available from the Southern HIV Alcohol Research Consortium on request.

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