

Understanding the Association of Internalized HIV Stigma with Retention in HIV Care

Eduardo Valverde^{1*}, Allan Rodriguez², Becky White³, Ying Guo⁴ and Drenna Waldrop-Valverde⁵

¹Division of Global HIV and TB, Centers for Disease Control and Prevention, Georgia

²Division of Infectious Diseases, University of Miami Miller School of Medicine, USA

³Division of Infectious Diseases, University of North Carolina at Chapel Hill, USA

⁴Department of Biostatistics, Rollins School of Public Health, Emory University, Georgia

⁵Nell Hodgson Woodruff School of Nursing, Emory University, Georgia

*Corresponding author: Eduardo Valverde, Division of Global HIV and TB, Centers for Disease Control and Prevention, Atlanta, Georgia, Tel: 404-639-2048; Fax Number: 404-639-8105; E-mail: evalverde@cdc.gov

Received: 01 Sep, 2018 | Accepted: 26 Sep, 2018 | Published: 04 Oct, 2018

Citation: Valverde E, Rodriguez A, White B, Guo Y, Waldrop-Valverde D (2018) Understanding the Association of Internalized HIV Stigma with Retention in HIV Care. *J HIV AIDS* 4(3): dx.doi.org/10.16966/2380-5536.159

Copyright: © 2018 Valverde E, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Abstract

Internalized HIV stigma plays a detrimental role in terms of linkage to HIV care and adherence to antiretroviral treatment. Yet, little is known regarding the association of internalized HIV stigma with retention in HIV care. We conducted an analysis of interview and medical record abstraction data collected from 188 HIV positive men and women receiving HIV care in Miami, Florida. Demographic characteristics, HIV risk behaviors and care related factors were used to explore the association of internalized HIV stigma with retention in care in a Poisson regression analysis. The relationship of internalized HIV stigma and retention in care was moderated by the patient's level of engagement with an HIV care provider ($p=0.004$) in that higher levels of provider engagement were significantly associated with higher retention in care rates among patients with moderate levels of internalized HIV stigma. Additionally, retention in care rates were lower for females than for males and for 18-44 year olds than for individuals 44 years and older. Our findings indicate that higher levels of patient-provider engagement may reduce the impact that internalized HIV stigma has on retention in HIV care for some patients. Interventions with HIV care providers or patients to enhance patient-provider engagement may be beneficial.

Keywords: Internalized HIV Stigma; Retention in HIV Care

Background

According to current estimates, almost 50% of individuals diagnosed and living with HIV are not retained in care in the United States [1]. Having HIV-infected individuals not retained in medical care can complicate HIV care and impact HIV prevention. Infected individuals not in care do not have access to HIV medications and other medical services, which can prevent diseases associated with HIV infection. Those who access care again, at a later stage in their disease, have a higher probability of negative clinical outcomes including death [2-3]. In addition, some studies have suggested that individuals who exhibit poor retention in care behaviors also engage in increased HIV transmission risk behaviors [4]. Models developed to estimate the rate and number of HIV transmissions from HIV-infected persons in the United States along each step of the HIV care continuum show that persons diagnosed with HIV, but not retained in care, were responsible for over 90% of HIV transmissions in 2009 [5].

Internalized HIV stigma has recently emerged as a potential individual level factor that may contribute to poor retention in HIV care. Ervin Goffman defined stigma as a deeply discrediting

attribute that reduces the bearer from a whole and usual person to a tainted, discounted one with a spoiled identity [6]. Link and Phelan conceptualized stigmas occurring *via* five processes: 1-people distinguish and label human differences; 2-the dominant cultural beliefs link labeled persons to negative stereotypes; 3-labeled persons are placed in distinct categories so they can be separated; 4-labeled persons experience status loss and discrimination that leads to unequal outcomes (including health outcomes), and finally; 5-the dominant group's power allows the stigmatization to become established in society [7].

Link advanced the idea that unequal outcomes among the stigmatized may occur without actual discrimination. In a "modified labeling theory" looking at the effects of stigma on people with mental illnesses [8], Link postulated that individuals would develop conceptions about a particular stigmatized behavior or condition as part of the socialization process that is constantly occurring within a culture. Once these conceptions of what it means to have a particular stigma become established as a lay theory, people will form expectations as to whether individuals possessing the stigma will be rejected by others. These expectations become particularly important

for those who have or acquire the stigma because the possibility of devaluation and discrimination becomes personally relevant. As Link would describe it, if one believes that, others will devalue and reject people because they possess a particular stigma, one must now fear that this rejection applies personally. Link presented the idea that patients who had been hospitalized for mental illnesses acted less confidently and more defensively, or simply avoided potentially threatening contact altogether because they were expecting and fearing rejection from others.

Internalized HIV stigma operates in a similar manner. More than 30 years into the HIV epidemic, individuals in society have developed a particular conception of what it means to be HIV positive. This conception has become part of the socialization process that is constantly occurring within societies. Given the negative connotations of this conception in our society, for many affected by HIV the possibility of devaluation, rejection and discrimination has become personally relevant. Entering HIV care has become for many, a step into fully confronting this stigmatized condition, and individuals may respond by withdrawing from care if they expect and fear rejection from others, particularly from those that are supposed to care for them. For HIV infected individuals in care, HIV care providers are an essential component of their social network. HIV care providers make the difference between a healthy life, infirmity, or even death. Perceptions of stigmatization by health care providers and how this stigmatization has negatively impacted accessing HIV care, HIV medication adherence and clinical outcomes (such as lower CD4 counts), has already been reported by HIV positive individuals [9-11]. These reports underscore that, at least in some instances related to HIV care, stigma is already playing an important role in the patient-provider interaction, leading to negative health behaviors and outcomes.

Given that almost 80% of patients in HIV care in the United States have reported some level of internalized HIV stigma [12], it is important to understand what are the factors associated with this phenomenon. Internalized HIV stigma has been associated with a variety of factors and negative outcomes among HIV positive individuals in the United States such as food insecurity [13], depression [13], delays in accessing HIV medical care [14] and HIV medication non-adherence [15]. Yet current research on internalized HIV stigma and retention in HIV care has produced mixed findings, with some studies reporting that internalized HIV stigma does not predict poor retention in care [16,17], while other studies report a significant association between higher levels of internalized HIV stigma and low retention in care [11,18]. None of these studies assessed the role that the patient-provider relationship plays in the associations between internalized HIV stigma and retention in HIV care.

This analysis seeks to not only confirm an association between internalized HIV stigma with retention in HIV care, but also following Link's premise that patient's expectations of relationships with others may influence clinical adherence behaviors, explore whether the patient-provider relationship affects this association. Understanding whether this is the case will help us develop better interventions to improve retention in HIV care.

Methods

The present study was a secondary data analysis conducted from a larger study of 210 HIV positive men and women receiving care at two South Florida clinics: The Special Immunology Clinic at the University of Miami/Jackson Memorial Hospital and the Borinquen Community Health Center. The parent study, conducted between May

2009 and May 2011, was designed to test the effects of health literacy and neurocognitive function on adherence to routine HIV care visits. The parent study included a baseline face-to-face study visit and a follow-up study visit, 28-weeks post-baseline. During these face-to-face interviews, demographic surveys, psychosocial questionnaires, and neuropsychological tests were administered. In addition, medical record data was obtained retrospectively, 14-months prior to each participant's final study visit. For the present study, data from demographic surveys and psychosocial questionnaires at the follow-up visit as well as medical record data on the number of scheduled medical visits missed were included.

Clinic patients were recruited through active referrals from clinic staff and through passive referrals *via* study flyers. Research recruiters were available in clinic for in-person eligibility screening and interested patients were also screened *via* the telephone. Inclusion/exclusion criteria for eligibility included ability to communicate comfortably in English, attending at least one routine HIV care appointment in the prior 28-weeks, no psychotic illnesses, and no reported episodes of loss of consciousness >30 minutes. After screening and provision of informed consent, medical data was verified *via* medical records. Patients who were deemed eligible for the study were scheduled for a baseline study visit that took place in a private research office not located in the recruiting clinics. Written informed consent procedures were followed prior to initiation of study activities. Follow-up study visits were completed 28-weeks post-baseline in the same location. Each face-to-face study visit lasted approximately two hours; participants were compensated for their time. Due to the likelihood of low literacy among study participants, the study interviewer read aloud all questions and responses, and marked the appropriate response in the questionnaires. The study was approved by the University of Miami's Institutional Review Board.

A total of 325 individuals were screened for the study; 210 participants completed baseline interviews and 188 completed 28-week post-baseline study interviews. Data from these 188 participants are used for the current analyses.

Dependent variable measure

The simplest and most widely used way of measuring retention in care is by counting missed clinic visits, regardless of how many visits were scheduled [19]. Missed visits were calculated as a count or the total number of scheduled visits that were missed (or no-shows) irrespective of the number of visits that were scheduled. Visits that were "cancelled" or "rescheduled" (by either patient or clinic) were not characterized as missing and were not included in the dependent variable measure.

Independent variables

Internalized HIV stigma: The 13-item HIV Stigma Scale was developed by Sowell et al., [20], and further validated by Emlet and colleagues for use with adults living with HIV/AIDS [21]. Construct validity was addressed for the overall 13-item scale and the correlations were as expected with higher scores representing higher levels of stigma.

Patient-Provider Relationships: The association of patient-provider relationship with retention in care was measured using the Engagement with Healthcare Provider Scale [22]. In this 13-item scale, higher scores indicate less engagement with providers.

Covariates

Social Support: Social support was assessed using the available Social Support subscale from the Social Support Questionnaire developed by

Zich and Temoshok [23]. This scale consists of eight items that assess four types of support that may have been received since acquiring HIV: 1. How desirable the type of support would be at this time in your life, 2. How available this type of support would be if you wanted it, 3. How often you have experienced this type of support since you were diagnosed with HIV, and 4. How useful this type of support has been when you have received it. The current study included the eight items assessing available social support. Scores range from 8 to 40 with higher scores indicating greater levels of available support.

Depression: The Center for Epidemiological Studies-Depression 10 (CES-D10) was used to measure current depressive symptomatology. Scores range from 0 to 30, with a score of ≥ 10 indicative of significant depressive symptoms [24].

Demographic characteristics included, sex, race/ethnicity, age, education, marital status, and sexual orientation, while health care related variables included time in HIV care, whether participant was taking ART, and time to travel to the clinic.

Statistical analysis

Summary statistics are provided for variables of interest including demographic and clinical characteristics describing the study sample. Bivariate analyses were conducted in order to examine factors associated with the number of missed clinic visits. Given the categorical and count nature of some variables in this analysis, associations between the retention in HIV care variable and independent variables were assessed using the Spearman rank correlation. The multivariate model included all demographic, covariate, and independent variables identified in the Spearman rank correlation to be associated at $p < 0.10$ with the dependent variable.

AA multivariate Poisson Regression model was used to test the relationship of the independent variables on missed clinical visits. After testing the association of internalized HIV stigma with missed clinic visits, we tested whether the engagement with provider construct moderated the relationship between internalized HIV stigma and retention in care. Results of this moderating effect are shown for pre-specified values that present scenarios when engagement with provider is equal to the first quartile (Low), second quartile (Moderate) or third quartile (High) of internalized HIV stigma scores. All statistical analyses were conducted using SAS software, Version 9.3 (Cary, NC.) and assessed at the $\alpha = 0.05$ significance level.

Results

Sample characteristics

Demographic characteristics of the study sample are presented in table 1. Of the 188 participants that completed the follow-up interview, the majority (54%) were female (2 participants identified as transgender were not included in analyses because no meaningful gender analysis could be done with only 2 participants), forty-five years old or older (74%), never married (55%), had used alcohol or non-injection drug use in the past 14 months (55%) and African American (83%). Forty-eight percent of participants had less than a high school degree. Of male participants, 30% identified as homosexual or bisexual.

The mean time since HIV diagnosis was 12.6 years. Participants took an average of 43.9 minutes (SD 30.6) to travel to the clinic for their HIV medical appointments. Ninety-five percent of participants reported taking antiretroviral medications. Sixty percent of participants had undetectable viral load. Of the 188 participants, 86% missed at least one HIV medical visit during the 14-month observation period. The mean number of missed appointments was 3.7 (SD 3.4, range 1-16).

Independent variables results

The 13-item HIV Stigma Scale had a good internal consistency reliability (Cronbach's $\alpha = 0.880$). The mean internalized HIV stigma score was 21.1 (SD 7.8). Only 16% of the sample reported experiencing no internalized HIV stigma at all, while 35% of the sample scored higher than the mean.

The average score on the Engagement with Healthcare Provider Scale was 16.2 (out of a range of 13 to 44). Since lower scores reflect better engagement, overall this sample was quite engaged with their provider. In this sample, the Cronbach's coefficient alpha for the Engagement with Healthcare Provider scale was good at 0.77.

The mean score for available social support for the sample was 32.3 (SD 7.0) with a range from 11 to 40. The scale showed good reliability in the current sample (Cronbach's $\alpha = 0.887$). The Center for Epidemiological Studies-Depression 10 scale had good internal consistency reliability (Cronbach's $\alpha = 0.827$). The mean depression score for the sample was 10.1 (SD 6.2). As previously noted a score of ≥ 10 is indicative of clinically significant depressive symptoms. Based on this cutoff, half of the sample had clinically significant depressive symptoms.

Results of the bivariate analysis

Results from the Spearman correlation analysis indicated that number of missed clinic visits was correlated at $p < 0.10$ with gender and age, while the main independent variable, Internalized HIV stigma, was correlated with depression, social support, and engagement with provider (Table 2).

Results of the multivariate analysis

Results from the Poisson regression analysis (Table 3) on the missed clinic visits count indicated that the model explained a significant amount of variance in missed clinic visits ($R^2 = .15$, $p < 0.001$). The Poisson regression analysis on the missed clinic visits count indicated that the adjusted incidence rate ratio for sex suggested that missed clinic visits were 74.9% higher (95% C.I. (1.480-2.045), $p < 0.001$) for females than for males. Likewise the adjusted incidence rate ratio for age suggested that missed clinic visits were 38.3% higher (95% C.I. (1.185-1.626), $p < 0.001$) for 18-44 year olds than for individuals 44 years and older in our sample.

The Poisson Regression model also revealed that the relationship of internalized HIV stigma and missed clinic visits was moderated by the level of engagement with the medical provider ($p = 0.004$) in that, for subjects with low and moderate internalized HIV stigma scores, lower levels of provider engagement were significantly associated with increases in missed clinic visits incidence rate.

Discussion

The purpose of the present study was to test whether internalized HIV stigma was associated with retention in HIV care and whether the patient-provider relationship influenced this association. Our findings indicate that, for patients like the ones in our study (84% reporting some level of internalized HIV stigma), the level of engagement with the medical provider moderates the association between internalized HIV stigma with retention in HIV care. Our results indicated that higher engagement with a provider is associated with better retention in care in patients reporting low to medium levels of internalized HIV stigma. However, for subjects with high-internalized HIV stigma, even a high level of engagement with a provider was not significantly associated with reductions in missed clinic visits.

Table 1: Demographic and clinical characteristics for study participants (N=188).

Characteristic (variable name)	Frequency	Percent (%)	Range	Mean (SD)
Sex				
Male	86	46	-----	-----
Female	102	54	-----	-----
Age			24-70	47 (7.4)
18-44	49	26	-----	-----
45 and above	139	74	-----	-----
Marital Status				
Never married/single	102	55	-----	-----
Married/living with partner	27	14	-----	-----
Divorced/separated/widow/widower	59	31	-----	-----
Race/Ethnicity				
White	9	5	-----	-----
African American	156	83	-----	-----
Hispanic	18	10	-----	-----
Other	5	2	-----	-----
Education				
Grades 1-8	20	11	-----	-----
Grades 9-11	70	38	-----	-----
12 or GED	65	34	-----	-----
Any college	33	17	-----	-----
Sexual Orientation				
Gay/Bisexual	30	16	-----	-----
Heterosexual	158	84	-----	-----
Admitted to mental health care in past 14 months				
Yes	9	5	-----	-----
No	179	95	-----	-----
Injection drug use ever				
Yes	33	18	-----	-----
No	155	82	-----	-----
Alcohol or non-injection drug use past 14 months				
Yes	103	55	-----	-----
No	85	45	-----	-----
Depression past 30 days	-----	-----	0-25	10.1(6.2)
Available Social Support	-----	-----	11-40	32.3(7.0)
Engagement with Healthcare Provider	-----	-----	13-44	16.2(5.4)
Internalized HIV Stigma	-----	-----	13-46	21.1 (7.8)
Time since diagnosis (days)	-----	-----	0-37	12.6 (7.4)
Currently taking ART				
Yes	179	95	-----	-----
No	9	5	-----	-----
Time to travel to the clinic (minutes) Viral Load	-----	-----	3-120	43.9(30.6)
Suppressed	113	60	-----	-----
Not Suppressed	75	40	-----	-----
Number of Missed clinic visits	-----	-----	0-16	3.6 (3.4)

Our findings corroborate the relationship found by others [11,18], but differ from those that found no association between internalized HIV stigma and retention in HIV care [16,17]. This may be for several reasons. The composition of our sample differed from that of studies finding no association. While our sample was comprised of a majority of heterosexual men and women, other studies finding no association recruited a significant number of men who have sex with men (50% & 100% vs. 16%). This implies that the impact of internalized HIV stigma on retention in HIV care may depend on the composition of the patient population. Baugher and colleagues also reported that homosexual men and women (as opposed to heterosexual men and women) reported significantly lower levels of internalized stigma [12].

More research in this area is warranted to understand if populations that have been stigmatized for other conditions are more resilient, and whether this resiliency is buffering the negative impact of internalized HIV stigma on retention in care, or if there are circumstances related to the HIV care that these populations receive, such as better services or better patient-provider interactions, that are the buffering elements. While sexual orientation may play a role in how internalized HIV stigma impacts retention in HIV care, no other study besides the present one has explored whether provider engagement affected the association. Our findings indicate that provider engagement is a key factor that needs to be considered when assessing the relationship of internalized stigma and retention in HIV care. Although no other

Table 2: Spearman Correlation Matrix for Characteristics Associated with Retention in HIV Care Measure.

Name	Missed clinic visits	Gender	Age	Marital	Race		Edu	Sex_orient	Mental Health		IDU ever	Non-inject	Depres	Available SocSup	Eng Provider	HIV_ Stigma	Time_ since_dx	ART _tx	Mins_ clinic	VL
					ethnic				ever											
Missed clinic visits	1	0.240**	-0.176**	0.018	-0.094	-0.107	0.067	0.064	-0.017	0.094	0.104	-0.01	0.087	-0.051	-0.048	-0.082	-0.114	0.075		
Gender	0.240**	1	-0.038	0.056	-0.097	0.018	0.081	-0.096	0.053	-0.146**	-0.055	0.132*	-0.039	-0.12	0.161**	-0.053	0.094	-0.102		
Age	-0.176**	-0.038	1	0.188**	-0.03	0.08	0.034	0.078	0.281**	0.006	-0.017	0.026	0.116	-0.023	0.178**	-0.134*	0.032	-0.046		
Marital	0.018	0.056	0.188**	1	-0.089	0.026	0.103	-0.054	-0.034	0.071	-0.087	0.032	-0.045	-0.088	-0.04	-0.089	-0.134*	0.041		
Raceethnic	-0.094	-0.097	-0.03	-0.089	1	-0.021	0.047	0.017	0.045	-0.001	0.139*	-0.155**	0.054	0.104	-0.154**	-0.143*	0.051	0.013		
Edu	-0.107	0.018	0.08	0.026	-0.021	1	-0.03	0.113	-0.087	-0.019	-0.052	-0.134*	-0.08	-0.05	-0.198**	-0.068	0.065	-0.031		
Sex_orient	0.067	0.081	0.034	0.103	0.047	-0.026	1	-0.038	0.087	-0.016	-0.063	-0.058	0.019	-0.108	-0.023	0.038	0.077	-0.024		
Mental Health	0.064	-0.096	0.078	-0.054	0.017	0.113	-0.04	1	0.025	0.005	0.239**	-0.178**	0.138*	0.062	0.007	0.05	0.02	-0.005		
IDU Ever	-0.017	0.053	0.281**	-0.034	0.045	-0.087	0.087	0.025	1	-0.015	-0.011	0.067	0.05	-0.116	0.174**	-0.025	0.039	0.04		
Non-inject	0.094	-0.146**	0.006	0.071	-0.001	-0.019	-0.02	0.005	-0.015	1	0.108	-0.125	0.161**	0.101	-0.051	-0.055	-0.003	0.133		
Depres	0.104	-0.055	-0.017	-0.087	0.139*	-0.052	-0.06	0.239**	-0.011	0.108	1	-0.353**	0.251**	0.458**	-0.135*	0.011	0.124*	0.018		
Available SocSup	-0.01	0.132*	0.026	0.032	-0.155**	-0.134*	-0.06	-0.178**	-0.353**	-0.125*	-0.353**	1	-0.377**	-0.357**	0.122*	-0.002	-0.084	0.016		
Eng Provider	0.087	-0.039	0.116	-0.045	0.054	-0.08	0.019	0.138*	0.05	0.161**	0.251**	-0.377**	1	0.253**	-0.053	0.015	-0.028	-0.091		
HIV_ Stigmatal	-0.051	-0.12	-0.023	-0.088	0.104	-0.05	-0.11	0.062	-0.116	0.101	0.458**	-0.357**	0.255**	1	-0.072	0.05	0.031	0.018		
Time_ since_dx	-0.048	0.161**	0.178**	-0.04	-0.154**	-0.198**	-0.02	0.007	0.174**	-0.051	-0.135*	0.122*	-0.053	-0.072	1	0.155**	0.02	0.167**		
ART_tx	-0.082	-0.053	-0.134*	-0.089	-0.143*	-0.068	0.038	0.05	-0.025	-0.055	0.011	-0.002	0.015	0.155**	0.155**	1	0.017	0.215**		
Mins_clinic	-0.114	0.094	0.032	-0.134*	0.051	0.065	0.077	0.02	0.039	-0.003	0.031	0.017	1	0.017	0.02	0.017	1	0.184**		
VL	0.075	-0.102	-0.046	0.041	0.013	-0.031	-0.02	-0.005	0.04	0.133	0.018	0.016	-0.091	0.018	-0.167**	-0.215**	0.184**	1		

Note 1: ** indicates p<0.05; * indicates p<0.10

Table 3: Multivariate Poisson Regression Model Assessing Factors Associated with Number of Missed Clinic Visits.

Characteristics	aIRR	95% CI	p value
Gender			<0.0001
Male	Ref	Ref	
Female	1.739	1.480-2.045	
Age			<0.0001
18-44	1.388	1.185-1.626	
45 and above	Ref	Ref	
Internalized HIV Stigma	1.053	1.012-1.096	0.009
Engagement with Provider	1.090	1.033-1.150	0.001
Internalized HIV Stigma * Engagement with Provider	0.996	0.994-0.999	0.004
Low Internalized HIV Stigma	1.033	1.013-1.053	0.001
Medium Internalized HIV Stigma	1.018	1.004-1.032	0.010
High Internalized HIV Stigma	0.9969	0.980-1.014	0.724

Note: Variables associated with appointment adherence and Number of Missed clinic visits at $p < 0.10$ in the Spearman Correlation analysis are included in the model as well as Engagement with Provider. aIRR: adjusted Incidence Rate Ratios

study has assessed this relationship, Katz and colleagues in a meta-analysis assessed the impact of HIV-related stigma on ART adherence and concluded that different aspects of the health system (both interpersonal and structural) potentially moderated the impact of HIV-related stigma on ART adherence [25]. They referred specifically to the perceived quality of the relationship with providers as key to foster better treatment adherence. This finding provides support to the notion that assessing interpersonal factors is key to understand HIV-related adherence behaviors.

For HIV-infected patients with characteristics similar to those in our sample (majority heterosexual, high rates of missed clinic visits, significant rates of viral failures, and 84% reporting some level of internalized HIV stigma), interventions that improve patient-provider relations should improve retention in care. Although we were unable to identify any interventions to improve patient-provider engagement in the HIV/AIDS area specifically, research in terms of improving patient engagement with a medical provider or a group of providers has been studied for many years and among a number of different patient populations. In a Cochrane review, Rolfe and colleagues examined ten randomized controlled trial interventions, all aiming at improving patients' relationships with their medical providers [26]. Among all the interventions assessed only three (one provider focused and two patient focused) proved to be effective. The provider focused intervention showed that patients whose oncologists were in a training program to improve communication skills reported higher trust in their oncologists than patients whose oncologists did not receive the training [27]. Findings from the patient focused interventions showed that patients who attended group educational visits reported an increase in provider trust compared to those who received usual care [28], and patients who were matched with their providers based on beliefs about care, were more likely to report greater overall satisfaction with their provider [29].

The previous interventions could be adapted to improve patient-provider engagement among HIV patients reporting moderate to low

levels of internalized HIV stigma. For example the patient focused intervention developed by Hsu and colleagues [29] could be easily implemented across clinics at minimal cost and could be implemented with all new patients to the clinic, while the intervention described by Tulsy and colleagues [27] could target a limited number of providers reducing the logistics of implementation and potentially the cost. Structural limitations such as provider time constraints and insurance requirements would need to be considered in the process of adaptation, but these limitations would not make it impossible for the adaptations to occur.

Yet, as previously mentioned, improving patient-provider relations may not be enough for patients with high levels of internalized stigma. For these patients, the priority is to decrease (or eliminate) the perceptions of stigma. Only one randomized control trial intended to reduce internalized HIV stigma and reporting positive outcomes has been tested in the last few years. Barroso and colleagues developed an intervention targeting HIV-infected minority women in the Southeastern United States [30]. Findings from their randomized controlled trial indicated that the intervention was successful in improving self-esteem and decreasing internalized stigma, as well as improving coping self-efficacy. Other interventions have also been tested, but found not to significantly reduce HIV-related stigma in the targeted population [31]. The fact that only one intervention to reduce internalized HIV stigma is currently available, highlights the urgent need to develop and test more interventions. Another approach to reduce internalized HIV stigma among patients could be to identify structural factors at the clinic level that could be changed to reduce provider-stigmatizing attitudes. Stringer and colleagues identified several provider and clinic level factors that predicted provider-stigmatizing attitudes [32]. One of their main findings was that lack of enforcement of discriminatory practices at the clinic level predicted stigmatizing attitudes among providers. Based on the finding they recommended that policies prohibiting discrimination by HIV care providers be enforced.

Limitations

The findings from the present study are subject to several limitations. First, study participants were a convenience sample of patients recruited from a publicly funded adult HIV clinic located in Miami, Florida; therefore, they are not representative of the larger population of HIV/AIDS patients in the United States. Nonetheless, our sample may reflect experiences of HIV infected individuals attending publicly funded health facilities who have similar characteristics. Second, findings from our analysis explained 15% of the variance of the retention in care measure, signifying that other constructs need to be assessed to fully understand what impacts retention in HIV care. Third, the study was not powered to explore whether sexual orientation or race/ethnicity were factors affecting retention in care. Future studies should explore how MSM stigma or perceptions of racial discrimination interact with internalized HIV stigma, and how this affects retention in care. Finally, data from this sample was collected eight years ago. It is possible that the experience of stigma and relatedly, the relationship with providers, could have evolved over this period, although to our knowledge, no interventions to reduce internalized HIV stigma or improve patient-provider relationships have been implemented in the clinic where this study was conducted.

Conclusion

Our findings report, for the first time a significant association between internalized HIV stigma with retention in care moderated by the level of patient-provider engagement, signifying that the patient-provider relationship needs to be considered when assessing the

relationship between internalized HIV stigma and retention in HIV care. Furthermore, our findings indicate that to improve retention in care among HIV positive individuals who experience low to moderate levels of internalized HIV stigma, we need to improve the patient-provider relationship by creating new or adapting existing patient and provider focused interventions designed to improve patient-provider engagement. However, for patients experiencing higher levels of internalized HIV stigma, directly targeting reductions in internalized HIV stigma may be necessary as well as enforcing policies prohibiting discriminatory practices in HIV clinics.

References

- Paltiel AD, Walensky RP, Schackman BR, Seage GR 3rd, Mercincavage LM, et al. (2006) Expanded HIV screening in the United States: effect on clinical outcomes, HIV transmission, and costs. *Ann Intern Med* 145: 797-806.
- Smit C, Hallett TB, Lange J, Garnett G, de Wolf F (2008) Late entry to HIV care limits the impact of anti-retroviral therapy in The Netherlands. *PLoS One* 3: e1949.
- Parienti JJ, Massari V, Descamps D, Vabret A, Bouvet E, et al. (2004) Predictors of virologic failure and resistance in HIV-infected patients treated with nevirapine- or efavirenz-based antiretroviral therapy. *Clin Infect Dis* 38: 1311-1316.
- Metsch LR, Pereyra M, Messinger S, del Rio C, Strathdee S, et al. (2008) HIV transmission risk behaviors among HIV-infected persons who are successfully linked to care. *Clin Infect Dis* 47: 577-584.
- Skarbinski J, Rosenberg E, Paz-Bailey G, Hall I, Rose C, et al. (2015) Human Immunodeficiency Virus Transmission at Each Step of the Care Continuum in the United States. *JAMA Intern Med* 175: 588-596.
- Goffman E (1963) *Stigma: Notes on the Management of Spoiled Identity*. Simon and Schuster, USA.
- Link BG, Phelan JC (2001) Conceptualizing Stigma. *Annu Rev Sociol* 27: 363-385.
- Link B, Struening E, Dohrenwend B, Cullen P, Francis T, et al. (1989) A Modified Labeling Theory Approach to Mental Disorders: An Empirical Assessment. *American Sociological Review* 54: 400-423.
- Sayles JN, Ryan GW, Silver JS, Sarkisian CA, Cunningham WE (2007) Experiences of social stigma and implications for healthcare among a diverse population of HIV positive adults. *J Urban Health* 84: 814-828.
- Eaton LA, Driffin DD, Kegler C, Smith H, Conway-Washington C, et al. (2015) The role of stigma and medical mistrust in the routine health care engagement of black men who have sex with men. *Am J Public Health* 105: e75-e82.
- Earnshaw VA, Smith LR, Chaudoir SR, Amico KR, Copenhaver MM (2013) HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. *AIDS Behav* 17: 1785-1795.
- Baughar AR, Beer L, Fagan JL, Mattson CL, Freedman M, et al. (2017) Prevalence of Internalized HIV-Related Stigma Among HIV-Infected Adults in Care, United States, 2011-2013. *AIDS Behav* 21: 2600-2608.
- Palar K, Frongillo EA, Escobar J, Sheira LA, Wilson TE, et al. (2018) Food Insecurity, Internalized Stigma, and Depressive Symptoms Among Women Living with HIV in the United States. *AIDS Behav*: 1-10.
- Sayles JN, Wong MD, Kinsler JJ, Martins D, Cunningham WE (2009) The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS. *J Gen Intern Med* 24: 1101-1118.
- Turan B, Smith W, Cohen MH, Wilson TE, Adimora AA, et al. (2016) Mechanisms for the negative effects of internalized HIV-related stigma on antiretroviral therapy adherence in women: the mediating roles of social isolation and depression. *J Acquir Immune Defic Syndr* 72: 198-205.
- Wohl AR, Galvan FH, Myers HF, Garland W, George S, et al. (2011) Do social support, stress, disclosure and stigma influence retention in HIV care for Latino and African American men who have sex with men and women? *AIDS Behav* 15: 1098-1110.
- Traeger L, O'Cleirigh C, Skeer MR, Mayer K, Safren S (2012) Risk factors for missed HIV primary care visits among men who have sex with men. *J Behav Med* 35: 548-556.
- Rice WS, Crockett KB, Mugavero MJ, Raper JL, Atkins GC, et al. (2017) Association Between Internalized HIV-Related Stigma and HIV Care Visit Adherence. *J Acquir Immune Defic Syndr* 76: 482-487.
- Mugavero MJ, Davila JA, Nevin CR, Giordano TP (2010) From access to engagement: measuring retention in outpatient HIV clinical care. *AIDS Patient Care STDS* 24: 607-613.
- Sowell RL, Lowenstein A, Moneyham L, Demi A, Mizuno Y, et al. (1997) Resources, stigma, and patterns of disclosure in rural women with HIV infection. *Public Health Nurs* 14: 302-312.
- Emler C (2005) Measuring stigma in older and younger adults with HIV/AIDS: An analysis of an HIV stigma scale and initial exploration of subscales. *Res Soc Work Pract* 15: 291-300.
- Bakken S, Holzemer WL, Brown M, Powell-Cope GM, Turner JG, et al. (2000) Relationships between perception of engagement with health care provider and demographic characteristics, health status and adherence to therapeutic regimen in persons with HIV/AIDS. *AIDS Patient Care and STDs* 14: 189-197.
- Zich J, Temoshok L (1987) Perceptions of social support in men with AIDS and ARC: relationships with distress and hardness. *J Appl Soc Psych* 17: 193-215.
- Andersen EM, Malmgren JA, Carter WB, Patrick DL (1994) Screening for depression in well older adults: evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). *Am J Prev Med* 10: 77-84.
- Katz IT, Ryu AE, Onuegbu AG, Psaros C, Weiser SD, et al. (2013) Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *J Int AIDS Soc* 16: 18640.
- Rolfe A, Cash-Gibson L, Car J, Sheikh A, Mc Kinstry B (2014) Interventions for improving patients' trust in doctors and groups of doctors. *Cochrane Database Syst Rev* 3: CD004134.
- Tulsky JA, Arnold RM, Alexander SC, Olsen MK, Jeffreys AS, et al. (2011) Enhancing communication between oncologists and patients with a computer-based training program. *Ann Intern Med* 155: 593-601.
- Clancy DE, Cope DW, Magruder KM, Huang P, Salter KH, et al. (2003) Evaluating group visits in an uninsured or inadequately insured patient population with uncontrolled type 2 diabetes. *The Diabetes Educator* 29: 292-302.
- Hsu J, Schmittiel J, Krupat E, Stein T, Thom D, et al. (2003) Patient choice: A randomized controlled trial of provider selection. *J Gen Intern Med* 18: 319-325.
- Barroso J, Relf MV, Williams MS, Arscott J, Moore ED, et al. (2014) A randomized controlled trial of the efficacy of a stigma reduction intervention for HIV-infected women in the Deep South. *AIDS Patient Care STDS* 28: 489-498.
- Rao D, Kemp CG, Huh D, Nevin PE, Turan J, et al. (2018) Stigma Reduction Among African American Women With HIV: UNITY Health Study. *J Acquir Immune Defic Syndr* 78: 269-275.
- Stringer KL, Turan B, Mc Cormick L, Durojaiye M, Nyblade L, et al. (2016) HIV-Related Stigma Among Healthcare Providers in the Deep South. *AIDS Behav* 20: 115-125.