



HIV-related Stigma, Personal Mastery, Mindfulness, and Social Support in Older Adults Living with HIV in Coachella Valley, California

Mariam Davtayan¹ · Annie L. Nguyen² · Jeff Taylor³ · Chris Christensen³ · Brandon J. Brown⁴

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Abstract

Half of individuals currently living with HIV in the US are older adults (age 50 years and older). Despite increases in lifespan, this population continues to experience HIV-related stigma, which is linked to poor clinical and social outcomes. Reduction efforts have expanded to focus on psychosocial factors that may offer protection against stigma. In this study, we estimated the prevalence of HIV-related stigma and examined its association with demographic, HIV-disease, and psychosocial factors, including personal mastery, mindfulness and social support in older adults living with HIV (OALWH). Coachella Valley, California. The study was approved by the Health Sciences Campus Institutional Review Board of the University of Southern California. OALWH from local AIDS service organizations completed a one-time in-person 30-min survey. No incentives were provided. Data analysis included descriptive statistics, ANOVA, and simple linear regressions. Data were analyzed using RStudio, version 4.0.2. Between August and October of 2019, thirty-two ($N=32$) OALWH completed the survey. The mean age of participants was 62.96 years and majority self-identified as white (84%), male (91%), gay (80%), and retired (48%). The prevalence of HIV-related stigma was 6% and there was a statistically significant relationship between HIV-related stigma and ethnicity, with Hispanics/Latinos reporting higher mean stigma scores ($p = 0.043$). Additionally, we observed a statistically significant relationship between HIV-related stigma and personal mastery ($p=0.002$), as well as HIV-related stigma and mindfulness ($p = 0.014$). Larger studies are needed to assess the role of psychosocial factors and the specific pathways by which they offer protection against HIV-related stigma in OALWH.

Keywords HIV stigma · Personal mastery · Mindfulness · Social support · Older adults living with HIV

Extended author information available on the last page of the article

Introduction

In 2018, more than half of people living with HIV (PLWH) in the United States (US) were 50 years of age and older, and this number is expected to increase substantially in the next few years (HIV and Older Americans, 2020; National HIV/AIDS and Aging Awareness Day Sept 18, 2015). The primary reasons for this demographic shift have been the effectiveness of antiretroviral medications (ARTs), accurate testing, and early diagnosis (Wing, 2017). Despite these milestones, older adults living with HIV (OALWH) continue to face significant barriers to optimal health, including HIV-related stigma. Stigma associated with HIV refers to exclusionary attitudes and behaviors directed towards PLWH and those presumed to be living with HIV and is associated with innumerable negative outcomes (Herek et al., 1998).

Approximately 70% of OALWH report experiencing HIV-related stigma (Emllet, 2006a). Furthermore, studies of OALWH have linked HIV-related stigma to disclosure difficulties, loneliness, depression, and internalized shame (Cahill & Valadéz, 2013; Grov et al., 2010; Payne Foster & Gaskins, 2009; Vanable et al., 2006). A mixed-methods study of 25 OALWH conducted in the Pacific Northwest region of the US found that HIV-related stigma was positively associated with depression, and that study participants frequently experienced rejection, disclosure concerns, stereotyping, protective silence, and feeling “othered” (Emllet, 2007). A cross-sectional study of 124 OALWH conducted in rural Namibia found that internalized HIV-related stigma (negative self-perception) was associated with higher levels of depression (Kalomo et al., 2020). A descriptive phenomenological study of 20 OALWH conducted in South Africa found that HIV-related stigma dissuaded serostatus disclosure to manage stigma, maintain privacy, and achieve some level of normalcy (Hlongwane & Madiba, 2020).

The existing body of knowledge on HIV-related stigma has established that it is a pervasive and debilitating social phenomenon in the lives of PLWH, including OALWH. It is also well-known that biomedical advances in HIV treatment and management have extended the life expectancy of PLWH, making this population vulnerable to stigma at multiple points in their life course. To improve quality of life and outcomes among PLWH, it is critical to identify factors that can mitigate the harmful effects of stigma. Fortunately, in recent years, the scholarship on HIV-related stigma has focused on internal and external psychological and social resources that may be protective against the injurious effects of HIV-related stigma. Such factors include personal mastery, mindfulness, and social support, which are theoretically and empirically linked to HIV-related stigma.

Personal mastery is defined as “the extent to which one regards one’s life-chances as being under one’s own control in contrast to being fatalistically ruled” (Pearlin & Schooler, 1978). Additionally, personal mastery is a protective internal psychological resource that prevents substantial distress resulting from exposure to HIV-related stigma (Emllet et al., 2013; Rueda et al., 2012). A study of 378 OALWH found that increased personal mastery was associated with

diminished enacted, internalized, and anticipated stigma (Emlet et al., 2013). A study of 825 PLWH showed that personal mastery moderated the negative effects of HIV-related stigma on depressive symptoms (Rueda et al., 2012).

Mindfulness is “a state of being attentive to and aware of what is taking place in the present” (Emlet et al., 2013). Moreover, mindfulness or acting with awareness and self-compassion, serves as a buffer in the relationship between self-stigmatization (internalized HIV-related stigma) and negative outcomes, by enhancing one’s perceived well-being (Brown & Ryan, 2003; Yang & Mak, 2017). While the impact of mindfulness on HIV-related stigma in OALWH is understudied, a few studies have shown its potentially therapeutic properties in other groups of PLWH. A study of 137 trauma-exposed PLWH found that internalized HIV-related stigma was associated with severe post-traumatic stress disorder symptoms and re-experiencing them and acting with mindfulness alleviated these symptoms (Gonzalez et al., 2016). A thematic content analysis of 20 youth living with HIV found that mindfulness-based training offered relief from the pressure of HIV as a stigmatized condition and improved ART adherence (Kerrigan et al., 2018).

Social support encompasses the assistance and protection given to individuals, which may include emotional, instrumental, informational, and appraisal (Langford et al., 1997). Provisions of social support as posited by the Social Support Theory, can help mitigate the effects of HIV-related stigma by changing the way that PLWH construe discrimination so that it is less destructive (Galvan et al., 2008). Research indicates that OALWH experience more loneliness and social isolation (Emlet, 2006b). A study of 378 OALWH found that emotional and informational social support was protective against multiple types of HIV-related stigma (Emlet et al., 2013). Similarly, a study of 914 OALWH found that among participants who self-identified as socially isolated, having lower levels of assistance, and lower perceptions of quality social support, there were greater levels of HIV-related stigma and psychological distress (Brennan-Ing et al., 2017).

To contribute to the existing literature on HIV-related stigma and its relationship to psychosocial characteristics such as personal mastery, mindfulness, and social support, we conducted a pilot study evaluating these factors in OALWH residing in Coachella Valley, California. This geographical region is home to more than 60% of all PLWH in Riverside County, the fourth largest county in California, and a quarter of PLWH who are at least 60 years of age (Brown et al., 2018).

The specific objectives of this study were to estimate the prevalence of HIV-related stigma and to examine its association with demographic, HIV-disease, and psychosocial factors. The current study is being expanded to include a larger sample size of OALWH and a comparison group of older adults not living with HIV. Here, we report findings from the pilot phase.

Methods

Ethical Considerations

This study was approved by the Health Sciences Campus Institutional Review Board of the University of Southern California under Exempt research. A study information sheet (informed consent for Exempt research) was provided to each prospective participant. Once the prospective participant read and acknowledged the study information sheet listing the study purpose and procedures, risks and benefits, privacy and confidentiality, the voluntary nature of participation in research and the investigator and IRB contact information, and verbally agreed to participate in the current study, he/she/they were administered the study survey. No personal identifiable information was collected from participants, and participants were not paid for completing the study survey.

Participant Recruitment

To be eligible for this study, prospective participants had to be living with HIV, aged 50 and older, able to complete the study survey in English, reside in Coachella Valley, California, and provide informed consent. The study included a convenience sample of OALWH residing in Coachella Valley, recruited by members of the HIV + Aging Research Project in Palm Springs (HARP-PS), California from local AIDS service organizations and community events. HARP-PS members, who were themselves OALWH, developed and disseminated a study flyer and helped administer the study survey. HARP-PS is a non-profit organization that aims to improve the lives of OALWH with evidence-based research and services (About Us, [2021](#)).

Data Collection

The study survey took approximately 30 minutes to complete and included items appraising demographic, HIV-disease, and psychosocial characteristics. The explanatory variables of interest were self-reported age, sexual orientation, race, ethnicity, gender identity, marital status, living arrangement, income, education, employment, disability, years living with HIV, viral load, history of AIDS diagnosis, personal mastery, mindfulness, and social support. The outcome variable of interest was HIV-related stigma. HIV-related stigma was measured with the abridged 12-item Berger HIV Stigma scale (Reinius et al., [2017](#)). Response categories included “Strongly Disagree-1,” “Disagree-2,” “Agree-3,” and “Strongly Agree-4” on a 4-point Likert scale. The score range for the HIV stigma scale was 12–48, with higher scores indicating higher levels of HIV-related stigma, based on four domains including personalized stigma, disclosure concerns, concerns with public attitudes, and negative self-image. Personal mastery was appraised with the 7-item Pearlin Mastery Scale with “Strongly Disagree-1,” “Disagree-2,” “Agree-3,” and “Strongly Agree-4” as the response categories on a 4-point Likert scale (Pearlin & Schooler, [1978](#)). The

score range for the personal mastery scale was 7–28, with higher scores indicating higher levels of perceived control over life events. Mindfulness was assessed with the 15-item Mindful Attention Awareness Scale with “Almost always-1,” “Very frequently-2,” “Somewhat frequently-3,” “Somewhat infrequently-4,” “Very infrequently-5,” and “Almost never-6” as the response categories on a 6-point Likert scale (Yang & Mak, 2017). The score range for the mindfulness scale was 1–6 based on the mean of each scale item, with higher means indicating higher mean levels of awareness and attention to what is taking place in the present. Social support was evaluated with the 8-item modified Medical Outcomes Study Social Support questionnaire with “None of the above-1,” “A little of the time-2,” “Some of the time-3,” “Most of the time-4,” and “All of the time-5” as the response categories on a 5-point Likert scale (Moser et al., 2012). The score range for the social support scale was 8–40, with higher scores indicating higher levels of emotional and instrumental social support.

Data Analysis

Data were analyzed using RStudio version 4.0.2. Descriptive statistics were utilized to summarize demographic, HIV-disease and psychosocial characteristics and included means, medians, standard deviations, and frequencies. To estimate the prevalence of HIV-related stigma, all 12 items of the HIV stigma scale were added together to form a cumulative HIV stigma score. We then combined the percentages of the “Strongly Agreed” and “Agreed” responses. To assess the association of the categorical demographic and HIV-disease explanatory variables with the continuous HIV-related stigma outcome variable, we employed ANOVA tests. To assess the relationship between the continuous explanatory variables (i.e., age, years living with HIV, personal mastery, mindfulness, and social support) and the continuous HIV-related stigma outcome variable, we conducted simple linear regressions. Statistical significance was evaluated at the $p < 0.05$ level.

Results

Between August and October 2019, thirty-two ($n = 32$) OALWH completed the study survey. The mean age of respondents was 62.96 years and majority self-identified as white (84%), non-Hispanic/Latino (84%), male (91%), gay (80%), retired (48%), with an undetectable viral load (97%), and history of AIDS diagnosis (69%). Other demographic and disease-related characteristics are summarized in Table 1.

The overall prevalence of HIV-related stigma was 6% in this population of OALWH. The mean HIV stigma score was 27.09 (SD = 5.57, min 13, max 40); the mean personal mastery score was 20.75 (SD = 4.08, min 10, max 20); the mean mindfulness score was 4.04 (SD = 0.86, min 2.4, max 6); and the mean social support score was 22.19 (SD = 9.4, min 10, max 40) (Table 1). A statistically significant association was observed between HIV-related stigma and ethnicity, with those

Table 1 Participant demographic, HIV-disease, and psychosocial characteristics

Variable	(N, %)
Age (mean, median, SD)	62.96 years, 65 years, 7.44
Years since HIV diagnosis (mean, median, SD)	27.89 years, 32 years, 9.57
Sexual Orientation	24 (80) Gay 3 (10) Bisexual 2 (7) Queer
Race	1 (3) Heterosexual 26 (84) White 2 (6) Black 1 (3) American Indian 1 (3) Asian 1 (3) Other
Ethnicity	23 (85) Non-Hispanic/Latino 4 (15) Hispanic/Latino
Gender Identity	29 (91) Male 3 (9) Female
Marital Status	19 (59) Single/Never Married 6 (19) Divorced 5 (16) Married/domestic partner 2 (6) Widowed
Living Arrangement	21 (68) Alone 7 (23) Spouse/Partner 2 (6) Roommate 1 (3) Friends
Annual Income	10 (33) < \$20,000 15 (15) \$20,000-\$49,999 3 (10) \$50,000-\$99,999 2 (7) \$100,000 +
Educational Level	13 (41) Some College 7 (22) College Degree 6 (19) Graduate Degree 4 (13) Professional Degree 2 (6) High School
Employment Status	15 (48) Retired 12 (39) Employed 3 (10) Unable to work 1 (3) Unemployed
Disability	13 (41) No 19 (59) Yes
Undetectable Viral Load	1 (3) No 31 (97) Yes
History of AIDS Diagnosis	10 (31) No 22 (69) Yes

Table 1 (continued)

Variable	(N, %)
HIV-related Stigma (mean, median, SD)	27.09, 27.00, 5.57
Personal Mastery (mean, median, SD)	20.75, 20.50, 4.08
Mindfulness (mean, median, SD)	4.04, 4.07, 0.86
Social Support (mean, median, SD)	22.19, 20.50, 9.42

self-identifying as Hispanic/Latino reporting higher mean stigma scores compared to non-Hispanics/Latinos (32.75 vs. 26.57 respectively; $p=0.043$) (Table 2). No other demographic or HIV-disease variables were significantly associated with HIV-related stigma. There was a statistically significant relationship between personal mastery and HIV-related stigma such that with one unit increase in personal mastery, there was an average decrease of 0.72 in HIV-related stigma ($p=0.002$) (Table 2). Similarly, there was a statistically significant relationship between mindfulness and HIV-related stigma in that with one unit increase in mindfulness, there was an average decrease of 2.78 in HIV-related stigma ($p=0.014$) (Table 2). There was no statistically significant relationship between social support and HIV-related stigma.

Discussion

The current study examined the relationship between HIV-related stigma and demographic, HIV-disease, and psychosocial characteristics in a small sample of OALWH residing in Coachella Valley, California. The prevalence of HIV stigma

Table 2 Associations between HIV-related stigma and demographic and psychosocial characteristics

ANOVA Results:

HIV-Related Stigma and Ethnicity					
	Df	Sum Sq	Mean Sq	F value	Pr(> F)
ETHNICITY	1	130.3	130.34	4.55	0.043*
RESIDUALS	25	716.4	28.66		
Linear Regression Results:					
HIV-related stigma and personal mastery					
	Estimate	Std. Error	t value	Pr(> F)	
INTERCEPT	41.9425	4.4895	9.342	2.18e-10*	
PERSONAL MASTERY	-0.7156	0.2124	-3.369	0.00209*	
HIV-related stigma and mindfulness					
	Estimate	Std. Error	t value	Pr(> F)	
INTERCEPT	38.334	4.395	8.722	9.99e-10*	
MINDFULNESS	-2.781	1.064	-2.613	0.0139*	

* $p < 0.05$

was low (6%) and there was a statistically significant association between HIV-related stigma and ethnicity, with those self-identifying as Hispanic/Latino exhibiting higher mean stigma scores compared to non-Hispanics/Latinos. Additionally, we found a statistically significant relationship between personal mastery and HIV-related stigma, as well as mindfulness and HIV-related stigma.

The low prevalence of HIV-related stigma in this sample of OALWH may be attributed to the study's geographical region, which houses a significant population of older people living with HIV, who are presumably well-integrated. Additionally, manifestations of HIV-related stigma among the study sample may have evolved such that the stigma scale used was unable to capture the depth and breadth of HIV-related stigma unique to OALWH.

Higher levels of HIV-related stigma among Hispanic/Latino participants vs. Non-Hispanic/Latino participants that we observed in this study is supported by existing studies conducted among other groups of PLWH and not specifically among OALWH. A study of intersectionality of marginalized group identities and enacted HIV-related stigma among PLWH in Florida (US) found that non-white Latinos had higher odds of experiencing high levels of stigma compared to white non-Latinos (Algarin et al., 2019). Similarly, in a study of internalized HIV-related stigma in a cohort of US patients in HIV care found that racial and ethnic minorities (African Americans and Latinos) had higher mean stigma scores which were in turn associated with concurrent viremia and poor retention in care (Christopoulos et al., 2019). These findings illustrate that additional work may be needed to ascertain the extent of HIV-related stigma among OALWH who self-identify as Hispanic/Latino.

The significant negative relationship between personal mastery and HIV-related stigma that we found in this study is also congruent with the available literature. A study of OALWH in Ontario, Canada found that having greater personal mastery was associated with lower levels of HIV-related stigma (Emlet et al., 2013). A similar study of PLWH also in Ontario, Canada found that mastery moderated the negative effects of HIV-related stigma on depressive symptoms (Brown & Ryan, 2003). These studies highlight two important factors. First, personal mastery appears to be a protective factor against HIV-related stigma. Second, additional studies are needed to examine the potentially beneficial role of personal mastery in reducing HIV-related stigma among US-based OALWH.

We observed a significant negative relationship between mindfulness and HIV-related stigma. There appears to be very little published on the relationship between mindfulness and HIV-related stigma among OALWH. However, there are several studies that report the beneficial role of mindfulness in decreasing HIV-related stigma in other impacted populations, including youth and trauma-exposed adults living with HIV (Gonzalez et al., 2016; Yang & Mak, 2017). A different study of the interaction of mindfulness-based attention and awareness and HIV-related stigma on anxiety symptoms also found that those who demonstrated lower levels of disengagement coping with stigma and higher levels of mindfulness reported the lowest levels of anxiety symptoms (Kerrigan et al., 2018). Despite the dearth of studies on mindfulness and HIV-related stigma in OALWH, its therapeutic effects among PLWH are somewhat established. Additional work is warranted to examine

the specific pathways by which mindfulness can be protective against HIV-related stigma in OALWH.

The current study offers important insights on HIV-related stigma among OALWH and how it relates to demographic, HIV-disease, and psychosocial factors. However, the following limitations must be considered. First, the sample size of the study population is small, limiting its statistical power and generalizability. Second, the sample consisted predominantly of white, gay, and male participants residing in a region with a substantial population of OALWH whose experiences may differ from other OALWH. Third, the validated scales used to measure our domains of interest (i.e., HIV-related stigma, personal mastery, mindfulness, and social support) may not have captured the full complexity of and nuances within participant experiences.

Conclusions

The current pilot study appraised the association of demographic, HIV-disease, and psychosocial characteristics with HIV-related stigma among OALWH residing in Coachella Valley, California. Larger studies of US-based OALWH are necessary to examine how HIV-related stigma relates to internal resources such as personal mastery and mindfulness. Further work is also required to assess the mechanisms and pathways by which personal mastery and mindfulness may provide protection against HIV-related stigma. Finally, given that HIV-related stigma varies across populations and over time, it is critical to develop and validate contemporaneous HIV-related stigma measurement tools salient to the experiences of OALWH.

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Availability of Data and Material The data that support the findings of this study are available on request from the corresponding author, (MD).

Code Availability The statistical codes used to analyze the study data are available on request from the corresponding author, (MD).

Declarations

Informed Consent Each participant was asked to acknowledge a Study Information Sheet before participating in this study. A study information sheet is the informed consent for Exempt research. This document listed the purpose of the study, study procedures, risks/benefits, privacy/confidentiality, voluntary nature of participation and IRB and investigator contact information.

Ethical Treatment of Experimental Subjects (Animal and Human) The study was approved by the Health Sciences Campus Institutional Review Board of the University of Southern California under Exempt research. Exempt research studies are studies that do not collect any personal identifiable information from participants and therefore do not require a signed informed consent. Instead, a study information

sheet is given. The ethical considerations section of the manuscript was slightly revised to ensure that this information was clear.

Conflicts of Interest The authors have no conflict of interest to disclose.

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Mariam Davtyan, PhD, MPH: Dr. Davtyan is an Assistant Professor at the Keck School of Medicine of the University of Southern California. Her research focuses on HIV-related stigma and its impact on social and clinical outcomes and understanding the mechanisms by which wellness factors such as personal mastery, mindfulness, and social support can reduce stigma and improve quality of life among people living with HIV.

Annie L. Nguyen, PhD, MPH: Dr. Nguyen is an Assistant Professor at the Keck School of Medicine of the University of Southern California. Her research focuses on strategies and behaviors for healthy aging for people living with HIV.

Jeff Taylor: Mr. Taylor is the Executive Director of the HIV+Ageing Research Project Palm Spring (HARP-PS), which conducts patient-centered, community-based research on aging and HIV in California's Coachella Valley.

Chris Christensen: Mr. Christensen is a Project Assistant at the HIV+Ageing Research Project Palm Springs (HARP-PS), an organization that supports long-term HIV survivors to live a high-quality life despite their chronic HIV infection.

Brandon J. Brown, PhD, MPH: Dr. Brown is an Associate Professor of Medicine at the University of California, Riverside School of Medicine who conducts community-based participatory research. His research interests focus on HIV and aging, and decision making for participant payment in clinical HIV studies.

Authors and Affiliations

Mariam Davtyan¹  · **Annie L. Nguyen²** · **Jeff Taylor³** · **Chris Christensen³** · **Brandon J. Brown⁴**

✉ Mariam Davtyan
mdavtyan@usc.edu

¹ Department of Pediatrics, Maternal, Child & Adolescent/Adult Center for Infectious Diseases and Virology, Keck School of Medicine, University of Southern California, Los Angeles, CA, United States

² Department of Family Medicine, Keck School of Medicine, University of Southern California, Alhambra, CA, United States

³ HIV+Aging Research Project-Palm Springs, Palm Springs, CA, United States

⁴ Center for Healthy Communities, Department of Social Medicine, Population and Public Health, University of California Riverside School of Medicine, Riverside, CA, United States