HHS Public Access

Author manuscript

AIDS Care. Author manuscript; available in PMC 2017 June 01.

Published in final edited form as:

AIDS Care. 2016 June ; 28(6): 717–721. doi:10.1080/09540121.2015.1124978.

Stigma, Activism, and Well-Being among People Living with HIV

Valerie A. Earnshaw,

Center for Interdisciplinary Research on AIDS, Yale University, New Haven, USA; Division of General Pediatrics, Department of Medicine, Boston Children's Hospital, Boston, USA; Department of Pediatrics, Harvard Medical School, Boston, USA, Address: Boston Children's Hospital, General Pediatrics BCH 3201, Attn: Valerie Earnshaw, Boston, MA 02115, Phone: 1 (857) 218-5577

Lisa Rosenthal, and

Center for Interdisciplinary Research on AIDS, Yale University, New Haven, USA; Department of Psychology, Pace University, New York, USA, Address: 41 Park Row, 13thFloor, Room 1317; New York, NY, USA 10037, Phone: 1 (212) 346-1784

Shawn M. Lang

Center for Interdisciplinary Research on AIDS, Yale University, New Haven, USA; AIDS Connecticut, Hartford, USA, Address: 110 Bartholomew Avenue, Suite 3050, Phone:1 (860) 247-2437

Valerie A. Earnshaw: valerie.earnshaw@childrens.harvard.edu; Lisa Rosenthal: lrosenthal@pace.edu; Shawn M. Lang: slang@aids-ct.org

Abstract

Evidence demonstrates that HIV stigma undermines the psychological and physical health of people living with HIV (PLWH). Yet, PLWH describe engaging in HIV activism to challenge stigma, and research suggests that individuals may benefit from activism. We examine associations between experiences of HIV stigma and HIV activism, and test whether HIV activists benefit from greater well-being than non-activists. Participants include 93 PLWH recruited from drop-in centers, housing programs, and other organizations providing services to PLWH in the Northeastern U.S. between 2012 and 2013 (mean age=50 years; 56% Black, 20% White, 18% Other; 61% non-Latino(a), 39% Latino(a); 59% male, 38% female, 3% transgender; 82% heterosexual, 15% sexual minority). Participants completed a cross-sectional written survey. Results of regression analyses suggest that PLWH who experienced greater enacted stigma engaged in greater HIV activism. Anticipated, internalized, and perceived public stigma, however, were unrelated to HIV activism. Moreover, results of a multivariate analysis of variance suggest that HIV activists reported greater social network integration, greater social well-being, greater engagement in active coping with discrimination, and greater meaning in life than non-activists. Yet, HIV activists also reported somewhat greater depressive symptoms than non-activists, suggesting that the association between HIV activism and well-being is complex. By differentiating between HIV stigma mechanisms, the current study provides a more nuanced understanding of which experiences of HIV stigma may be associated with HIV activism. It further suggests that engagement in activism may offer benefits to PLWH, while raising the

Correspondence to: Valerie A. Earnshaw, valerie.earnshaw@childrens.harvard.edu.

possibility that activists could experience greater depressive symptoms than non-activists. Given the preliminary nature of this study, future research should continue to examine these complex associations between HIV stigma, activism, and well-being among PLWH. As this work continues, PLWH, as well as interventionists and clinicians invested in improving well-being among PLWH, should carefully weigh the benefits and potential costs of activism.

Keywords

activism; depressive symptoms; people living with HIV; stigma; well-being

Introduction

HIV continues to be stigmatized, or socially devalued and discredited (Goffman, 1963), in the U.S. and worldwide. Evidence suggests that this societal stigma undermines the well-being of people living with HIV (PLWH), including psychological (e.g., depressive symptoms, stress) and physical (e.g., lower CD4 count, greater HIV symptoms) health (Logie & Gadalla, 2009). Yet, individuals' responses to stigma may determine whether they are negatively impacted by stigma. Research and theory suggests that activism is one response (Siegel, Lune, & Meyer, 1998), and that such empowered responses to stigma may have positive implications for individuals (Shih, 2004).

PLWH describe engaging in activism as a response to societal stigma (Siegel et al., 1998; Stanley, 1999), which enables them to challenge and resist societal stigma (including advocating for policy change), and to empower themselves and others (Brashers, Haas, Neidig, & Rintamaki, 2002; Deacon, 2006; Siegel et al., 1998; Stanley, 1999). PLWH may be motivated to engage in activism following personal experiences of stigma, including enacted stigma (past or present experiences of discrimination; e.g., being fired or not promoted), anticipated stigma (future expectations of discrimination; e.g., receiving poor healthcare), and internalized stigma (devaluation of the self; Earnshaw & Chaudoir, 2009). PLWH may also perceive public stigma, or recognize that societal stigma exists, without personally experiencing stigma (Bos, Pryor, Reeder, & Stutterheim, 2013). Enacted, anticipated and perceived public stigma may motivate engagement in HIV activism to challenge stigma and/or empower PLWH. Anticipated stigma may also be a barrier if individuals fear HIV activism will lead to discrimination (Cain et al., 2014), and internalized stigma may act as a barrier if individuals feel stigma is justified

Activism may also contribute to activists' well-being. PLWH describe benefits of activism, including connection to supportive social networks, and a sense of purpose and power (Siegel et al., 1998; Stanley, 1999). Activist PLWH employ more problem-focused coping and have greater HIV social network integration (i.e., greater connection to others living with HIV; Brashers et al., 2002). Other types of activists also experience greater well-being, including greater meaning in life, social integration, and positive affect (Klar & Kasser, 2009). Although most research suggests that activists enjoy greater psychological well-being, some work finds that activism is not statistically associated with depressive symptoms (Gilster, 2012).

In the current investigation, we differentiate between enacted, anticipated, internalized, and perceived public stigma to understand which experiences of stigma are associated with HIV activism. We control for collectivist identification with PLWH, or the extent to which individual PLWH view themselves as belonging to a larger group of PLWH, given that collective identification appears to play a key role in activism (Simon et al., 1998). We then explore whether HIV activists report greater well-being, as indicated by greater social network integration, social well-being, active coping with discrimination, and meaning in life, and lower depressive symptoms.

Methods

Procedure and Participants

Participants were recruited between November 2012 and April 2013 from drop-in centers, housing programs, and other organizations providing services to PLWH. Clients were eligible if they were HIV-positive, English-speaking, and 18 years or older. Interested clients met with research assistants at recruitment sites. Ninety-three PLWH provided consent, completed the paper-and-pencil survey, and were compensated $25 each. Participant sociodemographic characteristics reflect those of recruitment sites (Table 1). All procedures received approval from the Yale University Institutional Review Board.

Measures

Participants first reported socio-demographic characteristics. *HIV activism* was measured using the eight-item Activist Identity and Commitment Scale (Klar & Kasser, 2009), tailored to HIV activism (α=0.95). The scale includes items measuring identification as an HIV activist (e.g., “I identify myself as an HIV/AIDS activist”) and engagement in HIV activism (e.g., “I go out of my way to engage in HIV/AIDS activism”).

Enacted, anticipated, and internalized stigma were measured using the 28-item HIV Stigma Mechanism measure (Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013) (enacted α=0.82, e.g., “Family members have avoided me;” anticipated α=0.92, e.g., “Healthcare workers will not listen to my concerns;” internalized α=0.93, e.g., “I feel ashamed of having HIV”). Perceived public HIV stigma was assessed with the item “Overall, how do people in your community feel towards people who are HIV positive?”, with response options ranging from “very negative” to “very positive.” *Collective identification with PLWH* was measured with five items adapted from a scale designed to capture collective identification with older people (Simon et al., 1998) and gay people (Simon, Stürmer, & Steffens, 2000; α=0.88).

Social network integration was measured with five items based on a measure introduced by Brashers and colleagues (2002; α=0.82). *Social well-being* was measured with a four-item scale developed by Keyes (1998) (α=0.73). *Active coping with discrimination* was measured with the Brief COPE (Carver, 1997), with 10 items adapted to refer to coping with enacted stigma using active coping, religion, emotional support, instrumental support, self-distraction, and venting (α=0.90). *Meaning in life* was measured with the three-item Meaning in Life Questionnaire: Short Form (Steger, Frazier, Oishi, & Kaler, 2006; Steger & Samman, 2012; α=0.91). *Depressive symptoms* were measured with the 15-item short form

of the CES-D (Andresen, Malmgren, Carter, & Patrick, 1994; Radloff, 1977), excluding items referring to somatic symptoms (α=0.84).

Results

Correlates of HIV activism were examined using linear and logistic regression to provide more robust findings (Table 2). Step 1 of the linear regression analysis included socio-demographic characteristics and accounted for 8% of the variance in activism (p=0.10). Socio-demographic characteristics were generally unrelated to activism, with the exceptions that participants identifying as LGBT and completing high school or more education identified and/or engaged less as activists. Step 2 of the analysis included stigma-related characteristics and accounted for an additional 28% of the variance in activism (p<.001). Participants who reported greater enacted stigma and participants who reported that they collectively identified more with other PLWH identified more as activists. Results of the logistic regression, in which socio-demographic and stigma-related characteristics predicted HIV activism split at four (indicating that participants agreed or strongly agreed with items), replicated associations between stigma-related characteristics and activism.

To protect against Type I errors resulting from running a series of ANOVAs on multiple outcomes, associations between HIV activist identity and well-being were examined using multivariate analysis of variance (Tabachnick & Fidell, 2007) (Table 3). HIV activists reported greater social network integration, greater social well-being, greater engagement in active coping with discrimination, and greater meaning in life than non-activists. HIV activists also reported greater depressive symptoms than non-activists. Effect sizes were medium for social network integration, social well-being, and active coping but small for meaning in life and depressive symptoms.

Discussion

Results suggest that stigma, activism, and well-being are associated among PLWH, but that these relationships are complex. First, enacted stigma was associated with activism, whereas anticipated, internalized, and perceived public stigma were not. Second, activists generally reported greater well-being than non-activists, including on indicators of social network integration, social well-being, engagement in active coping with discrimination, and meaning in life. Yet, activists also reported somewhat greater depressive symptoms, complicating the relationship between activism and well-being in this sample. It is possible that experiences of burnout among activists – involving emotional exhaustion, depersonalization, and diminished achievements – could lead to depressive symptoms (Gilster, 2012).

The current investigation adds to the literature on stigma, activism, and well-being among PLWH. By differentiating between stigma mechanisms, it provides a more nuanced understanding of which stigma experiences may be associated with activism. Results are consistent with work suggesting that past experiences of discrimination may be a key motivator of engagement in activism (Brashers et al., 2002; Deacon, 2006; Siegel et al., 1998; Stanley, 1999). Fears of future discrimination, awareness of societal stigma, and

internalized stigma may not motive or act as barriers to activism. Results further support findings suggesting that there are benefits and costs of activism (e.g, Gilster, 2012). Although the benefits appear promising, the potential cost of greater depressive symptoms are concerning given associations between depression with lower medication adherence and greater disease progression (Boarts, Sledjeski, Bogart, & Delahanty, 2006).

The current investigation is limited by its small and relatively homogeneous sample and should therefore be considered preliminary. PLWH accessing AIDS service organizations may be particularly marginalized in terms of socioeconomics, education, and other resources. Results may differ among participants recruited from other settings (e.g., LGBT and more educated PLWH may engage in more activism). Future research should examine these associations among larger and more diverse samples. Future work may also employ qualitative methods to investigate which experiences of stigma motivate which forms of activism. It may be important to study these associations using experimental and longitudinal methods, to better understand direction of effects and causal processes involved.

This work suggests that activism may offer benefits to PLWH who experience HIV stigma, including social well-being, connection with other PLWH, and a sense of purpose or meaning in life. Yet, this work also raises the possibility that activists could experience greater depressive symptoms than non-activists. As this possibility is further investigated, PLWH, as well as interventionists and clinicians invested in improving well-being among PLWH, may carefully weigh the benefits and potential costs of activism.

Acknowledgments

This work was supported by the National Institute of Mental Health under Grants P30MH02294 and T32MH020031; and the Agency for Healthcare Research & Quality under Grant K12HS022986. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Center for Interdisciplinary Research on AIDS or the National Institutes of Health. We are grateful to the Community Research Core at the Center for Research on AIDS, Margaret Lippitt and Harry Jin, and our community collaborators for their contributions to this work. We are also grateful to the participants of this study for sharing their experiences with us.

References

Andresen EM, Malmgren JA, Carter WB, Patrick DL. Screening for depression in well older adults: Evaluation of a short form of the CES-D. American Journal of Preventive Medicine. 1994; 10:77–84. [PubMed: 8037935]

Boarts JM, Sledjeski EM, Bogart LM, Delahanty DL. The differential impact of PTSD and depression on HIV disease markers and adherence to HAART in people living with HIV. AIDS and Behavior. 2006; 10:253–261. [PubMed: 16482405]

Bos AER, Pryor JB, Reeder GD, Stutterheim SE. Stigma: advances in theory and research. Basic and Applied Social Psychology. 2013; 35:1–9.

Brashers DE, Haas SM, Neidig JL, Rintamaki LS. Social activism, self-advocacy, and coping with HIV illness. Journal of Social and Personal Relationships. 2002; 19:113–133.

Cain R, Collins E, Bereket T, George C, Jackson R, et al. Challenges to the involvement of people living with HIV in community-based HIV/AIDS service organizations in Ontario, Canada. AIDS Care. 2014; 26:263–266. DOI: 10.1080/09540121.2013.803015 [PubMed: 23724932]

Carver CS. You want to measure coping but your protocol's too long: Consider the brief cope. International Journal of Behavioral Medicine. 1997; 4:92–100. DOI: 10.1207/s15327558ijbm0401_6 [PubMed: 16250744]

Deacon H. Towards a sustainable theory of health-related stigma: Lessons from the HIV/AIDS literature. Journal of Community & Applied Social Psychology. 2006; 16:418–425. DOI: 10.1002/casp.900

Earnshaw VA, Chaudoir SR. From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures. AIDS and Behavior. 2009; 13:1160–1177. DOI: 10.1007/s10461-009-9593-3 [PubMed: 19636699]

Earnshaw VA, Smith LR, Chaudoir SR, Amico KR, Copenhaver MM. HIV stigma mechanisms and well-being among PLWH: A test of the HIV stigma framework. AIDS and Behavior. 2013; 17:1785–1795. DOI: 10.1007/s10461-013-0437-9 [PubMed: 23456594]

Gilster ME. Comparing neighborhood-focused activism and volunteerism: Psychological well-being and social connectedness. Journal of Community Psychology. 2012; 40(7):769–784. [PubMed: 27087709]

Goffman, E. Stigma : notes on the management of spoiled identity. 1. New York: Simon & Schuster; 1963. Touchstone ed

Keyes CLM. Social well-being. Social psychology quarterly. 1998; 2:121–140.

Klar M, Kasser T. Some benefits of being an activist: Measuring activism and its role in psychological well-being. Political Psychology. 2009; 30(5):755–777.

Logie C, Gadalla TM. Meta-analysis of health and demographic correlates of stigma towards people living with HIV. AIDS Care. 2009; 21:742–753. DOI: 10.1080/09540120802511877 [PubMed: 19806490]

Radloff LS. The CES-D Scale: A self-report depression scale for research in the general population. Applied Psychological Measurement. 1977; 1:385–401. DOI: 10.1177/014662167700100306

Shih M. Positive stigma: Examining resilience and empowerment in overcoming stigma. The Annals of the American Academy of Political and Social Science. 2004; 591:175–185. DOI: 10.1177/0002716203260099

Siegel K, Lune H, Meyer IH. Stigma management among gay/bisexual men with HIV/AIDS. Qualitative Sociology. 1998; 21(1):3–24.

Simon B, Loewy M, Stürmer S, Weber U, Freytag P, Habig C, … Spahlinger P. Collective identification and social movement participation. Journal of Personality and Social Psychology. 1998; 74:646–658.

Simon B, Stürmer S, Steffens K. Helping individuals or group members? The role of individual and collective identification in AIDS volunteerism. Personality and Social Psychology Bulletin. 2000; 26:497–506.

Stanley LD. Transforming AIDS: The moral management of stigmatized identity. Anthropology & Medicine. 1999; 6:103–120.

Steger MF, Frazier P, Oishi S, Kaler M. The meaning in life questionnaire: Assessing the presence of and search for meaning in life. Journal of Counseling Psychology. 2006; 53(1):80.

Steger MF, Samman E. Assessing meaning in life on an international scale: Psychometric evidence for the Meaning in Life Questionnaire-Short Form among Chilean households. International Journal of Wellbeing. 2012; 2:182–195.

Tabachnick, BG.; Fidell, LS. Using Multivariate Statistics. Boston: Pearson; 2007.

Table 1

Participant characteristics

Characteristic	Total [%(n) or M(SD)]
Socio-Demographic	
Age	50.07 (8.60)
Race	
Black	55.9 (55)
White	19.4(18)
Other	18.3 (17)
Ethnicity	
Latino(a)	38.7 (36)
Non-Latino(a)	61.3 (57)
Gender	
Male	59.1 (55)
Female	37.6 (35)
Transgender	3.2 (3)
Sexual Orientation	
Heterosexual	81.7 (76)
Gay, Lesbian, and/or Bisexual	15.1 (14)
Education	
Less than HS Degree	35.5 (33)
HS degree or More	64.5 (60)
Years Living with HIV	18.11 (8.14)
HIV Activism	
Activism: Mean	3.13 (1.07)
Activism: Dichotomized at 4	
Yes	29.0 (27)
No	67.7 (63)
Stigma-Related	
Enacted Stigma	1.51 (0.69)
Anticipated Stigma	1.60 (0.81)
Internalized Stigma	2.03 (1.03)
Perceived Public Stigma	3.18 (1.13)
Collective Identification with PLWH	3.68 (0.96)
Well-Being	
Social Network Integration	3.44 (1.14)
Social Well-Being	3.61 (0.75)
Active Coping with Discrimination	2.96 (0.80)
Meaning in Life	3.96 (1.02)
Depressive Symptoms	15.69 (8.59)

Note: HIV activism; enacted, anticipated, internalized, and perceived public stigma; collective identification with PLWH; social network integration; social well-being; and meaning in life were measured on 1–5 point scales and averaged. Coping with discrimination was measured on a 1–4 point scale and averaged. Depressive symptoms were measured on a 0–3 point scale and summed.

Table 2

Results of regressions predicting HIV activism

	Linear Regression		Logistic Regression	
	B(SE)	***B***	**B(SE)**	**OR (95% CI)**
Step 1: Socio-Demographic Characteristics				
Age	0.01 (0.02)	0.07	−0.03 (0.04)	0.97 (0.89–1.05)
Black Race	0.33 (0.45)	0.15	−1.39 (0.98)	0.25 (0.04–1.69)
White Race	0.30 (0.47)	0.11	−2.02 (1.05)	0.13 (0.02–1.04)
Latino(a) Ethnicity	0.09 (0.39)	0.04	−1.05 (0.80)	0.35 (0.07–1.68)
Male Gender	0.08 (0.28)	0.04	−0.75 (0.64)	0.47 (0.14–1.64)
LGBT Sexual Orientation	−0.85 (0.38)	−0.27 *	0.93 (0.91)	2.53 (0.43–14.92)
HS Education or More	−0.63 (0.29)	−0.28 *	0.48 (0.62)	1.62 (0.48–5.51)
Years Living with HIV	−0.01 (0.02)	−0.10	0.04 (0.04)	1.04 (0.97–1.12)
Step 2: Stigma-Related and Other Characteristics				
Enacted Stigma	0.65 (0.26)	0.35 **	2.09 (0.96)	8.07 (1.24–52.71) *
Anticipated Stigma	−0.15 (0.21)	−0.11	−0.96 (0.80)	0.38 (0.08–1.85)
Internalized Stigma	−0.13 (0.12)	−0.13	0.35 (0.43)	1.41 (0.61–3.26)
Perceived Public Stigma	−0.08 (0.11)	−0.09	−0.37 (0.40)	0.69 (0.31–1.52)
Collective Identification with PLWH	0.59 (0.13)	0.49 **	1.74 (0.55)	5.67 (1.93–16.68) **

Note:

* p<0.05;

** p<0.01.

The presented regression parameters for socio-demographic characteristics were calculated in step 1, and those for stigma-related and other characteristics were calculated in step 2.

Table 3

Results of MANOVA, including estimated marginal means

	Activist	Non-Activist	MANOVA Results
Social Network Integration	4.20 (0.25)	3.08 (0.14)	$F(1,72)=14.99$, $\eta 2=0.20^{**}$
Social Well-Being	4.03 (0.17)	3.46 (0.17)	$F(1,72)=7.82$, $\eta 2=0.11^{**}$
Active Coping with Discrimination	3.53 (0.18)	2.81 (0.10)	$F(1,72)=11.53$, $\eta 2=0.16^{**}$
Meaning in Life	4.35 (0.25)	3.74 (0.14)	$F(1,72)=4.28$, $\eta 2=0.07^{*}$
Depressive Symptoms	20.22 (2.03)	14.68 (1.17)	$F(1,72)=5.28$, $\eta 2=0.08^{*}$

Note:

$^{*}p<0.05$;

$^{**}p<0.01$.

Analyses controlled for socio-demographic characteristics in Table 1.