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# HIV-related stigma and psychological distress: the harmful effects of specific stigma manifestations in various social settings

Sarah E. Stutterheim<sup>a</sup>, John B. Pryor<sup>b</sup>, Arjan E.R. Bos<sup>a</sup>,  
Robert Hoogendijk<sup>c</sup>, Peter Muris<sup>c</sup> and Herman P. Schaalma<sup>a,\*</sup>

**Objectives:** Recent research has shown that experiences of stigmatization have an adverse impact on the psychological well being of people living with HIV/AIDS (PLWHA). Most studies investigating this relationship employ an aggregate measure of stigma. Although this approach provides useful information about the psychological implications of HIV-related stigma in general, it neglects to acknowledge the possibility that some manifestations in specific settings may be psychologically more detrimental than others. The present study examines which specific stigma experiences are most strongly related to psychological distress across a number of social settings.

**Methods:** A cross-sectional survey was administered to 667 PLWHA in the Netherlands. We examined participants' experiences of 11 manifestations of HIV-related stigma in six social settings. Linear regression analyses were conducted to determine which setting-specific manifestations best predict psychological distress after controlling for marital status, education and health status.

**Results:** Three manifestations in family settings, namely receiving advice to conceal one's status, being avoided and being treated with exaggerated kindness, and one manifestation in healthcare settings, namely awkward social interaction, best predicted psychological distress in PLWHA.

**Conclusion:** Manifestations of HIV-related stigma vary according to setting. Certain manifestations in specific social settings impact the psychological well being of PLWHA more than others. In this study, certain experiences of stigmatization with PLWHA's families and in healthcare settings were more strongly related to psychological distress than experiences occurring in other social settings. These findings suggest that stigma reduction interventions focusing on these influential settings may benefit the psychological well being of PLWHA. © 2009 Wolters Kluwer Health | Lippincott Williams & Wilkins

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**Keywords:** AIDS, HIV, mental health, stigma

<sup>a</sup>Department of Work and Social Psychology, Maastricht University, Maastricht, The Netherlands, <sup>b</sup>Department of Psychology, Illinois State University, Normal, Illinois, USA, and <sup>c</sup>Institute of Psychology, Erasmus University Rotterdam, Rotterdam, The Netherlands.

Correspondence to Sarah E. Stutterheim, Department of Work and Social Psychology, Maastricht University, 6200 MD Maastricht, The Netherlands.

Tel: +31 43 3881401; e-mail: s.stutterheim@psychology.unimaas.nl

\* deceased.

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## Introduction

HIV-related stigma is a social phenomenon whereby a person is considered to possess a discrediting attribute and thus deemed tainted, spoiled or flawed by others [1–4]. HIV-related stigma can hamper HIV prevention efforts [5], inhibit treatment adherence [6–8], function as a barrier to HIV testing [9,10] and negatively impact social relationships and the psychological well being of people living with HIV/AIDS (PLWHA) [11–14]. In fact, research conducted in various countries, including South Africa [15], China [16], Peru [17] and the USA [18–22], has demonstrated that HIV-related stigma independently contributes to psychological distress over and above health status and HIV-related symptoms.

Stigmatizing reactions to PLWHA manifest in a number of ways across a range of settings. Relevant manifestations include avoidance, exclusion, rejection, isolation, social ostracism, blaming, violence, service denial, physical distance, indifference, awkward social interaction and being advised to conceal one's status [7,22–32]. Relevant settings are families, communities, friends or acquaintances, sexual relationships, healthcare settings, the housing sector, the financial services sector, religious institutions, while travelling or migrating, work and educational settings [7,15,24,26,27,29,32–37].

To our knowledge, no previous quantitative study has explored how particular manifestations in specific social settings impact the psychological well being of PLWHA. In fact, most studies investigating the psychological impact of HIV-related stigma employ an aggregate measure of stigma (e.g. HIV stigma scale [38] and AIDS-related stigma scale [39]). Although this approach provides useful information about the psychological implications of HIV-related stigma in general, it neglects to acknowledge the possibility that some manifestations in specific settings may be psychologically more detrimental than others. The present study examines which specific stigma experiences are most strongly related to psychological distress across a number of social settings.

## Methods

### Participants and procedures

All data were obtained from an anonymous national survey with PLWHA in the Netherlands. Participation was voluntary, informed consent was provided and no monetary compensation was involved. Following approval from Maastricht University's Ethics Committee, a total of 2264 surveys were distributed by the Dutch HIV Association ( $n = 1433$ ) and by HIV nurses ( $n = 823$ ). The surveys distributed by the HIV Association were sent by mail to all members in May 2007 with a reminder letter 4 weeks later. The surveys distributed by HIV nurses were handed out to patients during consultations

between June and September 2007. A total of 669 participants completed the survey (response = 29.5%). Of these, 468 were recruited by the HIV association (response = 32.7%) and 193 by HIV nurses (response = 23.5%). Three participants contacted the researchers directly for a survey. For five other participants, data on how they were recruited was missing. Two surveys were excluded from the analyses because the corresponding participants were outliers with respect to age (6 and 97 years), thus yielding a total of 667 participants.

Of these 667, 86.2% were men and 13.8% were women. Age ranged from 17 to 75 years with a mean age of 46.6 (SD = 9.6) years. Almost half (49.5%) had at least a Bachelor's degree, 31.0% had a high school diploma and some vocational training and 19.5% had a high school diploma or less. Furthermore, 68.3% had paid employment and 48.4% had a long-term partner. The majority defined themselves as gay (79.5%), and from Europe or North America (90.6%). Most participants (87.5%) had acquired HIV through sexual intercourse. The mean time since diagnosis was 8.75 (SD = 6.0) years.

### Measures

#### *HIV-related stigma*

Stigma manifestations were measured using an index developed by the authors (available upon request) following a review of the social stigma literature and a focus group with experts, PLWHA and service providers working with various PLWHA populations in the Netherlands. This index measured 11 manifestations across six social settings. The manifestations were increased physical distance, awkward social interaction, indifference, avoidance, blaming, exaggerated kindness, aggression, exclusion, excessive hygienic measures, being told to disclose one's status and being told to conceal one's status. The settings were friends, family, partner, healthcare sector, work and leisure activities. The questions were formatted such that participants first indicated whether they had experienced a given manifestation. They then indicated the settings in which that manifestation occurred. Participants were permitted to mark more than one setting.

#### *Psychological distress*

Psychological distress was measured using a validated version of the Mental Health Inventory, which measures depression, anxiety, positive affect and behavioral control [40]. The scale comprises 18 items, all of which are answered on a six-point scale ranging from one (none of the time) to six (all of the time). A higher score is indicative of more psychological distress. Cronbach's  $\alpha$  was 0.94.

#### *Demographic and background characteristics*

Demographic characteristics measured included sex, age, educational attainment, employment, marital status, sexual orientation and ethnic background. Other background characteristics measured included the mode by which one

acquired HIV, time since diagnosis, the presence of visible symptoms, current treatment with antiretroviral therapy, self-reported health status and recruitment method.

**Data analyses**

To determine whether settings differ with respect to the mean number of manifestations, a repeated measures analysis of variance and paired samples *t*-tests were conducted. For the *t*-tests, *P* values less than 0.001 were considered statistically significant. This was followed by a series of setting-specific linear regressions of psychological distress on the 11 manifestations. Covariates were determined by initially establishing which demographic and background characteristics were correlated with psychological distress. All significant demographic and background characteristics were then entered into an initial linear regression model. Those that remained significant, namely having a partner, educational attainment and self-reported health status, were then included in the setting-specific regression analyses. Following these analyses, a final model was tested to determine which particular manifestation and setting combinations most strongly predicted psychological distress. This model included only those predictors that were significant in the setting-specific regression models. For all regression models, *P* values less than 0.05 (two tailed) were considered statistically significant.

**Results**

Repeated measures analysis of variance established that the mean number of stigma manifestations differed significantly across settings *F*(1, 634) is equal to 46.749, *P*

value is less than 0.001,  $\eta^2$  is equal to 0.07. Paired samples *t*-tests showed the mean number of manifestations in the setting *friends* (*M* = 1.14, *SD* = 1.67) was not significantly higher than with *family* (*M* = 0.96, *SD* = 1.55) but was significantly higher than all other settings, all *t*(634)s were greater than 4.11 and *P* values were less than 0.001. Also, the settings *family*, *healthcare sector* (*M* = 0.87, *SD* = 1.38) and *work* (*M* = 0.83, *SD* = 1.48), which did not differ significantly from one another, all had significantly higher means than the settings *partner* (*M* = 0.41, *SD* = 0.87) and *leisure activities* (*M* = 0.40, *SD* = 1.11), all *t*(634)s were greater than 6.83 and *P* values were less than 0.001.

Six hierarchical linear regression analyses investigated the relationships between stigma experiences in each of the specific settings and psychological distress (Table 1). Significant predictors were: (1) for friends: blame, awkward social interaction and exaggerated kindness (*P* < 0.05); (2) for family: being advised to conceal one's status, avoidance and exaggerated kindness (*P* < 0.01); (3) for the healthcare sector: indifference and awkward social interaction (*P* < 0.05; and (4) for partner: being told to conceal and exaggerated kindness (*P* < 0.05). The overall *leisure settings* and *work* models produced significant *r*<sup>2</sup> values but did not identify specific manifestations predicting psychological distress.

The 10 significant predictors from the setting-specific models were then entered into a final regression model (Table 2), which yielded an *r*<sup>2</sup> change of 0.09 (*P* < 0.001). Four significant predictors emerged: being told to conceal by family (*P* < 0.01), being avoided by family (*P* < 0.01), experiencing exaggerated kindness from family (*P* < 0.05) and awkward social interaction in the healthcare sector (*P* < 0.05).

**Table 1. Setting-specific multiple linear regression models predicting psychological distress.**

	Friends		Family		Healthcare		Partner		Work		Leisure	
	$\Delta r^2$	$\beta$										
Step 1	0.31***		0.31***		0.31***		0.31***		0.31***		0.31***	
Partner		-0.14***		-0.14***		-0.14***		-0.14***		-0.14***		-0.14***
Education		-0.12***		-0.12***		-0.12***		-0.12***		-0.12***		-0.12***
Health		-0.50***		-0.50***		-0.50***		-0.50***		-0.50***		-0.50***
Step 2	0.04***		0.07***		0.05***		0.03**		0.02*		0.03**	
Told to conceal		0.01		0.11***		0.06		0.10**		0.00		0.01
Blame		0.09*		0.04		0.02		0.01		0.06		0.04
Increased physical distance		0.01		-0.03		-0.05		0.01		-0.03		0.03
Avoidance		0.00		0.14**		0.02		0.02		0.06		0.04
Excessive hygienic measures		-0.04		-0.05		0.02		-0.04		0.04		-0.07
Told to disclose		0.05		0.06		0.02		0.02		0.00		0.06
Indifference		0.01		0.03		0.08*		-0.02		0.00		0.04
Exclusion		0.04		0.02		0.06		0.05		0.08		0.05
Awkward social interaction		0.10*		0.04		0.13**		0.06		0.02		0.05
Exaggerated kindness		0.07*		0.10**		0.04		0.09*		0.04		0.04
Aggression		-0.04		-0.01		-0.02		0.01		-0.05		-0.04

\**P* < 0.05; \*\**P* < 0.01; \*\*\**P* < 0.001. *n* = 601.

**Table 2. Final multiple regression model predicting psychological distress.**

	$\Delta r^2$	$\beta$
Step 1	0.31***	
Partner		-0.14***
Education		-0.12***
Health		-0.50***
Step 2	0.09***	
Blaming (friends)		0.06
Awkward social contact (friends)		0.05
Exaggerated kindness (friends)		0.00
Told to conceal (family)		0.09**
Avoidance (family)		0.10**
Exaggerated kindness (family)		0.08*
Indifference (healthcare)		0.04
Awkward social interaction (healthcare)		0.09*
Told to conceal (partner)		0.06
Exaggerated kindness (partner)		0.05

\* $P < 0.05$ ; \*\* $P < 0.01$ ; \*\*\* $P < 0.001$ .  $n = 601$ .

## Discussion

Although previous studies [15–22] have established that HIV-related stigma does indeed independently contribute to psychological distress in PLWHA, the present study is, to our knowledge, the first quantitative study to explore how specific manifestations of HIV-related stigma are associated with psychological distress across a number of social settings. Our findings suggest that certain setting-specific manifestations of stigma are indeed more psychologically damaging than others. Psychological distress was most strongly predicted by three specific manifestations of stigma occurring in family settings – avoidance, exaggerated kindness and being told to conceal one's status – and one manifestation in healthcare settings, namely awkward social interaction. Stigmatization by family may be particularly detrimental as families are not chosen and often considered an important source of unconditional love and support. Stigmatization by family may thus threaten a fundamental human need, namely the need to belong [41]. With respect to the impact of awkward social interactions, previous research has shown that many PLWHA assume that health professionals are knowledgeable about HIV and thus expect them to be at ease with them [35]. When health professionals' actions suggest otherwise, disappointment and subsequent psychological distress may ensue.

Our finding that different experiences of stigma impact psychological well being differently depending on the setting in which the stigma occurs has both theoretical and practical implications. First, it suggests that setting and manifestation-specific measures of HIV-related stigma likely provide insight that aggregate measures can not. Second, it points to the importance of gearing stigma reduction interventions to specific manifestations in specific settings. In order to do this effectively, additional research on family and healthcare settings is necessary (for recommendations, see [11,42]).

Some limitations to this study should be mentioned. First, compared with the general Dutch PLWHA population [43], our study over-represented homosexual men, people with a high level of education and people with a Western background. Although correlational analyses showed no associations between these variables and psychological distress, caution should be applied when generalizing findings. A second limitation is the response rate (RR). We endeavored to increase RRs via personal contact and follow-up reminders, and succeeded in reaching 6% of all diagnosed PLWHA in the Netherlands. Nonetheless, the potential for nonresponse bias cannot be dismissed. A third limitation is the cultural setting in which the survey occurred. The Netherlands is a fairly tolerant culture. As such, it is possible that Dutch PLWHA experience less stigmatization and psychological damage than PLWHA elsewhere. Although our findings support research on HIV-related stigma and psychological distress conducted in other countries [15–22], we nonetheless recommend replicating our findings in other cultural contexts. A fourth limitation is that this study did not consider the serostatus of interaction partners in settings (e.g. partner, family and friends). We suggest future research control for this. A final limitation is the cross-sectional study design. Although we presumed that stigma impacts psychological well being, one could contend that the direction of the relationship is the opposite. This, however, would require relatively similar bivariate correlations between psychological distress and most of the manifestations of HIV-related stigma in most of the settings. Instead, we found psychological distress to be most strongly associated with very specific manifestations in specific settings. Consequently, we contend that the direction of the relationship assumed is more likely than its alternative.

## Conclusion

This study has uniquely contributed to our understanding of the relationship between HIV-related stigma and psychological distress and added to previous research by demonstrating that it is possible to identify the specific manifestations occurring in specific social settings that are most detrimental to psychological well being.

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S.E.S. was involved in the design of the study, conducted analyses, interpreted the data and led the writing. J.B.P. also analyzed data, interpreted findings and revised drafts of the manuscript. A.E.R.B. and H.P.S. were responsible for the conception and design of the study. They also assisted with data analyses and interpretation, and reviewed drafts of the manuscript. R.H. and P.M. contributed to the analyses and interpretation of the data as well as manuscript revisions.

There are no conflicts of interest.

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