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PSYCHOLOGICAL AND SOCIAL CORRELATES OF HIV STATUS DISCLOSURE: THE SIGNIFICANCE OF STIGMA VISIBILITY

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HIV-related stigma, psychological distress, self-esteem, and social support were investigated in a sample comprising people who have concealed their HIV status to all but a selected few (limited disclosers), people who could conceal but chose to be open (full disclosers), and people who had visible symptoms that made concealing difficult (visibly stigmatized). The visibly stigmatized and full disclosers reported significantly more stigma experiences than limited disclosers, but only the visibly stigmatized reported more psychological distress, lower self-esteem, and less social support than limited disclosers. This suggests that having a visible stigma is more detrimental than having a concealable stigma. Differences in psychological distress and self-esteem between the visibly stigmatized and full disclosers were mediated by social support while differences between the visibly stigmatized and limited disclosers were mediated by both social support and stigma. These findings suggest that social support buffers psychological distress in people with HIV.

A stigma is a distinctive, discrediting characteristic that renders its bearer tainted, flawed, or inferior in the eyes of others (Bos, Kok, & Dijker, 2001; Crocker, Major, & Steele, 1998; Goffman, 1963; Jones et al., 1984; Major & O'Brien, 2005). A fundamental dimension of stigmas concerns the degree to which they can be concealed from others. People who choose to “pass” as “normal” by concealing their stigma nevertheless remain “discreditable” as long as there is a potential that the stigma can be revealed (Goffman, 1963). Concerns regarding who to tell and the fear of being discovered are significant sources of psychological distress among those who conceal

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stigmas (Pachankis, 2007). Those who voluntarily disclose their stigmatized status or those who have conspicuous stigmas must endure potentially being “discredited” in the eyes of others. People living with HIV (PLWH) run the gamut with regard to these three different varieties of stigma experience. Some try to pass, telling virtually no one or only a selected few. Others choose to openly reveal their status. Still others have conspicuous symptoms that make passing difficult. In the current study, we explored the psychological and social consequences of these three different kinds of disclosure choices.

The current literature indicates that both disclosure and concealment have positive and negative consequences. Numerous studies have documented negative reactions to HIV status disclosure (Alonzo & Reynolds, 1995; Black & Miles, 2002) and the subsequent detrimental consequences for psychological well-being (Bing et al., 2001; Heckman et al., 2004; Pence, Miller, Whetten, Eron, & Gaynes, 2006; Stutterheim et al., 2009) and social relationships (Lee & Craft, 2002), thus suggesting that it would be wise to keep one’s HIV status a secret. Others have shown that concealing a stigmatized condition also has very substantial psychological and social costs, including stress (Greenberg & Stone, 1992; Pennebaker, Colder, & Sharp, 1990), poor mental health outcomes (Derlega, Winstead, Oldfield, & Barbee, 2003; Steward et al., 2008; Ullrich, Lutgendorf, & Stapleton, 2003), strained social interactions (Smart & Wegner, 1999), social isolation (Corrigan & Matthews, 2003; Remennick, 2000), and the insufficient provision of social support (Alonzo & Reynolds, 1995; Chesney & Smith, 1999). The role of social support is particularly important as it not only enables PLWH to better cope with health concerns (Smith, Rossetto, & Peterson, 2008) but also buffers stress, anxiety, and depression that can result from, among other things, stigmatization (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003; Lam, Naar-King, & Wright, 2007; Li, Lee, Thammawijaya, Jiraphongsa, & Rotheram-Borus, 2009). However, a prerequisite for the receipt of social support is precisely that which can generate stigmatization: disclosure. In essence, PLWH must take the risk of being met with stigmatizing reactions in order to gain the support necessary to deal with stigmatizing reactions. Evidently, PLWH who are in a position to conceal their status are faced with difficult decisions regarding whether or not they should disclose or conceal.

For some PLWH, disclosure is involuntary. Disease progression and, more frequently, side effects of highly active antiretroviral therapy (HAART), such as lipodystrophy syndrome, can make HIV a condition with conspicuous symptoms. The psychological and social implications of HIV may vary according to the presence or absence of visible symptoms. PLWH with visible symptoms may, in fact, be better off than PLWH who can conceal their condition. Research conducted by Fribley, Platt, and Hoey (1998) compared concealable and visible stigmas and found that those with concealable stigmas (i.e., sexual orientation, bulimia, or very low socioeconomic status) had more anxiety, depression, and negative affect, as well as lower self-esteem, than those with visible stigmas (i.e., ethnicity or overweight). This would suggest that people with visible stigmas fare better than those who try to conceal, perhaps because they have access to an array of possible coping strategies that might not be readily available to those whose stigma is hidden (Quinn, 2006). For example, people with visible stigmas are often in a better position to find and compare themselves to in-group members, and they might more readily attribute negative treatment to prejudice (Crocker, Major, & Steele, 1998). To our knowledge, no prior studies have examined how the presence of visible symptoms impacts the stigma experiences of people with HIV.

In the current study, we examined HIV-related stigma, psychological distress, self-esteem, and social support in a sample of people known to have HIV. Our participants fit into three categories, namely people who have concealed their HIV status to all but a selected few (limited disclosers), people who are able to conceal their status but chose to be open about it to others (full disclosers), and people who felt they had visible symptoms that make their status difficult to conceal to others (visibly stigmatized). One of the unique features of this study is that we were able to compare the consequences of stigma visibility to those of stigma concealment or disclosure across groups that had essentially the same stigma. Although one might argue that having visible symptoms represents a qualitatively different stigma, some important factors such as the stereotypes about PLWH and the degree to which PLWH are blamed for their condition are constant across these different experiences of stigma.

METHOD

PARTICIPANTS AND PROCEDURE

Data were obtained via an anonymous survey for which participants provided informed consent. Participation was voluntary and did not involve monetary compensation. Approval from the ethics committee at Maastricht University's Faculty of Psychology and Neuroscience was provided. In total, 2,264 surveys were distributed to PLWH in 2007 by the Dutch HIV Association and by HIV nurses. Of the 2,264, 669 surveys were returned (response rate = 29.5%). Two surveys were excluded from the analyses as the corresponding participants were outliers with respect to age (6 and 97 years).

Of the 667 participants included, 86.2% were male and 13.8% were female. Ages ranged from 17 to 75 with a mean age of 46.6 ($SD = 9.6$). Almost half of the respondents (49.5%) had at least a Bachelor's degree. An additional 31.0% had a high school diploma and/or some vocational training and 19.5% had a high school diploma or less. Further, 68.3% of participants had paid employment and 48.4% of participants had a long-term partner. The greater majority of the sample defined themselves as gay (79.5%) and from Europe or North America (90.6%). Most of the participants (87.5%) had acquired HIV through sexual intercourse and the mean time since diagnosis was 8.75 years ($SD = 6.0$). A total of 79.3% of participants were being treated with antiretroviral therapy at the time of the study.

MEASURES

Disclosure of HIV status was measured using questions that addressed disclosure to several potential targets ("Who have you told that you have HIV?"). For their long term partner, mother, and father, participants answered "yes," "no," or "not applicable." With respect to disclosure to immediate and extended family members (excluding mother and father), friends, acquaintances, and colleagues, answers were provided on a 5-point scale ranging from 1 ([almost] no one) to 5 ([almost] everyone).

HIV-related stigma experiences were assessed using a 15-item scale developed by the authors. Participants indicated the degree to which they had experienced negative reactions to their HIV status in a number of social settings ("To what extent have you experienced negative reactions to your HIV status in each of the following situations?"; examples of settings: family, friends, other PLWH, work, health care sector, faith community, gay community) on a 5-point scale ranging from 1 (never)

to 5 (very often). A higher score is indicative of greater stigma. Cronbach's alpha is .77.

Psychological distress was measured using the 18-item Mental Health Inventory (MHI) which measures depression, anxiety, positive affect, and behavioral control (Veit & Ware, 1983). Answers were provided on a 6-point scale ranging from 1 (none of the time) to 6 (all of the time). A higher score is indicative of more psychological distress. This scale has been used extensively and is considered to be both valid and reliable (Rosenthal, Downs, Arheart, & Deal, 1991; Veit & Ware, 1983). Cronbach's alpha is .94. An example of an item is "How much of the time, during the past 4 weeks, have you felt downhearted and blue?"

Self-esteem was assessed using the Rosenberg Self-Esteem Scale (RSE; Rosenberg, 1965) which contains 10 items, all of which are scored on a 4-point scale ranging from 1 (strongly disagree) to 4 (strongly agree). A higher score is indicative of greater self-esteem. The RSE is a frequently used measure of self-esteem (Schmitt & Allik, 2005). Cronbach's alpha is .88. An example item is "I am able to do things as well as most other people."

Social support was measured using the 12-item short version of the Social Support List of Interactions (SSL-12) which measures the frequency of everyday support, social support in problem situations, and esteem support (Kempen & Van Eijk, 1995). Answers were provided on a 4-point scale ranging from 1 (seldom or never) to 4 (very often). A higher score is indicative of more social support. This scale has good psychometric properties (Kempen & Van Eijk, 1995). Cronbach's alpha is .73. An example item is "Does it ever happen to you that people drop in for a visit?"

The presence of visible symptoms was measured by one item, namely, "Do you currently have visible symptoms as a result of your HIV infection?" to which participants responded with "yes" or "no." Those that responded affirmatively were subsequently asked to describe those symptoms. Responses included lipodystrophy syndrome, dermatological complaints, and neurological symptoms.

Demographic characteristics and HIV-related characteristics were also measured. HIV-related characteristics included the mode by which one acquired HIV, the time since diagnosis, current treatment with HAART, and self-reported current health status. Demographic characteristics measured included gender, age, educational attainment, current employment, marital status, sexual orientation, and ethnic background.

RESULTS

Descriptive statistics showed that 97.9% of participants had disclosed their HIV status to their long term partner, 68.2% to their mother, and 64.7% to their father. Also, 65.0% reported having disclosed to most other family members and 64.1% to most friends. Disclosure rates to acquaintances and colleagues were lower with 31.1% having disclosed to most acquaintances and 28.8% to most colleagues.

As stated above, groups were distinguished according to their disclosure status (full disclosers, limited disclosers, and the visibly stigmatized). Full disclosers were those participants who had disclosed to their partner and most of their family, friends, acquaintances, and colleagues in the absence of visible symptoms ($N = 300$). Limited disclosers were those participants who did not have visible symptoms and

TABLE 1. Means, Standard Deviations, and Intercorrelations of Main Variables

	Mean	SD	1	2	3
1. HIV-related stigma	4.04	3.27	—		
2. Psychological distress	2.73	0.88	.24***	—	
3. Self-esteem	3.07	0.50	-.17***	-.73***	—
4. Social support	2.71	0.43	-.11**	-.19***	.27***

** $p < .01$, *** $p < .001$.

that had opted not to disclose their status in more public settings (i.e., to colleagues and acquaintances; $N = 163$). The visibly stigmatized were those participants who reported visible symptoms and disclosure to most disclosure targets ($N = 194$).¹ An additional group of nondisclosers comprised participants who had told no one ($N = 10$) but was not included in the analyses because of its size.

Means, standard deviations, and intercorrelations for HIV-related stigma, psychological distress, self-esteem, and social support are displayed in Table 1. One-way analyses of variance—least significant differences (ANOVA-LSD; see Table 2) showed that full disclosers and the visibly stigmatized reported significantly more stigma experiences than limited disclosers, $F(2, 654) = 27.08, p < .001$. They also demonstrated that visibly stigmatized participants reported significantly more psychological distress, $F(2, 637) = 4.43, p < .05$, lower self-esteem, $F(2, 637) = 4.62, p < .01$, and less social support, $F(2, 633) = 8.68, p < .001$, than limited disclosers or full disclosers. Limited and full disclosers, in turn, did not differ significantly from one another on psychological distress, self-esteem, and social support.

To better understand why significant differences were found between the visibly stigmatized and full disclosers on psychological distress, self-esteem, and social support despite similar levels of exposure to stigmatization, we conducted mediation analyses according to the method outlined by Baron and Kenny (1986). In brief, this method comprises a series of regression analyses. First, the dependent variable is regressed on the independent variable (Step 1); then the potential mediator is regressed on the independent variable (Step 2); subsequently, the dependent variable is regressed on the potential mediator (Step 3); and, lastly, the dependent variable is regressed on both the independent variable and the potential mediator (Step 4). Mediation is satisfied if the independent variable affects both the dependent variable (Step 1) and the mediator (Step 2), the mediator affects the dependent variable in the predicted direction (Step 3), and the effect of the independent variable is less significant in Step 4 than in Step 1. Our mediation analyses (Figure 1) demonstrated that

1. Given the nature of their disclosure, these groups differ with respect to certain demographic and HIV-related characteristics. Significant differences were found with respect to age (the visibly stigmatized were older than full disclosers who in turn were significantly older than limited disclosers), ethnicity (non-Western ethnicity was more common among limited disclosers), children (limited disclosers had more children), employment (paid employment was lower among the visibly stigmatized), sexual orientation (full disclosers were more likely to be gay), health (poorer health was reported among the visibly stigmatized), time since diagnosis (the visibly stigmatized knew about their HIV status longer than full disclosers who in turn have known their status longer than limited disclosers), combination therapy (the visibly stigmatized were more likely to be receiving therapy), and time since therapy was initiated (time was longest among the visibly stigmatized followed by the full disclosers and then the limited disclosers). No significant differences were found for gender, marital status, or educational attainment.

TABLE 2. Group Comparisons of Limited Disclosers, Full Disclosers, and the Visibly Stigmatized on Main Variables

		Limited Disclosers	Full Disclosers	Visibly Stigmatized
HIV-related stigma	Mean	2.50 ^a	4.39 ^b	4.78 ^b
	SD	2.84	3.12	3.37
	N	163	300	194
Psychological distress	Mean	2.66 ^a	2.65 ^a	2.88 ^b
	SD	.86	.86	.88
	N	158	292	190
Self-esteem	Mean	3.12 ^a	3.12 ^a	2.99 ^b
	SD	.54	.47	.50
	N	159	291	190
Social support	Mean	2.74 ^a	2.77 ^a	2.61 ^b
	SD	.46	.38	.45
	N	157	293	186

Note. ^{a,b}Means in a given row that do not share a common superscript differ at the .05 level.

differences in psychological distress and self-esteem between the visibly stigmatized and the full disclosers were fully mediated by social support, Sobel's $z = -2.91$, $p < .01$ (see Figure 1a) and Sobel's $z = 3.49$, $p < .001$ (see Figure 1b), respectively. Subsequent analyses also showed that differences in psychological distress and self-esteem between the visibly stigmatized and limited disclosers were fully mediated by not only social support, Sobel's $z = -2.70$, $p < .01$ (see Figure 1c) and Sobel's $z = 2.39$, $p < .05$ (see Figure 1d) but also by stigma experiences, Sobel's $z = -3.76$, $p < .001$ (see Figure 1e) and Sobel's $z = 2.12$, $p < .05$ (see Figure 1f).

DISCUSSION

This study is, to our knowledge, the first to explore the psychological and social correlates of full and limited disclosure of HIV status in the presence and absence of visible symptoms. In our comparison of limited disclosers, full disclosers, and visibly stigmatized PLWH, we found that participants with visible symptoms of HIV were at the greatest disadvantage, both psychologically and in terms of social support. These participants reported substantially more psychological distress, lower self-esteem, and less social support than participants that were in a position to conceal their status, be they full or limited disclosers. This suggests that having a visible stigma is more detrimental than having a concealable stigma.

One could argue that the reason why visibly stigmatized participants report poorer psychological and social well-being is because they experience more stigma than participants who can conceal. Our results, however, do not support this contention. In fact, in our study, the visibly stigmatized and the full disclosers did not differ from one another in terms of the amount or frequency of stigma experiences.

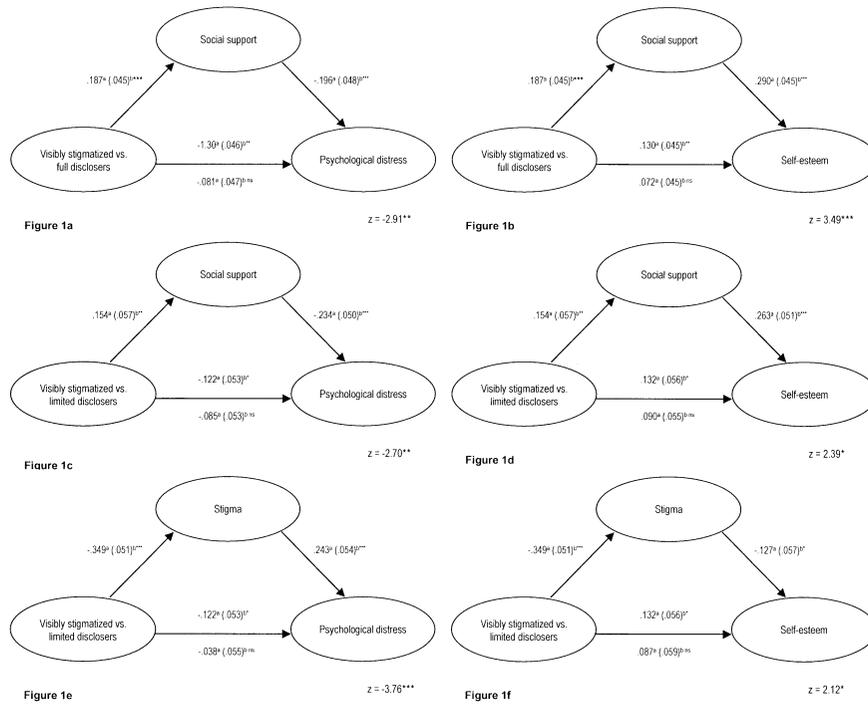


FIGURE 1. Mediation analyses of differences in psychological distress and self-esteem between groups.

Note. a = unstandardized regression coefficient; b = standard error. $*p < .05$; $**p < .01$; $***p < .001$. In accordance with Baron and Kenny (1986), Step 1: text above the horizontal line; Step 2: text to the left of the diagram; Step 3: text to the right of the diagram; Step 4: text under the horizontal line.

They did, however, vary significantly in their mental health outcomes. Our mediation analyses suggest that this is attributable to social support. Social support was found to mediate the differences in psychological distress and self-esteem between the visibly stigmatized participants and the full disclosers, thus suggesting that social support may be an important buffer against the negative psychological consequences of stigmatization.

When we explored the differences in psychological distress and self-esteem between limited disclosers and the visibly stigmatized, we found that both stigma experiences and social support mediated these differences thus suggesting that limited disclosers have less psychological distress not only because they experience less stigma but also because they receive the necessary support to buffer the stigma they do experience.

Clearly, social support can be a buffer against psychological distress in PLWH. In our study, PLWH with visible symptoms reported significantly less social support than their concealable counterparts. This may be attributable to the nature of their HIV status disclosure. Previous research has shown that the way in which disclosure

occurs can impact disclosure targets' responses (Bos, Dijker, & Koomen, 2007). The selection of the optimal setting, person, and time may thus enable more positive reactions to HIV status disclosure. Unfortunately, people with visible symptoms like lipodystrophy syndrome are less able to determine the conditions under which they disclose as they are often "outed" by their looks. As such, their disclosure is less likely to be voluntary (Joachim & Acorn, 2000). This is in line with research by Buzzella, Beals, and Peplau (2003) who, in their study on the disclosure of sexual orientation, found that involuntary disclosure is significantly related to less social support. It may also be that voluntary disclosers actually disclose for the purposes of gaining support and thus receive more social support upon disclosure than those who are subjected to involuntary disclosure.

Our finding that PLWH with visible symptoms experienced more psychological distress and lower self-esteem corresponds with work conducted by Reynolds, Neidig, Wu, Gifford, & Holmes (2006) and by Sanches, Mill, Machado, Donadi, and Morais Fernandes (2009), both of whom have demonstrated a relationship between psychological distress and visible HIV symptoms. However, it does not correspond with the work of Frable, Platt, and Hoey (1998) who have shown that people with a concealable stigma are at greater psychological disadvantage than people with a visible stigma. The incongruence between Frable et al.'s findings and ours may be the result of the fact that the former compared groups with fundamentally different stigmatized identities (sexual orientation, bulimia, and very low socioeconomic status versus ethnicity and overweight) whereas we compared three groups that all share the same stigmatized condition, namely HIV. In other words, factors that differentiated the stigmas studied by Frable and her colleagues other than concealability might have contributed to the psychological differences they found across stigmatized groups.

In our comparison of limited disclosers and full disclosers, we found that the only significant difference between the two groups was that the full disclosers had been exposed to more stigma experiences. This finding is in line with research by Bos, Kanner, Muris, Janssen, and Mayor (2009) who previously found that selective disclosure limits stigmatizing responses to mental illness disclosure. The fact that no differences were found in psychological distress, self-esteem, and social support, despite significant differences in stigma experiences, is noteworthy. Perhaps full disclosers possess certain attributes (e.g., self-efficacy, self-confidence) and coping mechanisms (e.g., a greater tendency to attribute externally) to a greater extent than limited disclosers. This corresponds with the work of Paxton (2002) who has shown that public disclosure can lead to psychological release. We recommend that future studies explore such attributes and coping mechanisms as possible mediators or moderators of the relationship between stigma experiences and psychological distress.

There are limitations to the study presented here. First, our study was conducted with a sample of predominantly gay men with a relatively high level of educational attainment and a European or North American background. This may impact the generalizability of our findings. Future research should endeavor to oversample ethnic minorities, heterosexual women, and people with a lower level of education. A second limitation is the cross-sectional study design and the resulting difficulties determining causality. We suggest that future studies adopt a longitudinal design. A third limitation is the response rate. We sought to increase response rates via personal contact and follow-up reminders, and were successful in reaching 6% of

all diagnosed PLWH in the Netherlands. However, the potential for nonresponse bias cannot be dismissed. Further, we acknowledge that our measurement of visible symptoms is self-reported and thereby impacted by participants' perceptions of what is visible and what is not. Future research may benefit from using a more objective measure of visible symptoms (e.g., medical diagnoses of lipodystrophy syndrome). A final limitation is that a group of nondisclosers was not included in this study. Although nondisclosers are hard to find and include in these kinds of studies, as was the case with our study, including such a group may shed greater light on the psychological and social impact of disclosure versus concealment. Future studies should seek to include such individuals despite the difficulties involved in their recruitment.

This study has a number of theoretical and practical implications. In terms of theory, the findings contribute to the debate on whether it is more advantageous to have a visible or concealable stigma (Frable et al., 1998; Pachankis, 2007; Quinn, 2006). Our findings clearly support the contention that visible stigmas are psychologically and socially more detrimental than concealable ones. Our findings also contribute to the ongoing discussion regarding whether concealment or disclosure is better among those that are in a position to conceal their stigmatized identity. Our findings have shown that although full disclosers experience more stigma than limited disclosers, they do not experience more or less psychological distress or social support. This suggests that future work on the psychological impact of concealment or disclosure should go beyond a dichotomous distinction between disclosers and nondisclosers and explore the impact of varying degrees of disclosure.

In terms of practice, the finding that social support plays an important protective role in the preservation of PLWH's psychological well-being and self-esteem is highly relevant. It points to the need to promote social support provision for PLWH, especially those with visible symptoms. Health care providers should endeavor to provide such support via their own personal contact with PLWH and also by referring PLWH to important support groups. Theory and evidence-based efforts and interventions to positively connect PLWH with their families and friends in ways that promote social support provision and reduce negative reactions to HIV status disclosure are also advised. Such interventions can focus on empowering PLWH, developing disclosure skills in PLWH, and providing information to disclosure targets that is likely to reduce negative responses (e.g., information indicating that HIV cannot be spread through casual social contact, information showing that PLWH can live long and healthy lives with HAART). For additional recommendations on how to reduce negative reactions to HIV status disclosure, see Bos, Schaalma, and Pryor (2008) and Brown, Macintyre, and Trujillo (2003). Clearly, the creation of supportive environments for PLWH and the development of HIV-related stigma reduction interventions are imperative to the promotion of positive HIV-status disclosure experiences.

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