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Shame among people living with HIV: a literature review

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Abstract

Shame is consistently associated with poor adjustment (e.g., depressive symptoms) among community samples but, surprisingly, has rarely been directly examined among people living with HIV/AIDS (PLWH). This limited research on shame is likely due, in part, to shame's having been subsumed within measures of internalized stigma, an imprecise construct with varied definitions in the HIV literature. The current review summarizes research directly examining the correlates of shame among PLWH. Findings indicate that shame is associated with greater depressive symptoms, less healthcare utilization, and poorer physical health among PLWH. Directions for future research examining shame among PLWH are highlighted, including the need for more prospective research examining shame as a predictor of future adjustment.

Keywords

shame; stigma; HIV; adjustment; depressive symptoms; physical health

People living with HIV (PLWH) are at increased risk for mental health problems such as depression and anxiety (Bing et al., 2001; Nanni, Caruso, Mitchell, Meggiolaro, & Grassi, 2015). The extensive stigma that many PLWH experience is believed to be a major risk factor for such problems (Logie & Gadalla, 2009; Mak et al., 2006), although the mechanisms by which stigma may cause distress remain largely unknown (Hatzenbuehler, Nolen-Hoeksema, & Dovidio, 2009; Kalichman, 2013). We propose that the stigma associated with HIV/AIDS leads to increased distress, in part, through shame.

While shame and stigma are related, important distinctions exist. Shame is a private albeit sometimes visible emotion whereas stigma generally refers to a public action (Lewis, 1995). Despite the potential importance of shame to adjustment, research has focused on the effects of stigma among PLWH (e.g., see reviews by Crawford, 1996; Katz et al., 2013; Logie & Gadalla, 2009; Lowther, Selman, Harding, & Higginson, 2014; Mahajan et al., 2008). The purpose of the current review is to examine the potential role of shame in the mental and

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physical health of PLWH. In so doing, we distinguish shame from internalized stigma, and examine the extent to which shame is related to health outcomes among PLWH.

Stigma

As defined by Goffman (1963), stigma reduces one “from a whole ... person to a tainted, discounted one.” Stigma may be present when people are labeled as different due to undesirable characteristics and subsequently experience status loss and discrimination (Link & Phelan, 2001). Stigma among PLWH stems in part from the association of HIV with AIDS, whose transmission is often perceived to be from controllable behaviors that are not sanctioned by societal, religious, and moral codes. PLWH often experience multiple stigmatized identities that include being a sexual minority, an ethnic minority, and living in poverty.

Stigma is defined in multiple ways within the HIV literature, leading to conceptual confusion (Bresnahan & Zhuang, 2011; Deacon, 2006; Earnshaw & Chaudoir, 2009; Florom-Smith & De Santis, 2012). Subtypes of stigma include: *enacted stigma*, the extent of discrimination actually encountered; *perceived stigma*, the extent that one is aware of negative societal attitudes and reduced opportunity (Cheung, Gilbert, & Irons, 2004; Logie & Gadalla, 2009); and *internalized stigma*, the self-defacing beliefs and perceptions about oneself stemming from the acceptance of negative attitudes from others as valid (Tsai, Bangsberg, & Weiser, 2013).

Internalized stigma

Most relevant to shame, *internalized stigma* has been described as encompassing feelings of being “less than” others, deserving of negative outcomes due to having HIV, and as including the shame and negative self-image felt by PLWH (Audet, McGowan, Wallston, & Kipp, 2013; Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013). As such, shame is often assessed as a component of internalized stigma measures. There is great variability, however, as to how internalized stigma is defined and assessed, including the extent to which shame is measured. For example, one measure of internalized stigma contains a self-acceptance subscale that includes shame-related items, but also assesses HIV stereotypes, social relationship stigma, and HIV disclosure concerns (Sayles, Wong, Martins, & Cunningham, 2009). A second set of internalized stigma measures (Kalichman et al., 2008, 2009) includes items assessing both shame and guilt, while a third measure contains only two items and assesses embarrassment and difficulty disclosing HIV (Lee, Kochman, & Sikkema, 2002).

These varied conceptualizations pose several challenges. First, by assessing diverse components it leaves unclear which specific components are most strongly associated with mental and physical health outcomes. Second, a lack of definitional clarity limits our understanding of the mechanisms by which PLWH experience health problems, potentially limiting the effectiveness of intervention efforts (Bresnahan & Zhuang, 2011). Third, such diverse conceptualizations may produce inconsistent or unexpected findings. For example, Mak et al.'s (2006) hypothesis that self-blame would predict internalized stigma was

unconfirmed. It is possible, however, that self-blame is most strongly related to the shame component of internalized stigma and that their hypothesized finding was obscured by the inclusion of items unrelated to shame in their internalized stigma measure.

Shame

Shame is a painful self-conscious emotion in which one perceives the self to be defective, often in response to a perceived failure (Lewis, 1995; Tangney & Dearing, 2002). While shame may follow from stigma, whose function may be to elicit shame in the recipient, not all stigmatized individuals experience shame. Factors such as whether one perceives a violation of societal standards for their behavior/condition and whether one blames themselves for such behavior increases the likelihood of experiencing shame (Lewis, 1995). As a potential consequence of enacted or perceived stigma, shame is the more proximal predictor of mental health problems (Lewis, 1995). Accordingly, shame should be a better predictor than enacted or perceived stigma of outcomes such as depressive symptoms. Shame may also be more readily addressed than stigma by clinicians (O'Hayer, Bennett, & Jacobson, in press).

Shame and guilt, components of some internalized stigma measures, are often confused despite their distinct characteristics and relationships with adjustment (Tangney & Dearing, 2002). Shame is more likely to be experienced if one makes stable and global attributions for negative events, whereas guilt is more likely following unstable, specific attributions for negative events (Lewis, 2008; Vliet, 2009). Moreover, shame is associated with a desire to escape potentially shame-inducing situations, whereas guilt is associated with reparative actions such as making an apology or attempting to undo the negative consequences of one's behavior (Lewis, 1971, 2008; Tangney & Dearing, 2002). For example, shame-prone individuals may avoid keeping a clinic appointment because doing so could further remind them of their HIV status and precipitate shame. In contrast, guilt-prone individuals may be highly motivated to keep appointments to maintain their health (e.g., PLWH who feel guilty that risky behavior caused them to have HIV may exhibit good adherence to medical recommendations). Important to one's adjustment, shame is associated with depressive symptoms, anxiety, substance use, and antisocial behavior, whereas guilt is less strongly related to negative adjustment and often is associated with positive adjustment (Bennett, Sullivan, & Lewis, 2010; Fergus, Valentiner, McGrath, & Jencius, 2010; Kim, Thibodeau, & Jorgensen, 2011; Lewis, 2008; Stuewig & Tangney, 2007). As a result, measures of internalized stigma that assess guilt might reduce associations found between stigma and negative adjustment.

Shame and depressive symptoms

Depressive symptoms are particularly concerning as they can lead to poor medication adherence, CD4 cell loss, and increased viral load (Bouhnik et al., 2005; Carrico et al., 2011; Gonzalez, Batchelder, Psaros, & Safren, 2011; Ickovics et al., 2001). Four studies have directly assessed shame among PLWH, and each reported a medium to large effect size between shame and depressive symptoms (Bennett, Hersh, Herres, & Foster, 2015; DeMarco, 1998; Li et al., 2010; Rodkjaer, Laursen, Balle, & Sodemann, 2010). These

studies of American, Danish, and Thai PLWH included adolescents through older adults, and both men and women. The studies, however, are each cross-sectional and as such unable to examine whether shame precedes increases in future depressive symptoms. Moreover, while Li and colleagues did include a prospective component in which “shame” was found to predict distress a year later, their measure included items assessing guilt, anger, and a sense of being punished, items not directly indicative of shame. Thus, while current evidence supports a concurrent relationship between shame and depressive symptoms, longitudinal studies documenting prospective relationships among PLWH are needed.

Shame and healthcare usage

Several studies suggest an important role for shame in initiating and maintaining the use of healthcare services. PLWH cited shame as a barrier to initiating a supervised injection program and a clinical medication trial (Krüsi, Small, Wood, & Kerr, 2009; Zuniga, Blanco, Martinez, Strathdee, & Gifford, 2007). Once in treatment, HIV-related shame is associated with poor medication adherence (Konkle-Parker, Erlen, & Dubbert, 2008). Collectively, these findings suggest that shame can hinder the use of important health-preserving behaviors.

Shame and physical health

Among PLWH, men who reported persistent shame regarding their HIV status had a greater decrease in CD4 cells, an indicator of HIV progression, over 7 years (Dickerson, Gruenewald, & Kemeny, 2004; Weitzman, Kemeny, & Fahey, 2004). Shame also predicted worse physical health a year later among PLWH (Li et al., 2010) and is associated with greater physical symptoms and reduced health-related quality of life among PLWH in cross-sectional studies (DeMarco, 1998; Persons, Kershaw, Sikkema, & Hansen, 2010).

Conclusion

Shame should be distinguished from stigma in models of adjustment among PLWH, as doing so could enhance our understanding of the processes by which PLWH develop adjustment problems and poor treatment adherence. In particular, scale development aimed at further distinguishing shame from stigma is needed, as is longitudinal and quantitative research examining the extent to which stigma precedes shame, and shame precedes future mental and physical health outcomes among PLWH. Greater recognition of the potential role of shame and implementation of interventions aimed at reducing shame may ultimately lead to improved mental and physical health among PLWH.

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