

Multiple Dimensions of HIV Stigma and Psychological Distress Among Asians and Pacific Islanders Living With HIV Illness

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Asians and Pacific Islanders (APIs) living with HIV/AIDS in the US are particularly vulnerable to HIV-related stigma largely due to ingrained socio-cultural norms that strongly associate HIV transmission with activities perceived to be immoral. This cross-sectional study examined the relationship between five HIV-stigma factors and psychological distress among 54 HIV-seropositive APIs. Social Rejection, Negative Self-Worth, Perceived Interpersonal Insecurity, and Financial Security were all significantly associated with psychological distress. Results from hierarchical multiple regression analyses indicated that Social Rejection, Negative Self-Worth, and Perceived Interpersonal Insecurity significantly predicted psychological distress after control for physical symptoms and country of birth. Undocumented Asians endorsed higher levels of Social Rejection, Negative Self-Worth and Perceived Interpersonal Insecurity than documented APIs. Future studies examining mechanisms of psychological distress among HIV-seropositive APIs are needed.

KEY WORDS: stigma; Asians; Pacific Islanders; HIV/AIDS.

INTRODUCTION

HIV-stigma has compromised the psychological and physical health of persons living with the illness since the earliest days of the HIV pandemic. Generally, stigmatized groups are “pejoratively regarded by the broader society and are devalued, shunned, or otherwise lessened in their life chances”

(Alonzo and Reynolds, 1995). Goffman’s (1963) classic conceptualization of stigma as a powerfully discrediting and tainting label that reduces individuals’ self perception has spurred numerous systematic accounts of how stigma impacts the lives of persons with HIV. In Asia where AIDS widens in a population that is approximately 60% of the world total, HIV-related stigma hampers provision of medical care (Songwathana and Manderson, 2001), perpetuates economic hardships and marginalization, and compromises family unity and cohesion (Busza, 2001). Similarly, in the US, HIV-related stigma impedes timely access to medical and ancillary services (Valdiserri, 2002), exacerbates psychiatric symptomatology (Fullilove, 1989; Miles *et al.*, 1997) and emotional distress (Alonzo and Reynolds, 1995), and perpetuates gender- and ethnic-based socioeconomic disparities (Bunting, 1996). Social isolation is also often recognized as a correlate of HIV-stigma (Lichtenstein *et al.*, 2002) largely due to negative public perceptions of persons living with

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HIV illness or who belong to specific groups at risk such as men who have sex with men and injection drug users (Triplet and Sugarman, 1987).

Asians and Pacific Islanders (APIs) living with HIV illness in the US are particularly vulnerable to the deleterious impact of HIV-related stigma due to ingrained sociocultural norms that strongly associate HIV transmission with activities perceived to be immoral, including sexual promiscuity, commercial sex work, homosexuality, and injection drug use (Gock, 1994). A steady rise of HIV infection among APIs is anticipated in the US given the escalating HIV prevalence in Asia—most notably China and India—and the rising influx of immigrants from these regions to New York City (NYC; Sy *et al.*, 1998). The cumulative AIDS cases reported among APIs in major US cities continues to grow (Centers for Disease Control and Prevention, 2001; New York State Department of Health, 2003). As a result of stigma, APIs living with HIV/AIDS delay accessing medical and supportive services (Eckholdt *et al.*, 1997; Chin *et al.*, 2003; Pounds *et al.*, 2002; Eckholdt and Chin, 1997), report difficulties adhering to their antiretroviral regimen (Kang and Rapkin, 2003), and avoid disclosing their HIV status in fear of being discriminated against by peers, employers (Chin and Kroesen, 1999), and family members (Yoshioka and Schustack, 2001).

In addition to illness-related stigma, HIV-seropositive APIs confront both subtle and overt discrimination on the basis of race, immigration status, and sexual orientation. Some APIs experience heightened stigmatization when their HIV/AIDS diagnosis reveals otherwise concealed lifestyles such as injection drug use, commercial sex patronage, or bisexuality (Herek and Glunt, 1988). API men who have sex with men (MSM) often experience exclusion from the mainstream MSM community, feeling “invisible” and “separate” (Yoshikawa *et al.*, 2001). Being marginalized for one’s HIV-serostatus in addition to one’s racial/ethnic identity and sexual orientation creates further ambiguity about whether discriminatory events occur as a result of any particular group membership.

Despite the personal and public health consequences of HIV-related stigma, little consideration has been given to the multiple dimensions and psychological sequelae of this phenomenon among APIs. The goal of this study was to further understand the relationship between five dimensions of HIV-related stigma and psychological distress among HIV-seropositive APIs receiving services at commu-

nity AIDS service organizations in NYC. It is important to note that the term “Asian and Pacific Islander” signifies persons of Asian and/or Pacific Islander heritage living in the US, representing a heterogeneous group of people, encompassing over 29 ethnic Asian groups and 20 Pacific Islander cultures in the US, who speak more than 100 language and dialects (US Bureau of the Census, 1993). Although the aggregate term “API” is referenced in this study, the authors acknowledge significant differences in cultural traditions and values, language, dialects, migration history, and acculturation among APIs. Moreover, one’s sexual orientation and respective social networks intensifies or mitigates the effects of HIV-stigma (Lichtenstein *et al.*, 2002) especially for APIs (Nemoto *et al.*, 2003). As such the implications of findings from this study are limited to specific groups represented in the sample and cannot be generalized to all APIs.

METHODS

Individual 1–2 hr semi-structured interviews were conducted with a non-random convenience sample of 54 HIV-seropositive APIs referred by two AIDS service organizations. Participants were recruited from the same organizations as the sample reported by Kang *et al.* (2003) and participants overlapped by 60% across studies. All participants consented to be audio-taped. On completion of the interview, they were reimbursed for their involvement in the study.

Trained bilingual, bachelor-level interviewers, and the principal researcher conducted the interviews in English, Cantonese, or Mandarin. Interview instruments were translated into Chinese because they were the largest Asian group, representing nearly half of all Asians in NYC (Scott, 2001). The interview battery was translated into written Chinese by: discussing the content equivalence and sensitivity of the instruments to Chinese with bi-lingual colleagues; translating the instruments into Chinese by one translator; back-translating instruments into English by another independent translator—conceptual rather than literal meaning was the goal; holding a meeting with the translator, back-translator, and the principal researcher, who was tri-lingual (English, Cantonese, and Mandarin) to examine and resolve differences that emerged from the back-translation (Chang *et al.*, 1999).

Measures

Nonspecific Psychological Distress

Nonspecific distress was measured using the 25-item Demoralization Scale that measures self-esteem, hopelessness or helplessness, sense of dread, confused thinking, sadness, and anxiety (Dohrenwend *et al.*, 1980). A total demoralization score was computed from the sum of all items with high scores reflecting greater experience of psychological distress, α .92.

Independent Variables

HIV-Stigma

Perception of being stigmatized was measured using a 24-item instrument, Social Impact Scale (Fife and Wright, 2000). A principal components analysis with varimax rotation resulted in a five-component solution that account for 69% of the total variance (see Appendix A). The five components included: Social Rejection; Negative Self-Worth; Perceived Interpersonal Insecurity; Financial Insecurity; and Discretionary Disclosure. Participants were asked to rate the extent to which they agreed with experiences of being stigmatized, 1 = *strongly disagree*, to 4 = *strongly agree*. Total scores ranged from 24 to 96, with a highest score indicating the strongest sense of feeling stigmatized, α 's .67 to .92.

Physical Symptoms

An 11-item physical symptom distress scale was adapted from the Adult AIDS Clinical Trials Group (AACTG; Chesney *et al.*, 2000) to measure participants' physical health status, such as pain, gastrointestinal discomfort, and high fever. Participants indicated the frequency of experiencing symptoms in the past 2 weeks, 0 = *Never* to 3 = *Often*, yielding total symptom scores ranging from 0 to 33.

Social Support

The 8-item Social Support Scale used by the AACTG was used to measure how frequently participants kept in touch with family members and friends, and how satisfied they were with their overall support. A total social support score ranging from 4 to 20 was calculated, with the highest score indicat-

ing high levels of social support from family members and friends.

Sociodemographic Information

Sociodemographic variables included age, ethnicity, country of birth, sexual orientation, language preference, education and employment history, housing, marital status, medical insurance coverage, and immigration status.

Medical Information

Participants self reported CD4 lymphocyte cell count, HIV/RNA viral load, date of and reason for HIV-antibody test, and HIV disclosure information.

Data Analyses

Prior to conducting the major analyses to determine the relationship between HIV-related stigma factors and psychological distress, we examined the bivariate relationships between sociodemographic variables and psychological distress and found that none were statistically significant. Country of birth (US-born vs. non-US born) approached significance and was included as a covariate in the analyses predicting psychological distress. Independent sample *t*-tests were conducted to compare mean group differences in predictor and outcomes variables between documented and undocumented immigrants. Simple linear regression was conducted to examine the independent contributions of HIV-related stigma factors (Social Rejection, Negative Self-Worth, Perceived Interpersonal Insecurity, Financial Hardship, and Discretionary Disclosure), self-reported physical symptoms, HIV disclosure, and social support in predicting psychological distress.

Hierarchical multiple regression analyses were performed to determine whether HIV-stigma factors in combination predicted distress. To minimize the number of predictors in the regression model, only those significant predictors from the initial simple regressions were included in the analyses. Variables were entered in three blocks, with self-reported physical symptoms entered on Step 1, country of origin on Step 2, and HIV-stigma factors simultaneously on Step 3. In order to obtain an independent measure of each stigma factor, exact-weighted scores were obtained on the basis of the principal

components solution after varimax rotation. Exact weighted scores effectively isolated variance related to major aspects of stigma onto different summary scales that were constrained to be orthogonal (the five orthogonal variables summarize 69.23% of the total variance among 24 items). As such, they were included in the regression analyses without concern for multicollinearity.

RESULTS

The ages of the 45 male participants ranged from 24 to 58 years ($M = 42$ years, $SD = 8.17$), of the 8 female participants, 20 to 65 years ($M = 42$ years, $SD = 13.60$), and the one transgender participant was 45-years old. The ethnic composition of the sample was Chinese (56%), Filipino (9%), Southeast Asian (the 19% included Burmese, Laotian, Malaysian, Thai and Vietnamese), Japanese (9%), Korean (4%), (2%), and Indian (2%). The majority of participants were born in Asia or the Pacific (93%), and only 12 (22%) spoke primarily English. Twenty-three participants self-identified as homosexual, 28 as heterosexual, and 3 declined to respond about their sexual orientation. Twenty-eight participants were single and 11 had partners.

There were 34 legally documented immigrants (includes US permanent residents, holders of valid temporary student of employment visas) or US citizens, and 20 undocumented who entered the US illegally or overstayed their visas. The documented participants had lived in the US for a mean of 21 years ($SD = 8.4$), and the undocumented for a mean of 8 years ($SD = 4.3$). Although a slim majority were employed ($n = 30$, 56%), 25 (46%) completed less than 12 years of education in the US and/or abroad. The majority lived in rental apartments ($n = 41$) with other occupants ($n = 37$). Many received health insurance coverage from the AIDS Drug Assistance Program (ADAP; $n = 23$) and/or Medicaid ($n = 22$).

The mean length of post-HIV/AIDS diagnosis was 6 years ($SD = 4.17$, range = 3 months–15 yrs), and the majority of participants reported stable immune functioning with 74% reporting undetectable HIV/RNA viral load, and 83% reporting CD4 lymphocyte cell counts greater than 200 cells/mm³. Most participants tested positive for HIV-antibodies after developing HIV-related symptoms ($n = 28$), and the majority ($n = 30$) had disclosed their HIV-status to four or more persons excluding providers.

Table I. Simple Regression Analyses with Illness-Stigma, Social Support, Disclosure to Family and Peers, and Self-Reported Physical Symptoms Predicting Psychological Distress^a

	R^2	p
Illness stigma factors		
Social rejection	.137	.006
Negative self-Worth	.126	.008
Perceived interpersonal insecurity	.147	.004
Financial hardship	.081	.037
Discretionary disclosure	.017	.348
Social support		
Family support	.015	.381
Peer support	.025	.258
Total social support	.033	.190
HIV disclosure to family and peers	.007	.537
Self-reported physical symptoms	.133	.007

^a $n = 54$.

Stigma and Associations with Psychological Distress

As hypothesized, stigma-related Social Rejection, Negative Self-Worth, Perceived Interpersonal Insecurity, and Financial Security were all significantly associated with psychological distress, with Perceived Interpersonal Insecurity accounting for 15% of the variance in psychological distress (see Table I). Self-reported physical symptoms were also associated with psychological distress. Receiving support from family members and peers, and disclosure of HIV-serostatus were not significantly correlated with psychological distress.

Independent sample t -tests showed that undocumented Asians endorsed higher levels of stigma-related Social Rejection, $t(52) = 2.56$, $p < .01$, Negative Self Worth, $t(52) = 2.59$, $p < .01$, and Perceived Interpersonal Insecurity, $t(52) = 2.79$, $p < .01$, than documented participants (see Table II). Also, compared to documented participants, the undocumented reported receiving less social support from peers and family members $t(52) = -3.52$, $p < .01$, and disclosed their HIV-serostatus to fewer people than documented participants, $t(52) = -3.61$, $p < .01$.

Hierarchical multiple regression analyses were conducted to determine whether the stigma factors were independently associated with psychological distress, controlling for self-reported physical symptoms and country of birth—both were significant variables in the bivariate analyses. As shown in Table III, self-reported physical symptoms were significantly associated with psychological distress, and entry of participants' country of origin at Step 2

Table II. Means and Standard Deviations of Predictor and Outcome Variables

	Documented immigrants (<i>n</i> = 34)		Undocumented immigrants (<i>n</i> = 20)	
	Mean	<i>SD</i>	Mean	<i>SD</i>
Psychological distress	24.12	11.51	27.55	11.58
Illness stigma				
Social rejection	20.38	6.60	23.90*	3.45
Negative self-worth	10.09	2.79	11.65*	1.66
Perceived interpersonal insecurity	5.38	1.50	6.25**	.78
Financial hardship	7.53	2.08	8.30	1.67
Discretionary disclosure	5.26	1.29	5.30	1.30
Social support				
Family support	7.00	1.63	6.40	1.43
Peer support	7.32	1.32	6.15*	1.63
Total social support	14.32	2.19	12.55*	2.44
HIV disclosure to family and peers	6.47	2.75	3.95**	2.72
Self-reported physical symptoms	11.91	6.85	10.10	5.33

Note. Higher scores indicate stronger indicators of psychological distress, illness stigma, social support, and more family members/ peers to whom one has disclosed their HIV-serostatus, and frequency of physical symptoms.

p* < .05; *p* < .01.

added significantly to the regression equation, adjusted $R^2 = .164$, with a significant R^2 change = .063, $p < .05$.

When HIV-stigma subscales were simultaneously added to the model at Block 3, the overall equation remained significant, Adjusted $R^2 = .379$, with R^2 Change = .26, $p < .01$. After adjusting R^2 for the small sample size, physical symptoms accounted for 12% of the variance in psychological distress, while country of origin explained an additional 5%. As a set, the stigma factors accounted for an additional 22% of the variance in psychological distress. Among the stigma factors, three stigma components

significantly predicted psychological distress, specifically negative self-worth, social rejection, and perceived interpersonal insecurity.

To clarify how different stigma factors influenced psychological distress, we examined 10 possible two-way interaction effects between pairs of stigma components after controlling for physical symptoms, country of origin, and the main effects of the five stigma components. Of these 10 interactions, two produced significant increases in psychological distress. Financial Insecurity compounded the deleterious effects of Perceived Interpersonal Insecurity (9% increase in adjusted R^2) and concerns about

Table III. Hierarchical Multiple Regression Predicting Psychological Distress

	R^2	Adjusted R^2	R^2 change	β	<i>t</i>
<i>Step 1</i>	.133**	.116**			
Self-reported physical symptoms				.364	2.82**
<i>Step 2</i>	.196**	.164**	.063*		
Self-reported physical symptoms				.361	2.88**
US-Born ^a				-.251	-2.00*
<i>Step 3</i>	.461***	.379***	.265**		
Self-reported physical symptoms				.318	2.83**
US-Born				-.314	-2.70*
Illness stigma factors					
Discretionary disclosure				.145	1.34
Social rejection				.268	2.45*
Perceived interpersonal insecurity				.266	2.44*
Financial hardship				.041	.373
Negative self-worth				.325	2.77**

Note. β , Standardized regression coefficients.

^aUS-coding (0 = Non-US born, 1 = US-born).

p* < .05; *p* < .01; ****p* < .001.

Discretionary Disclosure heightened the impact of Negative Self-Worth (5% increase in adjusted R^2). When entered together, these two effects added 13% variance to the original regression model, suggesting that these two interaction terms contributed unique variance to the explanation of psychological distress.

DISCUSSION

HIV-related stigma has been widely recognized as a complex social and individualized phenomenon that hampers HIV care, particularly among racial and ethnic minority groups (Herek, 1999). APIs living with HIV/AIDS who have contended with pre-existing inequalities in the US are particularly vulnerable to the effects of HIV-related stigma as evidenced by delay in accessing care, avoidance of HIV-disclosure, and poor adherence to medical treatment. Findings from this study, which represent the first research effort that we are aware of to examine the psychological sequelae of illness stigma among HIV-seropositive APIs in the US, clearly suggest that HIV stigma is a multidimensional construct that affects psychological distress. Social Rejection, Negative Self-Worth, and Perceived Interpersonal Insecurity were associated with heightened level of distress, after control for country of origin and self-reported physical symptoms, a well-documented predictor of psychological distress (Griffin and Rabkin, 2000; Pugh *et al.*, 1994). Numerous studies of persons living with HIV/AIDS have supported the associations between psychological distress and perceived social support (Hudson *et al.*, 2001; Fleishman *et al.*, 2000), HIV illness progression (Golub *et al.*, 2003), physical functioning (Vogl *et al.*, 1999) and spirituality (Tuck *et al.*, 2001; Ironson *et al.*, 2002). Findings from this study highlight two dimensions of stigma to consider when examining mechanisms that influence psychological distress among APIs living with HIV illness.

First, HIV-stigma creates and perpetuates feelings of negative self-worth and blame. Consistent with Goffman's (1963) description of the stigmatized as an individual who "stands a discredited person facing an unaccepting world" (p. 19), APIs in this study internalized negative values ascribed to persons with HIV/AIDS by society *and* themselves. Kang *et al.* (2003) found that self-attribution and blame for acquiring HIV among a cohort of HIV-seropositive undocumented Asians were rooted in discriminatory attitudes they harbored against persons with

HIV/AIDS prior to learning about their personal HIV-status. They regarded their HIV-serostatus as a mark of inclusion to marginalized groups (e.g., substance abusers, sexually promiscuous patrons of commercial sex workers, and homosexuals) regardless of whether this perceived stigma accurately reflected the views of others. Moreover, undocumented Asians in Kang *et al.*'s (2003) study perceived themselves as contagious susceptible of inadvertently transmitting the virus to others by casual contact. As APIs contend with various forms of self-devaluation, they are inclined to conceal their HIV status, the perceived source of their negative self-worth. Maintaining one's HIV status a secret and averting possibilities of unintended disclosure consume and become emotionally draining for APIs (Kang *et al.*, 2003). The significant interaction effect between Perceived Interpersonal Insecurity and Discretionary Disclosure on psychological distress in this study further suggests that fear of inadvertent (or deliberate) public disclosure by others who know about their serostatus heightened the influence of perceived interpersonal insecurity on psychological distress. Future longitudinal studies are necessary to guide intervention models that effectively address internalized stigma and self-devaluation within specific API sociocultural contexts and migration histories without indiscriminately applying presumed cultural values to all APIs (Sue and Zane, 1987).

Second, HIV-stigma compromised the quality and utility of interpersonal relationships and exacerbated fears of marginalization among APIs. Participants avoided establishing and maintaining meaningful supportive networks because they were fearful of disclosure and regarded themselves as unworthy of receiving or providing support. Their pre-illness experiences of both actual and felt marginalization on the collective basis of their racial identity, gender, immigration status, socioeconomic standing, and sexual orientation, were compounded by an overwhelming fear of being ostracized for their HIV status. Regardless of whether or not this cautious style of interaction arises from actual experiences of being discriminated against, it remains important to assist APIs foster both new and strengthen any existing supportive networks. Such supportive networks must be carefully selected, as not all forms of support are necessarily adaptive, as evident by the statistically non-significant relationship between social support and psychological distress reported in this study. Previous findings have also demonstrated that although social networks can buffer against disruptive

life events, the costs and benefits of social support are not equally shared across groups (Kawachi and Berkman, 2001; Smith and Rapkin, 1996). Moreover, particular API groups place value on their ability to cope with problems independently and differentiate between the support received from “in-group” (e.g., family and intimate friends) and “out-group” members (e.g., service providers; Matsudaira, 2003). Some HIV-seropositive APIs, for example, garner mutual support from other APIs living with the illness who function as a proxy for family (Eckholdt *et al.*, 1997), whereas others minimize their contact with other APIs in fear that suspicions of their illness will circulate within their community (Yoshikawa *et al.*, 2001). This underscores the importance of clarifying how APIs define and utilize supportive networks and identifying specific aspects of social support that buffer against psychological distress.

It is important to note that Discretionary Disclosure didn't significantly predict psychological distress. Having known about their HIV-serostatus for a median of 5-years, APIs in this study have likely adjusted to receiving support and assistance from a select group of friends and family. Forty-four percent of participants disclosed to 3 individuals or less, suggesting that patterns of disclosure remain highly selective. Hence, the fear that this group of close friends and/or family members would inadvertently or intentionally disclose their HIV-serostatus was of minimal concern. This raises the importance of moving beyond exploring the psychological risks and benefits of whether or not to disclose one's HIV-serostatus and to begin considering how HIV disclosure affects relationships within different supportive networks (Kalichman *et al.*, 2003).

Finally, efforts to reduce the negative consequences of HIV stigma among APIs necessitate integrating *both* individual and structural intervention models that account for “inequalities as well as policies and institutional practices that . . . concretely shape the spread of HIV infection” (Parker *et al.*, 2000). HIV stigma is shaped not only by individual perceptions and interpretations of micro-level interactions, but also by larger social and economic forces. Although it was beyond the scope of this study to examine how political, social, and cultural forces contribute to and heighten stigma, it is noteworthy to highlight particular inequalities from which HIV-related stigma possibly arises within APIs represented in this study. Undocumented Asians, for example, endorsed significantly higher levels of Social Rejection, Negative Self-Worth, and Perceived In-

terpersonal Insecurity than APIs with documented immigration status. Moreover, compared to documented APIs, the undocumented received less social support from peers and disclosed their HIV-serostatus to fewer people. Further studies are needed to broaden our conceptualization of illness stigma and to clarify what Parker and Aggleton (2003) accurately framed as the “specific contexts of culture and power” from which “stigma arises and stigmatization takes shape.” Moreover, if future studies are to capture the breadth of stigma-related processes among APIs, the complex relationships between HIV and other possible sources of stigma for APIs need to be elucidated (e.g., ethnic, racial, socioeconomic class, sexual orientation, gender, and immigration status).

This study has limitations that could affect its generalizability and interpretation. First, the cross-sectional study design and small sampling does not allow us to determine the temporal sequence of events. It is plausible, for example, that the relationship between stigma and psychological distress could be explained by the influence of distress on stigma. Second, the findings and implications of this study cannot be generalized to the experiences of all Asians and Pacific Islanders living with HIV/AIDS in the US. The findings are limited to a small convenience sample of HIV-seropositive APIs receiving supportive services from community-based AIDS organizations, 56% of which were ethnic-Chinese. Moreover, the majority of APIs in this sample were in medically stable conditions (74% reported undetectable HIV/RNA viral load). These self-selection biases limit the generalizability of the current findings to those who are not accessing or utilizing supportive services as well as other API groups with more significant immunocompromise. As such, future studies with a larger API sampling based on ethnicity, gender, and migration history will be important in identifying cultural distinctives and nuances that inform and mitigate HIV stigma.

Notwithstanding these limitations, findings from this study indicate that HIV-stigma is a multidimensional concept that is associated with heightened psychological distress. As the spread of HIV gains rapid momentum among APIs in the US and Asia, it is timely to clarify dimensions of HIV-stigma and its multiple relationships with psychological distress to develop and implement individual- and structural-based interventions that will reduce stigma and improve the overall quality of life for APIs living with HIV/AIDS.

APPENDIX A

Factor 1: Social rejection (nine items)^a

My employer/co-workers have discriminated against me because of my illness.

Some people act as though I am less competent than usual.

I feel that I have been treated with less respect than usual by others.

I feel others are concerned they could “catch” my illness through contact like a handshake or eating food I make.

I feel others avoid me because of my illness.

Some family members have rejected me because of my illness.

I feel some friends have rejected me because of my illness.

I encounter embarrassing situations as a result of my illness

Due to my illness others seem to feel awkward and tense when they are around me.

Factor 2: Negative self-worth (four items)^b

I feel I am at least partially to blame for my illness.

I feel less competent than I did before my illness.

Due to my illness, I sometimes feel useless.

Changes in my appearance have affected my social relationships.

Factor 3: Perceived interpersonal insecurity (two items)^c

I feel I need to keep my illness a secret.

I have a greater need than usual for reassurance that others care about me.

Factor 4: Financial insecurity (three items)^d

I have experienced financial hardship that has affected how I feel about myself.

My job security has been affected by my illness.

I have experienced financial hardship that has affected my relationship with others.

Factor 5: Discretionary disclosure (two items)^e

I do not feel I can be open with others about my illness.

I fear someone telling others about my illness without my permission.

Excluded items

I feel others think I am to blame for my illness; I feel set apart from others who are well; I feel lonely more often than usual; Due to my illness, I have a sense of being unequal in my relationships with others.

^aNine items; $\alpha = .917$; eigenvalue = 5.91; percent of the variance explained = 24.62.

^bFour items; $\alpha = .811$; eigenvalue = 3.50; percent of the variance explained = 14.60.

^cTwo items; $\alpha = .665$; eigenvalue = 2.57; percent of the variance explained = 10.69.

^dThree items; $\alpha = .777$; eigenvalue = 2.46; percent of the variance explained = 10.25.

^eTwo items; $\alpha = .715$; eigenvalue = 2.18; percent of the variance explained = 9.10.

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