

# Measuring Stigma in Older and Younger Adults with HIV/AIDS: An Analysis of an HIV Stigma Scale and Initial Exploration of Subscales

Charles A. Emlet

University of Washington, Tacoma

*The purpose of this study is to explore the validity of a scale designed to measure HIV stigma and identify potential subscales. A nonrandom sample of 88 individuals, 44 between the ages of 20 and 39 and 44 ages 50 and older, living with HIV/AIDS were interviewed and completed a 13-item HIV Stigma Scale. An exploratory factor analysis (EFA) found 12 of the 13 items loaded cleanly into three subscales labeled as Distancing, Blaming, and Discrimination, with an overall Cronbach's alpha of .83. The three newly identified subscales were found to have convergent validity with social support as expected. Overall, older adults were found to have higher, but nonsignificant scores on the Blaming subscale, whereas those 20 to 39 years old had significantly higher scores related to discrimination. The 13-item HIV stigma scale can discriminate experiences of stigma in older adults and support three subscales while maintaining internal consistency.*

**Keywords:** older adults; HIV/AIDS; stigma; discrimination; stigma scale

The HIV Stigma Scale is a 13-item instrument designed to measure subjective perceptions of stigma by persons living with HIV/AIDS. Sowell et al. (1997) developed the instrument to determine experiences of stigma among women infected with the HIV disease. The purpose of the current investigation is to examine the development of subscales as well as to extend the use of the scale to include a broader population, specifically older adults living with HIV/AIDS.

Despite beliefs to the contrary, older adults comprise a significant portion of individuals throughout the United States who have been diagnosed with HIV/AIDS. Historically, society has viewed HIV/AIDS as a young person's disease, heavily affecting those in young adulthood and early middle age (Riley, 1989). Because of this view, older adults who are infected or affected by HIV/AIDS have received limited research, program, and policy attention (Ory & Mack, 1998). Surveillance data from the Center for Disease Control and Prevention (CDC)

indicates that as of the end of 2000, 60,956 men and women older than 50 in the United States were living with AIDS (CDC, 2003). These figures do not include persons age 50 and older who are HIV positive. Data originating from a conference sponsored by the National Institutes of Health, Office of AIDS research, suggests that when numbers are adjusted to reflect actual age rather than age at diagnosis, the proportion of persons older than 50 living with AIDS is closer to 15% of all AIDS cases in the United States (Ory & Mack, 1998). The advent of highly active antiretroviral therapies in the 1990s has extended life for many persons with HIV disease and will allow, as never before, individuals who were infected in middle age to live into old age. As increasing numbers of older adults become infected with HIV and live longer lives, it is incumbent on the social work profession, as well as the health care system in general, to better understand the factors that contribute, either positively or negatively, to their quality of life.

An important element that affects the quality of life of all persons with HIV disease is stigma. HIV stigma is a ubiquitous phenomenon that the Joint United Nations Programme on HIV/AIDS (UNAIDS; 2002) suggests is "universal, occurring in every county and region of the world" (p. 5). UNAIDS has well-documented cases from throughout the world of persons being stigmatized and discriminated against and denied services because of their serostatus. In a recent report on this issue, UNAIDS

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(2003) theorizes that HIV-related stigma is a process of devaluation. This process, which begins with stigma, often leads to discrimination, which in turn leads to the violation of human rights for people living with HIV/AIDS. For example, Chandra, Deepthivarma, and Manjula (2003) have documented that the fear of breaches of confidentiality are common in countries such as India, and Busza (2001) documents AIDS orphans in Southeast Asia being forced to leave their villages and denied entry into schools. Despite its widespread existence, AIDS stigma is a widely recognized but little understood problem (Herek et al., 1998). A workshop convened by the National Institute of Mental Health found that AIDS stigma has not been extensively studied and suggests that research in this area is urgently needed. The members of the expert panel concluded that "AIDS stigma often appears to have been regarded by researchers principally as a backdrop against which the epidemic has occurred rather than as a phenomenon warranting study in its own right" (Herek et al., 1998, p. 41). Numerous studies have found HIV stigma to be associated with various interpersonal and psychosocial issues, such as feelings of shame and guilt (Bennett, 1990; Laryea & Gien, 1993), fear and anger (Bennett, 1990; Laryea & Gien, 1993), mental strain (Green & Platt, 1997), and feelings of self-loathing (Bennett, 1990; Herek, 1999; Herek et al., 1998). Also, HIV stigma has been associated with clinical symptoms of depression in a variety of HIV-infected populations (Crandall & Coleman, 1992; Hall, 1992; Heckman, Kochman, & Sikkema, 2002; Laryea & Gien, 1993; Siminoff, Erlen, & Lidz, 1991; Swendeman, Comulada, Lee, & Rotheram-Borus, 2002). Despite the fact we have entered the third decade of the HIV/AIDS pandemic, HIV stigma continues to exist. In a recent study of attitudes about HIV, Eroglu, Newman, and Peterman (2002) found that although HIV stigma is declining overall, some elements are on the rise. They found a significant increase between 2000 and 2001 in individuals who feel that the U. S. government should not pay for treatment for uninsured individuals with HIV/AIDS. In another recent study of a nationally representative sample of U.S. households, Herek, Capitanio, and Widaman (2002) found nearly one quarter of respondents felt people who got AIDS from sex or drug use "got what they deserved" (p. 372). This finding supports the work of Busza (2001), who found that Southeast Asian societies often use a "gradient of guilt and innocence" (p. 442) according to social perceptions of how one became infected. One important element of furthering this research agenda will be the development of instruments designed to measure the phenomenon of HIV stigma and

also the implementation of those instruments in study populations that include older adults. Our ability to accurately identify and measure HIV stigma is critical as it "interferes with effective societal responses to AIDS and has imposed hardships on people living with HIV as well" (Herek et al., 2002, p. 371).

Despite the work that has been done related to HIV stigma, a review of the literature reveals a paucity of research focusing on older adults. For example, in the studies done by Bennett (1990), Laryea and Gien (1993), and Green and Platt (1997), no older adults were included in the research. Although McCain and Gramling (1992) included several individuals older than age 50, a sole 71-year-old male was considered an outlier and eliminated from the study. In another recent study of stigma and shame among individuals recently tested for HIV or gonorrhea, Fortenberry et al. (2002) excluded from their analysis all individuals older than 59 years to "focus on the groups at greatest STD/HIV risk" (p. 379). Thus, a potential source of data on stigma, HIV, and aging is being ignored. Although Berger, Ferrans, and Lashley (2001) did include older adults in their study of HIV stigma, the final sample consisted of only 2 males and no females older than 55 years. Still, other studies on HIV stigma, such as Crandall and Coleman (1992) and Weitz (1990), have neglected age as a variable in their analysis.

When older adults have been included in some studies of HIV stigma, various measurement issues exist. For example, Heckman, Kochman, et al. (2002) examined HIV stigma as part of a quality of life model for older, HIV-infected adults. Because this study was primarily concerned with the development of a quality of life model, stigma was examined using only two items. Both items captured the perceptions of stigma as it related to community residents, which may fall short of obtaining necessary information on multiple aspects of stigma, including felt or personalized stigma and its effects. The second study by Heckman, Heckman et al. (2002) examined psychological symptoms including depression and paranoid ideation and found them associated with increased barriers to care because of stigma. As with the previously cited study, stigma was captured using four items as part of the Barriers to Care Scale (Heckman, Kochman et al., 2002).

## THEORETICAL FRAMEWORK

The concept of HIV stigma is based on the work of Goffman (1963), who pioneered the concept of stigma, suggesting that situations exist which spoil one's social

identity. The discrediting attributes of which Goffman spoke may take the form of physical deformity, blemishes of character, and tribal stigma (Goffman, 1963). Persons living with HIV/AIDS can be impacted by any or all of these forms of stigma. Recently, HIV stigma has been more specifically conceptualized and defined as prejudice, discounting, discrediting, and discrimination, which are directed at people perceived to have HIV or AIDS (Herek et al., 1998). Although stigma, or spoiled identity (Goffman, 1963), is felt by persons with a wide spectrum of diseases, four characteristics associated with higher levels of stigma are found with HIV/AIDS. These characteristics include the following: (a) diseases perceived to be the bearer's responsibility, (b) diseases that are associated with unalterable or degenerative conditions, (c) conditions perceived to be contagious, and (d) conditions that are readily apparent to others (Green & Platt, 1997; Herek, 1999).

The research that explores stigma and HIV/AIDS to date has suggested numerous negative psychological, interpersonal, and societal consequences. Green and Platt (1997) suggest HIV stigma may be enacted or felt. *Enacted stigma* refers to individually or collectively applied sanctions, such as discrimination or prejudice. *Felt stigma*, on the other hand, relates to feelings of shame, guilt, and the oppressive fear of enacted stigma. This conceptualization of HIV stigma suggests the existence of various components that may manifest differently from individual to individual. Thus, the use of a one- or two-item measure, which attempts to identify the multidimensional constructs of stigma, will likely fall short of the desired goal. Additionally, it will become increasingly important to examine this important psychosocial phenomenon among older adults to determine types and levels of stigma among various subpopulations of older adults.

It is impossible to examine the phenomenon of HIV stigma without recognizing the coexistence of homophobia and racism. Compounding the issue of HIV stigma are elements of institutionalized prejudice experienced by vulnerable populations impacted by HIV/AIDS. Historically, HIV has been seen as a disease of outsiders, exacerbating discrimination. According to UNAIDS (2002), "people with HIV/AIDS from racial and ethnic minorities [and this author suggests sexual minorities as well] are seen not as individuals living in the contexts of marginalization, but as the cause of their own misfortune" (p. 9). The portrayal of HIV/AIDS often plays into and reinforces existing social inequities regardless of whether the focus is on race and ethnicity, sexual orientation, or paid sex work. Although society may enact stigma based

on group membership, as well as HIV status, Green and Platt's concept of felt stigma is also relevant. Kraft, Beeker, Stokes, and Peterson (2000) have presented the concept of double minority in their study of 76 African American men who have sex with men. Participants in this study reported feeling marginalized by both the African American community and the gay White community because of homophobia and racism. Similar sentiments have been documented in gay and bisexual Latino men (Brown & Ramirez-Valles, 2002).

## THE HIV STIGMA SCALE

In the late 1990s, Sowell et al. (1997) developed a 13-item scale designed to measure the phenomenon of HIV stigma. The initial development of the scale grew out of qualitative research with HIV-positive women in the southeastern parts of United States (Moneyham et al., 1996). According to the authors, in their originally published presentation of the scale, the Stigma scale was "primarily developed from focus groups [and] additional questions were included by the researchers based on a review of the available literature" (pp. 304-305). The 13 items were developed using a 4-point Likert-type scale ranging from 1 to 4 and were designed to determine how often individuals had thoughts and feelings of being stigmatized or put in jeopardy because of their illness. The response choices were 1 = *not at all*, 2 = *rarely*, 3 = *sometimes*, and 4 = *often*. The questions in the scale ask respondents about various aspects of feeling stigmatized using items such as, "I felt blamed by others for my illness," "I feared people would hurt my family if they learned of about my illness," and "I felt ashamed of my illness." The scale was developed to be used as a summated scale with total scores ranging from a low of 13 to a high of 52, with higher scores equating to greater stigma. All 13 questions used in the HIV Stigma Scale are shown in Table 1. The scale was originally completed by 82 respondents, all of which were women. Only three individuals in the original sample were 50 years or older.

The original development and initial testing of the HIV Stigma Scale provided HIV researchers with some important tools for assessing the perceptions of HIV stigma. The scale recognized, first of all, that stigma is not a unidimensional phenomenon. As Green and Platt (1997) suggest, stigma can be experienced from an internal (felt) perspective or may manifest more externally as in direct or indirect discrimination (enacted). Unfortunately, little information regarding the internal consistency of the scale has been reported. No further research

**TABLE 1: HIV Stigma Scale (13 items)**

	1 = Not at All	2 = Rarely	3 = Sometimes	4 = Often
1. I felt blamed by others for my illness.				
2. I felt ashamed of my illness.				
3. I thought my illness was a punishment for things I've done in the past.				
4. I feared that I might lose my job if someone found out about my illness.				
5. I felt compelled to change my residence because of my illness.				
6. I avoided getting treatment because someone might find out about my illness.				
7. I feared that people would hurt my family if they learned about my illness.				
8. I thought other people were uncomfortable being with me.				
9. I felt people avoid me because of my illness.				
10. I feared I would lose my friends if they learned about my illness.				
11. I feared my family would reject me if they learned about my illness.				
12. I felt I wouldn't get as good health care if people knew about my illness.				
13. People who know I am HIV positive treat me with kid gloves.				

has been conducted on potential subscale development that may shed light on the various ways in which HIV stigma may manifest for the infected individual.

## METHOD

This research provides important information on psychometric properties of the HIV Stigma Scale while at the same time reports initial results of an EFA and subscale development. In addition, this research examines the results of the scale when administered to a population of older, HIV infected-individuals. As suggested previously, studies examining stigma that do involve older adults often use single item measures or limited questions to proxy the concept of HIV stigma.

### Participants and Procedures

Interviews of all participants were conducted during 2002 and 2003 in collaboration with an AIDS service organization (ASO) in the Pacific Northwest. According to agency data, 12.3% of unduplicated clients from this agency were age 50 and older, approximating the percentage of older adults living with AIDS found in national statistics as well as in Washington State.

As part of the cooperative research agreement, case managers from the ASO contacted clients (both active and inactive) in the agency database who were 50 years or older, notifying them of the opportunity to participate in this study. Because of the relatively small number of individuals aged 50 and older living with HIV disease, purposive sampling techniques were used. A comparison sample was developed using a matched case control design. Each older adult was matched as closely as possible on gender, ethnicity, HIV-transmission route, and

diagnosis with an individual between the ages of 20 and 39. During the initial contact with respondents, the study was briefly described; for those interested, an appointment was made for a face-to-face interview with the principal investigator or a research assistant. At that initial appointment, the study was described in detail, and participants who wished to continue signed the informed consent. Structured interviews lasted 45 minutes to 1 hour, during which time participants answered questions related to sociodemographic characteristics, including age, gender, race and ethnicity, education, income, employment status, Medicaid eligibility, and HIV diagnosis (HIV vs. AIDS). In addition to this information, participants completed the HIV-stigma questionnaire, as described previously, and the Lubben Social Network Scale (LSNS-18). Data related to the social networks of the sample has been reported elsewhere (Emlet, 2003) and is not included in this analysis except as relevant to HIV stigma. No in-depth or qualitative questions were asked. All but two of the interviews were completed in English, with the exceptions conducted in Spanish through an interpreter. The instrument itself was not translated, but rather the questions were translated by a bilingual interviewer. After the survey was successfully completed, participants were given \$25 for their participation. The university's institutional review board for the protection of human participants approved all study procedures.

### Scale Assessment and Development

As previously discussed, although the HIV Stigma Scale was developed in the late 1990s and first published in 1997, limited evaluation has been done on its psychometric properties. A recent communication with one of the leading architects of the original scale

suggested that, to his knowledge, no evaluation has ever been undertaken to identify or develop subscales for this instrument (R. Sowell, personal communication, January 28, 2004). The original 13 items of the scale were assessed using an EFA employing principal components extraction and Varimax rotation with Kaiser normalization. The analysis was conducted using SPSS for Windows (version 11.5). Because of the lack of previous scale development and no a priori assumptions about factors, an EFA was used (Kim & Mueller, 1978).

## RESULTS

### Sample Characteristics

The sample consisted of 88 adults with HIV/AIDS. Forty four of these individuals were 50 years or older, ranging in age from 50 to 71 years with a mean of 55.6. The 44 younger adults ranged in age from 20 to 39 years with a mean of 34.0. Both groups were approximately two thirds White with 22% identifying as African American. The younger group had a slightly higher makeup of Hispanics (11.1%) as compared to the older group (7.3%). Nearly half of the older adults lived alone compared to 18.8% of the younger group. The younger and older group had similar levels of education (12 years and 13.1 years, respectively) and more than half of both groups received Medicaid in the past year. Nearly three quarters of the younger group identified themselves as unemployed, as compared to 22% of those older than age 50. The older adults were more likely to identify themselves as retired because of either age or disability. Approximately 70% of both groups had met the CDC criteria for an AIDS diagnosis with the remainder being HIV positive. Both groups had been HIV positive for some time with the younger group averaging 8.8 years compared to 7.9 years for the older age group.

### Exploratory Factor Analysis

The EFA was conducted using data from the 88 adults with HIV/AIDS. The initial principal component analysis yielded four factors with eigenvalues greater than 1 (eigenvalues = 4.37, 1.27, 1.09, 1.03). Examination of the rotated factor loadings showed cross-loading and ambiguity for a four-factor solution. Based on the analysis of the scree plot, it was determined that a three-factor solution was optimal for distinguishing the underlying factors. These three factors accounted for 51.89% of the variance. The three factors consisted of the *distancing*

*factor* (eigenvalue = 4.37) the *blaming factor* (eigenvalue = 1.27), and the *discrimination factor* (eigenvalue = 1.09). The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was used to determine if the data were likely to factor well. The KMO statistic should be .60 or higher to proceed with a factor analysis (Kaiser, 1974). The KMO statistic for these data was .821. The Bartlett's Test of Sphericity was significant with  $\chi^2(78) = 303.83, p < .001$ .

Table 2 presents the factor loadings for the 13 items from the HIV Stigma Scale and EFA loadings for three subscales identified as *distancing*, *blaming*, and *discrimination*. Each of the subscales contains four items for a score ranging from 4 to 16. The 13th item was omitted from the subscales.

The factor loadings labeled as *distancing* consisted of four items, which included questions related to people being uncomfortable with the respondent, avoiding the respondent because of their illness, fearing the loss friends, and avoiding getting treatment. Although Questions 8 to 10 (see Table 2) were associated with distancing emanating from others, Question 6 (avoiding getting treatment because someone might find out about their illness) suggested respondent initiated distancing. There may be various reasons for this, including anticipated breaches of confidentiality. Ong, Clarke, Dunbar, and Mandal (1993) found 84% of the HIV-infected individuals in their study did not tell their general practitioner about their HIV because of fear of transgressions of confidentiality. Surlis and Hyde (2001) documented similar concerns almost a decade later in their sample of hospitalized HIV-infected individuals. The subscale items therefore shared the theme of social distance (i.e., uncomfortableness or avoidance) regardless of whether the social role with the HIV-positive person was that of friend, health care provider, or other and regardless of who initiated the distancing.

The second set of factor loadings were labeled *blaming* and also consisted of four items. The items that loaded to this subscale consisted of "I feared family would reject me if they learned of my illness," feeling blamed by others for their illness, and feeling ashamed of having HIV/AIDS. A fourth item concerned beliefs of receiving poorer health care if people know about their HIV. The concern over receiving poorer health care if their HIV status becomes known is consistent with findings that the general population (McDonnell, 1993), as well as service providers (Cobb and de Chabert, 2002), may attribute more blame and less willingness to help those with HIV/AIDS depending on the perceived responsibility of the individual for their infection. Other sociodemographic factors may also influence perceptions of health care. In a

**TABLE 2: EFA Pattern Matrix Loadings for 13 HIV Stigma Scale Items**

	<i>Distancing</i>	<i>Blaming</i>	<i>Discrimination</i>
(8) I thought other people were uncomfortable being with me	<b>.854</b>	-.019	.199
(9) I felt people avoid me because of my illness	<b>.836</b>	.060	.255
(10) I feared I would lose my friends if they learned about my illness	<b>.624</b>	.411	.159
(6) I avoided getting treatment because someone might find out about my illness	<b>.504</b>	.444	-.092
(12) I felt I wouldn't get as good health care if people know about my illness	.110	<b>.689</b>	.226
(11) I feared my family would reject me if they learned about my illness	.059	<b>.638</b>	.014
(1) I felt blamed by others for my illness	.079	<b>.523</b>	.275
(2) I felt ashamed of my illness	.438	<b>.487</b>	.330
(5) I felt compelled to change my residence because of my illness	.230	-.028	<b>.737</b>
(7) I feared that people would hurt my family if they learned about my illness	.134	.168	<b>.642</b>
(4) I feared that I might lose my job if someone found out about my illness	.225	.201	<b>.630</b>
(3) I thought my illness was a punishment for things I've done in the past	-.503	.362	<b>.511</b>
(13) People who know I am HIV positive treat me with kid gloves	.376	.456	.187

NOTE: EFA = exploratory factor analysis. The bold numbers are the loadings for the questions as they fit into the three subscales.

recent study of 110 HIV-positive individuals, 23.6% felt they received poorer services than others based on socioeconomic status, whereas 14.6% attributed poorer services to race (Bird, Bogart, & Delahanty, 2004). This subscale shared items associated with stronger emotional reactions to HIV than the distancing factor. Both external (rejection and blame) and internal (shame) reactions were included in this subscale.

The third factor included four items that shared the theme of discrimination. Items include questions associated with active discrimination by others, such as job loss, fear of harm to family members, and feeling the need to change residence (relocate) because of reactions by others to their HIV. The fourth item ("I thought my illness was a punishment for things I've done in the past") is less obviously connected to discrimination. The discrimination literature, however, supports the concept of discrimination and negative psychological outcomes. One type of discrimination, identified as *scapegoating discrimination*, seeks to suggest that the individual is to blame for some social evil (New South Wales Anti-Discrimination Board, 1991). Such an experience can lead to the internalization of blame. In a recent study of 1,248 gay and bisexual men, Heubner, Rebchook, and Kegeles (2004) found experiences of discrimination associated with lowered self-esteem and a two-fold increase in the odds of reporting suicidal ideation. The literature, therefore, supports the concept of discriminating experiences leading to self-blame and psychological distress.

These 12 items loaded cleanly into the three subscales of distancing, blaming, and discrimination, with most loading at .500 or above. The 13th item in the original scale consisted of the item, "people who know I have HIV treat me with kid gloves." This item has factor loadings that were less clear. Although there is insufficient data to

suggest elimination of this item from the overall scale at this time, use of this item in a subscale is not clear. The decision was made therefore to retain the item in the overall scale score, despite the ambiguity of the subscale factor loadings.

### Reliability

Cronbach's alpha was calculated for all 13 items in the HIV Stigma Scale based on the responses of the 88 individuals from both age groups recruited in the study. The reliability coefficient for the overall scale was .83. Reliability coefficients were also calculated for the three subscales identified in the EFA. The coefficients for the three subscales are as follows: Blaming subscale (4 items), .76; Discrimination subscale (4 items), .62; and Distancing subscale (4 items), .60.

### Validity

The authors of the original scale reported that the questions used in the scale were developed from focus groups of HIV-infected women and assessed for validity; however, little more is documented about that process. Although the original purpose of this research was not scale development, the available data did provide an opportunity to examine factors related to convergent construct validity. Numerous studies that examined HIV stigma have found a consistent relationship between this construct and that of social support. Crandall and Coleman (1992), in their study of 48 individuals with HIV/AIDS, found that those individuals with lower levels of social support experience higher levels of AIDS stigma, anxiety, and depression. Similarly, Berger et al. (2001) found social support availability to be negatively

correlated with HIV stigma in a sample of 318 adults aged 18 and older. In developing their quality of life model, Heckman, Kochman, et al. (2002) found AIDS stigma to be negatively correlated with perceptions of social support in 83 HIV-infected individuals aged 50 and older.

Previous research suggests that measures of social support should serve as a convergent factor in the measurement of HIV stigma. To test this hypothesis, the three constructed stigma subscales were subjected to a correlation analysis with five elements of social support derived from the LSNS-18. The LSNS has been used in a wide array of studies associated with aging and health for more than a decade (Lubben & Gironde, 2003). The 18-item version of the scale presents the highest level of internal consistency ( $\alpha = .82$ ) of the three versions of the LSNS (a 6-, 12-, and 18-item version).

The Distancing, Blaming, and Discrimination subscales were correlated to overall LSNS scores and subscores for relatives, friends, and neighbors. In addition, the three subscales were correlated with a combination of three items each that examine the availability of a confidant and instrumental assistance. As seen in Table 3, the three stigma factors under investigation consistently correlated negatively (as expected) with social support.

Of particular interest is the significant correlation with having a confidant and having someone who can provide instrumental help. Those with weaker resources in emotional and instrumental social support appear to have higher levels of stigma.

### Age and Group Differences in HIV Stigma Scores

One of the major purposes of this research was to examine the experiences of older and younger adults with HIV in relation to stigma. As previously mentioned, case studies and anecdotal information has suggested that older persons may experience higher levels of HIV stigma than their younger counterparts (Solomon, 1996). Mean scores for the overall stigma measure and subscales were calculated between age groups and by other sociodemographic characteristics. The results of this analysis are shown in Table 4.

Those individuals in the younger age group had slightly higher overall stigma scores than their older counterparts (25.18 vs. 23.02); although, these differences were not statistically significant. To determine if age differences were being confounded by duration of illness (how long one had been infected), a comparison of duration of illness between age groups was conducted.

The younger age groups had been infected for an average of 68 months versus 57 months for their older counterparts. These differences were not statistically significant. When stigma scores for the three newly identified subscales were calculated, some differences were found. The mean scores for the three subscales varied across the scales and in only one instance showed a significant difference. As seen in Table 4, those 20 to 39 years of age had slightly higher mean scores on the Distancing subscale and slightly lower scores than their older counterparts on the Blaming subscale. Younger adults, however, had significantly higher mean scores on the Discrimination subscale than their older counterparts (7.82 versus 6.05;  $t = 2.85$ ;  $df = 86$ ;  $p < .01$ ). This is an example of how differences can be obscured by overall or summated scores. As seen in Table 4, the older and younger groups' subscale scores differed in the opposite direction and, therefore, tend to wash out differences in the overall score.

In comparing the sample by gender, female respondents consistently had higher mean stigma scores across all three subscales and all 13 items than their male counterparts. In all instances, the scores were only slightly higher and did not reach statistical significance. Stigma scores across ethnic and racial groups were analyzed using a one-way ANOVA. The results of this examination found a significance difference in the Blaming subscores,  $F(2,85) = 4.47$ ,  $p < .01$ , as well as overall stigma scores,  $F(2, 85) = 3.65$ ,  $p < .05$ . Tukey HSD post hoc tests showed that African Americans had significantly higher scores on the Blaming subscale than their White counterparts or those in the other ethnic racial groups ( $p < .01$ ; 95% Confidence Interval [CI] 0.45 to 4.11). The same pattern held true for the overall stigma score ( $p < .05$ , 95% CI 0.15 to 10.26). Analysis of variance was also used to examine stigma scores by HIV exposure category. Exposure categories included men having sex with other men, having sex with others of the opposite sex, and injecting drugs or other. As seen in Table 4, those with an exposure risk of gay or bisexual transmission had lower scores on all subscales and the overall stigma score than the counterparts with heterosexual exposure or injection drug use. In no instances, however, did these differences reach statistical significance. Stigma scores were compared by HIV status (being HIV positive versus having an AIDS diagnosis). In all instances, those who had been diagnosed with AIDS had lower stigma scores than their HIV-positive counterparts; although, the differences did not reach statistical significance. Having AIDS may be a proxy for poz tenure, indicating those who had the illness for longer periods of time had found methods for

**TABLE 3: Convergent Validity of HIV Stigma Scale: Pearson Correlation Coefficients Between HIV Stigma Subscales and Measures of Social Support**

	Confidant	Receives Help	Relative Subscore	Neighbor Subscore	Friend Subscore	Total Social Support Score
Distancing	-.273**	-.319**	-.161	-.155	-.195	-.227*
Blaming	-.243*	-.222*	-.149	-.055	-.101	-.111
Discrimination	-.232*	-.161	.052	-.089	-.138	-.091
Total Stigma	-.309**	-.286**	-.096	-.133	-.193	-.182

\* $p < .05$ . \*\* $p < .01$ .

**TABLE 4: HIV Stigma Subscale Means and Total Score Means by Age and Sociodemographic Characteristics (N = 88)**

Variable (n)	Distancing	Blaming	Discrimination	Total Score
Age group				
20 to 39 (44)	8.09	7.23	7.82**	25.18
50+ (44)	7.84	7.41	6.05	23.02
Gender				
Females (27)	8.26	7.56	7.26	24.93
Males (61)	7.84	7.21	6.79	23.74
Race or Ethnicity				
Caucasian (62)	7.50	6.77	6.52	22.63
African American (18)	9.00	9.06*	7.78	27.83*
Other (8)	9.25	7.63	8.25	27.13
HIV exposure				
Gay/bisexual (39)	7.28	7.08	6.49	22.72
Heterosexual (35)	8.43	7.77	7.57	25.77
Injection drug use (10)	9.70	7.40	7.00	25.60
Other (4)	6.25	5.50	5.50	19.25
HIV status				
HIV+	8.50	7.90	7.00	25.40
AIDS	7.69	7.02	6.90	23.43
Education				
High school or less (66)	8.05	7.39	7.23	24.56
Some college (22)	7.73	7.09	6.05	22.73
Partnership status				
Never married or partnered (26)	9.42	7.69	7.50	26.92
With spouse or partner (29)	7.72	7.52	7.31	24.34
Other	7.03*	6.85	6.15	21.67*
Medicaid in past year				
Yes (57)	7.79	7.07	6.89	23.53
No (31)	8.29	7.77	7.00	25.16

\* $p < .05$ . \*\* $p < .01$ .

adjusting and coping with societal as well as internal stigma. Those with higher levels of education were once again found to have lower (but not significant) levels of stigma across all subscales and the total stigma score.

A one-way ANOVA found a significant difference when examining marital-partnership status. Differences were found in the Distancing subscale,  $F(2, 85) = 4.24$ ,  $p < .05$ , as well as the overall stigma score,  $F(2, 85) = 3.19$ ,  $p < .05$ . The Tukey HSD post hoc test found significance between those who currently have partners or were never in a long-term relationship and others in the distancing subscale ( $p < .01$ , 95% CI .40 to 4.38), as well as the overall scale scores ( $p < .05$ , 95% CI .28 to 10.23). Finally,

those who had received Medicaid in the past year had lower, but nonsignificant scores, on all subscales as well as total stigma scores.

## DISCUSSION AND APPLICATION TO SOCIAL WORK RESEARCH AND PRACTICE

This study examined the development of subscales from the HIV Stigma Scale through EFA. The study also sought to determine the effectiveness of the scale in working with older adults living with HIV/AIDS. The results



of this study determined that the scale under investigation showed good overall internal consistency among both age groups. The EFA identified three subscales that can be used to discriminate between various manifestations of HIV stigma. These findings reinforce the work of Green and Platt (1997), who viewed HIV stigma as multidimensional. Although these researchers suggested that stigma can be either felt or enacted, the subscale development undertaken here suggests that the concept of felt stigma can in fact be expanded to include feelings of blame and distancing. Although blame appears to be a direct and strong response to coming in contact with a person living with HIV, distancing seems less direct. The concept of distancing is consistent with the qualitative finding of Bennett (1990), who noted what she labeled in her study of 10 persons living with AIDS as *shy away*. This subtler form of rejection was characterized by “not trying to be obvious, but quite obvious” (Bennett, 1990, p. 146). The subscale associated more directly with discrimination also reinforces the concept of “enacted” stigma, as well as what Bennett (1990) called “cut off” (p. 147). Here, the feeling is being cut off from employment and housing, along with fear of retaliation (Bennett, 1990). This is clearly a distinct, obvious, and direct type of stigma associated with outright discrimination.

The identification of various manifestations of HIV stigma can assist social workers employed in AIDS service organizations, hospitals, medical clinics, and other venues to better identify how stigma related to HIV disease may impact the lives of their clients. Those individuals who are experiencing greater level of a discriminatory type of HIV stigma may need assistance and advocacy pertaining to issues of civil rights and social justice. Depending on the source of blaming or distancing stigma, interventions may involve psychosocial support, conflict resolution, and, perhaps, family counseling. The use of such subscales, therefore, have a direct clinical benefit to social work practice. The types and intensity of these experiences can be ascertained through the clinical use of these scales and more focused and meaningful interventions initiated. It is important for social workers to be mindful of service providers as a source for potential blaming and discrimination.

The research reported here requires us to take another look at anecdotal information or case studies suggesting that HIV stigma is greater for older persons. Although older adults showed slightly higher levels of stigma on the Blaming subscale, younger adults had scores that were significantly higher on the Discrimination subscale and in their overall scores. The research also found African American individuals with HIV disease to experience

higher scores on both the Blaming subscale and the overall stigma scale. Brown and Sankar (1998) discuss two reasons for higher levels of stigma among African Americans. First, there is often a secrecy that surrounds the revelation of the illness. Second, HIV transmission is associated with behaviors not condoned by traditional African American religious values. The findings that African American respondents had more pronounced experiences of internal and external blame are consistent with Brown and Sankar’s findings. Differences between stigma scores by relationship-partner status may represent strength in social networks. Those in the “other” category were individuals who had been in long term relationships (heterosexual or same sex) but were currently separated, divorced, or the equivalent of widowed. This could reflect differences in the quality and supportive nature (or lack of) in relationships with past partners.

The research was able to identify differences in subscale scores between groups who in some instances were counter to the prevailing thoughts (age), whereas others seem to be supportive of previous research (race or ethnicity). There are several important limitations to this research that should be pointed out. First, the sample was not randomly selected, which limits the ability to draw generalizations to larger population. All participants included in the study were selected from a similar geographical area, and most had some contact with the local AIDS service organization. The possibility exists of some selection bias, as individuals who have not developed at least a minimal working relationship with local AIDS organizations have not been included.

The findings presented here provide a beginning exploration of the development of subscales for the 13-item HIV Stigma Scale. Further research is needed to examine how the items may fit together, including to strengthen internal subscale consistency and to explore why the 13th item that did not factor well. The administration of this instrument and its subscales to larger and more generalizable populations may also serve to improve our understanding of HIV stigma.

## REFERENCES

- Bennett, M. J. (1990). Stigmatization: Experiences of persons with Acquired Immune Deficiency Syndrome. *Issues in Mental Health Nursing, 11*, 141-154.
- Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing and Health, 24*, 518-529.

- Bird, S. T., Bogart, L. M., & Delahanty, D. L. (2004). Health-related correlates of perceived discrimination in HIV care. *AIDS Patient Care and STDs*, 18(1), 19-26.
- Brown, A. U., & Ramirez-Valles, J. (2002, July). *The effects of stigma on community involvement in HIV/AIDS organizations among Latino gay and bisexual men*. Paper presented at the XIV International AIDS Conference, Barcelona, Spain.
- Brown, D. R., & Sankar, A. (1998). HIV/AIDS and aging minority populations. *Research on Aging*, 20, 865-884.
- Busza, J. R. (2001). Promoting the positive: Responses to stigma and discrimination in Southeast Asia. *AIDS Care*, 13, 441-456.
- Center for Disease Control and Prevention. (2003). AIDS cases in adolescents and adults by age—United States, 1994-2000. *HIV/AIDS Surveillance Supplemental Report*, 9(1), 1-24.
- Chandra, P. S., Deepthivarma, S., & Manjula, V. (2003). Disclosure of HIV infection in South India: Patterns, reasons, and reactions. *AIDS Care*, 15, 207-215.
- Cobb, M., & de Chabert, J. T. (2002). HIV/AIDS and health care provider attributions: Who's to blame? *AIDS Care*, 14, 545-548.
- Crandall, C. S., & Coleman, R. (1992). AIDS-related stigmatization and the disruption of social relationships. *Journal of Social and Personal Relationships*, 9, 163-177.
- Emler, C. A. (2003, November). *Social support and stigma in the lives of older adults living with HIV/AIDS*. Paper presented at the 56th Annual Scientific Meeting of the Gerontological Society of America, San Diego, CA.
- Eroglu, D., Newman, D. R., & Peterman, T. A. (2002, July). *Gauging stigma associated with HIV-infected persons*. Paper presented at the XIV International AIDS Conference, Barcelona, Spain.
- Fortenberry, J. D., McFarlane, M., Bleakley, A., Bull, S., Fishbein, M., Grimley, D. M., et al. (2002). Relationships of stigma and shame to gonorrhea and HIV screening. *American Journal of Public Health*, 92, 378-381.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.
- Green, G., & Platt, S. (1997). Fear and loathing in health care settings reported by people with HIV. *Sociology of Health and Illness*, 19(1), 70-92.
- Hall, B. A. (1992). Overcoming stigmatization: Social and personal implications of the Human Immunodeficiency Virus diagnosis. *Archives of Psychiatric Nursing*, VI(3), 189-194.
- Heckman, T. G., Heckman, B. D., Kochman, A., Sikkema, K. J., Suhr, J., & Goodkin, K. (2002). Psychological symptoms among persons 50 years of age and older living with HIV disease. *Aging and Mental Health*, 6(2), 121-128.
- Heckman, T. G., Kochman, A., & Sikkema, K. J. (2002). Depressive symptoms in older adults living with HIV disease: Application of the chronic illness quality of life model. *Journal of Mental Health and Aging*, 8(4), 267-279.
- Herek, G. M. (1999). AIDS and stigma. *American Behavioral Scientist*, 42(7), 1106-1116.
- Herek, G. M., Capitano, J. P., & Widaman, K. F. (2002). HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991-1999. *American Journal of Public Health*, 92, 371-377.
- Herek, G. M., Mitnick, L., Burris, S., Chesney, M., Devine, P., & Thompson, M. et al. (1998). Workshop report. AIDS and stigma: A conceptual framework and research agenda. *AIDS and Public Policy Journal*, 13(1), 36-47.
- Heubner, D. M., Rebchook, G. M., & Kegeles, S. M. (2004). Experiences of harassment, discrimination, and physical violence among young gay and bisexual men. *American Journal of Public Health*, 94, 1200-1203.
- Kaiser H. F. (1974). An index of factorial simplicity. *Psychometrika*, 39, 31-36.
- Kim, J. O., & Mueller, C. W. (1978). *Factor analysis: Statistical methods and practical issues*. Beverly Hills, CA: Sage.
- Kraft, J. M., Beeker, C., Stokes, J. P., & Peterson, J. L. (2000). Finding the "community" in community-level HIV/AIDS interventions: Formative research with young African American men who have sex with men. *Health Education and Behavior*, 27, 430-441.
- Laryea, M., & Gien, L. (1993). The impact of HIV-positive diagnosis on the individual, part 1: Stigma, rejection, and loneliness. *Clinical Nursing Research*, 2(3), 245-266.
- Lubben, J., & Gironde, M. (2003). Centrality and social ties to the health and well-being of older adults. In B. Berkman & L. Harootyan (Eds.), *Social work and health care in an aging society* (pp. 319-345). New York: Springer.
- McCain, N. L., & Gramling, L. F. (1992). Living with dying: Coping with HIV disease. *Issues in Mental Health Nursing*, 13, 271-284.
- McDonnell, J. R. (1993). Judgments of personal responsibility for HIV infection: An attributional analysis. *Social Work*, 38, 403-410.
- Moneyham, L., Seals, B., Demi, A., Sowell, R., Cohen, L., & Guillory, J. (1996). Perceptions of stigma in women infected with HIV. *AIDS patient care and STDs*, 10(3), 162-167.
- New South Wales Anti-Discrimination Board Definition. (1992). *Discrimination: The other epidemic*. Report of the inquiry into HIV and AIDS related discrimination. Retrieved October 19, 2004, from <http://www.lawlink.nsw.gov.au/adb.nsf/pages/index>
- Ong, E. L. C., Clarke, K. W., Dunbar, E. M., & Mandal, B. K. (1993). Health care of people with HIV/AIDS. *AIDS Patient Care*, 7(2), 98-101.
- Ory, M. G., & Mack, K. A. (1998). Middle-aged and older people with AIDS. *Research on Aging*, 20, 653-664.
- Riley, M. W. (1989). AIDS and older people: The overlooked segment of the population. In M. W. Riley, M. G. Ory, & D. Zablotsky (Eds.), *AIDS in an aging society: What we need to know* (pp. 3-26). New York: Springer.
- Siminoff, L. A., Erlen, J. A., & Lidz, C. W. (1991). Stigma, AIDS and quality of nursing care: State of the science. *Journal of Advanced Nursing*, 16, 262-269.
- Solomon, K. (1996). Psychosocial issues. In K. M. Nokes (Ed.), *HIV/AIDS and the older adult* (pp. 33-46). Bristol, PA: Taylor & Francis.
- Sowell, R., Lowenstein, A., Moneyham, L., Demi, A., Mizuno, Y., & Seals, B. (1997). Resources, stigma and patterns of disclosure in rural women with HIV infection. *Public Health Nursing*, 14(5), 302-312.
- Surlis, S., & Hyde, A. (2001). HIV-positive patient's experiences of stigma during hospitalization. *Journal of the Association of Nurses in AIDS Care*, 12(6), 68-77.
- Swendeman, D. T., Comulada, W. S., Lee, M., & Rotheram-Borus, M. J. (2002, July). *The impact of stigma on the adjustment of young HIV+ persons*. Paper presented at the XIV International AIDS Conference, Barcelona, Spain.
- UNAIDS. (2002). *A conceptual framework and basis for action: HIV/AIDS stigma and discrimination*. Geneva, Switzerland: Author.
- UNAIDS. (2003). *Fact Sheet on stigma and discrimination*. Available from <http://www.unaids.org/EN/resources/publications.asp>
- Weitz, R. (1990). Living with the stigma of AIDS. *Qualitative Sociology*, 13(1), 23-38.