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# The Latina Caregiver Burden Scale: Assessing the Factor Structure for Rapid Clinical Assessment

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The study of caregiver burden is important for those faced with chronic illnesses such as AIDS as caregivers are the first line of care provision, sustaining care recipients in the home. Because perception of burden may vary across caregiver cultural groups, accurate measurement of burden is crucial to offer culturally sensitive services for those providing in-home care. The purpose of this study was to test the factor structure of a rapid assessment instrument, the Latina Caregiver Burden Scale, in a sample of 154 newly immigrated Latina caregivers primarily of Mexican descent. Face-to-face interviews were conducted in Spanish and English by bilingual, bicultural interviewers. The findings suggest that aspects of caregiver burden for these low-income women are tied to factor structures associated with depression and guilt mentality, socioeconomic stress, and stigma linked with HIV/AIDS. Social workers have greater likelihood of accurate cultural assessment of caregiver burden in similar groups when using such research-supported measures.

KEY WORDS: *assessment scale; burden; caregiver; Latina/Latino; women*

**A**lthough burdens associated with extended caregiving for an ill relative have been well documented with valid and reliable measures in white groups, these same burdens have been little studied in ethnic minority samples (Awad & Voruganti, 2008; Land & Hudson, 2004). Such measures are needed as social workers in the health arena may find caregiver perceptions of burdens, and the emotional response to different aspects of the caregiving role, to be extremely valuable in comprising ongoing service plans. Moreover, caregivers' perceptions of burden may vary across cultural and ethnic groups; thus, accurate assessment of burden is crucial if social workers are to provide culturally sensitive services to relieve caregiver stress.

## **BACKGROUND**

With the rapid rise of immigration, especially in California, recent attention has turned to family caregiving in Latino cultures, where family values are strong and women constitute the backbone of caregiving (de Figueiredo & Turato, 2001; Madianos et al., 2004; Magana, 2006; Oliveros, 2008). Especially among newly emigrated Latinos, caregiving tasks fall to Latinas because of strong cultural role expectations and limited services for care outside the home (Oliveros, 2008). Nonetheless, adequate

culturally sensitive measures of caregiver burden are lacking (Janevic & Connel, 2001; Neff, Amodei, Valescu, & Pomeroy, 2003; Shurgot & Knight, 2004). The present study tested the factor structure of a rapid assessment instrument measuring burden in a sample of 154 newly immigrated Latina caregivers, a population underserved in both practice and research.

## **Burden and Caregiving in Latino Cultures**

Studies reveal that Latina female caregivers dedicate an enormous portion of their lives to the caregiving role and provide substantial assistance to ill, orphaned, and elderly relatives (Choppelas & Wilson, 2006; Shurgot & Knight, 2004; Wight, Aneshensel, & LeBlanc, 2003). For a variety of reasons, these tasks may be more burdensome for some Latino groups, such as caregivers who are poorer, recently emigrated, undocumented women of Mexican and Central American origin who have traveled North across the border in search of a better life in California. To meet the needs of a relative with a complex chronic illness, such as HIV or Alzheimer's disease, caregivers are often required to have knowledge of multiple services to promote disease management (Oliveros, 2008). Caregivers must understand the illness, facilitate

the required services, and likewise become familiar with the service systems and individuals involved in the care of the patient (Choppelas & Wilson, 2006; Magana, Ramirez Garcia, Hernandez, & Cortez, 2007; Oliveros, 2008). Concomitantly, many female caregivers of Mexican and Central American origin often cope with the burdens of acculturation, lack of documentation and accompanying fear of deportation, and resulting isolation (County of Los Angeles, Department of Public Health, HIV Epidemiology Program, 2009) and may not be knowledgeable about health care services (Flaskerud & Nyamanthi, 1990; Land & Hudson, 1997, 2004).

Furthermore, research suggests that Latinos are often reluctant to seek outside help or early care for their illnesses. This situation may exist because of disease stigma, as in the case of AIDS, and there being few services that validate and attend to the needs of Spanish-speaking people with specific beliefs and cultural values such as a preference for allocentric (smooth) relationships, familism, acceptance of life's suffering, and the sociocentric quality of many Latino cultures (Barrio, 2001; Herrera, Lee, Nanyonjo, Laufman, & Torres-Vigil, 2009; Magana, 2006). Most Mexican and Central American women caregivers reside in very poor communities, where health and social services are limited (Hackl, Somalai, Kelly, & Kalichman, 1997; Land & Hudson, 2004; Medrano & Klopner, 1992). Where outside resources do exist, family members may view them as unnecessary, insensitive to familial needs, or intrusive (Barrio, 2001; Borrayo, Goldwasser, Vacha-Haase, & Hepburn, 2007; Magana, 2006; O'Connor, 1995; Purdy & Arguello, 1992). Because many of these caregivers lack immigration documents, they often fail to qualify for physical and mental health benefits, child care, rent subsidies, or other supportive services (Dennenberg, 1997; Land, 1994). Agencies such as HIV clinics serving the undocumented population and faith-based home-health programs could benefit from accurate assessments of caregiver burden for this group of female caregivers.

Given the multiple demands of caregiving (such as feeding, cleaning, bathing, administering medication, laundering, shopping), coupled with limited financial and supportive resources, it is understandable that many recently emigrated female caregivers of Mexican and Central American origin are faced with a powerful stress process that predictably pushes the boundaries of human physical and emotional ca-

pabilities (Caqueo-Urizar & Gutierrez-Maldonado, 2006; Demi, Bakeman, Moneyham, Sowell, & Seals, 1997). Such Latina family caregivers constitute a burgeoning vulnerable group at risk for the physical and psychological sequelae of caregiving (Kaplan & Mertens, 1997; Sarmiento & Cardemil, 2009). The need for a rapid assessment tool to measure burden seems all the more pertinent given this group's heightened vulnerability to the stressors that can result in deleterious outcomes such as poor health and poor mental health for the caregiver (Madianos et al., 2004; Magana, 2006; Oliveros, 2008). To date, there are few studies regarding the unique experiences of burden for caregivers of Mexican and Central American descent in the literature (Land & Hudson, 1997, 2002).

### Construct Models of Caregiver Burden

In their seminal investigation of burden, Hoening and Hamilton (1966) delineated objective and subjective components of caregiver burden to better understand the construct in their study of family caregivers of relatives with schizophrenia. Generally, *objective burden* is conceptualized as the strain resulting from direct negotiation of situational stressors, such as financial strain, and the demands of the physical activities often required in the caretaking process, such as bathing and feeding the care recipient. *Subjective burden* is conceptualized as the emotional-experiential appraisal of caregiving, such as feeling entrapped by the tasks required, feeling anxious or depressed about what the future holds for the ill family member, and thinking about the additional conflicts between family members secondary to the strain of caretaking (Chimwaza & Watkins, 2004; Kung, 2003; Nabors, Seacat, & Rosenthal, 2002; Wight et al., 2003). Several important studies from the 1990s found that the cultural background of the caregiver influenced the appraisal of burden, in addition to stressful events, use of support, and coping behaviors (Aranda & Knight, 1997; Baronet, 1999). More recent findings have suggested that certain dimensions of burden remain constant in predicting caregiver well-being and that other dimensions of burden vary across cultural groups (Heymann, Earle, Rajaraman, Miller, & Bogen, 2007; Page, Geoff, O'Brien, & Felice, 2006).

Although the further growth of available burden inventories has brought an overall improvement of their psychometric properties (Land & Hudson, 1997, 2002, 2004), in our literature review, recent

investigations of burden continue to rely on burden inventories that have used white samples, such as the Robinson (1983) caregiver stress index and Given et al.'s (1992) measure of caregiver burden. These inventories are frequently used regardless of the ethnicity or race of the sample under study (Choppelas & Wilson, 2006; Oliveros, 2008; Pirraglia et al., 2005). Other studies used no inventory at all (Fredriksen-Goldsen & Hoy-Ellis, 2007).

To date, questions continue to surface as to whether the factor structures in burden inventories are similar across cultural groups. In an effort to respond to these concerns, we undertook a study that examined the factor structure of a short burden inventory in a sample of Latina caregivers—in this case, women of primarily Mexican and Central American descent. We were particularly interested in documenting whether factor structures were similar to or different from those normed on white caregivers. Second, we were interested in developing a rapid assessment tool for accurate measurement of burden among these caregivers for whom very little is known and that would be useful for home-health social workers in assessing and treating caregiver burden for these groups. A crucial first step was to run an exploratory factor analysis (EFA) on the factor structure of this burden inventory. We chose a validated caregiver burden measure—the Burden Assessment Scale (BAS) (Reinhard, Gubman, Horwitz, & Minsky, 1994)—as a comparison scale for assessing face validity of our burden items.

## METHOD

### Study Sample

The data were from a cross-sectional purposive sample of 154 Latina family AIDS caregivers in the greater Los Angeles area. All of the caregivers were female immigrants, and the majority identified their ethnicity as Mexican (71%) or Central American. The original study from which the sample was taken investigated the stress levels within this group (Land & Hudson, 2002). The study had annual institutional review board approval from the University of Southern California Institutional Review Board of Human Subjects (395 SOWK01, 3/1/95). Informed consent was explained both orally and in written form in Spanish or English and was obtained in writing before data collection. The sample was drawn between February 1996 and August 1997. Trained bilingual, bicultural interviewers administered face-to-face interviews and recorded

respondent answers on a written instrument. The interviews were conducted in a setting agreed on by the interviewer and the respondent; most took place in the caregiver's home.

To participate in the study, caregivers had to meet five inclusion criteria: (1) caregiving had to be provided in the community rather than in institutional settings; (2) caregiving could not be provided in conjunction with employment as a health provider, such as in nursing or attendant care; (3) assistance had to extend beyond offering emotional support to more instrumental types of caregiving and help with activities of daily living (ADLs); (4) the caregiver had to be currently providing care and be the primary provider of assistance to a loved one with AIDS; and (5) the caregiver had to be self-identified as Latina and over 16 years of age. We chose this age as a cutoff because it is normative in many Latino families for adolescents to be involved in caregiving (Diaz, Siskowski, & Connors, 2007).

Respondents were referred from 18 AIDS service organizations in the Los Angeles area as well as through hospitals, media announcements, flyers, and word of mouth. A total of 193 women were referred to the study; seven refused to participate after initial contact; another 17 were ineligible, 14 could not be contacted, and one case was removed due to missing data. Most of the 154 women who agreed to participate were poor and unemployed. Of the 154 women, 74% ( $n = 114$ ) were foreign born, and 71% ( $n = 109$ ) spoke Spanish only. Most cared for a partner, son, or daughter.

### Respondent Background Characteristics

The mean income of the respondents who had this information ( $n = 37$ ) was less than \$4,000 per year. Of the 40 (26%) born in the United States, 31 identified as being of Mexican descent, eight as Latina with Mexican heritage, and one as Mexican and Indian. Of those born outside the United States, 69 (44.8%) were from Mexico; thus, 109 women were of Mexican heritage (71%). Of the 45 others, approximately half were from Honduras, a quarter were from El Salvador, and the others were from Guatemala and Nicaragua. Of the total sample, 71% chose to be interviewed in Spanish. Only 16% were high school graduates, and nearly half of the respondents (44%) had completed eight or fewer years of formal education. In addition, only 22% reported that they had a job at the time of the interview. Half reported that they had health insurance, including

Medicare or Medi-Cal (California's version of Medicaid). The median age of participants was 37 years (range: 16 to 75). Most (62%) were married or living with a partner, 9% were widowed, 14% were divorced or separated, and 14% were never married (see Table 1).

**Table 1: Demographic and Background Variables (N = 154)**

Variable	n	%
Foreign born	114	74
Ethnicity		
Mexican	109	71
Honduran	23	
El Salvadoran	11	
Guatemalan or Nicaraguan	11	
Chose to be interviewed in Spanish		71
	<b>M</b>	<b>%</b>
Age (years)	37.2	
Education		
Eighth grade or less		44
Ninth–11th grades		28
High school graduate		16
Vocational training/some college		9
College graduate		1
Some graduate school/graduate degree		3
Annual income		
<\$4,000		49
\$4,000–\$7,999		18
\$8,000–\$11,999		14
\$12,000–\$19,999		13
\$20,000–\$27,999		4
\$28,000–\$35,999		2
\$36,000–\$43,999		1
≥\$44,000		0
Employed full or part time		22
Time caregiving (years)	2.15	
HIV-positive		37
Number of other chronic illnesses (0–9)	1.28	
Physical symptomatology (1–5)	2.29	
Has medical insurance		49
HMO insurance		12
Private insurance		5
Medicare		3
Medi-Cal		31
Veteran's insurance		0
Other insurance		0
Number of major life events (0–8)	1.13	

Note: HMO = health maintenance organization.

In addition, 37% carried the dual status of caregiver and patient. The majority (67.3%) reported that they worried at least a little or more about HIV-related issues. Eighty-two percent reported chronic illnesses such as asthma, high blood pressure, and diabetes. The sample included approximately one-third who cared for a child (36%) and one-third who cared for a spouse or partner (32%). Others cared for a sibling (8%), parent (5%), friend (4%), or other relative (15%). Eight (5%) provided care for more than one person with AIDS. The length of time participants provided AIDS caregiving ranged from three months to 14.5 years, with a median of one year and three months. Finally, 62.1% endorsed experiencing major life events beyond caregiving (see Table 1). Most of these were “exit events” involving loss, such as a close friend moving away or separating from a partner.

### Item Choice

The study from which our sample was drawn used Pearlin's scale (Pearlin, Mullan, Semple, & Skaff, 1990) in English and Spanish. Our purpose in this study was to create a shortened version of Pearlin's caregiver stress and burden scales, which were designed to measure caregiver burden across groups. For an extended discussion of instrument construction and other methodological translation science issues for scales, see Land and Hudson (1997). Pearlin's stress and burden instrument was first created from qualitative interviews with caregivers, and then Likert-type scales were composed. It was tested and updated with qualitative interviews over time in a number of empirical studies on various caregiver groups and revised accordingly (Pearlin, Aneshensel, & LeBlanc, 1997). Over time, these scales have been found to have well-documented internal consistency and test-retest reliability and noted content and face validity. Scale scores have been shown to correlate across caregiver studies and appear to be replicable (Pearlin et al., 1997). The English-language version was translated into Spanish, then back-translated by independent, bilingual, bicultural graduate students of Mexican descent. The back-translator was blind to the original English version of the instrument. Although the original English questionnaire and the back-translated version were highly comparable, a few subtle discrepancies were found. These differences were discussed with a bilingual, bicultural research team including Latina community residents, Latina

service providers, a Latina caregiver, the project director, and the principal investigator. Such item discrepancies were addressed by forming a consensus translation, then pilot testing the items in the field and following up with postinterview qualitative debriefings with respondents on the instrument. Some modification was made to accommodate low-income groups, such as changing wording from “house” to “place.” Items included were in both Spanish and English versions following pilot testing (see Table 1).

As an initial step in item selection for our scale, we looked for items from the scales used in previous investigations by Land and Hudson (1997, 2002, 2004) that appeared to focus on caregiver burden issues. We used the BAS, which is a 19-item self-report index that measures burden in family caregiving and has documented strong psychometric properties. These properties were established for the BAS using two samples: (1) caregivers who had an ill family member receiving support in a social club and (2) caregivers whose ill family members were receiving services from mental health centers and psychiatric hospitals. In each analysis, five factors were found. The original internal consistency reliabilities for the BAS are high ( $\alpha = .91$  and  $.89$  for samples 1 and 2, respectively). In addition, construct validity has been documented on this index (Reinhard et al., 1994). Both samples used were principally white.

The BAS includes items measuring both objective and subjective caregiver burden. The following factors were found with the original Reinhard et al. (1994) study: (1) disruption of activities, (2) personal distress, (3) guilt, and (4) time perspective (that is, lack of time to perform caretaking responsibilities). The fifth factor was found to be different across the original two groups. For the caregivers from the outpatient/hospital services, this factor referred to basic social functioning (that is, disruptions in basic tasks of daily living due to caretaking). For those from the social club group, this factor referred to caregiver worry.

All items were formatted on a four-point Likert-type response continuum, ranging from 1 = strongly disagrees to 4 = strongly agree, and were worded both positively and negatively. For this study, each item in the BAS was matched to one item on the new Latina Caregiver Burden Scale on the basis of similar content. Thus, for example, an item from the BAS factor 2, personal distress, that reads “[You] became embarrassed because of [your relative’s] behavior”

was matched with an item on the Latina sample reading “Even though [you] know better, [you] still feel embarrassed that \_\_\_\_ has AIDS.” Likewise, an item from the BAS factor 1, disruption of activities, reads “[You] found it difficult to concentrate on your own activities.” This item was matched with the item “How much were you distressed by trouble concentrating?”

Likewise, BAS items that pertained particularly to the financial strains of caregiving were used as matched items for those in our sample. For example, respondents were asked, “People have different financial concerns. How concerned are you about: (a) being forced to move from your place; (b) using up all your money; (c) having to spend all your income; (d) being in debt; (e) your ability to meet future medical costs?” This procedure resulted in 24 items for this study’s scale. As previously noted, our primary objective was to perform an EFA on our burden scale. Likewise, we wanted to compare the factors that we found with those identified for the BAS, which used primarily white samples. Other examples of matching items from the Latina Caregiver Burden Scale that conceptually corresponded to a BAS item for each of its factors are provided in Table 2.

## Analysis

To better understand the empirical structure of the scale, and to provide a conceptual organization for this, the original 24 items were submitted to a set of analyses. The first was a principal axis factor analysis with oblimin rotation using SPSS 17.0. The second was a unweighted least squares analysis, again using the oblimin rotation. The purpose of two analyses was to test whether similar factors were found across methods. Use of the oblimin rotation allowed for the possibility of correlated factors. In addition, the value of .400 was used as a cutoff point for factor loadings, and factors with at least three items loading on them were viewed as more psychometrically stable (Costello & Osborne, 2005; DeVellis, 1991; Kline, 2005).

## RESULTS

Responses were summed, with higher scores indicating a greater sense of burden. The internal reliability of the scale, estimated by Cronbach’s alpha, was .77. The eigenvalues greater than 1 (DeVellis, 1991) indicated an eight-factor solution accounting for 64% of the variance. However, as can be seen in

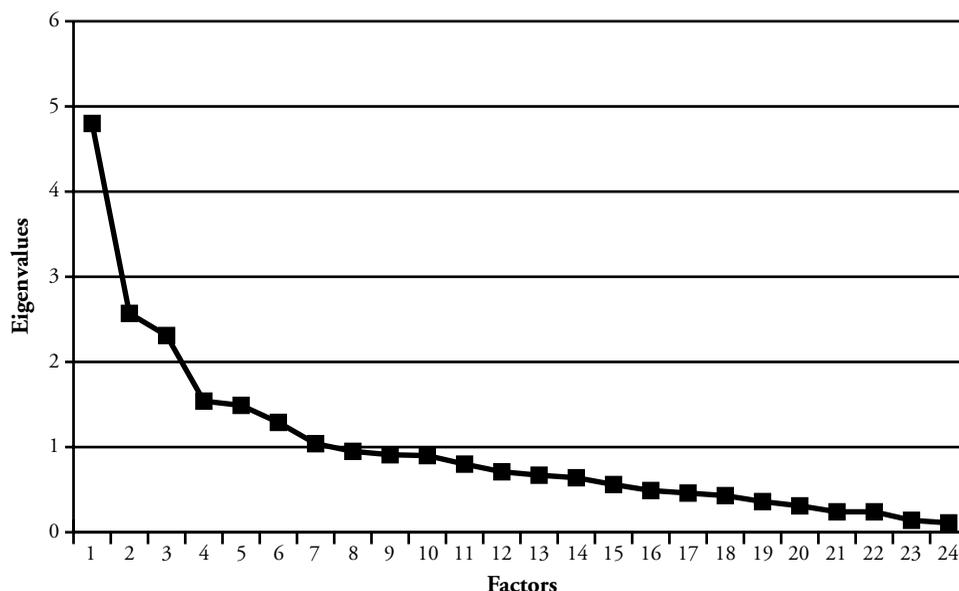
**Table 2: Examples of Matching Items between the Burden Assessment Scale (BAS) and the Latina Caregiver Burden Scale**

BAS Item	Latina Caregiver Burden Scale Item
Factor 1—Disrupted activities: “[You] found it difficult to concentrate on your own activities.”	“How much were you distressed by trouble concentrating?”
Factor 2—Personal distress: “[You] became embarrassed because of [your relative’s] behavior.”	“How strongly do you agree or disagree that even though [you] know better, [you] still feel embarrassed that ____ has AIDS”
Factor 3—Time perspective: “[You] were upset about how much ____ has changed from his or her former self.”	“How much have you lost the person that you used to know?”
Factor 4—Guilt: “Felt guilty because you were not doing enough to help.”	“Feel that you are not doing all that you should to care for ____.”
Factor 5—Basic social functioning (first BAS sample): “[You] experienced family frictions and arguments.”	“There have been more disagreements within your family.”
Factor 5—Worry (second BAS sample): “Found it difficult to concentrate on your own activities.”	“How much were you distressed by trouble concentrating?”

Figure 1, the scree test indicated a three-factor solution. Results for the eight-factor solution showed a wide dispersion of item loadings on the factors, with only one factor presenting as conceptually coherent. Thus, the factor analysis was run again with a fixed three-factor solution.

The principal axis with oblimin rotation results are presented in Table 3. As might be anticipated, loadings had a broad range. As previously noted, the study focused on items that loaded with a value of equal to or greater than .400. The item with the lowest value meeting this criteria was item 20 (.421)

**Figure 1: Three-Factor Scree Plot Results**



**Table 3: Principal Axis, Oblimin Three-Factor Solution (Structure Matrix)**

Item	Factor		
	1	2	3
1. Forced to move	.141	<b>.640</b>	-.162
2. Used up money	.258	<b>.787</b>	-.282
3. Used up savings	.212	<b>.798</b>	-.244
4. Went into debt	.312	<b>.734</b>	-.335
5. Meet medical costs	.234	<b>.556</b>	-.245
6. Trouble concentrating	<b>.459</b>	.097	-.004
7. Set aside time for self	-.055	-.129	-.011
8. Can't finish tasks	<b>.480</b>	.240	-.286
9. Visits with friends	.005	.115	-.262
10. Not paying attention enough to others	<b>.498</b>	-.264	-.015
11. Family disagrees	.324	-.344	.143
12. Family acts unpleasant	.324	-.373	.066
13. Feel ashamed	-.205	-.135	<b>.542</b>
14. Guilty taking rest	.390	.174	-.112
15. Not doing enough	.311	.138	-.195
16. Could have prevented illness	.213	.203	-.193
17. Feels angry about caregiving	.353	.076	-.089
18. Feels trapped by duties	<b>.551</b>	.306	-.263
19. Lost person used to know	.361	.103	.062
20. Fears has made mistakes in caregiving	<b>.421</b>	.125	-.213
21. Hopeless about future	<b>.534</b>	.186	-.113
22. People avoid me	-.124	-.168	<b>.910</b>
23. Others think less of me	-.138	-.177	<b>.923</b>
24. I wonder if other people think there is something wrong with my family	-.138	-.137	<b>.688</b>
Percentage of variance explained	18.02	8.24	7.75
Alpha	.638	.847	.849

Notes: Extraction method: unweighted least squares; rotation method: oblimin with Kaiser normalization. Boldface indicates heaviest loading for that item.

(“How much do you think about mistakes you’ve made in dealing with \_\_\_\_\_ and his/her/their illness?”) on factor 1. Item 23 (“People will think less of me knowing that someone in my family has AIDS”) on factor 3 had the highest loading (.910). In addition, there were no cross-loadings of items across factors, and each factor had at least three items load on it with a loading value greater than .400. The advantage of the oblimin rotation method is that it allows for correlations between factors. As can be seen in Table 4, none of the factors had strong correlations. The strongest correlation was between factor 2 and factor 3 (–.250), which is considered a weak to moderate correlation (Knoke, Bohrnstedt, & Potter Mee, 2002; Montcalm & Royse, 2002).

Given that very little is known about recently immigrated Latina caregivers (specifically those of Mexican and Central American descent), our

interest turned to how burden was experienced in this sample and how the structure of the instrument might represent this construct for them. Six items loaded on factor 1, representing depression and guilt mentality. Each of these items related to some sort of sense of loss, guilt, and role entrapment (for example, Item 6—“How much were you distressed by trouble concentrating?”; Item 18—“How much do you feel trapped by \_\_\_’s illness?”). This factor refers to the affective world

**Table 4: Factor Correlation Matrix**

Factor	1	2	3
1	—	.156	-.159
2	.156	—	-.250
3	-.159	-.250	—

Note: Extraction method: unweighted least squares; rotation method: oblimin with Kaiser normalization.

of the caregiver and includes elements of a sense of depression and anxiety that caregivers often report having (Magana et al., 2007). This factor (depression and guilt mentality) likewise taps into the subjective aspect of caregiver burden. Factor 1 accounted for 18.02% of the variance.

Factor 2 had five items load on it. This factor (financial strain) centered on financial and material strains. Examples from this factor include item 5 regarding medical costs (“How concerned are you about your ability to meet future medical costs?”) and item 3 regarding using up much of the family’s income due to the illness (“How concerned are you about having to spend all your income?”). This factor related well to objective burden (that is, circumstantial) and the impact it can represent for caregivers (Baronet, 1999; Horwitz & Reinhard, 1995; Solomon & Draine, 1995). This factor accounted for 8.24% of the total variance.

Four items loaded on factor 3. Each of these items related in some manner to a sense of stigma or shame, particularly feeling ashamed about the relative’s illness (for example, item 22—“People avoid me if they know there’s AIDS in my family”; item 23—“People will think less of me knowing that someone in my family has AIDS”). This factor (shame and stigma) appeared to tap into another aspect of subjective caregiver burden. It accounted for 7.75% of the total variance.

In addition, nine of the 24 items did not load on any of the factors. That is, the weight of these items was less than the specified .400 cutoff point for factor loadings. These nine items are items 7 (“During the past few months I made a special effort to set aside time for things I’m interested in or enjoy.”), 9 (“How often do you visit with friends?”), 11 (“Since \_\_\_’s been sick, there have been more disagreements within your family.”), 12 (“There are members of the family who act unpleasant and cold towards you.”), 14 (“I felt guilty taking time out for myself when there was still work to be done.”), 15 (“How much do you feel that you are not doing all that you should to care for \_\_\_?”), 16 (“How much do you wonder if there’s anything you could have done to prevent this from happening to \_\_\_?”), 17 (“How much do you feel angry when caring for him/her/they?”), and 19 (“How much have you lost the person that you used to know?”) These items were dropped from the final version of the scale.

Finally, it should be noted that the unweighted least squares analysis using the oblimin rotation had

the same results except for minor differences in loading values. Nonetheless, all the same items loaded on the same factors, as described earlier.

## DISCUSSION

Service providers and researchers are increasingly faced with diversity among caregiver groups. The primary goals of this study were to develop a rapid assessment burden measure for accurate measurement of burden among Mexican and Central American women immigrant caregivers, of whom little is known about their experiences of caregiving. For example, in this study, caregiving experiences ranged from providing instrumental help (such as cleaning, shopping, meal preparation, or visiting doctors) and coordination of services to performing extensive ADLs, such as coping with cognitive problems in the recipient of care. Such wide-ranging care needs elicit variability in caregivers’ responses to the perception of burden, especially for communities faced with additional challenges (that is, poverty, lack of adequate services, language barriers, and immigration issues). Our aim was to develop a brief inventory that could be administered with relative ease by service providers and research investigators, given the time constraints of caregiving in this population. Further, we wished to develop a theoretically based and psychometrically sound instrument. And we were interested in testing whether the factor structures found in our study were similar to or different from those normed on white caregivers. Although caregiving experiences do reflect commonalities across illnesses (Pearlin et al., 1997), caring for a relative with AIDS is also likely to affect the experience of burden in specific ways. We acknowledge these experiences in the following discussion.

Many caregivers, regardless of ethnic status, report objective strains. For example, recall that the original BAS scale was normed on a sample that primarily comprised white and middle-class families involved with caretaking activities for a family member with a serious and persistent mental illness. Reinhard et al. (1994) explained that two of the factors (disrupted activities and basic social functioning) reflected issues with the concrete elements of caretaking. The present sample had one factor that demonstrated issues regarding similar concerns (financial strain). Thus, these results appear to support the idea that objective burden, in this case, financial difficulties, is generally experienced across ethnic groups.

However, the subjective stress domains have been noted to be more group specific (Magana et al., 2007); thus, it is not surprising that the factor structure found in this study has a unique salience for the sample that we analyzed. The literature suggests that in many cases it is not the primary objective stressors that increase a sense of burden, but, rather, the subjective sense of burden in the caregiver, especially in female groups (Land & Hudson, 2004). And it is the sense of subjective burden that may differ as a result of cultural context (Awad & Voruganti, 2008; Bunting, 2001, Choppelas & Wilson, 2006).

Reinhard et al. (1994) found three factors (personal distress, time perspective, and guilt) that reflected issues of the subjective elements of caretaking. Our study likewise found two factors that reflect subjective burden: depression and guilt mentality (factor 1) and shame and stigma (factor 3). However, although there were clearly factors that suggest some sort of subjective burden, these factors present as somewhat different from the factors found with the original BAS samples. For example, although this sample endorsed items that pertained to some sort of distress, none of the items loaded in such a way as to suggest a concern with the pressures of time constraints or demands. This finding may be present because many of these caregivers were either unemployed or underemployed due to various institutional barriers to finding or maintaining adequate employment. The first factor from this study suggests subjective burden (depression and guilt mentality) that appears similar to the final factor (caregiver worry) found for those from the social club group in the original BAS study. Likewise, this study also had another factor (factor 3, shame and stigma) that is conceptually similar to that found in the original BAS study. Nonetheless, none of the items regarding family conflict, which loaded as a unique factor in the original BAS study, loaded in any substantial way on any factor for this study. This finding suggests that considerable family conflicts were not, at least for this sample, an ongoing concern.

Several of the nine items that did not load strongly on any of the aforementioned factors were items included in the fifth factor of guilt found in the original BAS studies (Reinhard et al., 1994). More specifically, these items seemed to pertain to individual wishes or desires of the caregiver (for example, item 7—"During the past few months I made a special effort to set aside time for things I'm interested in or enjoy"; item 9—"How often

do you visit with friends?") or with feelings of personal loss or anger (for example, item 17—"How much do you feel angry when caring for him/her/them?"; item 19—"How much have you lost the person that you used to know?"). In subsequent interviews with respondents, issues that seemed of a more individualistic nature were of less importance and might highlight a cultural attitude wherein obligation or duty is seen as more normative and routine in a sociocentric society (Land & Hudson, 2004; Neff et al., 2003).

Our findings suggest that many aspects of this sample's burden may be tied to background factors that influence caregivers' perceptions of burden. In particular, these factors may include access to care and socioeconomic status (SES); ethnic and culturally inscribed attitudes toward disease, such as feelings of stigma associated with AIDS; and the psychological beliefs around suffering and depression (Aranda & Knight, 1997; Borrayo et al., 2007; Shurgot & Knight, 2004).

Other explanations may stem from the differences in the caregiver's relationship with the recipient of care, the quality of the caregiver dyad, or the presence of ties to friends or other community resources that are relatively absent or underused for the particular communities from which the sample was drawn, as Pearlin noted (Pearlin et al., 1997). In fact, these Mexican and Central American female Latina caregivers were relatively more isolated than other caregiver cohorts, most likely because HIV disease stigma predominates, especially regarding the sexual- and drug-involved methods of disease transmission. Such is the case even within the family group, and it may result in inability of the caregiver to confide in others by revealing the particular stressors associated with HIV caregiving, such as caring for a gay relative, cleaning up bathroom accidents, and negotiating cognitive difficulties (Land & Hudson, 2004; Shattell, 2008). This latter feature of the sample might suggest one explanation for why no factor regarding family issues or conflicts was noted in this study.

### **Implications for Practice, Policy, and Research**

In light of our findings, implications for practice call for the use of culturally sensitive burden assessment inventories in case planning for social workers and home-health workers, especially because of the continued need for in-home caregiving in this

community (County of Los Angeles, Department of Public Health, HIV Epidemiology Program, 2009). Workers should be alerted to both objective—particularly financial stressors—and subjective signs of burden in caregivers, including shame and stigma associated with the illness and possible mood changes in the caregiver, including anxiety and depression. Normalizing such predictable responses to providing ongoing care for this group of caregivers may serve to decrease a sense of isolation and increase the acceptance of supportive services for caregiving, such as case management, in-home supportive counseling, and methods of stress reduction (Ward, 2007).

In addition, in light of our findings, future research will need to investigate the applicability of this rapid assessment burden measure with other populations that may hold similar values and be of the same SES as cross-culturally relevant instruments are valuable for both clinical and research use. Indeed, future research could include testing the factor structure with similar communities to see whether the factor structure found in our study is invariant across studies.

Likewise, policy implications point to the need for comprehensive health care coverage that includes caregivers from ethnic and marginalized communities. Often, health and mental health needs go unmet, yet demand is high among poor, immigrant groups (Willerton, Dankoski, & Martir, 2008). When caregivers' needs remain unsupported by health care policies, the results can include jeopardizing the health needs of the care recipients (Awad & Voruganti, 2008; Borrayo et al., 2007; Pirraglia et al., 2005).

### Limitations

Several considerations may limit the conclusions that can be drawn from these results. First, all variables were created from self-report measures. Second, the sample size was fairly modest, which limits the statistical power of some analyses. The results may not be generalizable to men or women of other ethnic group backgrounds. Likewise, as noted, this study did not find any factor related to family issues. This might be due to a specific feature of this sample, and it limits the generalizability of the findings. Future research might include family-related items to test whether family-related issues load as a unique factor for other Latino/Latina samples. Doing so makes sense given previous research that suggests that family life is important for many Latino communities (de

Figueiredo & Turato, 2001; Koneru & Weisman de Mamani, 2007; Rivera, Torres, & Carre, 1997).

In addition, as noted in Table 3, the coefficient alpha for factor 1 (depression and guilt mentality) was low (.638). As DeVellis (1991) noted, a level between .60 and .65 can be considered undesirable and suggests a lower reliability. Hence, future research should test the scale's reliability with other samples.

The present study does not offer construct validity for the scale. These data were taken from a previous study that included items from scales referencing caregiver burden (Pearlin et al., 1990). These items, as noted earlier, are the basis for the new shortened scale. Thus, our findings are preliminary, and the next step would be to use our scale with another sample while also using other psychometrically tested burden scales. These efforts would permit the testing for construct validity.

In addition, using data from the 1990s presents a number of limitations. The experiences of this sample may not be applicable to the situations of similar caregivers dealing with present-day social systems. Nonetheless, given the dearth of information regarding this population, the results offer important information regarding the day-to-day caregiving experiences of women of Mexican and Central American descent living in the United States. Likewise, we note that scales frequently used in the field are based on psychometric properties that were established on even older samples than the one we designed and tested (Given et al., 1992; Robinson, 1983). Moreover, we note that the factor structure of our scale of burden differs from that of the BAS; hence, it may be more useful in assessing burden in low-income Latina caregivers. Furthermore, in the absence of new data on this highly marginalized group of Latinas, we do not see the age of the data as a factor that inhibits their use in creation of this rapid assessment tool. Many instruments that are in continual use today were created using white samples, and data were collected considerably previous to the last decade (see, for example, the Ways of Coping questionnaire, the Rosenberg Self-Esteem Scale, and others). In spite of these limitations, the data we present and the situation they document are compelling.

### CONCLUSION

The design of burden instruments requires substantial knowledge of context-specific burden domains.

Although some dimensions of burden, such as caregiver guilt, appear to be present across groups and caregiving situations, other dimensions appear to vary. Such findings point to the importance of examining cultural and background factors in analyzing factor structures and strengthening the robustness of burden instruments. The considerable diversity across caregiver groups present significant challenges in measurement accuracy. Continued efforts along these lines may enhance our understanding of the role of perception in burden assessment that is distinctive across groups and the importance of accurate assessment in designing services to attenuate caregiver burden. **SWR**

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