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Psychometric Properties of a Spanish-Language Version of a Short-Form FAMCARE: Applications to Caregivers of Patients With Alzheimer's Disease and Related Dementias

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Abstract

Although family satisfaction is recognized as a critical indicator of quality care for persons with serious illness, Spanish-language measures are limited. The study aims were to develop a Spanish translation of the short-form Family Satisfaction With End-of-Life Care (FAMCARE), investigate its psychometric properties in Hispanic caregivers to patients with Alzheimer's disease and related dementias (ADRD; $N = 317$; 209 interviewed in Spanish), and add parameters to an existing item bank. Based on factor analyses, the measure was found to be essentially unidimensional.

Reliabilities from a graded item response theory model were high; the average estimate was 0.93 for the total and Spanish-language subsample. Discrimination parameters were high, and the model fit adequate. This is the first study to examine the performance of the short-form FAMCARE measure among Hispanics and caregivers to patients with ADRD. The short-form measure can be recommended for Hispanics and caregivers to patients with ADRD.

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Declaration of Conflicting Interests

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Keywords

Spanish language; Alzheimer's disease; palliative care; caregivers; item response theory; confirmatory factor analyses; FAMCARE; item bank

Satisfaction with care is a key outcome measure for evaluating quality of care for patients with advanced illnesses, including Alzheimer's disease and related dementias (ADRD). Directly measuring satisfaction in patients with ADRD can be difficult because of their cognitive status, especially in more advanced stages of illness. The measurement of family satisfaction, therefore, is critical both as a proxy measure for patients and as an independent measure of quality itself. Family satisfaction is posited to improve patient care because satisfied caregivers are better able to handle their challenging role (Andershed, 2006; Milberg, Strang, Carlsson, & Börjesson, 2003). Satisfaction with care is also associated with improved adjustment after the death of a care recipient (Stajduhar, Martin, & Cairns, 2010).

In the research setting, at least 14 different instruments have been used to measure family satisfaction in the context of serious illness and end-of-life care (Hudson et al., 2010). These existing measures of family satisfaction are lengthy and may be burdensome—particularly in the setting of advanced illness where families may be experiencing stress from heavy involvement in caregiving and end-of-life decision making and planning. The Family Satisfaction With End-of-Life Care (FAMCARE; Kristjanson, 1993) is a widely used 20-item scale designed to measure satisfaction with care (Dudgeon et al., 2008; Follwell et al., 2009; Grunfeld et al., 2004; Ringdal, Jordhoy, & Kaasa, 2003). The items are administered using a 5-point Likert-type response format (*very dissatisfied* to *very satisfied*).

Developed in Australia to measure satisfaction with cancer care (Kristjanson, 1986, 1989), the measure has been applied internationally to assess satisfaction with palliative care (Hwang et al., 2003; Kristjanson, 1989). The four domains identified in its original version (information giving, availability of care, psychosocial care, and physical patient care; Kristjanson, 1993) have not been replicated in subsequent efforts (Carter, Lewin, Gianacas, Clover, & Adams, 2011; Johnsen, Ross, Petersen, Lund, & Groenvold, 2012; Ringdal et al., 2003; Rodriguez, Bayliss, Jaffe, Zickmund, & Sevic, 2010). However, a unidimensional structure with a single underlying attribute has been supported through principal component and bifactor analyses (Carter et al., 2011; Kristjanson, 1993; Ringdal et al., 2003; Rodriguez et al., 2010; Teresi, Ornstein, Ocepek-Welkinson, Ramirez, & Siu, 2014). Psychometric analyses have favored shortened versions with adequate estimates of reliability (Carter et al., 2011; Kristjanson, 1993; Teresi et al., 2014). These shortened versions have been used in varied populations, for example, the 19-item version with terminal cancer victims in Norway (Ringdal et al., 2003), the 18-item version in long-term care settings in the United States (Rodriguez et al., 2010), the 17-item version (FAMCARE-2) in inpatient settings in Australia (Aoun, Bird, Kristjanson, & Currow, 2010), the FAMCARE-P16 (16 items) with patients in Canada (Lo, Burman, Rodin, & Zimmermann, 2009), and the FAMCARE-6 (six items) with family members in outpatient oncology palliative care settings in Australia (Carter et al., 2011). Validated translations of the measure are available in Swedish (Aoun et al., 2010) and Italian (D'Angelo et al., 2017).

Previous work with the FAMCARE (Ornstein et al., 2015; Teresi et al., 2014) using item response theory (IRT) on a large sample of Black and White caregivers to individuals with cancer resulted in the identification of 10 items that were most informative. Parameters were placed in an item bank, and short forms developed. This 10-item version is the subject of these analyses, with the intent of adding Spanish-language parameters to the item bank.

Although other measures of satisfaction with care have been translated into Spanish language (Benitez-Rosario, Caceres-Miranda, Aguirre-Jaime, & Grupo Español de Investigación en Cuidados Paliativos, 2016; Jean-Pierre et al., 2012), to our knowledge the study described here was the first to develop a Spanish translation of FAMCARE items, to test them in a sample of U.S. Hispanic caregivers, and to provide item parameters for Hispanics, including a subsample of Spanish speakers. Furthermore, this work focused on families caring for relatives with AD RD, a group which has received less focus in end-of-life care research. Assessing satisfaction with care in this growing population is of particular interest given the dramatic growth in the population of Hispanic individuals with dementia; in 2060 it is expected that there will be 3.6 million Hispanics living with AD RD in the United States (Wu, Vega, Resendez, & Jin, 2016).

Research examining the association between caregiver satisfaction with patient care and caregiving outcomes such as burden, stress, caregiver health, and mental health is scarce. Chang et al. (2013) and Naoki et al. (2017) found significant inverse associations between family satisfaction with patient care and caregiving burden among Korean and Japanese caregivers, respectively, for relatives with advanced cancer. Caregiver satisfaction with care has also been found to be negatively associated with caregiving unmet needs (Hwang et al., 2003) and positively associated with caregiver quality of life (Hannon et al., 2013) among caregivers to oncology patients. No data are available for Hispanic caregivers, the focus of this research.

Aims

The aims of this study were to develop a Spanish translation of FAMCARE items, and to investigate the psychometric properties of the Spanish-language version of a short-form FAMCARE as well as to examine its performance among a sample of Hispanic English and Spanish speakers. A secondary aim was to provide item parameters for a sample of Hispanic respondents to an existing item bank.

Method

Measures

Satisfaction with care.—Although the FAMCARE was developed to assess caregiver satisfaction with cancer care, the items lend themselves to evaluation of other types of care, including that related to AD RD. Earlier psychometric studies of the FAMCARE identified varying factor structures. One study using IRT examined the performance of items in terms of information and differential item functioning between Black and White subsamples (Teresi et al., 2015). Because of overlapping category response functions identified in the prior analyses, the response categories were collapsed from five into three: *very satisfied*

responses coded as 2, *satisfied* coded as 1, and indecision or *dissatisfaction* coded as 0. Based on previous analyses, the 10 most informative items that were least biased by education and race were included in the questionnaire embedded in two intervention studies of caregivers to patients with Alzheimer's disease and related disorders.

As reviewed above, the FAMCARE has been used successfully in studies of populations other than cancer and across different countries. The Spanish version of the scale was developed for this study using qualitative methods and included individuals who were caregivers to those with dementia in addition to other Spanish-speaking caregivers. Some modifications were made by including clarifying language in parentheses. However, there were few modifications to the 10 items selected because they performed best in terms of differential item functioning in earlier analyses and were less biased. The exact item wording that was used varied slightly from the original for some items.

Caregiver burden

Zarit Caregiver Burden Scale (ZCBS).—The ZCBS consists of 22 items; examples are “Do you feel embarrassed by his/her behavior?” and “Do you feel strained when you're around him/her?” (Gort et al., 2007). Items were rated on a 5-point Likert-type scale ranging from *never* to *nearly always*. The ZCBS score increases with higher caregiver burden. The ordinal alpha coefficient for this sample was estimated at 0.934, the explained common variance was 33.305, and the McDonald's Omega was 0.936.

Lawton Caregiver Appraisal Scale: Burden subscale.—The Lawton Caregiver Appraisal Scale consists of two subscales: burden and satisfaction (Lawton, Moss, Hoffman, & Perkinson, 2000). The burden subscale has nine items. Items include “Do you feel that because of the time you spend with your Elder that you don't have enough time for yourself?” and “Do you feel your health has suffered because of your involvement with your Elder?”. The 5-point Likert-type scale responses ranged from *never* to *nearly always*. Higher scores reflect higher caregiver burden. The alpha coefficient for this sample for the burden subscale was 0.914, the explained common variance was 83.700, and the McDonald's Omega was 0.914.

Montgomery Caregiving Objective Burden Scale.—The Montgomery Caregiving Objective Burden Scale consists of six items (Savundranayagam, Montgomery, & Kosloski, 2011). Caregivers are asked for examples if caregiving responsibilities have “decreased time you have to yourself” and “caused your social life to suffer.” Items were rated on a 5-point Likert-type scale ranging from *not at all* to *a great deal*. The scale is scored in the burdened direction. The alpha coefficient for this sample was 0.965, the explained common variance was 96.409, and the McDonald's Omega was 0.966.

Depression

Geriatric Depression Scale (GDS).—The GDS consists of 30 yes/no items measuring depression. Items include “Do you feel happy most of the time?” and “Do you frequently feel like crying?” (Yesavage et al., 1982). The scale is scored in the direction of higher

scores reflecting higher depression. The alpha coefficient for this sample was 0.957, the explained common variance was 65.723, and the McDonald's Omega was 0.959.

PROMIS Depression Short Form.—The PROMIS Depression Short Form contains eight items measured on a 5-point scale; responses range from *never* to *always* over the past 7 days. Items include “I felt worthless” and “I felt hopeless” (Choi, Reise, Pilkonis, Hays, & Cella, 2010; Teresi et al., 2009). The PROMIS depression score increases with higher depressive symptoms. The alpha coefficient for this sample was 0.957, the explained common variance was 80.132, and the McDonald's Omega was 0.957.

Patient Health Questionnaire (PHQ).—The PHQ-9 assesses nine depressive symptoms associated with depressive disorders as described in the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; *DSM-IV*; American Psychiatric Association, 1994) (Kroenke, Spitzer, & Williams, 2001). Responses range from *not at all* to *nearly every day* over the past 2 weeks. The PHQ-9 score increases with higher depressive symptoms. The alpha coefficient for this sample was 0.874, the explained common variance was 39.963, and the McDonald's Omega was 0.876.

Stress

Perceived Stress Scale.—The Perceived Stress Scale contains 10 items to appraise the stressfulness of life situations over the past month; responses are *never*, *almost never*, *sometimes*, *fairly often*, and *very often* (Cohen, Kamarck, & Mermelstein, 1983; Cole, 1999). Sample items include, “In the last month, how often have you felt that you could not cope with all the things you had to do?” and “In the last month, how often have you felt confident about your ability to handle your personal problems?” The Perceived Stress Scale score increases with higher reported stress. The alpha coefficient for this sample was 0.905, the explained common variance was 67.330, and the McDonald's Omega was 0.907.

Caregiver function

PROMIS Physical Function Short Form.—The PROMIS Physical Function Short Form contains eight items measured on a 5-point scale (Bruce et al., 2009; Rose, Bjorner, Becker, Fries, & Ware, 2008). Four items range from “without any difficulty” to “unable to do” (e.g., “Are you able to go for a walk of at least 15 minutes?”) and four range from “not at all” to “cannot do” (e.g., “Does your health now limit you in lifting or carrying groceries?”). The alpha coefficient for this sample was 0.970, the explained common variance was 89.228, and the McDonald's Omega was 0.970.

Sample

The FAMCARE items were embedded in two studies of Hispanic caregivers to patients with ADRD, conducted in New York, USA (Luchsinger et al., 2016; Luchsinger et al., 2015). The sample of caregivers to patients with ADRD was all Hispanic and community dwelling ($N = 317$), with 34% interviewed in English and 66% in Spanish (see Table 1). The majority (83%) were female with a mean age of 57.9 ($SD = 11.2$) years and mean education of 12.7 ($SD = 3.6$) years. Among the respondents interviewed in Spanish, slightly more were female

(88%) and older (mean age of 60.0; $SD = 11.3$) than the total sample. The mean educational level for the Spanish-speaking subsample was 11.9 years ($SD = 3.7$; see Table 1).

The sample of care recipients all carried a formal diagnosis of ADRD; the majority (78.8%) were diagnosed with AD, 7.4% with vascular, 1% mixed, and 12.9% other dementia. The average time from diagnosis to baseline assessment was 49.35 months ($SD = 46.68$); the median was 34 months.

Ethical Considerations

Written informed consent was obtained from all participants. The projects were approved by the Institutional Review Boards at Columbia University (protocols IRB-AAAL7251, IRB-AAAM5150) and the Hebrew Home at Riverdale (protocols 0313I/P089, 0214I/P094).

Statistical Approach

Instrument development and qualitative review

Translation procedures.: A multistep, iterative approach is the standard for developing quality translations of items. The following methodology is based on that required by the National Institutes of Health (NIH) Patient-Reported Outcomes Measurement Information System® (see Eremenco, Cella, & Arnold, 2005).. Two simultaneous forward blind translations were performed. Items (in English) were translated into Spanish independently by two bilingual experienced interviewers who are native speakers. A reconciled translation based on the two forward translations was produced by either choosing the better of the two forward translations and/or resolving discrepancies between them. The reconciliation task was performed by an experienced translator who is a native Spanish-speaking bilingual professional. The reconciled version was then back translated independently by two native English-speaking translators fluent in Spanish. The back translators were blind to the original English version. Two reviewers evaluated the back translations independently for harmonization, considering issues such as universality, cultural relevance, and idiomatic expressions. A reconciled final back translated version was then produced by consensus. Final adjudication was made by reviewing all the information provided, contrasting the original (English) version against the reconciled back translation, and determining the best secular phrasing and/or idiomatic expression in the target language (when applicable) for the final translated version.

Cognitive interviews.: The adjudicated Spanish version was pilot-tested through 10 structured cognitive interviews with Hispanic caregivers, including caregivers to individuals with ADRD. The goal was to achieve an equivalent measure (to the original [English] version) by capturing the meaning and/or the intent of the original items in contrast to performing a literal translation. When possible, universal terms were used to maximize comparability (See Angel, 2006).

Instrument analyses.: Exploratory and confirmatory factor analyses (CFA) and IRT using the graded response model (Samejima, 1969) were performed to evaluate the measure. IRT was used to provide Spanish parameters which can be used in item banking and to examine differential item functioning in comparison with other samples. The IRT score is somewhat

more precise in contrast to raw summary scores and provides an advantage because estimates of reliability at various points along the trait continuum are provided, rather than only one omnibus reliability statistic, as estimated using classical scoring methods.

Factor analyses.: A merged exploratory factor analysis (EFA) and CFA (Asparouhov & Muthén, 2009) was used to examine essential unidimensionality. A unidimensional model was fit using MPlus (Muthén & Muthén, 2011). Factor analyses to examine dimensionality were conducted for the total sample and for the Spanish-speaking subsample. EFA were performed with principal components estimation, and the results of tests of scree were plotted for both samples; in addition, CFA were conducted. Polychoric correlations based on the underlying continuous normal variables were estimated using M-PLUS (Muthén & Muthén, 2011). The explained common variance provided information about whether the observed variance covariance matrix is close to unidimensionality (Sijtsma, 2009). Several fit indices were examined, including the comparative fit index (CFI; Bentler, 1990) and the Tucker-Lewis index (Tucker & Lewis, 1973).

Reliability.: Reliability was evaluated with McDonald's (2009) omega total (ω); this reliability estimate is based on the proportion of total common variance explained. Reliability estimates were also calculated for various points along the latent continuum of family satisfaction using IRT.

IRT.: IRT was performed for the total sample and the subsample of Spanish speakers. The estimates for the discrimination and severity parameters (a and b , respectively) were evaluated. The item and test information functions were graphed and the reliability estimates were calculated for points along the dimension of the underlying construct, denoted as θ (theta). The discrimination parameter informs about the strength of the relationship between an item and the trait measured, for example, satisfaction, and is central in determining the information provided by items. The severity parameter indicates at what point along the satisfaction continuum the item maximally discriminates. Item Response Theory for Patient-Reported Outcomes (IRTPRO; Cai, Thissen, & du Toit, 2011) was used for IRT parameter estimation and tests of model fit. Model fit was examined using root mean square error of approximation (RMSEA); model assumptions were examined using indices of local dependency (LD; Chen & Thissen, 1997).

Construct validity.: Although there is little evidence extant regarding the relationship between satisfaction with care and caregiver burden and depression among Hispanic caregivers, it was posited that there would be an inverse relationship between satisfaction with care and caregiver burden, depression, and stress.

Results

Dimensionality and Factor Analyses

The measure was found to be essentially unidimensional, with the ratio of the first to second component of 34 for the total sample and 33 for respondents interviewed in Spanish (Table 2 and Appendix Figure 1). Although the two-factor solution fit slightly better for both samples (RMSEA of 0.086 vs. 0.097 for the total sample; 0.092 and 0.106 for Spanish interview

respondents), the differences in fit statistics between the two models were very small (Table 3).

Provided in Appendix Table 1 are the loadings on the first factor from a one-factor model as contrasted with those estimated on the first factor from a two-factor solution. As shown, the loadings were high, ranging from 0.88 to 0.99 across the two models and both samples, again providing evidence of essential unidimensionality in both samples.

Reliability

Shown in Appendix Table 2 are the item means and corrected item-total correlations, which ranged from 0.79 to 0.92; the overall coefficient alpha estimate of reliability was 0.97 for both samples. Most respondents answered that they were satisfied or very satisfied. McDonald's omega estimates were 0.99 for the total sample and the sample of Spanish speakers. The explained common variance for the total sample was 96.8 and 95.5 for the Spanish speakers (not shown).

Shown in Appendix Table 3 are the reliability estimates from a graded response IRT model, estimated at different levels of θ ; all were high, ranging from 0.84 (at $\theta = -2.4$) to 0.96. The average IRT reliability estimate was 0.93 for both samples.

IRT Parameter Estimates, Information and Distributions

Shown in Table 4 are the IRT-derived parameters; the discrimination parameters were all high; the highest estimates were for the items: "satisfaction with how the doctor assesses symptoms" and "information given about your patient tests" in both samples. The items for the total sample were located between $\theta -1.4$ and -1.2 , and between $\theta -1.6$ and -1.3 for the Spanish interview respondents. The item response categories were ordered from *dissatisfied* to *very satisfied*. The overall fit indices are shown in Table 3. The RMSEAs observed were 0.08 and 0.10 for the total sample, and those interviewed in Spanish, respectively. Local dependencies (not shown) were in an acceptable range (below 10) for most comparisons; however, for the Spanish speakers two items evidenced local dependency indices slightly higher for the item pairs, "Availability of the doctor to the patient" with "Coordination of care" and "Satisfaction with the way tests and treatments are followed by the doctor." For the total sample, elevated LDs (13.9 and 14.9) were observed for two different item pairs, "Time required to make a diagnosis" with "Satisfaction with doctor's attention to description of illness." No item pair evidenced very high discrimination parameters due to high LDs.

Appendix Table 4 shows the distribution of the summed scores mapped to the θ estimates for the total sample and Appendix Table 5 for the Spanish interview respondents. As shown, the scale is skewed in the satisfied direction. About 16% of the total sample and 15% of the Spanish interview respondents were one or more standard deviations below the mean θ of 0, indicative of dissatisfaction. About 43% of the total sample and 53% of the Spanish interview respondents were at the ceiling of the measure.

The information functions are shown in Figures 1 and 2, and Appendix Table 6 for the total sample and Figure 2 and Appendix Table 5 for the Spanish interview respondents. As was

observed in previous research (Ornstein et al., 2015), the information function for the total sample was bimodal (with maximal information provided at $\theta = -1.2$ and $0 = -0.4$) indicative of levels corresponding to dissatisfied and between dissatisfied and satisfied, respectively. On the contrary, the information function for the Spanish interview sample was not bimodal; the maximum information was also at $\theta = -1.2$.

Construct Validity

Shown in Table 5 are the associations of caregiver satisfaction with care and measures of caregiver burden, depression, stress, and function. Satisfaction with the care provided to the care recipient was related inversely to burden, depression, anxiety (not shown), and stress; although significant, the magnitude of coefficients was small. As shown in Table 5, the FAMCARE raw sum score and that derived from IRT correlated modestly and significantly with all burden and depression scores included. Correlations for burden ranged from -0.189 to -0.213 for the sum score measures and from -0.185 to -0.218 for the IRT scores. The range of correlations for the depression measures with the FAMCARE was from -0.144 to -0.202 for the sum scores and from -0.164 to -0.210 for the IRT-derived scores. Perceived stress and the FAMCARE correlated -0.182 and -0.191 ($p = .001$). Significant relationships were not observed between satisfaction and caregiver physical function or hours of care provided (see Table 5).

Discussion

The psychometric properties of the 10-item short form of the FAMCARE were generally very good. Reliability indices were greater than 0.90. The discrimination parameters were high, and the model fit adequate for both factor analyses and IRT. Essential unidimensionality was established indicating that the items could be best treated as a composite score rather than as subscales. The results of a recent study of a translation of the FAMCARE 2 (D'Angelo et al., 2017) into Italian also supported the essential unidimensionality of the scale. The FAMCARE 2 is a version of the FAMCARE that is specific to palliative care teams and is not appropriate for groups with individuals who may or may not be receiving palliative care.

Limitations

A limitation was the inability to examine differential item functioning between English-speaking and Spanish-speaking Hispanics due to relatively small sample sizes for such analyses. Another limitation is the lack of test-retest reliability estimates; low values could affect ability to measure change. An additional limitation was the ceiling effect observed, with a larger effect among Spanish speakers, of which about half were at the most satisfied score. On the contrary, about 15% to 16% were estimated to be at one or more standard deviations below the mean and about one third at 0.5 standard deviation or less, (cut scores of about 8 and 13 or less, respectively) indicative of dissatisfaction. Thus, enough variability was observed to measure change over time. Ceiling effects have been observed with satisfaction measures, and it is well known that such measures are skewed toward positive responses. In the context of an older cohort of Hispanic caregivers, older persons tend to provide "rosy" responses, and Hispanics have been found to use more extreme response

categories (see McHorney & Fleishman, 2006). Such tendencies could explain the ceiling effects observed here.

Strengths

This study addressed an important need to measure family satisfaction with care in ADRD, a progressive illness with a long end-of-life trajectory. The prevalence of dementia has been documented to increase after individuals reach 70 years of age (Seshadri et al., 1997). The prevalence of Alzheimer's disease in the United States is expected to increase incrementally with estimates reaching 13.8 million in 2050 (Alzheimer's Association, 2013). Thus, the number of informal caregivers to relatives with dementia will increase, taxed by the ongoing provision of supervision and personal care. Well documented are the associated caregiver burden, stress, health, and financial problems (Liu & Gallagher-Thompson, 2009; Pinquart & Sörensen, 2003; Sörensen, Duberstein, Gill, & Pinquart, 2006; Vitaliano, Zhang, & Scanlan, 2003). This study also supported the relationship of burden, stress, and depression with dissatisfaction with care. Concomitant chronic health problems and functional limitations associated with ADRD as well as the related caregiving impact increase the need to perform ongoing individual assessments of satisfaction with patient care. Such assessments should be part of the palliative care plan as suggested by Ringdal et al. (2003). In this context, the FAMCARE items may be informative to clinicians, suggesting direct actions regarding services and interventions needed. Such interventions may not only be helpful to better serve individuals with dementia but also to positively impact caregivers in their management of the stresses and burdens associated with their provision of care.

In addition, this study addressed a lack of evidence related to the performance of FAMCARE items among Hispanics, including a subset of Spanish speakers, a group which is growing both in proportions and absolute numbers. Hispanics are not only the fastest growing ethnic group in the United States (Humes, Jones, & Ramirez, 2011), but also as a group, experience a prevalence rate of dementia that is 1.5 times that of non-Hispanic White people (Alzheimer's Association, 2013). In addition, Hispanic caregivers spend more hours providing care and are more likely to experience higher levels of burden from caregiving as compared with non-Hispanic Whites (Alzheimer's Association). Thus, this work is timely given the documented applicability of the FAMCARE items to this population, and its potential clinical utility in the context of caregiving satisfaction with formal care services. This is of particular importance because, to our knowledge, this is the first study to develop a Spanish translation of FAMCARE items, the first study of family satisfaction with care among Hispanic caregivers to people with Alzheimer's disease and related disorders, and the first to demonstrate an association between caregiver burden, stress, and depression and dissatisfaction with care.

Conclusion

The Spanish-language version of the short-form 10-item FAMCARE performs well in terms of reliability, precision, and information provided. Although ceiling effects were observed, the measure has a sufficient distribution of individuals at the dissatisfied tail of the scale to measure change, while providing a less burdensome shorter form measure of satisfaction

with care. Evidence for construct validity was provided through the significant, albeit modest correlations of burden, stress, and depression in the hypothesized direction with dissatisfaction with care.

This is the first study to examine the psychometric performance of the short-form measure among Hispanics, and with respect to ADRD. The scale performed as well in a sample of Hispanic caregivers as it did in previous studies (Ornstein et al., 2015; Teresi et al., 2014) of samples of Black and White caregivers. It is concluded that this short-form FAMCARE version can be used among Hispanics and caregivers to patients with ADRD.

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Appendix

Table A1.

Item Loadings / Factor Structure (λ) From the Unidimensional and Two-Factor EFA/CFA Solutions After Rotation (MPlus).

Item description	All cases ($N = 317$)			Respondents interviewed in Spanish ($n = 209$)		
	One fact. ^a λ (SE)	Two-factor solution Factor structure		One fact. ^a λ (SE)	Two-factor solution Factor structure	
		F1 λ (SE)	F2 λ (SE)		F1 λ (SE)	F2 λ (SE)
How satisfied are you with the doctor's attention to your description of your _____ (care recipient's) symptoms?	0.93 (0.01)	0.94 (0.01)	-0.04 (0.04)	0.94 (0.02)	0.93 (0.03)	0.23 (0.07)
Availability of doctors to the family	0.94 (0.01)	0.94 (0.01)	-0.004 (0.04)	0.94 (0.02)	0.93 (0.03)	0.24 (0.05)
Coordination of care	0.88 (0.02)	0.89 (0.02)	-0.01 (0.04)	0.90 (0.02)	0.90 (0.03)	0.19 (0.05)
Time required to make a diagnosis	0.92 (0.01)	0.91 (0.02)	0.15 (0.04)	0.90 (0.02)	0.91 (0.02)	-0.03 (0.05)
How satisfied are you with the way the family is included in treatment and care decisions?	0.89 (0.02)	0.89 (0.02)	0.17 (0.04)	0.95 (0.01)	0.95 (0.01)	0.06 (0.01)
Information given about how to manage your _____ (care recipient's) pain	0.94 (0.01)	0.93 (0.02)	0.22 (0.03)	0.96 (0.01)	0.96 (0.01)	-0.01 (0.04)
Information given about your _____ (care recipient's) tests	0.96 (0.01)	0.95 (0.02)	0.33 (0.04)	0.97 (0.01)	0.98 (0.02)	-0.14 (0.05)
How satisfied are you with how thoroughly the doctor assess your _____ (care recipient's) symptoms	0.97 (0.01)	0.97 (0.01)	0.20 (0.03)	0.98 (0.01)	0.97 (0.01)	0.03 (0.04)

Item description	All cases (N = 317)			Respondents interviewed in Spanish (n = 209)		
	One fact. ^a λ (SE)	Two-factor solution Factor structure		One fact. ^a λ (SE)	Two-factor solution Factor structure	
		F1 λ (SE)	F2 λ (SE)		F1 λ (SE)	F2 λ (SE)
The way tests and treatments are followed up by the doctor	0.98 (0.004)	0.99 (0.004)	0.07 (0.004)	0.98 (0.01)	0.98 (0.02)	0.15 (0.05)
Availability of doctor to your _____ (patient)	0.95 (0.01)	0.95 (0.01)	0.01 (0.03)	0.94 (0.01)	0.93 (0.03)	0.28 (0.05)

Note. EFA = exploratory factor analysis; CFA = confirmatory factor analyses.

^aGeomin (oblique) rotation.

Table A2.

Classical Test Reliability Analysis Using Cronbach's Alpha (SPSS).

Item description	All cases (N = 317)			Respondents interviewed (n = 209) in Spanish		
	M (SD)	Corrected item-total correlation	Alpha if item deleted	M (SD)	Corrected item-total correlation	Alpha if item deleted
How satisfied are you with the doctor's attention to your description of your _____ (care recipient's) symptoms?	1.53 (0.66)	.84	0.97	1.61 (0.60)	.85	0.97
Availability of doctors to the family	1.48 (0.70)	.86	0.97	1.58 (0.65)	.85	0.97
Coordination of care	1.50 (0.66)	.79	0.97	1.60 (0.61)	.82	0.97
Time required to make a diagnosis	1.47 (0.67)	.83	0.97	1.59 (0.61)	.80	0.97
How satisfied are you with the way the family is included in treatment and care decisions?	1.53 (0.69)	.79	0.97	1.64 (0.62)	.87	0.97
Information given about how to manage your _____ (care recipient's) pain	1.46 (0.70)	.87	0.97	1.55 (0.69)	.89	0.97
Information given about your _____ (care recipient's) tests	1.51 (0.66)	.88	0.97	1.59 (0.64)	.89	0.97
How satisfied are you with how thoroughly the doctor assess your _____ (care recipient's) symptoms	1.52 (0.66)	.91	0.96	1.62 (0.62)	.91	0.97
The way tests and treatments are followed up by the doctor	1.48 (0.67)	.92	0.96	1.59 (0.64)	.92	0.97
Availability of doctor to your _____ (patient)	1.50 (0.67)	.88	0.97	1.58 (0.65)	.86	0.97
Reliability: Coefficient alpha Unstandardized (Standardized)		0.97 (0.97)			0.97 (0.97)	

Table A3.

Reliability Statistics at Varying Levels of the Attribute (Theta; θ) Estimate Based on Results of the IRT Analysis (IRTPRO).

Satisfaction (θ)	All cases ($N = 317$)	Spanish interview respondents ($n = 209$)
	Reliability	
-2.4	0.84	0.84
-2.0	0.93	0.93
-1.6	0.96	0.96
-1.2	0.96	0.96
-0.8	0.92	0.92
-0.4	0.90	0.90
0.0	0.94	0.94
0.4	0.96	0.96
0.8	0.95	0.95
1.2	0.91	N/A
Overall (Average)	0.93	0.93

Note. Reliability estimates were calculated for θ levels for which there were respondents. IRT = item response theory; IRTPRO = Item Response Theory for Patient-Reported Outcomes.

Table A4.

Distribution of the Summary Score Mapped to the Satisfaction Estimate Theta (θ) (IRTPRO): Total Sample ($N = 317$).

Summed score	Frequency	%	Cumulative percent	θ estimate	θ SD	Modeled proportion (%)	Cumulative modeled (%)
0	9	2.8	2.8	-2.13	0.41	3.61	3.61
1	2	0.6	3.5	-1.73	0.23	1.95	5.56
2	4	1.3	4.7	-1.56	0.16	1.48	7.04
3	7	2.2	6.9	-1.45	0.15	1.24	8.28
4	2	0.6	7.6	-1.34	0.13	1.19	9.47
5	3	0.9	8.5	-1.27	0.11	1.27	10.74
6	5	1.6	10.1	-1.20	0.12	1.37	12.11
7	8	2.5	12.6	-1.11	0.14	1.58	13.69
8	2	0.6	13.2	-1.01	0.14	2.11	15.80
9	8	2.5	15.8	-0.91	0.15	2.96	18.76
10	46	14.5	30.3	-0.81	0.15	3.73	22.49
11	8	2.5	32.8	-0.71	0.15	3.65	26.13
12	12	3.8	36.6	-0.60	0.14	3.23	29.36
13	5	1.6	38.2	-0.52	0.12	2.87	32.23
14	8	2.5	40.7	-0.44	0.13	2.55	34.78
15	3	0.9	41.6	-0.35	0.13	2.49	37.27
16	9	2.8	44.5	-0.26	0.12	2.88	40.15
17	7	2.2	46.7	-0.18	0.14	3.53	43.68

Summed score	Frequency	%	Cumulative percent	θ estimate	θ SD	Modeled proportion (%)	Cumulative modeled (%)
18	13	4.1	50.8	-0.05	0.19	4.82	48.50
19	12	3.8	54.6	0.17	0.26	8.81	57.32
20	144	45.4	100.0	0.89	0.61	42.68	100.00
Total	221	100.0	100.0			100.0	100.0

Note. The item and sum score direction is from not satisfied to very satisfied. IRTPRO = Item Response Theory for Patient-Reported Outcomes.

Table A5.

Distribution of the Summary Score Mapped to the Satisfaction Estimate Theta (θ ; IRTPRO) for Respondents Interviewed in Spanish ($n = 209$).

Summed score	Frequency	%	Cumulative percent	θ estimate	θ SD	Modeled proportion (%)	Cumulative modeled (%)
0	5	2.4	2.4	-2.23	0.40	2.79	2.79
1	0	0.0	2.4	-1.84	0.22	1.58	4.37
2	3	1.4	3.8	-1.66	0.16	1.23	5.61
3	3	1.4	5.3	-1.55	0.12	1.11	6.71
4	1	0.5	5.7	-1.49	0.11	0.99	7.70
5	2	1.0	6.7	-1.40	0.13	0.90	8.61
6	2	1.0	7.7	-1.30	0.11	1.03	9.63
7	4	1.9	9.6	-1.24	0.09	1.33	10.96
8	2	1.0	10.5	-1.17	0.12	1.65	12.61
9	5	2.4	12.9	-1.07	0.14	2.18	14.79
10	24	11.5	24.4	-0.98	0.13	2.83	17.62
11	2	1.0	25.4	-0.88	0.14	2.76	20.38
12	7	3.3	28.7	-0.79	0.11	2.53	22.91
13	4	1.9	30.6	-0.73	0.10	2.19	25.10
14	4	1.9	32.5	-0.65	0.13	1.90	26.99
15	1	0.5	33.0	-0.55	0.11	2.05	29.05
16	5	2.4	35.4	-0.49	0.10	2.53	31.58
17	5	2.4	37.8	-0.42	0.13	3.08	34.66
18	8	3.8	41.6	-0.29	0.17	4.28	38.93
19	11	5.3	46.9	-0.08	0.25	8.41	47.35
20	111	53.1	100.0	0.73	0.64	52.65	100.00
Total	221	100.0	100.0			100.0	100.0

Note. The item and sum score direction is from not satisfied to very satisfied. IRTPRO = Item Response Theory for Patient-Reported Outcomes.

Table A6.

IRT Item and Scale Information Functions by Theta (θ ; IRTPRO) for Total Sample ($N=317$).

θ	Attnsymp	Availdoc	Coorcare	Timediag	Famincl	Infomang	Infotest	Docsymp	Docfoll	Docpat	TOTAL	SE
-2.8	0.02	0.01	0.07	0.03	0.05	0.01	0.00	0.00	0.00	0.00	1.19	0.92
-2.4	0.11	0.06	0.32	0.18	0.22	0.05	0.03	0.00	0.00	0.04	2.02	0.7
-2.0	0.80	0.49	1.22	0.94	0.91	0.38	0.42	0.13	0.04	0.44	6.77	0.38
-1.6	4.02	2.99	3.06	3.50	2.71	2.70	4.39	3.86	2.00	3.95	34.17	0.17
-1.2	5.88	6.66	3.28	4.53	3.75	7.27	9.63	17.38	25.50	8.84	93.71	0.1
-0.8	4.03	4.12	2.68	2.79	3.48	4.13	4.00	3.75	2.16	3.91	36.05	0.17
-0.4	6.27	6.63	3.55	4.53	3.57	6.94	10.41	18.89	20.83	9.17	91.78	0.1
0.0	2.41	3.17	2.35	3.50	1.68	3.89	2.85	1.81	4.15	3.25	30.05	0.18
0.4	0.40	0.52	0.76	0.94	0.46	0.62	0.25	0.06	0.08	0.35	5.43	0.43
0.8	0.06	0.07	0.19	0.18	0.11	0.07	0.02	0.00	0.00	0.03	1.72	0.76
1.2	0.01	0.01	0.04	0.03	0.02	0.01	0.00	0.00	0.00	0.00	1.13	0.94
1.6	0.00	0.00	0.01	0.01	0.01	0.00	0.00	0.00	0.00	0.00	1.02	0.99
2.0	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	1	1
2.4	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	1	1
2.8	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	1	1
Rank	7	6	10	8	9	5	3	2	1	4		

Note. Highlighted rows indicate the highest level of information provided (at two modes). IRT = item response theory; IRTPRO = Item Response Theory for Patient-Reported Outcomes.

Table A7.

IRT Item and Scale Information Functions by Theta (θ ; IRTPRO) for Spanish Interview Respondents ($n = 209$).

θ	Attnsymp	Availdoc	Coorcare	Timediag	Famincl	Infomang	Infotest	Docsymp	Docfoll	Docpat	TOTAL	SE
-2.8	0.03	0.02	0.08	0.13	0.01	0.00	0.00	0.00	0.00	0.01	1.28	0.88
-2.4	0.28	0.15	0.43	0.63	0.09	0.02	0.02	0.00	0.00	0.09	2.71	0.61
-2.0	1.97	1.05	2.06	2.38	0.99	0.30	0.41	0.20	0.09	0.88	11.33	0.3
-1.6	6.65	4.79	4.90	4.18	7.17	3.63	6.12	7.70	5.63	5.85	57.62	0.13
-1.2	4.20	5.65	3.52	2.77	7.32	10.85	10.92	13.60	18.30	6.94	85.08	0.11
-0.8	5.16	5.39	4.06	3.23	9.27	6.86	8.32	14.73	8.81	6.32	73.15	0.12
-0.4	5.72	5.21	4.43	3.99	4.28	9.18	8.97	6.88	13.38	6.66	69.7	0.12
0.0	1.28	1.23	1.44	1.70	0.46	1.23	0.71	0.18	0.27	1.12	10.61	0.31
0.4	0.17	0.18	0.28	0.41	0.04	0.09	0.04	0.00	0.00	0.12	2.33	0.66
0.8	0.02	0.02	0.05	0.08	0.00	0.01	0.00	0.00	0.00	0.01	1.2	0.91
1.2	0.00	0.00	0.01	0.02	0.00	0.00	0.00	0.00	0.00	0.00	1.03	0.98
1.6	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	1.01	1
2.0	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	1	1
2.4	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	1	1
2.8	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	1	1

θ	Attnsymp	Availdoc	Coorcare	Timediag	Famincl	Infomang	Infotest	Docsympt	Docfoll	Docpat	TOTAL	SE
Rank	7	8	9	10	5	4	3	2	1	6		

Note. Highlighted rows indicate the highest level of information provided (at one or two modes.). IRT = item response theory; IRTPRO = Item Response Theory for Patient-Reported Outcomes.

Figure A1.
Scree plot from the exploratory factor analysis (MPlus).

Figure A2.

Test and item information functions (IRTPRO) for respondents interviewed in Spanish ($n = 209$).

Note. IRTPRO = Item Response Theory for Patient-Reported Outcomes.

Biography

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References

- Alzheimer’s Association. (2013). Alzheimer’s disease facts and figures. *Alzheimer’s & Dementia*, 9, 208–245. 10.1016/j.jalz.2013.02.003
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.
- Andershed B (2006). Relatives in end-of-life care—Part 1: A systematic review of the literature the five last years, January 1999–February 2004. *Journal of Clinical Nursing*, 15, 1158–1169. <http://dx.doi.org/10.1111/j.1365-2702.2006.01473.x> [PubMed: 16911057]
- Angel RJ (2006). Narrative and the fundamental limitations of quantification in cross-cultural research. *Medical Care*, 44, S31–S33. 10.1097/01.mlr.0000245428.03255.cf
- Aoun S, Bird S, Kristjanson LJ, & Currow D (2010). Reliability testing of the FAMCARE-2 scale: Measuring family care satisfaction with palliative care. *Palliative Medicine*, 24, 674–681. 10.1177/0269216310373166 [PubMed: 20621947]
- Asparouhov T, & Muthén B (2009). Exploratory structural equation modeling. *Structural Equation Modeling: A Multidisciplinary Journal*, 16, 397–438. 10.1080/10705510903008204
- Benitez-Rosario MA, Caceres-Miranda R, Aguirre-Jaime A, & Grupo Español de Investigación en Cuidados Paliativos. (2016). Spanish validation of the Care Evaluation Scale for measuring the quality of structure and process of palliative care from the family perspective. *Journal of Pain and Symptom Management*, 51, 609–614.e1. 10.1016/j.jpainsymman.2015.11.002 [PubMed: 26596881]
- Bentler PM (1990). Comparative fit indexes in structural models. *Psychological Bulletin*, 107, 238–246. 10.1037/0033-2909.107.2.238 [PubMed: 2320703]
- Bruce B, Fries JF, Ambrosini D, Lingala B, Gandek B, Rose M, & Ware JE (2009). Better assessment of physical function: Item improvement is neglected but essential. *Arthritis Research & Therapy*, 11, Article R191. 10.1186/ar2890
- Cai L, Thissen D, & du Toit SHC (2011). *IRTPRO: Flexible, multidimensional, multiple categorical IRT modeling* [Computer software]. Chicago, IL: Scientific Software International.
- Carter GL, Lewin TJ, Gianacas L, Clover K, & Adams C (2011). Caregiver satisfaction with outpatient oncology services: Utility of the FAMCARE instrument and development of the FAMCARE-6. *Supportive Care in Cancer*, 19, 565–572. 10.1007/s00520-010-0858-1 [PubMed: 20349317]
- Chang Y, Kwon YC, Lee WJ, Do YR, Lee KS, Kim HT, ... Yun YH (2013). Burdens, needs and satisfaction of terminal cancer patients and their caregivers. *Asian Pacific Journal of Cancer Prevention*, 14, 209–215. 10.7314/apjcp.2013.14.1.209 [PubMed: 23534725]
- Chen WH, & Thissen D (1997). Local dependence indices for item pairs using item response theory. *Journal of Educational and Behavioral Statistics*, 22, 265–289. 10.2307/1165285
- Choi SW, Reise SP, Pilkonis PA, Hays RD, & Cella D (2010). Efficiency of static and computer adaptive short forms compared to full-length measures of depressive symptoms. *Quality of Life Research*, 19, 125–136. 10.1007/s11136-009-9560-5 [PubMed: 19941077]
- Cohen S, Kamarck T, & Mermelstein R (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 386–396. 10.2307/2136404
- Cole SR (1999). Assessment of differential item functioning in the Perceived Stress Scale-10. *Journal of Epidemiology & Community Health*, 53, 319–320. 10.1136/jech.53.5.319 [PubMed: 10396541]
- D’Angelo D, Punziano AC, Mastroianni C, Marzi A, Latina R, Ghezzi V, ... De Marinis MG (2017). Translation and testing of the Italian version of FAMCARE-2: Measuring family caregivers’ satisfaction with palliative care. *Journal of Family Nursing*, 23, 252–272. 10.1177/1074840717697538 [PubMed: 28795900]

- Dudgeon DJ, Knott C, Eichholz M, Gerlach JL, Chapman C, Viola R, ... Bartfay E (2008). Palliative Care Integration Project (PCIP) quality improvement strategy evaluation. *Journal of Pain and Symptom Management*, 35, 573–582. 10.1016/j.jpainsymman.2007.07.013 [PubMed: 18358693]
- Eremenco SL, Cella D, & Arnold BJ (2005). A comprehensive method for the translation and cross-cultural validation of health status questionnaires. *Evaluation & the Health Professions*, 28, 212–232. 10.1177/0163278705275342 [PubMed: 15851774]
- Follwell M, Burman D, Le LW, Wakimoto K, Seccareccia D, Bryson J, ... Zimmermann C (2009). Phase II study of an outpatient palliative care intervention in patients with metastatic cancer. *Journal of Clinical Oncology*, 27, 206–213. 10.1200/JCO.2008.17.7568 [PubMed: 19064979]
- Gort AM, Mingot M, Gomez X, Soler T, Torres G, Sacristán O, ... Cabau J (2007). Use of the Zarit scale for assessing caregiver burden and collapse in caregiving at home in dementias. *International Journal of Geriatric Psychiatry*, 22, 957–962. 10.1002/gps.1770 [PubMed: 17299807]
- Grunfeld E, Coyle D, Whelan T, Clinch J, Reyno L, Earle CC, ... Glossop R (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*, 170, 1795–1801. 10.1503/cmaj.1031205 [PubMed: 15184333]
- Hannon B, Swami N, Krzyzanowska MK, Leighl N, Rodin G, Le LW, & Zimmermann C (2013). Satisfaction with oncology care among patients with advanced cancer and their caregivers. *Quality of Life Research*, 22, 2341–2349. 10.1007/s11136-013-0371-3 [PubMed: 23435667]
- Hudson PL, Trauer T, Graham S, Grande G, Ewing G, Payne S, ... Thomas K (2010). A systematic review of instruments related to family caregivers of palliative care patients. *Palliative Medicine*, 24, 656–668. 10.1177/0269216310373167 [PubMed: 20605852]
- Humes KR, Jones NA, & Ramirez RR (2011). Overview of race and Hispanic origin: 2010 Washington, DC: U.S. Department of Commerce.
- Hwang SS, Chang VT, Alejandro Y, Osenenko P, Davis C, Cogswell J, ... Kasimis B (2003). Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs (VA) medical center. *Palliative & Supportive Care*, 1, 319–329. 10.1017/s1478951503030475 [PubMed: 16594221]
- Jean-Pierre P, Fiscella K, Winters PC, Paskett E, Wells K, Battaglia T, & Patient Navigation Research Program Group. (2012). Psychometric validation and reliability analysis of a Spanish version of the patient satisfaction with cancer-related care measure: A patient navigation research program study. *Supportive Care in Cancer*, 20, 1949–1956. 10.1007/s00520-011-1297-3 [PubMed: 22038482]
- Johnsen AT, Ross L, Petersen MA, Lund L, & Groenvold M (2012). The relatives' perspective on advanced cancer care in Denmark. A cross-sectional survey. *Supportive Care in Cancer*, 20, 3179–3188. 10.1007/S00520-012-1454-3 [PubMed: 22526148]
- Kristjanson LJ (1986). Indicators of quality of palliative care from a family perspective. *Journal of Palliative Care*, 1, 8–17. [PubMed: 2453638]
- Kristjanson LJ (1989). Quality of terminal care: Salient indicators identified by families. *Journal of Palliative Care*, 5, 21–30. 10.1177/082585978900500104 [PubMed: 2715882]
- Kristjanson LJ (1993). Validity and reliability testing of the FAMCARE Scale: Measuring family satisfaction with advanced cancer care. *Social Science & Medicine*, 36, 693–701. 10.1016/0277-9536(93)90066-D [PubMed: 8456339]
- Kroenke K, Spitzer RL, & Williams JB (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16, 606–613. 10.1046/j.1525-1497.2001.016009606.x [PubMed: 11556941]
- Lawton MP, Moss M, Hoffman C, & Perkinson M (2000). Two transitions in daughters caregiving careers. *The Gerontologist*, 40, 437–448. 10.1093/geront/40.4.437 [PubMed: 10961033]
- Liu W, & Gallagher-Thompson D (2009). Impact of dementia caregiving: Risks, strains, and growth In Qualls SH & Zarit SH (Eds.), *Aging families and caregiving* (pp. 85–112). Hoboken, NJ: John Wiley.
- Lo C, Burman D, Rodin G, & Zimmermann C (2009). Measuring patient satisfaction in oncology palliative care: Psychometric properties of the FAMCARE-patient scale. *Quality of Life Research*, 18, 747–752. 10.1007/s11136-009-9494-y [PubMed: 19513815]

- Luchsinger JA, Burgio L, Mittelman M, Dunner I, Levine J, Kong J, ... Teresi J (2016). The Northern Manhattan Hispanic Caregiver Intervention Effectiveness Study: Protocol of a pragmatic randomized trial comparing the effectiveness of two established interventions for informal caregivers of persons with dementia. *BMJ Open*, 6, e014082. 10.1136/bmjopen-201601408
- Luchsinger JA, Tipiani D, Torres-Patino G, Eimicke J, Ramirez M, Teresi J, ... Mittelman M (2015). Characteristics and mental health of Hispanic dementia caregivers in New York City. *American Journal of Alzheimer's Disease & Other Dementias*, 30, 584–590. 10.1177/1533317514568340
- McDonald RP (2009). *Test theory: A unified treatment*. Mahwah, NJ: Lawrence Erlbaum.
- McHorney CA, & Fleishman JA (2006). Assessing and understanding measurement equivalence in health outcome measures: Issues for further quantitative and qualitative inquiry. *Medical Care*, 44, S205–S210. 10.1097/01.mlr.0000245451.67862.57 [PubMed: 17060829]
- Milberg A, Strang P, Carlsson M, & Börjesson S (2003). Advanced palliative home care: Next-of-kin's perspective. *Journal of Palliative Medicine*, 6, 749–756. 10.1089/109662103322515257 [PubMed: 14622454]
- Muthén LK, & Muthén BO (2011). *M-PLUS users guide* (6th ed.). Los Angeles, CA: Author.
- Naoki Y, Matsuda Y, Maeda I, Kamino H, Kozaki Y, Tokoro A, ... Takada M (2017). Association between family satisfaction and caregiver burden in cancer patients receiving outreach palliative care at home. *Palliative and Supportive Care*, 16, 260–268. 10.1017/S1478951517000232 [PubMed: 28462749]
- Ornstein KA, Teresi JA, Ocepek Welikson K, Ramirez M, Meier DE, Morrison RS, & Siu A (2015). Use of an item bank to develop two short-form FAMCARE scales to measure family satisfaction with care in the setting of serious illness. *Journal of Pain and Symptom Management*, 49, 894–903. 10.1016/j.jpainsymman.2014.10.017 [PubMed: 25546287]
- Pinquart M, & Sörensen S (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *Journal of Gerontology, Series B: Psychology Science & Social Science*, 58, 112–128. 10.1093/geronb/58.2.p112
- Ringdal GI, Jordhoy MS, & Kaasa S (2003). Measuring quality of palliative care: Psychometric properties of the FAMCARE Scale. *Quality of Life Research*, 12, 167–176. <https://doi.org/10.1023/A:1022236430131> [PubMed: 12639063]
- Rodriguez KL, Bayliss NK, Jaffe E, Zickmund S, & Sevrick MA (2010). Factor analysis and internal consistency evaluation of the FAMCARE scale for use in the long-term care setting. *Palliative & Supportive Care*, 8, 169–176. 10.1017/s1478951509990927 [PubMed: 20331914]
- Rose M, Bjorner JB, Becker J, Fries JF, & Ware JE (2008). Evaluation of a preliminary physical function item bank supported the expected advantages of the Patient-Reported Outcomes Measurement Information System (PROMIS). *Journal of Clinical Epidemiology*, 61, 17–33. 10.1016/j.jclinepi.2006.06.025 [PubMed: 18083459]
- Samejima F (1969). *Estimation of latent ability using a response pattern of graded scores* (Psychometricka Monograph, No. 17). Richmond, VA: William Byrd Press.
- Savundranayagam MY, Montgomery RJ, & Kosloski K (2011). A dimensional analysis of caregiver burden among spouses and adult children. *The Gerontologist*, 51, 321–331. 10.1093/geront/gnq102 [PubMed: 21135026]
- Seshadri S, Wolf PA, Beiser A, Au R, McNulty K, White R, & D'Agostino RB (1997). Lifetime risk of dementia and Alzheimer's disease: The impact of mortality on risk estimates in the Framingham Study. *Neurology*, 49, 1498–1504. 10.1212/WNL.49.6.1498 [PubMed: 9409336]
- Sijtsma K (2009). On the use, the misuse, and the very limited usefulness of Cronbach's alpha. *Psychometrika*, 74, 107–120. 10.1007/s11336-008-9101-0 [PubMed: 20037639]
- Sörensen S, Duberstein P, Gill D, & Pinquart M (2006). Dementia care: Mental health effects, intervention strategies, and clinical implications. *The Lancet Neurology*, 5, 961–973. 10.1016/S1474-4422(06)70599-3 [PubMed: 17052663]
- Stajduhar KI, Martin WL, & Cairns M (2010). What makes grief difficult? Perspectives from bereaved family caregivers and healthcare providers of advanced cancer patients. *Palliative and Supportive Care*, 8, 277–289. 10.1017/S1478951510000076 [PubMed: 20875171]
- Teresi JA, Ocepek-Welikson K, Kleinman M, Eimicke JP, Crane PK, Jones RN, ... Cella D (2009). Analysis of differential item functioning in the depression item bank from the Patient Reported

Outcome Measurement Information System (PROMIS): An item response theory approach. *Psychology Science Quarterly*, 51, 148–180. [PubMed: 20336180]

Teresi JA, Ocepek-Welikson K, Ramirez M, Kleinman M, Ornstein K, & Siu A (2015). Evaluation of measurement equivalence of the Family Satisfaction with the End-of-Life Care in an ethnically diverse cohort: Tests of differential item functioning. *Palliative Medicine*, 29, 83–96. 10.1177/0269216314545802 [PubMed: 25160692]

Teresi JA, Ornstein K, Ocepek-Welkinson K, Ramirez M, & Siu A (2014). Performance of the family satisfaction with the end-of-life care (FAMCARE) measure in an ethnically diverse cohort: Psychometric analyses using item response theory. *Supportive Care in Cancer*, 22, 399–408. 10.1007/s00520-013-1988-z [PubMed: 24091717]

Tucker LR, & Lewis C (1973). A reliability coefficient for maximum likelihood factor analysis. *Psychometrika*, 38, 1–10. 10.1007/BF02291170

Vitaliano PP, Zhang J, & Scanlan JM (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129, 946–972. 10.1037/0033-2909.129.6.946 [PubMed: 14599289]

Wu S, Vega WA, Resendez J, & Jin H (2016). Latinos & Alzheimer's disease: New numbers behind the crisis. Retrieved from https://www.ucdmc.ucdavis.edu/latinoaging/images/pdf/Latinos-and-AD-USC_UsA2-Impact-Report.pdf

Yesavage JA, Brink TL, Rose TL, Lum O, Huang V, Adey M, & Leirer VO (1982). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, 17, 37–49. 10.1016/0022-3956(82)90033-4 [PubMed: 7183759]

Figure 1.

Test and item information functions (IRTPRO): Total sample (N = 317).

Note. IRTPRO = Item Response Theory for Patient-Reported Outcomes

Item Name	Item Description
Attnsymp	How satisfied are you with the doctor's attention to your description of your ____ (care recipient's) symptoms?
Availdoc	Availability of doctors to the family
Coorcare	Coordination of care
Timediag	Time required to make a diagnosis
Famincl	How satisfied are you with the way the family is included in treatment and care decisions?
Infomang	Information given about how to manage your ____ (care recipient's) pain
Infotest	Information given about your ____ (care recipient's) tests
Docsympt	How satisfied are you with how thoroughly the doctor assess your ____ (care recipient's) symptoms
Docfol	The way tests and treatments are followed up by the doctor
Docpat	Availability of doctor to your ____ (care recipient)

Figure 2.

Test information function (IRTPRO): Total sample (N = 317).

Note. IRTPRO = Item Response Theory for Patient-Reported Outcomes.

Table 1.Demographic Characteristics of the Caregiver Sample (Total $N = 317$).

Language of the interview			
	English	Spanish	Total
	107 (34%)	209 (66%)	317
Gender			
Female	78 (73%)	183 (88%)	262 (83%)
Male	29 (27%)	26 (12%)	55 (17%)
Age			
$M(SD)$	53.8 (9.8)	60.0 (11.3)	57.9 (11.2)
Minimum-maximum	25–77	19–85	19–85
Education			
$M(SD)$	14.2 (2.9)	11.9 (3.7)	12.7(3.6)
Minimum-maximum	4–20	2–20	2–20

Note. Sample sizes do not add to the total due to one missing language of the interview preference.

Table 2.

Eigenvalues From the Exploratory Factor Analysis Using Principal Components Estimation.

Statistic	Component 1	Component 2	Component 3	Component 4	Ratio Component 1/Component 2
All cases (<i>N</i> = 317)					
Eigenvalues	8.85	0.26	0.21	0.20	33.9
Explained variance	88.5%	2.6%	2.1%	2.0%	
Respondents interviewed in Spanish (<i>n</i> = 209)					
Eigenvalues	9.00	0.28	0.19	0.15	32.5
Explained variance	90.0%	2.8%	1.9%	1.5%	

Note. MPlus was used for the analyses.

Table 3.

Model Fit Statistics: CFI, TLI, RMSEA.

MPlus exploratory/confirmatory factor analyses ^a						
One factor solution			Two factor solution			IRT: IRTPRO RMSEA
CFI	TLI	RMSEA	CFI	TLI	RMSEA	
All cases (<i>N</i> = 317)						
0.997	0.996	0.097	0.998	0.997	0.086	0.08 ^b
Respondents Interviewed in Spanish (<i>n</i> = 209)						
0.996	0.995	0.106	0.998	0.997	0.092	0.10 ^b

Note. CFI = comparative fit index; TLI = Tucker-Lewis index; RMSEA = root mean error of approximation; IRT = item response theory; IRTPRO = Item Response Theory for Patient-Reported Outcomes.

^a Geomin (oblique) rotation and fit statistics for one- and two-factor solutions.

^b Based on M₂ statistics which is based on full marginal tables.

Table 4.

IRT Item Parameters and Standard Error Estimates (IRTPRO).

Item description	All cases (<i>N</i> = 317)			Spanish interview respondents (<i>n</i> = 209)		
	<i>a</i> (SE)	<i>b1</i> (SE)	<i>b2</i> (SE)	<i>a</i> (SE)	<i>b1</i> (SE)	<i>b2</i> (SE)
How satisfied are you with the doctor's attention to your description of your _____ (care recipient's) symptoms?	4.99 (1.49)	-1.32 (0.61)	-0.42 (0.37)	5.24 (1.24)	-1.53 (0.24)	-0.57 (0.09)
Availability of doctors to the family	5.14 (1.32)	-1.23 (0.60)	-0.35 (0.35)	5.03 (1.20)	-1.38 (0.22)	-0.58 (0.09)
Coordination of care	3.74 (0.83)	-1.40 (0.61)	-0.35 (0.35)	4.44 (1.12)	-1.55 (0.24)	-0.55 (0.09)
Time required to make a diagnosis	4.39 (1.03)	-1.34 (0.60)	-0.26 (0.33)	4.07 (0.97)	-1.62 (0.26)	-0.50 (0.09)
How satisfied are you with the way the family is included in treatment and care decisions?	3.80 (0.88)	-1.31 (0.60)	-0.49 (0.39)	6.22 (1.65)	-1.42 (0.23)	-0.71 (0.09)
Information given about how to manage your _____ (care recipient's) pain	5.37 (1.24)	-1.20 (0.60)	-0.31 (0.33)	6.63 (1.93)	-1.25 (0.20)	-0.53 (0.08)
Information given about your _____ (care recipient's) tests	6.44 (1.34)	-1.29 (0.61)	-0.39 (0.34)	7.43 (2.27)	-1.34 (0.21)	-0.58 (0.08)
How satisfied are you with how thoroughly the doctor assess your _____ (care recipient's) symptoms	8.73 (2.88)	-1.27 (0.64)	-0.42 (0.33)	9.58 (2.09)	-1.36 (0.22)	-0.65 (0.07)
The way tests and treatments are followed up by the doctor	10.13 (7.64)	-1.21 (0.65)	-0.31 (0.30)	10.53 (1.53)	-1.33 (0.20)	-0.57 (0.07)
Availability of doctor to your _____ (care recipient)	6.07 (2.19)	-1.27 (0.66)	-0.37 (0.31)	5.84 (1.34)	-1.38 (0.22)	-0.57 (0.08)

Note. The item direction is from not satisfied to very satisfied. The instructions were: "The next set of questions is about your satisfaction with the medical care your _____ (care recipient) is receiving." IRT = item response theory; IRTPRO = Item Response Theory for Patient-Reported Outcomes.

Table 5.

Correlations of the FAMCARE Short Form Sum Score and IRT-Theta Score (θ) With Caregiver Burden, Stress, Depression, and Function Measures.

	Raw sum score			θ		
	Pearson correlation	<i>p</i> value	<i>n</i>	Pearson correlation	<i>p</i> value	<i>n</i>
Zarit Caregiver Burden Scale: Prorated (Higher score is indicative of burden)	-.189	.001	317	-.185	.001	317
Lawton Caregiver Appraisal Scale: Burden Prorated (Higher score is indicative of burden)	-.213	<.001	316	-.218	<.001	316
Montgomery Caregiving Objective Burden Scale: Prorated (Higher score is indicative of burden)	-.194	.001	314	-.200	<.001	314
Hours of total help/supervision per week provided by the caregiver	.084	.141	311	.088	.121	311
Perceived Stress Scale: Prorated (deviant)	-.182	.001	317	-.191	.001	317
Geriatric Depression Scale (GDS): Prorated (Higher score is indicative of depression)	-.144	.010	317	-.164	.003	317
PHQ-9 Severity Score (Higher score is indicative of greater depression)	-.202	<.001	305	-.210	<.001	305
PROMIS Depression SF8a T-score (50 = average; 10 = standard deviation; Higher score is indicative of greater depression)	-.178	.001	317	-.194	.001	317
PROMIS Physical Function (Higher score indicates greater functional ability of caregiver)	.037	.516	317	.031	.587	317

Note. FAMCARE = Family Satisfaction With End-of-Life Care; IRT = item response theory; PHQ = Patient Health Questionnaire; PROMIS = Patient-Reported Outcome Measurement Information System.