

Title

Psychometric evaluation and cultural adaptation of the Spanish version of the ‘Scale for End-of Life Caregiving Appraisal’.

Authors’ names and affiliations

José Manuel Hernández-Padilla¹⁻², Matías Correa-Casado³, José Granero-Molina²⁻⁴, Alda Elena Cortés-Rodríguez², Tamara María Matarín-Jiménez⁵, Cayetano Fernández-Sola²⁻⁴

¹Adult, Child and Midwifery Department. School of Health and Education. Middlesex University. Hendon Campus. The Burroughs. NW4 4BT. London. United Kingdom.

²Nursing, Physiotherapy and Medicine Department. Faculty of Health Sciences. University of Almeria. Spain. Postal address: Universidad de Almería. Edificio de Ciencias de la Salud. Carretera de Sacramento s/n. Almería. Postcode: 04120. Spain.

³Internal medicine ward at Poniente Hospital. Carretera de Almerimar 31. Postcode: 04700. El Ejido. Almería. Spain.

⁴Associate Researcher. Faculty of Health Sciences. Universidad Autónoma de Chile. Temuco. Chile.

⁵Internal medicine ward at Motril Hospital. Av. Enrique Martín Cuevas s/n. Postcode: 18600. Motril. Granada. Spain.

Corresponding author

Dr. José Manuel Hernández-Padilla.

Postal address: Universidad de Almería. Edificio de Ciencias de la Salud. Carretera de Sacramento s/n. Almería. Postcode: 04120. Spain.

Email address: J.Hernandez-Padilla@ual.es

Word count

Abstract=261 words

Manuscript=4074 words (excluding abstract, keywords and references)

Shortened title

Spanish Scale for End-of Life Caregiving Appraisal

Manuscript’s pages and tables

22 pages (excluding title page and abstract page) and 4 tables.

Title

Psychometric evaluation and cultural adaptation of the Spanish version of the ‘Scale for End-of Life Caregiving Appraisal’.

Abstract

Objective: To translate, culturally adapt and psychometrically evaluate the Spanish version of the ‘Scale for End-of Life Caregiving Appraisal’ (SEOLCAS).

Methods: Observational cross-sectional study. Convenience sample of 201 informal end-of-life caregivers recruited in a southern Spanish hospital. The reliability of the questionnaire was assessed through its internal consistency (Cronbach’s α) and temporal stability (Pearson’s correlation coefficient (r) between test-retest). The content validity index of the items ($I-CVI$) and the scale ($S-CVI/Ave$) was calculated. Its criterion validity was explored through performing a linear regression analysis to evaluate the SEOLCAS’ predictive validity. Exploratory factor analysis was used to examine its construct validity.

Results: The SEOLCAS’s reliability was very high (Cronbach’s $\alpha=0.92$). Its content validity was excellent (all items’ *content validity index*=0.8–1; *scale’s validity index*=0.88). Evidence of the SEOLCAS’ criterion validity showed that the participants’ scores on the SEOLCAS explained approximately 79.3% of the between-subject variation of their results on the Zarit Burden Interview. Exploratory factor analysis provided evidence of the SEOLCAS’ construct validity. This analysis revealed that two factors (‘internal contingencies’ and ‘external contingencies’) explained 53.77% of the total variance found and reflected the stoic Hispanic attitude towards adversity.

Significance of the results: The Spanish version of the ‘Scale for End-of Life Caregiving Appraisal’ has shown to be an easily-applicable, valid, reliable and culturally-appropriate tool to measure the impact of end-of-life care provision on Hispanic informal caregivers. This tool offers healthcare professionals the opportunity to easily explore Hispanic informal end-of-life caregivers’ experiences and discover the type of support they may need (instrumental or emotional) even when there are communicational and organisational constraints.

Keywords

Palliative care; end of life care; carers; family caregivers; questionnaire design; psychometrics.

1 **Introduction**

2 International literature suggests that patients with far-advanced diseases often
3 prefer to receive end-of-life care and die at home (MacArtney et al., 2016; Woodman et
4 al., 2016; Wright et al., 2016). The provision of end-of-life care at home is a complex
5 endeavour that would not be possible without the informal caregivers' support (Nuño-
6 Solinís et al., 2016). **Informal caregivers are laypeople who play a close supportive role**
7 **to patients, share in their illness experiences, and provide essential instrumental and**
8 **emotional support for them (Gardiner et al., 2014).** It is believed that the experience of
9 providing end-of-life care at home can be burdensome and informal caregivers may
10 experience difficulties in maintaining their own health and quality of life (Dalai &
11 Bruera, 2017; MacArtney et al., 2016). For this reason, it is crucial that healthcare
12 professionals explore informal end-of-life caregivers' experiences on an individual level
13 so that their real health needs are identified and meaningful support is offered
14 (Applebaum, 2017; Granero-Molina et al., 2016; Jack et al., 2015; Reblin et al. 2015;
15 Reyniers et al., 2014; Robinson et al., 2017; van der Steen et al., 2014).

16 The assessment of informal end-of-life caregivers' needs and the provision of
17 meaningful support are services offered by healthcare systems that have achieved
18 advanced integration of palliative care within their mainstream service provision (Lynch
19 et al., 2013). Unfortunately, this is not the case in many Spanish-speaking countries,
20 where the provision of palliative care is not fully integrated into all levels of care (e.g.
21 Spain, Argentina, Chile, and many more) (Lynch et al., 2013). In such contexts, informal
22 end-of-life caregivers may have limited access to palliative care services and they are at
23 risk of becoming 'invisible' to their healthcare systems (Lynch et al., 2013; Veloso &
24 Tripodoro, 2016). In order to avoid this, and until full integration of palliative care into
25 all levels of care is achieved in Spanish-speaking countries, it is necessary for all

26 healthcare professionals attending to end-of-life patients (irrespective of their work
27 setting and whether they are palliative care specialists or not) to be able to explore the
28 informal end-of-life caregivers' experiences so that their needs can be identified and the
29 appropriate support can be provided (Fernández-Sola et al., 2017). This could be done
30 *ad hoc*, for example, when informal caregivers accompany the end-of-life patient to
31 hospital admissions or to community-based consultations (Fernández-Sola et al., 2017;
32 Rocque et al., 2013). However, evidence suggests that healthcare professionals who are
33 non-specialists in palliative care often lack competence to manage emotionally-charged
34 conversations and have limited time available to effectively explore informal end-of-
35 life caregivers' experiences (Adams et al., 2011; Bloomer et al., 2013; Caswell et al.,
36 2015; Gagnon & Duggleby, 2014; Robinson et al., 2014; Smith et al., 2009; Willard &
37 Luker, 2006). In order to overcome such barriers, these healthcare professionals could
38 use standardised and culturally-adapted psychometric instruments that would allow
39 them to quickly assess the informal end-of-life caregivers' experiences without having
40 to have a difficult conversation for which they may not be prepared.

41 To the best of our knowledge, most of the psychometric instruments that are
42 available to explore informal end-of-life caregivers' experiences focus on assessing only
43 one particular dimension of end-of-life caregiving such as self-efficacy (Porter et al.,
44 2008), burden (Dumont et al., 2008; Higginson et al., 2010) or comfort (Novak et al.,
45 2001). Consequently, they would not allow healthcare professionals to easily and
46 quickly explore the experience of informal end-of-life caregivers as a whole using just
47 one questionnaire. In this context, the 'Scale for End-of Life Caregiving Appraisal'
48 (EOLCAS) emerges as a useful instrument in so far as it comprehensively assesses the
49 experience of end-of-life caregivers in four domains: 'physical suffering', 'caregiving
50 burden', 'positive caregiving appraisal' and 'social support pursuit' (Lee et al., 2010).

51 Using the EOLCAS as a tool to explore informal end-of-life caregivers' experiences
52 would allow healthcare professionals in any type of setting to better understand
53 individuals' subjective responses to potential stressors and identify whether their coping
54 mechanisms actually help them to maintain a healthy biopsychosocial balance (Lee et
55 al., 2010). However, only an English version of the EOLCAS (validated amongst a
56 Korean sample) has been published (Lee et al., 2010). The translation, cultural
57 adaptation and validation of its Spanish version would allow healthcare professionals to
58 explore the experience of Spanish-speaking informal end-of-life caregivers worldwide.

59 The aim of this study was to translate, culturally adapt and psychometrically
60 evaluate the Spanish version of the 'Scale for End-of Life Caregiving Appraisal'.

61 **Methods**

62 *Study design and participants*

63 An observational cross-sectional design guided this study. The pilot and main
64 study samples were recruited using the same convenience sampling method. Individuals
65 who attended the internal medicine ward in a general southern Spanish hospital between
66 April 2015 and May 2016 were formally invited to participate in the study if they met
67 the following inclusion criteria: [1] to be ≥ 18 years old, [2] to be the main informal
68 caregiver for a patient with a far-advanced disease, [3] to not suffer any cognitive
69 impairment that could interfere with the understanding and completion of the scale. A
70 total sample of 201 individuals volunteered to participate and their demographics were
71 collected (age, gender, occupation, relation to the patient, household income, level of
72 education completed, and time as main informal caregiver).

73 *Ethical considerations*

74 The institutional 'Research Ethics Committee' granted ethical approval before
75 initiating the data collection (TE_15_34). All individuals fulfilling the eligibility criteria

76 were invited to participate and given a written document with information about the
77 participants' rights, the study's aim and the data collection process. Volunteer
78 participants signed an informed consent form before participating. The collected data
79 were treated according to the current European legislation on data protection (Directive
80 95/46/EC, 1995).

81 *Translation, cultural adaptation and pilot study of the SEOLCAS' initial version.*

82 The English-to-Spanish translation of the EOLCAS was performed following a
83 forward-backward procedure (Koller et al., 2007). Two independent bilingual experts
84 (native Spanish, proficient in English) individually undertook an English-to-Spanish
85 translation of the EOLCAS. Minor differences between both translators' versions were
86 easily reconciled and a common initial Spanish version of the EOLCAS (i-SEOLCAS)
87 was created. An independent bilingual translator (native English, proficient in Spanish)
88 undertook a 'blind back-translation' of the i-SEOLCAS (Koller et al., 2007). Before
89 initiating the pilot study, the researchers and a panel of 5 independent bilingual experts
90 reviewed the English version of the original EOLCAS, the i-SEOLCAS and the 'blind
91 back-translation'. It was unanimously agreed that the i-SEOLCAS fully respected the
92 semantic and conceptual meanings of the original EOLCAS.

93 The i-SEOLCAS was critically revised by a panel of 15 independent experts in
94 palliative care from 6 different institutions and was tested among a sample of 51
95 participants who only participated in the pilot study. The experts were asked to score
96 each item as 1='not relevant', 2='somewhat relevant', 3='quite relevant' or 4='highly
97 relevant' for evaluating the experience of informal end-of-life caregivers. **Each item's**
98 **content validity index (I-CVI)** was calculated by adding the number of experts who rated
99 each item as either 'quite relevant' or 'highly relevant' and dividing it by the total
100 number of experts in the panel (Polit & Beck, 2006). An I-CVI \geq 0.78 is considered

101 acceptable when evaluated by 15 experts (Delgado-Rico et al., 2012; Polit & Beck,
102 2006); the items with an I-CVI<0.78 were removed from the i-SEOLCAS before
103 piloting it.

104 To examine the i-SEOLCAS' reliability and temporal stability, the 51 participants
105 comprising the pilot sample completed the scale on two different occasions separated
106 by a 4-week interval. After assessing and corroborating that the variable followed a
107 normal distribution, temporal stability of the i-SEOLCAS was examined by calculating
108 Pearson's correlation coefficient (r) for the test-retest results. The i-SEOLCAS'
109 reliability was assessed using the following three estimators: [1] scale's Cronbach's
110 coefficient alpha (α), [2] items' corrected item-total correlation (C-ITC), [3] estimated
111 α of the tool if a particular item was removed. Items were retained as part of the i-
112 SEOLCAS if: [1] the instrument's α did not increase after removing that item and [2]
113 item's C-ITC>0.3.

114 To explore the i-SEOLCAS' readability, understandability and cultural
115 appropriateness, the experts and the participants were requested to provide feedback on
116 whether they had any difficulties when reading or completing the scale. They were also
117 encouraged to add any other items that could contribute to better exploring the
118 experience of informal end-of-life caregivers.

119 The results of the content validity and reliability analysis are presented in Table
120 1. Before administering the tool to the pilot sample, items 2, 8, 13, 21 and 24 were
121 removed from the i-SEOLCAS as the experts considered they were redundant and
122 agreed that they were not relevant in measuring the experience of informal end-of-life
123 caregivers in the context of the study (all I-CVI<0.78). Then, the 27-item pilot version
124 of the SEOLCAS (p-SEOLCAS) was tested amongst the pilot sample ($N=51$) and
125 although it evidenced an excellent temporal stability ($r=0.87$; $p<0.001$), its internal

126 consistency was not sufficiently strong ($\alpha=0.76$). As Table 1 shows, items 3, 9-15, 18-
127 19 and 29-32 did not meet the criteria to remain part of the SEOLCAS. Furthermore, all
128 of these items received negative comments about their appropriateness to measure the
129 experience of providing informal end-of-life care from both the experts and participants.
130 Therefore, they were all removed from the already-piloted SEOLCAS version. After
131 this, the 14-item SEOLCAS evidenced an $\alpha=0.91$ and all its items' C-ITC >0.3 . Lastly,
132 neither the experts nor the participants in the pilot study reported any issues reading or
133 understanding the SEOLCAS and did not recommend adding any items. Consequently,
134 no changes in the scale were needed.

135 *Data analysis and psychometric evaluation of the SEOLCAS*

136 The already-piloted 14-item version of the SEOLCAS (see Appendix 1) was
137 administered to the main sample ($N=150$) and psychometrically tested following other
138 authors' recommendations and guidelines (Coaley, 2014; Delgado-Rico et al., 2012;
139 Hernández-Padilla et al., 2016; 2017; Polit & Beck, 2006). An independent statistician
140 was consulted for advice on the data analysis strategy and IBM® SPSS® v.21 was used
141 to perform the statistical analysis. The normality graphs (histograms and Q-Q plots), the
142 Shapiro-Wilk test and the skewness & kurtosis z-values demonstrated that the observed
143 variables were normally distributed. Linear regression analysis and exploratory factor
144 analysis (EFA) were performed (see below for more details).

145 The grade level and overall readability of the SEOLCAS was evaluated using the
146 Flesch-Kincaid tool in Microsoft Word® 2011. The scale's understandability was
147 assessed by asking the participants to provide feedback about the difficulties they might
148 have encountered when completing the SEOLCAS. The completion time for the
149 SEOLCAS was also recorded.

150 The methodology that guided the evaluation of the SEOLCAS' reliability and
151 content validity has already been described in the section 'Translation, cultural
152 adaptation and pilot study of the SEOLCAS' initial version'. Additionally, the scale's
153 content validity index (S-CVI/Ave) was calculated and a result higher than 0.78 was
154 interpreted as evidence of the SEOLCAS' ability to operationalize the experience of
155 informal end-of-life caregivers as a measurable construct (Coaley, 2014; Delgado-Rico
156 et al., 2012; Polit & Beck, 2006). The SEOLCAS' criterion validity was explored
157 through the assessment of its predictive validity. In order to do so, the SEOLCAS'
158 ability to predict the participants' caregiving burden was explored performing a linear
159 regression analysis. The Zarit Burden Interview (ZBI) was used to measure participants'
160 caregiving burden (Gort et al, 2005). Preliminary analyses were performed to ensure
161 that there was no violation of assumption of normality and linearity. For the evaluation
162 of the SEOLCAS' construct validity, an EFA using principal axis factoring (PAF) was
163 undertaken. Firstly, the pertinence of carrying out EFA was tested by performing the
164 Bartlett's Test of Sphericity and the Kaiser-Meyer-Olkin Measure of Sampling
165 Adequacy. Then, a PAF with Varimax rotation was performed. Items were kept in a
166 factor if they had a factor-loading value ≥ 0.45 (Tabachnick & Fidell, 2013). Factors
167 were considered a structural part of the SEOLCAS if they met the following criteria: to
168 have an eigenvalue ≥ 1 and to have a clear break in eigenvalues in the scree plot
169 (Tabachnick & Fidell, 2013).

170 ***Scoring and interpretation system for the SEOLCAS***

171 In order to facilitate the interpretation of the individuals' results on the SEOLCAS,
172 an internal scoring system was developed. Firstly, the sample's mean score and its
173 standard deviation (SD) were calculated. Then, the following three scoring categories

174 were developed: [1] scores >1 SD below the mean, [2] scores \leq 1 SD below or above the
175 mean, and [3] scores >1 SD above the mean (Van de Broeck & Brestoff, 2013).

176 **Results**

177 *Description of the main sample*

178 Table 2 shows the main sample's demographics in detail. Participants' mean age
179 was 55.69 years (SD=10.72; range=20-79) and 80% of the sample was female. The
180 mean 'time being the main informal caregiver' for the patient was 5.42 months
181 (SD=4.86; range=0.50-38).

182 *Psychometric properties of the SEOLCAS*

183 The reading level of the SEOLCAS equates to 5th grade. None of the participants
184 reported any difficulties when reading and completing the SEOLCAS. Moreover, the
185 mean time of completion for the scale was less than 13 minutes (range=5-20 minutes).

186 The results for the SEOLCAS' internal consistency analysis are presented in Table
187 3. In summary, the SEOLCAS' $\alpha=0.92$ and this would not have increased after removing
188 any of the items. The C-ITC for the 14 items ranged between 0.43-0.82.

189 Content validity analysis showed that the I-CVI for the 14 items comprising the
190 SEOLCAS ranged from 0.80-1 (see Table 3) and the S-CVI/Ave=0.88. Predictive
191 validity analysis showed a significant regression equation ($F(1,148)=567.69$; $p<0.001$)
192 in which the participants' scores on the SEOLCAS explained 79.3% of the between-
193 subject variation of their results on the ZBI. Participants' score on the ZBI is equal to
194 $4.32+0.58$ points when their scores on the SEOLCAS are also measured in points.
195 Participants' scores on the ZBI increased by 0.58 points for each point they obtained on
196 the SEOLCAS. Construct validity analysis results are as follows. The Barlett's Test of
197 Sphericity ($\chi^2=1164.51$; $p<0.001$) and the Kaiser-Meyer-Olkin measure of sampling
198 adequacy (KMO=0.91) showed that it was appropriate to conduct an EFA. Table 4

199 summarises the results of the PAF on the 14-item SEOLCAS. Two factors presented
200 eigenvalues ≥ 1 , a clear representation on the plot of eigenvalues, and all items with a
201 factor-loading coefficient ≥ 0.45 . These two factors accounted for 53.77% of the total
202 variance found and contribute to measure the extent to which either ‘external
203 contingencies’ (Factor 1) or ‘internal contingencies’ (Factor 2) impact the informal end-
204 of-life caregiver’s experience in Hispanic culture (see Table 4).

205 *Scoring and interpretation system for the SEOLCAS*

206 The scoring system developed allows for the interpretation of the participants’
207 results on the total SEOLCAS and its two subscales. Firstly, the mean score on the total
208 SEOLCAS was 28.99 and the SD was ± 11.09 . Consequently, the following three
209 scoring categories were created for the interpretation of the participants’ results on the
210 total SEOLCAS: ‘low impact’=0-17 points (scores >1 SD below the mean); ‘moderate
211 impact’=18-40 points (scores ≤ 1 SD below or above the mean); and ‘high impact’=41-
212 56 points (scores >1 SD above the mean). Secondly, the mean score on the ‘external
213 contingencies’ subscale was 16.80 and the SD was ± 5.98 . Therefore, the following three
214 scoring categories were created for the interpretation of the participants’ results on the
215 ‘external contingencies’ subscale: ‘low impact’=0-10 points (scores >1 SD below the
216 mean); ‘moderate impact’=11-23 points (scores ≤ 1 SD below or above the mean); and
217 ‘high impact’=24-28 points (scores >1 SD above the mean). Thirdly, the mean score on
218 the ‘internal contingencies’ subscale was 12.19 and the SD was ± 6.08 . Accordingly,
219 the following three scoring categories were created for the interpretation of the
220 participants’ results on the ‘internal contingencies’ subscale: ‘low impact’=0-5 points
221 (scores >1 SD below the mean); ‘moderate impact’=6-18 points (scores ≤ 1 SD below
222 or above the mean); and ‘high impact’=19-28 points (scores >1 SD above the mean).

223 **Discussion**

224 Many Spanish-speaking countries have not achieved an advanced level of
225 integration of palliative care into their mainstream service provision and informal end-
226 of-life caregivers are at risk of becoming ‘invisible’ to healthcare systems (Lynch et al.,
227 2013). For this reason and regardless of their speciality, level of expertise and work
228 setting, all healthcare professionals in such contexts should use the encounters with end-
229 of-life patients to also explore informal end-of-life caregivers’ experiences and discover
230 their specific health needs (Fernández-Sola et al., 2017; Rocque et al., 2013). However,
231 healthcare professionals’ ability to explore informal end-of-life caregivers’ experiences
232 may be hampered by their lack of competence to conduct difficult conversations and/or
233 their limited time availability (Adams et al., 2011; Bloomer et al., 2013; Caswell et al.,
234 2015; Gagnon & Duggleby, 2014; Robinson et al., 2014; Smith et al., 2009; Willard &
235 Luker, 2006). The use of valid and culturally-adapted psychometric instruments could
236 help healthcare professionals with little or no knowledge of palliative care not only to
237 overcome the aforementioned barriers but also to easily highlight those in need of extra
238 support. This study aimed to translate, culturally adapt and psychometrically evaluate
239 the Spanish version of the only already-published tool that assesses the experience of
240 informal end-of-life caregivers as a whole: the ‘Scale for End-of Life Caregiving
241 Appraisal’ (SEOLCAS) (Lee et al., 2010).

242 The psychometric analysis of the SEOLCAS focused on examining its ability to
243 measure the construct ‘informal end-of-life caregiving experience’ (validity), its ability
244 to accurately measure this construct (reliability), and its usability and cultural relevance
245 (Coaley, 2014; Furr, 2014).

246 In order to explore the SEOLCAS’ ability to measure the construct ‘informal end-
247 of-life caregiving experience’, its content, criterion and construct validity were assessed.
248 Regarding the instrument’s content validity, the results from the review performed by

249 the expert panel suggest that all the items included in the final 14-item version of the
250 SEOLCAS contribute to operationalize ‘informal end-of-life caregiving experience’ as
251 a measurable construct (Coaley, 2014; Furr, 2014; Hernández-Padilla et al., 2016;
252 2017). In terms of criterion validity, results have shown that the SEOLCAS can predict
253 the informal end-of-life caregivers’ burden. This can be seen as evidence of the
254 SEOLCAS’ ability to provide valid information about the experience of informal end-
255 of-life caregivers (Coaley, 2014; Furr, 2014). Construct validity analysis has clearly
256 shown that the SEOLCAS is comprised of two factors that represent different
257 dimensions in the experience of Hispanic informal end-of-life caregivers. All these
258 results evidence the SEOLCAS’ ability to provide valid and specific information about
259 the individual experiences of Hispanic informal end-of-life caregivers (Coaley, 2014;
260 Furr, 2014; Hernández-Padilla et al., 2016; 2017). Complementing these psychometric
261 properties, the SEOLCAS’s internal consistency and its pilot version’s temporal
262 stability can be interpreted as strong indicators of the instrument’s ability to measure
263 this construct reliably (Coaley, 2014; Furr, 2014). Having a valid and reliable tool like
264 the SEOLCAS would allow healthcare professionals to effectively explore the
265 experiences and understand the needs of informal end-of-life caregivers without having
266 to engage in emotionally-charged conversations that they may find difficult to manage
267 (Caswell et al., 2015; Robinson et al., 2014; Willard & Luker, 2006). Additionally,
268 evidence has shown that the SEOLCAS is very easy to understand and quick to
269 complete; hence why it can be considered not only a valid and reliable instrument but
270 also a usable one. Having an easily applicable tool like the SEOLCAS would help
271 healthcare professionals to overcome a potential lack of time to explore the informal
272 caregivers’ experiences.

273 Whereas the original EOLCAS was comprised of 32 items and 4 dimensions that
274 comprehensively assessed the experience of informal end-of-life caregivers as a whole
275 (Lee et al., 2010), the SEOLCAS is only comprised of 14 items and 2 dimensions that
276 mainly assess the impact of the experience on Hispanic informal end-of-life caregivers'
277 lives. The result of this transformation could be explained by the well-documented
278 influence of the stoic tradition on Hispanic culture (Benavente, 2013; de Ros & Omlor,
279 2017). In the stoic tradition, passions and emotions must be mitigated and life
280 experiences are confronted with serenity (Nussbaum, 2009). This could explain why
281 many items of the original EOLCAS did not meet the criteria to be kept as part of the
282 SEOLCAS. Firstly, the experts considered that some items represented feelings that are
283 very rarely associated with the experience of providing end-of-life care to a relative
284 within Hispanic culture (see items 13, 21 and 24 in Table 1). Consequently, these items
285 were removed from the questionnaire before its pilot study. Then, the participants'
286 responses in the pilot study led to poor correlation between several items and the rest of
287 the scale (see items 3, 9-12, 14 and 29-32 in Table 1). These results could reflect the
288 stoic attitude towards adversity that is often attributed to Hispanic culture (Im et al.,
289 2007; Scherz, 2017; Smith et al., 2009). Our participants were mostly middle-aged
290 women who might accept their caregiver role as a moral obligation and not as a source
291 of personal reward or extreme suffering (Scherz, 2017). The stoic tradition holds that
292 virtue is in itself sufficient for happiness; it is only by rejecting what is external to the
293 person ('external contingencies') and by cultivating reason as the ability to achieve
294 appropriate judgements of our impressions ('internal contingencies') that virtue and,
295 therefore, happiness can be attained (Becker, 2003; Nussbaum, 2009; Løkke, 2015).
296 This philosophical construct is clearly reflected in the two factors that emerged from the
297 SEOLCAS. The 'external contingencies' dimension includes all the items reflecting the

298 aspects of the caregiving experience that are external to one's virtue (i.e. money,
299 friendship, physical health, social relationships, etc.). The 'internal contingencies'
300 dimension includes all the aspects of the caregiving experience that are internal to the
301 individual and therefore fully dependent on his/her ability to achieve appropriate
302 judgements of his/her impressions (i.e. ability not to feel powerless, strained, anxious,
303 etc.). Consequently, the SEOLCAS has the ability to not only measure the impact that
304 providing end-of-life care has on Hispanic informal caregivers, but also to differentiate
305 between the type of support that they may need depending on their scores. For example,
306 information gathered from the dimension 'external contingencies' will indicate whether
307 instrumental support may be needed and it can orientate the decisions or interventions
308 that must be taken in order to offer the instrumental support an individual needs.
309 Equally, the information gathered from the dimension 'internal contingencies' will
310 indicate whether emotional support may be needed and it can orientate the decisions or
311 interventions that must be taken in order to provide it.

312 Although the SEOLCAS has shown robust psychometric properties, some
313 limitations must be highlighted. Firstly, having used a convenience sampling method
314 limits the generalisation of the study's results. All participants were Spanish caregivers
315 recruited from a single institution. This means that those willing to use the SEOLCAS
316 amongst samples with radically different characteristics may need to undertake a
317 validation study beforehand. Secondly, due to organisational constraints, the temporal
318 stability of the SEOLCAS was only examined in its pilot version. It is important that
319 future research tests the SEOLCAS' temporal stability using a larger sample of
320 participants. Thirdly, the cultural adaptation and validation processes of the SEOLCAS
321 have led to having an instrument with a narrower focus than the original one. Although
322 the SEOLCAS can confidently assess the impact that providing end-of-life care has on

323 Hispanic informal caregivers and can differentiate between whether instrumental or
324 emotional support may be needed, it is unclear as to whether its items and dimensions
325 will suffice to understand how Hispanic informal end-of-life caregivers experience the
326 phenomenon as a whole. **Lastly, it is important to consider that our sample was**
327 **predominantly middle-aged females and this may have impacted our results.**

328 **Conclusions**

329 Although the SEOLCAS has a narrower focus than the original EOLCAS, its
330 relevance remains unaffected. Following a rigorous validation test, the SEOLCAS has
331 evidenced very good psychometric properties. The SEOLCAS has proven to be an
332 easily-applicable, valid, reliable and culturally-appropriate instrument that can be used
333 to explore the impact that the experience of providing end-of-life care has on Hispanic
334 informal end-of-life caregivers. The SEOLCAS can enable healthcare professionals
335 with little or no knowledge of palliative care to effectively explore the informal end-of-
336 life caregivers' experiences regardless of their level of competence to manage
337 emotionally-charged conversations or their time availability. All of this could contribute
338 to discovering what the needs of Hispanic informal end-of-life caregivers may be so that
339 appropriate support can be offered. We actively encourage healthcare professionals to
340 use this tool in their clinical context (whichever this may be). This could be done *ad*
341 *hoc*, for example, when informal caregivers accompany the end-of-life patient to
342 hospital admissions or to community-based consultations. Furthermore, we also
343 encourage healthcare professionals to develop specific local protocols that allow them
344 to make appropriate decisions about the type of referrals and/or interventions that
345 caregivers may need on the basis of their results on the SEOLCAS.

Acknowledgements

This research was supported by the Ministry of Economy and Competiveness, Government of Spain (FFI2016-76927-P). The authors thank all the informal caregivers who voluntarily participated in this study and the authors of the original EOLCAS for giving us permission to use their tool.

References

- Adams, J.A., Bailey, D.E.Jr., Anderson, R.A., et al. (2011). Nursing roles and strategies in end-of-life decision-making in acute care: a systematic review of the literature. *Nursing Research & Practice*, 2011, 527834.
- Applebaum, A.J. (2017). Survival of the fittest ... caregiver? *Palliative & Supportive Care*, 15, 1-2.
- Becker, L.C. (2003). Human health and Stoic moral norms. *Journal of Medical Philosophy*, 28, 221-238.
- Benavente, K.P. (2013). Art echo: María Zambrano and the Kouroi Relief. *Synthesis*, 5, 94-119.
- Bloomer, M.J., Endacott, R., O'Connor, M., et al. (2013). The 'dis-ease' of dying: challenges in nursing care of the dying in the acute hospital setting. A qualitative observational study. *Palliative Medicine*, 27, 757-764.
- Caswell, G., Pollock, K., Harwood, R., et al. (2015). Communication between family carers and health professionals about the end-of-life care for older people in the acute hospital setting: a qualitative study. *BMC Palliative Care*, 1, 14-35.
- Coaley, K. (2014). *An introduction to psychological assessment and psychometrics*. London: SAGE.
- Dalai, S. & Bruera, E. (2017). End-of-life care matters: palliative cancer care results in better care and lower costs. *The Oncologist*, 22, 361-368.
- Delgado-Rico, E., Carretero-Dios, H., & Willibald, R. (2012). Content validity evidences in test development: an applied perspective. *International Journal of Clinical and Health Psychology*, 12, 449-460.
- Directive 95/46/EC of the European Parliament and of the Council of 24th of October 1995 on the protection of individuals with regard to the processing of personal data

- and on the free movement of such data. *Official Journal of the European Communities, L 281/31, 23.10.1995*, 31-39.
- Dumont, S., Fillion, L., Gagnon, P., et al. (2008). A new tool to assess family caregivers' burden during end-of-life care. *Journal of Palliative Care, 24*, 151-161.
- Fernández-Sola, C., Cortés, M.M., Hernández-Padilla, J.M., et al. (2017). Defining dignity in end-of-life care in the emergency department. *Nursing Ethics, 24*, 20-32.
- Furr, R.M. (2014). *Psychometrics: an introduction*. London: SAGE.
- Gagnon, J. & Duggleby, W. (2014). The provision of end-of-life care by medical-surgical nurses working in acute care: a literature review. *Palliative & Supportive Care, 12*, 393-408.
- Gardiner, C., Brereton, L., Frey, R., et al. (2014). Exploring the financial impact of caregiving for family members receiving palliative care and end-of-life care: a systematic review of the literature. *Palliative Medicine, 28*, 375-390.
- Gort, A.M., March, J., Gómez, X., et al. (2005). Escala de Zarit reducida en cuidados paliativos. *Medicina Clinica, 124*, 651-653.
- Granero-Molina, J., Díaz-Cortés, M.M., Hernández-Padilla, J.M., et al. (2016). Loss of Dignity in End-of-Life Care in the Emergency Department: A Phenomenological Study with Health Professionals. *Journal of Emergency Nursing, 42*, 233-239.
- Hernández-Padilla, J.M., Granero-Molina, J., Márquez-Hernández, V.V., et al. (2017). Design and validation of a three-instrument toolkit for the assessment of competence in electrocardiogram rhythm recognition. *European Journal of Cardiovascular Nursing*. Epub ahead of print 1 Jan 2017.
- Hernández-Padilla, J.M., Granero-Molina, J., Márquez-Hernández, V.V., et al. (2016). Development and psychometric evaluation of the arterial puncture self-efficacy scale. *Nurse Education Today, 40*, 45-51.

- Higginson, I.J., Gao, W., Jackson, D., et al. (2010). Short-form Zarit Caregiver Burden Interviews were valid in advanced conditions. *Journal of Clinical Epidemiology*, *63*, 535-542.
- Im, E.O., Guevara, E. & Chee, W. (2007). The Pain Experience of Hispanic Patients With Cancer in the U.S. *Oncology Nursing Forum*, *34*, 861-868.
- Koller, M., Aaronson, N.K., Blazeby J, et al. (2007). Translation procedures for standardized quality of life questionnaires: The European Organisation for Research and Treatment of Cancer (EORTC) approach. *European Journal of Cancer*, *43*, 1810–1820.
- Lee, J., Yoo, J.S., Kim, T.H., et al. (2010). Development and validation of a scale for the end of life caregiving appraisal. *Asian Nursing Research*, *4*, 1-9.
- Løkke, H. (2015). *Knowledge and virtue in early Stoicism*. London: Springer.
- Lynch, T., Connor, S., & Clark, D. (2013). Mapping levels of palliative care development: a global update. *Journal of Pain and Symptom Management*, *45*, 1094-1106.
- MacArtney, J.I., Broom, A., Kirby, E., et al. (2016). Locating care at the end of life: burden, vulnerability, and the practical accomplishment of dying. *Sociology of Health & Illness*, *38*, 479-492.
- Novak, B., Kolcaba, K., Steiner, R., et al. (2001). Measuring comfort in caregivers and patients during late end-of-life care. *American Journal of Hospital Palliative Care*, *18*, 170-180.
- Nuño-Solinís, R., Herrera-Molina, E., Librada-Flores, S., et al. (2016). Care costs and activity in the last three months of life of cancer patients who died in the Basque Country (Spain). *Gaceta Sanitaria*. Epub ahead of print 1 October 2016.

- Nussbaum, M.C. (2009). *The Therapy of Desire: Theory and Practice in Hellenistic Ethics*. New York: Princeton University Press.
- Polit, D.F. & Beck C.T. (2006). The content validity index: are you sure you know what's being reported? Critique and recommendations. *Research in Nursing & Health, 29*, 489-497.
- Porter, L.S., Keefe, F.J., Garst, J., et al. (2008). Self-efficacy for managing pain, symptoms, and function in patients with lung cancer and their informal caregivers: associations with symptoms and distress. *Pain, 137*, 306-315.
- Reblin, M., Cloyes, K.G., Carpenter, J., et al. (2015). Social support needs: Discordance between home hospice nurses and former family caregivers. *Palliative & Supportive Care, 13*, 465-472.
- Reyniers, T., Houttekier, D., Cohen, J., et al. (2014). What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses. *Palliative Medicine, 28*, 941-948.
- Rini, C., Emmerling, D., Austin, J., et al. (2015). The effectiveness of caregiver social support is associated with cancer survivors' memories of stem cell transplantation: A linguistic analysis of survivor narratives. *Palliative & Supportive Care, 13*, 1735-1744.
- Robinson, C.A., Bottorff, J.L., McFee, E., et al. (2017). Caring at home until death: enabled determination. *Supportive Care in Cancer, 25*, 1229-1236.
- Robinson, J., Gott, M. & Ingleton, C. (2014). Patient and family experiences of palliative care in hospital: what do we know? An integrative review. *Palliative Medicine, 28*, 18-33.
- Rocque, G.B., Barnett, A.E., Illig, L.C., et al. (2013). Inpatient hospitalization of oncology patients: are we missing an opportunity for end-of-life care? *Journal of*

- Oncology Practice*, 9, 51-54.
- Scherz, P. (2017). Grief, Death, and Longing in Stoic and Christian Ethics. *Journal of Religious Ethics*, 45, 7–28.
- Smith, A.K., Sudore, R.L. & Pérez-Stable, E.J. (2009). Palliative Care for Latino Patients and Their Families: “Whenever We Prayed, She Wept.” *Journal of the American Medical Association*, 301, 1047-E1.
- Stagg, B. & Lerner, A.J. (2015). Zarit Burden Interview: pragmatic study in a dedicated cognitive function clinic. *Progress in Neurology & Psychiatry*, 19, 23-27.
- Tabachnick, B.G. & Fidell, L.S. (2013). *Using Multivariate Statistics*. 6th ed. Essex: Pearson.
- Van den Broeck, J. & Brestoff, J.R. (2013). *Epidemiology: Principles and Practical Guidelines*. Dordrecht: Springer.
- van der Steen, J.T., Radbruch, L., Hertogh, C.M., et al. (2014). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine*, 28, 197-209.
- Veloso, V.I. & Tripodoro, V.A. (2016). Caregivers burden in palliative care patients: a problem to tackle. *Current Opinion in Supportive and Palliative Care*, 10, 330-335.
- Willard, C. & Luker, K. (2006). Challenges to end-of-life care in the acute hospital setting. *Palliative Medicine*, 20, 611-615.
- Woodman, C., Baillie, J. & Sivell, S. (2016). The preferences and perspectives of family caregivers towards place of care for their relatives at the end-of-life. A systematic review and thematic synthesis of the qualitative evidence. *BMJ Supportive & Palliative Care*, 6, 418-429.

Wright, A.A., Keating, N.L., Ayanian, J.Z., et al. (2016). Family Perspectives on Aggressive Cancer Care Near the End of Life. *Journal of the American Medical Association*, 315, 284-292.

de Ros, X. & Omlor, D. (2017). *The Cultural Legacy of Maria Zambrano*. London: Taylor & Francis.

Table 1.

Results of the content validity and internal consistency analysis of the i-SEOLCAS.

	I-CVI [†]	i-SEOLCAS [‡] Cronbach's α if item deleted	C-ITC [‡]
1. I feel fatigue while caring for the patient.	.87	.74	.79
2. I have sleep disturbance while caring for my patient.	.47	Removed before pilot study	
3. I have experienced a role change (e.g., job) while caring for the patient.*	.73	.78	.24
4. I have limited time for myself while caring for the patient.	.93	.76	.51
5. I have limited social relationships (e.g. meeting friends) when caring for the patient.	.93	.77	.39
6. I feel my health has got worse while caring for the patient.	1	.75	.63
7. I have a financial burden (e.g. decreased household income) while caring for the patient.	.80	.76	.42
8. I have indigestion while caring for the patient.*	.53	Removed before pilot study	
9. I feel I have grown personally while caring for the patient.*	.80	.79	-.11
10. I appreciate my life while caring for the patient.*	.80	.79	-.19
11. I appreciate my formal and informal support networks (e.g. religion, friends).*	.80	.79	-.05
12. I have a better relationship with the patient while caring for him/her.*	.80	.79	-.10
13. I feel good that I can do something for the patient.*	.47	Removed before pilot study	
14. I have a better relationship with other family members while caring for the patient.*	.80	.79	-.18
15. I need guidance for my caregiver role.*	.93	.77	.24
16. I want to deny my role as a caregiver.	.93	.76	.41
17. I feel I am powerless.	1	.76	.54
18. I worry about what will happen to my patient.*	.80	.77	.13
19. I feel grief/loss about losing my patient.*	.73	.77	.08
20. I feel depressed while caring for my patient.	.80	.76	.53
21. I regret for what I have been doing to my patient.*	.60	Removed before pilot study	
22. I feel strain/anxiety while caring for the patient.	.80	.77	.37
23. I feel intolerance while caring for the patient.	.80	.77	.38
24. I feel guilty while caring for the patient.*	.47	Removed before pilot study	
25. I need spiritual/emotional support.	.80	.76	.45
26. I feel loneliness while caring for the patient.	.93	.76	.50
27. I am exhausted with caring for the patient.	.80	.75	.65
28. I feel discomfort/uneasy while caring for the patient.	.87	.76	.51
29. I need useful resources (e.g. volunteers) while caring for the patient.*	.87	.79	.28
30. I want information about the patient's health status and how to care for the patient.*	.80	.77	.29
31. I need help regarding preparation for death and funeral services.*	.80	.79	.01
32. I feel uncertainty about my patient's future.*	.80	.77	.26

[†] I-CVI = Item Content Validity Index[‡] C-ITC = Corrected Item-total Correlation

* Item did not meet the criteria to be retained as part of the SEOLCAS

Table 4.
Factor loadings and total variance explained from the rotated factor structure of the SEOLCAS ($N=150$).

Item by Factor	Factor	
	1	2
External contingencies		
1. I feel fatigue while caring for the patient.	.71	.37
2. I have limited time for myself while caring for the patient.	.80	.13
3. I have limited social relationships (e.g. meeting friends) when caring for the patient.	.71	.19
4. I feel my health has got worse while caring for the patient.	.62	.38
5. I have a financial burden (e.g. decreased household income) while caring for the patient.	.50	.18
6. I feel loneliness while caring for the patient.	.52	.37
7. I am exhausted with caring for the patient.	.69	.42
Internal contingencies		
8. I want to deny my role as a caregiver.	.17	.65
9. I feel I am powerless.	.36	.54
10. I feel depressed while caring for my patient.	.39	.66
11. I feel strain/anxiety while caring for the patient.	.41	.68
12. I feel intolerance while caring for the patient.	.28	.73
13. I need spiritual/emotional support.	.37	.48
14. I feel discomfort/uneasy caring for the patient	.19	.68
% of variance	27.91	25.86
Cumulative % of variance	27.91	53.77

Table 3.

Results of the content validity and internal consistency analysis of the SEOLCAS.

	I-CVI [†]	i-SEOLCAS [†] Cronbach's α if item deleted	C-ITC [‡]
1. I feel fatigue while caring for the patient.	.87	.91	.73
2. I have limited time for myself while caring for the patient.	.93	.91	.58
3. I have limited social relationships (e.g. meeting friends) when caring for the patient.	.93	.91	.59
4. I feel my health has got worse while caring for the patient.	1	.91	.68
5. I have a financial burden (e.g. decreased household income) while caring for the patient.	.80	.92	.43
6. I want to deny my role as a caregiver.	.93	.92	.48
7. I feel I am powerless.	1	.91	.71
8. I feel depressed while caring for my patient.	.80	.91	.71
9. I feel strain/anxiety while caring for the patient.	.80	.91	.72
10. I feel intolerance while caring for the patient.	.80	.91	.61
11. I need spiritual/emotional support.	.87	.91	.64
12. I feel loneliness while caring for the patient.	.80	.91	.64
13. I am exhausted with caring for the patient.	.93	.91	.82
14. I feel discomfort/uneasy caring for the patient	.80	.91	.58

[†] I-CVI = Item Content Validity Index[‡] C-ITC = Corrected Item-total Correlation

Table 2.
Demographic characteristics of main sample

	Main Sample (<i>N</i> =150)
	<i>M</i> ± <i>S.D.</i>
Age (years)	55.69 ± 10.72
	<i>n</i> (%)
Gender	
Female	120 (80.0)
Male	30 (20.0)
Education level completed	
No formal education	3 (2.0)
Primary education	99 (66.0)
Secondary education	18 (12.0)
Vocational education	12 (8.0)
Higher education	18 (12.0)
Relatedness to patient	
Spouse	103 (68.7)
Children	19 (12.7)
Other relatives	28 (18.7)
Household income	
Preferred not to say	50 (33.3)
Below average	53 (35.3)
Average	41 (27.3)
Above average	6 (4.0)
Time as caregiver	
Less than 1 month	11 (7.3)
1-6 months	101 (67.3)
6-12 months	32 (21.3)
More than 12 months	6 (4.0)