

RESEARCH ARTICLE (ORIGINAL) 

Family caregivers of people with dementia: Translation, adaptation, and validation of the Boundary Ambiguity Scale

Cuidadores familiares de pessoas com demência: Tradução, adaptação e validação da Escala de Limites Ambíguos

Cuidadores familiares de personas con demencia: Traducción, adaptación y validación de la Escala de Límites Ambiguos

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Abstract

Background: Caring for people with dementia generates stress among family caregivers. One of these stressor events is ambiguous loss.

Objectives: To translate, adapt, and validate the Boundary Ambiguity Scale (BAS) into European Portuguese and assess its psychometric properties.

Methodology: Methodological study with a sample of 88 family caregivers of people with dementia. Internal consistency was assessed using McDonald's omega coefficient (ω). Construct validity was assessed through exploratory factor analysis (EFA) and criterion validity through the Perceived Stress Scale (PSS).

Results: The BAS showed excellent content validity. The EFA revealed a two-factor model, explaining 44% of variance, and a ω of 0.72. Family caregivers who live with people with dementia had greater ambiguous loss ($t = 2.823, p < 0.01$). A statistically significant moderate positive correlation was found between the BAS and the PSS ($r_s = 0.578, p < 0.01$).

Conclusion: The BAS has acceptable validity and internal consistency for assessing ambiguous loss.

Keywords: bereavement; older adult; dementia; family caregiver

Resumo

Enquadramento: Cuidar de pessoas com demência (PcD) é gerador de stresse entre cuidadores familiares (CF). Uma das situações geradoras desse stresse é a perda ambígua (PA).

Objetivos: Traduzir, adaptar e validar a Escala de Limites Ambíguos (ELA) para português europeu e determinar as características psicométricas da ELA.

Metodologia: Estudo metodológico a partir de uma amostra de 88 CF de PcD. A consistência interna (CI) avaliada com o Coeficiente de Ômega de McDonald (ω), a validade de constructo através da análise fatorial exploratória (AFE) e a validade de critério com a Escala de Perceção de Stresse (EPS).

Resultados: A ELA apresentou validade conteúdo excelente. A AFE determinou um modelo de dois fatores, explicando 44% da variância, ω de 0,72. Os CF que residem com a PcD apresentam maior PA ($t = 2,823, p < 0,01$). Correlação significativa positiva e moderada entre a ELA e a EPS ($r_s = 0,578, p < 0,01$).

Conclusão: A ELA é um instrumento com propriedade psicométrica de CI e validade aceitáveis para a avaliação da PA.

Palavras-chave: luto; pessoa idosa; demência; cuidador familiar

Resumen

Marco contextual: El cuidado de personas con demencia (PcD) genera estrés entre los cuidadores familiares (CF). Una de las situaciones que generan este estrés es la pérdida ambigua (PA).

Objetivos: Traducir, adaptar y validar la Escala de Límites Ambiguos (ELA) al portugués europeo y determinar las características psicométricas de la ELA.

Metodología: Estudio metodológico basado en una muestra de 88 CF de PcD. La consistencia interna (CI) se evaluó mediante el coeficiente omega de McDonald (ω), la validez de constructo mediante el análisis factorial exploratorio (AFE) y la validez de criterio mediante la Escala de Percepción del Estrés (EPS).

Resultados: La ELA presentó una validez de contenido excelente. El AFE determinó un modelo de dos factores, que explican el 44% de la varianza, ω de 0,72. Los CF que residen con PcD presentan mayor PA ($t = 2,823, p < 0,01$). Correlación significativa positiva y moderada entre la ELA y la EPS ($r_s = 0,578, p < 0,01$).

Conclusión: La ELA es un instrumento con propiedades psicométricas de CI y validez aceptables para la evaluación de la PA.

Palabras clave: luto; pérdida; anciano; demencia; cuidador familiar

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Introduction

Dementia is the seventh leading cause of death and a major cause of dependency among older people worldwide (World Health Organization [WHO], 2021). There are around 50 million people living with dementia worldwide, a number that is expected to grow to 152 million by 2050 (WHO, 2021). According to Alzheimer Europe (2019), more than 193,000 people live with dementia in Portugal, with an estimated prevalence of 20 cases per 1,000 population. Projections for 2050 suggest an increase to 25 cases per 1,000 population (Organization for Economic Co-operation and Development [OECD], 2019). Given that there is currently no treatment available to cure dementia, health and social care systems should be improved to enhance the quality of life of people with dementia (PwD) and their families (OECD, 2019). Indeed, the impact of dementia is devastating, leading to physical, emotional, and economic problems (WHO, 2021).

One of the major emotional problems is ambiguous loss, a relational phenomenon inherent in the care provided by family caregivers to PwD (Boss et al., 2017). Ambiguous loss integrates the family stress model and is a major stressor situation in family dynamics. It was studied by Boss et al. (2017) in various contexts (e.g., missing in action, divorce), such as in families with PwD. Thus, the Boundary Ambiguity Scale (BAS; Boss et al., 1990) was developed for caregivers of PwD. This study aimed to translate, adapt, and validate the BAS into European Portuguese and assess its psychometric properties.

Background

Pauline Boss developed the ambiguous loss theory in the 1970s based on her work with families of soldiers missing in action (Boss et al., 2017). According to the author, ambiguous loss is defined as a situation of unclear loss, that is, there is no official and physical verification of loss or rituals of grief, such as in funerals. Thus, when a family member is absent or the presence is unclear, the stressor event or situation is called ambiguous loss. There are two types of ambiguous loss: i) Type 1, referred to as *physical*, in which there is no certainty of death and the person is physically absent but kept psychologically present because there is no evidence of death or permanent loss; ii) Type 2, referred to as *psychological*, in which the person is physically present but psychologically absent as a result of cognitive impairment or memory loss from illness, injury, or addiction (Boss, 2016).

There are two different concepts in the ambiguous loss theory: ambiguity and ambivalence. Ambiguity arises from a situation outside the person or family, whereas ambivalence is expressed individually, such as through feelings of guilt (Boss et al., 2017). Ambiguity freezes the grief process and leads blocks decision-making processes, and the family has no choice but to construct its own truth about the person's *absent* status (Boss, 2007). This feeling of ambiguity immobilizes and traumatizes family caregivers of PwD, given that their family member

remains physically present but psychologically is not the person they recognize from the past (Boss et al., 2017). Thus, ambiguous loss is a relational disorder rather than a psychic dysfunction (Boss et al., 2017).

In the ambiguous loss theory, Boss et al. (2017) also mention the concept of boundary ambiguity, which is characterized by how the family members and the family as a whole perceive the stressor situation or event. Boundary ambiguity emerges as a barrier to how the family manages stress, destroying its resilience.

Ambiguous loss becomes a structural problem in case of boundary ambiguity, in which pre-existing roles are ignored and decisions are put on hold. The unresolvable situation blocks cognition, stress management, and coping, and freezes the grief process (Boss et al., 2017). In boundary ambiguity, there is no certainty of who is inside or outside the family, which reflects instability and disequilibrium in the family system and is likely to be resolved through the process of reorganizing and changing family and individual perceptions. The impact on family caregivers can carry over into their relationships, causing conflicts, including isolation of family members and divorce (Boss, 2016).

According to Van Wijngaarden et al. (2018), coping with ambiguous loss is one of the most challenging aspects for caregivers of PwD, as they deal with the complicated grieving process daily and face "compounded serial losses", that is, numerous and cyclical losses. As the disease progresses and family caregivers need to get more involved, they face unstable, fluctuating, and unclear changes, which is reflected in greater ambiguity due to the accumulation of experiences of loss. Thus, studies show that boundary ambiguity is a predictor of burden and depression among caregivers of PwD, especially among those who live with these people, such as spouses (Thomas et al., 2001). Thus, assessing boundary ambiguity and the health team's effective communication with the family caregivers of PwD may encourage them to move forward with the necessary adjustments and interrupt the cycle of ambiguity and denial (Smodic et al., 2019).

Research question

What is the validity of the European Portuguese version of the BAS to assess ambiguous loss in Portuguese family caregivers of PwD?

Methodology

This methodological study consisted of two phases: 1) Translation and cultural adaptation of the BAS into European Portuguese; and 2) Validation of the psychometric properties of the adapted version.

Authorization to translate and validate the scale was obtained from the scale's author (Boss et al., 1990). The linguistic validation process followed the principles of good practice for translation and cultural adaptation proposed by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR; Wild et al., 2005). This process consisted of the steps described in Table 1.

Table 1*Steps of the BAS translation and cultural and linguistic adaptation process*

Steps	Activities
1. Forward translation	Translation into European Portuguese by a bilingual nurse (English and Portuguese)
2. Reconciliation	Revision and adaptation of the translation by a professional Portuguese-speaking translator. After review and discussion for consensus, the first version of the instrument was designed.
3. Back translation	Translation of the first version into English by another professional translator, with advanced knowledge in English and European Portuguese.
4. Harmonization	Comparison of the original scale with the translated scale (version 1), and comparison with the back-translation into English, carried out by the researchers and a translator, resulting in the final version in European Portuguese (version 2).
5. Cognitive Debriefing	The panel analyzed each item of the scale to check understandability and interpretation and avoid any ambiguities, resulting in version 3 of the scale.
6. Proofreading	Version 3 was reviewed by a Portuguese language teacher, resulting in the final version of the instrument.

The first four steps occurred as described in Table 1. The Cognitive Debriefing step involved nine experts (holding a Ph.D. or Ph.D. students) from different disciplines that research family caregivers of PwD, such as Nursing, Psychology, and Education Sciences. Three rounds (January to February 2021) were set for evaluation and consensus building. In each round, an Excel file with an agreement form with a 4-point Likert scale (1 - *disagree* to 4 - *strongly agree*) was sent to each expert by e-mail. The form included a section for comments, suggestions, and/or changes in each item. At the end of each round, the Content Validity Index (CVI) was analyzed, as well as the convergences and discrepancies in the comments and/or suggestions, which were revised and evaluated again by the experts. The preliminary version of the BAS was pre-tested with 10 family caregivers (March to April 2021).

In the second phase, an observational, cross-sectional, descriptive, and correlational study was conducted with caregivers of PwD. A non-probability convenience sample was used based on the following inclusion criteria: adult (≥ 18 years old), being a caregiver of a PwD, and belonging to the list of users of the primary health care units. A minimum number of five participants per item was established to achieve the purpose of translating, adapting, and validating the BAS (Hair et al., 2019). Given that this scale consists of 14 items, a sample of 70 family caregivers of PwD was obtained. The study was approved by the Ethics Committee for Health of the Regional Health Administration - Center (Process no. 11/2021). Participation was voluntary, and participants signed an informed consent form.

Data were collected through 1) a sociodemographic questionnaire consisting of 14 questions (e.g., gender, age, marital status, degree of kinship, and living arrangements); 2) the BAS, developed and validated by Boss et al. (1990). This scale consists of 14 items rated on a 5-point Likert scale (1- *Strongly disagree* to 5 - *Unsure how I feel*). The final score is the sum of the answers to the items, and the higher the score, the higher the

caregiver's perception of boundary ambiguity. The scale's internal consistency (Cronbach's alpha) was 0.80 (Boss et al., 1990); and 3) the Perceived Stress Scale (PSS), which is a measure designed to assess the degree to which situations in one's life are appraised as stressful (Cohen et al., 1983) on a 5-point Likert-type scale (1 - *Never* to 5 - *Very Often*). It was translated and validated into Portuguese by Pais Ribeiro and Marques (2009) and consists of 13 questions, six of which have an inverted score (questions 4, 5, 6, 7, 9, and 10). Higher scores mean greater levels of perceived stress. Its internal consistency (Cronbach's alpha) was 0.88 (Pais Ribeiro & Marques, 2009). Data were collected between July and August 2021 through self- ($n = 5$) and researcher-administered questionnaires ($n = 83$; e.g., illiterate and/or with low education level). This step consisted of the following four phases: i) Identification of users in the units' lists based on the dementia code and the inclusion criteria; ii) Validation of the eligibility of each user identified to be part of the sample (e.g., institutionalized, home care by their family caregiver, existence of death certificate) by the respective family nurses; iii) Invitation sent to eligible family caregivers to participate in the study; iv) Scheduling of the date and time for data collection (due to the pandemic phase when the study was carried out, the majority of interviews were conducted by telephone ($n = 81$) and others face-to-face ($n = 7$)).

For data analysis, descriptive statistical techniques were used (frequency, percentage, mean, median, standard deviation, maximum, and minimum). Concerning content validity, an agreement greater than or equal to 80% was established for all items in the scale. In this study, the CVI was calculated in two ways: CVI for item (I-CVI) and CVI for scale (S-CVI/Ave [Average] and S-CVI/UA [Universal agreement]). Along with the CVI, the probability of chance (Pc) and Kappa were also calculated (good if between 0.60 and 0.74 and excellent if above 0.74; Yusoff, 2019).

An exploratory factor analysis (EFA) with principal components extraction and orthogonal Varimax rotation was

conducted to assess construct validity. The Kaiser-Meyer-Olkin (KMO) criterion and Bartlett's test of sphericity were used to measure sampling adequacy. EFA scores are considered adequate if KMO > 0.5 and Bartlett's test of sphericity $p < 0.01$ (Hair et al., 2019). The parallel analysis method was used to determine the number of factors to retain. To identify the number of items per factor, a factor loading > 0.30 and a variance > 40% were considered (Hair et al., 2019).

In known-groups validity, the results of ambiguous loss among people living with the PwD were compared to those of the people living nearby them. This validity is based on the assumption that people who live with PwD have more feelings of ambiguous loss (Boss et al., 2017). Student's *t*-test or the equivalent nonparametric Mann-Whitney U-test were used if normality assumptions were not met. For criterion validity, Spearman's correlation coefficient was used between the BAS and the PSS. Internal consistency was assessed using McDonald's Omega Coefficient (ω), which should be between 0.70 and 0.90 (Viladrich et al., 2017).

SAS analysis software was used for parallel analysis and

IBM SPSS Statistics software, version 26.0, for data analysis, considering $p < 0.05$ as statistically significant.

Results

Sample characterization

A total of 247 patients were diagnosed with dementia, of whom 85 did not meet the inclusion criteria and 73 refused to participate or could not be contacted. The final sample consisted of 88 family caregivers, mostly women (75%), with a mean age of 62.84 years ($SD \pm 14.46$ years), ranging from 25 to 92 years. The majority of them (72.7%) were married or cohabiting and were children of the PwD (45.5%), followed by spouses (39.8%), and other family members (14.8%), including grandchildren, daughters-in-law, and siblings. Most (79.5%) lived with the PwD and had 0 to 4 years of schooling (42%). More than half (61.4%) had no employment contract and received no home support (59.1%). They had been caregivers for a median (Q1, Q3) of 57 (36, 84) months, with a minimum of 8 months and a maximum of 648 months (Table 2).

Table 2

Sociodemographic characterization of the sample

QUALITATIVE VARIABLES	(n)	(%)		
Gender				
Male	22	25		
Female	66	75		
Marital status				
Married/Cohabiting	64	72.7		
Live alone	24	27.3		
Degree of kinship				
Spouse	35	39.8		
Children	40	45.4		
Other family members	13	14.7		
Living arrangements				
Lives with the PwD	70	79.5		
Lives nearby the PwD	18	20.5		
Schooling (in years)				
0-4 years	37	42.1		
5-12 years	39	44.3		
> 12 years (higher education)	12	13.6		
Professional status				
Without an employment contract	54	61.4		
With an employment contract	34	38.6		
Receives home support				
Yes	36	40.9		
No	52	59.1		
QUANTITATIVE VARIABLES	<i>M</i>	<i>SD</i>	min.	max.
Age (years)	62.84	14.46	25	92
	Median	Q1, Q3		
Time as caregiver (months)	57	36, 84	8	648

Note. *n* = Total sample; % = Percentage; *M* = Mean; *SD* = Standard deviation; min. = Minimum; max = Maximum; Q = Quartile; PwD = Person with dementia.

Content validity

At the end of the third round, item A (title of the scale) obtained a CVI = 0.89, $P_c = 0.018$, and a K of 0.887. Item

B (general information of the instrument), item C (rating scale), and all 14 items of the scale had a CVI = 1, $P_c = 0.002$, and K of 1, which is considered excellent (Table 3).

Table 3

Analysis of the Content Validity Index of the European Portuguese version of the BAS

Item	CVI	P_c	K	<i>Kappa</i> interpretation
A	0.89	0.018	0.887	Excellent
B and C	1	0.002	1	Excellent
1 to 14	1	0.002	1	Excellent

S-CVI/Ave = 0.99; S-CVI/UA = 0.94

Note. CVI = content validity index; P_c = Probability of chance; K = Kappa; S-CVI/Ave = content validity index of the scale, average; S-CVI/UA = content validity index of the scale, universal agreement.

Construct validity

The KMO test was 0.76 and the Bartlett's test of sphericity $p < 0.01$, showing that an EFA could be performed. The parallel analysis suggested a two-factor model. From the factor analysis, two factors emerged: factor A, "Ambiguity towards caring for the self or the PwD", consisting of eight

items with factor loadings ranging from 0.51 to 0.81 and an ω of 0.79, and factor B, "Ambiguity in connecting with the PwD and the network", consisting of six items with factor loadings ranging from 0.39 to 0.62 and an ω of 0.62 (Table 4). The internal consistency of the 14 items of the BAS was 0.72, with a variance of 44%.

Table 4

Exploratory factor analysis of the European Portuguese version of the BAS (n = 88)

	FA	FB	M	SD
BAS13	0.51		3.40	0.85
BAS5	0.54		3.10	0.84
BAS14	0.59		3.85	0.36
BAS3	0.62		2.82	1.07
BAS11	0.68		3.72	0.55
BAS2	0.73		3.49	0.82
BAS4	0.71		3.67	0.64
BAS9	0.81		3.67	0.56
BAS8		0.39	2.67	0.97
BAS1		0.49	2.56	0.90
BAS7		0.58	2.67	1.25
BAS6		0.62	2.35	0.94
BAS10		0.63	1.73	1.08
BAS12		0.62	2.23	1.15
Variance (%)	15.37	28.63		44
ω	0.79	0.62		0.72

Note. BAS = Boundary Ambiguity Scale; FA = factor A; FB = factor B; M = Mean; SD = Standard deviation.

Known-groups and criterion validity

Concerning the living arrangements, a statistically significant difference was found between the BAS ($t = 2.823$, $p < 0.01$) and factor A ($U = 526$, $p < 0.01$), with the highest scores of ambiguous loss among the family caregivers living with the PwD. No statistically significant

differences were found between factor B and the living arrangements ($U = 625$, $p = 0.965$), as shown in Table 5. A statistically significant moderate positive correlation ($r_s = 0.578$, $p < 0.01$) was found between the BAS and the PSS. Similar results were found for factor A ($r_s = 0.48$, $p < 0.01$) and B ($r_s = 0.486$, $p < 0.01$).

Table 5

Statistical differences and correlation between variables, total ambiguous loss, and factors A and B

Qualitative variables	Total Ambiguous Loss		factor A		factor B	
	Mean	Statistical test	Median	Statistical test	Median	Statistical test
Living arrangements						
Lives with the PwD	42.83	$t = 2.823$	51.75	$U = 526$	44.56	$U = 625$
Lives nearby the PwD	38.39	$p = <0.01$	32.99	$p = < 0.01$	44.25	$p = 0.965$
Quantitative variable	Total Ambiguous Loss Statistical Test		factor A Statistical Test		factor B Statistical Test	
Perceived stress	$r_s = 0.578$ $p < 0.01$		$r_s = 0.48$ $p < 0.01$		$r_s = 0.486$ $p < 0.01$	

Note. U = Mann-Whitney U -test; p = Significance level; r_s = Correlation coefficient; t = Student's t -test; PwD = Person with dementia.

Discussion

The boundary ambiguity of family caregivers of PwD is an emerging and innovative theme. In Portugal, the studies conducted with family caregivers do not assess feelings of ambivalence and ambiguity. This study translated, adapted, and contributed to the validation of the BAS into European Portuguese to help health professionals assess the presence of ambiguous loss in family caregivers. Strict compliance with the six steps proposed by ISPOR (Wild et al., 2005) ensured the semantic and idiomatic equivalence of this version of the BAS to its original version. In the validation process, individual and global CVIs were considered through the average of the items (S-CVI/Ave) and universal agreement (S-CVI/UA). Keeping in mind that the mean score can be skewed by outliers (S-CVI/Ave), both CVIs were considered in this study. The results are considered excellent if S-CVI/UA ≥ 0.8 and S-CVI/Ave ≥ 0.9 (Yusoff, 2019). In this study, S-CVI/Ave and S-CVI/UA were 0.99 and 0.94, respectively. According to Yusoff (2019), these data demonstrate that the European Portuguese Version of the BAS has excellent content validity and adequately assesses the construct of ambiguous loss/boundary ambiguity. Additionally, the number of experts ($n = 9$) is considered adequate for content validity, ranging in the literature from a minimum of three to a maximum of 10 (Boateng et al., 2018). In order to ensure representativeness, the quality of the expert panel was also considered. Hence, the authors invited experts from different disciplines with a research focus on family caregivers of PwD. Individual CVIs (Pc and K) are considered excellent. Finally, the pre-test reinforced that the BAS was well understood and that there was no ambiguity in the questions or suggestions that would justify changing it.

Three types of validity were used in this study: construct

validity through EFA, known-groups validity, and criterion validity, which is in line with Boateng et al. (2018), who suggest at least two types of construct validity. The construct validity data confirm sampling adequacy, factor loadings greater than 0.4 (except for item 8), and a two-factor model explaining 44% of variance, which reinforces the validity of the BAS (Hair et al., 2019). Greater factor retention could increase the percentage of variance, but the data from the parallel analysis showed two factors, with factor A explaining less variance of the BAS.

Known-groups validity is demonstrated when a test or questionnaire can discriminate between two groups known to differ on the variable of interest (Davidson, 2014). Thus, the results show that the group of family caregivers living with the PwD experience greater ambiguity, as also shown in other studies (Thomas et al., 2001). This closeness to the PwD is reflected in a continuum of care (24 hours, 7 days a week) in which family caregivers may be more confused about their roles and relationships, for example "Is he/she still my husband/wife? Does he/she still know who I am?". In these situations, family caregivers may question whether the PwD is present or absent, which is reflected in the ambiguity they feel. These experiences can cause insurmountable suffering and loss, leading to an ambiguity that worsens as the progression of dementia involves constant losses.

Convergent validity results demonstrate a moderate correlation between the BAS and the PSS, with both scales reflecting family caregivers' stress, which reinforces the validity of the BAS and the relevance of this study. These results highlight that ambiguous loss leads to situations of greater perceived stress, as shown in a study with 132 PwD and their family caregivers, which concluded that ambiguity was a predictor of caregiver burden and depression and that withdrawal and loss of motivation were the

main complaints of these caregivers (Thomas et al., 2001). Internal consistency was assessed using McDonald's Omega Coefficient (ω), with consistency being reflected in the form of accuracy and measurement error. According to Viladrich et al. (2017), the omega coefficient is an alternative method for determining reliability and its calculation is based on factor analysis. This coefficient works with factor loadings, unlike the alpha coefficient, which makes the calculations of internal consistency more stable and reliable. In this study, the omega coefficient of the BAS was 0.72, which indicates the reliability of the two-factor model obtained ($\omega > 0.70$). The omega values in factor A and B were 0.79 and 0.62, respectively. Thus, there is a consensus to consider that the total BAS has a good internal consistency, demonstrating that the instrument is consistent. This aspect is reinforced by factor A, with an omega coefficient greater than 0.70. The omega coefficient of factor B is not greater than 0.70 but is close to 0.65, which may be considered a satisfactory value (Katz, 2011).

This study has some limitations. First, sample size ($n = 88$) resulted from several factors: the unavailability of some family caregivers due to the COVID-19 pandemic and the denial of some family caregivers of their relatives' diagnosis of dementia. Concerning construct validity, a sample-item ratio higher than 10:1 is recommended (Hair et al., 2019), and this study had a sample-item ratio of 6:1. However, a minimum ratio of 5:1 is required to conduct an EFA (Hair et al., 2019). Future studies, namely those with confirmatory factor analysis, should consider a sample-item ratio higher than 10:1. Second, the restrictions regarding users' access to health units due to the pandemic situation led to the cancellation or reduction in the number of face-to-face activities, which limited face-to-face access to the family caregivers. Therefore, most data were collected by phone, which may have been difficult for family caregivers. Third, the inclusion of family caregivers of PwD regardless of the stage of the disease was also a limitation. The presence of feelings of ambiguous loss reflects the progression of the disease. These feelings may not be present in the early stages, which may be reflected in the participants' answers. Fourth, to our knowledge, no other validity studies of the BAS have been conducted. This information was confirmed by the author of this scale and may have limited the comparison of results.

Conclusion

The results of this study show that the European version of the BAS has linguistic equivalence to the original version, and the pre-test confirmed that it is easy to understand. The content validity of its 14 items revealed a CVI = 1, $P_c = 0.002$, and K of 1, which are considered excellent results. The analysis of the psychometric properties of the BAS showed acceptable construct validity and internal consistency. However, the authors suggest using the total scale to assess ambiguous loss, considering that the sub-scale "Ambiguity towards caring for the self or the PwD"

had low internal consistency. Since this is a recent area of research in the field of the family caregivers of PwD in Portugal, the implementation of this study contributed to the validation of the BAS. This instrument may be used to assess ambiguous loss and develop interventions to be implemented by health professionals, namely nurses, among family caregivers of PwD to manage family stress and, consequently, alleviate the associated burden.

Author contributions

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References

- Alzheimer Europe. (2019). *Dementia in Europe Yearbook 2019: Estimating the prevalence of dementia in Europe*. <https://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks>
- Boateng, G. O., Neilands, T. B., Frongillo, E. A., Melgar-Quinonez, H. R., & Young, S. L. (2018). Best practices for developing and validating scales for health, social, and behavioral research: A primer. *Frontiers in Public Health*, 6. <https://doi.org/10.3389/fpubh.2018.00149>
- Boss, P. (2007). Ambiguous loss theory: Challenges for scholars and practitioners. *Family Relations*, 56(2), 105–111. <https://doi.org/10.1111/j.1741-3729.2007.00444.xv>
- Boss, P. (2016). The context and process of theory development: The story of ambiguous loss. *Journal of Family Theory & Review*, 8(3), 269–286. <https://doi.org/10.1111/jftr.12152>
- Boss, P., Bryant, C. M., & Mancini, J. A. (2017). Ambiguous Loss: A Major Stressor. In P. Boss, C. M. Brayand & J. A. Mancini (Eds.), *Family stress management: A contextual approach* (3rd ed., pp. 71-85). SAGE.
- Boss, P., Greenberg, J. R., & Pearce-McCall, D. (1990). *Measurement of boundary ambiguity in families*. University of Minnesota.
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24(4), 385. <https://doi.org/10.2307/2136404>
- Davidson, M. (2014). Known-groups validity. In A. C. Michalos (Ed.), *Encyclopedia of quality of life and well-being research* (pp. 3481–3482). Springer Netherlands. https://doi.org/10.1007/978-94-007-0753-5_1581
- Hair, J. F., Black, W. C., Babin, B. J., & Anderson, R. E. (2019). *Multivariate data analysis* (8th ed.). Cengage.
- Katz, M. H. (2011). *Multivariable analysis* (3rd ed.). Cambridge University Press. <https://doi.org/10.1017/CBO9780511974175>
- Malhotra, N. K. (2019). *Pesquisa de marketing: Uma orientação aplicada* (7th ed.). Bookman.
- Organization for Economic Co-operation and Development. (2019).

Health at a glance 2019 OECD indicators. <https://doi.org/10.1787/e88a7402-en>

- Pais Ribeiro, J., & Marques, T. (2009). A avaliação do stresse: A propósito de um estudo de adaptação da escala de percepção de stresse. *Psicologia, Saúde & Doenças, 10*(2), 237–248. <https://www.redalyc.org/pdf/362/36218589008.pdf>
- Smodic, S., Forst, E., Rauschenberger, J., & McCoy, M. (2019). Financial planning with ambiguous loss from Alzheimer's disease: Implications, applications, and interventions. *Journal of Financial Planning, 32*(8), 34–45. <https://www.financialplanningassociation.org/sites/default/files/2021-10/AUG19%20JFP%20Smodie%20PDF.pdf>
- Thomas, P., Clement, J., Hazif-Thomas, C., & Leger, J. (2001). Family, Alzheimer's disease and negative symptoms. *International Journal of Geriatric Psychiatry, 16*(2), 192–202. [https://doi.org/10.1002/1099-1166\(200102\)16:2<192::aid-gps301>3.0.co;2-y](https://doi.org/10.1002/1099-1166(200102)16:2<192::aid-gps301>3.0.co;2-y)
- Viladrich, C., Angulo-Brunet, A., & Doval, E. (2017). Un viaje alrededor de alfa y omega para estimar la fiabilidad de consistencia interna. *Anales de Psicología, 33*(3), 755. <https://doi.org/10.6018/analesps.33.3.268401>
- van Wijngaarden, E., Wedden, H., Henning, Z., Komen, R., & The, A.-M. (2018). Entangled in uncertainty: The experience of living with dementia from the perspective of family caregivers. *PLOS ONE, 13*(6), e0198034. <https://doi.org/10.1371/journal.pone.0198034>
- Wild, D., Alyson, G., Mona, M., Sonya, E., Sandra, M., Verjee-Lorenz, A., Erikson, P., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., & Erikson, P. (2005). Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR task force for translation and cultural adaptation. *Value Health, 8*(2), 94–104. <https://doi.org/10.1111/j.1524-4733.2005.04054.x>
- World Health Organization. (2021). *Dementia*. <https://www.who.int/news-room/fact-sheets/detail/dementia>
- Yusoff, M. S. (2019). ABC of content validation and content validity index calculation. *Education in Medicine Journal, 11*(2), 49–54. <https://doi.org/10.21315/eimj2019.11.2.6>