Validation of the caregiver oncology quality of life questionnaire in Portuguese caregivers of myeloma patients

Original Article

Corresponding Author: M. Graça Pereira, School of Psychology, University of Minho, Campus de Gualtar, 4710-057 Braga, Portugal Email: gracep@psi.uminho.pt

M. Graça Pereira, PH.D.[1,2] (iD), Margarida Vilaça, PH.D.[2] (iD), Marta Pereira, M.S.[1,2] (iD), Rosário Bacalhau, PH.D.[3] (iD), Sara Monteiro, PH.D.[4,5], Bruna Fernandes, M.S.[4], Sara Faria, M.S.[1] and Gabriela Ferreira, M.S.[1,2] (iD)

[1]School of Psychology, University of Minho, Braga, Portugal; [2]Psychology Research Center (CIPsi), University of Minho, Braga, Portugal; [3]Portuguese Institute of Oncology Francisco Gentil, Lisboa, Portugal; [4]Department of Education and Psychology, University of Aveiro, Aveiro, Portugal and [5]Center for Health Technology and Services Research (CINTESIS), University of Porto, Porto, Portugal

Abstract

Objective. Cancer diagnosis affects patients, their families, and their caregivers in particular. This study focused on the validation of the CareGiver Oncology Quality of Life (CarGOQoL) questionnaire in Portuguese caregivers of patients with multiple myeloma, from the caregiver's point of view.

Method. This was a cross-sectional study with 146 caregivers of patients with multiple myeloma from outpatient medical oncology and clinical hematology consultations from five hospitals in north and central Portugal. Participants were assessed on quality of life (QoL), psychological morbidity and social support.

Result. The Portuguese version maintains 17 of the original 29 items version, maintaining general coherence and a dimensional structure that is clinically interpretable. Reliability findings indicated good internal consistency for the total scale (0.86) and respective subscales (0.75 to 0.88), which is in agreement with the alpha values from the previous CarGOQoL validation study for the corresponding subscales (0.74 to 0.89) and total scale (0.90).

Significance of results. The CarGOQoL is a reliable and valid tool for clinical trials and intervention programs to assess QoL in caregivers of myeloma patients. Future studies should validate the adapted version in caregivers of other types of cancer patients including other chronic diseases.

Introduction

A cancer diagnosis is considered a stressor that affects not only patients but also their families. In fact, family members assume the role of caregivers, providing instrumental and emotional support to cancer patients (Stenberg et al., 2010).

Multiple myeloma (MM) is the second most prevalent hematologic cancer (Gozzetti et al., 2014; Lamers et al., 2013). This disease is incurable in most patients (Smith et al., 2011) and its treatment occurs, mainly, in an outpatient setting. Median overall survival is less than five years (American Cancer Society, 2018). It is known that patients have to endure the most physical and emotional care at home placing a greater demand on caregivers (Molassiotis et al., 2011). Patients who undergo an allogeneic blood or marrow transplant need a full-time caregiver for at least 100 days (Simoneau et al., 2013).

Caregiving has a negative impact on a caregiver's life on physical (e.g., fatigue, sleep problems), emotional (e.g., anxiety, depression), and social (financial difficulties, isolation, the need for information) levels (Bevans & Sternberg, 2012; Stenberg at al., 2010). An association between higher caregivers' distress and lower physical, psychological, social, and spiritual quality of life (QoL) has been found in family caregivers of lung cancer patients (Fujinami et al., 2015). The caregiver's burden significantly predicted their own mental health and QoL, as well as MM patients' mental health, assessed by the Health Survey 36 (SF-36v2) (La & Yun, 2017).

Several authors suggested that family caregivers of advanced cancer patients and of allogeneic transplant patients in the peri-transplant period showed higher levels of anxiety, depression, and stress, when compared with population norms (Ratnakar et al., 2008; Simoneau et al., 2013). Caregivers with higher levels of distress, in turn, reported a higher number of care needs (Janda et al., 2008), lower support and higher burden (Kim & Given, 2008; Pitceathly & Maguire, 2003), as well as poor mental health and worse QoL (Colgrove et al., 2007; Friðriksdóttir et al., 2011; Iconomou et al., 2001). Distress did not differ according to caregivers' gender but younger caregivers showed higher distress than older ones (Simoneau et al., 2013).

Social support is an important resource to caregivers (Stenberg et al., 2010). Greater satisfaction with social support has been associated with better psychological well-being (Ownsworth et al., 2010), while less satisfaction with social support has predicted greater caregiver burden (Park et al., 2012; Teixeira & Pereira, 2013). Moreover, social support is considered to play a buffer role on the impact of caregiving on mental health. Ownsworth et al. (2010) found a moderator/ buffer effect of satisfaction with social support on the relationship between patients' functional impairments and caregivers' psychological well-being, i.e., caregivers more satisfied with their social support, whose patients had higher functional impairment, showed better psychological well-being than those less satisfied.

Considering that being a family caregiver is demanding and time-consuming (Stenberg et al., 2010) and impairs caregivers' QoL, it is important to have validated measures to assess QoL in caregivers of cancer patients in order to study the impact of interventions aimed at promoting their QoL (Edwards & Ung, 2002). In particular, with MM, it is imperative to have validated measures due to this disease specificities' particularly higher levels of symptoms and worse QoL, when compared with other hematological cancers (Johnsen et al., 2009).

According to a recent systematic review (Michels et al., 2016), the SF-36 (Ware & Sherbourne, 1992) was the most widely used generic instrument in the evaluation of caregivers in a palliative context, while the most used specific instruments were: the Caregiver Reaction Assessment (CRA; Given et al., 1992), the Caregiver Quality of Life of Index–Cancer (CQOLC; Weitzner et al., 1999), the Zarit Burden Interview (ZBI; Zarit et al., 1985), and the Caregiver Strain Index (CSI; Robinson, 1983).

The studies have focused mainly on burden, QoL, and strain in caregivers. In fact, to evaluate cancer caregivers' QoL, there are currently only three self-administered measures in addition to the Caregiver Quality of Life Index-Cancer (CQOLC; Weitzner et al., 1999), such as the Caregiver Quality of Life Index (CQLI; McMillan & Mahon, 1994) and the CareGiver Oncology Quality of Life questionnaire (CarGOQoL; Minaya et al., 2012). While CQLI was validated with a sample of five individuals, the CQOLC development was based on a combination of the perspectives of patients, caregivers, and experts and subsequently validated in a sample of spouses. Finally, the CarGOQoL comprises 29 items and assesses the impact of cancer and its treatment on the caregivers' QoL, based on the exclusive caregiver's point of view, identifying specific dimensions not addressed in other scales. The CarGOQoL original version (French language) was validated in a large and diversified sample of caregivers (partners, parents, and children) and also in English from the United States with satisfactory psychometric properties (Kaveney et al., 2016).

The present study aims to validate the CarGOQoL in a Portuguese sample of caregivers of patients with MM, being the first Portuguese study to use this questionnaire in this population.

Methods

Participants

The sample included 146 caregivers of patients with MM from outpatient medical oncology and clinical hematology consultations from five central hospitals in north and central Portugal. Caregivers were invited to participate by the researcher through referral of the patient's physician. The inclusion criteria were: 1) principal caregiver of a patient with MM, 2) age equal to or greater than

18 years; and 3) absence of psychiatric illness or cognitive deficit assessed through the Mini Mental State Examination (MMSE). Data collection took place between October 2016 and June 2018.

Measures

CareGiver Oncology Quality of Life (CarGOQoL; Minaya et al., 2012) is a multidimensional questionnaire for caregivers of patients with cancer designed to assess the caregiver's perspective of their own quality of life (QoL). The original version contains 29 items assessing 10 dimensions evaluated on a 5-point Likert scale ranging from "never/not at all" to "always/very much," with higher scores indicating better QoL (asterisks indicates inverted scores): Psychological well-being (4*; PsWB), Burden (4*; B), Relationship with health care (3; RHC), Administration and finances (3*; AF), Coping (3*; COP), Physical well-being (4*; PhWB), Self-esteem (2; SE), Leisure (2; LEI), Social support (2; SS), and Private life (2(1*); PL). The original version presents alphas for the total scale of 0.90 and between 0.72 and 0.89 for the subscales except for the private life dimension (0.55) (Minaya et al., 2012).

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983; Portuguese Version by Pais-Ribeiro et al., 2007) is composed of 14 items assessing anxiety and depression in clinical and community populations, through seven items, respectively for anxiety and depression. The items are answered on a 4-point scale, where higher scores indicate greater symptoms of anxiety and depression. According to the original version, a full score can be used as a clinical indicator and considered as an index of emotional distress. For the Portuguese version, Cronbach's alpha was 0.76 for the subscale Anxiety and 0.82 for the subscale Depression. In this study, only the total scale was used with an alpha of 0.80.

Satisfaction with Social Support Scale (SSSS; Portuguese Version by Pais-Ribeiro, 1999) assesses satisfaction with social support through 15 items divided into four subscales: Satisfaction with friends, Intimacy, Satisfaction with family, and Social activities. A total score is obtained through the sum of all of the items, where a higher score indicates greater satisfaction with social support. The original version showed Cronbach alphas of 0.85 for the total score; 0.83 (satisfaction with friends), 0.74 (intimacy and satisfaction with family), and 0.64 (social activities) for the subscales. In this study, only the total scale was used with an alpha of 0.89.

Procedure

The study used a cross-sectional design and was submitted and approved by the Ethics Committees of the hospitals where data collection took place. All procedures followed the principles detailed in the Declaration of Helsinki. Caregivers of patients with MM were contacted by the patient's physician and invited to participate in the study by the researcher on the day of the patient's medical oncology appointment or while waiting during treatment. All invited caregivers agreed to participate in the study. Participants were informed about the aims of the study, confidentiality of the data, and voluntary participation, signing an informed consent for this purpose. In addition to the 146 caregivers, 106 patients in the caregivers' group also agreed to complete a sociodemographic questionnaire while the remaining 40 were not available at the time.

Data Analysis

Descriptive analyses were used to describe the sociodemographic and clinical characteristics of caregivers and patients. To find the

Table 1. Sample characteristics

Caregivers (N = 146)		n (%) / M ± SD
Gender	Women	88 (60.3)
	Men	58 (39.7)
Age (years)		56.34 ± 16.17
Education	≤ Basic education	85 (58.2)
	≤ Secondary education	38 (26.7)
	≤ University degree	22 (15.1)
Professional status	Employed	57 (39.0)
	Unemployed with benefits	14 (9.6)
	Unemployed without benefits	12 (8.2)
	Retired	63 (43.2)
Partner	No	41 (28.1)
	Yes	105 (71.9)
Relationship with the patient	Partner	74 (50.7)
	Children	49 (33.6)
	Others	23 (15.8)
Caregiving duration (months)		38.49 ± 33.73
Patients (N = 106)		n (%)
Treatments Received	Chemotherapy	37 (34.9)
	Chemotherapy and transplant	18 (17.0)
	Chemotherapy and bisphosphonates	11 (10.4)
	Without treatment	6 (5.7)
	Others	34 (32.070)
Current treatment	Chemotherapy	40 (37.7)
	Maintenance therapy	47 (44.3)
	Others	21 (19.81)
Cancer stage	I	36 (34.0)
	II	28 (26.4)
	III	30 (28.3)
	Not provided	12 (11.3)

final factor solution of the Portuguese CarGOQoL version, principal component analysis (PCA) and confirmatory factor analysis (CFA) were performed. The CFA was performed using Structural Equations Modeling (SEM) technique, following the original authors' validation study procedures (Minaya et al., 2012). To evaluate the model's adequacy, the following fit indices were considered: the ratio of Chi-Square over the number of degrees of freedom (χ^2/df), the root mean square error of approximation (RMSEA), the non-normed fit index (NNFI), and the comparative fit index (CFI). Usually, values of χ^2/df under 2 are considered reasonably good indicators of fit (Ullman, 2001). RMSEA values below 0.08 are acceptable (Hair et al., 1995), while values near or higher than 0.90 reflect a good fit for NNFI and CFI indexes (Hoyle, 1995). Reliability of the scale was examined using Cronbach's alpha, with coefficients ≥ 0.7 suggesting good factor reliability (Hair et al., 2010).

A posteriori analysis was performed in order to assess the adequacy of the sample size to get a reasonable 0.8 level of power. To perform this task, the PROCESS macro from Preacher and

Coffman (2006) was used. Assuming a null hypothesis of close fit (H0: RMSEA = 0.70) and an alternative hypothesis of unacceptable fit (Ha: RMSEA = 0.10) (Preacher et al., 2007), as well as a significance level of alfa = 0.05 and 109 degrees of freedom, the Web procedure indicated that the minimum sample size required to achieve the desired level of 0.8 power was 105 subjects. Since the sample size of this study exceeds this minimum (146), the desired statistical power is achieved.

Subsequently, convergent and divergent validity were assessed using Pearson correlations between caregivers' QoL social support and psychological morbidity, respectively. Finally, independent sample t-tests and one–way ANOVA analyses were performed to determine the presence of differences in the caregivers' QoL with regard to their gender, age, presence/absence of a partner, relationship with the patient and caregiving duration, as well as the patient's gender, age, and disease duration.

Statistical analyses were performed with SPSS and AMOS software (version 25.0).

Results

Sample Characteristics

The CarGOQoL questionnaire was administered to a sample of 146 caregivers of MM patients in Portugal, whose ages ranged from 18 to 84 years, with 13.7% younger than 40 years old, 34.9% between 40–59 years old, and 51.4% over 59 years old. Most of the participants were women (88, 60.3%), had a partner (105, 71.9%), and, on average, were caregivers for more than three years (months: $M = 38.49$, $SD = 33.73$). The average age of the cancer patients was 69.65 years old ($SD = 9.18$, range 39–87), and they were mainly women (53.8%), with myeloma type IgG/K (33.7%), IgA/K (21.7%), IgA/L (13.2%), and IgG/L (11.3%) in phases I (34.0%), II (26.4%), and III (28.3%). Table 1 shows the sample characteristics.

Construct Validity

Results from the Bartlett's sphericity test ($\chi^2 = 2136.18$, $p < .001$) and the Kaiser-Meyer-Olkin sample adequacy test (0.73) supported the factorability of the correlation matrix. CFA did not confirm the adequacy of the original 10-factor solution for the sample data in this study, reporting poor reliability and poor fit to the data. Subsequently, the analysis of the PCA's results, based on eigenvalues > 1 (Kaiser, 1960) and the scree plot (Cattell, 1966) criteria, pointed to the retention of five factors. The conducted parallel analysis (Horn, 1965) also supported a five-component solution. Thus, a second CFA was computed in order to test the resulting solution and the five-factor structure was confirmed ($\chi^2/df = 1.769$, RMSEA = 0.07, NNFI = 0.90, and CFI = 0.92).

Although initial PCA identified nine factors, only five of them had more than two items with coefficients greater than 0.40, and the scree plot pointed to the extraction of five factors. The analyses were repeated, forcing a five-factor, but also other possible different solutions (from ten to one-factor models). The five-dimensional structure revealed to be the most feasible solution, both statistically and theoretically, when compared to the original version. Items 8*, 15*, 19*, and 29* were removed because none of them correlated strongly (< 0.40) with any factor, and they correlated simultaneously with three to five factors. CFA was run on the remaining 25 items, obtaining an improved, but still poor, fit between the hypothesized model and data. After an inspection of the item's error correlations and factor loadings, eight more items were excluded since they presented lower loadings (< 0.40). Figure 1 shows the final structural model.

Overall, the Portuguese CarGOQoL version contains 17 of the 29 original version's items (items 3*, 6*, 7*, 8*, 15*, 19*, 22, 23, 26, 27, 28*, and 29 were removed), presenting a comparable distribution to the original one (Table 2).

Reliability

Reliability coefficients for the total scale and five subscales were found to be appropriate and ranged between 0.75 and 0.88.

Convergent Validity

As presented in Table 3, the 17-item version of CarGOQoL scale and subscales showed good convergent validity for satisfaction with the social support scale (SSSS). Significant Pearson's correlations ranged between 0.20 and 0.49.
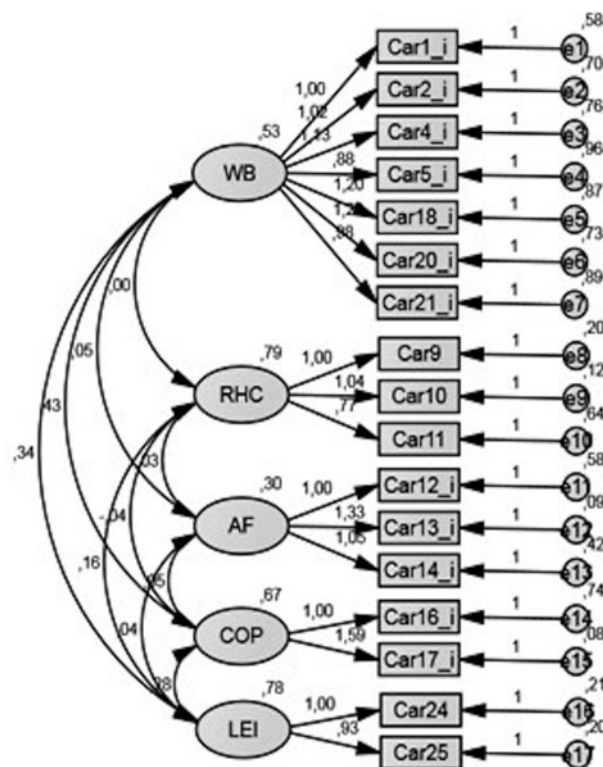

Fig. 1. CarGOQoL re-specified model. Legend: WB = Well-being; RHC = Relationship with Health Care; AF = Administration and Finances; COP = Coping; LEI = Leisure.

Divergent Validity

The Portuguese version of CarGOQoL correlated negatively with psychological morbidity with the exception of RHC. Significant correlations ranged between 0.25 and 0.57 (Table 3).

Differences in QoL according to Caregiver's Gender, Age, Presence of a Partner, Relationship with the Patient, and Caregiving Duration

Overall, female and male caregivers reported similar mean scores for the total scale and subscales, presenting non-significant slight differences. The results also showed no significant differences regarding the caregivers' age, having/not having a partner, and regarding the relationship with the patient. However, one exception was found in the LEI dimension of QoL since caregivers without a partner presented higher scores on this particular area. Also, caregivers that provided care for longer periods (months) showed worse QoL regarding the WB dimension (Table 4).

Differences in QoL according to Patients' Gender, Age, and Disease Duration

Table 4 shows that there were no significant differences in caregivers' QoL according to the patients' gender and age. Finally, no significant correlations were found considering the patient's disease duration.

Discussion

Regarding the construct validity, PCA and CFA revealed that the original 10-factor model proposed by Minaya et al. (2012) did

Table 2. Results of the CFA for the CarGOQoL Portuguese version

Model	Domain		Cronbach's alpha	Statistical fit indices
Original CarGOQoL model (Minaya et al., 2012)	PsWB:	1*; 2*; 3*; 4*	0.89	CFI = 0.92 NNFI = 0.90 RMSEA = 0.04
	B:	5*; 6*; 7*; 8*	0.82	
	RHC:	9; 10; 11	0.83	
	AF:	12*; 13*; 14*	0.74	
	COP:	15*; 16*; 17*	0.72	
	PhWB:	18*; 19*; 20*; 21*	0.83	
	SE:	22; 23	0.77	
	LEI:	24; 25	0.78	
	SS:	26; 27	0.72	
	PL:	28*, 29	0.55	
	TOTAL:	29 items	0.90	
Initial model	PsWB:	1*; 2*; 3*; 4*	0.77	Chi-square = 726.91 *df* = 332 CFI = 0.79 NNFI = 0.75 RMSEA = 0.09
	B:	5*; 6*; 7*; 8*	0.66	
	RHC:	9; 10; 11	0.86	
	AF:	12*; 13*; 14*	0.75	
	COP:	15*; 16*; 17*	0.70	
	PhWB:	18*; 19*; 20*; 21*	0.64	
	SE:	22; 23	0.50	
	LEI:	24; 25	0.88	
	SS:	26; 27	0.65	
	PL:	28*, 29	−0.71	
	TOTAL:	29 items	0.86	
Respecified model	WB:	1*; 2*; 4*; 5*; 18*; 20*; 21*	0.84	Chi-square = 192.79 *df* = 109 CFI = 0.92 NNFI = 0.90 RMSEA = 0.07
	RHC:	9; 10; 11	0.86	
	AF:	12*; 13*; 14*	0.75	
	COP:	16*; 17*	0.80	
	LEI:	24; 25	0.88	
	TOTAL:	17 items	0.84	

CFI = comparative fit index; NNFI = non-normed fit index; RMSEA = root-mean-square error of approximation. *Inverted items.

Table 3. Correlations between CarGOQoL Portuguese version, Satisfaction with Social Support (SSSS) and Psychological Morbidity (HADS)

QOL		WB	RHC	AF	COP	LEI	Total
SSSS							
	Total	0.40***	0.22**	0.20*	0.32***	0.38***	0.49***
HADS							
	Total	−0.55***	0.02	−0.25**	−0.41***	−0.46***	−0.57***

WB = Well-being; RHC = Relationship with Health Care; AF = Administration and Finances; COP = Coping; LEI = Leisure. *$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

not fit the analyzed Portuguese data. However, the resulting five-factor solution presented satisfactory goodness-of-fit statistics, close to those found in the original version (RMSEA = 0.07, NNFI = 0.90, and CFI = 0.92). In the Kaveney and colleagues' validation study (2016) based on a sample of 87 American cancer caregivers, authors corroborated the original factor structure, obtaining a reasonable fit (RMSEA = 0.08). However, since other fit indices were not presented, it is not possible to further analyze and compare the present results with the American adaptation.

With fewer items, the 17-item CarGOQoL version is similar to the original version, as most domains are exactly the same: RHC, AF, and LEI correspond to the original dimensions, while COP contains one less item. Also, WB aggregates three PsWB items (1*, 2*, 4*) and three PhWB items (18*, 20*, 21*), together with

Table 4. Comparisons (mean ± standard deviation) and correlations (r) between CarGOQoL Portuguese version scores and caregivers' and patients' characteristics.

		WB	RHC	AF	COP	LEI	Total
Caregiver							
Gender	Women	23.80 ± 6.63	11.97 ± 2.92	13.69 ± 1.87	7.90 ± 2.31	7.17 ± 1.86	64.53 ± 10.32
	Men	24.48 ± 4.66	12.09 ± 2.33	13.05 ± 2.42	7.81 ± 2.33	6.90 ± 1.78	64.33 ± 9.13
	p	0.463	0.793	0.074	0.824	0.377	0.907
Age group	< 40	25.65 ± 5.40	11.50 ± 3.05	13.65 ± 1.81	8.15 ± 2.41	7.20 ± 1.01	66.15 ± 8.40
	40–59	24.29 ± 5.26	11.88 ± 2.63	13.02 ± 2.48	8.10 ± 2.17	7.10 ± 1.87	64.39 ± 9.24
	> 59	23.49 ± 6.43	12.24 ± 2.64	13.67 ± 1.91	7.63 ± 2.39	7.00 ± 1.98	64.02 ± 10.62
	p	0.333	0.505	0.218	0.448	0.897	0.694
Partner	No	24.41 ± 5.90	11.78 ± 2.78	13.71 ± 1.52	8.00 ± 2.65	7.61 ± 1.64	66.54 ± 10.18
	Yes	23.54 ± 5.87	12.10 ± 2.66	13.32 ± 2.31	7.81 ± 2.18	6.85 ± 1.86	63.63 ± 9.62
	p	0.086	0.515	0.215	0.656	0.023	0.109
Relationship	Partner	23.08 ± 6.28	12.38 ± 2.57	13.39 ± 2.29	7.70 ± 2.36	6.97 ± 1.94	63.53 ± 10.41
	Children	24.53 ± 5.44	11.63 ± 2.69	13.43 ± 1.81	7.90 ± 2.37	7.27 ± 1.69	64.76 ± 9.32
	Others	26.26 ± 5.16	11.65 ± 3.02	13.61 ± 2.23	8.30 ± 2.08	6.91 ± 1.78	66.74 ± 8.85
	p	0.062	0.253	0.913	0.551	0.630	0.381
Caregiving duration	r	−0.168	0.038	0.109	−0.138	0.017	−0.097
	p	0.043	0.651	0.189	0.096	0.843	0.245
Patient							
Gender	Women	24.40 ± 5.32	11.79 ± 2.93	13.39 ± 2.18	7.70 ± 2.26	7.19 ± 1.71	64.47 ± 9.28
	Men	23.22 ± 7.12	12.53 ± 2.43	13.57 ± 1.70	7.65 ± 2.53	7.24 ± 1.75	64.22 ± 11.09
	p	0.343	0.164	0.630	0.917	0.878	0.901
Age group	< 60	21.15 ± 5.26	12.77 ± 2.55	12.54 ± 2.67	6.92 ± 2.47	6.69 ± 1.65	60.08 ± 10.14
	60–70	23.22 ± 5.49	12.24 ± 2.48	13.51 ± 1.61	7.44 ± 2.55	7.22 ± 1.73	63.63 ± 9.88
	>70	25.05 ± 6.76	11.88 ± 2.96	13.67 ± 1.99	8.06 ± 2.18	7.35 ± 1.74	66.00 ± 10.09
	p	0.091	0.551	0.174	0.219	0.475	0.141
Disease duration	r	−0.062	0.035	0.130	−0.131	−0.100	−0.051
	p	0.526	0.720	0.183	0.181	0.308	0.602

WB = Well-being; RHC = Relationship with Health Care; AF = Administration and Finances; COP = Coping; LEI = Leisure.

one item of the B dimension (5* - "Felt a lack of freedom?"), which theoretically makes sense, since they are all related to general well-being (psychological, physical, and emotional). Overall, 12 items were eliminated from the questionnaire, including SE, SS, and PL dimensions. Items 8 ("Been embarrassed to be the only person to provide assistance?"), 15 ("Experienced feelings of guilt?"), 19 ("Had problems with your appetite?"), and 29 ("Had a satisfying love and sexual life?") were eliminated since they showed no correlation with any specific dimension. In fact, an examination of the items' content shows that they address susceptible topics such as accountability for the sick relative, guilt, and sexuality, which in the context of the Portuguese culture may be considered very sensitive topics. Taking care of a relative is considered the right thing to do following society's expectations, and sexuality is a private topic particularly taking into consideration this sample's characteristics (mostly spouses older than 59 years). For the same reason, items 6 ("Been bothered by the feeling of being confined?") and 7 ("Been bothered by the fact that your life was entirely devoted to the care recipient?") from the B dimension were also excluded, as they did not saturate in

their corresponding factor, probably because they also refer to feelings of guilt and deprivation of freedom, representing negative and vulnerable emotions that caregivers may avoid to express (Coon et al., 2003; Cooper et al., 2008). SE's two items (22, 23), "Felt you made a difference for the person you are helping?" and "Felt useful?" respectively refer to the caregiver's perception of usefulness that may be difficult to evaluate since MM is an incurable disease with a bad prognosis. Items 26 ("Been assisted, supported, understood by your family?") and 27 ("Been assisted, supported, understood by your friends?") from the social network dimension (SS) did not saturate and were also eliminated, possibly due to the caregivers' difficulty to have a social life, frequently highly compromised by their caring demands. Finally, item 28 ("Had difficulties in your intimate, emotional life?") was excluded from the final version since the loading was low, probably for the same reason presented for item 29, that is, the fact that the private emotional and sexual life may represent a very confidential topic for elder people in the Portuguese culture.

Internal consistency of the resulting Portuguese version's dimensions was high (Cronbach's alpha: 0.75–0.88) and close to

the original version (Cronbach's alpha: 0.55–0.89) and the American version (Cronbach's alpha: 0.26-0.87) coefficients.

Regarding the convergent validity, the CarGOQoL scale and subscales correlated with the Satisfaction with Social Support Scale, which is expected given that social support is considered a protective factor in the face of stress and overload felt by caregivers (Park et al., 2012; Stenberg et al., 2010; Teixeira & Pereira, 2013), with a significant impact on QoL (Ownsworth et al., 2010). In terms of the divergent validity, CarGOQoL correlated negatively with psychological morbidity (Colgrove et al., 2007; Friðriksdóttir et al., 2011; Iconomou et al., 2001) as expected, except for RHC, which makes sense since the relationship with health care needs to be protected regardless of caregiver's psychological morbidity.

The CarGOQoL was also sensitive to caregivers' sociodemographic and clinical characteristics. Results indicated differences in the LEI dimension, i.e., caregivers with no partner showed higher scores in this dimension. In this study, with the majority of caregivers being female (60.3%), those with no partner are usually not married and therefore do not have to juggle the spousal role with the caregiver role. In contrast to other studies which found caring for a younger and male patient to be associated with higher QoL in caregivers (Shahi et al., 2014; Valeberg & Grov, 2013; Warapornmongkholkul et al., 2018), in this study there were no significant differences probably because the majority of the sample included middle-aged women.

Finally, a longer duration of caregiving was associated with lower well-being. In fact, the literature shows that the prolonged duration of care may expose the caregiver to burden, particularly as patient's functional status declines (Bevans & Sternberg, 2012; Grunfeld et al., 2004). However, these results are in contrast with a recent study of French caregivers of patients with gliomas using the CarGOQoL (Flores et al., 2014), which found that participants with a longer caregiving situation expressed better psychological and physical well-being. Future studies with longitudinal designs are required in order to clarify these results.

Limitations and Future Directions

This study has limitations that need to be acknowledged such as the sample size and the characteristics of the sample (e.g., age). Although the study sample includes a broad representation of Portuguese caregivers providing long-term care to MM patients, and is significantly larger than the sample used in the American study (Kaveney et al., 2016), the sample size is nonetheless smaller than the original French study (Minaya et al., 2012). In this sense, it is important to emphasize that as a rare disease, MM has a 1% prevalence among all cancers (Albagoush & Azevedo, 2019). Therefore, the sample size to validate this questionnaire was adequate when compared to other samples of caregivers of patients with different cancer types. Notwithstanding, MM showed a greater impact on caregivers, as the results of the present study have shown, justifying the validation of CarGOQoL in MM caregivers. At a first glance, the validation of CarGOQoL may seem difficult to generalize to other countries or cultures, but the authors believe that the present validation, especially with the elimination of some more sensitive topics (e.g. sexuality items), may have sociocultural relevance for countries in southern Europe, where there is a higher Judeo-Christian influence. However, a validation in those realities is also required. Further studies should also validate the adapted version in larger samples of caregivers of other types of cancer patients including

other chronic diseases as well. Furthermore, given that the caregivers' QoL changed over the care trajectory and the patient's disease stages, longitudinal studies with CarGOQoL should be undertaken in order to analyze the instrument sensitivity to change as well as better understand the impact of MM in caregivers' QoL.

Conclusion

Overall, the 17-item Portuguese version of the CarGOQoL seems to be representative of the original 29-item version, maintaining the questionnaire's general coherence and containing a dimensional structure that is clinically interpretable. Reliability findings indicate good internal consistency of the total scale (0.86) and respective subscales (0.75 to 0.88), which is consonant with the alphas found in the previous CarGOQoL validation study (Minaya et al., 2012) for the corresponding subscales (0.74 to 0.89) and total scale (0.90). Therefore, the CarGOQoL presents itself as a reliable and valid tool to be used in clinical trials and intervention programs to assess QoL in caregivers of myeloma patients in Portugal.

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