

Evaluation of the psychometric properties of the caregiver guilt questionnaire (CGQ) in a sample of Portuguese caregivers of persons with dementia

Abstract

Background: Informal carers of people with dementia verbalize guilt. Guilt is a feeling associated with depressive disorder, so the intervention is directed at the global depressive process without defining specific interventions to the phenomenon of guilt.

Aims: Our goal was to translate, adapt the language, and evaluate the psychometric properties of the Caregiver Guilt Questionnaire (CGQ) in a Portuguese population sample.

Design: An instrumental and cross-sectional study design with a 2week test-retest was used.

Methods: A convenience sample of 189 informal caregivers of people with dementia was obtained by non-random sampling.

Results: The procedures of the original authors of the CGQ were followed. In the principal components analysis with varimax rotation, five factors stood out, with saturation >40 per item, which explained 65.8% of the total variance. Item 16 was eliminated. Most of the 21 items were grouped differently from the authors. By content analysis we renamed the factors and formed the Portuguese version of CGQ, the QCC. The QCC has good fidelity: alpha Cronbach $\alpha = 0.90$ and stability with r values of Pearson between 0.93 and 0.99 in test-retest.

Conclusion: The analysis of the psychometric properties of the CGQ applied to dementia caregivers sample shows that the Portuguese version is a valid tool.

Keywords: guilt, depression, anxiety, caregivers, dementia

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Introduction

The problem of dementia and its association with the aging process are of particular relevance in the context of mental health and psychiatry. Over 20% of the adults aged 60 and over suffer from a mental or a neurological disorder (excluding headache disorders). The most common mental and neurological disorders in this age group are dementia and depression, which affect almost 5% and 7% of the world's older population, correspondingly (WHO, 2017).

There are substantial social and economic questions in terms of the direct costs of medical, social, and informal care associated with dementia. Additionally, physical, emotional, and economic pressures can cause great stress to families and carers (WHO, 2017). So, emotional support is needed for people with dementia and their carers. In Portugal, according to the National Statistics Institute (INE, 2014),¹ is about 19.9% of the total population is considered to be elderly (aged over 65). In line with current projections, by 2050, this population will represent 32% of the population (INE, 2014).¹ Portugal is ranked as the seventh most aged country in Europe.² Thus, the role played by the nurse specialized in mental health and psychiatry is essential since he/she can be a facilitator in the transitions inherent to dementia that are experienced by the individual living with this condition and by his/her family.

This study aims to translate the CGQ into European Portuguese and evaluate the psychometric properties of the CGQ in a Portuguese sample of caregivers of persons living with dementia. Our research question is: Is the QCC a valid instrument to assess guilt in Portuguese caregivers of persons with dementia?

Guilt is a feeling associated with depressive disorder, so the intervention is directed at the global depressive process without defining specific interventions to the phenomenon of guilt.

According to the International Council of Nurses (CIPE), guilt is expressed as a negative emotion: "feelings of having acted wrongly, conflict of values or internal tensions when someone falls below a set of rules traced by himself; guilt feelings are directed at the own person, not at others" (2015).

The Caregiver Guilt Questionnaire (CGQ) built by Losada et al.³ can be a useful tool to identify the feelings of guilt in informal caregivers and thereby facilitate the decision-making process in the definition of nursing diagnoses and respective therapeutic interventions. If we consider guilt as an important feeling for caregivers, it is essential to improve our knowledge of this variable, which will expand our ability to understand the factors that contribute to the caregiver burden and psychiatric symptoms.

Guilt in CGQ is assessed on five factors: guilt about doing wrong by the care recipient, guilt about failing to meet the challenges of caregiving, guilt about self-care, guilt about neglecting other relatives, guilt about having negative feelings towards other people.³

In most cases, informal caregivers are not prepared to give an adequate response to the needs of dependent relatives when they are in the family environment because caregivers live a transition process while at the same time providing care. The transition to the exercise of the role of caregiver is a complex process, a unique experience for each family Hopkinson et al.,⁴ so the nurses should be aware of this reality, particularly in the mental health area.

The provision of care should be addressed with a holistic view. The ideal behavior of nurses should be inevitably guided by the understanding of the person in his/her value as a total being, as part of a family, as a member of a culture, as a person with his/her beliefs, emotions and values that affect health and disease transitions.

Methods

The CGQ has 22 items assessing guilt and was originally developed and validated in a sample of 288 informal caregivers of people with dementia in Spain in 2010 by Losada et al. In 2013, Roach et al.⁵ validated the CGQ in a sample of 221 informal carers in a British sample.

Design

The study assumed as instrumental and cross-sectional study design with a 2week test-retest. Data were collected from participants using face-to-face interviews.

Table 1 Informal caregivers characterization: biographical component

	N	%	M	Mode	Median	Min	Max	SD
Sex								
Male	44	23,3						
Female	145	76,7						
Age	189		54,47	55,0	54,00	21	90	12,77
Years education	180		8,86	12	9,00	0	24	4,46
Marital Status								
Single	28	14,8						
Married	129	68,3						
Committed	6	3,2						
Widower	11	5,8						
Divorced	14	7,4						
Professional Situation								
Retired by age	36	19,0						
Retired due to disability	15	7,9						
Employee	82	43,4						
Domestic	23	12,2						
Unemployed	30	15,9						
Student	3	1,6						

Legend: M (Mean); SD (Standard Deviation).

Measures

The data collection was implemented from January to June 2015 using a questionnaire divided into three parts: first, the study explanation and informed consent; second, the collection of sociodemographic and clinical information of the informal caregiver and care receiver; and third, application of psychometric instruments. The psychometric instruments used were:

QUESTIONNAIRE - The questionnaire was designed specifically for this study in order to collect demographic information (age, sex,

Table 2 Care receiver characterization

	N	%	M	Mode	Median	Min	Max	SD
Sex								
Male	78	41,3						
Female	111	58,7						
Age	189		71,89	79	80,0	4	97	22,38
Years education	177		3,81	4	4,0	0	17	3,55
Type of dependency								
Physical	41	21,7						
Mental	30	15,9						
Physical and mental	117	61,9						

Participants

The target population for this research study consists of informal caregivers of people with physical and/or mental dependence living in the community. Informal caregivers who agreed to participate were contacted through daycare centers, nursing homes, hospitals, and other institutions.

The inclusion criteria were as follows: a) age over 18 years; b) main language - Portuguese; c) being a caregiver for a person with physical and/or mental dependence; d) live in the community; e) have been providing care for at least three months; f) express availability to participate in the study by signing the “informed consent”; g) the dependent person has a diagnosis of dementia, cognitive problems or other physical and/or mental disability. We obtained a convenience, accidental, non-probabilistic sample. The final sample characteristics (189 informal caregivers) are listed in Table 1.

marital status, employment status, relationship, type of caregiver, the number of people who provides care, duration and time spent caring), psychosocial (kind of emotional relationship with the beneficiary of the current care, kind of support they receive, type of health surveillance) and clinical (medical history, psychiatric history) to characterize the informal caregiver. As for the characterization of the care receiver (Table 2), sociodemographic (sex, age, and education) and clinical (the type of dependence, type of dementia, and stage of dementia) information were collected.

Table 2 Continued...

	N	%	M	Mode	Median	Min	Max	SD
Type of dementia								
Vascular	28	14,8						
Alzheimer	92	48,7						
Frontotemporal	3	1,6						
Mixed	3	1,6						
Lewis Bodies	1	0,5						
Another	59	31,2						
Stage dementia								
Light	53	28,0						
Moderate	79	41,8						
Serious	42	22,2						

Legend: M (Mean); SD (Standard Deviation).

QCC - Corresponds to the Portuguese version of the CGQ. It consists of 22 items that enumerate a list of feelings and thoughts to assess the guilt emotion centered in recent weeks.

ESC - Scale translated and validated in Portugal by Carlos Sequeira (2010), based on the Burden Interview Scale of Zarit. This scale supports an internal consistency of $\alpha = 0.82$ (Cronbach's alpha). Evaluate the objective and subjective burden of informal care and contains information about: health, social life, personal life, financial situation, emotional situation, and type of relationship.

CASI - Carers Assessment of Satisfaction Index validated by Carlos Sequeira (2010) in Portugal. This instrument had an internal consistency of $\alpha = 0.92$ (Cronbach's alpha). It is an index of 30 potential sources of satisfaction, that is, a set of 30 items with positive aspects related to the care and which are recognized by the caregiver as a source of satisfaction.

HADS - Hospital Anxiety and Depression Scale, translated and validated by Pais-Ribeiro et al.⁶ for the Portuguese population. It analyzes anxiety and depression in people with physical pathologies and in outpatient treatment, as well as in non-psychiatric populations. This scale had an internal consistency of $\alpha = 0.76$ (Cronbach's alpha).

Procedure

Potential participants were previously identified and addressed by the staff of the institutions to know about their availability to participate in the study. Then, they were contacted personally for scheduling the interview. To emphasize that all instruments used in the data collection were used with the permission of their respective authors. Furthermore, the data collection was carried out by the principal investigator and the research staff.

Statistical analysis

Data analysis was carried out using IBM SPSS Statistics 22.0 version. We used the descriptive and inferential statistics of the data. Pearson's correlation test was used to analyze the strength of the association between continuous variables. The values of r were read as follows: weak correlations $r \leq 0.2$; moderate correlations $0.2 < r \leq 0.4$, and strong correlations $0.4 < r \leq 0.6$.⁷ However, to examine the variance of means between two independent continuous variables, we used the Student t-test for independent samples. The SPSS computer application of the Student t-test automatically performs the Levene test to check the homogeneity of variances.

The calculation of fidelity, that is, the degree of confidence and accuracy we have in the information obtained, was divided into the analysis of stability (test-retest) and the analysis of internal consistency, using Cronbach's alpha coefficient.⁷

Cronbach's alpha was obtained by averaging the intercorrelations between all items on the scale. For good internal consistency, the alpha value must be greater than 0.80. However, values greater than 0.60 are acceptable when the scales have a reduced number of items.⁷ In the analysis of the main components, we use orthogonal rotation according to the Varimax method, where independent factors are obtained to approximate items and factors and make it easier to interpret the factors in the QCC, moving from the statistical domain to the domain of the evaluated behaviors that can be grouped into common underlying dimensions.⁷

In proving the number of factors, we obey the following criteria: (1) eigen-value > 1; (2) exclusion of factorial loads < 0.40; and (3) each factor must explain at least 5% of the variance.

As for the size of the statistical sample (N) for the exploratory factor analysis, we consider the proportion of participants for the items to be analyzed (P), as Kline⁷ recommends, that is, a minimum of 5:1 N:P.

The averages of guilt (factors) between some sub-samples were compared to inspect the sensitivity of the questionnaire under study.

The content validity of the QCC was assessed by an expert panel of tree intentionally selected nursing experts who were not directly involved in the research process. The criteria for choosing those professionals were: (a) being specialized in mental health nursing; (b) holding a Ph.D. degree. The experts reached consensus.

The concomitant validity will be ensured by comparing the results of the QCC with the results of the ESC "interpersonal relationship" factor, which measures similar parameters. The "Interpersonal relationship" factor is composed of five items, which reflect the implications for the relationship between the caregiver and the dependent elderly (shame, irritation, tension, etc.) Sequeira⁸ that is, having the guilt problem as an underlying issue.

One of the methods used to assess the construct validity is the factor analysis of the items and the results of the QCC, where it starts from the intercorrelations between the items or between the results to name the general and/or distinct components that can explain the common variance found in them.⁷ Another method used to ensure construct validity is the analysis of convergent and discriminant validity. That is, in convergent validity, the QCC must correlate significantly with other variables with which the construct is measured, according to the theory it is related for example, with the variables overload, depression, and anxiety (Idem). Hence, we used ESC and HADS to collect data.

As for the discriminant validity, the QCC should not be correlated with other variables with which the construct should differ, in

theoretical terms, for example, guilt and satisfaction of the caregiver (Idem). Thus, the application of CASI in data collection is justified. In general, for the analysis of the metric properties of the QCC we follow the procedures of the authors, that is, we focus on the evaluation of the parameters that were also measured in the study of construction and validation of the CGQ in Spain,³ as well as in the other validation study carried out in a British sample.⁵

Results

Participants' characteristics

The sample is constituted by 189 participants, 145 informal female, and 44 (23.3%) male caregivers. The analysis of Table 1 shows that female predominates with 76.7%. It appears that the mean age of informal caregivers in the study is 54.47 years, with a minimum age of 21 years and a maximum age of 90 years and a standard deviation of 12.77 years. The mean number of years of school of the informal caregivers in the sample is 8.86 years, with a mode of 12 years, that is, the answer is most often described in a 0-24 amplitude. Nine cases did not respond. There is a predominance of married, informal caregivers, corresponding to 68.3% of the total sample. Next are the "single" and "divorced" marital statuses (14.8% and 7.4%, respectively). In the professional context, there is a predominance of informal caregivers who are employed (43.4%), followed by informal caregivers retired

by age (19.0%) and informal unemployed caregivers (15.9%). Of the 189 informal caregivers, 107 (56.6%) reported not having any support, 22 (11.6%) reported having informal support, and six (3.2%) mentioned having instrumental support.

Regarding the gender of the care receivers, most of them are female, 58.7% (n = 111), and 41.3% (n = 78) are male. About the type of dependency of care receivers, 117 are physically and mentally dependent (61.9%), and 30 are mentally dependent (15.9%). As for the type of dementia, we found that the majority had a medical diagnosis of Alzheimer's dementia, corresponding to 48.7% (n = 92) of the sample. Then 31.2% (n = 59) does not specify the type of dementia and vascular dementia has a percentage of 14.8% (n = 28). Concerning the dementia stage, care receivers are in a moderate stage (41.8%, n = 79), 28% (n = 53) are in a mild stage, and 22.2% (n = 42) are in the low stage of condition's development. In this sample the specificity in QCC is 7% and positive predictive values of QCC 15%.

Construct validity

The final QCC is detailed in the Supplementary Material. In Table 3, we present the factors loadings of the items obtained in the QCC with participants of the study (N = 189). In the principal components analysis with orthogonal rotation by varimax method and reversal of item six proposed by Losada et al.³ This factor stands out conceptually, explaining 36.4% of the total variance.

Table 3 Factor loadings of QCC items*

Items	Content	Factor loading
1	I have felt bad about having made some plan or done some activity without taking my relative into account.	0,57
2	I have felt guilty about the way I've sometimes behaved with my relative.	0,61
3	I have felt bad for not looking after my other relatives (husband, wife, children) as I should, due to my caregiving	0,89
4	I have felt bad about not being able to devote more time to my family (husband, wife, children), due to my caregiving.	0,86
5	I have thought that I'm not doing things right with the person I'm caring for.	0,56
6	I have thought that, given the circumstances, I'm doing a good job as a caregiver.	0,41
7	When I've gone out to do some pleasant activity (e.g. eating out in a restaurant), I've felt guilty and unable to stop thinking that I should be caring for my relative.	0,56
8	I have felt bad about things I may have done wrong with the person I'm caring for my relative.	0,66
9	I have thought that perhaps I'm not caring well for my relative.	0,65
10	I have felt bad about getting angry with the person I'm caring for.	0,75
11	I have felt bad about telling off the person I'm caring for, for some reason.	0,73
12	I've got angry with myself for having negative feelings toward the person I'm caring for.	0,51
13	I've found myself thinking that I'm not up to the job.	0,64
14	I have felt bad about not having more patience with the person I'm caring for.	0,62
15	I have felt bad about leaving my relative in the care of someone else while I do my own things (e.g. work, shopping, going to the doctor).	0,64
16	I have felt bad for leaving my relative in the care of someone else while I had fun.	0,39
17	I have felt guilty about having wished that others "could have this burden" or suffer as I do.	0,70
18	I have felt like a bad person for hating and/or envying other relatives who could have taken responsibility for some caring and do not do so.	0,72
19	I have felt bad for having negative feelings (e.g., hate, anger or resentment) toward some relatives.	0,70
20	I have felt guilty about having so many negative emotions in relation to caring.	0,61
21	I have thought that the way I care for my relative may not be appropriate and may make his/her problem get worse.	0,64
22	I have felt guilty thinking that my lack of information and preparedness might mean that I'm not handling the care of my relative in the best way possible.	0,64
Eigenvalue: 7,65		
Variance explained: 36,4%		

*Analysis of key factors after Varimax rotation.

Item 16 shows a factorial load (<0.40), so we decided to remove it in accordance with the criteria established by Losada et al.³ The remaining QCC items have saturation values ≥ 0.40, resulting in a

QCC with 21 items. We obtained five factors with eigenvalues > 1 that explain 65.8% of the results, as shown in Table 4. This result overlaps with previous studies by Losada et al.³ and by Roach et al.⁵

Table 4 Factorial load of items per factor in QCC*

Items	Factors				
	1	2	3	4	5
5	0,69				
8	0,57				0,48
9	0,73				
13	0,75				
21	0,68				
22	0,74				
17		0,76			
18		0,85			
19		0,80			
20		0,50			
6		0,83	0,59		
10			0,73		
11			0,76		
12			0,48		
14			0,62		
1	0,65			0,69	
2				0,50	
7				0,65	
15				0,52	
3					0,93
4					0,89
Eigenvalue	7,65	1,91	1,69	1,43	1,13
Variance (total 65,8%)	36,4	9,11	8,05	6,84	5,39
Alpha de Cronbach (QCC Global 0,90)	0,85	0,83	0,78	0,69	0,89

*With orthogonal rotation by the Varimax method.

The factor analysis (Table 4) shows that most of the items saturate in different subscales in comparison with those described by the authors except for the fifth factor, which contains the two items of the original questionnaire. The first factor includes six items for the caregivers' performance and reflects feelings of the possibility of doing something wrong while providing care. We call this factor "guilt by performance in providing care," and it includes items 5,8,9,13,21,22.

The second factor includes four items concerning negative feelings that can be caused by the burden of care when the carer has to assume certain responsibilities that could have also taken over by another family member. We designate this factor of "guilt by negligence of other family members. It corresponds to the two-factor, and it agglomerates items 17,18,19 and 20, scored positively.

The third factor comprises five items related to negative feelings that caregivers experience during care of a dependent family member. The third factor contains items 6,10,11,12,14 and is designated "guilt over negative feelings during care."

The fourth factor includes four items that express feelings the caregiver experiences when care is interrupted for any reason. The fourth factor is constituted by items 1, 2, 7, and 15 and is called "Guilt by absences during care."

The fifth factor is constituted by two items, and it reflects negative feelings of the caregivers associated with the inability to dedicate the time they would like to devote to the other family. The fifth factor gathers items 3 and 4, and we call it by its original name3 because the items match, i.e., "guilt about self-care."

In Table 5, we verify that item six of the QCC saturates in factors two and three. However, after analyzing the semantic content of item six and considering the convergent analysis/discriminant of the items, we have decided to keep this item within factor three. We found that this item presents $r = 0.27$ (moderate correlation $0.2 < r < 0.4$) with three factors and lower values on other factors and a global scale.

Overall, we ascertained that the highest values of the Pearson Correlation r are located between the item and the factor to which they belong. We can say that, despite the moderate discriminatory capacity, the items are distributed by factors whose content is added to the QCC attributes. Therefore, the name of each factor corresponds to the measured guilt feeling attribute.

The association of the factors and the QCC (Global questionnaire) was determined by correlation. The results of such interaction are exposed in Table 6.

The factors that best explain the caregiver’s guilt are factor one “guilt by performance in providing care” and four “guilt by absences during care.” The guilt in informal caregivers evaluated by the QCC is explained in 60.8% by “guilt over performance in providing care and guilt over absences during care.”

Table 5 Correlation of items with the factors and overall questionnaire QCC (corrected for overlap)

Items	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Total
5	0,55	0,22	-0,27	0,39	0,20	0,45
8	0,65	0,33	-0,30	0,56	0,17	0,63
9	0,71	0,38	-0,28	0,46	0,13	0,62
13	0,65	0,39	-0,27	0,34	0,13	0,58
21	0,66	0,43	-0,33	0,45	0,12	0,63
22	0,63	0,36	-0,19	0,34	0,16	0,55
17	0,41	0,67	-21	0,44	0,16	0,57
18	0,30	0,62	-0,16	0,39	0,22	0,50
19	0,31	0,75	-0,09	0,39	0,27	0,52
20	0,51	0,55	-0,06	0,49	0,24	0,68
6	0,12	0,16	0,27	0,02	-0,02	0,16
10	0,49	0,36	0,69	0,49	0,19	0,62
11	0,48	0,40	0,61	0,43	0,14	0,61
12	0,47	0,52	0,51	0,43	0,27	0,61
14	0,51	0,49	0,63	0,43	0,23	0,65
1	0,34	0,39	-0,13	0,50	0,19	0,46
2	0,34	0,24	-0,02	0,36	0,38	0,47
7	0,41	0,32	-0,37	0,52	0,28	0,49
15	0,49	0,52	-0,36	0,52	0,14	0,59
3	0,15	0,23	0,07	0,27	0,81	0,32
4	0,23	0,29	-0,04	0,37	0,81	0,40

Table 6 Correlation between the factors and the QCC

QCC	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Global QCC	0,78**	0,74**	-0,10	0,78**	0,54**
Factor 1 – Guilt by performance in providing care		0,45**	-0,36**	0,55**	0,20**
Factor 2 – Guilt by negligence of other family members			-0,16*	0,51**	0,27**
Factor 3 – Guilt for negative feelings during care				-0,32	0,01
Factor 4 – Guilt by absences during care					0,34**
Factor 5 – Guilt about self-care					

** p<0,01; *p<0,05

Reliability

Table 7 shows the values of internal consistency (using Cronbach’s alpha) of each factor and the value of alpha if the item was deleted (The item with the highest internal consistency value is in bold when deleted). In factor three, the alpha value of the factor increased to 0.83 when item six was withdrawn. We chose to keep factor three and assume a Cronbach’s alpha $\alpha = 0.75$. The internal consistency index measured by Cronbach’s alpha in the globality of the questionnaire and in three factors of the Portuguese study sample is very good (Factor 1 $\alpha = 0.85$; Factor 2 $\alpha = 0.83$, Factor 5 $\alpha = 0.89$, Global QCC $\alpha = 0.90$). Concerning the internal consistency indexes of the factors 3 and 4, our overall impression is that it is acceptable (Factor 3 $\alpha = 0.78$; Factor 4 $\alpha = 0.69$). The internal consistency obtained in the Global QCC in the Portuguese sample does not differ much from previous studies, i.e., $\alpha = 0.88$ in the study Losada et al.³ and $\alpha = 0.93$ in the study by Roach et al.⁵

Stability of the results

In order to inspect the stability and consistency of the results, we used the method of test-retest to examine how the QCC evaluates when applied at two different times to the same subject. As shown in Table 8, there is a very strong and significant positive correlation between the QCC factors and the global questionnaire in the test and retest, except in factor 3 ($r=25$, $p= 0.36$). In Table 9, we present the internal consistency of the global questionnaire and each of the QCC

factors obtained in the test sample. As can be seen, the Cronbach alpha values in the test and retest go from 0.69 to 0.90, and from 0.77 to 0.95, respectively. These values indicate good internal consistency.⁷

Criterion validity

We found a moderate association between the caregiver guilt, anxiety, and depression assessed by global scales $r(189) = 0.41$, $p < 0.01$. The association of the factors alternates between moderate to weak. These values may indicate that there are no overlapping constructs assessed by the two psychometric instruments. Informal caregivers with high scores in the CQQ are associated with equally high scores in the HADS. For example, where anxiety is ($r(189) = 0.35$, $p < 0.01$), depression is ($r(189) = 0.41$, $p < 0.01$). We evaluated the convergent validity by correlating the QCC factors and the global questionnaire, and the factors “Impact of providing care -IPC” and “Interpersonal Relation -RI “ of the ESC. We realized that there is a moderate positive correlation between the IPC and the RI factors of ESC and the QCC factors and the global questionnaire, except for the case of factors three “Guilt over negative feelings during care” and five “Guilt about self-care.” The Global QCC and the IPC factor of ESC show a significant positive correlation ($r(189) = 0.67$, $p < 0.0001$). Thus, we concluded that informal caregivers of people with physical and/or mental dependency that show high results in the QCC also have high results in the IPC factor. That is, there is an overlapping of the constructs assessed by the two psychometric instruments.

Table 7 Internal consistency values of CQC (through Cronbach's alpha)

Factor/Item	Cronbach Alpha of each factor	Cronbach Alpha factor if item deleted
FACTOR 1 – Guilt by performance in providing care	5- I have thought that I'm not doing things right with the person I'm caring for.	0,85
	8- I have felt bad about things I may have done wrong with the person I'm caring for my relative.	0,82
	9- I have thought that perhaps I'm not caring well for my relative.	0,81
	13- I've found myself thinking that I'm not up to the job.	0,82
	21- I have thought that the way I care for my relative may not be appropriate and may make his/her problem get worse.	0,85
	22- I have felt guilty thinking that my lack of information and preparedness might mean that I'm not handling the care of my relative in the best way possible.	0,82
FACTOR 2 – Guilt by negligence of other family members	17 - I have felt guilty about having wished that others “could have this burden” or suffer as I do.	0,79
	18- I have felt like a bad person for hating and/or envying other relatives who could have taken responsibility for some caring and do not do so.	0,77
	19- I have felt bad for having negative feelings (e.g., hate, anger or resentment) toward some relatives.	0,83
	20- I have felt guilty about having so many negative emotions in relation to caring.	0,84
FACTOR 3 – Guilt for negative feelings during care	6- I have thought that, given the circumstances, I'm doing a good job as a caregiver.	0,83
	10- I have felt bad about getting angry with the person I'm caring for.	0,68
	11- I have felt bad about telling off the person I'm caring for, for some reason.	0,68
	12- I've got angry with myself for having negative feelings toward the person I'm caring for.	0,75
	14- I have felt bad about not having more patience with the person I'm caring for.	0,71
FACTOR 4 – Guilt by absences during care	1- I have felt bad about having made some plan or done some activity without taking my relative into account.	0,61
	2- I have felt guilty about the way I've sometimes behaved with my relative.	0,69
	7- When I've gone out to do some pleasant activity (e.g. eating out in a restaurant), I've felt guilty and unable to stop thinking that I should be caring for my relative.	0,69
	15- I have felt bad about leaving my relative in the care of someone else while I do my own things (e.g. work, shopping, going to the doctor).	0,59
FACTOR 5 – Guilt about self-care	3- I have felt bad for not looking after my other relatives (husband, wife, children) as I should, due to my caregiving.	-
	4- I have felt bad about not being able to devote more time to my family (husband, wife, children), due to my caregiving.	0,89

Table 8 Correlation between the results of the questionnaire and QCC factors in test-retest evidence

		1ª Review (N= 189)					
		QCC Global	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
2ª Review (N=27)	Global QCC	0,97**					
	Factor 1		0,94**				
	Factor 2			0,99**			
	Factor 3				0,36		
	Factor 4					0,98**	
	Factor 5						0,93**

** p<0,0001

Table 9 Internal consistency of QCC factors in the sample test and retest

		CRONBACH ALPHA	
QCC	Item No.	Sample (test) N=189	Sample (Retest) N=27
Factor 1	6	0,85	0,89
Factor 2	4	0,83	0,95
Factor 3	5	0,78	0,79
Factor 4	4	0,69	0,77
Factor 5	2	0,89	0,90
Global QCC	21	0,90	0,94

We evaluated the divergent validity by correlating the QCC factors and the overall questionnaire with the factors of CASI. As expected, we found that, in general, there is a weak negative correlation. The Global QCC and the “Caregiver Role Performance - DPC” factor of CASI have a weak negative correlation ($r(189) = -0.27, p < 0.0001$). Therefore, the informal caregivers of people with physical and/or mental dependency that show high results in QCC have low results in the DPC factor of CASI. To support the association between guilt, anxiety, depression, burden, and satisfaction in caregivers, we operationalized the Pearson Correlation among two groups of elements, i.e., the QCC and the QCC factors, on the one side, and the HADS, ESC, and CASI, on the other side. We found a strong association in caregivers between guilt in caregivers and burden, assessed by global scales $r(189) = 0.64, p < 0.0001$; a moderate correlation between the presence of guilt and the presence of anxiety ($r(189) = 0.35, p < 0.0001$) and depression ($r(189) = 0.41, p < 0.0001$); and a moderate negative correlation among guilt and caregiver satisfaction ($r(189) = -0.28, p < 0.0001$).

Associations between the QCC and sociodemographic variables

We analyzed the relationship between the QCC and the sociodemographic variables using the Student t-test for independent samples. We found statistically significant differences between the sex of the informal caregivers and the results of the factor “guilt for negative feelings during care” QCC ($t(187) = -2.68, p = 0.008$). So, on average, informal female caregivers experience more guilt during care ($M = 5.48, SD = 4.00$) compared to males ($M = 3.63, SD = 3.97$).

Concerning the marital status of informal caregivers, we decided to regroup the participants as single and double. We verified that there are statistically significant differences between the marital status and the factor “Guilt by negligence of other family members” ($t(143.860) = -2.17, p = 0.03$). On average, informal caregivers living in a *double* system (married, non-marital partnership) referred more guilt during care ($M = 2.70, SD = 3.36$) compared to *single* (single, divorced, separated and widowers) ($M = 1.79, SD = 2.20$).

We verified that there are statistically significant differences between the past medical history and the guilt categorized by the factor “Guilt by performance in providing care” ($t(175) = 2.22, p =$

0.028). On average, informal caregivers without medical past history experience more guilt during care ($M = 6.48, SD = 4.48$) compared to informal caregivers with medical history ($M = 4.90, SD = 4.90$).

Discussion

Health professionals strengthen their diagnoses and interventions by applying instruments to evaluate specific characteristics or behaviors that are difficult to measure, particularly in mental health and psychiatry. In this study, we highlight the technical and relational skills that are needed to build psychometric instruments based on theoretical knowledge. We refer especially to the skills of nurses who specialized in mental health and psychiatry. Specifically, we propose the translation, adaptation, and validation of the CGQ, a psychometric instrument built by psychologists, which has been used previously in other countries.

Thus, it is noted that the use of psychometric instruments, specifically of the QCC, is not exclusive to a single professional class. It becomes an asset for the many health professionals that are part of the multidisciplinary teams with which the informal caregiver interacts.

However, health professionals must be fully aware of the characteristics of this instrument and must base its use on solid theoretical knowledge of its validity, fidelity, and clinical sensitivity.

The high values obtained by r correlation test of Pearson between the results of the QCC and the factors suggest that the caregiver guilt is a homogeneous concept, characterized by five dimensions that reflect the various facets of guilt without being redundant.

Concerning the internal consistency of the questionnaire, we obtained results on the global scale that show good fidelity (0.90) for the test and the test-retest (0.94), according to Kline.⁷ The Global Cronbach’s alpha value identified in this study is slightly higher compared to those found by Losada³ in Spain (0.88), and slightly less than that found by Roach et al.⁵ in a British sample (0.93). We also found reasonable levels of internal consistency in all the QCC factors.

In the study of the QCC fidelity, the results achieved have given good stability to the questionnaire, showing correlation values in the test-retest proof > 0.80, except for the factor “Guilt for negative

feelings during care.” The results showed good internal consistency by Cronbach alpha with values that go from 0.77 to 0.95. In studies conducted by Losada et al.³ and Roach et al.,⁵ no test-retest was carried out, and the authors noted this fact as a limitation that we have attempted to overcome in this study.

We found a moderate positive association between caregiver guilt, anxiety, and depression assessed by global scales. In other words, dementia caregivers with high scores in the QCC are also associated with high scores in the HADS, such as anxiety and depression. These values are similar to those found by Losada et al.³ and corroborated by recent literature, as Hopkinson et al.⁴ tell us when considering anxiety and depression one of the current problems in caregivers of dependent people.

In convergent-discriminant validity of the items, we found moderate discriminative power of the items in the factors. Regarding the discriminant validity using the correlation between the QCC and the CASI factors, it was found that overall and as expected, there is a weak negative correlation, since both psychometric instruments evaluate different things. Losada et al.³ also obtained similar results concerning the determination of divergent validity.

The study sample consisted of 189 participants, 145 female, and 44 (23.3%) male informal caregivers. That is, most of the caregivers are female, as corroborated in the study conducted previously by the original author of the CGQ in Spain³ and Roach et al.⁵ in Great Britain.

Unlike previous studies and even though our sample consists mainly of primary informal caregivers, i.e., 159 (84.1%), we also included informal non-primary caregivers in the study to determine if they also verbalize feelings of guilt. The objective of this inclusion was to provide some information on this type of caregivers because the literature available on non-primary caregivers, i.e., people who care occasionally, is scarce. We did not find significant differences between primary and non-primary caregivers in our sample or the overall QCC. Therefore, guilt is not unique to primary caregivers, but it is inherent to those who simply care. This fact is important for many health professionals not to overlook secondary caregivers who also go through a transition process during care and can be targeted for intervention.

However, there are significant differences between the primary caregiver and the guilt associated with the factor “guilt about self-care.” On average, primary care providers report more guilt during care compared to non-primary caregivers.

We found statistically significant differences between the sex of the informal caregivers and the results of the factor “Guilt for negative feelings during care” in the QCC. Losada et al.³ and Roach et al.⁵ found similar results in their studies where female caregivers showed significant differences in some factors and the global questionnaire. These results must inevitably be framed in the culture where caregivers are inserted. We observed that female informal caregivers seem to show greater guilt than the male, in the global QCC, and in the factors “Guilt by negligence feelings during care,” “Guilt for negative feelings during care,” and “Guilt by absences during care.” However, the differences observed were not statistically significant.

We found statistically significant differences between the marital status and the guilt factor “Guilt by negligence of other family members” where informal caregivers living in a double regime (married, non-marital partnership) refer, on average, greater guilt during care compared to those living in a single system. We also confirmed there were no statistically significant differences between

the presence or absence of psychiatric history and guilt in informal caregivers evaluated by the QCC.

Given the transversal character of this study, the self-perception of guilt throughout the care process can be influenced by several factors. Nevertheless, it should be noted that the questionnaire serves as a device of self-awareness of guilt for caregivers. So, the benefit in its application should always be considered by the health professional.

Limitations

The nature of the study we conducted was based on a sample consisting of non-random sampling. This alone is a limitation in terms of representativeness and, consequently, a constraint to the generalization of the results which do not have external validity. The study carried out has a transversal character. So, several factors can influence the self-perception of feelings of guilt throughout the care process. The fact that we carried out a methodological study means that many questions could be explored in future studies to better understand the essence of guilt in the care process. Some of the aspects that can be addressed are, for example, the relationship of guilt and the spirituality of informal caregivers, and the relationship between guilt and family intervention approaches by the nurse specializing in mental health and psychiatry. Portuguese studies on guilt in dementia caregivers are scarce. In this study, only an exploratory factor analysis was performed.

Conclusion

The QCC measures the feelings of guilt in dementia caregivers. We found that QCC is an instrument with good sensitivity and stability. It is reliable and simple to use for recognizing feelings of guilt in informal caregivers in the Portuguese population. The QCC also has good convergent and discriminant validity. Our results show that most of the Portuguese population investigated in our sample have feelings of guilt. As the largest professional group in the health field in Portugal, nurses are an essential resource in promoting mental health, not least because the responsibility of caring for a person with physical and/or mental dependence, namely people with dementia, calls upon a further research on the indicators of physical, social and emotional overload for caregivers and the restricted effects on their personal life.⁹ Thus, understanding the concept of guilt and its relationship with the presence of burden, depression, and anxiety in dementia caregivers has proved to be essential.^{10,11}

Key points for policy, practice and/or research

- I. This study contributed to provide an effective psychometric instrument for Portuguese mental health professionals can measure and identify the different dimensions of guilt, through a correct diagnosis and interventions adjusted to each case.
- II. The use of a properly validated psychometric instrument to assess guilt, allows objectifying a theme such as emotions, which in itself is subjective.
- III. In future, assess guilt contributes to better mental nursing cares and to compare values between Spain, Great Britain and Portugal in this area.
- IV. Targeting caregivers’ guilt and the associated maladaptive cognitions and behaviors via early interventions to improve their care [Appendix](#).

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Conflicts of interest

The author declares there is no conflict of interest.

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