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RESEARCH ARTICLE (ORIGINAL)



Enhancing accuracy: The optimal cutoff point of the Informal Caregiver Burden Assessment Questionnaire

Melhorando a exatidão: O ponto de corte ideal do Questionário de Avaliação da Sobrecarga do Cuidador Informal

Mejorar la precisión: Punto de corte ideal para el Cuestionario de Evaluación de la Sobrecarga del Cuidador Informal

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Abstract

Background: The cutoff point of an instrument is a valuable clinical reference.

Objective: To study the cutoff point of the Informal Caregiver Burden Assessment Questionnaire (QASCI).

Methodology: A methodological cross-sectional study was conducted using secondary data analysis. The predictive validity of the instrument was assessed by measuring sensitivity and specificity, positive and negative predictive values, and the area under the ROC curve (AUC). The Portuguese versions of the Medical Outcomes Study 36-Item Short Form Survey Instrument (MOS SF36) and the Hospital Anxiety and Depression Scale (HADS) were used.

Results: Caregivers exhibited elevated levels of anxiety and depression. The cutoff point 40 yielded the highest Youden Index score (0.59), indicating that the model has an 84% accuracy for predicting anxiety and depression disorders. In addition, the model demonstrated a sensitivity of 78% and a specificity of 81%.

Conclusion: This study demonstrates that the QASCI effectively identifies caregivers at risk of anxiety and depression disorders and can inform interventions to enhance their mental health.

Keywords: caregivers; family; validation studies; psychometrics

Resumo

Enquadramento: O ponto de corte de um instrumento constitui uma referência clínica de grande valor. **Objetivo:** Estudar o ponto de corte ideal do Questionário de Avaliação da Sobrecarga do Cuidador Informal (QASCI).

Metodologia: Realizou-se um estudo metodológico transversal com recurso à análise secundária de dados. A validade preditiva do instrumento foi avaliada através da medição da sensibilidade e especificidade, dos valores preditivos positivos e negativos e do índice da área abaixo da curva (AUC) ROC. Foram utilizadas as versões portuguesas *do Medical Outcomes Study 36-Item Short Form Survey Instrumen*t e da *Hospital Anxiety and Depression Scale*.

Resultados: Os cuidadores revelaram níveis elevados de ansiedade e depressão. O ponto de corte 40 obteve o índice de Youden mais elevado (0,59), indicando que o modelo analisado possui uma exatidão de 84% na previsão de transtornos de ansiedade e depressão. O modelo demonstrou ainda possuir uma sensibilidade de 78% e uma especificidade de 81%.

Conclusão: O presente estudo comprova que o QASCI identifica eficazmente os cuidadores em risco de desenvolver transtornos de ansiedade e depressão e pode servir de base a intervenções destinadas a melhorar a sua saúde mental.

Palavras-chave: cuidadores; família; estudos de validação; psicométricos

Resumen

Marco contextual: El punto de corte de un instrumento es una referencia valiosa en la práctica clínica. **Objetivo:** Estudiar el punto de corte del Cuestionario de Evaluación de la Sobrecarga del Cuidador Informal (QASCI).

Metodología: Se realizó un estudio metodológico transversal con análisis secundario de datos. La validez predictiva se evaluó mediante la sensibilidad y la especificidad, los valores predictivos positivo y negativo, y el área ROC con la curva (AUC). Se utilizaron la escala de calidad de vida SF36 y la Escala Hospitalaria de Ansiedad y Depresión.

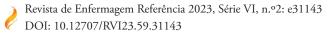
Resultados: Los cuidadores presentan puntuaciones elevadas de ansiedad y depresión. El Índice de Youden máximo (0,59) proporcionó un punto de corte de 40, lo que confirmó que la predicción de los trastornos de ansiedad y depresión mediante este modelo tenía una precisión del 84%. Además, el modelo mostró una sensibilidad del 78% y una especificidad del 81%.

Conclusión: Los resultados de este estudio sugieren que el QASCI es una herramienta valiosa para identificar a los cuidadores en riesgo de trastorno de ansiedad y depresión, y puede orientar las intervenciones para mejorar su salud mental.

Palabras clave: cuidadores; familia; estudios de validación; psicométricos

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Introduction

Measurement instruments offer an objective and structured approach to assessing health conditions. They help standardize evaluations and provide measurable data to aid in clinical decision-making. The quality and usefulness of a measurement instrument are determined by its validity, reliability, and sensitivity. Validity ensures that the instrument measures what it is intended to assess, while reliability guarantees consistent results over time and across different contexts (Borsboom et al., 2004; Nawi et al., 2020; Souza et al., 2017). The sensitivity of an instrument is also crucial for identifying changes in the conditions being analyzed, making it more effective in the early detection of symptoms or health problems (Souza et al., 2017).

Background

Caregiver burden is defined as the strain experienced by someone who cares for a chronically ill, disabled, or older dependent person (Liu et al., 2020) and refers to the persistent difficulties, stress, or negative experiences resulting from physical, emotional, social, and financial strain associated with unpaid care.

Caregivers are constantly concerned, experience a reduction in positive social interactions, and face conflicts associated with their family and social roles. They also struggle with the lack of support from health services, which can contribute to developing anxiety and other emotional and intrapsychic disorders. Furthermore, the constant demands of caregiving can lead to chronic stress and contribute to the onset of depressive symptoms. Anxiety and depression emerge as two of the most extensively studied outcomes among caregivers, manifesting as consequences of the caregiver burden (Imanian & Ramezanli, 2022; Lindt et al., 2020; Martins et al., 2003, 2004).

The role of family caregivers is crucial in modern societies as most older adults prefer to receive care at home. This allows them to benefit from comfort, safety, and social/ family ties, which are vital to their emotional and mental well-being (Hazzan et al., 2022). Therefore, health policies should prioritize the protection and support of family caregivers so they can perform their role efficiently. Nurses play a pivotal role in training and educating caregivers on care provision, injury prevention, use of supportive equipment, and medication administration (Yu et al., 2019). Additionally, nurses provide caregivers with information on the available community resources, such as emotional support, counseling, and health services. Nurses can also assist caregivers in identifying symptoms of potential complications, adopting preventive measures, or seeking appropriate treatment. By empowering informal caregivers, nurses enhance patient care quality, reduce caregiver stress and burden, and promote care safety while preventing medication errors or other adverse events.

The use of measurement instruments in nurses' daily practice within this context is considered crucial as it enables them to understand the actual needs of caregivers and guides them in implementing effective interventions to reduce/ prevent caregiver burden (Souza et al., 2017). Such instruments may also be helpful for other members of the health team. The Informal Caregiver Burden Assessment Questionnaire (QASCI) was developed based on the premise that the consequences of caregiving result from a complex network of positive and negative factors that tend to balance each other. However, when the situation persists over time, and the caregiver's internal resources become depleted, it can lead to adverse outcomes and compromise the caregiver's well-being and health status (Martins et al., 2003, 2004). The QASCI has been used to evaluate caregivers in Portugal and has demonstrated good psychometric characteristics. However, until this study was conducted, the values that identify caregivers at higher risk of anxiety and depression were unknown. Hence, the present study aimed to examine the cutoff points of the QASCI.

Research Question

Will the QASCI be an effective tool to identify family caregivers at risk of depression? At what threshold does this risk become more evident?

Methodology

Study Design and Procedure

A cross-sectional study was conducted using secondary data analysis with a sample of 148 participants. The primary data were extracted from studies conducted with caregivers (França et al., 2022; Peixoto, 2016) in the North of Portugal over the past few years.

The inclusion criteria for all primary studies were to be a family caregiver of a dependent person in self-care for at least six months, provide informed consent, and have no communication difficulties or significant cognitive impairment that would interfere with understanding the assessment questionnaires. One of the primary studies was conducted in a home setting with caregivers (n = 124) of individuals who had been hospitalized due to an acute illness or accident that affected their ability to self-care (Peixoto, 2016). This study focused on resilience, stress, adjustment, and family adaptation. França et al. (2022) analyzed the nursing documentation from two family health units in Porto to assess family caregivers' perceptions of the difficulties experienced, health, and quality of life (n = 24). The choice to use anxiety and depression as the basis for determining the cutoff points of the QASCI was due to the caregiver burden being repeatedly expressed through these symptoms (Imanian & Ramezanli, 2022; Lindt et al., 2020). The Medical Outcomes Study 36-Item Short Form Survey Instrument (MOS SF36) developed by Ware and Sherbourne is frequently used in clinical research and epidemiological studies to assess an individual's health-related quality of life. This measure provides a comprehensive assessment of the influence of health on individuals' lives, encompassing physical,



emotional, and social aspects (Ferreira, 2000a, 2000b). The present study applied the Portuguese version of the MOS SF36 to examine convergent validity.

Data on caregiver burden were assessed using the QASCI. Anxiety and depression indicators were evaluated using the Portuguese version of the Hospital Anxiety and Depression Scale (HADS), originally developed by Zigmond and Snaith. The study used the Portuguese version of the MOS SF36 to assess the data on quality of life. All instruments were selected from the original databases. The study also examined variables such as age, sex, marital status, education, having or not having informal care support, living or not living with the dependent family member, and the caregiver's perception of the dependent member's health status.

Measures

The QASCI originally consisted of 32 items, evaluated using an ordinal frequency scale ranging from 1 - 5 (Martins et al., 2003, 2004). It includes seven subscales: "implications for the caregiver's personal life" (11 items); "satisfaction with the role and the family member" (5 items); "reactions to demands" (5 items); "emotional burden imposed by the family member" (4 items); "family support" (2 items); "financial burden" (2 items) and "perception of efficacy and control mechanisms" (3 items). Higher scores correspond to greater caregiver burden in the first four subscales. In comparison, higher scores in the last three subscales indicate greater family support, self-efficacy, and satisfaction with the caregiver role. During the instrument rating procedure, the scores of each of the subscales were converted into a 0-100 scale. The global score of the scale is calculated by averaging the seven subscales. It is worth noting that the last three subscales were reversed to ensure that higher scores represent a more significant burden.

The Portuguese version of the MOS SF36 was used (Ferreira, 2000a, 2000b) to evaluate overall health and quality of life. It includes eight subscales: "physical functioning" (10 items), "role-physical" (4 items), "role-emotional" (5 items), "bodily pain" (2 items), "mental health" (5 items), "social functioning" (2 items), "vitality" (4 items), and "general health" (5 items). Additionally, the instrument contains an item that measures changes in health over the past year. The author's instructions regarding item coding and inversion were strictly followed, as well as the formulas applied to determine the scores for each subscale (Ferreira, 2000a, 2000b).

The Portuguese version (Pais-Ribeiro et al., 2007) of the HADS was also used. It includes 14 items, with four response options, rated from 0-3. Total subscale scores between 8 and 10 show the need for further validation to confirm a depressive state, while scores above 11 signal the need for immediate action and follow-up (Pais-Ribeiro et al., 2018). In the present study, to classify the dichotomous variable of cases versus non-cases and determine the cutoff points, scores greater than 11 in at least one of the HADS subscales were used as reference, following the authors' instructions (Pais-Ribeiro et al., 2018).

Statistical methods

The data were analyzed using IBM SPSS software, version 28.0 for Windows. Pearson's correlation coefficient was used to examine the association between continuous variables and the strength of correlation. Values from 0.40 to 0.69 represented a moderate correlation, 0.70 to 0.89 represented a strong correlation, and above 0.90 represented a very strong correlation (Schober et al., 2018). The internal consistency reliability of the scale was calculated for each subscale using Cronbach's alpha coefficient, with a minimum value of 0.70 being generally accepted (Nawi et al., 2020). The metric properties of the scale were assessed using the sensitivity and specificity of the scale for several possible cutoff points, using pairs of sensitivity /specificity for each cutoff point. The receiver operating characteristic (ROC) analysis was used to determine the optimal cutoff point. The measure's effectiveness was assessed by measuring the area under the ROC curve (AUC), the accuracy, and the Youden Index while considering a confidence interval of 95%. Higher AUC scores indicated a more significant adjustment. The Youden Index is the sum of sensitivity and specificity minus one and ranges between 0 and 1, with scores close to 1 indicating a perfect test and 0 demonstrating no diagnostic value (Chang et al., 2014).

Ethical considerations

The study adhered to the Declaration of Helsinki. The primary studies were approved by the ethics committee of the respective institutions, and the present secondary study was approved by the ethics committee of the institution where it was conducted (Reference ADHOC_1006-2022).

Results

Table 1 outlines the sociodemographic variables of family caregivers. Most caregivers were women, married, and living with the dependent family member. Their mean age was 55 years, and their education level was low, with a mean of six years. Over 50% of the participants believed their family members were in poor health.

The values of anxiety and depression were high among caregivers, with 54.1% (n = 80) of the participants scoring above 11 on the anxiety and/or depression scale. The subscales of "reactions to demands" and "financial burden" contributed the least to the overall burden, indicating the dependent family members displayed few behaviors perceived as inappropriate or undeserved by the respective caregivers. Positive subscales provided a good buffer against the general burden, with caregivers acknowledging their fundamental role in the well-being of their loved ones, feeling supported by their family, and recognizing their self-efficacy as caregivers. Regarding the perception of quality of life, it is worth noting that "role-physical," "role-emotional," "mental health," and "general health" were the most negatively impacted subscales, with mean values below the 50th percentile.



Table 1

Sociodemographic description of family caregivers

	Participants
	N (%)
Sex (<i>n</i> = 148)	
Female	131 (88.51)
Male	17 (11.49)
Age (Mean ± SD)	55.2 (± 13.54)
Education (Mean ± SD)	5.89 (±3.41)
Marital status (n = 148)	
Married	123 (83.10)
Not married	25 (16.89)
Has informal care support (n = 147)	
Yes	86 (58.5)
No	61 (41.5)
Lives in the same house as the dependent family member (n=147)	
Yes	126 (85.71)
No	21 (14.23)
Caregivers' perception of the health status of the dependent family member $(n = 148)$	
Good	9 (6.08)
Moderate/acceptable	50 (33.78)
Poor	89 (60.14)
QASCI (<i>n</i> = 148)	
Emotional burden	49.09 (± 20.41)
Implications for personal life	58.03 (± 22.55)
Financial burden	38.18 (± 32.36)
Reactions to demands	39.46 (± 23.15)
Perception of efficacy and control mechanisms*	62.86 (± 21.20)
Family support*	65.64 (± 31.04)
Satisfaction with the role and the family member*	75.63 (± 19.94)
Overall scale	39.71 (± 14.61)
MOS SF36 $(n = 148)$	
Physical functioning	59.70 (± 28.11)
Social functioning	53.65 (± 26.14)
Role-physical	43.02 (± 40.31)
Role-emotional	39.90 (± 40.43)
Mental health	43.02 (± 19.82)
Vitality	39.77 (± 21.22)
Bodily pain	55.82 (± 28.54)
General health	44.61 (± 20.34)
HADS $(n = 148)$	11.01 (= 20.01)
Anxiety	10.90 (± 4.35)
1	

* Higher values are indicative of greater family support, greater self-efficacy, and greater satisfaction.

Reliability Analysis

Table 2 shows the internal consistency of the QASCI subscales, ranging from 0.56 to 0.88. Except for the "per-

ception of efficacy and control mechanisms" subscale, all subscales had internal consistency values greater than 0.70.



Table 2

Cronbach's alpha coefficients for the QASCI

	Cronbach's alpha	Nº Items
Emotional burden	0.71	4
Implications for personal life	0.88	11
Financial burden	0.73	2
Reactions to demands	0.75	5
Perception of efficacy and control mechanisms	0.56	3
Family support	0.76	2
Satisfaction with the role and the family member	0.72	5
QASCI	0.89	32

Table 3 presents the correlation between the QASCI and the Portuguese version of the MOS SF36 subscales. The results show that the QASCI correlated negatively with the Portuguese version of the MOS SF36, with correlations exceeding 0.50 in the "mental health," "vitality," and "social functioning" subscales. The Portuguese version of the HADS showed a correlation value of 0.60 with the QASCI (Table 3).

Table 3

Correlations of the Portuguese versions of the MOS SF36 and the HADS with the QASCI

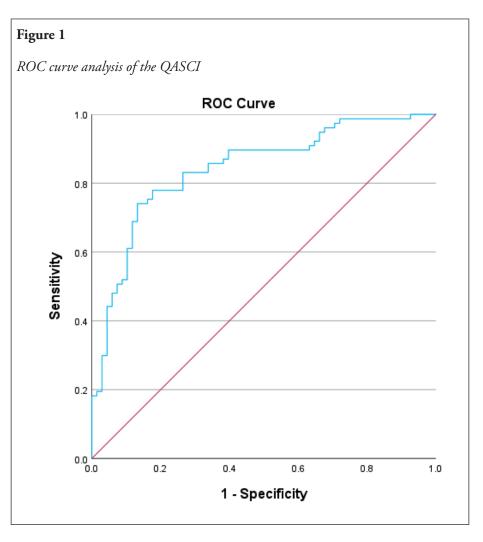
	QASCI
MOS SF36	
Physical functioning	-0.29***
Social functioning	-0.53***
Role-physical	-0.40***
Role-emotional	-0.32***
Mental health	-0.64***
Vitality	-0.56***
Bodily pain	-0.30***
General health	-0.45***
HADS	
Anxiety	0.55***
Depression	0.57***
Total scale	0.60***

*** p < 0.001

Figure 1 shows the ROC curve analysis for determining probable cases of anxiety and depression disorders. Only cases with a score equal to or greater than 11 on the anxiety and/or depression scale were considered. The Youden Index determined the optimal cutoff value for adequate sensitivity and specificity. The AUC was calculated as 0.84 (95%CI [0.77 – 0.91]), and the suggested cutoff point was 40 (maximum Youden Index of 0.59). These results confirm that the analyzed model predicts anxiety and depression disorder with an accuracy of 84%. The model also displayed a sensitivity of 78% and a specificity of 81%.



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Discussion

The study revealed that the QASCI subscales had good internal consistency. The correlations between the QASCI and the Portuguese version of the MOS SF36 were moderate, indicating adequate convergent validity based on the criteria established by Borsboom et al. (2004). These correlations suggest that the QASCI can be a valuable tool for evaluating the impact of caregiving on various aspects of quality of life. In turn, the QASCI showed stronger correlations with the anxiety and depression scale, suggesting that these measures have overlapping concepts, and one can be used to predict the other (Janse et al., 2021). Overall, the correlations between scales prove the validity of the QASCI to measure caregiver burden and its impact on mental health and quality of life.

The ROC curve analysis provided the sensitivity and specificity values for the QASCI. The cutoff point 40 on the QASCI yielded the maximum Youden Index, indicating that 40 is the optimal cutoff point for the QASCI to differentiate between caregivers at risk of depression and those not at risk. Therefore, according to these findings, nurses can use the QASCI to identify family caregivers at risk for depression. The use of the QASCI offers valuable information to health professionals involved in diagnostic activities and in guiding and training caregivers. Moreover, this instrument is a useful clinical tool that provides insight into caregivers' emotional and psychological commitment to pursuing their role, thus being an added value for health professionals. According to some authors, the ROC curve analysis is an effective method to determine cutoff points for diagnostic measures or tests (Gonçalves-Pereira et al., 2017; Hajian-Tilaki, 2013; Vázquez et al., 2019).

Determining cutoff points for a scale is useful for defining clear criteria to classify individuals into different groups. The QASCI has proven effective in detecting caregiver burden in 78% of cases considered true positives and 81% of true negatives. These results indicate that the QASCI has a good balance between identifying true positives and true negatives. Cutoff points allow instruments to determine whether the subjects under study have a particular condition. Thus, determining cutoff points is essential in risk measurement tools, such as the QASCI, as cutoff points can be used to classify individuals into risk groups or identify those who may benefit from preventive interventions. Moreover, it helps to interpret and apply a measure more accurately and effectively (Hajian-Tilaki, 2013). It should be noted that using an instrument alone, even with cutoff points, does not lead to a diagnosis. This calls for clinical judgment involving a comprehensive and holistic assessment.

The present study has limitations, particularly concerning the sample size. Although the sample is not too small,



it may not be large enough to detect small effects. Additionally, one of the primary studies is an experimental study conducted over five years ago. This may affect the mean values of the found burden, which, in turn, might be influenced by social and contextual measures.

Conclusion

Caregiving can be demanding and challenging, resulting in significant physical, emotional, and financial burdens for caregivers. Also, the caregiver burden can negatively impact the health of both the caregiver and the care receiver. Therefore, nurses must assess and monitor caregiver burden, specifically when the care receiver is at home. Regular assessments of the caregiver's well-being can assist nurses in identifying potential problems and providing interventions to prevent caregiver burden. By assessing and monitoring the risk of caregiver burden, nurses can ensure that the caregiver is prepared to provide the best possible care to the dependent person. The present study's results suggest that the QASCI is a valuable tool for the identification of caregivers at risk of developing anxiety and depression and the provision of guidance for practical interventions aimed at improving the mental health of caregivers.

Author contribuitions

Conceptualization: Martins, T., Araújo, F.

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Formal analysis: Martins, T., França, D.,

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Writing – review and editing: Martins, T., França, D., Peixoto, M., Araújo, F.

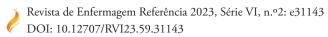
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