

Original Research

Construct validity and reliability of the Informal Caregiver Burden Assessment Questionnaire (QASCI) in caregivers of patients with COPD

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ABSTRACT

Introduction: COPD often leads to loss of independence in daily activities which may increase the dependency on the informal caregiver, resulting in caregiving burden. Several instruments have been used to assess caregiving burden in COPD; however, their measurement properties have been poorly investigated in this population. This study assessed the construct validity and reliability of the Informal Caregiver Burden Assessment Questionnaire (QASCI) in informal caregivers of patients with COPD.

Methods: Participants completed the QASCI (higher scores indicate higher burden) and the following questionnaires to assess construct validity: Zarit Burden Interview (ZBI), Hospital Anxiety and Depression Scale (HADS) and World Health Organization Quality of Life Instrument – Short Form (WHOQOL-Bref). QASCI was completed again one week later to assess test-retest reliability. Statistical analyses included: Pearson's (r) or Spearman's (ρ) correlations (construct validity); Cronbach's α (internal consistency); Intraclass Correlation Coefficient (ICC_{2,1}, test-retest reliability) and Standard Error of Measurement (SEM), Minimal Detectable Change (MDC₉₅) and Bland and Altman 95% Limits of Agreement (LoA).

Results: Fifty caregivers (62.7 ± 9.8 years, 88% female; patients' FEV₁ = 45.2 ± 21.3%predicted) participated. QASCI mean score was 28.5 ± 19.8 (moderate burden). QASCI was positively correlated with ZBI (r = 0.908; p < 0.01), HADS anxiety (r = 0.613; p < 0.01) and depression (ρ = 0.634; <0.01) and negatively correlated with WHOQOL-Bref (−0.476 to −0.739) (all p < 0.01). Cronbach's α was 0.793 for the QASCI total score (subscales: 0.747–0.932). The ICC_{2,1} was 0.924, SEM 2.8 and MDC₉₅ 7.8, and the LoA were −18.3 to 11.1.

Conclusions: The QASCI seems to be a promising measure to assess burden levels associated with informal caregiving in COPD.

1. Introduction

Chronic obstructive pulmonary disease (COPD) is a highly prevalent disease and it is one of the top 10 leading causes of Years Living with

Disability (YLDs) [1]. It is characterized by persistent respiratory symptoms and airflow limitation with unpredictable acute exacerbations [2]. Most common symptoms include dyspnea, cough and/or sputum production, associated with a progressive loss of independence

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in patients' daily life activities, resulting in reduced quality of life and care dependency [2–4]. Informal caregivers are the primary source of support for these patients, often dealing with the management of their symptoms, mobility problems and personal care [5,6]. Informal caregivers are individuals that provide unpaid assistance to a family member or friend who is unable to manage their daily life independently [7,8].

Previous research has shown that caring for a person with COPD can be a very rewarding experience with positive aspects, but it can also lead to a significant but variable impact on the physical, emotional, psychosocial, and financial dimensions of caregivers' lives [8,9], with higher levels of dependence being associated with a more severe impact in all dimensions [10–12]. Over time, this impact can lead to caregiving burden [13,14]. Caregiver burden has been defined as “*the strain or load borne by a person who cares for an elderly, chronically ill, or disabled family member or other person*” [8] and it may affect caregivers' psychological and physical health, as well as caregivers' social relationships, thereby impacting on caregivers' quality of life [10,11,15]. Therefore, the caregiving experience of informal caregivers of patients with COPD should be routinely and effectively assessed to develop interventions tailored to caregivers' specific support needs. One recent review on interventions to support informal caregivers supports this idea [16].

There are several instruments available to assess the caregiving experience; however, there are only a few studies that have described their measurement properties in the specific population of caregivers of patients with COPD, with limited results [17]. This assessment is fundamental considering the characteristics and progression of the disease [18]. The Informal Caregiver Burden Assessment Questionnaire (QASCI) is a caregiver burden tool which was initially developed to evaluate the physical, emotional and social burden in caregivers of patients with stroke, to be used in clinical practice and research [19,20]. This tool has been validated in caregivers of people with various chronic diseases, including respiratory diseases (not specified) [20], suggesting that it may also be a valuable tool to assess the caregiving experience in the COPD context. Therefore, this study aimed to assess the construct validity and reliability of the QASCI in informal caregivers of patients with COPD.

2. Methods

2.1. Study Design

This was a cross-sectional study. Ethical approval was obtained from the Ethics Committee of the Polytechnic of Leiria (CE/IPLEIRIA/14/2018) and the Leiria Hospital Center (07/11/2018). This study was designed according to the COSMIN Study Design checklist for Patient-reported outcome measurement instruments [21].

2.2. Participants

Participants were informal caregivers of patients diagnosed with COPD living in the community. Recruitment was conducted at the Respiratory Research and Rehabilitation Laboratory of the School of Health Sciences of the University of Aveiro (Lab3R-ESSUA) and at the Leiria Hospital Center. Inclusion criteria consisted of: being 18 years old and over, providing assistance to a relative with a clinical diagnosis of COPD (according to Global Strategy for the Diagnosis Management and Prevention of COPD (GOLD) criteria [2]) in a stable condition (i.e., no exacerbations in the previous month) and living in the community. Informal caregivers were excluded if they or their family member with COPD self-reported a significant cardiorespiratory (in addition to the diagnosis of COPD for patients), neurological, cognitive, or musculoskeletal impairment that could cause additional burden to the caregiver or the inability to understand the study and participate voluntarily. The aim was to recruit a minimum of 50 caregivers, according to the COSMIN guidelines for studies assessing construct validity and reliability of instruments [21].

2.3. Procedures

Patients with COPD were identified by health professionals working in the recruitment institutions. Patients were asked to provide the contact of their informal caregiver, after being informed about the purpose and procedures of the study. Caregivers were then contacted by the researchers to provide additional information about the study and ask their willingness to participate, if eligible. An appointment was scheduled with those agreeing to participate to receive more information about the study, sign the informed consent form and collect the following data:

- Sociodemographic data (age, sex, educational level and work status) and caregiving context (type and duration of caregiving in hours per week and number of years; relationship with the person receiving care);
- Caregiving burden using the QASCI [19] and the Zarit Burden Interview [22] (ZBI; distribution rights held by MAPI Research Trust);
- Anxiety and depression symptoms with the Hospital Anxiety and Depression Scale (HADS) [23];
- Quality of life with the World Health Organization Quality of Life Instrument – Short Form (WHOQOL-Bref) [24].

The ZBI, HADS and WHOQOL-bref were used for further assessment of construct validity of the QASCI, as these instruments have been identified in a recent systematic review as some of the most used to assess the impact of COPD on informal caregivers [17]. Criterion validity was not possible to evaluate since there is no gold standard to assess caregiver burden.

Participants were asked to schedule another meeting one week after the first appointment to complete the QASCI again so that test-retest reliability could be assessed. A time interval of 1 or 2 weeks between measurements has been defined as an appropriate time interval to evaluate test-retest reliability of health-related instruments [25,26], as it is a period long enough to prevent recall bias and short enough to ensure that caregivers remain stable in the interim period on the construct to be measured [21].

Participants' age, sex and lung function data (Forced Expiratory Volume in 1 s, FEV₁ and Forced Vital Capacity (FVC) absolute and percentage predicted values; FEV₁/FVC ratio) were obtained from the patient's clinical record with the collaboration of the healthcare professionals who identified the patients and asked for their informed consent to acquire this information. Values of FEV₁ were further used to classify COPD severity according to the GOLD criteria (GOLD 1 – mild FEV₁ ≥ 80%; GOLD 2 – moderate 50 ≤ FEV₁ < 79%; GOLD 3 – severe 30 ≤ FEV₁ < 49%; GOLD 4 – very severe FEV₁ < 30%) [2].

2.4. Instruments

2.4.1. Informal Caregiver Burden Assessment Questionnaire (QASCI)

The QASCI questionnaire is a Portuguese tool developed to assess caregiving burden with 32 items, scored on a 5-point Likert scale (1–5). It includes a total score and 7 subscales, namely Emotional burden (items 21 to 24), Implications for personal life (items 1 to 10 and 25), Financial overload (items 29 and 30), Reactions to demands (items 16 to 20), Perception of efficacy and control mechanisms (items 31 to 33), Family support (items 26 to 28) and Satisfaction with the role (items 11 to 15). The first author of the original study [19] was contacted to obtain permission and instructions on how to use the questionnaire. To calculate the score for each subscale, the minimum score of that specific subscale has to be subtracted from the sum of the subscale, then divided by the difference between the maximum and minimum score, and then multiplied by 100 [19], as provided in the following formula:

$$\frac{\sum -\text{minimum score of each subscale}}{\text{maximum} - \text{minimum}} \times 100$$

In the subscales Satisfaction with the role, Family support, and Perception of the efficacy and control Mechanisms, the results have to be inverted (by subtracting the score to 100) so that higher scores correspond to higher levels of burden, as in the remaining questionnaire. The total QASCI score is obtained by calculating the mean of all subscales and can be translated into four levels of caregiving burden: low (0–25 points), moderate (26–50 points), high (51–75 points) and extreme (≥ 76 points) [19].

In a previous study conducted in caregivers of patients with various chronic diseases, including respiratory diseases, this tool presented good results in construct validity (correlations with the Health Survey Short Form (SF-36) subscales ranging from -0.31 to -0.65 , $p < 0.01$, and correlations with HADS anxiety and depression subscales achieving $r = 0.55$ and $r = 0.52$, respectively, $p < 0.01$), test-retest reliability ($r = 0.81$, $p < 0.01$) and internal consistency (Cronbach's α of 0.90 in the total score and 0.62–0.88 in the subscales) [20].

2.4.2. Zarit Burden Interview (ZBI)

The ZBI [22,27] assesses the same construct as the QASCI questionnaire, i.e., caregiver burden. It consists of 22 items, rated on a 5-point Likert scale (0–4), which refer to problems in health and psychological wellbeing, finances, social life and in the relationship between the caregiver and care-receiver [28]. Item scores are summed to give a total score ranging from 0 to 88 points, with higher scores representing greater caregiver burden. Scores can be further categorized in 'mild to no burden' (≤ 40 points), 'moderate to severe burden' (41–60 points) or 'severe burden' (> 60 points). The ZBI has been widely used in caregivers of patients with a diverse range of chronic diseases, including COPD [11,29–32], with good internal consistency results (a Cronbach's α of 0.93 in the Portuguese tool [27] and 0.92 in a study conducted in COPD [32]).

2.4.3. Hospital Anxiety and Depression Scale (HADS)

The HADS [23] is commonly used in research and clinical practice to briefly assess symptoms of anxiety and depression in non-psychiatric populations [33]. In informal caregivers of patients with COPD, this is the most commonly used instrument to evaluate psychological status and mood, which is a domain related to the impact of caregiving in COPD [17]. The HADS consists of 14 items, 7 to evaluate anxiety (items 1, 3, 5, 7, 9, 11, and 13) and 7 to evaluate depression (items 2, 4, 6, 8, 10, 12 and 14), scored in a 4-point Likert-scale (0–3). For each subscale, a total score is obtained by summing all items of that subscale, ranging from 0 to 21 points. The severity of anxiety and depression symptoms can be then classified as: normal (0–7 points), mild (8–10 points), moderate (11–15 points) and severe (16–21 points) [20,34]. The Portuguese version of the tool presented good internal consistency values for both subscales, with a Cronbach's α of 0.76 for anxiety and 0.81 for depression, and a Pearson correlation of 0.75 in the test-retest analysis of the subscales [33]. This tool has also shown good internal consistency results (Cronbach's α : 0.80 for anxiety and 0.71 for depression) in caregivers of patients with COPD [35].

2.4.4. World Health Organization Quality of Life Instrument – Short Form (WHOQOL-Bref)

The WHOQOL-Bref is a shorter version of the WHOQOL-100, which is a questionnaire developed by the World Health Organization (WHO) to assess quality of life [24,36]. It has 26 items scored in a 5-point Likert scale (1–5). Two of the WHOQOL-Bref questions are related to general quality of life. The remaining 24 questions are organized in 4 domains: physical health (items 1 to 3 and 9 to 12), psychological health (items 4 to 8 and 24), social relationships (items 13 to 15), and environment (items 16 to 23). The score of each domain is obtained by calculating the mean of the item scores from that particular domain (after inverting

values of the items 3, 4 and 26) and multiplying them by 100, so that final scores of each domain present homogeneous and comparable values, with higher scores meaning better quality of life [24]. The WHOQOL-Bref has been commonly used in informal caregivers of patients with COPD [17], presenting good reliability [Cronbach's α ranging from 0.80 to 0.85, with no floor or ceiling effects ($< 7\%$ in all domains)], and item convergent validity results (success items/total items; 85.7% in the physical domain and 100% in the remaining domains) [37].

2.5. Statistical analysis

Statistical analysis was carried out using the Statistical Package for Social Sciences (SPSS) 20 (IBM, Armonk, New York, USA) and GraphPad Prism version 8.0.2 for Windows (GraphPad Software, San Diego, California, USA). Descriptive statistics were used to characterize the sample.

Construct validity of the QASCI was assessed through hypothesis testing, following the COSMIN recommendations [21]. Correlations were performed between the QASCI and the other questionnaires (ZBI, HADS and WHOQOL-Bref) using the Pearson (r) or Spearman (ρ) correlation coefficients, depending on the normality of data distribution. Normal distribution of data was assessed using the Kolmogorov-Smirnov test. Correlations were interpreted as follows: 0–0.09 negligible correlation; 0.1–0.39 weak correlation; 0.4–0.69 moderate correlation; 0.7–0.89 strong correlation; 0.9–1 very strong correlation [38]. Based on previous research exploring the relationship between caregiving and psychological status and quality of life [39–41], it was hypothesized that QASCI scores would be positively correlated with HADS anxiety and depression scores (range 0.3–0.5) and negatively correlated with the WHOQOL scores (range -0.3 to -0.7). Moreover, a stronger (positive) correlation between QASCI and ZBI than HADS or WHOQOL-Bref was expected, as QASCI and ZBI assess the same construct (i.e., caregiver burden). Current guidelines suggest that correlations with instruments measuring similar constructs should be 0.5 or higher [42].

Reliability consisted of internal consistency, test-retest reliability and measurement error, which were assessed as follows:

- Internal consistency – Cronbach's α was calculated for the QASCI total score and each subscale. Values between 0.70 and 0.95 were used to define good internal consistency [26,42];
- Test-retest reliability: Intraclass correlation coefficient (two-way random effects, absolute agreement, single measurement – ICC_{2,1}) [43,44] and its 95% confidence intervals (95%CI) were calculated for the QASCI total score and subscales using the data from QASCI-1 (first appointment) and QASCI-2 (second appointment). ICC values range from 0 to 1 and an ICC ≥ 0.70 is recommended as a minimum standard for reliability [44]. The 95%CI of the ICC can be interpreted as: values lower than 0.5 – poor reliability; between 0.5 and 0.75 – moderate reliability; between 0.75 and 0.9 – good reliability; and greater than 0.90 – excellent reliability [44].
- Measurement error: Standard error of measurement (SEM) of the total score was calculated using the formula $SEM = SD \cdot \sqrt{1 - ICC}$, where SD is the standard deviation of the total QASCI scores obtained from all individuals and ICC is the test-retest reliability coefficient [45]. SEM was provided in the same measurement units as the QASCI scale and in percentage (SEM%), calculated as: $SEM\% = (SEM / \text{mean}) \times 100$, where mean is the mean of the total QASCI scores. SEM was further used to determine the minimal detectable change (MDC), which refers to the smallest within-person change in score that can be interpreted as a 'real' change above measurement error [42]. MDC at the 95% level of confidence was calculated using the formula $MDC_{95} = 1.96 \cdot \sqrt{2 \cdot SEM^2}$. The MDC can also be converted in percentage (MDC%): $MDC\% = (MDC_{95} / \text{mean}) \times 100$. An MDC% below 30% is recommended [46]. The Bland and Altman 95% Limits of Agreement (LoA) were also conducted to assess test-retest agreement, using the equation $LoA = \text{mean}_{\text{diff}} \pm 1.96SD_{\text{diff}}$, where $\text{mean}_{\text{diff}}$

and SD_{diff} are the mean and standard deviation of the differences between QASCI-1 and QASCI-2, respectively [47].

Floor or ceiling effects of the QASCI were also determined as they may indicate limited content validity and reliability [26]. This was assessed by counting the number of participants who achieved the lowest (floor effect) or highest (ceiling effect) possible score in the QASCI. If more than 15% of participants achieved the lowest or highest possible score, floor or ceiling effects were considered to be present [26]. In addition, missing data were reported since a high number of missing data can introduce bias in the results if they are not random [21]. Missing items refer to the average number of missing items per instrument or the percentage of missing responses per item.

3. Results

3.1. Participants

Sixty-three (n = 63) caregivers were contacted; from these, four refused to participate and nine were not available at the time of data collection. Therefore, the final sample consisted of 50 informal

Table 1
Characteristics of informal caregivers of patients with COPD (n = 50).

Characteristics	Caregivers (n = 50)
Age (years) Mean ± SD	62.7 ± 9.8
Sex n (%)	
Female	44 (88%)
Male	6 (12%)
Educational levels, n (%)	
≤4 years of education	28 (56%)
5–9 years of education	7 (14%)
10–12 years of education	10 (20%)
Higher education	5 (10%)
Marital Status n (%)	
Married/Living together	43 (86%)
Divorced	3 (6%)
Single	2 (4%)
Widowed	2 (4%)
Work Status n (%)	
Retirement	27 (54%)
Full-time employment	15 (30%)
Domestic	4 (8%)
Unemployment	3 (6%)
Other	1 (2%)
Relationship with person cared for n (%)	
Spouse/Partner	39 (78%)
Daughter/Son	10 (20%)
Daughter-/Son-in-law	1 (2%)
Caregiving hours per week n (%)	
0–8 h	13 (26%)
8–20 h	8 (16%)
20–40 h	10 (20%)
>40 h	19 (38%)
Caregiving period (years) n (%)	
Less than 1	5 (10%)
1–2	4 (8%)
2–4	14 (28%)
More than 4	27 (54%)
Type of Care Provided (yes) n (%)	
Company in medical appointments	45 (90%)
Shopping	36 (72%)
Housework	36 (72%)
Transportation	25 (50%)
Bureaucratic issues	24 (48%)
Personal care	21 (42%)
Medication management	19 (38%)
Therapeutic support	15 (30%)
Money management	15 (30%)
Financial support	13 (26%)
Mobility	12 (24%)
Phone usage	9 (18%)

Legend: SD, standard deviation.

caregivers.

Table 1 presents caregivers' sociodemographic data and caregiving context. Participants had a mean (±standard deviation) age of 62.7 ± 9.8 years and were mostly women (n = 44, 88%). Most caregivers were married or living together (n = 43, 86%), had low educational levels: n = 28, 56%), and were retired (n = 27, 54%) or had a full-time paid employment (n = 15, 30%). Caregivers were predominantly patients' spouses (n = 39, 78%), caring for more than four years (n = 27, 54%) and more than 40 h per week (n = 19, 38%). The types of care more commonly provided were: joining the patient in medical appointments (n = 45, 90%); housework (n = 36, 72%); shopping (n = 36, 72%); transportation (n = 25, 50%); bureaucratic issues (n = 24, 48%); and personal care (n = 21, 42%).

Patients with COPD (n = 50) were mostly men (n = 40, 80%), with a mean age of 71 ± 8 years, a mean FEV₁ of 1.2 ± 0.6 L (45.2 ± 21.3% predicted), a mean FVC of 1.5 ± 0.7 L (73.8 ± 18.0% predicted), and a mean FEV₁/FVC ratio of 46.9 ± 16.0. Patients with COPD were distributed among the four GOLD grades: GOLD 1 n = 3 (6%), GOLD 2 n = 12 (24%), GOLD 3 n = 19 (38%) and GOLD 4 n = 16 (32%).

Fifty participants completed the QASCI for further assessment of internal consistency. From these, 46 completed the ZBI, HADS and WHOQOL-Bref, and 23 completed the QASCI-2 a week later for the assessment of test-retest reliability and agreement. This was due to logistical reasons, namely the caregivers' availability to return to the data collection center a second time to complete the questionnaire, as some caregivers lived in areas far from that location. Table 2 presents the scores of the QASCI, ZBI, HADS and WHOQOL-Bref scales and subscales.

The mean QASCI score (n = 50) was 28.5 ± 19.8 points, and the QASCI subscales with the highest values were Family support (32.3 ± 32.3 points) and Perception of efficacy and control mechanisms (36.0 ± 27.2 points). Regarding the four levels of burden, 24 (48%) caregivers presented a low level, 19 (38%) a moderate level and 7 (14%) a high level of caregiving burden. None of the caregivers was in the extreme burden level.

Table 2

Scores of the scales and subscales of the Informal Caregiver Burden Assessment Questionnaire (QASCI) (n = 50), Zarit Burden Interview (ZBI), Hospital Anxiety and Depression Scale (HADS) and World Health Organization Quality of Life Instrument – Short Form (WHOQOL-Bref) (n = 46).

	Mean ± SD
QASCI (n = 50)	
QASCI total score	28.5 ± 19.8
Emotional burden	27.0 ± 25.3
Implications for personal life	29.3 ± 24.4
Financial overload	27.3 ± 34.0
Reactions to demands	23.1 ± 18.6
Perception of efficacy and control mechanisms	36.0 ± 27.2
Family support	32.3 ± 32.3
Satisfaction with the role	24.4 ± 22.6
ZBI (n = 46)	24.3 ± 16.6
HADS (n = 46)	
HADS Anxiety	8.9 ± 4.9
HADS Depression	6.2 ± 4.3
WHOQOL-Bref (n = 46)	
General quality of life	60.1 ± 20.2
Physical health	65.6 ± 19.1
Psychological health	65.5 ± 19.3
Social relationships	61.2 ± 19.9
Environment	64.7 ± 15.5

Legend: HADS, Hospital Anxiety and Depression Scale; QASCI, Informal Caregiver Burden Assessment Questionnaire; SD, standard deviation; WHOQOL-Bref, World Health Organization Quality of Life Instrument – Short Form; ZBI, Zarit Burden Interview. Note: The results from the QASCI subscales Satisfaction with the Role, Family Support, and Perception of the Efficacy and Control Mechanisms are inverted so that higher values reflect higher burden levels. The items 3, 4 and 26 from WHOQOL-Bref are also inverted, with higher scores meaning higher quality of life.

The mean ZBI score ($n = 46$) was 24.3 ± 16.6 points. According to the ZBI categories, 40 (87%) caregivers had mild to no burden, 5 (11%) had moderate to severe burden, and 1 (2%) had severe burden.

The mean HADS Anxiety score was 8.9 ± 4.9 points and HADS Depression score was 6.2 ± 4.3 points. Regarding the four levels of anxiety symptoms, 20 (43.5%) caregivers were in the normal, 10 (21.7%) in the mild, 11 (23.9%) in the moderate and 5 (10.9%) in the severe level. When considering depression symptoms, 31 (67.4%) caregivers were in the normal, 8 (17.4%) in the mild, 4 (8.7%) in the moderate and 3 (6.5%) in the severe level.

Regarding the WHOQOL-Bref, the General Quality of Life score was 60.1 ± 20.2 points, and the subscales with the highest values were the Physical Health (65.6 ± 19.1 points) and Psychological Health (65.5 ± 19.3 points) subscales.

3.2. Construct validity of the QASCI

The QASCI total score presented a positive and very strong correlation with ZBI ($r = 0.908$, $p < 0.01$) and moderate correlations with HADS Anxiety ($r = 0.613$, $p < 0.01$) and HADS Depression ($\rho = 0.634$, $p < 0.01$). It also presented negative moderate to strong correlations with the WHOQOL-Bref (General quality of life, $\rho = -0.650$; Physical health, $r = -0.476$; Psychological health, $\rho = -0.633$; Social relationships, $\rho = -0.602$; Environment, $r = -0.739$; $p < 0.01$).

Fig. 1 shows the correlations between the QASCI total score and the remaining questionnaires. The correlations with the QASCI subscales are presented in the supplementary material (Table S1).

3.3. Reliability of the QASCI

3.3.1. Internal consistency

The QASCI presented good internal consistency, with a Cronbach's α of 0.793 for the total scale. The subscales presented similar results, with an α ranging from 0.747 (Reaction to demands) to 0.932 (Implications for personal life). The only exception was the subscale Perception of efficacy and control mechanisms which presented a slightly lower result ($\alpha = 0.671$) (Supplementary Material – Table S2).

3.3.2. Test-retest reliability

QASCI-2 had a mean score of 24.6 ± 15.9 points. The remaining mean scores of the QASCI-2 subscales can be found in the supplementary material (Table S3). Test-retest reliability was considered good to excellent, with an ICC_{2,1} of 0.92 (95%CI 0.80–0.97), as shown in Table S3.

3.3.3. Measurement error

The SEM of the QASCI was 2.8 points, converted into a SEM% of 9.8%. The MDC₉₅ was 7.8 points (MDC% of 27.4%).

The LoA plot showing the differences between the QASCI-1 and QASCI-2 total score is presented in Fig. S1. The average bias (i.e., the mean of the differences, meandiff) was -3.59 points and LoA ranged from -18.3 to 11.1 points (LoA of the subscales are shown in Table S3). Measurements from 2 participants fell outside the lower limit of the LoA. No evidence of systematic error was found.

3.3.4. Floor and ceiling effects

The minimum and maximum values obtained in the QASCI total score were 1.9 and 73.8 points, respectively, which means that no floor or ceiling effects were present since none of the participants reached the minimum or maximum possible score for the QASCI. When analyzing the QASCI subscales, floor effects were present and significant (above 15%) in the subscales: Emotional burden (26% of floor effect); Financial burden (46% of floor effect); Family support (38% of floor effect) and Satisfaction with the role (20% of floor effect). There were no missing data to report.

4. Discussion

Findings suggest that the QASCI is a valid and reliable tool to assess caregiving burden in caregivers of patients with stable COPD living in the community, although some subscales showed floor effects.

Regarding construct validity, the results were in accordance with the predefined hypotheses [42], with ZBI presenting the strongest correlation with the QASCI total score, as these tools assess the same construct [11]. Compared with the original validation study of QASCI, conducted in caregivers of stroke survivors [19], we found higher correlations between the QASCI and the questionnaires assessing related constructs, such as quality of life (SF-36 in the original study) and anxiety and depression symptoms (HADS). Some QASCI subscales presented significant floor effects, which suggests that they may not reflect the reality of caregivers of patients with COPD. Nevertheless, it may also be a result of the little variability found in the sample characteristics. Further work needs to be conducted to explore the validity of the QASCI, specifically the content validity, i.e., the degree to which the content of an instrument is an adequate reflection of the construct to be measured considering its relevance, comprehensiveness, target population and context [48]. Furthermore, it would be useful to assess if this questionnaire is more suitable for this specific population than other similar tools. A previous systematic review on measurement properties of instruments used to assess the caregiving experience in the COPD context showed that none of the questionnaires presented good validity results in this population, and the included studies were not specifically designed to validate the instruments [17]. The ZBI questionnaire has been the most studied tool to assess caregiving burden in caregivers of patients with COPD, also with limited results [17,49,50].

The HADS Anxiety and Depression subscales presented a moderate and positive correlation with the QASCI, above the values of the predefined hypothesis. Lower levels of psychological well-being have been positively associated with higher levels of caregiving burden in COPD [11,17]. Therefore, findings from the present study emphasize the relevance of the QASCI as a valid tool to assess caregiver burden in this population [17]. The HADS was also used to assess the construct validity of the QASCI in caregivers of patients with various chronic diseases [20] and in Brazilian caregivers of dependent older adults [51]. The HADS subscales showed the highest correlations with the QASCI Emotional burden subscale suggesting that, when the caregiving causes burden on an emotional level, caregivers are more likely to present anxiety and depression symptoms.

The correlations between the QASCI total score and WHOQOL-Bref domains were negative and moderate to strong, which means that lower caregiving burden levels are related to better quality of life. Previous studies have also found this relationship [11]. When analyzing the correlations between the QASCI total score and the WHOQOL-Bref domains, only the Environment domain presented a strong negative correlation. This domain includes questions about the environmental context, i.e., financial resources and access to health services, transports, and useful information to plan the day-to-day living. Previous research showed that environmental elements, like perceived access to professional, financial and/or psychosocial support, are one of the aspects that can influence caregiving burden [8,11]. The opposite was also observed in other studies, where the workload inherent to informal caregiving had an impact on caregivers' health, social and economic contexts [10,12]. In the current study, it was not possible to determine the direction of the relationship.

Similarly to previous studies [20,51], the QASCI total score and subscales presented good internal consistency (i.e., Cronbach's $\alpha \geq 0.7$), indicating a good intercorrelation between all items of the questionnaire, except for the subscale Perception of efficacy and control mechanisms which was slightly below the recommended ($\alpha = 0.671$). In previous validation studies of the QASCI, this subscale also presented the lowest internal consistency value, which can be explained by this subscale having only 3 items [19,51].

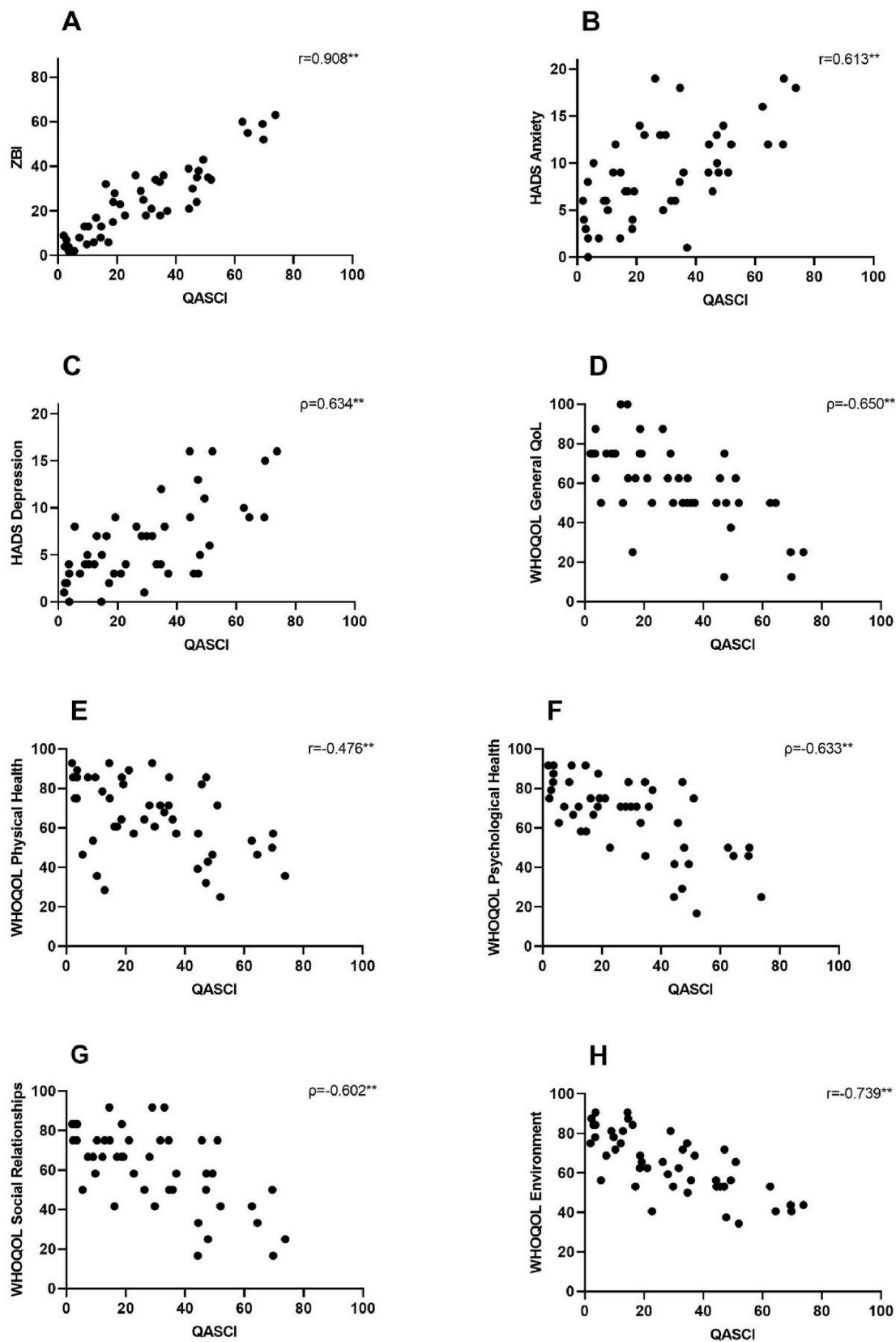


Fig. 1. Correlations between Informal Caregiver Burden Assessment Questionnaire (QASCI) total score and the remaining questionnaires. Legend: A) Zarit Burden Interview (ZBI); B) Hospital Anxiety and Depression Scale (HADS) Anxiety; C) HADS Depression; D) World Health Organization Quality of Life Instrument – Short Form (WHOQOL-Bref) General Quality of Life (QoL); E) WHOQOL-Bref Physical Health; F) WHOQOL-Bref Psychological Health; G) WHOQOL-Bref Social Relationships; H) WHOQOL-Bref Environment. ****** $p < 0.01$.

The test-retest reliability results were good to excellent, both considering the individual value of ICC_{2,1} and the 95%CI, which suggests that the measurements obtained with QASCI are both reliable and stable over time, and able to discriminate between individuals despite the measurement error [42]. The original validation study with various chronic diseases also presented good reliability results [20], although the authors used the Pearson's correlation coefficient, which is a limitation of the study as this is not the recommended method to assess reliability [21].

The SEM (SEM = 9.8%) and the Bland and Altman LoA of the QASCI total score were small, indicating a small variation in measurement error. To the authors' best knowledge, there are no previous studies assessing these variables in the QASCI. Findings suggest that, when assessing changes in the caregiving experience of caregivers of stable patients with COPD using this questionnaire, results within the LoA (-18.3 to 11.1 points) or smaller than the MDC (7.8 points) are likely to be due to measurement error and changes outside these values represent a true change in the caregiving experience of an individual [42].

The small percentage obtained in the MDC% (below 30%), together with the good results obtained in construct validity, test-retest reliability and internal consistency, suggest that the QASCI may be a good instrument to assess changes in caregiver burden levels. To confirm this ability to detect clinically important changes over time (e.g., after an intervention), responsiveness should be assessed in future studies [26].

4.1. Limitations

Some limitations of this study need to be acknowledged. Most caregivers were female, more than half of them were providing care for more than four years, and patients were mostly in the severe and very severe COPD grades, were in a stable condition, living in the community and were recruited in one single center, which hinders the generalization of the findings. However, these caregiver characteristics were also found in previous studies in COPD, with the caregiving taking place for more than 4 years and with more female than male caregivers [11,13,35]. This last characteristic may be due to the caregiver being mostly the spouse, as shown in similar studies [11,35,52]. It is also common for women to predominately assume the role of family caregiver for patients with different chronic conditions or disabilities [53].

The GOLD ABCD assessment tool was not possible to obtain from patients' clinical record, which could have been beneficial, as it is possible that more symptoms and more exacerbations have an impact on caregivers' outcomes.

It is also important to note that almost half of the sample was in the low level of caregiving burden (48%) and in the normal level of anxiety (44%) and depression (67%). A similar result was found in a previous study (36% of caregivers in the normal levels of anxiety and 66% for depression) [35]. Furthermore, although this study followed the COSMIN guidelines [21,42,48], it was only possible to reach the minimum recommended number of 50 participants when completing the first QASCI questionnaire but not in the remaining questionnaires or in the second QASCI, which may have had an impact on the results regarding construct validity and test-retest reliability of the instrument.

Future research should be carried out with a larger and heterogeneous sample to confirm the present findings, but also assess a subsample of caregivers of patients of COPD at different phases of the disease (e.g. during acute exacerbations or at the end of life), and explore the responsiveness of the QASCI to assess its ability to detect clinically important changes over time (e.g., after an intervention) to expand the applicability of this measure among caregivers of people with COPD.

5. Conclusions

The QASCI presented good construct validity and reliability results. This questionnaire seems to be a promising measure to evaluate the caregiving burden of informal caregiving in stable patients with COPD

living in the community.

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CRediT authorship contribution statement

Nádia Hipólito: Methodology, Formal analysis, Investigation, Writing – original draft, Visualization. **Sara Martins:** Methodology, Formal analysis, Investigation, Writing – original draft. **Adriana Ruivo:** Methodology, Investigation, Writing – review & editing. **Sofia Flora:** Investigation, Writing – review & editing. **Cândida G. Silva:** Validation, Formal analysis, Resources, Writing – review & editing, Supervision. **Alda Marques:** Conceptualization, Writing – review & editing, Supervision. **Dina Brooks:** Conceptualization, Writing – review & editing, Supervision. **Joana Cruz:** Conceptualization, Methodology, Validation, Formal analysis, Resources, Writing – review & editing, Visualization, Supervision, Project administration.

Declarations of competing interest

None.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.rmed.2022.107027>.

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