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Validation of the Portuguese Version of the Adult Carers Quality of Life Questionnaire (AC-QoL) among Informal Carers of Stroke Survivors

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Abstract—Stroke is a leading cause of disability worldwide, significantly affecting not only the health and quality of life of survivors but also of those who provide daily care to these individuals, requiring reliable measurement tools to assess these impacts. The Adult Carer Quality of Life Questionnaire (AC-QoL) is a recent and valid instrument, surpassing the limitations of previous tools. Given the lack of validated measures to assess the quality of life (QoL) of carers of stroke survivors, this study aimed to explore the psychometric properties of the AC-QoL among Portuguese informal carers of stroke survivors. After a linguistic adaptation to Portuguese of the AC-QoL, informal carers ($n = 443$) of stroke survivors hospitalized in all Stroke Units of the North of Portugal ($n = 12$), were invited to complete the AC-QoL and a structured questionnaire assessing their sociodemographic, caregiving-related, and psychological features, 18 to 24 months post-stroke (November 2019 and August 2021). Psychometric properties were investigated through confirmatory factor analyses and reliability evaluation. Linear regression models assessed convergent-discriminant validity with carers' sociodemographic, caregiving-related, and psychological characteristics. Our results found a replicable eight-factor structure from the original AC-QoL, revealing good adequacy (CFI = 0.899] and high internal consistency (alpha = 0.904]. Convergent-discriminant validity was satisfactory with burden, anxiety, and depression being inversely associated with the overall score of the AC-QoL. Being younger, married, with higher education, being the son/daughter, and living with the stroke survivor were associated with higher scores of QoL. The Portuguese version of the AC-QoL is a comprehensive, simple, reliable and valid instrument to assess informal stroke carers' QoL. The AC-QoL can be a valuable tool contributing to devise strategies promoting the well-being and social integration of stroke survivors and their informal carers.

Keywords: informal carers, quality of life, scale validation, stroke, survivors

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INTRODUCTION

A stroke is a sudden event that occurs when the blood supply to a part of the brain is interrupted or reduced, depriving brain tissue of oxygen and nutrients [1]. This can cause brain cells to die, leading to potential brain damage, disability, or death [2]. Stroke survivors frequently face long-lasting consequences, requiring the assistance of an informal carer [2, 3]. These unpaid workers are crucial in ensuring essential and daily practical and emotional support to survivors [3]. International literature has been highlighting the importance of informal caregivers in stroke rehabilitation and in maintaining or improving the health of their relatives, as they support their recovery and ongoing care [4]. At the same time, they see their own QoL being diminished [5]. Due to the demands that caring for a family member with disabilities requires this role is associated with physical and psychological impairments, being intensified by socioeconomic repercussions and unmet needs, which may lead to a decrease in carers' QoL [5−10]. Such may result in poor care provision, increasing the health costs for families and healthcare and social systems [11]. Thus, health and social policies, practices, and services should consider the promotion of informal carers'

well-being and quality of life as a key strategy to improve post-stroke care.

Accurately assessing informal carers' QoL is crucial for research and practice [12]. There is an extensive array of instruments for measuring the QoL in the general population that have been used to assess the QoL of informal carers of stroke survivors [5, 11]. However, because these instruments were not specifically validated among informal carers, they may be neglecting specific dimensions relevant to this group. Also, some studies used specific instruments designed for assessing informal carers' QoL. Some instruments designed for carers' QoL lack clarity in their definitions, using proxies like burden and depression [5]. Many focus on the elderly [13] and emphasize caregiving's negative outcomes of caring neglecting positive aspects [3, 13, 14]. Despite the existence of the Stroke Caregiver Quality of Life Measure [15], this instrument has several limitations, including sample size, weak reliability, and validity, making it less robust. Thus, more tailored and statistically robust instruments to evaluate stroke carers' QoL are needed. The Adult Carers Quality of Life Questionnaire (AC-QoL) [13] is a recent, reliable, and valid instrument designed specifically to assess the QoL of informal carers [12, 16, 17]. To the best of our knowledge, the AC-QoL is the only instrument previously validated in different populations to be used with informal carers of stroke survivors, demonstrating high reliability [16]. However, since there are possible culture and language differences, as well as a lack of Portuguese-specific tools to evaluate the QoL of stroke carers, our aim was to comprehensively assess the factorial validity and reliability of the AC-QoL among Portuguese informal carers of stroke survivors and to investigate its convergent-discriminant validity through sociodemographic and caregiving-related characteristics and psychological measures.

MATERIALS AND METHODS

Instrument

The Adult Carer Quality of Life Questionnaire (AC-QoL) is an instrument specifically designed to assess the QoL of adult informal carers [13]. It consists of a 40 self-rated items categorized into eight domains: support for caring (carers perception about the support received), caring choice (the extent to which carers feel they have control over their own life, and are able to choose activities outside caring), caring stress (the mental and physical stress from caring, such as exhaustion and depression), financial implications (carers perception and feelings about their financial situation), personal growth (carers perception of grown and development, and the positive experience of the carers' circumstances), sense of value (the extent to which carers feel they are valued and respected, and the positive relationship between the

carer and the person they are caring for), ability to care (carers perception about how able they are to provide care, how they cope with the caring role, and how they feel about their competency to care) and carer satisfaction (carers satisfaction with their own life and their role as a carer, and how they feel about being a carer). The majority of items are scored from 0 (never) to 3 (always), except items 6−16, 19, 37, and 38 which are scored in reverse. Each of the eight subscales has a possible range between 0 and 15, while the total possible score ranges between 0 and 120, with higher scores indicating better QoL. The instrument demonstrated adequate reliability, with an internal consistency value for the overall AC-QoL of 0.94 and internal consistency values for the eight subscales ranging from 0.78 to 0.89 [13].

Translation Procedure

The English version of the questionnaire was independently translated into Portuguese by two Portuguese native speakers, proficiently fluent in English and with backgrounds in Public Health, Psychology and Social Epidemiology, and merged into a single Portuguese version. This initial version was back-translated into English by a bilingual English native speaker. The original scale and the translated Portuguese version were then reviewed by the two Portuguese native speakers who compared and analysed the semantic, idiomatic, contextual, and linguistic discrepancies, obtaining a single version. To ensure the generalization of the terms and expressions, the synthesized version was evaluated in terms of structure, layout, instrument's instructions, scope and appropriateness of expressions contained in the items. A pretest of the AC-QoL was conducted with 20 informal carers who were able to understand the items easily, requiring an average of 15 minutes to fill the questionnaire.

Participants and Data Collection

The present study adhered to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines. We used a cross-sectional descriptive study design with a convenient sampling method. All informal carers of stroke survivors hospitalized between September 2018 and August 2019 in all Stroke Units of the Northern Region Health Administration of Portugal (ARS-Norte) were invited to participate in the study, 18 to 24 months post-stroke. Data collection occurred between November 2019 and August 2021. Informal care was defined as the unpaid assistance directly provided to individuals with limited autonomy, by a non-professional person with whom they have a social relationship (e.g., spouses, parents, children, other relatives, friends) [17, 18]. The inclusion criteria were (1) be the identified primary (non-professional and unpaid) carer of a stroke survivor who

needs assistance in the activities of daily living; (2) provide care in community-dwelling context; (3) have 18 years old or older; (4) have Portuguese as the native language; (5) be able to be contacted by telephone; (6) have no obvious cognitive or language disabilities; and, (7) be willing to be contacted by the research team. Stroke survivors were first approached by the stroke medical team asking for their permission to be contacted by the research team. After acceptance carer was invited to participate in the study, and a face-to-face interview was scheduled at participants' house or a phone/video call was planned to administer the questionnaire, according to participants' availability and convenience. A trained researcher read the questions, clarified doubts when existing, and recorded the answers. Data on carers' sociodemographic (sex, age, marital status, educational level, household monthly income, professional status, and neighbourhood), caregiving-related (dyad relationship, carer living with the survivor, hours of care provision per day, and previous experience as informal carer) and psychological characteristics (anxiety, depression, and burden) were collected. Participants completed the Hospital Anxiety and Depression Scale (HADS) [19] and the Zarit Burden Interview (ZBI) [20]. Of the eligible 2170 stroke survivors, 1775 agreed to participate in the study, with a participation rate of 81.8%. Among those, 443 informal carers were enrolled. The reasons for refusal were lack of time, lack of interest in the study, and psychological unavailability. Seven carers were excluded from the present analysis due to missing data on AC-QoL items.

Ethical Considerations

Permission was granted from the original authors to use and validate the instrument. The research was performed in accordance with the General Data Protection Regulation guidelines. The study protocol was approved by the Ethics Committees and the respective Data Protection Offices of all the 12 hospitals where the study was conducted (Centro Hospitalar de Entre o Douro e Vouga, Santa Maria da Feira (CA-0462/19-0t_MP/AC); Centro Hospitalar Universitário de São João, Porto (318/19); Centro Hospitalar de Trás os Montes e Alto Douro, Vila Real (348/2019-C.A.); Centro Hospitalar de Vila Nova de Gaia/Espinho, Vila Nova de Gaia (197/219-2); Centro Hospitalar do Médio Ave, Famalicão (C. Ética/24/2019); Centro Hospitalar do Tâmega e Sousa, Penafiel (PROC N° 48/2019); Centro Hospitalar Universitário do Porto/Hospital de Santo António, Porto (N/REF[a] 2019.308(247-DEFI/264-CE); Hospital da Senhora da Oliveira, Guimarães (Ref. 69/2019); Hospital de Braga, Braga (Ref[a] 223_2019); Unidade Local de Saúde do Alto Minho/Hospital Santa Luzia, Viana do Castelo (56/2019-CES); Unidade Local de Saúde de Matosinhos/Hospital Pedro Hispano, Porto (128/CE/JAS); Unidade Local de Saúde do Nordeste,

Unidade Hospitalar de Macedo de Cavaleiros (65/2019). All participants accepted by free consent to answer the questionnaire and an informed consent form was signed or audio recorded before inclusion in the study. Clear, transparent, and detailed information was provided about research objectives, name, and institution of researchers, voluntary nature of participation, expected duration of the questionnaire, reasons for audio recording, procedures taken to protect personal data, participants' entitlement to obtain additional information and clarification on any aspect related to the study and the option to be informed about the results of the study, guarantee of the possibility to withdraw from the study at any time without consequences, and data retention period. The anonymity, confidentiality, and data protection of all materials were assured.

Data Analysis

Statistical analyses were conducted using Stata, version 15.0 (College Station, TX, 2017). Due to the complexity of the analytical procedure, only questionnaires with a maximum of two missing values for AC-QoL were included in the present analysis. In these cases, missing values were replaced by items' median scores. Descriptive statistics, namely mean and standard deviation (SD) were calculated for each AC-QoL item. Kaiser-Meyer-Olkin (KMO) measure was used to verify sample adequacy, considering a value higher than 0.50 as the acceptability limit [21]. Confirmatory factor analysis (CFA) was then conducted, based on Structural Equation Modelling (SEM). The global goodness of fit of the Portuguese Version of the Ac-QoL was evaluated using the comparative fit index (CFI), the Tucker-Lewis Index (TLI), and the root mean squared error approximation (RMSEA), obtained from the confirmatory factor analysis. Cut off values above 0.9 for CFI and TLI, and below 0.10 for RMSEA indicated a good fit of the model [22, 23]. Internal consistency of AC-QoL was assessed through Cronbach's alpha for ordinal variables using the categorical principal component analysis procedure and a Cronbach alpha; a value between 0.70 and 0.80 was considered as acceptable and a value of 0.8 or higher was considered as good internal consistency [24]. Inter-item and corrected item-scale correlations were also evaluated through correlation coefficients. To assess the convergent and discriminant validity of the Portuguese version of the Ac-QoL, linear regression models were computed to measure the association between carers' characteristics and the QoL scores. Statistical significance was set at a value of $p < 0.05$.

RESULTS

The sociodemographic, caregiving-related and psychological characteristics of the participants are described in Table 1. The minimum and maximum

Table 1. Sociodemographic, caregiving-related and psychological characteristics of the participants ($n = 436$)

Sociodemographic characteristics	
Sex, n, %	
Female	383 (87.8)
Male	53 (12.2)
Age, years, *n*, %	
<50	108 (24.7)
50−65	213 (48.9)
>65	115 (26.4)
Marital status, *n*, %	
Married/cohabiting	350 (80.3)
Single/divorced/widowed	86 (19.7)
Educational level, years, *n*, %	
≤4	185 (42.5)
5−9	138 (31.7)
≥10	112 (25.8)
Household income, €/month, *n*, %	
≤1000	243 (55.7)
>1000	138 (31.7)
Does not know/Prefer to not answer	55 (12.6)
Professional status, *n*, %	
Employed	142 (32.6)
Non-employed[a]	294 (67.4)
Neighbourhood, *n*, %	
Urban	208 (47.9)
Rural	226 (52.1)
Caregiving-related characteristics	
Relationship, *n*, %	
Spouse	159 (36.5)
Son/Daughter	209 (47.9)
Other[b]	68 (15.6)
Living with the survivor, *n*, %	
No	327 (75.2)
Yes	108 (24.8)
Hours of care provision/day, *n*, %	
<8 h	66 (15.1)
≥8 h	370 (84.9)
Previous experience of informal caregiving, *n*, %	
No	303 (69.5)
Yes	133 (30.5)
Psychological characteristics	
Anxiety[c], Mean (SD)	8.74 (4.29)
Depression[d], Mean (SD)	6.36 (4.17)
Burden[e], Mean (SD)	54.6 (13.2)

Total does not add 436 in all variables due to missing data.
[a] Retired, unemployed, housewife, on sick leave; [b] Mothers, fathers, brothers, sisters, nephews and friends; [c] Higher values indicate higher levels of anxiety (range for the total scale: 0 to 21); [d] Higher values indicate higher levels of depression (range for the total scale: 0 to 21); [e] Higher values indicate higher levels of burden (range for the total scale: 22 to 110).

mean values (SD) of the AC-QoL items ranged between 0.74 (0.87) for item 18 ("I am able to save for a rainy day") and 2.76 (0.50) for item 32 ("I can take care of the needs of the person I am caring for") (Table 2). No item presented floor or ceiling effects (more than 90% of participants answering "never" or "always," respectively). Kaiser-Meyer-Olkin (KMO) measure was used to verify sample adequacy, with a total value of 0.88.

Confirmatory Factor Analysis

Confirmatory factor analysis supported that eight dimensions were reflected in the Portuguese Version of the AC-QoL (Fig. 1). Overall, items showed high loadings (80% above 0.60) on the expected factor. Also, significant correlations were detected among all the factors, except for the dimensions "caring choice" and "financial implications" (Choice and Growth, Choice and Ability, Money and Growth, Money and Value, and Money and Ability), indicating a considerable dependence between the subscales. The majority of factors presented moderate ($0.41 < r < 0.60$) to strong ($0.61 < r < 0.80$) correlations with each other. However, among the 28 correlations considered, 11 were fairly correlated ($0.21 < r < 0.40$). No correlation was poor ($r < 0.20$). The questionnaire showed a high degree of reliability, with Cronbach's alpha ranging from 0.690 for Satisfaction dimension and 0.977 for the Value dimension. The alpha coefficient for the AC-QoL summed score was also excellent (alpha = 0.904). The CFI, TLI, and RMSEA values obtained from confirmatory factor analysis indicated an adequate goodness of fit in this study sample ($X2(712) = 1887.31$; CFI = 0.899; TLI = 0.909; RMSEA = 0.062).

Convergent and Discriminant Validity

Being a male was positively associated with the perception of QoL in the domain "caring stress" but negatively associated with the perception of QoL in the domain "financial implications" (Table 2). Increasing age was significantly associated with a worst perception of overall QoL, "support for caring" and "personal growth". Also, an inverse association was described between single, divorced or widowed carers and their overall QoL, "caring choice" and "carer satisfaction." A higher educational level was directly associated with overall QoL, as well as the domains "support for caring," "financial implications" and "personal growth." Regarding household monthly income, those who reported an income above 1000€/month described better perceptions of their "financial implications" QoL, but worst perceptions of their "ability to care" QoL. Non-employed carers revealed a poor perception of their QoL on "caring choice" and "financial implications" domains. In comparison with being the spouse of the stroke survivor, being their son or daughter was directed associ-

ated with a higher perception of overall QoL, as well as on the "support for caring," "financial implications," "sense of value" and "ability to care" domains. Living with the survivors was significantly and positively associated with overall QoL, but the provision of care more than 8 hours per day was inversely associated with "caring choice" and "financial implications" domains. Carers with previous experience of caregiving reported lower QoL on "sense of value" domain. Finally, higher levels of anxiety, depressive symptoms and burden were negatively associated with the perception of QoL in all domains (Table 2).

DISCUSSION

The present study assessed the psychometric properties of the Portuguese version of the AC-QoL among informal carers of stroke survivors. To our knowledge, this represents the first attempt to culturally validate this tool in a European sample of stroke informal carers.

CFA supported the eight-factor structured adequacy, revealing significant correlations among all factors, except for the "caring choice" and "financial implications." A recent study conducted on stroke informal carers found an inverse association between carers' income and their ability to engage in health promotion behaviours and self-care activities, indicating that carers facing financial strain were less likely to have activities outside care [25]. Our sample had <1000€ monthly income, making outside care activities costly, which may be financially unfeasible [26]. As for the AC-QoL reliability, Cronbach's alpha value for the total score indicated an excellent level of internal consistency for the Portuguese version of the instrument, consistent with the values found in the original scale (alpha = 0.94) and in the Chinese validation (alpha = 0.92). Concerning its subscales, values were also adequate, with the maximum value found being higher than the original (alpha = 0.89) and the Chinese versions (Cronbach's alpha = 0.92) and the minimum being slightly lower than those two versions (alpha = 0.78 and 0.779, respectively). These findings suggest that the Portuguese version of the AC-QoL is a reliable instrument for informal carers of stroke survivors.

The associations between AC-QoL overall and subscale scores and carers' sociodemographic, caregiving-related and psychological indicate that multiple factors influence carers' QoL. Being older, single, non-employed, providing care for more than 8 hours per day, prior caregiving experience, and higher levels of burden, anxiety, and depression was associated with worst perception of QoL. Conversely, higher education, being the child of the stroke survivor, and sharing house were related to better perceptions of QoL.

These findings corroborate the ones obtained in a recent scoping review on the factors associated to the QoL of stroke informal carers [5], calling attention for

Table 2. Associations between the sociodemographic, caregiving-related, and psychological characteristics of the participants, and the AC-QoL scores

		Ac-QoL							
	Overall crude β (95%CI)	Support crude β (95%CI)	Choice crude β (95%CI)	Stress crude β (95%CI)	Money crude β (95%CI)	Growth crude β (95%CI)	Value crude β (95%CI)	Ability crude β (95%CI)	Satisfaction crude β (95%CI)
Sociodemographic characteristics									
Sex									
Male vs. Female	0.85 (−3.73; 5.42)	−0.44 (−1.32; 0.43)	0.26 (−0.92; 1.45)	**1.11 (0.05; 2.18)**	**−1.05 (−1.98; −0.12)**	0.40 (−0.65; 1.46)	1.01 (−0.35; 2.38)	−0.17 (−0.84; 0.50)	−0.29 (−0.99; 0.42)
Age, years	**−0.12 (0.24; −0.01)**	**−0.30 (−0.05; −0.01)**	−0.02 (−0.05; 0.02)	−0.01 (−0.03; 0.02)	−0.02 (−0.04; 0.01)	**−0.03 (−0.06; −0.01)**	−0.03 (−0.07; 0.01)	0.00 (−0.02; 0.02)	0.00 (−0.02; 0.02)
Marital status									
Single/divorced/widowed vs. Married/cohabiting	**−3.95 (−7.70; −0.21)**	−2.96 (−1.01; 0.42)	**−1.09 (−2.05; −0.12)**	−2.12 (−1.09; 0.67)	−0.23 (−1.00; 0.54)	−0.51 (−1.37; 0.36)	−0.50 (−1.62; 0.62)	−0.40 (−0.95; 0.15)	**−0.73 (−1.30; −0.15)**
Educational level, years									
5−9 vs. ≤4	**4.30 (0.81; 7.80)**	**0.87 (0.20; 1.53)**	0.86 (−0.04; 1.77)	0.27 (−0.55; 1.08)	**0.70 (0.01; 1.39)**	**0.99 (0.18; 1.80)**	0.36 (−0.69; 1.40)	0.10 (−0.42; 0.61)	0.17 (−0.37; 0.71)
≥10 vs. ≤4	3.36 (−0.36; 7.08)	**0.75 (0.04; 1.45)**	−0.27 (−1.23; 0.69)	−0.08 (−0.95; 0.79)	**2.29 (1.56; 3.03)**	0.42 (−0.44; 1.28)	1.01 (−0.10; 2.13)	−0.24 (−0.79; 0.31)	−0.52 (−1.10; 0.05)
Household income, €/month									
>1000 vs. ≤1000	0.71 (−2.62; 4.04)	0.36 (−0.27; 1.00)	−0.29 (−1.15; 0.57)	−0.68 (−1.46; 0.10)	**2.69 (2.07; 3.31)**	−0.42 (−1.19; 0.34)	0.10 (−0.89; 1.10)	**−0.67 (−1.15; −0.20)**	−0.38 (−0.89; 0.13)
Does not know/Prefer not to answer vs. ≤1000	0.73 (−3.93; 5.40)	0.61 (−0.28; 1.50)	−0.11 (−1.32; 1.10)	−0.59 (−1.67; 0.50)	**2.90 (2.03; 3.76)**	−1.05 (−2.13; 0.02)	0.87 (−0.52; 2.26)	**−1.66 (−2.32; −0.99)**	−0.24 (−0.95; 0.48)
Professional status									
Non-employed[a] vs. Employed	−3.08 (−6.26; 0.10)	−0.47 (−1.08; 0.13)	**−1.27 (−2.09; −0.46)**	−0.31 (−1.06; 0.43)	**−1.22 (−1.87; −0.58)**	0.28 (−0.46; 1.01)	−0.31 (−1.26; 0.64)	0.36 (−0.11; 0.82)	−0.12 (−0.61; 0.37)
Neighbourhood									
Rural vs. Urban	−0.64 (−3.64; 2.36)	−0.24 (−0.81; 0.34)	0.10 (−0.68; 0.88)	0.25 (−0.45; 0.95)	−0.18 (−0.79; 0.44)	−0.52 (−1.22; 0.17)	0.07 (−0.82; 0.97)	−0.32 (−0.76; 0.12)	0.19 (−0.26; 0.66)

Table 2. (Contd.)

	Ac-QoL								
	Overall	Support	Choice	Stress	Money	Growth	Value	Ability	Satisfaction
	crude β (95%CI)	crude β (95%CI)	crude β (95%CI)	crude β (95%CI)	crude β (95%CI)	crude β (95%CI)	crude β (95%CI)	crude β (95%CI)	crude β (95%CI)
Caregiving-related characteristics									
Relationship									
Son/Daughter vs. Spouse	**3.72** **(0.46; 6.98)**	**0.66** **(0.04; 1.28)**	0.02 (−0.83; 0.87)	0.29 (−0.48; 1.06)	**1.45** **(0.79; 2.10)**	0.40 (−0.36; 1.15)	**1.14** **(0.16; 2.11)**	−0.14 (−0.61; 0.34)	−0.10 (−0.60; 0.41)
Other[b] vs. Spouse	−0.89 (−5.38; 3.60)	0.76 (−0.10; 1.62)	−0.76 (−1.93; 0.41)	−0.19 (−1.24; 0.87)	**1.39** **(0.48; 2.29)**	−0.22 (−1.26; 0.83)	−0.29 (−1.63; 1.05)	**−0.98** **(−1.63; −0.32)**	−0.61 (−1.30; 0.09)
Lives with the survivor									
Yes vs. No	**3.76** **(0.31; 7.21)**	0.59 (−0.07; 1.25)	0.40 (−0.50; 1.30)	0.54 (−0.26; 1.35)	0.52 (−0.19; 1.22)	0.39 (−0.41; 1.19)	0.77 (−0.27; 1.80)	0.34 (−0.17; 0.84)	0.22 (−0.32; 0.75)
Hours of care provision/day									
≥8 h vs. <8 h	−3.81 (−7.97; 0.35)	−0.68 (−1.47; 0.11)	**−1.57** **(−2.64; −0.50)**	−0.79 (−1.77; 1.18)	**−1.81** **(−2.64; −0.97)**	0.79 (−0.17; 1.75)	−0.46 (−1.71; 0.78)	0.59 (−0.02; 1.20)	0.13 (−0.52; 0.77)
Previous experience of informal caregiving									
Yes vs. No	−2.70 (−5.94; 0.54)	−0.19 (−0.81; 0.43)	−0.73 (−1.57; 0.11)	−0.65 (−1.40; 1.11)	−0.17 (−0.84; 0.49)	−0.18 (−0.93; 0.57)	**−1.00** **(−1.97; −0.04)**	0.28 (−0.19; 0.76)	−0.06 (−0.56; 0.44)
Psychological characteristics									
Anxiety	**−1.44** **(−1.76; −1.12)**	**−0.17** **(−0.24; −0.11)**	**−0.36** **(−0.44; −0.27)**	**−0.41** **(−0.48; −0.33)**	**−0.16** **(−0.23; −0.10)**	−0.02 (−0.10; 0.06)	**−0.15** **(−0.25; −0.05)**	**−0.06** **(−0.11; −0.01)**	**−0.11** **(−0.16; −0.05)**
Depression	**−2.11** **(2.41; −1.81)**	**−0.28** **(−0.35; −0.22)**	**−0.45** **(−0.53; −0.36)**	**−0.46** **(−0.53; −0.39)**	**−0.24** **(−0.31; −0.17)**	**−0.18** **(−0.26; −0.10)**	**−0.24** **(−0.34; −0.13)**	**−0.10** **(−0.15; −0.05)**	**−0.17** **(−0.23; −0.12)**
Burden	**−0.78** **(−0.87; −0.70)**	**−0.06** **(−0.09; −0.04)**	**−0.21** **(−0.23; −0.18)**	**−0.16** **(−0.19; −0.14)**	**−0.07** **(−0.09; −0.04)**	**−0.03** **(−0.06; −0.01)**	**−0.12** **(−0.15; −0.09)**	**−0.04** **(−0.06; −0.02)**	**−0.09** **(−0.10; −0.07)**

95% CI—95% confidence interval; Bold type indicates statistically significant associations.
[a] Retired, unemployed, housewife, on sick leave; [b] Mothers, fathers, brothers, sisters, nephews and friends.
Support: support for caring; Choice: caring choice; Stress: caring stress; Money: money matters; Growth: personal growth; Value: sense of value; Ability: ability to care; Satisfaction: carer satisfaction.
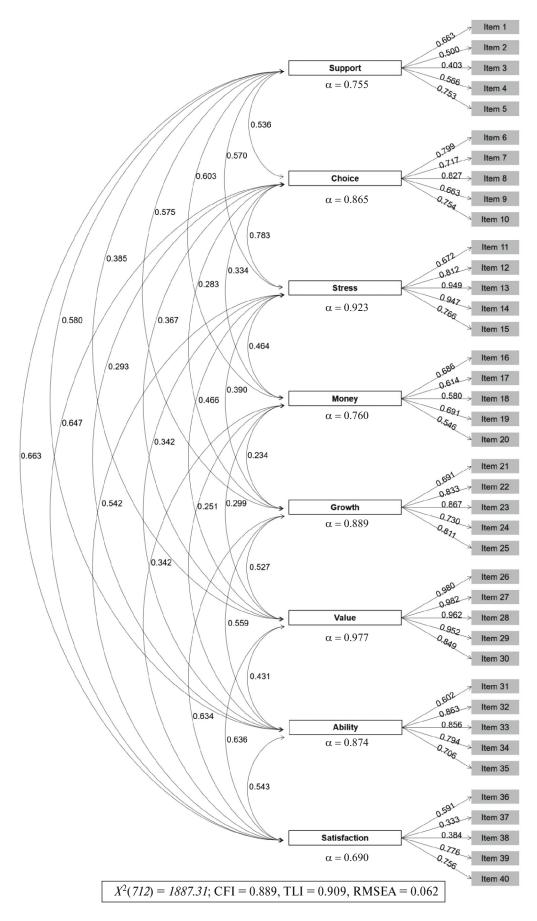
$X^2(712) = 1887.31$; CFI = 0.889, TLI = 0.909, RMSEA = 0.062

Fig. 1. Confirmatory factor analysis of the Portuguese Version of the AC-QoL. Confirmatory factor analysis supported that eight dimensions were reflected in the Portuguese Version of the AC-QoL. The majority of factors presented moderate ($0.41 < r < 0.60$) to strong ($0.61 < r < 0.80$) correlations with each other. The questionnaire showed a high degree of reliability, with an excellent Cronbach's alpha of 0.904. The CFI, TLI, and RMSEA values obtained from confirmatory factor analysis indicated an adequate goodness of fit in this study sample ($X^2(712) = 1887.31$; CFI = 0.899; TLI = 0.909; RMSEA = 0.062).

some "chains of risk" [27] in which carers' characteristics may increase strain, which may in turn adversely influence their mental health and QoL [3, 5, 7, 28, 29]. These results emphasize the relevance of AC-QoL as a valuable tool to identify groups at risk, allowing the development of proper target-oriented interventions.

Higher-income informal carers presented better perceptions of QoL [5, 7, 28], however, they also reported worst QoL concerning their caregiving ability. Being financially satisfied could be deeply related to carers' perception of financial capacity to care, which could be perceived as a form of instrumental support for caring [30]. While limited research explores the link between carers' income and their perceived caregiving capability, higher income often correlates with greater use of support services, especially among those with higher caring needs, namely, increased stress, burden and depression [31]. Our sample, experienced significant levels of burden and predominantly earning less than 1000€, which can increase the perception of caregiving incapacity. In the same way, carers' sense of frustration may arise from the unpredictability related to stroke survivor behaviors, their health condition evolution, and other unexpected events [32], leading to feelings of unmet needs and frustration toward the stroke survivor [30], that may affect the relationship between the dyad.

In our study, men from informal carers reported a better perception of QoL for "caring stress" and worse for "financial implications" than women, partially corroborating findings from previous studies. Some studies suggested that men may feel more stressed given having lower perceptions of caregiving preparedness [33], while studies highlighted their flexibility and resiliency, using more frequently problem-focused and action-oriented coping strategies [34, 35]. Thus, further discussion and extended distinction between coping strategies and forms of support according to carers perspectives is needed. Lower perceptions of QoL related to "financial implications" are consistent with previous studies [28, 33], relating them to caregiving-induced income loss, that can lead to significant decreases in family income and, consequently, in QoL perceptions. Additionally, and despite the lack of literature supporting associations between perceptions of financial strain, QoL and sex-role stereotypes [36], cultural expectations of men as financial providers, which is incompatible with a full-time carer, may explain these findings. Finally, being the spouse of the person needing assistance was inversely associated with QoL, as previously reported [5, 29].

The AC-QoL presented good psychometric properties and similar factorial structures with the original version, reinforcing the generalizability of the instrument. The Portuguese version of the AC-QoL was demonstrated to be a valid instrument not only to assess informal carers' QoL but also to detect groups at risk, allowing a holistic evaluation of carers' needs. By assessing both positive and negative aspects of the QoL, it will allow a more comprehensive view of stroke carers as well as more tailored and effective interventions.

At an intervention level, it represents a way of preventing negative outcomes and enhancing the positive consequences of caring, namely self-growth, resiliency, and social adjustment, which has been demonstrated to have a direct influence on the perception of the overall experience of caring, also contributing to improving carers' QoL [37]. From the clinical perspective, the AC-QoL enables a rapid assessment and monitoring of carers' QoL, providing a substantial source of information that may guide interventions, strategies, and recommendations aimed at reducing carers' psychological distress and promoting well-being and social integration of both stroke survivors and their informal carers.

Although this study addressed the underexplored multidimensional assessment of long-term QoL of informal carers of stroke survivors [7], it has limitations. We used a convenience sample from the North of Portugal that despite being the region with bigger population density [38] may differ in caregiving dynamics from other regions. Data collection methods varied (face-to-face and telephone/video calls), potentially introducing bias. However, the widespread smartphone use in Portugal (nearly 79%) [39] and research support the robustness of both methods suggesting no collecting data differences [40].

CONCLUSIONS

The Portuguese version of the AC-QoL is a comprehensive, simple, reliable, and valid instrument to assess informal stroke carers' QoL. For practice, it could be a valuable instrument, as it is a brief and easy to administer as well as valid for the Portuguese population. Integrating this instrument into healthcare settings and social practices will facilitate the identification of high-risk groups, and the development of more effective support strategies while empowering informal carers and promoting the main enablers for a better QoL. The use of AC-QoL provides researchers with a validated instrument to accurately measure the

impact of caregiving, facilitating the advancement of knowledge in this field and the development of targeted recommendations. Future studies should confirm the findings from this study using other European samples of stroke informal carers, throughout the care trajectory. Further analysis should confirm the instrument robustness and reliability in different cultural, economic, and political contexts, considering the duration of care provision and the survivors' level of dependency, and include model invariance across groups (e.g., age and sex).

INFORMED CONSENT

Both oral and written informed consent were obtained from the participants for their anonymized information to be published in this article.

SUPPLEMENTARY INFORMATION

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AUTHOR CONTRIBUTION

EA conceived the study and was involved in protocol development, while FT researched the literature and gained ethical approval. AM and FT were involved in participants' recruitment and EA in data analysis. FT wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

ETHICS APPROVAL
AND CONSENT TO PARTICIPATE

The study protocol was approved by the Ethics Committees and the respective Data Protection Offices of all 12 hospitals where the study is being conducted: Ethics Commission of the Centro Hospitalar de Entre o Douro e Vouga, Santa Maria da Feira (CA-0462/19-0t_MP/AC); Ethics Commission for Health of the Centro Hospitalar Universitário de São João, Porto (318/19); Ethics Commission of the Centro Hospitalar de Trás os Montes e Alto Douro, Vila Real (348/2019-C.A.); Ethics Commission for Health of the Centro Hospitalar de Vila Nova de Gaia/Espinho, Vila Nova de Gaia (197/219-2); Ethics Commission of the Centro Hospitalar do Médio Ave, Famalicão (C. Ética/24/2019); Ethics Commission for Health of the Centro Hospitalar do Tâmega e Sousa, Penafiel (PROC N° 48/2019); Ethics Commission of the Centro Hospitalar Universitário do Porto/Hospital de Santo António, Porto (N/REFª 2019.308(247-DEFI/264-CE); Ethics Commission for Health of the Hospital da Senhora da Oliveira, Guimarães (Ref. 69/2019); Ethics Commission of the Hospital de Braga, Braga (Refª 223_2019); Ethics Commission for Health of the Unidade Local de Saúde do Alto Minho/Hospital Santa Luzia, Viana do Castelo (56/2019-CES); Ethics Commission of the Unidade Local de Saúde de Matosinhos/Hospital Pedro Hispano, Porto (128/CE/JAS); Ethics Commission of the Unidade Local de Saúde do Nordeste, Unidade Hospitalar de Macedo de Cavaleiros (65/2019). In accordance with the General Data Protection Regulation, a set of procedures will be taken into account to comply with the requirements of the European Regulation regarding scientific research and the protection of personal data. The researchers provided clear, transparent, and detailed information about the following: research objectives, name, and institution of researchers, voluntary nature of participation, expected duration of the questionnaire, reasons for audio recording, procedures taken to protect personal data, participants' entitlement to obtain additional information and clarification on any aspect related to the study and the option to be informed about the results of the study, guarantee of the possibility to withdraw from the study at any time without consequences, and data retention period. Confidentiality, anonymity, and data protection were also guaranteed.

CONFLICT OF INTEREST

The authors of this work declare that they have no conflicts of interest.

REFERENCES

1. Murphy, S.J.X. and Werring, D.J., Stroke: causes and clinical features, *Medicine*, 2020, vol. 48, no. 9, pp. 561−566.

2. Gorelick, P.B., The global burden of stroke: persistent and disabling, *Lancet Neurol.*, 2019, vol. 18, no. 5, pp. 417−418.

3. Sennfält, S. and Ullberg, T., Informal caregivers in stroke: life impact, support, and psychological well-being—a Swedish Stroke Register (Riksstroke) study, *Int. J. Stroke*, 2020, vol. 15, no. 2, pp. 197−205.

4. Sidek, N.N., Kamalakannan, S., Tengku, I.T.A., Musa, K.I., Ibrahim, K.A., Abdul A.Z., and Papachristou, N.I., Experiences and needs of the caregivers of stroke survivors in Malaysia—a phenomenological exploration, *Front. Neurol.*, 2022, vol. 13, p. 996620.

5. Moura, A., Teixeira, F., Amorim, M., Henriques, A., Nogueira, C., and Alves, E., A scoping review on studies about the quality of life of informal caregivers of stroke survivors, *Qual. Life Res.*, 2022, vol. 31, no. 4, pp. 1012−1032.

6. Bucki, B., Spitz, E., and Baumann, M., Emotional and social repercussions of stroke on patient-family caregiver dyads: analysis of diverging attitudes and profiles of the differing dyads, *PLoS One*, 2019, vol. 14, no. 4, p. e0215425.

7. Pucciarelli, G., Ausili, D., Galbussera, A.A., Rebora, P., Savini, S., Simeone, S., Alvaro, R., and Vellone, E., Quality of life, anxiety, depression and burden among stroke caregivers: a longitudinal, observational multicentre study, *J. Adv. Nurs.*, 2018, vol. 74, no. 8, pp. 1875−1887.

8. Denham, A.M.J., Wynne, O., Baker, A.L., Spratt, N.J., Turner, A., Magin, P., Janssen, H., English, C., Loh, M., and Bonevski, B., "This is our life now. Our new normal": a qualitative study of the unmet needs of carers of stroke survivors, *PLoS One*, 2019, vol. 14, no. 5, p. e0216682.

9. Katan, M. and Luft, A., Global burden of stroke, *Semin. Neurol.*, 2018, vol. 38, no. 2, pp. 208−211.

10. Béjot, Y., Delpont, B., and Giroud, M., Rising stroke incidence in young adults: more epidemiological evidence, more questions to be answered, *J. Am. Heart Assoc.*, 2016, vol. 5, no. 5, p. e003661.

11. Okoye, E.C., Okoro, S.C., Akosile, C.O., Onwuakagba, I.U., Inegihu, E.Y., and Ihegihu, C.C., Informal caregivers' well-being and care recipients' quality of life and community reintegration—findings from a stroke survivor sample, *Scand. J. Caring Sci.*, 2019, vol. 33, no. 3, pp. 641−650.

12. Maltby, J., Hogervorst, E., Stephan, B., Sun, X., Tang, P., Law, E., and Mukaetova-Ladinska, E.B., The development of a quality of life scale for informal carers for older adults, *Gerontol. Geriatr. Med.*, 2020, vol. 6, p. 2333721420920424.

13. Joseph, S., Becker, S., Elwick, H., and Silburn, R., Adult carers quality of life questionnaire (AC-QoL): development of an evidence-based tool, *Ment. Health Rev. J.*, 2012, vol. 17, no. 2, pp. 57−69.

14. Chaknum, P., Harniratisai, T., Somprasert, C., and Chiang, L.C., Perception of the factors contributing to family happiness among caregivers of stroke survivors in a suburban community in Thailand: a qualitative study, *Malays. Fam. Physician*, 2023, vol. 18, p. 13.

15. White, C., Wood-Dauphinee, S., Mayo, N., Lauzon, S., Yaffe, M., and Hanley, J., Reliability and validity of a measure of quality of life for family caregivers of stroke survivors, *Stroke*, 2002, vol. 33, no. 1, p. 343.

16. Mei, Y., Lin, B., Li, Y., Ding, C., and Zhang, Z., Validity and reliability of Chinese version of Adult Carer Quality of Life questionnaire (AC-QoL) in family caregivers of stroke survivors, *PLoS One*, 2017, vol. 12, no. 11, p. e0186680.

17. Negri, L., Piazza, G., Sartori, R.D.G., Cocchi, M.G., and Delle, F.A., The adult carer quality of life questionnaire (AC-QoL): comparison with measures of burden and well-being, and Italian validation, *Disabil. Rehabil.*, 2019, vol. 41, no. 10, pp. 1207−1216.

18. Zhang, J. and Lee, D.T.F., Meaning in stroke family caregiving: a literature review, *Geriatr. Nurs.*, 2017, vol. 38, no. 1, pp. 48−56.

19. Pais-Ribeiro, J., Silva, I., Ferreira, T., Martins, A., Meneses, R., and Baltar, M., Validation study of a Portuguese version of the Hospital Anxiety and Depression Scale, *Psychol. Health Med.*, 2007, vol. 12, no. 2, pp. 225−237.

20. Sequeira, C., Adaptação e validação da Escala de Sobrecarga do Cuidador de Zarit, *Referência*, 2010, vol. 2, no. 12, pp. 9−16.

21. Hutcheson, G. and Sofroniou, N., *The Multivariate Social Scientist*, London: SAGE Publications, 1999.

22. Brown, T., *Confirmatory Factor Analysis for Applied Research*, New York: Guilford Publications, 2015.

23. Hu, L. and Bentler, P.M., Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives, *Struct. Equation Model.*, 1999, vol. 6, no. 1, pp. 1−55.

24. Taber, K.S., The use of Cronbach's Alpha when developing and reporting research instruments in Science Education, *Res. Sci. Educ.*, 2018, vol. 48, pp. 1273−1296.

25. Kavga, A., Govina, O., Galanis, P., Kalemikerakis, I., Vlachou, E., Fotos, N., Tziaferi, S., and Kalokairinou, A., Determinants of health promotion behaviors among family caregivers of stroke survivors, *Diseases*, 2021, vol. 9, no. 1, p. 10.

26. Rajsic, S., Gothe, H., Borba, H.H., Sroczynski, G., Vujicic, J., Toell, T., and Siebert, U., Economic burden of stroke: a systematic review on post-stroke care, *Eur. J. Health Econ.*, 2019, vol. 20, no. 1, pp. 107−134.

27. Litzelman, K., Skinner, H.G., Gangnon, R.E., Nieto, F.J., Malecki, K., and Witt, W.P., The relationship among caregiving characteristics, caregiver strain, and health-related quality of life: evidence from the Survey of the Health of Wisconsin, *Qual. Life Res.*, 2015, vol. 24, no. 6, pp. 1397−1406.

28. Willert, B. and Minnotte, K.L., Informal caregiving and strains: exploring the impacts of gender, race, and income, *Appl. Res. Qual. Life,* 2021, vol. 16, pp. 943−964.

29. Tsai, Y., Lou, M., Feng, T., Chu, T., Chen, Y., and Liu, H., Mediating effects of burden on quality of life for caregivers of first-time stroke patients discharged from the

hospital within one year, *BMC Neurol.*, 2018, vol. 18, no. 1, p. 50.

30. Campione, J.R. and Zebrak, K.A., Predictors of unmet need among informal caregivers, *J. Gerontol.*, 2020, vol. 75, no. 10, pp. 2181−2192.

31. Steenfeldt, V.Ø., Aagerup, L.C., Jacobsen, A.H., and Skjødt, U., Becoming a family caregiver to a person with dementia: a literature review on the needs of family caregivers, *SAGE Open Nurs.*, 2021, vol. 7, p. 23779608211029073.

32. Varughese, T., Casameni, M.T., Engebretson, J., Savitz, S.I., Sharrief, A., and Beauchamp, J.E.S., A person-centered approach understanding stroke survivor and family caregiver emotional health, *J. Neurosci. Nurs.*, 2022, vol. 54, no. 2, pp. 68−73.

33. Lopez−Anuarbe, M. and Kohli, P., Understanding male caregivers' emotional, financial, and physical burden in the United States, *Healthcare* (Basel), 2019, vol. 7, no. 2, p. 72.

34. Rahmani, F., Ranjbar, F., Hosseinzadeh, M., Razavi, S.S., Dickens, G.L., and Vahidi, M., Coping strategies of family caregivers of patients with schizophrenia in Iran: a cross-sectional survey, *Int. J. Nurs. Sci.*, 2019, vol. 6, no. 2, pp. 148−153.

35. Zygouri, I., Cowdell, F., Ploumis, A., Gouva, M., and Mantzoukas, S., Gendered experiences of providing informal care for older people: a systematic review and thematic synthesis, *BMC Health Serv. Res.*, 2021, vol. 21, no. 1, p. 730.

36. Tiegs, T.J., Heesacker, M., Ketterson, T.U., Pekich, D.G., Rittman, M.R., Rosenbek, J.C., Stidham, B.S., and Gonzalez-Rothi, L.J., Coping by stroke caregivers: sex similarities and differences, *Top. Stroke Rehabil.*, 2006, vol. 13, no. 1, pp. 52−62.

37. Qureshi, A., Hargest, C., Swain, N., Aldabe, D., and Hale, L., Psychosocial interventions for building resilience of informal carers of people living with stroke: a systematic review, *Disabil. Rehabil.*, 2023, vol. 45, no. 9, pp. 1419−1432.

38. Instituto Nacional de Estatística. Resultados provisórios Censos. https://www.ine.pt/ngt_server/attachfileu.jsp?look_parentBoui=535653930&att_display=n-&att_download=y. Cited October 19, 2021.

39. Instituto Nacional de Estatística. Inquérito à utilização de tecnologias da informação e da comunicação pelas famílias, https://www.ine.pt/ngt_server/attachfileu.jsp?look_parentBoui=465024825&att_display=n&att_download=y. Cited October 19, 2020.

40. Costantino, C., Mazzucco, W., Marotta, C., Saporito, L., Bono, S., Fiorino, G.R., Graziano, G., Maniglia, M., Marchese, V., Napoli, G., Palmeri, S., Provenzano, S., Raia, D.D., Santangelo, O.E., Ventura, G., Colaceci, S., Giusti, A., Casuccio, A., and Restivo, V., Methodological issues in a cross-sectional survey on cervical cancer screening using telephone interviews in Sicily (Italy): a SWOT analysis, *J. Int. Med. Res.,* 2019, vol. 47, no. 10, pp. 5174−5184.