RESEARCH

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The Informal Caregiver Burden Assessment Questionnaire: validation for Brazil

Questionário de Avaliação da Sobrecarga do Cuidador Informal: validação para o Brasil
Cuestionario de Evaluación de la Sobrecarga del Cuidador Informal: validación para Brasil

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ABSTRACT

Objectives: to analyze the dimensionality, convergent construct validity and internal consistency of the Informal Caregiver Burden Assessment Questionnaire (QASCI) after its semantic adaptation to Brazil. **Method:** this methodological study was developed with 132 informal caregivers of elders who are dependent of help for basic or instrumental activities of daily living, in a capital city in Northeast Brazil. Quality of life measures related to health, anxiety and depression were used in the analysis of the convergent construct validity of the QASCI. **Results:** the results of the instrument construct validation evidenced statistically significant correlations with the three measures. The confirmatory factor analysis evidenced good adjustment of the theoretical model of seven factors (domains) of the version used in the group studied. Cronbach's alpha for the scale total was 0.92. **Conclusion:** the Brazilian version of the QASCI was considered to be valid and reliable for assessing the burden of informal elder caregivers.

Key words: Nursing Methodology Research; Validation Studies; Caregivers; Elders; Geriatric Nursing.

RESUMO

Objetivos: analisar a dimensionalidade, validade de constructo convergente e consistência interna do Questionário de Avaliação da Sobrecarga do Cuidador Informal (QASCI) após sua adaptação semântica para o Brasil. **Método:** este estudo metodológico foi realizado com 132 cuidadores informais de idosos com dependência nas atividades básicas ou instrumentais de vida diária, em uma capital do Nordeste. Para análise da validade de constructo convergente do QASCI foram utilizadas medidas de qualidade de vida relacionada à saúde, ansiedade e depressão. **Resultados:** no geral, os resultados da validação de constructo do instrumento evidenciaram correlações estatisticamente significantes com as três medidas. A análise fatorial confirmatória evidenciou um bom ajuste do modelo teórico de sete fatores (domínios) da versão utilizada no grupo estudado. O alfa de *Cronbach* para o total da escala foi 0,92. **Conclusão:** a versão brasileira do QASCI mostrou-se válida e confiável na mensuração da sobrecarga de cuidadores informais de idosos.

Descritores: Pesquisa Metodológica em Enfermagem; Estudos de Validação; Cuidadores; Idoso; Enfermagem Geriátrica.

RESUMEN

Objetivo: analizar la dimensionalidad, validad de constructo convergente y consistencia interna del Cuestionario de Evaluación de la Sobrecarga del Cuidador Informal (QASCI), adaptado semánticamente para Brasil. **Método:** estudio metodológico realizado con 132 cuidadores informales de ancianos con dependencia en actividades cotidianas básicas o instrumentales, en una capital del noreste. Para análisis de la validad de constructo convergente del QASCI, se utilizaron medidas de calidad de vida relativas a salud, ansiedad y depresión. **Resultados:** los resultados de la validación de constructo del instrumento evidenciaron correlaciones estadísticamente significativas con las tres medidas. El análisis factorial confirmatorio evidenció un buen ajuste del modelo teórico de siete factores (dominios) de la versión utilizada en el grupo estudiado. El alfa de *Cronbach* para el total de la escala fue 0,92. **Conclusión:** la versión brasileña del QASCI se mostró válida y confiable para mensurar la sobrecarga de cuidadores informales de ancianos.

Palabras clave: Investigación Metodológica en Enfermería; Estudios de Validación; Cuidadores; Anciano; Enfermería Geriátrica.

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INTRODUCTION

Population aging is a global phenomenon that is related to changes in the age structure of the population, resulting from the decline in fertility and the increase in the number of elders(1). Upon aging, many elders start experiencing chronic and disabling diseases, with a frequent need to rely on the help of others in the family context to receive care(2).

Families have to be reorganized in order to take care of the elder in need of help, with a family member assuming the caregiver role, and carrying out activities that can occur on a sporadic or permanent basis. The relationship between caregiver and care dependent brings implications for the caregivers, most of them show levels of burden due to the practice of daily and uninterrupted care(3). Burden has been defined specifically as a resistance to providing care, caused by the addition or expansion of care activities(4).

Burden comprises two dimensions: objective and subjective. Objective burden is related to the activities performed in providing and monitoring care, as well as to disruptions and limitations imposed on the social and professional life of the family member and to financial conflicts. Subjective burden refers to the family members understanding and affection, concerns about the patient, the feeling of carrying a weight, and discomfort during care activities(5).

The burden of elder caregivers has been assessed in several ways, including with the use of instruments such as scales developed using the classical theory of items or psychometry. The use of such instruments has made it possible to identify that the process of caring for elders at home can determine limitations on the caregiver's life evidenced by the implications for the professional life, even because of job abandonment; lack of time to take care of themselves; marital conflicts; permanent tiredness; the perception of worsened health; excessive time dedicated to the care activity and the fact of not receiving help to take care of the elder person(6), as well as illness, social exclusion, depression, anxiety, imbalance between the activity and the rest period, compromised individual acceptance, as evidenced by the low influence on care situation and self-care(3).

In Brazil, some researches(7) have shown interest in this field of research, but the availability of instruments constructed or culturally adapted to assess the burden on Brazilian caregivers is still incipient. Therefore, there is a lack of systematic research in this area, which may result from lack of valid and reliable measurement instruments adapted to the Brazilian context for assessing the burden on family members providing care to elders. From this perspective, we highlight the need to semantically adapt and validate an instrument that can measure the specific changes to the provision of care to elders, specifically those considered dependents on help for activities of daily living.

The Informal Caregiver Burden Assessment Questionnaire (QASCI - Questionário de Avaliação da Sobrecarga do Cuidador Informal) was developed in Portugal to assess the physical, emotional and social burden on the informal caregiver diagnosed with cerebrovascular accident(8). Later, its psychometric properties were evaluated when it was used on informal caregivers of elders or persons dependent of help for at least one activity of daily living, including caregivers of patients with severe motor sequelae; heart, respiratory, digestive, or vascular diseases; diabetes; cataract; glaucoma; and blindness(9).

The contribution of the study is justified because we found that, in Brazil, most tools already validated for assessment of burden on elder caregivers were developed to specifically assess the burden on caregivers of people with psychiatric disorders(5).

In this study, we considered as informal caregiver (IC) the "unpaid person, family member or friend who assumed the role of main responsible for the organization or assistance and provision of care to the dependent person"(10). The proposed objectives were to assess the psychometric properties of the Informal Caregiver Burden Assessment Questionnaire (QASCI) after its semantical adaptation for use in Brazil.

METHOD

Study design, location and participants

A methodological and cross-sectional study was developed, which examined the validity and reliability of the QASCI instrument after its semantic adaptation for use in Brazil. The research was approved by the Ethics Committee of Lauro Wanderley University Hospital at the Federal University of Paraíba (UFPB), under protocol no. 345/2011, and authorized by the Municipal Secretariat of João Pessoa, state of Paraíba. The instrument main author provided authorization for the process of cultural adaptation of the QASCI instrument.

The research participants (caregiver of dependent elder) were identified through the registration on the Home Care Service of the Municipal Health Secretariat, whose information was passed on by community health agents (CHA). Data were collected through interviews held at households within the areas registered by the Family Health Teams, located in three Sanitary Districts (III, IV and V) in the city of João Pessoa.

Inclusion criteria selected for the functional dependent elders were as follows: age equal to or above 60 years; both genders; living in João Pessoa; experiencing, for at least six months, functional dependency situation in at least one Basic Activity of Daily Living (BADL)(11) or two Instrumental Activities of Daily Living (IADL) (12). For the elder caregivers, these were the criteria: age equal to or above 18 years, both genders and living in João Pessoa; having their cognitive conditions evaluated through the mini-mental state examination (MMSE)(13); being the main responsible for the care and assistance with daily activities of the family member or friend over 60 years old; and receiving no remuneration for exercising the caregiver role. It is noteworthy that the degree of dependence of the elders in basic and instrumental activities of daily living was assessed from the point of view of their respective caregivers.

Data collection and measurement instruments

Data collection relied on the participation of the main researcher and seven students from UFPB's Nursing Undergraduate Course who were trained by the researcher and divided into pairs during the interviews, which were scheduled and monitored by the CHAs of each coverage area. Data were collected between the months of September 2012 and February 2013. Data on sociodemographic characteristics of elder caregivers were obtained. Other instruments used were the following scales:

- Informal Caregiver Burden Assessment Questionnaire (QASCI), which consists of 32 items comprising seven dimensions: Implications for personal life (11 items); Satisfaction with the role and the family member (five items); Reactions to demands (five items); Emotional burden (four items); Family support (two items); Financial burden (two items) and Perception of efficacy and control mechanisms (three items). Each item is assessed by an ordinal frequency scale ranging from one to five answer categories: "No/Never", "Rarely", "Sometimes", "Almost always", "Always". The final score results from the sum of the answers obtained for the 32 items (possible range from 32 to 160) related to each field, divided by the total number of domains or by the mean of items (range from one to five) after reversal of scores in the items of the three positive dimensions. We consider that higher values correspond to situations with higher relevance or higher burden(8).
- The version adapted and validated to Brazil(14) of the Ware and Sherboune instrument named Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) was used to assess health-related quality of life (HRQOL). It consists of 35 items divided into eight domains (Functional capacity, Physical aspects, Pain, General health status, Vitality, Social aspects, Emotional aspects and Mental health) and another item that makes a comparative evaluation between current health conditions and the conditions in the previous year. Each domain is converted into a scale from 0 to 100, considering that the higher values correspond to situations with better health-related quality of life.
- The version adapted and validated to Brazil(15) of the scale published in 1983 by Zigmond and Snaith named Hospital Anxiety and Depression Scale (HADS) was used to assess the presence of symptoms of anxiety and depression in caregivers. The HADS contains 14 questions (seven for anxiety and seven for depression) addressing somatic and psychological symptoms, with a four-point answer scale. The answer values range from 0 to 3 and their sum can vary from 0 to 21 points for each of the emotional disorders researched. Thus, the evaluation of the answers can be made with the total amount of each subscale (HADS-Anxiety and HADS-Depression), and the higher the value, the higher the amount of anxiety and depression symptoms(15).

Validation of the QASCI adapted version and statistical analysis

The study considered the steps recommended in national and international technical literature and described as follows(16-17): the original QASCI European Portuguese version was initially semantically adapted for use in our country by the researchers of this study. This first version in Portuguese for Brazil was submitted to evaluation by a committee of five experts (with expertise in the subject and methodology) for analysis of semantic, cultural, idiomatic and conceptual equivalences, aiming to prove the face and content validity. The approval was granted upon the agreement of above 85% of the experts, resulting in the second version in Brazilian Portuguese. The psychometric properties of this version in Portuguese for use in Brazil were analyzed with 132 elder caregivers.

Construct validity was verified by three methods: the dimensionality of the QASCI adapted version, using confirmatory factor analysis (CFA); the correlation between caregiver burden measures (QASCI) with related construct measures - health-related quality of life (SF-36), depression (HADS-Depression scale) and anxiety (HADS-Anxiety scale).

In the Confirmatory Factor Analysis (CFA), the model parameters were estimated considering the maximum likelihood method, using PROC CALIS procedure of SAS® Program. To interpret the values obtained, we consider the values of Root Mean Square Error of Approximation (RMSEA), ranging between 0.05 and 0.08, with value near zero, considered acceptable; Goodness-of Fit Index (GFI) and Comparative Fit Index (CFI), both with variation from zero to one, where value zero indicates poor/week fit and value one the perfect fit(18).

For convergent construct validity, we established the following assumptions: that there would be negative correlations, at least, in moderate level between the total burden measure and SF-36 domains; and that there would be a positive correlation between the QASCI measure and the anxiety (HADS-Anxiety) and depression (HADS-Depression) subscales. These correlations were verified by calculating the Pearson linear correlation coefficient.

Internal consistency analysis of the items in the QASCI Brazilian version was verified by Cronbach's Alpha coefficient and results reaching from 0.70 to 0.90 were considered adequate(19).

The significance level adopted was 0.05 for hypotheses testing. Data were processed and analyzed in the Statistical Package for the Social Sciences (SPSS) Software Program, version 21.0, for Windows 7.0®.

RESULTS

The scale validation study included 132 informal caregivers of elders who are dependent of help for basic or instrumental activities of daily living. The mean age of caregivers was 49.74 years (ranging from 19 to 83), the majority were female (87.1%), and 47.7% were married. Regarding education, 31.8% had completed high school, with a mean of 8.3 years of schooling (ranging from 0 to 15), and 57.6% reported housework as the main activity/occupation.

Regarding the family relationship to the elder, 62.9% were children and 13.6% spouses. Most caregivers (88.6%) lived in the elder's house. The mean time devoted to care of the elder was 6.87 years (ranging from six months to 30 years). Regarding the possibility of having help to take care of the elder, 47.7% said they always or almost always counted on the help of another person, however 38.6% said they did not receive help. Regarding the amount of days dedicated to the care of the elder, during the weekdays and on weekends, caregivers had means of 4.95 weekdays (ranging from 3 to 5) and 1.89 days on weekends (ranging from 0 to 2), respectively.

Regarding the elders' sociodemographic characteristics, the mean age was 80 years (ranging from 64 to 100), with a predominance of older women (68.2%) with a mean time of education of four years, that is, they had not completed elementary school (43.2%). The mean number of people living with the elder was 3.8 individuals (ranging from 1 to 13). Among them, 22.7% were relatives of trigenerational arrangements (elder, children and grandchildren), and 19.7% were children.

Table 1 shows the frequency of answers given by caregivers to the 32 items of the QASCI adapted version according to the scale values from one to five. Most of the items had more than 50% of their answers to the extreme values of the answer scale ("No/Never" or "Always"), as occurred in 19 of the 32 items. Several participants marked value one ("No/Never") in the answer scale, making a total of 12 items (4, 5, 7, 10, 13, 15, 16, 17, 19, 20, 21, 22). In seven items (24, 25, 28, 29, 30, 31, 32), they marked value five ("Always"). The highest frequencies in the answer scale corresponded to items 30 and 31 with values of 81.8% and 84.8%, respectively.

Table 1 - Percentage of items to the answers of the QASCI* version adapted to Brazil for the 132 elder caregivers, João Pessoa, 2012-2013

QASCI Items	No / Never %	Rarely %	Sometimes %	Almost always %	Always %
1. Do you feel like getting out of the situation you are in?	45.5	9.1	30.3	6.8	8.3
2. Do you consider that taking care of your relative is psychologically difficult?	32.6	9.8	31.8	11.4	14.4
3. Do you feel tired and exhausted of taking care of your relative?	38.6	9.8	31.8	8.3	11.4
4. Do you conflict with yourself for taking care of your relative?	51.5	15.2	22.7	6.1	4.5
5. Do you think your health has worsened for taking care of your relative?	59.8	8.3	17.4	8.3	6.1
6. Is taking care of your relative requiring great physical effort?	30.3	15.9	26.5	7.6	19.7
7. Do you feel like you have lost control of your life since your relative got sick?	6.8	9.1	18.9	4.5	10.6
8. Have the plans you made for this stage of life changed for taking care of your relative?	41.7	9.8	28.8	6.1	13.6
9. Do you think you devote much time taking care of your relative and that your time is not enough for you?	37.1	13.6	28.8	9.8	10.6
10. Do you feel like life has played a trick on you?	54.5	6.1	13.6	9.8	15.9
11. Is it difficult to plan for the future since the needs of your relative are unpredictable?	28.0	6.1	36.4	8.3	21.2
12. Does taking care of your relative make you feel like being stuck?	34.8	8.3	25.8	9.8	21.2
13. Do you avoid inviting friends to your home because of your relative's problems?	64.4	4.5	12.9	3.8	14.4
14. Has your social life (e.g., vacations, socializing with family and friends) been hampered for taking care of your relative?	43.2	8.3	31.1	5.3	12.1
15. Do you feel lonely and isolated for taking care of your relative?	63.6	7.6	11.4	4.5	12.9
16. Are you experiencing economic (financial) difficulties for taking care of your relative?	55.3	6.1	28.8	2.3	7.6
17. Do you feel like your economic (financial) future is uncertain for taking care of your relative?	59.1	6.1	25.0	1.5	8.3

Continues

Table 1 (cont.)

18. Have you ever felt offended and angry due to your relative's behavior?	40.2	10.6	28.8	10.6	9.8
19. Have you ever felt ashamed due to your relative's behavior?	72.7	5.3	13.6	6.1	2.3
20. Do you feel like your relative often requests your help for unnecessary situations?	51.5	9.8	18.2	8.3	12.1
21. Do you feel manipulated (used) by your relative?	73.5	4.5	11.4	3.0	7.6
22. Do you feel like you do not have as much privacy as you like for taking care of your relative?	52.3	7.6	21.2	6.8	12.1
23. Can you do most activities you need despite the time you spend taking care of your relative?	9.8	10.6	14.4	27.3	37.9
24. Do you feel able to continue taking care of your relative for much longer?	3.0	3.0	12.9	10.6	70.5
25. Do you think you have knowledge and experience enough to take care of your relative?	3.0	4.5	10.6	17.4	64.4
26. Do your family members (relatives that do not live with you) value your work of taking care of your relative?	17.4	10.6	13.6	12.1	46.2
27. Do you feel supported by your relatives?	9.8	11.4	16.7	17.4	44.7
28. Does it feel good to take care of your relative?	0.0	1.5	12.1	10.6	75.8
29. Does your relative show gratitude for what you are doing for him/her?	11.4	7.6	18.9	7.6	54.5
30. Do you feel satisfied when your relative feels glad about little things you do to him/her (such as attention, affection and small gifts)?	0.8	3.0	5.3	9.1	81.8
31. Do you feel closer to your relative for taking care of him/her?	0.8	1.5	3.8	9.1	84.8
32. Has taking care of your relative increased your self-esteem, making you feel like a special person with greater value?	2.3	3.0	13.6	18.2	62.9

**QASCI (Informal Caregiver Burden Assessment Questionnaire) - version adapted to Brazil.*

Table 2 - Descriptive analysis and internal consistency of the QASCI* total score and its domains for the sample studied (N = 132), João Pessoa, 2012-2013

Domínios QASCI (nº de itens, intervalo possível)	Alfa de *Cronbach*	Intervalo obtido	Mediana	Média (Desvio-padrão)
QASCI total score (32 items, 32 to 160)	0.92	32 – 131	65.0	66.8 (22.86)
Emotional burden (4 items, 4 to 20)	0.80	4 – 20	9.0	9.29 (4.21)
Implications for personal life (11 items, 11 to 55)	0.88	11 – 54	23.5	25.68 (10.86)
Financial burden (2 items, 2 to 10)	0.59	2 – 10	3.5	3.94 (2.16)
Reactions to demands (5 items, 5 to 25)	0.76	5 – 22	9.0	10.04 (4.73)
Perception of effectiveness and control mechanisms (3 items, 3 to 15)	0.51	3 – 12	5.0	5.49 (2.44)
Family support (2 items, 2 to 10)	0.80	2 – 10	4.0	4.65 (2.69)
Satisfaction with the role and the relative (5 items, 5 to 25)	0.76	5 – 20	7.0	7.72 (3.46)

**QASCI (Informal Caregiver Burden Assessment Questionnaire) - version adapted to Brazil.*

With regard to the internal consistency of the items in the QASCI Brazilian version, we obtained a Cronbach's alpha of 0.92 for the scale as a whole. The alpha values for the domains ranged from 0.88 (Implications for personal life) to 0.51 (Perception of effectiveness and control mechanisms) (Table 2).

In the construct validity analyses, we found correlations between the total burden measure to its domains, with values ranging from r = 0.92 to 0.39, all statistically significant. There were also strong correlations between the total burden measure and four domains: Implications for personal life (r = 0.92; p = 0.001), Emotional burden (r = 0.81; p = 0.001), Reactions to demands (r = 0.76; p = 0.001) and Satisfaction with the role and the relative (r = 0.72; p = 0.001).

In convergent construct validation, we obtained high intensity correlations for Vitality (r = -0.57; p = 0.001) and Mental health (r = -0.55; p = 0.001) domains, and moderate intensity correlations with Social aspects (r = -0.45; p = 0.001), Emotional aspects (r = -0.33; p = 0.001) and Functional capacity (r = -0.30; p = 0.001) domains. We did not confirm our hypothesis for the other domains (Pain, General health status and Physical aspects). We confirmed the positive direction of the correlations between burden and anxiety measures (r = 0.50; p = 0.001) and burden and depression (r = 0.61; p = 0.001) measures among caregivers, in addition to the force among the measures.

The dimensionality of the QASCI adapted version was analyzed based on the confirmatory factor analysis. The seven-factor (domains) theoretical model of the instrument original version was tested through CFA, using data from 132 caregivers. As a result, we noticed that the root mean square error of approximation (RMSEA) had a value of 0.0709, which is considered acceptable. Goodness Fit Index (GFI) and Bentler's Comparative Fit Index (CFI) indices had values of 0.7533 and 0.8328, respectively. Both results also indicated good fit of the measure model to QASCI version validated for Brazil with correlations between its size and the caregiver burden construct.

DISCUSSION

The choice to adapt the QASCI for use in Brazil was encouraged since it is a valid and reliable instrument, tested on caregivers of elders with functional dependence and those experiencing chronic diseases(8).

The cultural adaptation process was based on national and international technical literature, which supported the studies previously performed by researchers from the Group for Research on Rehabilitation and Quality of Life in which we operate, evidencing the face and content validities of the QASCI scale(7).

In a recent study that evaluated the psychometric properties of two experimental versions of the QASCI, the author found that the results of the percentage of each item showed extreme answers, that is, No/Never or Always, in 27 items(20). Similar results were observed in our study.

In the descriptive analysis of the QASCI adapted version, we found a high burden total mean. We identified higher burden on caregivers who provided care to dependent elders. This corroborates the records in the technical literature stating that taking care of a dependent elder has been considered by family members providing care as a tiring and stressful task(3). In order to verify the tension attributes of the family member providing care to dependent elders registered in the Elder Care Program of João Pessoa University Hospital, in Paraíba, the authors found that most caregivers had a high level of tension during care activities, highlighting the presence of signs and symptoms of psychosomatic or chronic diseases; changes in emotional state, especially depression and anxiety; imbalance between the activity and rest period; and compromised individual acceptance, as evidenced by the low influence on care situation and self-care(3).

In the process of validation of an instrument, it is important to analyze reliability, considering the internal consistency of items. In our study, the Cronbach's alpha obtained for the QASCI full version was 0.92. This value was similar to the alpha of 0.90 obtained for the original version(8), as well as in the study for revaluation of its psychometric properties(9).

The seven-factor (domains) theoretical model of the instrument original version(8) was tested through CFA. The results of this analysis indicated good fit of the measure model to the QASCI version validated for Brazil with correlations between its size and the caregiver burden construct. Since there is no studies on the QASCI validation in other cultures using CFA to confirm the theoretical model in other countries, we cannot compare the results obtained in our study.

When evaluating the construct validity of the QASCI Brazilian version, considering the correlations of burden total measure with the scale domains measures, we noticed values ranging from strong to moderate intensity. These results were similar to those obtained in the study with the QASCI original version(8). When evaluating the convergent construct validity of the adapted version, correlating the burden total score to the SF-36 dimensions, used as health-related quality of life measure, we obtained similar values to those of the authors of the QASCI Portuguese versions(8-9).

As the Portuguese authors, we also correlated the burden measure with anxiety and depression measures to test the convergent construct validity. In our study, we found results contrary to those obtained with the original version(8), with positive correlation in strong magnitude among burden and depression measures and positive correlation in moderate magnitude among burden and anxiety measures. The results of revaluation studies on the characteristics of the QASCI and a reduced version found strong correlations between total burden and anxiety and depression measures(9,20), also differing from our results.

CONCLUSION

According to the proposed objectives and the results obtained in this methodological study, we conclude that the QASCI version adapted to Brazil kept the psychometric properties of the original version when tested in a group of elder caregivers residents in a capital city in Northeast Brazil. The results corroborate to indicate that the adapted version has adequate internal consistency for the total scale and most domains. The correlations between overload, health-related quality of life, anxiety and depression constructs also bring evidence of convergent construct validity of the adapted version. Confirmatory factor analysis showed that the theoretical model had good fit in the group studied.

Based on these results, we believe that the QASCI adapted version, although in need of being psychometrically tested in other groups of caregivers, could be used by health professionals, specifically nurses working in Basic Health Care, aiming at identifying the existence of burden in elder caregivers and proposing interventions in the care process towards the caregivers, which can contribute to the maintenance of their physical and mental health and their quality of life.

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