Content validity of the quality of life instrument for families of people with cancer

Validade de conteúdo do módulo de qualidade de vida para familiares de pessoas com câncer

Validez de contenido del instrumento de calidad de vida para familias de personas con cáncer

RESUMO
Objetivo: validar o conteúdo domódulo de qualidade de vidade familiares de pessoas com câncer. Método:Desenvolveu-se em etapas de elaboração do instrumento, avaliação por peritos e compreensão semântica pelo público alvo. Os dados foram descritos em frequência simples e analisados por meio do cálculo do Índice de Validade de Conteúdo, superior a 0,78.Resultados:Aconfecção dos itens do instrumento através dolevantamento de bases teóricas na literatura e a elaboração da matriz de especificações originou 40 itens. Após a análise por especialistas, obteve-se 21 itens para o pré-teste e Índice de Validade de Conteúdo global e razão de validade de conteúdo. No pré-teste, 5 itens foram reformulados e excluídos, obtendo-se 16 itens. Conclusão:O desenvolvimento e a validação de conteúdo do resultou em um instrumento conceitualmente apropriado para avaliar familiares de pessoas com câncer, estando apto a prosseguir para a validação empírica.
DESCRITORES: Estudo de Validação;Psicometria; Qualidade de vida; Família;Neoplasias.

ABSTRACT
Objective: to validate the content of the quality of life module for family members of people with cancer. Method: The instrument was developed in stages, evaluated by experts and semantically understood by the target audience. The data was described in simple frequency and analyzed by calculating the Content Validity Index, which was greater than 0.78. Results: The creation of the instrument's items through the survey of theoretical bases in the literature and the elaboration of the specifications matrix resulted in 40 items. After analysis by experts, 21 items were obtained for the pre-test and the overall Content Validity Index and content validity ratio. In the pre-test, 5 items were reformulated and excluded, resulting in 16 items. Conclusion: The development and content validation of the questionnaire resulted in an instrument that is conceptually appropriate for assessing family members of people with cancer and is ready to proceed to empirical validation.
DESCRIPTORS: Validation Study; Psychometrics; Quality of Life; Family; Neoplasms.

RESUMEN
Objetivo: Validar el contenido del módulo de calidad de vida para familiares de personas con cáncer. Método: El instrumento fue desarrollado por etapas, evaluado por expertos y comprendido semánticamente por el público objetivo. Los datos se describieron en frecuencia simple y se analizaron mediante el cálculo del Índice de Validez de Contenido, que fue superior a 0,78. Resultados: Los ítems del instrumento fueron creados a partir de la investigación de las bases teóricas en la literatura y de la elaboración de la matriz de especificaciones, que resultó en 40 ítems. Tras ser analizados por expertos, se obtuvieron 21 ítems para el pre-test y el Índice de Validez de Contenido global y el coeficiente de validez de contenido. En el pre-test, 5 ítems fueron reformulados y excluidos, resultando 16 ítems. Conclusión: El desarrollo y la validación de contenido del cuestionario resultaron en un instrumento conceptualmente apropiado para evaluar familiares de personas con cáncer, y está listo para proceder a la validación empírica.
DESCRIPTORES: Estudio de validación;Psicometría;Calidad de vida;Familia;Neoplasias.

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INTRODUCTION

The diagnosis of cancer in a family member leads to changes in the family structure. The situation is exacerbated by the fact that it is a stigmatized disease that is feared by the population, due to the suffering it causes the patient and the family(1,2).

Changes resulting from this impact generate stress and internal and external imbalances. Among the changes are: an overload of tasks, changes in sleep and eating habits, concern about disorganization in the family structure, symptoms of stress and depression, and restrictions on social activities due to caring for the sick family member. These impacts can affect the quality of life (QoL) of the other members of the family system (3-5,7,8).

For the World Health Organization (WHO), QoL is the individual's own conception of their position in life, their cultural and social values, their goals, expectations and concerns (3).

QoL is an emerging phenomenon in the literature and today there is a growing variety of instruments to assess it. Generic instruments can be used with the entire population, while specific ones assess people with specific conditions, are more sensitive to the population and investigate particular aspects of the clinical condition in question (3,9-11).

In view of the diversity of concepts and instruments for assessing QoL, generic QoL assessment instruments are the most widely used in the literature and assess general aspects related to family caregivers, especially when it comes to family members who are chronically ill(8,12,14,15).The widespread use of general instruments to measure QoL highlights the lack of specific instruments to assess family members of people with cancer. In view of this, it was necessary to build a module to measure the QoL of family members who have a relative with cancer, since this condition causes psychological, biological and social changes (4-7). In this context, this study is justified both by the need for more specific knowledge about the QoL of this group, based on the reality of the Brazilian family, and by the lack of specific instruments to measure it.

Thus, the aim of this study was to develop and validate the content of the QoL instrument for family members of people with cancer, considering the tenuous relationship between the family's experience and the aspects of QoL that are affected by the new demands.

METHODS

A methodological study that used systematic procedures to develop and validate the content of a quality of life module for relatives of people with cancer (MQV-FAMC) (16).

First stage: Development of the MQV-FAMC instrument

Initially, a literature review was carried out and manuscripts were selected that dealt with the experiences, feelings and perceptions of family members accompanying the treatment of relatives with cancer, in order to support the formation of the conceptual bases (16-19).

The facets and descriptors were drawn up based on the operational definitions and aspects raised in the exploration, containing the domains defined

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using the WHOQOL-bref. At this stage, three meetings were held with the research team to screen and review the items, which were grouped into domains and their respective facets (16-19).

The wording was then revised to improve clarity, avoid ambiguities and ensure that the answers were not suggested or induced. As a scoring criterion, the scale used in the WHOQOL- bref was maintained, a 5-point likert scale relating to frequency and intensity.

After defining the matrix, two focus groups were held with family participants, gathering information on whether they were representative and relevant to the context.

Second stage: Evaluation of the MVQ-FAMC instrument

A total of 13 experts were invited, health professionals with expertise in the subject area, but 10 took part. The evaluation by experts sought to analyze the suitability of the items in terms of clarity and relevance, in order to incorporate or remove the items evaluated, opting for modifications to improve the suitability of the instrument (16-19).

The Delphi technique was used to evaluate the experts, and a form was developed to evaluate the scope of the instrument in general, checking that the content contained in the domain was representative. A 4-point scale was used to indicate the degree of suitability with the quality of the item. The experts commented on the usefulness, suggestions, modifications, exclusions or additions to the questionnaire. In order to visualize the structure and composition of the items, the generic instrument, the WHOQOL-bref, which should be applied together with the MQV-FAMC (16-19,21, 22), was provided.

Esses profissionais foram selecionados a partir das consultas realizadas na Plataforma Lattes do Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq), e contatados via e-mail. Foi encaminhado, aos que aceitaram participar do estudo, o Termo de Consentimento Livre e Esclarecido (TCLE), o Instrumento de Caracterização dos Juízes, o módulo desenvolvido e o formulário de avaliação. Não foram reunidos presencialmente por questões geográficas e incompatibilidade de horários comuns a todos (16-19).

These professionals were selected based on consultations carried out on the Lattes Platform of the National Council for Scientific and Technological Development (CNPq), and contacted via e-mail. Those who agreed to take part in the study were sent the Informed Consent Form (ICF), the Judges Characterization Tool, the module developed and the evaluation form. They were not met face-to-face for geographical reasons and incompatibility of schedules common to all (16-19).

The data was analyzed by describing the opinions issued by the judges and calculating the Content Validity Index (CVI), to provide the proportion of judges in agreement on certain aspects of the instrument and its items. It was calculated by adding the score of the items that received a 3 or 4 for each criterion separately and dividing by the total number of responses (10 experts). An appropriate CVI index greater than or equal to 0.78 was adopted. The items in the instrument with a CVI of less than 0.78 were re-evaluated or excluded during the review process based on the considerations of the expert committee (16-19).

Third stage: Semantic comprehension

This stage investigated, from the perspective of the target population, whether the instrument was suitable for comprehension. It was carried out with 31 family members who were accompanying relatives undergoing treatment at a High Complexity Oncology Unit in a municipality in the interior of Bahia. The number of participants was chosen according to the criteria established in the literature, which recommends a sample of 30 to 40 people for the pre-test (19).

Those who met the eligibility criteria participated in the study: age 18 or over, having a relative undergoing cancer treatment, being the closest person to the relative with cancer, living with them and maintaining a continuous relationship, having accompanied the relative at least once during the course of treatment. For data collection, the Questionnaire for the Characterization of Family Members of People with Cancer and the preliminary version of the MQV-FAMC were used.

Family members were approached in the service's waiting room, and those who agreed to take part were informed about the research and ethical aspects. The instrument was applied by means of an interview, and the family members who took part provided information for refining the instrument by checking that the items were being understood. If an item was not understood, it was suggested that the interviewee provide synonyms. In this way, possible problems in understanding the item were identified (17-19).

The operational analysis was then carried out to assess aspects relating to the use of the instrument, such as the suitability of the instructions for answering, scoring, the format of the items, the place where the instrument was applied and the method of application. The study was submitted to the Research Ethics Committee of the State University of Feira de Santana and was approved under protocol number 3.026.668.

RESULTS

The construction of the preliminary version of the MQV-FAMC resulted in the specifications matrix, initially made up of 40 items distributed in the same domains as the generic instrument, the WHOQOL-bref (Chart 1). After the first evaluation of the matrix, a theoretical evaluation was carried out in order to decide which items should remain.

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A version with 24 items was obtained.

The MQV-FAMC was evaluated by two groups of family members who said that the items created were relevant, pertinent, clear, understandable and important.The analysis using the CVI calculation showed that there were no disagreements regarding the relationship established between the domains, facets and the respective items. As for the individual evaluation of the 24 items, in terms of clarity it was found that 6 items (25%) achieved a CVI of 1; 8 (33.3%) of 0.90; 3 (12.5%) of 0.80. It is worth noting that 17 items from the MQV-FAMC version scored above 0.78 in this assessment and 7 scored below 0.78 (Table 1).

The analysis of the relevance of the 24 items showed that 12 (50.0%) had a CVI of 1; 8 (33.3%) had a CVI of 0.90; 3 (12.5%) had a CVI of 0.80. Thus, 23 items in the version of the MQV-FAMC scored more than 0.78 and only one scored less than 0.78 and was excluded (Table 2). Given the few items that had a CVI of less than 0.78 in the analysis of pertinence and clarity in assessing the QoL of relatives of people with cancer, we decided to adjust and maintain four items, since at that point we carried out a theoretical analysis of the instrument.

Chart 1- Preliminary version of the MQV-FAMC. Feira de Santana, 2019

RESULTS OF THEORETICAL EXPLORATION	FACETAS	PRELIMINARY ITEMS
Physical Domain		
Inexperience and complexity of patient care Lack of willingness to carry out daily activities	Physical overload Capacity for daily activities	1. How much does your relative need your help to look after themselves? 2. Do you carry out any other daily activities apart from caring for your relative? 3. Are you able to look after your relative on your own? 4. How stressful is this experience for you? 5. Do you find it difficult to care for your relative with cancer? 6. How often do you accompany your relative during treatment? 7. How well are you able to feed yourself? 8. Do you feel tired when caring for your relative with cancer? 9. How much does caring for your relative prevent you from carrying out activities such as studying or working?
Psychological domain		
Lack of interest in health care Sadness, fear, anxiety, tension Guilt, feeling of powerlessness Spiritual practices seeking meaning in suffering	Selfcare Psychological overload Guilt Spiritual support	10. How often do you have medical check-ups? 11. How much do you care about your appearance? 12. How much does caring for your relative make it impossible to care for yourself? 13. How much did your health problem intensify after caring for your relative? 14, How much does your relative's illness cause you suffering? 15. How painful is it for you to accompany your relative to treatment? 16. Do you feel guilty about the situation your relative is experiencing? 17. How often do you go to a religious institution? 18. How important is religion in coping with this situation?
Social Relations		

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Changes in relationships with other family members The need to share the suffering experienced Need for emotional support Need information about your relative's medical condition	Family reorganization Social support Professional support Interaction with the team	19. How much your relative's illness affects your relationship with other family members. 20. How much has your relative's illness changed your family's daily life? 21. How often do you take on new roles in your family when your relative becomes ill? 22. How satisfied you are with the support you receive from your friends. 23. How much you would like to talk about your relative's illness with other people? 24. How important is it for you to talk about this situation? 25. Do you feel the need to have people around to support you? 26. How often do you have contact with the team psychologist? 27. How important is it for you to have contact with a psychologist? 28. How do you feel when you have contact with a psychologist? 29. How often do you have contact with health professionals while your relative is undergoing treatment? 30. How do you feel about the information given by the service professionals about your relative? 31. Is the guidance given on the care to be provided sufficient? 32. Do you receive words of support from health professionals? How much?
Domain Environment		
Transportation, accommodation and food costs Lack of time for other activities Change in routine	Financial difficulties Availability Rotina	33. How much has your relative's illness affected your family financially? 34. Are the financial resources sufficient during this situation? 35. How often do you go out to distrat? 36. Do you consider leisure activites importante at this time? 37. Would you like to do something you used to do for fun before your relative fell ill? 38. The care of your relative make you not do something? 39. Could you have a good night of sleep? 40. How Much you let to do things you do before you relative sickness?

Source: Own author

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Table 1 - Specification of the items in the QoL instrument for relatives of people with cancer (MQV-FAMC) that obtained a Content Validity Index (CVI) of less than 0.78 in the judges' analysis of clarity. Feira de Santana, Bahia, Brazil, 2019

Nº OF THE ITEM	ITEM	CVI	CONDUCT AFTER JUDGES SUGGESTIONS
3	How much are you able to take care of your relative on your own?	0,70	Writing kept, it was only flagged about the Whoqol semantic standard, "how much"
4	How exhausting is this experience for you?	0,60	Replaced the term "exhausting" with "tiring"
5	How difficult is it for you to care for your relative with cancer?	0,60	Excluded, because the content was included in another item
7	To what extent do you carry out more day-to-day activities besides caring for your relative?	0,70	Replaced by "To what extent does caring for your relative increase your daily activities?"
14	How often do you get medical evaluations?	0,70	Replaced by "How often do you go to professionals\ make appointments to assess your own health?
18	How much do you need contact with the psychologist?	0,70	Excluded, because the content was included in another item
23	To what extent did you stop doing activities that you did before your relative's illness?	0,70	Excluded, because the content was included in another item

CVI: Content Validity Index

Table 2. Specification of the items in the QoL instrument for relatives of people with cancer (MQV-FAMC) that obtained a Content Validity Index (CVI) of less than 0.78 in the judges' analysis of relevance. Feira de Santana, Bahia, Brazil, 2019

Nº OF THE ITEM	ITEM	CVI	JUDGES' COMMENTS AND SUGGESTIONS
23	To what extent did you stop doing activities that you did before your relative's illness?	0,70	Excluded, because the content was included in another item

CVI: Content Validity Index

As for exclusion, three items were removed according to the analysis of semantic adequacy, conceptual adequacy and items, leaving 21 items after data analysis and review by the research team. As for semantic understanding, the assessment with 31 family members showed that the item "How painful is it for you to accompany your relative to treatment?" would be adequate if it were written: "How painful is it for you to see your relative undergoing treatment?" because family members associate the physical ability to accompany them, and this item is present in the psychological domain.

The item "How guilty do you feel about the situation your relative is experiencing?" was excluded, as family members felt that the item was not representative of the context. The research team assessed the need to remove the items "How often do you accompany your relative to treatment?" and "How often do you need to go to: appointments, tests and reports?", which were condensed into "How often do you accompany your relative to: appointments, tests, treatment, reports?".

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Chart 2. Final version of the MQV-FAMC. Feira de Santana, 2019

Physical Domain
1. How much does your relative need your help to look after him or herself? 2. How capable are you of looking after your relative on your own? 3. How tiring is caring for your relative for you? 4. How well you can eat? 5. To what extent does caring for your relative increase their daily activities? 6. How often do you accompany your relative to: appointments, exams, treatment, pick up reports?
Psychological Domain
7. How satisfied are you with the care you provide to your relative? 8. How careful have you been about your appearance? 9. How much does your relative's illness cause you suffering? 10. How painful is accompanying your relative in treatment for you? 11. To what extent is your faith important in coping with your relative's illness? 12. How often do you see professionals/make appointments to assess your own health?
Social Relations Domain
13. How much does your relative's illness affect your relationship with others in your family? 14. How much do you think your relative's illness has changed your family's day-to-day life? 15. How much guidance do you receive on the care that should be given to your relative from the service's professionals?
Domain of the environment
16. How much has your relative's illness affected your financial costs?

The following items were excluded: "How difficult is it for you to care for your relative?", "How much have you taken on other roles in your family due to your relative's illness?" and "How often do you have contact with health professionals while your relative is undergoing treatment?", as they were already being addressed in similar items. Thus, the instrument now consists of 16 items (Chart 2).

The MQV-FAMC was well accepted by the group of family members, all the items were well understood and none of the respondents found it tiring. The place where the instrument was applied was suitable, the application by interview was considered satisfactory and the average response time was 10 minutes. The instructions were considered clear and objective, so the final version of the content analysis of the instrument was obtained, achieving operational equivalence.

DISCUSSION

Faced with the cancer of a family member, family members go through moments that provoke different ways of coping. The family member is terrified of the diagnosis, remembers the social stigma of cancer and, when facing treatment, fears the uncertainties. Thus, this mixture of feelings can affect QoL, making its assessment relevant (1,2,4,5,22). The construction of an instrument focused on the experience of family members requires immersion in theory and the search for scientific evidence as the main resource for its development.

The theoretical exploration and categorization of the results confirmed the physical, social, environmental and psychological dimensions as representatives of QoL and family members. The specific aspects, represented by the facets, emerged as the areas to be assessed, and as representatives of the construct and content to be assessed by the items themselves (3,16-19).

The specific aspects emerged as the areas to be assessed and as representatives of the family's QoL. Dimensionality was defined based on the general construct and after the items had been developed. The number of items was considered high, but necessary for an initial matrix. The number of items in an instrument is not a consensual issue; studies suggest that the initial construction of an instrument should have at least three times as many items as the final instrument (3,16-19,5).

The stage consisting of the experts analyzing the items made it possible to adjust the initial 24 items. It is suggested that, among the criteria established for selecting the experts, such as qualifications, years of training and area of work, skill and clinical experience were the main factors for success in the process of evaluating the items, which was able to provide information that broadened the suggestions and criticisms for adjustments (16-19,24).

The changes made to the wording of the item are expected in the process of adapting instruments in order to maintain semantic adequacy with language accessible to the population, thus allowing them to be compressed. For this stage, it is also recommended that the agreement of the committee members be determined using the Content Validity Index (CVI), which measures the proportion of agreement among experts with aspects of the instrument and the items developed. Thus, after evaluating this first group, 21 items remained, giving an overall CVI of 0.96 (16-19,21-24).

This calculation reveals the need to change or delete items, according to the suggestions made by the judges. It is recommended that CVI results of less than 0.78 require changes to the wording of the items in order to improve understanding by the target population. With the pre-test, it was possible to check the understanding, acceptability and emotional impact of the items with members of the population for whom the instrument is intended (19).

After the recommended steps, content validity was deemed to have been achieved. The final version now contains 16 items, distributed in the four domains represented by the facets initially identified (Chart 2). It should be noted that the theoretical model represented by the structure of this set of items will serve as the basis for the subsequent evaluation of the validity evidence of the MQV-FAMC.

In this study, in terms of the quality of the construction and validation stages, it was possible to observe that this instrument was short and appropriate, even when submitted to people with a low level of education (12-15).

It is recommended that the instrument should be applied to family members of people with cancer undergoing outpatient treatment, together with the general QoL instrument, and should be considered as a sequel to the WHOQOL-bref. There is no cut-off point, and the level of QoL is assessed on a score from 0 to 100, where the closer to 1, the worse the QoL and the closer to 100, the better the QoL. The answer options range from 1 to 5, showing the worst and best possible QoL, in terms of intensity and frequency. The recall requested when applying the MVQ-FAMC will be from the start of treatment (3).

As far as identifying inaccuracies in the process is concerned, there were some difficulties, such as identifying judges who met the established inclusion criteria and also the length of time it took for some judges to return the material they sent.

Validating a measuring instrument means not only constructing a matrix of specifications, but also finding the statistical indicators and psychometric parameters that attest to adequate theory-measurement congruence. From this perspective, the final version of the 16-item MQV-FAMC instrument is ready to be submitted to empirical validity, in order to continue the process of validating the instrument, with a view to future application to its intended audience (16-19).

CONCLUSION

This study achieved content validity in accordance with the stages recommended in the literature. The MQV-FAMC developed is considered to have content validity and is currently compatible with its intended purpose.

The scarcity of studies on the phenomenon has limited the discussion of the results of this research, while at the same time demonstrating its originality in addressing an area of knowledge that still requires exploration. It is therefore necessary to map out the reality in which we intend to operate, knowing the nuances involved in the relationship between health professionals and the use of instruments.

However, further studies are needed to carry out the empirical and clinical validation of the instrument developed together with the WHOQOL-bref. Although the MQV-FAMC has already been studied for its content validity, it is necessary to investigate the dimensional validity and reliability of this instrument before it can be used.

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REFERENCES

1. Bernard M, Strasser F, Gamondi C, Braunschweig G, Forster M, Kaspers-Elekes K, et al. Relationshipbetweenspirituality, meaning in life, psychologicaldistress, wish for hastened death, and theirinfluenceonqualityoflife in palliativecarepatients. J PainSymptom-Manage [Internet]. 2017[citado 15 mar 2023];54(4):514-22.Disponível em: https://doi.org/10.1016/j.jpainsymman.2017.07.019.

2. Arias-Rojas M; CarreñoS; Sepúlveda A; Romero I. Sobrecarga y calidad de vida de cuidadores de personas concánceren cuidados paliativos. Rev. Cuid. [Internet]. 2021 [citado 22 abr 2023];12(2):e1248. Disponível em: https://doi.org/10.1016/S0277-9536(98)00009-4.

3. The WhoqolLGroup. The World Health Organizationqualityoflife assessment (WHOQOL): development and general psychometricproperties. SocSciMed [Internet]. 1998 [citado 08 fev 2023];46:1569-85. Disponível em: https://doi.org/10.1016/S0277-9536(98)00009-4.

4. Marchi JÁ, Paula CC, Girardon-Perlini NMO, Sales CA. Significado de ser-cuidador de familiar com câncer e dependente: contribuições para a paliação. Contexto Enferm [Internet]. 2016 [citado 28 maio 2023];25(1):1-8. Disponível em: http://dx.doi.org/10.1590/0104-07072016007600014.

5. Izzo JM, Cunha AMR, Cesarino CB, Martins MRI. O impacto da dor crônica na qualidade de vida e na capacidade funcional de pacientes oncológicos e de seus cuidadores. Braz J Pain[Internet]. 2019[citado 11 mar 2023] ;2(4):336-41. Disponível em: https://doi.org/10.5935/2595-0118.20190062.

6. Hortense FTP,Bergerot CD, Domenico EBL. Qualidade de vida, ansiedade e depressão de pacientes com câncer de cabeça e pescoço: estudo clínico randomizado. RevEscEnferm USP[Internet]. 2020 [citado 23jun 2023]; 54, e03546. Disponível em: https://doi.org/10.1590/S1980-220X2018040103546.

7. Delalibera M, Presa J, Barbosa A, Leal, I. Sobrecarga no cuidar e suas repercussões nos cuidadores de pacientes em fim de vida: revisão sistemática da literatura. CienSaudeColet[Internet].2015 [citado 21 jan 2023]; 20(9):2731-2747. Disponível em: https://doi.org/10.1590/1413-81232015209.09562014.

8. Ladeira T, Grincenko F. Relação entre a saúde mental de pacientes com cânceravançado em quimioterapia paliativa e seus familiares cuidadores." Revista CES Psicologia [Internet]. 2020 [citado 05jun 2023]; 13(2):1-17. Disponível em: https://doi.org/10.21615/cesp.13.2.1.

9. Minayo MCS, Hartz ZMA, Buss PM. Qualidade de vida e saúde: um debate necessário. CienSaudeColet[Internet]. 2000 [citado 28ago 2023]; 5(1):7-18. Disponível em: https://doi.org/10.1590/S1413-81232000000100002.

10. Streiner, DL, Norman, GR. Health measurement scales: a practical guide to their development and use. 5. ed. New York: Oxford University Press; 2015.

11. Fleck, MPA. O instrumento de avaliação de qualidade de vida da OMS (WHOQOL-100): características e perspectivas. CienSaudeColet[Internet]. 2000 [citado 18 jul 2023];5(1):33-38. Disponível em: https://doi.org/10.1590/S1413-81232000000100004.

12. Pereira JA, Souza I D, Bazilio J, Figueira MCS, Silva EM. Análise da qualidade de vida e sobrecarga de cuidadores familiares de idosos assistidos pela atenção domiciliar. Res., Soc. Dev. [Internet]. 2022 [citado 95 abr 2023];11(11), e466111133853-e466111133853. Disponível em: https://doi.org/10.33448/rsd-v11i11.33853.

13. Estevam GA, Pereira ML, Rocha RGVDN, Silva LAD, Tezza MHS, Fernani DCGL, Dantas MTAP. Efeitos da pandemia em cuidadores de indivíduos com alterações neuropsicomotoras. Fisioter. mov. [Internet]. 2022 [citado 25 mar 2023];35: e351445. Disponível em: https://doi.org/10.1590/fm.2022.35145.0.

14. CostaAFD, Lopes MCBT, Campanharo CRV, Batista REA, Okuno MFP. Qualidade de vida e sobrecarga de cuidadores de idosos. Texto Contexto Enferm[Internet]. 2021[citado 24jun 2023];29: e20190043. Disponível em: https://doi.org/10.1590/1980-265X-TCE-2019-0043.

15. Cardoso ELDS, Santos SRD, Araújo YBD, Neves NTDAT, Nascimento JAD. Fatores associados à qualidade de vida de cuidadores de crianças e adolescentes com condições crônicas. RevGauchaEnferm [Internet]. 2021[citado 14 set 2023];42: e20190318. Disponível em: https://doi.org/10.1590/1983-1447.2021.20190318.

16. Reichenheim ME, Moraes CL. Operacionalização de adaptação transcultural de instrumentos de aferição usados em epidemiologia. RevSaude Publica. 2007[citado 19 jun 2023];41(4):665-73. Disponível em: https://doi.org/10.1590/S0034-89102006005000035.

17. Polit DF, Beck C. T. Fundamentos de pesquisa em enfermagem: avaliação de evidências para a prática da enfermagem. 7. ed. Porto Alegre: Artmed; 2011.

18. Matos FR, Rossini JC, Lopes RFF, Amaral JDHH. Tradução, adaptação e evidências de validade de conteúdo do Schema-ModeInventory. Psicologia: Teoria e Prática[Internet. 2020[citado 16 fev 2023]; 22(2), 18–38.Disponível em: https://doi.org/10.5935/1980-6906/psicologia.v22n2p39-59.

19. Coluci MZO, Alexandre NMC, Milani D. Construção de instrumentos de medida na área da saúde. CienSaudeColet[Internet]. 2015[citado 15 ago 2023];20(3):925-36. Disponível em: https://doi.org/10.1590/1413-81232015203.04332013.

20. Powell C. The Delphi technique: myths and realities. J AdvNurs[Internet]. 2003 [citado 30 maio 2023];41(4):376-382. Disponível em: https://doi.org/10.1046/j.1365-2648.2003.02537.x.

21. Revorêdo LS, Maia RS, Torres GDV, Maia EC. O uso da técnica Delphi em saúde: uma revisão integrativa de estudos brasileiros. Arq. Ciênc. Saúde [Internet]. 2015 [citado 19 maio 2023]; 22(2):16-21. Disponível em: http://dx.doi.org/10.17696/2318-3691.22.2.2015.136.

22. Marchi JÁ, Paula CC, Girardon-Perlini NMO, Sales CA.Significado de ser-cuidador de familiar com câncer e dependente: contribuições para a paliação. Texto Contexto Enferm[Internet]. 2016[citado 29 jul 2023];25(1):1-8. Disponível em: http://dx.doi.org/10.1590/0104-07072016007600014.

23. Medeiros RKS, FerreiraJúnior MA, Pinto DPSR, Vitor AF, Santos VEP, Barichello, E. Modelo de validación de contenido de Pasqualienlasinvestigacionesen Enfermería. Revista de Enfermagem Referência [Internet]. 2015[citado 18 abr 2023];4(4), 127–135. Disponível em: http://dx.doi.org/10.12707/RIV14009.

24. ChorD, Alves MGM, Giatti L, Cade NV, Nunes MA, Molina MCB, et al. Questionário do ELSA-Brasil: desafios na elaboração de instrumento multidimensional. Rev SaúdePública[Internet]. 2013[citado 15 jul 2023]; 47(2): 27–36. Disponível em: https://doi.org/10.1590/S0034-8910.2013047003835

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