

ORIGINAL ARTICLE

ELABORATION AND VALIDATION OF A QUESTIONNAIRE TO ASSESS INFORMAL CAREGIVERS' COMPETENCE

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ABSTRACT

Objectives: to elaborate and validate the content and constructs of a questionnaire to assess informal caregivers' competences. **Method:** a methodological study for the elaboration and validation of a questionnaire in the health area, conducted in a municipality from the Northwest region of Paraná - Brazil. The questionnaire was applied to two groups made up of 30 to 40 informal caregivers. The committee of judges consisted of nine specialists. Content validity, construct validity and verification of internal consistency were confirmed. **Results:** the elaboration presented four versions, the last of which comprised two parts, the first with 13 questions for sociodemographic characterization, and the second with 14 specific items, anchored in three constructs: cognitive-emotional, psychomotor, and relational competences. The final version presented a good agreement level among the judges, as well as internal consistency ($\alpha=89$). **Conclusion:** the questionnaire serves as a strategy to assess informal caregivers regarding their level of competence to provide care.

DESCRIPTORS: Caregivers; Psychometry; Surveys and Questionnaires; Validation Studies; Reproducibility of Tests.

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INTRODUCTION

In the home care context, there are two configurations regarding caregivers: formal and informal. Informal caregivers are those people who assume the role of main caregiver of the dependent person, be them consanguineous or not⁽¹⁻⁵⁾, without any formal contract. Formal caregivers are the workers, with or without higher education, who provide care with a previously established contract⁽⁶⁾.

When informal caregivers do not have specific knowledge, have no availability, are overloaded, or are not adapted to the role taken, the care to their loved one can be provided in an improper or insufficient manner, if there is no formal support⁽⁷⁻⁸⁾. Such competences must be stimulated and promoted in the family context of care, especially in the case of people who experience dependence for the first time⁽⁹⁾. Competence is conceptualized as someone's ability to do something with quality, knowing how to articulate and mobilize knowledge, skills and attitudes to solve problems and face unforeseen situations, making use of one's own resources⁽⁹⁻¹¹⁾.

The most frequently addressed competences in intervention and qualification studies at the international level were the cognitive, emotional, psychomotor and relational competences⁽²⁻¹¹⁾. Cognitive competence is the ability that the caregiver must have to know and learn the reason why certain care action should be performed. Psychomotor competence can be understood as the ability to know-how-to-do, the manual dexterity to provide care. The emotional competences are related to the burden and stress aspects. Finally, the relational competences refer to the ability to maintain an effective communication and to establish a bond with the person cared for⁽²⁻¹¹⁾.

Evaluation of these competences in informal caregivers can help the health teams to elaborate qualification and training policies and programs for this population, in order to promote care quality in the home context. Consequently, the objective of this research was to elaborate and validate a questionnaire to assess the informal caregivers' competences.

METHOD

This is a methodological research study for the elaboration and validation of a health questionnaire⁽¹²⁻¹³⁾, conducted from June 2018 to February 2019 using Pasquali's methodological model⁽¹³⁾. Such model proposes the elaboration of three sets of procedures: theoretical, empirical (experimental) and analytical (statistical)⁽¹³⁻¹⁴⁾ (Figure 1).

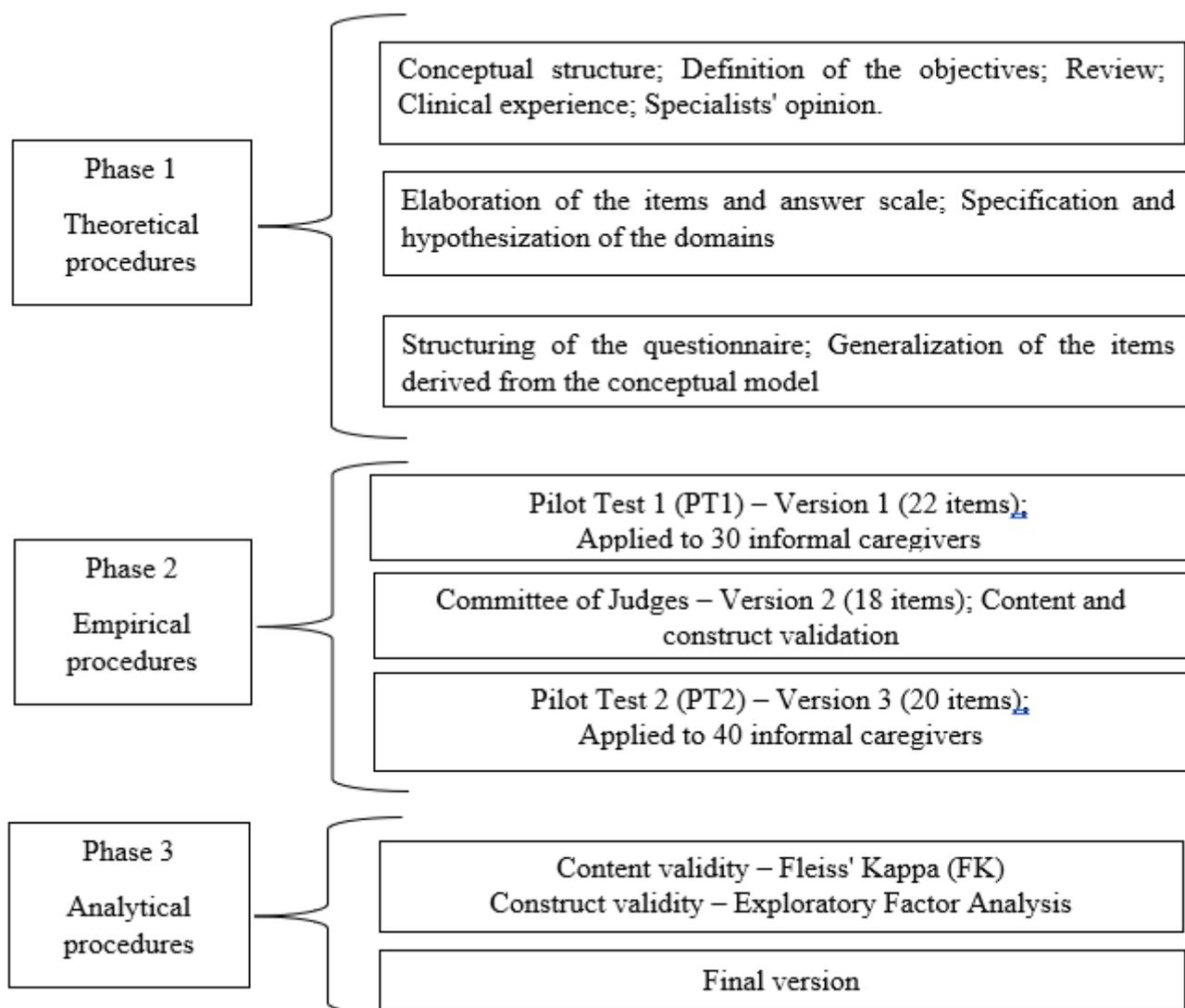


Figure 1 - Phases corresponding to the development and validation of the questionnaire to assess the informal caregivers' competences. Maringá, PR, Brazil, 2019

Source: Pasquali, 2010.

The theoretical procedures were initiated with an integrative review to verify the competences required for informal care, which evidenced the cognitive, psychomotor, relational and emotional competences⁽²⁻¹¹⁾.

Subsequently, the strategies of clinical observation and specialists' opinion survey were applied to eight Family Health Strategy (FHS) teams from three Basic Health Units (BHUs) during a three-month period. Each dimension surveyed in the theoretical model, items and answer scale was presented to the teams, in order to provide quality to the clarity, objectivity and sensitivity criteria⁽¹²⁻¹⁷⁾.

The measurement modality adopted was multidimensional, as four dimensions of the care competences were pre-established⁽¹¹⁻¹⁶⁾. The questionnaire, elaborated from the hypothesization of the conceptual model, is shown in Figure 2.

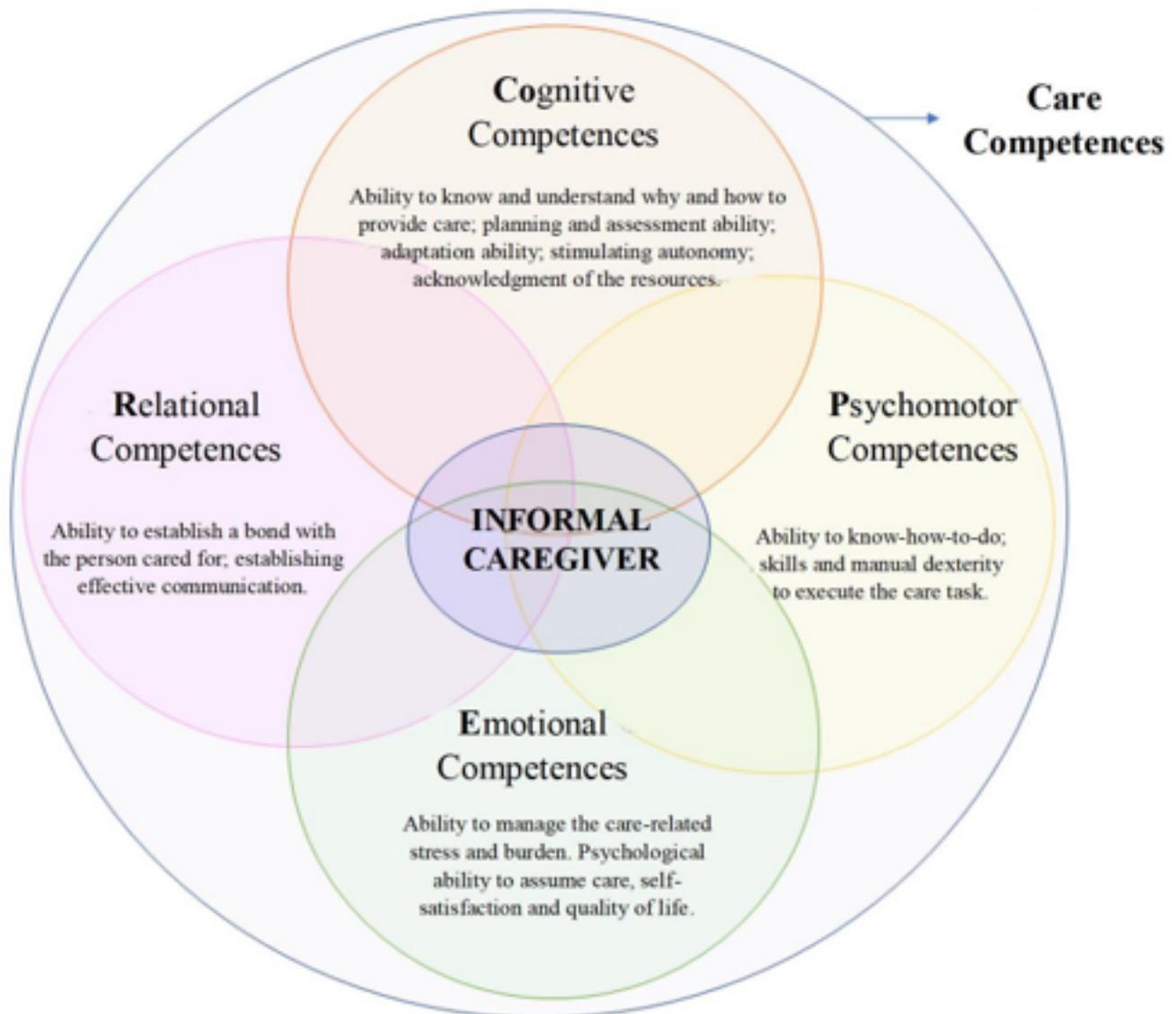


Figure 2 - Conceptual model with the hypothesized constructs of the questionnaire to assess informal caregivers. Maringá, PR, Brazil, 2019
Source: The authors (2019).

Based on the constructs, a total of 22 items (First version - V1) were elaborated, with a five-point Likert-type answer scale. Content and construct validation, as well as the previously elaborated items (V1), were tested in a sample of 30 informal caregivers, called Pilot Test 1 (PT1). The inclusion criteria were as follows: being over 18 years old, being the informal caregiver of an adult or aged individual and user of the Unified Health System (Sistema Único de Saúde, SUS) from the municipality. The participants were approached by means of visits to 34 BHUs, with request of a list with the name of the caregiver and forwarding to the nurses of the teams.

With PT1 concluded, Version two (V2) of the questionnaire was created, made up by 18 items and a header for sociodemographic characterization. In order to verify content validity, the questionnaire (V2) was submitted to appraisal by the judges, who were considered people qualified to assess clarity, content, layout and understanding of a questionnaire⁽¹⁶⁾. Choice of the judges followed these inclusion criteria: being a health professional with a PhD concluded at least one year ago, and having authored publications related to caregivers. The evaluators excluded were those who did not return the assessment questionnaire within the time frame established.

An email message with an invitation letter was sent to 15 judges, and nine returned it within the time frame established (30 days). These judges received an explanatory letter and the questionnaire including 84 questions with a three-point Likert-type scale (from -1 to +1), which assessed the header, layout, scope of items, clarity, content and objectivity^(12,16). In the validation phase, the judges justified the items scored with -1 or zero, with inferences in a space devoted to comments and suggestions, justification being mandatory for the -1 scores. After the judge's suggestions, Version three (V3), which consisted of two parts, the first for the caregiver's characterization and the second with 20 specific items, was forwarded for the application of Pilot Test 2 (PT2).

In PT2, V3 was applied to 40 caregivers. The caregivers who participated in PT1 were excluded from the list, and the questionnaire was applied following the same path as in PT1. The analysis indicated the exclusion of six items, resulting in the final version (V4), consisting of questions regarding the caregiver's characterization and of 14 specific items.

The data were imported into the Statistical Analysis Software (SAS, version 9.4) program. The Fleiss' Kappa (FK) test^(13-14,16) was applied to confirm content validity. Agreement among the judges was analyzed according to Landis and Kock⁽¹⁷⁾, with FK values showing slight agreement ($0 \leq FK \leq 0.20$), weak agreement ($0.21 \leq FK \leq 0.40$), substantial agreement ($0.61 \leq FK \leq 0.80$), and almost perfect agreement ($FK \leq 0.81$)⁽¹⁸⁾. The agreement percentage among the judges (ideal $\geq 0.75\%$), Standard Deviation (SD), correlation between the items ($r \geq 0.30$) and Cronbach's alpha (ideal $\geq 70\%$) were also verified⁽¹⁹⁾.

Construct validation was conducted using Exploratory Factor Analysis (EFA), considering eigenvalues ≥ 1 and with verification of the commonalities to explain the variances⁽²⁰⁾. The questions that presented lower values than the aforementioned were excluded. The study was approved by the Research Ethics Committee under opinion No. 2,584,897.

RESULTS

The questionnaire was called COPER 14 (final version) – (CO) Cognitive, (P) Psychomotor, (E) Emotional and (R) Relational Competences. Regarding the characteristics of the informal caregivers who participated in PT2 (n=40), 35 (87.5%) were female, 21 (52.5%) were aged from 18 to 59 years old, 24 (60%) were married, 21 (52.5%) had a family income from two to five minimum wages, 20 (50%) had completed high school, 10 (25%) had children, 10 (25%) had grandchildren, 20 (50%) worked as caregivers for more than 12 hours a day, 27 (67.5%) had been caregivers for more than a year, 22 (55%) had never taken care of anyone before, and 38 (95%) did not attend any training course.

In relation to the judges' characteristics, two were Post-PhDs and seven were PhDs, one in the Linguistics area, two in the Education area and six in the Nursing area. All of them were university professors.

Based on the results of the systematic review, along with clinical observation and specialists' opinion, the conceptual model, constructs, the items for each construct and the answer scales were established. V1 of the questionnaire consisted of 22 items with answers arranged in a Likert-type scale and two open questions (if the respondents had already attended a caregiver training course and/or if they had already taken care of somebody before – items considered in the analysis as items 23 and 24).

The results of PT1 indicated the need to exclude items six, 18, 20, 21, 23 and 24. After exclusion of the items indicated by the analysis, the set of competences presented an alpha value=0.79 and ideal correlation ≥ 0.30 . With the alpha analysis concluded, V2 was forwarded to the committee of judges.

The items of V2 presented substantial or almost perfect agreement (Table 1) regarding clarity, content, objectivity and validity.

Table 1 - Determination of the agreement among the judges regarding the assessment questionnaire of informal caregivers' competences, according to the Fleiss' Kappa (FK) statistics for the clarity, content, objectivity and validity domains. Maringá, PR, Brazil, 2019

Equivalence	Agreement percentage	FK	CI: 95%	Agreement
Clarity	79.96	0.70	[0.54 – 0.86]	Substantial
Content	93.85	0.91	[0.81 – 1.00]	Almost perfect
Objectivity	93.06	0.90	[0.82 – 0.98]	Almost perfect
Validity	89.68	0.85	[0.73 – 0.96]	Almost perfect

Source: The authors (2019)

According to the judges' assessment, it was necessary to review the header. Items one, two, three, 10 and 11 presented weak agreement in relation to content; therefore, they were reviewed and reformulated. Fleiss' Kappa(18) was conducted individually for the following domains: Clarity (FKc), Content (FKco), Objectivity (FKo) and Validity (FKv), shown in Table 2.

Table 2 - Distribution of the items of the assessment questionnaire of the informal caregivers' competences according to the committee of judges, Fleiss' Kappa coefficient for the Clarity (FKc), Content (FKco), Objectivity (FKo) and Validity (FKv) domains, suggestions proposed by the participants and reformulated items, Maringá, Paraná, Brazil, 2019 (continues)

N.	Item (V2)	FKc	FKco	FKo	FKv	N.	Reformulated item (V3)
	<i>Como você avalia o seu grau de conhecimento para</i>						<i>Como você avalia o seu conhecimento para</i>
1	<i>Identificar as limitações físicas da pessoa de que cuida (dificuldade de caminhar, andar, movimentar).</i>	1	0,3	1	1	1	<i>Identificar as limitações físicas da pessoa de que você cuida (dificuldade de caminhar, andar, movimentar-se).</i>
2	<i>Identificar os sinais e sintomas de emergência que a pessoa de que cuida pode apresentar (parada cardiorrespiratória, piora do estado da saúde).</i>	0,36	1	1	0,63	2	<i>Identificar os sinais e sintomas de piora do estado de saúde da pessoa de que você cuida (está respirando, coração batendo).</i>
3	<i>Identificar as necessidades de alimentação da pessoa de que cuida (seleção e oferta dos alimentos; cuidados com SNG).</i>	0,09	1	0,63	0,63	3	<i>Identificar as necessidades de alimentação da pessoa de que você cuida (seleção e oferta de alimentações, restrições alimentares, cuidados com SNG).</i>

4	Identificar sinais e sintomas de desidratação da pessoa de que cuida (pele seca, lábios e língua seca).	0,02	1	0,63	0,63	4	Identificar sinais de desidratação da pessoa de que você cuida.
5	Identificar os medicamentos de que a pessoa de que cuida faz uso (horários, efeitos colaterais, indicações, contraindicação, alergias).	0,36	1	1	1	5	Identificar os remédios de que a pessoa de que cuida faz uso (horários, efeitos colaterais, indicações, contraindicações, alergias).
6	Identificar expressões faciais (dor, raiva, felicidade) que a pessoa de que cuida pode apresentar.	0,63	1	1	1	6	Identificar expressões faciais (dor, raiva, felicidade) que a pessoa de que você cuida pode apresentar.
7	Reconhecer sinais de alterações nas eliminações da pessoa de que cuida (sangue nas fezes, urina, secreções).	0,63	0,63	1	1	7	Reconhecer sinais de alterações nas eliminações da pessoa de que você cuida (características das fezes, urina, secreções, presença de sangue).
Quanto você se sente adaptado				Quanto você se sente adaptado			
8	À rotina diária de cuidados.	1	1	0,63	0,63	8	À rotina diária de cuidados.
9	Para exercer o papel de cuidador.	1	1	1	0,63	9	Em exercer o papel de cuidador.
Com que frequência na semana você:				Com que frequência na semana você			
10	Realiza massagem na pessoa de que cuida.	1	0,36	0,63	1	10	Realiza atividades, além do banho, para promover o conforto da pessoa de que você cuida (massagem, banho de sol, mudança de posição, proteção das proeminências ósseas).
Quanto você está satisfeito com				Quanto você está satisfeito com			
11	O apoio financeiro para exercer o cuidado.	0,09	0,36	0,63	0,09	11	Excluded from the questionnaire
12	Em ser o cuidador principal (responsável).	1	1	1	1	12	Em ser o cuidador principal (responsável).
O quanto você se sente preparado(a) para executar as seguintes tarefas				Como você se sente em relação ao seu preparo para:			
13	Administrar/ ofertar os medicamentos.	1	1	1	1	13	Administrar/ofertar os remédios
14	Avaliar a temperatura corporal da pessoa de que cuida (extremidades frias, calor, suor, frio).	1	1	1	1	14	Avaliar a temperatura corporal da pessoa de que você cuida (extremidades frias, calor, suor, frio).
15	Despir e vestir a pessoa de que cuida.	1	1	1	1	15	Despir e vestir a pessoa de que você cuida.
16	Comunicar-se com a pessoa de que cuida.	1	1	1	1	16	Comunicar-se com a pessoa de que você cuida.
O quanto você concorda com as afirmações abaixo?				Você concorda com as afirmações abaixo?			

17	<i>Eu escolhi ser o cuidador principal da pessoa de que cuido.</i>	1	1	1	1	17	<i>Eu escolhi ser o cuidador principal da pessoa de que cuido.</i>
18	<i>Mantenho uma relação de vínculo com a pessoa de que cuido.</i>	0,63	1	1	1	18	<i>Mantenho uma relação de vínculo com a pessoa de que cuido.</i>

Source: The authors (2019).

Internal consistency of the questionnaire in its V3 version was verified by Cronbach's alpha, the correlation between the items was $\alpha=0.89$ and the correlations were above 0.44 (Table 3).

Table 3 - Pilot Test II, item after judges' validation, mean, standard deviation, Cronbach's alpha, correlation between the items, final version, and Exploratory Factor Analysis loadings for validation of the constructs of the assessment questionnaire of the informal caregiver's competences, Maringá, Paraná, Brazil, 2019 (n=40)

Item No.	Mean	SD	A	r \geq 0,30	Construct	Factors		
						F1	F2	F3
1	3,62	1,27	0,89	0,44	Cognitive/Emotional	0,88	0,08	0,03
2	3,85	1,05	0,88	0,75	Psychomotor	0,26	0,69	0,21
3	3,92	1,02	0,88	0,65	Psychomotor	0,33	0,60	0,22
4	3,57	1,00	0,89	0,56	Cognitive/Emotional	0,52	0,48	0,38
5	3,9	0,98	0,88	0,68	Cognitive/Emotional	0,5	0,39	0,40
6	4,15	0,89	0,88	0,70	Psychomotor	0,23	0,47	0,43
7	3,55	1,06	0,89	0,53	Relational	0,23	0,13	0,74
8	3,75	1,00	0,89	0,47	Relational	0,04	0,29	0,87
9	3,67	1,02	0,89	0,51	Relational	0,16	0,00	0,88
10	3,47	1,53	0,89	0,24	(Excluded)	-	-	-
11	3,92	1,04	0,88	0,17	(Excluded)	-	-	-
12	3,95	0,93	0,86	0,14	(Excluded)	-	-	-
13	3,90	0,81	0,88	0,61	Psychomotor	-0,07	0,89	0,03
14	3,72	0,96	0,88	0,60	Psychomotor	0,53	0,67	0,07
15	3,67	0,94	0,89	0,39	Cognitive/Emotional	0,83	0,29	0,13
16	4,27	0,96	0,88	0,69	Cognitive/Emotional	0,81	0,23	0,14
17	3,70	1,20	0,89	0,44	Cognitive/Emotional	0,58	0,27	0,20
18	3,80	1,24	0,85	0,09	(Excluded)	-	-	-
19	4,75	0,54	0,87	0,16	(Excluded)	-	-	-
20	3,82	1,21	0,87	0,19	(Excluded)	-	-	-

Source: The authors (2019).

Based on the results of the EFA, three factors (F1, F2, and F3) were maintained, which explained 66.33% of the total data variance. The first factor (F1) explains 43.48% of the total data variance (43.48%). This factor was interpreted as the cognitive-emotional domain, and is the most important dimension to explain the informal caregivers' competences (Table 2).

The second factor (F2) explains 12.86% of the total data variability, being interpreted as the psychomotor domain. The third factor (F3) explains 9.99% of the data variability, and was interpreted as the relational dimension. The commonalities varied from 0.44 (Q17) to 0.79 (Q8).

After all these stages, the final version (V4) comprised two parts, the first including 13 questions for the caregiver's sociodemographic characterization, and the second with 14 specific items anchored in three dimensions: cognitive-emotional, psychomotor and relational competences.

To verify the sums of the final scores for V4, the value of all the sums of the maximum answers was divided into quartiles, with the lower scores indicating lower level of competence for care: low competence (1-17); little competence (18-35); moderate competence (36-52); and good competence (≥ 53).

DISCUSSION

The COPER 14 questionnaire was developed to facilitate the task of classifying and stratifying informal caregivers, with the objective of assessing their care competences. The result was its final version made up by 14 items distributed into three constructs, with good internal consistency ($\alpha=89$). The sample size was adequate for factor analysis, and suitability of the model's fit was acceptable ($KMO=0.7419$)⁽¹⁸⁾.

In the construction of the conceptual model, using the integrative review and the previous clinical observation with the FHS teams were strategies that enhanced elaboration of the questionnaire. It is noted that the previous clinical observation is considered as one of the strategies that gathers the most information to elaborate the theoretical model⁽¹⁴⁻¹⁶⁾.

The questionnaire presented good agreement among the judges. The use of content validity relies on the participation of specialists in the committee of judges, who are individuals qualified to assess clarity, content, layout and understanding of the questionnaire. Such committee analyzed if the items of the questionnaire constitute a representative sample of what it is intended to assess⁽¹⁴⁾.

Although it is not considered in the literature, the use of two Pilot Tests allowed for a final assessment of the items, verifying their reliability and if all the items were adequate, in addition to confirming construct validity, which allowed greater confidence to continue validating the instrument. Psychometric validity in a significant population (>200 participants), a process inherent to the elaboration of assessment questionnaires, was later applied in a specific study.

The analysis of the factors indicated that factor 3 (F3) pointed to the combination of one item of the psychomotor competences (item seven) and two items of the relational competences (items eight and nine). This can be related to the fact that, in order to distinguish physiological and subjective changes in the person cared for, the caregiver should know the normal standard first. The informal caregivers' knowledge results from the time spent in caregiving and from the type of bond they have with the person cared for⁽⁷⁻⁸⁾. Such fact indicates the complexity of measuring capabilities and skills that permeate the subjectivity of human relationships^(2,9).

The estimates of commonalities presented satisfactory values in COPER 14. These

measures are interpreted as estimators of the proportion of variability attributed to each variable and can vary from zero to one: values close to zero indicate that the factors do not explain the variance, whereas values close to one indicate that all variances are explained by the common factors⁽¹³⁾.

The results showed that the COPER 14 questionnaire enables a broad assessment, encompassing more than one dimension comprising the complex task of care. The cognitive-emotional, psychomotor and relational competences are evidenced as fundamental for the informal caregiver to provide care, safely, in the home context⁽⁴⁻⁵⁾. Knowledge on the informal caregivers' characteristics, as well assessment of their level of competence and limitations, are fundamental for the elaboration of therapeutic projects specific for families in situations of vulnerability.

The study limitations are related to the competences herein surveyed and tested, which can be influenced by age, the patient's health status and level of dependence, financial and environmental conditions and level of support, among other factors. It is suggested that such limitations be considered for reproducibility of COPER 14.

CONCLUSION

The COPER 14 questionnaire presented internal consistency ($\alpha=89$) and equivalence among the judges with good agreement level. Its content was validated by the committee of judges' approach and its structural validity, by analyzing the factor load. Factor analysis retained three factors, and the estimates of commonalities explained all the variances.

The COPER 14 questionnaire identified the informal caregivers' difficulties in a preventive and anticipatory manner; thus, it may be used as a strategy to expand projects for caregivers' education and preparation to provide quality home care. It is a novel questionnaire capable of assessing cognition, relationships, emotions and psychomotor skills together in the same instrument, which can be applied to informal caregivers in different contexts, either in the home environment or in transitional care at the time of hospital discharge.

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