

# Validation of an instrument to assess the homecare competency of the family caregiver of a person with chronic disease

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## Validation of an instrument to assess the homecare competency of the family caregiver of a person with chronic disease

**Objective.** This work sought to develop, validate, and determine the reliability of an instrument on Competency in Homecare of the family caregiver of an individual with chronic disease.

**Methodology.** The test validation study was carried out in the following phases: 1) literature review; 2) analysis of results of programs to help family caregivers in Latin America; 3) exploration of the classification of nursing results (NOC) related to the family caregiver and discharge; 4) proposal of an instrument of care competence; and 5) psychometric tests: apparent validity with 25 family caregivers of individuals with chronic disease and six experts in the area; construct validity and reliability through internal consistency with 311 family caregivers of chronic patients. **Results.** The instrument on homecare competency of the family caregiver of an individual with chronic disease (CUIDAR, for the term in Spanish) has 60 items that inquire on six categories: knowledge, uniqueness, instrumentation, enjoyment of life, anticipation and relationships, and social interaction. The apparent validity evidences clarity, coherence, sufficiency, and relevance of the scale. With the factor analysis six components were obtained through the Varimax rotation in which most of the items are associated according to the categories proposed. The reliability (internal consistency) reported a Cronbach's alpha of 0.96. **Conclusion.** The Homecare Competency instrument permits assessing the capacity of a family caregiver to care for an individual with chronic disease, proving valid and reliable for the Colombian context.

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**Key words:** caregivers; chronic disease; factor analysis, statistical; reproducibility of results.

## Validación de un instrumento para la evaluación de la competencia de cuidado en el hogar del cuidador familiar de una persona con enfermedad crónica

**Objetivo.** Desarrollar, validar y determinar la confiabilidad de un instrumento de Competencia de Cuidado en el hogar del cuidador

familiar de una persona con enfermedad crónica. **Metodología.** Estudio de validación de pruebas que se realizó en las siguientes fases: 1) Revisión de la literatura; 2) Análisis de resultados de programas para asistir a cuidadores familiares en América Latina; 3) Exploración de la clasificación de resultados de enfermería (NOC) relacionados con el cuidador familiar y egreso; 4) Propuesta de instrumento de competencia de cuidado; y 5) Pruebas psicométricas: validez aparente con 25 cuidadores familiares de personas con enfermedad crónica y seis expertos en el área; validez de constructo y confiabilidad por medio de consistencia interna con 311 cuidadores familiares de enfermos crónicos. **Resultados.** El instrumento Competencia del Cuidado en el hogar del cuidador familiar de una persona con enfermedad crónica CUIDAR consta de 60 *ítems* que indagan acerca de seis categorías: conocimiento, unicidad, instrumentación, disfrute de la vida, anticipación y relaciones e interacción social. La validez aparente evidencia claridad, coherencia, suficiencia y relevancia de la escala. Con el análisis factorial se obtuvieron seis componentes mediante la rotación Varimax en las que se asocian la mayor parte de los *ítems* de acuerdo con las categorías propuestas. La confiabilidad (consistencia interna) reportó un alfa de Cronbach de 0.96. **Conclusión.** El Instrumento Competencia del Cuidado en el hogar, el cual permite valorar la capacidad de un cuidador familiar para cuidar de una persona con enfermedad crónica, demostró ser válido y confiable para el contexto colombiano.

**Palabras clave:** cuidadores; enfermedad crónica; análisis factorial; reproducibilidad de resultados.

### **Validação de um instrumento para a avaliação da competência de cuidado no lar do cuidador familiar de uma pessoa com doença crônica**

**Objetivo.** Desenvolver, validar e determinar a confiabilidade de um instrumento de competência de Cuidado no lar do cuidador familiar de uma pessoa com doença crônica. **Metodologia.** Estudo de validação de provas que se realizou nas seguintes fases: 1) Revisão da literatura; 2) Análise de resultados de programas para assistir a cuidadores familiares na América Latina; 3) Exploração da classificação de resultados de enfermagem (NOC) relacionados com o cuidador familiar e egresso; 4) Proposta de instrumento de competência de cuidado; e 5) Provas psicométricas: validez aparente com 25 cuidadores familiares de pessoas com doença crônica e seis experientes na área; validez de constructo e confiabilidade por meio de consistência interna com 311 cuidadores familiares de enfermos crônicos **Resultados.** O instrumento Competência do Cuidado no lar do cuidador familiar de uma pessoa com doença crônica CUIDAR consta de 60 itens que indagam a respeito de seis categorias: conhecimento, unicidade, instrumentação, desfrute da vida, antecipação e relações e interação social. A validez aparente evidencia clareza, coerência, suficiencia e relevância da escala. Com a análise fatorial se obtiveram seis componentes mediante a rotação Varimax nas que se associam a maior parte dos itens de acordo às categorias propostas. A confiabilidade (consistência interna) reportou um alfa de Cronbach de 0.96. **Conclusão.** O Instrumento Competência do Cuidado no lar permite valorizar a capacidade de um cuidador familiar para cuidar de uma pessoa com doença crônica, demonstrou ser válido e confiável para o contexto colombiano.

**Palavras chave:** cuidadores; doença crônica; análise fatorial; reprodutibilidade dos testes.

## Introduction

To the extent in which the epidemiological profile of Latin America is modified to go from acute to chronic disease,<sup>1</sup> a phenomenon emerges of interest to public health, which is caring for family caregivers who have been denominated invisible

patients.<sup>2</sup> Healthcare systems in the region seek to be cost-effective and due to said purpose do not always focus on the real needs of their users.<sup>3</sup> Day to day, lesser intramural care is sought and the responsibility of caring for chronic patients is

placed upon the families. It has been shown that the experience of caring for caregivers can vary according to their educational level, the support they receive, knowledge on what is happening, and the very conditions of the caregiver;<sup>4</sup> however, it has often been seen that family caregivers do not have the ability to assume this care.<sup>5</sup> Chronic disease results for many an important burden<sup>6,7</sup> and the care ends up affecting the caregivers health.<sup>8</sup>

Assessing the competency of home care permits the professional to support the family caregiver in this care demand. However, although some initiatives exist to estimate various aspects of this competency, reports have not been found on instruments to measure this capacity comprehensively; it has also not been possible to identify instruments available for this purpose in Spanish with results of psychometric tests. The aim of this work was to develop, validate, and determine the reliability of the instrument "Homecare Competency" to assess the capacity of a family caregiver to care for a person with chronic disease at home.

## Methodology

The test validation study conducted between 2012 and 2014 was endorsed by the institutional ethics committee and maintained all the requirements of norm 8430 of 1993, which establishes the scientific, technical, and administrative guidelines for health research in Colombia.<sup>9</sup> the study upheld the environmental policy of Universidad Nacional de Colombia in all pertinent aspects and, particularly, on the responsible use of resources.<sup>10</sup> It complied with the following five phases for its development, which are displaying ahead:

*Literature review:* initially developed under the metasearcher tool of the library system at Universidad Nacional de Colombia. From the abstracts it was possible to access the Medline, Science Direct, Ovid Nursing, and SciELO databases in the window of the last 30 years, in

English and Spanish, and under the descriptors competence, skill, capacity, dexterity and dexterity crossed with family caregiver and chronic disease, with their respective translations into English. This review related identifying categories related to the competence, skill, dexterity, and/or capacity of family caregiver must have: knowledge, personal conditions, procedures or instrumentation, conditions of well-being, capacity to foresee or anticipate, and the component of social support proposed by the instrument.

*Analysis of results of programs to help family caregivers in Latin America:* the study revise the results of 163 studies registered in the Latin American Network of Researchers on caring for chronic patients to identify from these the measurement used to evaluate the caregivers and if it is related to the competency of homecare. From these, 45 research projects were identified related to the care capacity of the caregiver: 38 on the ability for caring and which retake the concept by Ngozi Nkongho seven that included the construction of the scale of skills in caring in Colombia, the measurement of the preparation for caring with taxonomies from nursing, the measurement of the preparation of caregivers of children, and the analysis of the production on the caregivers' skills for caring.

*Exploration and syntheses of the classification of nursing results (NOC) related to the family caregiver:* to determine its utility in the evaluation of the competency for caring of the family caregiver in the home, the study retook all the elements of these classifications to elaborate a unified evaluation proposal.

Within the classification of nursing results (NOC)<sup>10</sup> related to the family caregiver, 11 were found reported with their respective codes: adaptation of the principal caregiver upon admission of the patient to a health center (2200); alteration of the principal caregiver's lifestyle (2203); well-being of the principal caregiver (2508); stress factors of the family caregiver (2208); preparation of the whole family caregiver (2202); relationship between the principal caregiver and the patient

(2204); performance of the principal caregiver: direct care (2205); performance of the principal caregiver: indirect care (2206); resistance of the role of the caregiver (2210); emotional health of the principal caregiver (2506); and physical health of the principal caregiver (2507).

In all, the results included 170 indicators, several of them repeated. During the analysis, these were revised seeking to avoid implications but maintaining each of the central ideas, recognizing groups of items and their denomination in light of the clinical practice and of the experiences periodically reported by individuals with chronic diseases and family caregivers.

*Proposal of the instrument of competency for caring:* an initial proposal was developed from the instrument of competency for caring, based on input from the prior phases.

*Psychometric evaluation of the instrument:* a) apparent validity: which determined the degree in which the items seem to measure what they propose,<sup>11</sup> for said purposes the following was carried out: (i) pre-testing-field trial: through the polling technique according to that described by Arribas<sup>12</sup> to evaluate the validity of form, conceptual equivalence, and acceptability of the instrument with a sample of 25 caregivers attending the program Caring for Caregivers of Universidad Nacional de Colombia and who voluntarily supported the exercise after its explanation. Each of the participants filled out the form which evaluated the clarity and comprehension of each of the items of the instrument and made suggestions to such respect; and (ii) validity with experts: a group was comprised of six experts in caring for chronic patients, with over five years of experience in the area and graduate degrees, to determine if the instrument truly measured what it proposed to measure. These experts evaluated the items in their clarity, coherence, sufficiency, relevance, and essence, according to that proposed by Tristan.<sup>13</sup> In addition, advice was received from two statisticians and a psychologist expert in psychometrics. b) construct validity was determined through the exploratory factor

analysis technique using the method of principal components and Varimax rotation;<sup>14</sup> and c) reliability was established through the internal consistency with Cronbach's alpha.<sup>15,16</sup>

## Results

### **Proposal of the instrument of competency for caring**

From the processes described, a first unified proposal was developed to address the competency for caring of the family caregiver in the home with a version of 62 items measured with a Likert-type scale with scores ranging from 1 to 4 (1 = never, 2 = a few times, 3 = frequently, and 4 = almost always for always). It contains six categories ordered under the acronym CUIDAR (for the terms in Spanish), given that it helps in memory retention of each of the items: knowledge, uniqueness (personal conditions), instrumental, enjoyment (well-being), anticipation, and social relationship and interaction.

*Competency for homecare* is defined as the capacity, ability, and preparation the family caregiver has to carry out the task of caring at home. The categories that comprise it are defined in the following manner: a) *knowledge*: refers to the notions and ideas with respect to the disease and the pharmacological and nonpharmacological therapies, the special indications of the therapy, management of devices and equipment during the patient's discharge, as well as knowledge of the activities to be conducted daily, like baths, dressing, feeding, ambulation, among others; b) *uniqueness (personal conditions)*: these are the internal and personality characteristics, the fundamental basis to one way or another confront the chronic disease and the role as patient or caregiver. From these conditions are conceived all those forms and tools available to confront problems and challenges, as well as coping mechanisms to better overcome them; c) *Instrumental*: corresponds to the abilities and

dexterities, as well as the skills to carry out the tasks of caring, which include administration of medications, satisfaction of the basic needs of daily life like feeding, elimination, ambulation, bathing, and dressing; d) *enjoyment* (well-being): permits recognizing the degree of well-being to understand how to assume the responsibility of caring at home. Inquiry is made on basic aspects of daily life, as well as the personal satisfaction related to the perceived quality of life; e) *anticipation*: this dimension includes the notions and ideas upon anticipating all those needs the person with chronic disease may have in the future, planning upon the occurrence of an unexpected event, preparation for an exam, and identification of risks; and f) *relationship and social interaction*: refers to social relationships and primary and secondary support networks available and are part of daily living, which become factors that favor strengthening the task of caring.

## Psychometric tests of the Instrument

**Pre-testing and field trial.** In total, 25 caregivers participated: 22 women and three men, 64% were between 36 and 59 years of age, 24% were between 18 and 34 years of age, and the remaining 12% were older than 60 years of age. Regarding educational level, high school education prevailed (54%) along with technical education (16%): 84% belong to socioeconomic levels two or three. By occupation, the most frequent was that of the home (52%), followed by employed (28%), student (12%), an independent worker (8%). Regarding comprehension and clarity of the statements of the scale, 60 of the 62 items scored 100%, the others were indicated as repetitive by the caregivers.

**Validity of experts.** 60 of the 62 items of the scale were evaluated by the experts as clear, coherent, sufficient, relevant, and essential for each of the categories to which they belonged. Two items were identified with low relevance and unessential, which were the same that had described the cares, which justified their elimination.

**Validity of construct and reliability.** The 60-item instrument was applied to 311 caregivers. The principal sociodemographic characteristics were: 74% were women, with a mean age of 58.5 years, nearly 76% belong to socioeconomic levels two or three. With respect to educational level, 70% of the caregivers had technical level schooling, followed by high school (21%); regarding occupation, 68% were dedicated to the home, 22% were employed, 7% were independent workers, and 3% were students.

Bearing in mind that, theoretically, the instrument has six dimensions and allowing the factor analysis to propose the number of components, six components were obtained through the Varimax rotation in which are associated most of the items according to the following dimensions: well-being, 11 of the 12 items with factor loading between 0.39 and 0.71; personal conditions, nine of the 12 items with factor loading between 0.39 and 0.72; relationships and social interaction, nine of the 12 items with factor loading between 0.37 and 0.75; knowledge, the 10 items are associated to this dimension with factor loading between 0.57 and 0.78; anticipation, four of the six items proposed with factor loading between 0.51 and 0.55; and the instrumental dimension in which six of the eight items are associated to factor loading between 0.57 and 0.59. With respect to reliability, the Cronbach's alpha value was 0.96 for the instrument in its totality with values between 0.87 and 0.92 in each of the dimensions (Table 1).

## Discussion

The competency of caregivers for homecare is part of the fundamental indicators to ensure continuity and security of caring for individuals with chronic diseases. Hence, having a multidimensional and specific scale of competency for homecare in family caregivers of individuals with chronic disease, a result of the literature review, of identifying the needs of caregivers within the local context, and with adequate validity and

reliability processes, are a fundamental reference to consolidate effective strategies in healthcare institutions that assure the continuity of care. A close relationship is identified among the categories proposed in the instrument with some scales that have been used to guide or measure the transition plan and that of discharge in the world, focused on characteristics of integrity, security, and continuity. Hadjistavropoulos *et al.*<sup>17</sup> developed and validated the “checklist for

continuous care” (CCC) to provide support to nurses in revising in simple manner the care of orthopedic patients. It resulted in a practical tool to assist nurses in the systematic qualification of the continuous care of orthopedic patients and an element of conceptual guidance to visualize continuous care with the use of few resources and great impact. The psychometric tests of said instrument are required.

**Tabla 1.** Cronbach’S alpha of the CUIDAR instrument for the total and by dimensions

	Cronbach’s alpha	Nº   of items
Knowledge	0.92	10
Uniqueness (personal conditions)	0.89	10
Instrumental and procedural	0.89	8
Enjoyment (well-being)	0.87	12
Anticipation (prediction)	0.88	6
Relationship and social interaction	0.89	12
Total	0.96	60

Kenner and Boykova<sup>18</sup> applied the “Kenner discharge questionnaire” to look into the parental experience of parents of newborn children. This is a standardized test in English, which proved valid and reliable in the review of the experiences of parents with care and social support. Its application permitted seeing that parents’ needs for information, their roles, stress level, type of coping, and supports or interactions required to assume the responsibilities for caring for the child; aspects related to the categories of knowledge, anticipation, relationships and social interaction in the instrument of competency for caring.

With respect to the knowledge, instrumental, and anticipation categories similarity is evident on aspects identified by other authors.<sup>2,19</sup> Holland *et al.*,<sup>20</sup> based on tests of the common needs in an evaluation instrument brought to practice with auditing purposes, revised what was required by nurses from the community and caring at home to include it in the hospital discharge plan. Thus, a plan was achieved to realistically support these

nurses and which upon being applied in the hospital takes little time from the routine and which generates as a result the “Instrument of assessment of nursing needs”. The tool used up little time from nursing for its use and contributed to the discharge plan with special relevance to understand the different needs of patients between acute care and that of long-term care. Bobay *et al.*,<sup>21</sup> in a study with 1982 patients, excluded from palliative care, who had orders for discharge to the home, completed the quality of education scale upon discharge and that of preparation for hospital discharge, to determine the differences in perceptions of quality in the education of the hospital discharge and the degree of preparation for the hospital discharge and its relationship with readmission to emergency service, required visits, and hospital readmission. Senarath and Gunawardena<sup>19</sup> developed and validated the “instrument to measure the patient’s perception on the quality of nursing care and similar services in a tier-three hospital”. This tool emerged from the work experience, literature review, and consultation

with experts. To validate it, the instrument was applied to 120 patients upon admission. The items were classified into eight categories, which include: interpersonal aspects, efficiency, competence, comfort, physical environment, cleanliness, personalized information, and general instruction. The final 36-item instrument had a Cronbach's alpha of 0.91 and proved valid for use in tier three complexity hospitals.

The conclusion of this study is that the CUIDAR instrument is a valid and reliable tool to evaluate the competency for caring of family caregivers at home of patients with chronic disease.

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