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# Caregiver role strain: bi-national study of content validation

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## Caregiver role strain: bi-national study of content validation

**Key words:** nursing; caregivers; validation studies.

**Objective.** To estimate content validity of the diagnosis Caregiver Role Strain. **Methods.** Content validation of the defining characteristics according to Fehring's model was undertaken by 6 Colombian nurses and 9 Brazilian counterparts. The relevance of each defining characteristic for the diagnosis was assessed using 5-point Likert type scale. The Mann-Whitney test was used to estimate differences in assessing the relevance of defining characteristics between Brazilian and Colombian nurses. **Results.** From 36 defining characteristics, 22 were identified as major, 13 as secondary and one as irrelevant (rash). The content validity index (sum of weighted averages divided by the total number of defining characteristics) was 0.79, considered adequate. **Conclusion.** Most of the defining characteristics were considered relevant to the nursing diagnosis Caregiver Role Strain. These findings reflect consensus among specialists from two different countries in relation to the relevance of the defining characteristics for this diagnosis.

## Cansancio del rol de cuidador: estudio binacional de validación de contenido

**Objetivo.** Estimar la validez de contenido del diagnóstico *Cansancio del rol de cuidador*. **Métodos.** Validación de contenido de las características definitorias por seis enfermeras colombianas y nueve enfermeras brasileñas, de acuerdo con el modelo de Fehring's. La relevancia de cada característica definitoria para el diagnóstico se evaluó utilizando una escala Likert de cinco puntos. **Resultados.** De las 36 características definitorias, 22 se identificaron como principales; 13, secundarias y una como irrelevante. No hubo diferencia entre las puntuaciones atribuidas por las enfermeras brasileñas y colombianas. El puntaje total de validez de contenido del diagnóstico (sumatoria de los promedios ponderados, medias ponderadas divididas por el número total de características definitorias) fue adecuado (0.79). **Conclusión.** La mayoría de las características definitorias fueron consideradas

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relevantes para el diagnóstico Cansancio del rol de cuidador. Estos hallazgos reflejan un consenso entre expertos de dos países diferentes con relación a la relevancia de las características definitorias para el diagnóstico.

**Palabras clave:** enfermería; cuidadores; estudios de validación.

### Tensão do papel de cuidador: estudo binacional de validação de conteúdo

**Objetivo.** Estimar a validade de conteúdo do diagnóstico de enfermagem *Tensão do papel de cuidador*. **Métodos.** Validação de conteúdo das características definidoras por 9 enfermeiros brasileiros e 6 enfermeiros colombianos, segundo o modelo proposto por Fehring. A pertinência

de cada característica definidora ao diagnóstico foi avaliada por meio de escala tipo Likert de 5 pontos. **Resultados.** Das 36 características definidoras 22 foram identificadas como principais, 13 como secundárias e uma como irrelevante. A pontuação total de validade de conteúdo do diagnóstico (somatória das médias ponderadas dividida pelo número total de características definitivas) foi adequado (0.79). Não houve diferenças entre as pontuações atribuídas pelos enfermeiros brasileiros e colombianos. **Conclusão.** A maioria das características definidoras foram consideradas pertinentes para Tensão do papel de cuidador. Os detectados refletem consenso entre expertos de dois países em relação à pertinência das características definidoras ao diagnóstico.

**Palavras chave:** enfermagem; cuidadores; estudos de validação.

## Introduction

It is well established that nursing diagnoses describe human responses, susceptible to nursing interventions. That means that the title, definition, defining characteristics, related and risk factors of nursing diagnoses should represent, in fact, the nurse inference as a phenomenon that occurs in practice.<sup>1</sup> However, much of the nursing diagnosis are accepted by NANDA-International for presenting a consistent theoretical argument based only on literature review, without the availability of empirical data about the diagnosis contents, giving low levels of evidence. To refine the set of clinical indicators of nursing diagnoses, the performance of validation studies is proposed.<sup>2,3</sup> The validation of a nursing diagnosis generates evidence that the phenomenon of interest exists and that its definition, defining characteristics, related factors/risk factors are appropriate; besides producing technical and scientific knowledge necessary for understanding the answers of patients to certain phenomena, which will enable its proper use in clinical practice, as well as contribute to teaching and nursing research.<sup>4</sup>

For this study, the diagnosis 'Stress of caregiver's role' has a special interest. It was accepted by

NANDA-International in 1992. Since then, it has been revised twice, in 1998 and 2000.<sup>3</sup> Currently, belongs to the 7 domain, Roles and relationships ("connections or positive and negative associations between people or groups of people and means by which these connections are demonstrated") and class 1, Caregiver's roles ("behavioral patterns, socially expected for people who provide care and who are not health care professionals"). It is defined as the "difficult to play the role of the family caregiver or other significant".<sup>3</sup> It has 36 defining characteristics, grouped into four categories: care activities; health of the caregiver; the relationship between the caregiver and the care receiver; and family processes. The 56 related factors are divided into groups which include, besides the already mentioned categories for the characteristics, the health of the care receiver, resources (physical, infrastructure, equipment and support) and socioeconomic factors.<sup>3,5</sup>

Family caregivers play an important role in promoting, maintaining and restoring the health of the people they care for, especially those with chronic diseases. They assume the responsibility to care for and perform the activities and tasks

of daily life that the person can not perform due to the consequences of the disease. Offering care may involve positive aspects for caregivers such as personal growth,<sup>6,7</sup> feeling of being participating in a rewarding and meaningful experience,<sup>7-9</sup> strengthening relations with the other<sup>9</sup> and increased self-esteem.<sup>10</sup> However, the care experience can also adversely affect the quality of life of caregivers, who usually tends to deteriorate in physical, psychological and social aspects.

It is known that family caregivers are more likely to get sick than not caregivers people, and may present a series of events that lead to the nursing diagnosis “Caregiver role strain.” The early detection of this diagnoses is fundamental for nurses since their presence has an impact on the caregiver well-being, family dynamics and the quality of care provided to the care receiver.

In the literature, two studies<sup>11,12</sup> that bother to conduct the clinical validation of the diagnosis “Caregiver role strain.” Although the literature shows studies that provide evidence of the validity of the diagnosis, it is necessary to confirm this validity in different contexts, with populations of different characteristics and different cultures to determine the power of generalization of taxonomy.<sup>13</sup> Therefore, under the premise that the clinical manifestations of the diagnosis “Caregiver role strain”, may differ depending on cultural aspects of family caregivers, and considering that in the literature there are no content validation works of this diagnosis in family caregivers of Brazilian and Colombian nationality and this study is prospected with the following objectives: to estimate the content validity of the diagnosis caregiver role strain, in family caregivers of people with chronic diseases in Brazil and Colombia, and to investigate the difference between the estimates of the two countries. It is noteworthy that validating the defining characteristics for the nursing diagnosis “Caregiver role strain” in two populations of different countries, is important for the nursing discipline because it contributes to diagnostic accuracy and provides the basis for the development and identification of nursing

interventions playable in different cultures, and can positively impact on family caregivers welfare.

## Methods

This is a content validation study of the defining characteristics of the nursing diagnosis “Caregiver role strain”, held with Brazilian and Colombian experts. This study of validation content was conducted in three phases: The first phase was the development of the conceptual and operational definitions of the defining characteristics proposed by NANDA-I 2012-2014. These definitions were based on scientific articles, as well as dictionaries of medical, psychology and nursing terms. Due to the difficulty of finding definitions for some defining characteristics, related to affective/emotional aspects, dictionaries of Portuguese, English and Spanish were also used. The second stage involved the validation of conceptual and operational definitions of the defining characteristics. The definitions developed from the reviewed literature were assessed by a group of experts, members of the Study Group about Diagnostics, Interventions and Nursing Results (DIREnf). On three occasions, the experts gathered to judge the conceptual and operational definitions of the defining characteristics, regarding the criteria of adequacy, clarity, and measurability.

In the third phase, the procedures of the method proposed by Fehring<sup>2</sup> were performed, involving the participation of a group of Brazilian and Colombian experts, different from the group that worked in the previous phase, which had the task of assessing the degree to which the defining characteristics are valid manifestations of the diagnostic study. The conceptual and operational definitions were presented with the defining characteristics under evaluation, to minimize possible differences between the experts regarding an understanding of the meaning of each feature. The methods of the third stage are described below.

*Participants.* A nurses convenience sample was identified in September 2013, through online research for curricula of the Lattes Platform

contained in the portal of the National Council for Scientific and Technological Development (CNPq) in the case of Brazilian nurses, and in the Curriculum Vitae Directory in Science and Technology (CvLAC) to Colombian nurses. 38 nurses were identified, 20 Brazilians and 18 Colombians. It is noteworthy that this study involved experts from two different nationalities being the first phase of a larger study which evidence was necessary on the equivalence of the contents of diagnosis between Brazil and Colombia. The experts were contacted by email and invited to participate in the study if fulfilled the following inclusion criteria: having, at least, one publication about diagnosis, intervention or result of nursing or on family caregivers; having master's degree or Ph.D. in diagnosis, intervention or result of nursing, or related to the care of people with chronic illnesses or family caregivers; and minimal clinical practice of one year in areas related to the care of people with chronic diseases or family caregivers. After four unanswered contacts, it was considered that the nurse did not agree to participate in the study.

*Instrument.* A registration form was developed in Spanish and in Brazilian Portuguese, so the expert could inform their judgment as to the relevance of each defining characteristic to diagnosis. Each item of the instrument was designed for each expert to evaluate the defining characteristic as, 1=absolutely not characteristic, 2=very little characteristic, 3=some characteristic mode, 4=considerably characteristic, and 5=very characteristic of diagnosis. Each defining characteristic was accompanied by a conceptual and operational definition developed for this study.

*Data collection procedures.* During the months from October to December 2013, all experts were contacted by email. The invitation letter, registration form and a guide that contained a summary of the background about the subject and the guidance about completing the registration form, were attached to the contact email. It was stipulated initially, 15 days to return the completed form, regardless, the deadline had to be extended for another 10 days.

*Data analysis.* The variables of interest in this study were, in addition to the experts characteristics, the own defining characteristics of the diagnosis "Caregiver role strain", according to NANDA-I classification 2011-2014.<sup>3</sup> This edition of NANDA-I indicates 36 defining characteristics for diagnosis and all of them were judged by the experts at this phase. The experts characteristics, as well as their responses about the degree of relevance of the defining characteristics that they judged, were recorded in Microsoft Excel® database and transported to the statistical program SPSS version 17 (SPSS Inc., Chicago, IL, USA ). The characterization variables of the experts were analyzed using descriptive statistics. The defining characteristics were categorized as primary, secondary or irrelevant, as proposed by Fehring.<sup>2</sup> In this proposal, each defining characteristic received a weigh (1 – very characteristic; 0.75 – considerable characteristic; 0.50 – some characteristic mode; 0.25 – uncharacteristic; 0 – nothing characteristic). Then, the weighted averages and subsequent classification of the characteristics were calculated – weighted average greater than or equal to 0.80: main; averages between 0.50 and 0.79: secondary and average less than 0.50: irrelevant. Finally, the total score of content validity of the diagnosis (total CVD) was calculated, from the sum of the weighted averages divided by the total number of defining characteristics.

Possible differences between Brazilian and Colombian experts in assessing the relevance of the defining characteristics at diagnosis were estimated using the Mann-Whitney test, and the used significance level was 5%.

*Ethical aspects.* This study complied with the ethical aspects recommended by Resolution Number 196/1996 of the National Health Council of Brazil, and by Resolution Number 8,430/1993 of the Ministry of Health of the Republic of Colombia. The project was submitted to the Research Ethics Committee (REC) of the University of São Paulo Nursing School (Assent No. 435,429) and the Ethics Committee of Scientific Investigation of the Industrial University of Santander (CEINCI-UIS Code Number 7083).

## Results

37 experts were identified and contacted, 21 did not respond to the invitation, and one refused for not being considered an expert on the research topic. The final sample consisted of 15 experts, all female, 9 Brazilian and 6 Colombian, with an average of years of clinical practice of 6.67 for Brazilians, and 5.8 for Colombian participants. Regarding the title, six of the experts had master's degree and 9 Ph.D. In all cases, the subject of titration was related to the care of people with chronic diseases or family caregivers. All participants had publications related to the care of family caregivers.

Of the total of 36 defining characteristics, proposed by NANDA-I for the diagnosis "Caregiver role strain," the sample of Brazilian and Colombian experts identified 22 characteristics as main (weighted average  $\geq 0.80$ ), 13 as secondary (weighted average  $< 0.80$  and  $> 0.50$ ) and as irrelevant (weighted average  $\leq 0.50$ ) (Tables 1 and 2). The Mann-Whitney test did not show differences between the scores given by the Brazilian and Colombian nurses. However, it is noteworthy that two defining characteristics (cardiovascular disease and denials of promotions in career) were considered irrelevant according to the answers of Brazilian experts and secondary according to the Colombians. The total CD of the diagnosis was 0.79.

**Table 1.** Defining characteristics of diagnosis "Caregiver role strain" identified as main, according to the score obtained in the validation of content. São Paulo, 2014

Defining characteristic	Weighted average (WA)			p-value*
	Brazil n=9	Colombia n=6	Total n=15	
Stress	1.00 (0.00)	1.00 (0.00)	1.00 (0.00)	1.00
Lack of time to meet the personal needs	0.92 (0.18)	1.00 (0.00)	0.95 (0.14)	0.23
Familiar conflict	0.92 (0.13)	0.96 (0.10)	0.93 (0.11)	0.49
Increased nervousness	0.92 (0.13)	0.92 (0.13)	0.92 (0.12)	1.00
Disturbed sleep pattern	0.89 (0.18)	0.96 (0.10)	0.92 (0.15)	0.45
Report of concern with family members	0.89 (0.18)	0.96 (0.10)	0.92 (0.15)	0.45
Fatigue	0.89 (0.18)	0.92 (0.20)	0.90 (0.18)	0.60
Increased emotional lability	0.89 (0.18)	0.92 (0.20)	0.90 (0.18)	0.60
Changes in leisure activities	0.92 (0.18)	0.88 (0.14)	0.90 (0.16)	0.39
Concern with the future regarding the health of the care receiver	0.94 (0.11)	0.83 (0.21)	0.90 (0.16)	0.23
Sleep deprivation	0.83 (0.18)	0.92 (0.13)	0.87 (0.16)	0.35
Removal from social life	0.89 (0.18)	0.83 (0.20)	0.87 (0.19)	0.54
Concern with the future regarding the caregiver's ability to provide care	0.92 (0.12)	0.75 (0.30)	0.85 (0.20)	0.23
Somatization	0.81 (0.24)	0.92 (0.13)	0.85 (0.21)	0.35
Ineffective coping	0.78 (0.26)	0.96 (0.10)	0.85 (0.23)	0.12
Frustration	0.81 (0.17)	0.92 (0.13)	0.85 (0.16)	0.19
Impatience	0.86 (0.18)	0.83 (0.26)	0.85 (0.21)	1.00
Depressive feeling	0.81 (0.21)	0.92 (0.13)	0.85 (0.18)	0.30
Weigh as a changed relationship with the care receiver	0.83 (0.22)	0.83 (0.22)	0.83 (0.22)	0.95
Apprehension about the care that the receiver must have if the caregiver is unable to offer them	0.86 (0.22)	0.79 (0.33)	0.83 (0.26)	0.78
Difficulty performing the necessary activities	0.81 (0.30)	0.83 (0.20)	0.82 (0.26)	0.89
Concern about the possible institutionalization of the care receiver	<b>0.81 (0.27)</b>	<b>0.83 (0.20)</b>	<b>0.82 (0.24)</b>	<b>1.00</b>

\*Mann-Whitney Test

**Table 2.** Defining characteristics of the diagnosis “Caregiver role strain” identified as secondary and irrelevant according to the score obtained in the validation of content. São Paulo, 2014

Defining characteristic	Weighted average (WA)			p-value*
	Brazil n=9	Colombia n=6	Total n=15	
Concern for the routine care	0.83 (0.25)	0.71 (0.29)	0.78 (0.27)	0.34
Rage	0.75 (0.25)	0.83 (0.13)	0.78 (0.21)	0.53
Difficulty completing the necessary tasks	0.75 (0.28)	0.79 (0.19)	0.77 (0.24)	0.90
Low productivity at work	0.75 (0.28)	0.79 (0.19)	0.77 (0.24)	0.90
Difficulty of observing the evolution of care receiver’s disease	0.67 (0.35)	0.88 (0.21)	0.75 (0.31)	0.21
Dysfunctional changes in care activities	0.67 (0.38)	0.79 (0.25)	0.72 (0.33)	0.57
Hypertension	0.69 (0.24)	0.75 (0.27)	0.72 (0.25)	0.57
Gastrointestinal problems	0.64 (0.25)	0.83 (0.20)	0.72 (0.25)	0.14
Uncertainty about the changed relationship with the care receiver	0.64 (0.36)	0.83 (0.30)	0.72 (0.34)	0.24
Weight change	0.61 (0.35)	0.75 (0.32)	0.67 (0.33)	0.41
Headache	0.58 (0.25)	0.75 (0.22)	0.65 (0.25)	0.28
Cardiovascular disease	0.47 (0.34)	0.71 (0.25)	0.57 (0.32)	0.14
Denials of career promotions	0.47 (0.40)	0.63 (0.38)	0.53 (0.39)	0.47
Exanthema	0.31 (0.37)	0.46 (0.43)	0.37 (0.39)	0.50

\*Mann-Whitney Test

## Discussion

This is the first bi-national study of content validation of diagnostic ‘Caregiver role strain’. The main result of this study was to identify the main defining characteristics, secondary, and irrelevant, based on the opinion of experts of two different cultures. The main defining characteristics are those that must be present to identify the diagnosis; that is to affirm that the diagnosis exists. The secondary defining characteristics only provide evidence supporting the diagnosis is present. This means that only the identification of these does not guarantee the existence of the nursing diagnosis.<sup>14</sup> Validation studies in different cultures and necessary in populations nursing discipline because enable to assess possible differences in the manifestations of a particular condition,<sup>15</sup> which may be due to the influence of cultural aspects. This suggests that each of the diagnostic categories approved by NANDA-I should be reviewed that carefully examine their cultural sensitivity to be able to develop nursing interventions that consider cultural factors.

In this study, all the experts evaluated the relevance of the defining characteristics of the diagnosis

“Caregiver role strain”, considering the conceptual and operational definitions, previously established and validated (unpublished data). Operational definitions are essential components of nursing diagnosis research because they favor the accuracy in establishing nursing diagnoses, establishing a link between observation and scientific research.<sup>16</sup> In particular, in the context of content validation studies, such definitions are important because they enable the analysis of relevance by experts on the basis of understanding, homogeneous, about what the defining characteristics “measure” and how will be “measured”.

In the national and international literature were not identified concept validation studies or content of nursing diagnoses. Although, content validation studies have a lower level of evidence,<sup>3</sup> the available clinical validation<sup>11,12</sup> have limitations as its external validity. Nevertheless, the results of this study are consistent with the available literature.<sup>11,12</sup>

The clinical validation study of “Caregiver role strain” was carried out by the evaluation of

225 family caregivers in the home environment in the Czech Republic.<sup>11</sup> It was found that, of the 36 analyzed defining characteristics, two were considered primary: concern about the future regarding the receiver health care and apprehension regarding the future concerning the caregiver's ability to provide care.<sup>11</sup> These two characteristics have also been identified as main in this study. In another study of clinical<sup>12</sup> validation of the diagnostic "Caregiver role strain", 42 family caregivers of people with stroke interviewed. Data collected from each caregiver were evaluated by six experts.<sup>12</sup> The authors identified four defining characteristics that suggested the presence of diagnosis when the defining characteristic stress was present in the caregiver; these are: removal from social life, changes in leisure activities, increased emotional lability, lack of time to meet the personal needs.<sup>12</sup>

It is noteworthy that in this study, the stress defining characteristic obtained weighted average equal to 1, both by Brazilian experts and by the Colombians, which is the highest score for a feature. Together, these data suggest that stress is an indicator of great relevance for the identification of "Caregiver role strain" in the experts view.

Although it is documented that, due to the care activities, family caregivers may have health problems such as increased blood pressure,<sup>17</sup> decreased immune function<sup>18-19</sup> and even increased mortality of spouse caregivers,<sup>20</sup> most of the defining characteristics of this study, related to the physical health of the caregiver, were classified as minors; regardless of the characteristics of "fatigue" and "exanthema" were evaluated as primary and irrelevant, respectively. In the case of "exanthema" characteristic, defined for this study as "widespread and acute short erythema", experts have argued that the multifactorial nature of this disorder contributes to the low specificity of this defining characteristic for diagnosis. Moreover, in the consulted literature, there was no relationship of "exanthema" with the diagnosis "Caregiver role strain".

The weighted average of the nursing diagnosis "Caregiver role strain" was 0.79, which is considered adequate. This suggests that most of the defining characteristics are relevant to diagnose the caregiver role strain on family caregivers of people with chronic diseases. Although the weighted average of "cardiovascular disease" and "refusal in career promotion" characteristics of Brazilian experts have been low (both 0.47) compared to weighted averages of Colombian experts (0.71 and 0.63) there was no statistically significant difference. In this sense, the fact that there were no differences between any of the scores given by Brazilian and Colombian nurses, suggests that while there may be social and cultural differences, these were not decisive to point out differences in the relevance of the defining characteristics of this diagnosis.

The limitations of this study include the sample size and the fragility of the expert selection criteria, by not considering that they should have mandatory experience in the use of NANDA-I. Fehring<sup>2</sup> suggests sample sizes between 50 and 100 experts to perform content validation of a nursing diagnosis. However, the difficulties in finding nursing professionals that met the criteria of experts proposed by the same author were barriers to obtaining sample of the recommended size. It is emphasized that further studies of clinical validation and construct of the studied diagnostic in different populations and cultures are needed, to increase the level of evidence of this diagnosis. In conclusion, the findings provide subsidies for the refinement of diagnosis "Caregiver role strain" in family caregivers of people with chronic diseases. Most of the defining characteristics were considered relevant to nursing diagnoses "Caregiver role strain", being 22 classified as main (weighted average  $\geq 0.80$ ), and 13 as secondary (weighted average  $\geq 0.50$   $\geq 0.79$ ). The findings reflect agreement among experts of the two countries (Brazil and Colombia) concerning to the relevance of the defining characteristics to the nursing diagnosis.



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