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Nursing diagnosis "Terminality Syndrome": a content analysis

Diagnóstico de enfermagem "Síndrome de Terminalidade": análise de conteúdo

Diagnóstico de enfermería "Síndrome de Terminalidad": análisis de contenido

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ABSTRACT

Objectives: to validate the nursing diagnosis "Terminality Syndrome" with experts. **Methods:** a quantitative research of content validation type based on collective wisdom approach. An online semi-structured questionnaire was used as an instrument for data collection, and Content Validity Index and Wilcoxon test were used for comparing possible differences. **Results:** the questionnaire was answered by 89 professionals after judges' assessment in relation to the structural components of the diagnosis proposed. The mean Content Validity Index of items was above that recommended, except for title, which was ≥ 0.8. The suggestions were reviewed and accepted, being forwarded for a new analysis, reaching 83.7% of agreement among participants. **Conclusions:** the diagnosis' content proved to be valid by judges. With that, it is expected to contribute with a useful nursing diagnosis for nursing practice documentation in palliative care.

Descriptors: Hospice and Palliative Care Nursing; Hospice Care; Palliative Care; Nursing Diagnosis; Validation Study.

RESUMO

Objetivos: validar o diagnóstico "Síndrome de Terminalidade" com especialistas. Métodos: pesquisa quantitativa, do tipo validação de conteúdo, baseada na abordagem sabedoria coletiva. Utilizou-se como instrumento de coleta de dados um questionário semiestruturado *online*, e foi adotado para análise o Índice de Validade de Conteúdo e o teste de Wilcoxon, utilizado para comparar possíveis diferenças. **Resultados:** o questionário foi respondido por 89 profissionais, após o julgamento destes juízes em relação aos componentes estruturais da proposta diagnóstica, o Índice de Validade de Conteúdo dos itens foi acima do recomendado, com exceção do título, que foi ≥ 0,8. As sugestões foram revistas e aceitas, sendo reencaminhado para nova análise, alcançando 83,7% de concordância entre os participantes. **Conclusões:** o conteúdo da proposta de diagnóstico foi considerado válido pelos juízes. Com isso, espera-se contribuir com um diagnóstico de enfermagem útil para a documentação da prática de enfermagem em cuidados paliativos.

Descritores: Enfermagem de Cuidados Paliativos na Terminalidade da Vida; Cuidados Paliativos na Terminalidade da Vida; Cuidados Paliativos; Diagnóstico de Enfermagem; Estudo de Validação.

RESUMEN

Objetivos: validar el diagnóstico "Síndrome de Terminalidad" con especialistas. **Métodos:** investigación cuantitativa, validación de contenido, basado en el enfoque de sabiduría colectiva. Se utilizó un cuestionario semiestructurado en línea como instrumento de recolección de datos, y para el análisis se utilizó el Índice de Validez de Contenido y la prueba de Wilcoxon, para comparar posibles diferencias. **Resultados:** el cuestionario fue respondido por 89 profesionales, luego del juicio de estos jueces en relación a los componentes estructurales de la propuesta diagnóstica, el Índice de Validez de Contenido de los ítems estuvo por encima de lo recomendado, excepto por el título, que fue ≥ 0.8. Las sugerencias fueron revisadas y aceptadas, siendo remitidas para un nuevo análisis, alcanzando un 83,7% de acuerdo entre los participantes. **Conclusiones:** los jueces consideraron válido el contenido de la propuesta de diagnóstico. Con esto, se espera contribuir con un diagnóstico de enfermería útil para la documentación de la práctica de enfermería en cuidados paliativos.

Descriptores: Enfermería de Cuidados Paliativos al Final de la Vida; Cuidados Paliativos al Final de la Vida; Cuidados Paliativos; Diagnóstico de Enfermería; Estudio de Validación.

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INTRODUCTION

According to the World Health Organization, "palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of distress by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"[1]. In this context, nursing would be one of those responsible for patient care at the moment of terminality. Even so, the record of nursing diagnoses is still diffuse[2].

Nursing care presents the Nursing Process as a methodological instrument, which in turn is divided into Data collection, Nursing Diagnosis, Nursing Planning, Nursing Implementation and Nursing Assessment[3]. However, there is a gap in the NANDA-I Taxonomy, as there is no diagnosis that meets the demand for Client Satisfaction: Symptom Management (NOC, Code 3011)[4] and Dying Care (NIC, Code 5260)[5]; however, there are several diagnoses that occur concurrently in palliative care, which could be better described if seen together, as a syndrome.

Nursing diagnoses of syndrome are defined as a clinical judgment that describes human responses forming a specific group of nursing diagnoses that occur simultaneously and are better treated together through similar interventions[6]. It is considered that patients with chronic degenerative disease in their last weeks and days of life may present, by the very characteristic of the pathology and deterioration of the organism, various signs and symptoms such as pain, dyspnea, anxiety, among others. Cascading functionality contributes to a simultaneous appearance of these clinical manifestations, leading to worsening of symptoms[6].

Thus, through the proposal of the nursing diagnosis "Terminality Syndrome", it is expected to enhance planning nursing care in symptom management in palliative care and to optimize the diagnostic reasoning in clinical practice by identifying the set of symptoms in a syndrome diagnosis appropriate for palliative care[7]. Therefore, a syndromic proposal can collaborate to offer symptom relief, minimization of distress giving comfort to patients on the verge of death, and, to family, support for coping with grief and understanding the natural course of the disease[7].

OBJECTIVES

To validate the nursing diagnosis "Terminality Syndrome" with experts.

METHODS

Ethical aspects

This project was approved by a Research Ethics Committee. All ethical requirements established in Resolution 466/2012 of the Brazilian National Health Council (CNS - *Conselho Nacional de Saúde*) were complied with, including the Informed Consent Form (ICF). The research subject's consent was requested in the "I agree" option, since data collection was electronic.

Design, period, and place of study

The validation process of a new nursing diagnosis is divided into Concept analysis, Validation by experts and Clinical Validation[8]. Content validation by experts is performed to measure the accuracy of clinical indicators of a diagnosis. In this stage, the proportion of experts who agree with the inclusion of defining characteristics and related factors as components of the diagnosis, with their operational definitions, as well as the definition and statement of the diagnosis with the class to which their domain belongs is estimated[8].

This is a quantitative content validity research based on the collective wisdom approach. This approach considers that the means obtained in the group are higher in relation to individual judgments and it is assumed that such judgments are independent of each other[8]. Thus, they were considered as potential study participants from newly graduated nurses to a group of experienced researchers on the diagnosis and clinical field of study[8].

The article is based on the diversity prediction theorem, which quantifies the relationships when considering that the quadratic error of the collective prediction (the difference between the mean validity attributed by the group and the real validity of the diagnostic content) is equal to the mean quadratic error (mean errors of judgment among participants) minus the predictive diversity (variability of experience among the subjects that make up the group). It is understood, then, that the greater the diversity of experience among the members of the group, the smaller the errors associated with estimates of validity of diagnostic content[8].

Population, inclusion and exclusion criteria

To search for judges, an active search for resumes and/or contacts in research groups, institutions and associations related to Palliative Care was used. The "snowball" technique was also used, which is a form of non-probabilistic sample carried out in reference chains, in which the initial study participants indicate other participants of interest[9].

In this case, the initial participants were members of the Center for Studies and Research in Gerontological Nursing (NEPEG - *Núcleo de Estudos e Pesquisa em Enfermagem Gerontológica*) and the Study Group on Nursing Care Systematization (GESAE - *Grupo de Estudos em Sistematização da Assistência de Enfermagem*) at UFF.

Study protocol

For sample calculation in collective wisdom studies, a formula is used that aims to estimate the mean content validity index (CVI) of the assessments of each diagnostic element as a CVI parameter calculated based on a continuous scale ranging from 0 (None) and 1 (Excellent).

The calculated sample was based on the estimate of the calculation of the mean of assessments (CVI) for each element, and were considered valid when CVI was statistically equal to or greater than 0.8. With 89 participants, considering 95% confidence level $\left(Z_{1 - \alpha/2} \right)$, standard deviation ($.S$) of 0.17 and a sample error (e) of 0.07, with the formula:

$$n_O = \left(\frac{Z_{1 - \alpha/2} \cdot S}{e} \right)^2$$

The instrument was built based on each diagnosis composed of the syndrome, which are also the main nursing diagnoses based on the literature on palliative care[7,10], followed by the conceptual and operational definition, and a space for participants' observations.

A pilot test for understanding was carried out with 5 nursing professionals who worked in palliative oncology care, which after considering allowed the construction of a definitive instrument containing two parts: a semi-structured questionnaire for judges' characterization data and an instrument for diagnostic content validation. These were considered in the final sample, after the final questionnaire was answered again.

Approximately 400 potential judges were approached, of which 89 responded to the instrument. Each selected judge received digitally an Informed Consent Form (ICF) with guidelines on the study. After signing the informed consent form, the experts received instructions to complete the digital data collection instrument. This assessment allowed individuals to identify the degree of adequacy of each criterion as being appropriate or not.

The diagnostic content validation instrument was composed of the structural components of the proposed nursing diagnosis according to NANDA-I taxonomy, such as Domain (Comfort), Class (Physical Comfort), Title (Symptom Deterioration Syndrome), Definition (state of disease that affects physical, psychological, social, and spiritual states of individuals and leads to increased susceptibility to one or more set of symptoms)[9].

The defining characteristics were selected according to the nursing diagnoses related to palliative care most present in the scientific literature[7,10], namely: Chronic Pain, Disturbed Sleep Pattern, Nausea, Imbalanced Nutrition: Less than Body Requirements, Anxiety, Fatigue, Ineffective Breathing Pattern, Impaired Comfort, Spiritual Distress, Ineffective Thermoregulation, Constipation, Diarrhea, Acute Confusion, Urinary Retention, Grieving[7].

As related factors, Palliative Care, End Of Life Care, Chronic Diseases in Stage, Chronic Physical Disability were chosen[7].

These components were assessed according to a Likert scale[11] composed of five levels related to the adequacy of this inclusion: 1- Nothing, 2- Little, 3- Somehow, 4- Very, 5- Excellent.

Analysis of results

Data were organized in a spreadsheet available in the Microsoft Office Excel 2016[tm] and analyzed by R[tm], version 3.2.0. Descriptive analysis includes the calculation of absolute and percentage frequencies and 95% confidence intervals for nominal variables. Shapiro-Wilk test was applied to verify data at normal distribution.

RESULTS

The semi-structured questionnaire for experts' characterization data was answered by 89 professionals (Table 1). There was a predominance of females (88.8%), from the southeastern region (53.9%), who worked in hospitals (36%), with *lato sensu* specialization (47.2%), referring to the main field of expertise in palliative care (53.9%), with experience of NANDA-I nursing taxonomy (85.4%).

Considering the calculation of Benner's level of expertise as $\frac{(2x + 2y + z)}{3}$, in which "x" is time of experience in NANDA-I nursing diagnoses, "y" is time of experience in palliative care and "z" is the maximum degree we reach most experts with being from the novice level (31.5%).

The content assessment results of "Terminality Syndrome" were analyzed according to normality using Shapiro-Wilk test, which after being assessed as non-parametric, Wilcoxon T test was used to compare whether the population mean ranks differ, shown in Table 2.

It is observed that the relationship between the mean CVI and the structural components of the diagnostic proposal was ≥ 0.8 with the exception of the title. The title "Symptomatic Deterioration Syndrome" was then revised based on experts' suggestions and forwarded for a new analysis, renamed "Symptom Decompensation Syndrome", and then, "Terminality Syndrome", reaching 83.7% approval of the 48 judges from the first stage who agreed to participate again.

Table 1 - Characterization data of judges according to a semi-structured questionnaire

Variables	n(%)
Sex	
Male	10 (11.2)
Female	79 (88.8)
Region/Country	
North	5 (5.6)
Northeast	16 (18)
Center-West	7 (7.9)
South	10 (11.2)
Southeast	48 (53.9)
Other country	3 (3.4)
Current workplace	
Hospital	32 (36)
University	24 (27)
Teaching hospital	15 (16.9)
Other	18 (20.2)
Academic Degree	
Specialization (lato sensu)	44 (49.4)
Master's degree	29 (32.6)
Doctoral degree	14 (15.7)
Postdoctorate degree	2 (2.2)
Main Practice Fields	
Palliative Care	48 (53.9)
Oncology	25 (28.1)
Cardiology	3 (3.4)
Gerontology	24 (27)
Teaching in Palliative Care	21 (23.6)
Experience with NANDA-I nursing diagnoses	76 (85.4)
Experience with Taxonomies	20 (22.5)
Expert level - Benner	
Beginner	28 (31.5)
Advanced beginner	22 (24.7)
Competent	21 (23.6)
Proficient	11 (12.3)
Expert	7 (7.8)

Table 2 - Validation of diagnostic content by judges

Item	Shapiro-Wilk test		CVI	95%CI			Wilcoxon test	
	W	p value					V	p value
1. Domain	0.730	**<0.001**	0.875	0.875		0.875	7503	**<0.001**
2. Class	0.789	**<0.001**	0.875	0.750		0.875	4186	**<0.001**
3. Title	0.835	**<0.001**	0.750	0.750		0.750	3003	**<0.001**
4. Definition	0.751	**<0.001**	0.875	0.875		0.875	6670	**<0.001**
Defining characteristic								
Chronic Pain	0.721	**<0.001**	0.875	0.875		0.875	7875	**<0.001**
Disturbed Sleep Pattern	0.788	**<0.001**	0.875	0.750		0.875	4950	**<0.001**
Nausea	0.734	**<0.001**	0.875	0.875		0.875	6555	**<0.001**
Imbalanced Nutrition: Less than Body Requirements	0.689	**<0.001**	0.875	0.875		0.875	8385	**<0.001**
Anxiety†	0.723	**<0.001**	0.875	0.875		0.875	8001	**<0.001**
Fatigue	0.666	**<0.001**	0.875	0.875		0.875	9730	0.021
Ineffective Breathing Pattern	0.734	**<0.001**	0.875	0.875		0.875	6903	**<0.001**
Impaired Comfort	0.658	**<0.001**	0.875	0.875		1.000	10153	0.061
Spiritual Distress	0.650	**<0.001**	0.875	0.875		1.000	10296	0.083
Ineffective Thermoregulation	0.661	**<0.001**	0.875	0.875		0.875	9453	0.010
Constipation	0.662	**<0.001**	0.875	0.875		1.000	9870	0.031
Diarrhea	0.783	**<0.001**	0.875	0.750		0.875	5671	**<0.001**
Acute Confusion	0.706	**<0.001**	0.875	0.875		0.875	8385	**<0.001**
Urinary Retention	0.666	**<0.001**	0.875	0.875		0.875	8911	0.002
Grieving	0.679	**<0.001**	0.875	0.875		0.875	8646	0.001
Related factors								
Palliative Care	0.704	**<0.001**	0.875	0.875		0.875	8128	**<0.001**
End of life Care	0.663	**<0.001**	0.875	0.875		0.875	7875	**<0.001**
Chronic Diseases in Advanced Stage	0.618	**<0.001**	0.875	0.875		1.000	10296	0.083
Chronic Physical Disability	0.712	**<0.001**	0.875	0.875		0.875	7140	**<0.001**

Notes: CVI – Content Validity Index, 95%CI – 95% Confidence Interval.

DISCUSSION

During a validation of diagnostic content, it is important to have experts' opinion in the thematic field of research. This requires a good definition for identification and choice of these professionals, as they are protagonists of this methodology. Inaccurate definitions and choices without the selection criteria of these experts can interfere with the veracity of results. Moreover, there is, in practice, a difficulty in obtaining experts to validate specific content of nursing diagnoses. This becomes more divergent when the literature provides few definitions necessary to define an expert.

For the nursing diagnosis in question, the signs and symptoms that constituted the syndrome proposal were the main ideas to be assessed by judges. Building the diagnosis itself was based on research studies that reported the presence of various signs and symptoms in this period of palliative care[9-10] as pain, which is the most evident clinical sign, followed by others such as dyspnea, fatigue, anxiety and disturbed sleep. These, among others, manifest themselves in the form of a cascade, such as pain that can lead to worsening dyspnea[12-14]. This indicates that when identifying one of the defining characteristics of the studied diagnosis, the intervention would be interconnected and can be efficient for its clinical conduct in dealing with a syndrome diagnosis[6].

Observable differences were noted in Wilcoxon test related to "Fatigue", "Impaired comfort", "Spiritual Distress" and "Chronic Diseases in Advanced Stage". In other words, there were differences between the population mean positions, which indicates that these items were considered more relevant among those assessed.

Fatigue is considered "an overwhelming sustained sense of exhaustion and decreased capacity for physical and mental work at usual level"[6], despite being one of the most relevant nursing

diagnoses for patients with cancer or heart failure and terminally ill[15-16]. It is difficult to assess in practice and requires reliable instruments for its assessment, being still considered by some evaluators as an isolated diagnosis.[14,16]. It is also important to consider the fact that fatigue can be caused both by the progress of the disease and by treatments often performed during cancer treatment or other chronic diseases[17-18]. This probably justifies their presence observed by judges.

NANDA-I defines spiritual distress as "the impaired ability to experience and integrate meaning and purpose in life through connectedness with self, others, art, music, literature, nature, and/or a power greater than oneself."[6]. Judges made relevant the issue that it is a distress that can be transient or prolonged, capable of altering the individual's sense of life. This corroborates findings in the literature that indicate that even if instruments exist to carry out the assessment of spiritual distress, its identification is often performed, or should be, based on the professionals' individual critical sense[19]. It is essential that nurses know how to incorporate spiritual practice in their practice, since they must act from a holistic perspective, not ignoring this dimension[20].

The nursing diagnosis "Impaired Comfort" is understood as a "*perceived lack* of ease, *relief*, and *transcendence* in *physical*, *psychospiritual*, *environmental*, *cultural*, and/or *social dimensions*."[6]. This definition has a broad meaning and it is possible to be identified as one of the most prevalent in the clinical practice of palliative nurses. Patients experience discomfort dealing with physical, psychosocial and spiritual signs and symptoms[21] either in a transient or continuous manner as indicated by judges' comments.

Moreover, "Chronic Diseases in Advanced Stage" present as a related factor refers to the need to implement palliative care actions for human dignity in the natural process of the disease course,

since its diagnosis, strengthening care and making it treatable as the disease progresses[17]; however, some judges considered the item impertinent due to the understanding that "Palliative Care" and "End Of Life Care" would be sufficient as central and would already welcome "Chronic Diseases in Advanced Stage".

The initial title, "Symptom Deterioration Syndrome", was chosen based on the scientific literature, making it necessary to review it after participants' judgment. According to them, the word "deterioration" was not suitable for referring to clinical worsening, while symptoms can be maintained indefinitely as well as in a pejorative sense. Moreover, some pointed out that the meaning could be lost in translation into other languages. After a new assessment, experts agreed on the new title proposal, "Symptom Decompensation Syndrome", as it was considered more appropriate to the proposed definition.

However, in the third round, "Terminality Syndrome" was suggested, as the highest degree of adequacy among participants. The experts' understanding of the title change demonstrates participants' involvement with the study. Therefore, the title was changed to Terminality syndrome having as definition "state of deterioration of a set of signs and symptoms, physical, social, and spiritual of individuals resulting from the disease". The comprehensive classification domain was domain 12, as it is about the complexity and indication of comfort interventions for this patient in palliative oncology care, because comfort is a feeling of well-being or mental, physical or social tranquility[6].

Study limitations

Due to the relatively small number of professionals working in the field, there was a need for experts to belong to different levels of expertise, and a good part was beginner or advanced beginner. This was compensated by using collective wisdom methodology as it addresses the possible biases and presents itself as a methodological potential for this type of study[7,22-23].

Contributions to nursing

This study contributes by validating with experts a new nursing diagnosis that will be useful for an objective documentation of nursing practice for a growing population/area. But mainly, it hopes to provide nurses and multidisciplinary teams with guidance to implement clinical reasoning aimed at offering comfort care and minimizing distress for patients and family members who face a chronic degenerative disease. With the validated diagnosis, it is possible in the future to determine which nursing interventions are more efficient to mitigate the impact of terminal illness, thus guiding its clinical management.

CONCLUSIONS

This study validated the content of the nursing diagnosis "Terminality Syndrome" with experts, when obtaining a mean CVI of items was above the recommended, ≥ 0.8, except for the title that was revised, and also for four items: "Fatigue", "Impaired Comfort", "Spiritual Distress" and "Chronic Diseases in Advanced Stage", which were valid, despite having discrepancies regarding the adequacy assessments by some experts. Therefore, the diagnostic proposal aims to enhance the nursing process in management and control of symptoms in palliative care, optimizing reasoning in clinical practice, with the joint identification of symptoms in a syndrome diagnosis.

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