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Elaboration and validation of the Brazilian Scale of Perception about Euthanasia

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Abstract

This research elaborated an instrument to identify nurses' perception on euthanasia and test its content validity, response process, internal structure and reliability evidences. A psychometric study was conducted through evaluation by a committee of judges, pre-test, and validation. The latter step included 821 nurses. Exploratory and confirmatory factor analyses were performed. A total of 55 items were elaborated based on a literature review. After review by judges and applying the suggested changes, all items showed agreement above 80% between evaluators. Exploratory and confirmatory factor analyses indicated a satisfactory fit of a two-dimensional model and good reliability indices ($\alpha=0.85$; $\Omega=0.89$). The 12-item scale showed good validity and reliability evidences, and can be used to measure nurses' perception on euthanasia.

Keywords: Euthanasia. Psychometrics. Ethics, nursing. Validation study. Bioethics. Health knowledge, attitudes, practice. Social perception.

Resumo

Elaboração e validação da Escala Brasileira de Percepção sobre Eutanásia

Esta pesquisa buscou elaborar um instrumento para identificar a percepção de enfermeiros sobre eutanásia e testar suas evidências de validade de conteúdo, processo de resposta, estrutura interna e confiabilidade. Realizou-se estudo psicométrico por meio de avaliação empreendida por comitê de juízes, pré-teste e validação. O processo de validação incluiu 821 enfermeiros. Realizaram-se análises fatoriais exploratórias e confirmatórias. Elaboraram-se 55 itens com base em revisão de literatura e, após análise por juízes, as alterações sugeridas foram aplicadas, e todos os itens apresentaram concordância acima de 80% entre os avaliadores. As análises fatoriais exploratória e confirmatórias indicaram um ajuste satisfatório de um modelo bidimensional e bons índices de confiabilidade ($\alpha=0,85$; $\Omega=0,89$). A escala de 12 itens demonstrou boas evidências de validade e confiabilidade, podendo ser utilizada para mensurar a percepção sobre eutanásia por enfermeiros.

Palavras-chave: Eutanásia. Psicometria. Ética em enfermagem. Estudo de validação. Bioética. Conhecimentos, atitudes e prática em saúde. Percepção social.

Resumen

Elaboración y validación de la Escala Brasileña de Percepción sobre la Eutanasia

Esta investigación buscó desarrollar un instrumento para identificar la percepción del profesional enfermero sobre la eutanasia y probar su evidencia de validez de contenido, proceso de respuesta, estructura interna y confiabilidad. Se realizó un estudio psicométrico mediante la evaluación realizada por un comité de jueces, pretest y validación. El proceso de validación incluyó a 821 enfermeros. Se realizaron análisis factoriales exploratorios y confirmatorios. Se elaboraron 55 ítems con base en una revisión de la literatura y, luego del análisis de los jueces, se aplicaron las modificaciones sugeridas, y todos los ítems mostraron concordancia superior al 80% entre los evaluadores. Los análisis factoriales exploratorio y confirmatorio indicaron un ajuste satisfactorio de un modelo bidimensional y buenos índices de confiabilidad ($\alpha=0,85$; $\Omega=0,89$). La escala de 12 ítems mostró buena evidencia de validez y confiabilidad y puede ser utilizada para medir la percepción del personal enfermero sobre la eutanasia.

Palabras clave: Eutanasia. Psicometría. Ética en enfermería. Estudio de validación. Bioética. Conocimientos, actitudes y práctica en salud. Percepción social.

The authors declare no conflict of interest.

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In their daily professional practice, nurses often face conflicting situations and must be prepared to deal with them in a critical and responsible manner¹. Ethical attitudes are especially difficult in situations involving life and death, due to the fact that the decisions to be taken are pervaded by values related to bioethics, morality, family and religion of all those involved^{1,2}. End-of-life dilemmas and the way they are handled are often questioned, as bioethical values may intervene, making it difficult to understand and resolve the situations^{1,2}.

Considering this context generated by the new paradoxes related to the advancement of medicine, several countries have been discussing the best way to address such ethical dilemmas and even reviewing their laws. Among them is Brazil, where a proposal to change the Penal Code (Bill 236/2012), regarding a new understanding of and punishment for cases of euthanasia, is currently going through Congress^{3,4}.

The word “euthanasia,” of Greek origin, was coined by Francis Bacon in 1605, and at the time meant “good death.” Currently understood as a medical act that deliberately causes the patient’s death, at his/her voluntary and explicit request¹, euthanasia can be conceptually classified, according to the patient’s act and will, as active or passive, and voluntary, involuntary or non-voluntary, respectively.

In active euthanasia, death is induced through the administration of medication by third parties, while in passive euthanasia, equipment is removed and medications that sustain life are suspended⁵.

In voluntary euthanasia, the decision is the result of individual, informed and enlightened deliberation by the patient; involuntary euthanasia, in turn, occurs when the person did not explicitly communicate the desire for this outcome, being characterized as homicide. Non-voluntary euthanasia, also called presumed, occurs when the patient’s will has not been made explicit, but considering their inability to make a decision at that time, it can be performed at the request of a health attorney⁵.

Although euthanasia is illegal in most countries, discussions on the subject are frequent. There are different points of view on the fact, considering mainly bioethical principles: some people

defend euthanasia to preserve the autonomy of individuals, while others are against it, as they especially value beneficence and non-maleficence^{1,5}. It is believed that nurses should reflect, individually and collectively, on their ethical and legal responsibilities and perceptions on the subject—a contemporary, complex and controversial concern⁶.

Aiming to measure the perception of nurses about euthanasia in a valid and reliable way, this study proposes to develop a specific instrument for this purpose, fully complying with scientific rigor in the stages of design and validation of psychological measurement instruments.

“Perception” is a broad term, understood in this work as the process of organizing and interpreting received data to develop self-awareness and awareness of the environment. It is an active and complex process that involves several cognitive activities, such as attention, memory, attitudes, opinion, feelings, beliefs and previous experiences⁷;

Therefore, this article aims to develop an instrument to identify the perception of nurses about euthanasia and test evidence to validate the content, response process, internal structure and reliability of the proposed instrument.

Method

This is a psychometric study to design and validate health measurement instruments, carried out in five steps, described below.

Step 1: Bibliographical review and design of instrument items

A bibliographical search was conducted in the MEDLINE, LILACS, Cochrane Library, Cinahl, *Bases de Dados de Enfermagem* (BDENF) and Education Resources Information Center (Eric) databases using the following descriptors and their respective versions in Portuguese and Spanish: “emotions,” “attitude,” “religion,” “euthanasia,” “psychometrics,” “bioethics” and “nursing.” The studies included were in Portuguese, English and Spanish, published between 2005 and 2015, that addressed feelings,

beliefs and attitudes about euthanasia. The data of the selected studies were tabulated in an electronic spreadsheet and, for each mention of a feeling, belief or attitude, an item was created to compose the instrument.

Step 2: Content validation

To evaluate the designed items, a panel was set up with ten specialists in bioethics from different professional fields, with more than five years of higher education and practical experience with ethical end-of-life dilemmas.

The specialists evaluated the clarity, relevance/pertinence and dimensionality of each proposed item, according to the following agreement scale: -1="I disagree with including the item"; 0="I partially agree with including the item"; and +1="I agree with including the item". For items evaluated as 0 or -1, suggestions for changes were requested, and the items were reformulated and submitted to a new round of evaluation, until a consensus was reached.

Agreement between the judges was evaluated using the Gwet's AC2 coefficient, with a 95% confidence interval (95%CI) and a significance level of 5%, and the content validity index (CVI) using the formula " $\% \text{agreement} = \frac{\text{sum of score on each question}}{\text{number of participants}} \times 100$." For both tests, values ≥ 0.80 were considered acceptable. The analyses were performed using the SPSS program.

A pre-test was also carried out to validate the response process with ten nurses, students of the specialization course in emergency nursing at a private institution of higher education in the city of São Paulo/SP, who were invited to answer the instrument. They were asked to evaluate the clarity and ease of understanding the proposed items, pointing out aspects for improvement in the answering process.

Step 3: Critical analysis of items and instrument development

The authors analyzed the items approved in the previous stage, considering the structure, composition and naming criteria of the Patient-Reported Outcome Measurement Information System (Promis) on scientific standardization of

instrument development and validation criteria⁸. Then, the instrument was designed with each item accompanied by a Likert-type scale ranging from 1="strongly disagree" to 5="strongly agree."

Step 4: Internal structure validation and reliability analysis

The instrument was administered to a sample of nurses, students of 18 different specialization courses at the aforementioned institution. The sample calculation was performed considering a minimum number of 20 respondents per item.

The sample was randomized into two subgroups (A and B). Subgroup A was used to perform exploratory factor analysis (EFA) and reliability, and subgroup B to perform confirmatory factor analysis (CFA). Data factorability was verified in subgroup A using the Kaiser-Meyer-Olkin test (KMO) and Bartlett's test of sphericity (BTS), with values >0.70 and <0.05 considered adequate, respectively⁹.

Data extraction was performed using the unweighted least squares method, based on a polychoric correlation matrix, with Oblimin rotation. Items with factor loadings <0.50 , communalities <0.40 or double saturation were excluded. Self-sufficient item sets were considered if total explained variance was $\geq 60\%$ ⁹.

Reliability was calculated using Cronbach's alpha (α) and McDonald's omega (Ω). Values between 0.70 and 0.90 were considered ideal, with a 95%CI for both⁹. The analyses were performed using the R program.

Items approved in this stage were submitted to CFA using the maximum likelihood estimation method, considering the following adequacy criteria: chi-square ratio ($\chi^2/\text{degrees of freedom (DF)}$), with <2 =excellent and from 3 to 5=good; goodness-of-fit index ($\text{GFI} \geq 0.95$); normalized fit index ($\text{NFI} \geq 0.95$); Tucker-Lewis index ($\text{TLI} \geq 0.95$); comparative fit index ($\text{CFI} \geq 0.95$); standardized root mean square residual ($\text{SRMR} \leq 0.08$); root mean squared error of approximation ($\text{RMSEA} \leq 0.05$)⁹. R software was used for EFA and AMOS software version 24 was used for CFA.

Step 5: Instrument score definition

Based on the results of EFA and the CFA with the final items selected to compose the instrument,

the weights were identified and the instructions for using the scale and obtaining the final score were designed.

This research was carried out in accordance with the ethical and legal precepts required by CNS Resolution 466/2012. It was approved by the Research Ethics Committee (REC) of Hospital Israelita Albert Einstein (Opinion no. 2,060,816).

Results

Step 1: Bibliographical review and design of instrument items

In total, 47 studies were selected. Most publications (23; 48.9%) were found in MEDLINE, mainly in 2009 (10; 21.2%). For each feeling, belief or attitude mentioned in the articles, an item was created to compose the instrument, totaling 55.

Step 2: Content and response process validation

The 55 designed items were separated into three domains (feelings, beliefs and attitudes) and submitted to content validation by the group of specialists, composed of five nurses, a lawyer, a priest/philosopher, two doctors and a psychologist. The mean age of the judges was 43.3 years, with equal distribution between genders. Five specialists had a PhD, four had masters' degrees and one had a specialist degree.

There were two rounds of evaluation. In the first, 15 items were approved, and inclusion of a new item was suggested, identified with the number 56—"I feel compassion when caring for a patient who desires euthanasia."

The 40 items that were not approved in the first round were adjusted according to suggestions and, together with item 56, were submitted to the second round of evaluation. Only six judges took part in this round, in which 27 items were approved and 14 were excluded, totaling 42 approved items, with Gwet's AC2 0.80 (95%CI: $p < 0.05$) and CFI $\geq 80\%$.

The ten nurses who took part in the pre-test to validate the response process stated that the proposed instrument was clear and easy to understand, and had no difficulty to answer it.

The participants in this step were not included in the study sample.

Step 3: Critical analysis of approved items and instrument development

The authors excluded three items for not meeting Promis⁸ recommendations (they had double negatives and/or two pieces of information in the same item). Thus, 39 items remained.

Step 4: Internal structure validation and reliability analysis

The instrument with 39 items was answered by 821 nurses. Most were female (731; 89.8%), aged between 20 and 64 (median 29 years). Professional training time ranged from zero to 33 years, with a median of two years. Most participants were single (452; 55%), without children (601; 73.2%) and Catholic (381; 46.4%).

The sample was randomized into subgroups A (n=411) and B (n=410). Data factorability was tested in subgroup A and confirmed by obtaining KMO=0.83 and TEB<0.001. Data were extracted and 25 items were excluded for having factor loadings <0.50, commonalities <0.40 and/or double saturation, with 14 items remaining in the instrument.

The model underwent further specification, in which two more items had to be excluded, as they had commonalities <0.40. Thus, 12 items remained, organized into two factors called attitudes and feelings, respectively, with explained variance of 69%. The reliability analysis was performed considering the total instrument— $\alpha=0.85$ (95%CI: 0.83; 0.87) and $\Omega=0.89$ (95%CI: 0.88; 0.90)—as well as each factor individually (Table 1).

These 12 items were submitted to CFA with data from subgroup B (n=410). The initial model was obtained considering two correlated dimensions, and the only satisfactory measure was SRMR (0.069). Error control was carried out, considering the high covariances between items 44, 45 and 46, so that the new model presented a good fit in all adequacy criteria: ratio $\chi^2/DF=2.384$; GFI=0.952; NFI=0.962; TLI=0.970; CFI=0.977; SRMR=0.037; RMSEA=0.058 (0.045; 0.072 – 90%CI).

Then, the final version of the instrument entitled Brazilian Euthanasia Perception Scale (BEPS) was designed.

Table 1. Exploratory factor analysis and reliability (n=411)

Item	F1	F2	Commonality	α (95%CI)	Ω (95%CI)
Q46	0.89	-0.01	0.80	0.95 (0.95; 0.96)	0.95 (0.95; 0.96)
Q43	0.89	-0.02	0.80		
Q45	0.86	0.03	0.72		
Q44	0.86	0.06	0.70		
Q48	0.86	0.02	0.72		
Q47	0.85	-0.01	0.72		
Q53	0.80	-0.02	0.66		
Q49	0.80	-0.08	0.70		
Q32	0.67	0.01	0.44		
Q6	-0.01	0.94	0.88	0.84 (0.82; 0.86)	0.85 (0.83; 0.86)
Q8	0.01	0.78	0.60		
Q4	0.00	0.71	0.51		

Step 5: Instrument score definition

To calculate the instrument score, all 12 items must be answered. The score is obtained by adding the responses on the Likert-type scale. The attitude domain score (items 1 to 9) ranges from 9 to 45, and the higher the value, the greater the favorable attitude towards

euthanasia, demonstrating positive connotations of the respondents.

For the feelings domain (items 10 to 12), the score ranged from 3 to 15, and the higher the value, the more negative the nurse's feelings in relation to euthanasia, imparting an inverse relationship to the score of the domains.

Chart 1 presents the instructions for completing the BEPS.

Chart 1. Instructions to complete the Brazilian Euthanasia Perception Scale

Please answer the items below according to your opinion about euthanasia. If you have never experienced a situation similar to the one described, answer what you imagine your ethical position would be in the situation. Check one alternative for each question, considering:

1. I strongly disagree with the statement
2. I partially disagree with the statement
3. I neither agree nor disagree with the statement
4. I partially agree with the statement
5. I strongly agree with the statement

Items	1	2	3	4	5
1. I suffer when a patient requests euthanasia					
2. I would agree to participate in the euthanasia of a patient, if it were legal in Brazil					
3. I am in favor of euthanasia					
4. I would turn off the life-sustaining devices of an incurable and terminally ill patient.					
5. I would administer drugs knowing that they would cause the death of a patient with an incurable terminal illness.					
6. I would request that a close relative be euthanized if he or she had an incurable terminal illness					
7. I would request to be euthanized if I had an incurable terminal illness					

continues...

Chart 1. Continuation

Please answer the items below according to your opinion about euthanasia. If you have never experienced a situation similar to the one described, answer what you imagine your ethical position would be in the situation. Check one alternative for each question, considering:					
1. I strongly disagree with the statement					
2. I partially disagree with the statement					
3. I neither agree nor disagree with the statement					
4. I partially agree with the statement					
5. I strongly agree with the statement					
Items	1	2	3	4	5
8. I support patients who request to be euthanized					
9. I would accept the euthanasia request of a relative of a patient with an incurable terminal illness					
10. I feel distressed when dealing with patients who wish to undergo euthanasia					
11. I feel sad when dealing with patients who wish to undergo euthanasia					
12. Performing euthanasia means being fair to a patient who has an incurable terminal illness					

Discussion

The instrument was designed with 12 items divided into two dimensions (attitudes, with nine items, and feelings, with three items), to be self-administered, with consistent psychometric properties that are able to explain a large part (69%) of the “nurses’ perception of euthanasia” phenomenon.

These BEPS characteristics are in line with recommendations in the literature that guide the creation of short instruments, with simple language, for faster administration, avoiding fatigue and lack of interest of respondents¹⁰. In addition, a self-reporting scale allows nurses to freely express their opinions, since the subject is naturally sensitive and controversial and their personal convictions may at times be at odds with legislation and professional codes of ethics^{1,6}.

Regarding attitudes, the instrument addresses aspects related to both the nurses’ stance (such as being favorable to euthanasia, accepting to participate and supporting a euthanasia request) and their possible actions (requesting euthanasia for themselves or for a family member considering presumed euthanasia, turning off life-support or administering medication for the purpose of helping a patient to die).

The feelings addressed in the instrument are distress, sadness and justice. By personalizing the subject, the instrument leads nurses to reflect more deeply on the reality of their feelings and likely attitudes.

Although the BEPS is intended to be used with nurses, it should be noted that the validation sample mostly comprised participants who were graduate students, young, single, without children and at the beginning of their professional careers, which may not represent the totality of the universe of nursing professionals in Brazil. Future studies may validate the use of this scale with other professional profiles and in different contexts, and also with health professionals from other areas.

Despite the good results obtained in the psychometric analysis, comparing the BEPS with other scales found in the literature is difficult. Few instruments have been published that assess constructs related to euthanasia.

After an extensive bibliographical search, the following instruments were found: Chinese Expanded Euthanasia Attitude Scale (EAS-EC)¹¹, Attitudes Toward Euthanasia (ATE) Scale¹², Attitude Towards Dignified Death^{13,14}, Attitudes van verpleegkundigen over beslissingen aan het levenseinde bij patiënte^{14,15} and Frommelt Attitudes Toward Care of the Dying (FATCOD)^{16,17}.

None of those scales had been validated for nurses nor did they specifically address the perception of such professionals on the subject. In addition, they were not available for consultation and/or had conceptual, methodological or psychometric flaws in their design, adaptation or validation, which made it impossible to compare the results¹¹⁻¹⁷.

The only Brazilian study identified on the subject was a master's thesis dated 1986, in which the researcher created and tested some properties of an instrument called Attitude about Euthanasia Scale¹⁷ in a group of physicians and lawyers. However, as significant social changes have occurred since then, the items that made up the scale do not meet the demands of contemporary contexts and concerns, preventing once again an adequate comparison of results.

Therefore, administering the BEPS is recommended to help nurses understand their perceptions (attitudes and feelings) about euthanasia, given the lack of knowledge on the subject by professionals—even among those who frequently deal with death¹⁸—and, based on the results, to enhance teaching activities and bioethical deliberations on the subject.

Final considerations

An instrument was designed to identify nurses' perception of euthanasia, consisting of 12 items divided into two domains, which showed good evidence of content validity, response process, internal structure and reliability.

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Participation of the authors

Beatriz Murata Murakami conceived the scientific project, performed data collection and analysis, and took part in the discussion of results and writing of the manuscript. Renata Eloah de Lucena Ferretti-Rebustini contributed to data analysis, discussion of results and writing of the manuscript. Fernanda Amendola conceived the scientific project, performed data analysis and took part in the discussion of results and writing of the manuscript. Fabiane de Amorim Almeida conceived the scientific project, performed data analysis and contributed to the discussion of results and writing of the manuscript.

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