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## Death anxiety in palliative care: Validation of the nursing diagnosis

Ansiedade relacionada à morte em cuidados paliativos: validação do diagnóstico de enfermagem

Ansiedad ante la muerte en cuidados paliativos: validación del diagnóstico de enfermería

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### Keywords

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### Descritores

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### Abstract

**Objective:** To identify the prevalence of the NANDA-I nursing diagnosis of death anxiety among family caregivers of palliative patients and to validate the associated defining characteristics.

**Methods:** This was a cross-sectional, exploratory, and descriptive study using Fehring's clinical diagnostic validity model in a sample of 111 family caregivers of palliative patients. The sensitivity, specificity, and predictive value of the defining characteristics were calculated. Questions formulated to operationalize the defining characteristics were validated by a panel of experts.

**Results:** The prevalence of the diagnosis was 38.7% in the study sample, and 17 defining characteristics were subjected to clinical validation, of which eight emerged from a previous literature review. Of the 17 defining characteristics, nine were classified as primary and eight as secondary.

**Conclusion:** The diagnosis was validated in family caregivers of palliative patients. The clinical validation of new defining characteristics confirmed the need to review these characteristics to ensure their clinical suitability. The prevalence of the diagnosis in the study sample indicates that death anxiety is a relevant phenomenon among family caregivers of palliative patients that professionals should be particularly aware of in order to implement specific interventions to minimize this condition.

### Resumo

**Objetivo:** Identificar a prevalência do diagnóstico de enfermagem ansiedade relacionada à morte da NANDA-I em cuidadores familiares de doentes paliativos; e validar as características definidoras associadas.

**Métodos:** Estudo transversal, exploratório e descritivo utilizando o Modelo de Validação Clínica de Fehring, em uma amostra de 111 cuidadores familiares de doentes paliativos. Foi calculada a sensibilidade, especificidade e valor preditivo das características definidoras. As questões formuladas para operacionalizar as características definidoras foram validadas por um painel de peritos.

**Resultados:** A prevalência do diagnóstico foi de 38,7% na amostra estudada. Foram alvo de validação clínica 17 características definidoras, oito delas emergiram de uma prévia revisão da literatura. Nove características foram classificadas como principais e oito secundárias.

**Conclusão:** O diagnóstico foi validado em cuidadores familiares de doentes paliativos. A validação clínica de novas características definidoras confirmou a necessidade da sua revisão de modo a estar adequado à clínica. A prevalência do diagnóstico na amostra estudada, indica que este é um fenómeno relevante a que os profissionais devem estar particularmente atentos, de modo a implementar intervenções específicas para minimizar a ansiedade relacionada à morte dos cuidadores familiares de doentes paliativos.

### Resumen

**Objetivo:** Identificar la prevalencia del diagnóstico de enfermería ansiedad ante la muerte de la NANDA-I en cuidadores familiares de enfermos paliativos y validar las características definitorias asociadas.

**Métodos:** Estudio transversal, exploratorio y descriptivo utilizando el modelo de validación clínica de Fehring, en una muestra de 111 cuidadores familiares de enfermos paliativos. Se calculó la sensibilidad, especificidad y valor predictivo de las características definitorias. Los temas formulados para poner en funcionamiento las características definitorias fueron validados por un grupo de peritos.

**Resultados:** La prevalencia del diagnóstico fue de 38,7% en la muestra estudiada. Fueron objeto de validación clínica 17 características definitorias, 8 de ellas surgieron de una revisión bibliográfica previa. Nueve características se clasificaron como principales y ocho como secundarias.

**Conclusión:** El diagnóstico fue validado en cuidadores familiares de enfermos paliativos. La validación clínica de nuevas características definitorias confirmó la necesidad de su revisión a fin de adecuarse a la clínica. La prevalencia del diagnóstico en la muestra estudiada indica que este es un fenómeno relevante al que los profesionales deben estar especialmente atentos, a fin de implementar intervenciones específicas para minimizar la ansiedad ante la muerte de los cuidadores familiares de enfermos paliativos.

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## Introduction

For the majority of us, dying means separation from loved ones, the impossibility of achieving our goals, and dealing with the unknown. In case of palliative patients and their relatives, the worry about when and how death will occur is a common concern. The awareness of the imminence of one's own death or that of loved ones can cause great anxiety,<sup>(1,2)</sup> which is referred to as death anxiety in the scientific literature.

Death anxiety is the subject of study in various fields of knowledge, and, probably for this reason, a consensus has not yet been reached on its definition. Death anxiety has been defined as "a relatively stable personality trait that reflects negative attitude, feelings, and cognition concerning death and dying, whether of one's own or of significant others or the idea of death in general."<sup>(3)</sup> Living with death anxiety is considered one of the most difficult experiences in life because it causes suffering and affects mental health<sup>(4,5)</sup> and quality of life.<sup>(6,7)</sup>

In a previous integrative review, we found that research on this topic has predominantly focused on healthy individuals, essentially health professionals. In the clinical context, these studies have been mostly conducted with palliative patients,<sup>(6,8)</sup> terminally ill or cancer patients.<sup>(7,9,10)</sup>

Studies have indicated that family caregivers who witness the rapid physical deterioration and suffering of their loved ones become more aware of their own mortality, which triggers their own fears of death and dying.<sup>(5,11)</sup>

Caregivers with death anxiety have greater difficulty in accepting the imminence of the patient's death,<sup>(12)</sup> have worse quality of life, and are at a greater risk of depression and caregiver overwork,<sup>(5,6)</sup> which thereby affects patient caregiving and jeopardizes the possibility of keeping patients in their homes until the moment of death, if that is the wish. These facts substantiate the importance of reducing death anxiety among caregivers of palliative patients.

The majority of professionals consider the diagnosis of death anxiety to be complex and subject to

subjective interpretations, despite the availability of various assessment scales.<sup>(13)</sup> Some authors believe that these instruments are inadequate for use in the clinical context and advocate the creation of a specific diagnostic tool.<sup>(5,14,15)</sup>

The classifications of nursing diagnoses help nurses in the process of clinical decision-making and facilitate communication between health professionals.<sup>(16)</sup> The NANDA International, Inc. classification of nursing diagnoses<sup>(17)</sup> is widely recognized for its objectivity and for being based on data obtained from research.

The inclusion of the diagnosis of death anxiety (00147) in this classification, in 1998, was justified by the need to define and describe specific care provided to individuals dealing with the dying process<sup>(18)</sup> and was reviewed only once, in 2007. Despite the importance of nursing diagnosis, particularly in the context of palliative care, its use continues to be complex and subjective,<sup>(19)</sup> which may be the reason why we did not find any published study on the prevalence of this diagnosis.

The aim of the present study was to determine the prevalence of the nursing diagnosis of death anxiety among family caregivers of palliative patients and to validate the associated defining characteristics.

## Methods

This was an exploratory, descriptive, and cross-sectional study conducted in a sample of 111 family caregivers of palliative patients of a palliative care regional network (PCRN) in Portugal.

We adopted the Fehring's clinical diagnostic validity model,<sup>(20,21)</sup> with some modifications. In this model, patients with the diagnosis are selected and the defining characteristics are classified based on their frequency, which does not mean that they would not be present among individuals without the diagnosis. The present study included caregivers with and without the diagnosis. The fact that the individuals' status was not established beforehand removes the influence of previous knowledge and selection bias.<sup>(22)</sup>

Because the diagnosis of death anxiety involves a predominantly affective and cognitive response, data collection was performed using a structured interview (form), administered by two researchers with expertise in the diagnosis of death anxiety.

The process of constructing this instrument included the following steps: literature review, consultation of other instruments, and evaluation by experts.

The objective of the integrative literature review was to identify the defining characteristics associated with death anxiety that were not listed in NANDA-I. This strategy has been used in several studies of this nature.<sup>(23,24)</sup> Some characteristics were rewritten and/or grouped to avoid redundancies, as recommended by the author of the model.

The data collection instrument included questions related to the sociodemographic characterization of caregivers and of the caregiving context. In the clinical validation model used, it is prescribed that a measurement instrument is used to assess the presence of the diagnosis. The Revised Death Anxiety Scale (RDAS) was selected,<sup>(25)</sup> which was the version tested for the Portuguese population (global = 0.92).<sup>(26)</sup> The RDAS comprises 25 items with five possible answers. The total score is the sum of the scores of items and ranges from 0 to 100. The higher the score, the greater is the death anxiety. The author of the original scale considered that individuals with a score of >49 points had greater anxiety.<sup>(25)</sup>

Each caregiver was introduced to the definition of death anxiety taken from the integrative review as “feelings of apprehension and concern, worries, and intrusive thoughts related to an excessive fear of death, whether of one’s own or of other individuals.” The caregivers were asked the following: “Do you feel that you have death anxiety?” and a “Yes” or “No” answer was recorded. The diagnosis under study is centered on an abstract cognitive response, the interpretation of which is complex. Therefore, the validation of the presence of the diagnosis by the client/caregiver may increase the accuracy of the diagnosis.<sup>(27)</sup>

There is no description in the literature regarding a gold standard for the diagnosis of death anxiety.

In our study, death anxiety was diagnosed when three criteria were simultaneously met: a score >49 in the RDAS scale; agreement between the two researchers regarding the presence of death anxiety, and the caregiver affirming that he/she has death anxiety. These three criteria have been used in previous clinical validation studies.<sup>(23,24)</sup>

One or two questions that were formulated based on a literature review and by consulting other instruments assessing the same construct were used to evaluate the presence of each defining characteristic. The relevance, clarity, and precision of each item or question were checked by a judging panel.<sup>(28)</sup>

Each participant was asked to state how much each characteristic was indicative of his/her feelings or behavior, with the following five answering scores (1) very uncharacteristic of me, (2) a little characteristic of me, (3) characteristic of me, (4) very characteristic of me, and (5) extremely characteristic of me.

In previous validation studies, the presence of each characteristic was determined based on the score 3.<sup>(24)</sup> However, because of the specificity of the diagnosis under study and because the fear of death is universal among humans,<sup>(2)</sup> the characteristic was deemed present only when a high score of 4 or 5 was obtained, which indicates a “abnormal or persistent death-related fears”.<sup>(9)</sup>

A pre-test was conducted in 10 family caregivers of palliative patients, of both sexes and of different age groups, who were not a part of the study sample. Although RDAS is a self-report instrument, some respondents had difficulties in filling the form during the pre-test; in such cases, the researchers filled the questionnaire themselves.

Family caregivers are defined as individuals who provide unpaid daily or weekly assistance to relatives, friends, or individuals in their social network who need help with activities of daily living (ADL) and instrumental ADL (IADL), irrespective of whether they live with them.<sup>(29)</sup>

The present study included family caregivers (family or affective ties) of patients followed at the PCRN, in a home or hospital setting. The inclu-

sion criteria were the following: being  $\geq 18$  years; providing care (ADL or IADL) to a relative at least twice a week, for at least 1 month; and being able to read and write and not having difficulties in verbal communication (understanding and speaking). Caregivers who, in the opinion of the PCRN nurse, were in a situation of great emotional instability were excluded.

The sampling method was non-probabilistic, by convenience, using a time criterion (18 months) to determine the sample size.

Data collection occurred at the palliative care unit or at the caregiver's home in a quiet and private place, arranged according to the participants' availability and preference, between March 2016 and September 2017.

The potential study participants were initially approached by the PCRN professionals with whom they had a closer relationship.

The average duration of the interviews was 50 min, and they were conducted by the two researchers. Debriefing was provided at the end of each interview so that the caregivers felt free to express their emotions and talk about their experience of participating in the study.<sup>(30)</sup>

A sequential numeric code was assigned to each form, and data were analyzed using Statistical Package for the Social Sciences software, version 20.

To classify the defining characteristics, the classification of Fehring's model was combined with an analysis of sensitivity and specificity, providing the value of the area under the receiver operating characteristic (ROC) curve. A value  $< 0.5$  determines that the indicator should not be used.<sup>(31)</sup> This criterion was used to classify the characteristics as irrelevant.

The characteristics were considered secondary if the area under the ROC curve was  $> 0.5$  and sensitivity was  $< 80\%$  and considered primary if they were very frequent in caregivers with death anxiety, i.e., when sensitivity was  $> 80\%$ .

Associations between the presence or absence of the diagnosis and the defining characteristics were analyzed using chi-square test ( $\chi^2$ ) for a 95% level of significance.

This study was approved by the Scientific Board of the Institute of Health Sciences of the Portuguese Catholic University and was conducted in accordance with the principles of ethical research involving humans. Data collection was preceded by a formal application to the Board of Directors of the health center, which was accepted following a favorable opinion by the Health Ethics Committee (Opinion no. 44/2014).

Autonomy and the right of refusal of participants were assured, with the latter being contacted by researchers only after they accepted the invitation from a professional of the PCRN team to participate in the study. At the beginning of each interview, the family caregiver was informed regarding the nature, duration, data collection procedure, objectives, and risks/benefits of the participation, as well as of the right of refusal to participate in the research and the possibility of revoking their consent at any moment. Each participant was provided with a document with all this information, which was signed by the researcher and participant.

## Results

The age of the family caregivers ranged between 18 and 88 years (mean  $\pm$  SD,  $50.8 \pm 15.4$  years). Most were women (82.9%), married or in a common-law marriage (68.5%), had completed compulsory education (73.8%), and were Catholic (83.8%). With regard to the degree of relatedness to the patient, 49.5% were sons or daughters and 31.5% were spouses. Most caregivers lived with the patients (67.6%) and had been providing care on a daily basis (91.9%) for an average of 18 months (SD  $\pm 25.0$  years) to cancer patients (93.7%). In 50.5% of the cases, patients were hospitalized in the palliative care unit at the time of data collection and 49.5% were cared for at home.

### Presence of the diagnosis

The three diagnostic criteria were simultaneously met in 38.7% of the family caregivers included in

the study, and this value was the prevalence of death anxiety in the study sample. The two researchers independently diagnosed death anxiety in 50.5% of caregivers ( $\kappa = 0.80$ ), and the same percentage of caregivers with the diagnosis was obtained by the score in the RDAS scale ( $\alpha$  global = 0.917). Only 41.4% believed having death anxiety, as per the presented definition. Death anxiety was more frequent among female caregivers (41.3% vs. 26.3%) and children of the patient (50.9% vs. 26.8% other degrees of relatedness). Caregivers with death anxiety were younger (mean  $\pm$  SD, 46  $\pm$  19.4 years) than those who did not have this diagnosis (mean  $\pm$  SD, 54  $\pm$  15.4 years).

### Defining characteristics of death anxiety

Nine primary characteristics were identified (Table 1), i.e., characteristics that were present in at least 80% of caregivers with death anxiety. Two of these are not included in the NANDA-I classification, namely, “fear of the loneliness and abandonment related to the process of dying” (97.7%) and “fear of physical deterioration associated with dying” (81.4%). The remaining eight characteristics were classified as secondary, and none were considered irrelevant (value under the ROC curve  $< 0.5$ ). The most frequent characteristic among all caregivers (with and without the diagnosis) was “feeling of powerlessness” (75.7%). There was a statistically significant association between the presence of the diagnosis and 16 of the 17 defining characteristics subject to the process of validation ( $p < 0.05$ ).

The most frequent characteristics in caregivers with the diagnosis had negative predictive values (NPVs) of 100% and 94%, respectively (Table 2). These results indicate that a caregiver who is not “afraid of the loneliness and abandonment related to the process of dying” or “afraid of losing his/her mental abilities when dying” also does not have death anxiety. Moreover, the high values obtained for the ROC curve reflect an excellent relationship between sensitivity and specificity, which reinforces the accuracy of these clinical indicators. They are relevant both in the determination of the presence and absence of

**Table 1.** Comparison of frequency and classification of the defining characteristics between family caregivers with and without the diagnosis of death anxiety

Classification	Defining characteristics	Diagnosis of death anxiety		p-value (*)
		Diagnosed (n = 43) n (%)	Not diagnosed (n = 68) n (%)	
Primary	Fear of loneliness and abandonment related to the process of dying *	42 (97.7)	27 (39.7)	$p < 0.001$
	Fear of premature death	40 (93.0)	29 (42.6)	$p < 0.001$
	Fear of losing one's mental abilities when dying	35 (93.0)	46 (67.6)	$p < 0.001$
	Fear of the dying process	39 (90.7)	42 (61.8)	$p < 0.001$
	Feeling of powerlessness	39 (90.7)	45 (66.2)	$p = 0.003$
	Fear of developing an incurable illness	37 (86.0)	40 (58.8)	$p = 0.002$
	Worry with caregiver overwork	35 (81.4)	46 (67.6)	$p = 0.112$
	Worry about the impact of one's death on significant others	35 (81.4)	34 (50.0)	$p < 0.001$
Secondary	Fear of physical deterioration associated with dying *	35 (81.4)	28 (42.2)	$p < 0.001$
	Negative thoughts and intrusive thoughts related to death	34 (79.1)	13 (19.1)	$p < 0.001$
	Emotional lability *	33 (76.7)	34 (50.0)	$p = 0.005$
	Avoidance of situations that evoke death *	30 (69.8)	18 (26.5)	$p < 0.001$
	Fear of death and of the process of dying of others *	27 (62.8)	18 (26.5)	$p < 0.001$
	Deep sadness	26 (60.5)	25 (36.8)	$p = 0.015$
	Fear of the body being destroyed after death *	24 (55.8)	9 (13.2)	$p < 0.001$
	Fear of life after death *	20 (46.5)	4 (5.9)	$p < 0.001$
	Worry about instructions for after death being followed	13 (30.2)	5 (7.4)	$p < 0.001$

\* New characteristics that were not listed in NANDA-I; (\*) Test of statistical significance

death anxiety and in distinguishing them from other frequent problems faced by informal caregivers of palliative patients.

Although the characteristics, “worry about caregiver overwork” and “feeling of powerlessness” were classified as primary, and their specificity values were the lowest (32.4% and 33.8%). This indicates that although these clinical indicators are frequent in the study sample,  $>30\%$  of caregivers have death anxiety but do not exhibit them.

The comparison between positive and NPVs showed that, in general, the negative values were higher ( $>70\%$ ) and only four indicators had PPV  $> 70\%$ , i.e., it is a complex task to select clinical indicators that highly indicate death anxiety and that may serve as a gold standard for the diagnosis of death anxiety.

**Table 2.** Sensitivity, specificity, and area under the ROC curve of the defining characteristics of the diagnosis

Defining characteristic		Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)	Area under the ROC curve (%)
PRIMARY	Fear of loneliness and abandonment related to the process of dying *	97.7	61.2	60.9	100.0	79,4
	Fear of losing one's mental abilities when dying	93.0	69.1	65.6	94.0	81,1
	Fear of the process of dying	90.7	38.2	48.1	86.7	64,5
	Feeling of powerlessness	90.7	33.8	46.4	85.2	62,3
	Worry about caregiver overwork	81.4	32.4	43.2	73.3	56,9
	Fear of premature death	93.0	57.4	58.0	92.9	75,2
	Fear of developing an incurable illness	86.0	41.2	1	82.4	63,6
	Worry about the impact of one's death on significant others	81.4	50.0	7	81.0	65,7
	Fear of physical deterioration associated with dying*	81.4	58.8	55.6	83.3	70,1
SECONDARY	Negative feelings related to death	79.1	80.9	72.3	85.9	80,0
	Emotional lability *	76.7	50.0	3	77.3	63,4
	Avoidance of situations that evoke death *	69.8	73.5	62.5	79.4	71.6
	Fear of death and of the process of dying of others*	62.8	73.5	60.0	75.8	68.2
	Deep sadness	60.5	63.2	51.0	71.7	61.9
	Fear of the body being destroyed after death*	55.8	86.8	72.7	75.6	71.3
	Fear of life after death*	46.5	94.1	83.3	73.6	70.3
	Worry about instructions for after death being followed *	30.2	92.6	72.2	67.7	61.4

\* New characteristics that were not listed in NANDA-I

## Discussion

Although the results of the present study had limitations with regard to their extrapolation because of the type of sample that was used, they showed that the nursing diagnosis of death anxiety is frequent among family caregivers of palliative patients and may even be more common than is shown in this study, given the strict criteria used to determine the presence of the diagnosis.

The high prevalence of the diagnosis among family caregivers, the fact that it causes suffering and affects quality of life,<sup>(6,7)</sup> and the fact that it is often underdiagnosed<sup>(19)</sup> reinforce the need for nurses to be particularly aware of the diagnosis and for the implementation of specific interventions.

The profile of the caregiver with death anxiety that emerged from this study (female, mean age of

46 years, daughter of the palliative patient) is relevant information for clinical practice, allowing an early identification of individuals at risk of developing death anxiety and opening the way to its prevention.

The fact that “fear of loneliness and abandonment related to the process of dying” was the most relevant characteristic may impact not only the diagnosis but also the choice of nursing interventions. This result emphasizes, for example, the importance of follow-up in palliative care and the need to reassure the family that the patient will never be abandoned.<sup>(32)</sup>

The results of this study may contribute to the creation of a diagnostic tool that allows reducing the subjectivity and complexity associated with the identification of this problem because they identify new defining characteristics of the diagnosis and highlight the most relevant among those described in the literature.<sup>(5,13)</sup> In addition, it is an incentive for the development of research on the efficacy of specific interventions, such as spiritual support<sup>(33)</sup> or logotherapy.<sup>(34)</sup> These measures will allow reducing death anxiety, which is deemed as a central outcome in palliative care.<sup>(14)</sup>

The high frequency of some characteristics observed in this sample that are not very specific of this diagnosis, such as the feeling of powerlessness and worry with caregiver overwork, suggests the presence of other diagnoses that eventually correlate with common indicators, such as caregiver overwork. The relationship between these diagnoses was identified in a previous study.<sup>(5)</sup>

Overall, the varied set of defining characteristics associated with death anxiety that were validated in the present study reflects a large diversity of fears, worries, and negative thoughts regarding death, which we believe are related to the fact that this is a subjective human response with diverse manifestations.

Many caregivers classified their participation in the study as a positive experience because they had the opportunity to express certain fears and concerns and felt that they were understood. Several researchers have reported similar benefits, identified

by relatives or caregivers of palliative patients, from participating in research studies.<sup>(30,35)</sup>

## Conclusion

The prevalence of the diagnosis of death anxiety in 38.7% of the participants, obtained in this study, confirms its relevance among family caregivers of palliative patients and the need for interventions in this field. Eight new defining characteristics related to the diagnosis were identified and clinically validated, which were not listed in the NANDA-I taxonomy. Some of these indicators are essential for the accuracy of the diagnosis. The methods used to determine the presence of death anxiety and defining characteristics were effective and, therefore, suitable for similar future studies in different populations.

## Collaborations

Abreu-Figueiredo RMS, Sá LO, Lourenço TMG, and Almeida SSBP declare that they contributed to the study design, data analysis and interpretation, article drafting, relevant critical review of the intellectual content, and approval of the final version to be published.

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