

## Nursing diagnosis of terminal syndrome in elderly with advanced dementia: cross mapping

*Diagnóstico de enfermagem síndrome de terminalidade em idosos com demência avançada: mapeamento cruzado*

*Diagnóstico de enfermería del síndrome terminal en ancianos con demencia avanzada: mapeo cruzado*

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### ABSTRACT

**Objective:** to identify elements of *Terminal Syndrome* by cross-referencing terms recorded by nurses providing end-of-life care for elderly people with advanced dementia. **Method:** in this retrospective, observational study, using a cross-mapping methodological tool, records of the last 10 days of life were collected from 38 medical records of people with advanced dementia. **Results:** 97 human-response terms were identified, and by cross-mapping, 22 nursing diagnoses were listed; of these, 11 nursing diagnoses displayed statistical importance in 50% or more of the patients, while eight nursing diagnoses were statistically important when assessed by prevalence in the 380 observations. *Terminal Syndrome* was found in all 380 evaluations, averaging 7.5 diagnoses of the syndrome. Cases were observed **Conclusion:** the high prevalence of *Terminal Syndrome* supports the inclusion of this nursing diagnosis in the NANDA-I Taxonomy II, as nurses already observe and record in practice.

**Descriptors:** Nursing Diagnosis; Palliative Care; Hospice Care; Geriatric Nursing.

### RESUMO

**Objetivo:** identificar elementos da *Síndrome de terminalidade* a partir do cruzamento de termos registrados pelos enfermeiros no cuidado ao fim de vida em idosos com demência avançada. **Método:** estudo observacional, retrospectivo, da ferramenta metodológica mapeamento cruzado. Foram coletados registros dos últimos 10 dias de vida de 38 prontuários de pessoas com demência avançada. **Resultados:** foram identificados 97 termos de respostas humanas, e através do mapeamento cruzado, foram elencados 22 diagnósticos de enfermagem, desses 11 diagnósticos de enfermagem apresentaram relevância estatística em 50% ou mais dos pacientes e oito diagnósticos de enfermagem apresentaram-se relevantes estatisticamente quando avaliados de acordo com a prevalência nas 380 observações. A *Síndrome de terminalidade* foi verificada em todas 380 avaliações, em média 7,5 diagnósticos da síndrome foram observados. **Conclusão:** a alta prevalência da *Síndrome de terminalidade* sustenta a inclusão do diagnóstico de enfermagem na Taxonomia II da NANDA-I, dado que os enfermeiros já a observam e a registram em sua prática.

**Descritores:** Diagnóstico de Enfermagem; Cuidados Paliativos; Cuidados Paliativos na Terminalidade da Vida; Enfermagem Geriátrica.

### RESUMEN

**Objetivo:** identificar elementos del síndrome terminal mediante términos de referencia cruzada registrados por enfermeras que brindan atención al final de la vida a personas mayores con demencia avanzada. **Método:** en este estudio observacional retrospectivo, utilizando una herramienta metodológica de mapeo cruzado, se recolectaron registros de los últimos 10 días de vida de 38 historias clínicas de personas con demencia avanzada. **Resultados:** Se identificaron 97 términos de respuesta humana y, mediante mapeo cruzado, se enumeraron 22 diagnósticos de enfermería; de estos, 11 diagnósticos de enfermería mostraron importancia estadística en el 50% o más de los pacientes, mientras que ocho diagnósticos de enfermería fueron estadísticamente importantes cuando se evaluaron por prevalencia en las 380 observaciones. El síndrome terminal se encontró en las 380 evaluaciones, con un promedio de 7,5 diagnósticos del síndrome. Se observaron casos **Conclusión:** la alta prevalencia de Síndrome Terminal apoya la inclusión de este diagnóstico de enfermería en la Taxonomía II de NANDA-I, ya que las enfermeras ya observan y registran en la práctica.

**Descritores:** Diagnóstico de Enfermería; Cuidados Paliativos; Cuidados Paliativos al Final de la Vida; Enfermería Geriátrica.

## INTRODUCTION

According to the World Health Organization, palliative care is defined as an approach to promote the quality of life of patients facing diseases that threaten the continuity of life and their families, by preventing and relieving suffering, through the early identification, assessment and treatment of pain and other physical, psychosocial and spiritual disorders<sup>1</sup>.

The need for palliative care for cancer patients has been recognized worldwide, but nowadays there are ongoing discussions on whether palliative care is needed for chronic diseases that are not oncological<sup>2</sup>. Therefore, publications concerning palliative care and end-of-life care are mostly aimed at cancer patients, but, increasingly there has been an increase in the number of studies in recent years regarding the elderly population with advanced dementia, due to the global estimates of growth in the elderly population<sup>3,4</sup>.

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Dementia has different stages of progress when compared to cancer. While cancer patients may experience a substantial decline in functionality in the last few weeks of life and there is a well-defined prognosis, patients with dementia, on the other hand, have a more prolonged cognitive, functional and physical decline, and its prognosis is more difficult<sup>3,5</sup>. However, the number of symptoms in the end-of-life care in patients with dementia may be equivalent to the number of symptoms experienced by cancer patients, but the duration of the prevalence of such symptoms will be extended in the first, due to the characteristics of the disease itself<sup>6</sup>.

End-of-life care must be provided by an interdisciplinary team, and nurses must have skills to systematically assess the signs and symptoms, in addition to promoting comfort to patients<sup>3</sup>. However, during symptom control in end-of-life care for elderly people with dementia, nurses have difficulty in elucidating and characterizing nursing diagnoses, due to the multiplicity of nursing diagnoses that may arise.

For such purpose, a proposal of a syndromic nursing diagnostic was developed, which was named 'Terminality Syndrome', and which is defined as: it is the state of deterioration of a set of physical, psychological, social, and spiritual signs and symptoms of the individual, resulting from the aggravation of the disease. The following defining characteristics were attributed: 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, Chronic confusion, Urinary retention, Grieving, Impaired physical mobility, Impaired skin integrity, Impaired tissue integrity, Excess fluid volume. The related factors were listed as: Palliative care, Chronic diseases at an advanced stage and Chronic physical disability. Population at risk: the elderly, and Associated conditions: End-of-life care.

Furthermore, the objective was defined as: to identify elements of the 'Terminality Syndrome', from the crossing of terms registered by nurses providing end-of-life care to the elderly with advanced dementia.

## METHODOLOGY

This is a retrospective observational study using cross-mapping, which made it possible to map and compare non-standardized nursing records against standardized terminologies, following the rules proposed by Lucena and Barros<sup>7</sup>.

The study was carried out at a hospital specialized in palliative care, based on the transitional care model. It is a hospital that offers extensive care, and full-time follow-up to patients undergoing rehabilitation, long-term care, and palliative care.

The inclusion criteria were: age greater than or equal to 18; being under end-of-life care; with or without previous curative treatment; minimum time of 10 days of hospitalization, with death outcome; with hospitalization date from 2013 to December 2017; both periods were chosen due to the year each unit of the hospital was opened: the Niterói Unit in 2013, and the Botafogo Unit in 2016. The length of 10 days of hospitalization was chosen as no consensus was found in the literature regarding the number of days to be considered as the end-of-life for patients with advanced dementia.

As for the temporal delimitation, 55 medical records of individuals in end-of-life care were available, all with an outcome of death; however, 17 medical records were excluded because they had hospitalization time inferior to that of 10 days, and therefore, the final sample was composed of 38 medical records. The data collection period was September through December 2018.

The period of 10 days for the follow-up was chosen to enable an analysis of the prevalence of the defining characteristics of the "Terminality Syndrome" over the subjects' last days of life. In addition, the literature does not have a consensus regarding the exact amount to consider as a definition for end-of-life care.

The data collection instruments comprised: patient identification data and previous history; collection of nurses' records; identification of free terms used by nurses. After filling out each instrument and mapping the free terms, the inference of the nursing diagnoses was carried out by three evaluators, including the researcher, an expert in nursing diagnosis, and another expert in palliative care, all carried out independently so as to avoid any selection bias in the nursing diagnoses. Last, there was a face-to-face meeting for consensus on the diagnoses listed.

In the initial stage of data collection, 176 free terms were identified and organized, later being the terms that denoted nursing results and interventions excluded, finally resulting in the final sample of 97 free terms.

In the second stage, nursing terms and their crossing with nursing diagnoses were evaluated individually by the three experts. In all, 44 nursing diagnoses were listed, but after a consensus meeting and discussions on critical

reasoning and diagnosis, and selection of priorities regarding the approach to end-of-life care, 22 nursing diagnoses were obtained.

In order to conduct the discussion and inference of nursing diagnoses, the experts considered the comparison between the terms listed and the definition of diagnoses, defining characteristics, related factors, associated conditions, and populations at risk.

After consensus was reached by the experts, a database was created in an electronic spreadsheet with data for the characterization of the individuals, the terms mapped, and the nursing diagnoses. The terms which crossed with nursing diagnoses were tabled and organized in accordance with the 10-day prevalence analysis, with characterization variables tabled for each patient. The data was analyzed with the use of the Statistical Package for the Social Science (SPSS), version 22.0.

The study was approved by the institution's Research Ethics Committee, in accordance with opinion No. 2,799,814.

## RESULTS

The majority of the population sample was female, that is, 28 individuals (73.7%). The average age was of 84.7 years of age, with a predominant age range from 80 to 102 years of age (81.6%). The sample's patients were predominantly Brazilians (78.9%), and 36 of them were in an advanced stage of dementia (94.7%), or chronic neurological diseases, such as multiple sclerosis and astrocytoma. The majority, or 31, of the subjects came from hospitals (81.6%), that is, they had a history of long-term hospitalization.

97 terms were identified concerning human responses. Table 1 below presents the prevalence of the free terms which had a significant frequency (>50%).

**TABLE 1:** Prevalence of terms arising from nurses' registers about end-of-life patients. Niterói, Rio de Janeiro, Brazil, 2019.

Terms	1	2	3	4	5	6	7	8	9	10	Total observations %	Total per patient %
Little interaction	68.4	65.8	73.7	65.8	78.9	73.7	81.6	78.9	84.2	86.8	75.8	89.5
Drowsiness	42.1	44.7	47.4	50.0	47.4	44.7	50.0	55.3	52.6	44.7	47.8	84.2
Zero diet	36.8	28.9	34.2	36.8	36.8	39.4	44.7	65.8	73.7	65.8	46.3	81.6
Constipation	39.5	36.8	36.8	39.5	44.7	52.6	47.4	47.4	52.6	55.3	45.3	78.9
Bedridden	60.5	60.5	63.2	60.2	63.2	60.5	63.2	60.5	60.5	63.2	61.6	68.4
Capillary fragility	47.4	52.6	50.0	52.6	52.6	52.6	50.0	55.3	52.6	47.4	51.3	65.8
Edema	47.5	50.0	42.1	44.7	42.1	50.0	47.4	42.1	42.1	47.4	45.5	63.2
Respiratory distress	2.6	0	13.2	7.9	7.9	13.2	18.2	21.1	28.9	39.5	15.3	60.5
Secretionary	36.8	31.6	42.1	42.1	44.7	39.5	42.1	47.4	47.4	36.8	41.1	60.5
Absent urinary output	5.3	5.3	5.3	15.8	7.9	15.8	23.7	23.7	28.9	36.8	16.8	57.9
Decreased urine output	21.1	26.3	26.3	31.6	28.9	31.6	21.1	26.3	28.9	18.4	26.1	55.3
Torpor	10.5	21.1	15.8	21.1	28.9	21.1	36.8	26.3	34.2	31.6	24.7	55.3
Gastric residual	26.3	28.9	21.1	23.7	21.1	21.1	26.3	26.3	26.3	15.8	23.7	55.3
Pallor	34.2	31.6	28.9	31.6	31.6	34.2	31.6	36.8	39.5	39.5	33.9	52.6
Sedated	10.5	10.5	13.2	15.8	15.8	18.4	23.7	42.1	47.4	50.0	24.8	52.6
Pain	34.2	23.7	23.7	18.4	23.7	28.9	13.2	21.1	23.7	13.2	22.4	50
Pressure ulcer	47.4	44.7	44.7	44.7	42.1	42.1	44.7	44.7	44.7	42.1	44.2	50
Hyperemia	36.8	36.8	34.2	39.5	36.8	36.8	39.5	36.8	28.9	28.9	35.5	50
Hypotension	18.4	7.9	13.2	10.5	21.1	15.8	23.7	18.4	26.3	36.8	19.2	50

According to the analysis, 19 terms were considered to have a 50% prevalence in any of the 10 observations, and three were considered prevalent in all 10 days observed: Little interaction, Bedridden and Capillary fragility.

The terms Respiratory distress, Secretionary, Absent urinary output, Decreased urine output, Torpor, Gastric residual, Pallor, Pain, Pressure ulcer, Hyperemia, and Hypotension did not present statistical significance along the days and in the total observations. However, it can be seen that these terms were present in the last days of life, which might suggest that although present, they had a resolution, were not prevalent along the days, and that they can be more specific in the last moments of life.

Table 2 shows the crossing of these terms with the nursing diagnoses proposed by the NANDA-I Taxonomy II.

**TABLE 2:** Prevalence of nursing diagnoses in the total of patients, total observations and in each one of the 10 observations, Niterói, Rio de Janeiro, Brazil, 2019.

Nursing diagnoses	1	2	3	4	5	6	7	8	9	10	Total observations %	Total per patient %
Imbalanced nutrition: less than body requirements	78,9	68,4	81,5	73,7	71,1	76,3	76,3	86,8	86,8	81,5	78,2	97,4
Disturbed sleep pattern	57,9	65,8	63,2	68,4	60,5	68,4	73,7	73,7	81,5	84,2	69,7	94,7
Impaired physical mobility	92,1	92,1	94,7	92,1	94,7	92,1	92,1	92,1	89,5	84,2	91,6	94,7
Ineffective breathing pattern	47,4	36,8	52,6	57,9	60,5	57,9	65,8	65,8	73,7	78,9	59,7	94,7
Impaired skin integrity	71,1	76,3	71,1	76,3	78,9	76,3	81,5	78,9	73,7	68,4	75,3	89,5
Impaired tissue integrity	84,2	81,5	81,5	78,9	81,5	76,3	78,9	73,7	78,9	78,9	79,5	86,8
Constipation	44,7	52,6	47,4	50	55,3	57,9	60,5	63,2	65,8	63,2	56,1	78,9
Ineffective peripheral tissue perfusion	42,1	34,2	31,6	39,5	39,5	44,7	44,7	47,8	55,3	57,9	43,7	76,3
Urinary retention	26,3	31,5	31,5	39,5	34,2	44,7	39,5	47,8	55,3	50	40	76,3
Chronic confusion	57,9	57,9	63,2	57,9	63,2	60,5	60,5	65,8	60,5	63,2	61,1	71,1
Excess fluid volume	50	50	42,1	44,7	42,1	50	47,8	42,1	42,1	47,8	45,8	63,2
Chronic pain	31,6	21,1	23,7	18,4	23,7	28,9	13,2	18,4	23,7	13,2	21,6	44,7
Grieving	13,2	13,2	18,4	21,1	10,5	15,8	10,5	21,1	21,1	18,4	16,3	42,1
Nausea	10,5	13,2	2,6	10,5	13,2	7,9	5,3	7,9	2,6	5,3	7,9	31,6
Fatigue	7,9	10,5	7,9	7,9	13,2	5,3	13,2	7,9	13,2	13,2	10	28,9
Ineffective thermoregulation	10,5	0	2,6	0	2,6	0	10,5	5,3	7,9	7,9	4,7	28,9
Anxiety	5,3	5,3	5,3	10,5	10,5	7,9	0	2,6	5,3	2,6	5,5	23,7
Deficient fluid volume	18,4	21,1	21,1	18,4	18,4	21,1	18,4	18,4	16,8	10,5	18,2	23,7
Impaired comfort	2,6	2,6	5,3	2,6	13,2	10,5	0	5,3	5,3	2,6	5	21,1
Impaired oral mucous membrane integrity	7,1	13,2	13,2	13,2	13,2	13,2	13,2	13,2	13,2	10,5	12,4	18,4
Diarrhea	7,9	5,3	5,3	7,9	5,3	7,9	2,6	7,9	2,6	5,3	5,8	15,8
Acute pain	2,6	2,6	0	0	0	0	0	2,8	0	0	0,8	5,3

Eight nursing diagnoses were noticed to be relevant: Imbalanced nutrition: less than body requirements, Disturbed sleep pattern, Impaired physical mobility, Ineffective breathing pattern, Impaired skin integrity, Impaired tissue integrity, Constipation, and Chronic confusion. The term Pain was identified in 50% of the sample, however, when time was considered, Chronic Pain stood out (44.7%).

From the nursing diagnoses mapped for patients in end-of-life care, only the diagnoses Ineffective peripheral tissue perfusion, Acute pain, Impaired oral mucous membrane integrity, and Deficient fluid volume are not part of the defining characteristics of the Terminality Syndrome. From the Terminality Syndrome, only the diagnosis of Spiritual distress was not observed.

The number of diagnoses of the syndrome had low variability ( $0.20 = CV = <0.40$ ) in all the days and in the total observations. In total, regardless of the assessment, the number of diagnoses per patient ranged from 3 to 13 diagnoses, with an average of 7.5 diagnoses per patient, a standard deviation of 1.9, which resulted in a  $CV = 0.25$  (low variability). In each one of the assessments, the statistics do not differ much from the global statistics and there is no significant difference between the distributions of quantities of diagnoses of the syndrome of the distinct assessments ( $p$ -value = 0.597 of the Friedman test). Therefore, the terminality syndrome was verified in 100% of the 380 assessments, with an average of 7.5 diagnoses per patient, in their last 10 days of life.

## DISCUSSION

The main data arising from this study is the demonstration of the presence of the Terminality Syndrome, based on the terms described in patients' records by nurses in clinical practice, in non-oncological palliative care for the elderly with advanced dementia. The high prevalence of a complexity of nursing diagnoses occurring simultaneously in end-of-life care demonstrates the relevance of this diagnosis in nursing practice.

In addition to the prevalence of elderly people with advanced dementia, an average high age of 84.7 years was also obtained. And that influences the global burden of serious health-related suffering, as a variety of physiological changes occur in the last hours and days of life<sup>8</sup>. And such changes are usually accompanied by functional decline and a multiplicity of symptoms, such as those found in this study through the free terms<sup>9-12</sup> mapping.

Prognosis and definition of the end-of-life stage in advanced dementia is a challenge for the health team and more difficult to identify than in cancer, due to its characteristics of low functionality, severe cognitive impairment, multiple comorbidities, advanced frailty, and organ failure<sup>3,5,13-15</sup>. Patients with advanced dementia and other chronic neurological diseases experience symptoms at the end of life for a longer period than patients with cancer, as, in this study, the prevalence of the Terminality Syndrome was in the follow-up that lasted for 10 days<sup>3,5</sup>.

Two nursing diagnoses can be identified in end-of-life care regarding cognitive and neurological changes: Acute and chronic confusion; in this study the diagnosis found was that of chronic confusion due to the prevalence of elderly patients with advanced dementia. However, in cancer patients, acute confusion may be related to the delirium commonly present at the end of life

The control and management of symptoms in end-of-life care in patients with dementia require the integration of assessments by the teams specialized in palliative care and the ones specialized in gerontological and/or long-term care<sup>3,16</sup>. Integrated care makes it easier to manage behavioral problems and to anticipate, assess and manage physical and cognitive problems, especially resulting in overcoming the difficulty existent in the communication of the expected symptoms in patients with advanced dementia. Therefore, health professionals working in this area need specific knowledge of distress in behavioral changes<sup>3</sup>.

Therefore, the syndrome of terminality in the palliative approach in end-of-life care for patients with advanced dementia can assist in the reasoning, evaluation, and management of symptoms, occurring simultaneously. During the monitoring of symptoms and approach of patients with advanced dementia, nurses need to have a perspective of supporting families, to help them in their role as decision-makers, and to help them deal with a high burden of care and anticipatory mourning caused by the continuous deterioration of the patient<sup>3,16</sup>.

A study compared symptoms before death in three different groups: patients with cancer, patients with dementia, and patients with chronic illnesses, and the analyzes showed significantly greater physical symptoms for those with dementia and chronic illness in the last month of life than for those with cancer<sup>3</sup>. Pain is one of the causes of grief, anxiety, and behavioral disorders in patients with dementia, characterized by: verbal agitation such as complaints, negativity, repetitive phrases and questions, constant request for attention and verbal cursing or aggression<sup>17,18</sup>. Chronic pain was present in 44.7% of patients, which is close to the WHO's estimate of 47% for patients with dementia in end-of-life care<sup>2</sup>. There was also a high frequency of impaired tissue integrity and impaired skin integrity (73.3%) which are expected, as they are associated with nutritional conditions, advanced age, incontinence, capillary fragility, low immunity, and mobility<sup>19-22</sup>. In addition, injuries in elderly patients with advanced dementia are indicators of end-of-life care<sup>23</sup>.

Psychological-social-spiritual diagnoses are inferior in this population profile, given that the majority of individuals have severe cognitive losses, which, therefore, do not allow identification of such symptoms. Another factor is the opportunity of family members throughout the disease process to elaborate on the losses, however, in some cases, they may be a priority, depending on the family context. A recent study on the diagnosis of Anxiety related to death showed a high prevalence in family caregivers of palliative cancer patients<sup>24</sup>. However, in the analysis of diagnostic sets, to compose the syndrome, the need for better differentiation between the diagnoses of Anxiety and Grieving and the diagnosis of Anxiety related to death has been identified.

The limitation found for this study was the sampling number. However, it is a specialized service, which justifies the extrapolation of the data. The cases are a novelty, with few studies on the subject in the world and Brazil. Therefore, studies in other populations (oncological, children, cardiological) and other scenarios are recommended to assess variations in the diagnostic profile in each population.

## CONCLUSION

Upon analysis of the prevalence of the *Terminality Syndrome* as a whole over the last 10 days of life, the simultaneous presence of an average of 7.5 nursing diagnoses was found, thus, we recommend that this nursing diagnosis be added to the Taxonomy II of the NANDA-I.

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