




Compromised end-of-life syndrome: Concept development from the condition of adults and older adults in palliative care

Antônia Rios Almeida MD¹  | Rosimere Ferreira Santana PhD²  |
Marcos Antônio Gomes Brandão PhD³ 

¹ Nurse, Department of Neurosurgery and Thoracic Surgery, José Alencar Gomes da Silva National Cancer Institute, Rio de Janeiro, Brazil

² Nurse, Teacher, Aurora de Afonso Costa Nursing School, Fluminense Federal University, Rio de Janeiro, Brazil
(Email: rfsantana@id.uff.br)

³ Nurse, Teacher, Anna Nery Nursing School, Federal University of Rio de Janeiro, Rio de Janeiro, Brazil

Correspondence

Antônia Rios Almeida, MD, Department of Neurosurgery and Thoracic Surgery, José Alencar Gomes da Silva National Cancer Institute, 23 Praça da Cruz Vermelha, CEP 20230-130 Rio de Janeiro, Brazil.
Email: antonia.rios.prof@gmail.com

Abstract

Purpose: This study aimed to develop the nursing diagnosis concept “compromised end-of-life syndrome” in palliative care.

Methods: The authors used the integrative strategy by Meleis to develop the concept in this study and identifying clinical indicators from a literature review. For data organization, we applied the Preferred Reporting Items for Systematic Reviews and Metanalysis (PRISMA).

Findings: Some clusters of unpleasant signs and symptoms in palliative care patients at the end of life, such as pain, dyspnea, depression, constipation, and anxiety, were identified. Through conceptualization, the authors propose a new nursing diagnosis, “compromised end-of-life syndrome.” The manuscript includes a model case of a patient with nursing diagnosis syndrome as a clinical example.

Conclusions: Simultaneous patterns of signs and symptoms present in the literature reinforce the utility of the proposition of end-of-life syndrome as a nursing diagnostic construct.

Implications for nursing practice: The concept development related to patients’ unpleasant signs and symptoms critically ill at palliative care supports the proposition of a new nursing diagnosis relevant to selecting adequate nursing interventions and nursing outcomes. Some clusters of unpleasant signs and symptoms in palliative care patients at the end of life, such as pain, dyspnea, depression, constipation, and anxiety were identified. Conceptualization was used to propose a new nursing diagnosis, “compromised end-of-life syndrome.” A model case of a patient with nursing diagnosis syndrome is described as a clinical example.

Conclusion: Simultaneous patterns of signs and symptoms present in the literature reinforce the utility of the proposition of end-of-life syndrome as nursing diagnostic construct.

Implications for Nursing practice: The concept development related to patients’ unpleasant signs and symptoms critically ill at palliative care supports the proposition of a new nursing diagnosis relevant to selecting adequate nursing interventions and nursing outcomes.

KEYWORDS

nursing diagnosis, palliative care, signs and symptoms, terminal care, validation studies as topic

INTRODUCTION

Currently, chronic diseases are the main causes of mortality in the world, and this because of the increase in life expectancy of the population with a better quality of life. Relevant chronic diseases are cancer, diabetes, cardiovascular, and respiratory system diseases (Figueiredo et al., 2021; Lee, Choi, Lee, Jiang, 2018; Maisto et al., 2021).

Some people with chronic diseases need palliative care (PC) through the disease progression. Data has shown that about 40 million people need palliative care (PC) each year in the world. Cancer patients are the population with the most significant level of complexity for PC with chronic disease, presenting signs and symptoms such as pain, dyspnea, fatigue, constipation, and lack of appetite, which are characteristic of the natural evolution of the disease. Nurses play an essential role in clinical judgment and symptom management (Chow & Dahlin, 2018; World Health Organization, 2018).

The recrudescence of the chronic disease process in the end-of-life phase and the deterioration of the patient's health causes an increment of unpleasant signs and symptoms. This deterioration process is related to the proximity of death and assumes more diagnostic relevance for nursing (Chow & Dahlin, 2018).

A syndrome nursing diagnosis is a clinical judgment concerning a cluster of nursing diagnoses that occur together, that require similar interventions (Herdman & Kamitsuru, 2021). In nursing practice, a nursing diagnosis syndrome frequently represents the group of unpleasant end-of-life symptoms of patients with chronic diseases, which are usually treated together by symptom management interventions (Butcher, Dochterman, Bulechek & Wagner, 2020), and evaluated by symptom control (Moorhead, Johnson, Swanson & Maas, 2020).

Content validation study and cross-mapping were carried out on the theme of chronic disease that threatens life, strengthening the phenomenon of complicated end-of-life syndrome to support the proposal of concept (Passarelles, Santana, Almeida, Silva & Pereira, 2020; Silva, Santana, Lopes, Passarelles & Almeida, 2021). Nursing diagnosis of the types of syndromes would provide a more integrated clinical judgment relating to different human responses and accurately show the complexity of the end-of-life process, providing a clustered judgment of the phenomena involved in the care of a nurse in palliative care.

NANDA's Diagnosis Development Committee (DDC) consider that a new nursing diagnosis can be included in NANDA-I terminology by a process named "conceptual validity" compatible with the development of a conceptual framework and/or substantive theory, starting with concept analysis to identify knowledge underlying the diagnosis (Herdman & Kamitsuru, 2021). The Integrative Strategy to Concept Development is a method to develop concepts by a process from phenomenon to concept (Meleis, 2018).

The integrative strategy applies to context, taking professional sense or experience and demanding a detailed description of the phenomenon before the labeling stage (Meleis, 2018). Therefore, the integrated strategy proves to be advantageous to generate concepts that represent phenomena of specific contexts of clinical practice, such as the one investigated in this study.

Thus, this study aimed to develop the nursing diagnosis concept "compromised end-of-life syndrome" in palliative care setting.

METHOD

The Integrative Strategy to Concept Development was used to conceptualize and support a new concept or nursing diagnosis construct. This methodological strategy has seven stages: sensing and taking in a phenomenon; describing a phenomenon; labeling; concept development; statement development; explicating assumptions; sharing and communicating. The seven stages are developed to a whole theory-building process; however, this study describes the first four stages (Meleis, 2018).

The first stage, sensing and taking in a phenomenon, was developed by two of the authors of this study debating their experiences of identifying signs, symptoms, and nursing diagnoses in the palliative care setting. Data obtained from the debates of authors were the cooccurrence of patient human responses in end-of-life situations; the relationship between different nursing diagnoses; patient behaviors and claims identified by nurses in their clinical judgment and decision making.

Authors conducted the second and third stages exhaustively, describing a phenomenon and labeling to explore the phenomenon's components and forming a concept throughout a discussion of terms. These stages were necessary to get a representation of the phenomenon.

In describing a phenomenon stage, questions to describe the phenomenon of signs, symptoms, and human responses in the palliative care setting during palliative care were elaborated upon and based on the Integrative Strategy to Concept Development (Meleis, 2018): What end-of-life signs and symptoms (phenomenon) do the nurses handle in patients experiencing palliative cancer care? Are signs and symptoms isolated or related? What are the boundaries of the phenomenon related to nursing practice and the patient's clinical conditions? What patterns of signs and symptoms do nurses face in end-of-life patients?

The integrative literature review was the methodological procedure used to get the descriptive elements of the phenomena because of its potential to include diverse methodologies, contributing to the presentation of varied perspectives on a phenomenon of concern (Whittemore & Knaf, 2005). We identified nursing diagnosis concepts, oncologic patients in palliative care settings, and unpleasant signs and symptoms in cancer patients at end-of-life and during the problem identification stage. The literature search stage was carried out in April 2019, using several academic research databases: PUBMED, Web of Science, Science Direct, CINAHL, and Scielo. The search used the terms *MeSH Signs and Symptoms AND Nursing AND Palliative care*, limited to English, Portuguese, and Spanish languages. For better organization and identification of studies for this integrative review, we applied the Preferred Reporting Items for Systematic Reviews and Metaanalysis (PRISMA). The authors included studies with various research designs: cross-sectional, case studies, randomized research, intervention, and cohort studies (PRISMA, 2015). A total of 2039 articles with full texts

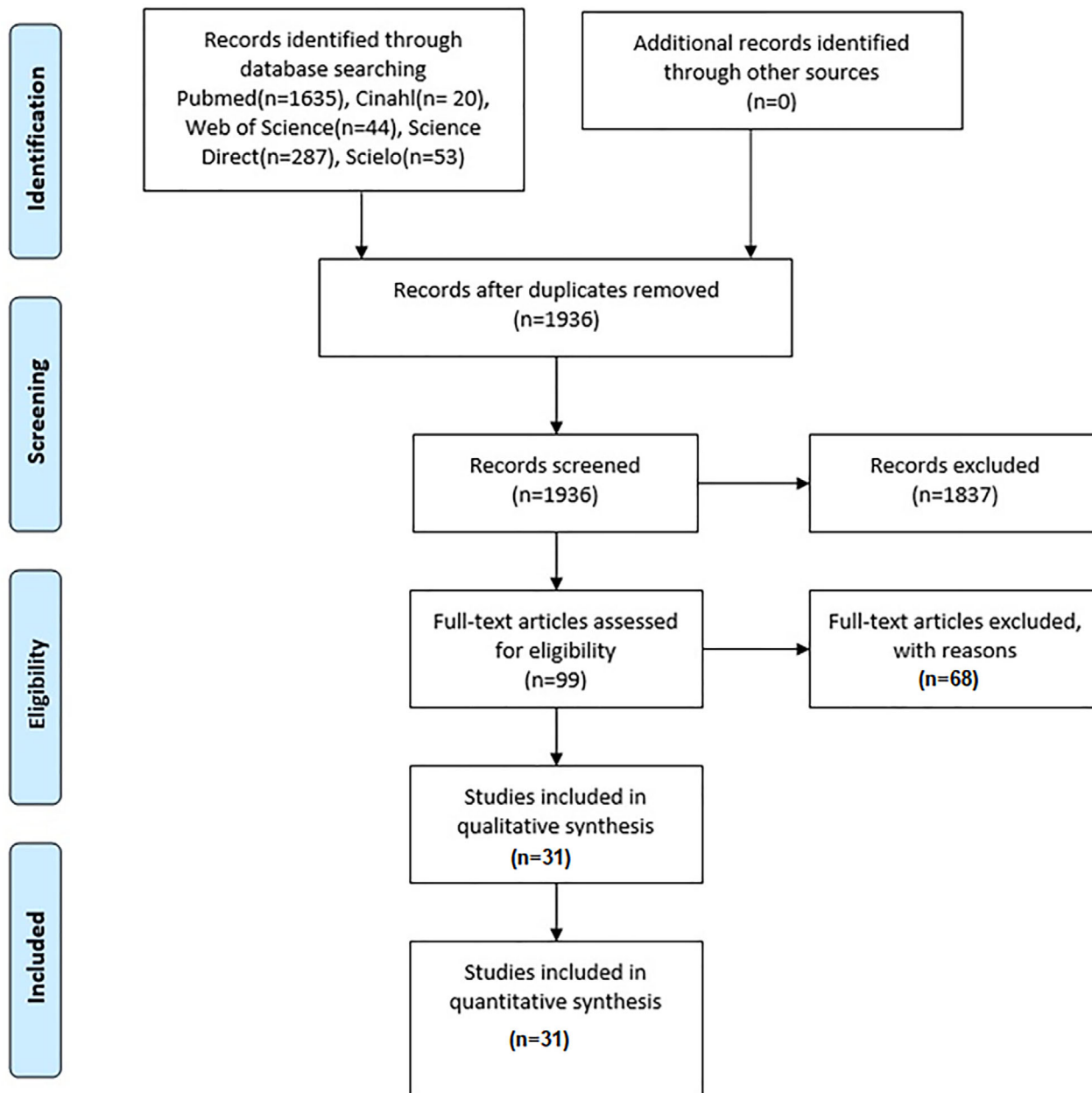


FIGURE 1 Prisma flow diagram. Source: PRISMA, 2015.

focusing on adults and older adults published between 2014–2018 were identified and selected. For this study, integrative reviews, systematic reviews, meta-analyses, and narrative reviews were excluded. The data evaluation stage considered aspects that allowed the identification of legitimacy, quality of the method, value of information, and representativeness of the source. The data analysis stage coded signs and symptoms, categorized elements of attributes, antecedents, and consequences of the concept, summarized in a conceptual qualitative approach (concept development). Finally, the authors used the presentation stage to synthesize the data (Whittemore & Knafel, 2005).

Two authors, independently through the EndNote bibliography manager, software analyzed the complete text of 99 studies and selected 31 papers for extracting essential attributes, antecedents, and

consequences for the concept development. The evidence obtained from the literature review served as a description of the investigated phenomenon.

The PRISMA flowchart allows clear visualization of the studies included in this study, as shown in Figure 1 (PRISMA, 2015).

Labeling is a stage of theorizing (or conceptualization) and allows for semantic analysis. Labeling a concept is a highly individualized experience that involves different interpretations and is more than selecting a specific label to describe the phenomenon involving semantic analysis (Meleis, 2018).

Through the consensus discussion, the authors carried out a qualitative iterative process to select focus and judgment terms from the 2021–2023 NANDA International Taxonomy (Herdman & Kamitsuru,

2021). Attributes and constitutive definitions offered valid and normalized labels. Initially, the authors chose a temporary label as a prototype to represent the clustering of signs and symptoms verified at the end-of-life of oncologic patients in palliative care settings.

The fourth stage, concept development, allows for the emergence of a concept as a representation of reality in its facts, events, or phenomena (Meleis, 2018). The authors used results from an integrative literature review and an expert panel for labeling. Several processes are essential in this stage: defining, differentiating, delineating antecedents and consequences, and modeling, analogizing, and synthesizing (Meleis, 2018). All concept development processes were applied to create a mental image of reality, a representation of the pattern of human responses and characteristics of end-of-life patients in palliative care.

FINDINGS

The sensing and taking in a phenomenon

Clinical observations of the conditions of people in palliative care and the emerging patterns of clustered signs and symptoms of end-of-life cancer patients attracted the consideration of the authors of this study and led to an interest in grouping them into a human response's syndrome concept. Researchers' retrospective experiences were used to discuss why nurses record nursing diagnoses separately, although they manage them together.

Describing a phenomenon and labeling

The phenomenon was characterized by unpleasant signs and symptoms, experienced by the end-of-life patients that occurred grouped or concurrently.

The authors found clusters of unpleasant signs and symptoms in 24 (75%) studies through the literature review. In these studies, several combinations included human responses classified by NANDA International Inc. These combinations describe a syndromic pattern of human responses at the end of life. The data used to characterize the phenomenon with simultaneous or clustered unpleasant signs and symptoms are included in Table 1. The primary and single unpleasant signs and symptoms present in eight studies are included in Table 2.

Previous labels for the labeling stage were: "Unbalanced Symptom Control," "Symptom Deterioration Syndrome," "terminality syndrome". However, after analyses, conjectures, and comparison with definitions and axes of Taxonomy of NANDA-I, the authors introduced the label "Compromised End-of-life Syndrome."

Concept development: Defining

Studies have shown that one symptom can trigger another: for example, pain can lead to depression, worsening fatigue, and sleep disor-

ders (Posternak et al., 2016), dyspnea can trigger insomnia, pain, and asthenia (Guirimand et al., 2015), and pain, anorexia, constipation, edema, depression, and anxiety can act simultaneously (Tai et al., 2016). The identification, in most studies, of the simultaneous occurrence of unpleasant signs and symptoms there are relationships between disconnected diagnosis setting syndromes.

For developing the definition of the concept, the authors used the multiaxial structure of NANDA-I taxonomy II. The NANDA's framework has axes that define the agreement and standardization of the terms used in the diagnostic construction, and these axes are essential and mandatory elements for the structure of a nursing diagnosis (Herdman & Kamitsuru, 2021). For the syndrome, three axes are of supreme importance: axis one, characterized by diagnosis concept (end-of-life); axis two that defines the individual (unnecessary at the label for this diagnosis); and axis three, the judgment diagnosis (compromised) (Romeiro, Caldeira, Herdman, Lopes & Vieira, 2020).

For axis 1, signs and symptoms were congruent with attributes compatible with NANDA-I's terms of nursing diagnosis (human response). These include visceral, neuropathic, and bone pain (chronic pain), dyspnea (ineffective breathing pattern), sleep disorder (disorder in the sleep pattern), nausea, cachexia/weight loss (unbalanced nutrition, i.e., less than what the body needs), mood swings, sadness (anxiety), discomfort (impaired comfort), suffering (spiritual suffering), fever (ineffective thermoregulation), constipation, diarrhea, and delirium (chronic confusion) (Chow & Dahlin, 2018; Dzierżanowski & Ciałkowska-Rysz, 2015; Smith et al., 2015; Star & Boland, 2018; Xu et al., 2015).

For axis 2, the authors did not recognize a particular individual, considering that the end-of-life condition itself specifies the subject of the diagnosis. For axis 3, the selected judgment diagnosis was "compromised."

The definition of compromised end-of-life syndrome was a state of deterioration of a set of the physical, psychological, social, and spiritual signs and symptoms of an individual due to the disease's aggravation.

Defining a concept is vital to delineate its subconcepts and dimensions, as this clarifies ambiguities, enhances precision, and relate sit to empirical referents (Meleis, 2018).

A nursing diagnosis definition should be clear and accurate in NANDA-I's classification, with a particular meaning useful for differentiation between diagnoses (Herdman & Kamitsuru, 2021).

Concept development: Differentiating

Although health literature reports clustering of unpleasant signs and symptoms, no global concepts semantically approximate to compromised end-of-life syndrome were found. However, during the conceptual differentiation, the authors have examined other NANDA International diagnoses: impaired Comfort and chronic pain syndrome (Herdman & Kamitsuru, 2021; Ward Sullivan, Leutwyler, Dunn & Miaskowski, 2018).

Physical, psychological, social, and spiritual multidimensional situations are not inherent to the end-of-life process. For example, chronic

TABLE 1 Characterization of primary signs and symptoms investigated, and simultaneous/clustered patterns of signs and symptoms identified in reviewed studies (*n* = 24)

Single or multiple signs and symptoms	Primary signs and symptoms	Simultaneous/clustered patterns of signs and symptoms
Multiple	Several signals and symptoms (Bruce, Smith & Price , 2017; Lavdaniti et al., 2018; Tai et al., 2016); six symptoms of revised ESAS-r (Kako et al., 2018); Management of cancer-related symptoms (Steel et al., 2016); signs and symptoms in the last seven days of life (Hui, Santos, Chisholm & Bruera , 2015); signs and symptoms in the last three days of life (Hui et al., 2014); Oral symptoms at the end-of-life (Fischer et al., 2014).	Pain, fatigue, dyspnea, depression, anxiety, and sleep disorder (Lavdaniti et al., 2018); Fatigue, pain, and shortness of breath (Bruce et al., 2017; Tai et al., 2016); Pain, anorexia, constipation, edema, depression, and anxiety (Tai et al., 2016); Pain, drowsiness, fatigue, nausea, dyspnea, and poor appetite(Kako et al., 2018); Pain, depression, and fatigue (Steel et al., 2016); Anorexia, fatigue, dyspnea, dysphagia, urinary/fecal incontinence, constipation, diarrhea, sweating, and depression (Hui et al., 2015); Apnea periods, peripheral cyanosis, decreased diuresis, dysphagia and breathing with mandibular movement (Hui et al., 2014);Xerostomia, orofacial pain, and mucosa erythema (Fischer et al., 2014).
Single	Depression (Fischer, Seow, Brazil, Freeman, Smith & Guthrie , 2014; Ullrich et al., 2017).	Depression, anxiety, and sadness (Ullrich et al., 2017); Depression, pain, sleep disorder, and caregiver stress (Fischer et al., 2014).
Single	Pain (Gupta, Sahi, Bhargava & Tawar , 2015; Lee et al., 2015; Okimasa et al., 2016; Pina, Sabri & Lawlor , 2015; Posternak et al., 2016; Rau et al., 2015; Song et al., 2015; Xu et al., 2015).	Pain and suffering (Okimasa et al., 2016); Pain, depression, fatigue, and sleep disorder (Posternak et al., 2016); Pain, depression, and psychosocial suffering (Lee et al., 2015); Pain, nausea, vomiting, and constipation (Song et al., 2015); Pain, suffering, anxiety, and depression (Pina et al., 2015); Pain, sleep disorder, and fatigue (Gupta et al., 2015); Pain, fatigue, sleep/mood disorders, depression, cachexia, and anxiety (Rau et al., 2015); Pain, weakness, sleep disorder, fatigue, and dyspnea (Xu et al., 2015).
Single	Dyspnea (Davies, Wagher, Boyle, Gallagher & Johnsen , 2015; Guirimand et al., 2015; Stevens et al., 2016).	Dyspnea and pain (Stevens et al., 2016); Dyspnea, insomnia, pain, and asthenia (Davies et al., 2015; Guirimand et al., 2015).
Single	Hydration (Nwosu et al., 2016).	Dry mouth, thirst, unpleasant taste, fatigue.
Single	Delirium (Davies et al., 2015)	Delirium, cachexia, nausea, vomiting, dyspnea, urinary incontinence, and respiratory secretion.
Single	Constipation (Dzierżanowski & Ciałkowska-Rysz, 2015).	Constipation, pain, and cachexia.
Single	Suffering (Krikorian & Limonero, 2015)	Suffering associated with psychological, physical, and spiritual factors.

TABLE 2 Characterization of primary unpleasant signs and symptoms investigated with identification of a single sign or symptom (*n* = 8)

Primary unpleasant signs and symptoms investigated	Simultaneous/clustered patterns of signs and symptoms
Depression (Meyer et al., 2015)	-
Pain (Miranda et al., 2016; Lebaron, Beck, Maurer, Black & Palat , 2014; Jho et al., 2014; Mendes, Boaventura, Castro & Mendonça , 2014)	-
Dyspnea (LeBlanc & Abernethy, 2014)	-
Delirium (Cruz et al., 2015)	-
Hearing loss (Smith et al., 2015)	-

pain and sadness related to depression can occur at different people. However, a cluster of signs and symptoms that compromise life in its last stages are characteristic of compromised end-of-life syndrome. Thus, the end-of-life context is an essential attribute of the concept.

The chronic pain syndrome NANDA-I nursing diagnosis and the compromised end-of-life syndrome are comparable, not only because of the similarity of their defining characteristics, but also the significant harm both can cause on patients' daily functioning or well-being. However, the end-of-life syndrome encompasses other subconcepts and dimensions more extensively than chronic pain syndrome (Herdman & Kamitsuru, 2021). Likewise, chronic pain syndrome does not have an essential attribute of the last stage of the disease and its proximity to death, reinforcing the uniqueness of the essential attribute of the end-of-life.

Concept development: Delineating antecedents and consequences

The antecedents include contextual conditions under which concepts are identified or occur (Meleis, 2018). The condition of palliative care and the manifestation of clustered signs and symptoms, secondary to physiological and psychosocial mechanisms and spiritual processes, are general antecedents to the end-of-life syndrome nursing diagnosis. Approximately 60–90% of oncologic patients in treatment can be diagnosed with advanced cancer characterized by metastases. A cascade of physical, psychosocial, and spiritual symptoms may be triggered for the patient (Fischer et al., 2014). In disease progression, immunity deficiency may occur, producing high levels of inflammatory cytokines released by the tumor individually or concomitantly with treatment, leading to deterioration and worsening of patients' health (Jho et al., 2014). These results suggest specific antecedents (related factors): progressive clinical deterioration, and associated condition: advanced cancer or advanced chronic disease, chronic physical disability, and risk population the aging process.

The suffering and unpleasant human responses to terminal illnesses are targeted in each defining characteristic of the compromised end-of-life syndrome and its influence on families, communities, and health care. The positive consequences will depend on the support systems and regulatory mechanisms, coping strategies of the patient, family, community, and health system.

Concept development: Modeling

Modeling defines and exemplifies aspects of the concept under development with clinical or research referents (Meleis, 2018). A case model with the essential attributes (defining characteristics included) is exemplified below to explain the nursing diagnosis of Compromised end-of-life syndrome.

MLE, 75 years old, female, white, with stage IV lung adenocarcinoma—the most advanced stage of the condition. She was admitted to the unit because of dyspnea upon minor efforts, fatigue, and pain in the thoracic region. Soon, she was indicated to be accompanied by a palliative care team. She was relatively awake, presenting symptoms such as time and space disorientation, moments of bed restlessness, weight loss, fatigue, dyspnea on exertion, cancer-related visceral pain, nausea, inappetence, productive cough, and upper airway secretion with difficulty expelling with cough, periods of sweating, lower limb edema 4+/4+, and lack of intestinal elimination for over 8 days. A lack of diuresis on abdominal examination revealed pain in deep palpation, distension of bladder, and inserted an indwelling urinary catheter for relief. She awakens to callings, with periods of disorientation, verbalizes worsening appetite, and questions the meaning of life. She becomes tearful during interaction with others and has cyanosis of the upper and lower limbs. Mandibular breathing and rhonchi resulted from the accumulation of secretion of the upper airways. The nurse observes a change in sleep pattern with poor night's

sleep and periods of daytime drowsiness. Palliative Performance Scale (PPS): 20% or 10%. Husband verbalizes fear of the patient's death and refuses to be absent.

CONCLUSION

The unpleasant signs and symptoms of patients critically ill at palliative care can generate a complicated process. However, they have been studied outside of the nursing discipline or from a conceptual perspective. Over the years, there has been a lack of research explaining these phenomena related to human response (nursing diagnosis). Simultaneous patterns of signs and symptoms present in the literature reinforce the utility of the proposition of the Complicated end-of-life syndrome construct.

Individuals with chronic end-of-life diseases experience these signs and symptoms that lead to progressive clinical deterioration, increasing physical, psychological, and spiritual suffering. The World Health Organization recommends some guidelines for this context to relieve suffering and offer comfort and dignity to the individual and family.

Compromised end-of-life syndrome as a new nursing diagnosis collaborates with expansion and refinement of the NANDA-I standardized language.

This concept can support advanced practices in palliative care and theory development. It can allow a better selection of interventions based on the new nursing diagnosis and contribute to decision making within the multidisciplinary team, providing comfort and quality of life to the individual and family.

IMPLICATIONS FOR CLINICAL PRACTICE AND RESEARCH

There is a relevant implication for practice in the development of concepts that guide nursing clinical judgment. It is help full to recognize operational definitions and attributes of concepts in the end-of-life phase. Also relevant is the profound knowledge of the relationship, clustering, and cooccurrence of essential characteristics, antecedents, and consequences. The potential advantages to the patient's life dynamics and their caregivers are diverse.

The deterioration of signs and symptoms in end-of-life is a complex phenomenon that nurses identify in clinical practice. The process probably requires extensive action on the physical, psychosocial, and spiritual aspects to provide comfort during oncologic disease evolution. Identifying the clinical aspects and offering syndromic approaches can maximize the management of symptoms associated with promoting comfort, physical, social, spiritual, and family support to the patient, care with dementia, heart failure, oncology in end-of-life palliative care.

Thus, research can guide decision making toward a provision of care that maximizes the quality of life of patients and families under the principle of dignity, management, and control of signs and symptoms in the last weeks and days of life.

Some signs and symptoms (for example, urinary retention) may be present in clinical practice that were not incorporated because of the absence of clinical studies in the literature, which is a limitation of the study. The scarcity of researches on specific symptoms may justify their absence in the literature, manifesting a research gap to be explored in clinical and conceptual studies, especially in nursing diagnosis research.

ETHICS STATEMENT

A Research Ethics Committee approved the study, and the participation of the experts in the expert panel took place after signing the Informed Consent Term forms.

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AUTHORS' CONTRIBUTION

Antônia Almeida: Conceptualization, Methodology, Writing- Original. Rosimere Santana: Writing- Reviewing; Marcos Brandão: Writing- Reviewing, Methodology and Editing.

CONFLICT OF INTEREST

The authors declare no conflict of interest

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ORCID

Antônia Rios Almeida MD  <https://orcid.org/0000-0003-1615-5042>

Rosimere Ferreira Santana PhD  <https://orcid.org/0000-0002-4593-3715>

Marcos Antônio Gomes Brandão PhD  <https://orcid.org/0000-0002-8368-8343>

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