

# Assessment methods for dyspnea and shortness of breath in palliative care patients: a systematic review.

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**Abstract.** Dyspnea is one of the main symptoms experienced by individuals diagnosed with chronic or life-threatening illnesses and in palliative care. This study aims to analyze the scales used to assess dyspnea in palliative care and identify which scales offer the most effective evaluation. It is a systematic review following the PECO framework and conducted in accordance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) protocol. The review was evaluated based on the JBI (The Joanna Briggs Institute) criteria and registered with the PROSPERO platform (International Prospective Register of Systematic Reviews). The search strategy ("Palliative Care" AND dyspnea AND (scale OR score OR questionnaire OR status OR test)) was applied to the databases PubMed, BVS, Scielo, and Lilacs. Three researchers selected the articles by reviewing titles, abstracts, and full texts, and the JBI tool for cross-sectional study evaluation was used. A total of 1,837 studies were identified, and after the analysis, 8 were included. The articles demonstrated varying results regarding the use of different dyspnea assessment scales in palliative care patients. The NRS (Numerical Rating Scale) was the most frequently used, appearing in 62.5% of the studies and often combined with other scales during patient evaluations. Other scales, such as the Borg and Edmonton scales, were also employed; however, the lack of standardized protocols and specific scales/questionnaires for assessing dyspnea in palliative care patients was evident. Despite the heterogeneity of the analyzed studies, this systematic review highlights the need for the development of a comprehensive scale to assess dyspnea in palliative care. Although numerous scales exist, none are multidimensional enough to holistically evaluate such a complex symptom, and no specific scale for palliative care settings is currently available.

**Keywords.** palliative care, dyspnea, scale, questionnaire.

## 1. Introduction

Palliative care is an approach that seeks to improve the quality of life for patients and their families facing life-threatening illnesses by preventing and alleviating suffering, and by assessing and treating pain and physical, social, psychological, and spiritual symptoms. According to the World Health Organization (WHO), the main conditions requiring palliative care are cardiovascular diseases (38.5%), cancers (34.0%), chronic obstructive pulmonary disease (10.3%), AIDS (5.7%), and diabetes mellitus (4.6%) [1].

The primary symptoms observed in palliative care patients include pain, dyspnea, nausea, vomiting,

fatigue, and anorexia, among others. These symptoms must be evaluated individually and require the intervention of a multidisciplinary team [2,3]. An integrative review published in 2021 investigated the main symptoms reported and assessed in palliative care patients. Of the 35 studies examined, 22 cited dyspnea as the primary symptom causing discomfort [4].

Dyspnea, or shortness of breath, is defined as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity" [5]. It is one of the main symptoms found in individuals with life-threatening illnesses and tends to worsen as the disease progresses. As a subjective experience, only the person experiencing

dyspnea can determine its severity. In patients with cognitive deficits, specific scales are used to assess its intensity [6,7].

There are currently various scales available for assessing the intensity of dyspnea, and when applied early, they allow better control of the symptom and pain relief caused by dyspnea, through either pharmacological or non-pharmacological means [8].

Thus, this research aims to analyze the scales used for assessing dyspnea in palliative care and to encourage a more precise and appropriate evaluation of this symptom, promoting the standardization of dyspnea assessment methods.

## 2. Research Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed to conduct this systematic review [9]. The study was registered on the International Prospective Register of Systematic Reviews (PROSPERO) under the number CRD42022352339.

### 2.1 Eligibility Criteria

Eligible studies were original cross-sectional studies focused on the treatment of dyspnea in palliative care patients, without restrictions on gender or age. Studies were included if they presented validated dyspnea evaluation methods, such as scales, tests, or questionnaires. There were no publication date restrictions. Studies were excluded if they did not address palliative care, lacked dyspnea evaluation methods, were unavailable in full text, or were not published in Portuguese, English, or Spanish.

### 2.2 Information Sources and Search Strategy

The search for articles began in July 2022, with the final search conducted in January 2023. The databases used were PubMed, Scielo, BVS, and Lilacs, using the search terms ("Palliative Care" AND dyspnea AND (scale OR score OR questionnaire OR status OR test)) without any filters applied.

### 2.3 Study Selection

Three authors (AZB, LPS, and MSS) independently selected the articles in four stages. First, articles were identified through database searches, exported to Excel, and checked for duplicates. In the second stage, titles were reviewed and excluded if they met exclusion criteria. In the third stage, abstracts were read, excluding studies that did not meet eligibility criteria. Finally, the full texts of the selected articles were saved and reviewed. Any disagreements were resolved either by consensus or through the evaluation of a fourth author (AMSS).

### 2.4 Quality Analysis

The methodological quality was independently assessed by three authors (AZB, LPS, and MSS) using the Joanna Briggs Institute (JBI) tool. Eight criteria were evaluated, including sample inclusion criteria,

population description, validity and reliability of measurements, confounding factors, and statistical analysis. Studies were graded as high quality (7-8 points), moderate quality (4-6 points), or low quality (0-3 points). Quality assessment was not a criterion for exclusion but was used to study heterogeneity and subgroup analysis. Discrepancies were resolved by consensus with a fourth author (LPS).

### 2.5 Data Extraction and Analysis

A protocol for data extraction was developed and carried out by two authors (LPS and AZB). Any disagreements were resolved by consensus. Extracted data included study type, study period, location, age of participants, sample size, dyspnea scales, and outcomes. The data were organized in Excel and analyzed using descriptive statistics. Due to the high heterogeneity of the studies, a meta-analysis was not feasible.

## 3. Results

### 3.1 Study Selection

A total of 1,837 articles were found (1,090 in PubMed, 732 in BVS, 2 in Scielo, and 13 in Lilacs), with 17 duplicates, leaving 1,820 articles for screening. Of these, 1,745 were excluded based on titles for not addressing palliative care or dyspnea. Out of 75 abstracts reviewed, 54 did not meet the eligibility criteria. After full-text review of 21 articles, 8 met the criteria and were included in this review. Figure 1 shows the flowchart of article selection and reasons for exclusion at each stage.

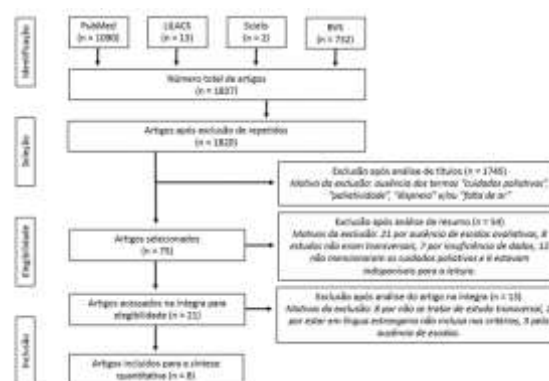


Fig. 1 - Flowchart of the study selection process for the systematic review.

### 3.2 Study Characteristics

The included studies were conducted in pediatric hospitals and palliative care centers in various countries, published between 2007 and 2021. All studies focused on patients in palliative care, not necessarily at the end of life. Several dyspnea evaluation scales were used, with 6 studies employing the Numerical Rating Scale (NRS) and 2 using the Borg Scale. Other methods were also used.

### 3.3 Critical Methodological Quality

Bias risk was evaluated using the Joanna Briggs Institute (JBI) tool, scoring studies as "yes" or "no"

for each criterion. Eight studies were assessed with positive critical reflection scores above 50%. Population detail, validation, and reliability of exposure and results received 80% positive scores, while inclusion criteria and statistical analysis scored over 50%. Confounding factors and strategies scored 20%. The studies by Weingaertner et al. [10], Zhuang et al. [11], and Tinti et al. [12] showed 80%, 90%, and 100% methodological quality, respectively. Clemens et al. [13], Dorman et al. [14], Ekstrom et al. [15], and Mularski et al. [16] scored 40% or higher due to weaker clarity on confounding factors. Puntillo et al.'s [17] study scored 30% due to a lack of inclusion criteria and subject detail.

### 3.4 Individual Study Results

The studies demonstrated diverse results regarding dyspnea assessment scales in palliative care. The NRS was used in 62.5% of the studies, often alongside other scales. Ekstrom et al. [15] began with the Australia-modified Karnofsky Performance Status (AKPS) to assess palliative care conditions, followed by symptom identification scales, the NRS, and the Edmonton Symptom Assessment Scale (ESAS). Clemens et al. [13] used the Karnofsky Performance Status (KPS) and NRS before and after opioid use. Dorman et al.'s [14] review of 15,671 articles identified the NRS, Borg Scale, and Visual Analogue Scale (VAS) as effective dyspnea assessments. Mularski et al. [16] reported using the Borg Scale, Dyspnea Transition Index, Modified Medical Research Council (MMRC) Dyspnea Scale, and other questionnaires. Puntillo et al. [17] discussed NRS and VAS, emphasizing pain as a key factor in dyspnea. Tinti et al. [12] used the KPS, IPOS, VAS, and cognitive function tests like the Glasgow Coma Scale (GCS). Zhuang et al. [11] used the Palliative Performance Scale (PPS) and Respiratory Distress Observation Scale (RDOS), later applying NRS for pain and dyspnea categorization. Weingaertner et al. [10] focused on patients with COPD (stage III or IV), using the Borg Scale and KPS.

All studies highlighted a lack of standardized dyspnea assessment protocols in palliative care, demonstrating significant heterogeneity among the scales used, which prevented a meta-analysis.

## 4. Discussion

According to the ANCP Palliative Care Manual, dyspnea should first be assessed thoroughly and holistically by healthcare professionals. Although there are many scales available—33 tools for evaluating dyspnea—there is no comprehensive tool to assess the symptom as a whole [18]. There is no gold standard for measuring dyspnea, but numerous scales exist. Instead of creating new ones, the focus should be on applying and validating them in palliative care settings. Even after a 2007 systematic review, no scale has been adapted or validated for palliative care use [14].

A 2010 study identified more than 40 instruments for assessing dyspnea, but none were suitable for

palliative care [16]. A 2021 cross-sectional study validated an Italian version of the Cancer Dyspnoea Scale, finding it useful in clinical practice for cancer patients, but noted the need for larger studies to assess its prevalence and impact on quality of life [12]. The Cancer Dyspnoea Scale (CDS) is multidimensional, effective, and requires further validation across languages and in palliative care settings [19].

The Numerical Rating Scale (NRS) is a subjective tool for assessing dyspnea intensity. It is recommended for its ease of use by patients in healthcare settings [16]. Since dyspnea is subjective and hard to report, the NRS helps quantify the experience [22]. However, one study found no significant correlation between dyspnea intensity, as measured by the NRS, and oxygen saturation [13]. Therefore, dyspnea should not be assessed based on oxygen saturation alone but through patient self-reporting.

The Visual Analogue Scale (VAS) is another subjective tool for quantifying dyspnea intensity [19]. Both the NRS and VAS are suitable for palliative care, allowing verbal or visual symptom reporting [16]. The modified Borg scale is also used for quantitative assessment, chosen in a longitudinal cohort study for its suitability for statistical analysis [10].

Dyspnea, being subjective, is often assessed through patient self-reporting. However, tools like the Respiratory Distress Observation Scale (RDOS) can assess dyspnea in non-verbal patients. A study showed a moderate-to-strong relationship between patient-reported dyspnea and the RDOS, supporting its reliability as an observational tool [11].

Some studies suggest that dyspnea intensifies as death approaches, but one cohort study involving 12,778 patients in Australia found that while dyspnea worsens in the last months of life, its severity remains stable in the final week [15]. Few studies have examined how healthcare professionals use these scales in practice, and some evidence suggests that palliative care physicians rarely use dyspnea scales routinely [20]. Nurses often diagnose dyspnea without formal criteria, and interventions are not multidimensional [6].

Despite the prevalence of dyspnea, it is often misdiagnosed and inadequately treated [21]. Proper assessment is essential to improve patient quality of life [23]. Although many scales exist, none have been fully validated for palliative care. Healthcare professionals should understand the importance of assessing dyspnea, study the available scales, and select the most appropriate one based on context, resources, and patient condition to better manage the symptom and improve the quality of life for patients in palliative care.

## 5. Conclusion

The results of this systematic review highlight the absence of specific scales to assess dyspnea in

palliative care. Therefore, the development of a multidimensional scale for evaluating patients in palliative care settings is necessary. More studies are required to better understand the application of these scales and the needs of patients in order to promote complete symptom control, particularly dyspnea, by evaluating it correctly using one or more validated tools suitable for global use in these patients.

It is important to emphasize the need for an individualized and holistic assessment of palliative care patients. Such evaluations can provide complete relief from undesirable symptoms like dyspnea. Furthermore, continuous education for healthcare professionals is essential to broaden their knowledge of palliative care, considering the subjectivity and complexity of each patient. This includes gaining a clear understanding of the impact that undesirable symptoms have on the lives of these patients.

## 6. References

- [1] Mattos DWFG. Avaliação do cuidado de fim de vida dos pacientes pediátricos com tumores sólidos atendidos na Seção de Oncologia Pediátrica do Hospital do Câncer I do Instituto Nacional de Câncer José Alencar Gomes da Silva. 2016.
- [2] Jardim PP, et al. Sinais e sintomas de pacientes com insuficiência cardíaca em cuidados paliativos: revisão de escopo. *Escola Anna Nery*. 2022; 26:20220064.
- [3] Silva MAS, et al. Equipe interconsultora em cuidados paliativos: alívio de sintomas nas primeiras 48 horas de hospitalização. *Revista Brasileira de Enfermagem*. 2020; 73
- [4] Bittencourt NCCM, et al. Sinais e sintomas manifestados por pacientes em cuidados paliativos oncológicos na assistência domiciliar: uma revisão integrativa. *Escola Anna Nery*. 2021; 25
- [5] Crombeen AM, Lilly EJ. Management of dyspnea in palliative care. *Current Oncology*. 2020; 27(3):142.
- [6] Alves ARMV, Pina PSR. Dispneia em cuidados paliativos: registros de enfermagem e a autoavaliação da dispneia. *Revista de Enfermagem Referência*. 2018; 4(16):53-62.
- [7] Berton DC, et al. Abordagem pneumológica na investigação de dispneia crônica inexplicada. *Jornal Brasileiro de Pneumologia*. 2021; 47
- [8] Berliner D, et al. The differential diagnosis of dyspnea. *Deutsches Ärzteblatt International*. 2016; 113(49):834.
- [9] Liberati A, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *Annals of Internal Medicine*. 2009; 151(4)
- [10] Weingaertner V, et al. Breathlessness, functional status, distress, and palliative care needs over time in patients with advanced chronic obstructive pulmonary disease or lung cancer: a cohort study. *Journal of Pain and Symptom Management*. 2014; 48(4):569-581.
- [11] Zhuang Q, et al. Validity, reliability, and diagnostic accuracy of the Respiratory Distress Observation Scale for assessment of dyspnea in adult palliative care patients. *Journal of Pain and Symptom Management*. 2019; 57(2):304-310.
- [12] Tinti S, et al. Italian Version of Cancer Dyspnea Scale: Cultural-Linguistic and Clinical Validation in Patients With Advanced Cancer Disease in Palliative Care Settings. *Journal of Pain and Symptom Management*. 2021; 61(3):571-578.
- [13] Clemens, Katri Elina, Ines Quednau, and Eberhard Klaschik. "Use of oxygen and opioids in the palliation of dyspnoea in hypoxic and non-hypoxic palliative care patients: a prospective study." *Supportive care in cancer* 17 (2009): 367-377.
- [14] Dorman S, Byrne A, Edwards A. Which measurement scales should we use to measure breathlessness in palliative care? A systematic review. *Palliative Medicine*. 2007; 21(3):177-191.
- [15] Ekström M, et al. Breathlessness during the last week of life in palliative care: an Australian prospective, longitudinal study. *Journal of Pain and Symptom Management*. 2016; 51(5):816-823.
- [16] Mularski RA, et al. A review of quality of care evaluation for the palliation of dyspnea. *American Journal of Respiratory and Critical Care Medicine*. 2010; 181(6):534-538.
- [17] Puntillo K, et al. Palliative care in the ICU: relief of pain, dyspnea, and thirst—a report from the IPAL-ICU Advisory Board. *Intensive Care Medicine*. 2014; 40:235-248.
- [18] Carvalho RT, Parsons HA. Manual de cuidados paliativos ANCP. *Manual de cuidados paliativos ANCP*. 2012. 590p.
- [19] Matsuda Y, et al. Research policy in supportive care and palliative care for cancer dyspnea. *Japanese Journal of Clinical Oncology*. 2022; 52(3):260-265.
- [20] Krajnik M, et al. Do guidelines influence breathlessness management in advanced lung diseases? A multinational survey of respiratory

medicine and palliative care physicians. *BMC Pulmonary Medicine*. 2022; 22(1):41.

[21] Severino R. Gestão da dispneia em cuidados paliativos: intervenções farmacológicas e não farmacológicas. *Revista Investigação em Enfermagem*. 2020; 31(2):9-23.

[22] Martins MA. Manual do residente de clínica médica. 2015.

[23] McInnes D, Bollen J. Writing a quality research paper. *Journal of Academic Development*. 2022; 13(1):27-36.