# RESEARCH PAPER (ORIGINAL) ARTIGO DE INVESTIGAÇÃO (ORIGINAL)

# Dyspnea in palliative care: nursing records and self assessment of dyspnea

Dispneia em cuidados paliativos: registos de enfermagem e a autoavaliação da dispneia Disnea en cuidados paliativos: registros de enfermería y autoevaluación de la disnea

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#### **Abstract**

Background: The integration of a quantitative assessment of dyspnea in nursing records (NR) allows adjusting nursing care delivery to each patient's needs.

Objectives: To compare NR and the self-assessment of dyspnea intensity using the Numerical Rating Scale (NRS) in patients with advanced progressive chronic disease and palliative care needs who were admitted to internal medicine wards.

Methodology: A quantitative study was conducted using a cross-sectional, descriptive, and observational approach. The NRS was applied to assess dyspnea intensity. Seventy-seven NR were selected using a non-random, purposive sampling technique.

Results: Nurses diagnosed dyspnea at rest and/or functional dyspnea correctly without using a dyspnea assessment tool. Not all patients diagnosed with dyspnea had nursing care plans. In addition, the specific nursing interventions do not consider all dimensions of total dyspnea.

Conclusion: Quantitative NR allow for a more accurate identification, monitoring, and management of dyspnea. A more systematic approach to dyspnea in patients with palliative care needs is required.

Keywords: dyspnea (nursing), dyspnea (classification), nursing records, palliative care, assessment of dyspnea

#### Resumo

Enquadramento: Os registos de enfermagem (RE) que englobam uma avaliação quantitativa da dispneia permitem adequar a prestação de cuidados de enfermagem às necessidades do doente.

Objetivos: Comparar os RE e a autoavaliação da intensidade da dispneia realizada com recurso à Escala de Avaliação Numérica (EAN) por indivíduos com doenças crónicas, progressivas e avançadas, com necessidades paliativas, internados em serviços de medicina interna.

Metodologia: Realizou-se uma pesquisa quantitativa, descritiva, transversal e observacional através da aplicação de EAN da intensidade da dispneia. Recolheram--se RE de 77 selecionados de forma intencional e não aleatória.

Resultados: Os enfermeiros diagnosticam corretamente a dispneia em repouso e/ou dispneia funcional sem recurso a uma escala de avaliação de dispneia. Não se observam intervenções autónomas de enfermagem em todos os indivíduos com o diagnóstico de dispneia, bem como, as intervenções não abrangem todas as dimensões da dispneia total.

Conclusão: Os RE quantitativos contribuem para maior rigor na identificação, monitorização e intervenção na dispneia. Considera-se necessária uma abordagem mais sistematizada da dispneia em indivíduos com necessidades paliativas.

Palavras-chave: dispneia (enfermagem), dispneia (classificação), registros de enfermagem, cuidados paliativos, avaliação da dispneia

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#### Resumen

Marco contextual: Los registros de enfermería (RE) que engloban una evaluación cuantitativa de la disnea permiten adecuar la prestación de cuidados de enfermería a las necesidades del paciente.

Objetivos: Comparar los RE y la autoevaluación de la intensidad de la disnea realizada con la Escala de Evaluación Numérica (EEN) por individuos con enfermedades crónicas, progresivas y avanzadas, con necesidades paliativas, internados en servicios de medicina interna.

Metodología: Se realizó una investigación cuantitativa, descriptiva, transversal y observacional a través de la aplicación de EEN de la intensidad de la disnea. Se recopilaron RE de 77 seleccionados de forma intencional y no aleatoria.

Resultados: Los enfermeros diagnostican correctamente la disnea en reposo y/o disnea funcional sin recurrir a una escala de evaluación de la disnea. No se observan intervenciones autónomas de enfermería en todos los individuos con diagnóstico de disnea, y las intervenciones no abarcan todas las dimensiones de la disnea total. Conclusión: Los RE cuantitativos contribuyen a un mayor rigor en la identificación, el seguimiento y la intervención en la disnea. Se considera necesario un enfoque más sistemático de la disnea en individuos con necesidades paliativas.

Palabras clave: disnea (enfermeira), disnea (clasificación), registros de enfermería, cuidados paliativos, evaluación de disnea

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## Introduction

In palliative care, dyspnea, which is commonly known as breathing difficulty, occurs both in patients with and without cancer at any stage of the disease (Coccia, Palkowski, Schweitzer, Motsohi, & Ntusi, 2016).

The prevalence of dyspnea in individuals with a chronic disease can range from 19% to 50% (Feio, 2016). In fact, there is no consensual statistical data because patients with dyspnea underestimate their breathing difficulty or health professionals consider patients' complaints as irrelevant (Banzett & O'Donnell, 2014).

Patients' self-assessment of dyspnea is a quick process that does not require patients to decide what is relevant or not to report to the health professional and allows accurate records (Banzett & O'Donnell, 2014).

This process has many advantages. On the one hand, the early and regular quantitative assessment of dyspnea improves its management, relieves the patient's suffering, and reduces the possibility of disease worsening (Baker et al., 2013). On the other hand, it allows more reliable nursing records (NR) about patients' complaints and, therefore, contributes to the development of nursing interventions adjusted to each patient's needs. However, although there are several scales to measure dyspnea intensity, it is known that the application of dyspnea assessment tools is not a common practice in nursing care delivery. In view of the above, it is important to assess the whole process, from the identification to the implementation of nursing interventions in cases of dyspnea using the Numerical Rating Scale (NRS).

To better understand the phenomenon under analysis, the sampled subjects' self-assessment of dyspnea using the NRS included in forms was analyzed and then compared with the NR. Therefore, this study aimed: to compare the NR with patients' dyspnea self-assessment; to identify the intensity of functional dyspnea; to identify the nursing care plans recorded by nurses; to determine the prevalence of nursing care plans; to achieve an optimal treatment for dyspnea; and to determine if patients' dyspnea self-assessment is biased by nursing shifts.

# Background

Dyspnea is a subjective experience of breathing discomfort that consists of distinct qualitatively sensations that vary in intensity (American Thoracic Society, 2012). The experience derives from interactions among multiple physiological, psychological, social, and environmental factors, and may induce secondary behavioral and physiological responses (Coccia et al., 2016).

Due to its subjective nature, only the person with dyspnea is in a position to determine its severity (Hayen, Herigstad, & Pattinson, 2013). Thus, whenever possible, dyspnea intensity should be self-reported.

There are multiple scales available for the self-assessment of dyspnea intensity (Berliner, Schneider, Welte, & Bauersachs, 2016), among which the NRS stands out due to its objectivity and easy interpretation and application (Johnson et al., 2016). In addition, according to Bailey et al. (2013), the NRS allows nurses to identify the presence of dyspnea, as well as to explain and assess the effectiveness of their interventions.

The NRS consists of a ruler divided into 11 equal sections, each numbered 0 to 10 (Wysham et al., 2015). In this scale, individuals are expected to rate their dyspnea intensity using a numerical rating, in which 0 corresponds to not breathless at all and 10 corresponds to breathlessness as bad as you can imagine (Wade et al., 2017).

Despite the recommendations to implement the NRS in nursing care delivery and, therefore, in NR (American Nurses Association, 2010), the state-of-the-art on this topic, both at national and international levels, is still very tenuous.

Yet, a pilot study by Baker et al. (2013) should be highlighted. In this study, the authors tested the feasibility of nurses measuring dyspnea in inpatient units using an assessment tool derived from three scales, including the NRS. At the end of the study, 92% of the nurses reported that it was important to assess dyspnea using an assessment tool. According to the authors, the integration of dyspnea assessment into care delivery did not increase the nursing team's workload. More recently, Johnson et al. (2016) recommended the use

of NRS in detriment of the modified Borg scale for the assessment of dyspnea intensity at various moments and in certain situations, such as at rest and during exertion. Finally, according to Wade et al. (2017), although the NRS is highly recommended for the assessment of dyspnea intensity, it requires accurate statements.

Therefore, an appropriate dyspnea assessment allows monitoring the intensity of dyspnea during hospitalization facilitates the assessment of the nursing interventions for relieving dyspnea, thus contributing to the visibility of nursing care and the combination of multidisciplinary care (Registered Nurses' Association of Ontario, 2012).

NR are defined as the information written down by nurses during their clinical practice, which includes information related to patients' nursing care needs (Ordem dos Enfermeiros, 2005). Nursing information systems (NIS) were created to enable the standardization and automation of this process. The NIS in use in the units under analysis is the Nursing Practice Support System (Sistema de Apoio à Prática de Enfermagem, SAPE<sup>®</sup>). The SAPE® allows diagnosing dyspnea at rest and/ or functional dyspnea and, based on clinical judgement, identifying, recording, and monitoring the patient's needs. However, and contrary to what is recommended by the abovementions scientific evidence, the SAPE® does not include a dyspnea assessment scale.

# Research question

What is the association between NR and dyspnea self-assessment (using the NRS) performed by adult individuals with advanced progressive chronic disease?

# Methodology

This study was approved by the Ethics Committee, and the Board of Directors of the Hospital Garcia de Orta, EPE (HGO), and the by Ethics Committee of the Lisbon Academic Medical Center.

This is a quantitative, descriptive, cross-sectional, and observational study. The target

population is composed of consecutive patients admitted to the medicine units I and II of the HGO between 13 May 2016 and 13 June 2016.

The inclusion criteria were: subjects aged over 18 years, diagnosed with advanced progressive chronic disease, who signed informed consent form, were capable of self-reporting the intensity of their dyspnea on a NRS, and had complete NR available.

Taking into account the guidelines of the Portuguese National Plan for Palliative Care (Direção-Geral da Saúde, 2005) and of the European Association for Palliative Care (2009), an *advanced progressive disease* is defined as a chronic disease that causes patients to require palliative care and is expected to result in the death of the patient within a period of 1 to 2 years.

The final sample was selected using a non-random purposive sampling technique. It was composed of all individuals who met the above-mentioned criteria and had less than four incorrect answers in the potuguese version of the Short Portable Mental Status Questionnaire (SPMSQ). A form, which included sociodemographic questions, the SPMSQ, and two NRSs for self-assessment of dyspnea at rest and functional dyspnea in light of the studies by Baker et al. (2013) and Johnson et al. (2016), was applied to the sampled subjects.

The first NRS asks the respondent to assess the intensity of dyspnea at rest: "How would you rate your shortness of breath and breathing difficulty when you are resting?". The second NRS asks "How would you rate your shortness of breath and breathing difficulty when you are performing an activity of daily living, such as eating or bathing?".

Data were also collected from the NR available in the SAPE® and gathered in a document created for this purpose.

Prior to the application of the final version of the form, a pre-test was applied to five subjects. It was concluded that the subjects' answers should be written down by the interviewer.

Finally, data were entered and processed in IBM SPSS Statistics, version 23.0, and a statistical and descriptive analysis was performed.

# Results

Ninety-two forms were applied, of which 15 were excluded because subjects did not meet the inclusion criterion related to the SPMSQ. Thus, the final sample consisted of 77 individuals. The sample was mostly composed of men, older

than 71 years (65%), with primary education. In addition, circulatory system diseases were the main cause of hospitalization, with stroke and heart failure (HF) representing almost 40% of health problems. More than half of the subjects had three or more health antecedents. Table 1 describes the characteristics of the sample.

Table 1
Sample sociodemographic characterization

Sociodemographic characteristics of	the sample
Age	Years
Mean	73
Median	74
Minimum-Maximum	28-90
Age, age groups	% of subjects
Under 70 years	35.1
71 to 80 years	29.8
Over 81 years	35.1
Gender	
Male	53.2
Female	46.8
Education level	
None	16.9
Primary education	68.8
Secondary education	10.4
Higher education	3.9

Table 2 shows that 16.9% of the patients reported dyspnea at rest. However, according to the NR, only 11.7% had dyspnea at rest.

Table 2

Dyspnea at rest

	Self-assessment % of subjects	Nursing records % of subjects
Dyspnea at rest		
Yes	16.9	11.7
No	83.1	88.3
Dyspnea at rest (yes)		
Mean	3.8	-
Median	4	-
Mode	5	-
Minimum-maximum	1-7	-
Standard deviation	1.9	-
Coefficient of variation	0.5	-

With regard to the assessment of functional dyspnea, 31.2% of patients reported dyspnea when performing an activity of daily living (ADL). As Table 3 shows, patients' self-assessment of func-

tional dyspnea intensity is very heterogeneous, with some of them experiencing a very intense sensation of dyspnea. According to the NR, 28.6% of the patients had functional dyspnea.

Table 3
Functional dyspnea

	Self-assessment % of subjects	Nursing records % of subjects
Functional dyspnea		
Yes	31.2	28.6
No	68.8	71.4
Functional dyspnea (yes)		
Mean	5.3	-
Median	5	
Mode	5 -	
Minimum-maximum	2-10	-
Standard deviation	2.5	-
Coefficient of variation	0.47	-

After reencoding the data for functional dyspnea in Table 3 into mild (NRS 1-3), moderate (NRS 4-6), and severe (NRS 7-10) functional dyspnea, it can be concluded that 7.8% of individuals had mild functional dyspnea, 14.3% had moderate functional dyspnea, and the remaining 9.1% had severe functional dyspnea. Equal percentages were obtained in the NR.

# Association between patient self-assessment and NR

In order to ensure data consistency between the  $NR_S$  and the NR, an eligibility filter was applied in the database of the IBM SPSS Statistics software, thus dividing the sample into two large groups. The first group was composed of the sampled individuals whose dyspnea self-assessment was consistent with the NR – consistent group; and the second group was composed of the sampled individuals whose dyspnea self-as-

sessment was inconsistent with the NR – inconsistent group.

For reasons of simplicity and organization, the filter was applied in two phases: the first phase focused on dyspnea at rest, and the second phase on functional dyspnea. Absolute frequencies were calculated after the eligibility filter was applied.

The first phase of filter application resulted in 60 consistent and 17 inconsistent cases. In 10 of the 17 inconsistent cases, the patient reported dyspnea at rest but it was not documented in the NR; in the remaining 7 cases, the patient did not report dyspnea at rest, but it was documented in the NR.

Later, the second phase of filter application resulted in 26 inconsistent cases. Table 4 shows a cross-comparison between the self-assessment of the subjects included in the inconsistent group and the NR, based on dyspnea intensity.

Table 4
Cross-comparison between patient self-assessment and the NR, based on the intensity of dyspnea

NR/NRS (n)	No functional dyspnea	Mild functional dyspnea	Moderate functional dyspnea	Severe functional dyspnea
No functional dyspnea	-	2	7	3
Mild functional dyspnea	6	-	0	1

Moderate functional dyspnea	4	1	-	1
Severe functional dyspnea	0	1	0	-

Nota. NR = Nursing records; NRS = Numerical Rating Scale; n = Number of subjects.

# Association between nursing shifts and response bias

The obtained results do not allow concluding on whether patients' answers were biased by the shift during which the form. Of the 77 eligible forms, 32 (41.5%) were collected during the morning shift (8:00 a.m. to 4:30 p.m.), 35 (45.5%) during the afternoon shift (4:31 p.m. to 10:30 p.m.), and 10 (13.0%) during the night shift (10:31 p.m. to 7:59 a.m.).

In the inconsistent group, which was obtained in the first phase of eligibility filter application, seven forms were collected during the morning shift, six during the afternoon shift, and three during the night shift. In the second phase, 14 inconsistent cases were obtained during the morning shift, 11 during

the afternoon shift, and one during the night shift.

### Autonomous nursing interventions

Nursing interventions can only be designed based on a diagnosis. In this study, only 38% of the sampled individuals were diagnosed with dyspnea at rest and/or functional dyspnea. Thus, Table 5 shows the autonomous nursing interventions identified within the sample under analysis and the percentage of subjects to whom they were provided. These data were collected by analyzing only the interventions that were designed using the SAPE®. Based on the NR, not all individuals diagnosed with dyspnea at rest and/or functional dyspnea receive targeted interventions (Table 5).

Table 5
Autonomous nursing interventions

Autonomous nursing interventions	% of subjects
Praising the learning of new skills	7%
Performing respiratory kinesiotherapy	28%
Optimizing ventilation through positioning techniques	62%
Optimizing inhalation therapy	10%
Monitoring breathing	90%

## Discussion

The sample was composed of 77 subjects, mostly men. It was very heterogeneous regarding personal health history and diagnosis, among which HF was the most prevalent. It is well known that dyspnea is one of the most common clinical manifestations of HF (Arrigo, Parissis, Akiyama, & Mebazaa, 2016). The results show that more than half of the

The results show that more than half of the sampled subjects did not report dyspnea at rest and/or functional dyspnea. Indeed, it should be noted that the forms and, consequently, the NRSs for assessment of dyspnea intensity, were applied at any moment during the patient's hospitalization at the internal medicine ward. It is likely that the patient had already received dyspnea care to manage

symptoms before completing the form, either in the emergency department or in the internal medicine ward. In addition, the heterogeneity of the sample in terms of diagnosis and comorbidities can influence the presence of dyspnea.

Based on the self-assessment of individuals who reported dyspnea at rest/functional dyspnea, its intensity, calculated through the NRS, was very heterogeneous. Some individuals experienced maximum intensity (NRS-10) while performing an ADL.

The results obtained from the NR reveal that the majority of the subjects did not have dyspnea at rest and/or functional dyspnea. Moreover, the eligibility test showed consistency between the NR and patients' dyspnea self-assessment.

Therefore, given that the SAPE® does not include a dyspnea assessment scale to be used by nurses, it can be concluded that nurses tend to diagnose dyspnea at rest and functional dyspnea correctly, even without a specific assessment tool.

According to Baker et al. (2013), only a small percentage of the nurses recognized the importance of implementing a dyspnea assessment tool in NIS<sub>S</sub>. Indeed, based on the obtained results, the lack of a standardized scale in NR does not bias nurses' judgment at the time of diagnosis of dyspnea. However, according to the recommendations of the American Nurses Association (2010) and the Registered Nurses' Association of Ontario (2012), the implementation of a dyspnea assessment tool provides objective and accurate NR that facilitate the multidisciplinary team's understanding of how dyspnea intensity will evolve throughout hospitalization.

The NR were analyzed based on these results. At the time of data collection, there was no differentiated therapeutic plan for the symptomatic management of different intensities of dyspnea. Only the autonomous nursing interventions targeting dyspnea from the SAPE® were considered. These interventions were not observed in all individuals diagnosed with dyspnea, possibly due to a documentation error or the lack of symptom management measures.

The most prevalent intervention was monitoring breathing, followed by optimizing ventilation through positioning techniques. According to Bailey et al. (2013), dyspnea can be reduced through positioning, however, in a study conducted by Costa (2016), nurses recognized the importance of an adequate positioning to relief dyspnea, but not all of them had enough knowledge about appropriate positioning techniques.

More specific and accurate NR, Based on interprofissional reflective practice, would certainly provide greater visibility to the profession, enable the monitoring of interventions, and promote care quality and development of indicators (Registered Nurses' Association of Ontario, 2012).

As previously stated, dyspnea is a subjective experience with physiological, psychological, social, and environmental factors (American

Thoracic Society, 2012). No nursing interventions were found that covered the social and environmental dimension. The psychological dimension is represented by praising the learning of new skills.

No NR were found on the effectiveness of the above-mentioned autonomous nursing interventions.

Finally, assuming that dyspnea intensity varies throughout the day (Mercadante et al., 2016) and that the most severe episodes of dyspnea occur more frequently during the day than at night (Weingärtner et al., 2015), the potential influence of the nursing shift in dyspnea assessment was also analyzed. Thus, the forms were applied during three different shifts (morning, afternoon, and night) and it was concluded that the shift during which the form was applied did not influence dyspnea self-assessment.

This study had some limitations, namely the use of a non-random purposive sample, the sample heterogeneity in terms of personal health history and diagnosis, regardless of any inclusion criteria, the institution's organizational aspects, and the lack of a protocol that defined the criteria for form application.

In view of the above, these findings can only be used to describe the context under analysis and cannot be generalized to other populations or situations. However, the importance of the findings and the innovative nature of the study should not be underestimated.

### Conclusion

Dyspnea is a subjective experience, which is often described as a feeling of breathlessness or breathing difficulty resulting from the interaction of multiple physiological, psychological, social, and environmental factors.

This study compared NR and patient self-assessment of dyspnea using a NRS. Although nurses lack dyspnea assessment tools, the obtained results show little discrepancy between nurses' and patients' assessment of dyspnea. The NR available in the SAPE® are structured based on the nursing process, thus each diagnosis of dyspnea at rest and/or functional dyspnea must have associated interventions. The analysis of the NR revealed the lack of a

differentiated therapeutic plan for managing dyspnea symptoms of different intensities. Similarly, it also revealed that autonomous nursing interventions did not cover all the dimensions of dyspnea. Due to documentation errors or lack of dyspnea management measures, no autonomous nursing interventions were associated with some diagnoses of dyspnea.

In addition, the effectiveness of the autonomous nursing interventions performed on patients was not assessed.

Therefore, according to the NR, and particularly in what concerns dyspnea, nurses diagnose dyspnea at rest and/or functional dyspnea without using standardized criteria, document non-differentiated autonomous nursing interventions that do not target the patient's needs, and, finally, do not reassess the effectiveness of their interventions.

Lastly, it can be concluded that the research question was answered and the study objectives were reached.

However, some aspects should be considered. The correct identification and monitoring of dyspnea is essential to ensure the quality of life of the patient with dyspnea. This procedure should be performed at the beginning of hospitalization and be regularly performed throughout it using a single assessment tool. The NRS is recommended for the assessment of dyspnea intensity because it enables the self-report of subjective conditions and the assessment of dyspnea at rest and functional dyspnea.

Furthermore, it would be interesting to conduct a study on nurses' perceptions about the use of dyspnea assessment tools for measuring and monitoring dyspnea. It is important to understand if the nursing team becomes more aware of dyspnea in nursing care delivery after using dyspnea assessment tools.

It would also be important to study whether nurses' greater awareness would translate into the development of a differentiated therapeutic plan for managing dyspnea symptoms of different intensities.

Finally, it is urgent to conduct a study on nursing interventions targeted at individuals diagnosed with dyspnea and their expected outcomes

In summary, despite the limitations and diffi-

culties experienced throughout this study, the research question was answered and the proposed objectives were achieved through the scientific method. This study contributed to the production of knowledge about this topic and opened the way to future studies. A more systematic approach to dyspnea is required in case of individuals with advanced progressive chronic disease and palliative care needs.

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