

# Series on Dyspnea. Part 5. Subjective Experience of Breathlessness: total dyspnea, refractory dyspnea, chronic dyspnea syndrome, terminal dyspnea

*Series en Disnea. Parte 5. Experiencia subjetiva de la dificultad para respirar: Disnea total, disnea refractaria, síndrome de disnea crónica, disnea terminal*

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## ABSTRACT

The concept of breathlessness emphasizes the multidimensional subjective nature of dyspnea with physical, psychological, social, spiritual, and existential components. “Total dyspnea” advocates a comprehensive, patient-oriented approach beyond the disease. The term “refractory dyspnea” should be avoided; it implies a certain therapeutic nihilism. For this reason, the term “chronic dyspnea syndrome” was coined to recognize treatment possibilities and raise awareness among patients, physicians, healthcare teams, and researchers. People with advanced respiratory disease and severe chronic dyspnea (and people who are close to them) have a poor quality of life. The Breathing-Thinking-Functioning clinical-conceptual model includes the three predominant cognitive and behavioral reactions that worsen and maintain the symptom by causing vicious circles. Various instruments are available for the comprehensive assessment of dyspnea that take into account the sensory-perceptual experience, affective distress, and the impact or burden of the symptoms. Breathlessness during the last weeks or days of life can be called “terminal dyspnea.” It is a common symptom and one of the most distressing in the latest phase of life of patients with cancer. Under these circumstances, self-report may underestimate respiratory distress. The Respiratory Distress Observation Scale is the first and only dyspnea assessment instrument designed to evaluate its presence and intensity in patients who are unable to communicate.

**Key words:** Breathlessness; Total dyspnea; Refractory dyspnea; Chronic dyspnea syndrome; Terminal dyspnea

## RESUMEN

El concepto de “dificultad para respirar” enfatiza la naturaleza subjetiva multidimensional de la disnea con componentes físicos, psicológicos, sociales, espirituales y existenciales. La “disnea total” aboga por un enfoque integral y centrado en el paciente más allá

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de la enfermedad. La noción de “disnea refractaria” debería ser evitada; implica cierto nihilismo terapéutico. Por tal motivo, se acuñó el concepto de “síndrome de disnea crónica” para reconocer las posibilidades de tratamiento y concientizar a los pacientes, los médicos, el equipo de salud y los investigadores. Las personas que viven con enfermedades respiratorias avanzadas y disnea crónica grave (y sus allegados) tienen una mala calidad de vida. El modelo clínico-conceptual “respirando-pensando-funcionando” incluye las tres reacciones cognitivas y conductuales predominantes que, al provocar círculos viciosos, empeoran y mantienen el síntoma. Para la evaluación exhaustiva de la disnea se dispone de diversos instrumentos que consideran la experiencia sensorial-perceptiva, la angustia afectiva (*distress*) y el impacto o carga de los síntomas. La dificultad para respirar durante las últimas semanas o días de vida puede denominarse “disnea terminal”. Es un síntoma frecuente y uno de los más angustiantes en la última fase de la vida de pacientes con cáncer. En estas circunstancias el autorreporte puede subestimar la dificultad respiratoria. La Escala de Observación de Dificultad Respiratoria es el primer y único instrumento de evaluación de la disnea destinado a evaluar su presencia e intensidad en pacientes que no pueden comunicarse.

**Palabras clave:** Dificultad para respirar; Disnea total; Disnea refractaria; Síndrome de disnea crónica; Disnea terminal

## MULTIDIMENSIONAL APPROACH TO DYSPNEA

The concept of “breathlessness” is widely used in the literature related to palliative care, instead of the biomedical term “dyspnea”, to emphasize the daily experience from the patient’s perspective.<sup>1</sup> The multidimensional subjective nature of dyspnea goes beyond merely the physical condition and highlights the importance of the psychological, social, spiritual, and existential components. Similar to the concept of “total pain” described by Dame Cicely Saunders in the early 1960s, the concept of “total dyspnea” has been suggested, advocating for a comprehensive and patient-centered approach beyond the disease itself.<sup>2</sup>

If dyspnea persists despite treatment of the underlying disease, it is sometimes referred to as “refractory dyspnea.” Since this term implies therapeutic nihilism, Johnson et al suggested calling it “chronic dyspnea syndrome” to acknowledge treatment possibilities and raise awareness among patients, physicians, healthcare teams, and researchers.<sup>2</sup> Chronic dyspnea syndrome is described as *the sensation of breathlessness that persists despite receiving optimal treatment of the underlying physiopathology and causes disability*.<sup>3-5</sup> Like total pain, total dyspnea encompasses multiple aspects and incorporates previously neglected constructs, such as the suffering related to the meaning patients assign to their symptoms. Total

pain includes four domains: physical, psychological, interpersonal, and existential, and these are assessed from the patient’s perspective. Dyspnea is subjected to a similar analysis.<sup>6</sup>

For more than a decade, the respiratory sensation (neural activation resulting from the activation of peripheral receptors) and perception (conscious and individual reaction to the sensation) have been clearly differentiated.<sup>7</sup> Consequently, the sensation of dyspnea doesn’t need to be related to identifiable physiological factors. Patients’ experiences with dyspnea vary widely depending on factors such as ethnicity, experiences with other diseases, and emotional state. Additionally, various psychological and cultural factors can influence the reaction to a sensation. A stoic individual may not perceive (or deny) respiratory discomfort. The context in which the sensation occurs can also modify the perception of the sensory experience.<sup>8-10</sup>

Anxiety, a particularly common psychological factor that correlates with dyspnea, can exacerbate the symptom, leading to a progressive spiral of increased dyspnea and higher distress.<sup>11,12</sup> Episodes of dyspnea can be predictable with known triggering factors, such as exertion, emotions, comorbidities, or the external environment, or they can appear to be unpredictable. Linde et al stated that many seemingly inexplicable episodes were known to have been driven by fear or panic when evaluated in depth.<sup>13</sup>

## IMPACT OF DYSPNEA

Dyspnea often triggers panic, fear, anxiety, depression, hopelessness, a sense of loss of control, and a feeling of imminent death.<sup>14,15</sup> It also affects daily and social functions, leading to dependency and loss of roles. This symptom is one of the six parameters used in the Palliative Prognostic Score, which predicts the 30-day survival of patients in palliative care.<sup>16</sup>

A qualitative study illustrated the meaning of the dyspnea experience in patients with cancer, COPD (chronic obstructive pulmonary disease), heart failure, and amyotrophic lateral sclerosis (ALS):<sup>17</sup>

- For individuals with cancer, dyspnea serves not only as a sign of the presence of cancer but also as a reminder of mortality, even in the face of treatment optimism.
- In people with COPD, dyspnea is perceived as self-inflicted due to lifelong smoking.
- For those with heart failure, dyspnea is associated with functional limitations and contributes to the negative effects of other symptoms.
- In individuals with ALS, dyspnea is related to mechanisms that are essential for living.

## DYSPNEA AND QUALITY OF LIFE

People with advanced respiratory diseases and severe chronic dyspnea (and the people close to them) have a poor quality of life.<sup>1,17</sup> Chronic dyspnea is an incapacitating symptom, and acute episodes are terrifying to experience and observe. Many millions of people around the world live with advanced respiratory diseases, such as COPD and interstitial lung disease (ILD).<sup>18</sup> These individuals aren't receiving the palliative care they need to have the best possible quality of life.

These prevalent diseases, as well as other less common ones, can progress rapidly or have a more chronic course, and younger patients may be awaiting a lung transplant. However, in all cases, as the disease progresses, the patient becomes very symptomatic and is unlikely to improve despite maximum treatment of the underlying disease.

Although there is no comparable infrastructure for providing palliative care in non-oncological respiratory medicine, it is recognized that the deficit in symptom control and psychosocial support leads to a poorer quality of life for patients not only with advanced respiratory diseases but also

in the general population, and it is likely to have a negative effect on medical outcomes.<sup>19</sup>

## ACUTE AND CHRONIC DYSPNEA AND PERSON-CENTERED CARE

Generally, more attention is given to the treatment of *acute* dyspnea than to *chronic* dyspnea. Therefore, it is the responsibility of every physician to provide the best *person-centered* care possible, ensuring the use of all available resources and knowledge.<sup>19</sup>

The term *person-centered care*, recognized as a hallmark of excellence in care, also encompasses the choice of specific treatments targeted at the disease, and provides a foundation for ensuring that patients receive individualized treatment, and that their symptoms and other concerns are identified. Healthcare professionals must play an active role in promoting quality of life as part of excellent medical care.

## DYSPNEA IN TERMINAL RESPIRATORY DISEASE

The cardinal symptoms of *advanced respiratory disease* are persistent dyspnea, fatigue, and cough, sometimes referred to as the *respiratory triad*.<sup>20</sup> <sup>21</sup> All these symptoms can be invisible at rest, so they need to be actively elicited to detect them. Scientific evidence for symptomatic treatments has improved in recent years; not using them in specialized respiratory care services should be considered inexcusable.

Other factors that greatly affect the outcomes and quality of life are outside the sphere of clinical influence, for example: financial anxiety, housing loss, lack of food, difficulty obtaining social assistance, concern about the continuity of health benefits, social isolation, caregiver burnout, and breakdowns in family relationships. Being outside the sphere of clinical influence does not mean they should be ignored.

## THE EXISTENTIAL MEANING OF DYSPNEA

The spiritual repercussions of dyspnea can be strong. Just like pain, patients may attribute a variety of meanings to dyspnea, ranging from God's punishment to a divine gift. Additionally, the patient's religious or metaphysical beliefs can influence the extent of their suffering.<sup>22-24</sup> The

secondary physiological and behavioral responses to dyspnea should be considered in the evaluation process. This concept has been subjected to experimental testing, supporting the hypothesis that the multiple dimensions or components can be measured as different entities. Some studies have demonstrated the existence of a separable “*affective dimension*” (i.e., distress and emotional impact).<sup>25</sup>

## SUBJECTIVE INDIVIDUAL EXPERIENCE

Dyspnea affects people in different ways and across different dimensions, which is well demonstrated by the Breathing, Thinking, Functioning clinical model.<sup>21</sup> This model conceptualizes the three predominant cognitive and behavioral reactions to dyspnea that, by creating vicious cycles, worsen and sustain the symptom (Figure 1).

**Breathing domain:** shortness of breath associated with dysfunctional breathing patterns, increased respiratory rate, the need to use accessory muscles, and dynamic hyperinflation, leading to inefficient breathing and increased respiratory work.

**Thinking domain:** misconceptions about the nature of dyspnea, such as its cause, and previous experiences and memories that profoundly impact the current experience. This negative cognition

and memories can cause anxiety, sadness, panic, and thoughts about death.

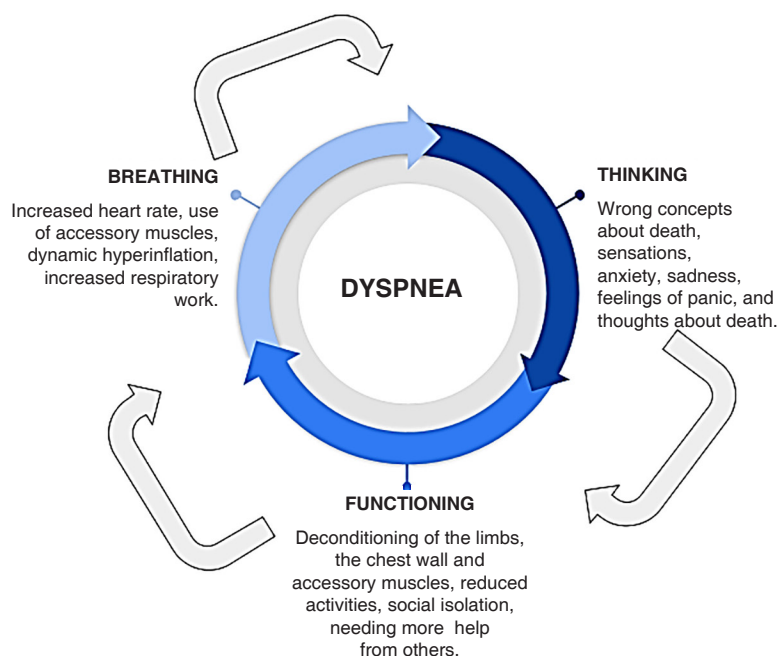
**Functioning domain:** individuals suffering from dyspnea often reduce their physical activity to avoid the sensation of breathlessness, leading to social isolation, increased dependence on others, and general deconditioning.

## FAMILY IMPACT OF DYSPNEA

The dyspnea experienced by patients also affects informal caregivers (family and friends). However, their burden and anxieties are often overlooked and the existence of those feelings is normalized.<sup>28</sup>

Caregivers of dyspnea patients perform many invisible caregiving tasks, such as hygiene, dressing, symptom control, and administering medication and oxygen, in addition to all the household chores.<sup>29</sup> They also provide emotional support not only during the day but also through difficult nights. They remain awake monitoring the patient’s breathing, and checking if they are still alive. Thus, it is not surprising for caregivers to report poor quality sleep, similar to people working shifts and mothers of young children.

Therefore, when treating patients with dyspnea, it is also necessary to focus on caregivers and their needs, providing them with education, support,



**Figure 1.** Breathing, Thinking, Functioning clinical model (BTF) by Spathis A et al 2017 (adapted)<sup>26,27</sup>

and resources, just like for the patients. Caregivers should be encouraged to also take care of their own health, both physical and emotional.

## EVALUATION AND IDENTIFICATION OF THE CAUSES OF DYSPNEA

The assessment of dyspnea must include the patient's subjective experience; therefore, the self-report of the symptom is essential. This should include the sensory component with its intensity and severity, the emotional burden reflected in the discomfort caused by dyspnea, and the impact on the patient's daily life.

Currently, there is no universally accepted measure of health outcomes in clinical or research settings, which poses a clear barrier to routine clinical evaluation and follow-up of dyspnea.

The evaluation of a patient should also include a physical examination with vital signs and a cardiopulmonary exam. Although additional diagnostic tests may be important to identify any treatable cause of dyspnea, it should be noted that more objective evaluations, such as respiratory rate, blood gas analysis, or lung function tests do not measure dyspnea and only moderately correlate with the patient's subjective experience. For optimal management of dyspnea, treating the underlying disease and addressing reversible symptoms are the first step.

## INSTRUMENTS FOR MEASURING DYSPNEA

For a comprehensive evaluation of its multidimensionality, an instrument must reflect each patient's subjective sensory experience, provide an objective measurement of dyspnea, and facilitate the effec-

tive communication with the healthcare team.<sup>31</sup> There are three domains of dyspnea measurement proposed by the American Thoracic Society in 2012 and 2013.<sup>11,12</sup>

**1. Sensory-perceptual experience:** this includes the ratings of symptom intensity, frequency, duration, and sensory quality. The intensity of dyspnea can be assessed using a Visual Analog Scale (VAS), the Borg Scale<sup>32</sup>, Likert-type ratings, or the Numeric Analog Scale (NAS). Dyspnea is also included in validated Spanish multidimensional assessment tools, such as the Memorial Symptom Assessment Scale and the Edmonton Symptom Assessment Scale (ESAS-r validated in Spanish).<sup>33,34</sup> For sensory quality, Simon et al<sup>35</sup> reported 15 descriptors of dyspnea used by patients in eight groups (rapid, exhalation, shallow, effort, choking, hunger, tight, and heavy). The authors suggested possible associations of the descriptors with specific conditions causing dyspnea, but a subsequent study by Wilcock et al<sup>36</sup> could not demonstrate the robustness of these descriptors in helping with the diagnosis when applied to patients with cancer and cardiopulmonary diseases.<sup>37</sup>

**2. Affective distress:** this can refer to immediate distress or the distress that patients feel when they understand the meaning or consequences of their symptom. Discomfort can be rated as a single item, as in the case of dyspnea intensity. Scales with multiple items, such as the one for dyspnea in cancer, assess emotional responses, including anxiety.<sup>38,39</sup>

Two validated measures, *Dyspnoea 12* and the *Multidimensional Dyspnea Profile* (MDP), are suitable for use in both clinical and research settings and are brief enough for assessment and follow-up.<sup>38-40</sup>

**TABLE 1.** Aspects that should be included in the medical records of a patient with dyspnea<sup>30</sup>

1. Pattern of dyspnea (onset, aggravating factors, characteristics, episodes, triggering factors).
2. Presence of other symptoms and their significance compared to dyspnea.
3. Impact on quality of life, including physical activities (for example: walking), ability for self-care, social life and psychological state.
4. Current symptomatic treatments for dyspnea (for example, handheld fan) and their efficacy in that particular patient.
5. Adverse effects of any current or past treatments.
6. All comorbidities.
7. The person's understanding and interpretation of the symptom.
8. Caregiver burnout.

*Dyspnoea 12* is a 12-item measure of dyspnea severity with 7 physical items and 5 affective items not related to physical activity. Response options are: none (0), mild (1), moderate (2), or severe (3). The time period refers to “*these days*.”<sup>40, 41</sup>

The MDP is also a 12-item scale that uses scores (0-10). Seven items refer to overall intensity, unpleasantness, and other qualitative sensory descriptions of dyspnea (increased respiratory muscle work, chest tightness, air hunger, breathing a lot, requiring mental effort), and five rate the emotional responses to dyspnea (depression, anxiety, frustration, anger, and fear).<sup>42,43</sup>

**3. Impact or burden of symptoms:** this includes the effect of dyspnea on behavior, functions, quality of life, or health status. The Medical Research Council (MRC) scale provides a unidimensional rating of disability,<sup>44-46</sup> while the Chronic Respiratory Disease Questionnaire (CRQ) is a multidimensional scale used for the assessment of functionality.<sup>47-49</sup>

The MRC scale evaluates the consequences of dyspnea in relation to functional limitations. It is particularly useful if dyspnea is the only symptom experienced by the patient but is too insensitive to detect subtle changes after an intervention.<sup>8</sup> Several quality of life scales have been validated for use in cancer or specifically for lung cancer and chronic lung diseases, such as the CRQ<sup>47,48,50,51</sup>, EuroQol 5D, FACT-L<sup>52</sup>, QLQ-C15-PAL<sup>53-55</sup> and QLQ-LC13.<sup>56,57</sup> Table 2 summarizes the dyspnea assessment instruments and their main domains.

Currently, there are more than 50 scales for measuring dyspnea, covering several dimensions and different diseases.<sup>11</sup> However, there is no unified measurement tool for clinical use in the palliative care setting. It may be possible to combine the assessment of dyspnea intensity with its

impact on the patient’s quality of life.<sup>58</sup> The NAS, the Modified Borg Scale, the CRQ dyspnea scale<sup>59</sup>, the ALS Assessment Scale (based on the CRQ)<sup>60</sup> and the Cancer Dyspnea Scale seem to be the most suitable for the palliative care settings.<sup>61</sup>

Dyspnea can also be measured in terms of exercise tolerance. Several instruments have been validated in advanced disease, namely, the Shuttle Walking Test<sup>62</sup>, the Reading Numbers Aloud Test<sup>63</sup>, and the Upper Limbs Test.<sup>64</sup> Unfortunately, the fact that these tests are slow and expensive currently limits their applicability in the clinical setting.<sup>58</sup>

## EVALUATION OF DYSPNEA CRISES

During crises, the patient is likely to experience an increase in intensity, distress, and fear.<sup>12</sup> Initially, dyspnea is often a component of several symptoms, including depression and anxiety. Self-report is the most valid and reliable method for assessing the patient’s experience, symptom progression, and response to treatment.

The simplest self-report is a dichotomous yes or no response to the question, “*Are you short of breath?*” However, yes or no responses are unlikely to help with palliative care, so the use of some rating of dyspnea intensity is expected. At least a standardized measure is recommended, such as the 0-10 Numerical Rating Scale, augmented by the evaluation of the patient’s subjective experience of distress and discomfort alongside the rating of dyspnea intensity.

## TERMINAL DYSPNEA

Dyspnea suffered by patients during the last weeks or days of their life can be called “*terminal*

**TABLE 2.** Dyspnea assessment instruments

Sensory-perceptual experience	Affective distress	Impact or burden of symptoms
Visual Analog Scale (VAS)	Dyspnoea 12 (12 items: 7 physical items and 5 affective items)	Medical Research Council (MRC)
Modified Borg Scale	Multidimensional Dyspnea Profile (MDP), 12 items (0-10)	Chronic Respiratory Disease Questionnaire (CRQ)
Numeric Analog Scale (NAS) Memorial Symptom Assessment Scale (MSAS) validated to Spanish Edmonton Symptom Assessment Scale (ESAS-r) validated to Spanish		

*dyspnea.*"<sup>65</sup> Timely assessment and proactive management of dyspnea in these patients are of vital importance. This symptom has unique clinical characteristics: it tends to worsen rapidly over days or hours as death approaches, even despite symptom control measures. The family is also deeply affected, experiencing anxiety, uncertainty, helplessness, and inability. An assessment of the family-caregiver, the need for information, the desired level of participation in care, and home resources will support caregivers and integrate them into the healthcare team.

International guidelines have recently recognized that dyspnea is common and one of the most distressing symptoms in the final stages of life for cancer patients<sup>66</sup> and that patients have difficulty self-reporting the symptom. Since self-report is the gold standard for assessing dyspnea, there is a need to seek alternatives for this group of patients.

In clinical practice, healthcare teams conduct indirect assessments of symptom severity. However, the accuracy of these subjective assessments may be poor. Studies conducted in advanced cancer populations and in intensive care units show that indirect assessments by physicians and nurses are significantly lower and poorly related to patient self-report. Given the fact that symptom severity assessments influence treatment decisions, a better method for assessing dyspnea in patients who cannot express themselves is necessary.

The Respiratory Distress Observation Scale (RDOS) is an ordinal 8-item scale designed to measure the presence and intensity of breathlessness in adults. This scale was developed from a bio-behavioral framework by Campbell.<sup>67,68</sup> It is the first and only dyspnea assessment tool developed so far to evaluate its presence and intensity in patients who are unable to communicate.<sup>68-70</sup> There are two modifications of the RDOS available for intensive care patients: the IC-RDOS (Intensive Care Respiratory Distress Observation Scale)<sup>68,69,71</sup> and the MV-RDOS (Mechanical Ventilation Respiratory Distress Observation Scale).<sup>72</sup>

The RDOS demonstrates strong inter-rater reliability, convergent validity, and divergent validity, suggesting its reliability and validity as an assessment tool for palliative care patients.

Most importantly, it shows clinical utility by demonstrating good discriminative properties in detecting patients with moderate and severe dyspnea. A new RDOS cutoff point of  $\geq 3$  has

been proposed for therapeutic intervention, with a sensitivity of 68% and a specificity of 77% for distinguishing between moderate to severe distress versus none (positive predictive value: 0.85 and negative predictive value: 0.61).<sup>69,70</sup> Table 3 shows the objective variables considered by the RDOS and the corresponding scores.

The evaluation of the use of accessory muscles is based on the observation of the *clavicle elevation during inspiration*. It does not refer to the palpation of accessory muscles such as the scalene, intercostals, sternocleidomastoid, or the contraction of the abdominal muscles during expiration. Clavicle elevation somewhat reflects the activation of the upper thoracic and neck muscles and is an easy-to-identify sign.

The prevalence and severity of dyspnea increase at the end stages of life. Many of the patients in that situation have difficulty reporting their symptoms. Dyspnea is a symptom, only the person experiencing it can say that they are short of breath. Certain operational aspects of the use of Table 3 should be emphasized:

- The RDOS is used in adults and is not a substitute for what the patient reports, as long as they can express it.
- The scale should not be used if the patient is paralyzed with a neuromuscular blocker and is not valid in cases of bulbar ALS or quadriplegia.
- Respiratory and heart rate can be measured during auscultation if necessary.
- Grunting can be audible even in intubated patients through auscultation.<sup>69</sup>

The RDOS is promising and has clinical utility as an observational dyspnea assessment tool. Further studies in less communicative patients are needed to determine clinical utility and the generalizability of the results.

## CONCLUSIONS AND FUTURE APPROACH

It is not possible to address a person with dyspnea without considering its multidimensional subjective nature, with its physical, psychological, social, spiritual, and existential components. The term "total dyspnea" encompasses these components. The term "refractory dyspnea" should be avoided and replaced by "chronic dyspnea syndrome" in order to recognize treatment possibilities and raise awareness among patients, physicians, healthcare teams, and researchers.

**TABLE 3.** Respiratory distress observation scale (RDOS).<sup>67-70</sup>

Variable	0 points	1 point	2 points	Sub-Total
Heart rate per min (beats/minute=bpm)	<90	90-109	>110	
Respiratory rate per minute (auscultated) (breaths/min)	≤18	18-30	>30	
Restless, non-purposeful movements	No	Yes - Occasional, slight movements	Yes - Frequent movements	
Paradoxical breathing pattern: abdomen moves in on inspiration	No		Yes	
Accessory muscle use: rise in clavicle during inspiration	No	Yes - Slight rise	Yes - Pronounced rise	
Grunting at the end-expiration: guttural sounds	No		Yes	
Nasal flaring: involuntary movement of nares	No		Yes	
Look of fear: – Eyes wide open – Facial muscles tense – Brow furrowed – Mouth open – Teeth together	No		Yes	
TOTAL				

- People living with advanced respiratory diseases and severe chronic dyspnea (and the people close to them) have a poor quality of life.
- The Breathing-Thinking-Functioning clinical model includes the three predominant cognitive and behavioral reactions against dyspnea that worsen and maintain the symptom.
- There are various instruments available for the comprehensive assessment of dyspnea as a multidimensional symptom. These instruments propose considering the sensory-perceptual experience, affective distress, and the impact or burden of the symptoms.
- Dyspnea suffered by patients during the last weeks or days of their life can be called “terminal dyspnea.” It is a common symptom and one of the most distressing in the latest phase of life of patients with cancer.
- While the self-report of the sensation of breathlessness is essential, some patients may not be able to express it, and it may be underestimated. The Respiratory Distress Observation Scale is the first and only dyspnea assessment instrument used to evaluate its presence and intensity in patients who are unable to communicate.

A better understanding of the brain processes underlying the perception of dyspnea will lead to new therapeutic approaches aimed at improving the quality of life for a very large group of patients.

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