Ensuring Breathing Comfort at the End of Life: The Integral Role of the Critical Care Nurse

By Margaret L. Campbell, PhD, RN

This article describes the author’s program of clinical research focused on assessment and treatment of respiratory distress among critically ill patients at the end of life. Dyspnea is a subjective experience of breathing discomfort that occurs in the presence of cardiopulmonary and neuromuscular diseases. Dyspnea is one of the most common and most distressing symptoms experienced by critically ill patients. Many critically ill patients, particularly those not expected to survive, become cognitively impaired or unconscious and lose the ability to report symptoms, although dyspnea can be known only from a patient’s report. When self-reporting ability is lost, the critical care nurse must rely on signs indicative of a patient’s respiratory distress. The critically ill patient unable to self-report is vulnerable to under- or overtreatment or undertreatment. When the patient is dying, there is only 1 chance to optimize the assessment and treatment of symptoms. (American Journal of Critical Care. 2018;27:264-269)
Dyspnea is “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity”\(^1\) and can only be known from a patient’s self-report. Respiratory distress is the observed corollary to dyspnea based on observed signs.\(^2\) Dyspnea is akin to suffocation and is one of the worst symptoms experienced by critically ill patients, including those who are receiving mechanical ventilation.\(^3,4\)

**Prevalence**

Puntillo et al\(^5\) conducted a prospective observational study of symptom prevalence, intensity, and distress among critically ill patients at high risk of dying. It was one of the first studies in which multiple dimensions of the symptoms were measured. Of patients who were able to respond, 44% reported dyspnea of moderate intensity producing moderate to severe distress. Of symptoms assessed, dyspnea was the most distressing.\(^5\)

Patients who receive mechanical ventilation are expected to have less dyspnea while ventilated than those without, because mechanical ventilation is the most reliable means of treating dyspnea associated with respiratory failure. However, in a prospective observational study,\(^4\) half of the patients receiving mechanical ventilation or who had a tracheostomy reported dyspnea while receiving mechanical ventilation. Dyspnea can be expected during spontaneous weaning trials and certainly during terminal ventilator withdrawal. The prevalence of respiratory distress among critically ill patients at risk of dying who are unable to report this distress is unknown.\(^5\)

**Assessment**

Symptom assessment guides treatment. To provide a dyspnea self-report, the patient must be conscious and able to interpret sensory stimuli, pay attention to clinician instructions, concentrate to form a dyspnea self-report, be able to communicate in some fashion, and be able to recall the previous report, if trending is requested.\(^7\) From 40% to 70% of critically ill patients sampled have been able to self-report dyspnea.\(^5,8,9\) Critically ill patients are often lightly sedated, cognitively impaired, or unconscious and limited in their abilities to use a complex instrument. The simplest assessment in patients able to report is to ask, “Are you short of breath?” The numeric rating scale, for those able to report, is an appropriate tool, although it is limited to identification of dyspnea presence and intensity only. Using a visual analog scale for dyspnea permits a unidimensional assessment of dyspnea intensity if the patient can point to a line.\(^10\) In one study,\(^11\) persons with chronic obstructive pulmonary disease preferred a vertical orientation of a dyspnea visual analog scale.

I developed the Respiratory Distress Observation Scale (RDOS) during my doctoral study in response to the lack of a way to assess dyspnea when the patient cannot self-report. The RDOS (see Table) is the only valid and reliable tool for measuring respiratory distress when patients, such as those who are critically ill and/or those near death, cannot provide a dyspnea self-report.\(^12-15\) The RDOS has application for clinical assessment of the patient in the intensive care unit (ICU) who is undergoing treatment of respiratory distress, mechanical ventilation, spontaneous weaning trials, and, in particular, terminal ventilator withdrawal to allow a natural death.\(^16\) Use of this objective, valid, reliable instrument takes the guesswork out of assessment of patients.

The RDOS is an 8-item ordinal scale that can be used to measure the presence and intensity of respiratory distress in adults unable to self-report dyspnea. Each variable is scored from 0 to 2 points and the points are summed. Scale scores range from 0, signifying no distress, to 16, signifying the most severe distress.

The scale was developed from a biobehavioral framework. One or more of the following constitute an asphyxial threat: hypoxemia, hypercarbia, and inspiratory effort. Areas in the brainstem and amygdala activate pulmonary stress behaviors and a fear response.\(^17\) The postulated behaviors in the framework

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**About the Author**

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were validated in the author’s observation study of patients receiving mechanical ventilation who were undergoing a spontaneous weaning trial. The patients were videotaped with framing from the waist up to capture signs of respiratory distress as distress developed during failed weaning trials.18

Subsequent psychometric testing for interrater and scale reliability, as well as construct, convergent, and discriminant validity, has been done.12,13 In these studies, the internal consistency (α) reported was from 0.64 to 0.86, and interrater reliability was perfect between nurse data collectors (r = 1.0). Construct validity was established through correlation with hypoxemia and with use of oxygen.12,13 Convergent validity was established by comparison with a dyspnea self-report from patients with chronic obstructive pulmonary disease after they had performed a treadmill exercise in pulmonary rehabilitation sessions; a vertical dyspnea visual analog scale anchored from 0 to 100 was used.12 Discriminant validity was established with comparisons of RDOS scores of patients with chronic obstructive pulmonary disease who had dyspnea, of patients with acute pain, and of healthy volunteers.12 Similar psychometric properties were established in a study of Taiwanese critically ill patients using an RDOS translated into Chinese.19

Intensity cut points were established in 2 studies using receiver operating curve analysis. We determined that an RDOS score of 0 to 2 suggests no respiratory distress, a score of 3 signifies mild distress, scores of 4 to 6 signify moderate distress, and a score of 7 or greater represents severe distress.14,15 The RDOS is not valid with neonates, young children, patients with cervical spinal cord lesions producing quadriplegia, or patients with bulbar amyotrophic lateral sclerosis.

**Treatment**

Dyspnea and respiratory distress are refractory when they persist after the underlying etiologic condition has been optimized. Treatment of refractory dyspnea may include positioning, oxygen, opioids, and noninvasive or invasive mechanical ventilation.

Positioning to optimize vital capacity and ventilation may be accomplished by using the patient as his or her own control and assessing dyspnea or respiratory distress to identify an optimal position. In obstructive lung disease, an upright, arms-supported (ie, tripod) position is often helpful.20,21

Oxygen may reduce dyspnea in patients with hypoxemia; however, no benefit has been found when the patient had mild or no hypoxemia. A large, multinational study of patients with chronic obstructive pulmonary disease and lung cancer was undertaken. Patients were randomly assigned to receive either nasal oxygen or room air via a concentrator for 7 days; dyspnea was measured every morning and evening. Patients had life-limiting illnesses and were not hypoxic. As expected, oxygen conferred no dyspnea relief compared with normal oxygenation.22

Oxygen can be withheld or withdrawn from patients who are actively dying and showing no signs of respiratory distress. In a repeated-measures observation study,23 patients who were near death

<table>
<thead>
<tr>
<th>Variable</th>
<th>0 points</th>
<th>1 point</th>
<th>2 points</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart rate, beats per minute</td>
<td>&lt;90</td>
<td>91-109</td>
<td>≥110</td>
<td></td>
</tr>
<tr>
<td>Respiratory rate, breaths per minute</td>
<td>≤18</td>
<td>19-30</td>
<td>&gt;30</td>
<td></td>
</tr>
<tr>
<td>Restlessness: nonpurposeful movements</td>
<td>None</td>
<td>Occasional, slight movements</td>
<td>Frequent movements</td>
<td></td>
</tr>
<tr>
<td>Accessory muscle use: rise in clavicle during inspiration</td>
<td>None</td>
<td>Slight rise</td>
<td>Pronounced rise</td>
<td></td>
</tr>
<tr>
<td>Paradoxical breathing: abdomen moves in on inspiration</td>
<td>None</td>
<td>Present</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grunting at end expiration: guttural sound</td>
<td>None</td>
<td>Present</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nasal flaring: involuntary movement of nares</td>
<td>None</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Look of fear</td>
<td>None</td>
<td>Eyes wide open, facial muscles tense, brow furrowed, mouth open</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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and in no respiratory distress received oxygen, medical air, or no flow via nasal cannula in random order; treatment was rotated every 10 minutes. The RDOS score was calculated at the end of every 10-minute epoch. Nearly all the patients (91%) showed no distress across conditions regardless of oxygen saturation.

Determining if oxygen can be withdrawn entails standing by and monitoring for reports from the patient or signs (using RDOS) of respiratory distress as the oxygen is decreased. If there is no distress after 5 to 10 minutes, the supplemental oxygen can be discontinued. A decreasing peripheral oxygen saturation rate and other changes in vital signs, such as tachycardia, are expected when a patient is dying and, by themselves, are not indicators of patients’ distress.

Opioids are the mainstay medications for treating refractory dyspnea, but the evidence is limited to oral or parenteral morphine and fentanyl. Nebulized opioids have not been rigorously tested. An effective dose regimen for dyspnea has not been empirically established, but based on anecdotal experience of this author, the initial dose is lower than what is typically recommended for a pain regimen. Thus, an initial dose of morphine in a naïve patient to treat dyspnea is 2 mg given intravenously or 6 mg given enterally. Titrating to the patient’s responses with a low-and-slow regimen is recommended.

Mechanical ventilation, invasive or noninvasive, is an effective means of treating dyspnea associated with respiratory failure. Yet, dying patients generally want to forgo mechanical ventilation. One study of noninvasive ventilation (NIV) used as a palliative strategy in patients with dyspnea associated with advanced cancer was undertaken; patients with hypercarbia had effective relief of dyspnea from NIV compared with relief experienced with oxygen treatment. However, some patients had difficulty tolerating NIV because of mask pressure and gastric insufflation. Use of NIV for symptom palliation was addressed by a Society for Critical Care Medicine task force. As stated by the task force, the appropriate end point for NIV for palliation at the end of life is symptom relief. Failure to improve dyspnea or worsening of distress warrants NIV discontinuation and a palliative approach to relieving dyspnea.

Mechanical Ventilator Withdrawal

Ventilator withdrawal is a palliative care process that entails the cessation of mechanical ventilatory support to allow a natural death. Opioids and/or benzodiazepines are routinely administered before, during, and after as an integral component of the ventilator withdrawal process to prevent or relieve dyspnea or respiratory distress. Little empirical evidence is available to guide the conduct of this common procedure; thus, clinicians rely on intuition, varying levels of experience, or local practice customs. The author is leading a multisite National Institutes of Health–funded stepped wedge cluster randomized trial of a nurse-led, respiratory therapist–supported algorithmic approach to ventilator withdrawal guided by RDOS compared with usual care (ClinicalTrials.gov identifier: NCT03121391).

Preparation

When the plan to withdraw mechanical ventilation is known 24 to 48 hours in advance of the process, the administration of 4 mg of dexamethasone every 6 hours may reduce the development of postextubation stridor. In addition, promoting diuresis in the patient who has interstitial pulmonary edema as evidenced by lung auscultation or radiography will minimize respiratory distress and/or retained airway secretions during spontaneous breathing. Cuff-leak testing predicts which patients are at high risk for postextubation laryngeal edema and the resulting airway obstruction and stridor. A cuff-leak test entails measuring the volume of air loss when the endotracheal tube cuff is deflated before extubation. Air loss of less than 180 mL is predictive of postextubation stridor.

Premedication

Not all patients will need premedication before withdrawal of mechanical ventilation (eg, patients who are comatose without signs of respiratory distress). Premedication is recommended if respiratory distress can be anticipated. Opioids and benzodiazepines are the most commonly used medications to prevent dyspnea during ventilator withdrawal, although reported doses have been highly variable.

Withdrawal Process

Rapid weaning and turning the ventilator off without weaning (ie, 1-step method, also known familiarly as terminal extubation) are conventional
withdrawal methods. These methods were directly compared in my pilot study in which patients with rapid weaning guided by the RDOS displayed significantly more respiratory comfort than did the control group who underwent 1-step withdrawal and extubation. More distress from immediate extubation compared with weaning was reported in a multisite observation study in French ICUs. That study was limited by using the Behavior Pain Scale to measure patients’ respiratory distress instead of a more sensitive measure, such as the RDOS. Rapid weaning in cases when the patient may experience distress is recommended because this process affords an opportunity to restore the patient to a previous ventilator setting while their distress is relieved. The 1-step method is recommended only for unconscious patients who are unlikely to experience distress.

**Extubation Considerations**

Maintaining the endotracheal tube in the presence of a swollen or protuberant tongue or after a failed cuff-leak test will prevent the development of partial or complete airway obstruction and stridor, which may be a source of distress for the patient and the patient’s family. Stridor is treated effectively with an aerosol treatment of racemic epinephrine 2.25% (22.5 mg/mL in 3 mL of normal saline).

**Postwithdrawal Considerations**

Supplemental oxygen is not necessary unless the patient is hypoxemic with respiratory distress. Continuing care in the ICU is important if the predicted duration of survival after ventilator withdrawal can be measured in minutes to hours. Patients who are likely to die quickly after ventilator withdrawal have concurrent multisystem organ failure and/or severe hypoxemia. Patients who are likely to live hours to a day or more include patients with neurologic illness or injury but who have no other major organs in failure. Other predictors for duration of survival after ventilator withdrawal have been reported, including need for vasopressors and older age.

**Future Studies**

Development and psychometric testing of an RDOS for infants is being planned with a nurse scientist with neonatal care expertise. Validation of the RDOS in adolescents also is planned; all the previous psychometric studies were done with adults. We postulate that adolescents manifest the same behaviors as adults in response to an asphyxial threat. We plan to conduct focus groups and surveys of the critical care nurses who work at the study sites participating in our ventilator withdrawal algorithm study to determine their perceptions, knowledge, and confidence about their role in this process. Measures will be done under the usual-care arm and repeated when the sites have implemented the nurse-led algorithm.

**Summary**

Dyspnea (reported) and respiratory distress (observed) are the worst symptoms that may develop in a dying patient in the ICU. The critical care nurse has an integral role to ensure that distress is assessed and treated expeditiously. There are no do-overs when a patient is dying—in other words, we have 1 chance to get it right. An evidence-based approach to assessment and treatment of patients has been the focus of my program of research. It is my hope that the evidence produced will translate to care at the bedside.

**FINANCIAL DISCLOSURES**

None reported

**REFERENCES**

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1. Identify tools for assessing dyspnea and respiratory distress in the critical care unit.
2. Describe interventions that may alleviate dyspnea.
3. Describe a process for withdrawal of mechanical ventilation at the end of life.

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