A Respiratory Distress Observation Scale for Patients Unable To Self-Report Dyspnea

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Abstract

Background: Standard measures of dyspnea rely on self-report. Cognitive impairment and nearness to death may interfere with symptom distress reporting leading to underrecognition and overtreatment or undertreatment. Previous psychometric testing of the Respiratory Distress Observation Scale (RDOS) demonstrated internal consistency and convergent validity with dyspnea self-report and discriminant validity with pain and no dyspnea. Additional testing was needed with patients unable to self-report. The aim of this study was to establish further the reliability and construct validity of a revised RDOS.

Methods: An observational design was used with 89 consecutive patients referred for inpatient palliative care consultation and at risk for dyspnea who had one or more of lung cancer, chronic obstructive pulmonary disease (COPD), heart failure, or pneumonia. Patients were observed and the RDOS scored once each day for up to three days after the initial consultation. Other measures included: dyspnea self-report, neurologic diagnoses, opioid or benzodiazepine use, peripheral oxygen saturation, end-tidal carbon dioxide level, consciousness, cognitive state, nearness to death, and patient demographics.

Results: Perfect interrater reliability across data collectors was achieved. No differences in RDOS scoring were found by patient demographics. RDOS was associated with use of oxygen ($p < 0.01$), oxygen saturation ($p < 0.01$) and nearness to death ($p < 0.01$). A significant decrease in RDOS was found over time corresponding with treatment ($p < 0.01$). The reliability of this 8-item scale using Cronbach α is 0.64.

Conclusions: Declining consciousness and/or cognition are expected when patients are near death. The RDOS performed well when tested with terminally ill patients who were at risk for respiratory distress, most of whom could not self-report dyspnea. The tool is sensitive to detect changes over time and measure response to treatment. The RDOS is simple to use; scoring takes less than 5 minutes. The RDOS has clinical and research utility to measure and trend respiratory distress and response to treatment.

Introduction

DYSPNEA IS MEASURED CURRENTLY using scales and instruments that rely on the patient's ability to self-report, such as a numeric rating, or a visual analogue scale (VAS). The simplest report is a "yes" or "no" response to the question "Are you short of breath?" Yet, as death nears the ability to provide a self-report may become difficult or impossible or yield an ambiguous response.[1,2] Cognitively impaired patients with pain retained some ability to self-report with coaching and assistance from clinicians when the cognitive impairment was mild or moderately advanced, but patients with severe cognitive impairment had poor report completion

rates.[3] More than half the patients observed in this investigation were unable to respond with yes or no; findings reported previously.[4]

Cognitive decline and decreasing consciousness from hemodynamic, blood gas or metabolic derangements typifies the period before death. Theoretically, the same physiological changes that evoke dyspnea in the patient with intact cognition will produce respiratory distress when the patient is experiencing declining cognition; respiratory distress may be observed if not reported.[5] Inability to report symptom distress is not synonymous with an inability to experience suffering. Patients who are unable to provide a report about any dyspnea experienced are vulnerable to undertreatment or overtreatment.

A focused audit of deceased nursing home residents' medical records was undertaken to assess characteristics during the last 48 hours of life. Fifty-one percent of residents were cognitively impaired from various causes and dyspnea was the most prevalent recorded symptom (62%) but it was not treated in 23% of residents with this symptom.[6] Similarly, in a mortality follow-back survey of the families of Medicare decedents nearly 24% of nursing home patients did not receive enough help with dyspnea.[7] Conversely, patients unable to self-report may be overtreated when unable to validate the clinician's assessment producing unintended hastening of death. In a systematic review of ventilator withdrawal methods wide variance in opioid administration with a trend toward high doses even in the context of patient unconsciousness was found.[8]

Objective measurement of respiratory distress using a biobehavioral framework may enhance the clinician's ability to recognize, treat, and measure response to treatment of respiratory distress. An observation method has the advantage of allowing an observer to elicit information when it is not obtainable by other methods.[9] Additionally, the systematic observation of respiratory distress behaviors may allow for inclusion of patients with impaired cognition in clinical studies of dyspnea, including those who are dying who heretofore have been largely excluded.

A Respiratory Distress Observation Scale (RDOS) was developed and preliminary testing, reported elsewhere,[10] demonstrated that the earlier version seven-item scale had sufficient internal consistency, construct, convergent, and discriminant validity when tested with cognitively intact patients with dyspnea or pain and healthy volunteers. Patient reports about dyspnea were compared to displayed behaviors in three groups of 70 patients or volunteers ($n = 210$). Pulmonary rehabilitation patients were assessed after controlled exercise while hypoxemic and subsequently asked to report current dyspnea on a dyspnea VAS. Patients with postoperative orthopedic pain were evaluated with the RDOS and asked to report current pain and dyspnea. Healthy volunteers were assessed with the RDOS at rest and asked to report current dyspnea. A positive correlation between the RDOS and VAS ($p < 0.01$) and an inverse correlation between RDOS and peripheral oxygen saturation (SpO_2; $p < 0.01$) were found indicating convergent and construct validity respectively. Significant mean differences were found when RDOS scores from dyspneic patients were compared to RDOS from patients with pain ($p < 0.01$) and with healthy volunteers ($p < 0.01$) indicating discriminant validity.[10] The instrument was subsequently revised with addition of another variable, paradoxical breathing pattern, because this clinical sign occurred with relative frequency in a previous study to determine the behavioral correlates to an asphyxial threat. Paradoxical breathing pattern was observed in 33% of patients at risk for respiratory distress while undergoing a mechanical ventilator weaning trial.[11] Testing the revised eight-item scale with terminally ill patients and/or patients unable to self-report dyspnea needed to be established and was the purpose of this study.

Methods

Design

An observation design was used during which adult patients were observed and the revised RDOS was scored.

Concurrent measures of end-tidal carbon dioxide (et-CO_2) and peripheral oxygen saturation (SpO_2) and the fraction of inspired oxygen (FiO_2) were done. Consciousness and cognitive testing was done. Conscious patients were asked to report about current dyspnea. Demographic and other data were obtained from the medical record, including age, gender, race, diagnosis, and the administration of opioids or benzodiazepines in the 24-hour interval prior to patient assessment. Opioid and benzodiazepine agents and doses were converted to parenteral morphine and diazepam equivalents to allow comparison across patients.

Sample size/sampling approach. A rough estimate of sample size based on 10 study participants per scale variable yielded 80 participants. We collected data from 99 consecutive eligible patients to allow for missing data which typifies palliative care research. Patients were included in the study if they had one or more of the following diagnoses putting them at risk for experiencing dyspnea: chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), pneumonia, or lung cancer. Eligible patients were terminally ill and referred for palliative care consultation. Patients who did not speak English were excluded. A waiver of consent was approved by the Human Investigations Committee at Wayne State University since the patient assessment was noninvasive and entailed examinations that are part of routine care.

Instruments. The RDOS is an ordinal level scale with eight observer-rated parameters: heart rate, respiratory rate, accessory muscle use, paradoxical breathing pattern, restlessness, grunting at end-expiration, nasal flaring, and a fearful facial display (See Appendix A). Each parameter 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. Psychometric testing is the purpose of this study.

The Reaction Level Scale (RLS85) categorizes consciousness and was developed for use in the ICU. It is an eight level ordinal scale with advantages over the more commonly used Glasgow Coma Scale (GCS) because it can be applied with patients who are intubated or have ocular swelling. There is no addition of covarying variables and the instrument tests favorably with the GCS.[12,13] The RLS85 is superior to the GCS in that a significant change signifies a significant change in patient status.[14] Scores range from 1 (alert with no delay in response) to 8 (unconscious with no response to painful stimuli).

Patients were categorized into levels of cognitive state (intact, mild, moderate, or severe impairment) by their performance on an investigator-developed Cognitive State Categorization Tool (CSCT). Cognitive tests from the Confusion Assessment Method-ICU (CAM-ICU)[15] that measure attention, concentration, memory, recall, and organized thinking were combined to quantify patient cognitive performance and categorize cognitive state. CSCT scores range from 0–28 points. Scores between 22 and 28 points signified intact cognition, 15–21 indicated mild impairment, 8–14 represented moderate impairment and less than 8 signified severe impairment. Construct validity of the CSCT with consciousness (RLS85) was established in this investigation ($r_s = -0.66$, $p < 0.01$).

SpO_2, et-CO_2, heart and respiratory rates were measured with a hand-held Nellcor® N-85 capnograph/oximeter. This

device provides exceptional pulse oximetry performance even during low perfusion states that may typify the study population. Capnography assessment is possible even in non-intubated patients via a nasal capnoline. A capnoline oral/nasal circuitry was applied in the same fashion as a nasal oxygen cannula.

The patient's self-report about any dyspnea being experienced was elicited by asking "Are you short of breath?" When patients could provide a "yes" or "no" response they were subsequently asked to quantify distress using a VAS. This was a 100 mm vertical line anchored at $0 =$ no distress to $100 =$ worst distress with tick marks every 10 mm along the length of the line. This simple to use instrument has been previously tested for reliability and validity.[16]

Terminal illness severity was quantified using the Palliative Performance Scale (PPS). This scale grades a patient's general condition as 0% (dead) to 100% (normal) in increments of 10 percentage points. The scale incorporates five observer-rated parameters: ambulation, activity, self-care, intake, and level of consciousness. The scale has been validated with patients with cancer (all types), patients in an acute tertiary hospital setting, home care setting, heterogeneous diagnoses, and a minority population.[17–21]

Data analysis

The internal consistency of the RDOS was measured with Cronbach α. Construct validity was ascertained by identifying the relationships among the RDOS and et-CO_2 and SpO_2 and between the CSCT and consciousness (RLS85) using correlation techniques. Convergent validity between VAS and RDOS was measured with correlation techniques. Differences in RDOS scores across patient diagnoses, time, and demographics were tested using t test and χ^2.

Results

Ninety-nine eligible patients were enrolled; the data collector was not available for 3 patients, 3 patients declined participation, 2 families did not want the patient disturbed, and eligibility was overlooked in 2 patients leaving a sample of 89 patients for analysis. Patients had an average age of 72 years (37–101 years) were evenly distributed by gender, and were predominantly African American (African American = 83%, Caucasian = 17%) reflecting the demographics of the hospital study site.

RDOS scores were obtained from 89 patients and yielded Cronbach $\alpha = 0.64$. Perfect interrater reliability for all parameters was achieved between data collectors conducting simultaneous blinded scoring with 5 patients. Data were obtained from 89 patients on day of enrollment, 41 patients on day 2, and 9 patients on day 3. Hospital discharge ($n = 28$) or death ($n = 18$) or the weekend ($n = 2$) precluded subsequent data collection after day 1. All the patients were terminally ill with an anticipated survival of less than 6 months. Most (63%) were very near death (PPS ≤ 20%); most (62%) patients were subsequently discharged from the hospital with 38% of the total sample dying in the hospital.

On the day of enrollment (before palliative care intervention), most patients (63%) had RDOS scores 4 or less, while 35% of the sample ranged from more than 4 to less than 12, 10% were scored at zero, and only 2 patients (2%) had scores greater than 12; no patients had the maximum score. Most patients had received no morphine (69%) or benzodiazepines (91%) in the 24-hour interval prior to palliative care consultation. One patient with COPD/CHF was treated as an outlier in subsequent analyses about morphine having received 400 mg in the 24-hour interval prior to data collection.

Patients had COPD (16%), CHF (15%), pneumonia (21%), or lung cancer (15%) with the remaining sample (33%) having more than one of these diagnoses. Neurological conditions included dementia (44%), coma from various causes (13%), and delirium (8%).

Most patients were conscious (78%; RLS85 ≤ 3) but only 13% of conscious patients were cognitively intact, the remaining patients were mildly impaired (13%), moderately impaired (5%), severely impaired (47%) or unconscious (23%). Twenty patients (22%) were able to provide a distress self-report with VAS; the average VAS was 41.9 (standard deviation [SD] 39.8) and scores ranged from 0 to 100 mm.

RDOS scores were not associated with age, race, gender, respiratory diagnosis, or neurologic diagnosis. RDOS scores were inversely correlated with oxygen saturation ($r_s = -0.369$, $p < 0.01$) and associated with FIO_2 ($r_s = 0.315$, $p < 0.01$) indicating hypoxemia and need for oxygen, and confirming construct validity. RDOS scores correlated with VAS ($r = 0.404$, $p < 0.05$, $n = 20$) confirming convergent validity. Table 1 summarizes this and previous tests of RDOS convergent validity with self-report.

No association between RDOS and et-CO_2 was found but few patients ($n = 6$) in this sample were hypercarbic at the time of evaluation. The RDOS score on day one was inversely associated with cognition ($r_s = -0.234$, $p < 0.05$) and nearness to death ($r_s = -0.280$, $p < 0.01$) suggesting that more distress was evident in patients with cognitive impairment or who were nearest to death.

A significant decrease in the RDOS was seen between day 1 (mean = 4.4 ± 3) and day 2 (mean = 2.9 ± 2; $t(40) = 3.06$, $p < 0.01$) with no change between day 2 (mean = 3.1 ± 2) and day 3 (mean = 2.7 ± 2; $t(9) = 0.63$, $p = $ ns) suggesting that treatment for respiratory distress started on day one was effective and the effectiveness continued into day 3 illustrating sensitivity of the RDOS to detect changes with treatment. This suggestion is supported by a significant increase in the 24-hour morphine dose between day 1 (mean = 3.5 ± 11 mg) and day 2 (mean = 9.2 ± 18 mg; $t(40) = -3.6$, $p < 0.01$) with one outlier eliminated from the comparison of means.

Discussion

Treatment of dyspnea must be guided by assessment but no other tool exists to quantify respiratory distress when the patient cannot self-report dyspnea putting the patient at risk for overtreatment or undertreatment. Symptom self-report has been held as the most reliable means for evaluating the patient's experience, disease progression and response to treatment. Yet, as patients reach the end of life many experience cognitive impairment of a severity that makes dyspnea reporting ambiguous, unreliable, or impossible.[4] Behavioral evaluation using the RDOS is proposed in the absence of any form of dyspnea report. Patients who are unable to quantify their distress may be able to provide a simple "yes" or "no" report to a query about distress.

Table 1. Self-Report (VAS) and RDOS Correlations Across Study Samples

Study samples	Cognitive state	n	r	p
COPD with dyspnea, post/surgical pain, healthy volunteers[a]	Intact	210	0.740	<0.01
COPD with dyspnea[a]	Intact	70	0.389	<0.01
Terminally ill at risk for dyspnea	Intact, mild, or moderately impaired	20	0.404	<0.05

[a]Campbell ML: Psychometric testing of a respiratory distress observation scale. J Palliat Med. 2008;11:44–50.
VAS, visual analogue scale; RDOS, Respiratory Distress Observation Scale; COPD, chronic obstructive pulmonary disease; *n*, number, *r*, Pearson's r, *p*, significance.

Although behavioral evaluation is a promising alternative to self-report validity of this method can be questioned. It is well understood that many chronically ill patients with lung disease have mastered their distress and will deny distress even in the face of signs of pulmonary stress. Thus, the use of behavioral signs may lack the validity of a self-report; however, in the absence of self-report there is no other means for evaluation. The RDOS is the only known instrument for the behavioral assessment of respiratory distress and this study and our previous investigation[10] have established the internal consistency, construct, convergent, and discriminant validity. We offer this instrument for both clinical application to assess patients and guide treatment and as a research tool.

The tool is intended for use with adult patients and possibly adolescents. There has been no testing with children or infants so we caution against application with those populations; infants display other behaviors than adults when in respiratory distress such as sternal retraction. We postulate that the RDOS can be applied to patients across settings of care and diagnoses, although all testing to date has been completed in the acute and critical care settings.

The RDOS will not produce a meaningful assessment if the patient is paralyzed with a neuromuscular blocking agent because heart rate would be the only detectable and dynamic variable on the RDOS. Likewise, patients who are in a "locked–in" state with paralysis of all muscle groups except ocular will not benefit from assessment with the RDOS. We have not included patients with advanced stage amyotrophic lateral sclerosis (ALS) in either of our investigations, so the application to that population is unknown and warrants further investigation. We suspect that some of the RDOS behaviors will not be detectable in ALS, such as accessory muscle use and paradoxical breathing pattern.

Patient assessment during the withdrawal of mechanical ventilation may be enhanced with the use of the RDOS. In a systematic review of ventilator withdrawal evidence most investigators did not report how patient distress was measured and when reported non-specific indicators were used such as "signs of dyspnea," "anxiety," "agitation," and "distress."[8] Similarly, the RDOS may be useful in ascertaining which patients may benefit from the application of oxygen at the end of life. Oxygen administered via face mask or nasal cannula may reduce dyspnea and is often routinely applied to patients when they are approaching death regardless of the patient's ability to experience or report distress and/or in the absence of behaviors that signify respiratory distress. Oxygen may, however, prolong dying without conferring comfort if the patient is not experiencing distress; additionally, oxygen administration is not without adverse effects and costs. Previous studies of the role of oxygen in advanced and terminal illness have yielded mixed results and an inability to reliably predict which patients benefit from this treatment.[22,23] No previous studies have included patients who were near death or who were unable to provide a self-report about distress.

Interrater reliability across members of the clinical team who may use the RDOS needs to be established; our perfect inter-rater reliability was achieved between nurse practitioners. Assessment with the RDOS is a registered nurse function; we do not know if the RDOS can be accurately scored by unlicensed personnel or family caregivers.

Studies about the treatment of dyspnea when patients have life-limiting illnesses are needed.[24–26] Gaps in our knowledge about treatment of the patients that are nearest to death exist because an inability to self-report dyspnea has excluded this population from studies. Yet, we found more distress in the patients who were nearest to death in our sample as reported by other investigators[27] supporting our call for more investigation of this vulnerable population. The RDOS is expected to serve as a research tool for measuring respiratory distress and allowing for the inclusion of cognitively impaired patients and those nearest to death in palliative care studies.

Our study was limited by completion at one institution where the instrument was originally developed and tested. Our demographic is largely African American so there were few Caucasian patients in our sample, however, we found no differences in RDOS scoring by patient race and racial characteristics were not expected to influence the variables that comprise the RDOS.

Of note, although not an aim of this study, we found a high proportion of patients with respiratory distress who had not received opioids or benzodiazepines before palliative care consultation in the face of strong evidence to support their use, particularly for morphine.[28,29] This finding supports our claim that respiratory distress may be undertreated in patients near death who are unable to self-report dyspnea. This finding further supports the need for the RDOS to guide assessment and treatment of the cognitively impaired patient.

Author Disclosure Statement

No competing financial interests exist.

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APPENDIX A. Respiratory Distress Observation Scale©

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

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Instruction for use:
1. RDOS is not a substitute for patient self-report if able.
2. RDOS is an adult assessment tool.
3. RDOS cannot be used when the patient is paralyzed with a neuromuscular blocking agent.
4. Count respiratory and heart rates for one-minute; auscultate if necessary.
5. Grunting may be audible with intubated patients on auscultation.
6. Fearful facial expressions: