Published in final edited form as:

Palliat Med. 2015 May ; 29(5): 436–442. doi:10.1177/0269216314564238.

Intensity cut-points for the Respiratory Distress Observation Scale

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Abstract

Background—The Respiratory Distress Observation Scale[®] is an innovative solution to assessment when a dyspnea report cannot be elicited. The Respiratory Distress Observation Scale has acceptable reliability and validity psychometrics.

Aim—To identify distress-intensity cut-points of the Respiratory Distress Observation Scale.

Design—Receiver operating characteristic curve analysis was conducted with inpatients stratified by four levels of respiratory distress—none, mild, moderate, or severe. Patients provided three self-report measures of dyspnea: dichotomous (yes/no); a ranking of none, mild, moderate, or severe; and a numerical rating scale. Respiratory distress was assessed using the Respiratory Distress Observation Scale instrument.

Setting/participants—Participants were 136 adult inpatients, mean age 61.8 years (standard deviation = 13.18 years), 89.7% African American, and 56.6% female, who were recruited from an urban, tertiary care hospital in the Midwest of the United States.

Results—In all, 47% ($n = 64$) self-reported dyspnea (yes/no). Ranking was distributed as follows: none = 36, mild = 35, moderate = 40, and severe = 25. Numerical rating scale scores ranged from 0 to 10, mean = 4.99 (standard deviation = 2.9). Respiratory Distress Observation Scale scores ranged from 0 to 7, median (interquartile range) = 2 (1–3). Receiver operating characteristic curve analysis—determined Respiratory Distress Observation Scale score of 0–2 suggests little or no respiratory distress; score ≥ 3 signified moderate to severe distress.

Conclusion—A Respiratory Distress Observation Scale score ≥ 3 signifies a patient's need for palliation of respiratory distress. An end-point for identifying responsiveness to treatment, in other words, respiratory comfort, is Respiratory Distress Observation Scale <3 . Because patients with imminent respiratory failure, as typified by dying patients, were not represented yielding lower than expected Respiratory Distress Observation Scale scores, further substantiation is needed to determine moderate or severe cut-points.

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Declaration of conflicting interests

The authors declare that there is no conflict of interest.

Keywords

Dyspnea; respiratory insufficiency; symptom assessment; psychometrics

Background

Dyspnea, akin to suffocation, escalates in the interval before death;¹ at the same time, patients begin to experience difficulties with providing a symptom self-report.² Although ability to report, qualify, or quantify distress is lost, the ability to *experience* unrelieved dyspnea persists until death. As a result, cognitively impaired patients near death are vulnerable to under-recognition and under-treatment of respiratory distress (RD).³ Alternatively, when a distress report cannot be elicited, patients may be over-treated, leading to over-sedation and unintentional hastening of death.

The Respiratory Distress Observation Scale[®] (RDOS) was developed in an observation of mechanically ventilated patients undergoing a failed ventilator weaning trial.⁴ The instrument is grounded in neurobehavioral physiology^{5,6} and has undergone psychometric testing, including construct, convergent, and discriminant validity, in patients with advanced lung disease and in terminally ill patients at risk for dyspnea.^{7,8} The RDOS has been used as the dependent measure in studies of oxygen benefit at near death and death rattle–associated distress; a 2-point change in RDOS score signified a meaningful change in patient condition in these previous studies.^{9,10} It is the only known tool for assessing intensity and distress in patients unable to report dyspnea. Although the RDOS has demonstrated acceptable psychometric properties when administered by nurses, additional testing was needed to determine what particular RDOS scores correspond to mild, moderate, or severe distress. Treatment regimens for symptom distress often use cut-point parameters, such as mild, moderate, or severe; therefore, establishing intensity cut-points is expected to give the RDOS increased clinical utility. No distress and severe distress can be identified by RDOS scores at either end of the 17-point scale (Table 1), but the cut-points signifying mild or moderate distress are unknown. The aim of this study was to identify distress-intensity cut-points of the RDOS.

Methods

Design

Receiver operating characteristic (ROC) curve analysis was carried out among patients stratified by four self-reported levels of RD: none, mild, moderate, and severe. These patients were cognitively intact surrogates for the intended RDOS population who are individuals unable to self-report and may be dying. Because this was an instrument evaluation study, it was important that an adequate number of patients were represented at all levels of RD. Therefore, patients were stratified by their self-reported dyspnea with continued recruitment until we had at least 25 at each of the four patient-reported levels. Two additional self-report measures of dyspnea were obtained. RD was determined by the RDOS. Approval to conduct the study was granted by the Institutional Review Board at

Wayne State University (IRB No. 115011B3E), with approval to waive the participants' written informed consent.

Participants

We recruited adult inpatients from an urban, tertiary care hospital in the Midwest of the United States between May 2012 and September 2013. Inclusion criteria were as follows: (1) at risk for dyspnea with one or more of the following diagnoses: lung cancer, heart failure, chronic obstructive pulmonary disease (COPD), or pneumonia; (2) spoke English; (3) were conscious and cognitively intact or with mild to moderate cognitive impairment. The RDOS is not valid in children or neonates and if the patient is quadriplegic or has bulbar amyotrophic lateral sclerosis;⁸ thus, we excluded patients with any of those conditions.

Sample size estimation

We expected, a priori, that 25 patients in each of the four strata defined by intensity would yield precision for our purposes since it would allow estimation of the area under the ROC curve (AUC) with a standard error not exceeding 4.9%.¹¹ With a sample size of 100, it would be possible with 80% power to reject a null-hypothesis of AUC = 0.5, assuming a true AUC of 0.67. As the actual study was larger than expected ($n = 136$), its precision and power exceeded these.

Measures

Patient demographics included patient age, gender, ethnicity, and primary diagnosis. Measurement of RD employed the RDOS—an 8-item ordinal scale to measure the presence and intensity of RD (Table 1). For each variable, 0–2 points are assigned and the points are summed. Scores range from 0 to 16, with higher scores signifying a greater intensity of RD.⁸

Patients' self-report of RD was elicited using three verbal report scales. The first was a dichotomous yes/no shortness of breath (SOB) response to the query “Are you short of breath?” The second was the ordinal numerical rating scale (NRS); patients were asked to assign a number between 0 and 10 to describe breathing distress, with 0 representing “none” and 10 signifying “severe distress.” Finally, the RD ordinal ranking scale (RD rank) was applied for sample stratification. The patient was asked to assign one of the following descriptors to distress currently experienced: none, mild, moderate, or severe.

Patient cognitive state was measured at baseline with the Cognitive State Categorization Tool (CSCT). The CSCT is an investigator-developed tool derived from the cognitive tests from the Confusion Assessment Method for the Intensive Care Unit (CAM-ICU)¹² that measure attention, concentration, memory, recall, and organized thinking. We combined these CAM-ICU features to quantify patient cognitive performance and to categorize cognitive state. CSCT scores range from 0 to 28 points. Scores between 22 and 28 points signify intact cognition, 15–21 indicate mild impairment, 8–14 represent moderate impairment, and <8 signify severe impairment. Construct validity of the CSCT with consciousness (Reaction Level Scale (RLS-85)) was established in a prior investigation ($r_s = -0.66, p < 0.01$).⁸ Patients with CSCT <12 were excluded from the study because in a previous investigation patients at levels <12 were unable to quantify their RD.²

Procedure

The Registered Nurse research assistant (RA) had RDOS training that entailed classroom instruction on RDOS variables (20 min) followed by hospital rounds and RDOS practice scoring with patients until an inter-class correlation of >0.90 between the research nurse and the principal investigator (PI) was achieved. The RA made daily hospital rounds and identified potential study participants using the admitting diagnosis. The study was explained to eligible patients, and assent to participate was established. Testing cognitive state with CSCT was completed. Next, the RA observed and scored the RDOS prior to seeking patient reports. Patients were asked to respond about current dyspnea using the question “Are you short of breath?” Patients were then asked to “Give a number from 0 to 10 that describes your current breathing distress, 0 means none and 10 means severe distress.” Finally, the patient was asked to “Give a word that describes your current breathing distress, is it none, mild, moderate, or severe.” Some patients wanted to describe to the RA how difficult their breathing *had been* on presentation to the Emergency Department and hospital admission. The RA was trained to re-orient the patient to respond about “current” SOB and distress.

Data analyses

Spearman’s rank-order correlations were used to examine the association among the ordinal self-report measures of RD and the correlation of self-report measures with the RDOS scale. Box and whisker plots were used to examine RDOS median and interquartile range (IQR) as a function of self-report ratings. ROC curve analysis was used to identify distress-intensity cut-points of the RDOS. Cut-points established with ROC are optimal in the sense of minimizing both kinds of errors that occur in a binary decision. For each of the category boundaries of the RD rank variable, we determined RDOS sensitivity, specificity, and AUC. Thus, the RD rank category boundaries were in the formal role of the disease category when ROC is used to determine cut-points of a diagnostic test. We used the empirical (nonparametric) approach to ROC curve analysis because it does not make normality assumptions.¹³ This approach is generally recommended when the test score distributions within disease categories (RD rank category boundaries) are not known. The cut-point with highest sensitivity and specificity was identified as the most clinically meaningful RDOS score to distinguish distress from little or no distress. IBM SPSS 21 was used for data management and analysis.

Results

At the study site, 1159 inpatients at risk for dyspnea were admitted to the hospital during the study interval, and 155 were approached for inclusion. In all, 19 patients refused participation because they were too sick ($n = 7$), did not speak English ($n = 1$), or gave no reason ($n = 11$). Patient characteristics are summarized in Table 2. Participants were 136 adult inpatients, mean age 61.8 years (standard deviation (SD) = 13.18 years), 90% African American, and 57% female. Patients’ diagnoses were heart failure (38%), COPD (24%), pneumonia (23%), and lung cancer (2%). These categories included dual diagnoses (17%); the most common dual diagnosis was COPD and heart failure (7%). The stratification

resulted in the following distribution: *none* = 36, *mild* = 35, *moderate* = 40, and *severe* = 25. Enrollment to reach adequate stratification took longest in the severe distress category.

In all, 64 patients (47%) self-reported dyspnea with the SOB; as stated previously, the RD rank was distributed as follows: *none* = 36, *mild* = 35, *moderate* = 40, and *severe* = 25. NRS scores ranged from 0 to 10, mean = 4.99 (SD = 2.9). These self-report distributions reflect the study design stratification goals. As expected, these measures were correlated: yes/no with ranking = 0.61, yes/no with NRS = 0.53; and NRS with ranking = 0.68.

RDOS scores ranged from 0 to 7, median = 2 (IQR = 1–3). The RDOS score was significantly correlated with each of the self-report measures as follows: 0.37, 0.53, and 0.44 for dichotomous yes/no (SOB), RD ranking, and NRS, respectively (all $p < 0.01$).

The distributions of RDOS scores within categories of the self-report variables are shown in Figure 1. The plots ((a)–(c)) show that the RDOS median (dark line) for each self-report measure increased with increased intensity of RD rating. The IQR (shaded box), on the other hand, shifts across RD ratings. For example, RDOS scores for the mild ranking (panel B) are all below the median; for moderate ranking, they are all above median. This kind of shifting indicates differences in skewness across category boundaries.

The results of the ROC curve analysis are shown in Table 3 and Figure 2. The AUC was significant and greater than 0.75 for each category boundary, indicating fair to good discriminability of the RDOS with respect to patient self-reported severity of dyspnea. The AUC was significantly greater than 0.5 with an estimated value just above 0.75 in all three instances, but confidence intervals suggested true values as low as 0.67. An AUC of 0.795 for the none/mild versus moderate/severe cut-point means a 79.5% likelihood that a randomly selected person in the study population with moderate to severe dyspnea will receive an RDOS score higher than a randomly selected person with no to mild dyspnea. No lower bound confidence intervals reached 0.5 which would indicate chance discrimination. An RDOS score of 3 or greater had sensitivity of 0.68 and specificity of 0.77 of distinguishing between perceived RD that was labeled moderate to severe versus none or mild. The positive predictive value = 0.85 and negative predictive value = 0.61.

Some patients provided seemingly inconsistent reports, for example, a “no” response to “are you short of breath” with an NRS of 5 and RD rank of moderate. Of 72 patients who reported “no” to “are you short of breath,” 38 (53%) reported distress greater than “none” ($\chi^2 = 52.3$, $p < 0.01$; see Table 4).

Discussion

In accordance with our study aim, we identified significant differences in RDOS scores when comparing those with little or no self-reported RD to those with moderate or severe distress. We determined that a reasonable cut-point for assigning clinical meaning is an RDOS score of 3. Scores of 3 or more signify RD, and the higher scores represent worsening distress. When scores of 0–2 are measured, it is likely that the patient is experiencing little or no RD.

Although the intended population for RDOS is cognitively impaired patients unable to report RD, in order to establish RD cut-points, it was necessary to use cognitively intact patients. As an alternative, we could have used brain imaging with cognitively impaired or unconscious patients; RD neural areas/centers have been identified.^{5,14–16} Future research could investigate how brain area activation corresponds with reliable behavioral measures.¹⁷ However, this alternative would be more expensive and not necessarily a better benchmark because the gold standard in dyspnea assessment continues to be patient self-report.¹⁸

Our study was limited by the over-representation of patients who were recovering from their acute condition or exacerbation and whose RD was minimal or absent as evident by the lower-than-expected RDOS scores. It was necessary to enroll patients who could provide the self-report measures we sought, which meant that no patients in our sample were experiencing imminent, naturally occurring respiratory failure as typified by the patient who is near death and who is generally unable to give a dyspnea self-report.² Hui et al.¹⁹ similarly found low RDOS scores among a sample of patients with cancer who were able to give a dyspnea self-report; patients who were unstable or delirious were excluded, as with the present sample. In our previous studies, patients who were dying had RDOS scores ranging 0–14⁸ and 0–12.⁹ Using stable, cognitively intact patients who can self-report as proxies for the intended population of patients who cannot self-report poses an unavoidable paradox because other factors may enter into the self-report. Thus, external validation of the cut-point with patients who are dying, experiencing naturally occurring respiratory insufficiency, and unable to self-report is indicated.

Another limitation was the inability to validate the RDOS scores obtained by a single data collector. Modest funding did not permit a more rigorous design such as having two different nurses measure the RDOS or videotaping the patient, which would have afforded external validation.

In the clinical experience of the study PI, some patients seem to be motivated to over-report distress intensity at times due to (1) lack of experience with the symptom and a predisposition to report in the middle ranges leading to response bias, (2) reporting based on emotional memory of worse experience, and (3) secondary gains. We found examples of lack of dyspnea experience and emotional memory in our sample. We included patients at risk for dyspnea who had pneumonia; these patients were unlikely to have had a previous dyspnea experience, and they reported in the middle ranges of the NRS and gave a moderate categorization. We also found patients who wanted to give the RA a high NRS to represent how they felt in the emergency department at a time previous to study testing. Several patients had to be coached to report about “current” RD.

Substantiating the RDOS cut-points identified in this investigation is indicated, given the lower-than-expected RDOS scores and the challenges of using a relatively stable, cognitively intact population as proxies for the intended population of cognitively impaired dying patients. A subsequent design using RD estimates from expert examiners such as palliative care nurse practitioners compared to RDOS scores may yield external validation of 3 as a cut-point and afford identification of an RDOS cut-point to distinguish moderate

and severe levels of distress. These results support an RDOS cut-point of 3 to distinguish need for palliation with higher scores signifying worsening RD.

Acknowledgements

We are grateful to the Research Nurses at the study site (Emily Dove-Medows, Pamela Mayes, and Tameaka Roundtree) for their conscientious attention to enrollment and data collection.

Funding

This work was supported by the National Institute of Health/National Institute of Nursing Research, grant R03NR012820.

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What is already known about the topic?

- The Respiratory Distress Observation Scale (RDOS) is the only known tool for assessing respiratory distress when a patient is unable to give a dyspnea self-report.
- Inter-rater and scale reliability and construct, convergent, and discriminant validity have been established previously.
- Clinician users have requested the identification of RDOS intensity cut-points to guide palliative treatment.

What this paper adds?

- RDOS scores <3 signify little or no patient respiratory distress.
- RDOS ≥ 3 represents a need for palliation of respiratory distress.
- Treatment end-point is RDOS <3 .

Implications for practice, theory, or policy

- RDOS is a valid, reliable tool for assessing respiratory distress when the patient is unable to report dyspnea.
- The additional psychometrics to identify intensity cut-points enhance the clinical and research utility of the RDOS.

Figure 1.
Distributions of Respiratory Distress Observation Scale scores within categories of the self-report variables.

Figure 2.
Results of the receiver operating characteristic curve analysis.

Table 1Respiratory Distress Observation Scale[®] (Margaret L. Campbell, PhD, RN, 19 February 2009).

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: non-purposeful 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				

Table 2

Patient characteristics.

Variable	N = 136
Age (years), mean (SD)	61.8 (13.18)
Gender (%)	
Men	59 (43)
Women	77 (57)
Ethnicity (%)	
Caucasian	14 (10)
African American	122 (90)
Diagnoses (%)	
Heart failure	52 (38)
COPD	32 (24)
Pneumonia	31 (23)
COPD + heart failure	9 (7)
COPD + pneumonia	4 (3)
Lung cancer	3 (2)
Heart failure + pneumonia	3 (2)
Lung cancer + pneumonia	1 (<1)
Lung cancer + COPD	1 (<1)
Cognitive state (%)	
Intact	130 (96)
Mild Impairment	6 (4)
RDOS, median (IQR)	2 (1–3)
Are you short of breath? (%)	
Yes	64 (47)
No	72 (53)
Numerical rating mean (%)	4.99 (2.9)
Respiratory distress ranking (%)	
None	36 (26)
Mild	35 (26)
Moderate	40 (29)
Severe	25 (18)

SD: standard deviation; COPD: chronic obstructive pulmonary disease; RDOS: Respiratory Distress Observation Scale; IQR: interquartile range.

Table 3

ROC results for each category boundary of RD rank.

Category boundary	RDOS cut-point	Sensitivity	Specificity	AUC	<i>p</i>	Confidence interval	
						Lower	Upper
None versus any	2	0.75	0.61	0.759	<0.001	0.673	0.845
None/mild versus moderate/severe ^a	3	0.68	0.77	0.795	<0.001	0.690	0.900
None/mild/moderate versus severe	4	0.35	0.94	0.758	<0.001	0.677	0.839

ROC: receiver operating characteristic; RD: respiratory distress; AUC: area under the ROC curve.

^aPositive predictive value = 0.85; negative predictive value = 0.61.

Table 4

Agreement between patient reporting and RDOS scoring.

		<u>SOB report</u>			% Agreement	<u>NRS</u>			% Agreement
		No	Yes	Total		6	7+	Total	
RDOS	0-2	55	16	71	77.5%	53	18	71	74.6%
	3	17	48	65	73.8%	15	50	65	76.9%

SOB: shortness of breath; NRS: numerical rating scale; RDOS: Respiratory Distress Observation Scale.