RDOS-Family: A Guided Learning Tool for Layperson Assessment of Respiratory Distress

Margaret L. Campbell, PhD, RN, FPCN and Thomas N. Templin, PhD

Dear Editor:

The authors have developed and completed pilot testing of a tool for family assessment of respiratory distress. The Respiratory Distress Observation Scale[®] (RDOS) was developed to guide *clinician* assessment when a patient's dyspnea self-report could not be elicited. Acceptable reliability and validity psychometrics are reported elsewhere.¹ RDOS-Family was developed for use in the home palliative care/hospice setting to guide *family* caregiving.

Family-caregivers (FC) receive variable amounts of training from hospice personnel regarding symptom management, yet they have the around-the-clock responsibility of ensuring patient comfort at the end of life. Patient and family outcomes are dependent on the quality of FC ability to accurately assess the patient and provide the relevant interventions. Increased feelings of guilt, despair, and anger over the suffering and symptoms of their loved ones because the FC felt responsible for the worsening symptoms have been identified.² Negative caregiver outcomes have been reported such as depression, fatigue, and mood disturbance.^{3,4} In addition, hospice diagnoses of heart and lung disease, with dyspnea as the most prevalent, distressing symptom, are associated with acute hospital admissions and a nonpreferred site of death.⁵

We've completed pilot testing of the RDOS-Family with a convenience sample of family caregivers of patients hospitalized with conditions that produce dyspnea. Family were instructed on RDOS-Family use by a registered nurse research assistant (RA). Subsequently, the family and the RA simultaneously and independently scored the patient. We enrolled 52 adult men and women (67%), mostly African-American (98%), family caregivers of patients admitted to an urban tertiary hospital. Most family caregivers were high school graduates (67%). Ages ranged 24 to 78 years (mean = 51). A minority (27%) had formal caregiving experience as certified nurses' aides (see Table 1).

RDOS-Family training was completed in about 20 minutes per person. There were no significant differences in total RDOS scores between RA and family ($t = -0.96, p = 0.34$). A strong significant intraclass correlation was found ($r_{ic} = 0.71, p < 0.01$). Family underreported heart and respiratory rates, accessory muscle use ($p < 0.01$), and paradoxical

breathing. Families with more caregiving experience were more likely to overestimate than underestimate patient distress ($p < 0.05$).

Lay family members of patients with dyspnea can learn to use a structured patient assessment, which may increase

TABLE 1. FAMILY CHARACTERISTICS

Variable	N	%
Gender		
Male	17	32.7
Female	35	67.3
Ethnicity		
Black	51	98.0
White	1	2.0
Relationship to patient		
Daughter	13	25.0
Spouse	9	17.3
Niece/nephew/cousin	7	13.5
Sister	6	11.5
Son	3	5.8
Brother	3	5.8
Grandson	2	3.8
Mother	2	3.8
Education		
High school	31	67.4
Grade 9	5	10.9
Associate degree	4	8.7
Bachelor's degree	3	6.5
Master's degree	2	4.3
Grade 6	1	2.2
Professional caregiving role		
None	37	71.2
Certified nurse's aide	14	26.9
LPN	1	1.9
<i>Range</i>	<i>Mean</i>	<i>Standard deviation</i>
Age (years)		
24–78	50.96	14.4
Caregiving experience (years)		
0–40	4.2	7.2

family confidence with dyspnea caregiving. Items that require more nursing experience to accurately judge appear to be underreported by family members. Subsequent family training will warrant more attention given to these RDOS variables. This pilot with relatively stable patients with mild to moderate dyspnea established the feasibility of nurse training of laypersons and an acceptable intraclass correlation. The RDOS-Family is intended to bridge the gap between family caregiver knowledge and experience and the need to assess and manage symptoms. Further testing in home hospice care is planned to determine if the FC of patients with imminent respiratory failure and heightened family emotionality will derive positive patient and family outcomes from using the RDOS-Family as a guided learning tool.

References

1. Campbell ML, Templin T, Walch J: A Respiratory Distress Observation Scale for patients unable to self-report dyspnea. *J Palliat Med* 2010;13:285–290.
2. Bialon LN, Coke S: A study on caregiver burden: Stressors, challenges, and possible solutions. *Am J Hosp Palliat Care* 2012;29:210–218.
3. Oliver DP, Wittenberg-Lyles E, Washington K, et al.: Hospice caregivers' experiences with pain management: "I'm Not a Doctor, and I Don't Know if I Helped Her Go Faster or Slower." *J Pain Symptom Manage* 2013;46:846–858.
4. Malik FA, Gysels M, Higginson IJ: Living with breathlessness: A survey of caregivers of breathless patients with lung cancer or heart failure. *Palliat Med* 2013;27:647–656.
5. Woolley DC, Old JL, Zackula RE, Davis N: Acute hospital admissions of hospice patients. *J Palliat Med* 2013;16:1515–1522.

Address correspondence to:
Margaret L. Campbell, PhD, RN, FPCN
Wayne State University College of Nursing
Office of Health Research
5557 Cass Avenue
Detroit, MI 48202
E-mail: m.campbell@wayne.edu