

## Palliative Care and Management of Dyspnea at End of Life

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### Educational Objectives:

1. Review prognostic tools for severe COPD
2. List three pharmacological and non-pharmacological palliative treatments for dyspnea
3. Review hospice eligibility guidelines for COPD

### Scenario:

You are meeting Mr. Edwards for the first time in the outpatient pulmonary clinic for a new patient appointment for shortness of breath. He is a 70 y/o male with severe COPD (FEV1 40%), diabetes, hypertension, and h/o CVA with residual right-sided weakness. He has had two hospitalizations in the past year for COPD exacerbations treated with IV steroids and has never been intubated. He is ambulatory with a cane due to arthritis and can walk one block on flat ground before becoming dyspneic. He is independent in his ADLs and still able to enjoy his hobbies, including fishing and bowling. His weight has been stable, and his BMI is 22. He is accompanied by his wife. Despite being on ICS, LABA, and LAM, he is experiencing an ongoing decline in functional capacity and wonders if there is any way to improve his dyspnea.

### Question 1: What tools would you use to prognosticate Mr. Edward's COPD?

Because prognostication is challenging in COPD, it can be overlooked in outpatient clinics. Objective prognostication is necessary to allow clinicians to introduce palliative care at the appropriate time for COPD patients. The BODE Index incorporates the MMRC score and is a validated prognostication tool in COPD<sup>(1)</sup>. The chart below shows the MMRC dyspnea scale, which you need to subjectively obtain from Mr. Edwards to calculate his Bode Index.

### MMRC Dyspnea Scale (Modified Medical Research Council)<sup>2</sup>

Grade	Description of Breathlessness
0	I only get breathless with strenuous exercise.
1	I get short of breath when hurrying on level ground or walking up a slight hill.
2	On level ground, I walk slower than people of the same age because of breathlessness, or have to stop for breath when walking at my own pace.
3	I stop for breath after walking about 100 yards or after a few minutes on level ground.
4	I am too breathless to leave the house or I am breathless when dressing

## BODE Index<sup>1</sup>

- The multidimensional BODE index (B = BMI, O = degree of airflow obstruction, D = dyspnea, E = exercise capacity) is a well-validated tool that provides prognostic information and predicts survival over 1-4 years. It does not help with predicting 6-month survival. Higher scores indicate a greater risk of death.
  - The Spanish trial that validated the BODE Index included patients with > 20 pack-year smoking history with an FVC < 0.7 L. They excluded patients with other life-limiting diseases.
- Determining variables for index
  - The study evaluated the following variables: age, sex, pack-years of smoking, FVC, FEV1 (absolute value and percent predicted), 6MWT, MMRC, BMI, functional residual capacity, inspiratory capacity, HCT, albumin, Charlson index (determine the degree of comorbidity)
  - Each variable was independently looked at to determine the association of one-year mortality.
- The combination of values in the BODE index had the strongest association with one-year mortality.
  - The hazard ratio for death from respiratory causes per one-point increase in the BODE score was 1.62 (95 CI 1.48 to 1.77)

### BODE INDEX

Variable	Points			
	0	1	2	3
FEV1 (% predicted)	≥65	50-64	36-49	≤35
Distance walked in 6 min (meters)	>350	250-349	150-249	≤149
MMRC dyspnea scale	0-1	2	3	4
Body-mass index (BMI)	>21	≤21		

BODE Index Score	One-year mortality	Two-year mortality	52-month mortality
0-2	2%	6%	19%
3-4	2%	8%	32%
4-6	2%	14%	40%
7-10	5%	31%	80%

**Tables adapted from** Celli BR, Cote CG, Marin JM, et al. The body-mass index, airflow obstruction, dyspnea, and exercise capacity index in chronic obstructive pulmonary disease. *N Eng J Med.* 2004; 350(10): 1005-12.

*Mr. Edwards earns 2 points for his FEV1 of 40% and 2 points for Grade 3 dyspnea on the mMRC dyspnea scale. Depending on his 6MWT, his calculated BODE Index would be 4 or 5, giving him a 40% mortality risk in the next 52 months.*

### Question 2: Given his BODE index, what should be your next steps in the outpatient visit?

In addition to ordering a 6-minute walk test to assess for oxygenation needs and formally completing the BODE index, and discussing referral to pulmonary rehab, it would be important to discuss advanced care planning with Mr. Edwards. Each state has different documents that can be completed, and it is important to encourage all patients to complete appropriate documents. As a pulmonologist, you can relay the prognosis of his COPD to him and his family and answer questions they may have about advanced care planning. This can be an adjunct to conversations with his primary spiritual support team (if any) and his family.

- Advanced care planning
  - Advanced directive
    - Living Will
      - Helps guide end-of-life preferences
      - Not legally binding
    - Health care agent (also known as a Proxy):
      - Patient appoints someone to make decisions about their healthcare if they cannot make their own
      - If no one has been previously appointed, each state has specific processes to follow to appoint a proxy
  - POLST = Physician Orders for Life-Sustaining Treatment
    - A standardized, portable, brightly colored single page that documents the conversation between the patient, his or her medical POA, and a physician
    - Provides medical orders for current treatment to guide EMS and inpatient treatment teams
    - Only appropriate for patients with serious illness
    - Available in 26 states
    - For more information, visit [www.polst.org](http://www.polst.org)

**Scenario:**

You complete a POLST with Mr. Edwards, which specifies that he would not want to be intubated or resuscitated. Mr. Edwards agrees to pursue pulmonary rehab, which he does find very helpful in teaching him pacing and decreasing his dyspnea. His exercise tolerance and mood improve significantly. He has been able to take two fishing trips with his friends.

Over the next two years, however, Mr. Edwards continues to decline. He slowly starts to require assistance with all of his ADLs and can no longer participate in the hobbies that he loves because of persistent shortness of breath. He can no longer climb the eight stairs to his bedroom without becoming dyspneic, making him increasingly anxious. He asks for medication to help with his dyspnea.

**Question 3: What palliative pharmacological and non-pharmacological options are available for the patient’s persistent dyspnea?**

- There are three distinct sensations of dyspnea: air hunger, work/effort, chest tightness
- Dyspnea ladder steps in management:
  - Optimize bronchodilators +/- supplemental oxygen
  - Non-pharmacological techniques (pursed lip breathing, fan relaxation techniques, paced activities)
  - Palliative pharmacological measures (opioids +/- anxiolytics)

Intervention	Evidence	Conclusion
Opioids	Cochrane of 18 studies <sup>6</sup> Small RCT of nebulized morphine <sup>7</sup>	<ul style="list-style-type: none"> <li>• Positive benefit: IV/PO opioids</li> <li>• No benefit: Nebulized opioids</li> </ul>
Benzodiazepines	Cochrane of 7 studies <sup>8</sup>	<ul style="list-style-type: none"> <li>• Slight but non-significant trend towards beneficial effect</li> </ul>
Pulmonary rehabilitation	Cochrane of 65 studies <sup>9</sup>	<ul style="list-style-type: none"> <li>• Positive benefit</li> </ul>
Non-pharmacologic	Cochrane of 47 studies <sup>10</sup>	<ul style="list-style-type: none"> <li>• High Evidence: chest wall vibration, neuro-electrical muscle stimulation</li> <li>• Moderate evidence: walking aids, breathing training</li> <li>• Low evidence: acupuncture/acupressure</li> <li>• No evidence: Music</li> <li>• Insufficient: relaxation, fan, counseling</li> </ul>

## Recommendations (adapted from relevant Cochrane reviews listed above by category)

- Pharmacological management
  - IV/PO opioids
    - All opioids (not just morphine) are effective in treating dyspnea
    - Unclear how opioids exert effect
    - Possible explanations include following:
      - Alter central perception of breathlessness
      - May be useful because they reduce effect of CO<sub>2</sub> and O<sub>2</sub> on ventilation
      - May reduce oxygen consumption at rest and during exercise
  - Benzodiazepines can be used as second-line or third-line treatment
- Non-pharmacological
  - Breathing training
    - Pursed lip breathing decreases respiratory rate and increases vital capacity
  - Fans
    - Adequately powered cross-over trial showed significant improvement
    - Flow of air to face, nasal mucosa, pharynx may alter ventilation but exact mechanism is unknown
  - Pulmonary rehabilitation
    - Deconditioning and peripheral muscle weakness are known to play major role in breathlessness in COPD
    - Therefore, exercise training is key component of pulmonary rehab programs
    - Exercise training can be done with or without educational and/or psychological support
    - Programs are usually 4 weeks
    - Clinically significant improvements in dyspnea and fatigue
    - Improves emotional function by enhancing a sense of control that patients have over their condition
  - Neuromuscular Electrical Stimulation (NMES) of leg muscles
    - Studied only in COPD patients
    - Effective alternative for patients who cannot exercise
    - High strength of evidence that over 4-6 weeks, NMES helps to relieve breathlessness by improving muscle strength
    - Improved performance in daily tasks
    - Possible in-home care setting
    - Earlier and regular treatments are recommended
  - Chest wall vibration
    - Tested in COPD and motor neuron disease
    - Activation of muscle spindles in intercostal muscles with consecutive modification of respiratory sensations
    - Not practical at home
  - Walking aids (walking aids, rollator, wheeled walker)
    - All studied in COPD participants
    - Improved breathlessness is probably due to increased maximal voluntary ventilation by bracing arms on a walking aid and adopting a lean-forward position.
    - Stabilizing the ribcage may improve accessory muscle function and allow muscles to be engaged in respiratory activities.

### Pursed lip breathing technique

1. Relax your neck and shoulder muscles. *(figure to right)*
2. Breathe in (inhale) slowly through your nose for two counts, keeping your mouth closed. Don't take a deep breath; a normal breath will do. It may help to count to yourself: inhale, one, two. *(figure to right)*



3. Pucker or "purse" your lips as if you were going to whistle or gently flicker the flame of candle. *(figure to left)*



4. Breathe out (exhale) slowly and gently through your pursed lips while counting to four. It may help to count to yourself: exhale, one, two, three, four. *(figure to right)*



With regular practice, this technique will seem natural to you.

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### Scenario:

You recommend starting low-dose morphine for dyspnea. You also train him in pursed lip breathing.

Six months later, Mr. Edwards is hospitalized for a severe COPD exacerbation. Based on his wishes, he is not intubated but is placed on BiPAP. He does not improve, and after discussion with his family, they decide to transition him to comfort care and enroll in hospice. He is requiring IV morphine intermittently for dyspnea.

### Question 4: Is this patient appropriate for home palliative care or home hospice? Why or why not?

- A palliative home care program (if available) is defined as:
  - Home-based nursing program with a specialized focus on symptom management
    - No standardization in terms of what services are provided.

Guidelines for hospice:

#### National Hospice and Palliative Care Organization (NHPCO) Guidelines:<sup>3</sup>

- The patient has severe chronic lung disease as documented by the following:
  - Disabling dyspnea at rest
  - Poor response to bronchodilators
  - Decreased functional capacity (e.g., bed to chair existence)
- Progression of disease as evidenced by the recent history of increased visits to the MD office, emergency room, and/or hospitalizations for pulmonary infections/respiratory failure
- Documentation within the past 3 months of one of the following:
  - Hypoxemia at rest
  - Hypercapnia ( $pCO_2 > 50$  mm Hg)
- Supporting evidence for hospice eligibility:
  - Cor pulmonale secondary to pulmonary disease
  - Unintentional weight loss ( $>10\%$ ) over the past 6 months
  - Baseline heart rate  $> 100$  bpm
- Limited role in predicting mortality - When using the above factors and clinical progression of the disease, 50% were alive at 6 months.<sup>4</sup>

- Inpatient hospice
  - General inpatient care is allowed when the patient’s medical condition warrants a short-term inpatient stay for pain control or acute or chronic symptom management that cannot feasibly be provided in other settings.
  
- Home Hospice
  - Patients are eligible for home hospice when the expected prognosis is 6 months or less if the terminal illness runs its natural course.

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## Pre/Post-Test Questions:

A 76-year-old male with a history of severe COPD presents to your office for ongoing management. You are concerned because you have noticed a continued decline in his functional status over time. He has also been hospitalized 4 times in the past year for COPD exacerbations. His FEV1 on his most recent PFTs was 37% predicted, and his DLCO was 34%. He gets short of breath while walking about 100 yards on flat ground. His last 6MWT revealed a walk distance of 200 feet. He does not currently require home oxygen. You notice that he has lost 15 lbs in the last year (about 6% of his total body weight), and his BMI is now 22. He asks you what his prognosis is, and thus, you decide to calculate his BODE index score.

1. Which of the following is NOT used to calculate the BODE index score?
  - a. FEV1
  - b. DLCO
  - c. 6MWT distance
  - d. BMI
  - e. Need for supplemental oxygen
2. Which of the following is reflective of this patient's BODE index score?
  - a. 5
  - b. 6
  - c. 7
  - d. 8
3. The same patient above notes continues significant dyspnea in spite of maximal inhaled therapies with fluticasone-salmeterol and tiotropium. You are contemplating additional strategies for treating his significant dyspnea to help improve his comfort and quality of life. Which of the following strategies has not proven to be beneficial in the treatment of dyspnea based on prior research?
  - a. Nebulized opiates
  - b. Chest wall vibration
  - c. Oral opiates
  - d. Benzodiazepines
  - e. Neuromuscular Electrical Stimulation of the lower extremities