**End of Life Care for the Pulmonary Patient Balancing Compassion with Evidence Based Medicine in the Era of COVID-19**

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**Case**

Patient is a 77 yr old F that presents for follow-up in clinic

- COPD requiring 2LPM continuous
- Independent
- Progressive dyspnea over last 3 yrs
- 4 admissions in the last 1 year
- Triple inhaler therapy, roflumilast
- CT chest with diffuse emphysematous changes

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**Doctor what can I do to improve my quality of life?**

- Pulmonary Rehab?
- More supplemental O2?
- Inhaler teaching?
- LVRS?
- Transplant?

*What would you do next?*

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**Objectives**

- Understand mortality and morbidity related to advanced lung disease (ALD)
- Appreciate how end of life (EOL) discussions are currently taking place and utilize key clinical clues to help facilitate these discussions
- Recognize common symptoms in ALD and be able to apply basic treatment strategies
- Identify when patients may benefit from hospice services
- Correlate learning points to current COVID-19 pandemic and be able to implement skills with broader population
Background

- 65 million people have moderate to severe COPD worldwide
- 3 million people died of COPD worldwide in 2005
- United States Data from 2017:

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>No.</th>
<th>% Total Deaths</th>
<th>% Change from 2016-2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Heart Disease</td>
<td>647,457</td>
<td>23</td>
<td>-.3</td>
</tr>
<tr>
<td>2. Malignant Neoplasms</td>
<td>599,108</td>
<td>21</td>
<td>-2.1</td>
</tr>
<tr>
<td>3. Accidents (Unintentional injuries)</td>
<td>169,936</td>
<td>6</td>
<td>4.2</td>
</tr>
<tr>
<td>4. Chronic Lower Respiratory Diseases</td>
<td>160,201</td>
<td>5.5</td>
<td>0.7</td>
</tr>
<tr>
<td>5. Cerebrovascular Diseases</td>
<td>146,383</td>
<td>5</td>
<td>0.8</td>
</tr>
</tbody>
</table>

CDC FastStats Deaths and Mortality https://www.cdc.gov/nchs/fastats/deaths.htm

Background

- Dyspnea is responsible for 50% of tertiary care admissions (14)
- $50 billion in direct and indirect health care costs related to COPD alone (10)
- Significant symptom burden and disproportionately reduced QOL at end of life (1)
- COPD Pts are less likely to be referred to palliative care (1)
- People with COPD are more likely than people with lung cancer to die in a hospital (1)

End of Life Discussions in Patients with Advanced Lung Disease
**End of Life Discussions**

- 68-99% of patients with COPD and advanced chronic lung diseases were interested in discussing end of life care preferences (11)
- All of pulmonologists surveyed in a study agreed that “knowing the patient” is very important to discussing goals (3)
- Pts infrequently discussed end-of-life issues in routine outpatient clinical care (11)
- Only 2 physicians out of every 10 self-reported discussing of EOL for their patients with chronic lung disease in outpatient setting (11, 16)
- Approximately 10% of patients recall having end of life discussions in the outpatient setting (16)

**Why Do We Have These Discussions So Infrequently?**

**Perceived Barriers to Advance Care Planning in Outpatient Clinic**

<table>
<thead>
<tr>
<th>Patients Perspective</th>
<th>Physician Perspective</th>
<th>System Related</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insufficient knowledge regarding their own disease</td>
<td>Unpredictable disease course/ Difficult prognostication</td>
<td>Lack of organizational support</td>
</tr>
<tr>
<td>Insufficient knowledge of meaning of palliative med</td>
<td>Worry of “taking away hope”</td>
<td>Lack of formal training</td>
</tr>
<tr>
<td>Unawareness that palliative medicine is an option</td>
<td>Perceived hesitance of Pt to want to have these discussions</td>
<td>Time constraints</td>
</tr>
<tr>
<td></td>
<td>Time restraints</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Uncertainty on whose responsibility it is to initiate discussion</td>
<td></td>
</tr>
</tbody>
</table>


**Predicting Prognosis is Difficult**

Adapted from: Lynn J. Perspectives on care at the close of life. Serving patients who may die soon and their families: the role of hospice and other services. *JAMA 2001; 285(12)*
Predicting Prognosis is DIFFICULT

- Very few chronic lung diseases follow a predictable course
  - IPF vs. Fibrosing NSIP
  - COPD
  - CF vs Non-CF Bronchiectasis

- COPD has predictive models but they are quite limited
  - FEV1
  - BODE index
  - Progression is very “heterogeneous”

End of Life Discussions

- “Prognostic paralysis”
  - Leads to less referrals to palliative medicine
  - Pts with advanced often have limited understanding of their disease

- Perfect timing of discussions is unclear- but markers include:
  - Declining functional status
  - Declining perceived QOL by patient
  - Recurrent admissions to the hospital
  - BODE and absolute FEV1 not as helpful

BODE Index

<table>
<thead>
<tr>
<th>BMI</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥ 21</td>
<td>&lt; 21</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obstruction</td>
<td>≥ 65</td>
<td>50-64</td>
<td>36-49</td>
<td>≤ 35</td>
</tr>
<tr>
<td>Dyspnea (MMRC)</td>
<td>Going uphill</td>
<td>Walking on level ground</td>
<td>Stop after 100 yards</td>
<td>Getting dressed</td>
</tr>
<tr>
<td>Exercise (6MWT)</td>
<td>&gt;1148</td>
<td>820-1149</td>
<td>492-819</td>
<td>&lt;492</td>
</tr>
</tbody>
</table>

Approximate 4 year survival based on score
- 0-2 → 80%
- 3-4 → 70% (67%)
- 5-6 → 60% (57%)
- 7-10 → 20% (18%)

What should Advance Care Planning (ACP) look like?

1. Discuss End of Life
2. Clarify Values and Goals
3. Involve a Personal Representative
4. Document Patients Wishes

**Advance Directives**

- **Health Care Power of Attorney**
  - Document that legally designates your surrogate decision maker
  - Activated when Pt lacks capacity for decision making
  - Can list 1st and 2nd agent
  - Can list multiple people for agent

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**Symptomatic Treatment of patients with Advanced Lung Disease**

- Even when medical treatment is optimized, a large proportion of people with COPD have significant symptom burden (1)
  - Insidious onset
  - Normalization of symptoms
  - Often require multidimensional approach to treatment

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**This is HARD!**

- Uncertainty
- **EMBRACE**
- Build prognostic awareness
- Allow patients to plan
Symptom burden of those with advanced lung disease

- Fatigue
- Cough
- Dyspnea
- Anorexia
- Frailty
- Social Isolation
- Depression/Anxiety

Advanced Lung Disease

Dyspnea

- Difficult to treat
- Multifactorial in nature
- Hypoxia ≠ dyspnea

Dyspnea

Fooling the Brain with a Fan

- Concept first demonstrated in 1950s
  - Forced apnea testing
- Use of fan has been studied since 1980s
  - Randomized controlled trial
    - N = 40; Applied to face vs leg (control)
    - Outcome: change in dyspnea score

Non-Pharmacologic Interventions

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Sample Size</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Handheld Fan</td>
<td>Multiple Trials RCT N= 40</td>
<td>↓ Dyspnea Score</td>
</tr>
<tr>
<td>Breathing Techniques</td>
<td>2 Trials N = 74</td>
<td>↑ 6min Walk Distance</td>
</tr>
<tr>
<td>Cognitive Behavioral</td>
<td>1 Trial N = 222</td>
<td>Large improvement in CRQ score</td>
</tr>
<tr>
<td>Pulmonary Rehabilitation</td>
<td>Multiple Trials N &gt;1,000</td>
<td>Improved CRQ score</td>
</tr>
<tr>
<td>Tai Chi</td>
<td>2 Trials N = 48</td>
<td>Improved CRQ score</td>
</tr>
</tbody>
</table>

Dyspnea

Pharmacologic Interventions

- **Oxygen**
  - There is no evidence that oxygen palliates the sensation of breathlessness in patients without hypoxia
- **Opioids**
  - Most well studied
- **Benzodiazepines**
  - No evidence to support use
- **Antidepressants**
  - Use has been suggested, but not well studied
- **Prednisone**
  - No evidence for use of low dose daily prednisone

Opioids for Dyspnea

"Randomised, double blind, placebo controlled crossover trial of sustained release morphine for the management of refractory dyspnea"

- **N = 48**
- **88% were patients with advanced COPD**
- **Randomized to 20mg sustained release PO morphine in the morning for 4 days, followed by placebo for 4 days**
- **No previous opioid use**
- **Measurements: quality of sleep, dyspnea, wellbeing, performance on physical exertion**
- **Participants reported significantly improved dyspnea scores when treated with morphine**


Opioids for Dyspnea

- **MOA**: Bind to three main receptors (mu, delta, and kappa)
- **Endogenous opioids are thought to be a natural mechanism in relieving dyspnea**
- **Study (5)**:
  - **N**: 17 patients with COPD
  - **Intervention**: treadmill exercise with randomization to 10mg naloxone or saline
  - Measured patients self reported dyspnea scores and β-endorphins
    - 3 fold increase in β-endorphins
    - Mean breathlessness higher in the naloxone group


Dyspnea in Patients with Advanced Lung Disease

- Optimize inhaler therapy and disease directed therapy, Oxygen
- Optimize Non-Pharmacologic Measures: Pulmonary Rehab, Breathing Techniques, Fan
- Increased Dyspnea
- Persistent Dyspnea
- Palliative Pharmacological Measures: opioids, multidimensional approach

### Dyspnea in Patients with Advanced Lung Disease

**Benzodiazepine use**

- Cochrane systematic review, published in 2016
- There were 8 studies included
- Population
  - Total of 214 patients
  - All patients had advanced cancer or COPD
- Results:
  - There was NO beneficial effect of BZDs for relief of breathlessness compared to placebo
  - BZD use was associated with statistically significant increase in drowsiness and somnolence


### Symptomatic Treatment of Patients with Advanced Lung Disease

#### Other Common Symptoms

- **Cough**
  - Difficult to treat (make sure easy reasons treated, ex: GERD, PND)
  - Gabapentin/Lyrica
  - Complex physiotherapy and speech and language intervention
- **Fatigue**
  - Pulmonary Rehab
  - Evaluate for NIPPV
  - Optimization of supplemental O2 requirements
- **Depression/Anxiety**
  - Don’t forget about depression
  - Ensure anxiety not just due to dyspnea (which is treated with opioids)

### Patients with ALD have significant symptom burden

Opioids are first line for refractory dyspnea

No evidence to support use of Benzodiazepines

### Hospice referral

- **Goals of Hospice**
  - Reduce suffering, Improve QOL
  - Physical symptom burden, emotional needs, and spiritual needs
  - Multidisciplinary approach
- **When to make referral**
  - Appropriate Timing
  - Patients goals
  - Poorly controlled symptoms despite initial management
- **Limitations**
  - High-cost medications
  - When the Pt is not ready- It’s okay! Evaluate prognostic awareness
Let’s Come Back to Our Case

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How does this relate to COVID-19?

COVID-19 & Comorbidities

"Clinical Characteristics, Comorbidities, and Outcomes Among Patients With COVID-19 Hospitalized in the NYC Area"
N= 5,700
Publish date: 4/22/2020

<table>
<thead>
<tr>
<th>Comorbidities</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Respiratory Disease</td>
<td></td>
</tr>
<tr>
<td>- Asthma</td>
<td>479 (9%)</td>
</tr>
<tr>
<td>- COPD</td>
<td>287 (5.4%)</td>
</tr>
<tr>
<td>Cardiovascular Disease</td>
<td></td>
</tr>
<tr>
<td>- HTN</td>
<td>3026 (56.6%)</td>
</tr>
<tr>
<td>- CAD</td>
<td>595 (11.1%)</td>
</tr>
<tr>
<td>Obesity (BMI&gt;30)</td>
<td>1737 (41.7%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1808 (33.8%)</td>
</tr>
</tbody>
</table>
Predicting Prognosis is DIFFICULT

- Mortality data surrounding COVID is evolving
- How do we predict those that will have poorer outcomes?
- “Prognostic Paralysis”

Advanced Care Planning still Needs to Happen EARLY

- This was the case prior to COVID and is even more imperative now
- Ideally with provider that patients is familiar and comfortable with
  - Primary care office setting
  - Specialty clinic
- If not done prior to admission to hospital, should be done early in presentation
  - Non-emergently, when Pt can do thoughtfully and be active participant
  - Our institution has made a strong recommendation that all admitted with COVID-19 should have undergone ACP within 1 hour

Tools for ACP in Era of COVID

<table>
<thead>
<tr>
<th>“COVID Ready Communication Playbook” by VitalTalk</th>
</tr>
</thead>
<tbody>
<tr>
<td>C Check-In</td>
</tr>
<tr>
<td>A Ask about COVID</td>
</tr>
<tr>
<td>L Lay Out Issues</td>
</tr>
<tr>
<td>M Motivate them to choose a Proxy &amp; Talk about what Matters</td>
</tr>
<tr>
<td>M Motivate them to choose a Proxy &amp; Talk about what Matters</td>
</tr>
<tr>
<td>E Expect Emotion</td>
</tr>
<tr>
<td>R Record the Discussion</td>
</tr>
</tbody>
</table>

Advanced Care Planning

Billing

- These ACP discussions do take time, but hopefully will allow you to better care for your patients in the future
- You can bill for this time
  - Time-based billing code in increments of 30 minutes with at least 16 minutes or more spent on ACP
    - 99497: the first 30 minutes face to face with patient, family members, and/or surrogate (1.5 RVU)
    - 99478: additional 30 minutes (with at least 16 min beyond the first 30 min), as many times as needed to cover time spent (1.4 RVU)
**Symptom Management**

*Treatment of Acute Dyspnea and Acute on Chronic*

- Treatment of acute dyspnea ≠ treatment chronic dyspnea
- Treat underlying cause
- Non-pharmacologic options including fans can be great options for patients

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**Summary**

Prognostication is difficult

More early ACP needs to occur with our Pts

Pts with ALD have significant symptom burden

Opioids are the only supported pharmacological treatment for chronic refractory dyspnea (this differs from acute dyspnea)

Fans are a great non-pharmacological option to treat acute or chronic dyspnea

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**Hospice Qualification for Advanced Lung Disease**

1. Disabling dyspnea at rest or with minimal exertion and little or no response to bronchodilators, resulting in decreased functional capacity, fatigue and cough

2. Progression of end stage pulmonary disease, as evidenced by prior increasing visits to the emergency department or prior hospitalizations for pulmonary infections and/or respiratory failure

3. Room air findings of hypoxemia or hypercapnia
   - pO2 < 55 mmHg and oxygen saturation < 88%
   - pCO2 > 50 mmHg

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**Acknowledgements**

Philip Diaz, MD
Jillian Gustin, MD
Sarah Tapyrik, MD
Todd Barrett, MD
Lauren Goodman, MD
James Allen, MD
Hospice Qualification for Advanced Lung Disease (continued)

4. Cor pulmonale and right heart failure (RHF) secondary to pulmonary disease
5. Unintentional progressive weight loss greater than 10% of body weight over the preceding six months
6. Resting tachycardia > 100/mm.

Dyspnea in Patients with Advanced Lung Disease

• Opioids as a class reduce dyspnea, however most of studies conducted use morphine
• Starting doses of morphine for opiate naïve patients
  - Extended release
    - Starting dose: 15mg PO daily (based on trial)
    - Usual dosing interval q8-12 hours
  - Immediate release
    - Starting dose: 15mg PO q4 hours as needed
    - Preparations with solutions can allow for lower starting doses
  - Contraindication: renal dysfunction

References

8. CDC FastStats Deaths and Mortality https://www.cdc.gov/nchs/fastats/deaths.htm

References