Palliative Care Challenges in Advanced Lung Disease
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Outline
• Introductions
• Staging, disease course, prognostication
  • Advanced obstructive lung disease (COPD)
  • Advanced fibrotic lung disease (IPF)
• Underutilization of Palliative Care
• Cases
  • Intubation
  • Advance care planning
  • Symptom management
• When to refer to palliative care?
• Summary
COPD: Predictably unpredictable

Look at x-axis...

A tale of two ladies...
"Physiology does not equal destiny."

-Walter J. O’Donnell MD

<table>
<thead>
<tr>
<th>Patient</th>
<th>Characteristic</th>
<th>Spirometric Classification</th>
<th>Exacerbations per year</th>
<th>mMRC</th>
<th>CAT</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Low Risk</td>
<td>GOLD 1-2</td>
<td>≤ 1</td>
<td>0-1</td>
<td>&lt; 10</td>
</tr>
<tr>
<td>B</td>
<td>Low Risk</td>
<td>GOLD 1-2</td>
<td>≤ 1</td>
<td>≥ 2</td>
<td>≥ 10</td>
</tr>
<tr>
<td>C</td>
<td>High Risk</td>
<td>GOLD 3-4</td>
<td>≥ 2</td>
<td>0-1</td>
<td>&lt; 10</td>
</tr>
<tr>
<td>D</td>
<td>High Risk</td>
<td>GOLD 3-4</td>
<td>≥ 2</td>
<td>≥ 2</td>
<td>≥ 10</td>
</tr>
</tbody>
</table>

"How long do I have?"

- FEV1 (severity of obstruction)
- GOLD staging (A,B,C,D)
- BODE (BMI, FEV1, dyspnea, 6MWT)
- BODEx (BMI, FEV1, dyspnea, exacerbation)
- e-BODE (combination)
- Exacerbations
- Other biomarkers?

Idiopathic Pulmonary Fibrosis
Symptoms at IPF Diagnosis

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Patients %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyspnea</td>
<td>65.9</td>
</tr>
<tr>
<td>Cough</td>
<td>39.0</td>
</tr>
<tr>
<td>Fatigue</td>
<td>14.5</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>13.2</td>
</tr>
<tr>
<td>Anxiety</td>
<td>9.4</td>
</tr>
<tr>
<td>Clubbing</td>
<td>7.9</td>
</tr>
<tr>
<td>Bilateral crackles on auscultation</td>
<td>19.0</td>
</tr>
</tbody>
</table>

Behr et al., Eur Respir J, 2015

IPF Natural History – Poor Prognosis

Prior View:
- Slow Steady Decline
- Asymptomatic
- Normal Lung Function
- Early Disease
- Late Disease
- Time →

Current View:
- Heterogeneous Progression
- Acute Exacerbation
- Slow Decline
- Rapid Decline
- Normal Lung Function
- Adapted from Ley et al. AJRCCM. 2011.

Revisiting Disease Progression in IPF
PERSPECTIVES

Inadequate Palliative Care in Chronic Lung Disease
An Issue of Health Care Inequality
Crystal E. Brown, Nancy S. Jecker, and J. Randell Curtis

- Palliative care services mostly utilized in patients with cancer
- However, chronic lung disease patients have
  - Increased burden of symptoms
  - Decreased quality of life
  - Increased social isolation
- Large proportion of patients with advanced lung disease do not receive advanced care planning or palliative care

Vignettes: Intubation

- Ms. D is a 75F caretaker of husband and disabled son, with COPD/emphysema, FEV1 0.82 (33% predicted), never before hospitalized... arrives in ED in extremis, hypoxemic, pCO2 >100. She had told her family in the past that she would never want a tube in her throat...
- Ms. B is a 76F with COPD/emphysema, prior lung cancer (resected), with growing hilar mass she does not want to have evaluated, on long term oxygen therapy, mostly home bound, uses wheelchair when she leaves the home. She discusses GOC only reluctantly, and after many attempts, with her PCP.
Intubation and COPD: Crazy to, or crazy not to?
• Overall, increase in mechanical ventilation, but over time, more and more NIV, less invasive mechanical ventilation.
• How do patients do?
  • In general, over 50% survive intubation
  • For patients on long-term O2 therapy, ~25% die in hospital, 45% in next 12 months, ~25% discharged to NH or SNF.
• What do patients think about it?
  • Majority would similar treatment...

Vignettes: Intubation
• Patient F is a 69 year old M with ICM (EF 25%) and IPF on 4L-6L continuous oxygen with worsening hypoxemic respiratory failure. Several months of decline followed by one week of rapid worsening. CT Chest imaging with diffuse ground glass overlying advanced honeycomb change. On arrival to the ICU he was tachypneic with O2 saturation of 90% on HFNC of 1.0.
  • Of note, he was declined for lung transplant due to his cardiovascular disease.
  • He has been taking nintedanib for the past 6 months.
Multiple retrospective studies demonstrating poor outcomes of IPF patients requiring ICU care, especially with mechanical ventilation needed.

Majority of patients with IPF placed on MV had not received palliative care in prior (Rush et al, Am J Hospice and Pall Med, 2017).

Vignettes: Re-admissions

- Mr. S is a 75M with COPD/emphysema, lung cancer, PE and pulmonary hypertension; admitted 15 times in a 12-month period.
- Ms. S is a 67F COPD, asthma, vocal cord dysfunction, severe anxiety, bipolar disorder, receiving ECT, at least monthly admissions.
- Ms. S is an 88F who lives alone, with COPD, bronchiectasis, anxiety develops frequent coughing paroxysms, calls 911, admitted at least once monthly, often more.

Readmissions: What can we do?

- Be patient (and recognize that it’s not a failure)
- Think about inpatient continuity
  - Pulmonary consultant, palliative care team, complex care team
- Consider home-based resources
- Don’t forget the basics (and the advanced) of disease management
  - Optimization of maintenance regimen
  - Exacerbation prevention
  - Use of non-invasive ventilation
  - Guidance with airway hygiene (Acapella device)
Vignette: Advanced Care Planning

- Patient J is a 71 M with IPF who returns to clinic for follow-up. He is very discouraged that he was recently declined for lung transplant. He continues to use 2-3 L oxygen. His spirometry has worsened slightly.

- Patient M is a 77 F with pulmonary fibrosis and pulmonary hypertension. She requires 2L oxygen at rest and 8L with activity. She is admitted to the ICU with respiratory failure in the setting of pneumonia.

Vignettes: Symptom management

Mr. E is a 48M with COPD, compensated systolic heart failure (EF 10%), wears Zoll vest (external defibrillator), on 3Lpm O2, uses scooter, admitted more than twice monthly for over a year, severe DOE & resting dyspnea.

His maintenance regimen consists of combined inhaled steroid/long-acting bronchodilator (i.e. Advair), long-acting muscarinic agonist (i.e. Spiriva, Incruse Ellipta), prednisone (20-30mg daily), standing nebulizers, roflumilast.
COPD: Symptom management

- Know the patient’s maintenance regimen (inhaler alphabet soup)
- Time for solely nebulized therapy?
- Pulmonary rehabilitation
- Non-invasive ventilation
- Airway hygiene (Acapella device)
- Opiates
- Nebulized lasix
- Thorazine

Consider N of 1 trial.

Vignette: Symptom Management

- Patient S is a 79 F with IPF and PH who returns to clinic accompanied by her daughter. She has not been able to tolerate anti-fibrotic therapy due to side effects. She is currently using 3L oxygen at rest and 6L with exertion. Her main complain is worsening dyspnea such that it’s difficult to perform her ADLS independently. She also have some dyspnea at rest.
  - She is very hesitant to take morphine prescribed to her by her palliative care provider.
  - She does take a small dose of morphine at bedtime which helps her not to awaken with coughing spells
IPF: Symptom Management

- Cough
  - Frequent, chronic, and debilitating
  - No benefit from antitussives
- Treatment options
  - Prednisone
  - Narcotics
  - Gabapentin
  - Thalidomide
- Other conditions contributing?
  - IPF - Albuterol
  - Reflux - IPP

Table 1: Frequent symptoms and symptom relieving measures during the last 7 days of life

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Number (%)</th>
</tr>
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<tbody>
<tr>
<td>Breathlessness</td>
<td>39.05%</td>
</tr>
<tr>
<td>Pain</td>
<td>16.05%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>11.02%</td>
</tr>
<tr>
<td>Dyspnea, depression</td>
<td>10.03%</td>
</tr>
<tr>
<td>Cough</td>
<td>9.12%</td>
</tr>
<tr>
<td>Nausea</td>
<td>6.21%</td>
</tr>
<tr>
<td>Constipation</td>
<td>4.19%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>4.07%</td>
</tr>
<tr>
<td>Anxiety, depression</td>
<td>4.01%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>3.04%</td>
</tr>
</tbody>
</table>

Rajala et al, BMJ Palliative Care, 2016

When to refer to palliative care?

Take home points...

- Educate about the disease
  - COPD: progressive (but unpredictable) nature, not one size fits all
  - IPF: heterogeneous (but often fast) progression
- Intubation & advance care planning, talk early & often
  - COPD: Be cautious about nihilism, admission # failure
  - IPF: Educate about ICU, intubation not to be taken lightly
- Symptom management: don’t be afraid to try off label medications
- Palliative care: refer early