Beyond Drug Treatment: Palliative Care, Oxygen, Pulmonary Rehabilitation, Support Groups

Susan S. Jacobs RN, MS
Research Nurse Manager, Pulmonary & Critical Care Medicine
Nurse Coordinator, Interstitial Lung Disease Program
Stanford University Medical Center
Beyond Drug Treatment

Symptoms → MD Visit → Diagnosis → Treatment Plan

Drug Rx
Lab tests
See GI, Rheum Bronchoscopy
Lung Biopsy
New Diagnosis
? Oxygen
? Transplant

Overload!
Education

Isolation, Depression, End of Life Concerns

Hypoxemia

Deconditioning

Dyspnea

Cough

Non-Pharm Symptom Mgmt
Beyond Drug Treatment

1) Palliative Care/Symptom Management
2) Pulmonary Rehabilitation
3) Oxygen
4) Support Groups
Beyond Drug Treatment: Palliative Care

Palliative Care

- Use a palliative approach for life limiting illness

End-of-Life Care
- Weeks to months
- Palliative and medical treatments
- Ongoing supports
- Hospice Care
- Respite and caregiver relief

Last Days/Hours Care
- Pain & Symptom Mgt
- Psychosocial & Spiritual supports

Optimizing Quality of Life

Maximizing community supports

Early symptom management

Advanced care planning

Palliate: to make a disease or its symptoms less severe or unpleasant
Beyond Drug Treatment: Palliative Care

• The most common troubling symptoms:
  • Cough
  • Shortness of Breath
  • Anxiety/Coping with chronic lung problem
Symptom Management: Cough

1. Why do I cough?
   a) Inflammation in the airways of ILD patients causes “up-regulation” of sensory innervation = cough
   b) Increased amount of proteins called neurotrophins in IPF sputum affects sensory nerves
   c) Mechanical ‘pull’ on airways from lung scarring may trigger cough
   d) MUC5B gene may be associated with cough severity in IPF patients

Symptom Management: Cough

**Post Nasal Drip**
- nasal steroids
- ipratropium
- antihistamines

**Asthma**
- dextromethorphan, guaifenesin
- benzonatate
- prednisone, inhaled steroids
- baclofen, gabapentin, tramadol
- nebulized anesthetics
- thalidomide
- anti-fibrotics
- cough suppression therapy
  - education, counselling, cough control, breathing retraining, and vocal hygiene
- oral opiates
- patient-reported strategies

**GERD-Reflux**
- lifestyle mod.
- dietary mod.
- PPI
- surgical Rx

*If no improvement:*
Symptom Management: Cough

• Patient-Reported Strategies to Decrease Cough (N=105):
  • Lozenges with cough suppressant/oral anesthetic (especially before making phone call, during ‘social times’)
  • Warm liquids - honey and lemon in hot water
  • Ginger tea, turmeric
  • Sips of water, ice chips, Biotene spray (moisture)
  • Chewing/swallowing carefully, slowly (MCTD pts)
  • Avoiding irritants, triggers
  • ↑ oxygen during coughing as needed
  • Hypnosis
  • Yoga/relaxation/slowed breathing techniques
  • Nothing (29%)

Symptom Management: Breathlessness
Symptom Management: Breathlessness

Lung Scarring or Inflammation
- Increased lung stiffness
- Restriction of lung inflation
- Difficult for oxygen to get from air sac into bloodstream

Increased WOB
Rapid Shallow Breathing with exertion

SOB
Lung receptors, hypoxemia, deconditioning, anxiety and depression
Treating Breathlessness

- Pursed lip breathing/breathing retraining
- Fan/cold air/open windows
- Relaxation/visual imagery/meditation
- Distraction: headphones, social interaction
- Yoga (modified)
- Small meals
- Ideal body weight
- Oxygen if hypoxemic
- Opiates/Narcotics/Anxiolytics
Impact of Exercise on Breathlessness

- Builds endurance
- Strengthens muscles
- Desensitization to SOB
- Improves mood
- Facilitates travel, work, and socialization
- Maintains ideal weight
- Decreases anxiety, panic
- Maintenance critical
- *Does not change PFTs*

http://www.cspr.org/find-a-program
Beyond Drug Treatment: Pulmonary Rehabilitation

“an evidence-based, multidisciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily activities. Integrated into the individual treatment of the patient, pulmonary rehabilitation is designed to reduce symptoms, optimize functional status, increase participation, and reduce health care costs through stabilizing or reversing systemic manifestations of the disease”.

Live Better with Pulmonary Rehab

WHAT IS PULMONARY REHABILITATION?  LEARN MORE

BENEFITS OF PULMONARY REHAB  LEARN MORE

PROGRAM DIRECTORY  LEARN MORE

GET STARTED  LEARN MORE

LIVEBETTER.ORG

Live Better with Pulmonary Rehabilitation is a pilot project of the American Thoracic Society (ATS) and the Gawlicki Family Foundation to increase public awareness of pulmonary rehabilitation. Live Better’s mission is to inform and educate individuals with chronic lung disease about the potential benefits to them of pulmonary rehabilitation.
Beyond Drug Treatment: Pulmonary Rehabilitation

- 6-8 Weeks
- 2/wk, 2 hrs
- Education
- Exercise
- Social Support

Health Benefits

Pulmonary Rehabilitation can help you realize some or all of the following health benefits:

1. Decrease shortness of breath/breathlessness
2. Increase exercise capacity
3. Increase energy and stamina
4. Improve feeling of well-being
5. Decrease feelings of depression and anxiety
6. Increase ability to do things in life that you need and want to do
7. Communicate more effectively with your healthcare team
8. Connect with other people with similar breathing problems
9. Increase your ability to manage your own lung problems in collaboration with your healthcare team
# Beyond Drug Treatment: Pulmonary Rehabilitation

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Δ 6MW, m</th>
<th>Dyspnea</th>
<th>QOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dowman et al 2017 RCT</td>
<td>142 ILD</td>
<td>25</td>
<td>Improved</td>
<td>Improved</td>
</tr>
<tr>
<td>Nakazawa et al 2017 Review</td>
<td>NA</td>
<td>NA</td>
<td>Improved</td>
<td>Improved</td>
</tr>
<tr>
<td>Ryerson et al 2014</td>
<td>54 ILD</td>
<td>57</td>
<td>Improved</td>
<td>Improved</td>
</tr>
<tr>
<td>Holland et al 2012</td>
<td>44 ILD</td>
<td>21</td>
<td>Improved</td>
<td>NA</td>
</tr>
<tr>
<td>Huppman et al 2013</td>
<td>402 ILD inpt.</td>
<td>46</td>
<td>Improved</td>
<td>Improved</td>
</tr>
<tr>
<td>Kozu et al 2011</td>
<td>65</td>
<td>31 (MRC 2)</td>
<td>Improved</td>
<td>NA</td>
</tr>
<tr>
<td>Swigris et al 2011</td>
<td>21</td>
<td>62</td>
<td>Fatigue improved</td>
<td>SF36 non sig</td>
</tr>
<tr>
<td>Garvey 2010 Review</td>
<td>NA</td>
<td>NA</td>
<td>Improved</td>
<td>Improved</td>
</tr>
<tr>
<td>Salhi et al 2010</td>
<td>11 RLD</td>
<td>107</td>
<td>Improved</td>
<td>SGRQ non sig</td>
</tr>
<tr>
<td>Ferreira et al 2009</td>
<td>99</td>
<td>56</td>
<td>Improved</td>
<td>NA</td>
</tr>
<tr>
<td>Holland et al 2008 RCT</td>
<td>57</td>
<td>35</td>
<td>Improved</td>
<td>Improved</td>
</tr>
<tr>
<td>Nishiyama et al 2008 RCT</td>
<td>30</td>
<td>42</td>
<td>No Change</td>
<td>Improved</td>
</tr>
<tr>
<td>Jastrzebski et al 2006</td>
<td>31</td>
<td>NA</td>
<td>Improved</td>
<td>Improved</td>
</tr>
<tr>
<td>Naji et al 2006</td>
<td>26</td>
<td>NA</td>
<td>Improved</td>
<td>Improved</td>
</tr>
</tbody>
</table>
Breathlessness: Key Points

“Complex interplay between mechanical, neurologic and psychological factors” (Garibaldi and Danoff, Respirology 2016)

- Exercise
  - Improved QOL
  - Less panic
  - Avoid deconditioning

- Educate
  - More benefit for SOB, Exercise Capacity and QOL than any IPF RCT

- Oxygen
  - Regularly check during rest and exercise
Beyond Drug Treatment: Oxygen

• Prescribed for relief of hypoxemia and breathlessness, improved mobility, QOL, and survival
Beyond Drug Treatment: Oxygen

• Regularly assess oxygen saturations at rest & exercise
  • 6 Minute Walk & Exercise Oximetry
  • High Altitude Simulation Testing
  • Overnight Oximetry
  • The need for oxygen is not based on shortness of breath

• Test oxygen sats in clinic & receive oxygen prescription:
  • At rest
  • With exertion
  • During sleep
  • Goal is to titrate oxygen to keep saturations >90%
  • Medicare covers oxygen if your saturation is ≤88%
Beyond Drug Treatment: Oxygen

• Pros:
  • May decrease breathlessness with activity
  • Improve ability to get out of the house, travel, work
  • Allow for higher levels of exercise to improve stamina and strength
  • Allow travel by plane or to altitude

• Cons:
  • Physically cumbersome treatment
  • Hard for some due to social issues
  • Risks of tripping, fire
  • Smaller, lighter portable oxygen concentrators (POCs) don’t go above 3 L/min continuous, or 6 pulse
Oxygen 101: Liquid Oxygen

- Oxygen cooled down to liquid; provides larger amt. oxygen in smaller canister
- Delivers up to 10 L/min. cont. flow (different units for higher flow).
- Uses homefill system
- Higher costs of liquid:
  - More frequent delivery
  - Longer time to service
  - More customer needs
  - Scarce availability
Oxygen 101: Compressed Gas

**E Tank:** compressed gas, semi-portable, lasts 3 hrs. on 3L/min continuous or 1.5 hrs on 5 L/min

**M6 (B) Tank:** compressed gas, portable, lasts with OCD or OCR

**Transfill Systems:**
- Homefill
- I Fill
- Ultra Fill
Portable Oxygen Concentrators: Size Matters!

- 3-20 lbs
- Uses battery; concentrates ambient air to 90-96% oxygen
- Can run off DC power
- FAA approved; need battery for 1.5 x hours of flight
- Higher liter flow=shorter battery life
- Very important to get tested on the system **BEFORE** pt. purchases it
- No *continuous* flow > setting of 3 or *pulse* flow over setting of 6
Oxygen Survey Results (1926 pts): 51% experienced oxygen problems

<table>
<thead>
<tr>
<th>Problem</th>
<th>Number of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equipment Not Working</td>
<td>499</td>
</tr>
<tr>
<td>Travel oxygen problems</td>
<td>268</td>
</tr>
<tr>
<td>Delivery Problems</td>
<td>267</td>
</tr>
<tr>
<td>Lack of portables I can manage</td>
<td>260</td>
</tr>
<tr>
<td>Other</td>
<td>220</td>
</tr>
<tr>
<td>Lack of high flow portable systems</td>
<td>219</td>
</tr>
<tr>
<td>Not enough tanks for activity outside home</td>
<td>201</td>
</tr>
<tr>
<td>Can't change companies</td>
<td>177</td>
</tr>
<tr>
<td>Company does not respond to calls</td>
<td>169</td>
</tr>
<tr>
<td>Incorrect or delayed MD orders</td>
<td>166</td>
</tr>
<tr>
<td>Can't mix systems</td>
<td>123</td>
</tr>
<tr>
<td>Need or used to use liquid and can't get</td>
<td>86</td>
</tr>
<tr>
<td>Bills not explained</td>
<td>68</td>
</tr>
<tr>
<td>Not enough portables so I can work</td>
<td>40</td>
</tr>
</tbody>
</table>

Average # problems per respondent = 3.5
Oxygen and Travel

- ALWAYS let your healthcare provider know of your plans to travel on oxygen a MONTH in advance
- ALWAYS check your airlines website and speak to their medical travel department to confirm forms needed
- Some POCs have an FAA stamp on them but older ones will not and for those you will need an MD letter/Rx
- ALWAYS carry a copies of the form/letter/MD order with you when you travel
- You will need 1.5 x the flight length in battery hours for your POC. Always plug in while waiting for your flight and confirm with airlines if your seat will have outlet.
Beyond Drug Management: Support Groups
Beyond Drug Management: Support Groups

Education, Socialization, Caregiver Support, Networking - all in one
Beyond Drug Management: Support Groups

• Options: (resource manual)
  • In Person
  • Online
  • Phone In
Beyond Drug Management: Support Groups
Beyond Drug Management: Support Groups
Clinical Trials: An Important Option

• National registries to collect long term data
• Trials coming up testing new anti-fibrotic drugs as ‘add-on’ therapy
• Close follow-up, support, hope
• More trials coming for non-IPF pts.
Beyond Drug Management: Summary

- Palliative Care
- Pulmonary Rehabilitation
- Oxygen
- Support Groups

Non-Pharm Symptom Mgmt
- Deconditioning
- Hypoxemia
- Cough
- Dyspnea
- Education

Isolation, Depression, End of Life Concerns

Beyond Drug Management: Summary

- Palliative Care
- Pulmonary Rehabilitation
- Oxygen
- Support Groups
Thank you!

Susan Jacobs RN, MS  (650) 725-8083  ssjpulm@stanford.edu
We would like to honor and thank a very special ILD nurse who dedicated many years to improving the quality of life for countless ILD patients at UCSF and beyond

Sally McLaughlin RN, MSN, ILD Nurse Coordinator UCSF