PCOs and Research Priorities for Sleep Apnea: What we learned from targeted surveys

To quantify patient-centeredness of outcomes in COPD and sleep apnea
<table>
<thead>
<tr>
<th>Outcome Variable</th>
<th>Variable Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Oxygen count</td>
<td>Oxygen use; Oxygen saturations; oxygen in blood stream</td>
</tr>
<tr>
<td>2 Symptoms (shortness of breath, cough, etc.)</td>
<td>Presence and severity of shortness of breath, cough, reduced exercise and activity tolerance</td>
</tr>
<tr>
<td>3 Stop smoking</td>
<td>Getting help to stop smoking</td>
</tr>
<tr>
<td>4 Reducing Risk for other coexisting disease/afflictions</td>
<td>Reducing the risk for cancers, heart problems, and other diseases associated with COPD</td>
</tr>
<tr>
<td>5 Prevent Hospitalizations</td>
<td>Prevent hospitalizations through better COPD management (unscheduled visits to ER, office, urgent care included)</td>
</tr>
<tr>
<td>6 Reduce Exacerbations</td>
<td>Influenza and pneumonia vaccinations; Emergency supply of prednisone and antibiotics for early use in illness onset</td>
</tr>
<tr>
<td>7 Improve physical activity</td>
<td>Pulmonary rehabilitation; Daily exercise</td>
</tr>
<tr>
<td>8 Advance directives and Transplant Candidacy</td>
<td>Discussing advance directives and end-of-life wishes and care. Assessing for lung transplant candidacy if eligible. Having difficult and important discussions about COPD condition</td>
</tr>
<tr>
<td>9 Improve sleep</td>
<td>Diagnose and treat insomnia and/or sleep apnea</td>
</tr>
<tr>
<td>10 Patient Education</td>
<td>Up-to-date information about COPD</td>
</tr>
<tr>
<td>11 Slowing the Loss of Lung Function</td>
<td>Prevent further damage to lungs by avoiding risks factors (i.e. smoking) and improving exercise tolerance</td>
</tr>
<tr>
<td>12 Improving General Health Status</td>
<td>Improving sense of well-being through nutrition, exercise, emotional, and spiritual support</td>
</tr>
<tr>
<td>13 Prevent &amp; Treat Complications</td>
<td>Preventing medication risks (i.e. prednisone effects on osteoporosis) and treating complications as they arise</td>
</tr>
<tr>
<td>14 Reduce Death</td>
<td>Reducing the chance of dying due to COPD</td>
</tr>
<tr>
<td>15 Treatment of Mental Comorbidities</td>
<td>Treatment of other mental health issues such as depression, and anxiety</td>
</tr>
<tr>
<td>16 Improve Access to Care</td>
<td>Facilitate fast access to doctors and nurses to enable prompt care in both non-urgent and urgent situation, enable communication between office and patient, provide for clinic availability for patient scheduling as needed</td>
</tr>
</tbody>
</table>
Chronic Obstructive Pulmonary Disease

N=435
Chronic Obstructive Pulmonary Disease

Importance

↓ Exacerbations
↓ Hospitalizations
↓ Death
Smoking cessation
↓ Dyspnea
↑ Physical activity
↓ Exacerbations
N=435

Providers

Patients
Patient-Centered Outcomes: Determining Patient and Provider Preferences

To quantify patient-centeredness of outcomes in sleep apnea
<table>
<thead>
<tr>
<th>Outcome Variable (Please select 10)</th>
<th>Variable Description</th>
<th>X</th>
<th>Importance Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Symptoms of sleep disorders</td>
<td>Daytime sleepiness, fatigue, difficulty sleeping, timing of sleep, etc.;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Stop habits that are bad for sleep (Sleep Hygiene):</td>
<td>Getting help to sleep better</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Reducing Risk for other coexisting disease/afflictions</td>
<td>Reducing the risk for cancer, heart problems, weight gain, hypertension, and other diseases associated with sleep disorders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Prevent Hospitalizations</td>
<td>Prevent hospitalizations, unscheduled visits to ER, office, urgent care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Improve daytime functioning</td>
<td>Better vigilance, cognition, ability to think and perform better</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Patient Education</td>
<td>Up-to-date information about Sleep and Sleep Disorders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Prevent long-term complications of untreated sleep Disorders</td>
<td>Prevent complications to heart (heart attacks, heart failure), Alzheimer dementia, Stroke, etc.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Improving General Health Status</td>
<td>Improving sense of well-being through nutrition, exercise, emotional, and spiritual support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 Prevent &amp; Treat Complications</td>
<td>Preventing medication risks (i.e. sleeping pills and risk of falls); device risks (skin erosions from mask and nasal discomfort) and treating complications as they arise</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 Reduce Death</td>
<td>Reducing the chance of dying due to sleep disorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Treatment of Mental Comorbidities</td>
<td>Treatment of other mental health issues such as depression, and anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Improve Access to Health Services</td>
<td>Facilitate insurance coverage for timely treatment of sleep disorder and treatments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 Improve Access to Provider</td>
<td>Facilitate fast access to doctors and nurses to enable prompt care in both non-urgent and urgent situation, enable communication between office and patient, provide for clinic availability for patient scheduling as needed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 Improve sleep disorders disease detection</td>
<td>Through educational and other efforts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 Promote support for improving adherence to treatment of sleep disorders</td>
<td>Educational, Behavioral, and other support for CPAP adherence, cognitive therapy, medications, etc.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Chronic Obstructive Pulmonary Disease

Sleep Apnea

N=435

N=1019
Importance

Providers

Patients

*P=0.02

- Sleep symptoms
- Sleep Hygiene
- Patient Education
- Daytime functioning
- Access to Healthcare
- Mental comorbidities
- Prevent complications
- Hospitalization
- Longterm complications
- General Health
- Reduce death
- Access to Provider
- Improve detection
- Promote adherence
- Comorbid condition
N=1019

↑ Sleep Hygiene

↓ Hospitalization

Providers

Patients
Importance

N=990

↓ Sleep symptoms

↑ Daytime functioning

Researchers  Patients

-20  0  20

0  20  40  60
Adherent to PAP therapy by CMS criteria
Non-adherent to PAP therapy by CMS criteria

170,641 (63.7% of database)
16 years of data
Socioeconomic inequity in Adherence to Positive Airway Pressure Therapy in Population Level Analysis

Pandey et al, Am J Respir Crit Care Med 2017; 195:A2924
Socioeconomic inequity in Adherence to Positive Airway Pressure Therapy in Population Level Analysis: Temporal pattern

Pandey et al, AM J Respir Crit Care Med 2017; 195:A2924
The stakeholder theory is a theory of organizational management and business ethics that addresses morals and values in managing an organization.

"The basic idea is that businesses, and the executives who manage them, actually do and should create value for customers, suppliers, employees, communities, and financiers (or shareholders)."

Edward Freeman (University of Virginia)
PCORI Patient-Stakeholder Engagement – Obstructive Sleep Apnea

Improving Health Care

Providers

Peer-Buddies

Patients

Public-advocacy

ASAA

Product maker

Purchaser

Payer

Principal Investigators

AASM

Policymaker

Clinical Psychology

DME

RT

RN

Sleep Tech
Summary

- OSA providers more patient-centered than COPD
- Providers more patient-centered than researchers?
- PCOs identified for patients with OSA
  - Concordant -> PCO for trials
  - Discordant -> Why?
- Inadequate engagement of payors & policymakers?
Thank you

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**COPD Foundation**
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PCORI EAIN-3394-UOA