

Developing a pulmonary rehabilitation-specific questionnaire to capture perspectives of COPD patients undergoing pulmonary rehabilitation: *An ongoing process*

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Introduction and Background

Assessing the effectiveness of pulmonary rehabilitation (PR) requires clinically derived outcome measures such as exercise tolerance, treatment adherence, functional status, mobility and survival. In addition, patient-reported outcomes (PROs) regarding symptom burden (dyspnea, fatigue, depression and anxiety) and overall health status (health-related quality of life) are often used to gauge the full benefit of PR to the patient. However, while valuable, generic or other respiratory-specific PROs may not reflect program outcomes that are meaningful to a PR patient; To our knowledge, there is no validated health status questionnaire specifically developed for COPD patients participating in PR. Use of pulmonary rehabilitation-specific PROs may direct scarce resources toward the specific needs of COPD patients and thereby improve its effectiveness.

Aim

Develop and validate a PR-specific health status instrument to capture the perspectives of COPD patients undergoing this treatment.

Methods

To date (Part A):

- This study was approved by the Trinity Health Of New England Institutional Review Board
- Cognitive interviews were held with 9 COPD patients who had completed or considered PR. Based on results, we developed a basic 15-item questionnaire.
- The questionnaire was reviewed by health care providers who were familiar with PR, an expert research panel, and additional COPD patients. Based on feedback, the new version included 45 items covering health status and quality of life. Content analysis identified 7 general categories.
- We used REDCap to distribute the updated questions to a new group of COPD patients (n=23), caregivers (n=2) and healthcare providers (n=11)¹. Respondents answered the questions based on what they considered to be important to COPD patients participating in PR. Items were rated on a scale of 1 (not important) to 5 (very important) and presented in no particular order.
- We then analyzed the data with an advisory panel of COPD patients (n=7) with various levels of disease severity and experience with PR. We refined the questionnaire based on their input. Items with a median score of 4-5 were retained while lower scored items were eliminated. New items were added based on patient comments. The current questionnaire contains 28 items across the 7 categories.

In process (Part B):

- To determine responsiveness and validity, we will examine associations between scores on the questionnaire and scores on standard assessments for symptom improvement and quality of life in a group of COPD patients before and after PR.

¹Paul A. Harris, Robert Taylor, Robert Thielke, Jonathon Payne, Nathaniel Gonzalez, Jose G. Conde, Research electronic data capture (REDCap) – A metadata-driven methodology and workflow process for providing translational research informatics support, J Biomed Inform. 2009 Apr;42(2):377-81.

Results: Current Health Status Questionnaire

The questionnaire is in its final stages of refinement, the current questionnaire is below, organized by identified domain areas.

In this first part of the study, we used the following:

Based on your experience with pulmonary rehabilitation and your own lung problems, please rate the following on a 1 – 5 scale based on how important this issue is to you.

- 1: This is not important to me.
- 2: This is slightly important to me.
- 3: This is moderately important to me.
- 4: This is important to me.
- 5: This is very important to me.

Because of my COPD...

Physical Activity

1. I have difficulty doing things with my loved ones.
2. I avoid exercise.
3. I cannot do things that I enjoy.
4. I tend to avoid leaving my home.
5. I can't walk as much or as far as I would like.

Social Activity

1. I feel held back from doing things I want to do.
2. I spend too much time alone.
3. I do not spend as much time with friends and family as I would like.
4. I feel trapped.
5. I feel helpless.

Psychological

1. I am nervous about having lung flare-ups.
2. I am anxious about not being able to catch my breath.
3. I am not very confident in my physical capabilities.
4. I have a negative outlook for the future.
5. I do not get enjoyment out of activities that I used to enjoy.
6. I am afraid of trying new things.
7. I'm frustrated with my limitations.

In part B, of this study we will use the following:

Based on your experience with your lung problems in the last two weeks, please rate each of the following on a 1-5 scale based on how often the statement applies to you.

1. None of the time.
2. Some of the time (1-5 days).
3. Half of the time (6-8 days).
4. Most of the time (9-13 days).
5. All the time (14 days).

Self – Efficacy

1. I must rely on others more than I would like.
2. I am not able to manage my everyday breathing problems.
3. I do not have enough energy for dressing or showering.
4. I do not have enough energy for cooking or shopping.

Fatigue

1. I feel fatigued throughout the day.
2. Physical activity wears me out quickly.
3. I get worn out or exhausted easily.

Breathlessness

1. Breathlessness is a major problem for me.
2. I get too breathless walking up a set of stairs.
3. I get short of breath while bending over.

Sleep

1. I do not sleep well.

Results

Prior to refining the questionnaire, we collected data from patients, caregivers, and healthcare providers on the items' importance on a scale of 1-5.

- For 27 items, 90-100% of health care providers (n=11) rated the item as important (≥4)
- There were no items where at least 90% of the patients and caregivers (n=25) agreed on the rating to be ≥4.
- There were only 2 items (mental health and knowledge of COPD) that a greater percentage of patients and caregivers rated the item as being important versus health care providers
- For items related to sleep and effects of breathlessness, compared to patients and caregivers 20-60% more health care providers rated it ≥4.

To further refine the questionnaire and understand the patient perspective, we hosted two separate patient advisory panels with 7 patients and caregivers, the research team, and PR professionals. During these panels, there were some notable findings that assisted us in refining the questionnaire.

- Items such as knowing how to use inhaled medication and knowing breathing techniques to manage breathlessness are not accurate measures of improvement as patients tend to have a false confidence prior to PR.
- Patients may not necessarily identify their COPD diagnosis as the reason for health-related quality-of-life issues. Regardless, PR did improve parts of their lives once symptoms and physical capabilities improved.
- While some items, such as sleep or managing a lung flare-up, are important for quality of life, they may not be improved upon by PR.

Conclusions

Excitingly, our research reveals a contrast between the responses of patients, caregivers, and healthcare providers. Health care providers consistently rated the items as moderately important, boasting higher average ratings across nearly every question. However, patients and caregivers demonstrated a more diverse range of ratings, indicating a clear discrepancy between these two groups. To address this disparity and ensure a comprehensive set of PROs for COPD patients, there will be further rigorous testing and refinement. Our active approach aims to bridge the gap between patients and their healthcare providers to enhance the overall quality of COPD care.

Honoring Mary Gawlicki



We thank Mary Gawlicki and the Gawlicki Family Foundation for sponsorship and ongoing involvement in our project. Mary suddenly and unexpectedly passed away this year. As a co-investigator in this project, her personal insight as a patient was invaluable. Moreover, her dedication and passion to improve the health of respiratory patients will be sorely missed. She was one of a kind. Requiescat in pace, Mary.