

Patient-reported Pulmonary Symptoms and Exacerbations in a Cohort of Patients with Alpha-1 Antitrypsin Deficiency

Radmila Choate, PhD, MPH (University of Kentucky)
 Robert A. Sandhaus, MD, PhD (National Jewish Health, AlphaNet)
 Kristen E. Holm, PhD, MPH (National Jewish Health, AlphaNet)
 David M. Mannino, MD (University of Kentucky)
 Charlie Strange, MD (Medical University of South Carolina)

BACKGROUND

- Pulmonary exacerbations in patients with Alpha-1 are associated with disease progression and poor quality of life
- Not all changes in pulmonary symptoms are recognized by patients as exacerbations

METHODS

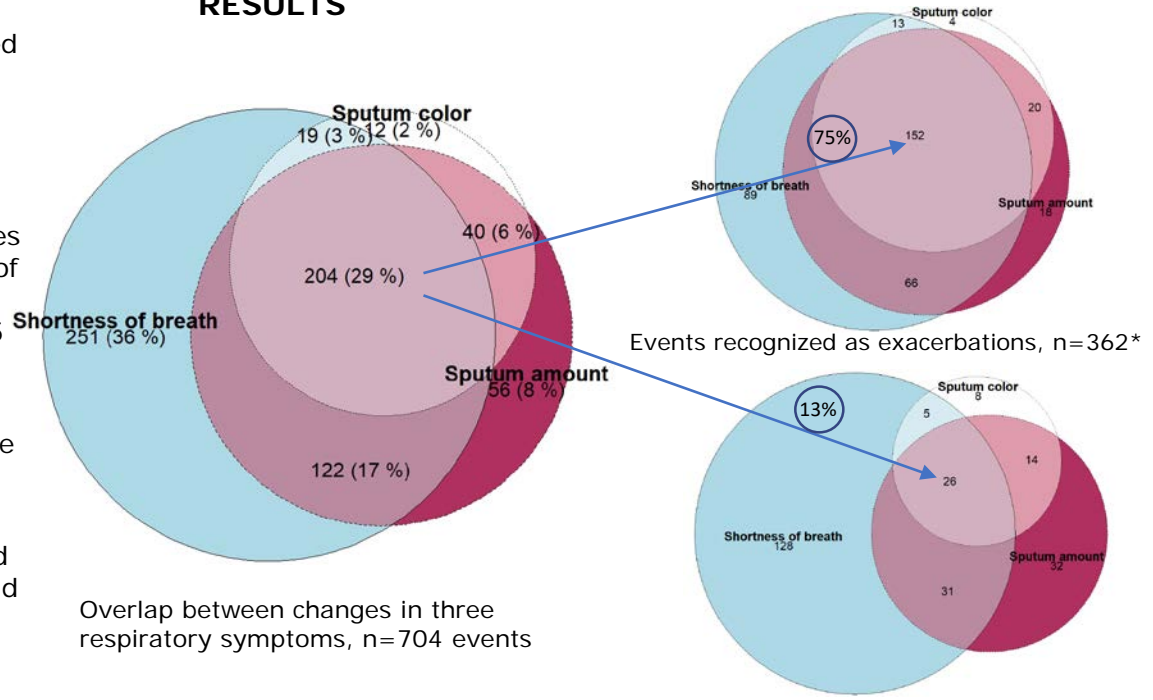
- Monthly survey of changes in usual respiratory symptoms, exacerbations, and management
- AlphaNet Step Forward Study participants
- One-year data, October 2009 - 2010
- Per-patient and per-event data analyses

CLINICAL IMPLICATIONS

- Changes in usual pulmonary symptoms are not universally recognized as exacerbations
- The need to incorporate both symptom-based and management definitions of COPD exacerbation

- 316 participants (mean age 58±10 years, 53% female, 88% ZZ phenotype, 57% used O₂)
- 33% of the participants reported no exacerbations, 37% reported 1, and 31% ≥2 exacerbations in one year
- In the overall cohort, 797 events of changes in respiratory symptoms in one year (704 of those with changes in shortness of breath, sputum color or amount), average 2.7±1.5 symptoms per event (range 1-7)
- 380 events (48%) recognized by participants as exacerbations, 81% of those managed with antibiotics, 53% with steroids, and 41% with both.
- 39% of exacerbation events were managed by speaking with a pulmonary specialist and 37% by going to the doctor's office
- 56% of the events not recognized as exacerbations were self-managed by the participants

RESULTS



*The above numbers do not add up to 704 due to missing data on exacerbation status

PATIENT'S PERSPECTIVE in recognizing changes in pulmonary symptoms as exacerbations is critical

PRESENTED AT

