SELECTING PROMIS ITEM BANKS FOR PATIENTS WITH COPD

AN INTERVIEW STUDY

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OUTLINE

1. Short introduction to our research project and collaborators
2. Goals of the current study
3. Short overview of PROMIS framework
4. Results
5. Preliminary results from ongoing parallel study
6. Summary
7. Questions?

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GOAL OF THE PROJECT

• Received funding from the Dutch Lung Foundation for a 3 year project
• Muirne Paap as postdoc, Job van der Palen senior investigator
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- Received funding from the Dutch Lung Foundation for a 3 year project
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- Ultimate goal: Computerized Adaptive Test (CAT) to measure QoL in patients with COPD
- QoL consists of several domains: multidimensional CAT
- Importance of comparability. Creating overlap with other QoL item banks facilitates this. PROMIS perfect candidate
- Disease specific vs generic
- Collaboration with PROMIS Netherlands (Caroline Terwee) and McGill University (Sara Ahmed)
GOAL OF THE PROJECT (2)

Most important steps:

- Determine what the most relevant/important domains of QoL are for patients with COPD
- Use/create item banks for these domains and callibrate them with IRT
- Build a CAT taking into account the relationship among domains
GOAL OF THE PROJECT (2)

• Determine what the most relevant/important domains of QoL are for patients with COPD

How?
• Interviews with patients
• Interviews with Health Professionals (HPs)

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INTERVIEWS WITH PATIENTS

1. Determine which **PROMIS domains** are most relevant and important for patients with COPD (completed)

1. Determine which components should be incorporated in the disease-specific item bank (future)
PROMIS FRAMEWORK (www.nihpromis.org)
PARTICIPANTS

- 21 patients were interviewed by a trained interviewer
- 2 GOLD-I, 8 GOLD-II, 9 GOLD-III, 2 GOLD-IV
- 13 male, 8 female
- Mean age 66.6 years (range 52-84)
- 4 patients were hospitalized
- 2 locations: Enschede (smaller city) and Rotterdam (large city)
INTERVIEW SETUP

• Open question: *In what way does your COPD impact your quality of life?*

• Then 16 PROMIS domains were presented: 5 had to be selected and ordered (importance)

• All comments made during this process were incorporated into the analysis
RESULTS

• Most popular domains: instrumental support, fatigue, physical functioning, ability to participate in social roles and activities, emotional support

• Effect of disease severity (GOLD I/II vs. GOLD III/IV): lower levels more focus on physical symptoms, higher levels more emphasis on social relationships

• 4 patients did not choose any domains!
GOAL OF THE PROJECT

• Determine what the most relevant/important domains of QoL are for patients with COPD

How?

• Interviews with patients
• Interviews with Health Professionals (HPs)
PRELIMINARY RESULTS

• Same interview setup as with patients

• So far 10 HP’s have been interviewed

• Most popular domains: fatigue, physical functioning, depression, satisfaction with participation in social roles and activities, emotional support

• Depression: choice based on literature, not own experience

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SUMMARY

• We will select 2-4 PROMIS domains based on results from interview studies

• Most likely candidates: fatigue, physical functioning, ability to participate in social roles and activities, emotional support, (depression??)

• Quite high agreement patients and HP’s, except for depression

• Next step: populating disease-specific bank with items

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VISUAL REPRESENTATION M-CAT (PRELIMINARY)

COPD specific

Fatigue

Emotional support

Physical functioning

Existing questionnaires

New items

PROMIS itembanks

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