DEVELOPING A M-CAT TO MEASURE HRQOL IN COPD

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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 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
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
• MP: background in clinical psychology and psychometrics
• Ultimate goal: Computerized Adaptive Test (CAT) to measure QoL in patients with COPD
• QoL consists of several domains: multidimensional CAT
• Collaboration with Bernard Veldkamp, PROMIS Netherlands (Caroline Terwee) and McGill University (Sara Ahmed, Jean Bourbeau)
GOAL OF THE PROJECT

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 calibrate them with IRT
- Build a CAT taking into account the relationship among domains

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GOAL OF THE PROJECT

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

- Important question when selecting/developing an instrument to measure HRQoL in any patient group: do you want to use GENERIC vs DISEASE-SPECIFIC instruments/domains?

- We propose to use both types of measures! Disease-specific measures have been found to be more sensitive to measuring change, and generic…
GOAL OF THE PROJECT

GENERIC INSTRUMENTS/DOMAINS

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

• Generic instruments can be used with any (patient) population, facilitating direct comparison among populations, including the general population.

• Important to identify “disease-relevant outcomes” – defined as domains that are considered relevant to individuals living with the disease (PROMIS Statistical Center Working Group, 2014)

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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)

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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 items 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)

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INTERVIEW SETUP

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

• *All comments made during this process were incorporated into the analysis*
**In what way does your COPD impact your quality of life?**

<table>
<thead>
<tr>
<th>Main theme</th>
<th>Sub-theme</th>
<th>Selected unit</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical health</td>
<td>Light physical activity causes physical complaints</td>
<td>“When I have to walk up and down the stairs, I move up the stairs in a sitting position and then I’m very short of breath.”</td>
<td>Going up the stairs is a difficult and laborious exercise, which causes shortness of breath.</td>
</tr>
<tr>
<td></td>
<td>Autonomy</td>
<td>“Now I have to ask others can you please help me? Mind you, I haven’t done it yet, but that’s very hard.”</td>
<td>It is difficult to ask others for help.</td>
</tr>
<tr>
<td></td>
<td>Autonomy</td>
<td>“Then I get irritable, because I like to do everything myself, and I’m not able to do that.”</td>
<td>Loss of independence causes anger.</td>
</tr>
</tbody>
</table>
RESULTS

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

- Number of times a domain was selected was counted

- And again, all comments made during this process were incorporated into the analysis

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RESULTS

- The most relevant PROMIS domains for patients with COPD were: **physical health** (fatigue, physical functioning) and **social health** (instrumental support, ability to participate in social roles and activities, companionship, and emotional support).

- Furthermore, another important domain emerged that is not yet covered by PROMIS: **coping with COPD**.

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

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PRELIMINARY RESULTS

• Same interview setup as with patients
• 14 HP’s were interviewed
• Open question: same as patients. Social health, physical health and coping with COPD.

• Most popular PROMIS domains: fatigue, physical functioning, emotional support, depression, satisfaction with participation in social roles and activities
• 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
Some authors advocate focusing only on the patient perspective if the agreement between patients and HP’s is not perfect

- We do not agree; depression is still a taboo-subject for many; especially elderly people have been found to underreport depressive symptoms. Therefore HP perspective has added value!!


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VISUAL REPRESENTATION M-CAT (PRELIMINARY)

COPD specific

Fatigue

Emotional support

Physical functioning

Existing questionnaires

New items

PROMIS itembanks

UNIVERSITEIT TWENTE.
WHY M-CAT?

Several reasons. I will name two, perhaps Bernard can elaborate.

1. Correlations among dimensions can be used to get more precise estimates

2. Attenuation effect; the correlation estimates are better than if you would use unidimensional CATs and calculate the correlations among the domains afterwards
Thank you