Multidimensional measurement of fatigue in patients with rheumatoid arthritis

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PhD project

Aim: Development of a multidimensional item pool to measure fatigue in patients with rheumatoid arthritis (RA)

- Based on patient perspective
- Analyzed with multidimensional IRT
- Basis for construction of multidimensional CAT

Execution in four studies
(November 2007 – October 2011)
RA: Rheumatoid arthritis

Progressive, invalidating disease with changing course, chronic inflammation causes erosion and deformation of bones and joints

Symptoms: Swollen and painful joints, pain, stiffness, fatigue, restrictions in daily activities, worse mental and social well-being

Measurement: laboratory values, radiographic damage, counting swollen and painful joints

But: Often no strong relation with subjective experience of health and quality of life => patient perspective: pain, physical functioning, general health and fatigue
RA: Rheumatoid arthritis
Patient perspective

- Patients’ perspective not always the same as perspective of health professional:
  e.g. What is the aim of the treatment? Which complaints are more important and which are less important? When are health status and well-being really improved? ....

“Nothing about us without us”

- Patient votum at OMERACT (Outcome measures in Rheumatology):
  Fatigue is an important symptom, mostly forgotten
Experience of fatigue

- Annoying symptom with far-reaching consequences
- Multidimensional (fatigue is a physical experience, but also cognitive and emotional)
- Different from normal fatigue (no longer earned, more extreme)
- Fatigue is often neglected by medical doctors in the severity and treatment of RA

“You feel like you’re carrying a load of flour on your back. That there’s always something weighing your shoulders down, that you’ve got to lug that around with you.” (woman, 58 years old).
Measuring fatigue

What´s “wrong” with existing fatigue measurement instruments?

- Unsatisfactory content validity (not developed from patient perspective)
- Traditional format (fixed length-questionnaires)
- Patient burden possibly higher than necessary
- Not measuring everything that should be measured (not all dimensions included)

→ Need for more appropriate and effective way of measurement
Adequate measurement of fatigue in RA is important...

- ... for science
  - to get more insight into fatigue and its causes
  - for the evaluation of interventions or treatments to reduce fatigue

- ... for clinical practice
  - to facilitate communication about fatigue between patients and rheumatologists / health professional

- ... for society
  - fatigue is an important predictor of work absenteeism and participation restrictions in patients with RA
Advantages of IRT and CAT

- Item response theory:
  - Model on item level
  - Separate parameters for persons and items

- Computer adaptive testing:
  - Individual measurement (per patient items selected based on previous response, tailored to individual level)
  - Precise and comprehensive measurement with few items

→ Reduction of patient burden; measurement of fatigue will not only be more precise, but will also take less time and energy
Steps for development of the fatigue CAT

- Two studies from patient perspective:
  - In-depths interviews on experience of fatigue
  - Q-sort study
- Delphi study with experts to select adequate items to measure fatigue in RA
- IRT analysis to develop multi-dimensional item pool
- Construction and validation of the CAT in consecutive project

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Construction of preliminary item pool

Aim: large and comprehensive item pool to cover all dimensions of fatigue experience in RA

- Inclusion of all items and dimensions of validated fatigue scales in RA
- Supplemented with items from interview material and Q-sort study
- To check for possibly missing aspects also looked at fatigue questionnaires not validated in RA

Resulted in 294 items spread among 12 dimensions

- Items from existing scales included in original format with belonging response options
Delphi study

- Patients, nurses and rheumatologists in the Netherlands
- Evaluation of the item pool (294 items)
  - Criteria: include if 80% of participants rated items as adequate, reject if 50% or less rated item as adequate, remaining items discussed and adjusted according to given comments and presented for re-evaluation
  - After two rounds all items included or rejected
    → item pool consisting of 245 items
Measuring fatigue – overview of fatigue dimensions and number of selected items

<table>
<thead>
<tr>
<th>Dimension (number items)</th>
<th>Meaning of the dimension</th>
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<tbody>
<tr>
<td>severity (5)</td>
<td>intensity of fatigue</td>
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<td>frequency (9)</td>
<td>occurrence of fatigue</td>
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<td>duration (5)</td>
<td>presence of fatigue over time</td>
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<td>changes in fatigue (9)</td>
<td>variability and unpredictability of fatigue</td>
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<td>perceived causes of fatigue (18)</td>
<td>circumstances that according to patients influence their fatigue</td>
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<td>energy (18)</td>
<td>amount of energy, for example to undertake an activity</td>
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<td>sleep/rest (14)</td>
<td>patients’ need for sleep or rest</td>
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<td>body feeling (15)</td>
<td>feeling/manifestation of fatigue in the body</td>
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<td>cognition/concentration (15)</td>
<td>impact of fatigue on the ability to concentrate, or on tasks that require thinking</td>
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<td>coping (23)</td>
<td>ways of dealing with fatigue, e.g. used strategies or thoughts about fatigue</td>
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<td>negative emotions/mood (29)</td>
<td>negative emotions or mood caused by fatigue</td>
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<td>consequences (85)</td>
<td>impact of fatigue on daily life</td>
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Dimensions for linking design

12 small dimensions connected to larger dimensions

- Severity, frequency, duration - SEVERITY
- Sleep/rest, body feeling - PHYSICAL
- Cognition/concentration, negative emotions/mood - MENTAL
  
  Energy – SPLIT UP in physical and mental

- Changes in fatigue
- Perceived causes of fatigue } “new” dimensions
- Coping

- Consequences – very large dimensions
## Linking design

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<th>Consequences II</th>
<th>Change</th>
<th>Causes I</th>
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Conducting IRT study

- 478 patients from three different hospitals from the region Twente completed one version of the questionnaire

- Currently further data collection and data analysis in progress
Analysis of the item pool

Aim: this study will show which of the fatigue dimensions, that came forward from previous studies, are important for the CAT development

- Factor analysis will be performed and subsequently a multidimensional IRT model will be fitted to the data
- Poorly fitting items or those showing differential item functioning (DIF; e.g. on age, gender) will be removed

Validated multidimensional item bank will be used for the construction of the multidimensional CAT
Multidimensional IRT / CAT

Unique source of information:
Knowledge of amount of association between dimensions in population of interest *in addition* to individual's performance / trait level

Simultaneous measurement of multiple dimensions increases efficiency of adaptive item selection and scoring algorithms

Multidimensional IRT / CAT

Cross information gathered from items of correlated dimensions can be effectively modeled by MIRT; in case of CAT it aids
- selection of items, leading to the choice of more informative items
- estimation of ability, leading to scores with added precision

Segall: multidimensional adaptive testing can provide equal or higher precision with about one third fewer items than required by unidimensional adaptive testing

→ increased measurement efficiency – manifested by either greater precision or reduced test lengths
Future steps

- **CAT:**
  - Construction of the multidimensional CAT in future project
  - Validation and cross-cultural validation of the fatigue CAT

- **Practical implications:**
  - Regular measurement of fatigue at outpatient clinic to make possible to provide tailored psychological treatment if necessary
  - Technology to efficiently gain data and have them available in consultation immediately
Thank you very much for your attention!

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