

# 3rd Research Forum of the European Association for Palliative Care “Methodology for Palliative Care Research”

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A European Association for Palliative Care Research Network study

## Palliative Assessment Tool - computerized - PAT-C

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### Background

- ☞ Palliative care patients have various subjective symptoms: often more than five at the time
- ☞ We want to assess the maximum of symptoms and minimize the burden of the patients
- ☞ Little consistency on how to measure subjective symptoms make comparisons difficult
- ☞ An international tool for symptom assessment will advance clinical care and research
- ☞ Hand-held bedside computer technology and item response theory (IRT) might facilitate this

### Overall PAT-C aims

- The overall objective is to develop and field test a dynamic, international and computer-based tool for symptom assessment in palliative care:
- ☞ simple enough to be used frequently with high compliance
  - ☞ comprehensive enough to gather the essential information in a standardized manner

### International collaboration

The EAPC Research Network expert group: Carl Johan Fürst, Franco De Conno, Philippe Poulain, Augusto Caraceni, Lukas Radbruch, Geoffrey Hanks

### Item response theory (IRT) and Computer adaptive testing (CAT)

IRT is a mathematical model for item calibration  
A calibrated item pool allows for the prediction of answers to items not even asked  
This yields individually tailored questionnaires with better sensitivity and precision  
A computer is programmed to select and present the most appropriate items on a touch screen monitor  
The score will be calculated and presented immediately

### PAT-C Pain module

Jacob Hølen

More than 70% of the palliative care patients report pain Pain assessment is crucial for pain management

Limitations with today's tools:

- Ceiling effects
- Missing data/missing items
- Burdensome to use for the patient
- Burdensome to calculate the score
- Difficult to interpret the score
- Lack of a standard to allow for meta-analyses
- PAT-C pain will be a multidimensional self-report tool. IRT and CAT can reduce the listed limitations

### PAT-C Cognitive function module

Marianne Jensen Hjemstad

Loss of cognitive functions is frequent in palliative care

- Impact on quality of life (QOL), informed consent, decision making, treatment compliance

Delirium is prevalent in palliative care

- 28% to 52%, although overlooked, misdiagnosed
- Frequently untreated, but potentially reversible
- Improvement in diagnostics seems warranted

Valid and reliable assessment of cognitive function is of great relevance for practice and research in palliative care

### A systematic approach

- I. Determination of the content of the measure within each symptom area
- II. Generation of specific item pools, with individual research protocols

### Methodology

- I. Literature searches, interviews with health care workers, expert panel and patients defining relevant issues for the specific symptom area
- II. Operationalization of these issues
- III. Pilot testing of the preliminary set of items/dimensions followed by interviews to define problematic areas/issues
- IV. When the preliminary version is approved by health care workers and the expert panel, it will be field tested in an international study

### PAT-C Physical function module

Marit Jordhøy

All palliative care patients experience deterioration in physical function

- reflects disease progression and symptom control
- impacts QOL, and is basic for treatment planning, incl. rehabilitation, and organization of care
- given little attention in assessment tools developed for palliative care, and methods from other setting shows considerable floor effect

A valid and reliable assessment of physical function is strongly needed for practice and research in palliative care

