An evaluation of quality-of-life measures for use in palliative care

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Relevance

- Improving QoL main focus of palliative care
- Large variety of QoL questionnaires
- What are adequate instruments regarding feasibility and quality of the instruments?
- Which instruments can best be used?
Purpose

- To give an overview of the QoL measurement instruments available for use in palliative care
- To evaluate the feasibility and clinimetric quality of QoL measurement instruments suitable for use in palliative care.
Methods

- Systematic literature research:
  
  Pubmed, Embase, CINAHL, PsycINFO
  
  1990 - April 2008

- 2015 hits

- Titles and abstracts were screened using the in-/exclusion criteria
### In- and exclusion criteria

<table>
<thead>
<tr>
<th>Inclusion:</th>
</tr>
</thead>
<tbody>
<tr>
<td>› Development or validation of an instrument</td>
</tr>
<tr>
<td>› Measurement of QoL in patients for whom there are no curative treatment options</td>
</tr>
<tr>
<td>› At least one measurement property evaluated</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion:</th>
</tr>
</thead>
<tbody>
<tr>
<td>› Non English and Dutch language studies</td>
</tr>
<tr>
<td>› Studies on instruments to measure quality or satisfaction with care</td>
</tr>
<tr>
<td>› Reviews, trials, letters, editorials etc.</td>
</tr>
</tbody>
</table>
QoL domains

- Physical comfort
- Physical functioning
- Cognitive functioning
- Psychological well-being
- Social well-being
- Spiritual well-being
- Perceived quality of care
Data extraction

- Instrument characteristics
  - Target population, domains, number of items and response options, completion time, etc.

- Measurement properties
  - Terwee et al. (2007): ‘Quality criteria for measurement properties of health status questionnaires’
  - Rating options: +/-?/-/0
Measurement properties I

- Content validity:
  - The degree to which the concepts of interest are represented by the items

- Construct validity:
  - The extent the instrument measures what is intended to measure

- Internal consistency:
  - The extent to which all items in a (sub) scale are correlated, measure the same construct
Measurement properties II

- Reliability:
  - The degree to which repeated measurements provide similar results

- Responsiveness:
  - The ability of an instrument to detect important change over time

- Interpretability:
  - The degree to which (change) scores on an instrument can be interpreted
Results

- 69 studies were studied full-text
- 33 studies were excluded
- 29 instruments
  - Of which 7 were revised or short versions of the original instruments
# Results - *Instrument characteristics*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Range/frequencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Target population</td>
<td></td>
</tr>
<tr>
<td>Cancer patients</td>
<td>11</td>
</tr>
<tr>
<td>Terminally ill/palliative patients</td>
<td>16</td>
</tr>
<tr>
<td>Hospice patients</td>
<td>2</td>
</tr>
<tr>
<td>Number of domains</td>
<td>1 - 6</td>
</tr>
<tr>
<td>Number of items</td>
<td>8 – 138</td>
</tr>
<tr>
<td>Completion time</td>
<td>2 - 76 minutes</td>
</tr>
<tr>
<td>Recall period</td>
<td>None / 24 hours – 1 month</td>
</tr>
<tr>
<td>Reporting</td>
<td></td>
</tr>
<tr>
<td>Self-report</td>
<td>23</td>
</tr>
<tr>
<td>Proxy</td>
<td>6</td>
</tr>
<tr>
<td>Interview</td>
<td>4</td>
</tr>
</tbody>
</table>
## Results – Measurement properties

<table>
<thead>
<tr>
<th>Measurement properties</th>
<th>Content validity</th>
<th>Construct validity</th>
<th>Internal consistency</th>
<th>Reliability</th>
<th>Responsiveness</th>
<th>Interpretability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>18 15 0 0</td>
<td>14 15 0 0</td>
<td>9 20 2 2</td>
<td>2 9 2 20</td>
<td>0 8 0 25</td>
<td>0 5 0 28</td>
</tr>
</tbody>
</table>

- **Interpretability**
- **Responsiveness**
- **Reliability**
- **Internal consistency**
- **Construct validity**
- **Content validity**
Discussion

- This study can help researchers and clinicians in their choice of an adequate instrument
- High standards for the assessment of measurement properties
- Negative ratings does not mean that the instrument is inadequate
- Further testing of existing instruments instead of developing new ones
- (Inter)national collaboration
Take home message:

Do not develop new instruments
Focus on (inter)national collaboration to further develop & test instruments

Thank you for your attention

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Reference

Evaluation of quality-of-life measures for use in palliative care: a systematic review

Albers G, Echteld MA, de Vet HC, Onwuteaka-Philipsen BD, van der Linden MH, Deliens L

Palliative Medicine. 2010 Jan;24(1):17-37