Background

Pain and discomfort are common in patients with severe dementia or patients dying with dementia. They are at risk for undertreatment because typically they are no longer able to verbalize pain or discomfort or indicate sources of suffering. The use of observational tools may assist in the recognition of a need to improve comfort, and as such is consistent with palliative care.

Whereas tools for pain assume the source of discomfort is pain, tools for (dis)comfort aim to detect symptoms other than pain; being cold, emotionally distressed or having another unmet need. Some tools focus on mixed constructs, not just pain or physical discomfort but, for example social and spiritual wellbeing. Thus the concept of “pain” and “discomfort” in people with advanced dementia has been broadened.

These various types of tools have been validated in severe dementia (but not all at the end of life) and there has been little or no cross-validation or even comparison of items.

Aim

To map and compare in detail items and domains covered by tools to assess pain and comfort in severe dementia or dementia at the end of life.

Methods

A collaborative project involving the EU funded Co-operation in Science and Technology (COST) Action “Pain & Impaired Cognition” network.

Our initial approach was three independent raters (a nurse, psychologist and epidemiologist) undertaking a conceptual analysis, classifying each individual item in a range of tools into domains, without referring to pre-existing frameworks.

There was less agreement on a psychological domain; on distinguishing between “affect” and “mood,” and on categorizing as “behavioural,” “social,” or “spiritual.”

Because of the complexity of classification, it was difficult to classify items that referred to different levels of observation: those requiring exact observation of vocalisation, facial expression or body language (e.g., frowning, leans to side) versus items indicating changes, or broader concepts requiring some interpretation (e.g., angry, peace).

We then adopted an additional approach to assess in detail how the items differed. We used categories from our initial work, supplemented by categories from the literature: automatic and controlled processes (McCraery, Craig et al., Pain 2011) and to communicative and protective pain behaviours (Martel et al., several publications).

Results

Domains identified

• There was less agreement on psychological domains; between “affect” and “mood,” and on categorizing “behavioural,” “social,” or “spiritual.”

• The pain and (dis)comfort tools covered almost identical domains

Differences between specific tools

• The differences between pain instruments (e.g. PACSLAC and Doloplus in addressing facial expressions) may be larger than between a pain tool and a comfort tool (PAINAD and DS-DAT)

• Regarding items, “guarding” was only included in a pain tool

• The largest differences concerned additional items in comfort tools, such as “positive” items (eye contact, content facial expression, relaxed body language), and items indicating other concepts (sadness and fear)

Table 2—Example classification from one pain and one discomfort tool

<table>
<thead>
<tr>
<th>DOLOPLUS items</th>
<th>Negative or positive indicator</th>
<th>Closeness to overall concept measured</th>
<th>Palliative care domain</th>
<th>Behaviours communicate pain to others vs. to protect the body</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somatic complaints</td>
<td>negative</td>
<td>refers to pain implicitly</td>
<td>physical/psychosocial</td>
<td>communicative</td>
</tr>
<tr>
<td>Protection of sore areas</td>
<td>negative</td>
<td>refers to pain explicitly</td>
<td>physical</td>
<td>protective</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EOLD-CAD items</th>
<th>Negative or positive indicator</th>
<th>Closeness to overall concept measured</th>
<th>Palliative care domain</th>
<th>Behaviours communicate pain to others vs. to protect the body</th>
</tr>
</thead>
<tbody>
<tr>
<td>MOAN</td>
<td>Response options:</td>
<td>positive</td>
<td>no reference</td>
<td>comfort but obviously related / indicative</td>
</tr>
<tr>
<td>CRY</td>
<td>Response options:</td>
<td>positive</td>
<td>no reference</td>
<td>comfort but obviously related / indicative</td>
</tr>
</tbody>
</table>

Limitations

• There are no validated frameworks with which to analyse pain tools

• Coding of items, even when done independently is subjective

Conclusions

• Pain and comfort tools cover almost identical domains

• Comfort tools include a broader item pool

• Some items (lack of positive indicator) may be tested for additional value to pain instruments

• Further concurrent testing of pain and comfort tools is needed to assess validity of each item for measuring pain or (dis)comfort

Main source of funding

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1UZ University Medical Center, EMGO Institute for Health and Care Research, Dept. General Practice & Elderly Care Medicine, Amsterdam, Netherlands; 2Maas Mira Palliative Care Research Unit, University College London, UK; Ghent University & VUB University Brussels, End of Life Care Research Group, Brussels, Belgium; 3University Hospital Gothenburg, Sweden; 4Lady Health Palliative Care Unit, Bear-Shave, Israel; 5Lancashire County Hospital, United Kingdom; 6Department of Palliative Medicine, University Hospital Born, Born, Germany; and 6Palliative Care Centre, Midwifery Hospital Born/Rhein-Sieg, Germany.

2Geriatric Medicine University Hospital Ghent, Belgium.