Assessment and management of pain in dementia

Dr Elizabeth Sampson
Reader, Marie Curie Palliative Care Research Department
Division of Psychiatry, UCL, London
Consultant in Liaison Psychiatry, North Middlesex University Hospital

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Overview

1. How common is pain in people with dementia
2. Challenges of assessing pain and how this can be improved
3. Management of pain
4. Future directions
Consequences of pain

- Quality of life
- Functional decline
- Changes in behaviour
- Carer depression
- Indicator of personhood
Prevalence of pain in people with dementia

• Nursing homes
  – “mild/moderate” 47% (Zwakhalen et al. 2009)
  – “severe” pain at rest 19%, on movement 60% (Sampson et al. submitted)

• Community
  – “slight/mild” 65% report pain
  – “moderate” 27%
  – “severe” 8% (Shega et al. 2004)

• Acute hospitals
  – at rest 28%
  – on movement 65%
  – persistent 36% (Sampson et al. 2015)
Chronicity of pain

(Sampson et al. submitted)
Causes of pain

• At rest “incident” or during movement care tasks “procedural”
• Acute pain
  – Dental
  – Headache/migraine
  – DVT
  – Heart attack
• Chronic pain
  – Ulcers
  – Contractures and lack of activity, poor positioning
  – Arthritis
## Challenges of identifying pain in people with dementia

<table>
<thead>
<tr>
<th>Person with dementia</th>
<th>System</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Memory</td>
<td>• Tools</td>
</tr>
<tr>
<td>– Episodic</td>
<td>• Integration onto practice</td>
</tr>
<tr>
<td>– Semantic</td>
<td>• Knowing the person</td>
</tr>
<tr>
<td>• Speech</td>
<td>• Staff beliefs</td>
</tr>
<tr>
<td>➢ Identifying location</td>
<td>– “They feel less pain”</td>
</tr>
<tr>
<td>➢ Describing</td>
<td>– “Its just their behaviour”</td>
</tr>
<tr>
<td>– Type</td>
<td></td>
</tr>
<tr>
<td>– Intensity</td>
<td></td>
</tr>
<tr>
<td>• Diagnostic</td>
<td></td>
</tr>
<tr>
<td>overshadowing</td>
<td></td>
</tr>
</tbody>
</table>
Wong-Baker FACES Pain Rating Scale

- only 49% could use the FACES pain tool which is commonly used in acute hospitals
- difficulties were associated with increasing severity of dementia (Sampson et al. 2015)
Memory

Human Memory

Sensory Memory
(< 1 sec)

Short-term Memory
(Working Memory)
(< 1 min)

Long-term Memory
(life-time)

Explicit Memory
(conscious)

Implicit Memory
(unconscious)

Declarative Memory
(facts, events)

Procedural Memory
(skills, tasks)

Episodic Memory
(events, experiences)

Semantic Memory
(facts, concepts)
How do you **know** you are in pain if you don’t know what pain is anymore?
Semantic pain memory

Test for the semantic memory of pain

9 pain pictures
6 related non-painful pictures
When pain memories are lost…

- Compared with the controls, people with dementia were less able to identify painful situations.
- They used fewer categories to define their concept of pain.
- Performance was related to the reported presence and severity of pain.

- Reduction in semantic memory for pain is associated with a decline in reported pain (Oosterman et al. 2014).
How do you show you are in pain if you don’t know what pain is any more?
Principles of pain assessment

- Ask
- Clinical observation
- Pain assessment tool (e.g. Abbey or Painad)
- Medical history (known painful conditions)
- Information from relatives and carers (individual pain indicators)
<table>
<thead>
<tr>
<th>INDICATOR</th>
<th>SCORE = 0</th>
<th>SCORE = 1</th>
<th>SCORE = 2</th>
<th>TOTAL SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing</td>
<td>Normal breathing</td>
<td>Occasional laboured breathing; Short period of hyperventilation</td>
<td>Noisy laboured breathing. Long period of hyperventilation. Cheyne-Stokes respiration</td>
<td></td>
</tr>
<tr>
<td>Negative</td>
<td>None</td>
<td>Occasional moan/groan. Low level, speech with a negative or disapproving</td>
<td></td>
<td></td>
</tr>
<tr>
<td>vocalisations</td>
<td></td>
<td>quality</td>
<td>Repeated troubled calling out. Loud moaning or groaning. Crying.</td>
<td></td>
</tr>
<tr>
<td>Facial expression</td>
<td>Smiling or inexpressive</td>
<td>Sad, frightened, frown</td>
<td>Facial grimace</td>
<td></td>
</tr>
<tr>
<td>Body language</td>
<td>Relaxed</td>
<td>Tense, distressed, pacing, fidgeting</td>
<td>Rigid, fists clenched. Knees pulled up. Striking out. Pulling or pushing away</td>
<td></td>
</tr>
<tr>
<td>Consolability</td>
<td>No need to console</td>
<td>Distracted by voice or touch</td>
<td>Unable to console, distract or reassure</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>TOTAL: (Max 10)</td>
<td></td>
</tr>
</tbody>
</table>
### Behavioural indicators of pain

<table>
<thead>
<tr>
<th>Motor</th>
<th>Emotional and cognitive</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Agitation</td>
<td>- Increased confusion</td>
</tr>
<tr>
<td>- Fidgeting</td>
<td>- Withdrawal</td>
</tr>
<tr>
<td>- Repetitive movements</td>
<td>- Increased calling out</td>
</tr>
<tr>
<td>- Tense muscles</td>
<td>- Changes in sleep pattern</td>
</tr>
<tr>
<td>- Decreased function</td>
<td>- Tears or crying</td>
</tr>
<tr>
<td>- Body bracing</td>
<td>- Panic</td>
</tr>
<tr>
<td>- Aggression</td>
<td>- Repetitive verbalisations</td>
</tr>
<tr>
<td>- Resistance to care</td>
<td></td>
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</tbody>
</table>
The association between pain and BPSD

<table>
<thead>
<tr>
<th></th>
<th>PAINAD (Pain during movement)</th>
<th></th>
<th>PAINAD (Pain at rest)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unadjusted</strong></td>
<td>(930 observations on 230 participants)</td>
<td><strong>Adjusted</strong></td>
<td>(928 observations on 229 participants)</td>
</tr>
<tr>
<td><strong>Behave-AD scale</strong></td>
<td>Coef.</td>
<td>95%CI</td>
<td>P</td>
</tr>
<tr>
<td></td>
<td>0.21</td>
<td>[0.08, 0.35]</td>
<td>0.002</td>
</tr>
</tbody>
</table>

*Adjusted for age, gender, hospital, Functional Assessment Staging category, Charlson score and reason for admission (Sampson et al. 2015)
Pain and BPSD

*Adjusted for age, gender, hospital, Functional Assessment Staging category, Charlson score and reason for admission (Sampson et al. 2015)
A malignant cycle

- Pain and discomfort
- Loss of centered care
- Loss of personhood
- Staff disengagement
- Needs Driven Behaviour
- Communication
It is worthwhile treating pain

Husebo et al. BMJ 2011
How can we help this person with dementia?
Managing pain- treatment strategies

- Regular **NOT** as required
- Consider specific cause of pain
- Consider alternate modes of administration
  - Patches
- Consider polypharmacy and renal or liver disease
- **Manage** the side effects
  - Constipation
  - Gastroprotection
  - Monitor for urinary retention
BePAID-management of pain

• Of those who experienced pain at any time during admission, at movement or at rest only 65% were prescribed an analgesic

• Preliminary analysis suggests that pain medications were only given to 30% of those who were in pain

• ONLY medication was prescribed
Managing pain - pharmacological options

- **Mild**
  - Simple
  - Paracetamol
  - Ibuprofen

- **Moderate**
  - Weak opioids
  - Codeine

- **Severe**
  - Strong opioids
  - Diamorphine
  - Fentanyl
Managing pain without drugs

- Movement
- Massage
- Heat or cold
- Physiotherapy
- Occupational therapy
- Distractions or activity
Comprehensive pain management cycle

Its complicated…

**Cognitive Process**
- **Information**
  - Cue acquisition
- **Judgment**
  - Hypothesis generation
  - Hypothesis evaluation
- **Decision**
  - Weighting of treatment options
  - Value associated with treatment options

**Clinical Process**
- **Formal pain assessment instruments:** Self-report and observational
- **Pain related information from MDT**
- **Pain related information from caregivers**
- The patient has pain:
  - Level of pain
  - Type of pain
- **Appropriate Pain Management Strategy**

**Feedback Loop**

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Fig. 1. Correspondence between cognitive and clinical process for the recognition, assessment and management of pain.

Dowding et al. 2015
What do we mean by pain?

Loeser pain model
The utility of PAINAD in assessing pain in a UK population with severe dementia.

- 79 care home residents
- 13 in pain (16%)
- 26 scored above 2 on PAINAD (33%), but non-pain causes
- Sensitivity of PAINAD: 92%
- Specificity of PAINAD: 61%
- Significant decrease in “pain” following intervention (p = 0.008)

(Jordan A et al. 2011)
Pain vs. distress?

- Controversial
- Specificity of behaviours
- ? May lead to over prescription of analgesics
- What else may be causing distress

(Cohen- Mansfield et al. 2013)
Moving on

• Deeper understanding of pain, discomfort and how people with dementia express these
• Complex and context sensitive interventions
• National and international collaborations
Thank you

E.sampson@ucl.ac.uk
@PainandDementia