Experience assessment and management of pain in people with dementia

MARIA FRAMPTON

Abstract

Pain is an inherently subjective experience that is difficult to prove. In a cognitively impaired older person whose verbal fluency is declining, both the experience and expression of pain are altered. Assessment poses many difficulties. Consequently the older person with dementia and pain may be under-treated and poorly managed. This review addresses each of these issues and makes recommendations for more effective care in the future. The search strategy for this review was carried out using Medline (1990–2002), Embase (1989–2001) and ClinPSYCH (1990–2001) databases. References cited within these sources were also reviewed. Searches were limited to English language studies. The quality of relevant studies retrieved was assessed and information from relevant papers synthesised using narrative summary.

Keywords: pain, dementia, cognitive impairment, assessment, management

Introduction

A comprehensive, systematic approach to physical assessment in cognitively impaired older persons is necessary not only to reveal covert pathology but also to investigate and remediate symptoms such as pain. Pain is defined as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage' [1]. It is a highly individual experience shaped by context and beliefs about its meaning [2].

The context

Dementia results from the development of multiple cognitive deficits manifested by both memory impairment and one of aphasia, apraxia, agnosia and disturbance in executive functioning. The course of illness is gradual and progressive resulting in significant impairment of social and occupational functioning [3]. The risk of developing dementia grows exponentially with age rising from 1 in 20 people over the age of 65 to 1 in 5 over 80 [4]. As the proportion of older people in society continues to grow the greatest increase in the next decade will be amongst those over 80 years [5]. Older people are more likely to have painful pathology due to the increased incidence of chronic medical conditions such as musculoskeletal, cardiovascular and respiratory diseases [6]. Pain prevalence studies in older people residing in nursing homes reveal rates varying from 45–80% while the incidence of cognitive impairment in the same population may be as high as 50% [7]. Dementia may affect ability to communicate, impairing expression of pain, thus presenting a substantial barrier to pain assessment and management. Ferrell’s survey of 325 nursing home residents found that 21% (with 217 patients in a final analysis with a mean age of 84.9 years) were unable to report pain; however other factors also influence an individual’s experience and reporting of this symptom (Table 1) [8, 9].

Mechanisms and experience of pain

Despite the increased frequency of painful pathology with advancing age, a number of studies have shown that...
older people report less pain than their younger counterparts [10, 11]. However, whether older people actually experience or simply report less pain remains unclear. In Alzheimer’s disease, limbic neuropathology affecting the amygdala, intralaminar nuclei of the hypothalamus and septohippocampal region may be an explanation for the decline in the qualitative experience of pain. The somatic sensory cortical areas are preserved explanation for the decline in the qualitative experience of pain. The somatic sensory cortical areas are preserved.

The use of visual analogue scales in studies of young children, who similarly have difficulty with understanding and expressing language, has been shown to increase the reliability of pain assessment in this population [23, 24]. These scales are cognitively less demanding. Scherder and Bouma administered three visual analogue scales, the Coloured Analogue Scale (CAS), the Facial Affective Scale (FAS) and the Faces Pain Scale (FPS) to patients in the early and mid-stage of Alzheimer’s disease and to a group of elderly persons without dementia [25]. The authors concluded that visual analogue scales might improve pain assessment in persons with dementia who fully comprehend them.

Patient distractibility, sensory and motor impairments impede the use of certain instruments. It may thus be helpful to adapt the administration and presentation of questionnaires by using large print, amplified hearing devices and a well-lit room [8]. Kovach et al. [12] used biobehavioural responses (heart rate, respiratory sinus arrhythmia, self reported anxiety and pain, and facial expression) to measure pain in patients with varying degrees of dementia compared to healthy individuals. Increasing severity of dementia in response to a mildly painful event (venepuncture) was associated with blunting of physiologic response, increased facial expression and impaired ability to respond to questions about anxiety and pain. Possible explanations for these changes in the bio behavioural system include Alzheimer’s related changes in the autonomic nervous system and inability to ‘perceive’ and therefore ‘prepare psychologically’ for an impending event [15]. Two studies demonstrating that patients with dementia suffer less from post-lumbar puncture headache, than elderly persons without dementia, provide further evidence of ‘an alteration in pain experience’ in Alzheimer’s disease [16, 17].

**Pain identification**

As dementia progresses and verbal skills diminish, carers and medical staff are forced to rely increasingly on non-verbal/behavioural cues of physical and emotional pain (Table 2) [18]. Language and cognitive skills are required for many pain assessment instruments including The McGill Pain Questionnaire, the most commonly used instrument in pain studies [19–21]. Ferrell et al. [8] studied a cognitively impaired nursing home population and found a 65% completion rate on the intensity scale of the McGill Questionnaire. Radbruch et al. [22] also found poor completion rates of lengthier and more complex instruments in a palliative care setting and recommended using simple categorical scales administered by interview (versus self-assessment with numerical rating scales) when assessing patients with advanced dementia.

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### Table 1. Factors influencing experience and report of pain [9]

<table>
<thead>
<tr>
<th>Mood state</th>
<th>Perception of control</th>
<th>Expectations</th>
<th>Social conditioning</th>
<th>Cultural conditioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agitation</td>
<td>Repetitive verbalisation/shouting</td>
<td>Fluctuating cognition</td>
<td>Falls/withdrawal</td>
<td>Decreasing functional ability</td>
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</tbody>
</table>

**Pain assessment and management**

**Table 2.** Non-verbal cues in expression of pain [18]  

<table>
<thead>
<tr>
<th>Agitation</th>
<th>Repetitive verbalisation/shouting</th>
<th>Fluctuating cognition</th>
<th>Falls/withdrawal</th>
<th>Decreasing functional ability</th>
<th>Sweating</th>
<th>Tachycardia/raised BP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linguistic</td>
<td>Non-verbal cues in expression of pain [18]</td>
<td>Verbal/behavioural cues of physical and emotional pain</td>
<td>Physical symptoms</td>
<td>Emotional symptoms</td>
<td>Cognitive symptoms</td>
<td>Social cues</td>
</tr>
</tbody>
</table>

**Table 3.** Commonest reasons for underdetection of pain [26]  

| Reporting habits of older people | Acceptance of reports by staff | Ability of carers to identify pain | Inappropriateness of existing pain measures |
and examined factors that might impede this. Chronic pain was detected less frequently in non-communicative patients and fewer non-communicative than communicative patients were receiving scheduled analgesia. Chronic pain was more likely to be detected in the context of musculoskeletal disease, and less likely with neurological diseases other than dementia. The authors concluded that detection of chronic pain could be improved by regular direct questioning of communicative patients, and that new methods of assessment needed to be developed for people unable to communicate. Weaknesses of the study include the absence of measurements of cognitive function or mood state important for clarifying the association between mental status and reporting of pain. Additionally, the authors relied on chart review which was not always reported in a consistent manner, to determine the physician’s assessment of pain.

The difficulties faced when assessing pain, ranging from the reliability of patient reports to the content and presentation of the actual scale used, supports the need for further research into more ‘objective’ methods of evaluation. The latter include behaviour observation and monitoring of physiological parameters which are especially important in those unable to communicate (Table 2) [18].

### Management of pain

The most critical aspect of pain management is accurate identification and assessment. Literature reports still highlight deficiencies in detection, thus leading to failure to remediate this symptom. In a study of postoperative pain management Bell found that elderly persons with cognitive impairment had more documented behavioural indicators of pain than those without, yet were prescribed fewer analgesics [27].

Several studies have shown that patients with Alzheimer’s disease are given fewer nonsteroidal anti-inflammatory (NSAIDs), and other analgesics than elderly persons without dementia [28–30]. Excepting communications difficulties and clinician under-detection and inaction, possible explanations include fears of inducing dependency on analgesics and fear of adverse reactions and polypharmacy [31]. Some authors however advocate a limited trial of analgesia in response to a wide range of physical and behavioural symptoms for patients with dementia who are unable to report pain [18].

By maintaining a strong index of suspicion and awareness of signs of physical discomfort as well as prescribing psychotropic agents (which can mask signs of physical pain) judiciously, under-treatment of physical discomfort can thus be minimised. Allowing nursing staff discretion to administer nonopioid analgesics as well as nonpharmacologic comfort measures such as massage, pain control can be particularly optimised for patients with dementia who have communication deficits (Table 4) [18].

### Table 4. Non-pharmacological comfort interventions [18]

<table>
<thead>
<tr>
<th>Intervention</th>
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<tbody>
<tr>
<td>Supportive verbal communication</td>
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<tr>
<td>Music therapy</td>
</tr>
<tr>
<td>Therapeutic massage</td>
</tr>
<tr>
<td>Soothing/supportive touch</td>
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<tr>
<td>Cold or heat therapy</td>
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<tr>
<td>Physical exercise/movement</td>
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### Implications

Identifying and managing pain in the context of dementia is fraught with difficulty. The consequences of unidentified or poorly treated pain are many and include exacerbation of pre-existing cognitive dysfunction, the causation of depression, possible inhibition of immune function and the worsening of medical conditions [32, 33]. Although pain is an inherently subjective experience, the expression of pain may be compromised by decline in language, attention and concentration. The validity and appropriateness of instruments used in the assessment of pain also come into question. Many studies in the area of pain assessment have methodological flaws, in particular small sample sizes, yet the utility of tools such as the ACPQ in dementia where the interviewee is required to imagine what a painful situation would be like if they had not experienced it before, must also be questioned. There is an urgent need for the development, testing and validation of instruments that would be more appropriate for a cognitively impaired population. Visual analogue scales and assessment protocols incorporating physiological parameters may hold some promise but at present research evidence supporting their widespread dissemination and use is lacking. Addressing clinician ignorance of pain prevalence in this population must constitute a major challenge in more effective pain management. The development of pain assessment protocols in collaboration between palliative care physicians, geriatricians and old age psychiatrists would complement better training for all carers, both formal and informal, in pain identification and management. Improving documentation of pain in terms of the clinical record is also essential if consistent action to treat pain is to be undertaken. Finally there is a need to listen to and encourage families and carers in taking a greater role in the reporting and remediation of pain to facilitate and maximise quality of life of people with dementia.

### Key points

- Pain is under-reported and under-treated in cognitively impaired older people.
- Decline in verbal communication makes assessment very difficult. Therefore assessment should take place at the earliest possible stage of dementia when communication abilities are preserved.
- There is a lack of validated and reliable assessment tools for confused non-verbal older people. The use
of visual analogue scales in those individuals who fully comprehend them looks promising.

- Poorly treated pain is associated with increased risk of disability and depression.
- There is a need for extensive research into the assessment and treatment of pain, the relationship between pain and cognitive impairment including the mechanisms of pain expression and finally the formulation of guidelines for management.

References

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Received 20 November 2001; accepted in revised form 29 October 2002