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Clinical review

Recent developments in pain in dementia

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Epidemiological studies show that, worldwide, the number of people aged over 65 will increase substantially in the next decades and that a considerable proportion of this population will develop dementia. Ample evidence shows that ageing is associated with a high rate of painful conditions, irrespective of cognitive status. The number of patients with dementia who will experience painful conditions is therefore likely to increase. A key question relates to whether and how patients with dementia perceive pain. Patients with dementia may express their pain in ways that are quite different from those of elderly people without dementia. Particularly in the more severe stages of dementia, therefore, the complexity and consequent (frequent) inadequacy of pain assessment leads to the undertreatment of pain.

The most commonly used pain assessment instruments seem to be selected primarily according to the communicative capacity of the patient (self report pain rating scales for communicative patients and observation scales for non-communicative patients) instead of according to two main aspects of pain—the sensory-discriminative and motivational-affective aspects. In particular, the motivational-affective aspects of pain are assessed by observation scales, which should therefore be applied to every patient, irrespective of ability to communicate. Distinction between the sensory-discriminative and motivational-affective aspects of pain is of great clinical relevance, as the motivational-affective aspects are particularly likely to reflect pain that needs treatment. Moreover, differentiating between these two aspects of pain in relation to the neuropathology of the various subtypes of dementia provides insight into the basis of the alterations in the pain experiences of elderly people with dementia. Future experimental and clinical studies should not only focus on subtypes of dementia but should go a step further and assess pain in disorders in which pain is already present at a stage without cognitive impairment and during the course of which patients become cognitively impaired.

Methods

We selected data for this review from our personal files and from searches of PubMed. We used the search terms pain, chronic pain, persistent pain, acute pain, pain assessment, pain treatment, human, clinical studies, experimental studies, dementia, Alzheimer’s disease, vascular dementia, frontotemporal dementia, Parkinson’s disease, and multiple sclerosis.

Summary points

Underreatment of pain in dementia is a frequent and frightening observation; its risk increases with the severity of dementia

The development of tools by which pain can be better recognised in non-communicative patients with dementia is one of the primary goals of future research

Experimental and clinical studies should differentiate more consistently between the sensory-discriminative and motivational-affective aspects of pain and among the various subtypes of dementia

Self report pain rating scales, administered to communicative patients with dementia, focus on the intensity of pain; observation scales, until now reserved for non-communicative patients, also assess affective aspects of pain

Observation scales should become a permanent part of pain assessment, irrespective of cognitive status

Pain assessment should be a regular component of care in such disorders as Parkinson’s disease and multiple sclerosis, in which pain is present at a stage in which cognitive function is relatively preserved

Underreatment of pain in dementia

Several observational studies indicate that pain is undertreated among cognitively impaired elderly people. Fewer analgesics are prescribed for the oldest category of cancer patients (>75 years) than for younger patients, and low cognitive performance was one of the independent predictors of this finding. In addition,
people in advanced stages of dementia who have had hip fractures receive significantly less opioid analgesics than do those who are cognitively intact. Another remarkable finding is that the prevalence of use of analgesic is considerably lower among patients with Alzheimer’s disease than in those with vascular dementia. One possible explanation for this finding is that an impairment in language, which limits patients’ ability to communicate about their pain, is more common in Alzheimer’s disease than in vascular dementia. These observations stress the importance of increasing our knowledge of pain recognition in this population.

Assessment of the sensory-discriminative and motivational-affective aspects of pain

In clinical practice, the selection of instruments to assess pain in dementia is based primarily on whether the patient is able to communicate verbally about the pain. For example, self report pain rating scales are administered to patients who can still communicate about their pain (table 1). These scales are unidimensional, however, as they generally target only the sensory-discriminative aspects of pain (that is, presence and intensity), instead of the important motivational-affective aspects. The reason these scales are used is that even patients with moderate cognitive impairment are able to use them easily to report the intensity of pain. To assess abstract thinking, some researchers have added prerequisites for understanding, including abstract pain scales—such as the visual analogue scales, the cognitive capacity screening examination, and drawing a clock—to their protocols.

Pain assessment in non-communicative patients relies primarily on observation scales (table 1). Such scales may provide information about the motivational-affective aspects of pain, as shown by both physiological signs (for example, frequency of breathing) and physical signs, such as facial expressions (for example, seeming to be frightened). Facial expressions can be evaluated by a specific coding system and seem to be reliable indicators of pain. One disadvantage of typical observation scales is the necessary assumption that signs that are normally indicative of pain (such as guarding, bracing, moaning) are also representative of pain in elderly patients with dementia. This assumption is doubtful, however, given the identification of less obvious or atypical behavioural presentations in some people with dementia. For example, “absence of a relaxed body posture,” one of the items of the discomfort scale-dementia of Alzheimer type (DS-DAT), may also be a reflection of the extrapyramidal symptoms that can occur in Alzheimer’s disease. On the other hand, assessing for pain only with tools that include typical pain behaviours but do not recognise subtle behaviours and changes in usual activities may result in under-recognition of pain in this population.

Additional insight into a patient’s pain experience could emerge from measuring such autonomic responses as blood pressure and heart rate, although evidence indicates that these measures are not particularly sensitive. In an experimental pain study, researchers observed that only high intensity pain provoked similar increases in systolic blood pressure among both patients with Alzheimer’s disease and elderly people without dementia. In contrast, low intensity painful stimulation induced smaller increases in heart rate among patients with Alzheimer’s disease than in elderly people without dementia. These results suggest that Alzheimer’s disease involves a higher threshold for autonomic activation. These findings have two important clinical implications: autonomic responses in non-communicative patients may indicate a high level of pain intensity, and low autonomic responses to pain do not reflect the absence of pain. Heart rate responses to pain have recently been found to be negatively correlated with degree of cognitive impairment and deterioration of electrical activity in the brain in Alzheimer’s disease, regardless of normal tactile and pain thresholds. These results provide further support for the suggestion that patients with Alzheimer’s disease can still differentiate between tactile and painful stimuli, even in advanced stages of the disease and in the presence of blunted autonomic responses.

Taken together, these data indicate that observation scales might be useful for assessing the intensity and motivational-affective aspects of pain in patients with dementia and that these scales should be administered to all patients, not only to those who are non-communicative as is the case in current practice. Assessing autonomic responses does not seem to be useful, as these responses do not provide an accurate reflection of the perceived intensity of pain.

Sensory-discriminative and motivational-affective aspects of pain in subtypes of dementia

The processing of sensory-discriminative aspects occurs in the lateral pain system, whereas motivational-affective aspects are processed by the medial pain system. Although the distinction between these aspects of pain, and subsequently between the two pain systems, has so far received too little attention in clinical studies on pain in dementia, experimental pain studies have shown its importance.
Persistent pain is characterised by “secondary” motivational-affective aspects of pain, however, in which the cognitive appraisal of the pain (for example, the future consequences of and behavioural responses to pain) plays a very important role. Instruments that assess pain in dementia should therefore focus on pain related cognitive processes as well.

In summary, with respect to Alzheimer’s disease, the change in the processing of the affective components of experimental pain (higher tolerance) resembles the decrease in the motivational-affective components of clinical pain. This is noteworthy, as experimental studies often use acute pain stimuli (such as electrical stimuli), although most elderly people in nursing homes have persistent pain. Interestingly, the incidence, severity, and duration of post-lumbar puncture headache (an acute painful condition) were found to be low in patients with dementia, supporting the role of the medial pain system in processing the initial motivational-affective aspects of experimental acute pain. Persistent pain is characterised by “secondary” motivational-affective aspects of pain, however, in which the cognitive appraisal of the pain (for example, the future consequences of and behavioural responses to pain) plays a very important role. Instruments that assess pain in dementia should therefore focus on pain related cognitive processes as well.

Future

In disorders with a high risk of cognitive impairment, such as Parkinson’s disease and multiple sclerosis, pain is a prominent clinical symptom at a stage in which patients’ cognitive status is relatively preserved. Pain syndromes that often occur in these patients include...
trigeminal neuralgia, pain related to spasticity and rigidity, radicular-neuropathic disorders, and central pain.\(^3\)\(^4\) To date, the relation between the site of the neuropathology, degeneration of the various brain stem areas (such as the locus coeruleus) that are normally involved in the inhibition of nociceptive stimuli at the spinal dorsal horn could hypothetically explain the clinically observed increase in the affective-emotional pain in multiple sclerosis. Furthermore, reductions have been observed in pain-temperature sensation (a sensory-discriminative aspect), possibly as a result of a dysfunction of the spinothalamic tract (table 2).\(^5\)\(^6\) Because of some of these patients inevitably develop cognitive impairments during the course of their disease, it is alarming to realise that the experience of pain and all of its aspects during this stage remain to be examined. This lack of knowledge hampers the development of effective pain treatment strategies with respect to not only the painful conditions in the cognitively impaired stage but also the side effects of drugs in Parkinson's disease and multiple sclerosis. For example, in Parkinson's disease, levodopa can provoke pain and burning paraesthesia,\(^7\) and an increase in pain has been observed when using interferon beta in multiple sclerosis.\(^8\) The extent to which these side effects are influenced by alterations in cognitive impairment is unknown. These examples illustrate that people who care for elderly patients should be alert to pain at all stages of neurodegenerative disorders, irrespective of a patient's cognitive status.

In the coming decade, this line of research should progress, particularly if researchers differentiate among the various aspects of pain and pay attention to the various subtypes of dementia and the stage of the neurodegenerative disorder. The role of pain in diseases that can cause cognitive impairment, such as Parkinson's disease and multiple sclerosis, must be incorporated into future experimental and clinical pain studies.

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