Commentary

Pain assessment in special patient groups such as those with dementia: At the finishing line or just starting from scratch?

There has been tremendous progress in the methodology of pain assessments. This applies to both clinical and experimental pain. Books can be filled with the description of manifold instruments. One might assume that we can settle back and focus our efforts exclusively on the clinical applications of this arsenal. However, most of these tools for pain assessment have been designed for middle-age adults without any sensory, cognitive, motor, or linguistic impairment and with English or another widely used language as the mother tongue. If the patient is a member of this “privileged” group of individuals, pain assessment is very likely appropriate to allow for adequate pain management.

The major challenge in this context has been created by the increasing number of elderly individuals with cognitive impairments of various kinds, especially those suffering from mild cognitive impairment and dementia. There are an estimated 35 million people with dementia across the world. Currently, 5% of people over 65 years old have a diagnosis of dementia, increasing to more than 50% in those over age 90 years. Demographic changes in the coming decades and the increasingly aging population will lead to substantial growth in the number of people affected and in the scale of the challenge of providing them with appropriate treatment and care. Pain presents a particular challenge in the treatment of dementia. The prevalence of pain, particularly chronic pain, is strongly related to age, hitting the oldest population the hardest, with prevalence rates of 70% above the age of 85 years. Given these circumstances, it is clear that pain is probably very common among people with dementia; nevertheless, current knowledge is poor, which frequently leads to inappropriate treatment and care. A major reason for that is inadequate pain assessment [1,8].

Various problems have remained unsolved, which will be briefly touched upon in the following. One should not dismiss the use of self-report measures as appropriate pain assessment tools in patients with dementia, especially in the early stages of the disease. However, the appropriateness of their use must be continuously monitored and adjusted if necessary. For example, cognitively more challenging self-report measures such as visual analogue scales usually have to be replaced by less challenging measures such as categorical scales with easily understood categories and only a few scaling points (e.g., 4- or 5-point scales). Furthermore, one needs to determine when the validity of self-report is no longer guaranteed and alternative pain assessment methods need to be added or used instead of self-report measures. Which institutions and research groups are that ambitious?

The present contribution of Jensen-Dahm et al. [5] targets these problems from a research perspective by not only reporting on changes in pain psychophysics in patients with dementia but also reporting on the psychometric quality of their data, allowing for a critical evaluation of the meaningfulness of their findings. The report might serve as an excellent example of how data should be presented in this clinical domain because it critically reflects on the methodological appropriateness of pain assessment approaches. A notable feature of this study was the use of a comprehensive experimental multimethod approach considering the well-known differences between pain induction techniques [4]. Comparing heat pain, cold pain, and pressure pain, only pressure pain tolerance produced a positive finding, with lower tolerance in the patients. These high-quality findings provided by Jensen-Dahm et al. might be decisive in the ongoing debate about the directions of change in pain sensitivity due to dementia [2,6,7], whether patients with dementia will be seen as more or less pain responsive in the future.

Other problems to be mentioned in the context of pain assessment in dementia are due to the different stages and forms of dementia as well as to special clinical situations. Not surprisingly, we have started to accumulate expertise in pain assessment for the early stage of dementia, which often still allows for the use of self-report measures. At this stage, behavioral indications of pain can be assumed to be differentiated to allow for the grading of pain by observational scales. The comprehensiveness of complex and still spontaneous behaviors, however, vanishes in the course of dementia and is replaced by simple and respondent behaviors, being more and more reflexive in nature. Therefore, in patients with advanced dementia, it is unlikely that a single observational tool will be sufficient. Instead, one might need to use a toolkit consisting of a variety of different observational tools for assessing changes in pain-indicative behavior.

The same applies to the variants of dementia. We cannot assume that pain assessment tools suitable for Alzheimer dementia or vascular dementia also fit the requirements set, for example, by frontotemporal dementia. The profiles of cognitive and emotional alterations are different, with varying impacts on pain and its assessment. Not surprisingly, the few studies on various types of dementia seem to produce different results [3,5].

Furthermore, while discussing pain assessment in patients with dementia, many of us seem to believe in the fata morgana of a general pain syndrome. In fact, we are faced, also in patients with
dementia, with functional back pain, neuropathic pain, headache, orofacial pain (e.g., toothache), etc. In other words, we are facing various specific pain syndromes. Accordingly, the many observational scales for pain in general require the addition of items or scales covering the specific signs of such pain syndromes. Similarly, the end-of-life situation is likely different regarding suffering from pain in patients with dementia and requires that we adjust observational tools to assess pain. By using more sophisticated observational methods, we can greatly enhance the likelihood that we effectively assess and treat patients experiencing pain at the end of life. In summary, the methodology of pain assessment has not reached the finish line, but rather has just started in this field. All of the developed methods have to be continuously evaluated regarding whether their usefulness is guaranteed when applied in special patient groups with linguistic and cognitive impairments such as dementia. The approach to be favored is to check the available tools for appropriate solutions. Only if there are definitely none should a new development be envisaged. Otherwise, legions of redundant pain assessment tools may result. International and interdisciplinary collaboration is needed to foster the development of metatools or toolkits for patients with linguistic and cognitive impairments. These should combine well-evaluated and established instruments with a few high-quality and necessary new instruments.

Conflict of Interest

There is no conflict of interest among authors.

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References


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