



FACT SHEET No. 3

Pain Assessment in Dementia

Individuals with dementia are at particular risk of untreated pain because their ability to recognize, evaluate, and verbally communicate their pain gradually decreases across the course of dementia [3,4]. As a consequence, alternative ways to assess pain – that do not rely on the capacity to self-report pain – are needed for this ever growing group of vulnerable individuals in order to ensure that pain can be accurately assessed in a timely fashion.

Pain assessment in dementia: self-report

Although the validity of self-report ratings of pain declines across the course of dementia, self-report might still be an appropriate method for pain assessment in the early stages of dementia, when the patient is still able to recognize and verbalize pain [10]. However, when assessing self-report of pain in dementia, certain precautions have to be taken, such as using simple scales (e.g. verbal descriptor scales), repeating the question and the instructions on how to use the scale, and leaving adequate time to respond [10]. Moreover, a more individualized approach should be used that takes into account the specific neuropsychological deficits of the individual (e.g. memory deficits, aphasia) as well as his/her cognitive resources. This can be achieved by a short neuropsychological screening. When dementia progresses to moderate and severe stages, self-report of pain is often absent [7]. Clinicians should be aware of this and should not interpret a lack of self-reported pain in individuals with severe cognitive impairments as an indicator of a pain-free state.

Pain assessment in dementia: observational pain scales

Over the last two decades a considerable number of observational pain behavior rating scales for individuals with dementia have been developed (e.g. PACSLAC [2], PAIC [1], MOBID2 [6], DOLO-Plus [9], PAINAD [11]). These scales usually include observational items related to facial expressions, vocalization, and body movements (see [5] and [12] for recent reviews on observational pain scales). The observational scales are completed when the patient is at rest (after some minutes of observation) or when the patient is performing daily life activities (ADL). Given that observation of the patient at rest may not disclose the pain, especially in chronic pain conditions, it is now recommended to observe patients during movements



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or transfer [6].

Despite the great number of scales that have been developed, these scales are often not well implemented in clinical practice. Implementation barriers include lack of incentive, lack of time, difficulty of observing patients pain behavior while simultaneously providing care, uncertainty on how to score, as well as uncertainty on how to interpret the scores. Thus, more effort is needed to overcome these implementation barriers and to ensure that the use of such observational pain scales becomes the routine standard when caring for individuals with dementia.

Pain assessment in dementia: automatic pain assessment with video systems

New developments in automatic pain detection systems hold the promise that such systems could be used as a complementary instrument supporting the human caregiver. Most attempts to develop automatic pain detection systems have focused on the automatic analysis of facial expressions [8]. Although progress in the development of automatic pain detection system is very impressive, there are still several obstacles that need to be overcome in order to be able to use these systems in clinical care. Nonetheless, given the fast development in this area, one can surely expect such systems to be available within the next decade.

Conclusion

- Pain assessment in dementia should always be a combination of self-report and observational pain assessment. With increasing severity of dementia, caregivers may need to rely more on behavioral indicators of pain. Neuropsychological screening could guide the choice of adequate pain assessment and allow more individualized assessment approaches.
- Observational pain assessment should be conducted during rest and during transfer situations (or other activities of daily living) using behavioral pain assessment scales.
- Excellent implementation concepts for pain assessment in dementia should be developed to ensure that the use of such observational pain scales becomes the standard when caring for individuals with dementia and to ensure standard usage.
- In the future, automatic pain detection in dementia might be used as a complementary instrument supporting pain assessment by the human caregiver.

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