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Pain and dementia

A diagnostic challenge

Assessment of older people in pain can be challenging, especially if they simultaneously suffer from dementia. In the daily routine at a clinic or in a nursing home, the combination of pain and dementia occurs frequently. As there is no known cure for dementia, it is important to alleviate the patients' symptoms as much as possible. Adequate treatment of pain in this group of people is an important way by which to improve quality of life. This requires valid and adequate pain assessment instruments for sufferers of dementia. Recent few years have seen the development of a range of pain assessment instruments [18, 36]. In the meantime, evidence of psychometric quality and clinical utility of these instruments is still limited. This paper is an attempt to characterise the importance of "pain and dementia" as well as to report current developments in the field.

Methodology

The review is based on a systematic literature search through MEDLINE® using the items "dementia" in combination with "pain", "assessment instruments/tools", "self-rating scales", "proxy-rating scales", "observational tools", "pain scales", "treatment" and "Behavioural and Psychological Symptoms of Dementia (BPSD) ". The references of the studies included were also reviewed to identify any other relevant studies. Evidence was extracted from the most recent and important articles.

Reasons for considering pain in older persons with dementia

Epidemiological aspects

Pain is a problem prevalent in older people [15]. As many as 80% of individuals living in nursing homes and up to 50% living at home report pain [15, 35]. Furthermore, many elderly suffer from a decline in their cognitive ability. Indeed, age represents the leading risk factor for dementia with prevalence rising substantially from 1% among 65 year olds to up to 30% of 90 year olds [6]. As the world population ages, the number of older adults with dementia is estimated to increase from the current 26.6 million to 106.2 million by 2050 [8]. Consequently many elderly people suffer simultaneously from pain and dementia. Depending on the setting (community-dwelling versus nursing home) and the method of measurement, prevalence varies from around 20% to higher than 50% [32, 34]. Pain results in considerable discomfort, as well as being a physical, emotional and social burden for persons with and without cognitive impairment [2].

Under-treated pain

Numerous studies have shown that in patients with cognitive impairment, pain is inadequately treated and that they consistently receive fewer analgesics than cognitively intact persons [1, 26, 29]. Furthermore, under-treatment occurs across all three WHO classes of analgesics. Morrison et al. [27] showed that people with dementia received only one-third the dose of morphine given to persons without cognitive impairment, even when suffering with the same underlying cause of pain. Pickering et al. [28] showed a 50% reduction in the dose of paracetamol in patients with dementia as opposed to those without. The treating physicians in these studies judged the need for pain relief to be equivalent in both groups. Scherder et al. [29] bring further complexity to the issue with the finding that pain sufferers with Parkinson's disease (no dementia) demand less analgesic medication even though they experience more pain than pain sufferers in comparison groups. Thus it is unclear whether the same amount of medication is needed to treat pain sufferers with and without dementia.

Lack of verbal communication

The main explanation for under-treatment and under-detection of pain in aged persons with dementia is that they report pain less often, less spontaneously and at a lower intensity than do those without cognitive impairment [36]. Generally, the more severe the dementia, the less capable the patients become of being able to verbally express their pain sensation. Important self-report information about localisation, quality, intensity and duration of pain are then inaccessible to the caregiver.

Tab. 1 **Main types of pain behaviour and indicators (adapted from [2])**

Capacities currently observable
Body movements (tense, rigid, striking out)
Facial expression (frown, grimacing)
Verbalization/vocalization (moaning, groaning)
Comparison with former condition
Changes in interpersonal interactions (aggression, apathy and physical activity)
Changes in activity patterns or routines (refusing food, increase in rest periods, increased wandering)
Mental status changes (crying or tears, irritability or distress)

Pathology and stage of dementia influence pain perception

Mainly based on self-report ratings, most current data indicate that the pain threshold (detection of pain) in persons with AD is comparable to that of patients without [23], though tolerance to experimentally induced pain increases with increasing cognitive deterioration [5]. Thus the evidence for alterations in pain perception is somewhat ambivalent. However, a recent finding leads to the statement that people suffering from Alzheimer dementia (AD) do not perceive pain as "less painful" than people without cognitive impairment. A study of brain activity in response to a moderate intensity painful stimulus revealed a prolonged and overall greater CNS activation in persons with mild AD when compared to healthy controls across all regions usually associated with the processing of painful stimuli [9]. This suggests that CNS processing of painful stimulation is not compromised by the neuropathology of AD at least in cases of mild dementia. People with AD seem to tolerate a wider range of pain but with the same detection ability. This might be one explanation of the reduction in demand for analgesics in this group. It ought to be emphasized that the above findings have arisen specifically in relation to AD. Studies focusing on other dementia forms have reached partially different conclusions. Both pathology and the stage of dementia seem to have a considerable influence on pain perception and pain behaviour [29, 30]. In this context, it is to be further noted that in normal ageing, age-associated peripheral and central nervous system changes are already observable [10].

Behavioural and psychological symptoms of dementia

People with cognitive impairment often show challenging behaviours such as screaming or aggression. These behaviours are collectively termed as Behavioural and Psychological Symptoms of Dementia (BPSD). Many specialists in pain medicine and geriatrics have already recommended to consider agitation as a possible manifestation of pain [2, 15] and people suffering from dementia are more likely to receive psychotropic medications rather than adequate pain treatment [7]. Considering the consequences of this, investigating the cause of BPSD through pain assessment may be a better approach than simply trying to suppress behavioural symptoms by use of psychotropic medications, or still more grave, the use of physical restraints. In the meantime, several studies [21, 22] have demonstrated the efficacy of treating pain in reducing behavioural symptoms.

Pain assessment in dementia

Self-rating scales are often inappropriate

Appropriate pain assessment is a key element of providing effective pain treatment. Self-report is the most accurate, reliable, and a well-established method for identifying and characterizing pain in cases of persons without and persons suffering from mild-to-moderate dementia [2]. However, self-report scales require the capacity to gauge pain intensity on a scale, to remember duration and frequency of pain, to report about localisation and quality of pain and at least to have an idea of the meaning of pain with regards to the integrity of the body. These capacities require higher cognitive functions such as memory, language and interpretation, which are typically altered during the degenerative dementing process. Therefore pain assessment should take into account the severity of cognitive impairment [30]. In advanced dementia, the utility of common self-assessment instruments such as the Numeric Rating Scale (NRS), the face pain scale and the Verbal Rating Scale (VRS) often become unusable, whereas proxy pain assessments become the method of choice [14, 20]. To find out the moment when older adults with dementia can no longer reliably report their pain on a self-rating basis can be a major challenge. Herr [17] proposes in this case to evaluate the conceptual appropriateness of a patient's response by asking them to indicate on a scale what a "severe" and a "mild" pain might be. Checking the reliability of responses can be evaluated by asking the patient the same question after a short interruption. If the patient shows that they are having difficulties with this task, then proxy rated behavioural pain assessment methods become more useful and necessary.

Proxy-rating scales are recommended

In the past 20 years several proxy pain assessment tools for people with advanced dementia have been developed. They are usually based on potential behavioural indicators that suggest the possible presence of pain. They all have in common ratings of presence or absence, intensity or frequency of certain types of behaviours. It has to be noted that not all researchers agree with current approaches. Snow et al. [33] recommended a broader framework by considering all current multidimensional aspects of pain sensory, behavioural, emotional and cognitive aspects. Up to now, no current proxy rated behavioural assessment tool has met all of these criteria. In a comprehensive framework from the American Geriatrics Society (AGS) guidelines six main types of pain behaviour and indicators were identified (◘ **Tab. 1**) [2].

During the last 5 years, a number of systematic reviews [16, 18, 19, 36] were published about proxy-rated pain assessment tools in people with dementia. All note the continued progress regarding the diagnostic quality of these instruments; however the current evidence of instruments with regard to psychometric qualities is insufficient. Zwakhalen et al. [36] identified in a systematic re-

view four assessments with the best psychometric qualities: PAINAD (Pain Assessment in Advanced Dementia), PACSLAC (Pain Assessment Checklist for Seniors with Limited Ability to Communicate), DOLOPLUS2 and ECPA (Echelle comportemental de la douleur pour personnes âgées non communicantes). Nonetheless, the overall psychometric quality remains relatively poor. A recent review from Herr et al. [19] recommended two tools, the PAINAD and the PACSLAC. They conclude that both can be, despite certain weaknesses, recommended as most representative of the current state of the science and are most clinically relevant and practically applicable. PAINAD is deemed useful for daily assessment, including follow-up evaluation of treatment, while the PACSLAC is recommended as a longer interval assessment.

Based on these findings a validation study is currently underway in order to improve the evidence for psychometric quality of the PAINAD (German equivalent: BESD-Scale, "Beurteilung von Schmerz bei Demenz" [4, 31]) (=PAINAD-G-II study, registered at http://www.drks.de). The main aim of this study is to examine the discrimination validity of the PAINAD scale through high-quality research without observer bias (double-blind randomised placebo-controlled trial). In addition, a further comparison of the PAINAD with other pain assessment scales BISAD ("Beobachtungsinstrument für das Schmerzassessment bei alten Menschen mit Demenz") [12] and CNPI (Checklist of Non-Verbal Pain Indicators) is ongoing. Initial results are expected by 2012. Direct comparisons of the many different proxy-rating instruments within the one sample are up to now very rare, but an important precondition for identifying the relative strengths and weaknesses of all currently available tools [16].

Psychological symptoms (e.g. fear) or unmet needs (e.g. hunger) or physical aspects (e.g. exertion) can be easily misinterpreted as being pain related. Up to now, the sensitivity and specificity of current pain behaviour scales has hardly been explored. A first step in this direction is a comparison between PAINAD and NPI (Neuropsychiatric Inventory Questionnaire) [34]. No significant correlation was found and this emphasizes the specificity of the PAINAD.

A future challenge will be to clarify what observational behaviour assessment tools actually measure. Up to now it is largely unclear whether they measure different intensity levels of pain or just the likelihood of pain presence or absence. There seems to be preliminary evidence that greater numbers of pain behaviours for some tools are associated with higher pain intensity [11]. Answering this question will have an important contribution to the daily practical use of these instruments.

Not all that one observes is pain, but pain is one of the most common reasons. All available information about the patient (history, physical examination, information from the relatives or carers) and differential diagnostic considerations should be taken into account, and if in doubt, a pain-specific treatment should be started, where appropriate. If behavioural symp-

Abstract · Zusammenfassung

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Pain and dementia. A diagnostic challenge

Abstract

Purpose. The aim was to present current knowledge about pain assessment in people with dementia and to discuss special challenges and possible solutions.
Methods. A literature search in MEDLINE® was performed.
Results. Due to the changing demographics of an aging population, an increasing number of people with dementia is expected. Many of these people will simultaneously suffer pain. Under-detection and under-treatment of pain in persons suffering from dementia is often described. As dementia progresses, the ability of the sufferer to verbally communicate his/her pain is often compromised, complicating the task of recognizing and treating pain. To improve pain recognition in dementia, many pain assessment tools have been developed. However, psychometric properties have to date been insufficiently examined.
Implications. Self-report ratings should be performed as long as justifiable. Behavioural pain assessment tools should be used in advanced dementia despite their current imperfections: in particular, the PAINAD for daily use and the PACSLAC at longer intervals. All available additional information about pain should be considered.

Keywords
Pain measurement · Dementia · Geriatric assessment · Behavioral and Psychological Symptoms of Dementia (BPSD) · Gerontology

Schmerz und Demenz. Eine diagnostische Herausforderung

Zusammenfassung

Ziel. Ziel war es, den aktuellen Erkenntnisstand auf dem Gebiet der Schmerzerkennung bei Demenz darzustellen sowie die besonderen Herausforderungen und mögliche Lösungen zu diskutieren.
Methode. Es wurde eine Literaturrecherche in MEDLINE® durchgeführt.
Ergebnisse. Aufgrund der demographischen Entwicklung erwarten wir immer mehr Demenzkranke. Viele von ihnen leiden parallel unter Schmerzen. Probleme in der Schmerzerkennung sowie eine schmerztherapeutische Unterversorgung bei Demenzkranken werden häufig beschrieben. Mit Fortschreiten der Demenz schwindet die Fähigkeit, verbal Schmerzen auszudrücken, was die Schmerzerkennung wesentlich erschwert. So wurden in den letzten Jahren zahlreiche Instrumente zur Schmerzerkennung bei Demenzkranken entwickelt. Ihre Testgütekriterien sind aber häufig immer noch unzureichend untersucht.
Schlussfolgerung. Schmerzselbstbewertungsinstrumente sollten so lange wie möglich eingesetzt werden. Bei fortgeschrittener Demenz werden Fremdbewertungsinstrumente empfohlen: Trotz weiter bestehender Schwächen sind PAINAD für die tägliche Schmerzerfassung und PACSLAC für Kontrollen im Intervall zu empfehlen. Alle verfügbaren den Schmerz betreffenden zusätzlichen Informationen müssen berücksichtigt werden.

Schlüsselwörter
Schmerzerfassung · Demenz · Geriatrisches Assessment · Herausfordernde Verhaltensweisen · Gerontologie

toms decrease, pain could be assumed as the likely cause and treatment should continue [4, 17].

Pain treatment in dementia

The consensus among experts is that multidimensional approaches including pharmacological and non-pharmacological treatments seem to have the best benefit in relieving persistent pain [2]. This applies also to older persons, who show a reduction in pain intensity and pain disability, improvement in life quality and physical performance [13, 25]. Up to now in normal medical care non-pharmacological approaches for older people are unfortunately still rare [25]. In the case of dementia, the treatment situation regarding multidimensional treatments is even worse and there is no evidence available about multidimensional approaches to pain management in people with dementia. However, we know that moderate physical activity (e.g. walking) has a double benefit on pain relief [13] and improved cognitive function [24]. In the face of multi-morbidity, polypharmacy and increased frailty, a frequent use of multidimensional approaches is desirable for persons with dementia. For a more detailed insight, see the 2002 and 2009 AGS Guidelines [2, 3].

Future directions for pain assessment in dementia

There are currently two ongoing European actions:

Guideline "Pain assessment in older nursing home residents"

This guideline will encompass the available evidence and benefits of appropriate pain assessment in nursing home residents from cognitively unimpaired people through to impaired individuals. The guideline will be developed under the leadership of the German special interest group of pain and age (German Section of the IASP; Methodenpapier zur S3-Leitlinien Entwicklung: "Schmerzassessment bei älteren Menschen in der vollstationären Altenhilfe" (Sirsch, Erika et al. in preparation). Results will be released in the next 2 years.

COST Action: TD 1005 (European Cooperation in Science and Technology)

"Pain assessment in patients with impaired cognition, especially dementia"

This action will bring together leading researchers from a wide range of scientific disciplines. The major aim is the development of a comprehensive and internationally agreed-on assessment toolkit for older adults targeting the various subtypes of dementia and various aspects of pain, including pain diagnostics, cognitive examination and guidelines for proper assessment. The project is supported by the EU RTD Framework Programme. For more information see http://www.cost-td1005.net.

Conclusion

In the next few years due to changing age demographics, a growing number of people are expected to suffer from dementia and simultaneously from pain. The combination of pain and dementia makes pain recognition much more difficult. This problem can be addressed by having proxy-rated scales with satisfactory psychometric properties. Up to now, no available proxy-rating scale meets all desirable criteria. Further efforts are currently underway to rectify this issue. Recent findings support the use of PAINAD as a daily assessment, including follow-up evaluation of treatment, and PACSLAC as a longer interval assessment despite their weaknesses. By following this advice we believe there will be an improvement in pain recognition and consequently pain therapy for the especially vulnerable and dependent older persons with dementia and suffering from bothersome pain.

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