Editorial

Pain in Dementia: A Distressing Combination of Several Factors

Dementia has been called “the 21st century plague” because of the enormous projected rise in the worldwide prevalence from over 35 million now to over 115 million in 2050 [1]. Although, this raises many medical, psychosocial and societal challenges, the recognition and assessment of pain in patients with cognitive impairment provide us with a major and comprehensive challenge [2]. Especially in long term care institutions, the vast majority of people with dementia are thought to experience pain regularly [3]. The exceptional difficulties in recognition and assessment of pain in people with more advanced dementia are reflected in the conflicting evidence regarding the exact incidence of pain compared to people without cognitive impairment. In the past decades, there have been several studies that showed lower prevalence of pain in dementia patients compared to age-matched subjects without cognitive impairment; however, many scholars now believe that this may be due to under-reporting pain, which is the consequence of insufficient skills of health care professionals in detecting pain [4]. Also in laboratory studies there have been conflicting results. Some authors concluded that the threshold for pain tolerance in people with Alzheimer’s disease (AD) is increased [5], while others could not demonstrate an alteration in pain threshold or even found evidence for an amplification of pain processing in people with AD in experimental studies using EEG, fMRI, psychophysical and observational measures [6].

Nociceptive and visceral pain in dementia is usually linked to pathological conditions in the musculoskeletal, gastro-intestinal and cardiovascular systems, to infections of the bladder and kidney, to wounds caused by pressure ulcers and to dental and oral problems. Neuropathic pain is also quite common, as conditions such as post-herpetic pain and diabetic polyneuropathy are age-related. Central neuropathic pain is especially common in people with vascular dementia (VaD), because of white matter lesions that lead to differentiation [7, 8]. Particularly worrying is the fact that the use of pharmacological pain management has consistently been shown to be inappropriate in people with cognitive impairment [9, 10]. Although, this has been shown in all care settings (community care, acute care, residential and nursing home care), in settings where people are likely to have more cognitive impairment and a higher reliance on prescription by health care professionals, this situation tends to be the worst, i.e. in institutional and hospital settings. These vulnerable people may suffer from the consequences of untreated pain, which include mental and physical impairment and may also copy the behavioral and psychological symptoms of dementia such as verbal and nonverbal agitation, apathy, depression and sleep problems, [11] reduced mobility and functionality, falls, hallucination, and even death.

One of the prerequisites for good clinical care and effective treatment is the comprehensive assessment of pain. For most persons, the preferred identification of pain is by self-report. As a result of the severe neuropathological damages in Alzheimer’s or other forms of dementia, patients may lose their ability to understand their situation and, in addition, also their capability of effectively communicating about their condition and experiences. In these patients, self-report may no longer be reliable or valid, and we have to rely on other signs of pain. Whereas in a laboratory setting one could also use autonomic responses or nociceptive reflexes to measure pain, in clinical situations with non-verbal individuals one has to exclusively rely on behavioral signs of pain [12]. Some types of pain may be even more difficult to detect: Whereas acute pain after a fall, can easily be detected because of the clear positive facial, vocal, and behavioral pain indicators, the identification of chronic and neuropathic pain is much more challenging and requires, in addition, consideration of negative pain behavioral indicators, such as withdrawal and apathy, reduction, avoidance or even absence of movement.

A number of systematic reviews have studied which observational tools have been developed for people with cognitive impairment, such as dementia. One recent review concludes that there are 12 promising pain assessment tools instruments available, furthermore it states that most of them have not yet been validated enough to employ them in every-day clinical dementia care [12]. Most of the instruments are based on more or less the same pain concepts, but their operationalization and the way they are
used are very heterogeneous [2]. One of the major problems in the development and validation of pain assessment tools is that they rely on behavioral symptoms of pain, which are very difficult to discriminate from behavior that is related to the dementia itself. Agitation, aggression and apathy are known as Behavioral and Psychological Symptoms of Dementia (BPSD) that eventually hit 90% of people with dementia, especially in the more severe stages of the dementia. These behaviors may be the result from unmet psychological needs, anxiety, sensory overload, or, indeed, from physical problems such as pain. In line with this argument, some studies have found a decrease in agitation, restlessness and pacing after a trial with analgesic medication [13]. Furthermore, these behaviors vary widely between individuals. Under these conditions, both under- and over detection of pain in dementia are frequent, which may lead to incorrect and potential harmful treatment approaches. One of the most feared incorrect treatment regimens is the use of antipsychotic medications for behavior that is actually caused by pain, because of the many unwanted and serious side effects of antipsychotics. However, there is also the risk of prescribing analgesics without a proper pain assessment and evaluation in the absence of pain.

To overcome this distressing situation for patients, relatives, and society, basic and applied research, which provide better diagnostics tools and treatment strategies, as well as education of a new generation of experts are urgently needed. As with many aspects of dementia research, the critical relevance of the distressing combination of pain and dementia was overlooked until the latter part of the last century. Similarly, dementia has yet been considered as a largely uniform condition, whose effects on pain and afflictions by pain are quite similar between patients. In fact, in most of the studies on the relationship between dementia and pain patients with Alzheimer disease were investigated. Thus, the insights gained in this matter mainly inform the clinical practice and research on Alzheimer disease although a better differentiation between types of dementia is urgently needed to object this myth of uniformity. As support of these arguments this special volume will address the question which of the known relationships with pain can be found only in Alzheimer disease and which can be generalized to other forms of dementia.

This special volume tries to delineate the state of the art in this search for solutions. A perfectly comprehensive picture is of course beyond the scope of such volumes. However, the most relevant focuses will be addressed by researchers from many different countries and disciplines.

The first focus tries to present the current knowledge about the clinical picture and prevalence of pain in dementia. It is unfortunate, that in the past research on pain in dementia did not differentiate between different types of dementia [5]. The article of Binnekade et al., especially reviews the evidence about which type of dementia is associated with pathophysiological changes in the pain system and presents the related symptoms [8]. Such knowledge helps to substantiate differential diagnostic considerations, and may help clinicians in understanding the full clinical picture.

A voluminous second focus of this special volume targets the still existing huge problems in pain assessment and diagnosis in patients with dementia. The contribution of Herr et al., shows the dependency of proper pain assessment from systematic behavioral observations and the pressing need for the development of internationally agreed on reliable and valid assessment tools [2]. A very useful observational indicator of pain appears to be the facial expression. Lautenbacher and Kunz, present the existing methods and results of the assessment of facial expression of pain in dementia [14]. The article of Lobbezoo et al. fits in this focus because it shows exemplarily the necessity and methodological ways of assessing specific pains, namely dental and orofacial pain in dementia [15]. As the oral hygiene has improved enormously in the last 50 years, we now encounter the side effect: (very) old persons with dementia that still have their own teeth, and therefore also a much higher risk of orofacial problems, including pain.

A third focus deals with the problems of pain management in patients with dementia. The article of Griffioen et al., reviews the likely analgesic under-treatment of patients with dementia by not-using or under-dosing opioids in this population and tries to present reasons for this alarming situation [10]. The apparent insufficiencies in pain assessment and management are not only due to a lack of knowledge but also due to barriers against its use. Such implementation problems are addressed in the fourth focus contribution by Chandler et al., who have tried to summarize the types of problems in certain organizations and institutions as well as the available ways of their assessment [16].

A special topic worth of considerations is the reciprocal relationships between pain, sleep disorder and de-
mementia. Flo et al., make a strong point in their review that miserable vicious circles may result from mutual influences of these dysfunctions, which have not yet sufficiently acknowledged in clinical practice and research [11]. It once more underlines the complex entanglement of several risk and resilience factors in dementia: pain, cognitive impairment, behavior, movement, sleep and so forth.

We thank the editors of Current Alzheimer Research who cordially allow us to present these urgent topics originating from scientific and clinical considerations of pain in dementia. Increased awareness, better knowledge and enhanced cooperation (internationally and interdisciplinary) might hopefully result from the seven articles forming this special volume. The cornerstone of this dissemination initiative was laid by a successful COST Action (European Cooperation in Science and Technology) to which many of the authors of this special volume belong as members. After these acknowledgements, we wish the readers new insights, an enlargement of expertise and many incentives for discussion and future research.

REFERENCES


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