Pain and Dementia. A Brief Review

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Abstract

Background: Advanced age is associated with increased prevalence of pain and of dementia.

Objective: To describe the phenomenon of pain in dementia.

Methods: A systematic research (Cochrane Library and PubMed) was carried out (only upper time limit: February 2018). Publications found through this indexed search were reviewed and manually screened to identify relevant studies. Search terms used included “assessment, dementia, elderly, management, pain”. We manually added chapters of books articles identified through other sources (i.e. Google Scholar and key journals).

Results: With increased cognitive impairment and dementia, people are less likely to report pain. It should be assessed routinely, and should be considered as a possible cause of any change in the person’s behavior. If pain goes unnoticed, the person with dementia may feel significant distress for a prolonged period of time.

Conclusions: People with dementia are at particular risk of untreated pain because their ability to understand, evaluate, and verbally communicate symptom severity gradually decreases. There are many available medications that can be used to treat pain. The type of medication chosen depends on different factors such as type and severity of pain, and if the person has other medical conditions and or is taking any other medications. The treatment of pain in people with dementia should involve both pharmacological and non-pharmacological measures.

Keywords: Assessment; Dementia; Elderly; Management; Pain

Abbreviations

AD: Alzheimer’s Disease; VaD: Vascular Dementia; LBD: Lewy Body Dementia; PDD: Parkinson’s Disease Dementia; FTD: Frontotemporal Dementia; BPSD: Behavioural and Psychological Symptoms of Dementia; NPI: Neuropsychiatric Inventory

Introduction

If people live long enough, they are more likely to develop multiple long-term conditions, a degree of disability or frailty, worsening mobility and dementia. Dementia is a progressive illness that has global impact upon the individual leaving few personal characteristics and functions unimpaired [1]. It is characterized by global cognitive impairment sufficiently severe to interfere with social or occupational functioning. The dementia spectrum encompasses mainly Alzheimer’s disease (AD), AD with cerebrovascular disease, vascular dementia (VaD), Dementia with Lewy bodies (DLB), Parkinson’s disease dementia (PDD) and frontotemporal dementia (FTD). Prevalence of dementia increases almost exponentially with age. There were an estimated 46.8 million people worldwide living with dementia in 2015. This number will increase by almost doubling every 20 years. It will reach 75 million in 2030 and 131.5 million in 2050 [2]. Changes in behaviour and neuropsychiatric symptoms, which increase across the course of dementia are usual. They comprise a range of problems.

including agitation/aggression [3,4], psychotic symptoms (hallucinations and delusions) [5,6], wandering [7], affective disorder [8], eating and appetite disturbances [9], sexual disinhibition [10] and apathy [11]. With rising growth rates in the elderly population, it is likely that the cases of dementia experiencing pain, will increase accordingly. The aim of the current review was to explore the phenomenon of pain and dementia.

**Methods**

A systematic research (Cochrane Library and PubMed) was carried out (only upper time limit: February 2018). Publications found through this indexed search were reviewed and manually screened to identify relevant studies. Search terms used included “assessment, dementia, elderly, management, pain”. We manually added chapters of books articles identified through other sources (i.e. Google Scholar and key journals).

**Result**

**General concepts**

Pain is a relatively common experience during life and we are all likely to experience it at one time or another. It is recognized as a multidimensional response system, with subjective, physiological and behavioural components [12]. We distinguish between two different kinds of pain: acute pain and chronic pain. Chronic pain (defined as pain persisting for 3 - 6 months or longer) has bio-psycho-social implications, affecting relationships, capacity for work, mood and quality of life [13]. Many demented patients will develop the presence of comorbid conditions and physical frailty. As dementia progresses, speech ability may decline so that the person can no longer communicate their thoughts, feeling and needs. Patients with dementia who have poor communication cannot express their experience of pain and we should be aware that patients who are severely cognitively impaired and uncommunicative should not be assumed to be in less pain than other patients [14]. The prevalence of pain in people with dementia is estimated to be about 50% [15]. This is not surprising as both pain than cognitive impairment are common among older people [16]. Many barriers exist that contribute to underreporting of pain, including the lack of pain management education, the failure to use a standardized pain assessment tool, inadequate documentation, resident inability to communicate pain, resident reluctance to report pain, perceptions of use of strong pain medication, and regulatory concerns [17-19]. Janine van Kooten and colleagues investigated prevalence of pain in nursing home residents in relation to dementia subtype and dementia severity [20]. Residents with severe dementia had pain more often and also higher pain intensities than residents with mild to moderate dementia (27% vs 15%). Pain prevalence of self-reported pain was estimated at 46% of AD patients, at 56% of VaD patients, at 53% in AD with cerebrovascular disease. According to other authors, the prevalence of pain do not differs between AD and VaD patients [21]. Insufficient research study was found for determining rates of pain in FTD and LDB populations [20,21]. However, the rate of analgesic use in people with dementia is far lower than in healthy older people, indicating a high likelihood of untreated pain in these people [22]. Around 40% of those in pain are not prescribed any form of analgesia [23,24]. Horgas and Tsai [25] reported that the more confused and disorientated a patient becomes, the less likely they are to be prescribed and administered analgesia. On the contrary, authors of a Swedish population-based study [26], reported similar pain treatment in samples of individuals with or without dementia. They stated that this may reflect a recent increased awareness of pain and pain management in persons with dementia, compared with previous studies that have reported an underuse of analgesics in persons with dementia.

**Is pain experienced differently in dementia?**

An important question is to determine if and how patients with dementia may experience painful conditions [27].

In recent years, researchers showed mutual correlation in neural circuits that control pain, cognitive functions and mood changes [28,29]. Relating neuropathology to pain is an intricate and stimulating process. Most studies on pain in dementia focus on patients with “dementia,” with no further specification of the diagnosis, for example, AD, LDB, VaD, combined AD and VaD, or FTD. Since

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neuropathological changes differ between dementia subtypes, it was advanced that the experience of pain may diverge according to the dementia profile. Studies focusing on patients with AD have revealed mixed results, showing diminished [30], unaltered [31], or even potentially increased pain experience [32,33] compared with healthy controls. It has been suggested that in patients with AD, cortical atrophy (including the hippocampus, for example) may cause a decrease in experienced pain [30]. Benedetti., et al. [34] observed that the pain thresholds (a sensory discriminative aspect) of patients with AD did not differ from those of elderly people without dementia, whereas pain tolerance (a motivational affective aspect) was significantly increased in the AD group. Conversely, Cole., et al. [35] investigated functional Magnetic Resonance Imaging pain-related brain activity and demonstrated that pain perception and processing were not diminished in AD, highlighting concerns about the current inadequate treatment of pain in people with dementia. Neuropathology indicates that atrophy in the prefrontal cortex in FTD and white matter lesions in VaD, in which areas become disconnected (de-afferentiation), could be responsible for the clinically observed respective decrease and increase in the motivational-affective aspects of pain [36-38]. Pain reported in 20 patients with possible VaD was compared to 20 non-demented elderly who had comparable pain conditions [37]. The results of the study indicated that patients with possible VaD experienced the intensity of pain somewhat more than the non-demented elderly. Landqvist Waldö., et al. [39] studied the prevalence of specific somatic complaints and pain in 97 neuropathologically verified patients suffering from FTD. Nine patients exhibited abnormal reactions to sensory stimuli: three subjects presented exaggerated reactions, the other three patients manifested lower discomfort. Pain perception in DLB is even less well understood. According to some authors, probably, it is altered due to brain damage induced by both cerebral atrophy and presence Lewy bodies [40].

The relationship between pain and neuropsychiatric symptoms

Neuropsychiatric symptoms are common in people with dementia (they are also called “behavioural and psychological symptoms of dementia” –BPSD-). Pain is thought to be an important underlying factor [41,42]. This association is, however, complex. There is no standard method for differentiating behaviour caused by pain from other BPSD [22]. Behaviours, such as verbalizations/vocalizations (e.g. sighing, moaning, calling out, verbal abuse), noisy breathing, facial expressions (e.g. grimacing, frowning), restless or strained body expressions (e.g. rigid, tense, guarding, fidgeting, increased pacing/rocking), are frequently the most prominent, or even the only feature of pain, but these behaviours are often not recognized as a symptom of pain, but frequently interpreted as a symptom of the dementia [43]. When pain and depression were assessed according to levels of cognitive function, pain was statistically significantly associated with increased depression in people with mild and moderate cognitive impairment [44-47]. Moreover, a research showed that, reduced pain intensity is associated with future reductions in depressive symptoms across all levels of cognitive [47]. Studies reveal a positive effect of pain medication on reducing disruptive behaviour in dementia (repetitive and persistent patterns of dangerous behaviour that are disruptive to the living and working environment) [48]. Some disruptive behaviours such as agitation and aggression correlate with the presence of pain; no association was observed with disruptive behaviours that are accompanied by locomotion such as wandering [48]. Ahn., et al. [49] observed that pain moderates the relationship between the level of cognitive impairment and aggression: pain exacerbate aggressive behaviours only for severely cognitively impaired patients. In a study of severely disabled nursing home residents, aggressive behaviour was significantly more common in patients with two or more pain-related diagnoses [50]. Other researchers [46] correlated chronic pain with anxiety and irritability, evaluated with The Neuropsychiatric Inventory (NPI) [51]. Evidence also suggest that sleep disturbances can predict pain [52]. Some authors sustained that delusions and hallucinations are features not associated with pain in dementia [53]. This data is contrasting; in fact, some articles described psychosis and delusions as being related to pain [44, 54]. Moreover, pain may reflect the variety of personalities in a population and show how differently people react to different situations or stimuli; some individuals may, for example, mask their pain by being quiet or depressive whereas others are more expressive and show aggression [55].

Assessment and management of pain in dementia

Pain can be particularly distressing for those with dementia. The lack of recognition of pain can cause a great deal of unnecessary suffering. It is therefore an obligation to identify and treat pain.

Accurate assessment of pain is critical to adequate treatment and of pain.

**Assessment**

To assess pain is a fundamental and preliminary action for its management. The approach to pain assessment must be just alike in patient population as in healthy population. A comprehensive pain assessment incorporates a complete pain history and physical examination that may include information provided by family members or informal caregivers concerning level of cognition, physical ability to function and consumption of medication [56]. A person’s self-report is the most accurate measure of pain, but the patient with advanced dementia may not be able to provide information about his/her pain [57]. When patients are unable to communicate, observation of pain behaviours may be the only means of obtaining information [58,59]. This means that a proxy rater; usually a nurse who knows the patient over time or the main caregiver, should be able to interpret the patient’s behaviour and transfer it into a measure of pain presence and preferably also into pain intensity [60]. There are potential pain-related nonverbal signs to be taken into account in severely cognitively impaired and uncommunicative patients. They can include vocal expressions (sighs, gasps, moans, groans, cries), facial expression (furrowed brow, narrowed eyes, clenched teeth, tightened lips, jaw drop, distorted expression), bracing (clutches, holds side rails, bed, table, or area of pain), restlessness (constant or intermittent shifting of position, rocking, intermittent or constant hand motions, inability to keep still), rubbing (touching, holding, or massaging affected area) [61]. The facial display of pain promises to be the most informative nonverbal form of communication, which might help an observer to infer whether an individual suffers from pain [62,63]. Surprisingly, findings also show that professionals with long-standing experiences with patients in pain nevertheless showed a limited decoding ability, given that they tend to underestimate pain in others more than non-professionals [64,65]. In fact, Lautenbacher, et al. [63] found that without further contextual information, “professional” observers do not show a superior competence in inferring pain in others by reading their facial display. Solid observational pain assessment should incorporate use of a standardized, well validated instrument, repeated results over time (under consistent circumstances), observation during movement, and pain assessment before and after pain management [29]. 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 [27]. However, pain behaviours may be severely limited in some patients, for example, in people with severe motor impairment or PDD, leading to under recognition of pain, whereas the characteristic writhing movement seen in people with Huntington’s disease and dementia may result in an incorrect diagnosis of pain [66]. It is necessary to emphasize that cultural factors among ethnic groups can impact different attitudes toward and meanings for pain; expression and reporting of pain can vary by culture [67].

**Management**

One of the main controversial issues in dealing with older adults has always been the use of pharmacological interventions to manage pain and the concerns expressed regarding the use of strong analgesics. Some clinicians manifest reluctance to prescribe them. In fact, their use may cause side effects such as delirium, hallucination and delusion [68]. Additionally, older people are underrepresented in clinical trials evaluating pain management interventions, resulting in limited evidence on which to base analgesic prescribing [69]. It is remarkable that, according to some authors [70], the pharmacologic treatment is intensified only at the end of life. Perhaps this is because physicians are more inclined to accept side effects, such as sedation, in case of a nearing death, or due to increasing pain or a new origin of pain at the end of life, requiring a different treatment strategy. Despite the benefits of adequate pain management, there is inconsistency in the literature regarding analgesic use and pain in residents with dementia. Analgesic selection is challenging due to the prevalence of frailty, multimorbidity and polypharmacy [71,72]. For example, though paracetamol (the most prevalent analgesic in people with and without dementia in Aged Care Facilities) [71], regarded a benign drug, after overdose or when misused in at-risk populations, is correlated with significant hepatotoxicity [73]. Pharmacological interventions treat inflammation and associated sensitisation of nociceptors (non-steroidal anti-inflammatory drugs), enhance endogenous analgesic mechanisms (opioids, tricyclic antidepressants) or dampen the

excitability of pain transmitting neurons (opioids, anticonvulsants) but some of these agents may be associated with cognitive dysfunction de novo, or further exacerbation of existing cognitive impairment [74]. Patients never treated with opioids should be start administration with a low-dose short acting agent. Furthermore, it remains unclear if different subtypes of dementia need different therapeutic approach [75]. The fact that behavioural symptoms in moderate and severe dementia are sometimes modes to manifest pain, has led several researchers investigating the efficacy of treating pain to reduce behavioural disturbances [36]. There is evidence that improved detection and treatment of pain may be an effective strategy in reducing both pain and BPSD [43]. However, it is interesting to note that Haasum, et al. [26] found that having a pain-related diagnosis was associated with use of any psychotropic, sedatives and antidepressants in persons with dementia: this could indicate that pain in patients with dementia may sometimes be inappropriately treated with psychotropics, which needs to be further investigated. Although pharmacological treatment with analgesics is the most common form of pain treatment in older individuals, the use of non-pharmacological and alternative treatment should also be considered, especially under the aspect of potentially less adverse events [76].

The impact of untreated pain

Inadequate pain management results in a poor quality of care for older patients with dementia in acute settings [77]. Undermanaged pain negatively affects a person’s recovery and prolongs hospital stays [78]. When left untreated, pain may be considered a separate disease process with a more complex pathophysiology [79]. Chronic pain negatively impacts multiple aspects of patient health being associated long-term sequelae. Researchers stated that chronic pain is a statistically significant predictor of hypertension. These results were obtained by considering independent predictors including age, sex, race, and family history [80]. Poor appetite [81] and disturbed sleep were associated with chronic pain [52]. Some studies have shown physical impairment and deterioration cognitive functioning [73]. A great deal of evidence suggests that disruption of attention associated with impaired working memory processes in individuals with chronic pain. These poor cognitive performances are due to interruptions in memory traces, which are important in the unconscious completion of many everyday tasks [82]. It was been observed that chronic pain negatively affects the patient’s social life [83,84]. Persistent pain may lead to functional consequences and limitation of activities such as gait disorders, decrease in occupational/recreational activities and difficulty in the performance of activities of daily living [85].

Conclusions

Pain is a frequent cause of discomfort and distress. It is so universal that its recognition should be an essential skill of all those working with older people. A way to approach a problem is to maintain a high index of suspicion that the problem may exist. There is some evidence that people with dementia experience pain just as any other older person; however, the ability to recall and interpret the experience of noxious stimuli as painful events is altered. An increased awareness of pain in patients with dementia can help caregivers to provide more effective care for these groups of patients, resulting in an improvement in their quality of life and a reduction in health care costs. A lack of pain detection and its poor control may include longer hospital stay and increases decline in function. Apart from emotional and social distress by untreated, persistent pain, failure to recognise and treat pain in people with dementia has profound implications for the prognosis and can lead to poor medical outcomes. A person’s background and circumstances, as well as their stage of dementia, need to be considered to determine whether they are at risk of under-reporting pain. It is claimed that people suffering from mild or moderate dementia can communicate current pain. However, with dementia progression, it is very important that ongoing pain assessment and management becomes part of the care plan for the person with dementia adopting combination of strategies detection and combined intervention strategies. Pain is also linked to behavioural abnormalities in those with dementia. Despite increased use of analgesics, pain is still prevalent in people with dementia: as in studies show, patients with dementia have lower rates of treatment with drugs for pain than those without dementia. Future research on pain in elderly dementia patients hinges on the development of better pain assessment tools, especially for patients who are non-communicative.

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Conflict of Interest
The author declares that no competing financial interests exist.

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