Übersichtsartikel

Pain Assessment and Treatment Challenges in Patients with Dementia


Abstract: Pain is likely to be equally prevalent in people with dementia, however, only a small minority are prescribed regular analgesics. This is a key issue since untreated pain leads to reduced quality of life and increases the likelihood of emergence of behavioural and psychological symptoms such as agitation. Better assessment and treatment of pain in this fragile patient group are therefore mandatory. In this context, we reviewed the literature on pain and dementia and summarised the best available evidence regarding the frequency of pain and pain diagnosis. Unfortunately, hardly any randomized, controlled studies of pain treatment efficacy in patients with dementia are available, with the consequence that most pain treatment recommendations are not based on the highest level of evidence.

Keywords: dementia, pain, pain assessment, pain treatment, pain assessment instrument, nursing homes

Introduction

Untreated chronic pain is a devastating symptom in older people with moderate to severe dementia who are unable to explain their suffering (Scherder et al., 2009). Persistent
pain has been associated with a progressive decline of functional and mental capacity (Moriarty, McGuire & Finn, 2011), social interaction (Lin, Lin, Shyu & Hua, 2011), quality of life (Cipher & Clifford, 2004; Cordner, Blass, Rabin & Black, 2010; Jakobsson & Hallberg, 2002), appetite (Bosley, Weiner, Rudy & Granieri, 2004) and sleep disturbances (Giron et al., 2002); and increased behavioural disturbances including agitation, depression and anxiety (Husebo, Ballard & Aarsland, 2011). Moreover, pain causes immense stress for the patient and their formal and informal care givers (Buffum & Haberfelde, 2007) and increases health care costs (Ferrell & Griffith, 1994). In the last decades, clinicians and scientists have started to conduct research on the prevalence (Takai, Yamamoto-Mitani, Okamoto, Koyama & Honda, 2010), assessment (Hadjistavropoulos et al., 2007; Herr, 2011) and treatment of pain in older people with cognitive impairment and the consequences of undetected and untreated pain (AGS Panel, 1998; 2009; Ferrell, 1991; Gloth, 2011). Such issues include the development of observational and behavioural pain assessment instruments, pain treatment recommendations, and staff educational programs. Although these are necessary and central investments, one of the most pressing matters for mentally impaired individuals is the affective analgesic treatment of pain.

Compared to community-dwelling older adults who experience daily pain in 35% to 48% of the cases, nursing home patients with dementia are described to be in daily pain in around 45% to even up to 80% of the cases (e.g. Husebo et al., 2008, Leong & Nu, 2007, Zwakhalen, Koopmans, Geels, Berger & Hamers, 2009). Numerous prevalence studies give a description of the undertreatment of pain in these settings. There are several explanations for insufficient management of pain in patients with mental impairment. Today, the evidence base is still limited with regard to the balancing act between under- and overtreatment of pain in dementia and guides for treatment decisions. The type and dosage of analgesics are still based on clinical judgment of older adults without dementia. Although efficacy studies of analgesics in nursing home patients with dementia are challenging, these trials are possible and tremendously necessary.

In this review, we provide an overview about the frequency of pain in in patients with dementia, about adequate strategies to assess pain in this patients group as well as about benefit and harm related to the use of analgesics. We will also briefly present current pain assessment tools and treatment recommendations.

Pain in elderly individuals with and without dementia

The American Geriatric Society (AGS) Panel on Persistent Pain in Older Persons defined persistent pain as “an unpleasant, sensory and emotional experience that continues for a prolonged period of time that may or may not be associated with a recognizable disease process” (AGS Panel, 1998). The definition is based on the declaration by the International Association for the Study of Pain (IASP), who underlines that the most exact and trustworthy verification of the assessment of pain is the patient’s self-report, depending on the patient’s memory, verbal capacity, expectations and emotions. Given that self-report of pain is often no longer available in elderly individuals with dementia (due to the decline in cognitive functioning), the AGS Panel underlined the wide variability and complexity of assessing pain and physical disabilities in this patient group (AGS Panel, 2002). A comprehensive, disease-specific, individual assessment of the patients’ typical pain behavior is recommended, using a validated pain assessment tool as a prerequisite for appropriate pain treatment.

Pain prevalence in individuals with and without dementia

Between 45% to 83% of the patients living in nursing homes experience acute or chronic pain, particularly those with moderate to severe dementia. Most of them (about 94%) suffer from persistent pain (3–6 months or more; Miro et al., 2007), often located in the musculoskeletal system (Grimby et al., 1999). Chronic musculoskeletal pain affects over 100 million people in Europe and is by far the most common limiting factor on activities of the ageing population. Musculoskeletal pain increases the risk of reduced mobility, disability and muscle weakness, and reduces the health-related quality of life (Woolf et al., 2004). In older people, chronic pain is often experienced in major joints, the back, legs and feet, and it is reported more often than visceral pain and headaches (Helme & Gibson, 2001). Chronic pain is mostly nociceptive, around 10% is neuropathic, and 1 of 3 patients is believed to suffer from a combination of neuropathic and nociceptive pain.

But pain problems are not only movement related. About 40% of elderly individuals experience pain in internal organs, head and skin, which is more challenging to quantify (Husebo et al., 2008). Elderly patients with visceral painful conditions are far more likely than younger adults to present atypical pain responses (Helme & Gibson, 2001). Peptic ulcers, intestinal obstruction, and peritonitis are other visceral conditions, often with reduced or absent abdominal complaints (Helme & Gibson, 2001), and about 45% of older persons with appendicitis do not have typical lower-right quadrant pain as a presenting symptom, compared with 5% of younger adults (Wroblewski & Mikulowski, 1991). Living in a nursing home, 53% of the elderly are at risk of developing a pressure ulcer (Horn et al., 2002), and skin diseases found in 95% of the patients were described as one of the most prevalent health problems (Black et al., 2006).
Pain in connection with genito-urinary infections is quite often described in elderly patients. Catheter-associated urinary tract infection is the most common nosocomial infection, accounting for more than one million cases every year in American hospitals and nursing homes (NHs; Tambyah & Maki, 2000).

A large-scale epidemiological study in The Netherlands has shown that oro-facial pain has an increasing incidence rate with age in the general population, with incidence rates as high as 30.6 [15.1–55.8] for trigeminal neuralgia and 44.2 [24.7–73.4] for post-herpetic neuralgia in the general population (Koopman et al., 2009; Lobbezoo, Weijenberg & Scherder, 2011). In nursing homes in Austria, it was found that 28.9 % of the institutionalized elderly experienced acute dental pain during the preceding year, and that almost half of these individuals required dental treatment for their pain complaints (Ghahak, Armetzl, Kirmeier, Jakse & Arnetzl, 2010). Our own data from 18 nursing homes in Norway suggest that 23 % of the individuals are judged to be in oro-facial pain (unpublished data).

**Assessment of pain in individuals with dementia**

Given the high prevalence of pain in the elderly, proper assessment of pain by onlookers such as health care professionals or family members is a prerequisite for successful pain treatment. The task of appropriately judging a sufferer’s pain is a very complex one due to pain being highly personal, private and subjective experience. Whenever older adults in pain also have severe cognitive impairment – which go along with lack of language and abstract thinking – the task of judging pain becomes even more complex. This is the case because one of the most important cues that judges rely on when assessing pain is the patient’s verbal report and this cue is often missing in cognitively impaired patients (Kappesser, Williams & Prkachin, 2006). Accordingly, older adults with dementia, particularly those in advanced stages of dementia, are at a very high risk for being under-diagnosed and, consequently, under-treated. Against this background, immense effort has been invested in the development of behavioural pain assessment tools that do not rely on the individual’s capacity to provide a self-report of pain (e.g. Herr, 2011; Herr, Bjoro & Decker, 2006; Zawhalen, Hamers, Abu-Saad & Berger, 2006). These assessment tools are based on observations of the patients’ typical behaviour that might be related to pain, such as vocalization (e.g. moaning), facial expression (e.g. grimacing), and body movements (e.g. defense). There is also strong evidence that some behaviours like agitation, pacing or resisting care are related to present pain problems. As stated above, a panel on Persistent Pain in Older Persons, convened by the American Geriatric Society (AGS Panel, 1998) has recommended a comprehensive disease-specific, individual assessment of the patients’ typical pain behaviour using a validated pain assessment tool as a prerequisite for appropriate pain treatment. However, recommendations of the AGS Panel are based on experiences in older adults without dementia. This is of key importance because in dementia, symptoms attributed to neuropsychiatric disturbances may overlap with indicators of pain and thus, make interpretation quite challenging (Herr et al., 2006).

**Self-Report of Pain**

As stated before, the validity of self-report ratings might be questionable in patients with dementia, given the decline in language ability across the course of dementia. However, 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 (Corbett et al., 2012). Nevertheless, a study which aimed to assess the performance of self-assessment scales (the verbal, visual, and faces pain scales) found that only 61 % of 129 demented patients demonstrated comprehension of at least one scale (Pautex et al., 2006). Comprehension was defined as the ability to explain the scale use and correctly indicate positions for no pain and extreme pain on two separate occasions. Future research is needed to include and test the patients’ self-report abilities, and clinicians and researchers should be careful to use a scale that suits the individual.

**The Facial Expression**

In the last 35 years, more than 35 pain assessment instruments for older persons with dementia have been developed, tested, and reviewed in the literature. Most of these instruments are based on the idea that the patients’ acute or chronic pain experience is communicated by changes in facial expression, vocalization, and body movements (see Figure 1). Especially the facial expression seems to be one of the most promising non-verbal pain indicator, given that items relating to the facial expression are included in all 35 pain assessment instruments. Interestingly, one of the first instruments developed that tries to assess non-verbal behavior is the Facial Action Coding System (FACS) that focuses exclusively on facial expressions (Ekman & Friesen, 1978). The FACS is based on anatomical analysis of visible facial movements which are categorized as Action Units. Using the FACS, it has been shown that there is a small subset of facial actions that occur in the context of pain (e.g. narrowing the eye aperture, contraction of the eyebrows; Prkachin, 1992) and that patients with dementia show the same types of facial responses as non-demented elderly individuals (Kunz, Scharmann, Hemmeter, Scheipelmann & Lautenbacher, 2007). These findings are very promising, given that they clearly suggest that the face seems to specifically encode the experience of pain and that this specific encoding does not change in the course of dementia. However, FACS-coding is very time-consuming.
sometimes only suitable for research purposes.

pain intensity make the use of the scales challenging and training. In addition, different scoring systems of presumed intensity, the scoring method, and instructions for staff types of items included, the interpretation of the total pain

tional scales differ to a certain extent with regard to the presence and absence by the rater. The different observa-

tion of these items are assessed by frequency, intensity, or body movements (see Figure 1) (Cohen-Mansfield, 2006). Most of these items are assessed by frequency, intensity, or presence and absence by the rater. The different observa-

tional scales differ to a certain extent with regard to the types of items included, the interpretation of the total pain intensity, the scoring method, and instructions for staff training. In addition, different scoring systems of presumed pain intensity make the use of the scales challenging and sometimes only suitable for research purposes.

Usually, these observational scales are filled out when the patient is at rest (after some minutes of observation), but sometimes the patients are observed during daily life activities (ADL). Recent findings clearly suggest that observation of the patient at rest may not disclose the pain, especially chronic pain conditions, and it is now recommended that movement-related pain are better disclosed during ADL activities. This idea has already been incorporated into at least four pain behaviour rating scales and these scales include instructions for spontaneous or guided movements during the pain observation process (Lefebvre-Chapiro, 2001; Snow et al., 2004; Husebo, Strand, Moe-Nilssen, Husebo & Ljunggren, 2010; Nygaard & Jarland, 2006).

Taking together, a valid outcome measure of pain is the prerequisites for trials of pain treatment and assessment of potential analgesic side effects. In the last years, the development of single instruments is derivative of other instruments, including different aspects of pain behaviour and pain intensity, location and duration of pain, pain observed at rest or during movements, and self-report if still possible. Evaluations of the most promising observational pain assessment scales in patients with dementia indicate that although a number of tools demonstrate some promising potential, the validity of those scales is still not satisfactory (Villanueva, 2003). A further limitation is that some instruments are not validated in English or only validated for one language. In addition, hardly any information is available on how to assess orofacial and/or dental pain (Lobbezoo et al., 2011). This is of key importance, because impaired chewing, infections, and pain in the mouth may result in chronic malnutrition, poorer physical activity and more suffering.

Another concern is related to the scoring system. Most instruments add up the number of observed behaviours to present a total score. This means that a high number of behaviours indicate more pain. However, a patient may be

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in severe pain although it is manifested only in a few items, for instance in connection with moving a leg or an arm, and the rest of the body is pain free. Some patients with for instance Parkinson disease or a severely reduced condition would not be able to express enough behaviour to be judged to be in pain. Others, such as patients with Huntington’s chorea, may express too much, even when there is no pain.

Treatment recommendations for individuals with dementia

Pharmacological management of chronic pain in older persons may be challenging. In 2009, the AGS Panel revised their previous recommendations on Pain Management in Older Adults with support of the American Pain Society and the American Academy of Pain Medicine. The new guidelines include key approaches for safer opioid prescribing in older adults. However, the current treatment recommendation guidelines, which aim to update the evidence base of the 2002 Guideline, are not yet evidence based and do not consider pain treatment in patients with severe dementia, who often are excluded from randomized clinical trials and pain treatment studies (Corbett et al., 2012).

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 (Ballard, Smith, Husebo, Aarsland & Corbett, 2011).

Prevalence studies of analgesic drug use in dementia

Traditionally, medications with analgesic effects are classified into three groups: periphery analgesics, such as acetaminophen, non-steroidal anti-inflammatory drugs (NSAIDs), and opioid agents. Adjuvant medication (such as antidepressants, antiepileptic, hypnotics, anxiolytics, antipsychotics, and steroids) supports analgesic effects, but research results are only available for patients without dementia. Persons with dementia reported pain less frequently, but the prevalence of pain-related diagnoses was similar compared to persons without dementia. In this study, persons with dementia had higher probability of use of paracetamol (acetaminophen) and psychotropics, whereas there were no significant differences in use of any analgesic, opioids, and NSAIDs compared to those without mental impairment. These results are supported by another study which compared the use of central nervous system drugs and analgesics among 546 people aged 65 years and older, with and without dementia living at home or institutions in Sweden and Finland (Lovheim et al., 2008). A significantly higher proportion of patients with dementia used paracetamol, antipsychotics, antidepressant and anxiolytics. No differences were found for opioids. These findings are very promising; since they clearly suggest that the research findings of the last decades – which reported an under-treatment of pain in dementia – have already impacted the clinical practice and have led to an intensification of pain management in this frail patient group.

Acetaminophen was the most frequently prescribed analgesic and often at doses <1300 mg/day. A study on the knowledge and beliefs of nurses caring for older adults with dementia in a nursing home setting found that a large number of the professionals thought patients should only receive analgesics “when necessary” rather than on a fixed schedule (Cramer, Galer, Mendelson & Thomson, 2000). However, deficits or misbelieves about the care of older adults can affect all clinicians, not just nurses.

Better cognition has been associated with a greater likelihood of receiving an analgesic other than acetaminophen. In a study of 551 nursing home residents in North Carolina, 56 % of the individuals with severe cognitive impairment received pain medications, compared with 80 % of the cognitively intact cohort (P < .001); despite a similar rate of pain-related conditions in both groups (Richards & Scott, 2002). Notably, cognitively impaired persons were more likely to be given “as needed” pain medications while their peers had regularly scheduled analgesics. “As needed” drug regimens are particularly inappropriate for individuals with moderate-to-severe cognitive impairment who are unable to verbally communicate the need for pain relief.

But time is changing. Recently, increasing awareness of pain management in patients with dementia has been reported in the Swedish National Study of Aging and Care – Kungsholmen (Haasum, Fastbom, Fratiglioni, Kåreholt & Johnell, 2011). The study analyzed use of analgesics and psychotropics in 2610 participants aged >65 years and found that 46 % of the patients with dementia used at least one analgesic drug compared with 25 % of those without dementia. Persons with dementia reported pain less frequently, but the prevalence of pain-related diagnoses was similar compared to persons without dementia. In this study, persons with dementia had higher probability of use of paracetamol (acetaminophen) and psychotropics, whereas there were no significant differences in use of any analgesic, opioids, and NSAIDs compared to those without mental impairment. These results are supported by another study which compared the use of central nervous system drugs and analgesics among 546 people aged 85 years and older, with and without dementia living at home or institutions in Sweden and Finland (Lovheim et al., 2008). A significantly higher proportion of patients with dementia used paracetamol, antipsychotics, antidepressant and anxiolytics. No differences were found for opioids. These findings are very promising; since they clearly suggest that the research findings of the last decades – which reported an under-treatment of pain in dementia – have already impacted the clinical practice and have led to an intensification of pain management in this frail patient group.
The Development of a European Solution

The authors of this article represent members of the COST2-Action 1005 (Pain Assessment in Patients with Impaired Cognition, especially in Dementia). COST-Action 1005 consists of basic and clinical scientists in pharmacy, dementia, pain, nursing and palliative care with members from Belgium, Cyprus, Denmark, France, Germany, Israel, Italy, Norway, Romania, Spain, Switzerland, The Netherlands, United Kingdom, and Australia (http://www.cost-td1005.net). It is the task of this mostly European group to take into consideration all those behavioral pain assessment scales that have been developed and based on these scales to develop a comprehensive and internationally agreed-on assessment toolkit of pain in older individuals with cognitive impairments (especially dementia). This toolkit should target the various subtypes of dementia and various aspects of pain, including pain diagnostics, cognitive examination and guidelines for proper assessment. Validation of this toolkit requires joint action of both basic and clinical sciences. Only hereby, the urgently needed improvement of pain management in dementia can be achieved.

Conclusion

Advanced age is associated with increased prevalence of pain and of dementia. Given that the ability to report about pain depends on the patient’s memory, expectation, and insight; patients with dementia (who are often limited in these aspects) are at high risk for being underdiagnosed and untreated for pain. Pain that goes unnoticed may contribute to increasing behavioural disturbances in patients with dementia; like agitation and aggression. International recommendations to assess and treat pain have been published and an impressive number of pain behaviour rating scales have been developed and tested. However, the validity of these scales is still unsatisfactory. It is, moreover, an alarming fact that patients with dementia are still excluded from high quality RCT trials of pain treatment in dementia. This underlines high needs of research as well as excellent implementation concepts for pain assessment and pain treatment in elderly individuals with dementia.

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References


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CME-Fragen

1. Welche Faktoren erschweren maßgeblich die valide Schmerzerfassung bei Patienten mit demenziellen Erkrankungen?
   a. Die Patienten sind oft einsam und übertreiben daher ihre Schmerzangaben, um mehr Aufmerksamkeit vom Pflegepersonal zu bekommen.
   b. Die Patienten sind auf Grund ihrer kognitiven Einbußen oft nicht mehr in der Lage über ihre Schmerzen zu berichten.
   c. Im Verlauf der neuronalen Degeneration kommt es zu Zelluntergang in Arealen, die maßgeblich an der Schmerzverarbeitung beteiligt sind. Dies hat zur Folge, dass Demenzpatienten Schmerzsignale aus der Körperperipherie fehlinterpretieren.
   d. Die Patienten fühlen sich oft hilflos und verschweigen das Vorhandensein von Schmerzen, um nicht noch bedürftiger zu erscheinen.
   e. Alle der oben genannten.

2. Wie sieht die mimische Schmerzreaktion bei Demenzpatienten (mit leichter bis mittelgradiger Demenz) aus?
   a. Genauso wie bei Gesunden.
   b. Vermindert.
   c. Gesteigert.
   d. Demenzpatienten reagieren oft mit Lachen auf Schmerz.
   e. Demenzpatienten zeigen nur wirre, unspezifische Mimikreaktionen bei Schmerzerleben.

3. Was ist bei der Schmerzerfassung mittels Beobachtungsskalen zu beachten?
   a. Patienten sollten während Ruhephasen und während aktiver Phasen beobachtet werden.
   b. Beobachter/Pflegepersonal sollten eine Schulung durchlaufen, bevor eine Beobachtungsskala zur Schmerzerfassung eingesetzt wird.
   d. Die eingesetzte Skala sollte validiert sein.
   e. Alle der oben genannten.

4. Welche Art von Schmerzen kommt bei alten Menschen am häufigsten vor?
   a. Kopfschmerz?
   b. Neuropathische Schmerzen?
   c. Muskuloskeletale Schmerzen?
   d. Abdominale Schmerzen?
   e. Alle Schmerzarten kommen mit ähnlichen Häufigkeiten im Alter vor.

5. Welche Probleme treten in der Schmerztherapie von Demenzpatienten auf?
   a. Demenzpatienten haben zumeist eine zu hohe Dosis an Schmerzmedikamenten verabreicht bekommen.
   b. Demenzpatienten wurden mit Schmerzmedikamenten, wie Paracetamol, ruhig gestellt.
   c. Geringere Dosen an Schmerzmedikamenten sind bei Demenzpatienten im Vergleich zu kognitiv Gesunden bereits ausreichend, da bei Demenzpatienten höhere Plazeboeffekte nachgewiesen werden konnten.
   d. Demenzpatienten haben zumeist deutlich weniger Schmerzmedikamente verabreicht bekommen im Vergleich zu kognitiv gesunden Personen.
   e. Schmerzmedikamente können nicht zusammen mit Antidementiva verabreicht werden, da die Schmerzmedikammente die Wirkung der Antidementiva aufheben.
Um Ihr CME-Zertifikat zu erhalten (mind. 3 richtige Antworten), schicken Sie bitte den ausgefüllten Fragebogen mit einem frankierten Rückumschlag bis zum 10.01.2013 an die nebenstehende Adresse. Später eintreffende Antworten können nicht berücksichtigt werden.

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Die Ärztekammer Niedersachsen erkennt hiermit 1 Fortbildungspunkt an.

Pain assessment and treatment challenges in patients with dementia

Die Antworten bitte deutlich ankreuzen!

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b. □ □ □ □ □
c. □ □ □ □ □
d. □ □ □ □ □
e. □ □ □ □ □

Ich versichere, alle Fragen ohne fremde Hilfe beantwortet zu haben.

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