Orofacial pain in dementia patients

ABSTRACT

This article presents a comprehensive review of the literature on the diagnosis of pain in the orofacial region of patients suffering from a cognitive impairment or a dementia. This review was based on a literature search yielding 74 papers most of which dealt with the assessment of pain in general in nonverbal individuals, for which several observational tools have been developed. Unfortunately, none of these tools have been designed for the specific assessment of orofacial or dental pain. Thus, none of them can be recommended for use in the dental setting. There is hardly any information available in the literature on how to assess orofacial and/or dental pain in patients with a cognitive impairment or a dementia. Given the expected increase in the incidence of dementia over the upcoming decades, it is of the utmost importance that dentists can use well-tested tools that can help them in the diagnosis of orofacial and dental pain in this vulnerable patient population. Such a tool should incorporate specific orofacial/dental pain indicators, such as the patient holding/rubbing the painful orofacial area, limiting his/her mandibular movements, modifying his/her oral behavior, and being uncooperative/resistant to oral care.

INTRODUCTION

Dementia is an acquired, organic, mental disorder that is characterized by a loss of intellectual abilities that is of sufficient severity to interfere with daily life activities. It is not a disease but rather a group of symptoms that may accompany certain diseases or conditions. The most common subtype of dementia is Alzheimer’s disease (about 54%), followed by vascular dementia (16%). The remaining 30% includes other subtypes of dementia, e.g., frontotemporal dementia. In Alzheimer’s disease, the most prominent clinical symptoms include memory disturbances, aphasia (i.e., a defect or loss of the power of expression by, e.g., speech, or of language comprehension), apraxia (i.e., loss of ability to carry out familiar, purposeful movements in the absence of paralysis or other motor or sensory impairments), and visual agnosia (i.e., loss of the power to recognize the import of visual stimuli). Vascular dementia is mainly characterized by deterioration in both cognitive and motor functions, e.g., gait disturbances. Frontotemporal dementia is primarily characterized by behavioral disturbances.

Age is the highest risk factor for dementia. More specifically, the higher the age, the higher the prevalence of dementia: in older persons of 60–65 years of age, the prevalence is approx. 1%; in older persons of 85 years of age and older, 10–35%.

Such a prevalence implies that the chance that a dentist will encounter a person with dementia is considerable. The dental care for this vulnerable patient population is complicated by several factors, among which a decline in communication and resistance to care. Moreover, orofacial dyspraxia has been described in a patient with frontotemporal lobar degeneration, while the severity of Alzheimer’s disease may be associated with failing the ideomotor (i.e., aroused by an idea or thought) face apraxia test. Ideomotor apraxia may compromise the patient’s own contribution to oral hygiene, e.g., brushing one’s teeth.

When professionals and family members were asked about the target outcomes for long-term oral health care in patients with dementia, a three-round Delphi study showed that the patients being free from oral pain was the number one target outcome. In another study using structured interviews, hospital dentists as well as patients’ relatives rated freedom of oral pain as the most important target outcome as well. In general, pain is often underdiagnosed and undertreated in patients with dementia. In part, this undertreatment may be due to concerns related to the increased risk of medication-induced adverse events in the elderly. However, results from several studies indicate that older patients with dementia are prescribed fewer analgesics (e.g., acetaminophen, opiates) and non-steroidal anti-inflammatory drugs (NSAIDs) than older persons without dementia, whereas they suffer from the same painful condition, e.g., hip fracture surgery. Undertreatment of pain in dementia is more alarming considering possible neuropathology-related pain alterations, e.g., an increase in pain experience. Within this scope, it is not surprising that pain with a dental etiology is also underdetected and under-
treated in persons with dementia, as is evident from a study of observed discrepancies between the presence of possible pain-causing conditions, e.g., fractured or broken teeth as assessed by a dentist, and the presence of possible dental-related pain, as assessed by a geriatrician as part of a general physical examination. However, the details of the pain-assessment method were not elaborated, which makes an unequivocal interpretation of this report impossible.

Reliable assessment of orofacial pain in dementia is not only clinically relevant for the pain as such. Orofacial pain is one of the clinical symptoms of a temporomandibular disorder, which is characterized, among others, by a reduction in chewing ability. In turn, impaired chewing may result in chronic malnutrition, while malnutrition, for example expressed in vitamin D deficiency, is associated with poorer physical activity. In Alzheimer’s disease, a decrease in the level of functionality hampers energy consumption, which reduces appetite, thus creating a vicious circle in nutrition. Reliable pain-assessment with subsequent adequate pain treatment may interrupt this vicious circle in dementia.

The literature lacks a focused overview regarding the diagnosis of pain in the orofacial region of patients suffering from dementia. Therefore, the aim of this article was to assess the literature on this topic by using PubMed of the U.S. National Library of Medicine (NLM) and the National Institutes of Health. The following query was used: (“facial pain”[MeSH Terms] OR (“facial”[All Fields] AND “pain”[All Fields]) OR “facial pain”[All Fields] OR (“orofacial”[All Fields] AND “pain”[All Fields]) OR “orofacial pain”[All Fields]) OR (“toothache”[MeSH Terms] OR “toothache”[All Fields] OR (“dental”[All Fields] AND “pain”[All Fields]) OR “dental pain”[All Fields]) OR TMD[All Fields]) AND (“dementia”[MeSH Terms] OR “dementia”[All Fields]). No limits were used to restrict the output of the search. The query yielded 69 papers that were published between 1969 and 2009 of which 25 papers were omitted for various reasons (mainly because they dealt with non-related topics). The remaining 44 papers were supplemented with 30 papers that did not show up in the above-described searches but were nevertheless considered applicable by using the reference lists of the 44 articles and the authors’ personal collections as sources.

Dementia influences both the reporting and experience of pain. In the central nervous system, pain is processed by the medial and lateral pain systems. The lateral pain system is mainly involved in the sensory-discriminative aspects of pain, whereas the medial pain system plays a role in, among others, the cognitive-evaluative and motivational-affective aspects of pain. There is ample evidence that cerebrovascular disease, which is characteristic not only for vascular dementia but also for Alzheimer’s disease, affects the white brain matter. White matter lesions dis-
connect brain areas, and consequently may cause a de-afferentiation pain, also paraphrased as ‘central pain’. In other words, two of the most prevalent subtypes of dementia, Alzheimer’s disease and vascular dementia, may coincide with an increase in (central) pain experience. These findings enhance the risk for undertreatment of pain in this population, emphasizing the need for reliable pain-assessment.

**ASSESSMENT OF PAIN IN GENERAL IN DEMENTIA**

During the last decade, several comprehensive reviews of pain-assessment tools for use in persons with dementia have been published. In communicative patients, a first step in pain-assessment could take place by self-report, using simple verbal descriptor scales, numerical scales (0 to 10), visual colored analogue scales (pain thermometers), or facial pain scales. It has been suggested that for pain-assessment in persons with mild to moderate cognitive impairment, it is advisable to have a variety of such instruments available, so that the best tool can be selected for each individual patient. For those who can no longer reliably communicate about pain, observations of specific behaviors are indicated, like vocalizations, facial expressions, and body movements. For the presence of pain, but not for pain severity, such observations can be used accurately. They can be made either directly by health professionals or indirectly through reports by family members or nursing staff.

An accurate estimation of pain in nonverbal individuals provides great challenges for the future. Even if physiological pain measurements are developed (e.g., registrations of brain activity or determinations of pain-related blood chemicals), the question remains how nonverbal individuals experience pain. For a proper assessment of pain experience, it is extremely important to know the person in pain well. Changes in behavior that may signal pain can best be recognized by those who care for a person with dementia on a daily basis. Indeed, the challenge for the observer of pain-related behavior lies in the interpretation of the individual’s personal pain expressions. This means that observational methods for pain-assessment work best in the hands of caregivers who are involved in the long-term care for the individual with dementia. Further, the nursing staff should be knowledgeable about pain and common pain conditions. However, Smith has realistically noted that such a situation will hardly ever be realized due to, among others, high staff turnover rates in most care facilities. Thus, reliable and valid tools that also work in the hands of caregivers who do not know the observed individual that well are also needed.

A host of observational pain-assessment methods for nonverbal patients have been described in the literature. Smith provided a detailed review of several pain-assessment tools, including their psychometric properties. She has concluded that each instrument has its strengths and limitations, and that all of them would benefit
from additional testing. Herr et al. \textsuperscript{27} systematically searched the literature for pain-assessment tools that were developed for or tested in nonverbal older adults. To be included in their review, tools had to fulfill a set of clearly described criteria, such as having undergone at least one psychometric assessment. Thus, the authors included 10 instruments and have provided a detailed overview of these instruments’ psychometric properties \textsuperscript{27}. An update of this overview can be found at http://prc.coh.org/PAIN-NOA.htm. The authors concluded that, unfortunately, none of the observation-based tools for pain-assessment in nonverbal individuals can be recommended for broad adoption in clinical practice \textsuperscript{27}. Until a strong, valid tool emerges, pain-assessment in nonverbal patients can be approached in several steps: (1) anticipate the presence of pain with or following disease, injury, or surgery; (2) establish baseline behavior so as to enable the observation of pain-related behavior; (3) look for less obvious indicators of pain, like agitation or aggression; and (4) in case of doubt, administer analgesics and observe possible changes in behavior, which may then be due to pain relief \textsuperscript{27,32}.

**ASSESSMENT OF OROFACIAL PAIN IN DEMENTIA**

As for the assessment of pain in general in communicative patients with dementia, also the assessment of orofacial pain in such patients could still take place by a variety of self-report instruments (see above). The vast majority of the articles that were reviewed, however, have dealt with instruments for the assessment of pain in nonverbal persons. Surprisingly, while orofacial pain undoubtedly comprises an important part of all pains in individuals with dementia, none of the tools found in the literature were specifically developed for orofacial pain-assessment. At best, dental problems and/or orofacial/dental pain were part of an assessment tool with a broader application (see below) \textsuperscript{33}. Therefore, all instruments that were found with the current search were scrutinized with respect to their possible qualities to assess orofacial and dental pains.

Of the 10 instruments that were selected by Herr et al. \textsuperscript{27}, five surfaced with the present search approach, viz., ADD, DS-DAT, Doloplus \textsuperscript{2}, PACSLAC, and PAINAD. Since these tools were found with a strategy that focused on orofacial and/or dental pains, the authors’ \textit{a priori} expectation was that they would, at least in part, focus on these conditions. Therefore, these five instruments will be reviewed first. The Assessment of Discomfort in Dementia (ADD) protocol was designed to assess not only physical pain but also affective discomfort \textsuperscript{34,35}. Semistructured interviews with experienced nurses of long-term facilities for older persons with dementia were used to collect signs and symptoms of pain and discomfort. Unfortunately, apart from a possible decrease in appetite (which is not specific for orofacial pain; see below), it remains unclear whether orofacial behavior is being observed as part of the ADD protocol. Reliability and validity have not been sufficiently
tested \(^2\), which so far hampers a widespread application of this tool. Further, the comprehensive nature of the ADD protocol makes it too complex for routine use in long-term care facilities for nonverbal individuals, let alone that the instrument could be used in a dental setting.

The Discomfort Scale for Dementia of the Alzheimer Type (DS-DAT) was developed for the assessment of affective discomfort and pain in patients with advanced dementia who lost their cognitive capacities and verbal communication abilities \(^3\). The system uses frequency, intensity, and duration scores for behavioral indicators like noisy breathing, negative vocalization, certain facial expressions (e.g., content, sad, or frightened), and body language (relaxed or tense). The scoring method is generally considered complex, time consuming, and mainly applicable in research settings. The instrument’s psychometric properties warrant further study, especially regarding its validity in patients with pain-related conditions \(^2\). The fact that observations of the jaw (‘a slack unclenched jaw’ is one of the indicators for a content facial expression) are part of the system, does not make this instrument applicable for the specific assessment of orofacial and/or dental pain. This applicability remains to be studied.

Another paper dealt with the (Norwegian version of) the Doloplus \(^2\), an originally French instrument that has been translated in several languages but still awaits extensive testing of its psychometric properties in English-language settings \(^2\). While facial expressions of pain are part of the Doloplus \(^2\) (as they are of all observational instruments examined), it is unclear whether orofacial behavioral observations are part of this pain-assessment tool. For example, indicators like ‘protective body postures adopted at rest’, ‘protection of sore areas’, and ‘changes in mobility’ can be observed in the body as a whole, but also specifically in the orofacial area. If the latter is the case, the instrument may be useful in dental settings.

The Pain-assessment Scale for Seniors With Severe Dementia (PACSLAC) is a 60-item observational tool for pain behaviors \(^3\). This originally Canadian-English instrument has been translated in several languages, including Dutch \(^3\), and has been used clinically \(^4\) as well as with video acquisition systems \(^4\). The instrument is in need of more psychometric testing to confirm its reliability and validity \(^2\). Some of the constituent items are related to the orofacial area; most of them concern facial expressions, notably teeth clenching and opening the mouth. Also, it is unclear whether any of the activities or body movements observed (e.g., refusing to move, moving slow, resistant to care, guarding sore area) include the orofacial area. Changes in appetite, another possible ‘orofacial pain indicator’, may be nonspecific, as noted below. Consequently, the PACSLAC cannot yet be recommended for use in the dental setting.

The Pain-assessment in Advanced Dementia Scale (PAINAD) was developed as an easy-to-use and clinically relevant tool for the assessment of pain in advanced dementia. This originally American-English tool \(^4\), that was translated in several target languages (e.g., German) \(^4\), relies on the observation of five behavioral in-
dicators of pain in nonverbal individuals: breathing, vocalization, facial expression, body language, and consolability. The tool is not comprehensive, which adds to its easy-to-use character, but compromises its ability to detect more subtle changes in pain. Further, both its reliability and its validity require more testing. Finally, although it is stated in the description of the indicator ‘body language’ that “the jaw may be clenched”, again no specific orofacial indicators are included in this instrument. Thus, the dental application of the PAINAD cannot yet be recommended.

Zwakhalen et al. evaluated the psychometric properties of the Dutch translation of three of the above-discussed instruments, viz., the Doloplus 2, the PACSLAC, and the PAINAD. They concluded that despite the common call for more reliability and validity testing, these aspects are generally acceptable for these three pain-assessment tools. Surprisingly, nurses preferred the PACSLAC not only over the rather difficult-to-use Doloplus 2 but also over easy-to-use the PAINAD. Nurses qualified the latter as being too concise. In another comparison study, the PAINAD was compared with the Abbey Pain Scale, an Australian tool that attempts to measure acute and chronic pain in late-stage dementia, again, with insufficient psychometric data available, and unfortunately without a specific focus on orofacial and/or dental pain. The authors concluded that neither of these tools met their standards, especially because the motivational-affective aspects of pain cannot be assessed properly. Importantly, in none of these comparison studies was attention given to orofacial/dental pain.

Besides the five pain-assessment instruments that were also selected by Herr et al., there are at least a couple of other tools for general (i.e., non-dental) application. Apparently, there is a large need for pain-assessment tools that can be used reliably and validly in nonverbal individuals. In one article, the authors suggested a trial of analgesics as part of the pain-assessment procedure, whenever a non-pharmacological approach turned out to be inadequate. As for the above-discussed instruments, also the so-called Mobilization-Observation-Intensity-Dementia Pain Scale (MOBID) and the Certified Nursing Assistant Pain-assessment Tool (CPAT) for nursing home residents with dementia lack a specific focus on orofacial and dental pains. Where the CPAT is a purely observational tool, the MOBID contains observations of pain behaviors during, among others, caregiver-imposed movements (mobilizations). Interestingly, tooth brushing/mouth care was originally among the imposed activities included in the protocol. Unfortunately, after initial testing, the item was removed from the instrument, because it seemed to assess a nonpain construct (the authors suggest ‘surprise’ or ‘confusion’). The authors also noted a difficulty to rate pain in relation to mouth care (disliking this activity was difficult to distinguish from pain behavior) as well as possible differences in the test procedure between patients with and without removable dentures. The resulting instrument thus lacks a focus on the orofacial area, as do all the other pain-assessment tools discussed above.

There are several studies that used the so-called Facial Action Coding System...
(FACS) as a tool to assess pain in nonverbal individuals. FACS is a comprehensive system that uses explicit, anatomy-based criteria to distinguish discrete facial actions, typically on video recordings. The usefulness of the system has been shown in studies on musculoskeletal pain among seniors undergoing rehabilitation after knee surgery as well as in cognitively impaired and demented patients following experimental pain stimuli. From these studies, it can be concluded that even though augmented facial expressions are not reflective of the presence or intensity of nociception, FACS has the potential to serve as a pain-assessment tool in nonverbal patients. Unfortunately, in none of these studies, was the (evoked) pain present in the orofacial area; rather, it was present in the arms and legs. Thus, the application of FACS in orofacial and dental pains remains to be assessed.

DENTAL PROBLEMS IN DEMENTIA PATIENTS

Three articles have focused on dental problems in patients with dementia, although without a (specific) focus on pain. In the first article, a review by Ghezzi and Ship, the gradual inability to perform oral self-care with the progression of dementia was highlighted because this aspect has major consequences for oral health. Among others, poorer gingival health, increased coronal and root caries, and more mucosal pathologies were described in comparison with gender- and age-matched healthy controls. While the authors did not address the difficulty of pain-assessment in dementia, they did state that “routine dental care must be performed to eliminate potential sources of pain (...).” The authors advocated, in their own words, “aggressive preventive measures (...),” to maintain the dignity and quality of life of a person with dementia.

The second article addressed denture use by institutionalized elderly people with various degrees of dementia. It was found that especially the individual’s ability to dress/undress oneself and to rinse his/her mouth were major indicators for non-use of dentures (either complete or partial), both factors having clinically relevant odds ratios larger than two (viz., 2.3 and 6.1, respectively). Unfortunately, pain in relation to use/non-use of dentures by persons with dementia was not assessed.

In the third article, the dental approach of patients with Alzheimer’s disease was discussed, preceded by an update on the medical aspects of the disorder. The authors proposed the use of a brief checklist for an accurate assessment of risk factors that may influence the diagnosis and treatment of oral problems in individuals with dementia. Unfortunately, pain is not part of this screening tool, although the authors did state that Alzheimer’s disease interferes with the patient’s ability to communicate, among others, dental pain symptoms.

Clearly, the absence of (specific) attention for orofacial/dental pain in these three articles suggests that future studies should take this important clinical symptom
into consideration. The present review found only one review article with a specific focus on pain in dementia from the dentist’s point of view\textsuperscript{68}, and one research paper describing an instrument that was specifically designed to assess oral health aspects (including dental pain) of the cognitively impaired and individuals with dementia living in residential care facilities\textsuperscript{33}. As part of a comprehensive review, Lapeer\textsuperscript{68} rightfully stated that in the absence of language skills, behavioral observations are critical to pain-assessment, even though they must be taken at ‘face value’, i.e., the determination of pain behavior is very difficult in nonverbal cases. The author concluded that oral health care professionals must favor the side of treatment rather than ignore a potentially painful condition. However, except by providing information on the assessment of pain in nonverbal individuals in general, the author does not clarify how orofacial/dental pain can be diagnosed in such cases.

Also to be discussed in this section is the above-mentioned research paper by Chalmers et al.\textsuperscript{33}. Using the Brief Oral Health Status Examination (BOHSE)\textsuperscript{69} as their starting point, the authors developed a simplified screening tool, the so-called Oral Health Assessment Tool (OHAT), which could be administered by a range of residential care staff. Importantly, while three out of the ten BOHSE categories were omitted, Chalmers et al.\textsuperscript{33} added a category for the assessment of behavioral problems and pain related to oral and dental problems. Hence, the OHAT consists of eight categories that can all be scored on a three-point scale, with 0 = healthy, 1 = oral changes (for dental pain defined as ‘verbal and/or behavioral signs of pain such as pulling at face, chewing lips, not eating, aggression’), and 2 = unhealthy (for dental pain defined as ‘physical pain signs [swelling of cheek or gum, broken teeth, ulcers], as well as verbal and/or behavioral signs [pulling at face, not eating, aggression]’). While the intraobserver and interobserver agreement of the dental pain category were both found to be substantial (kappa statistics), the correlation of this category with dental examination findings was low and non-significant. In other words: dental pain can be assessed reliably using the OHAT, but the validity is reason for concern. This may be due to the nonspecific character of part of the scale definitions (e.g., not eating, aggression). Another issue that negatively influences the psychometric properties of this dental pain category of the OHAT is the fact that a distinct subgroup of participating care staff indicated that they were not able to complete the dental pain category, among others due to an inadequate understanding of the 3-point scale definitions. In conclusion, even though it is promising that dental pain was added to this screening tool for the cognitively impaired and individuals with dementia living in residential care facilities, the moderate psychometric characteristics and the nonspecific assessment of dental pain prevent a broad application of this tool in the dental setting.
This review provides a focus on the diagnosis of pain in the orofacial region of patients suffering from dementia. There are only a handful of papers that actually have dealt with this topic, and in many of the papers, orofacial and/or dental pain only played an indirect role. It should be noted that nonverbal individuals with dementia are typically not being seen by dentists in community practices but rather by geriatric dentists affiliated to specialized residential facilities. Nevertheless, orofacial pain in dementia patients is a largely understudied topic that, given the growing population of persons affected by cognitive impairments or dementias with, possibly, alterations in pain experience \cite{21}, needs more attention from researchers in the near future.

When comparing the \textit{one} instruments for pain-assessment in nonverbal persons they selected after a systematic search of the literature, Herr et al. \cite{27} used the American Geriatrics Society (AGS) guidelines \cite{70}, a comprehensive framework for the organization of behavioral pain indicators, as their reference. The AGS guidelines distinguish six main types of behavioral pain indicators: (1) facial expressions (e.g., grimacing, closed or tightened eyes, rapid blinking); (2) verbalizations, vocalizations (e.g., noisy breathing, moaning, calling out); (3) body movements (e.g., guarding, restricted movement, mobility changes); (4) changes in interpersonal interactions (e.g., withdrawn, resisting care, aggressive); (5) changes in activity patterns or routines (e.g., refusing food, changes in rest pattern, increased wandering); and (6) mental status changes (e.g., increased confusion, distress, crying or tears). Unfortunately, most of these behavioral pain indicators have a general nature, i.e., they are not helpful in the specific assessment of pain in the orofacial area in nonverbal individuals.

However, some indicators from the AGS categories, ‘body movement’ and ‘changes in activity patterns or routines’, may have some differential diagnostic merits. As indicated above, the ‘body movements’ category includes indicators like rigid, tense body posture, guarding, restricted movement, and mobility changes. For example, for orofacial pain with a musculoskeletal origin, it is known that patients hold/rub the painful orofacial area and restrict their mandibular movements as to prevent the pain from getting worse, and to promote healing \cite{71}. The ‘changes in activity patterns or routines’ category includes, among others, indicators like refusing food and appetite changes. According to Dworkin \cite{72}, diet modifications can indeed be considered a result of pain. Clearly, these indicators might point towards an orofacial/dental origin of the pain, although they may also be positive in case of other, nonorofacial pains. Considering all the above, it may be possible to create an instrument capable of assessing orofacial/dental pain in nonverbal individuals.

From the above review of the literature, suggestions can be gathered as to how to compose a reliable and valid instrument for the assessment of orofacial and/or dental pain in persons with dementia, using relevant items from pain-assessment...
tools that were developed for general use. Importantly, specific orofacial/dental pain indicators must be used, like ‘the patient...’ (1) ‘...holds/rubs the orofacial area’, (2) ‘...limits his/her mandibular movements’, (3) ‘...modified his/her oral (e.g., eating) behavior’, and/or (4) ‘...is uncooperative or resistant to oral care’. Further, the instrument must be easy-to-use in a dental setting and should not require extensive training of the staff. Finally, a plan for implementation should be part of the study that includes the development and psychometric testing of the pain-assessment tool, as to achieve broad acceptance in an efficient and timely manner.

In conclusion, there is hardly any information available on how to assess orofacial and/or dental pain in patients with a cognitive impairment or a dementia. Nevertheless, suggestions can be gathered from the literature on how to develop a reliable and valid instrument for the assessment of orofacial pain in such cases. Given the expected increase in the incidence of dementia over the upcoming decades due to the increase of the ageing population, in combination with the fact that people tend to keep their own, natural dentition until old age, it is of the utmost importance that dentists can use a well-tested tool that can help them in the diagnosis of orofacial and dental pain in this vulnerable patient population. A proper diagnosis will prevent unnecessary suffering as well as unnecessary treatments, and will thus lead to a higher quality of life.
REFERENCES


