Which facial descriptors do care home nurses use to infer whether a person with dementia is in pain?

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Abstract

Objectives: Pain assessment in people with advanced dementia relies strongly on observable pain behaviors, such as facial expressions, body movement and vocalizations. However, the process of inferring pain in others, based on such observations, is not well understood. We aimed to investigate which features of facial expressions caregivers rely on when inferring the presence and intensity of pain in people with dementia.

Methods: A questionnaire, including items on thirteen facial descriptors, which were extracted from established observational scales for pain in dementia, was sent to 366 nursing homes in Germany. We asked the nurses to observe patients with dementia and then rate their observations using the facial descriptors as well as to provide an overall pain estimate of the residents' pain. We used regression analyses to identify which facial descriptors nurses use most commonly to infer whether a person with dementia is in pain and to grade its intensity.

Results: Seventy-nine nursing homes participated (22% response rate) and a total of 284 completed observer ratings were returned. The observed individuals suffered from moderate to severe dementia and were observed in everyday care situations. The average pain estimated by the caregivers was slight to moderate. Mainly, anatomically-based descriptors ("frowning", "narrowed eyes") and indicators of emotional arousal ("looking tense", looking frightened") significantly predicted the overall pain ratings by nurses; explaining approximately 45 % of the variance.

Conclusions: Although all presented facial descriptors were used by the nurses, some descriptors were used clearly more frequently than others to infer whether a resident with dementia is in pain. Development of observational pain tools and training in their use should consider the pre-existing assumptions that nurses use to infer pain as well as their potential bias.

1. Introduction

Prevalence rates for both dementia and pain increase with age. Given demographic changes in the coming decades, resulting in rapid growth of the older population, the number of individuals suffering from pain as well as from dementia will substantially increase. During the course of dementia, people become less able to self-report their pain [1]. This lack of verbal ability makes it difficult to assess pain in people with dementia and communication difficulties because, by definition, pain is a private experience. However, brain imaging studies demonstrate how people with Alzheimer's disease have difficulty integrating novel and previous pain experiences with contextual information, and thus, perceive every pain stimulus as new and threatening [2]. This impaired ability to harmonize past and present experiences as well as expected outcomes may lead to pain being more distressing and increases the impact of persistent pain on cognitive and behavioral functioning.

Given the difficulty in self-report of pain, pain is overlooked in these patients, and remains untreated. Untreated pain often results in challenging behavior which may be distressing for the person with dementia and those who care for them. Caregivers of people with dementia often feel helpless when trying to identify pain and have concerns that they may have missed this [3]; thus, they are quite eager to learn more about the pain-specific behavioral indicators. Behavioral indicators of pain can be signified by facial expressions, vocalization, body posture and movement. However, there is wide agreement that facial responses are most salient and easy to decode in this context [4].

When trying to infer pain in others by observation, it is important to identify which behavioral features are critical in the non-verbal communication of pain. Besides investigating how pain is encoded in different pain behaviors, which behavior can be most reliably observed or which behavior is best suited to differentiate pain from other negative affective states, it is also crucial to understand which behavioral features caregivers rely on when deciding whether a

person is experiencing pain. Or, in other words, (i) what kind of observations promotes the inference that another person is experiencing pain and (ii) how are these used to infer information about pain intensity levels.

 Previous studies have suggested that in clinical practice the inference of pain in people with dementia based on observations has several shortcomings. For example, caregivers often do not use systematic observations, structured protocols or rely on specific behaviors. Moreover, they often have difficulties differentiating pain from distress and lack knowledge about how to define pain in people with dementia [5]. In order to improve this, several groups of experts have specified and operationalized key observations that may help to correctly infer pain. This work has resulted in various observer-rated pain scales for people with dementia [6,7]. In an attempt to develop this work further, an international expert panel from an EU COST Action[1][2] has extracted the verbal descriptors of these observations from the most common dementia pain scales. These descriptors were grouped into the basic categories "facial expression", "vocalization" and "body movement" as per the well-established American Geriatrics Society (AGS)[3] classification [8].

There is general agreement that amongst the three AGS categories facial expression is of key importance in making observer-based decisions about the need for pain treatment and care [9,10]. Facial expressions are easily accessible for observation, can be graded, and can be used by human and computer-based automated pain detection systems. Therefore, we started our search for critical observations, which promote the inference of pain being present and influence the grading of its intensity by focusing on facial descriptors. We asked the nurses for structured observations of the facial expression of the patient by using 13 facial descriptor items extracted by the COST expert panel. We decided to use these 13 items instead of using

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the face subscale of one of the already established observational pain scales because most scales do not include several variants of facial descriptors (anatomical, emotional, cognitive, autonomic, etc.) but rely mainly on only one variant, which would have unreasonably narrowed the variety of descriptors we liked to offer for evaluation. Thus, the present study aims to identify which facial descriptors are used by caregivers to evaluate and influence their diagnostic decision-making process when assessing pain.

2. Methods:

Design of survey

The study focused on nurses for the elderly in nursing homes because they are crucial in providing pain care to residents with dementia. We used a questionnaire survey, assessing pain in every-day situations, including potentially painful activities of daily living (ADL), as recent findings clearly suggest that people with dementia at rest often display fewer observable pain indications than during ADL activities [4].

The survey comprised a cover letter, a short demographic questionnaire, 13 items of facial pain expressions and two general ratings of pain; all 15 items were designed as observer ratings. This questionnaire was sent out to 366 nursing homes in Bavaria (Germany) in February/March 2013 and we collected the returned questionnaires over a period of 5 months. The study protocol was approved by the ethics committee of the University of Bamberg.

<u>Selection of facial descriptor items</u>

We selected facial descriptor items from established observational pain assessment tools for people with dementia in several steps. This was conducted by the COST expert panel as described in detail elsewhere [11]. In brief, in step one, based on review articles that evaluated observational pain assessment tools for people with dementia (published between 2005 and 2011; e.g. [6-7,12-14], we identified 12 pain assessment tools recommended by the authors of review articles: The ABBEY Pain Scale [15], ADD [16-17], CNPI [18-19], DS-DAT [20-21], DOLOPLUS-2 [22], EPCA-2 [23], MOBID-2 Pain Scale [24], NOPPAIN [25], PACSLAC [26], PAINAD [27], PADE [28], and PAINE [29]. Out of these 12 scales, we extracted all items relating to facial expressions (in total: 47 items). In step two, we removed all largely or completely synonymic items (e.g. looking tense, tense facial expressions), resulting in 32 items. Interestingly, there was great overlap in items as regards inclusion in the 12 scales, with 41% of items being found in at least two scales. In the third step we grouped the 32 facial items into sub-categories, namely "cognition" (e.g. item "empty gaze"), "emotional state" (e.g. item "looking sad"), "anatomically-based description" (e.g. item "frowning") and "autonomic reaction" (e.g. item "pale face"). In the fourth and final step, we tried to further reduce the number of items by selecting the most promising facial descriptors within each sub-category based on published research on the facial expressions of pain [30-32], on the frequency of occurrence in existing pain assessment tools as well as on the opinion of the COST experts as regards their clinical utility. Items excluded in this last step can be found in the footnote[4]. This resulted in the final pool of 13 facial descriptors (see Table 2).

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[4] *Items excluded in step 4: absent gaze; blank look; blinking; change in eyes (dull, bright, increased movement); creasing forehead; dirty look; distorted expressions; drawn; atonic fixed gaze; grimacing; jaw drop; open eyes; rigid expression; quivering chin; screwing up nose; tighter face; wincing; looking worried; seeming withdrawn*

Questionnaire

In the cover letter, we informed participating nursing homes that we are developing a tool to assess pain in people with dementia, especially for those no longer able to report pain for themselves, and that we would be interested in which facial expressions nurses observe during potentially painful care activities (e.g. washing, mobilization). Before completing the observational part, nurses were asked for demographic information regarding themselves (e.g. age, years of work experience etc.) as well as regarding to the resident being observed (e.g. degree of cognitive decline (Global Deterioration Scale, GDS), analgesic usage).

We asked nurses to observe residents with dementia during these care activities and to use our questionnaire to rate which facial expressions they observed. They were then asked to specify the situation in which they observed the residents' facial expressions. They could choose between "washing", "getting dressed", "transfer", "wound treatment", "mobilization" and "others". They were further asked to complete which of the 13 facial descriptor items they had seen and two general ratings of pain directly after they completed their observations.

The instructions for the 13 facial descriptor items were: "Using the following scale, please indicate the degree to which you have observed the following items in the patient." The participants were instructed to record only facial activities that they observed during the specified care situations. Observations of facial activity were scored on a 4-point category scale (not at all - slight degree – moderate degree – great degree). There was also the option to select "not applicable/not scoreable" as an answer.

After this, nurses were asked to give two overall estimates of the pain that the resident may have experienced during the observed care activity on two 4-point category scales. Firstly a rating for pained expression and secondly a rating for pain intensity. These two items stress

both the observational aspect ("pained expression") and the inferential aspects of overall pain evaluation ("pain intensity").

Statistics

Since all the selected facial descriptors were originally devised for the same purpose, i.e. to indicate pain, it is likely that they are strongly associated with each other. We theoretically assumed that these descriptors fall into four subcategories, namely "cognition", "emotional state", "anatomically-based description" and "autonomic reaction" [11]. To test whether these theoretical dimensions were reflected in the observational use of the items by caregivers, a *factorial analysis* was completed. We applied principal component analysis on all facial items and used varimax rotation to maximize independence of factor scores. We examined the scree plot and applied the eigenvalue-greater-than-one rule to determine the number of factors.

The main aim of the present study, namely to identify which facial descriptors are associated with nurses' beliefs that a patient with dementia is in pain and the pain intensity was explored using regression analyses. First, we wanted to investigate which single facial descriptors can significantly predict the two general ratings of pain ("pained expression" and "pain intensity").Therefore we entered all 13 facial items as predictors in a forward stepwise regression analysis.

As well as examining single items, we also wanted to test which category of facial descriptors was most associated with nurses' inference of pain. We used the results of the factor analysis and entered factor scores (not single items) as predictors into the regression analysis. More precisely, from the results of the factor analysis we computed Bartlett factor scores [33]. These Bartlett factor scores are based on least squares procedures to minimize the sum of squares of the unique factors over the range of variables and are an estimate of the latent

factor constructs. These factor scores were then entered as predictors in the forward stepwise regression analysis to investigate which factors significantly predict the two general ratings of pain ("pained expression" and "pain intensity").

Descriptive statistics are given as frequencies and means with standard deviations. The alpha-level was set to 0.05. Analyses were conducted with SPSS 21.

3. Results

Response rates

Of the 366 nursing homes initially contacted, 79 nursing homes returned questionnaires (22% response rate). The number of questionnaires supplied by single nursing homes varied from 1 to 16; with an average of 3.6 questionnaires. Overall 284 completed questionnaires were returned and entered into the analyses.

Sample characteristics

Table 1 gives an overview of the characteristics of the nurses who took part in this study and the residents with dementia who were observed. Nurses were experienced, with an average of 14 years working in health care. More than 85 % were trained as elderly care nurses, 10% as general nurses, 2% were still training, and the remaining 3% had different backgrounds (e.g. occupational therapist). The nurses mainly worked in large nursing homes (mean number of nursing home residents: 100 (SD: 66.7), the average age of residents was 78.5 years (SD: 9.6)) and each nurse took care of an average of 32 (SD 22.1) residents.

With regard to the residents with dementia who were observed, they were mostly in the more advanced stages of dementia with an average score of 6.2 on the Global Deterioration Scale (GDS) for age-associated cognitive decline and primary degenerative dementia [34] (see

Table 1). This scale differentiates between 7 stages, with GDS stage 7 indicating the most severe stage of cognitive decline.

Observations of facial expression were most often done during washing, transfer and mobilization (see Table 1) with 57% of residents being observed during one single activity and 43% of residents being observed during two or more care activities.

Descriptives of facial descriptor items and overall pain ratings

Nurses provided two general ratings of pain ("pained expression" and "pain intensity") as overall estimates of the pain that residents with dementia experienced whilst being observed. On average, nurses estimated that residents with dementia mostly experienced mild to moderate levels of pain (mean: 1.31 (SD 0.79) on a scale from 0-3) during the period of observation. Similarly, the average score for the "pained expression" item was 1.15 (SD 0.81) on a scale from 0-3. The activity "wound treatment" seemed to trigger highest pain estimate ratings (see Table 1) compared to the other activities of daily living. Not surprisingly, we found that these two general ratings of pain were significantly correlated with each other (r=0.75; p<0.001), sharing 56% of explained variance. However, although closely associated, these variables may assess slightly different aspects of observational pain estimation; therefore, we kept these two pain estimates as separate criterion measures for further analysis.

The overall frequency with which the 13 facial descriptors were used differed between items. Some facial descriptor items were used in more than half of all the observations: "frowning" (60%), "narrowed eyes" (51%), "looking tense" (70%), and "looking frightened" (54%), others were used less frequently: "closed eyes" (31%), "raising upper lip" (30%), "opened mouth" (48%), "tightened lips" (45%), "empty gaze" (39%), "seeming disinterested" (37%), "pale face" (37%), "teary eyed" (23%), and "looking sad" (46%).

As well as examining the overall frequency with which the facial descriptor items were used, we also explored whether frequency of usage differed by the overall grading of pain intensity observed by the nurses. Figure 1 depicts frequency of usage of the 13 facial descriptors by whether A) the overall "pained expression" estimate was "no", "slight degree" or "moderate" combined with "strong degree"; or (B) whether the overall pain intensity rating was either "no pain", "slight pain" or "moderate" combined with "strong pain", respectively. The categories "moderate" and "strong" were collapsed for both ratings because of low frequencies. As can be seen in Figure 1, there are some facial descriptor items that were more frequently observed when residents were believed to be experiencing more intense pain or displaying stronger pained expressions , for example frowning. Other facial items were always observed with similar frequencies (e.g. seeming disinterested); thus, not reflecting increases in the two general observer ratings of pain.

Results of the factor analysis

We conducted an exploratory factor analysis on the 13 facial descriptor items. Examination of factor loadings and the scree plot as well as applying the eigenvalue-greater-than-one rule indicated that three factors were a plausible fit. These three factors accounted for 52.1% of the total variance (factor 1: 29.6 %; factor 2: 14.6 % and factor 3: 9.7 %). Table 2 shows the varimax rotated factor structure. As can be seen, those items loading on factor 1 with a coefficient of 0.64 or more show a close relation to items like "empty gaze" or "seeming disinterested"; thus, we labeled this factor "lack of affect". All items loading on factor 2 with a coefficient of 0.38 or more are anatomical descriptions of facial activity like "narrowing eyes" or "raising upper lip"; thus, we labeled this factor "anatomical descriptors". With regard to the third factor, the items loading on this factor with a coefficient of 0.41 or more commonly describe states of arousal like "looking tense" or "looking frightened"; thus, we labeled this factor "arousal".

Regression analyses – single facial descriptor items

When entering the single facial items into the two regression analyses with the criterion variables "pain intensity" and "pained expression" the results were slightly contradictory (see table 3). Out of the 13 facial descriptor items, we found that 5 or 6 items, respectively, contributed to a significant prediction of the nurses' ratings for "pained expression" or "pain intensity". However, only 50% of these significant predictive items were predictive for both criterion variables. As can be seen in table 3, "frowning", "opened mouth" and "looking tense" were significant predictors for both criterion variables, whereas the other significant predictors varied between the two criterion variables.

As can be seen in table 3, the criterion "pained expression" was best predicted by the item "looking tense" (explaining about 30% of the variance). When adding the anatomical descriptors "narrowed eyes", "tightened lips" and "frowning" as well as "teary eyed" the predictive value was significantly increased (the whole model explaining about 45 % of the variance). In contrast, the criterion "pain intensity" was best predicted by the item "frowning" (explaining 26% of the variance). Adding the two anatomical descriptors "tightened lips" and "opened mouth" as well as the items "looking tense", "looking sad" and "empty gaze" significantly increased the predictive power of the whole model explaining about 45% of the variance).

Regression analyses – factor scores

When entering the computed Bartlett factor scores into regression analyses, we found that the "anatomical descriptors" were the best predictors for the two general ratings of pain, namely the ratings for pain intensity and for pained expression (see table 4). Approximately 30 % of the variance in these two pain estimates could be explained by the anatomical descriptors

alone. As second best predictor, the factor "arousal" increased the predictive value significantly to approximately 40% for the two criterion variables. Interestingly, adding the last factor "lack of affect" also increased the predictive value of the model significantly, however, the gain in explained variance was small (see table 4).

Discussion

Pain assessment in people with dementia is very challenging due to difficulties with lack of self-report. In clinical practice this is a non-linear and iterative process where observation of the person's behavior is essential [35]. In the present study we used a questionnaire survey to identify which observations of facial expression coincide with the belief that a patient with dementia is experiencing pain of different intensities. We focused mainly on nurses for the elderly working in nursing homes because they often have to make judgments regarding pain using the facial expression of the older person with dementia. Observational items describing facial expressions were mailed to nursing homes in Germany and 79 nursing homes participated by returning 284 completed observer ratings. The observed individuals suffered mainly from moderate to severe dementia, were mostly female and were observed in everyday care situations. Caregivers rated the pain intensity of the residents as slight to moderate (on average) and more than 60% of the residents received pain medication.

Frequency of usage

The first question to be discussed is whether the facial descriptors we presented were, in fact, used by caregivers when inferring pain in others. Given that all facial descriptor items were extracted from well-known observer-rated scales for pain in dementia [6-7,12-14], we might

expect high usage of all items. Indeed, some of the facial descriptors were used frequently such as "narrowed eyes" (51%), "looking frightened" (54%), "frowning" (60%) and "looking tense" (70%), suggesting appropriate item selection. However, this was not true for all items. Some facial descriptors were used in less than half of the situations observed: "teary eyed" (23%), "raising upper lip" (30%), "closed eyes" (31%), "seeming disinterested" (37%) and "pale face" (37%). Moreover, only a few facial descriptors were associated with ratings of different pain intensities. These included, "frowning", "narrowed eyes", "tightened lips", "looking sad", "looking tense" and "looking frightened". These facial descriptors were used by the nurses more frequently when the pain appeared to be strong and less frequently when the residents were thought to be suffering less. Therefore, "frowning", "narrowed eyes", "looking frightened" and "looking tense" closely concur with the nurses pain judgement, especially given that these facial descriptors were used frequently in general and also to discriminate between different levels of pain. In factor analysis these four facial descriptors loaded on two different factors. Whereas "frowning" and "narrowed eyes" loaded on a factor, which we labelled "anatomically-based descriptors", "looking frightened" and "looking tense" loaded on a factor labelled "arousal".

The factor analysis both corroborated and discarded the theoretical subcategories, which the COST experts [11] assumed would underlie the extracted item pool. Only three factors were extracted but four sub-categories had been hypothesized. Theory and findings converged with the "anatomically-based descriptors": Five of six items of the (theoretical) subcategory called "anatomically-based description" resulted in the corresponding factor. This suggests the nurses were more confident of applying anatomically-based facial descriptors and used these facial responses consistently for their observations. Only the item "open mouth" was not included in the pool of items loading on this factor and appeared on the factor we labelled "arousal". It may well be that this item, which is rarely reported in healthy individuals and pain patients as pain-specific facial activity [30-31], is, in a person with dementia, an

unspecific manifestation of distress triggered by pain as likely as by other negative states [9,32]. The two frequently and differentially used items from the (theoretical) subcategory "emotional state", namely "looking frightened" and "looking "tense", both loaded on the factor "arousal". Thus, it seems that caregivers mainly used facial descriptors from the factors "anatomically based description" and "arousal" for their inference of pain.

Predictive value of facial descriptors

Using regression analyses, we were able to corroborate most of the findings discussed above. When entering all 13 single facial descriptors into regression analysis, we found that the items "frowning", "narrowed eyes" and "looking tense" were significant predictors of nurses' overall pain estimate; the pain intensity estimate of a nurse concurred with the intensity rating for the facial descriptors items "frowning", "narrowed eyes" and "looking tense". Interestingly, two of these three items, namely "frowning" and "narrowed eyes" describe facial features that have been repeatedly shown to be indicative for pain based on fine grained, slow-motion analysis using the Facial Action Coding System (FACS; [36]) [30-33]. Thus, nurses behaved – although untrained in objective facial expression analysis– like trained FACS coders, noticing especially "frowning" (Action Unit 4) and to a lesser degree "narrowed eyes" (Action Unit 6_7). As soon as the nurses observed these facial responses, the presence of pain was inferred to be more likely and the stronger these facial responses were, the stronger the caregiver rated the pain intensity. Caregivers seemed to have primarily relied on these anatomically-based facial indicators of pain. However, pain estimate ratings did not exclusively coincide with these anatomical descriptors but also with other facial items (especially with "looking tense"). There might be several reasons for this. Although the predictors "frowning" and "narrowed eyes" explained sizeable variance in the two general ratings of pain, there was still substantial unexplained variance left, which means that the caregiver did not exclusively rely on these indicators when making conclusions about the

presence and intensity of pain. Furthermore, the two Action Units "frowning" and "narrowed eyes" have indeed repeatedly been shown to be indicative for pain but they are nevertheless not unique for this condition. For example, the facial expression of disgust and anger often also includes the Action Units "frowning" and "narrowed eyes" [36,37]. Thus, the use of these signs alone cannot resolve the ambiguities of facial expression.

The other indicators which formed a stronger basis for the overall rating of pain were indicators of emotional arousal (e.g. "looking tense", "looking sad"). It is obvious that these observational items require psychological inference, i.e. basic forms of empathy as well as some longitudinal knowledge of the resident and how they behave in certain circumstances. Facial motor responses, as indicated by the Action Units, are less susceptible to observation errors than the attribution of overt behavior to internal states, which is necessary for empathic judgments. Nevertheless, nurses appeared to have used empathic interpretation to derive their overall pain ratings.

These assumptions were clearly supported by the regression analyses using factor scores (instead of single items) as predictors of nurses' overall pain estimates. We found that the factors "anatomically based description" and "arousal" proved to be the best predictors. Indeed, a sizeable 38% to 43% of variance in pain estimate ratings was explained by these two factors. Thus, the data on the frequency of usage as well as the regression analyses using single item predictors and factor score predictors all demonstrate how the use of "anatomically based description" and "arousal" are facial descriptors that concurred well with nurses beliefs that a patient is in pain and with their grading of its intensity.

There are several limitations to our study. We could not relate ratings of the facial pain items to an objective measure of pain from the residents. However, this was not the primary

objective of the study, which focused on how nurses use and interpret observational information, i.e. features of facial activity, to infer the presence and intensity of pain in residents with dementia. To be exact, we related the ratings of the single observational items to overall ratings of pain provided by the caregivers. Therefore, the present study examined the influence of certain pain-related observations on the diagnostic decision processes used by caregivers. As stated, we only focused on overall pain intensity estimates provided by nurses and not on the assessment of other relevant dimensions of pain (e.g. emotional, somatic, cognitive) or on general distress in distinction from pain [38]. Whereas this might have been possible in persons without cognitive impairment by relying on more comprehensive self-report, this cannot be based on the limited codes produced by facial expressions. Furthermore, our questionnaire survey was pragmatic and based in day to day practice. We could not control the selection of participants, the situations in which pain assessment took place or verify whether the facial descriptors were understood in the same way by all raters. However, most observational pain scales are used in this setting without special training and rely on compliance with the written instructions; thus, our setting does not deviate from that of similar studies. Moreover, we decided not to use open questions due to the time-pressure of everyday care in nursing homes, but instead relied on the very carefully selected facial descriptors.

Although, our study included a large number of observations, the overall response rate of nursing homes was only 22%. Thus, it is possible that mostly data from nursing homes where pain management in dementia is already an important topic entered our study. Moreover, given that we only studied nursing homes in Germany, our findings may be culture-bound. Finally, it has to be acknowledged that the high percentage of residents receiving pain medication may have reduced the occurrence of pain and its indicators. However, this high percentage also suggests the presence of multiple underlying indications for pain management

in these care home residents and the possibility that observations during care tasks may induce pain.

In the everyday evaluation of pain, caregivers may rely on multiple sources of information, including facial expression, body posture and verbal utterances. We decided to focus on studying facial expressions so that nurses could focus on only one behavioral domain and a restricted number of items. This allowed us to asses the feasibility and validity of this approach under under optimal conditions. This is important in the developmental phase of investigating pain-indicative descriptors. In future clinical practice, all behavioral indicators should be taken into consideration, and this may further enhance the accuracy of pain judgements.

It would also be helpful to assess which (facial) behaviors precipitate a nurse or a caregiver into requesting a prescription, or administering analgesics to, residents with dementia. It is possible that not the same but different facial behaviors are used to infer pain compared to those behaviors triggering a caregiver to administer analgesics. Last but not least, when the new observational tool has been developed, we should also analyze processes of social interaction between the nurse and resident dyad in more detail.

Conclusions

The pool of observational items we extracted from established and widely known observer-rated pain scales included facial descriptors which were highly relevant for inferring pain in residents with dementia by nursing staff in care homes, and were used in the process of diagnostic decision making. This has been discussed in the literature but rarely empirically tested. However, this does not apply to all facial items. Anatomically-based items like "frowning" and "narrowed eyes" and indicators of emotional arousal like "looking tense"

were mainly used as basis for the overall ratings of pain by caregivers. Future studies should explore whether such items commonly used by nurses to infer pain, can also differentiate pain from other negative states. Given that without training, nurses already seem to focus on "frowning", which is a key facial feature of pain expressions [30-32], further training could focus on the importance of other key facial features (e.g. opened mouth, raising upper lip) . Development of observational pain tools and training in their use should consider the pre-existing knowledge base and competence of nurses to infer pain.

Figures

Figure 1: Percentage of how often facial descriptors were used. (A) Percentages are given separately for observations were nurses rated the face to express "no pain"," slight pain" or "moderate/strong pain". (B) Percentages are given separately for observations were nurses believed the patient to be in "no pain", "slight pain" or "moderate/strong pain".

Literature

[1] Kaasalainen S, Crook J. An exploration of seniors' ability to report pain. *Clin Nurs Res* 2004;13:199–215.

[2] Cole L J, Farrell MJ, Duff EP, Barber JB, Egan GF, Gibson SJ. Pain sensitivity and fMRI pain-related brain activity in Alzheimer's disease. *Brain* 2006;129:2957-2965.

[3] Kankkunen P, Välimäki T. (2014). Pain among Persons with Dementia: The Family Caregiver's View Point. *Int J Caring Sci* 2014, 7: 460-467.

[4] Husebo BS, Kunz M, Achterberg WP, et al. Pain Assessment and Treatment Challenges in Patients with Dementia. *Zeitschrift f Neuropsychologie* 2012;23:237-246.

[5] Peisah C, Weaver J, Wong L, Strukovski JA. Silent and suffering: a pilot study exploring gaps between theory and practice in pain management for people with severe dementia in residential aged care facilities. *Clin Interv Aging* 2014; 9, 1767.

[6] Herr K, Bjoro K, Decker S. Tools for assessment of pain in nonverbal older adults with dementia: A state-of-the-science review. *J Pain Symptom Manage* 2006;31:170-192.

[7] Park J, Castellanos-Brown K, Belcher J. A Review of Observational Pain Scales in Nonverbal Elderly With Cognitive Impairments. *Res Soc Work Pract* 2010;20:651-664.

[8] AGS Panel on Persistent Pain in Older Persons: The management of persistent pain in older persons. *J Am Geriatr Soc* 2002;50:S205-224.

[9] Chapman C R: Progress in pain assessment: the cognitively compromised patient. *Curr Opin Anaesthesiol* 2008;21:610-615.

[10] Sheu E, Versloot J, Nader R, Kerr D, Craig KD. Pain in the elderly: validity of facial expression components of observational measures. *Clin J Pain* 2011;27:593–601.

[11] Corbett A, Achterberg W, Husebo B, et al. An international road map to improve pain assessment in people with impaired cognition: the development of the Pain Assessment in Impaired Cognition (PAIC) meta-tool. *BMC Neurology* 2014; 14:229.

[12] Stolee P, Hillier LM, Esbaugh J, et al. Instruments for the assessment of pain in older persons with cognitive impairment. *J Am Geriatr Soc* 2005;53:319-326.

[13] van Herk R, van Dijk M, Baar FP, Tibboel D, de Wit R. Observation scales for pain assessment in older adults with cognitive impairments or communication difficulties. *Nurs Res* 2007;56:34-43.

[14] Zwakhalen SM, Hamers JP, Abu-Saad HH, Berger MP. Pain in elderly people with severe dementia: a systematic review of behavioural pain assessment tools. *BMC Geriatr* 2006;6:3.

[15] Abbey J, Piller N, De Bellis A, et al. The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia. *Int J Palliat Nurs* 2004;10:6-13.

[16] Kovach CR, Noonan PE, Griffie J, Muchka S, Weissman DE. Use of the assessment of discomfort in dementia protocol. *Appl Nurs Res* 2001;14:193-200.

[17] Kovach CR, Weissman DE, Griffie J, Matson S, Muchka S. Assessment and treatment of discomfort for people with late-stage dementia. *J Pain Symptom Manage* 1999;18:412-419.

[18] Feldt KS, Warne MA, Ryden MB. Examining pain in aggressive cognitively impaired older adults. *J Gerontol Nurs* 1998;24:14-22.

[19] Feldt KS. The checklist of nonverbal pain indicators (CNPI). *Pain Manag Nurs* 2000;1:13-21.

[20] Hurley AC, Volicer BJ, Hanrahan PA, Houde S, Volicer L. Assessment of Discomfort in Advanced Alzheimer Patients. *Res Nurs Health* 1992;15:369-377.

[21] Warden, V, Volicer L, Hurley AC, Rogers EN. Pain assessment in advanced dementia. *Gerontologist* 2001;41, p. 146.

[22] Lefebvre-Chapiro S. The DOLOPLUS 2 scale - evaluating pain in the elderly. Eur J *Palliat Care* 2001;8:191-194.

[23] Morello R, Jean A, Alix M, Sellin-Peres D, Fermanian J. A scale to measure pain in non-verbally communicating older patients: The EPCA-2 Study of its psychometric properties. *Pain* 2007;133:87-98.

[24] Husebo BS, Strand LI, Moe-Nilssen R, et al. Mobilization-Observation-Behaviour-Intensity-Dementia Pain Scale (MOBID): development and validation of a nurse-administered pain assessment tool for use in dementia. *J Pain Symptom Manage* 2007;34:67-80.

[25] Snow AL, Weber JB, O'Malley KJ, et al. NOPPAIN: A nursing assistant-administered pain assessment instrument for use in dementia. *Dement Geriatr Cogn Disord* 2004;17:240-246.

[26] Fuchs-Lacelle S, Hadjistavropoulos T. Development and preliminary validation of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). *Pain Manag Nurs* 2004;5:37-49.

[27] Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc* 2003;4:9-15.

[28] Villanueva MR, Smith TL, Erickson JS, Lee AC, Singer CM. Pain assessment for the dementing elderly (PADE): Reliability and validity of a new measure. *J Am Med Dir Assoc* 2003;4:1-8.

[29] Cohen-Mansfield J. Pain Assessment in Noncommunicative Elderly Persons - PAINE: *Clin J Pain* 2006;22:569-575.

[30] Prkachin KM. The consistency of facial expressions of pain: a comparison across modalities. *Pain* 1992;51:297-306.

[31] Prkachin KM, Solomon PE. The structure, reliability and validity of pain expression: evidence from patients with shoulder pain. *Pain* 2008;139:267-74.

[32] Kunz M, Scharmann S, Hemmeter U, Schepelmann K, Lautenbacher S. The facial expression of pain in patients with dementia. *Pain* 2007;133:221-228.

[33] Bartlett MS. The statistical conception of mental factors. *Brit J Psychol* 1937;28:97-104.

[34] Reisberg B, Ferris S H, de Leon MJ, Crook T. The Global! Deterioration Scale (GDS). *Psychopharmac Bulletin* 1988;24:661-663.

[35] Dowding D, Lichtner V, Allcock N, Briggs M, James K, Keady J, Lasrado R, Sampson EL, Swarbrick C, Closs, SJ. Using sense-making theory to aid understanding of the recognition, assessment and management of pain in patients with dementia in acute hospital settings. *Int J Nurs Stud* 2016;53:152-162.

[36] Ekman PE, Friesen WV. Facial Action Coding System. Palo Alto, CA: Consulting Psychologists Press,1987

[37] Kunz M, Peter J, Huster S, Lautenbacher S. Pain and Disgust: The Facial Signaling of Two Aversive Bodily Experiences. *PLoS ONE* 2013;8:e83277.

[38] van der Steen JT, Sampson EL, Van den Block L, Lord K, Vankova H, Pautex S, Vandervoort A, Radbruch L, Shvartzman P, Sacchi V, de Vet HC, Van Den Noortgate NJ; EU-COST Action TD1005 Collaborators. Tools to Assess Pain or Lack of Comfort in Dementia: A Content Analysis. *J Pain Symptom Manage*. 2015 Nov;50(5):659-75