Pain in nursing home residents with dementia and its association to quality of life

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Journal: Aging and Mental health

Abstract 234

Word Count: ca 4400 words (numbered references, APA reference style increases the word count)

Key words: pain medication, drug use, cognitive impairment, pain, quality of life, long term facilities, quality indicator, elderly, older people, NPS

Abstract

Aim

We aimed to describe pain, use of analgesics and quality of life (QoL) in people with dementia admitted to a Norwegian nursing home (NH), and to explore if and how pain was associated with their QoL when adjusting for sociodemographic characteristics, other health conditions and use of analgesics.

Method

A total of 953 Norwegian NH residents with dementia (mean age 84.0, SD 7.5 years, 35.8% men) were included at admission to the NH. Pain and QoL were assessed using the Mobilization-Observation-Behavior-Intensity-Dementia-2 (MOBID-2) Pain Scale and the Quality of Life in Late-Stage Dementia (QUALID) scale, respectively. Severity of dementia, personal level of activities of daily living, general medical health, neuropsychiatric symptoms, and the use of psychotropic drugs and analgesics were assessed.

Results

In total, 36% of the participants had clinically relevant pain intensity (MOBID-2 ≥ 3) and 52% received analgesics. Paracetamol was most frequently prescribed (45%). In an adjusted linear mixed model, more severe pain was associated with higher QUALID total scores, indicating poorer QoL (regression coefficient 0.52, 95% CI 0.36-0.69).

Conclusion

Pain prevalence at NH admission was high in residents with dementia; half used analgesics, particularly paracetamol. More severe pain was associated with poorer QoL when adjusting for sociodemographic characteristics, other health conditions, and use of analgesics. The routine assessment of pain at NH admission can uncover undiagnosed and untreated pain and allow for adequate non-pharmacological and pharmacological pain management and likely increased QoL.

Introduction

People admitted to nursing homes (NHs) are often very old, have multiple impairments, and are in need of more care than the next of kin and domiciliary care in the municipality are able to provide (Achterberg et al., 2010; Agüero-Torres, von Strauss, Viitanen, Winblad, & Fratiglioni, 2001; Dramé et al., 2012; Johansen et al., 2020; Luppa, Luck, Brähler, König, & Riedel-Heller, 2008; Sverdrup et al., 2018; Wergeland, Selbæk, Bergh, Soederhamn, & Kirkevold, 2015). Up to 85% of people admitted to a NH have dementia, and the severity of dementia has increased over the years, at least in Norway (Helvik, Engedal, Benth, & Selbæk, 2015; Magaziner et al., 2000; Seitz, Purandare, & Conn, 2010; Sverdrup et al., 2018). The NHs provide care and treatment around the clock to limit negative health consequences of impairments and diseases and to promote their residents' quality of life (QoL). Norway, with a population of about 5.4 million, has about 40,000 NH places (beds) (*Statsbudsjettet 2013* 2013) and the jurisdiction to provide NH care, in addition to in-home care and rehabilitation services, lies with the local municipalities (omsorgsdepartementet, 2015).

QoL is a multidimensional concept which captures aspects of the individuals' subjective experience of their life situation (Bowling, 2005). There are a number of conceptual frameworks and definitions of QoL, and consequently no single, clear and universally accepted framework and definition (Spilker, 1996). As a result, several conceptual frameworks have been developed to capture QoL in persons with dementia (Jonker, Gerritsen, Bosboom, & Van Der Steen, 2004; Missotten, Dupuis, & Adam, 2016). Several have highlighted the need for a QoL framework for people with dementia that emphasize psychological status, as well as participation, comfort and/or joy in activities (Brod, Stewart, Sands, & Walton, 1999; Jonker et al., 2004; L & L, 2017 3rd edition; Lawton, 1994, 1997; Missotten et al., 2016). It is important to capture QoL in all individuals with dementia, regardless of the severity of their dementia. Among the wide variety of dementia-specific QoL inventories (Jonker et al., 2004), the Quality of Life in Late-Stage Dementia (QUALID) scale focuses on psychological status as well as comfort and engagement in activities (Weiner et al., 2000). QUALID is based on proxy reports from either next of kin or caregiver(s) and was developed for people with severe dementia who have severe difficulties to describe their situation (Weiner et al., 2000). Moreover, the inventory has been deemed useful in assessing

QoL in NH residents, independent of their state of dementia (Barca, Engedal, Laks, & Selbæk, 2011; Mjørud, Kirkevold, Røsvik, & Engedal, 2014a; Røen et al., 2015).

A systematic review that explored factors associated with QoL in NH residents with dementia in 10 cross-sectional studies found depression, neuropsychiatric symptoms, impairment in activities of daily living (ADL) and more severe cognitive impairment as well as use of psychotropic drugs to be associated with poorer QoL (Beerens, Zwakhalen, Verbeek, Ruwaard, & Hamers, 2013). The article reviewed studies up to 2011, and included five different dementia-specific QoL measures, although only one study used QUALID (Beerens et al., 2013). However, later studies that used QUALID have reported the same factors associated with QoL in NH residents with dementia (Habiger, Achterberg, Flo, & Husebo, 2019; Mjørud et al., 2014a; Mjørud, Kirkevold, Røsvik, Selbæk, & Engedal, 2014b; Rostad et al., 2017; Røen et al., 2015) which is also supported by a published scoping review of factors associated with QoL of people with dementia more generally (Holopainen, Siltanen, Pohjanvuori, Mäkisalo-Ropponen, & Okkonen, 2019).

Pain is a common symptom in NH residents with dementia. Internationally, studies have found the prevalence of pain to be up to 80% in NH residents (W. P. Achterberg et al., 2010; Fox, Raina, & Jadad, 1999; Husebo et al., 2008; Malara et al., 2016; Takai, Yamamoto-Mitani, Okamoto, Koyama, & Honda, 2010), while a recent Norwegian study reported that 43% of NH residents with dementia had clinically significant pain intensity (van Dam, Caljouw, Slettebø, Achterberg, & Husebo, 2019). It is reported that residents with severe dementia more often had pain than those with less severe dementia (Hendriks, Smalbrugge, Galindo-Garre, Hertogh, & van der Steen, 2015). A Dutch study reported that 52% of NH residents with dementia had pain at admission to the NH (Hendriks et al., 2015). To the best of our knowledge, few studies have reported the prevalence of pain in newly admitted NH residents with dementia in Norway (omsorgsdepartementet, 2015).

Typical pain behavior, such as verbalization/vocalization (e.g. sighing, moaning, calling out, gasping), facial expressions (e.g. grimacing, frowning), and defense postures (e.g. freezing, tensing, guarding, pushing, crouching), may be prominent signs of pain in people with dementia (AGS, 2002; "The management of chronic pain in older persons: AGS Panel on Chronic Pain in Older Persons. American Geriatrics Society," 1998; McMinn & Draper, 2005; Pieper et al., 2013). However, these features may also be related to dementia and thus can be difficult to interpret (McMinn & Draper, 2005). Moreover, undiagnosed and untreated

pain may trigger neuropsychiatric symptoms such as aggression, psychosis, affective and apathy symptoms (Husebø et al., 2019; Pieper et al., 2013).

The first guidelines for clinical management of chronic pain in/among older adults were published by the American Geriatric Society (AGS) as early as 1998 ("The management of chronic pain in older persons: AGS Panel on Chronic Pain in Older Persons. American Geriatrics Society," 1998). Systematic pain assessment and adequate pain treatment is essential ("The management of chronic pain in older persons: AGS Panel on Chronic Pain in Older Persons. American Geriatrics Society," 1998; Schofield & Abdulla, 2018). Paracetamol is recommended as the first-line pharmacological treatment for pain in older adults, whereas the use of opioids has been recommended for treatment of moderate to severe pain intensity (AGS, 2009). At the same time, safety issues must be considered carefully because anticholinergic side effects may provoke considerable adverse events in people with dementia (Achterberg, Lautenbacher, Husebo, Erdal, & Herr, 2020; Erdal et al., 2018). The prevalence of prescribed analgesics in Norwegian NHs has varied from 35% to 62%, with the highest prevalence in the most recently assessed cohorts. The use of paracetamol and strong opioids have especially increased (Sandvik, Selbaek, Kirkevold, Aarsland, & Husebo, 2016; Torvik, Kaasa, Kirkevold, & Rustøen, 2010; van Dam et al., 2019). However, none of these studies describes prescription of analgesics in newly admitted NH residents with dementia.

Cross-sectional studies that included NH residents with dementia independent of length of stay have found pain and use of analgesics associated with poorer QoL (Rostad et al., 2017; van Dam et al., 2019). A recent small study (n = 112) emphasized emotions and activities as a way to capture important aspects of QoL in NH residents with dementia. They found that neuropsychiatric symptoms need to be taken into consideration when studying the association between pain and QoL (Rostad et al., 2017).

In this large-scale study, the aim is to describe pain intensity, use of analgesics and QoL in people with dementia at admission to a NH. The study also explores the association between pain and QoL in these residents, adjusted for other health conditions and analgesic drug use. The present study emphasizes psychological well-being and activities of significance as a way to capture important aspects of QoL in people with dementia, and has thus used QUALID as the assessment tool (Beerens et al., 2013).

Method

Design

This was a cross-sectional study of newly admitted NH residents to 68 NHs in the south-eastern part of Norway from November 2014 to February 2020. The NHs were located in 32 municipalities in rural and urban areas of one county.

Participation and setting

In total, 1283 residents admitted to a NH with an expected stay longer than four weeks were recruited. All residents 65 years and older, independent of whether they had established dementia or not, and residents younger than 65 years with established dementia were recruited at admission. The only exclusion criterion was a life expectancy of less than six weeks. The present study only included people with dementia at admission. Based on all available information, two physicians independently diagnosed dementia at admission according to the ICD-10 criteria. A third physician was consulted in situations where the two physicians disagreed. All physicians had extensive experience with research and clinical old age psychiatry. In total, 1074 residents had dementia, 201 residents did not have dementia and 8 could not be diagnosed. Of those with dementia, 115 residents lacked information about pain and six residents lacked information about QoL. Thus, the present study included 953 residents admitted to a NH (Figure 1).

Measures

QoL was assessed by QUALID, a brief proxy-based inventory (Weiner et al., 2000). The University of Texas Southwestern Alzheimer's Disease Center Clinical Core developed QUALID based on a series of consensus meetings. QUALID has 11 items and rates different observable behaviors on a 5-point Likert scale (1-5), with a sum score from 11 to maximum 55, where a higher score indicates poorer QoL. The inventory includes both positively and negatively worded items. The inventory is administered as a structured, proxy-based interview. The informant can either be a family member or a healthcare worker who has spent a considerable part of at least three of the last seven days with the person (Weiner et al., 2000). In this study, the nursing personal who knew the resident best answered the interview.

Principal component analyses have shown that three dimensions of QoL; tension (including being physically uncomfortable, verbalization that suggests discomfort, irritable, and appears calm), sadness (including cries, appearing sad, and facial expression of discomfort) and well-being (including smiles, enjoys eating, enjoys social interaction, and enjoys touching/being touched) explains 53% of the variance (Mjørud et al., 2014a). QUALID has been translated to Norwegian and validated in several samples of NH residents with dementia (Barca et al., 2011; Mjørud et al., 2014a; Røen et al., 2015).

The Mobilization-Observation-Behavior-Intensity-Dementia-2 (MOBID-2) pain scale is an observational pain tool for people with dementia (Husebo, Ostelo, & Strand, 2014; Husebo et al., 2007). MOBID-2 assesses nociceptive, musculoskeletal pain during active, guided movements and pain that might be related to internal organs, head, and skin during the last week, documented on a body chart to show potential pain location. The scale consists of 10 items, with each item score ranging from 0 to 10, where a higher score indicates more severe pain. In addition, a separate item grades the overall pain intensity from 0 to 10 (most severe pain intensity). An overall score of ≥ 3 indicates that the resident has clinically significant pain intensity (Husebo et al., 2007). In this study, the nursing personal who knew the resident best answered the scale. The scale has been psychometrically tested for validity, reliability and responsiveness and has been used in several studies among NH residents, including in Norway (Husebo et al., 2014; Husebo, Strand, Moe-Nilssen, Husebo, & Ljunggren, 2010; Røen et al., 2017).

Prescribed medications regularly used were documented from the medical record of each resident. The medications were grouped according to the Anatomical Therapeutic Chemical (ATC) classification system (2015, 2015). ATC codes beginning with N02 were divided into opioids (N02A), and paracetamol (N02B E01, N02A J06 & N02A J13). NSAIDS (M01, nonsteroidal anti-inflammatory drugs) and antiepileptics (N03A) were categorized as analgesics (2015, 2015). Psychotropic drugs were categorized into antipsychotics (N05A except lithium), antidepressants (N06A), anxiolytics (N05B) and hypnotics/sedatives (N05C) (2015, 2015). Use of these medications were dichotomized into yes or no.

Neuropsychiatric symptoms (NPS) were measured using the Neuropsychiatric Inventory Nursing Home version (NPI-NH) (Cummings, 1997). The 12-item inventory covers the following symptoms: delusion, hallucination, euphoria, agitation/aggression, disinhibition, irritability/lability, depression/dysphoria, anxiety, apathy/indifference, aberrant motor

behavior, night-time behavior disturbances, and appetite and eating disorders (yes/no). Each symptom is scored from 0 to12, where severity (score 1-3) was multiplied by frequency (score 1-4). Three sub-syndromes have been established based on a factor analysis, i.e. psychosis (including delusions and hallucination), agitation (including agitation/aggression, disinhibition and irritability), and affective (including depression and anxiety) (Selbaek & Engedal, 2012). The NPI-NH has been translated to Norwegian and validated (Selbaek, Kirkevold, Sommer, & Engedal, 2008).

The severity of dementia was measured using the Clinical Dementia Rating (CDR) scale, which covers six domains (memory, orientation, judgment and problem solving, community affairs, home and hobbies and personal care) (Hughes, Berg, Danziger, Coben, & Martin, 1982). A score with five response categories (0, 0.5, 1, 2, 3) is calculated using an algorithm that gives priority to memory (Hughes et al., 1982; Morris, 1993). The categories indicate level of dementia, ranging from 0 (no dementia) to 3 (severe dementia). A sum-score of the six domains (CDR Sum of Boxes, CDR-SoB), ranging from 0 to 18 offers important advantages when analyzing data. A higher score indicates more severe dementia. The correlation between the categorical CDR and the CDR-SoB is high (Mjorud, Kirkevold, Rosvik, Selbaek, & Engedal, 2014; O'Bryant et al., 2008). The CDR scale has been translated to Norwegian and used in several NH studies (Helvik et al., 2015; Røen et al., 2017).

The Physical Self-Maintenance Scale (PSMS) (Lawton & Brody, 1969) was used to assess Personal Activities of Daily Living (P-ADL). The scale includes six items with a total score ranging from 6 to 30, where higher scores indicate a lower level of functioning (Lawton & Brody, 1969). The nursing personal who knew the resident best answered the scale. The scale is commonly used in Norwegian NH studies (Goyal, Bergh, Engedal, Kirkevold, & Kirkevold, 2018; Helvik, Selbæk, Šaltytė Benth, Røen, & Bergh, 2018).

The General Medical Health Rating (GMHR) was used to assess physical health (Lyketsos et al., 1999). This is a one-item global rating scale, with four response alternatives: excellent, good, fair, and poor. The rating was based on all available information of physical health and use of prescribed medication. The scale has previously been used in large NH studies, including older people with dementia in Norway (Helvik et al., 2018).

Demographic information (age, gender, and marital status) was collected from medical records. The type of NH unit was categorized either as a regular unit (RU), or a special care unit for people with dementia (SCU).

Procedure

Data were collected by healthcare workers, mainly registered nurses (74%) in the NHs, under the supervision of 10 research nurses. All information regarding one resident was collected over the first month of the NH stay. Data collectors completed a two-day training program prior to the data collection. The data came from a standardized interview with the residents, the next of kin, the residents' caregivers in the NH, and from medical records.

The NH staff, including the NH physician, assessed the residents' capacity to consent to participate in the study. All residents who had the capacity to give consent gave written consent. If a resident had reduced capacity to consent, the resident's next of kin consented on behalf of the resident. These procedures have been recommended and approved by the Norwegian Regional Ethics Committee South East (2014/917).

Statistics

Sample characteristics were described as means and standard deviations (SD) for continuous and frequencies and percentages for categorical variables. Means and SD were used to present MOBID-2 and QUALID total scores and single items. Mean scores of QUALID, total as well as three dimensions, were compared across groups of residents defined by dementia severity (mild, moderate, severe) and use of analgesics (yes, no) by estimating linear mixed models with fixed effects for dementia severity, analgesics use and the interaction between the two. A significant interaction would imply a difference between users and non-users of analgesics regarding the overall association between dementia severity and QoL. The post hoc analyses were conducted to assess differences between users and non-users among pairs of groups. The association between QoL, assessed as total QUALID score, as well as three dimensions, was assessed by linear mixed model with MOBID-2 as the main covariate. The models were adjusted for pre-chosen covariates. All linear mixed models included random effects for NH, as the data exhibit hierarchical structure with residents belonging to different

units nested within a NH. Clustering within units was negligible or not present and hence not adjusted for.

Linear mixed models were estimated for residents without missing values on covariates used for adjustment. All tests were two-sided. The results with p-values below 0.05 were considered statistically significant. The analyses were performed by SPSS v27 and SAS EG v 7.13 HF5.

Results

The mean (SD) age of the 953 admitted NH residents with dementia in the study was 84.0 (7.5) years, and 341 (35.8%) were men (see Table 1). The mean (SD) CDR-SoB was 11.2 (3.5).

Use of analgesics and prevalence of pain

In total, 494 (51.8%) of the participants used NSAIDS, antiepileptics, paracetamol, and/or opioids, where paracetamol and opioids were most frequently used (n=429, 45.0% and n=176, 18.5% participants, respectively, Table 1). The mean (SD) overall score of MOBID-2 was 2.0 (2.1) (Table 2) and the MOBID-2 score was ≥ 3, which indicated clinically relevant pain in 338 (35.5%) of the participants. For further information about single items scoring of pain in MOBID-2, see Table 2.

Quality of Life

The mean (SD) QUALID score was 19.8 (7.2). The scores of the single items are presented in Table 2. Overall, there was a significant difference between opioid users and non-users regarding the association between QUALID score and dementia severity ($p = 0.034$, Table 3). According to post hoc analyses, only the difference in QUALID score between opioid users and non-users in those with moderate dementia and those with severe dementia was significant ($p = 0.011$).

In the adjusted linear mixed model among the residents with complete responses on all covariates (n = 787), more severe pain intensity (higher MOBID-2 overall scores), was associated with higher QUALID total scores (poorer QoL) (Table 4). In an adjusted analysis of factors associated with the separate dimensions of QUALID, i.e. well-being, sadness and tension, higher pain scores were associated with higher sadness scores and tension scores, but not with well-being (Table 5).

In the same adjusted analyses, a higher CDR-SoB score (indicating more severe dementia) was associated with higher QUALID scores (total and three dimensions), i.e., poorer QoL, but the use of paracetamol or opioids was not associated with the outcomes (Table 4 and 5). The following associations were also observed: poor general medical health (GMHR) was associated with higher total QUALID and well-being dimension scores; poorer personal activities of daily living scores (higher PSMS score) were associated with higher total QUALID and the well-being and tension dimensions scores; a higher NPI agitation subsyndrome score was associated with higher total QUALID and tension dimension scores; a higher NPI affective subsyndrome score was associated with higher total QUALID and the three dimension scores; a higher NPI apathy score was associated with higher total QUALID and well-being dimension scores; and a higher NPI psychosis subsyndrome score was associated with higher tension dimension scores.

Discussion

In this sample of Norwegian NH residents with dementia, about one-third (36%) had clinically significant pain intensity at admission as indicated by the MOBID-2 overall assessment score. More severe pain was associated with a poorer QoL when adjusted for health conditions and sociodemographic characteristics. About half the residents used medication known to reduce pain, mostly paracetamol (45%). The use of prescribed analgesics (paracetamol or opioids) was not associated with QoL in the adjusted analyses.

Previous Norwegian studies of NH residents with dementia have reported a somewhat higher proportion of residents with clinically relevant degree of pain (MOBID-2 $\geq$ 3: 43-53%) (Husebo et al., 2008; van Dam et al., 2019), than in the present study of NH residents with dementia (36%). However, these studies did not assess pain intensity at admission to NH, but at a specific time independent of length of stay in the NH (van Dam et al., 2019) Nevertheless, a published Dutch study found that 52% of NH residents with dementia had pain at admission (Hendriks et al., 2015). Pain was defined as occurring over a month (versus not occurring). The intensity or frequency of pain was not assessed (Hendriks et al., 2015), and thus not surprisingly, it was reported to be higher than in the present study. Comparisons of prevalence of pain in NH residents may vary due to sample differences such as age and gender distribution (Schofield & Abdulla, 2018), length of stay, severity of dementia and

time before death (Hendriks et al., 2015) as well as the definitions and methodology used for pain assessments (Schofield & Abdulla, 2018). Even so, an international study did not find the prevalence of pain to differ between NH residents from France, Poland and Germany (190 residents from each country), even if age and length og stay varied considerably at study participation (Wróblewska, Talarska, Wróblewska, Susło, & Drobnik, 2019). This study contributes to the field of research by including all NH residents with dementia at admission and using a pain behavioral scale including pain intensity and location in addition to prevalence. Thus, we got a nuanced prevalence estimate of pain in NH residents with dementia at admission. This also made it possible to explore the association between pain and QoL, without having length of stay as a possible confounder that may not be completely adjusted for.

In the present study, QoL was somewhat better (mean QUALID 19.8) than in most other Norwegian cross-sectional NH studies independent of length of stay (mean QUALID between 21.2, and 24.1) (Barca et al., 2011; Ito, Berge, Husebo, Nouchi, & Sandvik, 2020; Mjørud et al., 2014b; Olsen et al., 2016; Røen et al., 2015), but was poorer than in one NH study (mean QUALID 18.1) (Telenius, Engedal, & Bergland, 2013). None of these studies that used the same definitions and measures to assess QoL have explored if and how pain was associated with QoL. As expected, we found that more severe pain was associated with poorer overall QoL, meaning a higher QUALID total score. This finding is in line with findings from an international review (Beerens et al., 2013) and smaller Norwegian cross-sectional studies (Rostad et al., 2017; Torvik et al., 2010) that explored the association between severity of pain and QoL using diverse assessment inventories for pain and QoL. To our knowledge we present the first study to assess the association between pain and the three dimensions of QoL in QUALID, i.e. well-being, sadness and tension. We found that more severe pain was associated with a higher degree of sadness and tension, but not with degree of well-being. We do not have a firm explanation for this finding, but the lack of association between pain and well-being may reflect the fact that the well-being dimension of QUALID, with items such as enjoying eating, social interaction and touching, reflects psychological aspects of well-being more than physical aspects of well-being. This may help explain why the well-being dimension of QUALID was not associated with the severity of pain.

In our analysis of differences in QUALID by use of pharmacological treatment, we found that the QUALID score was higher among opioid users than non-users in residents with moderate dementia and residents with severe dementia, but not in those with mild dementia. These analyses did not include sociodemographic information or information about the severity of pain or physical health, which may be linked to QoL as shown in the present study. However, in the analysis adjusted for sociodemographic and several health characteristics, including pain, the use of prescribed analgesics (paracetamol or opioids) was not associated with QoL (QUALID) or the three dimensions of QoL in QUALID among residents with dementia. These results are in line with a recently published cross-sectional study that explored the association between prescribed analgesics and QoL assessed with QUALIDEM in NH residents with dementia (van Dam et al., 2019). Moreover, a high proportion of the residents used prescribed analgesics (52%), for whom paracetamol (45%) was more often prescribed than opioids (19%). This is in line with other studies that included residents with dementia independent of length of NH stay (van Dam et al., 2019) and at admission (Hendriks et al., 2015). Furthermore, this is in line with the general recommendations that paracetamol be used as the first-line therapy for pain in older adults (AGS, 2009) and people with dementia (Achterberg et al., 2020). Paracetamol in recommended doses is relatively safe to prescribe to NH residents (Girard, Sourdet, Cantet, de Souto Barreto, & Rolland, 2019) and residents with dementia (Achterberg et al., 2020; Erdal, Ballard, Vahia, & Husebo, 2019), but knowledge about adverse effects after long-term use of paracetamol in residents with dementia is limited (Erdal et al., 2019). In older adults with dementia, safety issues related to pain treatment involving paracetamol and opioids need to be considered, and treatment with opioids should include a careful risk/benefit analysis for each individual (W. Achterberg et al., 2020). Pain is challenging to live with and interdisciplinary collaboration among healthcare providers is essential (Achterberg et al., 2020) to assess pain and its effects, as well as the side effects of pharmacological and non-pharmacological treatment in residents with dementia.

A major strength of this study is its methodology, chiefly the use of a well-known, internationally recognized scale for assessing pain, MOBID-2 (Husebo et al., 2014; Husebo et al., 2007), and QoL (Weiner et al., 2000), the use of a measure of cognitive functioning, and the experience of the research institution with such studies (Helvik et al., 2015; Røen et al., 2017). The large sample size allowed us to adjust for several factors known to be linked

to QoL in NH residents with dementia, such as physical health, activity of daily living, neuropsychiatric symptoms, use of psychotropic drugs and demographics, which limited the risk of confounding. Furthermore, the study was performed at admission to NH, which reduced the importance of the length of stay and characteristics of the formal caregivers in assessing QoL (Røen et al., 2019).

The study does have some limitations, however. Firstly, the study findings should be interpreted with caution, since this is a cross-sectional study and should not be mistaken as a study of causality. Secondly, information about non-pharmacological treatments of the residents was not available and could not be adjusted for when we adjusted for pharmacological treatment of pain in the analysis of the association between pain and QoL. Moreover, information about duration of pain and analgesic treatment, polypharmacy and the effect of given treatment were not available for the present study, which meant the association between these variables and QoL could not be explored. Diagnoses related to pain, such as cancer and musculoskeletal disorders, are common in older adults (AGS, 2009), but the associations between these diagnoses and QoL could not be explored due to the lack of information about these diagnoses and other comorbidities. However, information about general medical health was included in the analysis. Thirdly, there were quite some missing information in the data sample which may limit the internal validity. Furthermore, the data collection was performed in some but not all NHs in one of Norway's counties. Thus, the sample is not necessarily representative for older adults admitted to NHs in Norway, and caution should be taken in generalizing the study results. The present study used the QUALID inventory since we emphasized psychological well-being and activities of significance to capture important aspects of QoL in people with dementia. However, there are diverse conceptual frameworks and definitions of QoL for people with dementia, which has led to other inventories. Another approach could have been to broaden the scope of the study by including two dementia-specific QoL inventories, as has been done in other studies (Husebø et al., 2019).

Clinical implications

The absence of pain is an important quality indicator in NHs (Hjaltadóttir, Ekwall, Nyberg, & Hallberg, 2012), and assessing pain in a reliable way at admission to NHs is essential to uncover and facilitate non-pharmacological and pharmacological pain treatment. Assessment

of pain should be performed at admission to a NH and regularly thereafter, and thus, included in policy documents regarding NH requirements and quality indicators. Some Western countries (USA, Canada, Iceland) require NHs to assess pain of all residents at admission and quarterly thereafter using a specific standardized inventory (Estabrooks, Knopp-Sihota, & Norton, 2013; Hjaltadóttir et al., 2012; Rantz et al., 2000). In Norway, a systematic pain assessment of older adults is not required at NH admission (Helsdiretoratet, 2018) or thereafter. This study showed that about one-third of residents with dementia had clinically significant pain intensity. A routine assessment of pain should be considered required and included in policy documents for NH management, which consequently in turn may contribute to accommodate treatment and increase QoL. This is especially important since pain in NH residents with dementia may be mistaken as neuropsychiatric symptoms (McMinn & Draper, 2005), and untreated or under-treated pain in people with dementia may trigger neuropsychiatric symptoms (Habiger, Flo, Achterberg, & Husebo, 2016; Pieper et al., 2013), which is also associated with poorer QoL. Non-pharmacological management programs are the first line of choice, but may be given in combination with analgesics when needed (Achterberg et al., 2020). Older adults with chronic pain may benefit from non-pharmacological treatment such as cognitive behavioral therapy, exercise, massage, music therapy and reflexology (Abdulla et al., 2013; Achterberg et al., 2020; Guerriero & Reid, 2017). A clinical cluster randomized trial study found that a step by step pain management procedure in NHs also including non-pharmacological treatment lead to reduced pain severity in residents with dementia (Liu & Lai, 2017). However, currently there might be limited access to non-pharmacological treatment given a dearth of health care personnel who are trained to give such treatment (Guerriero & Reid, 2017). Even so, pain management procedures and medication reviews focusing on pain assessment and evaluation of use, efficacy and side effects of treatment given are important (Bullock et al., 2019; Liu, Pang, & Lo, 2012).

There are a considerable number (>15) of behavioral pain assessment inventories for residents with cognitive impairment/dementia (Schofield & Abdulla, 2018) that could be used as a routine assessment tool. Dementia in NH residents in Norway is highly prevalent (84%) and over the years its severity and prevalence have increased (Helvik et al., 2015). Thus, a pain assessment scale that uses a proxy assessment, which is also valid for residents with mild to moderate dementia, like MOBID-2 (Husebo et al., 2014; Husebo et al., 2007; Røen et al., 2017), could be considered to improve care. National requirements to assess pain using a

behavioral pain assessment inventory would increase the ability of researchers to compare the degree of pain in NH residents independently of severity of dementia within and between NHs and over time. A national requirement for pain assessment should be followed by strategies to improve health personnel competence and confidence in interpreting signs of and assessing pain, such as noises, facial expressions and defense related to body movements, in people with dementia. This will better the foundation both for non-pharmacological and pharmacological treatment.

Conclusion

The prevalence of clinically significant pain was high in Norwegian NH residents with dementia at admission. About half of the residents used analgesics, most frequently paracetamol. More severe pain was associated with poorer QoL when adjusted for sociodemographic and other health conditions and the use of prescribed analgesics. A routine assessment of pain in residents admitted to NHs could uncover untreated and undertreated pain in NH residents with dementia, which could improve care and QoL.

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Table 1. Sample characteristics of newly admitted NH residents with dementia (N = 953)

Characteristics	Statistics
Socio-demographics	
Age, mean (SD)	84.5 (7.6)
Males, n (%)	341 (35.8)
Married, n (%) (10 missing)	298 (31.6)
Health condition	
CDR-SoB, mean (SD) (38 missing)	11.2 (3.5)
GMHR, n (%) (64 missing)	
Fairly poor/Poor	459 (51.6)
Good/Fairly good	430 (48.4)
PSMS score, mean (SD) (3 missing)	15.0 (4.5)
NPI-NH sub-syndrome	
Agitation, mean (SD) (25 missing)	4.9 (7.5)
Affective, mean (SD) (28 missing)	3.5 (5.3)
Psychosis, mean (SD) (24 missing)	2.0 (4.1)
Apathy, mean (SD) (18 missing)	1.0 (2.4)
Use of psychotropic medication (yes), n (%)	
Antipsychotics	111 (11.6)
Antidepressants	454 (47.6)
Anxiolytics	136 (14.3)
Sedatives	217 (22.8)
Any	498 (52.3)
Use of analgesic medication (yes), n (%)	
NSAID	14 (1.5)
Antiepileptic medication	54 (5.7)
Paracetamol	429 (45.0)
Opioids	176 (18.5)
Any	494 (51.8)
NH characteristics, n (%) (18 missing)	
Regular care unit	544 (58.2)
Special care unit	391 (41.8)
Type of dementia, n (%)	
Alzheimer's disease	587 (61.6)
Vascular dementia	65 (6.8)
Alzheimer's disease mixed type	106 (11.1)
Frontotemporal dementia	91 (9.5)
Lewy body dementia/ Parkinson's disease	80 (8.4)
Unspecified	24 (2.5)

SD: Standard Deviation, CDR-SoB: The sum-score of the domains in the Clinical Dementia Rating scale, GMHR: General Medical Health rating, PSMS: Physical Self-Maintenance Scale, NPI-NH: Neuropsychiatric Inventory - Nursing Home version,
NPI-NH Agitation sub-syndrome: agitation/aggression, disinhibition and irritability, NPI-NH Affective sub-syndrome: depression and anxiety, NPI-NH sub-syndrome psychosis: delusions and hallucination, Antipsychotics: N05A minus lithium, Antidepressants: N06A, Anxiolytics: N05B, Sedatives: N05C, NSAID: non-steroidal anti-inflammatory drugs M01A, Antiepileptic: N03A, Paracetamol: N02B E01, N02A J06 and N02A J13, Opioids: N02A, NH: nursing home

Table 2. Pain and quality of life assessed with **MOBID-2** and **QUALID** in 953 NH residents with dementia

	N	Mean (SD)
MOBID-2 overall evaluation score (range 0-10)	953	2.0 (2.1)
Mobilization one day		
Opening hands (0-10)	949	0.4 (1.2)
Stretch arms (0-10)	949	1.0 (2.0)
Bend and stretch knees and hips (0-10)	949	1.3 (2.1)
Turn in bed (0-10)	949	1.1 (2.0)
Sit bedside (0-10)	949	1.1 (2.0)
Observations last week		
Head, mouth, neck (0-10)	951	0.6 (1.6)
Heart, lung, chest wall (0-10)	951	0.4 (1.3)
Abdomen (0-10)	949	0.4 (1.2)
Pelvis, genital organs (0-10)	951	1.1 (2.0)
Skin (0-10)	951	0.6 (1.5)
QUALID total score (11-55)	953	19.8 (7.2)
Dimensions		
Well-being dimension (4-20)	948	6.9 (2.4)
Sadness dimension (3-15)	953	5.7 (2.9)
Tension dimension (4-20)	953	7.2 (3.6)
Single items		
Smile (1-5)	953	1.4 (0.9)
Appears sad (1-5)	953	2.2 (1.5)
Cries (1-5)	953	1.5 (1.0)
Has facial expressions of discomfort (1-5)	953	2.1 (1.2)
Appears physically uncomfortable (1-5)	953	1.8 (1.1)
Verbalizations suggests discomfort (1-5)	953	1.9 (1.4)
Is irritable or aggressive (1-5)	953	1.7 (1.1)
Enjoys eating (1-5)	951	1.4 (0.9)
Enjoys touching and being touched (1-5)	952	2.2 (0.9)
Enjoys interacting with others (1-5)	951	1.8 (0.9)
Appears calm and comfortable (1-5)	953	1.9 (1.1)

MOBID-2: Mobilization-Observation-Behavior-Intensity-Dementia 2 Pain scale, QUALID: Quality of Life of Late Stage Dementia, SD: Standard Deviation,

Well-being dimension: smiles, enjoys eating, enjoys social interaction and enjoys touching/being touched, Sadness dimension: cries, appears sad and facial expression of discomfort, Tension dimension: physically uncomfortable, verbalization suggests discomfort, irritable and appears calm

Table 3. Assessing quality of life in NH residents stratified by dementia severity and by pain level and use of analgesics, numbers are means (SD); N = 915

	Mild (CDR ≤ 1) N=292	Moderate (CDR = 2) N=418	Severe (CDR = 3) N=205	p-value[1]
QUALID (N = 915)				
MOBID-2 overall evaluation score	16.0 (4.8)	18.1 (5.6)	23.0 (8.0)	0.160
No to mild pain (0-2)	19.0 (7.0)	22.1 (7.1)	24.2 (7.4)	
Moderate pain (3-6)	20.3 (7.9)	23.9 (7.3)	27.8 (8.6)	
Severe pain (7-10)				
Use of analgesics				0.138
Opioids	18.1 (6.7)	22.3 (7.1)	24.0 (7.3)	
Users	16.8 (5.6)	19.1 (6.3)	23.5 (8.1)	
Non-users Paracetamol				0.950
Users	18.2 (6.5)	20.6 (6.7)	24.6 (8.4)	
Non-users	16.2 (5.2)	18.9 (6.3)	22.7 (7.3)	
Opioids and/or Paracetamol				0.857
Users	17.9 (6.8)	20.8 (6.8)	24.7 (8.4)	
Non-users	16.2 (4.8)	18.6 (6.0)	22.5 (7.3)	
Well-being dimension (N = 910)				
MOBID-2 overall evaluation score	6.1 (2.0)	6.4 (2.0)	7.9 (2.8)	0.099
No to mild pain (0-2)	6.8 (2.7)	7.1 (2.2)	7.6 (2.6)	
Moderate pain (3-6)	6.9 (3.1)	7.3 (2.7)	9.2 (3.1)	
Severe pain (7-10)				
Use of analgesics				0.498
Opioids	6.5 (2.9)	7.3 (2.2)	8.2 (2.8)	
Users	6.3 (2.2)	6.5 (2.1)	7.8 (2.8)	
Non-users				0.667
Paracetamol	6.6 (2.5)	7.0 (2.3)	8.2 (3.1)	
Users	6.2 (2.2)	6.4 (2.0)	7.5 (2.4)	
Non-users				0.482
Opioids and/or Paracetamol	6.6 (2.7)	7.0 (2.2)	8.3 (3.1)	
Users	6.2 (2.0)	6.4 (2.0)	7.4 (2.4)	
Non-users				
Sadness dimension (N = 915)				
MOBID-2 overall evaluation score	4.6 (2.2)	5.3 (2.6)	6.3 (3.2)	0.169
No to mild pain (0-2)	5.4 (2.3)	6.9 (3.2)	7.1 (3.3)	
Moderate pain (3-6)	6.1 (2.8)	7.8 (3.1)	7.0 (3.9)	
Severe pain (7-10)				

Use of analgesics				**0.034**
Opioids	5.1 (2.3)	6.8 (3.2)	6.2 (2.6)	
Users	4.8 (2.3)	5.7 (2.9)	6.7 (3.4)	
Non-users				0.484
Paracetamol	5.2 (2.5)	6.2 (2.9)	6.6 (3.2)	
Users	4.6 (2.1)	5.7 (2.9)	6.6 (3.4)	
Non-users				0.437
Opioids and/or	5.1 (2.5)	6.3 (3.0)	6.7 (3.2)	
Paracetamol	4.6 (2.1)	5.6 (2.8)	6.6 (3.4)	
Users				
Non-users				
Tension dimension (N = 915)				
MOBID-2 overall evaluation score	5.3 (2.1)	6.4 (2.9)	8.8 (4.2)	0.328
No to mild pain (0-2)	6.8 (3.4)	8.2 (3.5)	9.4 (4.0)	
Moderate pain (3-6)	7.4 (4.0)	8.9 (3.9)	11.6 (4.1)	
Severe pain (7-10)				
Use of analgesics				0.363
Opioids	6.5 (3.2)	8.2 (3.7)	9.5 (4.1)	
Users	5.7 (2.5)	6.9 (3.1)	9.1 (4.2)	
Non-users				0.752
Paracetamol	6.4 (3.2)	7.5 (3.5)	9.7 (4.4)	
Users	55.4 (2.2)	6.8 (3.0)	8.6 (3.9)	
Non-users				0.926
Opioids and/or	6.3 (3.2)	7.6 (3.5)	9.7 (4.3)	
Paracetamol	5.4 (2.1)	6.6 (2.9)	8.6 (3.9)	
Users				
Non-users				

QUALID*:* Quality of Life of Late Stage Dementia, CDR*:* Clinical Dementia Rating, MOBID-2: Mobilization-Observation-Behavior-Intensity-Dementia 2 Pain scale, Paracetamol: N02B E01, N02A J06 and N02A J13, Opioids: N02A,
Well-being dimension: smiles, enjoys eating, enjoys social interaction and enjoys touching/being touched, Sadness dimension: cries, appears sad and facial expression of discomfort, Tension dimension: physically uncomfortable, verbalization suggests discomfort, irritable and appears calm

[1] p-value for interaction term in linear mixed model adjusted for cluster effect within nursing home

Table 4. Assessing factors associated with quality of life, QUALID total score; N = 787

	Unadjusted models		Adjusted model	
	RC (95% CI)	p-value	RC (95% CI)	p-value
MOBID-2	0.93 (0.70; 1.16)	**<0.001**	0.52 (0.36; 0.69)	**<0.001**
CDR sum of boxes	0.71 (0.58; 0.84)	**<0.001**	0.24 (0.12; 0.36)	**<0.001**
GMHR (Good/fairly good)	-2.69 (-3.66; -1.72)	**<0.001**	-0.91 (-1.60; -0.23)	**0.009**
PSMS	0.45 (0.34; 0.56)	**<0.001**	0.16 (0.07; 0.25)	**0.001**
NPI-NH Agitation sub-syndrome	0.50 (0.44; 0.55)	**<0.001**	0.22 (0.17; 0.27)	**<0.001**
NPI-NH Psychosis sub-syndrome	0.67 (0.56; 0.78)	**<0.001**	0.07 (-0.02; 0.17)	0.112
NPI-NH Affective sub-syndrome	0.84 (0.77; 0.91)	**<0.001**	0.59 (0.52; 0.67)	**<0.001**
NPI-NH Apathy	0.80 (0.61; 1.00)	**<0.001**	0.29 (0.15; 0.43)	**<0.001**
No psychotropic medication	-2.20 (-3.17; -1.22)	**<0.001**	-0.42 (-1.09; 0.25)	0.218
Use of analgesics				
Opioid	1.92 (0.66; 3.19)	**0.003**	0.38 (-0.53; 1.29)	0.407
Paracetamol	2.24 (1.27; 3.21)	**<0.001**	0.58 (-0.14; 1.30)	0.113
Demographics				
Age	-0.05 (-0.12; 0.01)	0.106	0.01 (-0.03; 0.06)	0.586
Males	0.05 (-0.96; 1.07)	0.917	-0.30 (-1.01; 0.42)	0.419
Married	2.19 (1.14; 3.23)	**<0.001**	0.24 (-0.51; 1.00)	0.530
NH characteristics				
Special care unit	1.03 (-0.03; 2.10)	0.057	-0.24 (-0.99; 0.52)	0.538

RC: Regression Coefficient, CI: Confidence Interval, MOBID-2: Mobilization-Observation-Behavior-Intensity-Dementia 2 Pain scale, CDR: Clinical Dementia Rating scale, GMHR: General Medical Health rating, PSMS: Physical Self-Maintenance Scale, NPI-NH: Neuropsychiatric Inventory-Nursing Home version,
NPI-NH Agitation sub-syndrome: agitation/aggression, disinhibition and irritability, NPI-NH sub-syndrome Psychosis: delusions and hallucination, NPI-NH Affective sub-syndrome: depression and anxiety, Opioids: N02A, Paracetamol: N02B E01, N02A J06 and N02A J13, NH: nursing home

Table 5. Assessing factors associated with QUALID dimensions score, N = 787

	Unadjusted models		Adjusted model	
	RC (95% CI)	p-value	RC (95% CI)	p-value
Well-being dimension				
MOBID-2	0.17 (0.09; 0.25)	**<0.001**	0.08 (-0.001; 0.15)	0.052
CDR sum of boxes	0.18 (0.14; 0.23)	**<0.001**	0.07 (0.01; 0.13)	**0.013**
GMHR (Good/fairly good)	-0.84 (-1.18; -0.50)	**<0.001**	-0.34 (-0.65; -0.02)	**0.036**
PSMS	0.18 (0.14; 0.21)	**<0.001**	0.09 (0.05; 0.13)	**<0.001**
NPI-NH Agitation sub-syndrome	0.06 (0.04; 0.08)	**<0.001**	-0.006 (-0.03; 0.02)	0.605
NPI-NH Psychosis sub-syndrome	0.08 (0.04; 0.12)	**<0.001**	0.02 (-0.02; 0.06)	0.334
NPI-NH Affective sub-syndrome	0.11 (0.07; 0.14)	**<0.001**	0.07 (0.04; 0.11)	**<0.001**
NP-NH I Apathy	0.38 (0.32; 0.45)	**<0.001**	0.30 (0.24; 0.37)	**<0.001**
No psychotropic medication	-0.36 (-0.70; -0.02)	**0.037**	-0.01 (-0.31; 0.30)	0.965
Use of analgesics				
Opioid	0.55 (0.11; 0.99)	**0.014**	0.12 (-0.29; 0.54)	0.562
Paracetamol	0.73 (0.39; 1.06)	**<0.001**	0.25 (-0.08; 0.58)	0.132
Demographics				
Age	-0.002 (-0.02; 0.02)	0.855	0.01 (-0.01; 0.03)	0.446
Males	0.20 (-0.15; 0.55)	0.269	0.21 (-0.13; 0.54)	0.219
Married	0.32 (-0.04; 0.69)	0.082	-0.14 (-0.48; 0.21)	0.439
NH characteristics				
Special care unit	-0.52 (-0.88; -0.16)	**0.005**	-0.49 (-0.83; -0.14)	**0.006**
Sadness dimension				
MOBID-2	0.32 (0.23; 0.41)	**<0.001**	0.20 (0.12; 0.27)	**<0.001**
CDR sum of boxes	0.18 (0.13; 0.24)	**<0.001**	0.08 (0.02; 0.13)	**0.005**
GMHR (Good/fairly good)	-0.74 (-1.14; -0.34)	**<0.001**	-0.28 (-0.59; 0.03)	0.079
PSMS	0.07 (0.03; 0.12)	**0.001**	0.005 (-0.04; 0.05)	0.832
NPI-NH Agitation sub-syndrome	0.13 (0.10; 0.15)	**<0.001**	0.01 (-0.01; 0.04)	0.357
NPI-NH Psychosis sub-syndrome	0.22 (0.18; 0.27)	**<0.001**	0.01 (-0.03; 0.05)	0.567
NPI-NH Affective sub-syndrome	0.35 (0.32; 0.38)	**<0.001**	0.31 (0.28; 0.35)	**<0.001**
NPI-NH Apathy	0.21 (0.13; 0.29)	**<0.001**	0.05 (-0.01; 0.11)	0.131
No psychotropic medication	-0.87 (-1.27; -0.48)	**<0.001**	-0.14 (-0.45; 0.17)	0.373
Use of analgesics				
Opioid	0.36 (-0.15; 0.88)	0.166	-0.03 (-0.45; 0.38)	0.875
Paracetamol	0.53 (0.13; 0.93)	**0.009**	0.13 (-0.20; 0.46)	0.454
Demographics				
Age	-0.02 (-0.05; 0.001)	0.060	-0.0004 (-0.02;	0.967
Males	-0.39 (-0.80; 0.03)	0.067	0.02)	**0.028**
Married	0.67 (0.25; 1.10)	**0.002**	-0.37 (-0.70; -0.04)	0.398
NH characteristics			0.15 (-0.20; 0.50)	
Special care unit	0.59 (0.17; 1.01)	**0.006**		0.457
			0.13 (-0.21; 0.47)	
Tension dimension				
MOBID-2	0.43 (0.32; 0.55)	**<0.001**	0.25 (0.17; 0.33)	**<0.001**
CDR sum of boxes	0.35 (0.28; 0.41)	**<0.001**	0.09 (0.03; 0.15)	**0.002**
GMHR (Good/fairly good)	-1.11 (-1.60; -0.62)	**<0.001**	-0.29 (-0.62; 0.05)	0.096
PSMS	0.20 (0.14; 0.25)	**<0.001**	0.06 (0.02; 0.11)	**0.007**
NPI-NH Agitation sub-syndrome	0.31 (0.29; 0.34)	**<0.001**	0.21 (0.19; 0.24)	**<0.001**
NPI-NH Psychosis sub-syndrome	0.37 (0.31; 0.42)	**<0.001**	0.05 (0.001; 0.09)	**0.046**

NPI-NH Affective sub-syndrome	0.38 (0.34; 0.42)	**<0.001**	0.21 (0.17; 0.25)	**<0.001**
NP-NH I Apathy	0.21 (0.11; 0.31)	**<0.001**	-0.06 (-0.13; 0.01)	0.077
No psychotropic medication	-0.96 (-1.45; -0.48)	**<0.001**	-0.28 (-0.61; 0.05)	0.092
Use of analgesics				
Opioid	1.00 (0.36; 1.63)	**0.021**	0.29 (-0.16; 0.74)	0.204
Paracetamol	0.99 (0.50; 1.48)	**<0.001**	0.22 (-0.13; 0.58)	0.221
Demographics				
Age	-0.03 (-0.06; 0.01)	0.116	0.005 (-0.02; 0.03)	0.644
Males	0.27 (-0.24; 0.78)	0.293	-0.11 (-0.47; 0.24)	0.523
Married	1.18 (0.66; 1.70)	**<0.001**	0.24 (-0.14; 0.61)	0.213
NH characteristics				
Special care unit	0.98 (0.44; 1.52)	**<0.001**	0.15 (-0.22; 0.52)	0.424

QUALID*:* Quality of Life of Late Stage Dementia, RC: Regression Coefficient, CI: Confidence Interval, MOBID-2: Mobilization-Observation-Behavior-Intensity-Dementia 2 Pain scale, CDR: Clinical Dementia Rating scale, GMHR: General Medical Health rating, PSMS: Physical Self-Maintenance Scale, NPI-NH: Neuropsychiatric Inventory-Nursing Home version,
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Well-being dimension: smiles, enjoys eating, enjoys social interaction and enjoys touching/being touched, Sadness dimension: cries, appears sad and facial expression of discomfort, Tension dimension: physically uncomfortable, verbalization suggests discomfort, irritable and appears calm