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A systematic review

Strand, L.I.; Gundrosen, K.F.; Lein, R.K.; Laekeman, M.; Lobbezoo, F.; Defrin, R.; Husebo, B.S.

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REVIEW ARTICLE

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Body movements as pain indicators in older people with cognitive impairment: A systematic review

Liv Inger Strand[1] | **Kim Fredrik Gundrosen**[1] | **Regina Küfner Lein**[2] | **Marjan Laekeman**[3,4] | **Frank Lobbezoo**[5,6] | **Ruth Defrin**[7] | **Bettina S. Husebo**[1,8]

[1]Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway

[2]Medical Library, University of Bergen, Bergen, Norway

[3]PhD Kolleg, University Witten/Herdecke, Witten, Germany

[4]Physiological Psychology, University of Bamberg, Bamberg, Germany

[5]Department of Oral Health Sciences, Academic Centre for Dentistry Amsterdam (ACTA), University of Amsterdam, Amsterdam, The Netherlands

[6]Vrije Universiteit Amsterdam, Amsterdam, The Netherlands

[7]Department of Physical Therapy, Sackler Faculty of Medicine, Sagol School of Neuroscience, Tel-Aviv University, Tel-Aviv, Israel

[8]Municipality of Bergen, Bergen, Norway

Correspondence
Liv Inger Strand, Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway.
Email: liv.strand@uib.no

Abstract

Background and objective: Pain assessment tools for cognitively impaired older people, unable to self-report pain, are commonly founded upon observation of pain behaviour, such as facial expressions, vocalizations and body movements. The scientific basis for claiming that body movements may indicate pain has not formerly been investigated in a systematic review. The objective was to explore research evidence for body movements being pain indicators in older people with cognitive impairment.

Data bases and data treatment: MEDLINE, EMBASE, CINAHL, PsycINFO and the Cochrane Library were searched systematically. Two researchers independently identified and consented on studies to be included. PRISMA statement for reporting systematic reviews was followed. Mixed Methods Appraisal Tool was used for critical evaluation of study quality.

Results: A total of 2,096 records from the literature searches were identified, and 17 quantitative and eight qualitative studies were included in the review, the studies mainly related to older people with dementia. Quality scores ranged from 50% to 100%. We combined 62 items of body movements into 13 similar or synonymous items, and criteria for evidence were defined. Strong evidence was found for *restlessness (agitation), rubbing, guarding, rigidity and physical aggression* as the behaviours frequently responded (increased or decreased) to pain provoking activities, painful procedures and/or pain medication.

Conclusions: Among 13 categories of body movements, we found five with strong and five with moderate evidence of validity. As few items were typically included in many studies reflecting criterion validity, all should be included in future studies of patients with different characteristics, location and duration of pain.

Significance: Pain assessment tools for older people with cognitive impairment or dementia should include valid pain behaviour items. Our review shows strong scientific evidence for the following body movements indicating pain: *restlessness (agitation), rubbing, guarding, rigidity and physical aggression*.

1 | INTRODUCTION

With the progress of modern medicine, life expectancy is increasing globally. Older people typically suffer from multiple morbidities, often associated with pain (Helvik, Engedal, Benth, & Selbaek, 2015). In addition, they may suffer from dementia or other cognitively limiting conditions. Pain prevalence in older adults with dementia is reported to range between 20% and 83% in different studies, indicating that pain assessment is a challenging task in these people (Zwakhalen, Koopmans, Geels, Berger, & Hamers, 2009), complicated by changes in memory, language and abstraction skills (Scherder, Sergeant, & Swaab, 2003).

The International Association for the Study of Pain (IASP) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage." Although pain is always subjective, it is acknowledged that the inability to communicate verbally does not negate the possibility that an individual is experiencing pain (IASP terminology). Despite of this agreed-upon understanding on the nature of pain, self-report measures of pain intensity are still the most commonly used (Lautenbacher & Kunz, 2017; Scherder et al., 2009). This limited scope of pain assessment is considered an ethical issue, because it may cause inappropriate pain management (Ferrell et al., 2001). This applies also to older people with cognitive impairment who are unable to report their pain in a valid way. Therefore, an interdisciplinary expert consensus statement on assessment of pain in older persons recommends the inclusion of observational methods for seniors with dementia (Hadjistavropoulos et al., 2007). These people also tend to react with more vigour to painful procedures compared to cognitively intact older people (Hadjistavropoulos & Fine, 2006). A diagnosis of dementia also implies behavioural and psychological symptoms (Corbett et al., 2014), and distinguishing these symptoms from pain behaviour is challenging. The pain behaviour may also differ according to cause and localization of the painful condition, and to actual neuropathology causing dementia (Scherder et al., 2003).

Facial expressions, vocalizations and body movements are among pain behavioural aspects recommended to be observed and assessed in older persons (AGS Panel on Persistent Pain in Older Persons, 2002). A multitude of behavioural pain assessment tools have been developed, but no tool is generally recommended (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011; Stolee et al., 2005; Zwakhalen, Hamers, Abu-Saad, & Berger, 2006). The EU-COST action TD 1005 program "Pain Assessment in Patients with Impaired Cognition, especially Dementia" initiated accordingly the development of a new meta-tool (Corbett et al., 2014), including common behavioural items of pain. The mere presence of an item in an assessment tool does not legitimize its validity as an indicator of pain. However, items addressed in this meta-tool occur repeatedly in a selection of best possible scales, which make their validity more likely. Still, the scientific evidence for considering body movement items valid as indicators of pain has not previously been examined in a systematic review.

As to facial expressions, core features, highly specific to the experience of pain, have been identified (Kunz, Scharmann, Hemmeter, Schepelmann, & Lautenbacher, 2007; Lautenbacher & Kunz, 2017), and a review study of vocalization items is presently undertaken. The aim of the present review was to examine the validity of body movements as pain indicators in older people with cognitive impairment. Research questions: (a) Which body movements have been reported by health personnel and/or proxies to indicate pain? (b) Have body movements considered indicators of pain been found associated with other pain measures? (c) Has change in body movements (increase or decrease) been documented, when exposed to pain provoking activities or procedures, or pain relieving treatment?

2 | METHODS

A systematic review was applied, described as a detailed and comprehensive plan and search strategy derived a priori, with the goal to identify, appraise and synthesize all relevant studies on the particular topic (Uman, 2011). The protocol for the review was registered in PROSPERO: ID record 90986. For reporting, we followed recommendations of PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) statement (Liberati et al., 2009).

2.1 | Search strategy

A systematic literature search of the electronic databases MEDLINE, EMBASE, CINAHL, PsycINFO and the Cochrane Library was conducted on 23 February 2015, and last updated on 31 May 2018. The search was built by combining subject headings and free text words for the following concepts: pain, behaviour or body movements, cognitive impairment or dementia, assessment and advanced age. Subject headings were adapted to the thesaurus of each database. The full search strategy for MEDLINE is presented in Appendix 1.

2.2 | Study selection

Different designs, qualitative as well as quantitative, were eligible for studies included in the review. Prerequisites for inclusion:

1. The study had to report on evidence for specific body movements being pain behaviours.

2. The study population included older people with cognitive impairment or dementia.
3. The full-text article must be available. No limitation was put on language or year of publication.

To identify eligible studies from the search results, two reviewers (KFG and LIS) screened titles and abstracts independently. If not sufficient information was provided, the full-text article was retrieved and screened. The reviewers then conducted a full-text screening of all eligible articles. In cases of disagreement, both reviewers considered the article for inclusion after reading it once more. Results were compared, and disagreements were resolved in a consensus meeting. A third reviewer (BSH) participated to discuss one article written in German, as she is native German. As the literature search was repeated due to a long course of the study due to practical reasons, the procedure of identifying eligible studies for inclusion was also repeated by the two reviewers (KFG and LIS), followed by consensus meeting.

2.3 | Quality assessment

As the eligibility criteria for this systematic review invited a large spectrum of study designs, the Mixed Methods Appraisal Tool (MMAT) was used for methodological quality assessment (Pluye et al., 2011). The MMAT has been designed for the appraisal of complex systematic reviews that include qualitative, quantitative and mixed methods studies. Depending on the type of study, four somewhat different quality criteria apply. However, the clarity of the research question and whether the collected data address the research question, apply to all. The same score metric for quality is used across all designs and can be 0% (no criterion met), 25%, 50%, 75% or 100% (all four criteria met). Three reviewers (KFG, LIS and ML) appraised the studies independently, using the MMAT, and results were compared and consensus reached after discussion in cases of uncertainty or disagreement.

2.4 | Synthesis of results

All authors participated in developing a plan for synthesizing the results. The first step was to extract information from each article in a table (Appendix 2), performed by the two reviewers, KFG and LIS: Typical study characteristics; aim, sample, design, method, quality and results were reported. Main findings were specific body movements reflecting pain as reported or examined in the study. Results in quantitative studies included various evidence depending on the methods used (i.e., odds ratio with 95% confidence interval of increased or decreased body movement as a function of higher pain, statistical ($p \leq 0.05$) or clinical significant difference or change in body movement as a result of increased or decreased pain).

Sixty-five body movements were derived in the review. The identification of body movements as part of a typical pain behaviour was a central element in work related to the EU-COST action TD 1005 "Pain in impaired cognition, especially dementia." Since many items, derived in the present review, appeared to express similar types of body behaviour, they were suggested to be combined into 13 main items by LIS and BSH, influenced by work in the EU-COST action. After a consensus process (by mail), including all authors, three items were considered not very relevant pain descriptors and were left out (refusing medication, impaired washing and dressing, and impulsive behaviour), while organizing the remaining 62 descriptors into 13 main items was supported by all (see Table 2).

Criteria for defining level of evidence for body movements being indicators of pain were suggested by three reviewers (LIS, BSH and KFG). After some communication by e-mail followed by adjustments, all authors reached consensus on the criteria. The level of evidence (strong to weak evidence) was based on both qualitative and quantitative studies. In order to be considered with strong evidence, the body movement item should be considered by health personnel or proxies, in at least three qualitative studies of high quality (MMAT 75%–100%), to be an indicator of pain, having face validity. This means that the item "indeed looks as though it is an adequate reflection of the construct to be measured" (Mokkink et al., 2010), here pain. To be judged with strong evidence, the item must also demonstrate criterion validity in at least three quantitative studies of high quality (MMAT 75%–100%). Criterion validity addresses the question of whether an item is "an adequate reflection of a *gold standard*" (Mokkink et al., 2010), here pain, by responding in line with other measures of pain, and/or respond to painful procedures or pain-relieving treatment. Quantitative measures of association, difference or change in behaviour by statistical or clinical significance were required. Criteria for strong, moderate and weak levels of evidence are described in Table 1.

3 | RESULTS

After removal of duplicates, 2,096 records were derived from the database searches, and 2,037 excluded after title and abstract screening. Fifty-nine full-text articles from the search were assessed for eligibility plus one article derived outside the search. Twenty-five articles were found eligible for inclusion. A flow chart of the study inclusion process is presented in Figure 1.

There were eight qualitative and 17 quantitative studies, and the majority of older people with cognitive impairment had a diagnosis of dementia. All studies were listed alphabetically according to first author in Appendix 2, with information about design, MMAT scores, sample, study aim, method

Strong evidence	Body movement reported to indicate pain in at least three qualitative, interview studies, and also found in at least three quantitative studies of high quality (MMAT 75%–100%) to be related to other measures of pain, or to change (increase/decrease) in connection with pain provoking activities, painful procedures or pain medication
Moderate evidence	Body movement reported to indicate pain in at least two qualitative, interview studies, and found in at least two quantitative studies of high quality (MMAT 75%–100%) to be associated with other measures of pain, or to change (increase/decrease) in connection with pain provocation activities, painful procedures or pain medication
Weak evidence	Body movement reported to indicate pain in at least on equalitative, interview study, and found in at least one quantitative study of moderate to high quality (MMAT 50%–100%), to be associated with other measures of pain, or to change (increase/decrease) in connection with pain provoking activities, painful procedures or pain medication

TABLE 1 Criteria for deciding level of evidence for body movement being a pain indicator

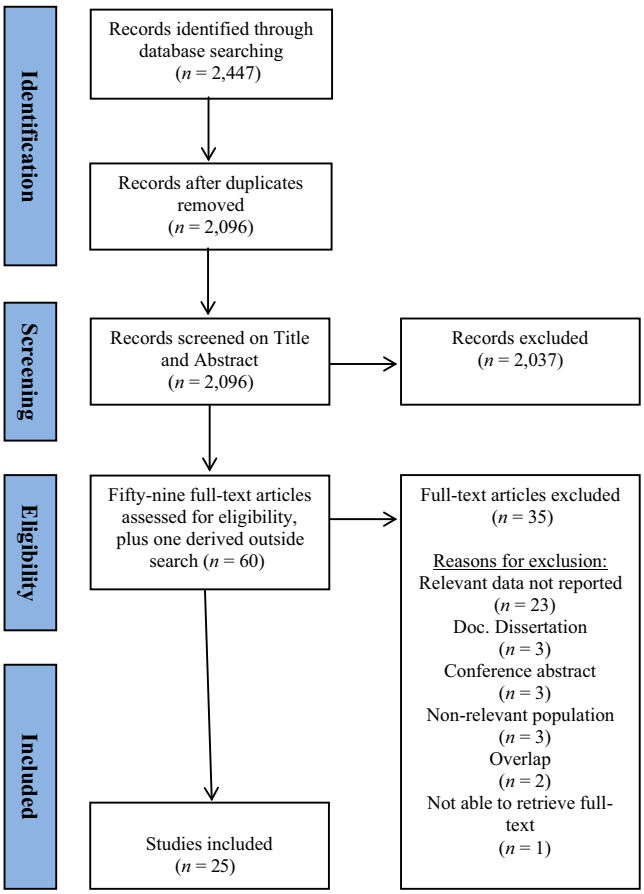

FIGURE 1 Flow chart of study inclusion

and main findings. Each article was numbered to facilitate linking to pain descriptors and type of study in Table 2.

Sixty-five body movement descriptors were derived from the studies. The identification of body movements as part of a typical pain behaviour was one central element addressed in the EU-COST action TD 1005 program. Since many items appeared to express similar types of body behaviour, they were suggested combined into 13 main items by LIS and BSH, influenced by discussions in EU-COST action meetings. After a consensus process (by e-mail) including all collaborating authors, three items were considered not relevant and were left out (refusing medication, impaired washing and dressing and impulsive behaviour), while organizing the remaining 62 descriptors into 13 main items was supported by all authors (Table 2, 1st column).

3.1 | Interview reported items

In the eight qualitative studies nurses, other caregivers and/or family were interviewed about observed behavioural indicators of pain in older people with dementia, providing evidence of face validity (Table 2, 2nd column). In these studies, the informants were not restricted by items included in a particular assessment tool, but could report any behaviour that they considered an expression of pain. Ten of the 13 body movement categories were reported in at least three studies.

3.2 | Questionnaire reported items

Items included in questionnaires were used in nine observational studies of pain behaviour (Table 2, 3rd column). This method limited the scope of assessment to those behaviours included in the questionnaire, sometimes only one or a few body movements. In some studies, the observed body movements were associated with other pain measures, providing evidence of criterion validity. Only three body movement categories were reported in at least three studies.

3.3 | Studies of pain provoking activities, procedures or pain treatment

Pain behaviour was examined in eight studies to examine criterion validity of body movements (Table 2, 4th column).

TABLE 2 Body movement indicators of pain combined into main items (bold face), organized according to type of study and ranked with strong, moderate or weak evidence

Body movement indicators of pain	Qualitative studies; items derived from interviews	Quantitative studies; items simply scored from questionnaires, in some studies related to other pain measures[a,b]	Quantitative studies; items from questionnaires found to increase or decrease with pain provoking activities/procedures/pain treatment	Evidence
Restlessness; agitation, fidgeting	4, 5, 6, 7, 12, 20, 23	1[a], 11, 14[b], 15[a], 19	8, 10, 17, 25	Strong
Rubbing; massages sore area, holding or clutching body part, tactility	4, 5, 6, 12, 20, 23, 24	11, 16[a],	10, 22	Strong
Guarding; reluctant to be touched, protecting body/sore area, not allowing people near or to be touched, pulling away, resisting care	6, 7, 12, 23, 24	16[a], 18, 19	9, 13, 22	Strong
Rigidity; stiffness, clenched hands or fists, restricted mobility	4, 5, 6, 12, 24	16[a],19	9	Strong
Physical aggression; combativeness, fighting, grabbing, hitting, kicking, pushing, throwing things, scratching, thrashing	4, 5, 6, 12, 20, 23	1[a],2[a],21[a]	25	Strong
Bracing; use object (for support)	6, 24	11, 16[a]	9, 10, 13, 22	Moderate
Decreased mobility/activity; moving slowly, reluctant or refusing to move, lying down, withdrawal, stopping, freezing	4,5,6,**7**,12,20,23,24	16[a],19		Moderate
Flinching	5, 12	19	25	Moderate
Pacing; Decreased or increased wandering, trying to leave/get to another place	6, 12, 23, 24	1[a]	17	Moderate
Poor posturing; position/weight shift, awkward sitting/standing/lying, dislocated limbs, contract body, stoop, curling up, going into foetal position	4, 6, 12, 23, 24	16[a],19		Moderate
Gait disturbance; limping, impaired gait, shuffling	4, 5, 6, 12, 20, 23, 24		3	Weak
Trembling; shaking, quivering	6, 7	19		Weak
Repetitive movements; rocking, tossing and turning, flailing/flapping arms, hand movements, moving back and forth	5, 6, 12			Weak

Numbers are related to articles listed alphabetically in Appendix 2.

[a]Item found in study to be associated with other pain measures. [b]Item not found in study to be associated with other pain measures.

The moderator variables of type and site of pain were not explicitly considered. The participants might be exposed to acute pain in localized parts of the body (influenza injection, chewing), or to pain medication or movement-exacerbated pain, influencing acute as well as long-lasting pain from different parts of the body. In some studies, a broad range of behaviours were to be observed while in others only a few body movements were to be observed, limiting information about body movement reactions to increased or decreased pain.

3.4 | Summary evidence for pain behaviours indicating pain

According to the criteria set for level of evidence for body movements being pain indicators, *restlessness (agitation), rubbing, guarding, rigidity and physical aggression* were found with strong evidence (Table 2, 5th column). Moderate evidence was found for *bracing, decreased mobility/stopping, flinching, pacing and poor posturing, and* weak evidence for *gait disturbance (especially limping), trembling* and *repetitive movements*.

4 | DISCUSSION

The aim of this review was to collate and analyse the available research evidence for body movements that might reflect pain in older people with cognitive impairment, especially dementia. In the absence of a universal valid assessment tool for persons with cognitive impairment, the EU-COST initiative TD1005 started the process of developing a meta-tool, Pain Assessment in Impaired Cognition (PAIC) based on the best elements of existing published tools (Corbett et al., 2014). Part of this project is to include the most valid pain behavioural items. The scope of the present study was evidence for body movements indicating pain.

4.1 | Methodology

Since narrative reviews are more descriptive, and usually do not include a systematic search of the literature, we decided to perform a systematic review, implying an agreed-upon search strategy a priori among the collaborating researchers, and with a comprehensive plan for the study. It was our goal to reduce potential bias by identifying, appraising and synthesizing all relevant studies on the particular topic for the study. As we have included both qualitative and quantitative studies, applying a variety of methods, we were not able to synthesize our data in some type of meta-analysis using statistical techniques or summary effect size from several studies.

4.2 | Main results

The 25 studies derived shed light on the research questions by reporting specific body movements considered or found to be pain related. A multitude of body movements were reported to be expressions of pain by experienced nurses and other caregivers in qualitative, interview studies providing evidence for face validity. However, as it may be difficult to distinguish neuropsychiatric symptoms from pain behaviour in dementia, supplementary evidence was needed for validating an item. We required evidence from high-quality studies to support criterion validity of the behaviour as a pain indicator, the studies either examining the relationship with other pain measures, or the impact on behaviour of pain-provoking or pain-relieving interventions. According to the defined criteria, there was strong evidence for *restlessness (agitation), rubbing, guarding, rigidity, and physical aggression* being valid indicators of pain, but also moderate evidence for *bracing, decreased mobility/stopping, flinching*, *pacing*, and *poor posturing*. However, *restlessness* and *physical aggression* are also considered neuropsychiatric symptoms, suggesting an interaction effect. A recent study (Regier & Gitlin, 2018) showed that persons with dementia and restlessness had significant higher pain scores than those without *restlessness*. As expected, all body movement items included in the draft of the meta-tool PAIC (*freezing, curling up, clenched hands, resisting care, pushing, guarding, rubbing, limping, restlessness, pacing*) are found within items with strong or moderate evidence in the present review.

4.3 | Validation by pain provoking activities

Potential pain provoking activities have been applied when examining criterion validity. Transfers were found to elicit the most frequent pain behaviours (Horgas, Elliott, & Marsiske, 2009), possibly due to the complex and varied movements required. In the study by Feldt (2000), patients who recently had undergone surgical repair of a hip fracture were observed for nonverbal signs of pain during transfer from bed to chair or from chair to bed. The activity protocols used in the studies of Horgas et al. (2009) and Hadjistavropoulos, LaChapelle, MacLeod, Snider, and Craig (2000) included daily activities, such as sitting, standing, lying on a bed, or walking in a place, as well as transfers between activities. Shega et al. (2008) used simulated daily activities; bridging, lying prone, supine to sit and long-leg sit, but did not include weight-bearing activities. Taking into consideration that many older persons have musculoskeletal pain or may get pain from internal organs in connection with movements, and that several daily activities are likely to provoke pain, we can still not be sure that the activities provoke the painful site in all individuals

assessed. Some body movements like *restlessness* and *rubbing* were most frequently seen during rest, while *bracing and guarded movements* most often were seen during activities such as transfers. It is therefore important that pain behaviour is observed during both conditions.

4.4 | Validation by pain provoking procedures

Influenza vaccination has face validity as a treatment procedure provoking acute pain. We can therefore be rather confident that the body movement reactions to this procedure, such as *restlessness, flinching, rubbing and guarding,* are pain related, although they may also express fear, surprise and offence and other emotional responses. The study by Zwakhalen, Hamers, and Berger (2007) is the only one found to use a painful treatment procedure to validate behavioural indicators of pain in this group of patients. The body movement reaction *flinching* may, however, be specific to acute and localized pain and less typical to long-lasting and generalized pain.

4.5 | Validation by pain medication

A few studies have used medical pain treatment to validate pain behaviours. The effect on behaviour captured by frequent assessment of patients with cognitive impairment and osteoarthritis during periods with and without pain treatment (acetaminophen) was investigated (Elliott & Horgas, 2009). Although this is a study of only three patients, it provides rather convincing evidence that the pain medication resulted in less *guarding, rigidity, bracing* and *stopping (movement).* In the study by Husebo, Ballard, Sandvik, Nilsen, and Aarsland (2011), Husebo, Ballard, Cohen-Mansfield, Seifert, and Aarsland (2014), agitation, restlessness and pacing behaviours were found to decrease in agitated patients who received a stepwise protocol of pain medications. The study investigated only behaviours included in the Cohen-Mansfield Agitation Inventory, and we do not know the response of other specific body movements. Although the application of pain medications seems to be a good approach to examine the validity of possible behavioural indicators of pain, the above studies are limited as to the range of body movements investigated.

4.6 | Comparison between cognitively impaired and intact older people

Older people with cognitive impairment seem more likely to express pain by changed behaviour than cognitively intact people do, as supported by Blomqvist and Hallberg (2001) and Closs, Cash, Barr, and Briggs (2005). In a longitudinal study, Alexander et al. (2005) reported that an increased awareness and assessment of pain in residents of long-term care facilities over time resulted in increased pain medication intake and a decrease in pain behaviours in a secure nursing home unit, but not in the open unit.

4.7 | The European COST action TD1005 (PAIC)

The EU-COST action "Pain in impaired cognition, especially dementia" was initiated in 2011 and included representatives from 16 European nations (Corbett et al., 2014). This 4-year initiative combined the expertise of clinicians and researchers to identify existing pain assessment tools for dementia, and to develop a consensus that aims to draw on the combined clinical, research and methodological expertise of its multidisciplinary members. Following the COSMIN guidelines (Mokkink et al., 2010], the identification of body movements as part of typical pain behaviours was a central element of this work. During this process, we discussed identification of relevant articles and items in several meetings, as well as the review processes. For instance, we utilized COST meetings in Brussels (February 2015) and the 7th International Congress of Pain in Dementia "Future Directions," in Bergen (April 2015), as meeting points to discuss and select appropriate items regarding body movements from existing assessment tools.

4.8 | Limitation of the study

Pain behaviour has been examined in many studies, but when only the sum score of assessment tools was reported, many had to be dismissed from the present review. Most articles included in the review, did not share our research questions, but still provided evidence regarding validity of body movements being indicators of pain. However, it is challenging to distinguish between typical behaviour related to dementia and behaviour that might be due to pain. Habiger, Flo, Achterberg, and Husebo (2016) suggest that pain is an underlying factor of neuropsychiatric symptoms commonly seen in dementia, such as agitated behaviour. Furthermore, some of the included studies report pain behaviour in the acute pain situation, whereas most pain experiences in nursing home patients with dementia seem to be related to chronic pain. Thus, different pain behaviours might be expected in conditions of acute and chronic pain. Further shortcomings are related to studies of patients with localized pain, causing limited body movement reactions in pain provoking activities. Only qualitative studies, some of them with lower sample sizes, opened up for a variety of body movements, as they were not limited by items included in a questionnaire. Unfortunately, only a few specific body movements were typically included when studying pain behaviours in connection with pain

provoking activities or procedures, or with pain treatment. The effect of nonpharmacological pain interventions on pain behaviour was not investigated in any of the studies. Validity of body movements considered indicators of pain was also examined by testing the contribution of a bodily movement reaction to the clinical experts' pain intensity scores (Hølen et al., 2005). Since pain is a subjective experience, methodological limitations are recognized regarding the validity of these pain scores.

5 | CONCLUSION

Based on our defined criteria, we found several body items with strong or moderate evidence to be indicators of pain in older patients with cognitive impairments, especially dementia. As expected, the suggested PAIC body movement indicators of pain were included in these items. To examine criterion validity further, several studies seem to be necessary, taking into consideration the different characteristics, location and duration of pain, and using different interventions or procedures expected to influence pain. Future studies should open up for registering all 13 body item categories registered in the present review, to give all a fair chance to be examined regarding criterion validity.

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NOTE

[11]MMAT: Mixed Methods Appraisal Tool; OPS-NVI: Orofacial Pain Scale for NonVerbal Individuals; CNPI: Checklist of Nonverbal Pain Indicators; NOPPAIN: Noncommunicative Patient Pain Assessment Instrument; PACSLAC: Pain Assessment Checklist for seniors with Limited Ability to communicate; BPSD: behavioural and psychiatric symptoms of dementia; CMAI: Cohen-Mansfield Agitation Inventory, PACI: Pain Assessment in the Communicatively Impaired; MMSE: Mini–Mental State Examination; PAIC: Pain Assessment in Impaired Cognition.

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APPENDIX 1

Database: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other NonIndexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>; 31.05.2018

1	exp Pain/ (358980)
2	pain.tw. (539191)
3	1 or 2 (686647)
4	exp Behaviour/ (1619279)
5	exp Movement/ (496920)
6	Psychomotor Agitation/ (4735)
7	exp affect/ or exp anger/ or exp anxiety/ or apathy/ or expressed emotion/ or exp fear/ or frustration/ or hostility/ (138844)
8	(motor behaviour* or motor behaviour* or motor disorder* or motor disabilit* or motor disease* or body gesture* or body posture or body response* or body movement* or movement related or pain avoidance effect or fear of movement or kinesiophobia).tw. (19522)
9	4 or 5 or 6 or 7 or 8 (2038857)
10	3 and 9 (77955)
11	exp cognition disorders/ or consciousness disorders/ or exp dementia/ (203815)
12	developmental disabilities/ or intellectual disability/ (67849)
13	cerebral palsy/ or persistent vegetative state/ (21605)
14	exp Consciousness Disorders/ (41319)
15	((Cogniti* adj1 (impair* or disorder*)) or (Alzheimer* adj2 disease) or Dementia or ((fronto-temporal or frontotemporal) adj2 (degeneration or dementia)) or Picks disease or (Lewy Body adj1 (disease or dementia)) or developmental disability or intellectual disability or mental retardation or cerebral palsy or vegetative state or (minimal adj2 state)).tw. (266470)
16	11 or 12 or 13 or 14 or 15 (429924)
17	10 and 16 (1880)
18	exp Aged/ (2817350)
19	(aged or old* or elderly).tw. (1773183)
20	18 or 19 (4066927)
21	17 and 20 (914)
22	Observation/ (5422)
23	Pain Measurement/(77049)
24	Symptom Assessment/(2998)
25	(observational adj (study or studies)).tw. (81754)
26	(measurement or assessment or observation*).tw. (1905907)
27	22 or 23 or 24 or 25 or 26 (1970457)
28	21 and 27 (422)

APPENDIX 2

Summary of articles listed in alphabetical order and assigned a reference number (1–25), linked to Table 2

Author(s) (year)	Ref	Design	MMAT (%)	Sample	Aim/objectives	Method used to validate body movement items	Evidence of body movements indicating pain
Ahn and Horgas (2013)	1	Quantitative, cross-sectional study	100	*N* = 56,577 nursing home residents with dementia. Mean age: 84 years. Country: USA	Investigate the effect of pain on disruptive behaviours	Logistic regression was used to evaluate the effect of pain on disruptive behaviours	Residents with more severe pain were less likely to display *wandering behaviors* (odds ratio, OR = 0.77, 95% confidence interval, CI [0.73, 0.81], but more likely to display *aggressive* and *agitated* behaviours (OR = 1.04, 95% CI [1.01, 1.08] and OR = 1.17, 95% CI [1.13, 1.20])
Ahn, Garvan, and Lyon (2015)	2	Quantitative, cross-sectional study	100	*N* = 71227 nursing home residents with dementia. Mean age: 85 years. Country: USA	Investigate the relationship between pain and aggression	Logistic regression analysis of data from Pain Severity Scale versus aggression (present or absent). Pain measured by staff	Pain was associated with physical aggression *(hitting, kicking, pushing, scratching and grabbing)*: adjusted odds ratio = 1.20, 95% CI [1.14, 1.26])
Alexander et al. (2005)	3	Quantitative, longitudinal pilot-study	75	Nursing home residents with dementia, *N* = 24 in secure and *N* = 17 in open unit. Mean age: 82 and 85 years, respect. Country: USA	Implement and evaluate a system for pain assessment in a long-term care facility.	Pain assessment daily for 6 months, using a self-report tool and a pain behavioural assessment tool. Limping/gait disturbance the only bodily pain behaviour registered among a total of four behaviours	Four patients (14%) demonstrated limping/gait disturbance at baseline. The use of pain medication was increased in the dementia unit, and over time the mean number of (four) pain behaviours decreased from 5 to 2
Blomqvist and Hallberg (2001)	4	Qualitative, interview	75	*N* = 66 nursing home residents (NHRs) with and without dementia, with and without pain, and contact nurses. Age NHRs: >80 years. Country: Sweden	To illuminate and compare nurses' and older adults' views about how pain is recognized in older adults with and without cognitive impairment	Cognitively intact nursing home residents and nurses were interviewed using open-ended questions about pain indicators. Also use of Verbal Descriptor Scale and semi-structured questions	Bodily pain behaviours reported; *stiffness*, *impaired gait, changing position, massaging painful area, contracting body, fighting, motor restlessness* and *withdrawal*

Author(s) (year)	Ref	Design	MMAT (%)	Sample	Aim/objectives	Method used to validate body movement items	Evidence of body movements indicating pain
Closs et al. (2005)	5	Qualitative, interview	75	$N = 65$ nursing home staff and $N = 36$ careers of 113 nursing home residents with cognitive impairment. Country: UK	Identify and examine pain cues and their association with level of cognitive impairment	The interviewed staff and informal careers answered open-ended questions about behavioural pain indicators	Body movements most frequently reported to be pain indicators by 101 nursing home staff and carers; *Restricted movement (39), tactility (33), gait (13), shuffling (8), hand movements (7), hitting (6), restless (6), and flinching (5)*
Cohen-Mansfield and Creedon (2002)	6	Qualitative, interview	75	$N = 72$ Nursing home staff. Country: USA	Identify behaviours in noncommunicative nursing home residents considered pain behaviours by staff	Interview about prevalence and importance of specific pain behaviours observed. Focus groups to validate behaviours	Pain behaviours considered important to extremely important: *tossing and turning, restlessness, rubbing, dislocated limbs, guarding, bracing, muscle tension, poor posturing, body stiffens, awkward standing and sitting position, limping, decreased activities, reluctant to move, agitation, pacing, pushes away, stiffness*
Decker (2009)	7	Qualitative, interview	75	$N = 16$ registered nurses and $N = 7$ experts in the field of pain and cognitive impairment. Country: USA	Identify post-op. pain behaviours in older adults with delirium, and examine content validity	Focus groups to identify pain behaviours. Survey: Experts rated each item to establish content validity	Body pain indicators reported: *Reluctant to move and to be touched, guarding affected side, restless, agitation, quivering, points to where it hurts, reluctant to do anything*
de Vries et al. (2016)	8	Quantitative, test–retest reliability study	100	$N = 237$ video clips of 153 nursing home residents with dementia. Mean age: 83 years. Country: Netherlands	Establish reliability of the "chewing" subscale of the OPS-NVI in orofacial pain	2 observers used the OPS-NVI for registering pain behaviour from 237 video clips of nursing home residents, recorded during meals	(Body movements seldom reported) Restlessness most frequently observed; in 2.9% of patients by observer 1, and in 5.1% by observer 2 (first assessment)

Author(s) (year)	Ref	Design	MMAT (%)	Sample	Aim/objectives	Method used to validate body movement items	Evidence of body movements indicating pain
Elliott and Horgas (2009)	9	Quantitative, intervention study	75	$N = 3$ community-dwelling older adults with dementia and osteoarthritis. Mean age: 85 years. Country: USA	Investigating the effect of scheduled pain medication, Acetaminophen, on observable pain behaviours	ABAB design, implying 2 control (a) phases alternated with 2 treatment (b) phases using Acetaminophen. Standard pain provoking activities videotaped.	Pain behaviours consistently decreased in mean duration (sec) across adults from baseline to medical treatment phases. *From phase A_1 to B_1, mean time for guarding decreased by 41%–56%, rigidity by 56%–67% and bracing by 16%–65%*
Feldt (2000)	10	Quantitative, descriptive and comparison study	100	$N = 88$ patients with hip fracture, 53 with cognitive impairment. Mean age: 83 years. Country: USA	Pilot testing of the CNPI	CNPI used at rest and during (pain provoking) movement	At rest, *restlessness* was observed in 20.4%, *rubbing* in 8.2% and *bracing in 6.1% of patients*. With movement, *bracing* was most frequent, 18.2%. The researchers' impression that *stillness* and *lack of mobility* were the most typical behaviour in the postoperative patients
Ford, Snow, Herr, and Tripp-Reimer (2015)	11	Quantitative, descriptive and comparison study	75	$N = 83$ older adults with moderate to severe dementia, and a pain-related diagnosis. Country: USA	Examine differences in presentation and intensity of nonverbal pain behaviours among different ethnic groups of older adults with dementia	Random selection of 28 videos from $N = 78$, during performance of morning activities. Nonverbal pain behaviours rated using NOPPAIN	Body movements observed *(rubbing, bracing and restlessness)*, but less than in 4% of ethnic groups
Fuchs-Lacelle and Hadjistavropoulos (2004)	12	Qualitative, interview (phase 1)	50	$N = 28$ primary caregivers of older adults with dementia. Country: Canada	Development of PACSLAC by generating a checklist of pain behaviours	Primary caregivers interviewed to develop a checklist of pain behaviours	20 items included: *fidgeting, pulling away, flinching, restlessness, pacing, wandering, trying to leave, refusing to move, thrashing, decreased activity, refusing medication, moving slow, impulsive behaviour, uncooperative, guarding, holding sore area, limping, clenched fist, going into foetal position, stiff, rigid*

Author(s) (year)	Ref	Design	MMAT (%)	Sample	Aim/objectives	Method used to validate body movement items	Evidence of body movements indicating pain
Hadjistavropoulos et al. (2000)	13	Quantitative, descriptive study	100	$N = 58$ frail older patients, $N = 29$ with cognitive impairment. Mean age 77 years. Country: Canada	Examine the utility of both self-report and nonverbal indicators of pain	The patients were filmed while they performed potential pain provoking activities. Observation of pain behaviour	More pain behaviours seen during activities than during rest. *Guarded behaviour* considered the most sensitive index of pain, and *bracing* was able to discriminate between activities
Hendriks, Smalbrugge, Galindo-Garre, Hertogh, and van der Steen (2015)	14	Quantitative, longitudinal observational study	75	$N = 372$ nursing home residents at various stages of dementia. Mean age: 82 years. Country: Netherlands	Explore the course of symptoms and treatment during nursing home stay.	Frequency of pain, shortness of breath, agitation and treatment recorded up to 6 times over max. 3.5 years	*Agitation* was the most prevalent symptom, varying from 57%–71%. In a longitudinal analysis, the likelihood of pain (frequency) tended to increase with agitation; OR = 1.2 (95% CI 0.95–1.6).
Hodgson, Gitlin, Winter, and Hauck (2014)	15	Quantitative, observational study	100	$N = 272$ older nursing home residents with dementia and their family caregivers. Mean age: 82 years Country: USA	Examine the relationship between pain and behavioural and psychiatric symptoms of dementia, BPSD	Dyads composed of 272 demented patients and their caregivers examined for presence or absence of 21 items of BPSD. Hierarchical multiple regression analysis	Pain explained a small (3%) but significant percent of variance in the number of behavioural symptoms. Pain, a more important predictor of the behaviours *agitation* and *restlessness* in severe ($p < 0.001$) than in low to moderate ($p = 0.034$) cognitive impairment
Horgas et al. (2009)	16	Quantitative, quasi-experimental correlation study	100	$N = 126$ older adults, 62 with cognitive impairment. Mean age: 83 years Country: USA	To investigate the relationship between self-report and behavioural indicators of pain in cognitively intact and impaired adults	Older adults filmed when performing an activity-based protocol to induce pain. Trained coders assessed tapes for pain behaviours	The mean number of pain indicators in the 62 cognitively impaired: *shifting 6, bracing 4.8, guarding 3, rubbing 1.7, rigidity 1, and stopping 0.6*. Pain behaviours increased with activity, especially in transferring
Husebo et al. (2014)	17	Quantitative, cluster randomized clinical trial	100	$N = 352$ older nursing home residents with dementia and behavioural disturbances. Mean age: 86 years Country: Norway	To examine if agitated behaviours responded to increased pain medication.	Intervention group received increased pain treatment, the control group-treatment as usual. Behaviours measured using CIMAI	Mean improvement of general *restlessness* and *pacing* scores in the intervention group over 8 weeks with increased pain medication was 0.8 (0.4, 1.2) for pacing and 0.8 (0.4, 1.1) for restlessness. *Pacing* ($p = 0.026$) and *restlessness* ($p = 0.001$) improved more in intervention than in control group

Author(s) (year)	Ref	Design	MMAT (%)	Sample	Aim/objectives	Method used to validate body movement items	Evidence of body movements indicating pain
Hølen et al. (2005)	18	Quantitative, descriptive study	75	$N = 59$ older nursing home residents with dementia. Median age: 82 years. Country: Norway	Translate the Doloplus-2 into Norwegian and examine criterion validity	Assessment with Doloplus-2 compared to an experienced clinician's pain rating. Regression analysis to explore each item's contribution to pain score.	Isolated contribution of *protective body postures* adopted at rest explained 47% of expert pain score, and was the second most important factor in the stepwise regression analysis explaining 68% of total variability
Kaasalainen, Akhtar-Danesh, Hadjistavropoulos, Zwakhalen, and Verreault (2013)	19	Quantitative, descriptive study	100	$N = 338$ nursing home residents from 6 long-term care units, with and without dementia. Mean age: 83 years. Country: Canada	Evaluate the extent to which pain behaviours vary as a function of ability to self-report pain	Pain behaviours assessed using PACSLAC and PACI at rest and during a potential pain provoking activity	Body movements observed in above 5% of residents not able to self-report pain; *Stiff/rigid (42%), touching/fidgeting (36%), holding sore area (28%), trembling (16%), shaking, restlessness (16%), guarding sore area (12%), refusing to move (11%), flinching (7%), wandering (6%), clenched fist (7%), not wanting to be touched (7%), not allowing people near (6%)*
Kovach, Griffie, Muchka, Noonan, and Weissman (2000)	20	Qualitative, descriptive	75	$N = 30$ nurses from long-term care facilities and later $N = 16$ nurses participated in focus groups Country: USA	Explore nurses' perceptions and experiences regarding assessment and treatment of pain in late-stage dementia	Semi-structured interviews about recognizing and treating pain. Initial findings presented to focus group for validation. 5 points on the Likert's scale indicate strong agreement that the item is an indicator of pain	*Restlessness obtained the highest rating of indicating pain (4.8).* Other scores were; *tense muscles (4.7), agitation (4.6), pull away when touched (4.6), changes in mobility/gait (4.5), and rubbing/holding body parts (4.5)*

Author(s) (year)	Ref	Design	MMAT (%)	Sample	Aim/objectives	Method used to validate body movement items	Evidence of body movements indicating pain
Malara et al. (2016)	21	Quantitative, observational prospective study	50	$N = 181$ nursing home residents with dementia Mean age: male 80.7, female 85.6 years, Country: Italy	Investigate prevalence of pain and its relationship with mood and behavioural and psychological symptoms	Pain assessed by Numeric Rating Scale in MMSE <20 and by PAINAD in MMSE ≥ 20. Behavioural disorders assessed by NPI and CMAI. Logistic regression models to examine associations	Pain increased the likelihood of aggressive behaviour in bivariate analysis, odds ratio 3.3 (1.3, 8.3), $p = 0.01$
Shega et al. (2008)	22	Quantitative, observational descriptive study	50	$N = 77$ participants > 65 years, with and without cognitive impairment and chronic low back pain. Mean age: 77 years. Country: USA	Evaluate the validity of traditional pain behaviours in persons with and without cognitive impairment	Two researchers reviewed video of possible movement-exacerbated pain, recording presence of the body movements; guarding, bracing, and rubbing during 20-sec periods of long-leg sit, bridging, lying prone and supine to sit	Guarding, bracing, and rubbing were observed during movements expected to provoke pain (lasting a total of 80 sec); guarding 4.6 (0.7) sec, bracing 2.8 (1.7) sec, rubbing 2.1 (0.5) sec
van Dalen-Kok et al. (2018)	23	Qualitative, descriptive study	100	$N = 40$ clinical nursing home experts (20 physicians and 20 nurses)	To describe the translation procedure and content validity of the Dutch version of the PAIC	A questionnaire survey administered to determine whether the PAIC items are indicative or specific of pain	All items (*freezing, curling up, resisting care, pushing, clenched hands, guarding, rubbing, limping, restlessness pacing*) were reported to indicate pain, while *guarding, rubbing, limping, freezing and curling up* were reported specific to pain by more than 50% of participants

Author(s) (year)	Ref	Design	MMAT (%)	Sample	Aim/objectives	Method used to validate body movement items	Evidence of body movements indicating pain
Weiner, Peterson, and Keefe (1999)	24	Qualitative, descriptive study	75	$N = 42$ nursing home residents with chronic pain, but no severe cognitive impairment. Mean age: 76 years. $N = 42$ Nurse, Caregiver $N = 42$ Family caregiver Country: USA	To identify behaviours considered pain related	Structured interviews about pain behaviours in nursing home residents	Pain behaviours of body movements frequently listed (>50% of participants): *shift, protect, slow, use object, limp, lie down, brace, stoop, clutch, and stiff*
Zwakhalen et al. (2007)	25	Quantitative, observational descriptive study	100	$N = 128$ nursing home residents with dementia. Mean age: 82.4 years. Country: Netherlands	Examine what PACSLAC items that represent the pain cues most frequently used when assessing pain in nursing home residents with dementia	Patients observed at rest and during influenza injection. A selected group also performed pain-provoking movements	The following body movements were the most frequently used pain cues: *Pulling away (46.4%), not wanting to be touched (28.6%), restlessness (25%), flinching (25%)*