Supplementary Material

Pain and Associated Neuropsychiatric Symptoms in Patients Suffering from Dementia: Challenges at Different Levels and Proposal of a Conceptual Framework

The main aim of this Supplementary Material is to provide the interested reader with further information on available pain assessment tools used in patients with dementia (see Supplementary Table 1). Because the present paper focuses on advanced dementia and thus, patients who usually have difficulty to verbally report pain and/or to understand and follow complex verbal instructions, self-report pain tools are not included in this table (e.g., verbal and numeric rating scales, visual-analogue scales, faces pain scales). Instead, we focus on observational pain assessment tools that do not require patients’ self-reports. Notably, though there are quite many observational assessment tools in use for patients with dementia, these instruments are reported to be rather heterogeneous in terms of underlying concepts as well as methodological and practical issues (e.g., administration time, training needed for administration, scoring characteristics, sensitivity to detect change in patients’ pain perception, psychometric properties; for respective reviews, see [1-8]. To overcome the resulting inconsistencies, a multinational consortium of experts in the field of pain assessment and management gathered with the aim to develop a meta-tool for pain assessment in dementia [4, 5]. This multinational consortium (funded by the European Union) identified 12 observational pain assessment instruments on the basis of 11 respective review articles that were considered to be the best already existing tools to detect and measure pain in elderly with impaired cognition and limited capacity to communicate [4]. Out of these eligible scales, 36 promising items (in terms of differentiating power and psychometric characteristics) were identified and further evaluated empirically (i.e., 13 clinical and experimental pain studies across seven countries, including more
than 600 elderly, thereof 587 with a diagnosis of dementia). This resulted in a final item set of psychometrically sound 15 items tapping three pain categories (facial expression, body movements, vocalizations) that also were reported to be the most agreed-on pain categories defined by the AGS [9]. These 15 items constitute the so-called ‘Pain Assessment in Impaired Cognition scale (PAIC15)’ [10]. In the following table, we provide more detailed information on the 12 eligible observational pain assessment tools from which the items for the PAIC15 were derived from as well as the PAIC15 itself [10].

SUPPLEMENTARY REFERENCES

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road map to improve pain assessment in people with impaired cognition: the development
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dementia. *Z Neuropsychol* **23**, 237-246.

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management of persistent pain in older persons. *J Am Geriatr Soc* **50**, S205-S224.

[10] Kunz M, de Waal MWM, Achterberg WP, Gimenez-Llort L, Lobbezoo F, Sampson EL,
van Dalen-Kok AH, Defrin R, Invitto S, Konstantinovic L, Oosterman J, Petrini L, van
der Stehen JT, Strand L-I, de Tommaso M, Zwakhalen S, Husebo B, Lauterbach S (2020)
The Pain Assessment in Impaired Cognition scale (PAIC15): A multidisciplinary and
international approach to develop and test a meta-tool for pain assessment in impaired cognition, especially dementia. *Eur J Pain* **24**, 192-208.

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[12] Kovach CR, Noonan PE, Griffie J, Muchka S, Weissman DE (2002) The Assessment of Discomfort in Dementia Protocol. *Pain Manag Nurs* **3**, 16-27.

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

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[17] Husebo BS, Strand LI, Moe-Nilssen R, Husebo SB, Ljunggren AE (2010) Pain in older persons with severe dementia. Psychometric properties of the Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID-2) Pain Scale in a clinical setting. *Scand J Caring Sci* **24**, 380-391.

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Supplementary Table 1. Observational pain assessment tools for advanced dementia (i.e., elderly individuals with cognitive impairments and limited capacity to communicate, listed in first column by name of first author). The second to fifth column lists considered behavior types (as reported in the respective assessment tools), scoring characteristics, interpretation, and usability. For detailed discussions regarding psychometric properties of the tools reported, we refer the interested reader to the seminal reviews provided by Lichtner et al. [1] and Zwakhalen et al. [2, 3]. To facilitate reading, full references of all assessment instruments are provided in the table below as well as in the Supplementary reference list.

| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|-------------------------------------------------------------|---------------------------|-------------------------------------------|----------------|----------|
| **Abbey pain scale** [11] Abbey J, Piller N, De Bellis A, Esterman A, Parker D, Giles L, Lowcay B (2004) The Abbey pain scale: A 1-minute numerical indicator for people with end-stage dementia. *Int J Palliat Nurs* **10**, 6-13. Australia | Six types of pain behavior (1 item each): 1) vocalization (e.g., whimpering, groaning, crying), 2) facial expression (e.g., looking tense, frowning, grimacing, looking frightened), 3) change in body language (e.g., fidgeting, rocking, guarding part of body, withdrawn), 4) behavioral change (e.g., increased confusion, refusing to eat, alteration in usual patterns), 5) physiological change (e.g., temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor), 6) physical change (skin tears, pressure areas, arthritis, contractures, previous injuries) | 6 items / Total score ranges from 0-18 / 4-point scale per item for behavior presence and intensity (0 = absent, 1 = mild, 2 = moderate, 3 = severe) / Scoring should be performed upon observing the patient during movement | *Pain intensity:* 0-2 = no pain, 3-7 = mild pain, 8-13 = moderate pain, 14-18 = severe pain; *Pain type:* acute, chronic, acute on chronic; Provides information regarding pain intensity and type, but neither regarding pain location nor frequency | Brief assessment scale; Easy to use; *Suggested use:* a) by health care professionals (e.g., registered nurses, facility staff); b) in acute and long-term care facilities; c) should be used across different situations: (i) during patients’ movement; (ii) one hour after interventions; (iii) hourly until patient scores mild pain (then every 4 hours for 24 hours, while treating pain if necessary) Taps all six common pain behaviors identified by the AGS *Potential limitations:* a) does not differentiate between pain and distress (therefore, the authors emphasize that it is
| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|-------------------------------------------------------------|---------------------------|-------------------------------------------|----------------|----------|
| **ADD Protocol** (Assessment of Discomfort in Dementia Protocol) | Five behavioral symptoms (i.e., indicators of discomfort): 1) facial expressions (7 examples), 2) mood (5 examples), 3) body language (8 examples), 4) voice (9 examples), 5) behavior (13 examples) optional: 6) other | Number of items and total score: not applicable No scoring, but behavioral symptoms that apply should be circled; If ‘Basic Need Interventions’ do not relieve behavioral symptoms of discomfort, the remaining steps of the ADD Protocol should be taken: **Step 1**: assessment of physical symptoms (e.g., blood pressure, pulse, internal organs, extremities), **Step 2**: review of patient’s current and past pain history, **Step 3**: if symptoms persist after steps 1 + 2, assess affective needs (i.e., environmental press, pace activity/stimulation, meaningful human interaction) and **intervene** | According to the authors, the ADD protocol is **not** a typical pain assessment tool but rather an intervention enabling the professional to detect pain (and changes of observed pain behaviors); Provides information regarding presence / absence of behavioral, physiological, and affective pain indicators (and responsiveness to intervention), but not pain intensity, frequency or location | Interactive tool, integrating various assessment approaches; Requires extensive training and complex clinical decisions; **Suggested use:** a) by trained nurses; b) in acute and long-term care facilities; c) for differential assessments as well as treatment plans (for physical pain and affective discomfort); Specifically provides: (i) common assessment parameters for physical assessment; (ii) nonpharmacological comfort interventions; (iii) guidelines for analgesic use; (iv) steps for an ADD acute protocol; |
| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|-------------------------------------------------------------|---------------------------|------------------------------------------|----------------|----------|
| CNPI (Checklist of Nonverbal Pain Indicators)               | Six types/clusters of pain behaviors (1 item each): 1) nonverbal vocalizations, 2) facial grimacing / wincing, 3) bracing, 4) rubbing / messaging, 5) restlessness, 6) vocal complaints | 6 items / Total score ranges from 0-6 / Binary yes/no responses (0 = behavior is not present, 1 = behavior is present) | Suggested cutoffs across the two situations (i.e., rest and movement, max. 6 points each) as follows: 1-2 = mild pain, 3-4 = moderate pain, 5-6 = severe pain; No further scoring information is provided; Provides information regarding pain intensity, but neither regarding pain location nor frequency | Brief instrument; Easy to use; |
| [13] Feldt KS (2000) The checklist of nonverbal pain indicators (CNPI). *Pain Manag Nurs* 1, 13-21. USA |  |  |  |  |
| USA | |  |  |  |
| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|------------------------------------------------------------|---------------------------|------------------------------------------|----------------|-----------|
| **DOLOPLUS 2**                                             | Three types of pain indicators: 1) somatic reactions (5 items), 2) psychomotor reactions (2 items), 3) psychosocial reactions (3 items) | 10 items / Total score ranges from 0-30 4-point rating scale per item (0 = behavior as usual, 1 = mild behavioral change, 2 = moderate behavioral change, 3 = severe behavioral change) | Suggested cutoff of 5 (beyond which the patient should receive pain management); However, the authors stress that older adults may experience pain if score is smaller than 5; Provides information regarding pain frequency (and potential impact on ADL and interpersonal interactions), but neither regarding pain intensity nor location | Potential limitations: a) tested on a convenience sample of hospitalized patients with hip fracture (with and without cognitive impairment); b) suggested cutoff scores (across the two situations) seem not validated; c) interpretation on one situation only (i.e., rest or movement) is unclear; d) rather poor psychometric qualities |

[14] Lefebvre-Chapiro S (2001) The DOLOPLUS 2 scale – evaluating pain in the elderly. *Eur J Palliative Care* 8, 191-194.

France
| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|-------------------------------------------------------------|---------------------------|------------------------------------------|----------------|----------|
| **DS-DAT** (Discomfort Scale – Dementia Alzheimer Type)     | Nine behavioral indicators reflecting discomfort: 1) noisy breathing, 2) negative vocalization, 3) lack of content facial expression, 4) sad facial expression, 5) frightened facial expression, 6) frown, 7) lack of relaxed body language, 8) tense body language, 9) fidgeting | 9 items / Total score ranges from 0 (no observed discomfort) – 27 (high level of observed discomfort) / Each item is scored independently (a) on a 4-point scale ranging from 0 (no observed discomfort) to 3 (high observed discomfort), and (b) on three dimensions: **frequency** (number of episodes during a five-minute period), **intensity** (low vs. high), **duration** (short <1 min. vs. long > 1 min) | The higher the score the higher the level of discomfort; No further scoring interpretation is provided by the authors; Provides information regarding intensity and frequency of patients’ discomfort (as well as duration), but not regarding potential pain location | Rather complex tool; Scoring requires extensive training; **Suggested use:** a) by registered nurses; b) in acute and long-term care facilities; c) in research settings (as it was developed for research); Provides rather useful descriptions of the behavioral indicators to be scored; Taps three of the six common pain behaviors identified by the AGS |
| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|-------------------------------------------------------------|----------------------------|------------------------------------------|----------------|----------|
| **EPCA-2 (Elderly Pain Caring Assessment 2)** [16] Morello R, Jean A, Alix M, Sellin-Peres D, Fermanian J (2007) A scale to measure pain in non-verbally communicating older patients: The EPCA-2: Study of its psychometric properties. *Pain* **133**, 87-98. France | Two dimensions of pain-related behaviors:  
**Before care/mobilization:**  
1) facial expressions,  
2) spontaneous posture adapted at rest,  
3) movements in and out of bed,  
4) interactions with other people (verbal and nonverbal)  
**During care/mobilization:**  
5) anxious reaction to intervention,  
6) reactions during mobilization,  
7) reactions when painful body parts are attended to,  
8) complaints during mobilization | 8 items  
Total score ranges from 0-32 /  
5-point rating scale per item (formulated as verbal statements in multiple choice format), ranging from 0 = (indicating no behavioral change) to 4 (indicating absolute behavioral change due to pain) | Beyond pain intensity, no further scoring interpretation is provided by the authors;  
Provides information regarding pain intensity, but neither on pain location nor frequency | Administration time about 15 minutes;  
Scoring requires some training and is rather time-consuming (however, according to the authors, administration is less time-consuming when caregivers are familiar with the patient);  
**Suggested use:**  
a) by health care professionals (according to the author ‘experienced nurses and caregivers’);  
b) in acute and long-term care facilities;  
c) seems to be sensitive to change in response to pain management  
Taps five of the six common pain behaviors identified by the AGS  
**Potential limitations:**  
a) unclear conceptual basis for ordering pain intensities (i.e., not clear whether and
| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|------------------------------------------------------------|--------------------------|------------------------------------------|----------------|-----------|
| **MOBID-2** (Mobilization-Observation-Behaviour-Intensity-Dementia) Pain Scale [17] Husebo BS, Strand LI, Moe-Nilssen R, Husebo SB, Ljunggren AE (2010) Pain in older persons with severe dementia. Psychometric properties of the Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID-2) Pain Scale in a clinical setting. *Scand J Caring Sci* 24, 380-391. Norway | Three types of pain behaviors: (i) pain noises (e.g., groaning, gasping), (ii) facial expressions (e.g., grimacing, frowning), (iii) defense (e.g., freezing, pushing) | 10 items | ‘Overall pain intensity’ is rated across all observed pain behaviors, thus yielding a total score between 0 and 10; No further scoring interpretation is provided by the authors; Provides information regarding pain intensity and location, but not regarding pain frequency | Brief instrument; Easy to use (but requires a certain amount of training); *Suggested use:* a) by nursing staff; b) in acute and long-term care settings; c) should be regarded as a prerequisite for pain management |
| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|-------------------------------------------------------------|---------------------------|------------------------------------------|----------------|-----------|
| **NOPPAIN (Non-Communicative Patient’s Pain Assessment Instrument)** | Four scoring components: (a) Observed pain in response to ADLs (e.g., bathing, dressing, transfer activities), (b) Six types of pain behaviors observed during ADLs: (1) pain words, (2) pain faces, (3) bracing, (4) pain noises, (5) rubbing (of body parts that hurt), (6) restlessness, (c) Indication of pain location (on the front and back site of a person’s drawing), (d) Global rating of pain intensity for that day during caregiving (pain thermometer) | 6 items; corresponding to (b) pain behaviors | No scoring interpretation is provided by the authors; Provides information regarding pain intensity and location, but not regarding pain frequency | c) no differentiation between acute and chronic pain; d) tested with a small sample of 28 nurses (in one nursing home); e) interpretation unclear; f) further psychometric testing is needed | Brief instrument (administration time less than 1 minute); Easy to use, requires little training; | Suggested use: a) by nursing assistants; b) in community settings (e.g., nursing homes); Taps all six common pain behaviors identified by the AGS | Potential limitations: a) tested in a small sample of nursing assistants (n=21), after an initial feasibility study comprising 37 patients; b) interpretation unclear; c) validity seems questionable because nurses’ training was based on a standardized patient approach; |
| USA | | | | | |
| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|-------------------------------------------------------------|---------------------------|------------------------------------------|----------------|----------|
| **PACSLAC** (Pain Assessment Checklist for Seniors with Limited Ability to Communicate) | Four types of pain behaviors: (1) facial expressions (13 Items), (2) activity/body movements (20 Items), (3) social/personality/mood indicators (12 items), (4) others, including physiological indicators, eating and sleeping changes, vocal behaviors (15 items) | 60 items | No scoring interpretation is provided; Total score ranges from 0-60 Subscale scores may also be calculated (the max. subscale scores corresponding to the max. number of items of each subscale) / Binary yes/no responses ((0 = behavior is not observed, 1 = behavior is observed) | Rather brief administration time (despite 60 items); Easy to use; Suggested use: a) by health care professionals (e.g., registered nurses, special care aides); b) in long-term care facilities; Taps all six common pain behaviors identified by the AGS Potential limitations: a) small sample size of 28 health care professionals for scale construction; and in validation studies caregivers reported on patients from memory); b) interpretation unclear; c) psychometric properties are promising (e.g., internal consistency), but further evaluation needed |
| **PADE** | Three-part tool: 1) physical component (facial expression, breathing pattern, posture) (13 items) | 24 items | No information on interpretation of assessment results provided; Total score: not applicable Different types of 4-point scoring scales: | Acceptable administration time (5-10 minutes); Rather comprehensive tool, requires some training on scoring procedures; |
| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|------------------------------------------------------------|---------------------------|------------------------------------------|----------------|----------|
| measure. *J Am Med Dir Assoc* 4, 1-8. USA                 | 2) global component (pain intensity evaluation) (1 items) 3) functional component (activities of daily living such as dressing and feeding oneself, transfer from wheelchair to bed) (10 items) | (i) Likert scale from 1 to 4 (items 1-12, 14, 22-24), (ii)Multiple-choice questions with scores ranging from 1 to 4; Items 1-14 should be scored after observing the patient for 5 minutes (however, items 8-10 not scorable in case patient is silent during observation period); Item 13 is multiple-choice Items 15-24 pertain to functional ADLs and should be scored according to chart documentations (of past 24 hours) | (and ADL functions), but neither on pain location nor frequency | **Suggested use:**  
 a) by health care professionals;  
 b) in acute and long-term care facilities;  
 Potential limitations:  
 a) rather complex scale, requiring different scoring methods;  
 b) some items need to be scored retrospectively;  
 c) interpretation unclear;  
 d) while some psychometric properties are promising (e.g., internal consistency), others are questionable (e.g., reliability of the ADL part of the scale) |
| PAINAD (Pain Assessment in Advanced Dementia) [21] Warden V, Hurley C, Volicer L (2003) Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. *J Am Med Dir Assoc* 4, 9-15. USA | Five types of pain behaviors (1 item each): 1) breathing, 2) negative vocalizations, 3) facial expression, 4) body language, 5) consolability | 5 items 3-point rating scale per item (0 = no pain, 1 = mild to moderate pain, 2 = severe pain); Before scoring, the patient should be observed for 2 to 5 minutes | Sum score between 1-3 = mild pain, 4-6 = moderate pain, 7-10 = severe pain; Provides information regarding pain intensity, but neither on pain location nor frequency | **Brief instrument:**  
 Easy to use, requires little training;  
 Provides comprehensive item definitions (i.e., descriptions for 3-point scoring scale);  
 **Suggested use:**  
 a) by health care professionals (i.e., registered nurses, clinical staff); |
| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|---|---|---|---|---|
| **PAINE (Pain Assessment in Noncommunicative Elderly)** [22] Cohen-Mansfield J (2006) Pain assessment in noncommunicative elderly patients – PAINE. *Clin J Pain* **22**, 569-575. USA | Three types of pain behaviors (total n=15): 1) specific repetitive behaviors motor (3 items), 2) specific repetitive behaviors vocal (4 items), 3) unusual behaviors (7 items), 4) activity (1 item) and 5) physical signs as clinical indicators (7 items; e.g., falls, trembling/shaking, swollen joints, changes in vital signs) | 22 items (15 pain behaviors and 7 physical signs) / Total score: not applicable / Two different scoring procedures: (a) 7-point frequency scale (items 1 to 15, rated for the past week); (b) binary yes/no responses (physical sign is present or not) The 7-point frequency scale scores are: 1 = never, 2 = less than once a week, 3 = once or twice a week, 4 = several times a week, 5 = once or twice a day, 6 = several times | No scoring information is provided by the author; With respect to pain behavior items only frequency is assessed (not intensity); Provides information regarding pain frequency (and physical signs), but neither regarding pain intensity nor location | Easy to use, requires little training; Suggested use: a) by direct professional caregivers (i.e., nursing staff, who should know the patient well); b) in community settings (e.g., nursing homes) and long-term care facilities; c) pain ratings over the past week; d) Comprises a comprehensive list of pain behaviors (and behavior clusters) identified by focus groups; |
| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|-------------------------------------------------------------|---------------------------|-------------------------------------------|----------------|----------|
| **PAIC15 (The Pain Assessment in Impaired Cognition scale/PAIC15)** | Three types of pain behaviors:  
(1) facial expression (5 items),  
(2) body movements (5 items),  
(3) vocalizations (5 items) | 15 items  
Total score ranges from 0-45  
4-(5-) point scale per item, requiring to evaluate whether pain-related behavior is present or not (0 = not at all, 1 = slight degree, 2 = moderate degree, 3 = great degree, x = not scorable) / Patient should be observed for at least 3 minutes and across various situations (at rest, during an ADL, during guided movement) / | No specific interpretation guidelines are provided; The authors state that future research is necessary to (i) empirically determine cutoff scores for different pain intensities, and to (ii) to evaluate the scale’s sensitivity to change (e.g., analgesic trials); Provides information regarding pain intensity, but neither on pain location nor frequency | Brief and reliable instrument; Easy to use, requires little training (a free and specifically developed E-training program is offered under https://paic15.com) Available in various languages, can be downloaded for free (https://paic15.com); |
| [10] Kunz M, de Waal MWM, Achterberg WP, Gimenez-Llort L, Lobbezoo F, Sampson EL, van Dalen-Kok AH, Debrin R, Invitto S, Konstantinovic L, Oosterman J, Petrini L, van der Stehen JT, Strand L-I, de Tommaso M, Zwakhalen S, Husebo B, Lauterbach S (2020) The Pain Assessment in Impaired Cognition scale (PAIC15): A multidisciplinary and international approach to develop and test a meta-tool for pain assessment in impaired cognition, especially dementia. *Eur J Pain* **24**, 192-208. | | | | |

**Potential limitations:**  
a) pain behavior items are evaluated regarding frequency only;  
b) interpretation unclear;  
c) psychometric properties promising (e.g., internal consistency; test-retest reliability), but further evaluation needed
| Name of pain assessment tool / Reference / Country of origin | Considered behavior types | Number of items / Scoring characteristics | Interpretation | Usability |
|------------------------------------------------------------|---------------------------|---------------------------------------------|----------------|----------|
|                                                            |                           | Taps three of the six common pain behaviors identified by the AGS |
|                                                            |                           | Potential limitations: |
|                                                            |                           | a) validation took place in several countries and different settings (making direct outcome comparisons difficult); |
|                                                            |                           | b) because many items showed floor effects at rest, the authors recommend that users should apply the PAIC15 during movement |

AGS, American Geriatrics Society; ADL, Activity of Daily Living
°The six common pain behaviors in cognitively impaired elderly according to the AGS Persistent Pain Guidelines [21] are: facial expressions, verbalizations/vocalizations, body movements, changes in interpersonal interactions, changes in activity patterns or routines, mental status change.