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Review Article

Tools to Measure Noncognitive Symptoms in Nursing Home Residents With Advanced Dementia: A Scoping Review

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A B S T R A C T

Objectives: Many instruments are validated for assessing agitation and other noncognitive symptoms in dementia (NCSDs) but their feasibility and psychometric properties in people with advanced dementia in nursing home settings is unclear. This scoping review aims to identify tools to measure (1) agitation and (2) other NCSDs and explore their usefulness in this population.
Design: Scoping review, including a systematic search of databases, trial registries, and gray literature sources.
Setting and Participants: Studies using formal tools for measuring agitation and other NCSDs in people with advanced dementia in nursing homes.
Methods: Searches were performed on published papers from January 1, 2000, to October 16, 2024, across multiple databases including MEDLINE, Embase, CINAHL, PsycINFO, Scopus, the Cochrane Database of Systematic Reviews and Central Register of Controlled Trials, TRIP, Google Scholar, and Google. The PRISMA-ScR checklist guided reporting.
Results: In total, 3634 unique titles and abstracts were identified. Of these, 455 underwent full-text screening resulting in 24 articles for data extraction. The most used assessment tools were the Neuropsychiatric Inventory (NPI; n = 13) and Cohen-Mansfield Agitation Inventory (CMAI; n = 13), with 6 studies using both. The Cornell Scale for Depression in Dementia (CSDD; n = 4) was also frequently reported. Agitation, apathy, and aberrant motor behaviors were frequently reported; psychotic symptoms were rare. Missing data were uncommon except in relation to sleep. Information on validity, accuracy, administration time, and responsiveness to change of the assessment tools was seldom provided. The CMAI scores reported to be "clinically significant" varied, as did symptom clusters (factors) derived from NPI data.
Conclusions and Implications: Measuring agitation and NCSDs seems feasible in the target population, using CMAI and NPI-Nursing Home version. However, the limited literature does not support robust sample size calculations for interventional studies. Future research should provide open-access datasets for enhanced utility and transparency of data collected from this vulnerable population.

Neuropsychiatric symptoms (NPS) of dementia, also referred to as behavioral and psychological symptoms of dementia (BPSD) and more recently as "noncognitive symptoms of dementia" (NCSDs), can be distressing for the person experiencing the symptoms and for those witnessing them.[1] Among these, agitation is cited as one of the most common neuropsychiatric symptoms experienced by people with dementia[2-4]; it can manifest as excessive motor activity and verbal or physical aggression[5] and can negatively impact the quality

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of life of nursing home residents and those who provide care for them.[2,6] NCSDs, which worsen as dementia severity increases,[7-9] often manifest as behavior change.[10] In advanced dementia, common NCSDs include agitation, delusions, hallucinations, anxiety, apathy, disinhibition, irritability, and aberrant motor behavior.[11]

Various scales and tools have been developed to measure agitation and other NCSDs. The Cohen-Mansfield Agitation Inventory (CMAI), originally developed for use in the nursing home setting, assesses 29 agitated behaviors.[12] These behaviors are not intended to be summed into a total score but rather examined individually or grouped using factor analysis.[12] The original CMAI manual describes 3 subtypes (factors): aggressive behavior (physical or verbal), physical nonaggressive behavior, and verbal agitation.[12] According to the tool's developer, it is acceptable to define study-specific criteria for meeting agitation thresholds based on a study's focus and population, or study-specific factor analysis, thereby analyzing specific behaviors of interest. However, the user manual suggests 3 threshold criteria: aggressive behavior occurring several times per week, or verbal agitation or physical nonaggressive behavior occurring at least once per day.[12] A short-form version of the CMAI (CMAI-SF), assessing 14 behaviors, also is available.[12]

The Neuropsychiatric Inventory (NPI) assesses 12 neuropsychiatric domains.[13] It has been used in more than 350 clinical trials and translated into 40 languages.[14] Several different versions exist including the NPI-Nursing Home version (NPI-NH), which was specifically developed for use in nursing home settings.[15] The NPI-NH includes 10 core domains, with 2 optional additional "neurovegetative" items—sleep and nighttime behaviors, appetite and eating changes—yielding a total of 12 items.[16] Unlike the CMAI, which measures frequency alone, the NPI-NH assesses both severity and frequency. These are multiplied to generate an item score, and the total NPI-NH score is the sum of all item scores (10 or 12, depending on inclusion of optional items). An additional "occupational disruptiveness" score, which reflects the impact on staff, is collected but not included in the total score.[16]

The rationale for this study is that agitation and other NCSDs may be less commonly expressed in advanced dementia, defined as Functional Assessment Staging Tool (FAST) level 6 (needing assistance with all personal care) or level 7 (limited speech; needing assistance to sit or take steps).[17] In this cohort, limited verbal skills and mobility may restrict the capacity to communicate and express symptoms. For example, CMAI items such as repetitive questioning, pacing, aimless wandering, hiding things, complaining, or negativism may be less observable. Similarly, NPI-NH domains such as delusions or euphoria or displaying aberrant motor behavior may be underrepresented. Furthermore, distinguishing apathy from psychomotor retardation or depression may be particularly challenging in individuals unable to articulate their emotional state.

This scoping review aimed to determine the most appropriate tools for measuring agitation and other NCSDs in the context of the *In-Touch* intervention, a cluster-randomized controlled trial across 7 European countries focusing on people with advanced dementia living in nursing homes.[18] Given that the use of appropriate, valid, and reliable tools is essential for accurately evaluating clinical trial outcomes, we sought to assess the use and feasibility of existing assessment instruments for this specific cohort and care setting. We anticipated that some NPSs may be less commonly expressed (or detectable) in advanced dementia due to limitations in verbal communication and mobility, and others more commonly expressed (like apathy), thus requiring an appropriately powered statistical sample to detect change.

This scoping review aimed to identify the tools currently used for measuring (1) agitation and (2) noncognitive symptoms in people with advanced dementia living in nursing homes, and to evaluate their usefulness in terms of feasibility, ease of use, data completeness, diagnostic accuracy, sensitivity to change, and other psychometric parameters.

Methods

The study was conducted using the Joanna Briggs Institute methodology for scoping reviews.[19] Reporting adhered to the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist[20] (Supplementary File 1). The review protocol was registered with Open Science Framework (https://osf.io/p7g86) and published with *BMJ Open* (https://doi.org/10.1136/bmjopen-2024–096540).

Search Strategy

Search terms were derived from the research question. Initial search strings were developed by the first reviewer (M.F.) and verified using the 2015 Peer Review of Electronic Search Strategies (PRESS) checklist.[21] A preliminary search of MEDLINE and CINAHL was conducted to identify relevant keywords (title and abstract) and subject headings/MeSH terms. These informed the full search strategy.

The following databases and registers were searched on October 16, 2024: MEDLINE, Embase, CINAHL, PsycINFO, Scopus, Cochrane Database of Systematic Reviews, and Cochrane Central Register of Controlled Trials. The MEDLINE search strategy is provided in Supplementary File 2. Gray literature sources included Google, Google Scholar, and TRIP. Reference lists of included articles and relevant systematic reviews were hand-searched for additional sources. In some cases, authors of primary studies were contacted for further information.

Study Selection

Inclusion criteria were defined using the Population-Concept-Context framework.[19] Inclusion criteria were as follows: adults with advanced dementia, defined as physical and cognitive disability due to a neurodegenerative disease and corresponding to a score of 6 or 7 using either the FAST or the Global Deterioration Scale (GDS), or an equivalent marker of advanced dementia as judged by the review team; studies using tools/instruments to measure agitation or other NCSDs through directly observed, or staff-reported outcome measures, with a focus on validity, sensitivity to change, ease, and completeness of data collection; nursing home settings, residential care facilities, long-term care settings providing care to older or general adult populations (including specific dementia units); randomized controlled trials (RCTs), non-RCTs, quasi-experimental before and after studies, prospective cohort studies, observational studies, retrospective cohort studies, case-control studies; and peer-reviewed articles published since January 1, 2000. This time period was chosen to balance comprehensiveness with feasibility, as preliminary searches indicated this timeframe would capture most relevant studies. Exclusion criteria were as follows: studies on pain-related behavior; nonresidential settings, acute-care hospitals, specialized units for people with intellectual disability or acquired brain injury, assisted living facilities; and literature reviews, books, book chapters, editorials, consensus statements, study protocols, discussion papers, and commentaries. Calibration of the screening process was conducted before title and abstract review (25 articles dual-screened by 2 reviewers: M.M.F. and L.A.O.). Discrepancies were discussed and resolved, with appropriate modifications made to the eligibility criteria before commencing full-title and abstract screening. A similar calibration process was conducted before commencing full-text screening, with 25 articles reviewed by 3 reviewers (M.M.F., L.A.O., and L.D.K.). Disagreements were resolved by a

fourth, senior reviewer (S.T.). Rayyan, Zotero (7.0.7), and Excel (Microsoft 365 Version 2503) were used to manage the data.

Data Charting

A data-charting table was developed in Excel. Extracted data included author, country, year, study purpose, population and sample size, dementia stage, methodology, intervention type (if relevant), key findings, outcome measurement tool(s) used, incidence and prevalence of NPS, administration time and administrator, ease of use, completeness of data, subscales, cutoff criteria for agitation and other behaviors, accuracy, sensitivity to change, reliability, and validity.

Data extraction was completed, independently, by 2 reviewers (M.M.F. and L.A.O.). Discrepancies were resolved though consensus or consultation with a third reviewer (S.T.), as necessary. A single reviewer (M.M.F. or L.A.O.) performed quality appraisal of included studies (Supplementary File 2) using the Hawker framework.[22] This appraisal was conducted to provide a concise assessment of study quality and did not influence data inclusion or synthesis.

Results

A total of 3634 citations were identified, of which 24 studies met the eligibility criteria (Figure 1). Source analysis revealed that 21 studies were identified through either MEDLINE or Embase, 1 through hand-searching of systematic reviews (Supplementary File 2), and 2 via PsycINFO (n = 1) and Cochrane Trials and TRIP (n = 1). Many of the excluded studies focused on quality of life or pain.

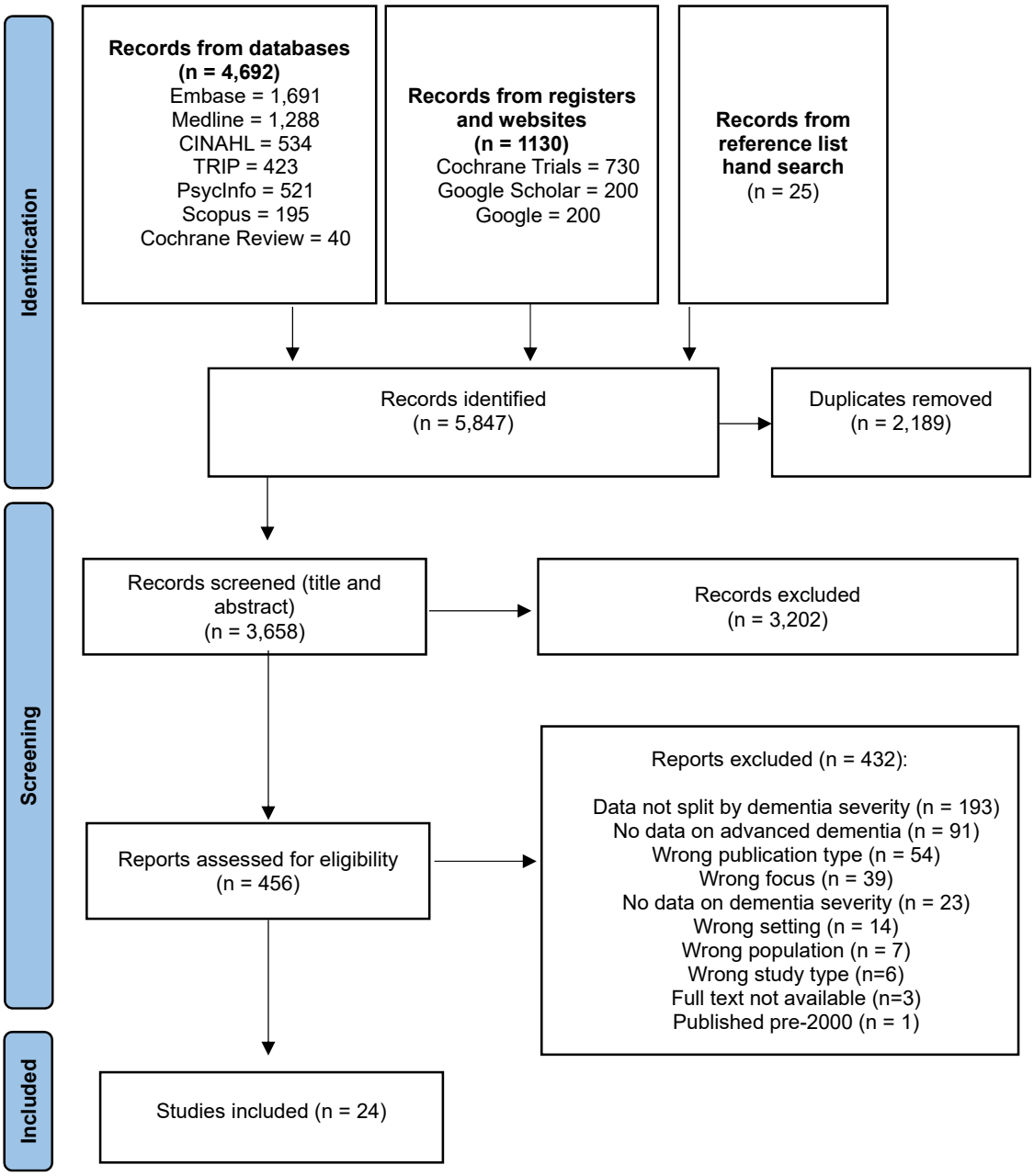


Fig. 1. PRISMA flow diagram.

Study Characteristics

Included studies were published between 2000 and 2024 and originated from Australia, Canada, Japan, France, Germany, Ireland, the Netherlands, Norway, Spain, United Kingdom, and United States. Seven were intervention studies, and sample sizes ranged from 31 to 350,850. Most studies were of moderate quality, with a modified Hawker framework average score of 21 (range: 10–24) (Supplementary File 2).

Advanced dementia was defined in the review protocol as a score of 6 or 7 on the FAST or the GDS, with allowance for equivalent markers of advanced dementia. Although 10 studies used FAST or GDS, 11 used the Clinical Dementia Rating (CDR 3) or the Mini Mental State Examination (MMSE <10). Substantial agreement between MMSE and CDR for severe dementia has been previously reported.[23] Some studies used the Cognitive Functioning Scale, Australian Aged Care Funding Instrument, and Système de Mesure de l'Autonomie Fonctionnelle (Iso-SMAF).

Range of Instruments Used

Table 1 summarizes the 24 included studies. The CMAI was used in 13 studies, 12 using the full-version CMAI (range: 29–203)[24-35] and 1 using the short-form CMAI-SF (range: 14–70).[36] Four studies used the Dutch translation of the full CMAI,[24,26,29,33] 1 used the Spanish version (range: 30–210),[28] and others did not report using a translated version.

For measuring NPS, 13 studies used a version of the NPI. Eight used the full 12 items of the NPI-NH (range: 0–144) in English, German, Spanish, or Chinese.[28,29,33,39,40,42,43,46] The other 5 studies used 9 or 10 of the NPI-NH domains,[3,24] all or part of the original NPI,[35,45] and the NPI-Q.[36]

As shown in Figure 2B, use of multiple instruments was common, with 6 studies using both the CMAI and the NPI.[24,28,29,33,35,36] The Cornell Scale for Depression in Dementia (CSDD) was used in 5 studies, typically alongside other tools.[32,37,38,42,44] Several other instruments were used in a single study only: Rating Anxiety in Dementia scale,[38] Dementia Mood Assessment Scale,[31] Minimum Data Set Agitated and Reactive Behaviors Scale,[41] and Gestalt scale for severe depression[32] (in conjunction with others).

CMAI

All 13 CMAI studies (Table 2) reported prevalence data. Three intervention studies presented pre- and postintervention results for both control and intervention groups.[28,32,35] Five studies reported the proportion of participants with "clinically significant" agitation[25-27,30,34] and 4 studies reported mean CMAI total scores.[25,28,33,34] Only Koopmans et al[33] gave the prevalence for each CMAI item, whereas 2 others reported prevalence by subscale.[7,31] Three studies provided data on the influence of dementia severity (GDS 6, 7 vs GDS 4, 5) on agitation.[7,27,29] Details on the CMAI administration, reported in 7 studies, indicated the tool was typically completed either by the study researcher or directly by nursing home staff (carer or nurse). Marston et al[30] reported 34% data incompleteness at 16 months due to participant death, whereas Mulders et al[29] excluded 2% of residents from their original sample due to incomplete CMAI or NPI data. Froggatt et al[36] reported high completion rates for the CMAI-SF. No study reported administration time or incidence rates for new occurrence of agitation.

Five studies grouped data into CMAI subscales.[7,29,31,35,36] As shown in Figure 2B, common symptom clusters were physically aggressive, physically nonaggressive, and verbally agitated,[7,29,31] whereas others used some of these in combination with verbal aggressive and verbal nonaggressive behavior,[35] hiding and hoarding,[31] and aggression.[36]

Reported total scores on the CMAI long-form (maximum score: 203) of >39,[30,34] ≥44,[33] and ≥46[30] were considered to indicate clinically significant agitation, with Wilchesky et al[25] defining "severe agitation" as a score >45. No study reported sensitivity or specificity data for the CMAI. Regarding sensitivity to change, the CMAI-SF (n = 32) detected score changes at 4 weeks.[36] Ballard et al[35] took a 30% improvement score in agitation to indicate a positive outcome, with 60% of the intervention group (n = 35 intervention; n = 71 total group) achieving this change.

Two studies highlighted the potential for observer bias, stemming from retrospective observations[33] or nursing home staff involvement in rating agitation levels.[30] One study noted the CMAI had not been specifically validated for people with young-onset dementia.[29]

NPI

For the NPI (Table 3), 4 studies reported scores across all 12 NPI-NH domains.[33,40,42,43] Selbaek et al used the original 10-item NPI,[3] omitting sleep and appetite domains as they "primarily capture vegetative symptoms" [p 82[3]], whereas Zuidema et al[7] omitted sleep, appetite, and euphoria. Two studies reported scores for apathy only.[45,46] Froggatt et al[36] itemized scores for the NPI-Questionnaire (NPI-Q). Ito et al[39] reported mean baseline scores for NPI-NH items, whereas Mulders et al[29] and Selbaek et al[3] provided relative data only. Ballard et al[35] used only the NPI irritability and aberrant motor behavior scores and also only recorded changes in median levels. Sánchez et al[28] reported pre- and postintervention mean NPI total scores.

Overall, agitation, apathy, and aberrant motor behavior were the most frequently reported symptoms, whereas euphoria, hallucinations, and delusions were uncommon.

Data were generally collected by nurses or other nursing home staff[3,7,33,36,40,42] or via researcher-led interviews with staff.[33,40,42,45,46] No studies reported data on ease of use, administration time, incidence rates, sensitivity, specificity, or responsiveness to change.

Two studies noted incomplete data due to staff being unable to rate certain items,[36,46] with one attributing this to work shift patterns affecting the ability to observe symptoms such as sleep disturbances.[36] For Wu et al,[46] data completion rates ranged from 79% to 100% across subscales/domains.

Four studies described NPI-NH subscales, although constituent items varied: psychosis, aggression, detachment/disinhibition, and eating and sleeping[40]; psychosis and agitation[29]; psychosis, agitation, restless behavior, and mood[43]; and psychosis, agitation, and affective symptoms.[3] Most studies defined clinically relevant symptoms as individual item scores (ie, frequency × severity) or mean cluster scores ≥4.[3,7,29,33,39,40,45]

Three studies commented on reliability, with 1 noting the risk of observer bias,[33] another confirming a high NPI-NH interrater reliability score (Spearman rank correlation coefficient between 2 raters of 0.996 in a pilot study; n = 10 residents[40]), and a third (n = 256) reporting Cronbach's alpha coefficients of 0.7 (agitation and restless behavior), 0.5 (mood), and 0.4 (psychosis).[43]

Regarding validity, Reuther et al[43] found that NPI-NH validity can be increased by using subscales such as agitation and restless behavior. Another study noted the NPI-NH was not specifically validated for young-onset dementia.[29] A third study found that their factor structure for aggression, psychosis, and sleep/appetite aligned with previous studies, but that their fourth (apathy, depression, and disinhibition) was less commonly reported.[40]

Table 1
All 24 Studies Measuring Agitation or Other NCSDs for People With Advanced Dementia in Nursing Homes

Author and Year	Title	Study Aim	Sample Size	Study Design	Key Findings	Outcome Measurement Tools
Ballard 2002[35]	Aromatherapy as a safe and effective treatment for the management of agitation in severe dementia: the results of a double-blind, placebo-controlled trial with Melissa	To determine the value of aromatherapy with essential oil of *Melissa officinalis* (lemon balm) for agitation in people with sev. dem.	N = 72 n = 36 int. n = 36 control	RCT, double-blind	Aromatherapy with essential balm oil is a safe and effective treatment for clinically significant agitation in people with sev. dem.	CMAI full (29–203 range) NPI part (0–24 range)
Buylova 2020[34]	Health care utilization and monetary costs associated with agitation in UK care home residents with advanced dementia	To calculate the monetary costs associated with agitation in advanced dementia patients in UK NHs	n = 79 n = 13 NHs	Prospective cohort study	Annual care costs varied from £23k with no agitation symptoms (CMAI agitation score 0–10) to £45k at the most severe level (CMAI agitation score >100)	CMAI full (29–203 range)
Erdal 2018[37]	Efficacy and Safety of Analgesic Treatment for Depression in People with Advanced Dementia: Randomised, Multicentre, Double-Blind, Placebo-Controlled Trial (DEP.PAIN.DEM)	To assess the efficacy and safety of analgesic treatment for depression in NH patients with advanced dementia and clinically significant depressive symptoms	N = 162, of whom n = 92 sev. dem. n = 47 NHs	RCT, double-blind	Analgesic treatment did not reduce depression, whereas placebo appeared to improve depressive symptoms significantly by comparison	CSDD (0–38 range)
Froggatt 2020[36]	A group int. to improve QoL for people with advanced dementia living in care homes: the Namaste feasibility cluster RCT	To establish the feasibility and acceptability to staff and family of conducting Namaste Care int. for people with advanced dementia in NHs	N = 32 (n = 18 int.; n = 14 control)	Cluster RCT	Staff and informal carers reported increased social engagement and greater calm for the person with dementia	NPI-Q CMAI-SF
Goyal 2021[38]	Effects of the Sonas program on anxiety and depression in NH residents with dementia	To examine the effects of the Sonas program on anxiety and depression in NH residents with dementia	N = 120 with n = 63 sev. dem.	RCT	The Sonas program had no effect on severity of anxiety, but depressive symptoms were reduced in PWD	Rating Anxiety in Dementia (RAID) scale (0–54 range) CSDD (0–38 range)
Ito 2020[39]	The Negative Impact of Psychotropic Drug Use on Quality of Life in NH Patients at Different Stages of Dementia: Cross-Sectional Analyses from the COSMOS Trial	To investigate the cross-sectional association between number of psychotropic drug use and QoL in NH patients at different stages of dementia	N = 431 with n = 228 sev. dem.	Cluster RCT, single blinded	Psychotropic drugs might pose a threat to QoL in NH patients at all stages of dementia	NPI-NH full (0–144)
Koopmans 2009[33]	Neuropsychiatric symptoms and QoL in patients in the final phase of dementia	To assess neuropsychiatric symptoms and QoL in a group of patients in the final phase of dementia	N = 216 considered with n = 39 eligible	Cross-sectional cohort study	Patients showed high prevalence of apathy, agitation, and behaviors that were mainly observed during morning care	CMAI Dutch version (29–203) NPI-NH full (0–144)
Magai 2000[32]	A controlled clinical trial of sertraline in the treatment of depression in nursing home patients with late-stage Alzheimer's disease	To evaluate the efficacy of the antidepressant medication sertraline	n = 31	RCT, double-blind	Sertraline had no significant benefits over placebo	CMAI full (29–203); CSDD (0–38); Gestalt Scale
Majic 2012[31]	Correlates of agitation and depression in NH residents with dementia	To investigate the relationship between dementia severity, age, gender, and prescription of psychotropics, and syndromes of agitation and depression in NH residents with dementia	N = 304 with n = 180 sev. dem. n = 18 NHs	Prospective cohort study	Dementia severity predicts agitation and depression; in advanced stages of dementia, depression in some patients might underlie aggressive behavior	CMAI full (29–203 range) DMAS (Dementia Mood Assessment Scale)

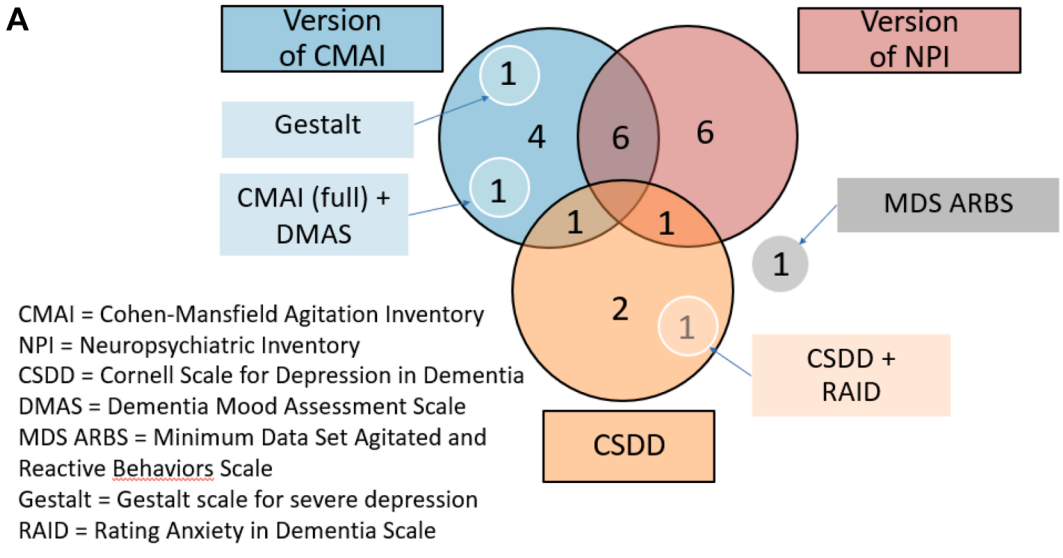
(*continued on next page*)

Table 1 (*continued*)

Author and Year	Title	Study Aim	Sample Size	Study Design	Key Findings	Outcome Measurement Tools
Makimoto 2019[40]	Prevalence of BPSD in cognitively impaired elderly residents of LTCF in East Asia: a cross-sectional study	To compare the prevalence of BPSD in cognitively impaired elderly residents of LTCF in East Asia and explore the factors associated with these patterns	n = 662	Cross-sectional study	For CDR 3 group, prevalence of some clinically significant BPSD was high even among study sites with low median total NPI-NH scores; dementia severity appears to be a major factor in prevalence of clinically significant apathy	NPI-NH full (0–144 range)
Marston 2020[30]	Becoming or Remaining Agitated: The Course of Agitation in People with Dementia Living in Care Homes. The English Longitudinal Managing Agitation and Raising Quality of Life (MARQUE) Study	To investigate agitation's course at 5 time points in people with dementia in English care homes.	N = 1424 with n = 535 with sev. dem. n = 16 NHs	Cohort study	88% of those with no agitation at baseline remained free of clinically significant agitation at all follow-ups (over 16 months); 70% of those exhibiting clinically significant agitation at baseline had clinically significant agitation at some follow-ups	CMAI full (29–203 range)
McCreedy 2019[41]	The Minimum Data Set Agitated and Reactive Behavior Scale: Measuring Behaviors in Nursing Home Residents with Dementia	To report the internal consistency and construct validity of the Agitated and Reactive Behavior Scale	N = 1,255,221 with n = 350,850 (27%) severe cognitive impairment	Cross-sectional study	Nationally available MDS data may significantly underestimate the prevalence of agitated and aggressive behaviors among NH residents with dementia	The MDS Agitated and Reactive Behaviors Scale (ARBS, 0–12 range)
Mulders 2016[29]	Prevalence and Correlates of Neuropsychiatric Symptoms in Nursing Home Patients With YOD: The BEYOnD Study	To explore the prevalence and correlates of NPS in nursing home residents with YOD	N = 230 with n = 131 sev. dem.	Cross-sectional cohort study	NPS prevalence was high, associated with dementia type, severity, and disease awareness. Agitation and apathy are most important symptoms in YOD	NPI-NH full (0–144 range) CMAI (29–203 range) Dutch version
Prado-Jean 2010[42]	Specific psychological and behavioral symptoms of depression in patients with dementia	To characterize the psychological and behavioral manifestations of depression in patients with dementia	N = 319 with n = 81 sev. dem.	Cross-sectional study	All BPSD were significantly ($P <$ .0001) more prevalent among depressed patients	CSDD (0–38) NPI full (0–144)
Reuther 2016[43]	Construct validity and internal consistency of the NPI-NH in German NHs	To evaluate the factor structure and internal consistency of the NPI-NH for 2 different stages of dementia severity in a large German NH population	N = 784 with n = 256 sev. dem. n = 40 NHs	Principal component analysis	Three factors (agitation and restless behavior, psychosis, and mood) appear to be robust over the various stages of dementia severity. Results support the hypothesis that NPI-NH can be subdivided into multiple domains.	NPI-NH full (0–144 range) German version
Sánchez 2016[28]	Multisensory Stimulation as an Intervention Strategy for Elderly Patients with Severe Dementia: A Pilot Randomized Controlled Trial	To compare the effect of a multisensory stimulation environment and one-to-one activity sessions in the symptomatology of older people with sev. dem.	N = 32 n = 11 int. 1 n = 11 int. 2 n = 10 control	Pilot RCT	Multisensory stimulation environment may have better effects on NPS and dementia severity compared to 1:1 activity sessions in people with sev. dem.	Spanish versions of CMAI (30–210) NPI (0–144) CSDD (0–38)
Selbaek 2014[3]	The course of neuropsychiatric symptoms in NH patients with dementia over a 53-mo follow-up period	To assess the long-term course of NPS in NH patients with dementia (53-mo follow-up)	N = 931 with n = 391 (42%) sev. dem. n = 26 NHs	Prospective longitudinal cohort study	More sev. dem. was associated with more severe agitation, psychosis, and apathy, but not more severe affective symptoms.	NPI-NH 10 (0–120)
Snowdon 2011[44]	Australia's use of the Cornell scale to screen for depression in NHs	To examine the utility of the CSDD, following its introduction as a routine measure in NHs	N = 223 with n = 118 sev. dem.	Cohort study	Meaningful CSDD ratings were not available for a substantial proportion of the residents	CSDD (0–38 range)

Sommerlad 2022[45]	Apathy in UK Care Home Residents with Dementia: Longitudinal Course and Determinants	To describe the longitudinal course of apathy in dementia, and identify sociodemographic and disease-related factors	N = 1419 with n = 530 sev. dem.	Prospective cohort study	Apathy increased over time and was associated with having more sev. dem.	NPI apathy subscale (0–12)
Veldwijk-Rouwenhorst 2017[27]	Nursing Home Residents with Dementia and Very Frequent Agitation: A Particular Group	To calculate the 2-wk prevalence and correlates of very frequent agitation in NH residents with dementia (using combined data of 4 studies)	N = 2074, with n = 1595 sev. dem. n = 26 NHs	Cross-sectional study	Study showed a 2-wk prevalence of very frequent agitation of 7.4%	CMAI full (29–203 range)
Veldwijk-Rouwenhorst 2021[26]	Very frequent physical aggression and vocalizations in NH residents with dementia	To calculate the 2-wk prevalence and correlates of very frequent physical aggression and vocalizations in NH residents with dementia	N = 1174; n = 1008 with sev. dem.	Multilevel modelling (mixed model)	Study showed a 2-wk prevalence of 2.2% (95% CI, 1.63–2.89) of very frequent physical aggression and 11.5% of very frequent vocalizations (95% CI, 10.23–12.98)	CMAI- (29–203 range) Dutch version
Wilchesky 2018[25]	The OptimaMed int. to reduce inappropriate medications in NH residents with sev. dem.: results from a quasi-experimental feasibility pilot study	To test the feasibility of an interdisciplinary knowledge exchange int. and to measure its impact on medication use, pain, and agitation levels	n = 44	Quasi-experimental (pre-post) study	Knowledge exchange resulted in an overall reduction in medication in NH residents with sev. dem. Agitation levels were unaffected; no clinically significant changes in pain levels	CMAI full (29–203 range)
Wu 2009[46]	A pilot study of differences in BPSD in NH residents in Sydney and Shanghai	To increase understanding of the effects of culture on BPSD by comparing rates of BPSD in NH residents across 3 residential facilities	N = 149 with n = 130 sev. dem.	Pilot cohort study	The prevalence of BPSD does not differ among nursing home populations of different cultural backgrounds	NPI-NH full (0–144 range) Chinese version
Zuidema 2009[24]	Predictors of neuropsychiatric symptoms in NH patients: influence of gender and dementia severity	To assess the influence of dementia severity and gender on NPSs in NH patients with dementia	N = 1319 with n = 1047 sev. dem.	Cross-sectional cohort study	NPSs were associated with dementia severity: most symptoms in (moderately) severe cognitive decline. Only physical aggression, anxiety, and apathy were more common in very severe cognitive decline.	NPI-NH-9 (0–108 range) CMAI (29–203 range) Dutch version

BPSD, behavioral and psychological symptoms of dementia; int., intervention; LTCF, long-term care facility; MDS, minimum data set; NCSD, noncognitive symptoms in dementia; NH, nursing home; sev. dem., severe dementia; YOD, young-onset dementia.



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	Zuidema 2009	Ballard 2002	Majic 2012	Mulders 2016	Froggatt 2020
Physically aggressive	●	●	●	●	
Physically non-aggressive*	●	●	●	●	●
Verbally agitated*	●		●	●	●
Verbal aggression		●			
Verbal non-aggression		●			
Hiding & hoarding			●		
Aggression*					●

* **Bolded headings** reflect the CMAI manual symptom clusters

Fig. 2. (A) Venn diagram showing the frequency and overlap in tool use across the 24 included studies. The CSDD is a 19-item instrument for detecting depression in people with dementia.[32] The Dementia Mood Assessment Scale is a 24-intem instrument for assessing depression in people with dementia.[31] The Minimum Data Set Agitated and Reactive Behavior Scale is a composite measure of physical behavioral symptoms directed at other people, verbal behavioral symptoms directed at other people, other behavioral symptoms not directed at other people, and rejection of care.[41] The Gestalt scale for severe depression is a 5-item scale for detecting depression in people with severe dementia.[32] The Rating Anxiety in Dementia Scale comprises 18-20 items.[38] (B) CMAI subscales: common symptom groupings of agitated behaviors.

Discussion

This scoping review aimed to identify instruments used to measure agitation and other noncognitive symptoms of dementia in individuals with advanced dementia residing in nursing homes, and where available, data on relative item frequency and tool usefulness (feasibility, ease of use, data completeness, diagnostic accuracy, sensitivity to change and other psychometric parameters).

Although a recent systematic review examined the diagnostic accuracy of tools for detecting agitation and aggression in people with dementia,[47] to the best of our knowledge, this is the first scoping review focused specifically on tools measuring agitation and other NCSDs for people with advanced dementia living in nursing homes.

Overall, the findings suggest it is feasible to measure NPS in nursing home residents with advanced dementia using the long-from CMAI, a version of the NPI, or both. These tools appear to be appropriate and reliable tools for measuring agitation and other NCSDs, with few missing data. Although information on validity, accuracy, administration time, and responsiveness to change was seldom reported, the tools demonstrated good psychometric properties when this information was available. We anticipated that some NPSs may be less commonly expressed in advanced dementia, thus requiring an appropriately powered statistical sample to detect change. Consistent with this, several studies reported very low scores for some symptoms, including psychosis (delusions and hallucinations)[7,33] and euphoria,[33,40] which brings into question the statistical power to detect meaningful change in these items in an advanced dementia cohort as an RCT intervention outcome measure. Conversely, the finding that agitation,[42,43] apathy,[7,33,40,43] and aberrant motor behaviors[7,40,42,43,46] were more frequently reported suggests that prioritizing outcome measures that effectively assess these symptoms might have value in an RCT. However, the limited published data makes it difficult to calculate an appropriate sample size for interventional studies for this cohort.

Table 2
Studies Using CMAI as a Measurement Tool

Author and Year	CMAI used and Variables (Subscales)	Advanced Dementia Scores	Frequency of Symptoms: Prevalence	Admin Time and Administrator	Ease of Use and Completeness of Data	Psychometric Properties	Cutoff Used for Agitation
Ballard 2002	CMAI full (29−203 range) Subscales: physically aggressive; physically nonaggressive; verbally aggressive; verbally nonaggressive	CDR 3	CMAI mean scores: Intervention T0 = 68.3 ± 15.3; T4 = 45.2 ± 10.4 Control T0 = 60.6 ± 16.6; T4 = 53.3 ± 17.6 CMAI median scores: Intervention T0 = 65, IQR = 58.3−83.8; T4 = 44, IQR = 37.0−53.0 Control T0 = 58.0, IQR = 48.3−67.5; T4 = 50.0, IQR = 43.3−63.3 T4 = 4 weeks	No data	No data	No data on sensitivity, specificity, responsiveness to change, reliability or validity	"To be clinically significant, agitation had to occur on at least a daily basis and cause moderate or severe management problems for care staff (as defined on the NPI)" (p 554)
Buylova 2020	CMAI full (29−203 range) Subscales: N/A	FAST 6e and above	Throughout study: mean CMAI = 45.5 (SD 16.5, range 7−107). 55% had CMAI score >39, 45% had CMAI ≤39 CMAI scores breakdown: 0.69% = CMAI 0−10; 21.67% = CMAI 21−30; 21.67% = CMAI 21−30; 24.09% = CMAI 31−40; 19.75% = CMAI41−50; 16.12% = CMAI 51−60; 8.49% = CMAI 61−70; 5.72% = CMAI 71−80; 3.46% = CMAI 81−107 CMAI 39+: Study entry = 44/79 people (56%) Final visit (if alive, n = 49) = 28 people (57%) Final visit (if died, n = 28) = 14 people (50%) Final visit (all PWD, n = 77, no data for 2 people) = 42 people (55%)	CMAI assessed by researcher or care home staff	No data	No data on sensitivity, specificity, responsiveness to change, reliability or validity	Score >39 considered clinically significant agitation (citing Livingston et al[9]) No agitation 0−10; most severe agitation >100
Froggatt 2020	CMAI-SF (14−70 range) Subscales: aggressive; physically nonaggressive; verbally agitated	FAST 6 and 7	[Results also split for intervention (n = 18) and control (n = 14); overall for n = 32 recorded here] CMAI-SF total overall, mean (SD) T0 = 23.3 (8.7); T1 = 22.2 (7.0); T2 = 21.6 (7.2) CMAI aggressive behaviors overall, mean (SD) T0 = 7.6 (3.7); T1 = 7.5 (3.3); T2 = 7.2 (3.3) CMAI physically nonaggressive behaviors overall, mean (SD) T0 = 7.5 (3.5); T1 = 7.0 (2.4); T2 = 7.6 (4.0) CMAI verbally agitated behaviors overall, mean (SD) T0 = 8.2 (3.0); T1 = 7.6 (2.9); T2 = 7.0 (2.7) T1 = 2 wk; T2 = 4 wk	Nursing home staff	Incomplete CMAI = 0/32 at baseline, 0/32 at wk 2, 2/32 at wk 4	Responsiveness to change: CMAI-SF "was shown to be useful in this population," although data were not analyzed for effect, it showed a change in scores at 4 wk No data on sensitivity, specificity, reliability or validity	No data

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Table 2 (*continued*)

Author and Year	CMAI used and Variables (Subscales)	Advanced Dementia Scores	Frequency of Symptoms: Prevalence	Admin Time and Administrator	Ease of Use and Completeness of Data	Psychometric Properties	Cutoff Used for Agitation
Koopmans 2009	CMAI (29−203 range) Dutch version Subscales: N/A	MMSE = 0, FAST 7a	CMAI prevalence rates (n = 39) Mean CMAI Total score = 37 (range 29−63) Making strange noises (44%), grabbing (33%), performing repetitious mannerisms (26%), scratching (21%), general restlessness (18%), spitting (15%), hitting (13%), cursing or verbal aggression (10%), screaming (10%), pushing (8%), biting (5%), repetitious sentences/questions (3%), kicking (3%), all 16 others (0%)	Licensed vocational nurses were trained and instructed to observe symptoms during a 2-wk period, after which they were interviewed by authors in order to complete the assessment-scales	No data	Reliability: CMAI retrospective observations bring a risk of observer bias and reflect the observations of a single nurse whose approach could influence the person's behavior No data on sensitivity, specificity, responsiveness to change or validity	Clinically relevant agitation defined as behavior occurring at least once a week or more (frequency score ≥3), or a total CMAI score ≥44
Magai 2000	CMAI full (29−203 range) Subscales: N/A	GDS 6 & 7	CMAI intervention (n = 15): T0 = 29.67 ± 22.37; T1 = 23.6 ± 21.36 CMAI control (n = 12): T0 = 21.25 ± 11.71; T1 = 18.17 ± 7.70 T1 = 8 wk	No data	No data	No data on sensitivity, specificity, responsiveness to change, reliability, or validity	No data
Majic 2012	CMAI full (29−203 range) Subscales: Physically aggressive; Physically nonaggressive; Verbally agitated; Hiding and hoarding	MMSE (0−9)	Prevalence of agitation, sev. dem. group Physically aggressive = 73/180 (40.6%) Physically nonaggressive = 121/180 (67.2%) Verbally agitated = 145/180 (80.6%) Hiding and hoarding = 40/180 (22.2%)	No data	No data	No data on sensitivity, specificity, responsiveness to change, reliability or validity	"any CMAI item occurring at least once a week (CMAI item score >2) was included for further analyses" CMAI factors "exhibiting overall prevalences >10% were saved and used for further analyses"
Marston 2020	CMAI full (29−203 range) Subscales: N/A	CDR 3	Baseline: 17% had no agitation (89/535), 39% had subclinical agitation (206/535), 45% had clinically significant agitation (239/535) At T = 16 months (n = 243): 23% had no agitation, 38% had subclinical agitation, 38% had significant agitation No agitation at all 5 time points, 7/21 (33%) had sev. dem. Subclinical agitation at all 5 time points, 13/59 (22%) had sev. dem. Clinically significant agitation at all 5 time points, 42/94 (45%) had sev. dem.	Administrator was staff member most involved in resident's care	By 16 mo, 489 (34%) of residents (all dementia severity categories) had died	Reliability: As study measures were obtained from care home staff that knew the resident best, CMAI scores are likely to reflect their agitation status No data on sensitivity, specificity, responsiveness to change or validity	No agitation (CMAI = 29) subclinical (CMAI = 30−45) clinically significant (CMAI≥46)
Mulders 2016	CMAI (29−203 range) Dutch version Subscales: Physically aggressive; Physically nonaggressive; Verbally agitated	GDS 6 and 7	GDS Stage 7 as reference; Data for GDS 6 (n = 66) Influence of Dementia Severity on Agitation, measured using CMAI, Odds Ratio (SD): Physically nonaggressive = 3.9 (1.5−10.1), Physically aggressive = 0.6 (0.2−1.5), Verbally agitated = 3.1 (1.4−6.9)		5/230 patients excluded because of incomplete CMAI or NPI data	Validity: CMAI not specifically validated for people with young-onset dementia	Presence or absence of agitated behavior (frequency score ≥3) on CMAI clusters

Sánchez 2016	CMAI (30–210) Spanish version Subscales: N/A	GDS	T1 = 16 weeks CMAI Total Score, mean (SD) Int. 1: T0 = 55.10 (15.83); T1 = 38.30 (13.35) Int. 2: T0 = 55.60 (29.93); T1 = 43.50 (14.23) Control: T0 = 52.89 (27.27); T1 = 51.10 (29.51) CMAI verbally agitated, mean (SD) Int. 1: T0 = 10.70 (2.67); T1 = 6.60 (2.17) Int. 2: T0 = 13.00 (8.07); T1 = 9.60 (4.33) Control: T0 = 9.60 (4.33), T1 = 9.30 (no SD) CMAI physically nonaggressive, mean (SD) Int. 1: T0 = 13.80 (7.22), T1 = 8.70 (4.67) Int. 2: T0 = 12.70 (8.14), T2 = 10.10 (5.74) Control: T0 = 10.70 (6.33), T1 = 10.80 (no SD) CMAI aggressive, mean (SD) Int. 1: T0 = 12.50 (6.04), T1 = 8.40 (4.43) Int. 2: T0 = 12.00 (8.63), T2 = 8.27 (4.38) Control: T0 = 14.8 (12.17), T1 = 13.20 (8.26)	No data	No data	No data on sensitivity, specificity, responsiveness to change, reliability or validity	No data
Veldwijk-Rouwenhorst 2017	CMAI full (29–203 range) Subscales: N/A	GDS 6 and 7	For GDS 6: 113/154 (73.4%) experienced very frequent agitation 865/1704 (50.8%) experienced less frequent agitation For GDS 7: 26/154 (16.9%) experienced very frequent agitation 436/1704 (25.6%) experienced less frequent agitation Correlates for very frequent agitation compared to GDS 4 and 5: GDS 6 had OR 3.636, 95% CI (1.929 −6.875), *P* value < .001 GDS 7 had OR 2.951, 95% CI (1.321 −6.588), *P* value 0.008	In 3 studies the CMAI was administered by a research assistant interviewing the care staff member most involved in resident's daily care. In one study an internet application was used for administering the CMAI	No data	No data on sensitivity, specificity, responsiveness to change, reliability or validity	Very frequent agitation = a score of 6 (several times a day) or 7 (several times an hour) on at least 5 CMAI items combined with a CMAI total score above the 90th percentile.

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Table 2 (*continued*)

Author and Year	CMAI used and Variables (Subscales)	Advanced Dementia Scores	Frequency of Symptoms: Prevalence	Admin Time and Administrator	Ease of Use and Completeness of Data	Psychometric Properties	Cutoff Used for Agitation
Veldwijk-Rouwenhorst 2021	CMAI (29–203 range) Dutch version Subscales: N/A	GDS 6 and 7	For GDS 6: 22/45 (48.9%) experienced very frequent physical aggression (PA) 271/498 (54.4%) experienced less frequent PA 113/239 (47.3%) experienced very frequent vocalizations 217/392 (55.4%) experienced less frequent vocalizations For GDS 7: 20/45 (44.4%) experienced very frequent PA 151/498 (30.3%) experienced less frequent PA 96/239 (40.2%) experienced very frequent vocalizations 118/392 (30.1%) experienced less frequent vocalizations	The care staff members most involved in resident's daily care	No data	No data on sensitivity, specificity, responsiveness to change, reliability or validity	Very frequent physical aggression = a score of 6 (several times a day) or 7 (several times an hour) on the items "hitting," "pushing," "biting" and "kicking" Very frequent vocalizations = a score of 6 or 7 on the items "screaming" and "making strange noises"
Wilchesky 2018	CMAI full (29–203 range) Subscales: N/A	Iso-SMAF (13 and 14 correspond to FAST 7)	Residents with severe agitation (>45) @T0 = 13.6%, SD 12.8 Level of agitation (mean ± SD): T0 = 21.1 ± 19.5 T1 = 21.3 ± 15.9 T1 = average 104 days (SD 13.5)	No data	No data	No data on sensitivity, specificity, responsiveness to change, reliability or validity	CMAI over 45 = severe agitation
Zuidema 2009	CMAI (29–203 range) Dutch version Subscales: Physically aggressive; Physically nonaggressive; Verbally agitated	GDS 6 and 7	CMAI, prevalence (%) agitation by dementia severity, GDS 6 (n = 681)/ GDS 7 (n = 366) Physically aggressive = 58.6%/62.6%, Physically nonaggressive = 69.5%/ 48.4%, Verbally agitated behavior = 65.3%/30.9% With GDS 7 as reference: Influence of dementia stage on agitation (CMAI), GDS 6 Physically aggressive = 0.8 [0.6–1.1], Physically nonaggressive = 2.0 [1.5 –2.7]*, Verbally agitated behavior = 3.4 [2.5–4.6]*	Vocational nurses interviewed by trained nurse assistants to elicit specific observations of all NPS	No data	No data on sensitivity, specificity, responsiveness to change, reliability or validity	CMAI: Aggressive or agitated behavior within each cluster was considered to be relevant when one or more items occurred at least once a week (any individual items score ≥3).

sev. dem., severe dementia.

Table 3
Studies Using Original NPI (or Variations) as a Measurement Tool

Author and Year	NPI Used and Variables (Subscales)	Advanced Dementia Scores	Frequency of Symptoms: Prevalence	Admin Time and Administrator	Ease of Use and Completeness of Data	Cutoff Used for Behaviors	Psychometric Properties
Ballard 2002	NPI part (0–24 range) Subscales: N/A	CDR 3	No data	No data	No data	Clinically significant = agitation occurring on at least daily basis, causing moderate or severe management problems for staff	No data on sensitivity, specificity, responsiveness to change, reliability or validity
Froggatt 2020	NPI-Q NPI-Q severity (0–36) Subscales: N/A	FAST 6 and 7	[Results also split for intervention (n = 18) and control (n = 14); overall for n = 32 recorded here]. T1 = 2 weeks; T2 = 4 weeks NPI-Q severity score **overall**, mean (SD) T0 = 8.0 (7.0); T1 = 6.0 (5.3); T2 = 5.4 (4.8) NPI-Q symptom presence at baseline (n = 32) agitation/aggression = 23; anxiety = 7; apathy/indifference = 7; appetite/eating = 10; delusions = 6; depression/dysphoria = 15; disinhibition = 3; elation/euphoria = 8; hallucinations = 7; irritability/lability = 7; motor disturbance = 14; nighttime behaviors = 12 NPI-Q symptom presence at week 4, T2 (n = 31) agitation/aggression = 18; anxiety = 3; apathy/indifference = 3; appetite/eating = 7; delusions = 3; depression/dysphoria = 12; disinhibition = 7; elation/euphoria = 7; hallucinations = 7; irritability/lability = 9; motor disturbance = 11; nighttime behaviors = 16	Nursing home staff	NPI-Q missing data due to noncompletion of questions on specific symptoms (eg, day shift staff unable to comment on sleep symptoms). No. incomplete NPI-Q severity = 7/32 at baseline, 6/32 at week 2, 6/32 at week 4	No data	No data on sensitivity, specificity, responsiveness to change, reliability or validity
Ito 2020	NPI-NH full (0–144 range) Subscales: N/A	MMSE 0–11*	NPI-NH at baseline, mean ± SD: total (0–144) = 19.5 ± 3.5, delusion = 1.9 ± 2.7, hallucination = 1.1 ± 3.2, agitation = 2.7 ± 4.0, depression = 1.9 ± 3.2, anxiety = 2.1 ± 3.6, emotion = 0.4 ± 1.5, apathy = 1.3 ± 2.3, disinhibition = 1.6 ± 3.0, irritability = 2.8 ± 3.7, aberrant motor behavior = 1.5 ± 3.2, sleep = 3.3 ± 5.1, appetite = 0.9 ± 2.6 No post data	No data	NPI-NH total score was summarized without substitution when 80% of the questions were answered	NPI-NH total score ≥4 indicates clinically significant neuropsychiatric symptom load	No data on Sensitivity, Specificity, responsiveness to change, reliability or validity

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Table 3 (*continued*)

Author and Year	NPI Used and Variables (Subscales)	Advanced Dementia Scores	Frequency of Symptoms: Prevalence	Admin Time and Administrator	Ease of Use and Completeness of Data	Cutoff Used for Behaviors	Psychometric Properties
Koopmans 2009	NPI-NH full (0–144 range) Subscales: N/A	MMSE = 0, FAST 7a	NPI-NH prevalence rates (n = 39) apathy (64.1%), anxiety (30.8%), agitation (17.9%), aberrant motor behavior (17.9%), depression (12.8%), eating change (12.8%), irritability (10.3%), nighttime disturbances (5.1%), disinhibition (2.6%), hallucinations (2.6%), euphoria 0%, delusions 0%	Licensed vocational nurses trained and instructed to observe symptoms during 2-wk period, after which they were interviewed by authors to complete the assessment	No data	Clinically relevant NPS measured with the NPI-NH were defined by a F x S score for each individual symptom ≥4	Reliability: NPI-NH retrospective observations bring risk of observer bias and reflect the observations of a single nurse whose approach could influence the person's behavior No data on sensitivity, specificity, responsiveness to change or validity
Makimoto 2019	NPI-NH full (0–144 range) Subscales: Aggression Psychosis Detachment/Disinhibition Eating and sleeping	CDR 3	Prevalence of frequency × severity ≥4 of NPI-NH, Japan LTCFs, CDR3 (n = 23), % delusions = 11.1, hallucinations = 14.8, agitation/aggression = 14.8, depression/dysphoria = 3.7, anxiety = 7.4, euphoria/elation = 0, apathy/indifference = 44.4, disinhibition = 7.4, irritability/lability = 18.5, aberrant motor behavior = 7.4, sleep and nighttime behavior disorders = 7.4, appetite and eating disorders = 18.5 Prevalence of frequency × severity ≥4 of NPI-NH, China NHs, CDR3 (n = 49), % delusions = 8.2, hallucinations = 6.1,agitation/aggression = 16.3, depression/dysphoria = 2.0, Anxiety = 6.1, euphoria/elation = 10.2,apathy/indifference = 53.1, disinhibition = 8.2, irritability/lability = 12.2, aberrant motor behavior = 24.5, sleep and nighttime behavior disorders = 12.2, appetite and eating disorders = 14.3	Duration and no. educational sessions on use of NPI-NH varied among study sites due to the differences in staff knowledge level In China, graduate student nurses interviewed staff to complete NPI-NH.	No data	NPI-NH subscale scores between 1 and ≤3 (clinically insignificant) and F × S ≥ 4 (clinically significant)	Reliability: interrater reliability conducted, pilot n = 10 people. Spearman rank correlation coefficient between 2 raters for total NPI-NH = 0.996; differing staff educational backgrounds and method of ascertaining "BPSD using the NPI-NH among study sites may have influenced the prevalence of BPSD." Validity: NPI-NH Chinese version was validated by co-authors. Factor structure aligns with previous studies for aggression; psychosis; sleep/appetite. Apathy, depression, and disinhibition factor less commonly reported. No data on sensitivity, specificity, responsiveness to change
Mulders 2016	NPI-NH full (0–144 range) Subscales: Psychosis-cluster (hallucinations and/or delusions) Agitation-cluster (agitation, disinhibition, irritability, and/or aberrant motor behavior)	GDS 6 and 7	GDS Stage 7 as reference; Data for GDS 6 (n = 66) Influence of Dementia Severity on Agitation, measured using NPI-NH agitation, Odds Ratio (SD): Total = 1.6 (0.7–3.9), aggression/agitation = 1.8 (0.8–3.9), irritability = 2.6 (1.2–6.0), aberrant motor behavior = 2.5 (1.1–5.9) Influence of Dementia Severity on Apathy, Odds Ratio (SD): NPI-NH Apathy = 0.4 (0.2–1.1)		Five of the 230 patients were excluded because of incomplete NPI or CMAI data	Presence or absence of individual and clustered symptoms on the NPI-NH (FxS cutoff score ≥4) as dependent variables	Validity: NPI-NH not specifically validated for people with young-onset dementia No data on sensitivity, specificity, responsiveness to change, reliability

Prado-Jean 2010	NPI full (0−144 range) Subscales: N/A	MMSE <10	NPI overall (depressive and nondepressive), n = 81 delusions 17/81 (20.9%), hallucinations 7/81 (8.64%), agitation 26/81 (32.1%), depression 30/81 (37%), anxiety 15/81 (18.5%), euphoria 5/81 (6.2%), apathy 15/81 (18.5%), disinhibition 18/81 (22.2%), irritability 20/81 (24.7%), aberrant motor behavior 21/81 (25.9%), nighttime disturbances 12/81 (14.8%), eating changes 20/81 (24.7%) Depressive, frequency of NPI item, n = 35 delusions 25.7% (9/35), hallucinations 5.7%, agitation 42.8%, depression 77.1%, anxiety 34.3%, euphoria 14.3%, apathy 25.7%, disinhibition 34.3%, irritability 34.3%, aberrant motor behavior 31.4%, nighttime disturbances 28.6%, eating changes 37.1% Nondepressive, frequency of NPI item, n = 46 delusions 17.4% (8/46), hallucinations 10.9%, agitation 23.9%, depression 6.5%, anxiety 6.5%, euphoria 0%, apathy 13%, disinhibition 13%, irritability 17.4%, aberrant motor behavior 21.7%, nighttime disturbances 4.3%, eating changes 15.2% There are associated *P* values re. significance	NPI: Data gathered by a trained examiner during a structured interview with a knowledgeable informant (nursing homes' staff)	No data	Those with a CSDD score >6 were considered depressive	No data on Sensitivity, Specificity, Responsiveness to change, Reliability or Validity
Reuther 2016	NPI-NH full (0−144 range) German version Subscales: Agitation and restless behavior Psychosis Mood	FAST 7	Prevalence for FAST 7 of NPI-NH, Factor 1 (agitation and restless behavior), n (%) agitation = 114 (45%), disinhibition = 44 (17%), irritability = 77 (30%), aberrant motor behavior = 88 (34%), nighttime behavior = 67 (26%) Prevalence for FAST 7 of NPI-NH, Factor 2 (psychosis), n (%) delusions = 34 (13%), hallucinations = 29 (11%), euphoria = 19 (7%) Prevalence for FAST 7 of NPI-NH, Factor 3 (mood), n (%) anxiety = 71 (27%), depression = 79 (31%), apathy = 122 (48%), eating disorders = 53 (12%)	Symptoms scored based on the caregivers' responses	No data	No data	Reliability: analysis using Cronbach alpha for FAST 7 sample: agitation and restless behavior (alpha 0.7); psychosis (alpha 0.4); mood (alpha 0.5) Validity: validity can be increased by using specific factors, such as agitation & restless behavior, as outcomes, instead of applying entire instrument No data on Sensitivity, Specificity, Responsiveness to change
Sánchez 2016	NPI (0−144 scale) Spanish version Subscales: N/A	GDS	NPI Int. 1: T0 = 27.7 (13.72), T1 = 11.9 (13.54) Int. 2: T0 = 18.1 (14.89), T1 = 23.3 (17.88) Control: T0 = 23.22 (24.02), T1 = 21.22 (21.75) T1 = 16 weeks	NPI completed according to the answers of the caregivers	No data	No data	No data on sensitivity, specificity, responsiveness to change, reliability or validity

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Table 3 (*continued*)

Author and Year	NPI Used and Variables (Subscales)	Advanced Dementia Scores	Frequency of Symptoms: Prevalence	Admin Time and Administrator	Ease of Use and Completeness of Data	Cutoff Used for Behaviors	Psychometric Properties
Selbaek 2014	NPI-NH 10 (0–120) Subscales: Agitation (aggression/ agitation + disinhibition + irritability; range 0–36) Psychosis (delusion + hallucination, range 0 –24) Affective symptoms (depression + anxiety, range 0–24) Apathy analyzed on its own	CDR 3 and CDR "sum of boxes"	For CDR 3 as predictor of NPI-sum and NPI subscales (95% CI): NPI10 sum score coefficient = 8.22 (6.11; 10.32), $P < .001$ Apathy coefficient = 2.31 (1.84; 2.77), $P < .001$ Agitation coefficient = 3.00 (2.0; 4.01), $P < .001$ Psychosis coefficient = 1.84 (1.11; 2.58), $P < .001$ Affective symptoms coefficient = 0.57 (−0.05; 1.19), $P = .076$	Data collection was done by registered nurses with wide experience of working in old-age psychiatry	Authors omitted nighttime behavior and appetite disturbance/eating change as they "primarily capture vegetative symptoms"	For NPS: an item score of 4 or higher was defined as a clinically significant symptom	No data on sensitivity, specificity, responsiveness to change, reliability or validity
Sommerlad 2022	NPI apathy subscale (0 –12) Subscales: N/A	CDR 3	Sev Dem, n = 530 57% (300/530) had no apathy, 10% (53/530) had subclinical apathy [score 1 –3], 33% (177/530) had severe apathy [score 4+] Non-Sev Dem, n = 886 73% (644/886) had no apathy, 13% (116/886) had subclinical apathy, 14% (126/886) had severe apathy [score 4+] NPI-NH total score, $P < .001$ All participants (n = 1419) 12.5 ± 13.7 No apathy (n = 946) 10.3 ± 12.3 Subclinical apathy (n = 169) 11.3 ± 9.5 Clinically significant apathy (n = 304) 20.2+/ = 16.8 Depression, $P < .001$ All participants (163/1419) 11.5% (6.2 ± 2.5) No apathy (70/946) 7.4% (5.9 ± 2.4) Subclinical apathy (16/169) 9.5% (5.1 ± 2.1) Clinically significant apathy (77/304) 25.3% (6.6 ± 2.5) Anxiety, $P < .001$ All participants (183/1419) 12.8% (6.4 ± 2.6) No apathy (98/946) 10.4% (6.4 ± 2.5) Subclinical apathy (20/169) 11.8% (4.9 ± 1.5) Clinically significant apathy (65/304) 21.4% (6.7 ± 2.8)	A trained researcher interviewed a staff member who worked closely with resident to complete proxy-rated measures	Data on dementia severity was missing for 3 of the 1419 participants	For NPI apathy subscale: "no apathy" = 0, "subclinical apathy" = 1 –3 and "clinically significant apathy" = 4 –12 For other NPS, a score of ≥4 considered clinically significant severity	No data on sensitivity, specificity, responsiveness to change, reliability or validity
Wu 2009	NPI-NH full (0–144 range) Chinese version Subscales: N/A	GDS 6 & 7	Mean NPI-NH scores: 32.7 for GDS 6 (n = 77) 24.4 for GDS7 (n = 53) % of residents with apathy/ indifference: 59.7% for GDS 6 (n = 77) 88.7% for GDS 7 (n = 53)	NH staff	Data incomplete when staff could not rate items; 118–149 valid cases for domain items	If NPI domain was present, frequency (1 to 4) and severity (1 to 3) of each symptom were rated; otherwise a score of zero was recorded	No data on sensitivity, specificity, responsiveness to change, reliability or validity

Zuidema 2009	NPI-NH-9 (0–108 range) Subscales: N/A	GDS 6 and 7	Prevalence % NPS by dementia severity, GDS 6 (n = 681)/GDS 7 (n = 366) agitation = 33.6%/31%, disinhibition = 24.5%/10.7%, irritability = 38.6%/20.8%, aberrant motor behavior = 34.9%/28.7%, delusions = 19.2%/4.9%, hallucinations = 8.5%/9.3%, depression = 23.5%/11.2%, anxiety = 22%/21.6%, apathy = 31.3%/48.6% With GDS 7 as reference: Influence of dementia stage on NPS (NPI-NH), GDS 6 agitation = 1.1 [0.8–1.5], disinhibition = 2.5 [1.7–3.7]*, irritability = 2.4 [1.7–3.3]*, aberrant motor behavior = 1.3 [0.95–1.8], delusions = 3.8 [2.2–6.5]*, hallucinations = 0.9 [0.6–1.5], depression = 1.9 [1.3–2.8]*, anxiety = 0.9 [0.6–1.3], apathy = 0.5 [0.4–0.7]*, *OR = 1 not included ($P <$ .05)	Vocational nurses were interviewed by trained nurse assistants to elicit specific observations of all neuropsychiatric symptoms	No data	NPI-NH: neuropsychiatric symptoms with an F x S score ≥4 considered to be clinically relevant	No data on sensitivity, specificity, responsiveness to change, reliability or validity

N/A, not applicable.
*Inclusion criteria required MMSE score below 10; however, this study was included as MMSE 0–11 range was considered sufficiently close.

During initial article screening, NCSDs were frequently assessed in studies examining quality of life (QoL). This is unsurprising given the overlap between NCSD and QoL instruments such as QUALIDEM, which includes items like restless tense behavior, mood disturbances, vocalization, and accusatory behavior.[48] Similarly, studies on "behaviors indicating pain" were common in search results, although not included within our scope.

A considerable number of studies (n = 193) were excluded during the full-text screening because data were not stratified by dementia severity. Moderate and severe dementia were often grouped together, limiting the ability to isolate findings for individuals with advanced dementia (defined as FAST/GDS stage 6 or 7). This reflects a broader issue in dementia research: the underrepresentation of individuals with advanced dementia. Kverno et al[49] found fewer than 10% of nonpharmacological studies (n = 215) focused on people with moderately severe to very severe dementia, with most studies targeting mild to moderate cognitive impairment. This highlights the importance of studies reporting and making openly available data stratified by dementia stage, and for more targeted research in this population. Similar underrepresentation has been noted in trials involving antidepressants and other psychotropic medications.[10] Analysis of the data sources revealed that MEDLINE and Embase contributed most of the included studies, whereas gray literature searches did not yield additional unique studies, likely because of the technical specificity of the concept of interest. The CMAI and NPI were the most frequently used tools, consistent with findings from the preliminary search.

A key strength of this review is that it focuses on the use and usefulness of instruments for measuring NPS specifically for people with advanced dementia in nursing homes, and highlights gaps in the literature, suggesting future research directions.

This review has several limitations. First, despite a broad search strategy, some relevant studies may have been missed if key terms were not included in the title or abstract. Second, studies that combined both moderate and advanced dementia data were excluded, as were studies in mixed care settings without disaggregated data. Third, although a quality appraisal of the studies was conducted using the Hawker framework, it focused on relevance to the extracted agitation/NCSD data and did not assess the overall risk of bias. Finally, we were unable to explore tool performance across dementia subtypes, despite known differences in NCSD prevalence (eg, psychosis) by dementia type.[50]

Conclusions and Implications

Assessing agitation and other NCSDs appears feasible in nursing home residents with advanced dementia using the long-form CMAI or an NPI version or both. These tools reported few missing data and, when reported, demonstrate good psychometric properties. The short-form CMAI should intuitively place less burden on staff for outcome assessment, but this has less available data.

However, the limited literature in this population does not support robust sample size calculations for interventional studies. The underrepresentation of individuals with advanced dementia in NCSD research is also concerning and limits the evidence base for care in this vulnerable population. Symptoms such as psychosis appear to be less commonly manifested in advanced dementia, whereas agitation, apathy, and aberrant motor behavior are more prevalent and may be more appropriate targets for intervention outcomes.

Future studies should consider the potential variability in agitation and NCSD by dementia severity, examine the properties of the short-form CMAI in this population, and prioritize provision of open-access datasets and stratified reporting by dementia severity to

maximize data utility to support evidence-based care for individuals with advanced dementia.

Disclosure

The authors declare no conflicts of interest.

Supplementary Data

Supplementary data related to this article can be found online at https://doi.org/10.1016/j.jamda.2026.106133.

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