VER
Vascular & Endovascular Review

Advanced Dementia End-of-Life Assessment measures: A systematic Review

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ABSTRACT

Background: Advanced dementia is a terminal condition characterised by profound cognitive decline, other significant and progressive symptoms, yet there is no consensus on which end-of-life assessment measures best capture all symptoms in this population. This study aims to identify and synthesise end-of-life assessment measures used in people with advanced dementia and to evaluate their measurement properties and clinical feasibility for nursing practice. Methods: This systematic review adhered to PRISMA 2020 and COSMIN guidance for measurement instruments. PubMed, ScienceDirect, Embase and the Cochrane Library were searched for peer-reviewed quantitative studies from 2016 to 2025 using terms related to advanced or severe dementia, end of life or palliative care, and assessment or measurement. Ten studies met the inclusion criteria and were charted in a review matrix; because of heterogeneity in designs, settings and outcomes, findings were synthesised narratively across four domains: global end-of-life and prognostic measures, cognitive tools, behavioural pain scales and documentation-based assessments. Results: The included studies showed that multidomain tools (EoLCAD, CADEOLD, SMEOLD, SWCEOLD) and the ADEPT prognostic score generally have acceptable internal consistency and basic construct validity but only modest prognostic discrimination and limited evidence on responsiveness. SIRS offers a brief severe-stage cognitive assessment with minimal floor effects, while behavioural pain measures (PAINAD, PAINAD-K, PATCIE) demonstrate good reliability, although PAINAD may partly reflect general distress in acute settings. Conclusion: The combination of end-of-life tool, SIRS and a behavioural pain scale is suggested to be more reliable than depending a single measure, but further COSMIN-informed validation and implementation research is needed to improve end-of-life assessment in advanced dementia.

KEYWORDS: Advanced dementia, Assessment, End of life, Measurement.

How to Cite: Faten Ahmed Ibrahim Shab, Ebtisam Mohammed Alhindi, Nurah Abdulrahman Aldehaim, Waleed Mousa Salem Alfaifi , Mohammed Fahad H Alanazi, (2025) Advanced Dementia End-of-Life Assessment measures: A systematic Review, Vascular and Endovascular Review, Vol.8, No.4s, 413-422

INTRODUCTION

Dementia affects millions of people worldwide and is currently the seventh leading cause of death, as well as a major cause of disability and dependence in older adults (Tsai et al., 2022). It results from a range of brain diseases and injuries, with Alzheimer's disease being the most common form, and can eventually make long-term residential care necessary for many individuals. Dementia is a fatal condition thats why staff caring for patients with dementia especially advanced dementia need the skills and knowledge to provide the palliative care that is specialized to each patient's psychological and physical condition (Bourke et al., 2025). as neurological illness, dementia gradually adversely impacts the process of thinking, behaviours and everyday activities, and the symptoms worsen with time as the disease progress(Carrarini et al., 2024) .This impairment occur over several years, and the families and caregivers supposed to provide increasing levels of care during these years, until the patient often needs admission to a long-term care facility (Kroenke et al., 2025).

In the advanced stage of dementia, the individual is often frail, exhibits severely decreased memory, understanding and language skills, experiences diminished physical functioning and self-care capability, and encounters challenges with eating and swallowing. They may have concurrent cardiac and/or vascular conditions, dyspnoea and discomfort, and will be prone to urinary and respiratory infections as well as delirium, and may also exhibit neurological symptoms, emotional and physical agitation and/or indifference (Bourke et al., 2025). Advanced dementia is a gradual, terminal condition marked by a significant risk of pneumonia, difficulties with eating, and discomfort, along with profound memory and language deficits, immobility, lack of self-care capacity, and incontinence of bowel and bladder (Hua et al., 2022). Patients with severe dementia often have very limited ability to speak for themselves, are unable to convey symptoms consistently, and are entirely dependent on healthcare providers for all their care requirements; therefore, assessment of their condition is essential (Hendricksen et al., 2022).

Advanced dementia (AD) is the last phase of dementia, defined by enduring cognitive deficits resulting from brain deterioration, with Alzheimer's disease as the predominant cause. Individuals with AD frequently have prolonged bed rest and diminished quality of life owing to various complications, resulting in an elevated end-of-life mortality rate; however, precisely assessing life expectancy in AD continues to be difficult. Several tools are used to estimate life expectancy in advanced dementia, and the

ADEPT score is one that some geriatric and palliative teams now use as a guide, even though it cannot predict the future for each patient exactly (Liu et al., 2024). One recent study reported that six symptoms—pain, trouble swallowing, breathlessness, anxiety and restlessness are seen again and again near the end of life in advanced dementia, and argued that paying attention to these can help staff and families talk more clearly about what to expect (Kroenke et al., 2025). Another study created the EoLC-AD so nurses in aged-care settings have a simple dementia-specific checklist that helps them notice symptoms and plan palliative and end-of-life care more systematically (Bourke et al., 2025).

Pain is also very common in advanced dementia, but it is still often not picked up or not treated enough, especially in people from minority ethnic groups and in those with more severe cognitive problems (Kwon et al., 2021). As dementia damages the brain, people lose memory and language and can no longer describe their pain, and these brain changes may also affect how they feel pain, so nurses and doctors have to look for signs in behaviour and changes from the person's usual pattern instead of relying on what the person says. Communication obstacles between patients and nurses further complicate pain assessment and management in this population (Tsai et al., 2022). Inadequate pain identification in patients with dementia may result in insufficient analgesic prescriptions, caregiver distress, heightened functional decline and an elevated risk of falls, while unmanaged pain has been linked to behavioural and psychological symptoms of dementia, including anger and anxiety (Dunford et al., 2022).

Other symptom domains are also important elements in the assessment of advanced dementia. Progressive and sever impairment in autonomous and voluntary movement is often seen at advanced stages of dementia, which affect a lot aspects of life as daily activities, safety, caregiving and quality of life(Cullen et al., 2022). cognitive impairment is also prevalent with dementia and both are significant health concerns, impacting more than 8% of older people and the prompt identification of them is crucial for implementing supportive strategies and allocating resources for people with dementia and their caregivers. Recent work on rapid, simple questionnaires, such as the Standard Assessment of Global Everyday Activities (SAGEA), suggests that assessment of everyday functioning may be useful for predicting dementia progression, although most evidence comes from earlier disease stages rather than advanced dementia (Phelps et al., 2025).

Although there is increasing acknowledgment of advanced dementia as a terminal illness necessitating a palliative approach, consensus on the most effective end-of-life assessment measures to accurately reflect the intricate symptom burden, comfort, and quality-of-care requirements of this demographic remains elusive, with the current evidence on these measures being inconsistent and of varying quality.

Aim of the review

The aim of this systematic review is to identify and synthesise the available content on assessment measures used at the end of life in individuals with advanced dementia, and to evaluate their measurement characteristics and reliability to inform practice and guide future measure development and validation.

METHODS

Design

This study is a systematic review of advanced dementia end-of-life assessment measures and was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement. Methods for identifying and appraising measurement instruments were informed by COSMIN guidance for systematic reviews of outcome measurement instruments.

Search methods

Information sources: A comprehensive literature search was conducted to identify studies reporting assessment measures used in individuals with advanced dementia. **PubMed, ScienceDirect, Cochrane Library and Embase** were searched, and reference lists of included studies and relevant reviews were screened to identify additional eligible articles. A comprehensive literature search was conducted to identify studies concerned with end of life. Only peer-reviewed articles published in English were included. The Keywords used for searching were: "advanced dementia" AND "severe dementia" OR "end-stage dementia" AND "end of life" OR "palliative care" AND "assessment" OR "measurement" OR "scale" OR "instrument" AND "pain" OR "symptom burden" OR "comfort" OR "quality of dying" AND "nursing care" OR "long-term care" OR "End of life care".

Table 1: Literature search strategy

Database	Date searched	Results	Query
PubMed	15/08/2025	426	advanced dementia AND severe dementia OR end-stage dementia AND end of life OR palliative care AND assessment OR measurement OR scale OR instrument AND pain OR symptom burden OR "quality of dying" AND nursing care OR long-term care OR end of life care. Filters: Peer-reviewed – English – Human.
ScienceDirect	15/12/2025	248	advanced dementia AND severe dementia OR end-stage dementia AND end of life OR palliative care AND assessment OR measurement OR scale OR instrument AND pain OR symptom burden OR "quality of dying" AND nursing care OR long-term care OR end of life care. Filters: Peer-reviewed – English.

Embase	16/12/2025	82	(advanced dementia OR "severe dementia" OR "end stage dementia") AND ("end of life" OR "palliative care") AND (assessment OR measurement OR scale OR instrument) AND (pain OR "symptom burden" OR "quality of dying") Filters: Humans – English.
Cochrane Library	18/12/2025	189	(advanced dementia OR "severe dementia") in Title/Abstract/Keywords AND ("end of life" OR "palliative care") AND (assessment OR scale OR instrument) AND (pain OR "symptom burden" OR "quality of dying") Filters: Trials/Reviews – English.

Inclusion and exclusion criteria

Inclusion criteria

- Studies that report assessment measures or documented assessments (e.g. scales, scores, ratings, or clearly described assessment forms) used with people with advanced or severe dementia.
- Measures or assessments used to evaluate end-of-life–related aspects, such as comfort, symptoms, satisfaction with care, prognosis/survival, pain, or cognitive status in advanced/severe dementia.
- Original quantitative studies (observational, psychometric, cohort, or trial) involving human participants, published in peer-reviewed journals in English.

Exclusion criteria

- Studies focused on early dementia or mild cognitive impairment diagnosis where assessment measures are evaluated only in mild or moderate stages, without application to advanced or severe dementia.
- Studies not associated with the identified search concepts (e.g. not addressing dementia, end-of-life, or assessment/measurement).

Search outcomes

The database search provided 945 records, of which 456 duplicates were removed prior to screening. Titles and abstracts of the remaining 489 records were screened, and 284 were excluded as not relevant to advanced dementia end-of-life assessment measures, leaving 205 full-text articles for eligibility assessment. of these, 194 were excluded for not meeting the inclusion criteria, resulting in 10 studies being included in the final analysis. The study selection process followed the PRISMA framework, progressing through the phases of identification, screening, eligibility and inclusion, as showed in Figure 1.

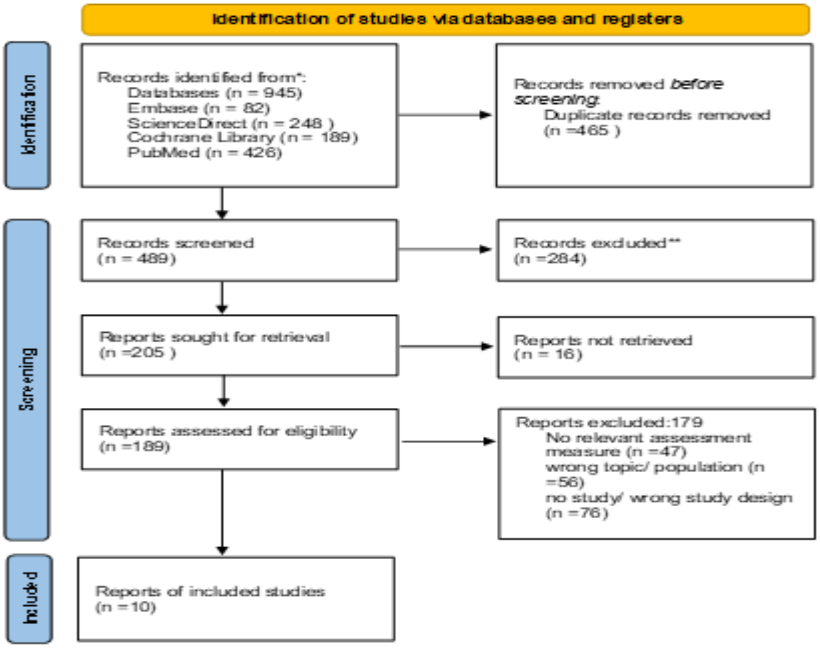
Quality appraisal

The appraisal of included studies were conducted using criteria informed by reliable guidance on evaluating outcome measurement tools, also focusing on the design of study and size of sample, measurement properties (e.g. reliability, validity, responsiveness) and reliability of statistical methods. each study was evaluated descriptively (for example as having low, moderate or unclear risk of bias) Each study was rated based on the completeness of reporting; no single summary score was calculated because of heterogeneity in designs, settings and outcomes.

Synthesis

Owing to the methodological and clinical heterogeneity across studies in terms of care setting, sample characteristics, and the specific end-of-life measures evaluated, a meta-analysis was not feasible. Instead, findings were synthesised narratively, grouping instruments into four domains: global end-of-life and prognostic measures, cognitive assessment tools, behavioural pain scales, and documentation-based assessments. Within each domain, measurement properties (reliability, validity, floor effects, and feasibility) and key clinical implications were compared using a structured review matrix to highlight convergent and divergent evidence across studies.In addition, data from each included study were charted in a review matrix capturing study identification details, population and setting, the primary aim and assessment focus, the specific end-of-life measure used, key findings on its measurement properties, and implications for practice as seen in table 2.

Figure 1: PRISMA flow diagram



RESULTS

Ten quantitative studies (2016–2025) were identified: five applying global end-of-life or prognostic measures in advanced dementia, and five focusing on pain-related assessment tools or documentation of pain practices in people with advanced dementai.

Overview of included studies

The search and selection process yielded 10 quantitative studies published between 2016 and 2025 that evaluated or used assessment measures at the end of life in people with advanced or severe dementia. Studies were conducted in the United Kingdom, United States, China, Singapore, Korea and Australia, across nursing homes, long-term care hospitals, acute hospitals, emergency departments, hospices and community/home-based services. The main measures identified were global end-of-life assessment measures (EoLC-AD, CAD-EOLD, SM-EOLD, SWC-EOLD), a prognostic score (ADEPT), a severe-stage cognitive measure (SIRS), pain assessment scales (PAINAD, PAINAD-K, PATCIE) and documented pain assessments in routine nursing records.

Characteristics of included studies

Sample sizes ranged from 80 to 230 participants, with all studies focusing on populations described as advanced or severe dementia, including nursing home residents at FAST stage 6a or higher, non-verbal long-term care residents, and community-dwelling individuals with advanced dementia at the end of life. Designs included psychometric evaluations of new or adapted measures (EoLC-AD, SIRS, PAINAD-K, PATCIE, PAINAD in hospital and ED), prospective cohorts using existing measures as outcomes (IN-PEACE, ADEPT and in the study of Sampson et al., 2018 which focused in the symptoms), and one retrospective chart review of documented pain assessments (Tsai et al., 2022).

Table2: Literature Review Matrix

Study	Population & setting	Aim (assessment focus)	Assessment approach	Main findings about assessment	Implications for practice
Bourke et al. (2025) – Development and validation of the End-of-Life Assessment Tool for Advanced Dementia (EoLC-AD)	People with advanced dementia receiving end-of-life care across hospitals, hospices and long-term care; ratings from clinicians and family carers.	To develop and psychometrically validate a multidimensional measure (EoLC-AD) to assess comfort, symptom burden and quality of end-of-life care in people with advanced dementia.	Multi-phase development: item generation, expert and carer review, pilot testing and larger validation; factor analysis; assessment of internal consistency, test–retest and inter-rater reliability, and construct validity versus related measures.	EoLC AD covered physical symptoms, emotional distress, comfort, and care processes; the subscales had a good degree of internal consistency; content and construct validity of the tool were supported through testing it in different	EoLC-AD tool provides a distinct way to assess end of life experience, supports monitoring of comfort and care quality for clinical practices and research, the feasibility and impact in routine care need more testing

				recommended conditions.	
Kroenke et al. (2025) – End-of-life symptoms in persons dying with advanced dementia in the community (IN-PEACE trial)	80 deceased community-dwelling persons with advanced dementia in a 24-month home-based care trial in the USA; post-mortem caregiver interviews; most enrolled in hospice and about half died at home.	To determine symptom burden and comfort at end of life among community-dwelling persons with advanced dementia receiving home-based palliative care, and to compare CAD-EOLD, SM-EOLD and SWC-EOLD scores with prior cohorts.	Post-death caregiver interviews using CAD-EOLD (primary outcome), SM-EOLD and SWC-EOLD (secondary outcomes); comparison of scores between intervention vs usual care and with prior CAD-EOLD samples; multivariable modelling of CAD-EOLD predictors.	Mean CAD-EOLD was 30.7, similar to the median across 10 prior advanced-dementia samples (31.3), suggesting comfort levels comparable to nursing-home deaths; SM-EOLD scores improved from baseline to post-mortem, indicating better symptom management over time.	CAD-EOLD, SM-EOLD and SWC-EOLD are feasible caregiver-reported measures to assess comfort and symptom burden for advanced dementia deaths at home; with structured EOLD measures and hospice/home-based support, dying with advanced dementia can be symptom-tolerable in community settings.
Sampson et al. (2018) – Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life	Patients with advanced dementia in England, from care homes and hospitals and followed until death or study end; data from family carers and healthcare records.	To describe trajectories of symptoms, comfort and service use towards end of life in advanced dementia and evaluate recognition and management of distress.	Repeated structured proxy-rated assessments of symptom burden, comfort and quality of care (EOLD and related measures); data on hospitalizations, interventions and place of death; proxy reports from family and staff.	Participants suffered from symptoms and had variable degrees of comfort, with many symptoms while receiving care until getting close to death, frequent hospital admissions and significant interventions were conducted despite the limited prognosis	Structured, repeated end of life assessments can reveal distinct symptom burden that may be ignored; integrating standardized symptom/comfort measures and improving communication with families are essential to provide a good palliative care.
Liu et al. (2024) – Prediction of survival of persons with advanced dementia using the Advanced Dementia Prognostic Tool: A 2-year prospective study	115 persons with advanced Alzheimer's disease in Chongqing, China, recruited from geriatric hospitals and nursing homes; followed for up to 2 years.	To evaluate the prognostic value of the ADEPT risk score for predicting 2-year survival in people with advanced dementia.	ADEPT risk score calculated at baseline; survival had following tracking at 6, 12 and 24 months; ROC analyses for AUROC and optimal cut-off; comparison of outcomes between ADEPT ≤11.2 and >11.2 groups.	ADEPT showed modest discrimination for 2-year mortality (AUROC ≈0.62); a threshold of 11.2 gave AUROC 0.63, sensitivity 83.3% and specificity 41.8%; scores >11.2 were associated with higher 2-year mortality; the Chinese cohort had higher ADEPT scores but lower short-term mortality than North American cohorts.	ADEPT can classify longer term survival in advanced dementia in Chinese geriatric settings but should be used with clinical judgement and local prognostic factors when planning end of life or palliative care, which indicate that for the assessment it better to combine tools.

Yeo et al. (2016) – Severe Impairment Rating Scale: A useful and brief cognitive assessment tool for advanced dementia for nursing home residents	96 nursing home residents with advanced dementia in Singapore; all at FAST stage 6a or higher.	To evaluate the usefulness of the Severe Impairment Rating Scale (SIRS) as a cognitive assessment measure for advanced dementia, compared with AMT, Chinese MMSE and CDT.	Cross-sectional administration of SIRS, AMT, CMMSE and CDT; dementia severity staged with FAST; analyses of floor effects, ROC curves to detect severe dementia (FAST ≥7a), and correlations with FAST, function and mood; assessment of age, education and gender effects.	SIRS showed minimal floor effect even in very severe dementia, while AMT, CMMSE and CDT scores clustered at the bottom; SIRS had the highest AUC (~0.80) for detecting severe dementia and strongest correlation with FAST, and was less influenced by education or ethnicity.	SIRS is a brief, feasible cognitive measure tailored to advanced dementia that can distinguish levels of severe impairment better than standard screening tests; it may complement functional and end-of-life assessments in this population.
Kwon et al. (2021) – Reliability and feasibility of the Pain Assessment in Advanced Dementia Scale–Korean version (PAINAD-K)	192 older inpatients in a 270-bed long-term care hospital in Korea; non-verbal patients unable to self-report pain.	To culturally adapt PAINAD into Korean and test its validity, reliability and feasibility for assessing pain in older long-term care patients who cannot self-report.	PAINAD-K used as an observational pain measure with 1- and 5-minute observations; inter-rater reliability at 1 minute; agreement between 1- and 5-minute scores; criterion validity versus FLACC and NRS; discriminant validity between patients with and without pain; sensitivity/specificity for 1-minute PAINAD-K.	Inter-rater reliability was substantial (kappa ≈0.62); agreement between 1- and 5-minute scores was almost perfect (≈0.95); validity was high versus FLACC but low versus NRS; PAINAD-K discriminated between patients with and without pain, but sensitivity was low (≈41%) and specificity high (≈93%).	PAINAD-K is valid and reliable to determine absence of pain in non-verbal older long-term care patients, but low sensitivity means low scores cannot exclude pain; it should be part of a broader pain assessment strategy in advanced dementia.
Dunford et al. (2022) – Psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale in an acute general hospital setting	230 medical inpatients with dementia in two acute general hospitals in London, UK.	To evaluate reliability and validity of PAINAD at rest and during movement for people with dementia admitted to acute general hospital wards.	PAINAD applied at rest and during movement; self-reported pain measured using Wong–Baker FACES when possible; BEHAVE-AD used for behavioural and psychological symptoms; analyses of internal consistency, inter-rater and test–retest reliability and validity.	Inter-rater reliability was excellent (ICC 0.92 rest, 0.98 movement); internal consistency acceptable/good (α 0.76–0.80); PAINAD scores were higher in movement than rest; concurrent validity with FACES was weak and there was no correlation with BEHAVE-AD.	PAINAD can be used reliably by ward staff and is sensitive to rest–movement differences, but may not fully capture the construct of pain in acute hospitals and should not be used as a stand-alone measure.

Fry & Elliott (2018) – Pragmatic evaluation of an observational pain assessment scale in the emergency department: The PAINAD scale	181 ED patients ≥65 years in Sydney with suspected long-bone fracture; 139 had cognitive impairment (Six-Item Screener ≤4).	To evaluate the usefulness, reliability and validity of PAINAD for assessing acute pain in older adults with cognitive impairment in the emergency department.	Six-Item Screener for cognition; PAINAD for cognitively impaired patients; NRS 0–10 when self-report was possible; comparison of PAINAD with NRS and injury characteristics.	Median NRS was 5.5 but median PAINAD 1.0, suggesting possible underestimation of pain with PAINAD alone; internal consistency was good (α≈0.80); correlation between PAINAD and NRS was moderate.	PAINAD is feasible and reliable as an adjunct pain measure in cognitively impaired older ED patients, but low scores do not indicate significant pain and should be interpreted with clinical judgement.
Richey et al. (2020) – Development and testing of the Pain Assessment Tool in Cognitively Impaired Elders (PATCIE)	125 nursing home residents with dementia from nine US nursing homes.	To develop and test PATCIE, an observational pain assessment measure capturing nonverbal pain behaviours in cognitively impaired elders.	Observation of 15 then 28 nonverbal pain behaviours at four time points around movement; 0–2 scoring per behaviour; comparison with CNPI; repeated-measures analysis by time and ethnicity/cognitive status.	The final 28-item PATCIE had acceptable internal consistency during movement (α≈0.73), high inter-rater agreement (74–100%; kappa up to 0.79); scores were higher during movement than rest, supporting construct validity; some ethnic differences in behaviours were observed.	PATCIE provides a structured approach to assessing pain via nonverbal behaviours in residents with dementia, especially during movement; it should complement comprehensive clinical assessment and consider cultural variation.
Tsai et al. (2022) – Documented nursing practices of pain assessment and management when communicating about pain in dementia care	100 hospital records of older adults with dementia admitted to acute hospital wards.	To examine how nurses document pain assessment and management for hospitalized older patients with dementia, and to identify gaps that interfere with recommended practice for further improvement in assessment and management of pain.	Retrospective review of nursing records; extraction of whether and how pain was assessed (scales, observational measures, vital signs, behaviour), frequency and specificity of documentation and related interventions; comparison with guideline expectations.	Pain assessment documentation was often infrequent and non-specific; observational measures were rarely documented and links between assessment and timely or appropriate analgesia were inconsistent.	Even with available measures, bedside pain assessment for people with dementia is not consistently or clearly documented; systematic use of structured pain assessments and explicit recording of behaviours, measures used and response to analgesia are needed to improve pain recognition and management.

Across studies, end-of-life assessment focused on: overall comfort and quality of dying (EoLC-AD, CAD-EOLD, SM-EOLD, SWC-EOLD), survival prognosis (ADEPT), cognitive severity (SIRS), pain and symptom behaviours (PAINAD, PAINAD-K, PATCIE), and how pain assessments were recorded in practice for hospitalised patients with dementia. Overall, most studies were single-centre with modest sample sizes and incomplete reporting of some measurement properties (such as measurement error and responsiveness), suggesting generally moderate methodological quality and some risk of bias.

Global end-of-life measures

Five studies evaluated or applied global end-of-life assessment measures capturing comfort, symptom burden, quality of care, prognosis and cognitive severity in people with advanced dementia. Bourke et al. (2025) developed and validated the EoLC-AD, a multidimensional tool covering physical symptoms, emotional distress, comfort and care processes in hospital, hospice and long-term-care settings; factor analyses supported a coherent structure and acceptable subscale reliability, but further validation in other contexts was recommended.

In the IN-PEACE trial, Kroenke et al. (2025) used the CAD-EOLD (primary) and SM-EOLD/SWC-EOLD (secondary) in 80 community-dwelling people with advanced dementia receiving home-based palliative and hospice care, finding comfort scores comparable to prior nursing-home cohorts and improved symptom scores over time. Sampson et al. (2018) applied EOLD-type

measures longitudinally in care-home and hospital residents and showed persistently high symptom burden, variable comfort and frequent burdensome interventions near death, indicating that repeated use can reveal unmet palliative needs.

Prognostic and cognitive tools

Liu et al. (2024) tested the ADEPT survival score in 115 people with advanced Alzheimer's disease in Chinese geriatric hospitals and nursing homes, reporting modest discrimination for 2-year mortality (AUC about 0.62–0.63) and recommending its use for risk stratification only alongside clinical judgement. Yeo et al. (2016) evaluated the SIRS in 96 Singaporean nursing-home residents with advanced dementia (FAST ≥6a), finding minimal floor effects, the highest AUC for severe dementia, strong correlation with FAST and less influence of education and ethnicity than traditional cognitive screens, suggesting it can complement symptom-focused end-of-life measures by providing a brief, stage-appropriate index of cognitive impairment.

Pain-related measures

Kwon et al. (2021) culturally adapted and validated PAINAD-K in 192 Korean long-term-care inpatients, demonstrating substantial inter-rater reliability (kappa 0.62–0.64), near-perfect agreement between 1- and 5-minute observations and high specificity but low sensitivity for pain, so the tool appears better at ruling out pain than grading its intensity, with scores correlating strongly with FLACC and only weakly with NRS self-reports. Dunford et al. (2022) assessed PAINAD in 230 medical inpatients with dementia in two London acute hospitals and found excellent inter-rater reliability and acceptable internal consistency, but weak concurrent validity with FACES and no convergent validity with BEHAVE-AD, concluding that although scores are higher on movement than at rest, PAINAD may reflect general distress and should not be used alone in acute wards.

Additional pain tools and documentation

Fry and Elliott (2018) pragmatically tested PAINAD in 181 cognitively impaired emergency-department patients with suspected long-bone fractures, reporting good internal consistency and only moderate correlation with NRS scores, with low median PAINAD scores even in femoral fractures, highlighting floor effects at rest and the need to assess during or after movement and combine ratings with clinical and caregiver input. Richey et al. (2020) developed the PATCIE observational tool for African American and Caucasian nursing-home residents with dementia, extending to 28 nonverbal behaviours and showing acceptable internal consistency during movement and construct validity via higher scores during transfers than at rest with only small ethnic differences. Tsai et al. (2022) reviewed 100 Australian hospital records, finding that pain was common and often moderate–severe, nurses relied mainly on self-report scales with minimal observational-tool use, and documented pain scores were poorly linked to cognition and analgesic administration, indicating a gap between pain assessment and management in dementia care.

DISCUSSION

Ten quantitative studies published between 2016 and 2025 examined end-of-life assessment in people with advanced or severe dementia across long-term care, acute hospital, emergency department, hospice and community settings. Global end-of-life and prognostic measures (EoLC-AD, CAD-EOLD, SM-EOLD, SWC-EOLD, ADEPT and SIRS) showed that multidimensional tools can capture comfort, symptom burden and cognitive severity, while ADEPT provided only modest discrimination for survival and requires combination with clinical judgement. Pain-focused measures (PAINAD, PAINAD-K, PATCIE) demonstrated generally acceptable reliability but variable validity, with floor effects and concerns that PAINAD may reflect general distress in acute hospitals, and the chart-review study highlighted frequent, often moderate-to-severe pain but a persistent gap between recorded pain scores and timely, appropriate analgesic management in routine practice.

Across settings, several measures demonstrated acceptable reliability and basic construct validity in advanced dementia populations. EoLC-AD and the EOLD family instruments capture multiple end-of-life domains relevant to comfort and quality of dying, while SIRS offers a stage-appropriate index of cognitive severity with minimal floor effects and reduced influence of education or ethnicity. Pain tools such as PAINAD-K and PATCIE showed good internal consistency and sensitivity to change with movement, suggesting they can support behavioural pain assessment when self-report is no longer feasible.

However, the psychometric evidence base remains limited and uneven, particularly for survival and pain measures. ADEPT showed only modest discrimination for 2-year mortality, indicating that prognostic scores cannot replace clinical judgement, and PAINAD raised concerns about validity in acute hospitals, where scores may reflect general distress rather than pain alone. Many studies were single-country with modest samples, restricted settings, and incomplete COSMIN-level evaluations (e.g. little information on responsiveness, interpretability or measurement error), limiting confidence in generalisability and in how these instruments should be combined in routine end-of-life care for advanced dementia.

Implications for practice

The findings indicate that no single instrument can cover the full assessment and needs of people with advanced dementia at the end of life, so combining tools to make the assessment is essential. A practical approach is to use the end of life measure such as EoLCAD or an EOLD scale to assess the quality of dying and comfort, alongside SIRS when self report is difficult to occur. Routine nursing documentation should clearly record which tool, the observed behaviour or symptoms and the resulting score and it should be embedded in protocols that affect clinical actions as pain assessment reviews, medication prescription, family consultation or further procedures when scores indicate the need for that. Education and ongoing support are needed to help nurses interpret behaviours of patients, distinguish pain from other causes and assess the symptoms appear on patients, and advocate for the right and timely palliative interventions based the assessments conducted.

Future research should focus on psychometric evaluation of the measures of end of life in patients with advanced dementia, with

the use of COSMIN-informed methods to address content validity, structural validity, responsiveness and interpretability through different care settings and cases. There is a need for more types of studies as multicentre, cross-cultural, also for comparisons of instruments, and evaluations of how integrated assessment bundles (combining global, cognitive and pain measures) affect clinical decision-making, family communication and patient-centred outcomes at the end of life.

LIMITATIONS

This review was limited to peer-reviewed quantitative studies published in English, which may have excluded relevant evidence from other languages or grey literature. The number of studies focusing on the assessment of advanced dementia at end of life were limited, that's why the there where more focus on the pain assessment as that topic attracted attention in people with advanced dementia. most included studies were single centre with modest size of samples in limited number of countries, and this may limit the generalisability of the findings and the feasibility assessments to other health care systems and different cultures. reporting of several COSMIN domains such as responsiveness, measurement error and interpretability was incomplete in many studies which restricted the ability to compare instruments rigorously Considerable heterogeneity in designs, settings, populations and outcome definitions meant that meta-analysis was not feasible, and the synthesis therefore relied on narrative grouping, which may introduce some subjectivity despite the use of a structured review matrix. Considerable heterogeneity in designs, settings, populations and outcome definitions meant that meta-analysis was not feasible, and the synthesis therefore relied on narrative grouping, which may introduce some subjectivity despite the use of a structured review matrix.

CONCLUSION

Available end-of-life assessment measures for advanced dementia provide important, but partial, coverage of comfort, symptom burden, prognosis, cognition and pain. The combination of end-of-life tool, SIRS and a behavioural pain scale is suggested to be more reliable than depending a single measure, but further COSMIN-informed validation and implementation research is needed to improve end-of-life assessment in advanced dementia. Further COSMIN-informed validation and implementation research is needed to refine these instruments, test them in diverse care settings and ensure that assessment meaningfully informs person-centred palliative care at the end of life in advanced dementia.

Author Contributions

Faten and Ebtisam collaborated on the study title and protocol, Nurah completed the search strategy, reviewed by Mohammed, Faten and Ebtisam handled screening, quality appraisal, and data extraction, supervised by Nurah, Ebtisam drafted the manuscript, with input from Mohammed and Nurah. All authors approved the final manuscript.

Funding

The authors did not receive any funding for this work.

Availability of data and materials

The data that supports the results and findings of this systematic review can be found in either the main paper. Any other data from the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate Not applicable. Consent for publication Not applicable.

Competing interests

The authors declare no competing interests.

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