



DEVELOPMENT OF A TERMINAL PATIENT ASSESSMENT INSTRUMENT BASED ON ADVANCE CARE PLANNING: A SYSTEMATIC REVIEW

Erwin Aprilia Puji Lestari^{1,2*}, Ah. Yusuf¹, Ika Nur Pratiwi¹, Daniel Nong Danche¹

¹Faculty of Nursing, Universitas Airlangga, Mulyorejo, Surabaya, Jawa Timur 60115, Indonesia

²Nursing Profession, Islamic Sakinah Hospital, Jl. R.A Basuni No.12, Jampirogo, Sooko, Mojokerto, Jawa Timur 61361, Indonesia

*aprilwinpl@gmail.com

ABSTRACT

Terminally ill patients in the Intensive Care Unit (ICU) require a comprehensive assessment to support clinical decision-making and individualized care. However, existing assessment instruments do not fully integrate Advance Care Planning (ACP). This systematic review aimed to identify the key components of terminal patient assessment instruments incorporating ACP. A systematic review was conducted following the PRISMA guidelines. Electronic databases were searched using keywords related to terminal patients, assessment instruments, ACP, and ICU. Eligible studies were analyzed using narrative synthesis. The review identified key assessment domains, including neurological status, physical symptoms, functional performance, psychosocial condition, spiritual needs, communication with patients and families, and goals of care. Most instruments did not comprehensively integrate ACP components, resulting in variations in assessment and documentation practices. Integrating ACP into terminal patient assessment instruments may improve identification of patient needs, documentation quality, and nursing decision-making in the ICU.

Keywords: advance care planning; assessment instrument; intensive care unit; palliative care; terminal patient

INTRODUCTION

Assessment of terminally ill patients is a comprehensive evaluation process conducted to identify clinical conditions, symptoms, functional status, and the patient's psychological, social, and spiritual needs, as well as their goals of care, to serve as the basis for clinical decision-making and the development of nursing care plans. The accuracy of clinical decision-making is greatly influenced by the quality of the assessment conducted. This multidimensional assessment process is conducted to gain a comprehensive understanding of the patient's condition, encompassing physical, psychological, social, and spiritual aspects, as well as the goals of care, to support patient and family centered clinical decision-making (Gray et al., 2022).

Terminal illness is an incurable disease that typically occurs in advanced stages. The orientation of services provided to patients no longer curative, but rather focused on care that assists patients in achieving the best possible quality of life for themselves and their families (Maulana et al., 2024). Standard instruments utilized in terminal patient care encompass the management of pain and symptoms, psychological, social, and spiritual support, as well as advance care planning (Permenkes. 2023). The lack of standardized assessment instruments for terminal patients potentially results in unidentifiable physical, psychological, social, and spiritual needs, as well as their care goals, thereby hindering the development of an appropriate care plan. This can result in the patient's preferences regarding end-of-life care not being properly documented, increasing the risk of interventions that do not align with the patient's values and wishes, exacerbating conflicts in shared decision-making with the family, and reducing the quality of palliative care and the patient's quality of life during the terminal phase (Gray et al., 2022).

Various instruments assess different aspects of terminally ill patients, including consciousness (GCS), functional status (PPS), symptom intensity (ESAS), and palliative care needs (PCST and NECPAL), requiring multiple tools for comprehensive assessment (Zhang et al., 2026). Combining instruments

can improve prognostic accuracy, as shown by PPS and MEWS in advanced cancer patients (Tashkandi et al., 2024), the Surprise Question and PCST for end-of-life identification (Yen et al., 2022) and NECPAL for identifying palliative care needs and ICU mortality risk (Spadaro et al., 2025). These findings indicate that no single instrument adequately captures the complexity of terminal illness; therefore, assessment should integrate clinical, functional, psychosocial, spiritual, and follow-up care aspects to support appropriate care goals.

According to WHO, although more than 80% of countries have policies supporting palliative nursing services, only 14% of patients with critical or chronic conditions receive palliative care (Huriani et al., 2022). Documentation of goals of care also remains incomplete, with only 68% of patients in Australia and New Zealand having documented care goals (Yeo et al., 2026). In Indonesia, 73.8% of nursing documentation at Dr. Zainoel Abidin Hospital was incomplete (Mardevian et al., 2025). While international studies similarly found limited documentation of family meetings, psychosocial needs, standardized symptoms, patient wishes, and wellbeing (Bijnsdorp et al., 2023; Lo et al., 2020; Sjöberg et al., 2021). Meanwhile, in East Java, no specific study has reported the completeness of terminal patient assessments incorporating goals of care.

In alignment with this, standards for terminal patient care have also been officially regulated (Permenkes, 2023). The assessment instruments for terminally ill patients currently in use have proven effective in evaluating patients' conditions; however, their implementation in hospitals remains suboptimal. Clarity regarding the preferred course of action to be taken in the event of a deterioration in the patient's condition is also crucial for achieving the goals of palliative care (Huriani et al., 2022).

Previous research indicates that advancements in palliative care emphasize the importance of Advance Care Planning (ACP) as a communication process that helps patients, families, and healthcare providers discuss values, goals, and future care preferences. ACP is now viewed as an integral part of patient-centered care and must be documented so that this information is available when clinical decision-making is required. However, the implementation of ACP in various healthcare facilities still faces challenges, primarily because ACP documentation is often not integrated with clinical documentation or nursing assessments, meaning that information regarding care goals and preferences is not always easily accessible to healthcare providers. The implementation of ACP integrated into electronic health records has been shown to improve the completeness of documentation and support continuity of care (Mcmahan et al., 2023).

Nevertheless, the clinical benefits of ACP remain inconsistent across settings. A cluster-randomised controlled trial among care-dependent, community-dwelling older persons found that a structured ACP counselling intervention produced no statistically significant improvement in patient activation, quality of life, anxiety, or depression after 12 months compared with usual care (Hoffmann et al., 2023). This suggests that documenting ACP alone is insufficient; the manner in which ACP is integrated into a comprehensive, structured assessment instrument is equally important for it to meaningfully affect patient-centred outcomes.

Observations conducted in the palliative care ICU at RSI Sakinah Mojokerto revealed that assessments of terminally ill patients admitted to the palliative care ICU were performed using a terminal patient assessment tool comprising components related to pain management, symptom management, and psychological, social, and spiritual support; however, the component regarding advance care planning (ACP) has not yet been integrated into the existing assessment instrument. This indicates that the terminal patient assessment used in palliative care services at RSI Sakinah has not yet been structured in accordance with the standards set forth in Law No. 17 of 2023 on Health and Ministry of Health Regulation No. HK.01.07/MENKES/2180/2023 on guidelines for the implementation of palliative care services (Kemenkes RI, 2023).

The lack of systematic and comprehensive assessments in terminal patients can lead to physical, psychological, social, and spiritual needs, as well as care goals, not being optimally identified. This can affect timely symptom management, cause mismatched communication and decision-making, and increase the psychological burden on patients and their families. Prospective research shows that after palliative needs and symptoms are identified and addressed systematically, improvements occur in various patient symptoms, including shortness of breath by 86%, pain 72%, weakness 71%, constipation 69%, and restlessness 64%. Additionally, in the ICU population, different palliative needs are linked to differences in communication quality, healthcare provider-family relationships, and decision-making processes, while changes in palliative needs during ICU care are also related to changes in family psychological distress (Ashana et al., 2024)

Based on the results of the literature review and the identified problems, there is a need to develop a more comprehensive terminal patient assessment instrument by integrating Advance Care Planning (ACP) components into the assessment of patients in the Palliative ICU. This study aims to develop a comprehensive and holistic terminal patient assessment instrument based on Advance Care Planning (ACP), and to evaluate the validity and reliability of the instrument as an assessment tool capable of identifying patients' physical, psychological, social, and spiritual conditions, as well as patient and family communication, treatment goals, and patient care preferences. The development of this instrument is expected to provide a more comprehensive and holistic assessment, improve the quality of nursing documentation, support more appropriate decision-making regarding nursing interventions, and enhance the quality of nursing care for terminally ill patients in the Palliative ICU.

METHOD

This research employed a systematic review method following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines to identify scientific evidence regarding the barriers, readiness, and implementation of Advance Care Planning (ACP). A literature search was conducted across four databases: SINTA, ProQuest, Garuda, and PubMed, using the search terms “*Palliative Care*” OR “*Quality of Care*” AND “*Terminally Ill Patients*” AND “*Assessment Instruments*” AND “*Advance Care Planning (ACP)*” AND “*ICU.*” A total of 459 articles were initially identified from the four databases. After removing records based on language, publication year, open-access availability, and duplicates, 48 articles remained for screening. Subsequently, 27 articles were retrieved for full-text assessment, of which 21 articles were assessed for eligibility. After excluding 6 articles due to a high risk of bias, 15 articles were ultimately included in the systematic review.

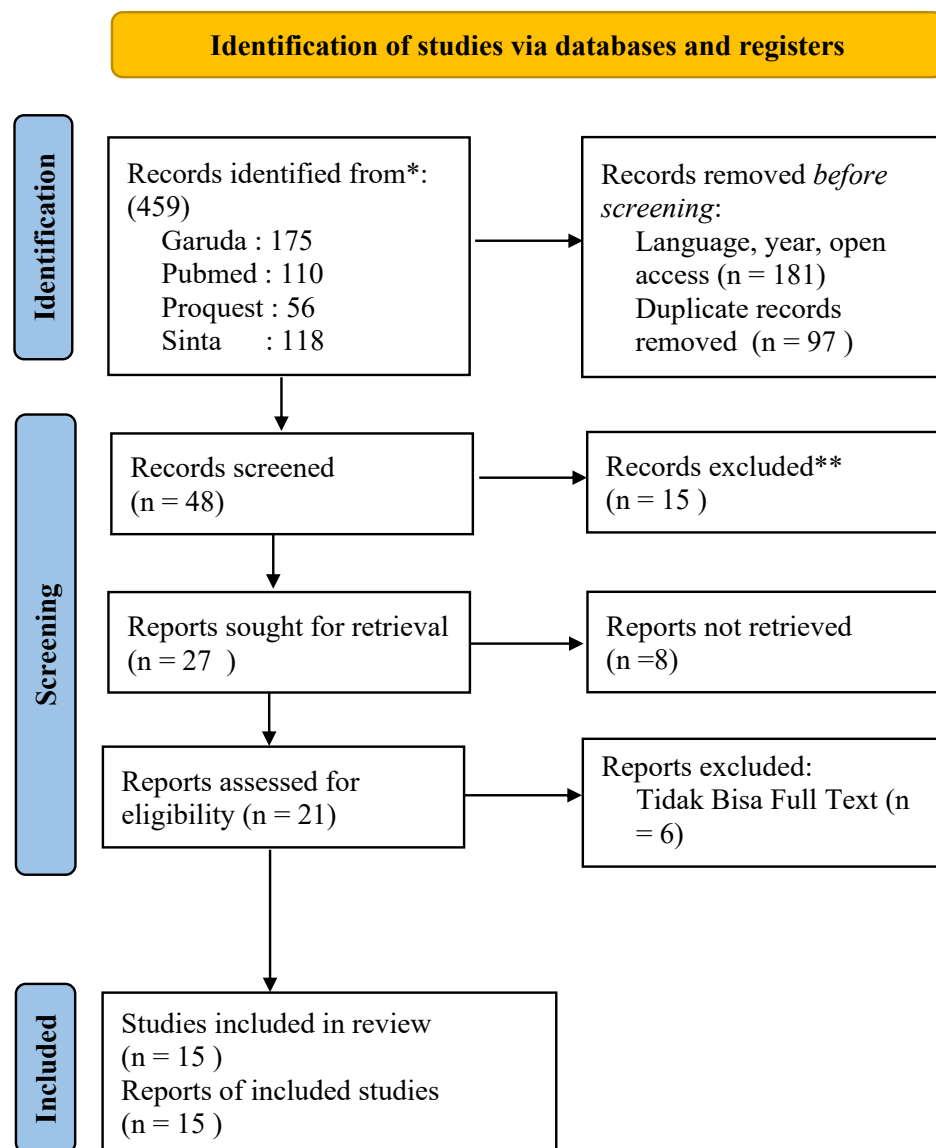
Tabel 1.
PICOT *framework*

PICOT FRAMEWORK	INCLUSION CRITERIA	EXCLUSION CRITERIA
Population	Studies discussing the assessment of terminal patients integrated with advance care planning in palliative care	Studies not discussing the assessment of terminal patients integrated with advance care planning in palliative care
Intervention	Studies discussing the development of terminal patients assesments integrated with advance care planning	No discussion regarding terminal patients assesments instruments or advance care planning in palliative care
Comparison	Development of terminal patients assesments	No exclusion criteria
Outcomes	Development of terminal patients assesments	No exclusion criteria
Publication years	2020-2025	Before 2020
Study design	<i>Retrospective, Cross sectional, Cohort study, Quasi Experiment, RCT</i>	No exclusion criteria
Language	Indonesian and English	Language other than Indonesian and English

The literature search was restricted the last five years of research, spanning from 2021 to 2025. Various studies have been conducted using a variety of research methods, including Retrospective, Cross-sectional, Cohort, Quasi-Experimental, And Randomized Controlled Trials (RCTs).

RESULT

Literature Search Result



The literature selection process was conducted systematically through four stages: identification, screening, eligibility assessment, and inclusion. A total of 459 articles were identified from four databases (Garuda, PubMed, ProQuest, and SINTA). After excluding articles that did not meet the initial criteria and duplicate articles, 48 articles were selected for the screening process. Subsequently, 27 articles proceeded to the full-text retrieval stage; however, 8 articles could not be obtained. A total of 21 articles were then assessed for eligibility, and 6 articles were excluded due to a high risk of bias. Ultimately, 15 articles met all inclusion criteria and were used in the synthesis process for this systematic review. The article selection process was conducted transparently and in accordance with the PRISMA guidelines

Table 2.
Article Characteristics

No	Author (Year)	Design	Sample	Research Focus
1	(Jeong et al., 2021)	Quasi Experimental	1,897	ACP Implementation
2	(Bijnsdorp et al., 2023)	Retrospective Review	Medical records Patient	Quality documentation EOL
3	(Choudhuri et al., 2020)	Retrospective	107	End-of-Life Care in the ICU
4	(Mulyatsih et al., 2021)	Cross-sectional	959	Nurses' perceptions
5	(Lo et al., 2020)	Prospective	27	ICU EOL Documentation
6	(Spadaro et al., 2025)	Prospective	85	NECPAL
7	(Ruhmadi & Santosa, 2022)	Comparative	24	Quality of Life
8	(Yen et al., 2022)	Cohort	111,483	PCST
9	(Huriani et al., 2022)	Cross-sectional	46	Nurses' knowledge
10	(Tashkandi et al et al., 2024)	Cohort	310	PPS and MEWS
11	(Abera et al., 2026)	Meta-analysis	856	ACP Readiness
12	(Hoffmann et al., 2023)	RCT	380	ACP Effectiveness
13	(Sjöberg et al., 2021)	Retrospective Review	92	Palliative care documentation
14	(Yamamoto et al., 2022)	Cross-sectional	598	Healthcare workers' perceptions health
15	(Jaschke et al., 2024)	RCT	80	Validation of Treat-Me ACP

The included studies comprised various study designs, namely 3 retrospective reviews, 3 cross-sectional studies, 3 cohort studies, 2 randomized controlled trials (RCTs), 1 quasi-experimental study, 1 mixed-methods meta-analysis, and 2 prospective observational studies. Most of the studies were conducted in hospitals, particularly in intensive care units (ICUs), while some were conducted in community-based and home care settings. Sample sizes varied across studies, ranging from 24 to 111,483 participants. The instruments used were also diverse, including the Advance Care Planning (ACP) form, the Palliative Performance Scale (PPS), the Edmonton Symptom Assessment System (ESAS), the Palliative Care Screening Tool (PCST), NECPAL, the WHOQOL-BREF, the Hospital Anxiety and Depression Scale (HADS), as well as various instruments for medical record documentation and the quality of palliative care services. In general, these studies addressed components of terminal patient assessment, the implementation of Advance Care Planning, palliative care documentation, palliative care needs, and factors influencing the quality of care for terminal patients.

Table 3.
Syntesis of Results

Domain	GCS	PPS	ESAS	PCST	NECPAL	ACP
Neurological	✓				✓	
Physical symptoms			✓	✓	✓	
Functional		✓				
Psychosocial			✓			✓
Spiritual						✓
Communication						✓
Goals of Care						✓

Domain 1. Neurological Status

The results of the synthesis indicate that neurological status is a key component in the assessment of terminally ill patients. Neurological assessment is used to identify clinical deterioration, determine prognosis, and aid in decision-making regarding palliative care. Several studies have used instruments such as the Palliative Performance Scale (PPS), the Modified Early Warning Score (MEWS), and NECPAL as indicators of patient condition related to mortality and palliative care needs.

Neurological assessment serves as the basis for determining the appropriate time to initiate an Advance Care Planning (ACP) discussion.

Domain 2. Physical Symptoms

Most studies indicate that the assessment of physical symptoms is a key component in terminally ill patients. The most commonly assessed symptoms include pain, shortness of breath, nausea, fatigue, impaired consciousness, and vital signs. Documentation of physical symptoms is necessary to evaluate patient needs, determine appropriate interventions, and improve the quality of palliative care. However, some studies suggest that documentation still focuses more on physical aspects than on other aspects

Domain 3. Functional Performance

Assessment of functional performance is widely used to predict prognosis in terminally ill patients, with the Palliative Performance Scale (PPS) being one of the most common instruments. A decline in PPS scores is associated with an increased risk of death and supports clinical decision-making. Studies also indicate that functional status is closely related to multidimensional quality of life, including physical, psychological, social, and environmental dimensions (Ruhmadi & Santosa, 2022). Therefore, a comprehensive terminal patient assessment should assess functional performance together with its broader impact on quality of life.

Domain 4. Psychosocial Needs

Psychosocial aspects are crucial in assessing terminally ill patients, as anxiety, depression, family support, emotional readiness, and communication affect palliative care quality. However, psychosocial needs are assessed less frequently than physical needs and should therefore be integrated into comprehensive assessment tools. A survey of Indonesian hospital nurses found psychosocial interventions were the least understood, while pain and breathing-difficulty interventions were better understood; higher position, experience, and prior training were associated with better understanding (Mulyatsih et al., 2021).

Domain 5. Spiritual Needs

Spiritual needs are one of the domains that are increasingly receiving attention in the care of terminally ill patients. Several studies indicate that documentation of spiritual support is still not consistently performed, even though spiritual needs play a crucial role in improving patients' quality of life at the end of life. Therefore, spiritual assessment needs to be part of an integrated assessment instrument for terminally ill patients.

Domain 6. Patient and Family Communication

The synthesis results indicate that communication among healthcare providers, patients, and families is a key component in the implementation of Advance Care Planning (ACP). Various studies report that discussions regarding treatment goals, prognosis, and patient preferences are often conducted too late due to time constraints, a lack of training among healthcare providers, and low readiness on the part of patients and families. These conditions result in suboptimal ACP documentation across various healthcare facilities

Domain 7. Treatment Goals and Preferences for Medical Interventions (ACP)

Nearly all studies on Advance Care Planning (ACP) emphasize documenting treatment goals, medical intervention preferences, decision-makers, and continued care. ACP improves documentation and supports decisions aligned with patients' values, although its impact on outcomes such as quality of life varies. The validated Treat-Me-ACP instrument demonstrates the importance of assessing preference changes across worsening health states and their consistency with patients' overall care goals (Jaschke et al., 2024). Thus, comprehensive terminal patient assessment tools should capture both current treatment preferences and their evolution as the patient's condition changes.

DISCUSSION

The use of prognostic tools such as the Palliative Performance Scale (PPS) combined with clinical signs can improve identification of terminally ill patients and support earlier Advance Care Planning (ACP). However, palliative care documentation remains dominated by physical aspects, while psychological, social, spiritual needs, patient values, and preferences are less systematically documented (Bijnsdorp et al., 2023; Lo et al., 2020; Sjöberg et al., 2021). Evidence shows that combining prognostic tools improves end-of-life identification, with NECPAL demonstrating higher predictive accuracy for ICU mortality than the Surprise Question alone (Spadaro et al., 2025), while combining the Surprise Question with the Palliative Care Screening Tool improved 12-month mortality prediction (Yen et al., 2022), and PPS ≤ 40 was associated with higher mortality risk (Tashkandi et al., 2024). Therefore, a comprehensive instrument integrating prognostic, functional, psychosocial, and ACP components is needed, particularly for critically ill patients in the ICU (McMahan et al., 2023).

Advance Care Planning (ACP) is a critical component of collaborative healthcare between physicians and nurses that is centered on the patient and family, particularly for patients with chronic or terminal illnesses, as well as critically ill patients. ACP is no longer understood merely as the drafting of Advance Directives (AD) or the designation of a Do Not Attempt Resuscitation (DNAR) status, but has evolved into a continuous communication process among patients, families, and healthcare providers to identify values, life goals, and future treatment preferences (Jeong et al., 2021). The evolution of the ACP concept has also been accompanied by changes in its success indicators, which are no longer focused solely on the completion of AD documents but also on improving the quality of communication, the preparedness of patients and families, behavioral changes, the involvement of surrogate decision-makers, and the alignment of care with patient preferences (McMahan et al., 2023). Various studies show that ACP implementation remains hindered by patient-level barriers such as fear of death, low health literacy, and cultural influences; family-level barriers such as conflict and poor communication; and provider-level barriers including limited time, training, confidence, and role clarity (Yamamoto et al., 2022). A systematic review and meta-analysis of 29 studies further identified barriers across patient, family, provider, and system levels, with a pooled global ACP readiness score of 77.23 (95% CI: 67.86–86.61), indicating moderate readiness (Abera et al., 2026). Therefore, comprehensive terminal patient assessment tools integrating ACP should address not only clinical and functional status but also family readiness and provider preparedness for effective implementation in the Palliative ICU.

CONCLUSION

The qualitative synthesis successfully identified barriers and enabling factors for the implementation of Advance Care Planning (ACP) stemming from patient, family, healthcare provider, and healthcare system perspectives, while the meta-analysis results indicated a high level of heterogeneity in ACP readiness. The results were appropriately interpreted through a discussion of the factors contributing to variations in findings across studies. Thus, the results of this study provide comprehensive evidence regarding the implementation of ACP while emphasizing the need for a multidisciplinary approach and strengthening of the healthcare system to improve readiness for ACP implementation in clinical practice.

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