

Quality indicators for palliative care in intensive care units: a systematic review

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Background: Establishing appropriate quality assessment indicators for palliative care in intensive care units (ICUs) is vital. This systematic review summarizes the existing quality indicators (QIs) for palliative care in ICUs. It assesses the methodological quality of QI development to pave the way for more valid QIs. **Methods:** A literature search was conducted using MEDLINE, PsycINFO, CINAHL, Cochrane databases, and the Ichushi-web database for Japanese literature for all studies published until November 2021. The included QIs were drawn from the National Consensus Project for Quality Palliative Care (NCP) and the Donabedian model of quality. Methodological quality was assessed based on the appraisal of indicators through the research and evaluation tool.

Results: Five studies were included, from which 109 indicators were extracted: 78% were process indicators, 5% were outcome indicators, and 17% were structure indicators. The most common indicators addressed the palliative care domain of "ethical and legal aspects of care" (n=38, 30%). Another distinctive feature of some indicators was a focus on supporting ICU staff. Regarding methodological quality, the "scientific evidence" varied (11–89%). Most of the data on QI measures and data sources were obtained from a review of electronic medical records (EMRs). Administrative data also provided a few measurable indicators.

Conclusions: Out of all the QIs covered in this review, most were process indicators, and only a few were outcome indicators. Ethical and legal aspects of care and support for the ICU staff emerged as unique to palliative care. Although the existing QIs can be used for palliative care in ICUs, more specific indicators are urgently needed. Continuous quality assessment and improvement, as well as the addition of more palliative care practices in ICUs, would provide further evidence and help develop valid QIs.

Keywords: Quality indicator (QI); palliative care; critical care; intensive care units (ICUs); systematic review

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Introduction

In intensive care units (ICUs), many critically ill patients and their families require palliative care to improve their quality of life and provide relief from distress (1,2). Such care can be provided simultaneously with critical or

therapeutic care (3). Approximately 20–70% of critically ill patients in ICUs experience pain, dyspnea, thirst, anxiety, depression, and other distressing issues; their physical and cognitive functions decline, causing emotional distress post discharge (4-7). Their families (4–94%) also experience

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psychological distress, including depression, anxiety, and post-traumatic stress disorder (8,9). Thus, it is crucial to maintain high-quality palliative care for such patients and their families in ICUs (10-14).

To maintain and improve the quality of care, it must be measured (15); quality indicators (QIs) are critical for taking measurements (16). QIs can indicate good quality care (e.g., the proportion of patients whose pain assessment is well documented within the first day of hospitalization) and aspects that need improvement. Several studies have developed QIs of palliative care in the context of critical care (17-19). Additionally, some reviews of palliative care QIs in critical care settings, including cardiac ICUs (20), as well as in cases of cardiovascular diseases (21) and surgical patients (22), have clarified aspects requiring evaluation. Intensive care has developed rapidly worldwide over the last few decades, providing life-sustaining treatment and other advanced medical care to critically ill patients (23-25). Since ICUs cater to various serious illnesses, studying the QIs of ICU-specific palliative care is necessary. However, no systematic review has focused on this issue so far. The integration of palliative care in ICUs in recent years has increased the importance of identifying the relevant QIs and evaluating current practices.

This systematic review aims to provide an updated summary of the existing palliative care QIs in ICUs. It

Highlight box

Key findings

- 109 indicators were identified from 5 studies, and all 8 domains of the National Consensus Project for Quality Palliative Care were covered.
- Indicators pertaining to the ethical and legal aspects of care were the most common, highlighting the importance of support for ICU staff.

What is known, and what is new?

- The integration of palliative care in ICUs in recent years has increased the importance of identifying relevant QIs and evaluating current practices.
- This systematic review provides an updated summary of the existing palliative care QIs in ICUs.

What is the implication, and what should change?

- This article provides current information on an aspect that would improve palliative care provided to critically ill patients and also bears implications for health care providers in palliative medicine.
- The findings pave the way for developing more appropriate quality indicators in palliative care, especially in the context of ICUs.

organizes the current aspects of palliative care quality assessment in ICUs to enable their further development. Specifically, it explores the coverage of the eight domains of quality palliative care listed in the National Consensus Project for Quality Palliative Care (NCP), which contains practice guidelines for palliative care (26). The methodological quality of QI development was assessed based on the appraisal of indicators through a research and evaluation (AIRE) tool (27,28). We present this article in accordance with the PRISMA reporting checklist (available at https://apm.amegroups.com/article/view/10.21037/apm-22-1005/rc).

Methods

Our systematic review procedure was designed according to PRISMA guidelines and registered with PROSPERO in December 2021 (Registration: CRD42021291436).

Data sources and search strategy

We performed a literature search in December 2021 through the MEDLINE, PsycINFO, CINAHL, and Cochrane databases, along with the Ichushi-web database for Japanese literature. The search strategy was based on previous systematic reviews of palliative care QIs and a systematic review of ICU care (22,29-31). The search terms are presented in Appendix 1. The literature search was supplemented by a secondary manual search of citations of relevant studies. All studies published before November 2021 were included in the search. There were no language restrictions.

Inclusion/exclusion criteria

All studies that presented the development process or characteristics of palliative care QIs in ICUs that explicitly stated the numerator and denominator of the palliative care QIs or enabled inference of this information from descriptions or that focused on QIs for the care of adult patients (18 years or older) were included in this systematic review.

The review excluded studies that only reported measures related to treatment or clinical care and did not include a palliative care component, studies that measured and reported performance and adherence as outcomes of an intervention, and other publications that were not original studies.

Table 1 National Consensus Project Domains of Palliative Care (26)

Palliative care domains	Examples	N (% of total indicators)*
1. Structure and Process of Care	Organizing training and education for professionals; providing continuity of care	24 (19%)
2. Physical Aspects of Care	Measuring and documenting pain and other symptoms; assessing and managing symptoms and side effects	24 (19%)
3. Psychological Aspects of Care	Measuring, documenting, and managing anxiety, depression, and other psychological symptoms; assessing and managing the psychological reactions of patients/families	8 (6%)
4. Social Aspects of Care	Conducting regular patient/family care conferences to provide information, discuss goals of care, and offer support to patients or families; developing and implementing comprehensive social care plans	6 (5%)
5. Spiritual, Religious, and Existential Aspects of Care	Providing information about the availability of spiritual care services to patients or families	9 (7%)
6. Cultural Aspects of Care	Incorporating cultural assessments, such as the locus of decision-making and preferences of patients or families regarding the disclosure of information and truth-telling, language, and rituals	3 (2%)
7. Care of the Imminently Dying Patient	Recognizing and documenting the transition to the active dying phase; ascertaining and documenting patient/family wishes about the place of death; implementing a bereavement care plan	16 (12%)
8. Ethical and Legal Aspects of Care	Documenting patient/surrogate preferences for care goals, treatment options, and the care setting; making advance directives; promoting advance care planning	38 (30%)

^{*,} nineteen indicators covered multiple domains: fifteen indicators fell under two domains and four under three domains.

Study selection and data extraction

The study selection was conducted in two phases. First, two authors (Y.T. and K.M.) independently screened titles and abstracts. Second, they independently screened the full texts of these studies. A third author (M.M.) reviewed any disagreements over study inclusion until a consensus was reached. Rayyan, a software tool useful in supporting the screening for systematic reviews in healthcare research, was used for study selection (32,33).

For the selected studies, we summarized the country of origin, developmental design, data sources measured, and the Donabedian model of healthcare QI type (e.g., structure, process, and outcome) (34). Care structure refers to the ability of healthcare providers to fulfill patients' needs with available physical and human resources. Care signifies an action performed in response to patients' needs. Outcomes are the observed results or changes in the patient's status due to the healthcare provider's actions.

Three authors (Y.T., K.M., and M.M.) categorized each extracted indicator into eight palliative care domains, as defined by the NCP (*Table 1*) (26). If an indicator was

relevant to multiple domains, we assigned its relevance to each category. The NCP domains are as follows: (I) Structure and Process of Care; (II) Physical Aspects of Care, (III) Psychological and Psychiatric Aspects of Care; (IV) Social Aspects of Care; (V) Spiritual, Religious, and Existential Aspects of Care; (VI) Cultural Aspects of Care; (VII) Care of the Imminently Dying Patient; (VIII) Ethical and Legal Aspects of Care.

Critical appraisal of methodological quality

We used the AIRE tool to evaluate the methodological quality of the QI determination process across the sets of indicators. Prior systematic reviews of QIs (22,29,30) use the same method. The AIRE tool has 20 items across the four domains: purpose, relevance, and organizational context; stakeholder involvement; scientific evidence; and additional evidence, formulation, and usage. The tool uses a four-point Likert scale (1= strongly disagree, 2= disagree, 3= agree, 4= strongly agree) to score each item based on whether it meets the criteria. Four authors (Y.T., K.M., A.K., and H.H.) independently evaluated the data according to

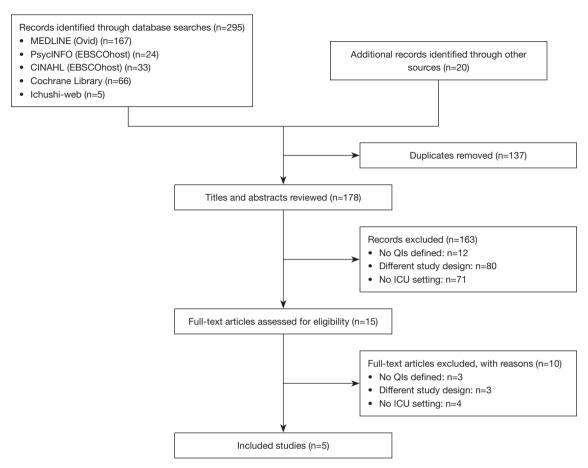


Figure 1 PRISMA flow diagram of literature search and selection process. QI, quality indicator; ICU, intensive care unit.

the recommendations of the original AIRE tool, which was prepared in Dutch.

We used the English translation of the AIRE tool available from the developer (Amsterdam UMC). The sum of the scores in each category was standardized as a percentage from 0% to 100% based on the category's maximum score, with higher percentages indicating higher methodological quality. Any additional information in the indicator development needed to complete the AIRE tool-based assessment was supplemented with external references. We summarized all QIs related to palliative care for ICU patients. Therefore, no QIs were excluded due to methodological quality.

Results

Search results

A total of 295 studies were identified during the initial search, and the manual search identified an additional

20 (*Figure 1*). After excluding duplicates, 178 titles and abstracts were reviewed; of these, 163 were excluded because they did not meet the inclusion criteria. A full-text screening of 15 studies was performed, and 5 matched the inclusion criteria. Finally, 5 studies published between 2003 and 2019 were included, and 109 indicators were extracted.

Overview of the QI sets

Table 2 shows the included studies and their characteristics (17-19,35,36). In most of these studies, a formal consensus process was used to develop indicators, and stakeholder consensus was obtained.

Patients and families were the target audience for many indicators, but some were related to healthcare team support. All five studies were conducted in the United States. The seven domains of "quality measures in palliative and end-of-life care" presented by Clarke *et al.* (17) were referenced in every study.

Table 2 Characteristics of quality indicator sets

Studies	Author, year (country)	Development methodology	Data source to measure	Structure (%)	Process (%)	Outcome (%)	Total
A	Clarke <i>et al.</i> , 2003 (USA) (17)	Literature review, expert consensus	No specific description	9	44	0	53
В	Nelson <i>et al.</i> , 2006 (USA) (18)	Literature review, expert consensus, pilot study	Medical records, Review of ICU policies and protocol	1	9	0	10
С	Mularski <i>et al.</i> , 2006 (USA) (19)	Literature review, expert consensus	Medical records, Review of ICU policies and protocol	4	14	0	18
D	Mularski et al., 2016 (USA) (35)	RAND/UCLA method: Literature review, expert panel	Medical records	0	14	0	14
Е	Kruser <i>et al.</i> , 2019 (USA) (36)	Literature review	Registry database, REDCap	5	4	5	14
Total				19 (17%)	85 (78%)	5 (5%)	109

ICU, intensive care unit; REDCap, Research Electronic Data Capture.

Based on the Donabedian model of quality categories, process indicators were the most common, accounting for 78% (n=85) of the total. For example, some process indicators focus on the provision and documentation of care, such as the record of desire for life-maintaining treatment and assessment and management of pain and dyspnea. Structural indicators accounted for 17% (n=19) of the total. They included protocols to standardize palliative care, free family visits, leaflets to provide information to families, and support available for health care providers. Outcome measures were presented in only one study (5%, n=5). These included lack of pain in the day of life, no CPR in the last hour of life, and the presence of family members at the moment of death. Most data on QI measures and data sources were derived from a review of electronic medical records (EMRs).

QIs by the domains of palliative care

Tables 1,3 show the results of the categories pertaining to palliative care listed in the NCP. The identified indicators covered all eight palliative care domains of the NCP. A total of 19 indicators addressed multiple domains; of these, 15 covered 2 domains, and 4 covered 3 domains. Since the contents of each indicator overlapped, every indicator was integrated, and sub-domains of palliative care in ICUs were established.

The most frequent NCP domain pertained to ethical and legal aspects (n=38, 30%). It included the sub-domains

"patient and family-centered decision making" and "communication within the ICU team and with patients and families". This was followed by physical aspects (n=24, 19%), which included the sub-domain "symptom management and comfort care", and structure and process of care (n=24, 19%), which included the sub-domain "support for ICU staff". By contrast, cultural aspects (n=3, 2%) and social aspects (n=6, 5%) had fewer indicators.

Critical appraisal of methodological quality of indicator development

Table 4 presents the evaluation results of the methodological quality of indicator development. The indicators were estimated from descriptions, even when the numerator and denominator were not clearly described. QI set scores were reliably high-ranking (exceeding 70%) for all constructs regarding "purpose, relevance, and organizational content." The "scientific evidence" used to develop the indicators varied between 11% to 89%. The stakeholders were mostly physicians and nurses; no patients or family members participated. Scores varied (24–77%) across the indicator set, "additional evidence, formulation, usage", which indicates specific measures and actual applications.

Discussion

This systematic review identified 5 existing indicator sets for the quality assessment of palliative care in ICUs

Table 3 Indicators classified by the National Consensus Project Domains of Palliative Care and sub-domains of palliative care in ICUs

Donabedian	Indicators: sub-domains of palliative care in ICUs	Measurement: Numerator/Denominator	Data sources	NCP		dies cove	ies covered*		
model (n, %)	maisació. Cas de maine en pamatine care in reces	modelionona Numeratori Bonominator	Data ddalood	domains**	Α	В	С	D	E
Structure	Support for ICU staff								
(n=19, 17%)	A policy that supports a regular, structured opportunity for staff to reflect on the experience of caring for dying patients	Numerator: Presence of a forum for ICU clinicians to review, discuss, and debrief the experience of caring for dying patients and their families. Denominator: ICU	Review of facility policies	1	√		√		√
	Facilitate rituals for the staff to mark the death of patients	Numerator: N/A. Denominator: ICU	Review of facility policies	1	√				
	Enlist palliative care experts, pastoral care representatives, and other consultants to teach and model aspects of end-of-life care	Numerator: N/A. Denominator: ICU	Review of facility policies	1	√				
	Communicate regularly with an interdisciplinary team regarding goals of care	Numerator: N/A. Denominator: ICU	Review of facility policies	1	√				
	Adjust nursing staff and medical rotation schedules to maximize continuity of care providers for dying patients	Numerator: N/A. Denominator: ICU	Review of facility policies	1	√				
	Open visitation policy and meeting room for family members								
	Open visitation policy for family members	Numerator: The presence of a policy in the ICU that allows for family members and friends to spend time in the patient's room, regardless of the time of day. Denominator: ICU	Review of facility policies	1			√		√
	Family meeting room: Dedicated meeting space between clinicians and ICU families	Numerator: Family meeting room: dedicated space for meetings between clinicians and families. Denominator: ICU	Review of facility policies	1, 8	√	√			
	Providing information on ICUs and continuity of care								
	Policy for continuity of nursing services	Numerator: The presence of an ICU policy that supports arranging nursing continuity for patients who stay multiple days in the ICU. Denominator: ICU	Review of facility policies	1	√		√		√
	Symptom management and comfort care								
	Emphasize the comprehensive comfort care that will be provided to the patient rather than the removal of life-sustaining treatments	Numerator: N/A. Denominator: ICU	Review of facility policies	1, 2	1				
	Institute and use uniform quantitative symptom assessment scales appropriate for communicative and non-communicative patients on a routine basis	Numerator: N/A. Denominator: ICU	Review of facility policies	1, 2	√				
	Standardize and follow best clinical practices for symptom management	Numerator: N/A. Denominator: ICU	Review of facility policies	1, 2	√				
	EOL ICU care								
	EOL-specific protocols for general symptom management	Numerator: Presence of protocols for general symptom management. Denominator: ICU	Review of facility protocols	1, 2, 7					√
	Protocol for analgesia/sedation in terminal withdrawal of mechanical ventilation	Numerator: Presence of a protocol that can be applied in settings of terminal withdrawal of mechanical ventilation. Denominator: ICU	Review of facility protocols	1, 2, 7				√	√
Process (n=85, 78%)	Providing information on ICUs and continuity of care								
	Transmission of key information with the transfer of the patient out of the ICU	Numerator: Total number of patients transferred out of the ICU with documentation showing that the goals of care and resuscitation status were communicated to the receiving team. <i>Denominator</i> : Total number of patients transferred from the ICU alive to another service in the hospital or other care facility	Review of individual medical records	1	√		√		
	Family information leaflet that includes orientation to the ICU environment and an open visitation policy for family members	Numerator: Total number of patients whose families received information leaflets from ICU team members. Denominator: Total number of patients in the ICU for 24 h	Review of individual medical records, Review of facility policies	1	√	√			
	Symptom management and comfort care								
	Documentation of pain assessment	a) Numerator: Total number of 4-h periods during the portion of the 24-h day that a patient is in the ICU or under the care of the ICU nurse for which pain is assessed and recorded using a quantitative rating scale; b) Numerator: Documentation of pain over the last 48 h; c) Numerator: Documentation of pain over the first 48 h. Denominator: Total number of 4-h periods during the portion of the 24-h day that the patient is in the ICU or under the care of the ICU nurse	Review of individual medical records	2		√	√	√	

Table 3 (continued)

Table 3 (continued)

Donabedian	Indicators: sub-domains of palliative care in ICUs	Measurement: Numerator/Denominator	Data sources	NCP	Studies			es covered*		
model (n, %)	indicators. Sub-definants of paintative state in research	Weddard Hell. Nameratory Benefit Indiana.	Data sources	domains**	Α	В	С	D	Е	
	Documentation of pain management	Numerator: Total number of 4-h periods during the portion of the 24-h day that a patient is in the ICU or under the care of the ICU nurse for which pain is assessed as 3 (or greater than mild), and there is documentation of treatment provided and of reassessment within 2 h after treatment. Denominator: Total number of 4-h periods during the portion of the 24-h day that a patient is in the ICU or under the care of the ICU nurse for which pain is assessed as 3 (or greater than mild)	Review of individual medical records	2		√	√			
	Documentation of respiratory distress assessment	a) Numerator: Total number of 8-h periods during the portion of the 24-h day that a patient is in the ICU or under the care of the ICU nurse for which dyspnea/dyssynchrony is assessed and recorded using a quantitative rating scale; b) Numerator: Documentation of dyspnea over the last 48 h; c) Numerator: Documentation of dyspnea over the first 48 h. Denominator: Total number of 8-h periods during the portion of the 24-h day that the patient is in the ICU or under the care of the ICU nurse	Review of individual medical records	2			√	√		
Process (n=85, 78%)	Documentation of respiratory distress management	Numerator: Total number of 8-h periods during the portion of the 24-h day that a patient is in the ICU or under the care of the ICU nurse for which respiratory distress/dyssynchrony is assessed as 3 (or greater than mild), and there is documentation of treatment/management plan provided and of reassessment within 2 h after treatment/management plan. Denominator: Total number of 8-h periods during the portion of the 24-h day that a patient is in the ICU or under the care of the ICU nurse for which respiratory distress/dyssynchrony is assessed as 3 (or greater than mild)	Review of individual medical records	2			√			
	Use non-pharmacologic as well as pharmacologic measures to maximize comfort as appropriate and desired by the patient and family	Numerator: N/A. Denominator: N/A	Review of individual medical records	2	√					
	Reassess and document symptoms following interventions	Numerator: N/A. Denominator: N/A	Review of individual medical records	2	√					
	Minimize noxious stimuli (monitors, strong lights)	Numerator: N/A. Denominator: N/A	Not specified	2	√					
	Attend to patient's appearance and hygiene	Numerator: N/A. Denominator: N/A	Not specified	2	√					
Process	Psychological and practical support for patients and families									
(n=85, 78%)	Documentation showing that psychosocial support has been offered	Numerator: Total number of patients in the ICU for 72 h with psychosocial support offered to the patient or family by any team member. Denominator: Total number of patients in the ICU for 72 h	Review of individual medical records	3, 4			√	√		
	Elicit and attend to the dying person's needs and their family	Numerator: N/A. Denominator: N/A	Not specified	3	√					
	Facilitate strengthening of patient-family relationships and communication	Numerator: N/A. Denominator: N/A	Not specified	3	√					
	Social work support for patients and families									
	Documentation showing that social-work support was offered to the patient/family	Numerator: Total number of patients in the ICU for 72 h with documentation showing that social-work support was offered to the patient/family. Denominator: Total number of patients in the ICU for 72 h	Review of individual medical records	4		√				
	Arrange for social support for patients without family or friends	Numerator: N/A. Denominator: N/A	Review of individual medical records	4	√					
	Distribute written material (booklet) containing essential logistical information and listings of financial consultation services and bereavement support programs/resources	Numerator: N/A. Denominator: N/A	Review of individual medical records	4	√					
	Spiritual support for patients and families									
	Documentation showing that spiritual support was offered	Numerator: Total number of patients in the ICU for 72 h with an offering of spiritual support by any team member. Denominator: Total number of patients in the ICU for 72 h and with family members visiting	Review of individual medical records	5	√	√	1	√	√	
Process	Encourage access to spiritual resources	Numerator: N/A. Denominator: N/A	Not specified	5	√					
(n=85, 78%)	Elicit and facilitate spiritual and cultural practices that the patient and family find comforting	Numerator: N/A. Denominator: N/A	Not specified	5, 6	√					

Table 3 (continued)

Table 3 (continued)

Donabedian	Indicators: sub-domains of palliative care in ICUs	Management Newsonts //Demander	5.	NCP		ered*			
model (n, %)		Measurement: Numerator/Denominator	Data sources	domains**	Α	В	С	D	Е
	Utilize expert clinical, ethical, and spiritual consultants when appropriate	Numerator: N/A. Denominator: N/A	Review of individual medical records	5	√				
	Recognize the adaptations in communication strategy required for patients and families according to the chronic vs. acute nature of illness, cultural and spiritual differences, and other influences	Numerator: N/A. Denominator: N/A		5, 6	√				
	Value and support the patient's and family's cultural traditions								
	Value and support the patient's and family's cultural traditions	Numerator: N/A. Denominator: N/A	Not specified	6	√				
	End-of-life ICU care								
	Appropriate medications are available during withdrawal of mechanical ventilation	Numerator: Total number of non-comatose patients for whom mechanical ventilation is withdrawn in anticipation of death who have orders written for opiates or benzodiazepines as scheduled or as needed. Denominator: Total number of non-comatose patients for whom mechanical ventilation is withdrawn in anticipation of death	Review of individual medical records	2,7			1	√	
	At least 1 pain assessment is documented in the EHR in the last 24 hours of life	Numerator: Total number of patients in the ICU for 24 h with documentation showing at least 1 pain assessment. Denominator: Total number of patients in the ICU for 24 h	Review of individual medical records	2,7					√
	At least 1 delirium assessment was documented in the EHR in the last 24 hours of life	Numerator: Total number of patients in the ICU for 24 h with documentation showing at least 1 delirium assessment. Denominator: Total number of patients in the ICU for 24 h	Review of individual medical records	3, 7					√
	Prepare the patient and family for the dying process	Numerator: N/A. Denominator: N/A	Not specified	3, 7	√				
Process (n=85, 78%)	Know and follow best clinical practices for withdrawing life-sustaining treatments to avoid patient and family distress	Numerator: N/A. Denominator: N/A	Not specified	2, 3, 7	√				
	Eliminate unnecessary tests and procedures (laboratory work, weights, routine vital signs) and only maintain intravenous catheters for symptom management in situations where life-support is withdrawn	Numerator: N/A. Denominator: N/A	Review of individual medical records, Administrative database	7	√				
	Care to the family after a bereavement								
	Support the family through the patient's death and bereavement	Numerator: N/A. Denominator: ICU patients' family	Review of individual medical records	7	√				
	Patient and family-centered decision making								
	Assessment of the decisional capacity of the patient	Numerator: Total number of patients in the ICU with documentation of decisional capacity made within 24 h of admission. Denominator: Total number of patients in the ICU for 24 h	Review of individual medical records	8	√		√	√	
	Documentation showing the surrogate decision maker(s) within 24 h of admission	Numerator: Total number of patients in the ICU for 24 h with documentation showing the surrogate decision maker(s) or documentation regarding the absence of any surrogate decision maker(s). Denominator: Total number of patients in the ICU for 24 h	Review of individual medical records	8	√	√	√	√	
	Documentation showing the presence and, when so, the contents of advance directives	Numerator: Total number of patients in the ICU for 24 h with documentation showing the presence or absence of an advance directive (including a living will or durable power of attorney for health care) and, when so, documentation showing the contents of the advance directive or a copy of the advance directive in the patient chart. Denominator: Total number of patients in the ICU for 24 h	Review of individual medical records	8	√	√	√	√	√
	Documentation of the goals of care	Numerator: Total number of patients in the ICU for 72 h with documentation of the goals of care. Denominator: Total number of patients in the ICU for 72 h	Review of individual medical records	8	√		√	√	
	Documentation of resuscitation status	Numerator: Total number of patients in the ICU for 72 h with documentation of the resuscitation status. Denominator: Total number of patients in the ICU for 24 h	Review of individual medical records	8	√	√			
	Recognize the patient and family as the unit of care	Numerator: N/A. Denominator: N/A	Not specified	8	√				
	Assess the patient's and family's decision-making style and preferences	Numerator: N/A. Denominator: N/A	Not specified	8	√				

Table 3 (continued)

Table 3 (continued)

Donabedian	Indicators: sub-domains of palliative care in ICUs	Measurement: Numerator/Denominator	Data sources	NCP _		Studies covered*				
model (n, %)	mulcators. sub-domains or paillauve care in 100s	Weasurement. Numerator/Denominator	Data Sources	domains**	Α	В	С	D	Е	
Process	Address conflicts in decision-making within the family	Numerator: N/A. Denominator: N/A	Not specified	8	√					
(n=85, 78%)	Initiate advance care planning with the patient and family	Numerator: N/A. Denominator: N/A.	Not specified	8	√					
	Assure patients and families that decision-making by the healthcare team will incorporate their preferences	Numerator: N/A. Denominator: N/A	Not specified	8	√					
	Follow ethical and legal guidelines for patients who lack both capacity and a surrogate decision-maker	Numerator: N/A. Denominator: N/A	Not specified	8	√					
	Help the patient and family assess the benefits and burdens of alternative treatment choices as the patient's condition changes	Numerator: N/A. Denominator: N/A	Not specified	8	√					
	Forego life-sustaining treatments in a way that ensures patient and family preferences are elicited and respected	Numerator: N/A. Denominator: N/A	Not specified	8	√					
	Communication within the ICU team and with patients and families									
	Documentation showing timely physician communication with the family	Numerator: Patients in the ICU for 24 h for whom there is documentation showing that a physician communicated with a family member or friend of the patient in person or by phone. Denominator: Total number of patients in the ICU for 24 h for whom a family member or friend can be identified	Review of individual medical records	8			√	√		
	Documentation showing a timely interdisciplinary clinician-family conference	Numerator: Patients in the ICU for 72 h for whom there is documentation showing that an interdisciplinary clinician-family conference took place that included at least one family member or friend of the patient, a physician, and another clinician (other than a physician) and for which the documentation includes a description of what was discussed. Denominator: Total number of patients in the ICU for 72 h for whom a family member or friend can be identified	Review of individual medical records	8	√	√	√	√		
	Address conflicts among the clinical team before meeting with the patient and/or family	Numerator: N/A. Denominator: N/A	Not specified	8	\checkmark					
	Meet with the patient and/or family regularly to review the patient's status and answer questions	Numerator: N/A. Denominator: N/A	Not specified	8	√					
	Communicate all information to the patient and family, including distressing news, in a clear, sensitive, unhurried manner and an appropriate setting	Numerator: N/A. Denominator: N/A	Not specified	8	√					
	Clarify the patient's and family's understanding of the patient's condition and care goals at the beginning and end of each meeting	Numerator: N/A. Denominator: N/A	Not specified	8	√					
	Designate primary clinical liaison(s) who will communicate with the family daily	Numerator: N/A. Denominator: N/A	Not specified	8	√					
	Identify a family member who will serve as the contact person for the family	Numerator: N/A. Denominator: N/A	Not specified	8	√					
Outcome	End-of-life ICU care									
(n=5, 5%)	Extubation or discontinuation of invasive mechanical ventilation before the time of death among patients receiving mechanical ventilation	Numerator: Total number of extubations or discontinuations of invasive mechanical ventilation before the time of death among patients receiving mechanical ventilation. Denominator: Total number of patients who died that received mechanical ventilation in the ICU for 24 h	Review of individual medical records, Registry database	7					√	
	Absence of CPR in the last hour of life	Numerator: Total number of patients who did not receive CPR in the last hour of life. Denominator: Total number of patients who died in the ICU	Review of individual medical records, Registry database	7					√	
	Being delirium-free in the last 24 hours of life	Numerator: Total number of delirium-free patients in the last 24 hours of life. Denominator: Total number of patients who died in the ICU	Review of individual medical records, Registry database	3, 7					√	
	Being pain-free in the last 24 hours of life	<i>Numerator</i> : Total number of pain-free patients in the last 24 hours of life. <i>Denominator</i> : Total number of patients who died in the ICU	Review of individual medical records, Registry database	2, 7					√	
	Presence of family members or other significant persons at the time of death	Numerator: Total number of patients with family members or other significant persons present at the time of death. Denominator: Total number of patients who died in the ICU	Review of individual medical records, Registry database	7					√	

^{*,} studies, A: Clarke et al., 2003 (17). B: Nelson et al., 2006 (18). C: Mularski et al., 2016 (35). E: Kruser et al. 2019 (36). **, National Consensus Project (NCP) Domains are 1: Structure and Processes of Care; 2: Physical Aspects of Care; 3: Psychological and Psychiatric Aspects of Care; 4: Social Aspects of Care; 5: Spiritual, Religious, and Existential Aspects of Care; 6: Cultural Aspects of Care; 7: Care of the Patient Nearing the End of Life; 8: Ethical and Legal Aspects of Care. ICU, intensive care unit; NCP, National Consensus Project; EOL, end of life; EHR, electronic health record; CPR, cardiopulmonary resuscitation; N/A, not available.

Table 4 Critical Appraisal of Methodological Quality of Quality Indicator Sets Using the AIRE Tool*

Methodological Characteristics	Category 1: purpose, relevance, and organizational context, %	Category 2: stakeholder involvement, %	Category 3: scientific evidence, %	Category 4: additional evidence, formulation, usage, %
Clarke EB et al. 2003	70	19	33	24
Nelson JE et al. 2006	85	86	89	62
Mularski RA et al. 2006	82	86	75	48
Mularski RA et al. 2016	90	72	28	77
Kruser JM et al. 2019	72	3	11	47

^{*,} AIRE tool, Appraisal of indicators through research and evaluation tool.

and extracted 109 indicators. These existing indicators cover all eight palliative care domains listed in the NCP, although the number of items varies by domain. As per the Donabedian classification, most indicators were process indicators (78%, n=85). Many of these were not specifics of care but were related to the presence or absence of assessment documentation. The most unique palliative care QI domain in ICUs was related to ethical and legal aspects, indicating the importance of "support for ICU staff". There were few outcome indicators (5%, n=5). Additionally, only a few studies had a high level of scientific evidence regarding the methodological quality of indicator development.

This systematic review yielded several findings. First, the high proportion of process indicators (60-70%) in palliative care QIs is similar to that reported in previous studies (22,30). Although other QI studies emphasized the importance of documenting care (37-41), documentation alone may not adequately measure the quality of care. Thus, QIs that evaluate the care itself are needed, along with those that assess documentation. To develop QIs, it is necessary to define the desired care and to propose recommendations for palliative care in ICUs. In an ICU setting, it may be difficult to establish a specific denominator and present a standard or recommended treatment approach because of each patient's various illnesses and trajectories. Clinical practice guidelines and consensus statements about pain management in critically ill, end-of-life patients propose a management algorithm to improve the overall care of such patients, but these have not been validated (42). Evidence for care other than for pain has not been well established. When the evidence for the care of distress symptoms is established in the future, it will be necessary to propose QIs consistent with the standard of care.

Second, ethical and legal aspects emerged in a high percentage as a unique attribute of palliative care QIs in ICUs; some indicators focused on supporting ICU staff. The domain of "ethical and legal aspects of care" included assessing decision-making capacity, determining surrogate decision-makers, and having discussions with the health care provider about the goals of care. Lack of decisionmaking ability is a major characteristic of patients admitted to the ICU, and the decision-making process and discussion about care goals are essential components of palliative care in ICUs (10,43,44). The lack of patients' decisionmaking capacity is a distinctive issue related to decisions to discontinue or withhold advanced life-sustaining treatments, such as being put on a ventilator or receiving dialysis. Healthcare providers must balance various medical, ethical, and legal considerations (45-49). Inadequate communication about decision-making is associated with unwanted invasive treatments at the end of life, low family satisfaction with care, and an increased prevalence of posttraumatic stress disorder-related symptoms and anxiety among family members (50-53). Thus, documentation of patient/proxy preferences regarding care objectives, treatment alternatives, and care environment, as well as instructions for and promotion of planning for care, can be indicators for supporting patient- and family-centered decision-making.

Support for ICU staff is a measure of structural aspects. It includes the availability of psychological support for ICU staff and the availability of consultation with a clinical ethics committee or palliative care expert. ICU staff who participate in end-of-life decision-making show a higher prevalence of burnout than providers in other departments (54,55). The availability of a consultation system for palliative care and a clinical ethics committee have been suggested as measures to reduce the burnout risk among ICU medical staff (54,56,57). In brief, managing the mental health of ICU staff is critical to continue providing quality care to ICU patients. Adequate training in palliative care for ICU staff is another important issue related to improving

the quality of palliative care (58). Receiving training on palliative care is associated not only with the staff's improved professional knowledge and skills but also with a reduction in their moral distress (59).

Third, a few outcome indicators (5%, n=5) were identified. Outcome indicators are essential components in the evaluation of the quality of care. While many process indicators can be evaluated without involving patients or their families, outcome indicators require asking patients about their attitudes and perceptions regarding the care they receive. A large cohort study of end-of-life patients in ICUs measured outcomes in the following categories: withholding life-prolonging treatment, discontinuing lifeprolonging treatment, actively shortening time to death, failure of cardiopulmonary resuscitation, and brain death (60). Although patient-reported outcomes (PRO) have gained importance as an outcome measure (61,62), ICU patients often cannot express their opinions. They have difficulty providing PRO data because of their reduced level of consciousness caused by illness or treatment. However, quality evaluation projects for palliative care, such as Measuring What Matters (MWM) (41) and the Palliative Care Outcomes Collaboration (PCOC) (63), have recommended and collected PRO data and family members' assessment of the quality of care.

Outcome indicators must be established to assess the quality of palliative care in ICUs. Several measurement tools have been developed and used to assess palliative care in ICUs. For example, the Family Satisfaction in the Intensive Care Unit (FS-ICU) questionnaire (53,64) evaluates the quality of care based on family satisfaction. The Quality of Death and Dying (QODD) questionnaire evaluates the quality of ICU palliative care provided to patients from the perspective of family members after the patient's death (65-69). A survey of patients/families and bereaved families using such a scale may be required to understand the outcomes of palliative care in the future.

Fourth, studies with a high level of scientific evidence for the methodological quality of QI development are lacking. This may reflect the limited effectiveness of palliative care interventions in the ICUs that were not well established at the time of the QI development. In a previous review of surgical palliative care QIs (22), the range of scores for the scientific evidence category for 17 studies was 33–100%, with the same variability as the 5 studies in this review (range, 11–89%). Scores varied between 24–77% across the indicator set "additional evidence, formulation, usage", indicating specific measures and actual applications. This

reflects the paucity of studies that piloted the indicators and discussed their actual application. QIs with high AIRE scores might be appropriate for daily evaluations, while the other sets require further development and enhancement before consideration as QIs. Palliative care practices in ICUs and their effectiveness must be evaluated and evidence accumulated to develop important QIs that should be prioritized and continuously evaluated in the future.

Future research

Future studies need to establish methods for evaluating the QIs of palliative care in ICUs following the Donabedian model of quality. While this article summarized palliative care QIs according to the traditionally used Donabedian model, classifying and measuring palliative care using the new palliative care quality assessment framework proposed by Kamal *et al.* (70) may be useful for improving patient and system outcomes. Previous studies used appropriate methods for quality assessment, such as facility surveys (71), medical chart reviews (72,73), patient surveys (74), family (bereaved family) surveys (75-77), and administrative data surveys (78-81). Therefore, it is important to consider methods for collecting and evaluating QIs of palliative care in ICUs, as well as to establish a specific QI set.

The handling of EMRs is crucial for QIs of palliative care in ICUs, and methods for dealing with these data are being developed. As this review showed, QIs of palliative care in ICUs were mostly based on content that could be obtained from EMRs. As data from EMRs are routinely collected, they have the advantage of providing clinical information without imposing any burden on healthcare providers or patients regarding secondary uses, such as research or quality assessment. Thus, the retrospective measurement of the care process from EMRs using QIs is a traditional method for measuring the quality of care. Specifically, documentation about communication, such as decisionmaking and discussion of goals of care, is important in assessing the quality of care, and it is recorded as text data in EMRs (82,83). However, evaluating these data requires both time and money, rendering manual evaluation difficult. Natural language processing and machine learning techniques have recently demonstrated the ability to handle textual data from EMRs, putting a little burden on healthcare providers or patients in palliative care settings (84-86). Chan et al. demonstrated that automatic evaluation using a deep learning algorithm system could perform accurate automated text-based information classification of serious illness conversations in the context of ICU palliative care QIs (87). This state-of-the-art technology could enable rapid auditing and feedback on documentation at the systemic and individual practitioner levels. Therefore, it is necessary to incorporate these techniques to continuously evaluate the quality of palliative care in ICUs.

Strengths and limitations

This systematic review adhered to the PRISMA guidelines and the methodological quality of QI development was assessed using the AIRE tool. However, it has several limitations. First, we systematically searched international databases containing primarily peer-reviewed scientific literature. However, we could not search EMBASE at our institution because we did not have a database subscription. Nevertheless, a manual search including gray literature was performed, which was considered complementary. It also should be noted that some QIs may have been missed, as QIs for palliative care has not always been published (88). Second, since all the studies were conducted in the United States, the results are not generalizable to other countries. While guidelines for palliative care have been reviewed and published in many countries because of the need for consideration of ethical and legal aspects (89-91), uniform international quality standards for palliative care are generally lacking, and the development and measurement of QI have not been consistently reported. Quality palliative care is also important in low- and middle-income countries (92). Future development of an international and universally applicable QI is necessary. Third, although the methodological evaluation was based on information obtained from the literature, the indicator development process was not always described in detail. Consequently, the methodological quality of the indicator set described in this review could be underestimated because the AIRE tool focuses primarily on the development process.

Conclusions

The QIs of palliative care in ICUs and 109 indicators covered all 8 palliative care domains of the NCP. Most of these indicators were process indicators, whereas few were outcome indicators. Ethical and legal aspects of care emerged as a unique domain of ICU palliative care. Most indicators pertained to this domain, and the emphasis on support for ICU staff was evident. Although existing QIs can be used to implement palliative care in the ICU, more

specific indicators are needed. In the future, implementing continuous quality assessment and improvement and adding more palliative care practices in ICUs could provide further evidence and help develop valid QIs.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work and ensure that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Supplementary

Appendix 1

Search Strategy

MEDLINE

- 1. exp Palliative Care/
- 2. ((palliative or terminal or hospice) and care).ti.
- 3. exp Life Support Care/
- 4. exp Advance Care Planning/
- exp Resuscitation Orders/
- 6. exp Withholding Treatment/
- 7. exp Hospice Care/
- 8. exp Hospices/
- 9. exp Terminally Ill/
- 10. exp terminal care/
- 11. exp Living Wills/
- 12. exp Advance Directives/
- 13. or/1-12
- 14. ("quality measure" or "quality measures" or "quality criterium" or "quality criteria" or "quality assessment").mp.
- 15. exp Quality Indicators, Health Care/
- 16. ((Quality or performance or satisf*) and (indicator* or criteri* or assess* or measur* or scale or validat*)).ti.
- 17. 14 or 15 or 16
- 18. exp Burn Units/
- 19. exp Coronary Care Units/
- 20. exp Respiratory Care Units/
- 21. exp Critical Care/
- 22. exp Emergency/
- 23. exp Trauma/
- 24. ((intensive or critical or acute or emergency or trauma) adj3 care).kw,tw.
- 25. (ICU or ICUs or SICU or SICUs or CCU or CCUs or ED or ER),kw,tw.
- 26. (burn? adj3 (unit? or centre? or center?)).kw,tw.
- 27. ((cardiac or coronary or heart) adj3 (unit? or centre? or center?)).kw,tw.
- 28. (respiratory adj3 (unit? or centre? or center?)).kw,tw.
- 29. ((surgical or surger*) adj3 (unit? or centre? or center?)).kw,tw.
- 30. (high dependency adj3 (unit? or centre? or center?)).kw,tw.
- 31. ((stepdown or step-down) adj3 (unit? or centre? or center?)).kw,tw.
- 32. (HDU or HDUs or SDU or SDUs or EDSDU or EDSDUs).kw,tw.
- 33. or/18-33
- 34. 13 and 17 and 34
- 35. (letter or editorial or comment or case reports).pt.
- 36. 35 not 36

PsycINFO

- 1. exp Palliative Care/
- 2. ((palliative or terminal or hospice) and care).ti.
- 3. exp Life Sustaining Treatment/
- 4. exp Advance Directives/
- 5. exp Treatment Withholding/
- 6. exp Hospice/

- 7. exp Terminally Ill Patients/
- 8. Terminal care.mp.
- 9. or/1-8
- 10. ("quality measure" or "quality measures" or "quality criterium" or "quality criteria" or "quality assessment").mp.
- 11. ((Quality or performance or satisf*) and (indicator* or criteri* or assess* or measur* or scale or validat*)).ti.
- 12. 10 or 11
- 13. exp Intensive care/
- 14. exp Trauma/
- 15. ((intensive or critical or acute or emergency or trauma) adj3 care).ti,ab.
- 16. (ICU or ICUs or SICU or SICUs or CCU or CCUs or ED or ER).ti,ab.
- 17. (burn? adj3 (unit? or centre? or center?)).ti,ab.
- 18. ((cardiac or coronary or heart) adj3 (unit? or centre? or center?)).ti,ab.
- 19. (respiratory adj3 (unit? or centre? or center?)).ti,ab.
- 20. ((surgical or surger*) adj3 (unit? or centre? or center?)).ti,ab.
- 21. (high dependency adj3 (unit? or centre? or center?)).ti,ab.
- 22. ((stepdown or step-down) adj3 (unit? or centre? or center?)).ti,ab.
- 23. (HDU or HDUs or SDU or SDUs or EDSDU or EDSDUs).ti,ab.
- 24. or/13-23
- 25. 9 and 12 and 24
- 26. (letter or editorial or comment or case reports).pt.
- 27. 25 not 26

CINAHL

- 1. MH "Palliative Care"
- 2. TI ((palliative or terminal or hospice or end of life) and care)
- 3. MH "terminal care"
- 4. MH "life support care"
- 5. MH "advance care planning"
- 6. MH "Resuscitation Orders"
- 7. MH "Hospice Care"
- 8. MH "Hospices"
- 9. MH "Terminally Ill Patients"
- 10. MH "Advance Directives"
- 11. MH "Living Wills"
- 12. S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11
- 13. TI ((Quality or performance or satisf*) and (indicator* or criteri* or assess* or measur* or scale or validat*))
- 14. TI ("quality measure" or "quality measures" or "quality criterium" or "quality criteria" or "quality assessment")
- 15. S13 or S14
- 16. TI (intensive or critical or acute or emergency or trauma)
- 17. TI (ICU or ICUs or SICU or SICUs or CCU or CCUs or ED or ER)
- 18. TI (burn? adj3 (unit? or centre? or center?))
- 19. TI ((cardiac or coronary or heart) adj3 (unit? or centre? or center?))
- 20. TI (respiratory adj3 (unit? or centre? or center?))
- 21. TI ((surgical or surger*) adj3 (unit? or centre? or center?))
- 22. TI (high dependency adj3 (unit? or centre? or center?))
- 23. TI ((stepdown or step-down) adj3 (unit? or centre? or center?))
- 24. TI (HDU or HDUs or SDU or SDUs or EDSDU or EDSDUs)
- 25. S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24

- 26. S12 AND S15 AND S25
- 27. PT (letter or editorial or comment or case reports)
- 28. S26 not S27

Cochrane Library

- 1. [Palliative Care]
- 2. [Terminal Care]
- 3. [Life Support Care]
- 4. [Advance Care Planning]
- 5. [Resuscitation Orders]
- 6. [Withholding Treatment]
- 7. [Hospice Care]
- 8. [Hospices]
- 9. [Terminally III]
- 10. [Palliative Medicine]
- 11. [Advance Directives]
- 12. [Living Wills]
- 13. #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12
- 14. "Quality Indicators, Health Care"
- 15. "Quality Improvement"
- 16. "Outcome and Process Assessment"
- 17. "Quality Assurance, Health Care"
- 18. "quality measure"
- 19. "quality assurance"
- 20. "quality improvement"
- 21. "14 or 15 or 16 or 17 or 18 or 19 or 20"
- 22. (intensive or critical or acute or emergency or trauma)
- 23. (ICU or ICUs or SICU or SICUs or CCU or CCUs or ED or ER)
- 24. (burn? adj3 (unit? or centre? or center?))
- 25. ((cardiac or coronary or heart) adj3 (unit? or centre? or center?))
- 26. (respiratory adj3 (unit? or centre? or center?))
- 27. ((surgical or surger*) adj3 (unit? or centre? or center?))
- 28. (high dependency adj3 (unit? or centre? or center?))
- 29. ((stepdown or step-down) adj3 (unit? or centre? or center?))
- 30. (HDU or HDUs or SDU or SDUs or EDSDU or EDSDUs)
- 31. #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30
- 32. #13 and #21 and #31
- 33. PT (letter or editorial or comment or case reports)
- 34. #32 not #33

Ichushi-web database for Japanese literature (医中誌)

- 1. (緩和ケア/TH or 緩和ケア/AL)
- 2. (ターミナルケア/TH or 終末期ケア/AL)
- 4. (緩和医学/TH or 緩和医療/AL)"
- 5. ("ターミナルケア"/TH or "End of life care"/AL)
- 6. ("アドバンスケア計画"/TH or "Advance Care Planning"/AL)
- 7. (ACP/AL)

- 8. ("ホスピスケア"/TH or "Hospice Care"/AL)
- 9. ("患者による事前指示"/TH or "Advance Directives"/AL)
- 10. ("リビングウィル"/TH or "Living Wills"/AL)
- 11. #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10
- 12. ("品質指標(保健医療)"/TH or "Quality Indicators, Health Care"/AL)
- 13. ("品質改善"/TH or "Quality Improvement"/AL)
- 14. 質評価指標/AL
- 15. "quality measure"/AL
- 16. #12 or #13 or #14 or #15
- 17. (ICU/TH or ICU/AL)
- 18. (救急/TH or 救急/AL)
- 19. (クリティカルケア/TH or 集中治療/AL)
- 20. (HCU/TH or HCU/AL)
- 21. (CCU/TH or CCU/AL)
- 22. (SICU/TH or SICU/AL)
- 23. (救命センター/TH or 救命センター/AL)
- 24. (創傷と損傷/TH or 外傷/AL)
- 25. #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24
- 26. #11 and #16 and #25
- 27. not (PT=Q&A,講義,会議録,座談会,レター,症例検討会,コメント)