A Content Analysis of Forms, Guidelines, and Other Materials Documenting End-of-Life Care in Intensive Care Units

Ellen B. Clarke, John M. Luce, J. Randall Curtis, Marion Danis, Mitchell Levy, Judith Nelson, and Mildred Z. Solomon for the Robert Wood Johnson Foundation Critical Care End-of-Life Peer Workgroup Members

Objective: **The purpose of this study was to determine the extent to which data entry forms, guidelines, and other materials used for documentation in intensive care units (ICUs) attend to 6 key end-of-life care (EOLC) domains: 1) patient and family-centered decision making, 2) communication, 3) continuity of care, 4) emotional and practical support, 5) symptom management and comfort care, and 6) spiritual support. A second purpose was to determine how these materials might be modified to include more EOLC content and used to trigger clinical behaviors that might improve the quality of EOLC.**

Participants: **Fifteen adult ICUs–8 medical, 2 surgical, and 4 mixed ICUs from the United States, and 1 mixed ICU in Canada, all affiliated with the Critical Care End-of-Life Peer Workgroup**

Methods: **Physician-nurse teams in each ICU received detailed checklists to facilitate and standardize collection of requested documentation materials. Content analysis was performed on the collected documents, aimed at characterizing the types of materials in use and the extent to which EOLC content was incorporated.**

Measurements and Main Results: **The domain of symptom management and comfort care was integrated most consistently on forms and other materials across the 15 ICUs, particularly pain assessment and management. The 5 other EOLC domains of patient and family centered decision-making, communication, emotional and practical support, continuity of care, and spiritual support were not well-represented on documentation. None of the 15 ICUs supplied a comprehensive EOLC policy or EOLC critical pathway that outlined an overall, interdisciplinary, sequenced approach for the care of dying patients and their families. Nursing materials included more cues for attending to EOLC domains and were more consistently preprinted and computerized than materials used by physicians. Computerized forms concerning EOLC were uncommon. Across the 15 ICUs, there were opportunities to make EOLC- related materials more capable of triggering and documenting specific EOLC clinical behaviors.**

Conclusions: **Inclusion of EOLC items on ICU formatted data entry forms and other materials capable of triggering and documenting clinician behaviors is limited, particularly for physicians. Standardized scales, protocols, and guidelines exist for many of the EOLC domains and should be evaluated for possible use in ICUs. Whether such materials can improve EOLC has yet to be determined.**

AVAILABLE EVIDENCE indicates that death in the intensive care unit (ICU) is often an isolated and painful experience that affords limited dignity and solace for patients and families. The same evidence suggests that communication, continuity of care, the administration of sedatives and analgesics, and other aspects of end-of-life care (EOLC) frequently are inadequate.[1-5] As a result, there is a growing commitment within the critical care community to improving EOLC in the ICU. This commitment has been evidenced by position statements from nursing and medical societies,[6-9] a directive from the Institute of Medicine,[10] the publication of a clinical text on comprehensive EOLC for critically ill patients,[11] and a variety of educational initiatives.[12-14]

Increasingly, medical and nursing practices have been influenced by the use of evidence-based management guidelines, critical pathways, and protocols. Within the ICU, the use of practice guidelines and protocols covering such areas as the management of mechanical ventilation and the administration of sedatives and neuromuscular blocking agents has resulted in improved patient outcomes and lower costs.[15-22] In other instances, however, the development and dissemination of practice guidelines has not resulted in improved patient outcomes.[23-26] A number of recent studies, examining the use of evidence based pathways and

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From the Department of Critical Care Medicine, Brown University, Rhode Island Hospital, Providence, RI; Division of Pulmonary and Critical Care Medicine, University of California, San Francisco and San Francisco General Hospital; Division of Pulmonary and Critical Care Medicine, University of Washington, Seattle, WA; Department of Clinical Bioethics, National Institutes of Health, Bethesda, MD; Division of Pulmonary and Critical Care Medicine, Mount Sinai School of Medicine; and Center for Applied Ethics and Professional Practice, Education Development Center, Inc., Newton, MA.

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Address reprint requests to Ellen B. Clarke, RN, MSN, Ed.D– 188 Union Street, Hingham, MA 02043; e-mail: pinzetta@comcast.net.

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protocols in the treatment of acute cornary syndromes, have resulted in significant improvements in patient outcomes.[27-30] What these studies have also demonstrated is that the gap that exists between evidence based therapy and the therapy that occurs in practice results mainly from inadequate guideline(s) implementation efforts at the local level, rather than a knowledge deficit.[27-30] Numerous other studies have identified the range of strategies needed for the successful implementation of practice guidelines such as, translation into behavior-triggering forms (computerized algorithms, protocols, flowsheets, and standing orders); patient and site specificity of forms; support from medical and nursing leaders, and ongoing monitoring, refinement, and feedback.[31-43] Practice guidelines translated into behavior-triggering clinical forms, when implemented successfully, have served to standardize EOLC in hospice and other settings.[44-46] Whether the successful implementation of similar evidence based clinical guidelines will result in improved EOLC in the ICU has not been examined.

Assuming that the quality of EOLC in the ICU can be improved by the successful implementation of forms, guidelines, and other materials that might trigger clinical behavior, questions exist as to whether such materials are generally available within ICUs and, if so, how they might be better designed. With these questions in mind, we conducted the following study in 15 adult ICUs in North America to determine: 1) what kinds of policies and routine forms of documentation are currently in use, 2) to what extent is EOLC content currently represented on those forms, and 3) to what extent can current documentation and data entry forms be modified to incorporate more EOLC items. We did not attempt to evaluate the consistency or quality of the materials or to determine if they had improved EOLC in the ICUs involved in the study.

MATERIALS AND METHODS

Participants

The ICUs selected for inclusion in this study were located in 15 of the 18 hospitals represented by members of the Critical Care End-of-Life Peer Workgroup. This workgroup is an interdisciplinary task force of clinicians, educators, and investigators involved in critical care and EOLC, convened under the auspices of the Robert Wood Johnson Foundation (RWJF). The hospitals were predominately urban teaching facilities with more than 300 beds and more than one ICU (Table 1).

Table 1. Demographics of 15 Intensive Care Units

Variable	Description	N
Type of hospital	University	12
	Community (university-affiliated)	2
	Federal research agency	1
Location	Urban	14
	Rural	1
Number of hospital beds	101-300	2
	301-500	7
	501-1000	4
	>1000	2
Type of ICU	Medical	8
	Surgical	2
	Combined Med/Surg	3
	Combined Med/Cardiac	2
No. of ICU beds		X = 14 Range = 9-14
No. of additional ICUs in setting		X = 3 Range = 2-6

Our goal was to involve 1 adult ICU in each hospital where a workgroup member worked. We chose not to include pediatric or neonatal ICUs because most of the workgroup members cared only for adult patients. If a workgroup member was not currently in a clinical leadership role in a particular ICU, that member appointed an appropriate institutional colleague to participate in the project. To ensure that this project proceeded from an interdisciplinary perspective and that data collection was complete and accurate, workgroup members, the majority of whom were physicians, were asked to recruit a nurse colleague to collaborate with in data collection.

Fifteen physician-nurse teams representing 8 medical ICUs, 2 surgical ICUs, and 5 mixed ICUs in the 15 North American hospitals participated in the study. Fourteen of the ICUs were from US hospitals in 13 states and the District of Columbia, and 1 was from Canada (Table 1).

Data Collection

Identified EOLC domains in the ICU. The EOLC domains were developed from 2000-2002.[47] In brief, this development was based on an extensive review of EOLC issues in the critical care setting conducted by the study coordinator (EBC) and a consensus-generating process involving the authors and other members of the RWJF Critical Care End-of-Life Peer Workgroup. The literature review did not rank articles and texts quantitatively because so little evidence-based literature was available. The consensus process involved a modified Delphi approach over a series of meetings. Six EOLC domains for use in the ICU were identified: 1) patient and family centered decision-making, 2) communication within the team and with patients and families, 3) continuity of care, 4) emotional and practical support for patients and families, 5) symptom management and comfort care, and 6) spiritual support. Subsequently, a seventh EOLC domain, emotional and organizational support for ICU staff, was identified as key in the ICU setting. Data analysis in this study did not include this domain.

Checklists. To assure standardized data collection across all 15 sites, we developed 5 checklists with an accompanying set of detailed instructions for completing each checklist, and a demographic inventory. The physician-nurse teams were asked to collaborate in completing the checklists and to return one set of completed checklists, the requested forms, and the demographic inventory to the project director.

Checklist 1 asked for medical and nursing forms used routinely in the respondents' ICUs, including assessment forms, standing orders, and bedside flowsheets. Our purposes in collecting routinely used forms were to explore the extent to which current documentation and data entry forms addressed EOLC domains and to assess how they might be modified to incorporate more EOLC items.

Checklist 2 asked for general hospital and ICU policies that were implemented in the study ICUs. We defined policies as overarching standards of care regarding a particular area of clinical practice. We listed nine policies that we thought most ICUs would have in place, and we asked for any other policies that guided care and clinical practice in their ICUs.

Checklist 3 asked for symptom assessment scales used routinely to assess pain, agitation/sedation, dyspnea, and confusion and delirium with both communicative and non-communicative patients. We selected these symptoms because they are known to be prevalent in and distressing to dying patients in the ICU, and because reliable and valid scales exist to assess them. In addition, we asked for any hospital or ICU-specific forms regarding the management of these four symptoms.

Checklist 4 asked for a range of ICU forms related to end-of-life, palliative, and comfort care. We specified the range of forms to include policies, pathways, flowsheets, procedures, caremaps, standing orders, protocols, management and/or educational guidelines, and documentation forms. We also asked for any forms that included the assessment and documentation of any items related to the six identified EOLC domains.

Checklist 5 requested forms related to caring for patients whose diagnoses are associated with an increased risk of dying in the ICU including, end-stage renal, lung, liver and heart disease, multisystem organ failure, sepsis, metastatic cancer, neurological injury, mechanical ventilation for more than 5 days, and an extended ICU stay.

Data Analysis

When all forms and checklists had been returned to the study coordinator, their accuracy and completeness were confirmed prior to content analysis. Follow-up interviews were conducted to clarify any areas of ambiguity or obtain additional forms. Forms were coded according to the following criteria:

a. whether forms were preprinted or formatted,
b. whether forms were computerized,
c. data categories represented on forms,
d. use/non-use of validated assessment scales for four specified symptoms in communicative and non-communicative patients,
e. specific assessment scales used,
f. specific form(s) where symptom assessment documented,
g. frequency with which ICU forms addressed, cued, or documented attention to items within the six EOLC domains,
h. type of form (policy or behavior-triggering document) that included EOLC domain items (We defined policies as documents that outline broad standards of care in a particular area, but which do not directly cue or trigger clinician behavior or document that a behavior has occurred. Under the category of behavior-triggering and documenting forms, we included preprinted routine data entry forms (flowsheets, admission assessments, progress notes), management guidelines, caremaps or

pathways, and standing orders and associated protocols.), and

i. Target audience (interdisciplinary, medical, and/or nursing) addressed by or routinely using each kind of form.

RESULTS

Types of Routine Documentation

Extent of medical and nursing data entry forms preprinted and computerized. Medical and nursing routine data entry forms differed according to frequency of use of preprinted formatted forms and extent of computerization. Across the 15 ICUs, nurses used the following preprinted forms routinely: a flowsheet in 100% (n = 15) of the ICUs (this was computerized in 33% (n = 5) of the ICUs); a preprinted admission assessment form in 73% (n = 11) of the ICUs [this was computerized in 20% (n = 3) of the ICUs]. Medical forms were less likely to be preprinted or computerized. Physicians used preprinted standing orders in 60% (n = 9) of the ICUs, a formatted progress note in 47% (n = 7) of the ICUs, and a formatted admission assessment in 33% (n = 5) of the ICUs. In only 2 ICUs were some medical forms computerized.

Symptom assessment scales and forms documenting symptom assessment. Across the 15 units, nurses in 93% (n = 14) of the ICUs reported using a numerical rating scale (0-10) to assess pain intensity in communicative patients; the score was charted in an identified space on the flowsheet in 78% (n = 11) of these 14 ICUs. In addition, pain assessment questions or reports appeared on: 5 of the 11 preprinted nursing admission assessments, 1 of the 7 preprinted physician's progress notes, and none of the 5 preprinted physician's admission assessments. Thirteen per cent (n = 2) of the 15 ICUs reported using a standardized scale to assess indicators of pain intensity in non-communicative patients: 1 ICU used a modified Ramsay Scale,[48] 1 ICU used a scale with behavioral and physiologic indicators.[49]

Nurses in 60% (n = 9) of the 15 ICUs used a standardized scale to assess agitation and sedation level and documented the score on the flowsheet: seven units used the Ramsay Scale,[48] 1 unit used the Sedation Level Scale,[50] and 1 ICU used the Sedation/Agitation Scale.[51] None of the participating ICUs reported using specific scales to assess either dyspnea, confusion, or delirium in communicative and non-communicative patients.

Extent of End-of-Life Care Content in Existing ICU Documents

Frequency of representation of EOLC domains on ICU forms. Table 2 (far right-hand column) displays the number of times each of the 6 EOLC domains was represented on forms and other materials used for documentation across the 15 ICUs. Collectively, the 6 EOLC domains were represented on 189 ICU forms. Across the 15 ICUs, among the 189 forms collected that addressed EOLC domains, symptom management and comfort care was the EOLC domain addressed most frequently, appearing on 60% (n = 114/189) of these ICU forms. Of the 114 symptom-related forms, pain assessment and management was integrated the most consistently, appearing on 37% (n = 42/114) of the forms related to symptoms and comfort care.

Patient and family centered decision-making was the only other EOLC domain addressed with some frequency, appearing on 21% (n = 39/189) of the EOLC-related forms. Of the 39 ICU forms which addressed patient and family centered decision-making, advance directives (n = 26/39) and patient and family bills of rights (n = 13/39) were the only items within this domain that were represented on any forms in these 15 ICUs.

The remaining 4 EOLC domains were addressed the least frequently on the 189 EOLC-related forms across the 15 ICUs: spiritual support on 6% (n = 12/189) of the forms, communication on 6% (n = 11/189) of the forms, emotional and practical support on 5% (n = 10/189) of the forms, and continuity of care on 2% (n = 3/189) of the forms.

Policies addressing EOLC domains and audience addressed. Table 2 also presents the analysis of forms according to type (policy and/or behavior-triggering form) that included items within the 6 EOLC domains and the professional audience addressed or routinely using the forms. Among 70 policies applicable to EOLC practice across the 15 ICUs, 87% (n = 61/70) addressed an interdisciplinary audience. No ICU supplied a comprehensive interdisciplinary EOLC policy. In 3 institutions, EOLC and palliative care were mentioned briefly, either as part of a bereavement pathway or on a 1-2 page broad policy statement.

The majority (96%) of the 70 EOLC-related

Table 2. Number of Times Each End-of-Life Care Domain Addressed by Type of Form and Audience Addressed

Six EOLC Domains	Policies: Interdisciplinary	Policies: Medical	Policies: Nursing	Total Policies in Each Domain (%)	Behavior-Triggering Forms*: Interdisciplinary	Behavior-Triggering Forms*: Medical	Behavior-Triggering Forms*: Nursing	Total Behavior-Triggering Forms in Each Domain (%)	Total Combined Forms Addressing Each Domain (%)
Symptom management and comfort care	33	0	7	40/70 (57)	31	14	29	74/119 (62)	114/189 (60)
Patient & family centered decision-making	27	0	0	27/70 (38)	0	2	10	12/119 (.10)	39/189 (21)
Spiritual support	0	0	0	0/70 (0)	1	0	11	12/119 (.10)	12/189 (6)
Communication	1	0	1	2/70 (.28)	3	4	2	9/119 (.07)	11/189 (6)
Emotional and practical support	0	0	1	1/70 (.01)	1	0	8	9/110 (.07)	10/189 (5)
Continuity of carey	0	0	0	0/70 (0)	0	0	3	3/119 (.02)	3/189 (2)
Behavior-triggering forms by audience addressed	61/70 (87%)	0	9/70 (13%)	70	36/119 (3%)	20/119 (2%)	63/119 (53%)	119	189

*Behavior-triggering forms include: preprinted routine data entry forms (flowsheets, admission assessments, progress notes), management guidelines, caremaps or pathways, standing orders, and protocols.

policies were associated with legal and regulatory incentives: 21% (n = 15/70) were DNR policies, 20% (n = 14/70) were forgoing life-sustaining treatment policies, 20% (n = 14/70) were advance directive policies, 19% (n = 13/70) were patient and family bill of rights policies, and 16% (n = 11/70) were pain assessment and management policies. Two ICUs had policies describing standards for clinician communication with patients and families. There were no EOLC-specific interdisciplinary policies submitted which addressed attention to patient and family centered decision-making, communication, continuity of care, emotional and practical support, and spiritual support for dying patients and their families.

Behavior-Triggering Forms Addressing EOLC Domains and Audience Using Forms

Items related to the 6 EOLC domains were represented on a total of 119 behavior-triggering forms across the 15 ICUs. Of the 119 behavior-triggering forms attending to EOLC domains, the majority, 53% (n = 63/119), were used by nurses; 30% (n = 36/119) were used by an interdisciplinary audience, and 17% (n = 20/119) were used by physicians. These disparities in the use of behavior-triggering forms addressing EOLC domains can be explained, in part, by the fact that, as previously discussed, formatted behavior-triggering forms, particularly admission assessment forms and progress notes, were not widely used by physicians across the 15 ICUs.

None of the ICUs supplied an interdisciplinary EOLC critical pathway which detailed the essential steps clinicians might follow when caring for dying patients and their families in the ICU. Nor did they have pathways or caremaps related to caring for patients whose diagnoses may increase their risk of dying in the ICU (such as end-stage renal, lung, liver and heart disease; multi-system organ failure; sepsis; metastatic cancer; neurological injury; prolonged mechanical ventilation; and an extended ICU stay).

Cues for attending to the EOLC domain of symptom management and comfort care were integrated the most consistently on a variety of the 119 behavior-triggering forms, appearing on 62% (n = 74/119) of the behavior-triggering forms. Of the 74 behavior-triggering forms addressing the domain of symptom management and comfort care, cues for pain assessment and management were integrated the most consistently, appearing on 42% (n = 31/74) of the symptom-related behavior-triggering forms. Cues for the assessment and management of the following symptoms appeared on symptom-related behavior-triggering forms with less frequency: agitation and sedation on 23% (n = 17/114) of these forms, dyspnea on 11% (n = 8/114) of the forms, and confusion/delirium on 1% (n = 1/114) of the symptom-related behavior-triggering forms within the symptom management and comfort care domain.

Preprinted nursing data entry forms included cues and questions for the assessment and documentation of the patient's physical, psychological, social, and spiritual status. Pain assessment and management cues were the EOLC items addressed most frequently on formatted nursing behavior-triggering forms, appearing on 30% (n = 19/63) of the preprinted nursing behavior-triggering forms. Preprinted medical forms included cues regarding the assessment and ongoing documentation of data related to the patient's physiology and disease, documented under system categories (ie, cardiovascular, neurological). Four of the 7 preprinted medical progress notes included a section related to counseling and communicating with patients and families and a place for the physician to indicate the time spent doing so. Cues for attending to patients' resuscitation status were the EOLC-related items that appeared most frequently on formatted physician behavior-triggering forms, appearing on 3% (n = 6/20) of the preprinted medical behavior-triggering forms.

DISCUSSION

Limited Representation of Most EOLC Domains on ICU Forms

Although certain aspects within the key EOLC domains such as symptom management were incorporated into a variety of policies and routinely used behavior-triggering forms, representation of the majority of EOLC domains on materials across the study ICUs was limited. For example, there were few policies and behavior-triggering forms that established and cued attention to communication with patients and families, despite the fact that critically ill patients and families consistently rate quality communication with ICU clinicians as one of the most valued caregiver behaviors.[52-55] The domain of patient and family centered decision-making was mainly represented in terms of cues about advance directives, although it is now well-established that advance directives are of limited usefulness in the ICU.[56-58] In addition, there was scant attention on forms to cueing caregivers about offering spiritual or religious resources to dying patients and their families.

Opportunities to Increase the Use of EOLC Behavior-Triggering Forms

In our sample, there were ample opportunities to convert EOLC policies or standards of care into behavior-triggering forms so that there could be more "cues-to-action" in the daily work environment. For example, the majority of ICUs had policies regarding forgoing life-sustaining treatments, but only half of them had caremaps, protocols, or standing orders to cue and guide clinicians in the care of patients from whom mechanical ventilation is being withdrawn. In a few ICUs, physicians wrote orders for "comfort measures only (CMO)," but it was difficult to determine how such orders should be interpreted and how they affected EOLC. Only 1 ICU had specific formatted standing physician's CMO orders for dying patients which detailed which burdensome treatments and monitoring devices should be discontinued, the guidelines for sedation and analgesia, the sequence of steps to be followed in ventilator withdrawal, and the liberalization of visitation for dying patients.[59]

Opportunities to Increase the Routine Use of Symptom Assessment Scales, Particularly in Non-Communicative Patients

Although 14 ICUs did report using a standardized pain assessment scale for communicative patients, 13 ICUs did not use a standardized scale for assessing pain indicators in non-communicative patients. Some explanations for the consistent omission across these ICUs of the use of standardized scales to assess not only pain, but dyspnea, confusion, and delirium in non-communicative patients may be related to the difficulty in reliably assessing and distinguishing symptom indicators in many critically ill patients because of intubation, severity of illness, and/or sedating medications. In addition, until quite recently, there has been a lack of reliable standardized scales to assess symptoms in non-communicative critically ill patients and few studies comparing their usefullness. A number of valid and reliable behavioral pain scales are now available for assessing pain indicators in sedated non-communicative critically ill patients.[60-63] Dyspnea severity assessment scales, such as the modified Borg Scale and the Bizek Agitation Scale, have been used to assess symptoms associated with breathlessness in those who are unable to communicate.[64-65] In addition, the Delirium Rating Scale,[66] the modified Memorial Delirium Assessment Scale,[67] and the Confusion Assessment Method for ICU[68-69] have also been validated for the evaluation of delirium in the critically ill patient.

Use of Computerized Forms, and Potential Advantages Thereof

Using pain assessment and management as an example, we observed that, in the majority of ICUs using non-computerized (paper) formatted bedside flowsheets where space is at a premium, one space was provided for the documentation of a single pain intensity score. There was no room for charting multiple pain locations, pain characteristics, type of analgesia used, or post-treatment assessment data on most of the flowsheets. In the 5 ICUs where bedside flowsheets were computerized, this additional data could be documented in a central location. In addition, some computerized flowsheets had a number of "pop-up" menus designed to trigger additional pain assessment and management options. The use of computerized flowsheets appears to enhance the clinician's ability to comprehensively assess, document, manage, and follow multiple pain loci over time, as directed by the current pain standards of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO).[70]

Was the Documentation We Observed Indicative of Poor EOLC?

We did not monitor clinical practice, collect patient outcome data, interview physicians and nurses, investigate ongoing quality improvement efforts, or undertake chart review in the ICUs included in this study. Therefore, we are unable to correlate the limited representation of EOLC domains on forms and other materials that we reviewed with the quality of EOLC in these units. We have no reason to believe that the quality of EOLC in these ICUs was poor; in fact, given the interest of clinicians in improving EOLC in the ICUs, one might expect the quality of such care might be better than average. Nevertheless, documentation is used both as an indicator of the degree of attention given to a particular practice and as an indicator of the quality of that practice by the JCAHO and other organizations. Although the shortcomings we observed do not necessarily translate into poor EOLC, they suggest at the least the need for improved documentation of EOLC, if not a need for improving EOLC itself.

LIMITATIONS

We did not study a random sample of ICUs but instead a select, albeit geographically diverse group of ICUs whose medical and nursing leadership were represented in the RWJF Critical Care End-of-Life Peer Workgroup. The ICUs were limited to North America, and most were from the U.S. Furthermore, none of the ICUs admitted children or neonates. Given that the members of the Peer Workgroup share an interest in improving EOLC, one might assume that the ICUs in which they work have as many as or more policies, data forms, and other materials that document and cue attention to EOLC than ICUs elsewhere. That we found an overall paucity of such materials suggests, but does not prove, that EOLC materials may be lacking in most ICUs.

Unfortunately, because we did not collect data on the operational characteristics of our study ICUs, we cannot explain the paucity of EOLC forms and guidelines within them and, by extension, within ICUs elsewhere. Assuming that such materials are useful, their incorporation into practice seemingly would depend on a number of factors, including a perceived need to improve such practice, institutional acceptance of the use of guidelines and forms, and their ongoing monitoring and refinement. Although the physicians and nurses in our study are interested in EOLC, local conditions may have inhibited the development and implementation of forms and guidelines within their units. In addition, because our study was performed from 2000-2002, the general lack of documentation of EOLC we observed may have reflected a lack of consensus about EOLC and the need to improve it at the time. Hopefully, such a consensus is emerging now.[6-14,47,70-72]

CONCLUSION AND RECOMMENDATIONS

The purpose of practice guidelines and derivative behavior-triggering clinical forms such as caremaps, protocols, and standing orders that we sought in the ICUs in our study is not just to document interventions but also to standardize clinical practice and improve patient care. This approach appears to succeed in areas such as the management of mechanical ventilation and the administration of sedatives and analgesics in the ICU, provided site-specific factors and strategies are employed.[15-22] Although the use of forms and guidelines has not been successful in all instances,[23-26] numerous recent studies have demonstrated improved patient outcomes when sufficient attention is given to local implementation and follow-up.[27-36] These studies and others have identified the factors needed to effect successful implementation of evidence based guidelines at the local level.[27-43] Attention to the same factors may be of potential value in improving EOLC in ICUs. Although this study could not demonstrate such improvement, we have shown that opportunities exist to improve and implement ICU guidelines and forms that might trigger clinician responsiveness to EOLC issues.

Because we believe that the effective implementation of practice guidelines and behavior-triggering forms may help improve EOLC, we recommend their development and implementation in the critical care setting. At the same time, agreement about the essential domains of EOLC in the ICU should be sought through research; consensus statements regarding how best to deliver EOLC, such as the recent recommendations for end-of-life care by the Ethics Committee of the Society of Critical Care Medicine; and other medical and nursing documents.[6-14,47,70-72] Once an EOLC guideline or pathway is written, it could be put into a computerized format and distributed among ICUs. Then, other tools, such as those used to assess pain and delirium in non-communicative patients, could be developed and evaluated.

As indicated earlier, implementation of practice guidelines are inhibited by insufficient attention to a number of factors at the local level. At the very least, such implementation requires a perceived need for improved care, institutional commitment and resources, endorsement by medical and nursing leaders, educational initiatives, and ongoing quality assurance monitoring.[27-43] To interest various institutions in adopting EOLC guidelines and forms for use in ICUs, the successful implementation of these materials must be demonstrated in pilot settings. Therefore, we recommend that, once they are developed, EOLC guidelines and forms be tested and implemented in interested sites supported by grant funding. Once they are refined, implemented, and evaluated successfully, these EOLC materials could be introduced into ICUs elsewhere. In this fashion, the opportunities for improving and standardizing quality EOLC in the ICU suggested by our study may be realized.

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REFERENCES

1. Desbiens NA, Wu AW, Broste SK, et al: Pain and satisfaction with pain control in seriously ill hospitalized adults: Findings from the SUPPORT research investigations. Crit Care Med 24:1953-1961, 1996

2. Lynn J, Teno JM, Phillips RS: Perceptions by family members of the dying experiences of older and seriously ill patients. Annals of Internal Medicine 126:97-106, 1997

3. Nelson JE, Meier DE: Palliative care in the intensive care unit, Parts I and II. J Intensive Care Med 14:130-139, 189-199, 1999

4. Nelson JE, Meier DE, Oei EJ, et al: Self-reported symptom experience of critically ill cancer patients receiving intensive care. Crit Care Med 29:277-282, 2001

5. Somogyi-Zaloud E, Zhong Z, Lynn J, et al: Dying with acute respiratory failure or multiple organ system failure with sepsis. J Am Geriatr Soc 48:S140-145, 2000

6. American Association of Critical Care Nurses Paper presented at: Designing an agenda for the nursing profession on end-of-life care: Report of the nursing leadership consortium on end-of-life care. 1999. Washington, DC

7. American Thoracic Society: Fair allocation of intensive care resources. Am J Respir Crit Care Med 156:1282-1301, 1997

8. Cassel C, Foley KM. Principles for care of patients at the end-of-life: An emerging consensus among the specialities of medicine. Milbank Memorial Fund Special Report; 1999

9. Troug RD, Cist AF, Brackett SE, et al. for The Ethics Committee of the Society of Critical Care Medicine: Recommendations for end-of-life care in the ICU. Crit Care Med 29:2332-2348, 2001

10. Institute of Medicine. Committee on Care at the End of Life: Approaching Death: Improving Care at the End of Life, Washington, DC, National Academy Press, 1997

11. Curtis JR, Rubenfeld GDEManaging Death in the ICUThe Transition From Cure to Comfort: New York: Oxford University Press; 2001

12. Education for Physicians on End-of-Life Care (EPEC). An initiative of the American Medical Associations' Institute for Ethics. Supported by a grant from the Robert Wood Johnson Foundation, EPEC Project, 1999

13. End-of-Life Nursing Consortium (ELNEC), American Association of Colleges of Nursing and the City of Hope National Medical Center, 2000

14. Danis M, Federman D, Fins J, et al: Incorporating palliative care into critical care education: Principles, challenges and opportunities. Crit Care Med 27:2005-2013, 1999

15. Meade Mo, Ely EW: Protocols to improve the care of critically ill pediatric and adult patients. JAMA 20:2601-2603, 2002

16. Brook AD, Ahrens TS, Schaiff R, et al: Effect of a nursing-implemented sedation protocol on the duration of mechanical ventilation. Crit Care Med 27:2609-2615, 1999

17. Mascia MF, Koch M, Medicis JJ, et al: Pharmacoeconomic impact of rational use guidelines on the provision of analgesia, sedation, and neuromuscular blockade in critical care. Crit Care Med 28:2300-2306, 2000

18. Devlin JW, Holbrook AM, Fuller HD: The effect of ICU sedation guidelines and pharmacist interventions on clinical outcomes and drug cost. Ann Pharmacother 31:689-695, 1997

19. Liu LL, Gropper MA: Postoperative analgesia and sedation in the adult intensive care unit: a guide to drug selection. Drugs 8:755-767, 2003

20. Hynes-Gay P, Brindley A, Chu W, et al: Implementation of an RN/RT-initiated extubation protocol. Dynamics 4:12-16, 2000

21. Pronovost PJ, Jenckes M, To M, et al: Reducing failed extubations in the intensive care unit. Jt Comm J Qual Improv 11:594-604, 2002

22. Chan PK, Fischer S, Stewart TE, et al: Practising evidence-based medicine: the design and implementation of a multidisciplinary team-driven extubation protocol. Crit Care 6:349-354, 2001

23. Grimshaw J, Russel I: Effects of clinical guidelines on medical practice: a systematic review of rigorous evaluation. Lancet 342:1317-1322, 1993

24. Kanouse D: When does information change practioner's behavior? In J Technol Assess Health Care 4:27-33, 1988

25. Horbar JD: Increasing use of antenatal corticosteroid therapy between 1990 and 1993 in Vermont Oxford Network. J Perinatol 17:309-313, 1997

26. Merritt TA, Palmer D, Bergman DA, et al: Clinical practice guidelines in pediatric and newborn medicine; implications for their use in practice. Pediatrics 99:100-114, 1997

27. Pearson TA, Laurora I, Chu H, Kafonek S: The lipid assessment project (L-TAP): a multicenter survey to evaluate the percentages of dyslipidemic patients receiving lipid-lowering therapy and achieving low-density lipoprotein cholesterol goals. Arch Intern Med 160:459-467, 2000

28. Rogers WJ, Canto JG, Lambrew CT, et al: Temporal trends in the treatment of over 1.5 million patients with myocardial infarction in the US from 1990 through 1999: the National Registry of Myocardial Infarction 1, 2 and 3. J Am Coll Cardiol 36:2056-2063, 2000

29. Mehta RH, Montoye CK, Gallogly M, et al: Improving quality of care for acute myocardial infarction: The Guidelines Applied in Practice (GAP) Initiative. JAMA 287:1321-1323, 2002

30. American Heart Association, American Stroke Association. Get with the guidelines quality improvement program. http://americanheart.org/getwiththeguidelines. Accessed Jan 4, 2004

31. Hammond JJ: Protocols and guidelines in critical care: development and implementation. Curr Opin Crit Care 6:463-468, 2001

32. Morris AH: Treatment algorithms and protocolized care. Curr Opin Crit Care 3:236-240, 2003

33. Grimshaw JM, Shirran L, Mowat G, et al: Changing provider behavior: An overview of systematic reviews of interventions. Medical Care 39(Supplement II):II-1-II-45, 2001

34. Gross PA, Greenfield S, Cretin S, et al: Optimal methods for guideline implementation: Conclusions from Leeds Castle Meeting. Medical Care 39(Supplement II):II-85-II-92, 2001

35. Daly BJ: Organizational change and improving the quality of palliative care in the ICU, in Curtis JR, Rubenfeld GDE (eds): Managing Death in the ICU: The Transition From Cure to Comfort. New York, Oxford University Press, 2001, pp 257-272

36. Bergman DA: Evidence-based guidelines and critical pathways for quality improvement. Pediatrics 103:pp 225-232(Supplement, Jan. 1999), 1999

37. Kitson A, Harvey G, McCormack B: Enabling the implementation of evidence based practice: a conceptual framework. Qual Health Care 7:149-158, 1998

38. Morris AH: Treatment algorithms and protocolized care. Curr Opin Crit Care 3:236-240, 2003

39. East TD, Heermann LK, Bradshaw RL, et al. Efficacy of computerized decision support for mechanical ventilation: Results of a prospective multi-center randomized trial. Proc AMIA Symp. 251-255, 1999

40. Carney PA, Dietrich AJ, Keller A, et al: Tools, teamwork, and tenacity: An office system for cancer prevention. J Fam Pract 35:388-394, 1992

41. Berard CM, Mahoney CD: Cost-reducing treatment algorithms for antineoplastic drug-induced nausea and vomiting. Am J Health Syst Pharm 52:1879-1885, 1995

42. Delaney CP, Zutshi M, Senagore AJ, et al: Prospective, randomized, controlled trial between a pathway of controlled rehabilitation with early ambulation and diet and traditional

postoperative care after laparotomy and intestinal resection. Dis Colon Rectum 46:851-859, 2003

43. Bader MK, Palmer S: Keeping the brain in zone. Applying the severe head injury guidelines to practice. Crit Care Nurs Clin North Am 4:413-427, 2000

44. Wrede-Seaman L. Symptom Management Algorithms: A Handbook for Palliative Care. Yakima, WA: Intellicard; 2002

45. Beresfor L. The Hospice Handbook: A Complete Guide. Boston: Little Brown; 1993

46. Poppel DM, Cohen LM, Germain MJ: The renal palliative care initiative. J Palliat Med 6:321-326, 2003

47. Clarke EB, Curtis JR, Luce J, et al: Quality indicators for end-of-life care in the intensive care unit. Crit Care Med 31: 2255-2262, 2003

48. Ramsay MA, Savage TM, Simpson BR, et al: Controlled sedation with alphaxalone-alphadolone. Br Med J 2:656-659, 1974

49. Puntillo KA: Pain management, in Schell HM, Puntillo KA (eds): Critical Care Nursing Secrets. Philadelphia, Hanley-Belfus, Inc, 2001, pp 339-34

50. Avramov MN, White PF: Methods for monitoring the level of sedation. Crit Care Clin 11:803-826, 1995

51. Riker RR, Picard JT, Fraser GL: Prospective evaluation of the Sedation-Agitation Scale (SAS) for adult critically ill patients. Crit Care Med 27:1325-1329, 1999

52. Johnson D, Wilson M, Cavanaugh B, et al: Measuring the ability to meet family needs in an intensive care unit. Crit Care Med 26:266-271, 1998

53. Meier DE, Morrison S, Cassel C: Improving palliative care. Ann Intern Med 127:225-230, 1997

54. Curtis JR, Patrick DK, Caldwell ES, et al: Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. Arch Intern Med 160:1690-1696, 2000

55. Covinsky KE, Fuller JD, Yaffe K, et al: Communication and decision-making in seriously ill patients: Findings of the SUPPORT project. J Am Geriatr Soc 48:S187-193, 2000

56. Danis M, Southerland LI, Garrett JM, et al: A prospective study of advance directives for life-sustaining care. N Engl J Med 324:882-888, 1991

57. Teno JM, Lickes S, Lynn J, et al: Do advance directives provide instructions that direct care? J Am Geriatr Soc 45:513-518, 1997

58. Teno JM, Lynn J, Wegner N, et al: Advance directives for seriously ill hospitalized patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT intervention. J Am Geriatr Soc 45:500-507, 1997

59. Reubenfeld GD, Crawford SW: Principles and practice of withdrawing life-sustaining treatment in the ICU, in Curtis JR, Rubenfeld GD (eds): Managing Death in the ICU: The Transition From Cure to Comfort. New York, Oxford University Press, 2001, pp 127-148

60. Campbell M: DMC Pain Assessment Behavioral Scale. Detroit, MI, Detroit Medical Center, 2001

61. Kwekkeboom KL, Herr K: Assessment of pain in the critically ill. Crit Care Nurs Clin North Amer 13:181-194, 2001

62. Payen J, Bru O, Bosson J, et al: Assessing pain in critically ill sedated patients by using a behavioral pain scale. Crit Care Med 29:2258-2263, 2002

63. Puntillo KA, Miaskowski CA, Gleeson S, et al: The relationship between behavioral and physiological indicators of pain, critical care patients'self-reports of pain, and opioid administration. Crit Care Med 25:1159-1166, 1997

64. Mancini I, Body JJ: Assessment of dyspnea in advanced cancer patients. Support Care Cancer 7:229-232, 1999

65. Wilson RC, Jones PW: A comparison of the visual analogue scale and modified Borg scale for the measurement of dyspnoea during exercise. Clin Sci 76:277-282, 1989

66. Trzepacz PT, Baker RW, Greenhouse J: A symptom rating scale for delirium. Psychiatry Res 23:89-97, 1998

67. Breitbart W, Rosenfeld B, Roth A: The Memorial Delirium Assessment Scale. J Pain Symp Manage 13:128-167, 1997

68. Jacobi J, Fraser GL, Coursin DB, et al: Clinical practice guidelines for the sustained use of sedatives and analgesics in the critically ill adult. Crit Care Med 30:119-141, 2002

69. Ely EW, Margolin R, Francis J, et al: Evaluation of delirium in critically ill patients: Validation of the Confusion Assessment Method for the Intensive Care Unit (CAM-ICU). Crit Care Med 29:1370-1379, 2001

70. Joint Commission on Accreditation of Healthcare Organizations. Pain Standards for 2001. Available online at: http://www.jcaho.org/standard/pm.html Accessed January 10, 2002

71. Angood PB: The end of life: Why instensivists should care (more). Crit Care Med 31:2399-2400, 2003

72. Troug RD, Burns JP: Excellence in end-of-life care; A goal for intensivists. Intensive Care Med 9:1309-15, 2002