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


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.

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protocols in the treatment of acute coronary syndromes, have resulted in significant improvements in patient outcomes.\textsuperscript{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.\textsuperscript{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.\textsuperscript{31-43} Practice guidelines translated into behavior-triggering clinical forms, when implemented successfully, have served to standardize EOLC in hospice and other settings.\textsuperscript{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).

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.\textsuperscript{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/sepsis, 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, multi-system 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...
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-triggereing 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
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


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<tr>
<th>Table 2. Number of Times Each End-of-Life Care Domain Addressed by Type of Form and Audience Addressed</th>
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<tr>
<td><strong>Six EOLC Domains</strong></td>
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<td><strong>Symptom management and comfort care</strong></td>
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<tr>
<td><strong>Patient &amp; family centered decision-making</strong></td>
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<td><strong>Spiritual support</strong></td>
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*Behavior-triggering forms include: preprinted routine data entry forms (flowsheets, admission assessments, progress notes), management guidelines, caremaps or pathways.
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 usefulness. A number of valid and reliable behavioral pain scales are now
available for assessing pain indicators in sedated non-communicative critically ill patients. 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. In addition, the Delirium Rating Scale, the modified Memorial Delirium Assessment Scale, and the Confusion Assessment Method for ICU 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).

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.

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.\textsuperscript{15-22} Although the use of forms and guidelines has not been successful in all instances,\textsuperscript{23-26} numerous recent studies have demonstrated improved patient outcomes when sufficient attention is given to local implementation and follow-up.\textsuperscript{27-36} These studies and others have identified the factors needed to effect successful implementation of evidence-based guidelines at the local level.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.

ACKNOWLEDGMENT

We thank the Robert Wood Johnson Foundation for their generous support of this project. In addition, we would like to recognize and thank all the members of The Robert Wood Johnson Foundation Critical Care End-of-Life Peer Workgroup and, in particular, the following physicians and nurses for their participation in this study:

- Timothy G. Buchman, PhD, MD and Shawn Ray, RN, MS
- E. Wesley Ely, MD, MPH and Kate Payne, RN, JD
- John Heffner, MD and Winnie Hennessey, RN, MS
- Donald Robert McCaffree, MD, Barry Gray, MD, and Yvette Gonzalez, RN, BSN
- Anne C. Mosenthal, MD and Linda McGinnis, RN, MS
- Michael Nozdrovicky, RN, MS
- Molly Osborne, MD, PhD, Dane Nichols, MD, and Devorah Overbay, RN, MS
- Henry Masur, MD and Tammy Jenkins, MSN, RN, CRNP
- Thomas J. Prendergast, MD and Ingrid Mroz, RN, MS, CNS
- Kathleen Puntillo, RN, DNsC, FAAN
- Sue Ross, RN, MS, CNS
- Cynda Rushton, DNsC, RN, FAAN and Dana Moore, RN, MS, CNS
- William J. Sibbald, MD, FRCPC, FCCHSE, Cameron Guest, MD, MEd
- Julie MacDonald, RN, MS
- Rita Smith, RN, MS
- Patsy Treece, RN, MS, CNS

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