Clinical science \_

# End-of-life care in the intensive care unit: the perceived barriers, supports, and changes needed

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### Introduction

In the United States, the majority of adult deaths occur in a hospital (1), and more than one in every five deaths occurs during or following admission to the intensive care unit (ICU) (2). Critical care physicians and nurses care for critically ill patients with the primary goals of saving lives and restoring function. Yet, despite advances in medical

Objective. To identify perceived barriers, supports and changes needed to improve end-of-life care (EOLC) in the intensive care unit (ICU) and to compare physicians' perceptions with those of nurses. Methods. We conducted a survey of critical care physicians and nurses in an academic medical center via a 3-item survey with open-ended statements regarding the strongest barriers, supports and changes needed to improve EOLC in ICU. Results. Thirty-four percent of all respondents identified physicians as the biggest barrier and thirty-three percent recognized nursing staff as the strongest support towards optimal EOLC. Improved communication was identified by 30% of respondents as the change most needed to improve EOLC. No significant differences between physicians and nurses were observed. Conclusions. Critical care physicians and nurses identified similar barriers, supports and the changes most needed to improve EOLC in the ICU. Recognition of physicians as the strongest barrier, and communication as the change most needed indicate areas for improvement. The finding of nurses as the strongest support for good EOLC provides the opportunity to strengthen their role in the care of the dying patient. Further study of these findings will help develop strategies to improve EOLC in the ICU.

Key words: End-of-life care, Intensive care unit, Physicians, Nurses.

sciences and technology, the transition from primarily curative goals to palliative goals is frequent, which makes end-of-life care (EOLC) discussions regular occurrence in the ICU. Therefore, optimizing EOLC in the ICU is a critical component of the practice of ICU medicine.

With the advent of Hospice and Palliative Medicine, specialists in EOLC such as hospital based palliative care teams are playing an increasingly important role in facilitating good EOLC in the ICU. While the number of hospitals with a palliative care team continues to increase, almost half of the hospitals with over 50 beds do not have a hospital based palliative care team (3), highlighting the need for critical care staff to be comfortable in their roles as providers of EOLC. However, even when consultative palliative care services are available, both the National Hospice and Palliative Care Organization and the American College of Critical Care Medicine emphasize the responsibility of intensivists in providing optimal EOLC (4, 5).

Cooperation and teamwork between ICU staff members is recognized as an integral component of optimal EOLC. Two essential parts of the ICU team are nurses and physicians. Both nurses and physicians identify EOLC as a frequent and challenging area of patient care (6). Previous studies comparing critical care physicians and nurses attitudes towards EOLC highlight discrepancies between their opinions (7, 8). Nurses experienced greater moral distress than their physician counterparts when dealing with EOLC (7). Although physicians felt that they included nurses and support staff in making decisions regarding EOLC; nurses perceived that their input into the plan of care was minimal (8).

The discrepancies in critical care staff's opinions regarding the delivery of EOLC suggest that there is need for improvement. Consequently, this study aimed to identify and compare the perceptions of critical care physicians and nurses in regards to barriers, supports and the changes most needed to improve EOLC in the ICU at our institution.

# Methods

The study is a cross-sectional survey of critical care physicians and nurses working at the academic tertiary medical center in the Midwestern region of the USA. The study was approved by the Mayo Clinic Institutional Review Board. A survey packet was mailed to all critical care physicians, including fellows and nurses involved in direct patient care in adult ICUs at Mayo Clinic, Rochester, MN (total of 382 mailings). The packet contained the survey, a pre-addressed return envelope, and a cover letter explaining the survey. Participants were asked to complete next 3 open-ended questions relating to EOLC in the ICU; 1. The biggest barrier towards providing good End-of-Life Care in the ICU is... 2. The strongest support towards providing good End-of Life Care in the ICU is... 3. The one change that I would make to improve current End-of-Life Care is...

The survey was self-administered and anonymous, however participants were asked to identify themselves as a physician or nurse. All responses received with proper identification (MD or RN), were included in the analysis.

The investigators independently analyzed free text responses and categorized these in terms of content and themes. The responses that could not be categorized were grouped under "Other". Disagreement was resolved by consensus. The participants' responses were compared by dividing them by professional role as physician and nurse.

# Statistical analysis

Chi square and Fisher's exact test for comparisons between two groups were used. A 2-sided P value of less than 0.05 was to be considered statistically significant. Statistical analysis was performed with JMP software (JMP, Version 5, SAS Institute inc., Cary, NC).

# Results

#### Response rates

There were 263 individual responses to at least one question with proper identification

by professional role, out of 382 mailings for a total response rate of 69%. Sixty-nine percent, 65% and 54% of participants responded, respectively, to statements related to the strongest barriers, supports and changes needed to improve EOLC in the ICU (Table 1). Due to the open-ended nature of the survey, some participants recorded more than one response to each question, and therefore the total percentages for each question could exceed more than 100 percent (Tables 4, 5).

Table 1 Survey respondents and responses by each item

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Surveyed	Total	Items					
		Barrier		Support		Change	
	N	Ν	%	Ν	%	Ν	%
Physicians	50	31	62	24	48	23	46
Nurses	332	232	70	224	67	184	55
Total	382	263	69	248	65	207	54

# *Strongest barriers to improvement of EOLC in the ICU*

A total of eight distinct categories of barriers were identified. The most identified barrier

by all participants was categorized as "physicians", as identified by 34% of respondents. Interestingly, both nurses and physicians identified physicians as the greatest barrier to optimal EOLC in the ICU with similar frequency (35% v. 29% respectively, p=0.52). Examples of responses that were categorized as "physicians" include "Drs don't like to give up even though families request comfort care" and "Physician unwillingness to "let patient go". Although not statistically significant, 23% of responses within the category of "physicians" specifically identified surgeons as hindering EOLC in the ICU. Other identified barriers along with their frequencies are listed in Table 2.

The second most commonly reported barrier, communication issues, was further broken down into three categories: communication between physicians and nurses, communication with families, and communication-in general, including communication between different services (Table 3). Overall, there were no statistically significant differences in the barriers identified by physicians and nurses.

Table 2 Barriers to end-of-life care in the intensive care unit

Barrier	Total	Total		Nurses		Physicians	
	Ν	%	Ν	%	Ν	%	— Р
Physicians	90	34	81	35	9	29	0.52
Lack of Communication	62	24	53	23	9	29	0.45
Family Issues	33	12	26	11	7	23	0.07
Lack of Education	27	10	20	9	6	19	0.06
Over-Treatment	26	10	24	10	1	3	0.20
Inadequate Time	11	4	8	3	3	10	0.12
Pain	10	4	10	4	0	0	0.61
Advance Directives	9	4	6	3	3	10	0.07
Other	59	22	55	24	4	13%	0.25

Table 3 Lack of	communication as a	barrier
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Communication	Total (63)		
Communication	Ν	%	
Between physicians and nurses	11	17	
With Families	28	44	
In general	24	38	

#### Biggest support for good EOLC in the ICU

Thirty-three percent of respondents identified nursing staff as the strongest support for good EOLC in the ICU. There was no significant difference between responses from nurses and physicians (34% RNs and 29% MDs, p=0.63) identifying nurses as the biggest support. Some of the statements identifying nursing staff include "Nursing care given to patient and family", "Freedom to use nursing judgment to increase pain medication", "Good nursing support", "Time that we are able to spend with patients". Table 4 reviews additional categories of the responses. Examples of responses categorized as "Other" include: "Feeling comfortable with it yourself", and "It is the way I would like to be treated".

Table 4 Strongest supports for good end-of-life care
in the intensive care unit

Support	Percentage*
Nursing Staff	33
Teamwork	17
Communication	14
Chaplain	11
Physicians	8
Comfort Care	8
Education	7
One on one nursing Care	6
Other	9

\*Percentages add up to more than 100% because some respondents offered more than one answer.

# *The change most needed to improve EOLC in the ICU*

Improved communication with patients, families, and among the ICU-team members, was identified by 30% of respondents as the change most needed to improve EOLC. As with the other categories, there was no significant difference between nurses and physicians (29% RNs and 30% MDs, p=0.81) identifying improved communication as the change most needed. Examples of statements categorized as communication include: "More communication between nurses/physicians and families", "Honest and compassionate communication between medical staff and patients/families early on in the patients stay here in the ICU", and "More openness to discussion". Other suggestions for the change most needed to improve EOLC in the ICU are listed in Table 5. Examples of responses categorized as "Other" include: "Quicker response from eye bank, life source, and funeral directors although the funeral home directors are usually better than donor personnel" and "Have a specialized team assists with the transition from 'fighting the illness' to providing a dignified death".

Table 5 The change most needed to provide good end-of-life care in the intensive care unit

Change Most Needed	Percentage*		
Better Communication	30		
More Education	17		
Improved Comfort Care	11		
Clear Goals/Advanced Directives	9		
Change in Physician's Attitudes	6		
Improved Environment	4		
More Time Devoted to Dying Patients	4		
More Family Support	2		
Other	18		

\*Percentages add up to more than 100% because some respondents offered more than one answer.

### Discussion

As the principal health care providers for critically ill patients, collaboration among critical care nurses and physicians is essential for providing good EOLC in the ICU. The lack of significant discrepancies between the critical care nurses' and physicians' perceptions of existing barriers, strengths, and ideas for improvement is very encouraging, but differs from previous studies. Although we are uncertain why our findings do not mirror previous literature, we hypothesize that increased focused education on EOLC at our institution (9) is likely the primary factor.

Interestingly, this study revealed that the perception of the physician as a barrier is maintained equally by both nurses and physicians. The perception by nurses of physicians being an impediment to EOLC has been demonstrated previously (6-8). However, self identification by physicians as creating a barrier to EOLC is novel. As we explore opportunities for improvement in EOLC in the ICU, it is critical to identify why physicians are perceived, by themselves and others, as the greatest barrier to the process. Previous studies on physicians' skills with EOLC have found that physicians are uncomfortable in providing EOLC (10, 11). At the time of this study, an online curriculum on EOLC (9) was a mandatory training requirement for fellows in critical care, and was available to all ICU staff. Although this study was not powered to detect differences between staff physicians and critical care fellows, we hypothesize that educational tools in EOLC will improve physician performance in this realm. In part, this finding may also represent the recognition by physicians of the disagreement that can often exist between various consultants.

Numerous physician-led consulting teams are typically involved in the care of an ICU patient. Conflicting assessments of prognosis and goals of therapy may contribute to physician impediment of optimal EOLC. A small qualitative nursing study subsequently validated by a larger investigation found that nurses felt physicians from different specialties not only had differing opinions about the patient's care and prognosis, but also gave conflicting information to family members (12, 13). Many of the respondents in our survey who categorized physicians as a barrier indicated that surgeons in particular impeded good EOLC. Examples of such responses include: "Physicians (particularly surgeons) seeing death of a patient as a direct reflection of their failure. "For example, a surgeon does a palliative surgery on a cancer patient and the pt dies from the cancer, surgeons don't want their patients to die because they just did surgery", "Death is often dragged out and prolonged", "Multisystem organ failure on 89 yr old equals death." This finding mirrored a trend found in another study done at our institution14.

Podnos and Wagman (15), highlight that surgical training has only recently begun to focus attention on palliative medicine principles. Previous work by Galante et al. (16) has identified deficiencies in education on EOLC for surgeons. An ethnographic study conducted at several ICUs by Cassell et al. (17) found that surgeons and intensivists viewed their roles and responsibilities towards patient care, and in particular EOLC, quite differently. Surgeons tended to view their role as preserving life at all costs, whereas medical critical care specialists more readily incorporated quality of life into their patient care values. Improved communication between healthcare teams and attention to the consistency of the messages to patients and their families is integral to improved EOLC. Closed ICU models of care, in which an intensivist oversees all care provided to a patient, will likely provide the best opportunity to improve the uniformity

of information regarding prognosis and recovery given to a patient and family.

In this study, physicians and nurses alike identified nurses as the strongest support for providing good EOLC in the ICU. Clearly ICU nurses spend considerably more time than physicians at the bedside with patients and their families. This additional time facilitates the building of relationships with patients and their families. These relationships between nurses and patients and families should be supported and encouraged to evolve in order to optimize EOLC in the ICU. One of the interventions described by Billings et al. (18) is a three-year project integrating the palliative care consultative service (PCCS) into the ICU setting included the Palliative Care Nurse Champions, which builds upon the existing support that critical care nurses provide for EOLC. This was a program whereby nurses who demonstrated interest in EOLC were selected to receive training on a variety of EOLC topics including communication skills, provided by a palliative care nurse-practitioner. These specially trained nurses served as advocates for good EOLC in the ICU. Subsequent training sessions filled up easily indicating the perceived benefit of the program. The final analysis of the project has not yet been reported.

Our findings are consistent with previous studies that indicate that providers of critical care consider communication as an important barrier, as well as the change most needed to providing good EOLC (7, 8, 19). Interestingly, in our survey, communication between nurses and physicians was the area within communication that was least identified as a barrier. This is in contrast to other studies which found larger discrepancies in the perceived lack of communication between nurses and physicians (8, 20). This finding may reflect the practice of multidisciplinary rounds, which are a daily occurrence at our institution. During these rounds, each ICU patient was discussed

amongst physicians, nurses, and other critical care staff including case managers, pharmacists, and nutrition support, to develop a plan of care for that patient. This practice is supported by studies investigating interventions aimed at improving communication in the ICU, led to improved satisfaction and patient care (21, 22, 23). In this study, communication with families was the area within the communication category that was most frequently thought of as a barrier. Lilly et al. (24) studied the intervention of a weekly multidisciplinary meeting with patients and families, and found that ICU staff had higher rates of agreement on plans of care. Integration of ICU families into multidisciplinary rounds is one mechanism by which communication with patients and families may be enhanced.

At the time this study was conducted, the institution did have a hospital based palliative care team, although its role in the ICU was limited. The creation of a palliative care team was cited by respondents as a change that would improve EOLC. Palliative care teams are often interdisciplinary, and collaboration between the various disciplines is highly valued. In addition to providing and teaching the knowledge and skills associated with EOLC, the palliative care team can help foster a more supportive environment within the entire healthcare team as discussions are held regarding EOLC in the ICU. In their project integrating palliative care in the ICU, some of the interventions described by Billings et al. (18) include collaboration between the PCCS and ICU staff, palliative care nurse champions, and staff education on a variety of issues. Their findings thus far indicate that ICU staff has higher satisfaction and comfort with EOLC as a result of integrating the PCCS in the ICU.

Cooperation between critical care providers and palliative medicine services is integral to optimal EOLC in the ICU. The primary goals of critical care medicine is

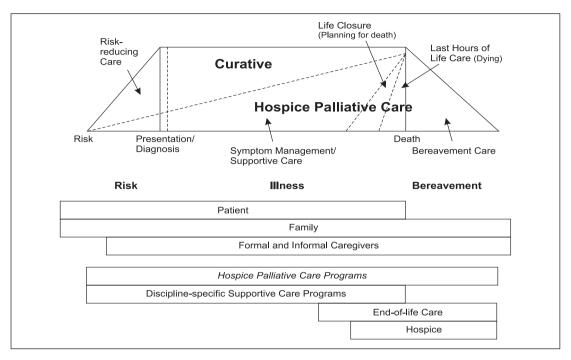


Figure 1 Continuum of curative modalities and palliative care

Palliative care within the experience of illness, bereavement, and risk. From Frank D. Ferris, MD, Medical Director, Palliative Care Standards/Outcomes, San Diego Hospice, 4311 Third Avenue, San Diego, CA, USA 92103–1407

saving or prolonging life, and that of palliative care is alleviating suffering and improving quality of life. In a model demonstrating the integration of these two disciplines, Byock (25) highlights that the primary goal of each discipline, is the secondary goal of the other. Ferris (26) further illustrates this model whereby curative modalities and palliative care coexist upon a continuum and should be addressed simultaneously upon presentation (Figure 1).

#### Limitations

The study was conducted at a single large academic institution in the Midwestern United States, and results may not be applicable to all critical care settings. The lack of significant differences in the views of physicians and nurses could potentially be due to the small sample size of physicians. While the open-ended nature of this survey did allow for a range of responses, the depth of responses was limited by the survey format of the study. Additionally, the perceptions of other critical care team members, such as case managers and hospital chaplains, the opinions of patients and family members, and the effects of an evolving hospital based palliative care team on EOLC in the ICU, are areas that were not examined and that deserve further study.

# Conclusions

Both critical care nurses and physicians identified similar barriers, supports, and changes needed to improve EOLC in the ICU. Physicians were more than any other category considered to be the strongest barrier. Nurses were thought of as the strongest support by the most respondents. The change most needed to improve EOLC in the ICU was found to be improved communication in general. Recognition and improved understanding of these factors is critical for designing strategies for improved EOLC in the ICU. This study illustrates the need to enhance physician education and the practice of EOLC, and improving teamwork between physicians of differing specialties. Additionally, increased attention to the development, and support of the role of nurses is integral to providing good EOLC. This study serves as a starting point for further focused quantitative and qualitative analysis, including in-depth interviews, of EOLC in the ICU.

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**Conflict of interest:** The authors declare that they have no conflict of interest. This study was not sponsored by any external organisation.

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