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Integrating Palliative Care in the ICU:

The Nurse in a Leading Role

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The IPAL-ICU Project™*

Abstract

Palliative care is increasingly recognized as an integral component of comprehensive intensive care for all critically ill patients, regardless of prognosis, and for their families. Here we discuss the key role that nurses can and must continue to play in making this evidence-based paradigm a clinical reality across a broad range of ICUs. We review the contributions of nurses to implementation of ICU safety initiatives as a model that can be applied to ICU palliative care integration. We focus on the importance of nursing involvement in design and application of work processes that facilitate this integration in a systematic way, including processes that ensure the participation of nurses in discussions and decision making with families about care goals. We suggest ways that nurses can help to operationalize an integrated approach to palliative care in the ICU and to define their own essential role in a successful, sustainable ICU palliative care improvement effort. Finally, we identify resources including The IPAL-ICU Project™, a new initiative by the Center to Advance Palliative Care that can assist nurses and other healthcare professionals to move such efforts forward in diverse critical care settings.

Keywords

intensive care; nurse's role; palliative care

Over the last decade, the idea that palliative care should be provided along with intensive care, regardless of prognosis, has evolved from a novel formulation to a clinical practice guideline.¹⁻⁴ Almost all critically ill patients and their families have palliative care needs, including relief of distressing symptoms; effective communication about goals of care; alignment of therapies with patient values, goals, and preferences; and planning for transitions to other settings. Meeting these needs is important both for patients expected to benefit from ICU treatment and those likely to die despite intensive care, as well as for their families. Integration of palliative care in the ICU is also important for supporting critical care clinicians and for appropriate use of scarce and expensive critical care resources.

How, then, do we integrate palliative care with intensive care? How does this paradigm become day-to-day practice? How is the idea translated into clinical reality across a broad range of ICUs? In this article, we discuss the key role that nurses can continue to play in addressing the ongoing challenge of implementation. We review the contributions of nurses to implementation of ICU safety initiatives as a model that can be applied to ICU palliative care integration. We focus on the importance of nursing involvement in design and application of work processes that facilitate this integration in a systematic way, including processes that ensure the participation of nurses in discussions and decision making with families about care goals. Finally, we identify resources including The IPAL-ICU Project™, a new initiative by the Center to Advance Palliative Care,⁵ that can help nurses and other healthcare professionals to integrate intensive care and palliative care successfully in diverse critical care settings.

LESSONS FROM THE CATHETER-RELATED BLOODSTREAM INFECTION INITIATIVE

Efforts led by the Johns Hopkins Safety and Quality Research Group have achieved extraordinary and sustained successes in reducing catheter-related bloodstream infections in

ICUs across the entire state of Michigan and many other parts of the country.^{6,7} These successes were not the result of new research on more effective antiseptic strategies, nor did they entail the use of sophisticated technology or other expensive resources. Instead, they were the product of more consistent performance of evidence-based care processes, which in turn was supported by a well-designed system for care and by a shared commitment to safety and quality improvement by all members of the ICU team and hospital leaders.^{8,9} ICU physicians and nurses worked together to identify barriers to performance, such as lack of proximity of essential antiseptic supplies, and to develop strategies to overcome these barriers, such as a bedside cart stocked with all necessary equipment for sterile catheter insertion. Primary responsibility for ensuring compliance with the protocol was given to nurses. They used a simple checklist to confirm performance of essential steps. More importantly, they had authority to suspend a procedure until the physicians performed all of these steps. In a few months, catheter-related bloodstream infections disappeared—for good. The necessary care processes, such as strict hand washing and full barrier precautions, had been known for years. Guidelines directing physicians to use these processes had long been published. But successful implementation depended on design of a simple and efficient system, on empowerment of nurses to enforce adherence, and on a conducive culture supported by the interdisciplinary ICU team.⁸

Lessons from the catheter-related bloodstream initiative are relevant and important for improving ICU palliative care integration. Just as for prevention of catheter-related infections, evidence already supports certain care processes as best practices for ICU palliative care,^{10–12} and professional societies and other organizations have issued guidelines recommending performance of these processes.^{1,13–15} Still, clinical practice lags behind research knowledge, and implementation is inconsistent. For example, a series of studies has established the value of proactive clinician-family communication about appropriate care goals for critically ill patients, showing favorable impact on family psychological well-being, consensus among decision makers, and utilization of ICU resources.^{16–20} An interdisciplinary approach to such communication is a standard of high-quality care.^{11,14} Yet, timely and reliable performance of interdisciplinary family meetings remains the exception rather than the rule in many ICUs. In some hospitals, ICU work systems have been redesigned to facilitate such meetings, using creative approaches to call attention to patients and families for whom a meeting is due, to simplify scheduling and maximize both availability and convenience of clinicians, to involve palliative care specialists in challenging situations, to prepare families so that their questions and needs are addressed, and to ensure appropriate documentation of the discussion.^{21,22} Nurses have been especially innovative and resourceful in developing approaches for this purpose, which have improved family meeting performance in their ICUs.²¹ They have also embraced training in relevant knowledge and skills to support their own active participation in family meetings as essential members of the interdisciplinary ICU team.

As Dr Pronovost,⁸ who conceived and led implementation of the catheter infection initiative, has emphasized, the sustainability of any improvement effort requires a conducive “culture” in the ICU and hospital. Essential components of this culture are inclusiveness and respect for all members of the ICU team, with open communication between physicians and nurses. Whereas attention has been focused mainly on checklists, Pronovost²³ recently stressed that these kinds of tools “only get us part way down the field. To reach our ultimate goal... we must engage teams to embrace the concepts behind checklists and become full partners in developing and improving [them].”²³ He points out that his “first bloodstream infection checklist failed because doctors didn’t use it. And when nurses tried to remind doctors, they were ignored, or berated. Many were reluctant to speak up. In order to achieve the results we wanted, we had to change the way teams worked together and improve communication. Until a junior nurse can correct a senior physician who forgot to use the checklist, until that

conversation goes well, we will continue to harm patients. In most US hospitals, that conversation does not go well.”²³ For efforts to improve ICU palliative care integration, the value of interdisciplinary collaboration, which in turn requires open communication and mutual respect between physicians and nurses, may be the single most important lesson from the catheter-related bloodstream infection initiative. ICU nurses bear significant responsibility for implementation of the patient care plan and have the most extensive and intimate involvement with patients and families. Nurses should therefore be full partners in developing more efficient and effective systems for this care and in communications that determine the care they will be required to provide.

PRACTICAL APPLICATIONS FOR ICU PALLIATIVE CARE INTEGRATION

The approach used to prevent catheter-related bloodstream infections emphasized redesign of the work system to promote performance of important care processes and team building to strengthen a shared commitment to quality improvement. These key components can be applied to encourage more effective integration of palliative care in the ICU. Recognizing that each institution and ICU is different in some important respects, we offer several suggestions (summarized in Table 1) that could be adapted across a range of specific settings. One is that nurses should be strongly represented in the planning of any improvement effort. Often, it is nursing leaders and staff who seek to motivate such an effort because they have identified unmet needs of patient or families or experienced distress of their own. If physicians and others are successfully engaged, the next step should be the creation of a workgroup in which nurses play an active role, participating in—or leading—all important meetings.²⁴ In addition, as the initiative goes forward, a series of larger interdisciplinary meetings should be scheduled in which nurses from all shifts, physicians, and other team members collaborate on strategies to overcome obstacles for the initiative. These meetings are ideally a forum for open discussion in which nurses and others can contribute ideas, voice concerns, enhance teamwork, and foster a culture to support and sustain the initiative.⁷ Another strategy used successfully by nurses and others is to promote an expanded role in the ICU for palliative care specialty clinicians. Palliative care nurses and physicians can contribute their expertise not only directly in patient care but also in educating ICU clinicians, addressing emotional and moral distress arising from the work, and optimizing systems for palliative care processes. Fortunately, these specialists are now available to support ICU clinicians in the majority of hospitals across the United States.²⁵ The development of standardized criteria to trigger palliative care consultation may be a more effective and acceptable approach than reliance on persuasion of individual physicians to engage palliative care experts on a case-by-case basis.²⁶ A variety of triggering criteria have been defined for this purpose.^{18,19,26,27}

A recent study showed that, within the investigators' own institution, a nurse-focused quality intervention involving education and feedback was able to improve nurses' ratings of the quality of dying and reduce the number of ICU days before death for patients who died in the ICU.²⁸ When applied to community-based hospitals in a subsequent, cluster-randomized trial, however, this intervention did not show any benefit.²⁹ One interpretation of these two studies is that development and implementation “from within” by nurse and physician leaders in the ICU and hospital can be more effective in enhancing the success of such quality improvement interventions.

Nurses can also play a valuable role in evaluating the impact of an improvement effort on the quality of ICU palliative care. As part of the “Transformation of the ICU” performance improvement initiative by the Voluntary Hospital Association, Inc, nursing professionals with expertise in ICU safety and quality improvement and with administrative and clinical responsibilities contributed to development and validation of a new “Care and

Communication Bundle” of process measures of ICU palliative care quality.¹¹ These measures have been posted with detailed specifications on the National Quality Measures Clearinghouse Web site, which is sponsored by the Agency for Healthcare Research and Quality.¹⁴ At hospitals that support nurses or others to collect quality data, it may be feasible and useful to include data for measures in the “Care and Communication Bundle” or other such measures, with performance feedback to all clinicians caring for critically ill patients and their families. Baseline and interval collection of these data can identify opportunities and priorities for improvement and help to justify allocation of further resources for the initiative. An experienced nurse manager or nursing-trained quality monitor may be very helpful in developing or adapting data collection tools and templates for clinical documentation that facilitate the measurement process.

THE INTERDISCIPLINARY FAMILY MEETING

Apart from assessment and management of pain, in which the nurse's key role has been clearly recognized, no palliative care process is more important in the ICU than the family meeting to establish goals of care. It is in this process that families are helped to understand the patient's condition and prognosis, can share their knowledge of the patient's values and preferences along with their own concerns and questions, and receive emotional and practical support. Thus, the family meeting is the backbone of informed, patient-focused, decision making about appropriate care goals and the corresponding treatment plan. Nurses can contribute to these meetings in many important ways. The ICU bedside nurse has the latest information about the patient's condition. Usually, this nurse is also the clinician with the best knowledge of and strongest relationship with the family. The nurse at the bedside often has extensive discussions with family members before the family conference, including discussions of the patient's values and treatment preferences.³⁰ In addition, the nurse at the bedside has the most continuous presence, seeing and hearing interactions with the patient and family by clinicians from all disciplines, including the many specialists who are typically involved in care of the critically ill. Nurses can be particularly effective in providing information about critical illness and treatment in clear terms that laypeople understand, with sensitivity and compassion. After a family meeting in which they participated, nurses can provide continuity for family and professional care-givers who did not attend, helping to ensure that answers to questions and clinician communications and decisions are consistent. And palliative care nurse specialists are specifically trained to address communication and other needs of patients and families in the context of complex and life-threatening illness. In general, physicians believe that nurses are competent to participate in discussions about treatment preferences in relation to prognosis and goals³¹ and welcome nursing participation in family meetings. Finally, when the decisions are made and orders entered, nurses will be the ones to carry them out. For all these reasons, the ICU family meeting is defined for purposes of palliative care quality measurement as interdisciplinary.^{11,14} Specifications for the family meeting measure in the “Care and Communication Bundle,” which evaluates the proportion of ICU patients for whom an interdisciplinary family meeting is documented in the medical record by day 5 in the ICU, provide “Whenever possible, a nurse should be involved along with the physician.”¹⁴

Nurses should endeavor to ensure that this standard is implemented and embedded as routine practice in their ICUs. In some institutions, they will need to focus on work system adjustments, such as developing a plan for coverage of patient-care responsibilities, while the nurse attends a family meeting; including discussion of plans for meetings early in patient-care rounds, so that breaks and coverage can be arranged to allow the nurse to participate without disrupting the flow of care; posting reminders about nurse participation in family meeting areas and clinician work stations; and providing printed information to families, such as a leaflet or brochure that includes the expectation that the patient's nurse

will participate in family meetings and encourages the family to require this. In many ICUs, it will be important to enculturate both physicians and nurses with respect to nursing participation. This might be promoted by an ICU team meeting in which benefits of nursing participation in family meetings are reviewed, and there is candid discussion of the nurses' desire to participate, physicians' attitudes, perceived barriers to this participation, and strategies to address barriers. In addition, nurses can advocate for training in skills for communicating with ICU families as part of the interdisciplinary team. If available, palliative care specialists in the institution are often willing to help train other clinicians in these skills.

In the Veterans Integrated Service Network (VISN) 3, which serves the New York/New Jersey region, palliative care leaders have sponsored an innovative 1-day communication skills training workshop that is specifically designed for ICU staff nurses. This on-site workshop, which has been conducted at each of the five acute care hospitals in the VISN, uses a small-group pedagogical approach with role playing, case studies, and expert supervision and feedback. It has been enthusiastically received by over 100 participating nurses to date. Communication training is also part of the ICU-specific curriculum in the End-of-Life Nursing Education Consortium Critical Care course that is given annually at a central location.^{32,33} Many institutions have sponsored ICU nurses to attend this carefully designed course, helping them to enhance skills and become role models and trainers for local nursing colleagues.

THE IPAL-ICU PROJECT™

The Center to Advance Palliative Care (CAPC), www.capc.org, provides healthcare professionals with tools, training, and technical assistance for palliative care program development in hospitals and other settings. Recently, with cosponsorship from the National Institutes of Health, CAPC launched The IPAL-ICU Project™, a new initiative that focuses specifically on improving palliative care in the ICU (<http://www.capc.org/ipal-icu/>). IPAL-ICU shares resources including expertise, evidence, and tools to help clinicians across disciplines, and ICU and hospital leaders, integrate intensive care and palliative care successfully. For The IPAL-ICU Portfolio (<http://www.capc.org/ipal-icu/monographs-and-publications/>), the project's interdisciplinary team of experts, which includes strong nursing representation, has collaborated on a series of monographs and presentations addressing key issues for efforts to improve palliative care in critical care settings. Materials in this portfolio, which will be expanded to cover new topics of importance, are original and peer reviewed. IPAL-ICU also provides and regularly updates a Reference Library of literature relating to diverse aspects of ICU palliative care. In the Improvement Tools category, nurses and others can access tools developed by colleagues at a range of institutions across the country. These include, for example, the Care and Communication Bundle of ICU Quality Measures with a corresponding data collection tool, templates for documentation of ICU family meetings, a Family Meeting Planner to ensure that preparation proceeds in a timely way, and pocket cards to assist clinicians in conducting family conferences and managing pain. Other IPAL-ICU resources include professional education materials in a variety of formats; materials that clinicians can provide to patients and families, such as a brochure guiding preparation for a family meeting; and links to information about activities of interest by societies representing professionals who care for critically ill patients and their families. The CAPCconnect™ online discussion forum (<http://www.capc.org/forums/>) is a central venue for healthcare professionals who want to share information and get advice on operational aspects of a range of topics including palliative care in the ICU.

CONCLUSION

For prevention of catheter-related bloodstream infections and achievement of other safety and quality goals, success has depended on the ICU nurse's active involvement and leadership. The same is true for successful integration of palliative care into critical care practice. Nurses must define their essential roles in symptom management, communication, and patient/family decision-making within the interdisciplinary critical care team and help to develop systems by which these roles can be actualized. This should occur at every level, from strong nursing representation on hospital and ICU governance committees that establish policies and priorities, to activities by critical care and palliative care nurses with direct patient-care responsibilities. Only an integrated team of caring, competent professionals working within well-designed structures and processes can provide high-quality palliative care for critically ill patients and their families.

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TABLE 1**Examples of Practical Steps Nurses Can Take to Promote ICU Palliative Care Improvement**

Take a leadership role within the interdisciplinary committee and/or workgroup that is responsible for planning and implementation of ICU palliative care improvement efforts
Plan an active role in interdisciplinary team meetings to identify potential obstacles for ICU palliative care improvement and strategies for overcoming them
Participate fully in regular interdisciplinary staff meetings to enhance teamwork, voice concerns, and foster a culture supporting ICU palliative care improvement
Help to design and apply ICU work processes that systematically integrate palliative care, including processes for participation of nurses in interdisciplinary ICU family meetings ^a
Promote an expanded role for palliative care specialists in ICU clinical care and staff education
Help to develop and implement a system for formal evaluation of ICU palliative care quality
Use the resources newly provided by The IPAL-ICU Project™ of the Center to Advance Palliative Care (www.capc.org/ipal-ciu) to assist in efforts to improve ICU palliative care

^aSome examples of such processes are provided in the text.