

# Merging cultures: Palliative care specialists in the medical intensive care unit

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**We summarize the key interventions and general findings from a 3-yr project titled, "Merging Palliative and Critical Care Cultures in the Medical Intensive Care Unit." This multifaceted demonstration project was designed so palliative care and intensive care clinicians would share their expertise and develop projects that promote end-of-life care in a medical intensive care unit (ICU) setting. A variety of interventions are described, including collaborating with ICU leaders, training nurses as "palliative care champions," opening visiting hours, educating house officers and other staff about relevant pallia-**

**tive practices, establishing the presence of a palliative care specialist during work rounds, teaching about and promoting family meetings, introducing a "Get to Know Me" poster, staff support efforts, and modeling of interdisciplinary teamwork. Additional problems were noted but not well addressed, particularly routine communication with families and continuity of care for complex patients leaving the ICU. (Crit Care Med 2006; 34[Suppl.]:S388-S393)**

**KEY WORDS: intensive care unit; palliative care; end of life**

**O**ur goal in this article is to describe the role of palliative care in an intensive care unit, particularly the potential contribution of palliative care specialists. For this task, we have two audiences. The first is all the health professionals who work in intensive care and lack extensive first-hand knowledge of the new specialty of palliative care yet are interested in what this discipline and these specially trained "outsiders" from palliative care have to offer in the intensive care unit (ICU). We ask, "What observations will be particularly useful to intensive care specialists to appreci-

ate and utilize the 'outsider' perspective of palliative care?" Our second audience consists of palliative care or hospice clinicians who are attracted to the notion of extending their practice into intensive care and wonder what they can offer and how to demonstrate their usefulness in an unfamiliar setting. Here we ask, "What practical information and methods will be helpful to the palliative care and hospice community arriving in a foreign medical culture?"

## Background

*Information Sources.* This article is based on 1) an extensive review of the literature, 2) many opportunities for discussion with an interdisciplinary leadership team and with other clinicians and administrators involved with the integration of palliative care in the ICU, and 3) observations and quality improvement activities in one medical ICU (MICU) in the course of about 2.5 yrs. The core contributors were either ICU clinicians from the Massachusetts General Hospital (MGH) MICU or specialists from the MGH Palliative Care Service (PCS). Our activities were carried out as part of a demonstration project, Merging Palliative and Critical Care Cultures in the Medical Intensive Care Unit, sponsored by the Robert Wood Johnson Foundation through its national Program Office for Excellence in Palliative Care.

Three other demonstration sites were funded nationally, and although each project was unique, all had physician and nurse co-principal investigators and were committed to improving palliative care for all ICU patients, not just those who died. By gathering together throughout the study period, each interdisciplinary team met regularly with colleagues at the other sites and with consultants sponsored by the national Program Office and thus shared plans, materials, results, and impressions. Therefore, this presentation reflects some of the observations of the larger group and the observations of our team and the many collaborators in our MICU. Members of our interdisciplinary leadership team are listed as contributors to this article.

*Setting.* MGH is an urban, tertiary care, academic hospital populated by residents, fellows, medical students, and by trainees in nursing and respiratory therapy.

The MGH MICU setting deserves a few descriptive notes that help distinguish its similarities and differences from other ICUs, including those at the other sites. It is a closed unit with about 12 intensivists trained in pulmonary and critical care and responsible for all patients. Cardiac patients at MGH are generally admitted to a cardiac care unit, and there are separate neuroscience and transplant units, surgical

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units, and a ventilator unit focused on weaning. Practically all of the patients in the MICU require ventilators.

The PCS is a 10-yr-old program at MGH and an established feature in care provided in many parts of the hospital, although it has had a rather limited role in intensive care. Focusing primarily on inpatients, an interdisciplinary team provides consultation for patients and their families with life-threatening or terminal disease.

*What Is Palliative Care?* Our broad assumptions about palliative care require elaboration. Palliative care is a new specialty in the United States. It emerged from the hospice movement that developed in the 1960s in response to the distress and dissatisfaction so many patients, family members, and health professionals experienced in dealing with a terminal illness. Hospice in the United States is primarily a home care program and is limited in this country to persons with a terminal illness likely to last  $\leq 6$  months and who choose to forego life-prolonging measures. Palliative care in the United States can be described as a “second wave” of the hospice movement. Palliative care, based primarily in academic centers and hospitals, attempts to broaden the impact of the hospice philosophy by extending the hospice approach to any patients or families facing a life-threatening or terminal illness and who may benefit from a specialized, interdisciplinary, comprehensive, coordinated approach to their care.

Palliative care is defined as comprehensive, interdisciplinary services for patients with life-threatening or terminal disease and for their families when the primary focus on care is comfort and quality of life.

A palliative care team consists of specially trained and supported physicians, nurses, social workers, and chaplains who share a strong interest in end-of-life care, try to address broad biopsychosocial needs, and provide coordinated services across various sites to help patients and families live as well as possible in the face of a serious, complex illness. Palliative care focuses on:

1. Physical suffering: pain and symptom management.
2. Psychosocial and spiritual suffering: support for the patient and family, including bereavement care.
3. Patient- and family-centered care,

with a goal of informed, shared decision making.

4. Coordination of care across settings, with attention to home care and other alternatives to the acute care hospital, including home-like inpatient units.
5. Staff support.

Why would a palliative care program be interested in an ICU? Of course, many deaths occur there—20% of all U.S. deaths and about a quarter of hospital deaths—and many of the survivors will subsequently die in the hospital or in the year after admission, including a subset that may undergo unnecessary, undesirable, and even multiple readmissions. Likewise, family distress and dissatisfaction can be high in intensive care, and good family support, including in the period of bereavement, may be lacking. Finally, family or staff conflicts are common, and many staff report considerable moral distress around burdensome treatments and decisions to limit life-sustaining measures. Such matters concern and attract palliative care clinicians who think they may offer a variety of services to improve care. These issues, too, are quite familiar to palliative care clinicians, and they believe they have experience and expertise that may be helpful.

*Evaluation.* We evaluated our project by collecting data during a baseline pe-

riod, then piloting our interventions, and finally carrying out the interventions while collecting the same data retrieved during the baseline phase. Data analyses have not been completed.

*Initial Assumptions.* The theme of “merging cultures” reflects our preliminary impression that improving palliative care in our medical ICU would involve considerable attention to the ingrained attitudes and practices of both the MICU and PCS. Happily, the nursing and physician directors of both units were eager to engage in this project, and we enjoyed early support from nursing leadership in the hospital. This report especially focuses on what we discovered about merging these cultures and thus is a story about cultural change.

A few important generalities about culture change are summarized in Table 1.

## Interventions

Table 2 lists the main interventions that we found successful, practical, replicable, and efficient. These interventions are discussed below.

*Collaborating with ICU Leaders.* Cultural change requires support from leadership. This support foremost gained us access to physicians and nurses in a variety of settings where we could teach and

Table 1. Principles of culture change

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1. Understand the culture
    - Educate yourself through careful observation and listening
    - Listen for the “hidden curriculum”
    - Listen for distress about which you can provide some relief
    - Find the “hooks”—clinical and administrative—that will engage your audience and help them see the value of your work
  2. Engage leadership from nursing and medicine and from the front-line workers
    - Change is facilitated by direction and support from leadership
    - System changes can promote changes in clinical behavior
  3. Don't act as if you are bringing “truth to the unwashed”
    - Respect habits and conventions, appreciate competencies, and avoid the hubris of thinking you have the answers
    - But educate, educate, educate where invited, particularly through modeling and demonstrating desired behaviors
    - Visibility and accessibility are essential
    - Be there and do whatever is needed
    - Model key skills and attitudes rather than trying to teach them
    - Expand the scope of the discourse to include palliative care concerns during routine discussions
  4. Change is a slow process
    - Choose “low hanging fruit”
    - Be patient (and surprised)
    - Repeat and reinforce
  5. Embed the change into existing processes
    - Do not add work
    - Help the front-line workers promote change
  6. Persuade by using data and stories
    - But bedside examples have the most impact
  7. Success breeds success
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Table 2. Key interventions

1. Collaborate with intensive care unit leaders—nursing and physicians as partners in the “top-down” direction of the project
2. Palliative care nurse champions as “bottom-up advocates”
3. Staff education, especially around:
  - Communication skills
  - Goals of care and shared decision making
  - Psychosocial assessment and management
  - Cultural sensitivity
  - Symptom management
  - Existential/spiritual suffering
4. Palliative care specialist on rounds for modeling and teaching key behaviors:
  - Interdisciplinary teamwork
  - Patient- and family-centered care
  - Concern for psychosocial distress
  - Attention to physical comfort
  - Review of goals of care
  - Family communication
5. Promote family meetings through teaching, role play, modeling, coaching, and providing and encouraging feedback
6. Open visiting hours
7. “Get to know me” poster to help deliver patient from anonymity
8. Staff support

be role models, and it also gained us access to patients and families. The project legitimized the presence of palliative care staff on the MICU floors and also allowed for some structural changes. Collaborative leadership provided extensive guidance during the development and piloting of interventions. A particularly important contribution from MICU leadership was allowing Palliative Care Nurse Champions to attend 24 hrs of training as part of their workdays. Firm guidance from nursing leadership was also essential for data collection. The PCS contributed large amounts of staff time and administrative work to the project.

An early outcome from collaboration among our interdisciplinary leadership was a realization that we shared similar values. We easily agreed on goals for the project, including addressing such broader concerns as physician–nurse collaboration, clinician–family communication, and helping the house staff to appreciate the complexity of establishing goals of care and making clinical decisions with families in intensive care. Although our priorities for interventions and sense of the possibility for meaningful change varied among individuals in leadership, these differences led to productive negotiations, refinement of our interventions, and reasonable compromises.

*Palliative Care Nurse Champion Program.* Many nurses were deeply concerned about end-of-life care and eager to adopt palliative care approaches to their daily practice. We identified an initial group of eager nurses who applied to be Palliative Care Nurse Champions, and we

trained nine of them in a 24-hr program that was modeled on the End-of-Life Nursing Education Curriculum and led by an experienced palliative care nurse-practitioner. Their major role was to promote palliative care principles in the MICU, especially with nursing colleagues, but also with physicians and other healthcare professionals in the ICU. They formed a core of nurses who felt empowered to promote palliative care in the unit, and they each developed a project to meet these goals (e.g., sending bereavement cards to surviving family members). Communication skills, including talking to patients about end-of-life issues and being tactfully direct about the nursing viewpoint in talking to physicians, were addressed. Graduates were honored by invitations to attend or present at meetings about palliative care in the ICU, and a videotaped interview of selected nurses was shown at a national nursing meeting. Twelve nurses enrolled in the second training program, and a third program is filling easily.

*Open Visiting Hours.* Open visiting in the MICU allowed families to spend more time with the patient and the nurses, thus promoting family-centered care, communication, and support. Some nurses did not appreciate this change, especially initially, saying that the family always looking over their shoulders intimidated them. Many, however, embraced it, recognizing that visiting in the patient’s room was often easier and more satisfying for families compared with sitting in the waiting room. This policy is now widely endorsed in the MICU. An

empty waiting room became a sign of good care. Of course, nurses suggest that the family step out for certain procedures, but family members are encouraged to be present during rounds, and some prefer to stay at all times. Accommodating family members who want to sleep in the patient’s room is difficult but can be arranged.

*Staff Education.* Specialized training was conducted in a variety of forums: through the daily work of the Palliative Care Nurse Champions, standard and new teaching sessions, discussions on rounds, informal consultations, and written materials. Common topics were communication skills, assessing goals of care and promoting shared decision making, psychosocial assessment and management, cultural sensitivity, symptom management, existential/spiritual suffering, ethics, family meetings, and humane withdrawal of ventilatory support.

We introduced the project and, later, the interventions at a variety of regular staff meetings, grand rounds, specially arranged gatherings, and a new weekly multidisciplinary psychosocial rounds that was documented in the medical record with comments by an interdisciplinary team, usually including nurses, physical therapists, house officers, social workers, chaplain, palliative care specialists, the dietician, and occasionally the attending. Nursing ran this meeting, and the case was often presented first by the primary nurse. Over time, the patient’s family was increasingly invited to present the history. These regular teaching sessions allowed for reinforcement and expansion of the educational curriculum.

We also created a variety of forms that were meant to cue the staff to attend to palliative care issues. Most of these were not adopted broadly, including a daily goals sheet for the medical teams, an addition to the house officer’s daily note that is written on morning rounds (where we tried to add on regular notations about family communication and goals of care), and changes in the nursing recording of vital data, medication, and laboratory results (where we intended to introduce more attention to pain and communication). Attempts to adjust computerized medical records and orders were challenging, so we were limited to handouts and templates. Successful additions in print, however, included 3 × 5-inch cards and brief handouts on family meetings, the “Get to Know Me” posters, a ventilator withdrawal protocol, a brochure for patients and families to introduce them to MICU organization and procedures, and

brochures on advance care planning and acting as a proxy. Many of these forms are available on the Web (<http://www.massgeneral.org/palliativecare/>).

**Palliative Care Specialists on Rounds.** One of the most time-consuming but also radically different and effective interventions was having a palliative care physician participate in morning work rounds, a 2- to 3-hr session during which the attending, residents, and occasional nurses reviewed each case in detail and made plans for the day. The palliative care specialists, who, in our case, were physicians, would mostly listen to the discussion, but they would also interject occasional questions and suggestions, particularly when psychosocial issues, family communication, or discussion of goals of care seemed relevant. The palliative care physicians had a great deal to learn about intensive care, and much of the discussion on rounds was irrelevant to our goals, but this presence during the key teaching and team communication event of the day allowed for modeling and teaching key behaviors, such as consulting with the nurse about how the family was doing or whether the patient was comfortable (demonstrating interdisciplinary teamwork and the need to address suffering), asking about the family's coping and expressing concern about psychosocial distress, raising questions about the need for a family meeting,

and introducing discussions about the goals of care. Occasionally, the palliative care specialist provided suggestions on physical symptoms, especially cognitive changes, but symptom management was rarely an issue. The presence of the palliative care team in the MICU led to a large increase in consultations, both formal and informal.

**Promote Family Meetings.** Family meetings, especially when they are instituted prophylactically for higher-risk cases or scheduled routinely rather than only in crises, are the best studied and proven interventions in intensive care that could affect our desired outcomes (Table 3).

We engaged attendings and staff in one of our weekly grand rounds by focusing on the conduct of a family meeting, and the physician staff agreed that attendings would participate more in such meetings to model behaviors for residents and fellows and to provide feedback.

We found that almost no residents had been taught how to do family meetings, and thus, we instituted a routine teaching conference each month in which they "discovered" or "invented" a set of rules for conducting these meetings and then role-played with feedback an end-of-life discussion about withdrawal of life-sustaining treatment. Some of the principles taught in these meetings were made available on a

double-sided, full-page handout and on a 3 × 5-inch laminated card (available on the Web at <http://www.massgeneral.org/palliativecare/>).

We also insisted that the patient's nurse attend family meetings, and we demonstrated in teaching sessions the nurse's key role. We offered to help run meetings or just to provide coaching on them and thus had an occasional role in these regular ICU events. Emphasizing the value of feedback, we encouraged staff to debrief after meetings, using a prescribed format, and to ensure that the meeting was well documented and the outcome shared systematically with the staff.

**"Get to Know Me" Poster.** This poster, which has already been adopted by a number of other ICUs, roughly 18 × 24 inches in size, was placed in ICU rooms soon after a patient arrived. The poster has places for the family to describe the patient's background, hobbies, and other interests and to share pictures of the patient at times of health and pleasure. The poster helped the staff see the patient more fully and reduced the anonymity of a ventilated person who cannot communicate. Importantly, it also conveyed to the family that we cared about the patient as a person. Knowing more about a patient's interests in life, we could also better understand what they might consider "acceptable states" as outcomes of ICU care.

**Staff Support.** Although we hoped that the nurses and perhaps the house officers would want to start a support group, this never materialized. However, modeling of staff support on rounds and other venues by the palliative care clinicians seemed to raise awareness of this issue and increased informal support activities. Staff support became more regularly a part of multidisciplinary psychosocial rounds and ethics rounds. At the end of the intervention period, many of the nurses, especially the champions, seemed much more adept at recognizing and addressing nurse and house officer distress. In our preliminary analyses, nursing staff reported considerable improvement in job satisfaction and comfort with end-of-life care.

### Key Issues Omitted in the Demonstration

Two major issues were discussed in planning the demonstration, but we decided that we lacked resources to address them. These issues were also repeatedly noted in our observations about the MICU during the course of the project.

Table 3. Guide to intensive care unit (ICU) family meetings

Guide to ICU Family Meetings	Talking with ICU Families
1. Prepare agenda and setting Ensure team consensus on facts Decide who comes to the meeting and who leads the discussion	1. Communicate regularly, using family meetings prophylactically. Beware of family members who are nonparticipants. Involve the staff, especially the nurse
2. Introduce participants Bring tissues	2. Listen, listen, for family understanding, affect, and how they make decisions. Establish trust. Acknowledge emotions. Avoid jargon. Lecture less and let the family guide you to further topics
3. Assess family understanding, coping, and wishes for information	3. Provide psychosocial and spiritual support. Offer hope, not false hope. Bad news is a shock. Use support from the team. Culture and religion play key roles
4. Summarize the patient's medical condition and key clinical decisions	4. Inform family regularly about goals of care and how we know if goals are met
5. What is it like for the patient now? Is the patient suffering?	5. Convey uncertainty; avoid false certainty. Describe treatment as a "therapeutic time trial" aimed at specific short-term goals
6. What was the patient like? What would the patient want in such circumstances = "substituted judgment"	6. "Care" always continues, but treatments may be withdrawn or withheld
7. Explore and address family fears, concerns, coping. Reassure	7. Don't ask the family to decide about each diagnostic or treatment option; ask them what the patient would want and allow them to concur with a plan consistent with patient values
8. Frame recommendations	
9. Plan for follow-up	
10. Document meeting and communicate content to team	

First, routine family communication is extremely challenging in the ICU. We hoped that we could improve this situation by fostering the role of the primary care physician, but these physicians were infrequently present in the MICU, and we were ineffective at conveying information to or involving such physicians.

We observed how different family members call or visit at different times, speak to different nurses and physicians (often to the least experienced physicians), have multiple specialists and ICU team members who provide input, and experience a bewildering staff rotation system that guarantees that the attending and at least part of the medical team changes every few weeks and that a number of nurses are responsible for the patient during the course of a week. Consistent, clear communication and development of a trusting relationship between family and staff, especially the medical staff, is problematic. A family can get quite confused about how the patient is doing when multiple sources are not coordinated. The intern may announce with great satisfaction that the pressors have been reduced from 100 mg/min to 90 mg/min, a specialist may raise a question about performing a procedure that offers some hope for improvement in one organ system, and the nurse may describe meaningless suffering for an inevitably dying patient. Although the common, unproven method of designating one family member to be the conduit for information for the rest of the family may reduce the number of times that information is conveyed and perhaps allow for greater consistency in the telling of the information, it does not meet well the needs of multiple visitors and callers who are concerned about the patient and seek updates. We are now planning some interventions in this arena.

Second, much of the expertise about the patient and family that develops in one hospital ward, especially the MICU, where so many life-and-death discussions are held, is not well conveyed to the next ward when a patient moves. Whatever trust and familiarity happened in one unit gets lost or significantly diluted at transfer. Transitions of this sort, including at the time of hospital discharge, are a major problem in medical care and can cause overt errors, family misunderstandings and dis-

Table 4. Project evaluation

Category	Sample Measures
Patient demographics Illness severity and comorbidities Resource utilization	Age, gender, marital status, religion, insurance APACHE III, admission diagnoses, DRG Length of stay in MICU and hospital, use of daily radiographs
Health outcomes	Deaths, hospital survival, discharge to institution vs. home
Advance care planning	Documentation of proxy and living will; orders to limit life-sustaining treatments; time from admission to DNR and from DNR to death
Management of withdrawal of life-sustaining measures, including ventilator withdrawal	Use of feeding tubes, parenteral nutrition, antibiotics, pressors, dialysis; use of sedatives and analgesics in final day of life
Palliative care utilization	Referrals to palliative care service
Quality of clinical care	Nurse ratings of the quality of death and dying
Staff job satisfaction	Nurse ratings
Family satisfaction	Satisfaction with ICU care; ratings of quality of death and dying
Costs	Direct cost

*APACHE*, Acute Physiology and Chronic Health Evaluation; *DRG*, diagnosis-related group; *MICU*, medical intensive care unit; *DNR*, do-not-resuscitate order; *ICU*, intensive care unit.

Table 5. Hooks: Motivating adoption of palliative care

Clinical Hooks	Administrative Hooks
Moral distress and staff turnover Troubling family or staff conflicts Difficult communication with families and help with family meetings	Reduced length of stay and opening up beds Reduced costs Time savings, extra help
Introducing discussion of goals of care and limitations on life-sustaining treatment	Increased hospice referrals and home death
Continuity of care, coordination with community services	Family satisfaction Complying with national recommendations and standards Safety Improving advance care planning

Table 6. Major lessons learned

- Culture change requires careful assessment, takes considerable time, and is a gradual process requiring regular reinforcement
- Role modeling is a powerful learning tool; the presence of a palliative care clinician in the intensive care unit is highly effective in promoting cultural change
- System changes, such as a policy about open visiting, can have dramatic changes on clinician behavior and the clinician–family relationship
- Palliative care clinicians have a lot to learn about intensive care medicine and nursing and will tend to focus on a different set of problems than intensive care unit clinicians, but the concerns of each overlap. Agreement on goals is easy; changing behavior is difficult
- Initial support largely comes from nurses and house staff, whereas the attendings are variable: “herding cats”
- Staff education and support has a big payoff
- Pain and symptom control are relatively minor issues for palliative care interventions

stress, and a variety of other problems. Again, the lack of an involved primary care physician and the presence of multiple providers compounds this issue. We saw this problem particularly with

“difficult” families for whom issues in appropriate management often seemed to be created from scratch after a transfer. We believe that a PCS can provide some needed continuity.

## Outcomes

Table 4 shows some of the outcomes we measured and are in the process of evaluating.

## Discussion

In Table 5, we return to a few guidelines about how advocates for palliative care can identify concerns and distress—the hooks—that help a demonstration project of this sort to engage clinicians and administrators.

From the point of view of the palliative care staff addressing ICU colleagues, we have attempted to identify some of the strengths and weakness that we discovered about ourselves and noted in our palliative care and hospice collaborators. Foremost, we have lots of experience with family conflict, difficult decisions about the goals of care, conducting family

meetings, interdisciplinary teamwork, and staff support. Palliative care practitioners generally have a strong affinity to and considerable skills in psychosocial support for patients and families, including determining information preferences, sharing clinical information, appreciating the patient as a person and identifying their values and goals of care, introducing “death talk” and other difficult issues, presenting relevant ethical constructs, and dealing with conflict and strong emotions (Table 6).

Palliative care clinician weaknesses include their outsider status and lack of familiarity with biomedical and nursing aspects of intensive care, and being used to patients who are already referred to as “terminally ill,” different skills apply in a setting that strives for “great saves” and deals with great uncertainty about sur-

vival. Also, as in other settings, consultants in palliative care, feeling naturally that they are good at the job, may have an eagerness to intervene a bit quickly into complex situations and may tend to take over the case. Major turnoffs include notions, often transmitted inadvertently, that “We REALLY CARE about our patients and their families” or “We can show you how to do things right and fix this [intractable] problem.”

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