NIH Public Access
Author Manuscript
J Crit Care. Author manuscript; available in PMC 2008 June 1.

Published in final edited form as:
J Crit Care. 2007 June ; 22(2): 159–168.

NIH-PA Author Manuscript
NIH-PA Author Manuscript
NIH-PA Author Manuscript

Intensive Care Unit Cultures and End-of-Life Decision Making

Judith Gedney Baggs, PhD, RN, FAAN[*,#,1], **Sally A. Norton, PhD, RN**[+,2], **Madeline H. Schmitt, PhD, RN, FAAN, FNAP**[*,2], **Mary T. Dombeck, PhD, DM in, RN**[*,2], **Craig R. Sellers, MS, RN, APRN, BC, ANP**[^,2], and **Jill R. Quinn, PhD, RN, CS-ANP**[+,2]

1*School of Nursing Oregon Health & Science University, Portland, OR, USA*

2*School of Nursing University of Rochester, Rochester, NY, USA*

Abstract

Purpose: Prior researchers studying end-of-life decision making (EOLDM) in intensive care units (ICUs) often have collected data retrospectively and aggregated data across units. There has been little research, however, about how cultures differ among ICUs. This research was designed to study limitation of treatment decision making in real time, to evaluate similarities and differences in the cultural contexts of four ICUs and the relationship of those contexts to EOLDM.

Materials and Methods: Ethnographic field work took place in four adult ICUs in a tertiary care hospital. Participants were health care providers (e.g., physicians, nurses, and social workers), patients and their family members. Participant observation and interviews took place 5 days/week for 7 months in each unit.

Results: The ICUs were not monolithic. There were similarities, but important differences in EOLDM were identified in formal and informal rules, meaning and uses of technology, physician roles and relationships, processes such as unit rounds, and timing of initiation of EOLDM.

Conclusions: As interventions to improve EOLDM are developed, it will be important to understand how they may interact with unit cultures. Attempting to develop one intervention to be used in all ICUs is unlikely to be successful.

Keywords

Critical care; Intensive care [units]; Critical illness; Terminal care; Palliative care; Withholding treatment; Decision-making; Professional-family relations

Introduction

Researchers studying end-of-life decision making (EOLDM) and limitation of life supporting technologies in intensive care units (ICUs) have found difficulties with both care and the decision making process. Problems identified include perceptions of overuse of technology (1); treatment of dying patients not congruent with preferences (2); failures in communication

---

Corresponding author: Judith Gedney Baggs OHSU School of Nursing 3455 SW US Veterans Hospital Road, SN -ADM Portland, OR 97239-2941 United States Telephone: 503-494-1043 FAX: 503-494-4350 Email: baggsj@ohsu.edu.

[*] Professor

[+] Assistant Professor

[^] Senior Teaching Associate

[#] Senior Associate Dean

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

The study took place at the University of Rochester.

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

and pain control (3,4); lack of family access, lack of sensitivity to the family (4,5); wide variation in how life support is used (6); and a high burden of patient symptoms (7).

Most studies have been retrospective, either provider or family focused rather than including both, based in a single ICU, or comprised of data aggregated across multiple ICUs. Until very recently, researchers have focused on individual provider-patient/family interactions, ignoring the unit level context for these interactions and how that context may differ across ICUs. The limitations of this work have been identified as the need to address the health care context, not just individual behavior (8), the need for more family perspective (9), and a lack of focus on the culture of the organization (10,11). We chose to focus on the cultures of ICUs, the organization in which they resided, and the broader social context in order to identify additional insights and approaches to addressing already identified difficulties in EOLDM in these settings.

Culture is shared knowledge and customary actions, constituted by social systems, manifest in the the rules, roles, relationships, and actions of persons (12-17). Persons in an institutional setting, such as an ICU, fill roles, exercise rights and privileges, and are expected to conform with established rules for action (18,19) The rules may be explicit and written, assumed, taken for granted, or not acknowledged. Decision making is affected by the culture in which it takes place.

Three recent ethnographic studies about the culture of end of life in adult ICUs were identified (20-27). One researcher studied only British ICUs (25-27). Another studied dying patients in US acute care hospitals and incidentally included ICUs (23,24). Neither researcher focused on comparisons of cultures across ICUs. The third study (20-22) was undertaken to assess EOL issues in surgical ICUs and involved comparisons of two units from different parts of the United States and one in New Zealand. These ethnographies were not designed to explore variation among types of ICUs within one institution.

People in many different roles may be involved in making decisions about limitation of treatments in ICUs. Health care providers may include physicians (43-48; attendings, intensivists, residents, consultants), nurses (49-51; staff, managers, practitioners), social workers, chaplains, and others, who interact with each other (41,43,44-62). Patients (63-69) may or may not be able to participate in decision making. Families (70-83) may be large or small, related by blood or legal ties (e.g., marriage) or neither (e.g., significant others, close friends). Obviously persons in these multiple roles have been studied in some depth, but few researchers have attempted to study all participants interacting within a unit context. Persons in these roles bring different expectations, and, for providers, these expectations vary by discipline and specialty.

This research was designed to study EOLDM in four U.S. adult medical and surgical ICUs within one hospital by systematically examining their cultures, evaluating similarities and differences and the relationship of those cultures to EOLDM. We studied instances of both problematic and non-problematic decision making to identify barriers and facilitators. Problematic EOLDM involves conflicts among family members, among providers, and/or between providers and family members. Conflicts are not uncommon. There are many recent studies of conflict or its management in dying patients, several focused on EOLDM (28-42).

Our purpose was to clarify unit cultures surrounding EOLDM in each of the four units studied. Understanding differences in ICU cultures and expectations of different participants about EOLDM could contribute to the design of interventions mutually acceptable to patients, families, and health care providers, to improve the quality and outcomes of decision making.

NIH-PA Author Manuscript NIH-PA Author Manuscript NIH-PA Author Manuscript

Design and Methods

This was a prospective ethnographic study of four adult ICUs. A 6-member research team used participant observation, fieldnotes, and semi-structured interviews of providers, patients, and families to describe the EOLDM cultures of each unit and to provide an understanding of differing expectations. Team members were faculty and doctoral students in a school of nursing. They represented the disciplines of sociology, anthropology, and nursing. Their clinical backgrounds included medical and surgical critical care, inpatient and ambulatory psychiatric, cardiac, emergency, and gerontologic nursing. An ethnographic design allowed us to interview participants and observe actions surrounding events and processes related to individual cases of EOLDM from multiple perspectives as they occurred in real time. While some numbers are provided, we did not routinely track numbers of occurrences of different types of events.

Setting

The setting was a 740-bed academic health center in the mid-Atlantic United States. Units studied were a 17 bed medical ICU (MICU), a 20 bed surgical ICU (SICU), a 15 bed burn and traum a ICU (BTICU), and a 14 bed cardiovascular ICU (CVICU). Data were collected from 2001 to 2004.

Participants

Participants included health care providers, patients, and family members (see Table 1). When possible we interviewed providers and patients or family members involved in the same situations. The university Research Subjects Review Board approved the study. All interviewed family members signed informed consents; interviewed health care providers were informed of their rights in a written information sheet. Family and providers were interviewed for eight EOLDM cases on two units and nine cases each on the other two. Of the 34 cases, 19 died in the ICU, 6 died in the hospital, 6 were discharged from the hospital (2 to hospice, 2 to nursing homes, 1 to a rehabilitation facility, 1 to home), and 3 were transferred to another floor and lost to follow-up.

Instruments

Tape-recorded semi-structured interviews lasting 15 to 60 minutes were conducted. An interview guide was based on key issues of importance to the study (e.g., perceptions about decision making, barriers and facilitators) derived from ongoing analysis, fieldwork, and the literature (1,4,62,82-83). Most interviews and family meetings were audiotaped and transcribed. Transcripts of interviews, family meetings, and field notes were reviewed for accuracy and entered into the ATLAS.ti program.

Procedure

Data were collected for approximately 5 hours a day, 5-7 days a week for 7 months on each unit sequentially. EOLDM situations and key persons to interview were identified through our participant observation in rounds and the day to day work of the staff and by discussions, primarily with intensivists, charge nurses, care coordinators, and resident physicians (residents). Once a potential EOLDM situation was identified, the attending physician (attending) was asked for permission to contact the patient and family and to attend family meetings. Data collection began as soon as possible after identification of an EOLDM situation and ended with the patient's death or discharge from the ICU or hospital. Patients were followed over time, as decisions were often revisited.

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

Data Analysis

Analysis, using an ethnographic approach (84), began at the time of the first observation and continued throughout the study. The purpose of the analysis was to look for themes, patterns, connections, and relationships that had meaning for the patients, families, and providers related to EOLDM (85). Data were coded and recoded with comparisons of new and old data; codes were grouped and categorized. Hypotheses about patterns observed were developed, discussed, and tested by repeated observations and questions asked of interviewees. “Deliberate or focused sampling” of observations was used for validation or comparison of data (85). Regularity and comparability of data collection and coding was developed and maintained by the weekly research team meetings. Trustworthiness was assured by prolonged engagement on each unit, discussion of findings and their interpretation at team research meetings to a point of agreement, by hypothesis generation and testing, and by involvement of the entire team in development of this publication.

Comparisons were made of each interview with other interviews about the same patient, with other interviews from the same group (e.g., nurses), and with interviews on the same and other units. This offered the opportunity to compare attitudes, beliefs, and behaviors within situations, identify similarities and differences that cut across situations and units, and clarify patterns and key variables that might otherwise be missed (86).

An inductive method of analysis was used. The process remained close to the data in early analysis, progressing to more abstract levels through an iterative process of analysis and data collection. We reflected on aspects of the data that revealed information about rules, roles, and relationships of persons and institutions (e.g., hospital, unit, family, work). As themes emerged the most abstract questions were asked: for example, Is this case reflective of the unit and/or larger hospital culture? What are common patterns? How do these patterns relate to EOLDM?

Results

Both similarities and differences in EOLDM among the four ICUs were influenced by formal (written) and informal rules, by unit structure, by participant roles and relationships (e.g., physicians, nurses, family members, patients), and by unit processes reflective of the cultures (see Table 2). Key aspects of similarities and differences in unit cultures and their implications for EOLDM are highlighted below. To preserve confidentiality of our participants, the individual units are not identified in the following presentation; rather we have chosen to highlight concepts on which units differed without identifying where each unit is located within the concepts. Sources of quotations are indicated by fieldnotes [fn], nurses [RN], physicians [MD], family members [F], ethicists [E], and social workers [SW].

Key Similarities and Differences Among ICU Cultures

EOLDM rules—Certain formal societal rules were common to all of the units; for example, the ICUs were all regulated by the federal Patient Self Determination Act and state regulations about advance directives (ADs [living wills or health care proxy/surrogate designations]). Of the 34 patients we studied closely, 17 had an AD. ADs helped families assert the need to follow patient wishes when members of the provider team did not agree, an issue that arose only on surgical units and only with surgeon providers.

In at least two cases on surgical units families used ADs to stand firm in requesting withdrawal of life supporting technologies despite strong pressure from surgeons not to do so. In one instance two sons were clear that their mother's condition would not improve to what she considered acceptable after complications of coronary bypass surgery. The surgeon disagreed. F: “And her feelings are she does not want to be kept alive. Her brother was in intensive care

NIH-PA Author Manuscript NIH-PA Author Manuscript NIH-PA Author Manuscript

for 7 months. And she pleaded with us not to do it. I'm her healthcare proxy person, and I mean here I am, it's now 2 days into the treatment, she's no response whatsoever and we're saying, you know, ‘What are we going to do.’” The sons insisted on ventilator withdrawal. The surgeon directed a nurse practitioner to withdraw the ventilator. When a researcher asked him about the case, he said, “[She] was allowed to die by her family's wishes, a situation which I felt was premature in a patient who given the appropriate support had an excellent chance for survival. End of discussion.” In the other case it took an ethics consultant to indicate that the health care proxy (a daughter who was a nurse and who had the full agreement of all her siblings) had the authority to demand withdrawal of treatment despite a covering neurosurgeon's reluctance to withdraw when the attending neurosurgeon was out of town. No such occurrences were seen on the medical unit, where the usual culture was to accept ADs or family decisions to limit treatments as an expression of patient wishes.

The units were governed by the same institutional policies and procedures, with common formal rules; for example, hospital rules about DNR orders. However, there were profound differences in interpretation and implementation of formal rules that contributed to unit-based informal rules.

DNR orders were managed differently across the four units we observed. On the combined medical/surgical unit a nurse practitioner said, “We'll usually push for a DNR; that will be the first step.” The physician director on a medical unit followed that pattern in planned family meetings, getting a DNR before discussing limitation of ongoing or potential treatments. On one surgical unit, a DNR order was not considered a high priority. MD: “It's paperwork…and sometimes if things are happening very quickly I'll skip the DNR paperwork.” He expected the same of other attendings on the unit. This informal rule was perceived as a facilitator to good EOLDM by the physician, who believed that it was painful for families and unnecessary to address DNR in a patient's final moments and that ICU patients seldom die of a cardiac arrest. He said that if he “skips” it, “I haven't had to make some 90-year-old who's about to be a widow or widower, take them the paper [ask them to sign for a DNR], and then watch them suffer as they can't write and tears are on the paper, and the whole experience is miserable to me.” In another interview the same physician said, “My feeling about the full code issue is that these patients rarely die of a cardiac arrest, so I don't push that DNR part because I don't think it ever helps.”

But some nurses saw not having a DNR order as a barrier because it could lead to confusion when patients were dying. The physician was aware of this conflict, MD: “Sometimes the nurses want to get the families to talk about it so they have a DNR on the chart so should something happen, we don't resuscitate but…in the ICU…that, in my experience, is not all that practical or useful.”

There were unit level informal rules governing communication about EOLDM. On all units there were informal rules discouraging nurses, and, on some units, also medical residents from raising the topic of limitation of treatment with families. One medical unit attending was very clear: MD: “I'm not trying to minimize the nurse and the social work[er], but they have to be part of the team rather than the spearhead.” However, on that same unit physicians attended closely to what nurses said on the topic during rounds. MD: “Sometimes they'll initiate [discussion about EOLDM],…they will mention at rounds that, ‘The family told us that they had a living [will], advance directive we didn't know about.’” Rounds were one systematic way nurses' perspectives were included on this unit; such efforts were not common to all the ICUs.

Technology, a structural variation—Structurally ICUs were technology-intensive. All the ICUs used “routine” technologic interventions such as ventilators, bedside dialysis, and

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

hemodynamic monitoring, but they differed in levels and use of other types of technology. On the MICU the routine technology was as described; the other three units added specialty technology associated with their patient populations. On the CVICU the use of cardiac ventricular assist devices seemed to reach the highest level of technology.

In a complex interplay between technology, patient types, and provider patterns, the role of technology as a trigger for EOLDM varied by unit. Two technological interventions were commonly considered simultaneously: tracheostomies and placement of percutaneous endoscopic gastrostomy (PEG) tubes for feedings. For medical patients, decisions about tracheostomy and PEG placement were treated as an opportunity to initiate EOLDM discussions. For example in several stroke patients, lengthy discussions about patient goals and wishes preceded discussions about tracheostomy and PEG placement. The following is taken from fieldnotes on rounds in a medical unit, [fn] “The questions are about whether to do a trach or a PEG to help him with the pneumonia and get him out of the unit, but then the family has to wonder to what end. ‘This man lived in fear of going into a nursing home,’ which is the R3's [third year medical resident] recollection of what the daughter had said yesterday. It is very likely, according to the R3, that he will need nursing home placement. It might be possible to do the PEG and the trach only temporarily, but for now he has no swallow, and if that function doesn't return, then he would continue to need those if they wanted to sustain his life.”

For patients of surgeons, these decisions often were treated as routine, presented to families as standard care. Two medical nurses spoke about the differences between medical intensivists and surgeons: RN1: “And [surgeons] often…they like trach and PEG everybody after…” RN2 (completing her sentence): “so many days.” RN1: “Everybody is trached and PEGed…They [surgeons] do a lot more rapid, just about everything. Boom, boom, boom, boom, boom… trach, PEG them, get them out.”

Roles and relationships: Physicians—Societal recognition of physicians' importance was seen across units in an influential physician hierarchy. Physicians held a high place in the hierarchy on all units, but they differed in their beliefs, attitudes, roles, and relationships with others in EOLDM. One key difference was whether the physicians were primarily surgical or medical. Medical intensivists were more likely to consider moving away from disease-driven care earlier in the illness trajectory, to call for an ethics or palliative care consultation, to talk with families and other providers about options and to share decision making. Medical intensivists made deliberate attempts to ascertain patient goals and facilitate patients and families changing those goals to ones more in line with patients' prognoses if and when they deemed it necessary. In contrast, attending surgeons usually worked with an understanding (explicit or implicit) that the patient's goal was to survive, and there was seldom a surgeon-initiated attempt to question this goal until they believed treatment options had been exhausted.

These differences might be attributed to differences in types of patient care for (e.g., differing demographics. However, more important than patient demographic differences were the role expectations for medical and surgical physicians. Surgeons typically saw patients for a discrete intervention. They had specific immediate, focused goals for the patient related to the patient's underlying diagnosis. Life sustaining treatment was considered something that might be needed after the intervention. Medical intensivists in the MICU saw generally older, chronically ill patients admitted unexpectedly. Often the immediate goal for their patients was to sustain life while the intensivist evaluated whether there were interventions to treat or palliate the underlying problems.

Differences in how physicians approached families about making limitation decisions were perceived by many. An intensivist: “The surgeons never say this to the families, never tell them that, ‘Yes, we can save your daughter's life, but we don't think she will be anything but a

NIH-PA Author Manuscript NIH-PA Author Manuscript NIH-PA Author Manuscript

vegetable after that'"; and an anesthesia resident: "Surgeons…want to get the job done and get out…Medicine you want to be a little more touchy feely, you want to talk to people." Nurses commented on differences between medicine and surgery; a nurse researcher: "The surgeons when they come through on their rounds, they are dashing in saying four or five sentences to a patient and dashing out again…The medical attendings appear to take more time"; a staff nurse: "Surgeons…have that need to do everything possible." Other providers also noted the differences, E: "In surgery the value system is…the surgeon has the most information…and can make the best decision…Medical doctors…are more likely to see themselves (in) the role of an educator"; SW: "[Internists] work more collaboratively related to end-of-life decision making…[Surgeons] are just a lot less available to families." In part, this lack of availability related to surgeons' need to be in the operating room for a large portion of many days.

Physician specialties and individual personalities, particularly of the unit medical directors, and how attending rotations were managed on all the units, strongly influenced unit cultures. Some unit directors, in general those who were often physically present on the unit, influenced EOLDM of other attendings. In these situations we observed fewer differences in how EOLDM was managed despite the rotation of attendings. Other unit physician directors, often those less present on the unit, asserted less influence over rotating attendings, creating situations when EOLDM changed drastically with attending rotation. On such occasions, nurses, who were aware of the various attendings' attitudes toward EOLDM, were observed to time their efforts to influence the process to coincide with particular attendings' rotations. A staff nurse speaking about a dying patient, [fn]:"Dr. X is on. One of the first items on yesterday's agenda was a family meeting… She [the patient] is now DNR, comfort care only. The RN at the meeting said it was like her husband was ready and just waiting for someone to ask the question. I asked why the question wasn't asked last week, and the RN responded that it was because, 'Dr. Y was on. He's uncomfortable with everything so he just avoids these discussions. He even has a hard time talking to a family about a trach.'"

Drastic change in the EOLDM process related to attending differences was also hard on families, who had difficulties with a lack of continuity in EOLDM and, in keeping track of who was in charge. One family member described how he attempted to ascertain who was the attending physician: F: "I look them over and see who was the oldest one, and then I can figure out who was boss."

Rounds, an important unit process. Processes associated with EOLDM such as patient rounds were similar in that rounds occurred on all units; yet there were important differences in this process across units that did not divide by medical versus surgical. Morning rounds were an opportunity for all providers to plan together for the day's care and to discuss issues of concern. On two units (one medical, one surgical), nurses took part in rounds related to the patients for whom they were caring. On the medical unit, [fn] "In closing off the rounds, [the attending] turned to the nurse and asked whether there was anything else she wanted (another practice that seemed–along with inclusion of the patient's nurse in the discussion–to be routine with every patient)." On the surgical unit [fn] "Bedside nurses usually came up to the group for rounds and participated, asking questions, sometimes answering the attending's teaching questions." On the other surgical unit, nurse participation was variable. If they were not present, they were not sought out.

On the combined unit there were three physician-led teams that rounded at unpredictable times and with unpredictable interest in nurse participation. The lack of one central rounding team generated complexity for the nurses. A nurse on that unit compared her unit's rounds to those on a medical ICU, "We try to do something similar, but we don't have any physician present." Often the groups that rounded did not include an attending physician, so nurses had to work

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

with a fellow or resident leading the rounds, which frustrated them when they had issues they believed needed to be considered by an attending, such as EOLDM.

These varying rounding processes shaped the communication patterns among providers and families surrounding EOLDM. In the first two units, multidisciplinary discussions regarding treatment limitation were routine and addressed daily. In a third unit, EOLDM discussions were triggered by critical events, and, in the fourth such discussions often proceeded via a nurse or nurse practitioner among separate rounding groups.

Timing of EOLDM—EOLDM was affected by all the key similarities and differences previously discussed: rules, technology, roles and relationships, and unit processes, such as rounds. Some parts of the process for EOLDM were similar across units, in that patients generally lacked capacity to participate by virtue of their illness severity and sedation. Lack of ADs compounded the loss of personhood of the patient, resulting in frequent circumstances where providers interacted with families to ascertain patient wishes. Families comprised a separate domain of customs, rules, and roles that added to the complexity of the interaction. These circumstances were rife with opportunities for conflict.

Although there were these similarities across units, the EOLDM process differed from unit to unit in important ways, for example in timing. The timing of discussions surrounding EOLDM was patterned by unit. Judgments of the appropriateness of the timing varied by provider type, for example decisions made days to weeks before a patient's death were seen as timely by most nurses and medical ICU physicians and premature and/or not an option by most surgeons. Decisions to limit or withhold treatment made hours before a patient's seemingly unavoidable death were seen as appropriate by some, usually surgeons, and delayed or avoided by others, usually medical physicians and nurses.

For surgical patients on several of the units, decisions were more commonly left until the providers thought death was imminent and inevitable meaning no additional treatment interventions were deemed available. An RN compared work in a surgical ICU to a medical ICU and said it took longer before EOLDM was “approached to the family.” Families sometimes were contacted and asked to agree to withdrawal in situations where withdrawal meant only a small difference in time to death, leaving them little time to prepare for the loss of their family member. This upset the nurses who had less time for EOL care.

Another option exercised more commonly on surgical units was transfer of patients or of responsibilities for them when death was thought to be near or no surgical options were thought to exist. On one occasion a neurosurgical patient was assessed to be dying despite treatments and not a candidate for further surgery. Attending responsibility for her care was transferred to an intensivist, who said she could be transferred out of the ICU. According to a surgical ICU nurse practitioner, [fn] “Now that she's extubated, she doesn't need to be here either.” She was transferred out of the ICU later that night.

Timing has implications for the involvement of nurses and families. For patients cared for by medical intensivists, who in general raised EOLDM issues early, the provider team had open discussions, and families were involved. Families were almost always asked what the patient would have wanted; nurses had a longer time to develop and provide EOL care; patients were seldom transferred out of the unit during withdrawal.

Problematic decision making also often had a timing issue. For medical patients the conflicts we observed almost always involved what providers characterized to us or to each other as patients/families being unable or not ready to let go. For surgical patients, the conflicts in

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

decision making we observed were fairly evenly divided between cases where either the attending surgeon or the patient/family was uncertain, unable, or not ready to let go

Discussion and Conclusions

In assessing key similarities and differences in the cultural context of adult ICUs in one hospital that influenced EOLDM, we found that ICUs were not monolithic, one like another. However, EOLDM occurred repeatedly within units in a patterned fashion related to structure and culture of each unit. Both similarities and differences across units influenced EOLDM. Whether key aspects of the culture were viewed as facilitators or barriers depended upon the role perspective of the participant. Identifying the predictable, but different, EOLDM unit cultures and role perspectives is necessary for developing interventions to improve EOLDM.

Differences in interpretation of formal rules, such as those about DNR orders, and informal rules, such as those discouraging nurse-initiated discussions with families, had the potential to generate conflict between nurses and physicians, complicating EOLDM. Identifying both formal and informal rules would allow tailoring of unit-based EOLDM interventions.

Technology was ubiquitous in the ICUs. The development of increasingly complex technology has created EOLDM in which the patient seldom has capacity for full involvement. Decision making often is left to others. One solution would be to initiate discussions with patients earlier, before they are unable to participate. This would certainly be feasible for patients undergoing elective surgeries.

Whether the use of particular technologies served as a trigger for EOLDM was unit and physician specialty dependent as other researchers have found (87). When decision making about the use of technology was viewed as an opportunity to begin EOLDM, providers perceived it as a facilitator. Identifying and capitalizing on technological triggers as opportunities to initiate EOLDM is an area that holds promise.

The role of attending physicians in EOLDM was central. Their high place in the institutional hierarchy as well as their power over the use of technology meant that they were important shapers of the unit's culture. Whether an ICU was primarily surgical or medical or some combination influenced EOLDM, as did the specialties of the attendings (e.g., whether they were attending surgeons or intensivists, and whether intensivists were originally internists, anesthesiologists, or surgeons).

Our findings are congruent with others. Recently a group of ICU surgeons and an anthropologist (20,47) studying SICUs identified the surgeon's sense of accountability for patient outcomes, their covenantal ethic, and a need to rescue as creating difficulties in making decisions to limit treatments (47,48). They contrasted this surgical mind set with that of the intensivist, who is likely to have a more utilitarian perspective, considering resource use (20).

Medical attendings in our study tended to do what Back, Arnold, and Quill (88) identified as “hoping for the best; preparing for the worst” from the time they assessed that any patient had the potential not to do well. For medical units, an intervention built on proactive anticipation of EOLDM between and among providers and families early in a petient's ICU stay (e.g., 89-93) would be congruent; in surgical units such an intervention might clash with the culture. Because of the central role of physicians in EOLDM, the structure of physicians' work was of central import. Disruption of EOLDM arose around attendings' rotations or unavailability, where there was no strong director overseeing the unit, and when the timing of rounds was not predictable. Nurses and social workers often were adept at tailoring their approaches to physicians' work patterns to achieve care decisions or order they sought. However, families generally lacked knowledge and had difficulty or were confused by the work patterns. These

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

patterns disrupted communication, relationships, and trust, all critical in EOLDM. An identified physician leader with authority over other attendings, willing to listen and share decision making, and support collaborative structures, such as interdisciplinary rounds on all patients to begin the day, could facilitate provider care coordination.

The process of scheduled interdisciplinary rounds also could serve as a facilitator of collaboration in EOLDM when participation of multiple providers was encouraged, and family members were not excluded. On some units, the lack of interdisciplinary rounds during which all patients were considered, led to missed opportunities for shared decision making about patient care. These rounds also could lead to explicit consideration of EOLDM earlier in a patient's course of illness. That early discussions facilitate EOLDM is well accepted in current literature (86-91), however it was not the practice we observed, particularly on surgical units. Rounds could also serve as a time to explicitly clarify communications and set daily goals, which could improve level of agreement among providers (94,95).

With most patients unable to participate fully in EOLDM because of lack of advance directives, illness, and technology of care, there are many difficulties for physicians and nurses on the one hand, and families on the other, who function in separate domains, in interacting to navigate these complex ICU cultures to engage in EOLDM.

This study was limited in that it took place solely within one institution. Aggregating results from multiple units in a single hospital and drawing conclusions expected to relate to all ICUs would be problematic. The research team included no physicians, although there were multiple interview with physicians, who are quoten extensively here to provide their perspective.

To understand and improve EOLDM greater attention needs to be paid to the structure, culture, and variations in provider roles of specific units. As interventions to improve EOLDM are developed, it is important to understand how they may interact with unit-based culture, including formal and informal rules, the meaning and uses of technology, roles and relationships, and processes such as unit rounds.

Acknowledgements

The study was supported by the National Institutes of Health, National Institute of Nursing Research, RO1 NR04940.

We thank the patients, families, and health care providers who allowed us into their lives during the data collection for this study and Dr. Margarete Sandelowski for her critique and wisdom.

References

1. SUPPORT Principal Investigators: A controlled trial to improve care for seriously ill hospitalized patients. JAMA 1995;274:1592–1598.
2. Alpert HR, Emanuel L. Comparing utilization of life-sustaining treatments with patient and public preferences. J Gen Intern Med 1998;13:175–181. [PubMed: 9541374]
3. Hanson LC, Danis M, Garrett JM. What is wrong with end-of-life care? Opinions of bereaved family members. J Am Geriatr Soc 1997;45:1339–1344. [PubMed: 9361659]
4. Jacobson JA, Francis LP, Battin MP, et al. Dialogue to action. J Clin Ethics 1998;8:359–371. [PubMed: 9503086]
5. Wilson D. A report of an investigation of end-of-life care practices in health care facilities and the influences on those practices. J Palliat Care 1997;13:34–40. [PubMed: 9447810]
6. Prendergast TJ, Claessens JM, Luce JM. A national survey of end-of-life care for critically ill patients. Am J Respir Crit Care Med 1998;158:1163–1167. [PubMed: 9769276]
7. Desbiens NA, Mueller-Rizner N, Connors AF, et al. The symptom burden of seriously ill hospitalized patients. J Pain Symptom Manage 1999;17:248–255. [PubMed: 10203877]

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

8. Berwick DM. The SUPPORT project: Lessons for action. Hastings Cent Rep 1995;25(suppl):S21–S22. [PubMed: 8609001]
9. Hardwig J. SUPPORT and the invisible family. Hastings Cent Rep 1995;25(suppl):S23–S25. [PubMed: 8609002]
10. Lynn J, Arkes HR, Stevens M, et al. Rethinking fundamental assumptions: SUPPORT's implications for future reform. J Am Geriatr Soc 2000;48(suppl):S214–S221. [PubMed: 10809478]
11. Solomon MZ. The enormity of the task: SUPPORT and changing practice. Hastings Cent Rep 1995;25 (suppl):S28–S32. [PubMed: 8609004]
12. Fortes, M. Time and Social Structure and Other Essays. Athlone; New York, NY: 1970.
13. Douglas, M. How Institutions Think. Syracuse University Press; Syracuse, NY: 1986.
14. Fortes, M. Kinship and the Social Order. Aldine; Chicago, IL: 1969.
15. Dombeck M. Professional personhood: Training, territoriality and tolerance. J Interprof Care 1997;11:9–21.
16. Fortes, M. On the concept of person among the Tallensi. In: Dieterlen, G., editor. La Notion de Personne en Afrique Noire. Edition de la Recherche Scientifique; Paris, France: 1973. p. 283-319.
17. Fortes, M. Problems of identity and person. In: Jacobson-Widding, A., editor. Identity: Personal and Socio-Cultural. Humanities Press; Atlantic Highlands, NJ: 1983. p. 389-401.
18. Breitborde LB. Levels of analysis in socio-linguistic explanation: Bilingual code switching, social relations, and domain theory. International Journal of the Sociology of Language 1983;39:5–43.
19. Breitborde LB. Rebuttal essay. International Journal of the Sociology of Language 1983;39:161–177.
20. Cassell J. Stories, moral judgment, and medical care in an intensive care unit. Qual Health Res 2004;14:663–674. [PubMed: 15107169]
21. Cassell, J. Life and Death in Intensive Care. Temple University Press; Philadelphia, PA: 2005.
22. Cassell J, Buchman TG, Streat S, et al. Surgeons, intensivists, and the covenant of care: Administrative models and values affecting care at the end of life– Updated. Crit Care Med 2003;31:1551–1559. [PubMed: 12771632]
23. Kaufman SR. Intensive care, old age, and the problem of death in America. Gerontologist 1998;38:715–725. [PubMed: 9868851]
24. Kaufman, SR. … And a Time to Die: How American Hospitals Shape the End of Life. Scribner; New York, NY: 2005.
25. Seymour JE. Revisiting medicalisation and ‘natural’ death. Soc Sci Med 1999;49:691–704. [PubMed: 10452423]
26. Seymour JE. Negotiating natural death in intensive care. Soc Sci Med 2000;51:1241–1252. [PubMed: 11037214]
27. Seymour, JE. Critical Moments – Death and Dying in Intensive Care. Open University Press; Buckingham, UK: 2001.
28. Back AL, Arnold RM. Dealing with conflict in caring for the seriously ill: “It was just out of the question.”. JAMA 2005;293:1374–1381. [PubMed: 15769971]
29. Bowman KW. Communication, negotiation, and mediation: Dealing with conflict in end-of-life decisions. J Palliat Care 2000;16(suppl):S17–S23. [PubMed: 11075529]
30. Buchanan SF, Desrochers JM, Henry DB, et al. A mediation/medical advisory panel model for resolving disputes about end-of-life care. J Clin Ethics 2002;13:188–202. [PubMed: 12624887]
31. Goold SD, Williams B, Arnold RM. Conflicts regarding decisions to limit treatment: A differential diagnosis. JAMA 2000;283:909–914. [PubMed: 10685716]
32. Miller RB. Extramural ethics consultation: Reflections on the mediation/medical advisory panel model and a further proposal. J Clin Ethics 2002;13:203–215. [PubMed: 12624888]
33. Way J, Back AL, Curtis JR. Withdrawing life support and resolution of conflict with families. BMJ 2002;325:1342–1345. [PubMed: 12468486]
34. Weisman DE. Managing conflicts at the end of life. J Palliat Med 2001;4:1–3. [PubMed: 11291389]
35. Luce JM. Three patients who asked that life support be withheld or withdrawn in the surgical intensive care unit. Crit Care Med 2002;30:775–780. [PubMed: 11940744]

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

36. Abbott KH, Sago JG, Breen CM, et al. Families looking back: One year after discussion of withdrawal or withholding of life-sustaining support. Crit Care Med 2001;29:197–201. [PubMed: 11176185]
37. Breen CM, Abernethy AP, Abbott KH, et al. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. J Gen Intern Med 2001;16:283–289. [PubMed: 11359545]
38. Fetters MD, Churchill L, Danis M. Conflict resolution at the end of life. Crit Care Med 2001;29:921–925. [PubMed: 11378597]
39. Norton SA, Tilden VP, Tolle SW, et al. Life support withdrawal: Communication and conflict. A J Crit Care 2003;12:548–555.
40. Studdert DM, Mello MM, Burns JP, et al. Conflict in the care of patients with prolonged stay in the ICU: Types, sources, and predictors. Intensive Care Med 2003;29:1489–1407. [PubMed: 12879243]
41. Workman S, McKeever P, Harvey W, et al. Intensive care nurses' and physicians' experiences with demands for treatment: Some implications for clinical practice. J Crit Care 2003;18:17–24. [PubMed: 12640608]
42. Norton SA, Bowers BJ. Working toward consensus: Providers' strategies to shift patients from curative to palliative treatment choices. Res Nurs Health 2001;24:258–269. [PubMed: 11746057]
43. Curtis JR, Wenrich MD, Carline JD, et al. Understanding physicians' skills at providing end-of-life care: Perspectives of patients, families, and health care workers. J Gen Intern Med 2001;16:41–49. [PubMed: 11251749]
44. Curtis JR, Wenrich MD, Carline JD, et al. Patients' perspectives on physician skill in end-of-life care. Chest 2002;122:356–362. [PubMed: 12114382]
45. Kelly WF, Eliasson AH, Stocker DJ, et al. Do specialists differ on do-not-resuscitate decisions? Chest 2002;121:957–963. [PubMed: 11888982]
46. Good M-JD, Gadmer NM, Ruopp P, et al. Narrative nuances on good and bad deaths: Internists' tales from high-technology work places. Soc Sci Med 2003;58:939–953.
47. Buchman TG, Cassell J, Ray SE, et al. Who should manage the dying patient? Rescue, shame, and the surgical ICU dilemma. J Am Coll Surg 2002;194:665–673. [PubMed: 12022609]
48. Wax ML, Ray SE. Dilemmas within the surgical intensive care unit. J Am Coll Surg 2002;195:721–728. [PubMed: 12437263]
49. Asch DA, Shea JA, Jedrziewski MK, et al. The limits of suffering: Critical care nurses' views of hospital care at the end of life. Soc Sci Med 1997;45:1661–1668. [PubMed: 9428086]
50. Kennard MJ, Phillips R, Speroff T, et al. Participation of nurses in decision making for seriously ill adults. Clin Nurs Res 1996;5:199–219. [PubMed: 8704666]
51. Murphy PA, Price DM, Stevens M, et al. Under the radar: Contributions of the SUPPORT nurses. Nurs Outlook 2001;49:238–242. [PubMed: 11677518]
52. Coombs M, Ersser SJ. Medical hegemony in decision-making – A barrier to interdisciplinary working in intensive care? J of Adv Nurs 2004;46:245–252. [PubMed: 15066102]
53. Hawryluck LA, Espin SL, Garwood KC, et al. Pulling together and pushing apart: Tides of tension in the ICU team. Acad Med 2002;77(suppl):S71–S76.
54. Manias E. Professional journaling overtime: Position of the inside nurse-researcher in intensive care. Intensive Crit Care Nurs 2000;16:111–120. [PubMed: 11868586]
55. Manias E, Street A. The interplay of knowledge and decision making between nurses and doctors in critical care. Int J Nurs Stud 2001;38:129–140. [PubMed: 11223054]
56. Oberle K, Hughes D. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. J Adv Nurs 2001;33:707–715. [PubMed: 11298208]
57. Brett AS. Problems in caring for critically and terminally ill patients: Perspectives of physicians and nurses. HEC Forum 2002;14:132–147. [PubMed: 12141007]
58. Ferrand E, Lemaire F, Regnier B, et al. Discrepancies between perceptions by physicians and nursing staff of intensive care unit end-of-life decisions. Am J Respir Crit Care Med 2003;167:1310–1315. [PubMed: 12738597]
59. Nordgren L, Olsson H. Palliative care in a coronary care unit: A qualitative study of physicians' and nurses' perceptions. J Clin Nurs 2004;13:185–193. [PubMed: 14723670]
60. Melia KM. Ethical issues and the importance of consensus for the intensive care team. Soc Sci Med 2001;53:707–719. [PubMed: 11511047]

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

61. Asch DA, Hansen-Flaschen J, Lanken PN. Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: Conflicts between physicians' practices and patients' wishes. Am J Respir Crit Care Med 1995;151:288–292. [PubMed: 7842181]
62. Simmonds A. Decision-making by default: Experiences of physicians and nurses with dying patients in intensive care. Hum Health Care Int 1996;12:168–172. [PubMed: 11660296]
63. Cook DJ, Guyatt G, Rocker G, et al. Cardiopulmonary resuscitation directives on admission to intensive-care unit: An international observational study. Lancet 2001;358:1941–1945. [PubMed: 11747918]
64. Smedira NG, Evans BH, Grais LS, et al. Withholding and withdrawal of life support from the critically ill. N Engl J Med 1990;322:309–315. [PubMed: 2296273]
65. Teno JM, Stevens M, Spernak S, et al. Role of written advance directives in decision making: Insights from qualitative and quantitative data. J Gen Intern Med 1998;13:439–446. [PubMed: 9686709]
66. Wilson D. A report of an investigation of end-of-life care practices in health care facilities and the influence on those practices. J Palliat Care 1997;13:34–40. [PubMed: 9447810]
67. Terry PB, Vettese M, Song J, et al. End-of-life decision making: When patients and surrogates disagree. J Clin Ethics 1999;10:186–293.
68. Puchalski CM, Zhong Z, Jacobs MM, et al. Patients who want their family and physician to make resuscitation decisions for them: Observations from SUPPORT and HELP. J Am Geriatr Soc 2000;48 (suppl):S84–S90. [PubMed: 10809461]
69. Heyland DK, Tranmer J, O'Callaghan CJ, et al. The seriously ill hospitalized patient: Preferred role in end-of-life decision making? J Crit Care 2003;18:3–10. [PubMed: 12640606]
70. Heyland DK, Cook DJ, Rocker GM, et al. Decision-making in the ICU: Perspectives of the substitute decision-maker. Intensive Care Med 2003;29:75–82. [PubMed: 12528026]
71. Heyland DK, Rocker GM, O'Callaghan CJ, et al. Dying in the ICU: Perspectives of family members. Chest 2003;124:392–397. [PubMed: 12853551]
72. Tolle SW, Tilden VP, Rosenfeld AG, et al. Family reports of barriers to optimal care of the dying. Nurs Res 2000;49:310–317. [PubMed: 11093695]
73. Buchman TG, Ray SE, Wax ML, et al. Families' perceptions of surgical intensive care. J Am Coll Surg 2003;196:977–983. [PubMed: 12788436]
74. Kirchhoff KT, Walker L, Hutton A, et al. The vortex: Families' experiences with death in the intensive care unit. Am J Crit Care 2002;11:200–209. [PubMed: 12022483]
75. Norton SA, Talerico KA. Facilitating end-of-life decision making. J Gerontol Nurs 2000;26(9):6–13. [PubMed: 11883616]
76. McDonagh JR, Elliott TB, Engelberg RA, et al. Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction. Crit Care Med 2004;32:1484–1488. [PubMed: 15241092]
77. Tilden VP, Tolle SW, Nelson CA, et al. Family decision-making to withdraw life-sustaining treatments from hospitalized patients. Nurs Res 2001;50:105–115. [PubMed: 11302290]
78. Tilden VP, Tolle SW, Nelson CA, et al. Family decision making in foregoing life-extending treatments. Journal of Family Nursing 1999;5:426–442.
79. Bartels DM, Faber-Langendoen K. Caring in crisis: Family perspectives on ventilator withdrawal at the end of life. Families, Systems, & Health 2001;19:169–176.
80. Meeker MA. Family surrogate decision making at the end of life: Seeing them through with care and respect. Qual Health Res 2004;14:204–225. [PubMed: 14768458]
81. Jacob DA. Family members' experiences with decision making for incompetent patients in the ICU: A qualitative study. Am J Crit Care 1998;7:30–36. [PubMed: 9429681]
82. Swigart V, Lidz C, Butterworth V, et al. Letting go: Family Decisions to forgo life support. Heart Lung 1996;25:483–494. [PubMed: 8950128]
83. Tilden VP, Tolle SW, Garland MJ, et al. Decisions about life-sustaining treatment: Impact of physicians' behaviors on the family. Arch Intern Med 1995;155:633–638. [PubMed: 7887760]
84. Morse, JM.; Field, PA. Qualitative Research Methods for Health Professionals. Sage; Thousand Oaks, CA: 1995.

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

85. Germain, CP. Ethnography: the method. In: Munhall, PL.; Boyd, CP., editors. Nursing Research: A Qualitative Perspective. National League for Nursing; New York: 1993. p. 237-268.
86. Huberman, AM.; Miles, MB. Data management and analysis methods. In: Denzin, N.; Lincoln, YS., editors. Handbook of Qualitative Research. Sage; Thousand Oaks, CA: 1994. p. 428-444.
87. Christakis NA, Asch DA. Medical specialists prefer to withdraw familiar technologies when discontinuing life support. J Gen Intern Med 1995;10:491–494. [PubMed: 8523151]
88. Back AL, Arnold RM, Quill TE. Hope for the best, and prepare for the worst. Ann Intern Med 2003;138:439–443. [PubMed: 12614110]
89. Lilly CM, DeMeo DL, Sonna LA, et al. An intensive communication intervention for the critically ill. Am J Med 2000;109:1533–1551.
90. Lilly CM, Sonna LA, Haley KJ, et al. Intensive communication: Four-year follow-up from a clinical practice study. Crit Care Med 2003;31(suppl):S394–399. [PubMed: 12771590]
91. Schneiderman LJ, Gilmer T, Teetzel HD. Impact of ethics consultations in the intensive care setting: A randomized controlled trial. Crit Care Med 2000;26:3920–3924. [PubMed: 11153636]
92. Schneiderman LJ, Gilmer T, Teetzel HD, et al. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: A randomized controlled trial. JAMA 2003;290:1155–1172.
93. Campbell ML, Guzman JA. Impact of a proactive approach to improve end-of-life care in a medical ICU. Chest 2003;123:266–271. [PubMed: 12527629]
94. Pronovost P, Berenholtz S, Dorman T, et al. Improving communication in the ICU using daily goals. J Crit Care 2003;18:71–75. [PubMed: 12800116]
95. Dodek PM, Raboud J. Explicit approach to rounds in an ICU improves communication and satisfaction of providers. Intensive Care Med 2003;29:1584–1588. [PubMed: 12898001]

NIH-PA Author Manuscript NIH-PA Author Manuscript NIH-PA Author Manuscript

Table 1

Numbers of Interviews and Interviewees

Participant Groups	Participant Subgroups	MICU Interviews *n*	MICU Persons *n*	SICU Interviews *n*	SICU Persons *n*	BTICU Interviews *n*	BTICU Persons *n*	CVICU Interviews *n*	CVICU Persons *n*	Total Interviews	Total Persons
Physicians	Intensivists	4	3	10	3	8	3	0	0	22	9
	Attendingsy	2	1	1	1	2	2	3	3	8	7
	Consultants	1	1	0	0	1	1	2	2	4	4
	Fellows	2	1	0	0	0	0	0	0	2	1
	Residents	4	4	1	1	4	3	1	1	10	9
Subtotal										46	30
Nurses	Nurse Managers	1	1	1	1	1	1	1	1	4	4
	Nurse Leaders	2	2	2	2	3	1	0	0	7	5
	Staff Nurses	14	11	6	7	7	5	9	6	36	29
	Nurse Practitioners	0	0	1	1	3	2	5	3	9	6
	Care Coordinators	0	0	1	1	1	1	1	1	3	3
	Researcher	1	1	0	0	0	0	0	0	1	1
Subtotal										60	48
Other Providers	Social Workers	2	2	2	1	2	2	2	1	8	6
	Ethicists	3	2	0	0	0	0	0	0	3	2
	Chaplain	0	0	0	0	1	1	0	0	1	1
	Pharmacist	0	0	0	0	0	0	1	1	1	1
Subtotal										13	10
Patients		1	1	2	2	1	1	0	0	4	4
Family Members		11	11	11	12	6	6	6	9	34	38
Total Interviews	157									157	130
Family Meetings		8		2		8		4		22	

NIH-PA Author Manuscript NIH-PA Author Manuscript NIH-PA Author Manuscript

Table 2

Brief Summary of Cultural Differences Among Units

Type of Unit	Informal rules about DNR	Technology: Tracheostomy/PEG tube placement	Physician time with family	Physician EOLDM	Physician timing of EOLDM
Medical	First step in EOLDM	Initiate EOLDM	Quite extensive	Scheduled and unplanned	Earlier in patient trajectory
Surgical	Low priority	Routine care	Brief	Unplanned	Delay until options exhausted