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Rethinking Interventions to Improve Surrogate Decision Making in Intensive Care Units

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Many aspects of care for critically ill patients that were once managed exclusively by physicians are now collaboratively managed by clinicians from several disciplines.¹⁻³ However, most of the responsibility remains with physicians to help surrogate decision makers deliberate about goals of care for patients with advanced critical illness. This is rational if decision making is conceptualized as a purely cognitive process requiring only physicians' technical biomedical knowledge. However, this narrow conceptualization is at odds with the reality that surrogate decision making is also an emotional and moral endeavor.

Moreover, the simple goal of ensuring timely, consistent communication in intensive care units (ICUs) is an organizational challenge. When conceptualized in this way, the importance of multidisciplinary collaboration is clear—no single individual has sufficient skills and time to attend to the diverse challenges that surrogates face in ICUs. In this article, I present a multidimensional framework of the barriers to high quality surrogate decision making in ICUs and present 5 ways that clinical nurses could be more explicitly incorporated into interventions to improve surrogate decision making in ICUs.

Multiple Barriers to High Quality Surrogate Decision Making

Early attempts to improve surrogate decision making focused on providing better information to physicians and surrogates. For example, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)⁴ was a carefully conducted randomized trial that tested an intervention to reduce the frequency of highly technological deaths. The intervention provided physicians with computer-derived prognostic estimates and information about the patient's values. The intervention did not improve any of the prespecified study outcomes. Although there are several potential reasons for this, most experts agree that SUPPORT illustrated the shortcomings of interventions that focus narrowly on informational deficiencies.⁵

Multiple other factors contribute to the difficulty of surrogate decision making in ICUs. The Donabedian structure-process-outcome theory is a frequently used framework to study complicated health care delivery problems.⁶⁻⁸ Accordingly, quality of care is determined by the causal linkages and interactions among patients, clinicians, the structural attributes of the health care setting, and the processes of care.⁹ Applying this theory to end-of-life care in ICUs, poor quality surrogate decision making results from the interplay of clinician factors, family factors, process of care factors, and environmental factors. The figure summarizes the diverse barriers to high quality surrogate decision making.

Surrogates face emotional, psychological, interpersonal, and moral barriers to surrogate decision making. An example of an emotional barrier is the high levels of anxiety and depression surrogates experience when a loved one is critically ill.¹⁰ A growing amount of empirical literature from decision psychology indicates that emotions can profoundly impact decision making. Very intense emotions can impair one's ability to process information and deliberate carefully.¹¹ Those experiencing strong emotions (ie, those in “hot states”) make different decisions compared to subjects not experiencing strong emotions (ie, those in “cold states”).¹² These changes may be particularly problematic for surrogates who are being asked to deliberate about complex, trade-off filled decisions, such as those that balance quantity and quality of life. Thus, failing to attend to surrogates' emotions may introduce biases that could threaten patient-centered decision making.

There are also physician-level barriers to high quality surrogate decision making. For example, physicians may be uncomfortable talking about uncertainty and may not fully attend to the important aspects of these conversations.¹³⁻¹⁵ Physicians may be reluctant to discuss a transition from curative goals to comfort-oriented goals out of an unconscious belief that it signals that they have failed their patient. Moreover, physicians in ICUs often have very substantial constraints on their time because of the high patient volume and acuity encountered in many ICUs.

Structural and process of care attributes of ICUs pose barriers to good surrogate decision making. For example, the need to coordinate the schedules of multiple busy professionals and families is a complex organizational barrier. In many ICUs, there is no dedicated consultation room for clinician-family meetings. Another challenging structural attribute is the shift-based nature of work in ICUs, which makes it difficult to ensure a coherent plan of communication and decision making week-to-week. It is likely that these factors each contribute to inadequate clinician-family interactions that in turn mediate poor patient and family outcomes. In short, because the nature of the difficulties with surrogate decision making are multidimensional, so too must be the solutions.

The Rationale for Nursing Involvement

The traditional physician-driven approaches to counseling surrogates are not legally or ethically required. Moreover, these processes may not work well in ICUs given the ever-increasing time constraints on physicians. Other disciplines have responded to these pressures by developing models that give some responsibility to nonphysicians for helping patients or surrogates make decisions. For example, prenatal genetic counseling for pregnant women and couples is now largely performed by trained genetic counselors.¹⁶ The Dartmouth-Hitchcock Center for Shared Decision Making has developed interactive decision aids for patients facing a wide range of preference sensitive medical choices; these decision aids are meant to help patients begin to formulate preferences at their own pace and style, rather than within the constraints imposed by physicians' schedules and communication skills.¹⁷

Within the intensive care environment, the nursing ethic of caring and family-centeredness makes nurses well suited to help families with this aspect of care.¹⁸⁻²⁰ In addition, the clinical nurse's near-continuous presence at the bedside creates opportunities to work with families in ways that are not feasible for physicians. Moreover, the bedside nurse may have a deeper experiential understanding of the needs of individual patients' families.

Five Ways Nurses Could Facilitate High Quality Surrogate Decision Making

To illustrate the potential of nurse-physician collaborations, I describe 5 ways that clinical nurses could be given augmented role responsibilities to improve the quality of surrogate

decision making in ICUs (Table). It is worth noting that some nurses already carry out at least some of these functions. However, there has been little in the way of formal description of this model of collaboration and even less explicit sharing of responsibility in this aspect of care. This is a problem because a clear description of what a collaborative approach to improve surrogate decision making would “look like” is a necessary step toward refinement, stakeholder buy-in, and implementation.

1. Educate the Family About the Role of the Surrogate

Families of critically ill patients often “don’t know what they don’t know.”²¹ This is especially true regarding the process of surrogate decision making. Recent empirical evidence suggests that many family members feel unprepared for the role as a surrogate; independent predictors of this include lack of prior experience as a surrogate, lack of prior conversations about treatment preferences with the patient, and poor quality communication with the clinical team.²² The latter association raises the possibility that improving how families are educated about surrogacy may increase their comfort with the role. Unfortunately, audio recordings of ICU family meetings suggest that physicians often miss opportunities to educate families about surrogate decision making.¹³

The bedside nurse could oversee educating family members about how to function as a surrogate. The educational goals could be as simple as a 3-point conversation: discussion of who will be the patient's surrogate(s), explanation of the ethical goals of surrogate decision making, and a conversation about patient's prior articulation of health care preferences. Clearly, such a conversation is emotionally difficult and must be conducted in a sensitive manner. In addition, it is necessary to develop a process of care to ensure clear communication of this information to the patient's physician.

2. Organize Regular Meetings Between Family and Multidisciplinary Team

Although there is substantial evidence that structured communication between clinicians and surrogates promotes higher quality decision making, achieving regular communication is difficult. It is often time consuming and logistically complex to arrange multidisciplinary family meetings. Although more than 90% of ICU directors endorse the importance of multidisciplinary meetings with surrogates, they occur regularly in only 35% to 40% of ICUs.^{23,24}

A main barrier to implementation is the logistics of coordinating schedules.²⁵ In many ICUs, physicians must actively choose whether and when to meet with the family. Changing this default to required meetings at a prespecified interval may be more effective.²⁴⁻²⁶

Clinical nurses may be well positioned to oversee these efforts. They typically have a good understanding of physicians’ and families’ schedules, as well as the ability to be in easy contact with both. Giving responsibility for ensuring regular communication to someone other than the patient's attending physician may lead to higher rates of implementation. By analogy, studies on weaning patients from mechanical ventilation (another task that must occur regularly in ICUs for optimal outcomes) suggests that performance and outcomes are improved when responsibility is given to respiratory therapists for daily weaning trials rather than left to physicians.¹ The same logic may apply to ensuring regular communication with surrogates.

3. Prepare the Family for Each Multidisciplinary Meeting

Just as physicians are taught to prepare for each meeting with families,²⁷ it stands to reason that families may benefit from a process of preparation for multidisciplinary meetings. Adult learning theory suggests it is beneficial for learners to identify in advance their goals and

questions.²⁸ This may be especially important in the ICU because of the complexity of the decisions that surrogates face and the potential salutary effect of additional time to organize their thoughts. Learning how to be a surrogate can be likened to other complex learning tasks. Self-efficacy theory has frequently been used as the basis for interventions designed to change patients' and clinicians' behavior in health care settings.²⁹ The goal of the nursing interventions is to increase family members' self-efficacy over difficult communication tasks through coaching, skills training, and vicarious experience.

The clinical nurse could conduct a "pre-meeting" with family immediately before each multidisciplinary meeting. Although the particulars of each "pre-meeting" could be tailored to the individual needs of the family and stage of illness, 4 goals are generalizable. First, and most simply, the nurse could coach and motivate surrogates to highlight how important the family's role is in decision making. Second, nurses could help surrogates formulate their main questions for the physicians. The use of "question prompting" approaches has been used successfully in improving doctor-patient collaboration in oncology.³⁰ Third, the nurse could elicit the family's understanding of the patient's prognosis. Such an effort may be beneficial both in facilitating the crucial yet challenging discussion of the possibility of death, and also in bringing to light potential discordance expectations within the family.³¹ Fourth, the nurse could assess the family's preferred role in decision making³²; this effort could be accomplished in a structured way by using a brief instrument such as the Degner Control Preferences scale.^{33,34}

A final crucial element of the pre-meeting process is the sharing of this information with the other members of the multidisciplinary team. This information can be consolidated onto a 1-page "Individualized Feedback Form" and reviewed with the attending physician prior to the meeting. Important domains of content include (1) a summary of the patient's values and preferences, (2) the surrogates' main questions, (3) surrogates' quantitative estimates of the patient's prognosis for survival and return to baseline function, and (4) surrogates' preferred role in decision making.

4. Provide Emotional Support and 'Nudges' During the Multidisciplinary Meeting

Nurses could ensure that the multidisciplinary meetings "stay on track" and are conducted in a way that is emotionally supportive of families. Empirical studies of clinician-family conferences in ICUs reveals that emotional support is often missing or inadequate. Family satisfaction is high when clinicians express empathy³⁵ and other forms of emotional support.³⁶ The clinical nurse could have the "assigned role" of monitoring the families' emotional state and responding to observed emotional cues in supportive ways.

The clinical nurse could also help ensure that key topics are covered, such as the family's main questions, the patient's values and prognosis, the treatment options available, and the key clinical milestones by which to assess the patient's progress. In testing a similar intervention at the University of Pittsburgh Medical Center, we have found that the "Individualized Feedback Form" gives nurses an opportunity to "nudge"³⁷ participants toward a discussion of difficult topics by saying, "one of the things the family has listed as a question is what are the likely outcomes of treatment." These nudges are often crucial in initiating deliberation about the emotionally difficult topic of whether the patient's goals can be achieved.

5. Facilitate the "the meeting after the meeting."

Although much research has focused on ICU family conferences, there is another meeting that occurs after this meeting that is essentially unstudied—and it is a potential opportunity for nurses to support families. After physicians exit, families often remain in the meeting

room to debrief and discuss the new information and decisions. Areas of disagreement or confusion sometimes surface, and nurses and social workers are often present for this “meeting after the meeting.”

Some nurses intuitively help families cope with the emotional and moral aspects of the medical information from physicians. This meeting is often a source of important insight about the family's understanding, emotions, and attitudes. The bedside nurse can contribute substantially to supporting the family by regularly creating the space for this conversation, facilitating it, and also by communicating to the other clinicians involved concerns or misunderstandings that come to light.

Potential Objections

Some might object that it is not feasible for nurses to acquire the skills needed for this type of collaborative model of decision support. Although it is true that this approach will require skills training, each component of the intervention role can be broken down into teachable steps and can be manualized. Moreover, the skills are generally refined versions of what some nurses already do. An alternative strategy is to consolidate these skills in the hands of a few nurses in every unit rather than attempt to train all nurses. Some ICUs already have “nurse care coordinators” whose job is to facilitate high quality care across multiple domains. These nurses could also be given the responsibility to implement this intervention for patients at high risk of poor outcomes. Pilot efforts of both types of nurse-physician collaboration are warranted.

Physicians may object to sharing any responsibility regarding highly sensitive decisions with nurses. It is likely that this intervention will require a shift in the culture of some ICUs and a willingness to embrace a new model of care. Many ICUs have established quality improvement programs and this model of collaborative support for surrogates could be tested using existing quality improvement infrastructure. This will be more difficult in units in which there is not a strong degree of collegiality between different disciplines and in which change is resisted. Nonetheless, ICU cultures do evolve over time in the face of improvements in health care delivery, and there are evidence-based strategies to change physicians' behavior.^{38,39}

Future Directions

Three decades of research in decision psychology suggests that there are complex cognitive, emotional, and situational barriers to good decisions. Although the expert technical guidance of physicians is indispensable, it is only part of what is needed to help surrogates make patient-centered decisions about goals of care. Collaborative models in which responsibilities are shared between nurses and physicians make more sense than the traditional physician-driven model. The next step is carefully controlled trials of such interventions, with rigorous assessment of the intervention's impact on meaningful patient, family, and health services outcomes.

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REFERENCES

1. Ely EW, Baker AM, Dunagan DP, et al. Effect on the duration of mechanical ventilation of identifying patients capable of breathing spontaneously. *N Engl J Med*. 1996; 335(25):1864–1869. [PubMed: 8948561]
2. Girard TD, Kress JP, Fuchs BD, et al. Efficacy and safety of a paired sedation and ventilator weaning protocol for mechanically ventilated patients in intensive care (awakening and breathing controlled trial): a randomised controlled trial. *Lancet*. 2008; 371(9607):126–134. [PubMed: 18191684]
3. Schweickert WD, Pohlman MC, Pohlman AS, et al. Early physical and occupational therapy in mechanically ventilated, critically ill patients: a randomised controlled trial. *Lancet*. 2009; 373(9678):1874–1882. [PubMed: 19446324]
4. SUPPORT: A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients. *JAMA*. 1995; 274(20):1591–1598. [PubMed: 7474243]
5. Lynn J, De Vries KO, Arkes HR, et al. Ineffectiveness of the SUPPORT intervention: review of explanations. *J Am Geriatr Soc*. 2000; 48(5 Suppl):S206–213. [PubMed: 10809477]
6. Richie ND. An approach to hospice program evaluation. The use of Donabedian theory to measure success. *Am J Hosp Care*. 1987; 4(5):20–27. [PubMed: 3650092]
7. Closs SJ, Tierney AJ. The complexities of using a structure, process and outcome framework: the case of an evaluation of discharge planning for elderly patients. *J Adv Nurs*. 1993; 18(8):1279–1287. [PubMed: 8376667]
8. Schiff GD, Rucker TD. Beyond structure-process-outcome: Donabedian's seven pillars and eleven buttresses of quality. *Jt Comm J Qual Improv*. 2001; 27(3):169–174. [PubMed: 11242722]
9. Donabedian A. The quality of care. How can it be assessed? *JAMA*. 1988; 260(12):1743–1748. [PubMed: 3045356]
10. McAdam JL, Dracup KA, White DB, Fontaine DK, Puntillo KA. Symptom experiences of family members of intensive care unit patients at high risk for dying. *Crit Care Med*. 2010; 38(4):1078–1085. [PubMed: 20124890]
11. Loewenstein, G.; Lerner, JS. The role of affect in decision making.. In: Davidson, RJ.; Scherer, KR.; Goldsmith, HH., editors. *Handbook of Affective Sciences*. Oxford University Press; New York: 2003. p. 619-642.
12. Loewenstein G. Hot-cold empathy gaps and medical decision making. *Health Psychol*. 2005; 24(4 Suppl):S49–S56. [PubMed: 16045419]
13. White DB, Braddock CH III, Bereknyi S, Curtis JR. Toward shared decision making at the end of life in intensive care units: opportunities for improvement. *Arch Intern Med*. 2007; 167(5):461–467. [PubMed: 17353493]
14. White DB, Engelberg RA, Wenrich MD, Lo B, Curtis JR. Prognostication during physician-family discussions about limiting life support in intensive care units. *Crit Care Med*. 2007; 35(2):442–448. [PubMed: 17205000]
15. White DB, Malvar G, Karr J, Lo B, Curtis JR. Expanding the paradigm of the physician's role in surrogate decision-making: an empirically derived framework. *Crit Care Med*. 2010; 38(3):743–750. [PubMed: 20029347]
16. Veach, PM.; LeRoy, BS.; Bartels, DM. *Facilitating the Genetic Counseling Process: A Practice Manual*. Springer; New York: 2003.
17. The Dartmouth-Hitchcock Center for Shared Decision Making. [March23, 2011] http://www.dhmc.org/shared_decision_making.cfm.
18. American Nurses Association. *Code of Ethics for Nurses With Interpretive Statements*. American Nurses Association; Silver Spring, MD: 2001.
19. Rushton CH. Respect in critical care: a foundational ethical principle. *AACN Adv Crit Care*. 2007; 18(2):149–156. [PubMed: 17473543]
20. Spichiger E, Wallhagen MI, Benner P. Nursing as a caring practice from a phenomenological perspective. *Scand J Caring Sci*. 2005; 19(4):303–309. [PubMed: 16324052]
21. Rabow MW, Hauser JM, Adams J. Supporting family caregivers at the end of life: 'they don't know what they don't know.'. *JAMA*. 2004; 291(4):483–491. [PubMed: 14747506]

22. Majesko A, Hong SE, Weissfeld L, White DB. Predictors of surrogates' perceived ability to make decisions for incapacitated ICU patients [abstract 731]. *Crit Care Med.* 2010; 38((12) (Suppl)):A205.
23. Nelson JE, Angus DC, Weissfeld LA, et al. Critical Care Peer Workgroup of the Promoting Excellence in End-of-Life Care Project: End-of-life care for the critically ill: A national intensive care unit survey. *Crit Care Med.* 2006; 34(10):2547–2553. [PubMed: 16932230]
24. Nelson JE, Mulkerin CM, Adams LL, Pronovost PJ. Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback. *Qual Saf Health Care.* 2006; 15(4):264–271. [PubMed: 16885251]
25. Gay EB, Pronovost PJ, Bassett RD, Nelson JE. The intensive care unit family meeting: making it happen. *J Crit Care.* 2009; 24(4):629, e621–e612. [PubMed: 19327312]
26. Halpern SD, Ubel PA, Asch DA. Harnessing the power of default options to improve health care. *N Engl J Med.* 2007; 357(13):1340–1344. [PubMed: 17898105]
27. Curtis JR, Patrick DL, Shannon SE, Treece PD, Engelberg RA, Rubenfeld GD. The family conference as a focus to improve communication about end-of-life care in the intensive care unit: opportunities for improvement. *Crit Care Med.* 2001; 29(2 Suppl):N26–N33. [PubMed: 11228570]
28. Newman P, Peile E. Valuing learners' experience and supporting further growth: educational models to help experienced adult learners in medicine. *BMJ.* 2002; 325(7357):200–202. [PubMed: 12142310]
29. Holloway A, Watson HE. Role of self-efficacy and behaviour change. *Int J Nurs Pract.* 2002; 8(2): 106–115. [PubMed: 11993577]
30. Clayton JM, Butow PN, Tattersall MH. Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *J Clin Oncol.* 2007; 25:715–723. [PubMed: 17308275]
31. Cox CE, Martinu T, Sathy SJ, et al. Expectations and outcomes of prolonged mechanical ventilation. *Crit Care Med.* 2009; 37(11):2888–2894. quiz 2904. [PubMed: 19770733]
32. Johnson SK, Bautista CA, Hong SY, Weissfeld L, White DB. An empirical study of surrogates' preferred level of control over value-laden life support decisions in intensive care units. *Am J Respir Crit Care Med.* Oct 29.2010 [epub ahead of print].
33. Degner LF, Kristjanson LJ, Bowman D, et al. Information needs and decisional preferences in women with breast cancer. *JAMA.* 1997; 277(18):1485–1492. [PubMed: 9145723]
34. Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. *Can J Nurs Res.* 1997; 29(3): 21–43. [PubMed: 9505581]
35. Selph RB, Shiang J, Engelberg R, Curtis JR, White DB. Empathy and life support decisions in intensive care units. *J Gen Intern Med.* 2008; 23(9):1311–1317. [PubMed: 18574641]
36. Stapleton RD, Engelberg RA, Wenrich MD, Goss CH, Curtis JR. Clinician statements and family satisfaction with family conferences in the intensive care unit. *Crit Care Med.* 2006; 34(6):1679–1685. [PubMed: 16625131]
37. Thaler, R.; Sunstein, C. *Nudge: Improving Decisions About Health, Wealth and Happiness.* Yale University Press; New Haven: 2008.
38. Cabana MD, Rand CS, Powe NR, et al. Why don't physicians follow clinical practice guidelines? A framework for improvement. *JAMA.* 1999; 282(15):1458–1465. [PubMed: 10535437]
39. Grol R, Grimshaw J. From best evidence to best practice: effective implementation of change in patients' care. *Lancet.* 2003; 362(9391):1225–1230. [PubMed: 14568747]

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Figure.

Multiple factors contribute to the difficulty of surrogate decision making in ICUs. The characteristics in the green circle illustrate optimal attributes of clinicians, surrogates, and structures/processes of care. The red boxes outside the circle indicate the multiple barriers that can threaten high quality surrogate decision making. The square boxes on the right indicate desirable and undesirable outcomes of surrogate decision making.

Table**Five ways for nurses to foster high quality surrogate decision making**

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1. Prepare family for the role of surrogate
 2. Organize regular meetings between family and multidisciplinary team
 3. Prepare family before each intensive care unit family meeting
 4. Provide emotional support and “nudges” during meetings
 5. Be present for “the meeting after the meeting”
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