Communication in intensive care settings: The challenge of futility disputes

Joseph J. Fins, MD; Mildred Z. Solomon, EdD

In intensive care settings, suboptimal communication can erode family trust and fuel so-called “futility” disputes. Presenting a teaching case used by >225 hospitals participating in the Decisions Near the End-of-Life program, we identify critical communication challenges and opportunities. We emphasize that good communication requires not only clear and sensitive language but also clinician self-awareness, psychological insight, and an institutional culture that promotes good communication with families. The article concludes with two examples of steps institutions can take to foster good communication between families and healthcare professionals.

KEY WORDS: end-of-life; palliative care; communication; intensive care; doctor-patient relationship; family; futility; medical education; case study

With the current national interest in improving end-of-life care, there is growing attention to the importance of good communication. The literature on this topic includes many suggestions for the content, timing, and settings in which bad news can best be delivered (1–5). Most of this literature focuses on effective strategies for delivering bad news to patients, with much less attention to the best ways of building alliances with family members. Yet in intensive care settings, patients usually are not conscious, so healthcare professionals must communicate with families in crisis. The success of these communications has a direct consequence for family trust and ultimately for the life and death decisions that families and healthcare professionals must make on behalf of patients.

BACKGROUND

For more than a decade, we have participated in a sustained multidisciplinary research effort to better understand decision-making and communication problems among physicians, nurses, patients, and families as they face questions about the use of life-sustaining medical treatments (6). In one study, one of us (MZS) interviewed physicians at a Harvard-affiliated teaching hospital, probing for examples of how they think and talk about end-of-life treatment decisions (7–8). In another study, 1,400 physicians and nurses in five geographically diverse hospitals were surveyed to ascertain their views about the quality of terminal care decision-making in their institutions and their own views about the criteria that should guide the decision-making process (9). As part of this effort, we have worked face-to-face with thousands of physicians, nurses, social workers, and clergy from >225 hospitals and nursing homes in 37 states to develop quality improvement efforts aimed at enhancing the care of the dying. These workshops and our growing dataset indicate that many physicians and nurses struggle with finding the right words to initiate end-of-life discussions with patients and families.

Communication with families in intensive care settings is complicated by the fact that admission to an intensive care unit (ICU) is often sudden and unexpected, and intensivists usually meet families for the first time under difficult emotional circumstances. Often in ICUs, there is little conversation with families, particularly about quality-of-life issues that are at the heart of end-of-life conversations (7). Avoiding direct discussion of quality of life and failing to stage bad news gradually can result in ill-phrased questions that are put to families without adequate preparation or context. Thus, physicians sometimes say things like, “If your father’s heart should stop, would you like us to do everything we can to start it again?” When conversations about the goals of care do not occur gracefully in the intensive care environment, when they occur suddenly or very late, families that have been striving hard to sustain hope can be caught off guard. They may become distrustful when their loved one’s professional caregivers finally reveal that death is imminent. So-called “futility” disputes easily can ensue.

In this article, we present a teaching case that we and our colleagues developed to help healthcare professionals improve communication and build alliances with families. This case is one in a series of seven cases, developed and used in numerous educational seminars as part of the Decisions Near the End of Life program. Decisions Near the End of Life is a multidisciplinary quality improvement initiative initially funded by the W.K. Kellogg Foundation and jointly developed by Education Development Center, Inc., of Newton, Massachusetts, and The Hastings Center of Garrison, New York (10). We offer the case, with commentary, drawing on our extensive experience using this case vignette as a teaching vehicle. We discuss it here as a way of teasing apart some of the many communication challenges that in-
The case of Justine Jackson involves a futility dispute (11). It is a complex case in which there are conflicts at two levels. The first is between the attending physician and a resident about the appropriateness of continuing ventilator support for an elderly woman, Mrs. Jackson, with an extremely poor prognosis. The second conflict comes later and involves a difference in views between Mrs. Jackson’s son, who wants “everything done” for his mother, and her attending physician, who believes that “nothing more can be done.” The commentary focuses on communication strategies that might have prevented or reduced the likelihood of such conflicts, as well as strategies that might help physicians and nurses handle such conflicts when they do arise.

In teaching circumstances, we present the case in three segments to encourage small group discussion at critical junctures in the unfolding story. Here, we follow that pattern. Stopping the narrative at moments of uncertainty allows adult learners to anticipate problems and try out, in conversation with their colleagues, how they might solve them. Learners then can compare their thinking against the eventual evolution of the case, as it is revealed in later segments.

In this case, segment 1 demonstrates how clinician communications can fuel unrealistic family expectations and hopes, which, in turn, increase the likelihood of a later conflict. In segment 2, a full-fledged conflict emerges, and in segment 3, seminar participants are encouraged to consider what institutional mechanisms are available for mediating such conflicts. Quotations are reprinted with permission (11).

**Segment 1**

At age 82, Justine Jackson was an avid gardener, growing roses in the backyard of her home in a working-class African American neighborhood where she had lived most of her adult life. One morning, after an hour of strenuous pruning, she developed chest pain, felt light-headed and passed out on the ground. An hour later, a neighbor found her there, awake but groggy and called an ambulance. When Mrs. Jackson arrived in the emergency room of City Hospital, her ECG suggested that she had had a heart attack involving her right ventricle. The cardiologist, Dr. Winston, concerned about the development of a complete heart block, inserted a temporary pacemaker.

Although Dr. Winston told his resident, Dr. Rodriguez, that Mrs. Jackson “was still not out of the woods” he sounded optimistic when he spoke with her son, Robert, a high school social studies teacher. He told Robert, “your mother had a heart attack, but she’s stable right now. We’ve given her a temporary pacemaker and we’re taking her upstairs to the CCU to keep an eye on her.”

Mrs. Jackson made slow progress in the CCU and Robert was pleased that she was able to sit in a chair for a couple of hours a day. Her heartbeat was still irregular, however, and Dr. Winston decided to place a permanent pacemaker. At that point, Mrs. Jackson’s course started to go downhill. During the placement of the pacemaker, she suffered a stroke that made it difficult for her to swallow and required placement of a nasogastric feeding tube. She soon developed an aspiration pneumonia and was transferred to the ICU on ventilatory support. Although her infection cleared, after a month in the ICU she could not be weaned from the respirator. In the interval, she required blood transfusions because of a bleeding ulcer, attributed to heparin treatment she had received subsequent to her stroke. The ulcer precluded PEG placement and her nutritional status deteriorated.

In conversations with Dr. Winston, the medical residents are increasingly questioning continuing ventilator support for Mrs. Jackson, given her age, her poor nutritional status and her inability to control her secretions. Dr. Rodriguez thinks the ventilator is now “futile” treatment and should be withdrawn, or that at the least a “do not resuscitate” order should be written. The residents feel that Dr. Winston is dismissing their concerns, focusing instead on the patient’s ventilator settings and blood chemistries.

This introductory segment of the case raises questions about what constitutes adequate disclosure of a patient’s medical situation at the outset of a hospitalization. Most futility disputes have their genesis in failures of communication and a subsequent discordance in expectations. Was Dr. Winston’s initial conversation with Robert appropriate? Should more have been said about Mrs. Jackson’s likely prognosis? Although physicians quite rightly want to sustain hope in family members, it is usually best to present a balanced picture of both positive and negative future scenarios. This is especially true when interventions that carry potentially significant complications are considered. The case, therefore, should encourage seminar participants to consider alternative ways to frame the dialogue. For example, Dr. Winston might have signaled the potential severity of Mrs. Jackson’s condition, by saying:

It’s a bit too soon to tell. Obviously, I have great hope that your mother will fully recover, but it is also possible that things will not get better. In either case, I want you to know that I will consult with you all along the way. Are there others in your family or among your mother’s friends whom we should be apprising of the situation?

When Mrs. Jackson’s heartbeat does not regularize, it is another opportunity to paint a hopeful but realistic picture of her progress, including the potential complications that could follow from the placement of the pacemaker. Although the routinization of procedures can inure physicians to adverse outcomes, it is important that we sensitively remind family members that no intervention is risk-free. Such disclosure to families is especially critical when a family member sees some evidence of progress that clinicians know is short-lived and is sustainable only with additional therapy.

In addition, this segment of the case demonstrates that there can be a sharp difference in perspective between residents and attending physicians concerning the utility or “futility” of continuing life-prolonging measures in very ill patients in the ICU. Indeed, the difference in views between Dr. Rodriguez and Dr. Winston can be construed as characteristic of the relationship between many residents and attending physicians in the intensive care environment. The differential status and power that Dr. Rodriguez has, by virtue of being a resident, may pose an ethical and political dilemma for him: Should he speak with Robert directly, if he holds a different view from Dr. Winston’s?

One study conducted in a surgical ICU as part of the field-test of the Decisions program found that involving surgical residents in case-based discussions of end-of-life decision-making led to greater
communication between residents and attending intensivists and to greater discussion about goals of care among residents, attending physicians, and families. Holloran et al. (12) reported greater advance care planning notation in the medical record and documented shortened lengths of stay, because families were more actively involved in decision-making and often chose treatment withdrawal as the best option for their dying loved ones. Thus, one outcome of discussing this segment of the Justine Jackson case might be to encourage a climate of greater openness among residents and attending physicians, purposefully soliciting diverse viewpoints that could be aired openly among them—rather than on larger issues of prognosis and survival.

Recalling the initial optimism communicated to them, families may seek refuge from a futility determination in a variety of ways, including wishful thinking and religious invocations. The clinician, in turn, may grow impatient with the family, finding them discordant with the “scientific” view of what is realistic. Family and physician, once allied, now confront one another as adversaries.

Furthermore, this segment demonstrates the problem of focusing on the question of resuscitation with phrases like “do everything” and “do nothing.” In the first place, they are misnomers. One would never do “everything,” because that could encompass a whole range of highly inappropriate and potentially harmful interventions. Nor would one ever do “nothing,” as any committed physician and nurse would strive hard to provide aggressive comfort measures. Second, the phrase “do nothing” creates a “deficit” framework for the conversation, where the focus is on what is being taken away rather than on what is to be gained by withdrawing life supports and providing comfort measures.

What alternative approaches might Dr. Winston have used to begin the conversation with Mr. Jackson about the changing goals of care? Dr. Winston might have started the conversation by emphasizing his commitment to protecting Mrs. Jackson from harm. Moreover, he could have done so in a way that eased, rather than exacerbated, Robert’s emotional transition from expecting cure to accepting his mother’s mortality. The following language is offered as an example, although in reality, such a long “speech” would be unwise, because the conversation should be a dialogue, with silences and opportunities for Robert to speak and to ask questions. Moreover, such bad news most often should be staged over several conversations. Nevertheless, one plausible way to frame the conversation in a nondeficit manner might go something like this:

You and I have both been hoping for the best, and I have been reluctant to come to this conclusion, but it is now very clinically clear. Your mother is not getting better, and it is now clear to us that she is dying.

We cannot know for sure how long she will linger in this last phase, but whatever happens, I want you to know that I will do everything in my power to assure that she remains comfortable. Our powerful tools here in the ICU can sometimes bring great benefits, but at other times, they can create unnecessary pain and suffering without any benefit to the patient at all. I am committed to ensuring that nothing we do harms your mother.

There will be some important decisions that you and I are going to have to make, and I hope you and I will talk through these choice points together, so that we make the kinds of decisions your mother would make herself, if she were able to tell us.

Framing the conversation this way would have helped Robert realize that Dr. Winston was on Robert’s side and on his mother’s side, working hard to create the best possible situation for Mrs. Jackson. This segment points out how easily families might be led to suspect a link between questions about the costs of care and the futility of continued treatment. Amid external pressures from case managers, politicians, and utilization reviewers, it should come as no surprise that many families, particularly poor or disenfranchised ones, would hold such perceptions. In this instance, lack of coordination among the care team, in this case between the physician and the social worker, proved especially deleterious. It was profoundly unfortunate that issues of cost and payment should have arisen just before the discussion about goals of care. Had there been a regular team meeting to plan the approach to the family, such poor timing might have been avoided.

Finally, this segment provides an opportunity for discussants to consider the impact of race and ethnicity on communication and trust in the intensive care setting. Are Robert’s suspicions about the doctor’s broaching of a do-not-resuscitate order prompted by his concern that as a black patient, his mother’s welfare may
somewhat be discounted? Given documented disparities in treatment referrals for black and white patients of similar health status and treatment preferences (13, 14), it is important to recognize the legitimacy of these concerns when they arise.

Segment Three

At Dr. Winston’s request, City Hospital’s ethics committee met the following day to discuss the Jackson case. Dr. Winston expressed his frustration with the family. He gave a detailed description of the patient’s deteriorating medical condition and suggested that Robert was in denial about his mother’s impending death. He asked the committee to consider invoking the Medical Board’s recently adopted “futility policy,” which gave the attending physician considerable clinical discretion in futility disputes. Turning to his medical colleagues on the committee, Dr. Winston asked, “Is not this precisely the sort of case those guidelines were written for?”

The chief of medicine, who sat on the ethics committee, agreed with Dr. Winston, noting that “the patient is not going to get better and all we would be doing would be to protect her from additional harm. The ICU is no place for this woman to die. Families shouldn’t force us to do things that hurt our patients.”

Rabbi Braverman, another member, agreed that while the patient would be better served if she did not die in the ICU, “it would be better if Mr. Jackson came to that conclusion himself without imposing this on him.” Rabbi Braverman suggests, “It’s possible that our own staff may have inadvertently raised Mr. Jackson’s hopes for his mother’s recovery or fueled his distrust of the healthcare system. He may also simply be having trouble accepting his mother’s decline.” The rabbi then suggested that a call to Reverend Curtis at Mr. Jackson’s own Neighborhood Baptist Church might be a productive first step.

This segment illustrates that families are not the only ones with feelings that must be managed through communication. The fracturing of the family-physician alliance can be difficult for physicians, who now may believe that they have failed on two fronts—in promoting a cure and in cultivating a dialogue with the patient and family. Although clinician anger is rarely acknowledged explicitly, it fuels impatience and informs words and actions. Families who are persistent in their requests for “futile” care are seen as “difficult” and described as “failing to get it.” Note in this case that Dr. Winston suggests that Robert is “in denial.” Typically, under these circumstances, it becomes increasingly easy to be judgmental. There may be a psychological incentive to withdraw from the case and avoid the family or a desire to engage in unilateral decision-making, without the involvement or consent of the family. Sometimes even labeling care as futile is an exercise in announcing to the family that they are now excluded from the decision-making process.

Unfortunately, professionals may fail to appreciate how personal anger and frustration can influence their clinical responses in conflicts over futility. It is easy to be governed by an unconscious dynamic, what psychoanalysts term “countertransference” (15–17). In futility disputes, countertransference can manifest itself in power struggles over authority as well as in clinicians’ needs for approval, defensiveness, and overidentification with the case (17). Countertransference has practical consequences for patient care, because patients and families are sensitive to clinician anger and frustration and may lose faith and trust when their caregivers’ feelings break through. Futility cases are especially ripe for the distortions wrought by countertransference, because such cases force healthcare professionals to confront their own limitations as clinicians, evoke memories of personal loss, and call attention to one’s own mortality.

In making determinations about futility, it is important to avoid becoming too judgmental. Because most futility disagreements hinge on failed or missed opportunities to communicate, it is essential that we appreciate when interactions with patients and families are being distorted. Countertransference can never fully be avoided in the human complexity that marks all futility cases. However, it can be a source of insight and can be understood diagnostically by clinicians to promote more productive interactions with patients and families. Only then can we hope to minimize adversarial encounters in times of stress and work collaboratively with families in reconfiguring goals of care in the intensive care environment (18). As this discussion has suggested, good communication is not simply a matter of choosing felicitous words and appropriate timing, although of course poor phrasing at the wrong time and place can undo the best of intentions. Rather, good communication is fundamentally a matter of psychological insight and self-awareness, not just language skills. Communication flows most easily when clinicians and families are comfortable discussing the full range of potential alternative scenarios, when they are allied and tolerant of each other’s views, when they accept the inevitability of having to discuss quality of life, and when they are willing to grapple with the inherent trade-offs between various goals of care.

Finally, good communication is not just about the skills and psychological orientation of individual practitioners. Institutional policies and procedures can create a climate conducive to good family communication and enhanced decision-making. In the final section of this article, we present two examples of promising institutional practices.

Creating Institutional Support for Good Family Communication

The value of dialogue can be nurtured at both the individual and the institutional level, and interaction between these two levels is essential. For example, hospital futile care policies that sanction unilateral decision-making on the part of physicians can diminish the impulse to sustain an exchange between patient and physician and can erode patient and family trust (5). However, institutional policies that stipulate the conditions which ought to trigger a mandatory conversation with families can be very helpful.

Dowdy et al. (19) instituted such a policy in the ICU of a Virginia hospital and reported on their results in a 1998 article in Critical Care Medicine. As part of their involvement in the Decisions Near the End of Life program, Dowdy et al. achieved an impressive improvement in advance care planning, the quality of end-of-life decision-making, and lower resource utilization when they established an institutional routine requiring a conversation about goals of care whenever any patient in their hospital’s ICU was on a ventilator for ≥ 96 hrs. The goal was to ensure that the attending physician would speak with the family (or patient, if he or she were able) about their understanding of the patient’s prognosis and then develop a mutually agreed-upon goal for care that could include either continued ventilatory support, terminal weaning, or a variety of intermediate trials of treatment. The point was not to
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advocate for any particular substantive decision but simply to ensure that families were apprised of the kinds of issues they were likely to face in the coming days and that caregivers were aware of family values and preferences.

The important factor in this intervention’s success was that the conversation was not left to occur by happenstance, dependent on the interest, skill, or time of individual attending physicians, who vary greatly in their willingness and comfort levels with conversations of this sort. Instead, Dowdy’s team established objective criteria (96 hrs of continuous mechanical ventilation) that were used to trigger an institutional mechanism (an interdisciplinary team comprised of healthcare professionals who are comfortable holding end-of-life discussions). It was decided that having a team member speak directly with the family would be an inappropriate circumnavigation of the attending physician. Instead, whenever the trigger event occurred, a team member would approach the attending physician to ask if he or she had talked with the family. In many cases, this question alone succeeded in motivating the attending physicians to have the awaited conversations with families. Other attending physicians, less inclined to hold these conversations, welcomed assistance from members of the ethics consult team, who made themselves available for more direct participation with families, on the attending physician’s request. This study established that when colleagues, with full backing from the institution’s leadership, raise the issue with attending physicians, the attending physicians’ willingness to hold conversations with families increases, there is greater documentation of families’ values and preferences in the medical record, and resource utilization is decreased in the ICU.

Clinicians and families also can benefit from the use of structured instruments that gather and organize the data needed to make judgments about appropriate goals of care. For example, the Goals of Care Assessment Tool (GCAT) is a structured tool used to collect pertinent clinical and narrative information essential to the formulation of cogent goals of care at the end of life (20). In a readily usable format, the GCAT prompts the clinician to estimate the patient’s prognosis and note whether the patient or surrogate knows the diagnosis and prognosis. It also catalogues the presence or absence of do-not-resuscitate orders and advance directives, family support and involvement, and relevant psychosocial and cultural issues. The adequacy of pain and symptom management also is assessed. Once this information is collected, the practitioner is directed to formulate goals of care and undertake agreed-upon clinical interventions that will help achieve these goals.

Use of the GCAT can be prompted by developments in the patient’s course which suggest that a change in the goals of care is warranted. Such prompts include patient or surrogate knowledge about a terminal diagnosis or prognosis, articulated preferences for palliative care, an expressed desire for death, or the completion of a do-not-resuscitate order. In addition to these patient or surrogate prompts, GCAT use can be triggered when clinical staff think that the patient is dying, when there is new diagnostic or prognostic information, or when there is a change in the patient’s clinical course indicating the need to reconsider life-sustaining therapy or to introduce palliative care interventions.

Instruments like the GCAT can promote a collaborative process of end-of-life decision-making in complex institutional settings by providing a structured way for clinicians to work with patients and families at key nodal points. By encouraging clinicians to collect and assess available clinical and narrative information and identify information that may be missing and essential to adequate decision-making, use of tools like the GCAT should minimize futility disputes and lead to more timely palliative care interventions.

CONCLUSION

Effective communication hinges on the clinician recognizing that a problematic situation needs to be addressed (21). Unfortunately, it is often easier to appreciate problems—such as futility disputes—retrospectively once they have emerged. Therefore, it is critical that healthcare institutions employ educational strategies that encourage clinicians to become self-reflective and to identify brewing futility disputes prospectively (8, 22–24). Use of clinical parables and case histories can help clinicians read complicated situations and thereby minimize subsequent disputes (25). Well-constructed fictional cases are especially useful because they allow adult learners to analyze clinical scenarios in which they were not personally involved, thereby avoiding blame and shame, emotions that inhibit forthright discussion and compromise learning. We encourage readers to collect real-life cases, fictionalize them, and create opportunities for intensivists to discuss them in small, multidisciplinary groups.

Communication challenges in the intensive care environment not only require practice in the use of felicitous language or conversations with families in appropriate places at the appropriate time. Good communication also requires self-awareness on the part of clinicians, psychological insight, and an institutional culture that promotes good communication among all the staff and with families.

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