Family Engagement Regarding the Critically Ill Patient

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concerns. Communication between the medical team and the family during these meetings is vitally important, and yet is often inadequate. The ICU Working Group, convened to develop an ICU end-of-life research and education agenda, identified communication as a necessary area of improvement. Numerous studies, including the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), have found serious shortcomings in physician-family communication.

Open communication benefits both patients and their families. Families in the SUPPORT trial reported that 50% of patients able to communicate spent more than half of their final days in moderate or severe pain. Reduced family participation in the decision-making process is associated with increased unnecessary treatments as well as physician-family conflicts. The French FAMIREA group showed that a lack of regular meetings with the medical team increases anxiety in the patient’s family members, and perceived contradictions in the information received is associated with an increased rate of depression in these families. A similar study showed that posttraumatic stress disorder, a common finding among family members of patients who are dying in the hospital, can be lessened by increasing the length of family meetings as well as by allowing the family members more time to talk.

Although there are several studies looking at the quality of communication during family meetings, few examine the documentation of these meetings, despite its importance in communication between care providers. Sharing information through the medical record reduces risk, reduces duplication and waste, and improves decision making. This written record also supports other functions, such as billing. Documentation can be addressed by a standard form for physicians to use during family meetings, but the outcomes of such an intervention have not been studied.

This increased emphasis on communication may not be enough; there is ample evidence that family members do not understand everything discussed during these meetings. Azoulay and colleagues found that 54% of patient representatives failed to comprehend the patient’s diagnosis, prognosis, or treatment. Another study found that only 19% of primary patient surrogates reported poor understanding, but 47% of surrogates surveyed met the study’s criteria for poor understanding. Better understanding was not associated with more time spent with the medical team. Given this pervasive poor understanding, it is important that multiple members of the patient’s care team help the patient’s family by consistently reemphasizing the most important aspects of the patient’s condition and treatment, and that this information is consistent across specialties. One way of ensuring the consistency of communication is with thorough documentation of family meetings in the patient’s medical record.

Having a written record of what occurs in family meetings is important from a legal standpoint. Decisions to sign a do-not-resuscitate (DNR) order or withdrawal/withhold treatment are routinely made in these meetings, and there should be a record of not only when the decision was reached, but why the decision was made and who was there when it happened. If this information detailing this discussion is not documented in the medical record, then there is no proof that it actually occurred. Without proper documentation of how decisions were made, decisions can be challenged. Such challenges undermine family and provider trust and can result in family complaints or dissatisfaction, and even legal action.

Family meetings can easily consume 30 minutes or more of a physician’s time, multiple times per week. These meetings are integral to patient care, and proper documentation of the meetings and time spent are still an important component of physician billing practices. Notes should document who attended the meeting, how long it lasted, what decisions were made, and any conflicts that might have been voiced.
ADVANCE DIRECTIVES

According to federal law, an advance directive is defined as a written instruction, such as a living will or durable power of attorney for health care, that is recognized under state law (whether statutory or as recognized by the courts of the state), relating to the provision of health care when the individual is incapacitated. The 2 most common examples are living wills and health care powers of attorney. A living will is a legal document in which the patient describes and defines what life-sustaining treatments he or she would want in the event of incapacity and terminal illness. Patients may also designate a power of attorney for health care; this person has the legal authority to make health care decisions on behalf of the patient should he or she lose decision-making capacity. Decision-making capacity refers to the capacity to make medical decisions and to provide informed consent to treatment. This is different from competence, a legal term. Competence is determined by a court, not by a physician. With or without this legal document, the surrogate, or proxy, is expected to use substituted judgment—to reconstruct what the patient would have wanted in a particular situation using formal and informal statements the patient may have made previously. DNR status is often included under this heading, although DNR orders represent the specific order written in a medical record that is intended to carry out the patient’s wishes outlined in an advanced directive.

The Patient Self-Determination Act, passed in 1990, requires any institution receiving Medicare or Medicaid funds to inform patients in writing of their right to accept or refuse treatment and their right to an advance directive. The act itself does not help guide subsequent care in any way. Unfortunately, advance directive completion rates remain low, with population-based studies reporting their use in only 15% to 25% of adult patients.

Buy-In

Lack of formal advanced directives is not the only barrier to patient-directed care in the surgical ICU. There is a general consensus by intensivists and nonsurgical providers that surgeons hesitate to withdraw life-sustaining therapy on their operative patients despite a competent patient’s or surrogate’s request to do so. One reason may be the phenomenon of surgical buy-in.

Surgeons’ preoperative discussions with patients cover the risk of the operation as well as a long list of therapies that patients might need to undertake in the postoperative setting, such as ventilatory support or hemodialysis. Consent for surgery is often taken as consent for these postoperative therapies—“buy-in.” Conflicts about buy-in may arise in the postoperative setting as patient preferences change, depending on the clinical picture and the potential for recovery. Surgeons may refuse entirely to withdraw life-sustaining procedures or argue demonstrably for continuation of life-sustaining therapy based on the surgeon’s vision of the patient’s potential for meaningful recovery and interpretation of the preoperative discussion surrounding operative consent.

PALLIATIVE AND END-OF-LIFE CARE

Half of all patients who die in the hospital have been in the ICU within the last 3 days of their lives. Up to 90% of these deaths involve withdrawing or withholding treatment. In the ICU, many patients suffer uncontrolled pain, and their families experience severe depression and anxiety. A palliative care team can aid the attending physician with symptom control, with an emphasis on controlling pain as well as providing spiritual and psychosocial support.
One possible next step to increase palliative services for patients would be the institution of a palliative care bundle. This approach has been used by Mosenthal and colleagues and has been shown to decrease time to signing a DNR or withdrawing life support, as well as shorten the length of ICU and hospital stay in patients who die within that year, without any overall change in mortality. A palliative care bundle is a standardized set of procedures used by critical care physicians to assess the palliative care needs of all of their patients. This assists critical care physicians in providing palliative care services to their own patients, identifies other aspects of care, such as social work or spiritual support that may be necessary, and identifies patients most likely to benefit from an increased level of expertise in palliative care. Bundle elements include:

- Identification of a medical decision maker
- Determination of advance directive status
- Investigation of resuscitation preference
- Distribution of family information leaflet
- Regular pain assessment
- Optimal pain management
- Offer of social work support
- Offer of spiritual support
- Interdisciplinary family meeting

Good palliative and end-of-life care for patients with an unexpected illness has some significant differences compared with patients with a known terminal illness. Some differences include young age, unknown goals of care, and lack of an established relationship. Families of these patients who die are at high risk of a complicated grief response. Part of caring for these patients is caring for their families, and doing what one can to minimize the risk of complicated grief. Advocating family presence during resuscitation and ensuring that families can visit after death is an important part of decreasing risk, as is clear communication and time spent when giving bad news.

**Specific Protocols**

Specific activities at or near the end of life requiring either protocols or guidelines include terminal weaning, pain management, and palliative sedation. Known protocols help all caregivers to understand these treatments as accepted components of care, and provide a reference for new or unfamiliar providers as well as family members. Although palliative care consultants are intimately familiar with these activities, they should also be familiar to all who practice in an ICU setting. An example of a terminal weaning protocol is shown in Fig. 1.

**Sedation**

A sedation protocol uses any number of different medications to achieve the desired effect. If the desired effect is ordinary symptom management, relief without altering consciousness is the goal. However, when sedating medicines, along with other measures of symptom relief, are titrated to effect, this could result in increased levels of sedation. This concept is sometimes referred to as proportionate palliative sedation. It is understood that although proportionate palliative sedation occasionally results in sedation to unconsciousness, this is not its intent.

Palliative sedation, on the other hand, is the controlled administration of sedative medications to reduce patient consciousness to the minimum extent necessary to render intolerable and refractory suffering tolerable. Although not intended, this
may result in respiratory depression. This scenario is an illustration of the principle of double effect, a bioethical term that refers to 2 types of consequences (the intended consequences and the unintended side effects) that may be produced by a single action.

When palliative sedation is planned, it should be done with a fully informed patient (if the patient has decision-making capacity) and family, along with involvement of the multidisciplinary care team. An advance directive should be completed along with a DNR order. Specific documentation is imperative. The documentation should address the reasons for the decision, the legal agent making the decision, individuals who participated in the decision, expectations of the decision, and any alternatives to the decision that were discussed.

Family presence during resuscitation
Family presence during resuscitation (FPDR) means that the family is present in a location that affords visual and/or physical contact with the patient during resuscitation. This locale may be the emergency department, trauma bay, hospital ward, or ICU. Resuscitation is a sequence of events initiated to sustain life or prevent further deterioration of the patient’s condition during an acute health episode. Benefits for families who witness the resuscitation of a family member include knowing that everything possible was being done for the patient, reducing anxiety, feeling of being supportive and helpful to the patient and staff, sharing critical information about the patient’s condition, maintaining family-patient relationships, closure on a life shared together, and fostering grieving.

There are a variety of concerns expressed by health care professionals with respect to FPDR: That the event may be too traumatic for the family; that clinical care might be impeded; that family members may become too emotional or out of control; that staff may experience increased stress; that staff are focused on the patient and may not be available to assist the family; and the risk of legal action.

Despite the concerns of health care providers, family members who experience FPDR report that they would agree to be present again if a similar event occurred. Family members not only emphatically asserted the right to be
present but stated that FPDR was important and helpful to them.  

In addition, prior research indicates no adverse psychological effects for family members and the operations of the critical care providers was not disrupted by the family presence.  

Although anecdotal reports of legal action exist, the legal action does not appear to be due to the actual presence of a family member but a result of actions of health care providers that could (and likely would) be ascertained from the medical record.

There are several important steps in a family presence program, including the protocol itself, in addition to the preparation, education, and culture change necessary in many institutions before implementation. Successful programs require a designated support staff (family facilitator) available at all times, ideally with no other clinical responsibilities. This support staff can be a medical social worker, chaplain, or nurse, but must be specifically trained in the amount of medical information to relay and in recognizing the family response to the resuscitation events. This person first assesses the family to determine whether they would be appropriate candidates for family presence. Sometimes this involves an independent decision; sometimes the family is asked. Providers are then asked whether family presence is appropriate; a “no” decision is absolute. If family, support staff, and provider are in agreement, the family is prepared for what they might see, are told where to stand/sit, what to do if they feel faint, and that they might be asked to leave at any time. During the resuscitation, the support staff member explains interventions, interprets jargon, provides information about expected outcomes, supplies comfort measures, gives opportunities to ask questions, and grants an opportunity to see, touch, and speak to the patient. Given the medical background of the support staff, they might or might not be able to fulfill all of these responsibilities. Once the resuscitation is over, the support person remains with the family, providing support and another opportunity to ask questions. If appropriate, a bereavement protocol is implemented. An abbreviated example of a family presence protocol is shown in Fig. 2.

**Brain death**

An individual with irreversible cessation of all functions of the entire brain, including the brain stem, is dead. This is both a medical and legal definition. It does not require consent or participation by family or surrogate decision makers. However, appropriate efforts should be made to discuss the patient’s medical condition in the process of determining brain death with family or surrogate decision makers before evaluating the patient for brain death.

In accordance with the Uniform Determination of Death Act, passed in 1980, which replaced the Uniform Brain Death Act of 1978, guidelines for determination of brain death are developed at an institutional level. Unfortunately, guidelines for determining brain death vary widely across institutions, and in many cases do not conform with current guidelines established by the American Academy of Neurology. These include:

- Establishing a known cause of brain death
- Ensuring normothermia, normotension, absence of toxic substances
- Performing a clinical neurologic examination (Fig. 3)
- Performing an apnea test

If a certain period of time has passed since the onset of the brain insult that excludes the possibility of recovery (in practice, usually several hours), 1 neurologic examination should be sufficient to pronounce brain death. However, in the United States some state statutes require 2 examinations. Legally, all physicians are allowed to determine
Starting Point: The Physician/Team Decision

- The physician/team is informed that family is present
- Physician/team agrees to offer family presence option
- Physician/team determines positioning of the family within the treatment area

1. **Patient Assessment** (proceed to Step 2 if patient not alert)
   - If patient is alert and oriented, FF or other staff asks patient if he or she would like to have family present provided team or other circumstances allow

2. **Family Assessment**
   - FF assesses family for appropriateness of family presence
   - **Exclusion criteria:**
     - Combativeness
     - Agitation
     - Extreme emotional instability
     - Altered mental status
     - Intoxication

3. **FF prepares family for actual presence at resuscitation**
   - FF explains/describes the setting and the circumstances
   - FF explains ground rules for family presence

4. **Procedure for Actual Family Presence**
   - FF announces family’s presence to the team
   - FF provides comfort measures to family – chairs, tissues
   - **FF remains physically present (within arm’s length or closer of family members) throughout resuscitation**
   - FF provides general description of events without offering diagnosis or prognosis
   - When feasible, team invites family members to bedside to touch patient or for other contact

5. **FF assesses advisability of continued family presence and directs break as indicated**

6. **Completion of Family Presence Option**
   - Address family concerns
   - Help family process what they saw
   - Provide additional resources
   - Arrange for further medical update/conference
   - Address other psychological/social needs

7. **Documentation in Medical Record**

Fig. 2. Abbreviated protocol to guide family presence during resuscitation. FF, family facilitator.

brain death in most states. Neurologists, neurosurgeons, and intensive care specialists may have specialized expertise.

Confirmatory testing is not mandatory in most clinical situations. In adults, confirmatory testing cannot supersede (such as transcranial doppler ultrasound) clinical observations that are not consistent with brain death, because establishing death by brain criteria is a clinical diagnosis. The interpretation of each of these tests requires expertise.

**ORGAN DONATION**

Under United States law, the regulation of organ donation is left to states within the limitations of the Uniform Determination of Death Act, the National Organ Transplant Act of 1984, and the United Network for Organ Sharing. Each state’s Uniform Anatomic Gift Act seeks to streamline the process and standardize the rules among the various states.

The demand for organs significantly surpasses the number of donors everywhere in the world. In the United States about 108,000 people are on the waiting list. As one way of addressing this shortage, in 2003 the Department of Health and Human Services collaborated with leading transplantation organizations to launch the
Breakthrough Collaborative, calling on all hospitals to increase their organ donation rates to 75% or higher.

Most organ donation for organ transplantation is done in the setting of brain death. As another strategy to address the ever-increasing demand, transplantation has returned to its roots; as of July 2007, all transplantation hospitals are required by the United Network for Organ Sharing to develop and follow protocols that facilitate organ donation after cardiac death. There has been a subsequent order-of-magnitude increase of donation after cardiac death.

Regulations from the Centers for Medicare and Medicaid Services require hospitals to notify the local Organ Procurement Organization (OPO) of individuals whose death is imminent or who have died in the hospital. One way to achieve this threshold is to establish specific triggers for notification of the local OPO. All health care providers are trained to recognize these triggers and initiate contact with the OPO; this does not require physician or family consent or notification. Examples of such clinical triggers include:

- Any discussion of withdrawal of life-sustaining therapies by the physician or family
- Glasgow Coma Score of less than or equal to 4
- Patients with a neurologic insult
- Absence of 2 or more cranial nerve reflexes
- First indication of brain death or brain death testing
- Cardiac death

Regulations from the Centers for Medicare and Medicaid Services require that the person who initiates the request to the family is a representative of the OPO or a trained, designated requestor. Although it is theoretically possible for hospital clinicians to be trained as designated requestors, in practice this person is almost always an OPO representative.

The Uniform Anatomic Gift Act of 2006 legally bars others from revoking the consent of a donor after death who legally registered as a donor during his or her lifetime.
(without an indication that the consent was no longer valid). This rule has led to the increasing adoption of “first-person registries,” whereby a patient registers his or her wishes via a driver’s license or Web site. Although legally valid, many OPOs choose to obtain either assent or consent from next of kin as well. Occasional conflict arises when the wishes of the family are not congruent with the expressed wishes of the patient.

The Uniform Anatomic Gift Act also requires that the OPO determine whether all organs are suitable for transplantation, even if the patient had an advance directive in place stating that such treatment was not wanted. A 2007 amendment emphasizes that the attending physician should consult with the patient or surrogate as early as possible to determine and follow the patient’s wishes, even if doing so results in the loss of potentially transplantable organs.35

SUMMARY

Much of what has been discussed revolves around communication. Communication is a crucial part of intensive care, yet it often falls short of expectations. Because of the nature of the illness requiring intensive care, much of the communication involves families without the benefit of patient interaction; many times, caregivers and family members have never met. Clear communication can be difficult when there is no prior relationship, the event requiring intensive care is unexpected, the outcome is unknown, and there is little information to guide prognostication. Scheduled, time-based meetings are an effective strategy to improve communication about all aspects of care, and increase the likelihood for successful discussions about goal-directed care. Clear, thorough documentation of these meetings is a critical part of this communication to allow all health care providers to understand these important discussions. Family-centered care is an extension of patient-centered care, because the family will likely be the primary support system when the patient survives a critical illness. Should the patient not survive, enhanced communication with family through scheduled meetings and FPDR lessens the risk of complicated grief.

REFERENCES