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CLINICAL CASE

Planning End-of-Life Conversations: Hospitalist and Primary Care Physician Roles

Commentary by Mary Ehlenbach, MD

At the end of a busy day in her pediatric clinic, Dr. Smith was going to visit the Johnson family. Even though she and her partners now admitted their patients to the pediatric hospitalist service at the nearby children's hospital, Dr. Smith still visited her patients there whenever her clinic schedule permitted. She had been notified by the emergency department earlier that day that Claire, the Johnsons' third child, had been admitted with a fever and dehydration. Dr. Smith knew the Johnson family well—she had taken care of their older children, both healthy, for the past 7 years, and had gotten to know Mr. and Mrs. Johnson even better during Claire's first year of life.

Claire was born healthy, but stopped making developmental progress at age 6 months. By the time Claire was 1 year old, an extensive workup showed that she had a rare, progressive metabolic disorder. Despite strictly adhering to a special diet and routinely seeing subspecialists, Claire continued to decline. Feeding problems resulted in the need for placement of a gastric tube and Claire's development never progressed beyond that of a 6-month old. Now 4 years of age, Claire had been hospitalized several times for metabolic crises associated with mild infections. Specialists had told the Johnsons that Claire would never walk, talk, or eat by mouth.

While Dr. Smith had never had a discussion specifically about end-of-life issues with the Johnsons, she knew that they wanted Claire to stay out of the hospital as much as possible and hoped she would not have to undergo medical interventions that would cause her to suffer. In light of this admission, Dr. Smith knew the time had come to talk with the Johnsons about goals of care and, specifically, code status for Claire.

Dr. Smith stopped at the nurses' station to review Claire's chart before meeting with the Johnsons. She was surprised to discover that the pediatric hospitalist caring for Claire had already documented a detailed discussion about code status and what medical interventions, if necessary, the Johnsons wanted Claire to have. Dr. Smith recognized the hospitalist, Dr. Adams, sitting at the nurses' station, and decided to approach her. Dr. Adams was surprised that Dr. Smith was interested in this aspect of Claire's care.

"Usually, primary care physicians leave these discussions to us," said Dr. Adams. "It can be a bit awkward to have conversations about end-of-life issues with someone you've never met before, but we do it so often that it has become second nature with families of patients like Claire. Most primary care physicians don't like to talk about dying during a 20-minute clinic visit."

Commentary

End-of-life discussions can be difficult for both physicians and patients. "See one, do one, teach one" is a paradigm entrenched in the culture of medical education. Some argue that this method is insufficient for mastering *any* skill, but studies suggest that medical students and physicians-in-training are expected to discuss end-of-life issues with patients without even experiencing the meager educational benefit of this 3-step method [1]. Medical students and housestaff generally have not acquired sufficient mentoring to conduct end-of-life conversations with patients and families even though some attending physicians believe they are the responsibility of less-experienced members of the team [1, 2].

Ill-prepared physicians who have end-of-life discussions with patients and families are at a high risk of miscommunicating. If a physician does not have a clear understanding of the likelihood of success and complications of cardiopulmonary resuscitation, he or she may inaccurately present the expected clinical course to the patient and family. The risks and benefits of other life-prolonging interventions, such as intubation and mechanical ventilation, may also be inaccurately represented. And even physicians who draw a balanced, accurate picture of the outcomes of these interventions often mistakenly assume that their sick and vulnerable patients or worried families have "heard" and understood the message, when in reality neither party understands the other.

An equally serious mistake on the part of a physician who is not equipped to have end-of-life discussions is underestimating the integral role that a family's values and beliefs play in making goals-of-care decisions [3]. Here, it is not a matter of patients not understanding what doctors are saying, but of the doctor not hearing or understanding how the patient's or family's end-of-life values guide their thoughts [4]. If patients and physicians are thinking and talking about the end of life in different terms with different vocabularies, care plans are bound to be confusing to the medical team and unsatisfying to the family.

On the other hand, a physician who has had a long-term relationship with a patient and family often understands the role their belief system plays in their life. Religious, cultural, and personal convictions are key factors in helping patients and families make end-of-life decisions [3]. Here, the primary care physician has the advantage of a perspective over time and can gauge the evolution of the illness, as well as the degree to which patients and families have accepted the reality of the illness and thought about death. A trusted primary care doctor need not have up-to-the-minute information on the patient's condition to provide valuable support and counseling to families who are overwhelmed by the decisions they confront.

Some primary care physicians may feel that discussing end-of-life wishes during a routine clinic visit is inappropriate. Barriers to the conversation in the outpatient setting include: (1) lack of time, (2) feeling that such a dialogue will upset a patient or family if the condition is stable or improving, and (3) general discomfort or lack of skill in communicating on the topic. Yet it can be very helpful to the patient and family to introduce this subject when a crisis is not impending. Broaching this topic during a clinic visit can give surrogate decision makers more insight into a patient's wishes [6] and make a primary care physician aware of when a patient or family (e.g., families with children with complex medical needs) may be struggling with these decisions. A multidisciplinary approach—involving a palliative care team, nurse, and social worker—can further mitigate against communication errors and help the patient and family in making a decision that accords with their values and belief system [5].

In the case of Claire Johnson, it would have been beneficial for Dr. Smith, who has known Claire's family for several years, to have initiated a *formal* end-of-life discussion with the Johnsons in the outpatient setting before Claire became acutely ill. The Johnsons would have been introduced to the topic, had a chance to consider their options, and felt better prepared when Dr. Adams initiated the conversation. Dr. Adams then could have focused on explaining pertinent clinical information to guide the Johnsons through decision making in their emotionally fraught state. Alternatively, if Dr. Smith felt she could not do the best job discussing Claire's end-of-life decisions with the Johnsons, she could have referred them to palliative-care services before this hospitalization.

Dr. Smith's participation in the end-of-life discussion that Dr. Adams had with the Johnsons would have proved valuable. As a hospitalist, Dr. Adams' daily practice exposes her to patients and families like the Johnsons during serious, acute illnesses, so she may have been more prepared than Dr. Smith to discuss the details of resuscitation, CPR survival, and complication statistics. She may have felt more comfortable overall having this conversation with patients and families. But Dr. Smith could have supported the Johnsons, making sure they felt comfortable in introducing their values and belief system into the goals-of-care decision making. It may be difficult to coordinate an end-of-life discussion with a hospitalist and a clinic-based primary care physician when a patient is hospitalized with an acute illness, but both parties can work to arrange such a meeting if it seems to be in the best interest of the patient and family.

References

1. Tulsky JA, Chesney MA, Lo B. See one, do one, teach one? House staff experience discussing do-not-resuscitate orders. *Arch Intern Med.* 1996;156(12):1285-1289.
2. Wear D. "Face-to-face with it": medical students' narratives about their end-of-life education. *Acad Med.* 2002;77(4):271-277.
3. Kelly WF, Eliasson AH, Stocker DJ, Hnatiuk OW. Do specialists differ on do-not-resuscitate decisions? *Chest*. 2002;121(3):957-963.
4. Deep KS, Griffith CH, Wilson JF. Discussing preferences for cardiopulmonary resuscitation: what do resident physicians and their

hospitalized patients think was decided? *Patient Edu Couns.* 2008;72(1):20-25.
5. Agich GJ, Arroliga AC. Appropriate use of DNR orders: a practical approach. *Clev Clin J Med.* 2000;67(6):392, 395, 399-400.
6. Handy CM, Sumalsky DP, Merkel CK, Ury WA. The surrogate's experience in authorizing a do not resuscitate order. *Palliative and Supportive Care.* 2008;6:13-19.

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