Original Contribution

AMEN in Challenging Conversations: Bridging the Gaps Between Faith, Hope, and Medicine

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Abstract

All health care practitioners face patients and families in desperate situations who say, "We are hoping for a miracle." Few providers have any formal training in responding to this common, difficult, and challenging situation. We want to do our best to preserve hope, dignity, and faith while presenting the medical issues in a nonconfrontational and helpful way. We present the acronym AMEN (affirm, meet, educate, no matter what) as one useful tool to negotiate these ongoing conversations.

Introduction

The patient is a middle-aged man on a ventilator and dying as a result of a recurrent brain tumor. He is having seizures despite three medications to control them. He has just returned from debridement of a large sacral decubitus, has MRSA (methicillin-resistant *Staphylococcus aureus*) septicemia, and is unresponsive. The patient's wife and daughter insist that he be treated with bevacizumab after consulting with another academic medical center. The family has also requested that the patient continue at full-code status and that no discussion of hospice occur. "We are positive people and believe in miracles," said the patient's daughter, "and are hoping for one here."

Challenging Conversations

Challenging conversations are a matter of course in patient-provider communication. An oncologist is frequently the bearer of bad news, whether of disease progression, inefficacy of treatment interventions, or introduction of end-of-life considerations. The recent literature[1] suggests that patient-centered communication can improve outcomes, such as psychosocial adjustment, patient satisfaction, and treatment adherence, thus contributing to better overall quality of life.[2-7] This includes encouraging patients to talk about their feelings and/or concerns in response to new information.

Conversations regarding the transition of a patient's treatment from aggressive to palliative are difficult for many physicians. Although patients consistently report that they desire open and honest communication with their physicians, these discussions become more challenging with time constraints or when patients express disbelief or disagreement with the medical evidence presented. Relationships cannot be compressed and are by nature built incrementally. The physician-patient relationship is no different; however, we are increasingly living in an environment of compressed time. Specialty practice physicians may be even more vulnerable in this expectation, in that the nature of their work as consultants significantly compresses time with even more complex medical, surgical, and technical content to review with patients and families.

Although oncologists often think they are good at having these discussions, and they have them regularly, patients do not always hear—or accept—the important points. Among patients with incurable colon or lung cancer, two thirds think it is possible to be cured with chemotherapy[8] or radiation therapy.[9] If any end-of-life discussions are held with patients with lung cancer—and only 27% of medical records have any documentation—half of the time, they occur with physicians other than the oncologist, and the average time at which they take place is 33 days before death.[10] Two months before death, half of all terminally ill patients with lung cancer have not had their physicians mention hospice.[11] Additionally, most oncologists prefer to bring up hospice, advance directives, and so on only when there are no more treatment options. Despite the challenges in communication, having these difficult discussions matters.[12]

Health care decisions are not mechanical. These decisions are emotional and often rooted in patients' values, personalities, thought processes, family considerations, priorities, and beliefs, both religious and spiritual.[13] To add to the complexity, the physician's own emotional and psychological makeup is a factor in the communication.[14,15] After all, providers are not devoid of feelings, preferences, or strongly held beliefs, especially when dealing with sensitive issues of life and death. To this point, at least one hospital has provided an educational opportunity for physicians to become more practiced in mindful reflection before and after challenging conversations.[16,17] A program in mindful communication for primary care physicians and mindfulness interventions for physicians have been proposed to address job satisfaction as well as attrition concerns.[18-20]

Miracles

Many physicians will share stories of breaking bad news to a patient or family, with the response being, "Thanks, doctor, but I am hoping for a miracle and fully expect that it will happen." What ensues is often awkwardness, a rote repetition of the

medical information without acknowledging the religious or spiritual implications of the response, or perhaps even defensiveness. Whether this occurs because of time constraints, lack of experience, belief that talking about religion is not within the provider's role, or simple discomfort with spiritual or religious dialogue, the result is the same. The patient may feel unheard, anxious, or disconnected from his or her provider at the level of utmost concern (ie, his or her mortality and, as a corollary, the meaning of his or her life).[21,22]

Most patients seek treatment for life-threatening illness with hearts full of hope for a cure. Daniel Sulmasy, OFM, MD, PhD, has contributed notably to this discussion from the vantage point of his role as both a practicing physician and a Franciscan friar in the Roman Catholic Church.[23] He might also agree that for some, medical interventions are conduits of God's healing energy and intent. For many, divine intervention—a miracle—becomes the ultimate treatment option when all others have failed. However, the medical team may be disconcerted by a patient or family who insists on seemingly futile interventions or refuses to engage in plan-of-care discussions (eg, concerning code status or withdrawal of life-sustaining measures) in the hope of a miracle.[24]

In a study that dealt mostly with questions about death resulting from trauma, more than half of the randomly surveyed adults (57%) said that God's intervention could save a family member even if physicians had declared that treatment would be futile. Nearly three quarters said patients have a right to demand such treatment. Even one of five of the physicians and medical workers surveyed said they believed that God could reverse a hopeless outcome.[25] Despite this commonly held belief, there may be a tendency for providers to personalize comments about hope for a miracle rather than remember that this particular hope has more to say about the patient or family than the provider's competence, skill, or trustworthiness.[26]

AMEN

We developed a conversational protocol for providers called AMEN (affirm, meet, educate, no matter what), a simple mnemonic similar in spirit to the VALUE (value, acknowledge, listen, understand, elicit) communication system.[27] The aim of AMEN is to help providers remain engaged with patients and families during challenging conversations that involve patients' religious beliefs, particularly in response to a poor prognosis. In the patient case presented in the Introduction, for instance, the physician could respond to the stated hope for a miracle in several ways. He or she could remain silent, change the subject, or challenge the family's belief. Conversely, he or she could take the opportunity given by the patient's daughter to affirm the family in their hope for the father's recovery and therefore further the conversation, despite their differing perspectives. In other words, the provider may respond by validating the family's position and joining them in their hope while remaining in his or her role as a purveyor of important medical information.

- Affirm the patient's belief. Validate his or her position: "Ms X, I am hopeful, too."
- Meet the patient or family member where they are: "I join you in hoping (or praying) for a miracle."
- Educate from your role as a medical provider: "And I want to speak to you about some medical issues."
- No matter what; assure the patient and family you are committed to them: "No matter what happens, I will be with you every step of the way."

Although some suggest that the clinician's appropriate response to the hope for a miraculous cure is to discuss alternative religious interpretations with the patient or family (assisted by chaplain or clergy, if possible), many providers believe this type of theologic discussion is not within their scope of practice.[28] Others point out that there is a difference between authentic faith and denial and suggest that this might be a way to frame the discussion of miracles.[23] Still others suggest that engaging family members on their own terms may at least bring partial rapprochement with providers who counsel cessation of aggressive treatment as a patient nears the end of life.[29] Regardless of the strategy, there is a likely chance that the patient or family and provider do not share the same religious or spiritual beliefs. Therefore, the chance for misunderstanding and resistance is increased exponentially.

Our conversational tool can help normalize what is often viewed as religious by framing it in the concept of hope. The belief in the possibility of miraculous medical recoveries is held by adherents of many religious traditions, including Islam,[30] Judaism,[31] Buddhism,[32] and Christianity. However, all too often, clinicians unintentionally place themselves in direct competition with the God of the patient's or family's understanding. The provider may be thinking, "Well, you can believe all you want, but that miracle is not going to happen." When the provider verbally responds to the patient's or family's hope for a miracle with the word "but," the patient is dismissed, and simultaneously, the provider places him- or herself in competition with God. For a religious patient, not even an esteemed or beloved physician will win in a contest with God.

The heart of the AMEN protocol is the commitment to joining rather than placing more distance between patient and provider. The "and" aligns rather than distances and possibly opens dialogue by allowing the physician to say, "It is God's role to bring the miracle, and it is my role as your physician (or nurse) to bring you some important information that may help us in our decision making." Hope becomes the common ground for provider and patient or family as all parties concerned reason together for the best care possible.[33] We have found that the specific statements of van Vliet et al[34] about nonabandonment, such as "No matter what, we will be with you every step of the way," are helpful for both the patient and practitioner.

We contend that as either generalists or specialists, medical providers are called on to enter this difficult conversation with patients as incrementalists, not perfectionists. Just as a relationship cannot be compressed and is built progressively, in stages, so also is the conversation between provider and patient.

Widera et al[35] comprehensively reviewed the literature about miracles and suggested the VALUE (value, acknowledge, listen, understand, elicit) approach to communication, noting such conversations have only a small impact on the number of patients who changed their mind about life-sustaining treatments. Therefore, the outcome to measure as a result of the AMEN approach is not acquiescence or total agreement between the parties. The desired outcome of the AMEN protocol is the continued engagement of the provider and patient.

We further maintain that the most appropriate frame for the miracle conversation is in the context of hope rather than religious belief. With the use of the AMEN protocol, we expect that the provider's connection will be maintained or strengthened with the patient or family member who hopes for a miracle in the face of poor medical odds. AMEN gives the provider the opportunity to join the patient and family at their comfort level conversationally and enter the portal offered by the patient or family member to continue the dialogue.

A few weeks after this protocol was presented in rounds, one of the experienced palliative care nurses told the story of consulting with a patient with disease progression whose options for aggressive therapy were nearly extinguished. The patient shared with fervency his belief that he would be healed through a miracle from God. In the past, the clinician said, she would have avoided the miracle discussion and would have instead redirected the conversation when the subject arose, as it often does in end-of-life discussions. However, in this instance, the provider felt empowered by the AMEN protocol to engage with the patient in a meaningful way. When the patient stated that he believed a miraculous healing would occur despite the grave medical prognosis, the nurse was able to say, "I pray for your healing as well," thus joining him. She then continued the conversation: "I firmly believe that it is God's role to heal, and I also want to be faithful in my role as your caregiver and share with you my medical perspectives as we plan your care."

If the provider is able to walk through the conversational doorway or portal offered by the patient or family hoping for miraculous healing, he or she is also able to live in the reality that clinical uncertainty is a fact of medical practice. "As long as patients visit their primary care clinicians for front-line help with undifferentiated symptoms, disabling chronic conditions, and for end-of-life decision-making, uncertainty will remain an insistent companion."[36(p3)] This is no less true for the oncologist or other provider who is also aware of the challenge of managing uncertainty in the treatment of his or her patients.

Hope

Both religious belief and medical practice require a certain amount of hope. Providers might at times be surprised at the specifics of those hopes for the patient and/or his loved ones. In pediatric medicine, for instance, communication becomes more complex in large part because of the nature of the physician-parent-child triad. Although empathy, availability, and respectfulness have been identified as key interpersonal behaviors of the "phenomenal doctor" in the delivery of bad news, so also has allowing room for hope been experienced as vital.[37] Furthermore, "for the very sick, maintaining or restoring hope is an important function of physicians."[38(p231)]

Hope is not simply being optimistic, being positive, or expressing the expectation of cure; it is also the belief that everything will be done that is humanly possible for the good of the patient, as well as the belief that something meaningful is yet to come. Hope is assurance that the medical team is committed to the patient, regardless of the medical outcome. Hope becomes both the way to reframe a conversation as well as the way to continue it. In short, hope becomes the meeting place between provider and patient, between what is possible and what is probable.

Hope can be seen as a process of thought in which the personality and experiences of the individual influence its expression and content. Hope can reside in the meaning people make of the circumstances of their lives as well as their expectation for the future. However, the difference between the well and the ill is that the latter usually need assistance in achieving their purposes. That being said, providers may be surprised at the answers they receive after asking patients or family members what they hope for in the face of serious, even terminal, illness.

"For what purpose, this miracle?" the physician may respectfully inquire. He or she might learn, as does the nursing assistant who takes vital signs hourly throughout the long night, that a man's first grandchild will be born in a few months. The hope may be to simply cradle that baby for a few sacred hours before succumbing to his disease. The physician, on inquiring, may learn that a mother hopes for remission to see the last of her children graduate from high school or college. Hope takes many forms. "Even dying people have work to do or work to finish; relationships to enjoy or mend, goodbyes to say, lessons to teach their families."[38(p239)] The only sure way to know what hope means for the individual is to inquire, respectfully and reverently.

Effectiveness of AMEN Protocol

How can we evaluate the efficacy of the AMEN protocol? Is its effectiveness based on getting the desired decision after a discussion concerning, for instance, code status or withdrawal of life-sustaining measures? When time is of the essence, can there be a meeting of minds about the best course of action for the patient by using the conversational protocol? Simply put, will AMEN work? These are valid questions and concerns. Gaining buy-in of all involved in terms of the goals of care is a pressing and challenging task. Another question is whether the standard for effectiveness relies only on the perception of agreement between parties with diverse perspectives or instead on the maintenance and deepening of the trust level between the provider and patient or family who are part of the conversation? In other words, have the provider and patient or family stayed engaged, despite the differences in perspective?

Given that hope and uncertainty exist side by side, the provider can afford to view his or her role in communication, even of bad news, as an incrementalist rather than a perfectionist. Perhaps providers know this intuitively, as evidenced by the common assumption that a person must hear bad news a number of times to fully comprehend it. The use of a protocol such

as AMEN cannot be viewed as a quick fix for challenging conversations. Certainly, if the patient or family senses that AMEN is simply a means to manipulate the conversation in a way more favorable to the provider, they will become resistant because of the fear of losing that which is most valuable—the patient—as well as their often frayed thread of hope.

In the midst of these challenging conversations that are daily occurrences in medical professions, success cannot simply be equated with a perfectionistic expectation that everyone is on the same page, apart from acknowledging the hopes—and fears—of those receiving care. When the provider claims the role of an incrementalist, joining with and/or actively engaging the patient and family can be the best possible outcome. Continued conversational engagement between provider and the patient and family may well be the best measure of successful communication.

Discussion

Relationship-centered care involves an understanding that "knowledge and meaning emerge through social interaction between clinician and patient and between clinician and clinician."[36(p8)] The reality is that physicians will face increasingly compressed time constraints with patients in both initial consultations and follow-up visits. During strictly allotted appointment times, medical providers will be expected to engage patients and families in the discussion of highly complex issues and incorporate emotional components. Any strategy or tool that assists providers in engaging with the patient and family, especially in the midst of challenging conversations, is invaluable.

For times when a poor medical outcome is expected by the team, and the patient and family are hoping for a miracle, the AMEN tool makes it more likely that the conversation will be collaborative rather than adversarial. Despite the differences in perspective and perception, both provider and patient are empowered and enabled to enter more fully into the dialogue. Perhaps most important, the patient can wholeheartedly believe the provider when assured, at the end of the meeting, that he or she will walk with the patient and family every step of the way.

Acknowledgment

We thank Ali Sargent of ARK Media, Brooklyn, NY, for revising the AMEN acronym.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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Conception and design: All authors

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DOI: 10.1200/JOP.2014.001375; published online ahead of print at jop.ascopubs.org on May 6, 2014.

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