Invited Commentary

Changing the conversation at the end of life: How the language we use impacts surrogates’ decision-making burden

Life is pleasant. Death is peaceful. It’s the transition that’s troublesome. —Isaac Asimov (1920–1992)

While death is an indisputable fact of life, we seem to have difficulty acknowledging this fact amid a rapidly evolving and cure-focused health care system. We hope each of us will experience a Lazarus-like raising from serious illness and return to a normal life. Likewise, physicians are raised in a culture of treatment, focused on cure at all cost, and consider death a failure to be avoided. Certainly, most of us want to be cured when it is possible, but how to care when cure is not possible and treatment becomes harmful is a neglected conversation.

Two similar but divergent scenes play out in “Viaticum,” by Dr. Fine and Dr. Michel (1). One tells the story of what often happens at the end of life; the other a story of what should happen at the end of life. While physicians are often aware of the nonbeneficence of certain treatments at the end of life, they may lack the training and skills needed to engage in difficult conversations. Several studies have shown people are aware of their own mortality and, when asked, can identify specific values they want honored at the end of life. They want to be at home, to be mentally aware, to be at peace with God, to be pain-free, and to avoid burdening their family. Interestingly, these preferences have remained stable in the published literature for about 20 years (2–4). Despite these expressed preferences, people also recognize they are unlikely to die at home and, when asked, cited an institution as the most likely place they expect to die (4). This discrepancy between what people hope for at the end of life and what usually happens is clearly illustrated in “Viaticum.”

In the first scene of “Viaticum,” Dr. Michel calls his patient’s family to confirm he is doing the “right thing” for their loved one. His hesitation to pursue aggressive medical intervention is challenged after he hears the daughter say, “Do whatever you need to do to save her,” even after he explains the invasive procedure and then confirms the patient has dementia and is on hospice care. This interaction is all too familiar to health care professionals: the provider knows the procedure may fix an immediate problem but won’t improve overall quality of life, yet the family wants the procedure, perhaps driven by the simple fact it was offered.

Contrast this scenario with scene 2, where Dr. Michel takes a step back before discussing what a procedure would entail and, instead, says, “Let me start by sharing my understanding of just how seriously ill your mother is and how near the end she is in her life’s journey.” This statement prepares the daughter for what will come next: breaking serious news and creating a plan of care that takes both her dementia and advanced cardiac disease into account. This second scenario includes more conversation about what care will be helpful in this situation and what treatment options would cause harm; it includes the words “may be dying,” and it places the physician in the position of making a recommendation rather than asking the family to make a choice.

The conversation illustrated in scene 2 in “Viaticum” represents the ideal for care at the end of life. In practice, this may not occur as frequently as it should, but it certainly is not due to a lack of evidence. Numerous studies in the past 20 years have focused on evaluating and improving care at the end of life. The lack of benefit of aggressive treatments in the final months of life has been well documented, and avoiding nonbeneficial interventions is supported by expert guidelines created decades ago. For example, the American Medical Association’s Council on Ethical and Judicial Affairs published guidelines in 1991 for the appropriate use of do-not-resuscitate orders, which remain a guiding statement more than 25 years later. The document describes nonbeneficial treatment as that which will not restore cardiorespiratory function or won’t achieve a patient’s goals (5). Read that last phrase again: won’t achieve a patient’s goals. Unfortunately, a patient’s goals and values are rarely elicited before treatment options are offered and, if they are, they are poorly documented. The lack of documentation also means this information is almost never available to guide care in an emergency.

The second key principle illustrated in “Viaticum” is the burden of decision-making that is placed on surrogates. In the first scene after Dr. Michel outlines what procedure is needed, he says, “I wanted to make sure that she and you, . . . the family would want that.” The family is now burdened with accepting or rejecting the proposed procedure based on their knowledge of medicine and their loved one who “seemed fine” earlier in the day.

There are two aspects of this situation worth exploring. The first is that physicians should use their expertise to make a recommendation. It is clear Dr. Michel is looking for any reason to avoid this procedure. If it was deemed nonbeneficial in his medical opinion, then the procedure should not be recommended (6). A 2012 study investigating patient preferences for medical decision-making reported that 97% of participants wanted their doctors to offer them choices and consider their opinions. But when it came time to decide, two-thirds of participants preferred that the doctor make the final decision (7). The second notable aspect is, without an expert recommendation,
the burden of decision-making falls entirely on the family. This burden is well known to cause harm: caregivers suffer negative emotions of stress, doubt, and guilt which can last for years, especially if an advance directive is not present (8). Caregivers can also be wrong about patient preferences (9) and often opt for more aggressive treatment (10)! While many caregivers may be involved in making medical decisions for their loved ones at the end of life, it should be noted that a living will may be more beneficial than a medical power of attorney alone when it comes to making decisions about code status and limiting aggressive treatment (11), and the presence of a living will reduces the emotional burden on caregivers (8).

Shared decision-making is a spectrum that ranges from patient choice to paternalism. “Viaticum” illustrates an attempt to honor patient autonomy for an acute problem in scene 1 and a clear medical recommendation that takes the whole person into account in scene 2. Hard paternalism would be decision-making without any input from patients or their loved ones and should be avoided, just as uninformed patient choice without any physician input should be avoided. Ideally, medical decisions should involve a collaboration between physician and patient: patients should share their understanding of their medical problems and what is most important to them given their situation (i.e., their goals and values), and physicians should offer treatment options aimed at accomplishing those goals (and avoid treatments that won’t accomplish the goal).

At first glance, this makes a lot of sense, but in practice it can be difficult to achieve without a framework to follow or additional training in communication skills. While palliative care as a medical specialty exists to support seriously ill patients and help with difficult conversations, the number of professionals practicing palliative care is small and growing slowly in comparison to the need. Truthfully, all health care professionals who will someday take care of patients with serious illness should achieve some measure of proficiency in serious illness conversation skills by the time they finish training.

Fortunately, changes within medical training and the health care system are supporting a greater focus on shared-decision making and communication skills. Structured programs like the Serious Illness Care Program (SICP) give health care providers a framework and the skills needed to engage in difficult conversations. SICP has grown out of a collaboration between a leading palliative care expert, Dr. Susan Block, and renowned surgeon Dr. Atul Gawande, as he wrote his bestselling book Being Mortal. The Serious Illness Guide, a set of eight questions used to guide conversations with seriously ill patients, aims to improve care by encouraging health care providers to have more, earlier, and better conversations. Baylor Scott and White is the first health care system in the US to partner with Ariadne Labs to fully implement the program across an organization of our size.

As a palliative care professional, I am frequently consulted when providers are struggling with how to care when cure is not possible. This is never an easy situation, but a few basic and universal principles can guide us through these conversations. First, we must understand both the biology and biography of our patient. Where is our patient in the trajectory of disease, but also who and where is our patient in the story of his or her life? Next, armed with that knowledge, we must utilize both the art and science of medicine to recommend interventions we believe are most appropriate—not for the disease, but for the patient who suffers with the disease. Finally, we must communicate our recommendation carefully, for language truly matters (12). Medicine well practiced is a team effort, and if we collectively continue to learn new skills (such as those embedded in the SICP), then we will truly provide our patients and their families with the most beneficial treatments and highest level of care that can be given.

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