Patient Advocate Corner

Finding the Language to Talk About Death

By Lidia Schapira, MD

The summer of 2009 brought a surge in media coverage of and public interest in the medical care of dying patients. News articles addressed the role of palliative care, and television shows analyzed the human and monetary costs associated with expensive and intensive treatment during the final weeks of life. What started as a reasonable discussion about fair compensation for physicians who counsel patients about resuscitation and take the time to discuss preferences for care at the end of life evolved into a shrill debate over “pulling the plug on Grandma” and imaginary death panels. This was unwelcome news for those who understand the need to engage the public sector in a mature dialogue regarding the care of dying, sick, and disabled patients.

It is not easy to talk about dying, and yet it is almost routine work for oncologists. Euphemisms abound, and patients and doctors are often reluctant to initiate the discussion, preferring instead to concentrate on interventions and actions that distract from a grim reality. Studies have shown just how easy it is to collude with patients to avoid discussing prognosis and settle instead on conversations about available treatments or interventions to manage symptoms.¹ There are many reasons for this avoidance on the part of the physician: the wish to spare the patient more suffering, hope for an exceptional outcome, a personal sense of failure, and perhaps a desire to maintain a cheerful front to get through the day.

The problem with avoidance is that failure to discuss a grim prognosis leaves patients and families unprepared and leads to requests for excessive, costly, and even painful therapies on the basis of unrealistic expectations of success. It abandons patients to receive the news instead from strangers in unplanned situations, such as a trip to an emergency room. Frank and honest dialogue serves to help patients cope and provides support and expert guidance. Indeed, there is evidence that patients receiving comfort care want to discuss their prognoses truthfully with their physicians.^{2,3}

If patient and physician have a longstanding and trusting relationship, it may be easier to begin the conversation by warning the patient that circumstances have changed. This segues nicely to a conversation that addresses the plan and goals of care. I have found that conversations about death flow naturally from conversations about life. Knowing what gives meaning and purpose to an individual's life and what really matters inform our discussions. I cannot assume I know what my patient hopes for or what he or she fears unless I ask. I have heard patients tell me they do not know how to prepare their children for a time when

they will no longer be physically present. Or that a wife of more than 60 years fears her husband will not be able to care for himself after she passes. In these important and intimate exchanges, I find the language and metaphors we both need to talk about how to prepare for the final months, weeks, or days. From that point on, our conversation focuses on what needs to be accomplished to make sure that the time remaining is lived in peace and in a way that is concordant with the patient's wishes.

This may sound reasonable to experienced physicians who are inclined to be realists. But what happens when patients cannot accept bad news? There is considerable societal pressure to think optimistically and demand good outcomes. Some patients specifically ask their physicians to remain optimistic when facing adversity.⁴ Such optimism can be conveyed through positive framing of statistics, stories of exceptional survivors, references to novel therapies with unproven clinical efficacy, or avoidance of any mention of uncertainty. Although this may initially serve some patients well, it is ultimately confusing and may leave patients feeling terrified when all options have run out.

An important part of our job is to help patients assimilate serious information that alters their sense of self and concept of the future. Another is to help them understand the hope that remains.⁵ In its broadest sense, hope is an expression of vitality. What we can do, within the context of medical visits, is to explore and nurture individual hope. We can direct patients to hope for things within their reach: surviving with dignity, feeling and expressing love, attending important family events, or leaving enduring legacies. After all, we know what typically lies ahead and how to best meet the challenges and losses that accompany a serious and life-threatening illness like advanced cancer.

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