

Clinical Commentary on “Finding a Better Way”

Ellen K. Hummel, MD

I recognize many aspects of Mary’s journey in the stories of patients I care for every day as a palliative care physician. Mary’s experience traversing the last precious months of her life as a chronically and critically ill patient is unfortunately not unique. A palliative care team could have been an enormous help to Mary, her family, and her healthcare team. The future looks brighter as awareness and understanding of palliative care continues to expand among the general population, in part because of books such as *Being Mortal: Medicine and What Matters in the End* by Atul Gawande¹ and documentaries like *Extremis*.² A big part of this is because physicians are gradually learning that palliative care is not synonymous with hospice or end-of-life care but rather is a philosophy of care that aims to improve the quality of life for all patients and their families at any stage of an illness.

See Viewpoint by Kane and Meadows

Although Mary’s care was extraordinary in some aspects, it was not always adequately patient and family centered. Most of the deficiencies were related to poor communication, which can be challenging even in the best of circumstances. I see 2 gaps that were particularly tough. First, it appeared no one solicited Mary’s values and goals before providing her and her family with treatment recommendations, either at the beginning of her journey or during one of the many setbacks she experienced. Second, no one presented Mary and her family with clear alternatives to placing a left ventricular assist device (LVAD) or complete information about complications and downsides to having an LVAD. Both of these issues would have benefitted from some assistance with advance care planning.

Understanding why these types of breakdowns in communication occur, often despite the best intentions of medical teams, is important to appreciate. For several reasons, well-intentioned clinicians may bypass important conversations about goals and values as well as advance care planning and treatment alternatives. The first is that most physicians have not received formal training in how to facilitate these tough discussions. Medical culture traditionally operated on the belief that empathy and interpersonal skills cannot be taught. Only those physicians who are naturally inclined to do so will discuss difficult topics. However, it is increasingly being

recognized that these are defined skills that can be taught, and there has been a proliferation of resources over recent years to help clinicians learn to improve their communication skills in these discussions (eg, Vital Talk). A second important reason is that most physicians are not allotted the time needed to have them. Our payer system continues to reward disproportionately for procedures and interventions rather than for spending time at the bedside. Recently, there has been a push to rectify the disincentives to spending time counseling patients, and new advance care planning billing codes were released in 2016 to reimburse for time spent in these activities. This is a first step in the right direction.

Even when clinicians have the training and time to have these conversations, a remaining barrier is our cultural fear of death. When the only major alternative treatment available is facilitating a peaceful and comfortable death, many clinicians hesitate. They implicitly view death as the enemy that we are fighting, rather than a natural and inevitable event. Allowing a patient to embrace their dying process is viewed as a failure where medicine has nothing more to offer. However, there are always things that can be done to care for and support our patients, even as they die. Avoiding talking about a comfortable death as an alternative, sometimes simply leads to a protracted, uncomfortable, and undignified death over a much longer period of time.

Some of the communication problems were specific to the process of living and dying with the LVAD itself.³ It is particularly important to discuss the complications that can occur with an LVAD as they are more common than in many other types of surgery and can have a dramatic impact on a patient’s quality of life (eg, a debilitating stroke). This is tough because the therapy can also be life-saving—and sometimes clinicians may struggle with their desire to give patients every shot imaginable. Given that the proliferation of LVAD technology has been so rapid, not all centers may have as much experience talking through all of the key aspects of life with an LVAD to patients considering implantation so that they can balance these issues in an informed manner. Fortunately, there are some good decision aids available to share with patients and families to help them understand the pros and cons of having an LVAD placed.⁴ Peer support programs may also be helpful to patients and families.

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As a result of published studies⁵ and a JCAHO (Joint Commission on the Accreditation of Healthcare Organizations) requirement for Centers of Excellence, care for LVAD as destination therapy is changing and now requires that palliative care consultation be available to these patients as a part of the interdisciplinary LVAD team. In addition to the usual advance care planning topics, conversations with patients considering an LVAD should include discussions of (1) concerns the patient may have about dying with an LVAD in place, (2) the fact that the LVAD will need to be turned off at some point in the dying process, and (3) what constitutes an acceptable quality of life in case major life-altering complications occur.

Palliative care providers are skilled experts at communication and decision support. Their expertise and purpose is to have detailed conversations about a patient’s values and goals as they relate to how they wish to live and die. Furthermore, palliative care can often support other clinicians in broaching and discussing a comfort-focused plan of care as an alternative to continuing life-sustaining treatments. Unfortunately, there are too few palliative care providers to meet the exploding demand in our country.⁶ For this reason, it will be important for providers to learn some primary palliative care communication skills in addition to reaching out to their palliative care colleagues for assistance when available.

Mary’s daughter and sister have honored her memory by writing a beautiful call to action for all of us to provide better palliative care to our patients throughout every step of their journey.

Disclosures

None.

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