

## Finding a Better Way

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It is no secret that our healthcare system can do a better job taking care of patients. A simple trip to the emergency room or a week long hospitalization because of an acute illness or injury can highlight some of the most glaring issues in our healthcare delivery system. But in the case of a chronic illness that suddenly spirals out of control, things can become both complex and dangerous.

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### See Commentary by Hummel

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Our patient was Mary (please note that the name has been changed to protect confidentiality). She was a mother to one daughter and 3 sons and a grandmother to 5 young children. She was a sister, a daughter, and a dear friend to many. She was a physical therapist whose patients adored her. We, her daughter and sister, were her caregivers. We experienced Mary's slow demise firsthand, from October 2014 to May 2015. We have both spent our entire careers in health care. Finding ourselves on the patient and family/caregiver side of health care was eye-opening.

On October 13, 2014, Mary was driving to a routine pacemaker check. Beginning in the summer of 2013, she had been experiencing shortness of breath, fatigue, and edema of the legs and feet. Her cardiologist was attempting to manage her disease with medication and a pacemaker to regulate a slow heart rate; despite this, she continued to experience symptoms diagnosed as heart failure of unknown cause. As she pulled into the parking deck of the physician's building, her heart stopped beating. By the grace of God, a Good Samaritan came to her rescue, and shouted for help. Several physicians happened to be nearby, and they quickly responded and started cardiopulmonary resuscitation (CPR). She was then transferred to the hospital emergency department, just a few hundred feet away. After a cardiac catheterization, they determined that a fatal arrhythmia caused by her heart failure was the likely cause of her cardiac arrest, and she was quickly admitted to the cardiac care unit, intubated, and unconscious.

Her condition was grave, and not knowing how long her heart had stopped, she was put on therapeutic hypothermia. Her condition continued to deteriorate, and she experienced 2 more cardiac arrests. Less than 48 hours after her initial resuscitation, she was placed on extracorporeal membrane oxygenation (ECMO), followed a week later by an open-heart surgery to implant a left ventricular assist device (LVAD). Major, life-threatening complications occurred after both surgeries.

In the 7 months that followed, Mary endured 9 surgeries, 9 transfers back and forth from the cardiac intensive care unit (ICU) to a nearby long-term acute care hospital (LTACH), and multiple brushes with death. We both took leaves of absence to care for Mary and to ensure she had an advocate at the bedside every day of her long hospitalization. It was a miracle that she survived those first few days, and we are forever grateful to many staff members who strived to provide the best care possible. Unfortunately, we also experienced many systems and process failures, primarily related to the following areas.

### Shared Decision Making

During her initial hospitalization, we were suddenly confronted with the need to make immediate decisions on life-altering procedures, with Mary unconscious and on life support. We found that the LVAD educational materials provided to us and the decision-making process were woefully inadequate for the magnitude of the decision we faced. The educational materials portrayed only the most positive picture of LVAD implantation, with no information on possible downsides and complications. In addition, we felt extreme pressure by Mary's medical team to make a decision in favor of the LVAD. Mary had clearly told Ginny before her cardiac arrest that she did not want to consider an LVAD, so we felt bound to honor her wishes unless she could awaken enough to listen to the physicians and determine what she wanted.

Although we both realized that a decision was urgently needed, the lack of communication with Mary's medical team made this decision that much more difficult. Although Mary was beginning to regain consciousness, no formal determination had been made that she was competent to make medical decisions. And, although we had requested them not to, several members of the heart failure team repeatedly showed up in her ICU room and attempted to start the LVAD education process directly with Mary, while she was intubated and barely conscious. We asked for a conference in Mary's ICU room with each physician involved in her care to further discuss the pros and cons of the LVAD implantation but were told that it was not possible to get all the physicians in the room at one time. We continued to persevere, and the critical conference finally occurred. After listening to the discussion, Mary agreed to go forward with the LVAD. However, looking back, we realize how severely impaired her cognition and overall comprehension about her condition was at the time.

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Providers have a moral imperative to ensure that decisions on LVADs are made using tools that provide a balanced view of the options available, including declining the LVAD. The positive and negative aspects of each option should be discussed, and patients and their caregivers should be encouraged to consider their values, goals, and personal preferences during the decision-making process.<sup>1</sup> Because caregivers experience a high personal burden in caring for LVAD patients, they should be considered equal partners in the decision-making process.<sup>2</sup> And, when discussing statistics and complication rates with patients and caregivers, the numbers should be personalized as much as possible.

### Coordination of Care

Because of Mary's continued reliance on ventilator assistance and general physical deconditioning, once she was deemed ready to leave the acute care hospital, she was transferred to an LTACH. Not only do we feel that Mary was pushed toward an LTACH much too soon; once she was actually ready, care coordination from the acute care hospital ended. There were numerous problems with care transitions as Mary was transferred back and forth between the 2 organizations 9 different times. For example, even though we personally visited the LTACH and met with the leadership team before Mary's transfer, the initial transition was a failure, occurring over a change of shift at the receiving hospital, with no nurses available or prepared to receive her as a patient. It took hours for them to take vital signs, put Mary on telemetry, and determine what medications she was taking. We found ourselves in the uncomfortable position of being the educators, as many of the nursing staff had no experience with taking care of a patient with an LVAD. In addition, for the duration Mary spent at the LTACH, there was no one person in charge of her care and, as such, that role fell to both of us.

### Patient- and Family-Centered Care

Although we were both coordinating Mary's care and we, or another member of our family, were present at the bedside every day she was hospitalized, there were numerous occasions when we insisted something was wrong with Mary, only to be ignored or, even worse, informed that we were wrong and that all was fine, often in a patronizing way. The most common response from physicians and staff at both institutions was she's just tired, she had a busy day. It was not until we repeatedly asserted our concerns to multiple clinicians, often over the course of several days, that someone would finally listen and begin the necessary testing, only to discover in almost every instance that something was not right.

We feel that if the care team had listened to us and acted earlier, some of the complications Mary experienced might have been averted. Time and time again we found ourselves in the position of having information that could have helped Mary that nobody seemed to want. The most extreme example of this occurred during the last days of Mary's life, when we insisted something was drastically wrong to the clinicians caring for her. On the day she went into septic shock,

as we all continued to raise alarms with staff, we were told once again that she was just tired. Several hours later as the team frantically worked to transport her back to the ICU at the primary acute care hospital she went into respiratory failure.

### Palliative Care

We made the heart-wrenching decision to turn off Mary's LVAD the night before Mother's Day—May 9, 2015. This was a result of the severe septic shock she had experienced just 2 days before, which shut down all neurological function. Turning off the device was every bit as difficult and complex as making the decision to implant it, although no one had ever discussed the fact that we would one day likely have to make this excruciatingly painful decision. A frank discussion with a palliative care team to develop an Advanced Care Plan should have happened before the LVAD surgery occurred. This should have included a discussion with Mary and her family about how a patient's advance directives may change after having an LVAD implanted, and Mary's wishes for deactivating the device in the event she was not able to make the decision for herself.

As medical and technological advances continue to be made, helping people live longer lives, the role of advance care planning and palliative care becomes critical to ensure an understanding of a patient's wishes and to avoid a loss of dignity by the patient and additional distress for the patient and their family. This is especially relevant to patients with heart failure.<sup>3</sup> Unfortunately, this was only mentioned once to us, by Mary's primary cardiologist, in the early days as we were trying to decide whether to move forward with the LVAD. Unfortunately, it seemed that any further discussion on this topic was quickly shut down by others, as they strongly urged the LVAD for Mary and to us, her healthcare proxies, as the only viable option. As critically ill as Mary was throughout her stay, we should have been in touch with a palliative care team or, at the least, a psychologist skilled in helping Mary determine her desires and needs. Knowing the strong, intelligent, and confident woman that Mary was before this happened and remembering the scared, confused, and helpless person she became haunts us to this day.

### Conclusions

We experienced this journey from both the family/emotional side and from our experience in the caregiving/quality/operations side—we often questioned why things were done the way they were throughout the almost year-long process. We are eternally grateful for the amazing technology and talent that was available to Mary, but, along with technology and talent, there must also be transparent and consistent communication, peer-reviewed decision aids, extensive training for bedside staff caring for these patients, protocols for the possible complications associated with LVADs, and a highly effective, coordinated care team that includes the patient and her caregivers at the center. Yes, Mary's life was saved with expensive technology and highly trained staff. But, tragically, her life was ultimately lost, in part because of poor communication and coordination of care and a lack of training. And

Mary's quality of death was needlessly poor, with no true palliative care provided at any time.

We hope our experience can not only help future patients and their families enjoy better quality of care during a most difficult time but can also help cardiac programs provide the safest, most efficient, and dignified patient and family-centered care—a basic right all individuals should have during their most challenging days. The good news is that there is a better way, and it is achievable with transparency and collaboration between healthcare institutions, patients, and family members.

### Addendum

After Mary's death, we sent a letter to both healthcare institutions, expressing our gratitude to all who went out of their way to provide the best-quality care possible to Mary, while also describing the issues we felt needed to be addressed. The executive and clinical staffs at the acute care hospital have been receptive, and we have had several opportunities to work with them on improvement initiatives. We look forward to

continuing this work in honor of Mary and the courage she demonstrated throughout her hospitalization.

### Disclosures

G. Meadows has been appointed to a National Quality Forum Technical Expert Panel on Patient Decision Aids. The other author reports no conflicts.

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