

## EDITORIAL

# Knockin' on Heaven's Door: End of Life Decisions and Discussions

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### INTRODUCTION

*I have often thought that there should be a set of rules for the practice of medicine. —CK Meador, MD, A Little Book of Doctor Rules*

More than 2.5 million people die in the United States each year. For the majority who live out their final days in various institutions or in hospice care, decisions must be made about which treatments to administer, which treatments to stop, which treatments to continue, and which treatments to back off of. Thus, while death remains inevitable, its timing is often very much a function of human agency. Once it was common to speak of “nature taking its course,” but now it has become as common to view death as something about which people have some control [Meisel 2008].

Though we, as cardiovascular surgeons, encounter many challenging situations in our careers, few are more difficult than dealing with end-of-life decisions in patients on whom we have operated. Furthermore, training in dealing with these situations is sparse. As Atul Gawande writes in his book, *Being Mortal*, “tending to the needs of the dying and their loved ones seemed beside the point in medical school [Gawande 2014].” Similarly, patients and their families are often unprepared for these scenarios. As Dr. Bryce Mendelsohn wrote in a recent essay, patients often need to be reminded “that they are still a part of Nature they can neither cheat nor escape [Mendelsohn 2013].”

In this editorial, I aim to collate lessons and suggestions that may prove helpful when these situations arise, which they inevitably will, for all of us.

### NO TREATMENT FOR MORTAL DISEASE CAN BE PROVIDED WITHOUT RISK: SETTING THE STAGE PREOPERATIVELY

*Everything has a price and miracles are no exceptions. —Timothy Buchanan, MD*

*It's more important to know the patient who has the disease, than the disease which has the patient. —Sir William Osler*

When discussing cardiovascular interventions with our patients preoperatively, most of us do a reasonable job of

outlining the need for the intervention, the expected outcome, and the potential risks of the contemplated procedure. In fact, in the modern era, we can provide fairly accurate prognostic information, based on published information and large databases. However, for a variety of reasons, most involved in these discussions tend to avoid discussing how suboptimal outcomes will be dealt with, if and when they occur.

While some patients will have formal advanced directives, most do not. And, even for some who do have these types of directives, it is fairly common that these directives are out of date or no longer relevant for one reason or another, such as the loss of capacity by a named surrogate decision maker that has occurred between the time the directive was created and the current time. Many practitioners tend to avoid in-depth discussion about these directives, thinking, perhaps, that they want to sound a note of optimism, while avoiding seeming as though they might be even somewhat pessimistic. An approach that I have found comfortable is to say that the patient will be unconscious during the operation and for a variable period of time after the operation, and, therefore, we must discern who, specifically, will make decisions for them during this time. I even developed a form to facilitate these conversations, on which I insist on recording the name of the one person that the patient wants us to consult, should decisions need to be made for them while they are unable to make decisions for themselves. I have often been somewhat surprised by who the patients choose as their surrogates, further illustrating the value of discussions of this sort. In addition, I insist on recording the designated person's contact information, and I suggest, strongly, that this person be present, or at least easily available, during and after the operation. Patients will almost always understand the value of this request, when couched in these terms. It is worth noting that this designation also protects this decision maker, should difficult decisions be required, as there can be controversy among the family and friends about these decisions. Thus, we must always be aware of possible tensions among the family and friends of a patient. To reemphasize a theme, you will never, ever regret having had this discussion with the patient preoperatively.

While striking a balanced, cautionary note in pre-op discussions can be a good thing, reassurance is also appropriate. Thus, these preoperative discussions should end with a note of cautious optimism, perhaps with a phrase such as “we will hope for good things,” while avoiding phrases that can seem disingenuous, such as “everything will be fine.”

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If the circumstances seem to require a more granular discussion about advance directives, there are very useful online resources that can facilitate such discussions. One of these sites, which has useful forms that can be downloaded, is the Physician Orders for Life Sustaining Treatment website [POLST].

Finally, it is essential that our cardiovascular residents be involved in these discussions, though getting them involved in the earliest phase of care can be a scheduling challenge in most training programs. Therefore, they may have to occur just prior to and immediately after the operation, rather than in the pre-operative clinic or office meeting.

### **A CRUCIAL DISCUSSION: THE POST-OP MEETING WITH THE FAMILY**

The meeting with the family (and friends) immediately after the operation is a crucial opportunity to ensure that all involved continue to understand the concerns of the operating team. It is likely to be the one time when virtually all of the patient's family and friends are together in one place. We have previously reviewed, in a more granular way, the primary topics that should be addressed in these discussions [Tribble 2017].

In these meetings it may be useful to say something such as: "I am worried as a physician, but my concerns are not the same as your worries as a family member. Therefore, we will worry together, but we will each have a different type of worry." These post-op meetings are also often the most expeditious time to introduce the resident with whom you have done the operation. I like to introduce the resident as "my colleague who helped me with the operation and who will be helping regularly with the postoperative care." This introduction legitimizes to the family the role of the resident in the care of the patient and empowers these senior trainees to be actively involved, not only in day-to-day clinical decisions but also in the more challenging discussions that arise when end-of-life issues must be addressed.

In general, a reasonable way to wrap up these conversations is to say that we will continue to hope for good things, but that significant unknowns remain.

### **FRAMING THE DISCUSSION IF THE CLINICAL SITUATION DETERIORATES**

*Talk to patients and/or families alone (as the attending surgeon). Sit down quietly. Try...addressing a group of beings, all clad in white and standing around the bed. This situation chokes off open conversation, to say the least. —Francis Moore, MD*

*I've learned that people will forget what you said; People will forget what you did; But people will never forget how you made them feel. —Maya Angelou*

The conversations that must occur when a patient's postoperative trajectory is not what had been hoped for are hard to conduct without having a solid preexisting relationship with the family. One must put considerable effort into maintaining frequent contact with the family, particularly when patients are not progressing optimally in the postoperative period. While one might tend to avoid these conversations, they are infinitely more

valuable than the easy ones we are able to have with the families of the majority of our patients who are doing well. If an end-of-life family meeting then becomes necessary, you will have already established with the family that you care, both about the patient and about them. It can be useful to recap, perhaps frequently, the whole medical episode, which can help lead up to conveying a sense that a meaningful recovery may not be possible.

When this sort of conversation becomes necessary, we must remember that many, if not the majority, of the families and friends participating in it will have at least some doubt about the physician's assessment of a poor prognosis [Zier 2008]. The patient's family should be reminded that it is the initial condition or disease that is responsible for the patient's condition, not necessarily the attempt to save them from the natural history of that condition with operations that may not have been possible even a few decades prior to the current time. It can also be useful to tell families not to cross any bridges until they have to, but to also note that if we come to believe we are prolonging death rather than prolonging life, we will begin to discuss if and when it is time to let go.

It is worth noting that there is almost always support available from chaplain services and palliative care teams, and these practitioners should be asked to become involved early in these challenging situations. In this setting, sometimes families will say that they do not want to play God. A response that can be useful in this situation is to note that "we may actually be playing God by keeping someone alive when their body is actively dying [Gubar 2017]."

It is also worth remembering the stages of grief, memorably outlined by Dr. Elisabeth Kubler-Ross. These stages are anger & denial, bargaining & depression, followed by acceptance & hope. And, we must also be aware that different members of the family will move through these stages at different rates and may even move back and forth between them. In these discussions, one should always strive to answer all questions as thoroughly as possible, to find something uplifting to say, and to ask "how can I help?"

Finally, at this juncture, it is frequently appropriate to say "you don't have to make any decisions right now," particularly when there remains some hope that the situation could improve.

### **I SHALL BE RELEASED: DEFINING POTENTIAL END-OF-LIFE STRATEGIES**

*I see my light come shining; from the west down to the east. Any day now, any day now; I shall be released. —Bob Dylan, "I Shall Be Released"*

*The transition between life and death should be gentle in the winter of life. —Rudolf Matas (The Father of Vascular Surgery)*

*Hope does not lie in a way out, but in a way through. —Robert Frost*

We need to remember that our top priority is to ameliorate suffering, not to prolong life forever. As noted earlier, we need to remind families that when we get to a point at which we think we're prolonging dying rather than prolonging life,

we should change direction. Still, it is worth saying repeatedly that we never withdraw care, as we will always care for the patient, but that the goals of that care may change, depending on the evolving circumstances. Comfort for the patient and the family must always be a primary goal, and, sometimes, that will become the most important or even the only goal.

Under these conditions, it is essential to remind everyone involved that the person or persons making decisions are supposed to do what the patient would have wanted and not necessarily what others might want. Emphasizing this principle can help relieve the decision makers of feelings of guilt. It is also important to remind all involved that if death becomes inevitable, the goal will be to allow it to occur with appropriate dignity and respect.

It is not infrequent to encounter situations in which members of the family disagree on the proper course that should be taken. It is worth noting, particularly when the patient has not designated a specific person who will make decisions for them, that there are guidelines (some of which are specific to certain states in the United States) about the hierarchy of surrogate decision makers. While an outline of these stipulations is beyond the scope of this essay, a review of this subject was published recently. [DeMartino 2017].

### **I'LL FLY AWAY: DISCUSSIONS OF WITHDRAWAL OF ARTIFICIAL LIFE SUPPORT**

*When the shadows of this life have gone, I'll fly away; Like a bird from these prison walls I'll fly; I'll fly away, I'll fly away, oh glory; I'll fly away in the morning; When I die, Hallelujah by and by, I'll fly away. —Allison Kraus & Gillian Welch, "I'll Fly Away"*

*I don't mind dying. I just don't want to be there when it happens. —Woody Allen*

When a decision has been made to withdraw artificial life-support mechanisms, all caring for the patient and the family must focus on continuing to provide kind, dignified, and professional care. A moving tribute to a care team dealing with such a situation can be found in an open letter by Peter DeMarco, whose wife suffered an anoxic brain injury after a severe asthma attack, in which he wrote:

"Every single one of you treated Laura with such professionalism and kindness and dignity as she lay unconscious. When she needed shots, you apologized that it was going to hurt a little, whether or not she could hear. When you listened to her heart and lungs through your stethoscopes, and her gown began to slip, you pulled it up to respectfully cover her. You spread a blanket, not only when her body temperature needed regulating, but also when the room was just a little cold, and you thought she'd sleep more comfortably that way [DeMarco 2016]."

It is worth remembering that various people in a family may be on very different timelines in coming to and understanding or accepting the end of the life of a loved one. Sometimes it just takes a day or two for all in a family to come to an understanding about what should be done.

Thus, when feasible, and if it doesn't create or prolong suffering on the part of the patient, these days can be very valuable for the family.

Most practitioners avoid initiating conversations about religious issues with patients and their families, but one can certainly listen patiently when families frame a conversation for themselves in religious terms. In other words, it is always reasonable to give these types of thoughts a quiet, respectful hearing. It is also worth noting that a summary of all of these discussions should be included in the medical record, not only for medicolegal reasons but also so that all others involved in these complex cases will know what the families have been told.

A detailed discussion of the issues of the important subject of palliative sedation is beyond the scope of this essay, but specific guidance is available [Olsen 2010]. However, one can always say, accurately, that we have the capacity to minimize suffering when withdrawing artificial support.

### **ALL WE ARE IS DUST IN THE WIND: HELPING THE FAMILY DEAL WITH LOSS**

*Because I could not stop for Death/He kindly stopped for me/The Carriage held but just Ourselves/And Immortality. —Emily Dickinson*

*Our patients and families can't be expected to be at their best. In fact, we should accept the fact that they are often at their worst. We, on the other hand, always have to be at our best for them. —Joe Layon, MD*

As noted earlier, it is essential to understand Kubler-Ross's concepts of dealing with grief. After the death of a loved one, most will eventually be able to move into the stages of acceptance and hope. Specifically, it may be worth saying "we hope that they have found peace." However, it is often difficult for those providing care and helping the family manage this sad and emotional time to know what to say to those family members. One concept that some have found comforting is expressed in this short poem by Henry van Dyke [Gone From My Sight]:

*I am standing upon the seashore. A ship, at my side, spreads her white sails to the moving breeze and starts for the blue ocean. She is an object of beauty and strength.*

*I stand and watch her until, at length, she hangs like a speck of white cloud just where the sea and sky come to mingle with each other.*

*Gone from my sight. That is all. She is just as large in mast, hull and spar as she was when she left my side.*

*And, she is just as able to bear her load of living freight to her destined port. Her diminished size is in me—not in her.*

*And, just at the moment when someone says, "There, she is gone," there are other eyes watching her coming, and other voices ready to take up the glad shout, "Here she comes!"*

We know that we will all follow, in due time.

## I FEEL THE TRACES THEY'VE LEFT ON MY SOUL: TAKING CARE OF YOURSELF & YOUR TEAM

*Sometimes at night, I see their faces; I feel the traces they've left on my soul; Those are the memories that make me a wealthy soul; Those are the memories that make me a wealthy soul. — Bob Seger, Travelin' Man*

*In seeking absolute truth we must aim at the unattainable and must be content with finding broken portions. —Osler, Aequanimitas, 1889*

*Every surgeon carries within himself a small cemetery, where from time to time he goes to pray. —Rene Leriche*

As cardiovascular surgeons, we must recognize the toll taken on not only ourselves, our patients, and their families, but also our teams. In fact, one can imagine that the stress experienced, especially by those caring for the patient at the bedside day to day, can be greater than that experienced even by the surgeons themselves. After all, we are often distracted by many other obligations, while the bedside providers must be present with the patients for extended periods, day by day. Furthermore, these providers see the patients and their families at their worst, while we usually have seen them at a better time, such as during preoperative discussions. We must not only recognize the strain this different perspective can place on these providers, but we must also listen patiently to their concerns and tell them, over and over, how much we appreciate their care of our patients and their assessments of the patients and the families.

A relatively new term, “moral distress,” has been coined to describe this type of concern in these frontline practitioners. However, this term has some associated ambiguity, in that these providers cannot know all that the leader of the surgical team knows of the patients, their families, their conditions, and these providers may not fully appreciate the possibility that the patient in question may improve over time.

In a newsletter to an ICU team, a nursing leader, with whom I have had the privilege to work, pointed out that “we do things to patients that may be distressing to us. Some patients may not have understood the extent to which we must sometimes go to save their lives. We do not see these patients prior to surgery. We do not know the conversations that occurred between the patient and their surgeon. We do not know about a particular patient’s dreams, goals, and reasons for wanting to have a procedure and to get back home. Imagine signing the consent giving someone permission to place someone else’s heart into your chest. If you sign that paper, you have said you want to do whatever is necessary to continue living.”

And, we must also recognize the toll these difficult situations take on us, the surgeons leading the care of the patient. As one of my former trainees wrote, “patient deaths are hard on us cardiac surgeons. While I’m sure internists take deaths hard, we feel them even more personally. So, I encourage my residents and students to take care

of themselves after dealing with these difficult situations. Learn what you can and move on. Formal or informal morbidity and mortality reviews with colleagues and trusted friends can help. And don’t look to alcohol when you’re saddened by an outcome. Rather, recall that exercise can take the sharp edge off this misery fairly effectively [Simmons 2012; Tribble 2016a].”

## FOLLOW-UP, WITH FAMILIES AND PHYSICIANS

*The single biggest problem in communication is the illusion that it has taken place. —George Bernard Shaw*

When meeting with a family after a patient has died on my watch, I first try to help them understand that the attempted treatment was worth a try and that neither they nor we should feel that the operation was done in vain, even when the outcome was not what had been hoped for. The family will generally have questions that should be answered patiently and thoroughly. I always conclude such a meeting with a family by giving them my contact information and offering to hear from or even meet with them at any point in the future. These offers are made in recognition of the reality that virtually all involved will have additional reflections or questions that come to mind later, when “the fog of the battle” has lifted. I have been surprised by how often families will accept such an offer. Furthermore, I have yet to experience such an exchange that proved to be a negative one. In fact, the reactions when such exchanges have occurred have almost always been cathartic and quite positive for all involved.

Similarly, one must communicate expeditiously with the referring physicians. As many of these physicians will point out, they do not want to learn of the death of one of their patients while shopping in a grocery store or attending a church service. In such a communication, one should also provide an explanation of the decision-making involved in the case and offer to discuss the case with them, in a manner and at a time convenient to them [Tribble 2016b].

### Conclusion

*The meaning of life is that it ends. —Franz Kafka*

*It is a compassionate God or a compassionate nature, as one chooses, which provides an escape mechanism from our corruptible bodies when they become uninhabitable. Physicians should strive to understand when an escape mechanism is preferable. —Jim Jones & Laurence McCullough [JVS, July 2011]*

Dealing with end of life issues is never easy, and dealing with the death of a patient after an attempt to surgically correct a serious cardiovascular condition has its own particular set of challenges and approaches. More often than not, these situations are poignant but not tragic. Learning to deal with these patients, their families, our teams, and ourselves is essential for all, including our trainees, who practice in this realm.

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