How would you like to die? When I was a child, I hoped that I would die of old age in my sleep. Simply not waking up one day didn't seem so scary. However, my transition into adulthood and medicine has forced me to recognize that “old age” has little to do with one's actual years of life, and it happens to go by a variety of aliases: heart failure, cancer, arthritis, kidney failure, diabetes, and so many more. Today, we have a physiologic understanding of what is happening to the body; we have a thousand different terms to describe the events of living and dying. This expansion of evidence-based medicine has helped to transform end of life rituals, and we have incorporated medicine into every element of dying. However, if we see death as failure, we will always fail.

For millennia, humankind has been trying to understand and interpret death. With this desire for understanding, humans have developed rituals. As one article describes, “A ritual [is] a sequence of activities involving gestures, words, and objects performed in a specific place and sequence of time. Rituals help participants to cross from their present situation to another and, therefore, describe an important change in status.” [1] While end of life rituals have traditionally been steeped in cultural and religious significance, the modern narrative is increasingly dominated by science and medicine. It is the presence of machines and a hospital bed that signals a transition.

“One of the most documented and well-characterized end of life rituals is cardiopulmonary resuscitation, better known as CPR. The practice of CPR involves physically pumping an individual’s chest and applying electrical shocks via a defibrillator with the intent of restarting a stalled heart. Gregory L. Larkin expertly frames CPR, “CPR is still regarded more as a part of resuscitation science wherein its chief benefit is in prolonging life. Rarely successful in its scientific role of restarting the heart, CPR may give providers and families themselves the reassurance that we are correct to say goodbye to our loved ones.” [2] Humans need closure at the time of death of a loved one, and intensive CPR has become a symbol of fighting for life. Interestingly, many hospitals now allow families to watch professionals perform CPR on their loved ones to show the dedication and effort that the code team puts into practice. While the family’s presence does not improve rates of survival or overall quality of CPR, it may help the family’s ability to deal with the death [3]. Supporting the notion that when CPR fails, is it okay to let go.
Before CPR becomes an option, older patients or patients who are living with complex medical conditions are often informed of a “do not resuscitate” (DNR) order, which states that an individual does not want CPR, when their heart stops. This conversation itself has become a ritual to many physicians and families. These orders have been subject to large ethical debate, and the consensus is that it must be up to the individual and family. However, physicians often bring their own biases, and the choice to use or deny a DNR can be made without a complete understanding of CPR [4]. DNR conversations are among the many instances in which patients are asked to confront their own mortality. While DNRs and CPR are common rituals at the end of life, they are only a few of the many. Most of the deaths in the United States are from chronic disease with heart disease and cancer topping the list [5]. In the cases of chronic disease, the question becomes at what point should the family, individual, and medical professionals stop fighting for more life and start fighting for a better life? Being a very difficult question to answer, this question is one that must be answered by both the patient and the family.

I am sitting in the passenger side of the car as my mom drives to one of her patient’s houses. She is giving me the basic background of this patient’s diagnosis, prognosis, and life situation. This will be the first time that I see someone who she describes as “actively dying.” My mother is a family doctor in rural Northern Michigan, and she, along with her colleagues, perform house calls when patients are homebound. We arrive at a modest apartment and are greeted by the patient’s best friend. My mom has only a stethoscope; her job is to reassure, to support, to show the patient that she is cared for at all moments of her life. The visit is comfortable. There is no medical equipment, but Christmas decorations are hung and a half-completed Santa puzzle sitting on the dining table. There is no rush. We spend most of the time talking to the best friend about pain control and supporting her in her role as caregiver. From mother to daughter and physician to medical student, I am being shown how to care for patients.

“This will be the first time that I see someone who [my mom] describes as actively dying.”
While CPR is a dramatic and climactic event aimed at lengthening life, there are other medical narratives near the end of life. For the many individuals with a terminal disease, hospice can provide support. Hospice programs are based on a palliative care model in which the goal is to use medical resources to provide comfort as opposed to curing illness. Patients on Medicare (age 65+ or disabled) or who qualify through other insurance programs must have their doctor confirm that they have less than 6 months to live. The patient must also be willing to give up all “lifesaving” or curative treatments [6]. For example, a terminal cancer patient would no longer receive chemotherapy, radiation, or routine scans, but they would have access to pain medication, general quality of life medications, and other palliative procedures (draining fluid off the lungs for example). Hospice programs are independently run, nationally-certified, and typically consist of a team of professionals: doctors, home-visiting nurses, social workers, pharmacists, spiritual counselors, and others [7]. These programs provide a double service of combating high healthcare spending near the end of life while prioritizing family and individual values.

Hospice supports over 1.6 million patients every year and is continuing to expand. With the rapid growth, there is an ongoing debate as to how programs fit into our current healthcare system (Figure 1). In 2014 (the last year for which data is currently available through the National Hospice and Palliative Care Organization), the median length of services was 17.4 days, and it has been well documented that patients with shorter stays tend to receive more intensive care including more hospitalizations and ICU stays near the end of life [8, 9]. Patients may enter very close to death because they want to exhaust curative medications and therapies first. This begs the question, should Hospice programs be supplemental or complementary to traditional cure-based care? Short hospice stays may not help families and patients leverage all of hospice’s social and emotional supports such as in-home help, social work services, and respite care, but patients and families may feel that they have gained more time through other medical treatments. Like CPR and DNR orders, families and individuals must determine their priorities; so too must America.

“Like CPR and DNR orders, families and individuals must determine their priorities; so too must America.”

Figure 1. Hospice utilization rates [8]
With hospice's shifting role in society, Medicare is currently piloting a new program: The Medicare Care Choices Model. In this program, patients can receive traditional hospice services (up to $400 per month) while continuing with curative treatments [10]. This test project is following in the footsteps of another successful study by a large national health plan. The researchers completed a retrospective analysis of patients who all received comprehensive case management consisting of a nurse with palliative care training to help patients navigate and coordinate care. Patients also received either regular hospice benefits or expanded-eligibility hospice benefits in which they did not have to give up curative treatment. In each group, hospice-utilization rates more than doubled, but acute inpatient and ICU stays were halved. The researchers speculate that increased communication between the families, case managers, and physicians helped to drive up hospice utilization rates [11]. With increased communication, patients opted for less expensive and intensive care. Potentially, this shows that more families and individuals want support in the end of life as opposed to more medicine. Moving forward, the US will need to build lasting and effective care programs as our demographics shift towards older ages.

When I was sixteen years old, I began volunteering at my local hospice in-patient facility. With other high schoolers, I helped to put on holiday parties, bake treats, assist the nursing staff, and visit with patients. I still have vivid memories of some of the patients and staff.

I find myself in that same location again, this time, shadowing my mom. We enter the beautiful room filled with people. A single hospital bed has been pulled up to the large window that overlooks the garden. There is a shrunken, peaceful individual lying in the bed surrounded by loved ones. My mom takes her hand and speaks to her. She tells her that she is there and that she wants to say goodbye. After a moment of silence, my mom turns to the patient's daughter, only a few years older than me, and tells her that this is her opportunity to say goodbye, let her mom know that she will be okay, and tell her that it is okay to let go. This woman died in her sleep surrounded by family, without pain while facing the garden on a beautiful day.
So how exactly does one achieve a “healthy death”? What even is a “healthy death”? From CPR and DNRs to hospice, the decisions lie with the family and the individual. However, these values can only be recognized if discussed in the open. It is the responsibility of healthcare providers to initiate these conversations. Unfortunately, there exist substantial barriers to discussing end of life issues. Periyakoil et al. observed that “99.99% doctors reported barriers [to having end of life conversations] with 85.7% finding it very challenging to conduct [end of life] conversations with all patients and especially so with patients whose ethnicity was different than their own.” [12] However, these incredibly difficult conversations must happen before crisis strikes.

Atul Gawande has written extensively on end of life care issues in his book, “Being Mortal.” He provides very concrete advice on how to frame these conversations. Each doctor simply needs to ask five questions:

1. What is your understanding of where you are and of your illness?
2. What are your fears or worries for the future?
3. What are your goals and priorities?
4. What outcomes are unacceptable to you, and what are you willing to sacrifice?
5. Near the end, what would a good day look like? [13]

These five simple questions can help physicians make informed decisions as well as guide patients to resources that will align with their values. However, humans are fickle, and these conversations must be had repeatedly particularly after a change in health status. Open and continuous conversations help to build the patient-physician relationship while ensuring that the patient’s values are directing the care.

The end of life can be and often is a critical transition period. As patients and their families grapple with mortality, they are also called upon to make a variety of difficult decisions, many related to medical care. Medicine is now a core part of many dying rituals, and healthcare providers must strive to elicit patient values while providing the high-quality care. However, the definition of “high-quality” does not have to mean curative, in fact, it should be defined by the patient.

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References