

## Chapter 4

# End-of-Life Care, Costs, Concerns, and Conflict

## *Too Much of the Wrong Kind of Care?*

*I* so desperately need to get on my bike and hit the trails, Katie thought on the bus ride home from work. Either that, or open up a pint of Ben and Jerry's double fudge. Not that I won't end up doing both.

Until very recently, if asked, Katie would have without hesitation declared that she loved her position as a medical social worker at Regis Memorial Hospital. She had landed a job at Regis after completing her internship there while pursuing her undergraduate degree. In the 10 years since she was first hired, she obtained her master's in social work, left the hospital to work at a mental health facility for older adults, and then returned to the hospital setting. She enjoyed her position at the mental health clinic, but despite some policies at the hospital that she believed were not necessarily in all patients' best interests, she felt Regis was where she belonged.

At the hospital, Katie thrived on the fast pace, meeting people from diverse backgrounds, and the constant problem solving required. And she knew no matter where she worked, she would encounter individuals struggling with mental health issues, and the hospital setting provided lots of chances to work with older adults. Moreover, she had many interests outside of work, and the schedule she worked at the hospital afforded her more time, and a bit more money, to engage in those activities.

Recently when the opportunity to move to the intensive care unit (ICU) arose, Katie decided to go for it. She thought it would allow her to spend more time with families than was the case in the emergency room where she currently worked or the other units that she had previously been assigned to. One frustration she had at the hospital is that it seemed that discharge planning started the second someone

entered the hospital, with too little time to assess the nonmedical needs of the patients. Katie believed a more holistic approach to patient care would reduce the number of readmits, increase patient satisfaction, and improve patients' overall well-being.

What Katie had not realized was that work in the ICU would take more of an emotional toll on her than had been the case in other units she had worked in. Now, if asked, she would still say she loved her job, but although she didn't admit it to many others, she was worried that the stress was already starting to get to her.

Katie often felt conflicted about choices that doctors or family members made regarding end-of-life interventions that she believed were merely prolonging suffering. There were also the cases where, for the elderly in particular, symptoms were addressed by different specialists, yet there was no one trying to determine the underlying cause of the symptoms. Katie understood that doctors were too busy to take all the time it would require to figure out the puzzle, and understood their going the extra mile for children, but it galled her that it seemed our society could so easily just write off the elderly. Another major stressor for Katie was what the health care system did, and did not, provide funding for. This too often meant older people died in an institution rather than at home.

As the bus neared her apartment, Katie was mulling over a couple of the cases she had dealt with earlier that day that were unsettling. She had met with Mr. Panthian previously when he had been transferred from the nursing home to the ICU, then back to the nursing home. Katie heard that this time, once his infection was under control, the doctor wanted to insert a feeding tube. Mr. Panthian was having trouble swallowing and was even frailer than when he was admitted 3 weeks ago with a raging infection.

"I am done with hospitals and endless treatments," were Mr. Panthian's first words to Katie when she entered his room. His voice was weak, and Katie had a hard time making out what he was saying. "All I want is to die in peace at home, not hooked up to machines with tubes sticking out of me, and sure as hell not in this hospital, or in that damn nursing home. I should've gone with my intuition and never started the chemotherapy treatments. All they did was poison my system, make me violently sick, and weaken me." Just making his case wore Mr. Panthian out, and as Katie started to respond, she could see he had drifted off to sleep, so she slipped out of the room to call Jason, Mr. Panthian's only living child.

Prior to being diagnosed with lung cancer 3 years prior, Mr. Panthian, then 79, had lived by himself in the home he had built shortly after he married. Once the side effects from the chemotherapy started, his son, Jason, moved in with him. The two had always been close, and the arrangement worked well for both of them. Mr. Panthian had lost his wife to ovarian cancer in 2005, and Jason, who experienced a few heartbreaking relationships over the years, was single. He had told Katie, "I am

swearing off romantic relationships.” He had added with a chuckle, “At least for the foreseeable future.” In a more serious tone he added, “I want to be there for Dad as much as possible.”

“Jason here,” Katie heard in the receiver. “Hi Jason, this is Katie Francis. I know you are on the road and already got a call letting you know your dad is in the hospital.”

“Yes, another infection I was told, and the docs thought it might take him. I figure Dad is wishing that it had. I know he is pretty out of it most of the time, but I will try to call later and at least let him know I will stop in at the hospital tomorrow to see him. That is, if they haven’t shipped him off to the nursing home again. This back and forth between facilities is ridiculous. Why can’t they just treat an infection at the nursing home? Anyway, Katie, what did you call about?”

“I didn’t know you were back in town tonight,” Katie responded. “It will lift your dad’s spirits to see you. How about if we meet tomorrow after you see your dad? Well actually, I would like to meet with both of you together if he has the energy to do so. I want to talk to the both of you to clarify his wishes. I hope I am not the one informing you that one of the ICU doctors wants to put in a feeding tube. Also, we can talk about your concern regarding the frequent transfers.”

“Sounds like a plan. And yes, I heard about a feeding tube but have some questions about it, and I am doubtful it is something my dad will be interested in. Oh, heavy traffic. Gotta go. Thanks, Katie. Talk to you tomorrow.”

Katie had chosen not to mention the possibility of hospice<sup>1</sup> care for Mr. Panthian at the nursing home. She knew it was better to wait and talk in person, not on the phone, especially since she was not sure what Jason knew about hospice. Jason had tried to sound cheerful on the phone, but Katie could hear the sadness in his voice as he talked, and she assumed, based on past conversations, he was likely still feeling guilty that he couldn’t stay home and care for his dad. It was just not financially feasible, nor was hiring the care needed to be able to keep Mr. Panthian at home. While less than ideal, Katie figured that hospice care in an institutional setting was better than no hospice care. Mr. Panthian was competent and therefore able to make his own decisions, so for legal reasons, Jason’s input was not required, but Mr. Panthian had made it clear that he wanted Jason there when care decisions were made.

---

<sup>1</sup> Hospice is a program of care and support for people who are terminally ill and who are determined to have 6 months or less to live. It may be paid for through Medicare or Medicaid. The purpose of hospice is helping the person live comfortably but not on trying to cure the illness. Care can be provided in the home or in a hospice facility. Hospice focuses on addressing the needs of the whole family (close loved ones). “A specially trained team of professionals and caregivers provide care for the ‘whole person,’ including physical, emotional, social, and spiritual needs. Services typically include physical care, counseling, drugs, equipment, and supplies for the terminal illness and related conditions” (Centers for Medicare and Medicaid, n.d., p. 4).

After her call to Jason, Katie made some other calls to set up arrangements for patients, then went to meet with three of Vivian McCallister's four adult children. All three of them had been up most of the night hanging out at the hospital, and Katie figured they must be exhausted. Mrs. McCallister had been admitted to the hospital the previous evening when Christy, her oldest daughter and who Mrs. McCallister had been residing with for the past 5 years since the death of her husband, called the paramedics. Although Christy believed her mom would want to die peacefully at home rather than be rushed to the hospital, and Christy wanted to respect that wish, she panicked when she noticed that her mom didn't seem to be breathing normally.

Before meeting with them, Katie checked Mrs. McCallister's file and found that there were no advance directives in her file, despite the fact that she had been admitted to the hospital two other times in the past 4 months. Katie figured this was likely due to the fact that Mrs. McCallister had advanced dementia and had not established advance directives when she was still cognitively able to, nor unfortunately had she given anyone the durable power of attorney. In her review of the file, Katie was surprised to see that Mrs. McCallister was getting no services outside of the hospital. The social worker who had met briefly with them was no longer at Regis, so Katie did not have that person as a possible source for more information. At the very least, she would have thought a visiting nurse would have been assigned to see Vivian in her home and that there would have been more interaction with a licensed social worker.

The first thing Katie heard when she entered the meeting room, just down the hall from Vivian's room, was Christy's distressed voice: "Enough is enough. Let's just let Mom die in peace instead of prolonging her suffering. You don't see her every day like I do. She is miserable. I only brought her to the hospital because I knew you two would never forgive me if I didn't."

"Christy, you're too dramatic. It's not like Mom is brain dead and has been on a ventilator for months to keep her alive. Dr. Phinney says that she's not in distress, so what is your hurry in depriving her of medical treatment that may help her to live longer?" responded Catalina, Christy's youngest sister, almost sounding accusatory.

Their brother James chimed in, "Christy, we know you want what's best for Mom, but I have to agree with Catalina. You can see that Mom appears to be resting comfortably, and the fact that she has periods when she is alert is promising. None of us want her to suffer, but I don't think it is accurate to assume that she is."

He started to say more, but Christy cut him off, "Oh James, please, don't give me that crap, and Catalina, if you get on your moral high horse again I'm going to scream. You have no idea what it is like to care for her day in and day out. She can't do anything for herself, she doesn't sleep much of the night, and I hear

her moaning and muttering but making no sense. And she has no control of her bladder or bowels. That is not living; it's existing in a state of frustration. I have no doubt she's suffering. How many times should she be brought to the hospital and put on a machine that may help her for a short time but doesn't in any way improve her life?"

"Sorry to interrupt the three of you," Katie quietly said, knowing she had walked in at a tough moment. But, there was no good time to interrupt, and given what little she had heard of the conversation, she was pretty sure the conversation was going nowhere positive. This thought was confirmed when Katie heard an audible sigh of relief from each of them, followed by James saying they were thankful for the interruption. Her entry may have stopped the arguing, but it didn't put them at ease. Katie suddenly understood that old cliché and felt that she could have almost physically cut the tension in the room with a knife. She also worried that she was seen by the sisters as more of an intruder than someone who could help.

"Hi, I am Katie Francis, the social worker for the ICU. Dr. Phinney, of course, is the primary person who will provide you with information about your mom's medical condition and medical treatment options. If you are willing, though, I would be glad to help you think through some of the decisions that have to be made and can also discuss resources that may be helpful to you."

Christy's defensiveness was strong, and she was the first to speak. "I really don't want some social worker butting into our family affairs."

"Oh, for Pete's sake, Christy, give us all a break, and let's move on," James shot back. "Let's see what Katie has to say. What are you afraid of anyway? We don't have to hide our family secret anymore. Dad is dead, and he is not coming back to hurt us or Mom. We are adults now. We don't have to live in fear of reaching out for a little help." Christy shot James a look of anger, but it was clear she was on the verge of tears. Catalina, who had been quiet, went over and gave Christy a hug, and the floodgates opened. They wept.

Christy said nothing as Katie spent the next 20 minutes listening to James and Catalina tell her how the three of them had promised each other they would take care of their mom, who had spent their childhood protecting them from their dad, who had been emotionally and physically abusive to all of them. They had hoped she would leave him, but that did not happen. It was Dave, the second oldest, who had gotten heavily involved in drugs, likely as a way to escape the reality of their home life, and had left the family. They rarely heard from him, and right now they had no way of contacting him.

Christy had gained control of her emotions and interjected, "Yes, Dad was a jerk, but that doesn't help us figure out what to do for Mom. I don't think the two of you get how exhausting it has been for me these last few months. When Mom could take care of herself and was just losing it slowly, I could deal, but now I just

can't take much more of this. And don't start thinking I want to let her die to get rid of her since it is more than I can handle."

"Christy, if you didn't try to play the martyr and had simply told us how hard it was, we could have tried to help out more," James responded, without much sensitivity to how upset she was. Catalina, seeing Christy was about to cry again, came to her defense. "James, Christy did try to ask for help in her own way, which I will give you wasn't very direct. Still, I knew she was struggling, and I think we both just figured she would handle it like she always has everything else."

A million thoughts were going through Katie's mind. She could have spent hours with the McCallisters talking about issues that went well beyond the immediate situation but that still impacted how they were dealing with it. Katie, always aware that she had other patients to meet with but never wanting to appear rushed, attempted to get to the task at hand. "Just to make sure we heard the same message from Dr. Phinney, please tell me what your understanding is as far as the medical status of your mother and what he is recommending or the options he provided." Katie did not share with them that Dr. Phinney, the primary doctor in the ICU who had been involved with Mrs. McCallister's care, was one who didn't want a patient to die on his watch. He believed that it was his responsibility to do what he could to extend life and not give up on keeping the patient alive. Though partially admirable, the consequences were often harmful and counter to what families and patients wanted—and she wished he would be more up front about how his beliefs affected his recommendations.

Katie looked up just as the bus drove by her stop. This wasn't the first time she was thinking about work and missed her stop. Thank goodness this time, unlike some of the others, she didn't have far to backtrack. Despite her headache, she would be home, on her bike, and out on the trails that were only a couple of miles from her house in no time.

## BACKGROUND INFORMATION

Discussing families who want ever more tests and medical treatments conducted on their chronically ill loved ones, instead of accepting that more treatment is futile, hospitalist Dr. Bowron (2012) writes, "We want our loved ones to live as long as possible, but our culture has come to view death as a medical failure rather than life's natural conclusion" (p. 1). Although many deny it, avoid thinking about it very much or at all, or look to the promising advances in science and medicine that suggest we may be able to delay death to a much greater extent than ever before, there is no doubt that our death is inevitable. Moreover, there is a very strong likelihood that at the end-of-life, many difficult medical decisions, along with other end-of-life decisions, must be made.

For those who live into old age, simply passing away peacefully during sleep after a long life with no complex health issues is rare, not the norm. Thus, it is crucial that, as a society, we figure out how to ensure that the dying process is marked by compassion, comfort, dignity, and as much choice as possible. In other words, what is needed to foster a good death,<sup>2</sup> not merely extending life regardless of quality. What does the current reality mean for a dedicated medical social worker such as Katie Francis?

To address these overarching questions, it is necessary to first provide foundational information and context. Therefore, this section includes some information on demographics of the aging population;<sup>3</sup> research on medical treatments at end of life; costs of treatments; public opinion regarding end-of-life care; progress made and key challenges still faced; and recommendations for end-of-life health care that doesn't prolong life at all costs and that is holistic in approach. This chapter is intentionally and necessarily limited in scope and not intended to address all issues relevant to end-of-life care. For example, whether physician-assisted suicide ought to be considered part of a good death is a necessary discussion. However, it is outside the scope of this chapter even though some of the most visible and wrenching cases involve younger people such as Brittany Maynard,<sup>4</sup> whose situation and YouTube video about her choice moved many people. Another critical issue that merits more attention than given here is that of caregiver stress.

The 2010 Census Bureau report indicates that adults in the United States who are 65 or older make up 13% of the population (40.3 million people). That number has jumped 15.1% between 2000 and 2010 and will continue to climb as the baby boomers age (Brandon, 2012). By 2050, the number of those 65 and older is projected to be 88 million (Vincent & Velkoff, 2010). This demographic change will have a profound impact on society. At the same time that there will be more elderly, with end-of-life needs, there will be fewer younger people available to provide care. A huge impact will be the significant costs. Currently “one out of every four Medicare

<sup>2</sup>The Institute of Medicine defines a good death as “one that is free from avoidable suffering for patients, families and caregivers in general accordance with the patients’ and families’ wishes” (Gustafson, 2007, para. 4). Kehl (2006) reviewed relevant articles and came up with the following as what people considered a good death: “Being in control, being comfortable, having a sense of closure, having one’s values affirmed, trusting in care providers, and recognizing impending death, beliefs and values honored, burden minimized, relationships optimized, leaving a legacy, and family care” (Abstract, para. 1).

<sup>3</sup>While end-of-life care decisions must be made by, and for, people of all age groups, the focus of this background information is on older adults.

<sup>4</sup>Maynard, a 29-year-old woman diagnosed with terminal brain cancer, gained national attention as a death with dignity advocate. Following her diagnosis and her decision that she wanted to end her life with dignity, she moved to the State of Oregon, which allows for terminally ill patients, who met specified criteria, to end their lives with lethal medication that is prescribed by a physician. Brittany shared her situation and reasoning for her decision with millions of people through social media. She did not take the lethal medication immediately but is said to have waited until she was having continual seizures and significant neck and head pain (Bever, 2014).

dollars, more than \$125 billion, is spent on services for the 5% of beneficiaries in their last year of life” (Wang, 2012, p. 1). That does not include out-of-pocket expenses for Medicare recipients that, for 40% of households, exceed their financial assets. Of critical importance is that, without a continued shift away from futile treatments, the elderly will be getting care that does not necessarily result in improved quality of life and, in fact, can cause more discomfort or pain (Adamopoulos, 2013; Allen, Beres, Herring, & Seller, 2011; Bakalar, 2013; Bowron, 2012; Hsieh, 2014; Wang, 2012).

There are a few signs that suggest America is undergoing a paradigm shift in our medical approach to end-of-life care, yet there is strong evidence, based on research, indicating the state of affairs is nuanced, and that an overhaul is badly needed (Adamopoulos, 2013; Bakalar, 2013; Callahan & Lawler, 2012; Teno et al., 2013). On the upside, there has been progress made. More people are dying at home, more people are using hospice<sup>5</sup> services, more people are using advance directives to inform doctors of their wishes for end-of-life care, and more discussions between doctors, patients, and their family members are occurring (Adamopoulos, 2013). Unfortunately, the positive signs are only a small part of the overall story.

### Where One Dies

In their trend study assessing data from 2000, 2005, and 2009, Teno et al. (2013) concur with Centers for Disease Control and Prevention (CDC) reports that decedents age 65 years and older are more likely to die at home today than in the past. In comparing the end-of-life care of Belgium, Canada, England, Germany, the Netherlands, Norway and the United States, a study found that the percentage of people who died in the hospital was lowest in the United States (Vora, 2016). Still, even though most Americans express an interest in dying at home, between 2000 and 2009 there was only a 10% increase in Medicare beneficiaries who did. It rose from approximately 24% to 33.5% (Gleckman, 2013). As Bernstein (2014, para. 13) puts it, “In their last days, older patients are increasingly likely to be shuttled among hospitals, nursing homes and hospices in pursuit of Medicare and Medicaid coverage. Ultimately, most die in an institution, rather than at home.”

Just how much shuttling occurs was well captured in a study by Teno and colleagues (2013). In 2009 they found that “nearly one-half of decedents experienced

<sup>5</sup> There has been a slow but steady climb in the percentage of people in the United States using hospice services in the past 15 years. Just in the last five years the increase was from approximately 1.38 million to 1.66 million. This is over 45%. Hospice is often accessed only very close to the end of life. In 2014, for 50% of individuals, hospice was accessed in the last 2 weeks of life, and 35% were on hospice for 7 days or less. The median for the length of time on hospice was 17 days (National Hospice and Palliative Care Organization, 2015).



a transition in the last 2 weeks of life” (Teno et al., 2013, “Health Care Transitions,” para. 4), and “there was a slight increase in the number of people who were moved from one facility to another in the last 3 days of life” (para. 2). Getting moved around at the end of life is stressful, and the average number of moves was three times in the last 90 days of life. Some of the transfers were to a hospice facility. While hospice care overall is viewed very positively, 31% of the transitions occurred in the last few weeks of life, with 28% of hospice transfers entering hospice care only for the final 3 days of their life (Gleckman, 2013). “We have these frail older people moving about in the medical-industrial complex that we’ve constructed,” Dr. Teno said in an interview. “It’s all about profit margins. It’s not about caring for people” (Bernstein, 2014, “On Dying in America,” para. 3).

### Too Much of the Wrong Type of Care at End of Life?

Surely, litigation concerns also play into this situation. Cleveland Clinic’s Department of Bioethics states in their policy guidelines on foregoing life-sustaining or death-prolonging therapy that health care providers have a legitimate moral and legal presumption in favor of preserving life and providing beneficial medical care with the patient’s informed consent. Clearly, however, avoiding death should not always be the preeminent goal. Not all technologically possible means of prolonging life need be or should be used in every case. For the gravely ill patient and for his or her family, friends, and health care providers, decisions about the use of life-sustaining treatment have profound consequences (Cleveland Clinic, 2005).

While it is likely that most hospitals across the nation share a similar philosophy, there is empirical research and a plethora of people who have witnessed the care and death of a loved one who claim that, too often, aggressive or futile<sup>6</sup> care is provided at the end of life.<sup>7</sup>

Of course there are cases when one party believes that not enough aggressive care is provided. A 2007 study conducted by Barnato et al. sets forth that there is a “marked geographic variation in Medicare end-of-life spending [that] is well documented, and this variation is believed to be driven by physician practice style rather than by differences in patients’ preferences for aggressiveness of treatment at the end-of-life” (cited in Nicholas, Langa, Iwashyna, & Weir, 2011, “Conclusion,” para. 2). But, the concern most prominent in the literature and in this chapter is the overuse of medical interventions at the end of life that have no physiological

<sup>6</sup> Futile medical care is treatment that serves no useful purpose and there is no physiological benefit to the patient. There are cases where there is not universal agreement regarding what is futile care.

<sup>7</sup> Dr. Erik Fromme, a palliative care specialist, points out that “emergency medical service protocol is to provide full treatment including resuscitation and transport to a hospital” (Oregon Health and Science University, 2014, para. 3).

benefit. Dr. Ezekiel Emanuel, in a study published in the *Journal of the American Medical Association*, found that patients in the United States were twice as likely to spend time in the intensive care unit in the last 6 months of their life as in Belgium, Canada, England, Germany, the Netherlands, or Norway. And almost 40% of patients with cancer were administered at least one round of chemotherapy in their last 6 months of life (Vora, 2016).

Geriatric health care expert Dr. Joanne Lynn, director of the Center for Elder Care and Advanced Illness at the Altarum Institute, is among the many advocating for major changes to end-of-life practices, which she refers to as “wasteful and misdirected.” She discusses the tests, surgeries, and medical procedures encountered by Medicare beneficiaries that don’t lead to improved health but that beneficiaries “endure” during their last days. Terry Berthelot, senior attorney with the Center for Medicare Advocacy, states that “currently folks are getting all types of end-of-life care that’s very, very expensive that doesn’t in any way save lives. It only prolongs life at a huge cost with very, very little real benefit because of all of the misery at the end-of-life when somebody’s dying in a hospital” (Adamopoulos, 2013, “Too much care,” para. 7).

Dr. Teno et al.’s (2013) study provides evidence showing that in the first decade of the 21st century, there has not been a trend toward less aggressive care at the end of life. In fact, between 2000 and 2009, the use of ICUs in hospitals actually increased for people in the end-of-life situation. In the last month of life, almost 30% of Medicare beneficiaries spent time in the ICU. Nicholas et al. (2011) state their finding, in a *Journal of the American Medical Association* article, that end-of-life hospital treatment is a major driver of end-of-life expense and a setting in which many aggressive procedures to sustain life are performed.

In their study of intensive care units in the UCLA Health System from December 15, 2011, to March 15, 2012, Huynh et al. (2013) found that “treatment that is perceived by physicians to be futile is common: more than 1 in 10 patients received such treatment during their ICU stay. The outcomes of these patients were uniformly poor; two-thirds died during the hospitalization and 85% died within 6 months” (“Discussion,” para. 1). The researchers do note that a limitation of their study is that the University of California, Los Angeles Health System is known for its resource intensive treatment and so is not necessarily generalizable. Still, Huynh et al.’s study, along with the other studies discussed above and innumerable anecdotes and their own experiences with loved ones, certainly provides evidence that aggressive care that prolongs life but does not improve one’s health occurs on a regular basis.

Dr. Ken Murray (2012), a clinical assistant professor of family medicine at the University of Southern California, arguing we need to rethink futile care, sets forth with brutal honesty the harm he believes comes from futile care. “The patient will

get cut open, perforated with tubes, hooked up to machines, and assaulted with drugs. All of this occurs in the Intensive Care Unit at a cost of tens of thousands of dollars a day. What it buys is misery we would not inflict on a terrorist” (para. 4). In further making his point, Murray powerfully speaks of the countless physicians he knows that choose not to get the aggressive treatment they provide for others (Murray, 2012).

### Key Challenges to Progress

Keeping in mind there are some signs of a paradigm shift, moving in that direction takes us on a path laden with large obstacles that will not be easily overcome. Key challenges to a good death include what patients want, or very often what their loved ones want for them when they cannot make the choice, the role doctors play, and the structure of our current health care system. Research published in the *American Journal of Critical Care* adds to and expands on these challenges. The study assessed the views of over 1,400 critical care nurses on how to improve end-of-life care. The nurses expressed challenges that relate to some of those just stated. Lack of appropriate education of physicians on end-of-life care; communication problems, including doctors not wanting to be forthcoming with patients and family members regarding the patient’s condition; and family members having unrealistic expectations were all seen as standing in the way of increasing the number of good deaths. Many nurses in the study believed that a key obstacle is that many doctors see death as a personal failure and make treatment decisions based on their needs rather than the patients’ needs. Staffing patterns and staff shortages were also mentioned as problems (Beckstrand, Callister, & Kirchhoff, 2006).

In addition to doctors having varying views on treatment at the time of death, a PEW Foundation (2013) poll indicates variability among expectations of doctors for end-of-life care:

Fifty-seven percent [of participants] say they would tell their doctors to stop treatment if they had a disease with no hope of improvement and were suffering a great deal of pain. And about half (52%) say they would ask their doctors to stop treatment if they had an incurable disease and were totally dependent on someone else for their care. But about a third of adults (35%) say they would tell their doctors to do everything possible to keep them alive—even in dire circumstances, such as having a disease with no hope of improvement and experiencing a great deal of pain. In 1990, by comparison, 28% expressed this view. (p. 1)

Moreover, a national study by Barnato et al. (cited in Nicholas et al., 2011) found that 42% of White Medicare beneficiaries worried about receiving too much care at the end of life, whereas an equal proportion worried about receiving too little.

Doctors often are not aware of the wishes of the patient (because they are not documented or the document is not in the chart) and fear not doing what the family asks, if the patient can't communicate. Speaking about family members who are in a position of making end-of-life care decisions for loved ones, Dr. Ken Murray (2012), writing from his experience as a hospital physician, states that "poor knowledge and misguided expectations leads to a lot of bad decisions" (para. 8).

Doctors often find themselves in an uncomfortable and ethically challenging position regarding this issue of what care to provide or not provide. It is particularly complex, according to Kasman (2004), "when physicians have less experience with these discussions, when families and providers disagree about benefits from treatment, and when cultural disparities are involved in misunderstandings" ("Abstract," para. 1). There are circumstances, as suggested by the Barnato et al. 2007 study, when the disagreement may have more to do with philosophy about end of life rather than the benefit(s) of a specific medical treatment (cited in Nicholas et al., 2011).

The health care system is viewed as being a huge part of the problem preventing good deaths. Wilensky (cited in Riley & Lubitz, 2010) points out that while medical technology has changed significantly in the last 3 decades, Medicare's basic payment approach for doctors continues to largely be a "fee-for-service system, with financial incentives to produce more services" ("Discussion," para. 1). In an interview, Dr. Teno expands on this point:

What you pay for is what you get. There are financial incentives to provide more care in fee-for-service care. We don't get paid to talk with patients about their goals or care or probable outcomes of care. We do pay for hospitalizations, and there are financial incentives for nursing homes to transfer patients back to acute care. We need to restructure how we pay hospital systems. (Kuehn, 2013, para. 5)

Bernstein (2014), in a *New York Times* article describing how a daughter fought for months to honor her father's wishes to die at home rather than in a hospital or one of the nursing homes that he continuously was shuffled back and forth between, interviewed Dr. Jack Resnick, who has a geriatric house call practice. Resnick claims, in regard to one's wishes to die at home, "you can't believe the forces of the system that are arrayed against it. The way the reimbursement system works, these decisions are not made on the basis of what the individuals need. They're based on what the institutions need" (Bernstein, 2014, "Dying in America," para. 7). Terry Berthelot, senior attorney with the Center for Medicare Advocacy, concurs that there are problems with the system itself, which too often fails to make long-term care plans for the trajectory of a patient's illness beyond the hospital doors. Not only is

this not beneficial for the patient, Berthelot notes that this kind of care is driving up health care costs. (Adamopoulos, 2013).

In *Knocking at Heaven's Door*, the author, Katy Butler (2013) recalls a conversation she had with her father's internist, Dr. Fales, who was opposed to a pacemaker for her father. A different doctor, a cardiac specialist, focused only on the fixable problem and not the whole person's condition, argued in favor of it, and surgery to insert a pacemaker was carried out. The pacemaker later prolonged her father's life beyond when he had any quality of life left. Butler writes that "Medicare reward[ed] the surgeon and the cardiologist far better for doing the procedure than it would have Dr. Fales for making a reasoned argument against it" (p. 63). Dr. Fales stated, "I spend 45 minutes thinking through the problem, and I get 75 to 100 bucks. . . . Someone spends 45 minutes putting in a pacemaker and is paid six times as much" (p. 63). The point is not whether putting in the pacemaker was the best option or not. The point is that long-term planning, taking into account the person's overall health status, not just one specific, potentially fixable problem, is critical and often overlooked.

The wasted dollars, inefficiencies, and inhumaneness of the system is echoed in Dr. Lynn's comments regarding the consequences of what she calls "perverse financial incentives" that prevent needed types of care. She points out that while other developed countries spend much less per person on medical care than the United States, they spend about twice what the United States spends on social supports. In response to the federal spending cut for meals for seniors in 2013, she asked the question, "Why can I get a \$100,000 drug but I can't get supper?" (Bernstein, 2014, "Dying in America," paras. 10 & 11).

## Advance Directives

Advance directives, or living wills, are legal documents that set forth a person's wishes regarding end-of-life medical care. They let doctors and loved ones know ahead of time what medical measures to take, or not take, if the person is not competent to make the decision or cannot communicate his or her wishes. Poll results released by the PEW Foundation (2013) reported that approximately 60% of adults 65 or older said they had an advance directive, leaving close to 40% with none. There are numerous reasons for not completing an advance directive such as not understanding the importance of having one, thinking it is up to the doctor to initiate, putting it off, and spiritual and cultural beliefs (Pullen, 2012).

In addition to patient self-determination, an expectation of advance directives is that they will reduce costs at the end of life. "The Centers for Medicare & Medicaid Services estimate that more than 25% of Medicare spending goes towards the five percent of beneficiaries who die each year" (Adamopoulos, 2013, para. 6).

Research indicates advance directives, if accessible, increase the likelihood that patient wishes will be honored, but there are mixed findings regarding reduced expenditures for medical costs.

Tierney et al. (2001) found that study participants, who included elderly patients with chronic illness, conveyed greater satisfaction with their primary care doctor and a significant improvement in outpatient visits when advance directives were discussed. Research by Silveira, Scott, & Langa (2010) published in the *New England Journal of Medicine* found that between

2000 and 2006, many elderly Americans needed decision making near the end-of-life at a time when most lacked the capacity to make decisions. Patients who had prepared advance directives received care that was strongly associated with their preferences. These findings support the continued use of advance directives. (Abstract, “Conclusion,” para. 1)

A study by Nicholas et al. (2011) that appeared in the *Journal of the American Medical Association* led them to conclude that “advance directives specifying limitations in end-of-life care were associated with significantly lower levels of Medicare spending, lower likelihood of in-hospital death, and higher use of hospice care in regions characterized by higher levels of end-of-life spending” (Abstract, “Conclusion,” para. 1). They add that advance directives appear to be most important for those who don’t want aggressive treatment but live in an area where aggressive treatment is the norm.

More recently, Silveira, Wiitala & Piette (2014) published research in the *Journal of the American Geriatric Society* that indicated an increase in the percentage of decedents with advance directives from 47% in 2000 to 72% in 2010. Their sample included 6,122 people age 60 or older, who died from 2000 to 2010. They also found an increase in hospitalizations but a decrease in the number of people dying in the hospital. What they concluded was that the significant increase in rates of advance directives completion during the study period “has had little effect upon hospitalization and hospital deaths, suggesting that AD completion is unlikely to stem hospitalization before death” (Abstract, “Conclusion,” para. 1).

To supplement advance directives, the Physician Orders for Life-Sustaining Treatment program (POLST) was developed in Oregon 2 decades ago. Since then, POLST programs have emerged across the United States. Today all but about five states either have POLST or are in the development stages of a program (National POLST Paradigm, 2012). The POLST program is intended for those who are critically ill or fragile and likely to be in their last year of life. In those cases, the patient, loved ones, and health care professionals have conversations regarding the care the person wishes to have. Then the person’s wishes are documented

on a POLST form. A study conducted at Oregon Health and Science University (OHSU) showed that of those in their study of 58,000 Oregonians who died from 2010 to 2011, 18,000 (31%) had a POLST form completed. Of those 18,000

only 6.4 percent of patients who specified comfort measures only orders on their POLST form died in a hospital, while 22.4 percent of patients who chose limited additional interventions died in a hospital and 44.2 percent of patients who chose full treatment died in a hospital. (OHSU, 2014, para. 5)

It seems likely that if the number of people who complete advance directives continues to increase, and if there are more people, when appropriate, completing POLST forms, the number of hospital deaths and unwanted treatment will continue to decline.

### Improving the End-Of-Life Experience

Throughout this background section major obstacles to providing good end-of-life care have been presented and discussed. We can do better. In 2014, a panel of experts, convened by the Institute of Medicine (IOM), drafted a report, “Dying in America: Improving Quality and Honoring Individual Preferences Near the End-of-Life.” The report sets forth that “improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end-of-life, but may also contribute to a more sustainable care system” (National Academies of Science, 2014, para. 2).

A significant change called for in the report is clinicians paying “more attention to patients’ social, emotional, and spiritual needs by collaborating closely with nurses, social workers, psychologists, pharmacists, and chaplains. . . . Death ‘is not a strictly medical event’ and many patients’ and families’ most pressing needs ‘are not medical’ in nature” (Graham, 2014, p. 1845). This requires improved communication, which is another needed change emphasized in the report. Conversations with patients to make sure all parties are clear regarding goals and wishes of the patient are critical to improve the quality of care.

Dr. Dzau, president of IOM, stated that doctors can’t let their own discomfort prevent them from talking about end-of-life issues with patients (Graham, 2014). Without conversations between patients (or loved ones) and health care professionals, proper advance planning, which is critical, won’t occur. Advance directives should be drafted not by the patient alone but after conferring with the patient’s physician and should be revisited periodically with the passage of time and circumstances. More important, the panel asserts that conversations regarding medical care at end of life take physicians’ time, and their value must be acknowledged by

making reimbursements from government or private insurance standard practice (National Academies of Science, 2014).

Related to reimbursement, the panel stressed the need to remove the incentive for expensive medical care that is not beneficial and to move away from a fee-for-service approach. The fee-for-service, in part, leads to a mismatch between the needs of patients and the services they receive. Patients end up being transferred between medical institutions too much, and too often, and then spend too little time in hospice care. The panel recommends that what needs to be incentivized are medical and social supports, for example, training and respite for caregivers, assistance with personal care, and nutrition services, that will reduce the need for acute medical care (National Academies of Science, 2014).

The use of palliative care, including hospice, was given the strongest of endorsements by the panel members. It was emphasized that needed changes be made throughout the health care system to incentivize the use of comprehensive palliative care, which is known to improve patients' quality of life. One of the needed changes is to better educate and train health care professionals on palliative care. Also recommended are methods for educating the general public regarding palliative care and end-of-life care. We need informed and meaningful conversations about dying and suffering.

Information in this section leaves no doubt that patients, caregivers, loved ones, medical professionals, and society as a whole stand much to gain if we take the needed steps to transform the health care system. Dying in America provides a blueprint. The policy changes it calls for will require a great deal of advocacy. As social workers, we have a responsibility and will benefit greatly if we are part of the movement to put in place a more holistic, compassionate health care system that enhances quality of life at the end-of-life.

### **A Night's Rest and Back at It**

As was often the case, Katie returned home from the ride physically spent and mentally refreshed. Although she wasn't stress-free, her headache had subsided. After making plans for the weekend with friends, she showered, grabbed a bite to eat (topped off with Ben and Jerry's ice cream she figured she had earned), and sank into her favorite chair to curl up with *The Lord of the Rings*. The next thing she knew, light was streaming through the windows. She had never slept all night in the chair before, and her back was achy. It was only 5:10 a.m. so she decided to crash for another hour in her bed, leaving herself about 20 minutes to get out the door to catch the bus. When it went off, the alarm was not a welcome sound.



As usual, Katie arrived at work about 10 minutes before the morning huddle, when the nurses from the night shift met briefly with the oncoming day nursing staff to report on any pressing patient needs. Although the information was logged in the chart, Debi, the head nurse, felt strongly that verbal communication, in addition to detailed charting, led to better patient care. She welcomed Katie joining them. Travis started out by reporting that “sadly, Joyce Oliver is back again. She needs to be receiving palliative care, not more testing and ineffective procedures.” Not one to hold back on his opinion, he went on, “The surgery performed last month only made things worse, and she just can’t bounce back to even the weakened state she was in presurgery. She was brought in last night with pneumonia that is causing breathing problems, with a urinary tract infection, and she is experiencing severe abdominal pain.”

Debi mentioned that “Mr. Jeffrey is back again as well. He shouldn’t have been sent home when he was actively bleeding internally. This may be a case where surgery is warranted and will improve Mr. Jeffrey’s health. Dr. Evenson will be in later this a.m. to see Mr. Jeffrey. In the meantime, we are giving him another transfusion to try to keep him stable.” The reports continued for another 5 minutes. The huddles served the purposes of the nurses, and some of the therapists, allowing them to vent and support each other, as well as gather updates on patients.

Following the huddle, Katie determined her priorities for the day. She knew she must first attend to some of the paperwork she had not gotten to the day before, or a couple of patients would not have the resources they needed upon discharge. Meetings with the Panthians and McCallisters, along with three other patients, were high on her list. As always, Katie thought through her approach to each of the meetings—not that they would go as planned, but she at least needed to have end goals in mind. Planning seemed to help her keep in check her personal beliefs about what should and shouldn’t happen at end of life. She also kept in mind the approach to end of life taken by the attending physician, as different doctors definitely had different philosophies. While she might not agree with a doctor’s medical advice, she knew it would not be appropriate or helpful to the family to voice disagreement. Her role was to assist patients and loved ones in processing what they wanted to do after educating them about available resources. She then linked them to needed services. Katie felt like most of the doctors on the ICU appreciated her ability to address the psychosocial needs of patients and families as this was not a skill set of many of them. She also wondered if there was something she could be doing to help change public policy or at least the organizational orientation to make progress toward better outcomes.

Katie felt relieved that she would be talking to Jason before meeting with the McCallister family. He was not under any illusion regarding the limits of modern

medicine or about his dad's condition. Based on past conversations, Katie thought he would fully support his dad's end-of-life wishes as far as medical treatment. She figured she would suggest that they meet privately after meeting with his dad as she wanted to give him a chance to talk, if he wanted to, about the guilt he felt for not being able to take his dad home. What they needed to accomplish first, and Katie was surprised it hadn't been dealt with at the nursing home, was crafting very specific advance directives.

Jason greeted Katie just outside his dad's room. "Katie, I really appreciate your support and assistance." He added in a quiet voice, "The doctors are good, but their primary concern seems to be keeping Dad alive, not letting him die naturally or increasing his comfort. He is semi-awake now, so let's go in."

"Good morning, Mr. Panthian," Katie said, and got a little smile but no verbal response. After a bit of small talk with Jason, which included Mr. Panthian but didn't require his input, Katie said, "Okay, ready to talk about your situation?" Mr. Panthian weakly said yes. Katie let Mr. Panthian know that she and Jason would do everything to ensure that his wishes regarding his medical care were respected. She explained that the advance directive he had signed included a Do Not Resuscitate (DNR) order but no other specific direction on what treatment to provide and what treatment he did not want. Katie knew he would be asleep before long so had prepared a draft that named certain treatments and just asked him to say yes or no to them. She included treatment that fell under palliative care (and briefly explained hospice) as well as more aggressive treatment such as a feeding tube. Panthian said weakly but firmly that "palliative care is all I want. I want to go home."

Jason responded, "Dad, I am working on that." Katie glanced at him with a look of surprise as she had no idea what he was "working on" and was pretty confident it was not something that was going to happen in the next few days. She said, "In the meantime, Mr. Panthian, there is a wing at the nursing home, away from where you were staying, that is for people who only want hospice care, which falls under palliative care. If you give the okay, I will make arrangements for you to stay there once you leave the hospital." Katie knew they wouldn't keep him at the hospital long, as his fever was already down, and his vitals were holding steady. She actually had already started making arrangements. Medicare was a stickler on who could get hospice care, so she made sure that the doctor at the nursing home would verify that Mr. Panthian's prognosis was "6 months or less to live." Katie realized that Mr. Panthian was asleep again and wasn't sure he had even heard Jason's comment. She motioned Jason to follow her, figuring they could take care of the signing of the advance directive later that day.

"Sorry, Katie, it just slipped out," Jason said sheepishly. "I may have landed a job that doesn't take me out of town so what I told Dad is not completely a lie."

I just don't know how I can afford to pay for care for him while I work, although it would cost a lot less than the state paying to keep him in a nursing home."

"No need to apologize to me, Jason. Your dad is a lucky guy to have a son who cares so much. And I agree, the way the system works doesn't make sense. How about we talk a little more after I meet with another family who is waiting for me? How soon are you leaving the hospital?"

"Other than an appointment at 1:00 for the possible job, I plan to hang out at the hospital."

"Try the rolls at the cafeteria; they're surprisingly tasty. Just page me when you get back, and I'll break away and talk to you. Good luck with the interview."

As Katie headed down the hall to Vivian McCallister's room, she thought back to the siblings' conversation she'd overheard yesterday and the one she had with them. Catalina and James were in denial that their mother's life on earth was coming to an end. Christy accepted that her mother was dying but felt guilty that she was overwhelmed, and even though she had insisted her mom live with her, she was angry at her siblings for not helping out more.

First things first, Katie told herself as she entered the room to see Christy and James nodding off in the chairs. After two nights and a day on the ventilator, Mrs. McCallister was breathing on her own again. The doctor had just written up orders to have her discharged that afternoon with an oxygen tank. "Good morning, you are here early," Katie cheerfully said.

"Where else would we be?" Christy responded. James ignored Christy's response and addressed Katie, "Hi Katie, Mom is going to be discharged today it looks like. She is tough and not ready to kick the bucket."

"Geez, James," Christy said, clearly irritated. Just then, Vivian stirred, and their attention quickly shifted to her. They spoke to her softly, and when she appeared to drift off again, Katie motioned for them to follow her to the meeting room. As they walked down the hall to the meeting room, Catalina saw them as she got off the elevator and joined them. Katie had her mental list of issues to discuss that included some respite for Christy (all three had made it clear they would fight tooth and nail against their mother being transferred to a nursing home even though Dr. Phinney had mentioned that a nursing home might be in order), home visitations by a home-health nurse, and what hospice care entailed. Katie had talked to Dr. Phinney, who said he would verify that Vivian likely had 6 months or less to live, but he had not mentioned this to her children. She expected resistance to hospice at first from James and Catalina but figured once they fully understood that it could improve the quality of their mother's life, they might change their mind. It still amazed Katie that so many misperceptions of hospice existed. *Here goes nothing*, Katie said to herself as she opened the discussion.

## QUESTIONS FOR DISCUSSION

1. Discuss the demographics provided regarding the aging population, the costs of end-of-life care, and the relevance of this information to the overall challenges discussed in this case.
2. Discuss the issue of multiple transfers between hospital and nursing homes at the end of life.
3. What signs suggest that America is undergoing a paradigm shift in our medical approach to end-of-life care? Discuss the evidence that indicates otherwise.
4. Why is it so challenging to make decisions on what, and how much, medical care should be given at the end of life? Identify and discuss the reasons.
5. What are advance directives, and how much of a difference does having them make relative to care provided?
6. What changes need to be made to ensure that the dying process is marked by compassion, comfort, dignity, and as much choice as possible.
7. Be prepared to discuss the challenging position that Katie finds herself in, and provide your thoughts on how she might work effectively and with integrity in the existing system. Does the social work code of ethics provide guidance? Explain your answer.
8. Is broaching the issue of spirituality important during a person's hospital stay when the social worker is trying to connect the patient with resources and has lots of tasks to carry out. If yes, how might Katie work this issue in? If not, why not?
9. Taking care of a loved one who is at the end of life while working and taking care of children is extremely challenging. The following link provides a summary of the Family and Medical Leave Act (FMLA): <https://www.dol.gov/whd/regs/compliance/whdfs28a.pdf>
  - (a) Based on the summary, does the FMLA appear sufficient to address these challenges? Explain.
  - (b) Do we need national legislation to better address the issue, or should it be left up to individual employers to address through agency policy? Provide a rationale for your answer.
  - (c) If you could change the FMLA, what changes would you make, if any? What would the impact of the changes have on employees and

employers? (The point of these questions isn't to fully assess and critique the FMLA. It is to give some thought to a social welfare issue that has a significant impact on many and, as is typically the case, has far-ranging implications.)

10. What was your understanding of hospice before reading this case? Has this case impacted in any way your views regarding hospice. Explain.

## CASE ANALYSIS WRITING ASSIGNMENT

1. Read the assigned case study thoroughly prior to class in order to be fully prepared to join in the discussion.
2. You have been assigned to a panel charged with improving our health care system to increase the likelihood of people experiencing a "good" death. The first step, and the goal of your analysis, is to provide the panel members with an understanding of the complexity of some of the key issues and challenges. (For this assignment, do not attempt to address physician-assisted suicide.)
3. The analysis should be an approximately two-and-a-half-page, typed, double-spaced essay. Your essay should reflect the standards and expectations of college-level writing: spelling, grammar, and appropriate use of paragraphs all matter. If you quote directly from the case study, use quotation marks, and at the end of the quote, indicate the page number the quote appeared on. For example, "By 2050 the number of those 65 and older is projected to be 88 million" (Vincent & Velkoff, 2010, as cited in Lewis, 2017, p. 55).
4. Your case analysis is due \_\_\_\_\_ and worth a maximum of \_\_\_\_\_ points.

## INTERNET SOURCES

Institute of Medicine of the National Academies ([www.nationalacademies.org/hmd/~media/Files/Report Files/2014/EOL/Key Findings and Recommendations .pdf](http://www.nationalacademies.org/hmd/~media/Files/Report%20Files/2014/EOL/Key%20Findings%20and%20Recommendations.pdf))

National Hospice and Palliative Care Organization (<http://www.nhpco.org/learn-about-end-life-care>)

National Institute on Aging: Health and Aging (<https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/introduction>)

National Institute of Health (<http://www.ncbi.nlm.nih.gov/pubmed/19615621>)

NHS Choices (<http://www.nhs.uk/Planners/end-of-life-care/Pages/what-is-end-of-life-care.aspx>)

NIH Senior Health (<http://nihseniorhealth.gov/endoflife/preparingfortheendoflife/01.html>)

Physician Orders for Life Sustaining Treatment (POLST) ([www.polst.org](http://www.polst.org))

U.S. Department of Health and Human Services (<https://healthfinder.gov/search/?q=Hospice+Care>)

## REFERENCES

- Adamopoulos, H. (2013, June 3). Cost and quality conundrum of U.S. *Medicare News Group*. Retrieved from <http://www.medicarenewsgroup.com/context/understanding-medicare-blog/understanding-medicare-blog/2013/06/03/the-cost-and-quality-conundrum-of-american-end-of-life-care>
- Allen, S., Beres, S., Herring, R., & Seller, S. (2011, June 11). *The use of medical technology to prolong life*. Retrieved from <http://www.cyberessays.com/Term-Paper-on-The-Use-Of-Medical-Technology-To/50045>
- Bakalar, N. (2013, September 11). Futile care at life's end. *New York Times*. Retrieved from <http://well.blogs.nytimes.com/2013/09/11/futile-care-at-lifes-end>
- Beckstrand, R., Callister, L., & Kirchoff, K. (2006, January). Providing a "good death": Critical care nurses' suggestions for improving end-of-life care. *American Journal of Critical Care*. Retrieved from <http://ajcc.aacnjournals.org/content/15/1/38.full>
- Bernstein, N. (2014, September 25). Fighting to honor a father's last wish: To die at home. *New York Times*. Retrieved from <http://www.nytimes.com/2014/09/26/nyregion/family-fights-health-care-system-for-simple-request-to-die-at-home.html>
- Bever, L. (2014, October, 8). Cancer patient Brittany Maynard, 29, has scheduled her death for Nov. 1. *Washington Post*. Retrieved from <https://www.washingtonpost.com/news/morning-mix/wp/2014/10/08/terminally-ill-brittany-maynard-29-has-scheduled-her-death-for-nov-1>
- Bowron, C. (2012, February 17). Our unrealistic views of death, through a doctor's eyes. *Washington Post*. Retrieved from [http://www.washingtonpost.com/opinions/our-unrealistic-views-of-death-through-a-doctors-eyes/2012/01/31/gIQAeaHpJR\\_story.html](http://www.washingtonpost.com/opinions/our-unrealistic-views-of-death-through-a-doctors-eyes/2012/01/31/gIQAeaHpJR_story.html)
- Brandon, E. (2012, January 9). 65-and-older population soars. *US News*. Retrieved from <http://money.usnews.com/money/retirement/articles/2012/01/09/65-and-older-population-soars>
- Butler, K. (2013). *Knocking on heaven's door: The path to a better way of death*. New York, NY: Scriber
- Callahan, D., & Lawler, P. (2012, July 24). End-of-life care: Role of ethics and health care. *Heritage Foundation*. Retrieved from <http://www.heritage.org/research/reports/2012/07/ethics-and-health-care-rethinking-end-of-life-care>
- Centers for Medicare & Medicaid Services. (n.d.). *Medicare hospice benefits*. Retrieved from <https://www.medicare.gov/Pubs/pdf/02154.pdf>
- Cleveland Clinic. (2005). *Policy on forgoing life-sustaining or death-prolonging therapy*. Retrieved from <http://www.clevelandclinic.org/bioethics/policies/policyonlifesustaining/ccfcode.html>

- Gleckman, H. (2013, February 6). More people are dying at home and in hospice, but they are also getting more intense hospital care. *Forbes*. Retrieved from <http://www.forbes.com/sites/howardgleckman/2013/02/06/more-people-are-dying-at-home-and-in-hospice-but-they-are-also-getting-more-intense-hospital-care>
- Graham, J. (2014, November 12). IOM report calls for transformation of end-of-life care. *Journal of the American Medical Association*, 312(18). Retrieved from <http://jama.jamanetwork.com/article.aspx?articleid=1930814>
- Gustafson, D. (2007, March 14). A good death. *Journal of Medical Internet Research*, 9(1). Retrieved from <http://www.jmir.org/2007/1/e6>
- Hsieh, P. (2014, September 29). Who decides what medical care you receive at end of life? *Forbes*. Retrieved from <http://www.forbes.com/sites/paulhsieh/2014/09/29/who-decides-what-medical-care-you-receive-at-end-of-life>
- Huynh, T. N., Kleerup, E. C., Wiley, J. F., Savitsky T. D., Guse, D., Garber, B. J., & Wenger, N. S. (2013, November 11). The frequency and cost of treatment perceived to be futile in critical care. *JAMA Internal Medicine*, 173(20). Retrieved from <http://archinte.jamanetwork.com/article.aspx?articleid=1735897>
- Kasman, D. (2004, October 19). When is medical treatment futile? *Journal of General Internal Medicine*, 19(10). Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1492577>
- Kehl, K. A. (2006, August-September). Moving toward peace: An analysis of the concept of a good death. *American Journal of Hospital Palliative Care*, 23(4):277–86. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/17060291>
- Kuehn, B. (2013, February 5). Author insights: Patients face too many burdensome care transitions at the end of life. *News @ JAMA*. Retrieved from <http://newsatjama.jama.com/2013/02/05/author-insights-patients-face-too-many-burdensome-care-transitions-at-the-end-of-life>
- Murray, K. (2012, February 8). How doctors die. *The Guardian*. Retrieved from <http://www.theguardian.com/society/2012/feb/08/how-doctors-choose-die>
- National Academies of Science. (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Retrieved from <http://www.nationalacademies.org/hmd/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>
- National Hospice and Palliative Care Organization. (2015). *NHPCO's fact and figures: Hospice care in America*. Retrieved from [nhpco.org/sites/default/files/public/Statistics\\_Research/2015\\_Facts\\_Figures.pdf](http://nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf)
- National POLST Paradigm. (2012). *State programs*. Retrieved from <http://www.polst.org/programs-in-your-state>
- Nicholas, L., Langa, K., Iwashyna, T., & Weir, D. (2011, October 5). Regional variation in the association between advance directives and end-of-life Medicare expenditures. *Journal of the American Medical Association*, 306(13). Retrieved from <http://jama.jamanetwork.com/article.aspx?articleid=1104465#qundefined>
- Oregon Health and Science University. (2014, June 9). *POLST orders successfully guide end of life medical treatment*. Retrieved from [http://www.ohsu.edu/xd/about/news\\_events/news/2014/06-09-polst-orders-successfull.cfm](http://www.ohsu.edu/xd/about/news_events/news/2014/06-09-polst-orders-successfull.cfm)
- PEW Foundation. (2013, November 21). *Views on end-of-life medical treatments*. Retrieved from <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments>
- Pullen., E. (2012, March 5). *Why don't patients have advance directives?* Retrieved from <http://drpullen.com/advancedirectives>

- Riley, G., & Lubitz, J. (2010, April). Long-term trends in Medicare payments in the last year of life. *Health Services Research Journal* 45(2). Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2838161>
- Silveira, M., Scott, K., & Langa, K. (2010, April 1). Advance directives and outcomes of surrogate decision making before death. *New England Journal of Medicine*. Retrieved from <http://www.nejm.org/doi/full/10.1056/NEJMsa0907901>
- Silveira, M., Wiitala, W., & Piette, J. (2014, April 2). Advance directive completion by elderly Americans: A decade of change. *Journal of the American Geriatrics Society*, 62(4). Retrieved from <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12736/abstract>
- Teno, J., Gozalo, P., Bynum, J., Leland, N., Miller, S., Morden, N., . . . Mor, V. (2013, February 6). Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *Journal of the American Medical Association*, 309(5). Retrieved from <http://jama.jamanetwork.com/article.aspx?articleid=1568250>
- Tierney, W., Dexter, P., Gramelspacher, G., Perkins, A., Zhou, X., & Wilinsky, F. (2001, January). The effect of discussions about advance directives on patients' satisfaction with primary care. *Journal of General Internal Medicine*, 16(1). Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1495157>
- Vincent, G., & Velkoff, V. (2010, May). The next four decades: The older population in the United States: 2010 to 2050. *U.S. Census*. Retrieved from <http://www.census.gov/prod/2010pubs/p25-1138.pdf>
- Vora, P. (2016, February, 2). Comparing end of life care for cancer patients in 7 developed countries. *American Journal of Managed Care*. Retrieved from <http://www.ajmc.com/newsroom/comparing-end-of-life-care-for-cancer-patients-in-7-developed-countries>
- Wang, P. (2012, December 12). Cutting the high cost of end-of-life care. *Money Magazine*. Retrieved from <http://time.com/money/2793643/cutting-the-high-cost-of-end-of-life-care>