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End-of-Life Care and Policy

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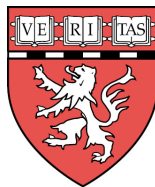
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Background

Physicians' roles are in constant evolution. In recent years, for example, doctors have increasingly emphasized the value of preventative services. Similarly, assistance with advance care planning has become integral to the care that physicians provide seriously ill patients (Fried and Drickamer 2010). Advance care planning exposes patients and their families to the many dimensions of end-of-life care and equips them with information to navigate the process. It also encourages individuals to consider issues and influences that often become relevant during such periods. These include the potential to prolong life, ability to alleviate pain and suffering, effect on family, and religious preferences. Lastly, advance care planning involves many people: the patient, family members, physicians, nurses, social workers, chaplains, and others.

In this background, we provide a brief overview of prominent legislation relating to end-of-life care. Next, we describe several of its components: advance directives, health care proxies, palliative care, and hospice care. We then discuss broader policy topics relating to end-of-life decisions, such as cost and government policy. Finally, we integrate these issues in a clinical case that illustrates the complex nature of end-of-life care.

Influential Policy and Ethics

End-of-life issues garnered the attention of the American public and government in 1990. In the historic ruling of *Cruzan v. Director, Missouri Department of Health*, the Supreme Court upheld the principle of patient self-determination: patients may accept or refuse any treatment offered to them. It further entrenched patient autonomy as a guiding principle of medical ethics in the US. The decision also precipitated passage of the Patient Self-Determination Act later in the same year (Gillick 2004). The Patient Self-Determination Act requires Medicare-certified institutions to inform patients of the following: “(1) the right to participate in and direct their own health care decisions; (2) the right to accept or refuse medical or surgical treatment; (3) the right to prepare an advance directive; and (4) information on the provider’s policies that govern the utilization of these rights” (Wilkinson, Wenger, and Shugarman 2007).

Concurrent with these developments, the public health and medical communities began researching the subject. Investigators assessed areas of weakness in end-of-life services as well as the efficacy of existing and proposed mechanisms to improve them. In 1995, a team of experts in the field published the results of the landmark “SUPPORT” trial in *JAMA*. SUPPORT was a combined observational study and controlled clinical trial aimed at understanding and improving end-of-life decision-making and care. The investigators concluded that “substantial shortcomings [existed in caring] for seriously ill hospitalized adults...” and that “patient-physician communication, although

advocated as the major method for improving patient outcomes, may be inadequate...” (The SUPPORT Principal Investigators 1995, p. 1591).

The Patient Self-Determination Act and other government measures popularized advanced care planning in a legal context. This resulted in patients and physicians initially approaching the matter from a legal standpoint. Over time, though, a more discussion-based approach has come to direct end-of-life planning (Sabatino 2010). Communication between patients, families, and health care providers is important in balancing patient autonomy with the other cornerstone values of medical ethics in the United States. These include beneficence (promotion of patient well-being), non-maleficence (“do no harm”), and justice (fairness in the distribution of scarce resources) (Beauchamp and Childress 2008). Relative to patient autonomy, the other principles may seem less significant in bedside decision-making. In end-of-life settings, however, these values are more likely to conflict. This may occur when a patient requests a mode of therapy that physicians judge will not ultimately improve health and/or well-being. Communication helps ensure that patients make informed choices and understand the risks, benefits, and alternatives associated with their decisions (Savory and Marco 2009).

Advance Directives and Health Care Proxies

When advance care planning was first promoted in the 1990s, advance directives emerged as the focus of policymakers’ efforts. Advance directives attempt to capture patients’ wishes regarding end-of-life care while they are competent. They delineate patients’ views on specific life-sustaining interventions in hypothetical circumstances. The documents intend to promote patient autonomy in future situations when patients may lack decision-making capacity. Written advance directives suffer from various shortcomings, though. They are often unclear and inflexible and therefore difficult to apply in many situations (Brown 2003; Wilkinson et al. 2007). Designating a health care proxy may be a more effective approach to advance care planning.

Patients may appoint a health care proxy, or surrogate decision-maker, to make medical decisions on their behalf in the event of incapacitation. A proxy should understand the patient’s preferences and values and be able to communicate them accurately. While a potentially more useful strategy, health care proxies also have constraints. Some individuals, such as those lacking a family, may be unable to identify a proxy. In addition, applying a “substituted judgment” of the patient’s preferences (i.e., what would the patient want if able to express herself?) may prove a difficult task (Gillick 2004). States may require an individual to complete a living will (written advance directive), appoint a health care proxy, or both.

Advance directives and health care proxies aim to promote end-of-life care that aligns with a patient's values and preferences. While data remain inconclusive, proponents find that patients who complete such measures usually seek less “aggressive care” (opting for more “comfort care”), enroll in hospice at higher rates, and experience a higher quality of life before death (Flory et al. 2004; Silveira, Kim, and Langa 2010; Zhang et al. 2009). In reality, however, the percentage of Americans who utilize advance directives is low—between 18% and 30% (Wilkinson et al. 2007). The elderly, however, are more likely to participate in them. A study at the University of Michigan determined that 67.6% of older patients eventually needing an advance directive or health care proxy had completed the necessary paperwork in advance (Silveira et al. 2010). Today, advance care planning focuses more on exploring a patient's values regarding end-of-life care than elaborating the basic legal guidelines. Such information—for instance, views regarding quality vs. quantity of life—may be informative during the administration of comfort care services.

Palliative Care

Palliative care is a comprehensive approach to caring for patients and their families at every stage of advanced illness (i.e., from the time of diagnosis through death). Its provision does not necessarily presume a transition to death, as palliative care may be offered concurrently with active treatment (Savory and Marco 2009). Providers maintain open dialogue about their patients' values and preferences, so that they be integrated and honored throughout the course of care. Palliative care addresses patients' physical, mental, and social needs, in a greater effort to improve quality of life (Wilkinson et al. 2007). A core principle of palliative care is alleviating pain and suffering through treatment of symptoms (see Figure 1 for examples of common symptoms and treatments). These programs use an interdisciplinary team approach to provide appropriate psychosocial, spiritual, and bereavement support. Not surprisingly, offering this range of services requires a high degree of care coordination (Morrison and Meier 2004). While palliative care is a rapidly expanding concept in health care, it faces certain obstacles. In particular, access issues exist in various settings. Other challenges include the following: developing a more streamlined and equitable reimbursement system, incorporating palliative care into disease-modifying therapies, and earning wider support from the medical and nonmedical professionals involved in end-of-life care (Welsfeld, Miller, Gibson, and Schroeder 2000).

A recent widely publicized randomized controlled trial indicates that, despite these challenges, palliative care administered to patients from the time of diagnosis can have many positive effects on end-of-life care, including the prolongation of life. The trial, which took place at a Massachusetts General Hospital, involved the random assignment of 151 patients with metastatic non-small cell lung cancer to receive either standard oncologic care combined with palliative care or standard

oncologic care alone (Temel et al. 2010). The researchers found that patients assigned to the palliative care group reported significantly better quality of life and fewer symptoms of depression 12 weeks later. While less aggressive end-of-life care was delivered to these patients, they had a median survival that was significantly greater than those randomized to oncologic care alone (11.6 months vs. 8.9 months). The study's authors hypothesize that the prolongation of life associated with palliative care may be directly related to their enhanced quality of life, better management of symptoms, and decreased incidence of depressive symptoms. Further investigation of the specific factors leading to the observed survival benefit as well as replication of this study in other care settings and in patients with other terminal illnesses is needed to understand the full benefits of palliative care (Kelley and Meier 2010).

Hospice Care

After a patient with life-limiting illness decides to forgo further treatment, she may elect to enroll in hospice care. Hospice programs offer comfort and support care. Unlike palliative care, hospice care is usually not provided alongside any life-sustaining therapy. A hospice team—consisting of nurses, social workers, chaplains, a bereavement coordinator, and a medical director—attempts to ease the process of dying and to help patients and families enjoy the remainder of life to the greatest extent possible. These programs promote dying with dignity, without pain, at home (or preferred location), and with social support (Gazelle 2007). Medicare typically pays for hospice services. They may be offered in various places, such as inpatient hospice units and skilled nursing facilities; however, a patient's home is often the preferred location (Quill 2004; Savory and Marco 2009).

Hospice care is growing in popularity and usage. In 2004, nearly 797,000 Medicare patients received hospice services—almost a 50% increase from the number in 2000. Approximately half of hospice patients suffer from a terminal cancer, while about 40% have end-stage cardiac disease, end-stage dementia, debility, pulmonary disease, or stroke (Gazelle 2007). An investigation recently published by researchers at Brigham and Women's Hospital and Harvard Medical School found that approximately 20% of patients with heart failure were referred to hospice (Setoguchi et al. 2010). (See Table 1 for the leading causes of death.)

Lastly, it is important to note certain challenges and dilemmas embedded in the Medicare hospice reimbursement. Providers and patients alike express dissatisfaction in the forced choice between receiving the benefit and continuing active treatment (Casarett et al. 2009). In terms of the actual payment, health economists have suggested adjusting hospice rates based on current technology and prices in addition to revising the per diem reimbursement policies. Other issues that deserve

attention are high-cost outlier patients and travel costs (Huskamp, Buntin, Wang, and Newhouse 2001).

1. Heart disease: 616,067
2. Cancer: 562,875
3. Stroke (cerebrovascular diseases): 135,952
4. Chronic lower respiratory diseases: 127,924
5. Accidents (unintentional injuries): 123,706

Source: FastStats: Leading Causes of Death. CDC/National Center for Health Statistics, 2009. (Accessed at <http://www.cdc.gov/nchs/fastats/lcod.htm>.)

End-of-Life and Health Care Expenditures

The US annually spends over \$2.5 trillion on health care, or 17% of its gross domestic product (Kaiser Family Foundation 2009). As health care expenditures continue to rise, policymakers have considered the costs of end-of-life care, which consume a significant portion of health care budgets.

Health expenditures are not evenly distributed across age groups. In 2004, the elderly (65 and older) spent nearly six times more on health care than children and three times more than working-age adults (Centers for Medicare and Medicaid Services 2004). While expenditures escalate with age, they also tend to rise sharply at the very end of a patient's life. One-third of health expenditures during the last year of life are incurred in the final month (Emanuel et al. 2002). Health economists attribute this trend to expensive interventions more frequently utilized during this period. These include life-sustaining measures, such as mechanical ventilation and resuscitation, as well as various other services associated with acute hospital care (Yu 2006). Thus, spending near the end of life contributes considerably to overall health care costs.

Whether increased adoption of advance care planning, palliative care, and hospice care can significantly lower overall health care expenditures is under debate. An early study looking at hospice care suggested that it may reduce costs by 31% to 64% (Kidder 1992). More recent investigations have shown that well-coordinated palliative care has lowered costs by 40% in certain settings (Payne, Coyne, and Smith 2002). Similarly, a randomized study at Virginia Commonwealth University showed that palliative care is associated with a decrease in hospitalizations, fewer days in the ICU, and lower overall costs (Smith and Cassel 2009). Another large retrospective study comparing patients receiving palliative care to standard care also detected savings—between \$1,700 and \$5,000 for patients receiving palliative care (Morrison et al. 2008).

In contrast, many other reports have not found a link between lower costs and advance care planning or comfort care services. Multiple randomized control trials of long-term hospice care have demonstrated that it does not reduce expenditures (Greer et al. 1986; Kane, Wales, Bernstein, Leibowitz, and Kaplan 1984). Several studies have found that advanced directives do not lower costs (Schneiderman, Kronick, Kaplan, Anderson, and Langer 1992; Teno, Lynn, Phillips, et al. 1993). Furthermore, a recent review article in the *Journal of Palliative Medicine* detected no association between palliative care consultation and reduced hospital length of stay (Cassel, Kerr, Pantilat, and Smith 2010).

Moreover, Medicare continues to devote a quarter of its annual budget to care spent on beneficiaries' last year of life. This may suggest that increased adoption of advance care planning and comfort care in the past years has not succeeded in reducing overall expenditures (Hogan, Lunney, Gabel, and Lynn 2001). Some experts argue that trying to lower spending near the end of life is unlikely to succeed. They cite various reasons: end-of-life care is labor-intensive; high-quality palliative care requires costly personnel and management; and it is difficult to predict who will soon encounter life-threatening disease and should consider these measures in advance (Emanuel and Emanuel 1994). Physicians stress the value of these innovations, regardless of their ability to lower costs. As recently published in the *American Journal of Respiratory and Critical Care Medicine*, "When restorative efforts fail, they should give way to a palliative approach if patients or surrogates agree, not because this approach will save money—which is unlikely to be the case for the reasons we have given—but because palliation will be of the greatest benefit regardless of its impact on health care costs" (Luce and Rubenfeld 2002, p. 753).

End-of-Life Counseling, Medicare, and Health Care Reform

In the summer of 2009, the health reform debate focused squarely on end-of-life issues. Representative Earl Blumenauer (D-OR) incited national controversy after adding language to incentivize end-of-life counseling through Medicare reimbursements. Blumenauer "found it perverse that Medicare would pay for almost any medical procedure, yet not reimburse doctors for having a thoughtful conversation to prepare patients and families for the delicate, complex and emotionally demanding decisions surrounding the end of life" (Blumenauer 2009). Critics argued that end-of-life counseling would decrease patient autonomy. Through the new Medicare reimbursements, the state could indirectly exert influence over the decision-making process of patients near death. As described in a recent JAMA article, "This section of the bill was distorted by many politicians and commentators into a mandate by which older and disabled individuals would be forced to forgo life-sustaining treatments" (Fried and Drickamer 2010, p. 269). Thus, some characterized the new Medicare payments as the creation of "death panels."

Uproar against the proposal eventually forced lawmakers to remove the provision before passing the Patient Protection and Affordable Care Act in 2010. In a broader sense, the discussion generated a fear of advance care planning. Numerous other measures concerning comfort care and other topics were dropped from the health reform debate. The authors of the legislation and most experts in the field, however, believed that such payments and supporting policies would have enhanced patient autonomy. By receiving a more accurate impression of the future care available, patients would have the ability to make more informed choices (Corn 2009; Fried and Drickamer 2010). This debate has received more attention since the publication of the randomized controlled trial discussed above which found that early palliative care integrated with standard oncologic treatment can, in fact, prolong life (Temler et al. 2010). As described by the palliative care specialist Dr. Diane Meier, “[The study] shows that palliative care is the opposite of all that rhetoric about ‘death panels’ ... It’s not about killing Granny; it’s about keeping Granny alive as long as possible—with the best quality of life” (as cited in McNeil 2010).

Figure 1

Table 1. Approaches to the Management of Pain and Other Common Symptoms.*		
Symptom	Assessment	Treatment
Anorexia and cachexia	Is a disease process causing the symptom, or is it secondary to other symptoms (e.g., nausea and constipation) that can be treated? Is the patient troubled by the symptom?	Consider megestrol acetate or dexamethasone.
Anxiety	Does the patient exhibit restlessness, agitation, insomnia, hyperventilation, tachycardia, or excessive worry?	Recommend supportive counseling and consider prescribing benzodiazepines (in the elderly, avoid benzodiazepines with long half-lives).
Constipation	Is the patient taking opioids? Does the patient have a fecal impaction?	Prescribe a stool softener (ineffective alone) plus escalating doses of a stimulant; if escalation of the dose is ineffectual, agents from other classes (e.g., osmotic laxatives and enemas) should be added.
Depression	How does the patient respond to the question “Are you depressed?” Does the patient express or exhibit any of the following feelings: helplessness, hopelessness, anhedonia, loss of self-esteem, worthlessness, persistent dysphoria, and suicidal ideation? (Somatic symptoms are not reliable indicators of depression in this population.)	Recommend supportive psychotherapy, cognitive approaches, behavioral techniques, pharmacologic therapies, or a combination of these interventions; prescribe psychostimulants for rapid treatment of symptoms (within days) or selective serotonin-reuptake inhibitors, which may require three to four weeks to take effect; tricyclic antidepressants are relatively contraindicated because of their side effects.
Delirium	Was the onset of confusion acute? Is the patient disoriented or experiencing changes in the level of consciousness or minute-to-minute fluctuations? Is the condition reversible?	Identify underlying causes and manage symptoms; recommend behavioral therapies, including avoidance of excess stimulation, frequent reorientation, and reassurance; ensure presence of family caregivers; prescribe haloperidol, risperidone, or olanzapine. (Chlorpromazine can be used for agitated or terminal delirium, but benzodiazepines have been found to exacerbate delirium and should be avoided.)
Dyspnea	Does the symptom have reversible causes?	Prescribe oxygen to treat hypoxia-induced dyspnea or to provide symptomatic relief, when hypoxia is absent, through stimulation of the V2 branch of the trigeminal nerve. Opioids relieve breathlessness without measurable reductions in respiratory rate or oxygen saturation; effective doses are often lower than those used to treat pain. Consider anxiolytics (e.g., low-dose benzodiazepines) and use reassurance, relaxation, distraction, and massage therapy.
Nausea	Which mechanism is causing the symptom (e.g., stimulation of the chemoreceptor trigger zone, gastric stimulation, delayed gastric emptying or “squashed stomach” syndrome, bowel obstruction, intracranial processes, or vestibular vertigo)?	Prescribe an agent directed at the underlying cause. Multiple agents directed at various receptors or mechanisms may be required.
Pain	How severe is the symptom (as assessed with the use of validated instruments)?	Prescribe medications to be administered on a standing or regular basis; as-needed or rescue doses should be available for breakthrough pain or pain not controlled by the standing regimen; start a regimen to prevent constipation for all patients receiving opioids. For mild pain: use acetaminophen or a nonsteroidal antiinflammatory agent (consider opioids in older adults). For moderate pain: titrate short-acting opioids. For severe pain: rapidly titrate short-acting opioids until pain is relieved or intolerable side effects develop; start long-acting opioids (e.g., sustained-release morphine or oxycodone and transdermal fentanyl) once pain is well controlled; use methadone only if experienced in its use. Rescue doses: prescribe immediate-release opioids consisting of 10% of the 24-hour total opioid dose to be given every hour (orally) or every 30 minutes (parenterally) as needed. Concomitant analgesics (e.g., corticosteroids, anticonvulsants, tricyclic antidepressants, and bisphosphonates) should be used when applicable.

* For details of recommendations and more information about the management of symptoms, see Foley,³⁵ American Geriatrics Society Panel on Persistent Pain in Older Persons,³⁶ Luce and Luce,³⁷ Casarett and Inouye,³⁸ Strasser and Bruera,³⁹ Block,⁴⁰ and Regnard and Comiskey.⁴¹

Source: Morrison RS, Meier DE. Clinical practice. Palliative care. N Engl J Med 2004;350:2582-2590.

Part I

After a long morning of administrative meetings, Catherine Jones took a labored breath as she exited the school. Catherine served as a guidance counselor and coach of the girls' soccer team at a middle school outside Los Angeles. Earlier in the day, she had received a voicemail from her primary care physician, Dr. Alexander Steel. Dr. Steel asked Catherine to come into the office to discuss the results of a chest X-ray taken earlier in the week. Catherine, a recently engaged, 41-year-old Caucasian woman, had been experiencing shortness of breath and a dry cough with occasional blood for several weeks. Due to the demands of her job and wedding planning, Catherine had ignored her symptoms. Finally, her fiancé, Ben, persuaded her to see Dr. Steel. As she began the drive that morning, Catherine thought of her mom's sister, Beatrice, who died the previous year from lung cancer at age 65. Beatrice passed away within six months of her diagnosis.

Ben, a researcher at UCLA, met Catherine at Dr. Steel's office. Ben's research focused on neuroanatomical changes associated with Alzheimer's disease. A nurse escorted the couple to an exam room shortly after they arrived, but Dr. Steel did not join them for another 20 minutes. He offered a curt greeting and immediately began, "Catherine, I'm afraid I have some bad news. I reviewed the radiologist's report on your chest X-ray, and it appears that you have a mass in your upper left lung that is suspicious for malignancy. I'm very sorry to say that you may have lung cancer. I know this is a lot to handle. For now, I suggest that we schedule a CT scan, order some lab tests, and refer you to a thoracic surgeon for biopsy. This will help us confirm the diagnosis. And if it is cancerous, these steps will help us stage the disease. Additionally, I would like to refer you to an oncologist." Before either Ben or Catherine could process the information, Dr. Steel's beeper started buzzing. He glanced at it and mumbled, "Excuse me," as he turned toward the door.

Catherine turned to Ben and said, "How can I have lung cancer? I've never even smoked." But Catherine knew one potential cause—both of her parents were heavy smokers. She grew up fearing that their smoking habits would damage her own health. The subject had always been a source of tension within the family. "This can't be!" Catherine cried. "What if I end up like Aunt Beatrice? She suffered a horrible death. This can't be happening. Not to me."

Discussion Questions

- What are some important considerations when relaying the diagnosis of a life-threatening disease to a patient? How could Dr. Steel have improved his communication of the radiological report to Catherine?

- What are common reactions and questions to expect from patients who receive the diagnosis of a life-threatening disease?
- At this point, what may be Catherine's biggest fears?

Part II

One week later, Catherine and Ben met with the oncologist, Dr. Sarah Winter. Following an initial physical examination and history in the clinic, Dr. Winter suggested that they meet in her office, where they would be more comfortable. Dr. Winter began the conversation by asking Catherine about how she had been feeling over the past week. Dr. Winter then reviewed Catherine's clinical history and shared the results from the CT and biopsy. "Catherine, I'm sorry to tell you this, but the CT and biopsy of the primary tumor in your lung and lymph nodes confirm that you have stage IIIB non-small cell lung carcinoma. This is a relatively advanced form of the disease, with a median survival of 13 months. It's difficult to tell you this, but I need to be frank and honest. It is unlikely that our therapies will completely eliminate the cancer, but we do have numerous treatments that can help with the disease."

Catherine first asked, "How can I have lung cancer? I've never even smoked." Dr. Winter explained that substantial exposure to certain risk factors, such as secondhand smoke, may put individuals at risk for this type of lung cancer. Catherine lowered her head and shared that both of her parents had smoked her entire life. After waiting a few moments, Dr. Winter asked Catherine whether she was ready to discuss treatment options. Catherine nodded and immediately responded, "I'm going to beat this. I'll go through whatever it takes. I'm not going to give it time and end up like Aunt Beatrice." Dr. Winter learned Beatrice's story and the pain both she and her family had suffered.

Dr. Winter continued, "Your primary treatment options are surgery (pneumonectomy), chemotherapy, radiation therapy, or a combination of these. I'd like to talk about the benefits and risks involved with each therapy. We should also discuss more generally how we can ensure that the care you receive over the next few months is as close to what you would like as possible. It is important that we take into account your values, for instance, in weighing quality of life against prolongation of life as treatment options are explored."

"I don't want to talk about anything except how I can get rid of this cancer as soon as possible," Catherine interrupted.

Ben attempted to ask a few questions, but Catherine persisted, "I want to do everything possible, no matter how difficult it may be. We can discuss the rest later." Dr. Winter explained that it was her duty to explain all the options with Catherine. After they reviewed the options, Catherine reaffirmed a commitment to the most aggressive course. Dr. Winter then eased into the subject of appointing a health care proxy in the event that Catherine could not make or express decisions regarding her care.

“While this is not relevant right now, and we hope it is never necessary, I’d like for you to begin thinking about who you would want to serve as your health care proxy and what he or she needs to know about your values and wishes regarding treatment. Unfortunately, patients with stage IIIB non-small cell lung cancer are at risk for spread to the brain, which can impact their abilities to reason through and express their wishes.”

“I don’t need to go through all this now. I’m going to make it and marry Ben this coming Christmas. He is my rock and confidant. Obviously, he’s the person I trust most, and we don’t need paperwork to prove that. God is going to see us through this time.”

Discussion Questions

- How should physicians address feelings of guilt, anger, and blame? How might Dr. Winter address the fact that Catherine’s parents’ smoking may have caused her illness?
- What is the role of physicians in outlining treatment options? Is it their duty to present nonstandard treatment options that seem overly aggressive or costly but that some patients might desperately request? When, and to what extent, should physicians insert their opinions into conversations regarding therapeutic options?
- To what extent should Catherine’s unrealistic expectations be addressed?
- When is the best time to begin discussions regarding advance care planning? How should the physicians broach the subject?

Part III

After a few months of combined surgical, chemotherapeutic, and radiation treatments, a new series of imaging tests (CT and PET scans), laboratory tests, and biopsies revealed that Catherine's non-small cell lung cancer had metastasized to her brain and liver. The brain tumor was one-half centimeter in diameter, although Catherine did not yet exhibit any impaired cognitive functioning. Catherine's blood tests revealed elevated AST, ALT, and bilirubin levels—her skin now had a slightly yellowish tinge. Recently, she had been finding it increasingly difficult to breathe.

After consulting with the radiation oncologist, Dr. Winter presented Catherine further treatment options. "Catherine, unfortunately your cancer has progressed to stage IV and appears to have spread to your brain and liver. Surgery is not going to be possible, but we can try steroids or whole brain radiation. Whole brain radiation may add three to six months to your life, but there are numerous side effects, including fatigue, nausea, and hair loss. Some side effects are potentially more serious, such as cognitive impairment. I would suggest that you take your time to make a decision. Also, I do think that we need to know who your health care proxy is at this point. I would also like to discuss with you some of the palliative care services that we offer. Palliative care is a service that helps you manage your pain and other symptoms in conjunction with your current treatments. The service involves an interdisciplinary team that will also help address your psychological, social, and spiritual needs and aim to improve your quality of life in the coming months." Catherine, however, refused to consider the possibility that she would not survive the cancer. She insisted that Dr. Winter schedule immediate whole brain radiation in combination with any and all other measures.

Before the couple left her office, Dr. Winter once again suggested that they consider their treatment options and advance care planning. Catherine reiterated her desire to move forward. "I'm not going to take any chances and end up like Aunt Beatrice."

Catherine underwent several courses of whole brain radiation.

Discussion Questions

- When, if ever, should a doctor refuse to offer aggressive treatments?
- Should cost factor into a physician's decision-making as a patient nears the end of life? If so, distinguish the ways in which caring for the terminally ill may be unique.
- How can the physician address the suffering of the patient?
- How should physicians respond when patients avoid engaging in conversations regarding advance care planning?

Part IV

About a week after beginning whole brain radiation, Catherine became confused and agitated during dinner one night. She eventually began coughing violently and had severe trouble breathing. Ben rushed her to the hospital, where her laboratory tests and X-ray indicated extensive pneumonia. When the chief resident on service brought up the issue of “code status,” Catherine did not appear to comprehend the situation; she seemed bewildered and could not express her wishes. Distraught and upset, Ben immediately called Catherine’s parents to share the unfortunate news. They rushed to the hospital, where they met with the chief resident. He began, “Catherine may stop breathing on her own any minute. We don’t have any documented or clear wishes from her. What would she want us to do?” Dr. Winter was flying back from a conference and unavailable for consultation. While it hurt Ben to watch Catherine endure the suffering, he knew that she wanted this fight. She would want ventilator support and any other necessary life-sustaining measures. But since Catherine never officially designated a health care proxy, her parents were the default proxies by law.¹ When he was informed of this, Ben became infuriated and pleaded for decision-making authority.

“Catherine and I have been living together for five years, and we’re getting married in a few months. I know her better than anyone else in this world. Dr. Winter knows that, too. I’ve been to every appointment she’s ever had. Her parents barely know her.” While the doctor sympathized with Ben, he made it clear that Catherine’s parents retained authority at present. Catherine’s parents did not want her to suffer any further and rejected potential life support, remarking that the cancer was not going to be cured anyway. Her mother believed that this event may have been a “blessing in disguise.” Ben continued to argue that this was not what Catherine would want but rather what her parents desired.

Fortunately, Catherine recovered from the pneumonia and returned to a stable state. At this time, she agreed to engage in a discussion with her health care providers and Ben on future services that she may need. After Ben was named the official proxy and Dr. Winter returned, she focused on educating both of them about palliative and hospice care. After hearing all the options, Catherine agreed to receive palliative care services and reevaluate her treatment plan. The benefits were significant. With the treatment of her pain and shortness of breath, Catherine was happier and more active. In addition, the program helped educate Ben to build a supportive environment for his

¹ The reality in California and most other states is more complex. Since Catherine is over 18 years old and has communicated her values to Dr. Winter and likely other doctors involved in her care, how to proceed would probably be less straightforward and require more discussion and thought. For the purposes of this case, though, we have simplified the scenario and chosen a potential outcome.

fiancée. A hospital chaplain was consulted who engaged Catherine and Ben in several meaningful conversations regarding their deepest beliefs, questions, and fears.

Catherine expressed her ultimate wishes to Dr. Winter. “I want you to do everything possible, regardless of what I can communicate at any stage. I hope that I survive, but if it’s not in God’s will for me to live, I have one request: I want to marry Ben in our backyard, just like we’ve always planned.”

Discussion Questions

- How might events have unfolded if Catherine, Ben, and her physicians had engaged in advance care planning at an earlier stage?
- What are potential problems with Catherine’s parents issuing an order that Catherine should not be resuscitated?
- Are there instances in which it would be ethical, if not morally obligatory, for a health care provider to violate the wishes of his or her patient or that patient’s proxy?

Part V

Three weeks later, Catherine's condition worsened. Lab tests demonstrated increasing hepatic failure, and she was extremely confused and agitated. She also seemed to be in pain. In the emergency room, Dr. Winter told Ben, "Unfortunately, our best efforts have not succeeded in combating the cancer. At this point, I would recommend that we transition to focusing on treating her pain and symptoms and enroll Catherine in a hospice care program. She probably has a few days to weeks left. I'm so sorry."

Catherine opened her mouth to speak, but no words came out; it was clear that she did not understand Dr. Winter. Ben's face collapsed in his hands, and Dr. Winter left him alone with Catherine for a few minutes. When Dr. Winter returned, Ben asked, "How can we bring her home to let her enjoy the last few days of her life? Our wedding is supposed to be in four weeks, but we can move it up to this weekend. That's all Catherine wants—for us to get married in our backyard before she dies." Dr. Winter explained that Catherine had good health insurance through the school system. It would pay for hospice care, but that would require forgoing all curative treatment.

The hospice team began treating Catherine with vigorous medication to reduce the elevated toxins in her blood—a consequence of her liver failure—so that she could be awake and aware. Within 48 hours, Catherine was awake and able to interact, although she still suffered moments of confusion and other signs of cognitive impairment. She did, however, continue to remind everyone that her only wish was to marry Ben. Catherine's parents remained at her side during this period, and the conflict over their smoking dissipated. They benefited from the guidance of the bereavement counselor as Catherine's death neared.

With Catherine lying in her bed, the couple wed in their backyard. She was joyful about the marriage. Catherine died three days later.

Discussion Questions

- What are the roles of palliative and hospice care in end-of-life care?
- What are the consequences of Medicare's policy to provide hospice care only after a patient elects to forgo further treatment?
- What is the hospital chaplain's role in health care? How should the hospital chaplain discuss and respond to patients' religious beliefs and questions?
- How did advance care planning help Catherine and her family?

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