

Virtual Mentor

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Medicine's Role in the "Good Death"

From the Editor

- Dying in the Twenty-First Century** 1013
Sophia Cedola and Kenneth Prager

Educating for Professionalism

Ethics Cases

- Integrating Palliative Care with Disease-Modifying Therapy** 1017
Commentary by Craig D. Blinderman
- When Physicians and Surrogates Disagree about Futility** 1022
Commentary by Kenneth Prager
- Medical Students and Dying Patients** 1027
Commentary by Audrey Tan

Medical Education

- The Flipped Classroom Paradigm for Teaching Palliative Care Skills** 1034
Vyjeyanthi S. Periyakoil and Preetha Basaviah

The Code Says

- AMA Code of Medical Ethics' Opinions on Care at the End of Life** 1038

Journal Discussion

- Physician Characteristics Influence Referral to End-of-Life Care** 1041
May Hua

State of the Art and Science

- Serious Illness Communications Checklist** 1045
Rachelle E. Bernacki and Susan D. Block

The Appropriate Use of Increasingly Sophisticated Life-Sustaining Technology	1050
Darryl C. Abrams, Kenneth Prager, Craig D. Blinderman, Kristin M. Burkart, and Daniel Brodie	

Law, Policy, and Society**Health Law**

Legal Constraints on Pursuit of a “Good Death”	1056
Richard Weinmeyer	

Policy Forum

Legislative Attempts to Improve End-of-Life Care in New York State	1062
Beth Popp	

Medicine and Society

Whole-Person, Whole-Community Care at the End of Life	1069
Christina Staudt	

Treatment of Terminally Ill Patients According to Jewish Law	1081
Rabbi Dov Linzer	

History, Art, and Narrative**History of Medicine**

When Medicine Is Powerless	1088
Thomas W. Laqueur	

Resources

Suggested Readings and Resources	1092
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About the Contributors	1110
-------------------------------	-------------

Upcoming Issues of *Virtual Mentor*

January: Ethics and Technology for Assisting Reproduction
February: Unwarranted Variations in Health Care
March: The Problem of Mistreatment in Medical Education
April: Third Parties in the Clinical Encounter

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LETTER FROM THE EDITOR Dying in the Twenty-First Century

It hath often been said that it is not death, but dying, which is terrible.
–Henry Fielding, *Amelia*, 1751

There is an appointed time for everything. A time to give birth and a time to die.
–*Ecclesiastes* 3:2

Every living thing dies. Because of the mystery of this event, humans throughout history have created cultural and religious rituals surrounding the dying process and post-death period. Songs may be sung, texts read, prayers chanted, incense lit, special clothes donned. The *Oxford English Dictionary* defines “ritual” as “a religious or solemn ceremony consisting of a series of actions performed according to a prescribed order” [1]. The United States system of medical care has developed death rituals of its own as medical technology has evolved, particularly in our hospitals and intensive care units. These rituals are characterized by increasingly aggressive medical interventions that too often serve only to prolong the dying process. Even following cessation of a patient’s heartbeat and respiration, we routinely attempt resuscitation of everyone who does not have a documented do-not-resuscitate (DNR) order, regardless of that patient’s diagnosis or chance of recovery.

It has become increasingly clear to many physicians and laypersons over the years that these medical interventions for the dying too often have no medical rationale and may in fact violate a cardinal principle of medical ethics: first, do no harm [2, 3]. In these cases, patients are often subjected to invasive and painful procedures that are of no medical benefit and that rob them of the dignity and peace that we all wish for ourselves when our time to die has come.

Due to these ethical concerns as well as to patient [4], family [5], and clinician [6] dissatisfaction with U.S. end-of-life (EOL) standards of care, our culture has been undergoing a change. We are rethinking whether CPR should be the default standard of care for every dying patient [7]. We are searching for ways to spare patients inappropriate aggressive treatment wanted by well-meaning and desperate relatives during what is clearly the dying process. We are trying to refine our medical judgment and prognostic skills so as to employ sophisticated technology only when appropriate to stave off death. Above all, we are seeking to train young doctors to help patients and their families navigate the dying process in a way that upholds the dignity of the patient and ensures that he or she experiences the highest possible *quality* of life until the end.

As proof that society perceives deficiencies in end-of-life care, laws and court decisions now require certain patient-physician interactions pertaining to it [8-10], a circumstance that is rare in medicine. Although our profession is trying to ensure better care for terminally ill patients (and their families), physicians too often poorly navigate the difficult and complex ethical situations that arise. This has led to legislation in New York and California mandating that physicians offer palliative and hospice care to all terminally ill patients [8, 9]. One of the goals of our profession should be universal familiarity with, comfort with, and training in palliative care among doctors so that we offer the best possible care without the need for legislation to dictate our practices.

Thankfully, we are moving in that direction. Palliative care has been shown not only to improve patient quality of life [11-14] but also to increase the value of medical care (the quality-to-cost ratio) [15, 16]. The number of hospitals offering palliative care has increased from more than 600 in 2000 to more than 1,600 in 2010 [17], and this number continues to grow.

This issue of *Virtual Mentor* discusses end-of-life ethical issues that we believe all physicians should have an awareness and understanding of. One theme of the issue is the distinction between palliative care and end-of-life care. The Center to Advance Palliative Care defines palliative care as “specialized medical care...focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family” [18]. Palliative care can and should be offered to terminally ill as well as non-terminally-ill patients, and, contrary to popular belief, palliative care can be given in conjunction with curative medical interventions. Our contributing authors also explore innovations in teaching end-of-life topics, religious dictates concerning EOL decisions, the moral questions raised by treating patients with increasingly sophisticated medical technologies at the end of their lives, and the history and future of this field.

A single journal issue can only scratch the surface of the ethical complexities involved in end-of-life care with patients and their families. We suggest not only reading the articles within this issue but also consulting the suggested readings list.

Our hope is that exposure to and comfort with palliative care come to be seen as essential for all medical school graduates. Any physician involved in patient care will almost certainly encounter patients who are dying. Dermatologist, pediatrician, cardiac surgeon, or psychiatrist, whether or not you are the physician in charge, you should have the ability to listen to dying patients, attend to their needs, and help them assess their goals of care. Furthermore, physicians and other health care professionals are often approached by acquaintances for advice on how to relate to friends and family members who are dying. In these instances we have the opportunity to offer constructive suggestions that can contribute to a better societal understanding of the proper roles of medical treatment and palliative care in end-of-life situations.

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ETHICS CASE

Integrating Palliative Care with Disease-Modifying Therapy

Commentary by Craig D. Blinderman, MD

Mr. James had been a heavy smoker most of his life. At 76, he had moderately severe chronic obstructive pulmonary disease (COPD) and coronary artery disease, and he had been feeling weak and coughing for several months. When he began to cough up blood his son took him to the emergency room, where a chest x-ray showed a speculated 3-centimeter right upper lobe mass and enlarged mediastinal nodes. Mr. James was admitted to the hospital. A positron emission tomography (PET) scan showed both the mass and the nodes to be highly reactive. A needle biopsy of the mass showed poorly differentiated adenocarcinoma (non-small cell cancer) that was stage III-B.

Mr. James's tumor did not have any of the mutations that would have enabled him to be treated with targeted therapy, so he was offered standard chemotherapy with cisplatin and paclitaxel. After two rounds of chemotherapy he began to feel slightly better. He had more energy and was no longer coughing up blood. His three children and their families had been a constant source of support; everyone tried to be optimistic, hoping that a remission would last for many years. But within 2 months, Mr. James began to notice back pain.

His first follow-up computed tomography (CT) scan revealed that, despite the chemotherapy, the tumor mass in his right lung was larger and the cancer had metastasized to his ribs and spine. The oncology resident on Mr. James's care team, Dr. George, had the responsibility of delivering this news to Mr. James and his family. Dr. George was aware of studies that had found associations between early referral to palliative care services and improved quality of life.

So, when he met with Mr. James and his family, Dr. George explained that the cancer had metastasized to Mr. James's ribs and spine. He said that, if chemotherapy were to continue, different agents would be needed and that radiation was indicated for the areas of Mr. James's spine that showed evidence of cancer. Dr. George introduced palliative care by saying, "I would also like you to talk to the staff in our palliative care service."

"Wait, what?" exclaimed Mr. James's daughter. "We've barely started fighting this thing and you want us to give up? You want us to just let him die? To help him die faster?" Murmurs and exclamations from the family followed. "No. No way. We're not going to let them pull the plug, Pops. We're going to fight this, and we're going to win."

Dr. George was unsure of how to proceed. He believed the sooner palliative care measures were started, the better off Mr. James would be. At the same time he wanted to assure the family that he wasn't "giving up" on Mr. James.

Commentary

This case addresses the common—and challenging—issue of when and how to bring up referral for palliative care services to patients with serious illnesses, such as class-IV heart failure, end-stage chronic obstructive pulmonary disease, or, in this case, advanced, incurable lung cancer.

Palliative care attends to the physical, emotional, and spiritual condition of patients and their families. Research has consistently shown that cancer patients experience high symptom burden (e.g., pain, lack of energy, difficulty sleeping) associated with poor quality of life [1, 2] and have significant psychological distress [3, 4]. Families of patients with cancer also experience a high degree of emotional and psychological distress [5]. It would, therefore, seem appropriate that care dedicated to the alleviation of patients' symptoms be integrated early in the disease course to decrease the level of suffering experienced by patients and their families.

While multiple studies have shown the benefits of palliative care services on symptom distress and quality of life, physicians may feel that merely mentioning the words "palliative care" to patients and families suggests that the patient's life is nearing its end, that palliative care hastens death, or that a referral to palliative care is a sign that we are "giving up" and the best we can hope to do is simply treat the patient's pain and symptoms. In addition, some physicians may believe that a referral to palliative care is only appropriate when "there is nothing more that we can do." This dichotomous construct—that the patient can receive *either* disease-modifying therapy *or* palliative care—is incorrect. Palliative care should be integrated with disease-modifying therapy, regardless of prognosis or the success (or failure) of disease-specific treatments.

The most important study to date demonstrating the benefits of palliative care in advanced lung cancer patients [6] has recently led the American Society of Clinical Oncology to update its guidelines—with a provisional recommendation that patients with metastatic or advanced cancer be offered concurrent palliative care and oncologic care starting at initial diagnosis [7]. In this landmark study by Temel et al., 151 patients with stage-III-B or -IV adenocarcinoma of the lung were randomly assigned to receive either standard oncologic treatment or standard oncologic treatment and outpatient palliative care visits initiated at the time of diagnosis. Patients who received early-intervention palliative care experienced better quality of life and lower rates of depression, and, despite receiving less "aggressive" end-of-life care (32.7 percent versus 53.6 percent, $p=0.01$), survived longer than those assigned to usual care (11.6 months versus 8.9 months, $p=0.02$).

In addition, patients who received early palliative care were less likely to be hospitalized (55 percent standard care arm, 38 percent palliative care arm) and less

likely to die in the hospital. They had increased referral to hospice, increased length of stay in hospice, and were less likely to receive chemotherapy close to death. Another study, using a retrospective statistical analysis on selected cohorts from large databases of Medicare beneficiaries with cancer and congestive heart failure, showed a similar survival benefit for patients who received hospice services. Patients enrolled in hospice had a mean survival of 29 days longer than patients who were not ($P=0.08$) [8].

In my own clinical experience, palliative care services are most beneficial when they are integrated early in the disease course. Indeed, the coordination of care and collaborative relationships that result from early involvement of palliative care services positively impact the entire care team, as well as the patient and family.

So how can we improve referral to palliative care services while patients are receiving disease-modifying therapy? One strategy is to introduce palliative care services “as an extra layer of support” at the time of initial diagnosis of advanced cancer or other life-limiting condition (assuming an appropriate level of palliative care outpatient services is in place). Another strategy is to identify a set of criteria or “triggers” to alert the primary clinician that palliative care services should be offered as a matter of best medical practice when the patient is found to have a high symptom burden or difficulty coping with the diagnosis, prognosis, or treatment plan.

A self-administered screening tool to assess unmet palliative care needs and patient distress can be implemented at each visit. Appropriate tools for this function are the Edmonton Symptom Assessment System (ESAS), the Memorial Symptom Assessment Scale (MSAS), or a disease-specific quality of life measurement tool (e.g., FACT-L for lung cancer patients). A cutoff score suggesting significant distress or poor quality of life (e.g., rating 5 or more symptoms as being moderate to severe on the ESAS) can be identified prior to implementing such measurement tools, and a score above the cutoff score could trigger a referral to palliative care. The oncologist can then simply say the following: “Given the number and severity of symptoms you are experiencing, I would like to refer you to our palliative care service. They have the expertise to focus on improving your symptoms and can help you and your family best cope with all the stress of living with advanced cancer while I continue to find ways to treat the tumor.”

Indeed, the Center to Advance Palliative Care (CAPC) has led the way by providing a comprehensive definition of “palliative care” cognizant of the phrase’s connotations. Palliative, after all, is related to the Latin word *palliare*, “to cloak.” After testing it with focus groups, CAPC has offered the following definition, which may help both clinicians concerned about referring their patients to palliative care and patients and families, who may misunderstand what palliative care is and how it may be helpful to them:

Palliative Care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support.

It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment [9].

This definition, which accurately characterizes the role of palliative care, is certainly far from “giving up,” and does not imply that “there is nothing more we can do.” Indeed, it provides the kind of medical attention patients and their families expect and deserve.

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ETHICS CASE

When Physicians and Surrogates Disagree about Futility

Commentary by Kenneth Prager, MD

Mrs. Smith was 46 when she suffered a cardiac arrest at home. Her 20-year-old daughter was with her at the time and called 911. Mrs. Smith was resuscitated by the paramedics and rushed to the nearest hospital, but had suffered severe loss of oxygen to the brain during the episode. She was admitted to the intensive care unit (ICU) and required intubation and mechanical ventilation. An EKG revealed that Mrs. Smith had long QT syndrome, which her daughter said had never been diagnosed. Her daughter insisted that “everything be done” for her mother.

After 2 months in the ICU, Mrs. Smith’s brain functioning had not returned or shown improvement; she had not awakened or been conscious of where she was or who was in the room. Mrs. Smith’s care had been complicated by infections from the intravenous lines into and from her body, kidney failure and the need for dialysis, and worsening heart function that required an intra-aortic balloon pump. Her physicians judged that further treatment would be futile; it was highly unlikely that Mrs. Smith would leave the hospital alive, or, if she did, it was likely that she would return within days or weeks. Mrs. Smith was too sick to be placed in an outpatient center and remained in the medical ICU.

The medical team, treating complication upon complication, believed they were not helping Mrs. Smith heal in any way. They felt that continuing aggressive treatment violated medicine’s fundamental “first-do-no-harm” precept. When end-of-life care measures such as comfort care, withdrawing treatments, or assigning do-not-resuscitate status to Mrs. Smith were suggested, her daughter became extremely upset, saying “My mom gave me life, how can I take hers away?” At one point her daughter broke down and said, “I would rather visit my mom in the hospital than in the graveyard.”

Commentary

The tragic case of Mrs. Smith illustrates an all-too-common ethical dilemma facing doctors in ICUs throughout the country. Seeing the daughter visit her mother daily, stroking her hair and kissing her, only the most hard-hearted individual could fail to be moved and feel empathy for this young woman whose most beloved person is lying unresponsive in an ICU bed with no chance of recovery.

And yet...

Medical technology has advanced to the point where it is getting more and more difficult to die in an ICU. We have machines that can replace failing hearts, lungs, kidneys, and the gastrointestinal tract. More potent antibiotics can treat myriad infectious agents. Sophisticated monitors enable physicians to maintain physiologic homeostasis in the most unstable of patients. These interventions are a godsend when they can help patients recover from devastating illnesses and injuries. But the flip side is that they can prolong the dying process for weeks or months in patients with no hope of recovery. The human and material resources expended can be enormous, and the emotional effect on clinicians who feel their professionalism compromised is significant.

The problem of what many would consider the misuse of sophisticated medical technology to prolong suffering and the dying process will almost certainly get worse as the tidal wave of baby boomers advances into old age in the next 2 decades, and the development of ever-more-powerful and -expensive medical technology continues. As the sad case of Mrs. Smith illustrates, there are no easy answers to this ethical dilemma, and both sides have compelling arguments.

“Medical Futility”

Not infrequently one reads in the medical record of a patient like Mrs. Smith: “further treatment is medically futile.” Although the statement makes a powerful declaration, implying that further treatment is inappropriate and even misguided, the statement is meaningless out of context. An action cannot be considered futile unless its goal is clearly stated. Continued ICU treatment of Mrs. Smith is indeed futile if its goal is to have her recover mentally and physically. If the goal of continued ICU treatment, however, is to keep her alive as long as possible, such treatment is anything but futile. From the viewpoint of the physicians who have in mind restoring the patient to a state of consciousness and medical stability, treatment is futile; from the daughter’s viewpoint it is extremely effective in realizing her goal of keeping her mother alive as long as possible.

Ethical Issues: Multiple Perspectives

From the perspective of Mrs. Smith’s daughter, patient autonomy is clearly an issue. When patients or their surrogates exercise autonomy by asking that treatments be limited and even that life support be withdrawn, physicians are unlikely to object, assuming that the reasons for these requests are reasonable. However, when patients exercise that same right of autonomy to make what are often perceived as unreasonable demands for “futile” interventions, physicians react differently. Patient autonomy must be respected not only when patients wish to limit their end-of-life care in accordance with a physician’s recommendations but also when they do not. Defining “reasonable” and “futile” is often difficult, based on values that may not be shared between physicians and their patients. This can lead to anger, distrust, misunderstanding, and failures of communication between the medical staff and families.

The point of view of physicians is very different. When physicians are asked by patients or their families to provide aggressive treatment in situations deemed futile for meaningful recovery, they often feel that they are violating the ethical mandate to avoid maleficence by contributing to their patients' suffering and violating their dignity. Clinicians "may feel distress at the lack of trust from the family and the fact that the family is not willing to follow their recommendations for withholding or withdrawing life support" [1]. In addition, physicians in these situations develop "feelings of distaste and even repugnance that administering such treatments without reasonable prospect of success amounts to the infliction of physical abuse on dying...people" [1].

In many cases, such as that of Mrs. Smith, however, there is no evidence that the patient *is* suffering. Such patients are often totally unaware of their surroundings because of brain damage or are sedated and narcotized for the sole purpose of sparing them the suffering that physicians invoke as a reason to withhold further treatment.

As for the physicians' claim that they are depriving hopelessly ill patients on life support of their dignity, this is a question for families to decide; different people have different notions of human dignity based on individual, cultural, and religious values that may not be shared by the treating physicians. "Families live with memories of the death of a loved one for years; certainly their religious, cultural, and personal preferences during that process should be honored, or at least tolerated, whenever possible" [2].

Physicians often cite the waste of costly medical resources as ethical justification for withholding life support technology from ICU patients who are clearly dying. However this argument loses force when monetary analysis of the savings to be had from withholding treatment from such patients fails to show that a dent would be made in the \$2.7 trillion U.S. medical budget. "Even if life support were consistently denied to patients whose situations met common definitions of futility, the monetary savings would be trivial" [3].

Is Legislation the Answer?

Physicians have been grappling with the issue of so-called medical futility for decades [4]. Not only has there never been an agreed-upon definition of this term, but only one state, Texas, has enacted legislation allowing physicians to unilaterally withhold or withdraw treatment in such cases with legal protection [5]. That there is not a consensus on how to define or deal with this issue, either in the medical community or in state legislatures, attests to its complexity and sensitivity. Legislators are understandably loath to grant physicians the power to make life-and-death decisions for patients against the wishes of their families. In addition, the U.S. population's diverse views and values on all matters, including death and dying, make it virtually impossible to create a national policy that would be acceptable to the vast majority of Americans. Lastly, the "can-do" attitude of Americans facing all sorts of challenges has given rise to an approach to sickness that some wags have

characterized as an American belief that “death is an option,” to be combated if one chooses, rather than an inevitability.

The absence of consensus on medical futility does not mean there is no appropriate way for physicians to handle this problem. They should do so with empathy, expert clinical judgment, skillful communication, and patience. This approach does not always enable physicians to persuade families to see things their way. But it is our only resource.

What is clearly *not* ethically acceptable is for physicians to withhold, withdraw, or in other ways modify their treatment of a hopelessly ill patient without the knowledge (and, except in Texas, consent) of the patient’s family. This is unacceptable deception. This does not mean that every conceivable intervention must be offered. On the one hand, it would be wrong to withhold from the family the fact that their loved one is developing renal failure in an attempt to avoid the question of dialysis; on the other hand, dialysis need not be offered if the clinical situation makes such an intervention medically inappropriate. This is a nuanced area and, once again, the definition of “inappropriate” might differ in the eyes of physicians and family. How to phrase this information is a skill that experienced and empathic physicians should learn. Optimally, the physician can take the burden of deciding against dialysis off the shoulders of the family, if they allow it.

Finally, there are many different scenarios that fall within the overall category “futility.” In the case of Mrs. Smith, the patient was not suffering, her daughter was sincerely involved in her care, and one can easily empathize with her desire to hold on to her mother as long as possible. But supposing Mrs. Smith had a daughter who was estranged, who flew in from afar to see her mother once, demanded that “everything” be done to keep her mother alive as long as possible, then left and was unreachable while complications kept recurring? Supposing Mrs. Smith had a huge and deep sacral decubitus, winced every time her wound was changed, developed severe anasarca, required multiple courses of pressors and antibiotics for recurrent episodes of sepsis, and was completing her fourth month in the ICU?

Clearly the latter two scenarios would try the patience and empathy of the most saintly physician—and rightly so. There is always the possibility of legal recourse, although most hospitals are loath to invest the time and expense to use this approach. There is no easy answer for cases in which the family seems not to be acting in good faith or in which patient suffering appears to be uncontrollable. But these cases are relatively uncommon and would not seem to warrant legislation giving physicians unilateral power to withhold or withdraw treatment *in all* cases of perceived futility.

The Future of EOL Decision Making

The coming decades will present formidable ethical challenges concerning hopelessly ill patients being kept alive at their families’ insistence with ever more sophisticated, powerful, and expensive technologies. The context in which these

challenges will play out has evolved as the role and the authority of the physician has changed. Eric Wold summed up this evolution nicely:

With medical information much more readily available through the internet and other media sources, physicians' authority and, similarly, the respect with which we are viewed by the public may have less to do with our clinical judgment...and more to do with our ability to participate in medical decision making as one voice among many. Although some may mourn the day when physicians were held in such esteem that they could consider unilaterally denying care, such regret misses the point of larger social changes that go to the very heart of the way in which physicians' authority is constructed. The better question is not, "What do doctors think is appropriate," but simply, "How can doctors share their wisdom?" [6].

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Virtual Mentor

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ETHICS CASE

Medical Students and Dying Patients

Commentary by Audrey Tan, DO

Kelsey is a first-year medical student in her second semester. One of her classes focuses on bedside manner. The purpose of the course is to give students time to speak with patients and understand their perspectives—their knowledge, hopes, and fears. Kelsey and a few of her classmates are assigned to a hospice, where each spends time talking in a nonmedical capacity with a patient.

In the previous semester, the students heard lectures on how to take histories from different types of patients (e.g., children, the elderly) and on special topics (e.g., cultural sensitivity and end-of-life care). Kelsey had had one lecture about talking with the elderly and one lecture about end-of-life issues and options before her first visit to the hospice.

On one trip, Kelsey was assigned to spend time with Mrs. Walsh, an amiable 70-year-old woman who had entered hospice care 2 days earlier. Mrs. Walsh's chart said that she and her family members had elected to discontinue chemotherapy, which was making her feel terrible and not having any effect on her cancer, which had metastasized to her spine and lungs. Mrs. Walsh had a do-not-resuscitate (DNR) order in place. The visit was going well: Mrs. Walsh was talking happily about her husband, her children, and her grandchildren. Then Mrs. Walsh related her struggles with cancer and the decision to enter hospice care. Next Mrs. Walsh began to talk about facing mortality and said she was frightened about how she would die. She was not sure what the end would be like for her and questioned whether hospice was the right choice, though she was not really sure what would have been a better choice.

Throughout this time, Kelsey remained quiet. She wanted to empathize with Mrs. Walsh, to encourage her to continue thinking about these tough topics, and to ask questions that would help Mrs. Walsh flesh out her own ideas. She wanted to talk about the other options (not having a DNR order, receiving aggressive treatment, dying in an ICU on a ventilator) in ways that might remind Mrs. Walsh why she and her family had chosen hospice care in the first place. But Kelsey didn't know whether she was allowed to enter into this type of conversation with a patient—she'd barely begun her medical training, after all.

Commentary

The end of life (EOL). The dying process. Most physicians grapple with caring for patients during this period in their lives, marked by personal conflict, unfamiliarity, and anxiety.

For physicians, death is often seen not as an inevitable event and a natural process but instead as a medical failure. The doctrine that “saving lives” is the ultimate goal of medical care is one that is transmitted beginning early in training and traditionally continues through residency and into clinical practice. Put simply, overcoming death is success in the medical world. Physicians spend 4 years learning the ins and outs of this process—the medications, the procedures, and the technology focused on evading death. Once death is near and medical interventions have reached their limit, doctors often find themselves lost and uncertain about how to proceed, feeling inadequate and, at times, even experiencing a sense of dishonor and guilt about the death of a patient.

In an article on physician learners’ perceptions of death, first-year medical students were asked to anticipate their feelings after the death of their first patient [1]. One said, “I’m going through all of this training only to stand around and watch/help someone die” [1]. Another,

I feel afraid that I will not have the knowledge I need in order to save the life of a patient.... I am afraid I will need to tell family members of the unexpected death of a loved one.... I am afraid of what my colleagues will think and I wonder will they continue to trust me as a doctor [1].

Even the most highly revered humanist physicians describe discomfort about caring for a dying patient. Abraham Verghese candidly writes of his discomfort with death, undoubtedly expressing the sentiments of many other physicians.

I had always felt inept when a patient was near death.... Give me a patient with massive gastric bleeding or ventricular fibrillation and I am a model of efficiency and purpose. Put me at a deathbed, a slow dying, and purpose is what I lack. I, who till then have been supportive, involved, can find myself mute, making my visits briefer, putting on an aura of great enterprise—false enterprise. I finger my printed patient list, study the lab results on the chart, which at this point have no meaning. For someone dealing so often with death, my ignorance felt shameful [2].

The fear, unease, and helplessness described in these passages are undeniable.

The end of life is also unpredictable. In the evolving world of standardized medicine, algorithms and scores and clinical guidelines have become commonplace. There are the Rivers protocol for sepsis, the MELD score for liver failure, and the NEXUS

criteria for diagnosing cervical spine injuries. But, although there are general guidelines, there are no set standards to help physicians navigate dying with a patient and family. One patient may opt for continued parenteral nutrition in the hopes of living until her daughter's college graduation. Another patient may opt to discontinue all aggressive measures immediately if it means spending another day in the hospital away from his wife. It is a poignant, individualized process that requires delving into the more personal side of patients' lives, including their hopes, goals, and values. This is an uncomfortable place for most physicians.

And, finally, there is the personal anxiety that physicians experience around death. Doctors' fears, thoughts, and concerns surrounding death, a term coined "death anxiety," preclude many from speaking frankly and honestly with patients. This can "impair the display of empathy on the physician's part.... [The] physician's fears may be displayed in physician's gestures and postures, which may influence the proper communication" [3]. What is even more concerning is that, according to studies, a personal fear of death may discourage inexperienced medical professionals from breaking bad news to patients [4]. Doctors' own apprehensions may impede the provision of optimal care.

These are the issues that arise for seasoned physicians encountering death, and they are certainly magnified in a newly white-coated medical student such as Kelsey. Despite this, she senses that Mrs. Walsh is looking for support as she navigates the remainder of her life. Understandably, Mrs. Walsh has questions, concerns and apprehensions, but Kelsey is confused about how she is to help her through this process. Is she allowed to enter this conversation? What are the goals? As a learner, what are her boundaries?

There are two pieces to supporting a patient like Mrs. Walsh during the dying process. The first is the exploratory piece—eliciting fears and concerns, walking alongside the patient—inviting Mrs. Walsh's full participation in the process. The second is the supportive piece. This is the part during which physicians allay fears, provide information, and support the patient through this journey. "Communication can be a route to finding meaning in death and to making and deepening connections with the living" [5]. During the dying process, Richard McQuellon and Michael Cowan explain [6], "conversation is the bridge that permits professional and family caregiver to join in the experience of living-toward-death" [7]. By engaging in conversation with Mrs. Walsh, Kelsey can help her glean life-enhancing meaning and value from a situation in which many find only despair.

This is much more easily said than done, and, although Kelsey senses the need to talk to Mrs. Walsh, doing so can be difficult. The first step in conversing with patients near death is allowing oneself to "go there." For professional caregivers, family members, spiritual care chaplains, or any caregiver, this is often the most challenging part. To many people, the topic of death is to be avoided [8], and even hospice nurses have admitted to diverting conversations away from concerns about illness or feelings because they did not know what to say, felt inadequate or

intrusive, or did not want to upset the patient [5]. For physicians and physician learners, recognition and acceptance of this discomfort is a critical first step.

After these reservations are acknowledged, physicians must recognize the difficult but important task of moving forward and creating the space that makes it easier for patients to enter this difficult conversation. The best way of doing so, oftentimes, is just sitting with the patient. “Conversation is more than exchanging words; sometimes all it requires is silent, attentive presence” [9]. Beyond simple presence, Patricia Thompson writes that “you must try to go where the patient is mentally...on a street corner waiting for the trolley rather than in a nursing home, if necessary. Inquire about the patient’s past. Empathize with the patient’s feelings even if you have to throw reality out the window” [10]. As is taught during introductory classes of medical school, open-ended questions directed at comprehension and expectations are helpful. “Mrs. Walsh, what is your understanding of your disease?” “What are your hopes and concerns for the remainder of your life?”

Physicians must realize that patients in “mortal time,” the psychological state human beings enter when confronted with the prospect of death [6], move back and forth from everyday coping to thoughts and feelings about their impending death. Coping is a dynamic process with peaks during which acceptance predominates and valleys during which questions, worries, fears, and doubts predominate. Patients may vacillate between the two, the peaks or valleys may predominate, or patients may be elsewhere, a place where they need time and space to gain footing as they grapple with their diseases.

The power of embracing this process of exploration and conversation is very eloquently described by McQuellon and Cowan:

Whatever the details of a fatal illness, and however great the differences in backgrounds, roles and responsibilities of those communicating about it, authentic conversation has the power not only to enhance how people cope practically with dying, but to illuminate and enrich the very meaning of life for patients and caregivers alike as they enter the sacred moment of mortal time together. The terrifying and liberating paradox of mortal time is that in order to tap the depth of meaning available to those facing death together, we must embrace what we mortals fear and ordinarily avoid with every fiber of our being. We must turn toward death together [11].

This is the extraordinarily powerful piece that Kelsey can certainly partake in with Mrs. Walsh.

The second portion of this process is providing guidance. Mrs. Walsh wants to speak about this process but she is also searching for direction and support. She has doubts which require thoughtful guidance. Though these two steps are certainly not separate

processes, they are divided for the purpose of delineating roles for a physician learner.

This is the role that requires experience and clinical knowledge. It is a complex process. As a clinician, your goals in this context are many and include affirming that you will not abandon the patient or patient's family, informing the patient about the pros and cons of further aggressive disease-modifying treatments, exploring advanced directives, and discussing palliative care options including aggressive pain and symptom management, all communicated in a compassionate and kind manner.

How will Kelsey be trained to do this?

Medical school training in caring for patients at the end of life is evolving slowly. Although the necessity of teaching end-of-life care in medical school curricula has been established, educators continue to struggle to find the optimal means and venues for teaching these skills. Currently, most of EOL education occurs in the preclinical years, often in the form of lectures focused primarily on knowledge, including the legal aspects of advance directives, the key topics of palliative care, and the basics of skillful communication, rather than skills and attitudes [12]. These lectures are useful in laying the groundwork for quality EOL care, but, just as with most other skills, formal instruction must continue within the clinical setting.

In one study, the gaps in medical education were evident. When fourth-year medical students were asked to describe their clinical experiences with end-of-life care, they described situations in which they “stood frozen,” not knowing what to do, and scenarios during which they “did not have enough medical experience to explain the necessity or issues surrounding intubation, respirators, etc., to concerned patients, and certainly did not have the medical knowledge to advise patients on such major decisions” [13]. One student felt as if she were “left to her own devices” in caring for a patient with end-stage lung cancer [13].

In a study of third-year medical students, all reported that they had cared for a dying patient, yet 41 percent had not observed a physician talking to a dying patient, 35 percent had never discussed care of a dying patient with the attending physicians, and 85 percent had never witnessed a surgeon telling a family that someone had died [14].

Why does this seem to be the case? As Grauel and colleagues argue, “competence in the care of the terminally ill is an area that many physicians have considered to be of low priority” [15] and, thus, though students and residents are put in situations where they are confronted with these issues on a daily basis, they are learning about care at the EOL through “baptism by fire.” Though there is undoubtedly value in learning through actual patient encounters and direct exposure in the clinical setting, supervision and guidance during these difficult conversations is a critical component that is often overlooked.

The literature on medical education consistently argues that learning about end-of-life care in all its forms should be integrated into rather than isolated from the rest of the curriculum [12]. Although in-classroom lectures are necessary and important, the process of learning needs to be continued in the clinical setting. It is within this forum, during the day-to-day clinical encounters, that doctor-family communication can be developed, initially through observation and then through such methods as direct feedback and debriefing sessions.

The value of mentorship cannot be overemphasized. This can mean working under the tutelage of other practitioners who are more experienced and comfortable with communication with dying patients, such as social workers, hospice nurses, hospice volunteers or spiritual care counselors. The multidisciplinary approach of hospice care is a rich environment for medical students. In a study of medical students placed within hospices, participants emphasized the importance of experienced hospice volunteers, whom they regularly looked to for guidance and support. Students reported that they learned much from observing their volunteers' communication skills and comfort with patients' conditions [16].

Kelsey finds herself in this setting, and it is the ideal environment for her to begin to acknowledge her own personal anxieties surrounding death as well as her own concerns and reservations as a budding medical practitioner. She can look to the hospice practitioners, including the physician, for guidance. And following her conversations, Kelsey can look to debrief and explore her emotions and feelings regarding these undoubtedly difficult encounters.

With the continued development of hospice and palliative medicine as a specialty and the growing realization among educators, clinicians, and administrators that EOL care requires as much emphasis as cardiology and pediatrics, care at the EOL will certainly continue to gain momentum as an area of focus and interest within medical school curricula. As this occurs, physicians will enter clinical practice with increasing comfort and ease in dealing with dying patients and, in turn, will serve as more experienced and facile mentors and teachers for young physician learners.

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MEDICAL EDUCATION

The Flipped Classroom Paradigm for Teaching Palliative Care Skills

Vyjayanthi S. Periyakoil, MD, and Preetha Basaviah, MD

The Liaison Committee on Medical Education (LCME) standards state that medical education must cover all important aspects of end-of-life (EOL) care [1]. End-of-life care learning is thought to be categorized into formal curriculum taught in lectures; informal curriculum, conveyed through clinical experiences; and “hidden curriculum,” inferred from behaviors and implicit in the culture of biomedicine [2]. Research demonstrates both the need for development of formal curriculum on end-of-life topics and the importance of clinical care experiences with seriously ill patients to prepare medical students to provide quality end-of-life care [3]. Deans of medical schools agree that end-of-life instruction is an important part of the medical curriculum but support an integrative diffusion approach by which EOL instruction is provided as a part of the existing clerkships [4]. While this strategy may sound workable in theory, in practice non-palliative care faculty in the various clerkships do not have specific EOL expertise and thus may not be able to effectively mentor medical students on the core palliative care skills and clinical competencies. Hence, it is vitally important to provide skill-based immersive experiences as a part of preclinical training in palliative care.

We describe Stanford University School of Medicine’s longitudinal approach to effective, skill-based palliative care instruction integrated into the third, fifth, and sixth quarters of preclinical education (see table 1) [5, 6].

Table 1: Stanford University School of Medicine palliative care curriculum 2012-2013

Topic	Length	Goal	Learning Activities
Breaking bad news	3 hours (Q3)	Improve students’ ability to break bad news and build their confidence in that ability.	Flipped classroom: <ul style="list-style-type: none">• Pre-work: 1-hour online video lecture and case study module.• 1-hour 50-minute immersive learning and skill practice.
Clinical reasoning in diagnosis and management of serious illness	4 hours (Q5)	Understand that sometimes patients die unexpectedly despite having a preventable and treatable illness. Reflect on how adverse patient outcomes can impact	Case study: <ul style="list-style-type: none">• Differential diagnosis, assessment, and management of a case of meningitis in a Stanford sophomore.• Video simulation learning followed by debrief.

		doctors.	
Principles of palliative care	6 hours (Q6)	Understand and apply essential practices and principles of palliative care.	<p>Through a variety of activities including mini-didactics, small and large group case discussion, role play, video cases and reflective activities, students:</p> <ul style="list-style-type: none"> • Gain an understanding of how to explore patient and family knowledge of illness, concerns, goals, and values that inform the plan of care • Gain an initial understanding of advance directives and POLST (physician orders for life-sustaining treatment). • Gain an initial understanding of how to identify patients' and families' cultural values, beliefs, and practices related to serious illness and end-of-life care. • Gain an initial understanding of assessment and management of non-pain symptoms. • Complete self-assessment of attitudes related to advance directives.
Self-care	2 hours (Q6)	Inculcate self-care behaviors as a vital part of professional and personal life in all our medical students.	<ul style="list-style-type: none"> • Define burnout. • List at least three reasons why the medical profession is at high risk for burnout. • Define moral distress and identify the etiology of moral distress. • Define compassion fatigue. • Reflect on the impact of burnout, moral distress and compassion fatigue on your personal well-being and professional productivity. • Identify tools to monitor burnout, moral distress and compassion fatigue in yourself. • List at least one practical strategy that you can implement on an ongoing basis for promoting your self-care and well-being.

We use a variety of immersion learning techniques and experiences based on the flipped classroom model [7]. Our students view online videos to learn new concepts at their own pace and place. Interactive video case quizzes reinforce learning and help deepen their conceptual understanding of the theoretical principles and the

evidence base. This frees class time for discussion and clarification of the nuances of materials studied and then solidification of the knowledge through immersive skill-based learning exercises. What follows is an example of an immersive learning exercise devoted to breaking bad news.

Step 1. Pre-work: students in the third quarter completed the online video module on the theory of and evidence behind breaking bad news, followed by video vignettes of less- and more-optimal versions of an oncologist's giving bad news to a patient with metastatic lung cancer.

Step 2. Brief large-group refresher of the SPIKES protocol (a six-step technique for communicating well and attending to the patient's distress while delivering bad news) and nuances of the principles and practice of giving bad news to patients and families.

Step 3. Students split into small groups to watch a professionally filmed, 5-minute video of a palliative care clinician interacting "suboptimally" with a standardized patient and his daughter. The patient has been hospitalized for urosepsis, myocardial infarction, and a new diagnosis of congestive heart failure.

Step 4. In small groups, students brainstorm and script out what could have been said or done differently to make the interaction better and more patient-centered.

Step 5. One or two volunteers from each small group re-enact the same patient-physician interaction more optimally, drawing from principles learned in the online module and the small group discussions.

Step 6. The volunteers split into two groups to film a more optimal version of the interaction. In each group, students take on the parts of the director, producer, and videographer as well as patient, doctor, and the patient's daughter.

Step 7. The student reenactments are watched in the large group and discussed.

Step 8. Finally, the students watch a "more optimal" version of the professionally filmed, 5-minute video demonstrating how to skillfully and effectively break bad news.

Highlights

We have been using the flipped classroom model for the last 5 years. Our student feedback has been uniformly positive in the last few years. Students feel that the flipped classroom model is, in one student's words, "very effective in teaching material that is difficult to disseminate via lecture only." Many students stated that watching their classmates enacting the scene gave them a new level of confidence in their own ability to give bad news effectively and have a crucial conversation with patients and families. They then began brainstorming spontaneously about how best to deliver bad news effectively and support patients and families in difficult situations. One student stated that she had been struggling with the death of a real patient. When she played the part of the doctor in the film reenactment, she was able

to process the stressful emotions doctors experience and was finally able to reflect on the loss of her patient.

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THE CODE SAYS

AMA Code of Medical Ethics' Opinions on Care at the End of Life

Opinion 2.20 - Withholding or Withdrawing Life-Sustaining Medical Treatment

The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail. The principle of patient autonomy requires that physicians respect the decision to forgo life-sustaining treatment of a patient who possesses decision-making capacity. Life-sustaining treatment is any treatment that serves to prolong life without reversing the underlying medical condition. Life-sustaining treatment may include, but is not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration.

There is no ethical distinction between withdrawing and withholding life-sustaining treatment. A competent, adult patient may, in advance, formulate and provide a valid consent to the withholding or withdrawal of life-support systems in the event that injury or illness renders that individual incompetent to make such a decision. A patient may also appoint a surrogate decision maker in accordance with state law.

If the patient receiving life-sustaining treatment is incompetent, a surrogate decision maker should be identified. Without an advance directive that designates a proxy, the patient's family should become the surrogate decision maker. Family includes persons with whom the patient is closely associated. In the case when there is no person closely associated with the patient, but there are persons who both care about the patient and have sufficient relevant knowledge of the patient, such persons may be appropriate surrogates. Physicians should provide all relevant medical information and explain to surrogate decision makers that decisions regarding withholding or withdrawing life-sustaining treatment should be based on substituted judgment (what the patient would have decided) when there is evidence of the patient's preferences and values. In making a substituted judgment, decision makers may consider the patient's advance directive (if any); the patient's values about life and the way it should be lived; and the patient's attitudes towards sickness, suffering, medical procedures, and death. If there is not adequate evidence of the incompetent patient's preferences and values, the decision should be based on the best interests of the patient (what outcome would most likely promote the patient's well-being).

Though the surrogate's decision for the incompetent patient should almost always be accepted by the physician, there are four situations that may require either institutional or judicial review and/or intervention in the decision-making process: (1) there is no available family member willing to be the patient's surrogate decision maker; (2) there is a dispute among family members and there is no decision maker

designated in an advance directive; (3) a health care provider believes that the family's decision is clearly not what the patient would have decided if competent; and (4) a health care provider believes that the decision is not a decision that could reasonably be judged to be in the patient's best interests. When there are disputes among family members or between family and health care providers, the use of ethics committees specifically designed to facilitate sound decision making is recommended before resorting to the courts.

When a permanently unconscious patient was never competent or had not left any evidence of previous preferences or values, since there is no objective way to ascertain the best interests of the patient, the surrogate's decision should not be challenged as long as the decision is based on the decision maker's true concern for what would be best for the patient. Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care. This includes providing effective palliative treatment even though it may foreseeably hasten death.

Even if the patient is not terminally ill or permanently unconscious, it is not unethical to discontinue all means of life-sustaining medical treatment in accordance with a proper substituted judgment or best interests analysis.

Issued December 1984 as Opinion 2.18, *Withholding or Withdrawing Life-Prolonging Medical Treatment*, and Opinion 2.19, *Withholding or Withdrawing Life-Prolonging Medical Treatment—Patients' Preferences*; updated June 1994 based on the reports "Decisions Near the End of Life" and "Decisions to Forego Life-Sustaining Treatment for Incompetent Patients," both adopted June 1991.

Opinion 2.225 - Optimal Use of Orders-Not-to-Intervene and Advance Directives

More rigorous efforts in advance care planning are required in order to tailor end-of-life care to the preferences of patients so that they can experience a satisfactory last chapter in their lives. There is need for better availability and tracking of advance directives and more uniform adoption of form documents that can be honored in all states of the United States. The discouraging evidence of inadequate end-of-life decision making indicates the necessity of several improvement strategies:

(1) Patients and physicians should make use of advisory as well as statutory documents. Advisory documents aim to accurately represent a patient's wishes and are legally binding under law. Statutory documents give physicians immunity from malpractice for following a patient's wishes. If a form is not available that combines the two, an advisory document should be appended to the state statutory form.

(2) Advisory documents should be based on validated worksheets, thus ensuring reasonable confidence that preferences for end-of-life treatment can be fairly and effectively elicited and recorded, and that they are applicable to medical decisions.

(3) Physicians should directly discuss the patient's preferences with the patient and the patient's proxy. These discussions should be held ahead of time wherever possible. The key steps of structuring a core discussion and of signing and recording the document in the medical record should not be delegated to a junior member of the health care team.

(4) Central repositories should be established so that completed advisory documents, state statutory documents, identification of a proxy, and identification of the primary physician can be obtained efficiently in emergency and urgent circumstances as well as routinely.

(5) Health care facilities should honor, and physicians should use, a range of orders on the Doctor's Order Sheet to indicate patient wishes regarding avoidable treatments that might otherwise be given on an emergency basis or by a covering physician with less knowledge of the patient's wishes. Treatment avoidance orders might include, along with a Do Not Resuscitate (DNR) order, some of the following: Full Comfort Care Only (FCCO); Do Not Intubate (DNI); Do Not Defibrillate (DND); Do Not Leave Home (DNLH); Do Not Transfer (DNTransfer); No Intravenous Lines (NIL); No Blood Draws (NBD); No Feeding Tube (NFT); No Vital Signs (NVS); and so forth. One common new order, Do Not Treat (DNT), is specifically not included in this list, since it may unintentionally convey the message that no care should be given and the patient may lose the intense attention due to a dying person; FCCO serves the same purpose without the likely misinterpretation. As with DNR orders, these treatment avoidance orders should be revisited periodically to ensure their continued applicability. Active comfort care orders might include Allow Visitors Extended Hours (AVEH) and Inquire About Comfort (IAC) b.i.d. (twice daily).

Issued June 1998 based on the report "Optimal Use of Orders-not-to-Intervene and Advance Directives," adopted June 1997.

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JOURNAL DISCUSSION

Physician Characteristics Influence Referral to End-of-Life Care

May Hua, MD

Coulourides Kogan A, Brumley R, Wilber K, Enguidanos S. Physician factors that influence patient referrals to end-of-life care. *Amer J Manag Care.* 2012;18(11):e416-e422.

As evidence has made the benefits of end-of-life (EOL) care clearer, the provision of appropriate, high-quality EOL care has become part of the national health care agenda. EOL care has been associated with reduced costs, improved quality of life, and, in some instances, longer survival [1-3]. Furthermore, EOL care is highly desired by patients and their families, who may prefer to avoid aggressive and burdensome care in the context of a poor prognosis [4]. Both California and New York have enacted laws requiring that EOL information and counseling be offered to patients with terminal illnesses [5-7], and other states are considering similar laws [8]. Yet access to adequate EOL care is variable. Patients, families, clinicians, and institutions contribute to underutilization of EOL care [9] and data suggest substantial variation in physicians' referral to EOL care [10-13].

Coulourides Kogan et al. delve into the issue of physician-related barriers to end-of-life care by examining whether physicians' personal experiences or level of comfort with discussing end-of-life care affect referral patterns [14]. Using a cross-sectional sample of physicians from a large health maintenance organization in Southern California, the authors administered a survey to assess self-reported patterns of referral to end-of-life care services, which included home-based palliative care and hospice. Data on demographics, medical practice background, physicians' comfort with discussing end-of-life care, and their personal experience with hospice were also collected. The authors then used logistic regression models to identify factors associated with referral to end-of-life care.

Eighty-three (83) percent of respondents reported at least a single referral in the last year and 50 percent reported four or more referrals over the past year. Eighty (80) percent of respondents also expressed comfort conducting end-of-life conversations. Less than half (43 percent) reported having had a family member receive hospice care.

The authors found that being a family or internal medicine practitioner and self-reported comfort with having end-of-life care discussions were significantly associated with referral, and age was inversely associated with likelihood of referral. Family and internal medicine practitioners were twice as likely to refer frequently

than were specialty and emergency medicine practitioners, and those who reported comfort with end-of-life care discussions were five times as likely to refer frequently than those who did not. Previous personal experience with hospice did not significantly affect referral patterns.

What to make of these findings? The fact that physicians' comfort level with conducting EOL conversations was positively associated with referral to EOL care services is hardly surprising. What makes the finding noteworthy is that physician comfort with having EOL discussions is a modifiable factor and, hence, a possible target for educational interventions. The authors also found that younger physicians were more likely to refer patients to EOL care services. As the authors surmise, this may reflect changes in medical education over the past decade; training in EOL care is now a mandated part of the medical school curriculum. Family and internal medicine practitioners are perhaps more likely to initiate EOL discussions because they have a "closer relationship" with their patients [14].

While these findings are intriguing, they also warrant qualification. The study has significant limitations. Given the survey design and the chosen outcome measure of self-reported referral to EOL care, the results are subject to both non-response and recall bias. The rate of referral to EOL care and rate of physicians who reported feeling comfortable with having EOL discussions were quite high (80 percent). Physicians likely to respond to this type of survey may also be more likely to refer to EOL care services than nonresponders. Also, because referral to EOL care was self-reported, the validity of the authors' conclusions would be strengthened by administrative data or some other objective measure demonstrating that physicians' actual practices correlated with their reported practice.

The authors conclude that, on an organizational level, physician comfort with having EOL discussions should be a target for quality improvement since this may lead to increased referrals to EOL care. However, changing physician behavior may not be so straightforward. A large multicenter trial of a complex intervention to improve EOL care in intensive care units did not appear to improve the majority of palliative care elements; nor did it improve family satisfaction or nurse and family ratings of quality of death [15]. Although changes in clinician attitudes were not measured, objective measures of physician practice and outcomes were not significantly changed by the intervention. The results of this trial exemplify how resistant physician behaviors may be to change. While it is tempting to accept Coulourides Kogan and colleagues' conclusion, whether referrals to EOL care can be increased by simply promoting physician comfort with EOL discussions is uncertain.

Furthermore, physician-related factors are only one type of barrier to EOL care [9]. Because of these barriers, other methods to increase referral to EOL care, such as the use of screening criteria or triggers, have been advocated. The Center to Advance Palliative Care has published criteria for identifying hospitalized patients for whom a palliative care needs assessment would be appropriate [16], and the IPAL (Improving Palliative Care) Project offers resources to structure and implement

palliative care initiatives [17]. Although many hospitals are moving towards developing screening criteria specific to their patient populations, referral to EOL care may or may not be automatic when patients meet them.

Physicians are the “gatekeepers” to EOL care services, and since prior studies have demonstrated variability in referral to EOL care, ways to circumvent or remove barriers to physician referral merit consideration. The work of Coulourides Kogan and colleagues adds to an ongoing discussion of the challenges and barriers to quality EOL care and highlights the fact that physicians and the systems in which they provide care may need to be targets of interventions. Future studies will be necessary to determine what interventions will most effectively result in increased physician referral of appropriate patients to EOL care.

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STATE OF THE ART AND SCIENCE

Serious Illness Communications Checklist

Rachelle E. Bernacki, MD, MS, and Susan D. Block, MD

End-of-life care in America has changed dramatically over the last 40 years. Prior to the 1970s, there were no do-not-resuscitate (DNR) orders, hospices, or palliative care units, little research or physician education on how best to care for patients at the end of life, and little attention on the decisions surrounding end-of-life care. Since then, concerted educational, political, social, cultural, and legal efforts have led to significant changes in the way doctors, patients, families, and society think about and respond to advanced illness.

The remarkable advances in medicine in the last half century have also created many new challenges in thinking about and planning for end-of-life care. Median life expectancy in the U.S. has increased from 46 years in 1900 to 78.7 years a century later [1]. In the past, death often just happened. Now, an increasing number of people are living longer, often with chronic illness, and facing choices about how, when, and where they prefer death to occur. The proliferation of high-tech, life-sustaining interventions and a culture of “never say die” have forced patients and families to confront difficult end-of-life choices. We do not have an adequate process to systematically support patients and their families in considering the choices they might confront.

Numerous studies show that patients want to have conversations about end-of-life care and expect their physicians to initiate these discussions [2-4]. The goal of conversations between patients and clinicians about end-of-life care is to help patients to live as well as possible, adjust to the realities of their illnesses, consider alternative treatment priorities, and plan and prepare for the end of life. And much evidence suggests that, when these conversations occur, there is greater concordance between patients’ wishes and the care they receive [5]; better patient quality of life [6]; less use of nonbeneficial life-sustaining treatment [7]; more use of hospice care (which allows patients to remain at home) [7]; reduced family distress [7]; and reduced overall resource use [8].

Physicians, however, do not feel comfortable having these conversations and, in fact, identify more barriers to having these discussions than patients do [9]. Physicians are often uncomfortable with the strong emotions that are often stirred up by discussions about end-of-life issues. Yet addressing emotions directly is consistent with best practices by palliative care experts and is associated with improved outcomes [7].

The many therapeutic options now available to patients with advanced disease may lead physicians to focus on the details of intervention options, rather than the patient's goals, such as being at home, minimizing suffering, or not burdening family members. Many clinicians are unprepared and untrained to conduct high-quality end-of-life conversations [10] and may avoid them as a consequence [11].

Palliative care experts routinely use emotion-focused conversations to elicit values and goals. Many physicians fear that these conversations will take too long—and they do take time. However, this process allows patient, physician, and often family to come to understandings that create a personalized end-of-life care plan that is aligned with patient wishes and goals.

Another practice supported by palliative care specialists is the concept of “just in time” decision making [12]. Rather than making *final* decisions regarding future care and interventions, the goal is to encourage earlier end-of-life communication that aims to *prepare* the patient, his or her family members, and clinicians to make better decisions when challenges arise in the future. In this way, “just in time” decision making avoids some of the pitfalls of advance care planning [13] such as premature decision making without enough information.

While palliative care physicians are an excellent resource for end-of-life conversations, there is already a shortage of approximately 11,000 palliative medicine physicians for hospices and hospital-based palliative care programs [14]. Thus, it is not possible for all patients to be seen by palliative care physicians to discuss end-of-life issues. Hence, all physicians who care for seriously ill patients must become competent in conducting these discussions.

In addition, physicians need training in evaluating and communicating about prognostic information, including the challenges in dealing with uncertainty. Assessing the patient's understanding of prognosis and desires for information about the future allows the clinician to provide prognostic information in a patient-centered manner, and patients choose less aggressive treatments when they understand that their life expectancy may be short [15].

Advance care planning should encourage patients to express individual preferences and concerns in an open-ended manner. At the same time, certain key information should be ascertained and communicated to all clinicians in an electronic format, especially given the multiple care transitions that are likely to occur. Crucial aspects of patient information regarding values and goals are often not readily accessible in the electronic medical record.

To address these needs, we developed a structured communication format called the Serious Illness Communication Checklist for physicians to use at the point when they “would not be surprised” if the patient died within the coming year [16, 17]. Clinicians are asked to review their patient panels, ask the “surprise question,” and then conduct a “checklist conversation” with appropriate patients. Checklists are

tools developed to ensure adherence to key processes and are commonly used in high-stress, high-risk fields such as aviation and nuclear power. They ensure completion of necessary tasks during complex, stressful situations in which memory alone may not be sufficient, or when stress and discomfort felt by those participating in the scenarios may cloud clear thought processes, interfere with effective communication, and prevent accomplishment of desired outcomes.

The goal of the Serious Illness Communication Checklist is to improve care for patients with serious illnesses and their families by providing clinicians with a tool to facilitate discussions about end-of-life issues at the right time in the right way and to document the vital information that the discussion elicits. This discussion is patient-centered and assesses their understanding of prognosis, their information preferences, personal goals, fears and worries, willingness to tolerate suffering, and quality of life considerations. These are relatively standard topics of goals-of-care discussions; the structure of the checklist provides a systematic approach to developing a personalized end-of-life treatment plan for each patient.

Conversations between patients, families and clinicians about values and goals will enhance patient understanding and control of their own medical decisions, ease the burdens of decision-making on family members, and help patients toward achieving peace as they approach the end of life. This systematic approach to patient-centered communication based on best practices and existing evidence could transform the way end-of-life care is delivered.

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STATE OF THE ART AND SCIENCE

The Appropriate Use of Increasingly Sophisticated Life-Sustaining Technology

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The field of medicine has seen significant advances in the ability to support or replace native organ function over the last several decades. Renal hemodialysis, in existence since the 1940s [1], has become standard treatment for patients suffering from end-stage kidney disease and is often used in the outpatient setting as a bridge to transplantation or as a destination therapy, where it permanently replaces organ function [2]. Likewise, continuous venovenous hemodialysis (CVVHD) may be used in the critical care setting for potentially reversible kidney injury, among other indications [3]. Ventricular assist devices (VADs) may partially or completely replace cardiac function; a total artificial heart (TAH) completely replaces it [4], and either one may be used as a bridge to heart transplantation or a destination therapy [5, 6]. Liver replacement alternatives, which include the extracorporeal liver assist device (ELAD) and the molecular adsorbent recirculating system (MARS), replaces the detoxification function of a failing liver [7].

Extracorporeal membrane oxygenation (ECMO) uses a pump to withdraw deoxygenated blood from a central vein, provide oxygen and remove carbon dioxide via diffusion across a semipermeable membrane, and return oxygenated blood into a central vein or artery, essentially functioning as an external artificial lung, heart, or both [8]. In cases of respiratory failure, ECMO is being used with increased frequency as a supplement to, or occasionally in place of, invasive mechanical ventilation [9-12]. While this technology has the ability to replace a patient's native lung function, its use, like use of liver replacement therapies and CVVHD, requires ongoing attention in an intensive care unit (ICU). ECMO can serve as a bridge to recovery from reversible illnesses or as a bridge to transplantation for select patients, but not currently as a destination therapy.

As organ replacement technologies become increasingly sophisticated and more readily available, we will have the ability to prolong organ function for longer, which raises significant questions about their appropriate use.

Appropriate Use of Organ-Replacement Interventions in Individual Cases

The fact that we have the ability to sustain organ function does not mean that it is always medically or ethically appropriate to do so. It is reasonable to base assessment of the medical appropriateness of a technology on the likelihood of its achieving reasonable goals. In the case of these sophisticated organ-replacement technologies, reasonable goals are not only replacing the failing organ but also

bridging the patient to recovery, transplantation, or destination therapy. It would be inappropriate to use these technologies only to prolong the dying process in critically ill ICU patients with low quality of life and no chance of achieving any of the abovementioned goals. Although the lives of patients with end-stage pulmonary disease with no hope for transplant or recovery might be extended by days or even weeks using, for example, ECMO, it would be hard to justify employing such resource-intensive technology, especially when ICU beds and often the machines themselves are in limited supply.

What should be the approach in such a case when the patient or surrogate insists on using the technology? Is it medically or ethically appropriate to refuse a request for a potentially life-prolonging intervention when the chance of the patient's surviving to leave the hospital is remote or nonexistent and the intervention itself may cause physical and emotional suffering? What should be done, then, when a sentient patient with multi-organ failure and minimal to no chance of survival to discharge from the hospital requests organ-replacement therapy in order to have more time with his or her family? And does that case differ significantly from one in which a surrogate, acting on behalf of a moribund patient without capacity, requests life-prolonging therapies that will only prolong the dying process?

Patient autonomy is a fundamental principle of contemporary Western medical ethics, but it is not absolute. For instance, a patient dying in an ICU with cardiogenic shock and irreversible multi-organ failure whose surrogate requests an aortic balloon pump does not have the absolute right to such technology, although it might prolong the patient's life. Such an intervention would unquestionably be deemed medically inappropriate. There seems to be a general, if unofficial, consensus among most intensivists that surrogate requests for intubation, vasopressors, and antibiotics be granted even when patients are irreversibly ill and will not survive to discharge. A line is drawn, however, at more sophisticated and resource-intensive technologies such as ECMO and surgical procedures because the burden for the patient and the use of resources is far in excess of any therapeutic benefit gained. Hospital policies and physicians differ with regard to renal replacement therapy in irreversibly ill patients. Some physicians will agree to CVVHD for such patients, while others will refuse.

In our opinion, whether or not organ-replacement therapy should be employed rests on how likely it is to bridge a patient to recovery or successful destination therapy [13]. If these goals cannot be met we would withhold such therapy, not only because these goals are unattainable but also because the patient would likely be harmed by its administration. In circumstances in which a patient who has no hope for recovery or destination therapy requests organ-replacement therapy to prolong life long enough to spend time with family or prepare for the end of his or her life, the decision to offer such therapy depends on the type of intervention needed. Invasive mechanical ventilation has generally been accepted for these purposes, but use of more sophisticated therapies such as ECMO and VADs is rarely considered justified

in these circumstances because of their significant potential for harm to the patient and high resource burden.

More broadly, does the clinician have an ethical obligation to offer, or even disclose, all potential therapies, including those that would merely prolong the dying process? Although we feel that families need to be apprised of the fact that their loved ones are experiencing organ failure, we do not feel a concomitant ethical obligation to offer an intervention that we feel is not medically indicated because it will not be of any therapeutic benefit.

Larger Social Questions

As noted above, it is our impression that, many, if not most, intensivists currently find it difficult to refuse to grant patients' or their surrogates' requests for invasive mechanical ventilation, CVVHD, vasopressors, potent antibiotics, and other expensive and resource-intensive life-sustaining interventions even when the likelihood of the patient's surviving to discharge is remote to nonexistent. In fact, in our state of New York, the law mandates resuscitation of every patient unless the patient or surrogate elects a do-not-resuscitate (DNR) order [14]. Absent a DNR, state law, or court decision, "full resuscitation" is the default treatment for all patients [15]. On the other hand, we know of no legal precedent to support the idea that physicians must perform surgical interventions against their medical judgment because the patients or their surrogates demand it.

Will changing risk-benefit calculations influence ideas about appropriate use of organ-replacement therapies? Smaller circuit components and lower levels of anticoagulation needed to maintain function have reduced the complication rates of ECMO, improving its risk-to-benefit ratio [16]. As technology improves and devices like VADs and ECMO become simpler to deploy, will ethical and even legal determinations about their appropriate use change? Will ECMO ever become a standard accompaniment of cardiopulmonary resuscitation so that patients who decline a DNR order will thereby mandate the use of ECMO? We can and do keep dying patients alive for weeks or months in accordance with the wishes of their relatives with ventilators, CVVHD, vasopressors, and antibiotics. Will ECMO join this list of interventions as it becomes easier and less resource-intensive to employ, or will physicians continue to refuse this intervention?

And what will the role of concerns about health care costs be in determining when to use organ-replacement therapies? As the tidal wave of baby boomers reaches old age in the coming decades, it is likely that the competition for ICU beds will intensify, the cost of increasingly sophisticated technology will rise, and pressures to contain costs will increase. Will our society make collective determinations about when organ-replacement interventions should be used and when they should not [17]? The process of evaluating these technologies requires, in part, a societal judgment about whether the allocation of the associated financial and physical resources is acceptable. Society may decide that such resources should only be used when rigorously designed clinical trials demonstrate particular benefits or that the

benefits involved are worth a very high cost. Cost-benefit analyses, which are crucial to such policy decisions, should be undertaken for all of the newer life-sustaining technologies to inform such judgments [18, 19].

Conclusion

Criteria for appropriately initiating organ-replacement therapy to benefit patients, and, of equal importance, criteria for stopping these sophisticated treatments when therapeutic goals can no longer be met are currently not well defined. For resource-intensive therapies to be offered to those who are most likely to benefit well-designed studies with a focus on clinically meaningful, patient-centered outcomes are of the utmost importance. When data on efficacy is lacking, the decision about whether to use such technology becomes more difficult. Furthermore, although there are laws that give patients the right to refuse or discontinue life-sustaining treatments, there is no societal consensus about who should have the last word when patients or their families and physicians disagree about the appropriateness of using sophisticated medical technology in situations where such treatment clearly serves only to prolong the dying process [20, 21].

Up to now, patients and families in the U.S. have been given considerable leeway in having requests for such technology granted, even against medical advice. Our society has been generous in this regard out of respect for family values, religious beliefs, and hope. Whether in the coming years, with an increase in elderly patients requiring ever more sophisticated and expensive medical technology, this liberal policy of following patient and family wishes is sustainable remains to be seen. At the very least, the medical community should begin to formulate guidelines that delineate the appropriate use of organ-replacement therapies, taking into consideration the resources involved and the clinical expectation of success.

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HEALTH LAW

Legal Constraints on Pursuit of a “Good Death”

Richard Weinmeyer, JD, MPhil

Introduction

Death is an inevitable topic of conversation all families grapple with at one time or another. Whether it is the steady deterioration of an aging grandfather, or the sudden and unexpected passing of a young child, the simple fact that we are all going to die is a realization that can surprise us and our loved ones when we are least prepared. Yet these seemingly disarming discussions can be illustrative; they can clarify the kind of death each of us wants to have, the “good death,” if you will. Some people want the intervention of medical science to keep them alive for as long as is humanly possible, while others want nature to take its swift course. Either way, when the time to depart this world arrives, each of us would like to die in a way that accords with our values.

A dignified death has become quite a hot topic in medicine in recent years. This trend is attributed in particular to the baby boomer generation, many of whose members have had to witness the difficult and prolonged deaths of their parents and are now considering how they would like to die [1]. More and more personal accounts of aging adults who have asserted control over how they would like to die have come to the public’s attention [2, 3] and a growing number of organizations and resources are speaking to society’s struggles with end-of-life decision making [4, 5]. The law plays a role in defining what is allowed when a person wishes to take the end of life into his or her own hands.

This article briefly discusses where federal law has spoken on the topic of achieving a “good death” during the last 30 years, focusing on the two main cases that have come before the United States Supreme Court on this matter. Since 1990, the court has chosen to hear four cases that have dealt with the right to die, examining situations in which citizens have sought the ability to determine how they die either through the removal of life-sustaining treatment or by obtaining the assistance of a physician in taking their own lives. The two cases below exemplify the court’s effort to grapple with this emotionally and politically charged subject.

Cruzan v. Director, Missouri Department of Public Health

Facts of the case. On the night of January 11, 1983, a 25-year-old woman by the name of Nancy Cruzan was driving home from work when her car overturned on a winding road near Carthage, Missouri [6]. Nancy was not wearing her seatbelt and was thrown from the vehicle [7]. When state troopers and paramedics arrived at the scene of the crash, they found Cruzan lying face down in a water-filled ditch where

she exhibited no respiratory or cardiac function [8, 9]. Medical personnel were able to restart her heart, but Nancy had stopped breathing for almost 15 minutes and as a result suffered severe brain damage [8, 9]. A month after the accident, Cruzan's then husband consented to the implantation of a feeding and hydration tube to keep her alive, although she was able to breathe without the assistance of a ventilator [8, 9]. Following the accident, all rehabilitative efforts failed, and Nancy remained in a persistent vegetative state for years in a Missouri state hospital [9]. She experienced occasional seizures, vomited, and, at times, opened and moved her eyes, yet she displayed no cognitive activity [8]. Nancy had no documentation of her wishes for medical treatment under such circumstances and had only mentioned in passing to a roommate that she would never want to be a "vegetable" [10].

Struggles in state court. Nancy's parents, believing in their hearts that their daughter would never want to live life as she now did, sought and received authorization from a state trial court to remove her feeding tube [11]. A divided vote by the Supreme Court of Missouri reversed this decision, however [12]. The court did not find a right under the Missouri Constitution that would support a person's refusal of medical treatment in every circumstance and doubted whether such a right even existed in the U.S. Constitution [13]. Furthermore, the state supreme court, guided by the state's living will statute and policy favoring the "preservation of life," found that the evidence provided by her family did not offer "clear and convincing" proof of Nancy's wish to be removed from life-sustaining treatment [14]. The Cruzans appealed their decision to the U.S. Supreme Court.

The Supreme Court's review. The specific question before the Supreme Court was whether the U.S. Constitution permitted Missouri to set an evidentiary standard requiring surrogate decision makers to provide "clear and convincing" evidence that a decisionally incapable person would wish to forgo life-sustaining treatment [15]. In a five-to-four decision, the court found that it did. The Fourteenth Amendment's due process clause holds that no state "shall deprive any person of life, liberty, or property, without due process of law" [16], and, through its examination of legal precedent, the court determined that the ability to refuse medical treatment lies within an individual's right to liberty [17]. The court reached this conclusion through its analysis of substantive constitutional freedoms supported by the Fourteenth Amendment, which looked to whether the right in question was "deeply rooted in [the] Nation's history and tradition" [18].

In its review of existing law, the court found that time and again state courts had come to recognize a right *not* to consent to treatment, just as there existed a right to consent to treatment (e.g., the common-law doctrine of informed consent), and that this spoke to a decisionally capable person's ability to decline life-sustaining medical care [15]. The majority determined, however, that the right of an individual to decline life-saving medical interventions was not absolute and must be balanced against the reasonable interests of the state in preserving life [19]. In the specific case of Nancy Cruzan, despite the questionable evidence that she herself stated she would not want to be kept alive, or her parents' fervent belief that continuing artificial

feeding and hydration were not in her best interest, Missouri's policy of preserving life was held to be reasonable under the U.S. Constitution unless there was clear and convincing evidence to the contrary [20]. As the court concluded in its opinion:

Close family members may have a strong feeling—a feeling not at all ignoble or unworthy, but not entirely disinterested, either—that they do not wish to witness the continuation of the life of a loved one which they regard as hopeless, meaningless, and even degrading. But there is no automatic assurance that the view of close family members will necessarily be the same as the patient's would have been had she been confronted with the prospect of her situation while competent. All of the reasons previously discussed for allowing Missouri to require clear and convincing evidence of the patient's wishes lead us to conclude that the State may choose to defer only to those wishes, rather than confide the decision to close family members [21].

The Supreme Court's decision upheld the right of states to establish their own reasonable standards for evaluating evidence in favor or against the termination of a life-sustaining treatment for incompetent persons. Following the court's ruling, the Cruzans presented the state of Missouri with additional support regarding Nancy's wishes to bypass continued treatment, and this time the state found the evidence to be "clear" [8]. On December 14, 1990, Nancy Cruzan's feeding tube was removed, and, less than 2 weeks later, she passed away [8].

Washington v. Glucksberg

Facts of the case. In 1979, the state of Washington passed the Natural Death Act [22]. The act revised the state's criminal code to say that "withholding or withdrawal of life-sustaining treatment...shall not, for any purpose, constitute a suicide" but also that "nothing in this chapter shall be construed to condone, authorize, or approve mercy killing" [22]. Twelve years later, a ballot initiative in Washington that sought to permit a form of physician-assisted suicide failed to pass, and subsequently the state amended the existing Natural Death Act to expressly exclude physician-assisted suicide [23]. In response to the act, four physicians who practiced in Washington, along with three terminally ill patients and a nonprofit organization that counseled people considering physician-assisted suicide challenged the state's ban on physician-assisted suicide in federal court in 1994, claiming that the law was unconstitutional [24].

Challenging the state ban. The specific claim of the suit was that the statute unconstitutionally interfered with a competent, terminally ill adult's right to commit physician-assisted suicide, a right that they argued was found in the Fourteenth Amendment's protection of liberty [25]. Based in part on the precedent of *Cruzan*, the federal district court determined that the ban was unconstitutional and that the law placed an "undue burden" on the interest asserted by the physicians, patients, and organization bringing the case [26]. A three-judge panel of the U.S. Court of Appeals for the Ninth Circuit disagreed with the lower court's ruling [27]. However,

when the case was reheard by the Ninth Circuit en banc (i.e., with all eleven active judges hearing the case), the court agreed and ruled that “the Constitution encompasses a due process liberty interest in controlling the time and manner of one’s death—that there is, in short, a constitutionally recognized ‘right to die,’” and that, according to this reasoning, the Washington state ban was unconstitutional [28].

The Supreme Court’s review. The U.S. Supreme Court reversed the conclusion of the Ninth Circuit, finding that Washington’s prohibition against “causing” or “aiding” suicide did not contradict the Fourteenth Amendment [29]. As the court had done in *Cruzan*, the majority examined whether there existed a specific right under the due process clause to pursue physician-assisted suicide, but the justices found nothing in the nation’s history and traditions to support such a right [30]. Distinguishing the present case from *Cruzan*, Chief Justice Rehnquist wrote, “The decision to commit suicide with the assistance of another may be just as personal and profound as the decision to refuse unwanted medical treatment, but it has never enjoyed similar legal protection. Indeed, the two acts are widely and reasonably regarded as quite distinct” [31]. Justice Rehnquist added that “the history of the law’s treatment of assisted suicide in this country has been and continues to be one of rejection of nearly all efforts to permit it” [32].

Furthermore, the court’s majority stated that Washington’s ban of assisted suicide was rationally related to legitimate government interests, including: pursuing the preservation of human life, understanding and preventing the occurrence of suicide, upholding the integrity and ethical duties of the medical profession, protecting vulnerable people who face coercion when making end-of-life decisions, and guarding against the slippery slope from voluntary to involuntary euthanasia [33]. Because the legal tradition of the country opposed the legality of assisted suicide, and given the rational state interests forwarded by Washington State, the Supreme Court upheld the ban in a decision in which all of the justices either joined the majority or concurred in its judgment.

Conclusion

As the cases of *Cruzan* and *Glucksberg* demonstrate, people place a tremendously high value on the right to achieve a death that accords with the dignity and respect so many of us desire in our lives. Both rulings clarified the boundaries of what is legally permissible: *Cruzan* in its announcement that the Constitution allows a state to require a reasonable standard of evidence when it comes to an incompetent patient’s wishes to be removed from life-sustaining treatment, and *Glucksberg* in demarcating the U.S. Constitution’s perspective on physician-assisted suicide. Since both cases were decided, Americans have become more knowledgeable about end-of-life care [34], and four states have made it legal for their citizens to seek the assistance of physicians in pursuing an end to terminal illnesses [35-38].

The discussions we have with our loved ones about death may seem grisly and even macabre, but, as contemporary Supreme Court jurisprudence demonstrates, these are

important conversations to have if we want to realize our desires to die on our own terms.

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POLICY FORUM

Legislative Attempts to Improve End-of-Life Care in New York State

Beth Popp, MD

The development of cardiopulmonary resuscitation, mechanical ventilators, minimally invasive techniques to place feeding tubes, and other technological advances has resulted in radical changes in the myriad ways people with chronic progressive illnesses live their lives and receive medical care. The possibilities for technological intervention increase as patients enter the final stages of their lives. Our society has grappled with the questions of how best to care for patients with terminal illnesses, and the specialty of hospice and palliative medicine has developed in part from a consensus that we could do a better job caring for patients at all stages of their illnesses, but especially at the end of their lives.

Going back to the SUPPORT studies in the 1990s, we know that patients' goals for their care were frequently not clear to treating physicians. Surviving family members reported that symptoms were not optimally treated at the end of life and that bereavement could be complicated by memories of loved ones dying with uncontrolled pain or dyspnea. Treatments patients received often failed to correlate with statements of their preferences and advance directives [1]. The location of the majority of deaths (hospital or home) did not correlate with surveys about where patients stated they would like to be when they died [2, 3]. Families struggle to provide patients with the practical care they need and may impoverish themselves doing so for relatives with chronic progressive, eventually fatal, illnesses. High rates of resource utilization in the last month of life are illustrated year after year in the Dartmouth Atlas studies [4].

Many efforts to improve end-of-life (EOL) care have come from within the health care professions, but even these efforts have generally been felt to be inadequate to ensure that all patients get end-of-life care that is efficient and satisfying to them and their families. Recently states [5-8] have begun to implement legislation and regulations aimed at improving end-of-life care. This article examines some of those initiatives in New York State and discusses their impact and the mismatch between these efforts and the actual barriers to optimizing end-of-life care in practice. Recent initiatives in New York state include the Palliative Care Information Act [5], The Palliative Care Access Act [6], and The Hospice Modernization Act [7], among others [8-10]. While each of these has potential to improve end-of-life care, each also, sadly, misses the mark in a key way.

Attempts to Better Inform and Identify Patients

The Palliative Care Information Act (PCIA), passed in 2010, effective in February 2011, and amended in 2012, requires that physicians and nurse practitioners

offer to provide information to patients about (1) the full range of treatment options available to them if they have a terminal illness, defined as a medical condition with an anticipated survival time of 6 months or less, (2) their prognosis and (3) the risks and benefits of the various treatment options as well as (4) the patient's legal rights to comprehensive pain and symptom management at the end of life [5].

The legislation was sponsored by a nonprofit advocacy group called Compassion and Choices that is "committed to helping everyone have the best death possible" [11]. The group offers free counseling, planning resources, referrals, and guidance and works throughout the U.S. "to protect and expand options at the end of life" [11] (including physician-assisted suicide) by advocating for legislation and assisting in court cases that support its agenda. Compassion and Choices sponsored similar legislation in California called The Terminal Patients' Right to Know End-of-Life Options Act, which passed in 2008 [8]. The California legislation is more prescriptive in detailing the specific treatments about which physicians are obligated to inform patients, including voluntary cessation of eating and drinking and palliative sedation, but does not require them to offer the information unless a patient asks about it.

A key distinction between palliative care and hospice is that palliative care is triggered by symptom burden and not by prognosis. It can be appropriate at any point in the course of a chronic progressive illness when symptoms are inadequately controlled and additional psychosocial support is needed. The name "Palliative Care Information Act" is a misnomer—it is really an *end-of-life* care information act—its provisions are triggered by a 6-month prognosis. The law legislates the physician's basic obligation to engage in an informed consent discussion with patients when changes in treatment are contemplated, emphasizing that this obligation applies to patients with a prognosis of 6 months to live or less.

The law was deemed necessary because, for example, most physicians do not have a formal informed consent process with signed documents when changing end-stage congestive heart failure patients from one oral medication to another, and as a result it is difficult to know whether such a counseling takes place. The presumptions of the law's sponsors were that physicians don't discuss the range of options with their patients with advanced disease, that this is a more urgent problem than failure to discuss it with patients at earlier stages in illness, and that patients get poor end-of-life care because they are inadequately informed about options like hospice and hospital-based palliative care and their right to refuse unwanted treatments. If only patients were aware of these options, the thinking goes, they would choose them, and they would get more suitable care at the end-of-life. It seems almost intuitive that if patients were better informed more of them would enroll in hospice and enroll

earlier, refuse unwanted invasive and nonbeneficial treatments, and be more satisfied with their end-of-life care.

But there are several problems with these presumptions. First, the PCIA doesn't ensure that patients (or their surrogate decision makers) will be provided accurate information in an unbiased manner. There is no question that the information provided is inadequate in many cases. There is no question that information may be presented in a highly biased manner that influences the choices made by patients and families. There is no formal monitoring of the discussions patients and families have with their physicians. We don't know when physicians who have a bias against the use of percutaneous endoscopic gastrostomy (PEG) tubes present evidence about their nonbeneficial use in patients with advanced dementia to patients with other causes of dysphagia where evidence suggests a benefit. Nor do we know when a physician with a bias in favor of the use of PEG tubes extrapolates the evidence about their benefit for patients with head and neck cancer who are receiving combination chemoradiation therapy to patients in different clinical situations where the evidence does not suggest a benefit or there simply is no evidence base.

There is reason for concern about inaccurate or biased information being given in this context: ignorance about hospice care, at the systems-based practice level and as a medical specialty, abounds among physicians and nurses. Nothing in the PCIA prescribes the information to be provided or monitors for accuracy.

Some of the lack of physician knowledge about hospice is the result of the huge changes in hospice care over the relatively short time since its introduction in the U.S. in the late 1960s and its incorporation into the Medicare program in the early 1980s. There have been many changes in the Medicare hospice benefit since 1984 [12], and the physician unaware of this may discuss hospice care in a way that misinforms the patient and family about what it has to offer them. An uninformed physician trying to comply with the PCIA might advise a patient with a refractory malignant small bowel obstruction that her options are surgery or inpatient hospice. When asked what hospice will do for the bowel obstruction, the uninformed physician might answer "nothing," while the well-informed physician might answer, "treat your pain and nausea, help you decide whether you want artificial nutrition and hydration and provide it if you want it, and help you and your family cope with the frustrating reality that we don't have a way to fix this problem caused by your cancer." The decision made is likely to depend a great deal on which answer was given.

It is clear to me, as a physician who has practiced palliative medicine for 20 years in a variety of hospital, ambulatory, and home-based settings, that accurate information is necessary for optimal end-of-life care—necessary but not sufficient. That is the weakness of the PCIA. Better information does not address systemic constraints on patients' choices. The nature of the Medicare hospice benefit creates a program that is not able to be tailored to every patient's end-of-life care choices. Often, after a detailed discussion of the benefits and limitations of hospice care, my patients make

a well-reasoned decision *not* to enroll in hospice. Of course, they want the benefits of hospice care: skilled symptom management, home-based care, integrated interdisciplinary management, and psychosocial and spiritual support. But my hospice-eligible patients regularly choose to forgo the hospice care option for two reasons: it does not include concurrent care or extended home-care hours.

Lack of concurrent care is a frequent practical obstacle to optimal end-of-life care that can be brought to light in an informed conversation. Some patients forgo a hospice referral because they are not willing to discontinue a disease-specific therapy that is helping to control symptoms or slow the course of their disease progression, thereby improving their quality of life. Such a therapy seems like it ought to be covered by hospice benefits, but often such therapies are considered “curative” (though no one expects them to effect a cure) and are not covered by Medicare (or, in many cases, private insurance). This misuse of “curative” is intentional, an artifact of the low reimbursement rates for routine hospice home care (\$189.37 per day in New York City in 2013) [13]—if a disease-specific palliative therapy costs too much, it cannot be provided by most hospices at present. Pediatric hospice has permitted concurrent care [14], and demonstration projects that allow concurrent “curative” and palliative care for adults are expected in the coming year [15].

Additionally, until recently, dually eligible (for both Medicaid and Medicare) patients with extended hours of home care paid through Medicaid managed long-term care programs (MLTP) had to disenroll and give up their extended hours to enroll in hospice. This was often a barrier to hospice utilization, especially for patients with diagnoses other than cancer who were likely to need extended hours of home health aide assistance for long periods of time before becoming hospice-eligible. The regulations changed in August 2013 [16], allowing patients to enroll in hospice without giving up their extended home-care hours, and we expect this practical change will have a bigger impact on hospice referrals by the end of the calendar year than we have seen from the PCIA in the nearly 3 years since it was implemented.

Other recent New York initiatives came out of the Medicaid Redesign Team, a task force created in 2011 to restructure fundamentally the New York Medicaid program to achieve measurable improvement in health outcomes, sustainable cost control, and a more efficient administrative structure [17]. Several proposals related to hospice and palliative care were ultimately included in the MRT program and have been or will soon be implemented. The Palliative Care Access Act is one of these programs, and it requires health care facilities (as opposed to practitioners) to have policies and procedures in place that improve access to palliative care services for all patients with advanced life-limiting illnesses or conditions.

The Palliative Care Access Act requires that care facilities develop mechanisms for identifying patients who might benefit from palliative care services and those who are making decisions on behalf of patients who are unable to do so themselves. This effort is commendable but does not account for the significant shortage of trained

staff, limited capacity of existing programs, inadequate funding for palliative care services, or the common assumption that palliative care necessarily means “end of life.” Since patients may benefit from palliative care throughout a long portion of a chronic progressive illness, they may well want concurrent care during this time. Making sure that identifying patients as those who might benefit from palliative care does not bring with it an incorrect assumption that they want *only* palliative care is a challenge, given the way “hospice and palliative care” or “palliative and end-of-life care” are often lumped together as a single category.

Attempts to Lengthen Hospice Stays

Another initiative of the Medicaid Redesign Team was incorporated into the Hospice Modernization Act of 2011 (written communication with Kathy McMahon, October 2013). This was an effort to expand hospice use by changing the definition of terminal illness from a life expectancy of 6 months to one of 12 months. For this to apply to Medicare and Medicaid beneficiaries in New York state would require action at the federal level, but it can be used to expand hospice eligibility for patients with commercial insurance. But eligibility does not seem to be the problem.

It is well known that typical stays in hospice are far shorter than the 6 months’ life expectancy required for hospice eligibility—50.1 percent of patients die or are discharged within 14 days of admission [18, 19]. Furthermore, prognostication is more difficult the further the patient is from death. Our ability to prognosticate 6 months’ survival for cancer patients is reasonably accurate, but far less accurate for those with end-stage organ failure or dementia. Our ability to prognosticate 12 months’ survival is likely to be even less so. Some physicians might make earlier referrals if the eligibility criteria were 12 months rather than 6, and some patients might avail themselves of earlier referrals, but only if hospice is seen as a program that helps people cope better and live well with their progressive illnesses. In my experience, patients (and their families) want to see themselves as living well until they die, but want the “dying” phase of their illness to be relatively short.

Conclusion

There is no question, for those patients and families who want to focus on preparing for death, hospice programs continue to do “death and dying” well. But hospice isn’t just about death and dying; hospice is a program to help patients live as best they can despite the presence of a life-limiting illness. As professionals and as a health care system, we can and should aspire to improve the quality of care provided to patients who are dying of chronic progressive illnesses. If we don’t make the efforts from within the health care system, “solutions” will be imposed on us by those who are not involved in provision of care. These may easily address problems that exist but that are not the rate-limiting steps in the process of improving care. We must also be attentive to the diversity of our patients and recognize that, while there may be strong majority views about what constitutes excellent care at the end of life and strong views from much of our society about what they would like their dying to be like, there are also wide variations in such beliefs. A health care system that strives to

provide excellent care for all patients at all phases of their lives must be able to accommodate these variations.

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Whole-Person, Whole-Community Care at the End of Life

Christina Staudt, PhD

Dying is a Human and Communal Experience, Not a Medical Event

As human beings, we are programmed from birth to grow and develop in all our dimensions—biological, social, psychological, spiritual—to change, and to die. A small percent of us die suddenly and unexpectedly without previous warning, but the vast majority of us today experience dying as a process characterized by progressive illness or gradual frailty. Making the now all-but-universal experience of deteriorating and eventually dying as comfortable and as rich as possible for each person and those closest to her is an ethical responsibility of caregivers and the community, as well as an opportunity for all involved to advance in knowledge and compassion.

To live as well as possible until the end requires more than attention to our bodies. One's whole being participates in the process of living and ending life. The totality of who we are needs care. Physicians have always had a role at the end of life, but during the last half century medical care has so overtaken all aspects of the dying process that we mistakenly have come to assume that death is a disease and dying a medical condition [1].

We are social animals who live and die in social settings with particular histories and traditions. With changes in the stages of life, our roles in our families, our social circles, and community life evolve. Old bonds may be broken and new ones forged; our vision of what is meaningful often changes; and we are likely to grow increasingly aware of the looming end. We may seek transcendence, focus on personal relationships, become concerned about leaving legacies, or try to ignore what is happening to us. We may feel anxious at the prospect of dying or we may look forward and backward with a sense of fulfillment. These feelings and ruminations may be common among people of advanced ages or those facing serious illness, but they may also be present in someone who is still young and active.

Who Is Dying?

Before we consider what care is appropriate for “the dying,” we need to identify who they are. Individuals who are in their last days or hours and exhibit common signs of “actively dying” are comparatively easy to recognize [2], but this description only fits those in the ultimate stage of the dying process. How would we have characterized these people a week earlier, or a month, or a year? When is it warranted to start thinking of a person as “at the end of life” and decide that it is time for “end-of-life care”?

Reflecting on this, it becomes clear there is no “trigger point”—in years lived or disease progression—when the process of “dying” can be said to begin. Since birth, all of us are on a trajectory to death with the potential of the process speeding up or slowing down. Healthy people have a straight downward sloping trajectory to the date set by actuarial tables until illness strikes (or creeps up) and the curve changes [3]. Hence, “end-of-life care” should not be separated from a continuum of care that begins at birth and varies over time according to individual need. A continuum of care is ongoing across time, across diagnoses, across medical, custodial, and supplementary care providers, and across family units and community support groups. Good end-of-life care manifests as the intensification of care that is, ideally, already and always ongoing.

The Needs of the Dying

Those who have the end in sight are still living [4]. As human beings, albeit in the last stage of life, their needs are not so different from the needs of the rest of us. They have ordinary needs that require special, sometimes extraordinary, support. All of us, presumably, like to live in a dignified manner, in a safe environment, free of pain and troubling symptoms, with clean bodies and clothing, appropriately hydrated and nourished, in nurturing and loving relationships, with the right amount of mental stimulation, and at peace with ourselves and the world. Although these needs may not be exceptional, the hurdles to achieve them may increase as illness and frailty set in, and the urgency with which they must be satisfied may be magnified as life constricts toward its end.

To learn how we can provide the necessary enhanced support, we have to look beyond medical care to a multidimensional solution. People at the end of life—and those close to them—need assistance with the activities of daily living—dressing, bathing, getting on and off the toilet, cooking and cleaning, managing bill payments, and completing insurance forms. Access to transportation and a wheelchair-friendly residence outfitted with handrails and a hospital bed become critical. Friendly companions safeguard against depression. Pain and symptom management are essential, but existential suffering can be as burdensome as physical discomfort. A chaplain or someone else to talk to about meaning, value, and connectedness can be indispensable.

Whether we remain in our private homes or move into residential facilities, being part of a caring community fosters satisfaction [5]. We seek dignity and respect, and the best quality of life possible, according to how we as individuals and members of our cultural groups perceive those concepts, based on our traditions and values. Conveying *I see you, I hear you, I value you* goes a long way when caring for someone who is losing functionality. This is when the full humanity of the individual is often ignored and the medical diagnosis dominates all interaction. As caregivers we need to be receptive to the whole person, her story, and her wishes and hopes for the time that remains. We show that we value her by supporting her according to her wishes and our professional or personal roles—mitigating pain, explaining insurance forms, treating pressure sores, ensuring hygiene, preparing meals and feeding,

reading a book, performing a ritual, sitting quietly and holding a hand—but also by fully “being with” as much as “doing.” “Being with suffering” is the root meaning of “compassion,” and, regardless of our relationships to the dying person, the underlying nature of our response needs to be one of compassion and love.

Meeting the Needs in an Integrated Service System

To effectuate appropriate care, the receptive and responsive caregiver needs to be part of a coordinated network of services that takes into account the families and communities that are affected by the approaching death. Joanne Lynn argues that we should start by looking at *need*, rather than a system of care to which the individual is made to conform [6]. To accomplish this goal, the current health care system would need to be reformed in multiple ways. Fees for services, a general lack of advance directives, and the default practice of “full code” regardless of the age or health status of the patient are among the most problematic practices [7, 8].

In meeting the needs of those with progressive serious illness and frailty, the most promising health care models are currently hospice care and palliative care. The Medicare hospice benefit mandates a coordinated care team: physicians and nurses manage pain and symptoms; social workers navigate the social service system, answer insurance questions, and offer counseling; aides assist with activities of daily living; chaplains address spiritual needs; and trained volunteers provide social interactions and perform nonprofessional chores. Speech, occupational, and physical therapists and necessary pharmaceuticals to keep the patient comfortable are also included in the benefit. In addition, many hospices provide massage, Reiki, pet, and music therapy, among other complementary services that enhance the patient’s well-being [9]. Palliative care is defined as a philosophy and a system of care, an interdisciplinary care system that embraces the whole person as well as the surrounding family, and potentially the whole community [10, 11]. Palliative medicine is the medical component of palliative care.

Almost half of the people who die in the United States receive hospice services in their dying hours [12]. Because the hospice benefit requires that the patient forgo curative treatment and that a physician certify that life expectancy is less than 6 months, many who could benefit from the support by enrolling early hesitate; more than a third of hospice patients enroll only for the last several days of life [13]. One reason for the late referrals to hospice is many physicians’ reluctance to recognize that their task has changed from seeking disease improvement and cure to offering comfort care. Palliative care services are designed to meet this challenge by creating an additional layer of care that can be provided without the patient’s forgoing curative treatments. Palliative care services can be as comprehensive as hospice services but are often circumscribed due to current restrictions in the reimbursement system.

An expansion of insurance payments for palliative care services and reforms to better align hospice care with a continuum of care appear to offer the best short-term prospects for meeting the health care needs of the dying under our current insurance

system. Regardless of when such reforms may occur, other changes can be initiated among caregivers and among the general public on a broad societal level. All social services and all communal life across the life span potentially intersect with good end-of-life care.

Expanding Roles of Care Providers

Medical and other professional caregivers share the responsibility of all citizens to work for a whole-person, whole-community approach to care. This means being open to integrating our own care system with other support systems and allowing the breaking down of traditional separations among domains that designate and circumscribe who is responsible for what aspect of the care. When disease-modifying measures are no longer possible, the roles among the medical team members shift as the palliative medicine experts enter or become more dominant in the care. Controlling pain and alleviating symptoms are the most important services that medicine can offer at the end of life [14]. However, many patients worry about insulting their primary or disease-specific physicians if they suggest that their pain is not well managed and that they want to consult a pain specialist. This can be avoided if the attending physician suggests a referral to a palliative medicine specialist him- or herself.

A comprehensive support plan for the final journey, which goes beyond the traditional care plan, needs to be drawn up by a professional caregiver who looks at the whole person and those closest to her. In addition to medical directives, the values and wishes of the patient should be included, as well as custodial arrangements and other matters of importance to the patient. The plan should note favorite activities (and substitutes if they are no longer possible), preferences about dress and skin care products, when visitors are welcome, and what gifts are well received. Such details may strike the clinician who is grappling with a complex disease situation as incidental, but to the patient whose functionality is deteriorating they can be sources of comfort and pleasure [15, 16].

Home care medicine is gaining inroads in certain states and showing positive results [17]. Increased volumes of home visits by palliative care-trained physicians, nurse practitioners, and nurses are a positive development for end-of life care. Along with a return to the physician house call may come a return to a personal and empathic relationship between the physician and his or her patients. Medical schools increasingly recognize the need for physicians to communicate more effectively and empathically with their patients [18]. Good bedside manners include taking time with patients [19], being generous about consulting colleagues, and being careful not to medicalize all suffering. Forgiveness, gratitude, sorrow, and love belong in the room of the dying individual, and these sentiments need to be acknowledged—when appropriate—by the visiting physician as well as by the chaplain and grief counselor.

Possibly the most important action that physicians—including disease specialists—can take to show their empathy, especially after treatments have ceased to have disease-improving effect, is to remain in contact, *not* to abandon the patient and her

family. The physician's training and experience endow her with authority. We need our trusted doctors to be with us in shared—even wordless—humanity when we struggle with leaving this life. It matters who the doctor is and how she acts [20].

Outside the field of medicine, other professional institutions and community organizations are initiating and expanding care models, which serve the whole person at the end of life. Education of health care advocates and case managers increasingly includes tools to help families navigate the final journey and locate helpful resources [21]. Training of doulas for the dying—people who offer practical, emotional, and spiritual support but whose primary role is being available as experienced, reassuring presences when someone is “actively dying”—is in its infancy but a growing field [22]. Not-for-profit organizations and faith groups have stepped up their training of “friendly visitor” programs and volunteer drivers [23-27]. Community and professional associations are promoting and creating appropriate educational programs and certification so that these new vocations can become part of a formalized system, similar to the aides with specialized end-of-life training who are now available through licensed or certified home health agencies [28, 29]. The advocacy work is in its early stage but is gaining momentum in large part through caregiver associations and other lay entities [30].

Beyond Integrated Service Models

As discussed, comprehensive, integrated end-of-life care involves adding a layer of palliative care to current medical practices and expanding traditional caregiver roles. Additionally it requires breaking down the “silos” of care to better manage patient transfers among the different care settings of home, hospital, and nursing home [31, 32]. Further, it entreats us to embrace innovative ideas and, ultimately, rethink traditional service systems.

A fundamental hurdle to comprehensive care is the existing strict separation on the managerial and financial level between health care and whole-person (social) care systems. Separate funding sources and a lack of coordination among providers lead to deficiencies, inefficiencies, and, often, high overall costs. Currently in the United States, the expense for repairing a broken leg—a medical necessity—is covered by Medicare (and most insurance companies), but preventive measures, such as reviews of a private residence and removal of slippery rugs and other hazards are rarely covered or subsidized [33]. A hip replacement is paid for but, in general, reimbursement is not available for custodial care such as assistance with bathing and dressing, shopping and cooking when the patient gets home, making the recovery period difficult [34]. Comprehensive, coordinated care has proven to be both cost-effective and beneficial to patients in foreign countries as well as in selected projects and entities within the United States [35-41].

Whole-community care also entails many social services that respond to a variety of needs (e.g., transportation, daycare) and extend seamlessly into the end of life. If good, communal childcare services and after-school programs are available, they provide a measure of ongoing stability for the family as a parent struggles with

treatments and worries about the prognosis and the prospect of arranging care for her children after her death. If good public and subsidized transportation and housing are in place for the disabled, elderly, and poor, these services can be made accessible to those newly diagnosed with a terminal illness without creating new systems of care. Such structural reforms may be difficult to achieve in the current political climate. We can nevertheless envision—and work for—a network of care that spreads on the grassroots level and reaches into the life of the community [42].

Advocating for Political and Social Change

As members of a political system and a civil society that empower us by law and tradition, we can all act to effect positive change in the end-of-life experience. If we believe in reforming our care system so it responds to the needs of the individual—and not vice versa—then we have to advocate and work for improvements. We have constitutional ways to promote favorable legislation and appropriation on the federal, state, and county government level, and we can join groups that educate and advocate around these issues [43]. We can, for example, urge our political representatives to support legislation that reimburses end-of-life conversations between physicians and their patients [44] and we can lobby for a more flexible reimbursement system that breaks down the boundaries between medical and social support services. We have access to faith congregations, social media, and cultural entities to share our experiences and knowledge, and to encourage our families, friends, and colleagues to engage in a whole-person, whole-community approach to end-of-life care. All of us have a stake in the outcome and we also have an ethical responsibility to engage in improving the care of others.

Experience and the literature have shown that successful integration and coordination among entities occur when projects are initiated from the ground level, rather than imposed from the top; when collaborations are undertaken among service providers at the local level; and when all stakeholders are included [45]. These basic tenets indicate that the healthy general public must be roused in the quest for an optimal care system.

Preparing Ourselves

We will all one day die and we will want to receive appropriate care. Thus all of us age 18 and older should complete an advance directive assigning health care agents to represent us in case we lose capacity. We teach teenagers about the perils of drugs and unprotected sex; we also need to make sure that our 18-year-olds have conversations with their parents, siblings, and doctors about whom they would want to speak for them if they lost capacity to make health care decisions for themselves.

Widespread conversations about our wishes at the end may be the most effective ways to promote improved end-of-life care on a personal and communal level. Designating an agent provides a natural opportunity for a conversation about care preferences with the agent and family members and to share thoughts about the kind of care that would be desired at the end. The advance directives we give to our health care agents may change as time goes by, so conversations need to be repeated when

our circumstances alter or our physical conditions deteriorate [46, 47]. If we get serious progressive illnesses and when we become frail and elderly, in-depth conversations about life-sustaining measures become critical. At that point, a physician needs to document our wishes and, if appropriate, prepare portable documents with medical orders stating them [48].

Beyond these basics, we can help ourselves and our families by creating a personal “goals-of-life” plan. Such a plan covers what we would want for ourselves if we were given a limited time to live, say, a final year, final month, or final few days. It includes where we would want to be and with whom, doing what [49]. If all adults became accustomed to considering such things, responding when a similar situation occurred would be easier. The majority of us will have to face how we want to live when we are elderly and frail and—not unlikely—have multiple medical conditions. Many of us will lose capacity and need to rely on others to make decisions for us.

The “goals-of-life” plan differs from a traditional care plan in that it is the patient, in conversation with his or her intimates, who initiates and develops the plan. Creating the plan is almost akin to a parlor game [50], but the product serves well as the foundation of a future personalized “support plan.” The “goals-of-life” exercise is like a fire drill. The real-life situation will never compare exactly to the training sessions but stark panic might be replaced by a sense of knowing some of the necessary action steps. The plan may be revised with our evolving circumstances and health status but, with ongoing conversations, we and our loved ones will have an idea of our wishes and can advocate for them with enhanced confidence.

In Conclusion

As members of the general public and as lay and professional caregivers, we need to acquire “end-of-life competence.” We need to become comfortable around those who are living in their last days and show them compassion. We need to allow them to enter into our individual and communal lives by working for major systemic change and by performing small, daily acts of kindness—and by being available and present when the need arises.

The cultivation of compassion may be our most powerful tool in the quest to improve the end-of-life experience for the person who is dying and those closest to her [51]. The possibility of creating a more compassionate society may sound farfetched, but attitudes and values change over time, sometimes remarkably quickly [52]. Witness broadly accepted changes in attitudes towards civil rights and corporeal punishments in schools during the last half-century. Acts of compassion can be fostered on a personal level and have a communal effect [53]. The ability to listen and respond with sensitivity, to be caring and empathic, is not the exclusive domain of any particular profession. It is a skill set that everyone can acquire.

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MEDICINE AND SOCIETY

Treatment of Terminally Ill Patients According to Jewish Law

Rabbi Dov Linzer

A central tenet of Jewish law and tradition is the sanctity of all human life. The commandment to observe the Sabbath and almost all other religious laws may be violated to protect or save a life and even to extend life for a brief period of time. There is thus a widespread perception that *halakha*, Jewish law, mandates that all measures be taken to extend a dying person's life regardless of financial cost, emotional burden to the family, and prolonged suffering of the patient. This is the perception both within much of the Orthodox Jewish community and among medical health professionals. In truth the well-established and majority position of the authorities of Jewish law is that, in the case of a terminally ill patient, particularly one in pain, such life-extending measures are not mandated and they may even be forbidden.

This article provides an overview of the sometimes competing principles that come into play in such cases and the range of rabbinic opinions in these matters. We will look at: (a) the duty to heal and patient autonomy; (b) the sanctity of life, the duty to alleviate suffering, and the balance between the two; (c) withholding as opposed to withdrawing treatment; and (d) feeding tubes and treatment of secondary conditions.

A few brief comments about the nature of *halakha*. Jewish law derives from the Talmud—a voluminous collection of the rulings, discussions and debates of the rabbis from 100 BCE to 500 CE—and its medieval commentators. The final law is often a matter of debate, hinging on which passages are seen to be authoritative and how to interpret and apply them. Unlike secular law, there is almost no new legislation in *halakha*. All law has to be based on rulings and principles already articulated in the Talmud and its commentators. This proves to be particularly challenging in the area of medical *halakha*, inasmuch as many of the most pressing issues today were not imaginable even a century ago. Questions about such topics as surrogate motherhood, the moment of death, and use of feeding tubes, respirators, and the like were never addressed in the Talmud. Some of the knottiest questions come down to the translation of these ancient texts and applying their abstract principles to the concrete realities of today.

The Duty to Heal and Patient Autonomy

Jewish law recognizes a Biblically derived duty to heal the sick and to preserve life. When a life is at risk, even when the risk is small, this duty is so great that it overrides religious prohibitions. This is true even when the life cannot be saved but only extended for a brief period of time [1].

This duty to preserve life applies to all those who can offer aid and even to the patient herself. A person's life is not seen as his to dispose of as he wishes but as having intrinsic sanctity or, to put it in religious terms, as belonging fully or partly to God. Not only suicide, but also any form of self-injury, is prohibited [2-4].

This raises important questions about the permissibility according to Jewish law of a patient's refusing life-saving treatments, given that the key consideration is not that of self-determination but of the duty—of the doctor and the patient—to protect life. Nevertheless, Rabbi Moshe Feinstein, the preeminent halakhic authority of the twentieth century, among others, allows for a significant role for patient autonomy. He rules that, when the treatment entails even a small element of risk, the patient has the right to refuse it, even if such risks are minimal compared to the risk of forgoing the treatment [5].

Rabbi Feinstein goes further to state that, even when a curative treatment entails no risk, if forcing such a treatment will cause the patient to become highly distressed then it should not be administered. It can be assumed that forcing treatment in such a case will only serve to worsen the patient's condition. This is not applicable when the patient is unconscious, even if he or she had expressed wishes beforehand. In that case, the treatment will be administered.

The Sanctity of Life and Alleviating Suffering

In addition to a duty to preserve life, Jewish law also recognizes a duty to alleviate suffering. The Talmud states that extreme suffering can be a fate worse than death [6-8]. The question then becomes how one is to balance the duty to preserve life when it conflicts with the duty to alleviate suffering. Inasmuch as suffering is always the subjective experience of the person herself, all authorities agree that a terminally ill patient can choose to tolerate suffering and to take interventions that will extend life. But in a case in which she would prefer a quick death or we cannot know his desires, what is the proper course of action? Should the duty to preserve life take priority and demand that life-extending treatments be administered, or should the duty to alleviate suffering take priority and demand that no intervention, save those to alleviate pain, be taken?

A small number of rabbinic authorities assert that the duty to protect life is paramount in all situations. They require that any and all life-extending measures be taken [9, 10]. Contrary to popular misconception, this is only a minority opinion. The majority of decisors, including the most authoritative and influential ones of the last half century, rule that one should allow natural death to take its course, and that one is not required [11-13], and according to some even forbidden [14-16], to intervene in such a case. As evidence of this, these decisors cite the Talmudic story of Rabbi Judah the Patriarch, who was dying in great pain. His students prayed for his life to be extended while his maidservant interrupted their prayers so that his soul could pass and his suffering could end. The Talmud's sympathies are with the maidservant [17, 18].

Another relevant source is *Sefer Hasidim*, a pietistic-halakhic work written by Rabbi Yehudah haHasid (“the pious one”) at the end of the thirteenth century in Germany. He writes as follows:

We do not cry out for a moribund person at the moment of the departing of the soul, lest his soul return and he will then suffer affliction. “There is a time to die” (Eccl. 3:2). What is the meaning of this? It is to teach that when a person is moribund and his soul is departing, we do not pray that his soul return to him because he would in any event be able to live only a few more days, and those days would be in pain [19].

In the case of an unconscious terminally ill patient, some authorities rule that, since suffering is not a factor, life-extending measures must be taken [20]. Others disagree, asserting that we must assume the patient is experiencing pain even subconsciously and we may not use life-extending measures [21, 22, 23].

While this issue has been framed in terms of balancing the obligation to prolong life against the obligation to alleviate suffering, we will see in the next section that it may also be framed as the difference between prolonging life and postponing death. Suffering aside, Jewish law may mandate that we do not obstruct a natural death from running its course. This is an additional reason to allow or require noninterference in the case of an unconscious terminally ill patient [24].

Withholding versus Withdrawing

The position that one need not or is actually forbidden to administer life-prolonging treatment for a terminally ill patient is limited to the passive nonadministration of treatment. To actively shorten a life, either directly or indirectly, is strictly forbidden regardless of the life expectancy, mental state, or capacities of the patient [14, 25-28]. Euthanasia is considered murder, and assisted suicide is indirect murder.

None of this would seem to be relevant to the question of withdrawing treatment. From the medical perspective there is no difference between withdrawing a treatment and choosing not to administer it in the first place [29-31]. Some have argued, however, that, from the perspective of Jewish law, the withdrawing of certain treatments is tantamount to actively hastening death. A key text in this regard is another passage from *Sefer Hasidim*:

We do not act to postpone a person’s death. For example, if a person was moribund and a woodchopper was near that house and the soul could not depart (because of the sound of the chopping of the wood), we remove the woodchopper from that area. We [also] do not place salt on a patient’s tongue to prevent him from dying. [However,] if he is moribund and says: “I cannot die until I am moved to another location,” he is not to be moved [32].

This text has been the subject of heated debate [33-39], with authorities attempting to clearly delineate the difference between removing the woodchopper, which is required as it will allow for his death to proceed according to natural course, and moving the person to allow her to die, which is forbidden. The key principle, however, is clear: one may not hasten a death (the case of moving the patient), but one must not obstruct a natural death from taking place (the cases of not placing the salt on the tongue and of removing the woodchopper).

On the basis of this distinction, many authorities have ruled that, while withholding life-prolonging treatment from a terminally ill patient would be permitted, withdrawing treatment that would lead immediately to the patient's death would be forbidden since this would constitute an active hastening of death. This ruling would be moot in many cases, inasmuch as most treatments once started have to be readministered on a regular basis. The choice could thus be made to not readminister the treatment which would constitute withholding rather than withdrawing treatment.

The case of a ventilator, however, is different since without intervention this treatment will continue unabated. Moreover, a ventilator takes over a vital function of the body and can be considered to become integrated into the person's physiological functions. Thus, according to many decisors, once a person is put on a ventilator he or she cannot be taken off, as doing so would constitute hastening death [40, 41]. This creates tremendous challenges for the medical team and the family by closing off options after ventilation has begun and making the decision to put a person on a ventilator that much more difficult, since there will be no going back from that decision. However, this position is not unanimous; a number of decisors have ruled that there is no substantive difference between not administering ventilation and discontinuing it once begun [42-44]. In either case, the ventilator is obstructing nature from taking its course. According to this position, removal of a ventilating machine is considered to be allowing a natural death to occur and is permitted.

Finally, in the case of a terminally ill patient, most authorities would allow the cessation or gradual altering of a treatment when such actions would not lead to the immediate death of the patient, even though death may occur within a few hours. This would not be considered hastening death, merely the cessation of a therapy [45].

Feeding Tubes and Secondary Conditions

The U.S. Supreme Court, in *Cruzan v. Director, Missouri Department of Health*, ruled that nutrition and hydration were no different than any other medical intervention and could be withdrawn from a patient [46]. This position is generally rejected in Jewish law; most authorities deem the withholding of nutrition even by forgoing insertion of a percutaneous endoscopic gastrostomy (PEG) tube to be a form of starvation [12, 47]. If the patient refuses such interventions and they would have to be physically forced upon him, some rule that such treatment should be withheld. Others insist that this treatment be administered against the patient's will [12]. In cases of a terminally ill and suffering patient, these latter authorities would

allow the administration of concentrated nutrients to be replaced with that of sugar and water [41] so as not to overly prolong the dying process.

There are some authorities who rule against this majority position. According to them, feeding tubes are medical interventions and may be withheld from a dying patient in pain, in particular when their insertion is of questionable medical value and may increase the patient's suffering [48].

Like the insertion of feeding tubes, treatments of conditions unrelated to the underlying illness and treatments for the sake of preventing complications are therapies that, according to many authorities, cannot be withheld from a terminally ill patient. These therapies would fall under the normal duty of care, as the secondary conditions themselves are treatable [49-51]. Other authorities disagree, ruling that such treatments need not be administered since they only serve to prolong the suffering of a terminally ill patient [52, 53].

Conclusion

The mandate to alleviate suffering and to allow death to take its natural course allows and may even require that no life-prolonging interventions be made. Whether such passive nonintervention allows for the withdrawal of treatment, in particular taking a patient off a ventilator or not administering feeding tubes, is a matter of some debate. The widespread perception that Jewish law unequivocally demands that all measures be taken to prolong the life of a dying patient is incorrect. According to most authorities, the sanctity of human life and the duty to protect that life does not translate into a duty to prolong suffering for a terminally ill patient for whom there is no hope of a cure.

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HISTORY OF MEDICINE

When Medicine Is Powerless

Thomas W. Laqueur, PhD

An 1897 painting by the 16-year-old Pablo Picasso—*Reason and Charity*—illustrates the oft-perceived epistemological divide between comforting patients and treating them. In the corner stands a nun holding a child in one arm and offering the patient a drink; in the foreground sits a doctor taking the patient’s pulse and looking at his watch. Physiology is the domain of reason; care the domain of charity. Of course the contrast is overblown, but by then it had already been commonly felt for some time.

Almost a century earlier, in 1798, John Ferriar (1761-1815), a learned, experienced and socially engaged physician in Manchester, England, added a chapter called “Of the treatment of the dying,” to the end of his three-volume *magnum opus* because, he said, there was no topic “less studied in its minute details” [1]. He wanted to make three points. First, that death is often not painful. By and large a dying person becomes weaker and weaker: “the approach of actual death produces a sensation similar to that of falling asleep” [2]. Some people, largely because of respiratory distress, are agitated as death approaches, but those “who resign themselves quietly to their feelings” seem to fare well and die “insensibly” [3]. Fear and apprehension, he suggested, are as much the cause of suffering as physiology. These can be quieted.

Ferriar’s second point had to do with what we would call end-of-life care. The suffering of patients near death is often, he thought, “aggravated by the prejudices and indiscretions of their attendants” [4]. The precise timing of dissolution varies, i.e., prognosis is not easy, but “when the approach of death is ascertained, either from the symptoms of the disease, or by the patient’s own feelings” the good physician should offer what we would call palliative care, i.e., he ought to switch modes [5]. (I might add that Ferriar probably got this from Hippocrates, who was being translated into Latin at the time: “refuse to treat those who are overmastered by their disease,” argued the ancestral physicians, “realizing that in such cases medicine is powerless” [6].)

It “belongs to his province, to determine when officiousness becomes torture” [7].
He

will not, like ignorant practitioners, torment his patient, with unavailing attempts to stimulate the dissolving system, from the idle vanity of prolonging the flutter of the pulse for a few more vibrations:

if he cannot alleviate his situation, he will protect him against every suffering, which has not been attached by nature [8].

(Ferriar's toolkit for palliative care was more limited than that of today's physician and he therefore held out little comfort for suffering "attached by nature" [9], i.e., the sorts of pain today's physician might treat with opiates.)

Finally, he suggested that the doctor's work is not finished when there are no more clinical tasks to be done. When he makes the decision that "all hopes for revival are lost" [7], his job merely changes. It "remains the duty of the physician to soothe the last moments of existence" [9]. His "friendly offices" "are not less grateful to the sick, than satisfactory to surrounding relations" [9]. It becomes the doctor's job to comfort.

All of this seems as sensible today as it did more than 200 years ago. Why then do we still know so little about the experience of dying? Why is palliative care only now and still begrudgingly accepted as part of standard medical care? And, finally, why is a doctor's role at the deathbed so profoundly circumscribed that few would expect her to offer comfort and support? "Soothing the last moments of existence" is not an intervention commensurate with anything on the list of diagnosis-related groups.

Let me take these questions in order. Except for anecdotal evidence like that provided by Ferriar, there were no empirical studies of how we die before William Osler's unpublished survey of some 500 patients in the Johns Hopkins teaching hospital between 1900 and 1904. Based on reports from nurses and colleagues, Osler reported that about a fifth of his subjects ended their lives in some measure of discomfort. For the rest, "their death was 'a sleep and a forgetting,'" he concluded [10], quoting a commonplace that Ferriar would have known.

In 1994 Sherwin Nuland published his bestselling *How We Die*, which concluded on anecdotal evidence that Ferriar and Osler were wrong. Death is nothing more than a physiological event that is "glutted with mental suffering and physical distress" [11]. Then in 1995, a century after Osler, came the massive SUPPORT study showing that Nuland might have had a point but not because suffering was an inevitable part of the natural history of death, as he had argued. Rather it revealed what his story had hidden: that dying was a process profoundly affected by what doctors did and by a multitude of mixups and failures in communication between everyone involved. A natural history of dying scarcely exists today. Sharon Kaufman's *A Time to Die* makes this clear in exquisite ethnographic detail: in many cases, the way we die is as much a result of the institutional, legal, and cultural constraints of the hospital and the medical system in general as it is of what Ferriar would have recognized as "dissolution."

There is a reason for why we know so little about "dissolution:" a rupture that began in the eighteenth century between our understandings of death as a biological event and as a cultural one has, until very recently, kept the question of how we experience

dying off the research agenda of medicine. While the dead body and death as a biologically defined legal category became of greater interest to doctors, death as it was experienced by the dying was not considered their problem.

This has been the case since at least around 1760, when an article in the great Enlightenment *Encyclopédie* defined death for its wide, educated readership. It asserted that, whether a human being is made of body and soul is a religious question that science cannot answer; life is “the continual movement of solids and fluids through the whole living body,” and death, as far as the doctor is concerned, is merely the opposite of that [12]. As far as medicine is concerned, the suffering human, the creature with a soul, belongs to others.

The reluctance of the medical profession to shift from treatment to palliation has if anything increased since Ferriar’s day. Prognosis has never been easy, but is probably more difficult today, when the majority of people in the West die from chronic diseases whose courses are more difficult to foresee than those of the more predictable infectious diseases that felled the majority of people in Ferriar’s day. Furthermore, we now have more means by which to “maintain the flutter of the pulse” [9] for just a while longer than did physicians back then. Doctors also tend to wildly overestimate the time a patient has to live in part because, increasingly in the nineteenth century, it became a norm of medical practice that a physician’s job was to hold out hope even at the cost of lying [13, 14].

But Ferriar points to the most important reason: it is only “if he cannot alleviate his situation” [9] that the physician should ease the patient’s suffering. Palliation was already then a mark of defeat and is even more so today. Hospitals have for decades provided birthing rooms that can be advertised as happy places to deliver one’s children. But, as the head of a hospital told a medical colleague of mine, Sunnyside cannot advertise that it is a good place to die. Hospitals in the popular imagination are triumphalist institutions, and only recently has medicine come to see that dying well may be a victory of sorts. Palliative care is beginning to get the recognition it deserves not as a specialty of surrender but as part of what medicine owes the sick.

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Suggested Readings and Resources

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