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FROM THE EDITOR

Ethical Dimensions of Caring Well for Dying Patients

Ilana Stol, MD

Dying is a uniquely individual yet deeply shared and universal experience; it profoundly impacts perceptions of culture, personhood, and identity. For many Americans, it is also an experience widely discrepant from the one they want and envision for themselves and their loved ones.¹ Over the past decade, there has been growing awareness of the incongruence between the way Americans say they want to die and how they actually do.¹ But while most would agree that this reality is not the ideal that clinicians or patients strive for, what is less agreed upon is what the roles of clinicians and patients should be in defining what actually constitutes dying and good care of dying people. What do patients and clinicians need to know about dying and care at the end of life? What barriers exist to accessing and employing this knowledge in the face of difficult decisions?

To best answer these questions, it is useful to examine the social structures and supports already in place for end-of-life care and to understand how they are being utilized. To begin with, hospital palliative care programs are expanding rapidly in order to meet the physical and emotional needs of patients with serious or terminal illness.² Robust evidence now exists demonstrating that early palliative care improves the dying experience for both patients and families while generally reducing health care costs and potentially prolonging survival.^{3,4} Despite these facts, there is significant variation in physician practice in the care of patients at the end of life and a general consensus that palliative and hospice care are underutilized by physicians.⁵ Underlying these facts is an intricate network of social, political, and cultural factors that have real consequences for dying patients and their families. In order to provide the highest quality end-of-life care, clinicians have to both recognize and reconcile the complex patient and physician factors influencing the dying experience. This issue of the *AMA Journal of Ethics* aims to explore each of these factors and their critical implications for care at the end of life.

The ethics cases in this issue examine a number of important themes crucial to discussion of care for the dying patient. Alexander Craig and Elizabeth Dzung examine the potential roles and ethical limits of physicians in facilitating patients' control over their own death experience through a clinical case of a patient with amyotrophic lateral sclerosis (ALS) who asks for assistance in ending his life. In doing so, they provide a framework for exploring the ethical implications of active [physician aid in dying](#) in cases in which the nature of patients' terminal condition renders them unable to exercise the

right granted to them in states that have passed death with dignity laws. In the case of a [patient who refuses tracheostomy](#) as part of a planned perioperative intubation, Katherine Gentry and Aaron Wightman examine the moral quandary of an anesthesiologist who wishes to respect the patient's autonomy but fears deviating from the standard of care and being culpable should the patient die. Shyoko Honiden and Jennifer Possick navigate end-of-life decision making in situations in which [physicians don't agree](#) on whether to pursue comfort-only care for a complex patient in the intensive care unit. The authors argue that shared decision making allows for physician variation but that clinical momentum—the escalation of aggressive care at the end of life—might lead clinicians to pursue care that puts them in conflict with patients' wishes and agreed-upon treatment plans. In the fourth case, James L. Bernat and Nathaniel M. Robbins examine the medical definitions of death and their impact on the [organ donor dying experience](#) in the case of organ donation in a young woman whose heart stopped in the operating room. The authors highlight the variation in definitions of donor death among hospitals in cases of organ donation and how physicians justify their roles in the dying process of living donors for the benefit of preserving the transplanted organ for the recipient.

In our current health care climate, it is becoming more and more self evident that clinicians must think critically about systemic implementation of effective communication concerning patients' prognosis and end-of-life care. Carin van Zyl and Dawn M. Gross discuss the significance and inherent challenges of recent legislation under which Medicare now provides [reimbursement for advance care planning](#).⁶ The authors deliberate on the fact that, unlike other reimbursable interventions such as medical procedures, formalizing standards and measuring outcomes for advance care planning conversations is both ethically challenging and fundamental to the competent delivery of patient-centered end-of-life care. Bryan A. Sisk and Jennifer W. Mack define the [purpose and process of prognostic communication](#) and argue that while most interventions aimed at improving prognostic communication have been focused on the process, more work needs to be done to address the purpose of such communication. Providing an example of the importance of diagnostic communication, Sabhyta Sabharwal, Jason W. Mitchell, and Victoria Y. Fan discuss the need for [policies mandating serostatus disclosure to adolescents](#) who, when they become adults, will be required by law to disclose their positive serostatus to needle-sharing or sex partners.

Two articles address ways in which training and education in end-of-life communication can deepen physician comfort with and effectiveness in engaging in difficult conversations. Mark Pfeifer and Barbara A. Head provide an overview of [evidence-based communication skills](#) necessary for meaningful end-of-life conversations as well as a discussion of established frameworks for developing clinician competency in these skills. Indrany Datta-Barua and Joshua Hauser discuss [similarities between psychiatry and palliative care](#) and how certain skills and approaches key to the practice of psychiatry can

be applied and incorporated in the practice of palliative care.

In further exploring the events leading up to death, 3 articles examine the impact of medical interventions on the dying process. Peter T. Hetzler III and Lydia S. Dugdale discuss the modern [transformation of death](#) as a natural process into one that must be intervened upon or “medicalized.” Helen Stanton Chapple examines clinical momentum through the lens of ritual, reimbursement patterns, and actor network theory and considers how dying patients are underserved when this happens. And, in the [podcast](#), Chapple discusses how hospital clinicians can allow patients and their families to take the lead in the dying process, and Caitlin Doughty discusses what clinicians can do to help families begin a grieving process in the immediate aftermath of a death.

Two other articles focus on personal experiences of providing care to highlight the importance of individual perspectives on illness and death. One article discusses unique and underexplored needs of veterans at the end of life. Tracy Shamas and Sarah Gillespie-Heyman emphasize the impact of military culture, war, and posttraumatic stress disorder on [veterans’ end-of-life care](#) and discuss their own experiences in individualizing their approach to care for veterans with challenging needs. From a patient perspective, Nora W. Wong explores the seemingly paradoxical [role of compassion](#) in the lack of, or late, palliative care referral by physicians and discusses how this potential barrier can be overcome through improved communication.

Individual perspectives take a visible form in 4 artistic contributions. In his graphic narrative, Nathan A. Gray explores the irony and implications of [“compassionate” dialysis](#) provided to immigrants without health insurance. Two images provide different perspectives on resuscitation. While Tracy A. Brader portrays a [team effort resuscitation attempt](#), Munir H. Buhaya portrays the solitariness of an [unrepresented patient](#) for whom a physician completes a do-not-resuscitate order. And Cheyanne Silver portrays the hope of [physicians struggling](#) with dashed career expectations and disappointment.

The diverse array of clinicians, scholars, and trainees who have contributed to this month’s issue of the *AMA Journal of Ethics* focus our attention on many challenges facing end-of-life care and implore us to regularly include these issues in our conversations with patients. In order to care well for dying patients and their families, it is necessary to understand how prognosis, culture, policy, and training all shape a physician’s capacity to provide exceptional care for those navigating an experience that is, without exception, shared by all.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Refusal of Tracheostomy as Part of an Adolescent's Perioperative Planned Intubation Be Regarded?

Case and Commentary by Katherine Gentry, MD, MA and Aaron Wightman, MD, MA

To claim one AMA PRA Category 1 Credit™ for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming AMA PRA Category 1 Credit™ are available through the [AMA Education Center](#).

Abstract

Here we present a case of a patient in terminal respiratory failure refusing to consent to emergent tracheostomy in the setting of an anticipated difficult intubation. We examine ethical concerns that arise from deviations from the standard of care in the operative setting and the anesthesiologist's sense of culpability. Finally, we will review the ethical arguments and guidelines that support anesthesiologists' participation in palliative operative procedures when limitations on resuscitation are in place.

Case

Kelly is a 16-year-old girl with spinal muscular atrophy type 1. Her weakness made it difficult to perform needed pulmonary clearance treatments, leading her to develop pneumonia and progressive air hunger that required her to be hospitalized. After discussion with her pulmonologist, she and her parents requested intubation to facilitate aggressive attempts at improving pulmonary toilet. If these attempts proved to be unsuccessful, Kelly's parents, with her assent, requested that the endotracheal tube and ventilator be discontinued and that goals of care be shifted to focus on comfort only.

As Kelly's weakness and contractures prevented her from fully opening her mouth, oral intubation was predicted to be difficult; therefore, anesthesiology and otolaryngology services were consulted to consider performing a fiberoptic nasal intubation in the operating room. During discussion of the plan, the anesthesiologist explained that in the case of a failed intubation attempt, her next step would be to secure the airway surgically (ie, via a tracheostomy). This troubled Kelly and her family, as they considered life with a tracheostomy to be an unacceptable outcome. Over the years, they had consistently refused tracheostomy and chronic ventilation as a potentially life-sustaining treatment. For Kelly, a life worth living included retaining some ability to speak. Given her

degree of weakness, a tracheostomy would render her unable to vocalize, and she would require mechanical ventilation without respite.^{1,2}

Kelly's acceptance of short-term intubation but refusal of an emergency tracheostomy was difficult for the anesthesiologist to accept. She rejected the notion that a tracheostomy could be refused in the setting of an operating room intubation, as the provision of anesthesia could directly precipitate respiratory insufficiency, and a tracheostomy could immediately treat this iatrogenic complication. Prohibiting a tracheostomy would limit the anesthesiologist's ability to secure Kelly's airway successfully. Furthermore, Kelly could die of respiratory failure in the operating room if the intubation attempts were unsuccessful. The anesthesiologist expressed moral concerns that she had a duty to rescue a patient under her care and that by honoring the patient's wish for no tracheostomy she could be playing a role in "killing" or "euthanizing" the patient.

Commentary

Spinal muscular atrophy (SMA) is considered the most common lethal disease of children younger than 2 years of age in the United States.² SMA results in weakness and wasting of voluntary muscles due to degeneration of anterior horn cells. Intellect is normal and sensation is intact.² In SMA1, also known as Werdnig-Hoffman disease, symptoms of hypotonia and diffuse motor weakness present before the age of 6 months; children with SMA1 typically are never able to sit without support.³ Most children with SMA1 die by the age of 2 due to respiratory failure.³ Survival rates for children with SMA1 have improved for patients born after 1994, likely due to increased use of noninvasive ventilation, invasive ventilation, feeding via gastrostomy, and nutritional supplementation.⁴ The recent introduction of nusinersen can significantly improve functional status and survival in SMA patients who receive this therapy.^{5,6} Nevertheless, for Kelly to have survived to the age of 16 without the need for chronic invasive ventilation is quite unusual.

It is generally accepted that parents or guardians of children with SMA1 may refuse tracheostomy. In a 2012 multinational survey of pediatric pulmonologists and intensivists, 95% felt that parents should be able to refuse tracheostomy in children with SMA1.⁷ In the same survey, 78% felt that intubation and ventilation would be acceptable in the setting of acute respiratory failure, but only 60% felt that it would be an acceptable therapy for chronic respiratory failure.⁷ In Kelly's case, intubation was intended to be a short-term intervention to enable her to recover from an acute pulmonary infection and thus would likely be viewed as appropriate by many physicians, based upon the responses in the survey cited above.

Anesthesiologists are responsible for the "support of life functions under the stress of anesthetic, surgical, obstetrical and radiological manipulations."⁸ This support is

necessary for the safe provision of anesthesia (eg, securing the airway) and for mitigating the undesirable effects or complications of anesthesia and surgery (eg, administering fluids to treat hypotension). In Kelly's case, the administration of sedatives for intubation could cause respiratory depression and airway obstruction; if face mask ventilation and intubation both became impossible, a tracheostomy would be necessary to prevent death. Thus, Kelly and her family's request constrains the usual practice for difficult airway management and could result in Kelly's death under the anesthesiologist's care.

Ethical Analysis

The ethical rationale for allowing patients to request limitations on resuscitation is respect for autonomy—individuals' "right to hold views, make choices, and to take actions based upon their values and beliefs."⁹ This respect is granted to adults in part because they are presumed to have the capacity to understand the decision at hand and to freely accept or reject proposed treatment options. Adolescents, on the other hand, are not considered to be fully autonomous due to a lack of decision-making capacity. In general, the assent of adolescents is sought, but their parents have ultimate authority to make medical decisions.¹⁰ However, several empirical studies have demonstrated that adolescents do not differ from adults in their ability to make rational health care decisions.¹¹⁻¹³ Additionally, it has been suggested that the experience of chronic illness furthers the development of decision-making capacity in adolescents.¹⁴ Capacity assessments employ a series of questions that probe patients' understanding, their ability to express a choice, their appreciation of their particular situation, and their reasoning.¹⁵ In Kelly's case, given her long-standing experience of SMA and consistently demonstrated preferences, we suspect that she has capacity to make the decision to refuse tracheostomy. For this reason, Kelly's assent or refusal should be taken seriously by her parents, as they provide the ultimate authorization for her medical care.

The issue of [adolescent refusal of life-saving treatment](#) remains controversial.¹⁶ Adolescents might focus on short-term outcomes and be overly influenced by socioemotional concerns.¹⁶ Ross has proposed that agreement between adolescent and parent preferences may justify refusal of experimental or low-efficacy treatments.¹⁷ In this case, Kelly's views are concordant with those of her parents. The tracheostomy can be considered a low-efficacy treatment given that it would not alter her prognosis and in light of her goals of retaining the ability to speak and survive independently of long-term mechanical ventilation. Given Kelly's apparent capacity, the concordance between her wishes and those of her parents, and the understanding that a tracheostomy would not change her prognosis, we argue that Kelly's preferences should be respected.

The anesthesiologist's moral quandary stems from concerns about deviating from the standard of care and her perceived potential culpability in a patient's death. Some physicians have argued that placing [limitations on resuscitation in the operating room](#)

demands that anesthesiologists act as if “one hand [were] tied behind the[ir] back” and are “an unreasonable intrusion and distortion of practices that form the very core” of their professional identity.¹⁸ From the perspective of the anesthesiologist in Kelly’s case, intubation and tracheostomy are bundled because the intubation is predicted to be difficult, and the ultimate rescue maneuver for a failed intubation is an emergent tracheostomy.¹⁹ Thus, she sees refraining from a tracheostomy to be an unacceptable deviation from the standard of care.

However, intubation and tracheostomy are distinct concepts for Kelly. The intubation is a temporary intervention aimed at helping her recover from pneumonia. She is willing to accept the incapacity associated with being intubated for a short time if it allows her to return to her prior level of functioning. After much consideration and with her parents’ support, Kelly has decided that life with a tracheostomy would be untenable. To her, life with a tracheostomy would be worse than death. The goals of care established by Kelly and her parents render the typical standard of care less pertinent.

A second concern the anesthesiologist expressed is her perceived potential culpability in a patient’s death. The active nature of care in the operating room has led some to argue that deaths that occur in the operating room are acts of commission, since anesthesia and surgery actively change the patient’s state and can often be said to be the proximate cause of death, while deaths that occur on the medical ward are perceived to be acts of omission, as the patient’s underlying disease is presumed to have prevailed.²⁰ When a patient dies in the operating room, anesthesiologists and surgeons are not asked, “What happened?” They are asked, “What did you do?”²⁰ While acts of commission and omission may feel emotionally different, it is generally accepted that there is no ethical distinction between the two; what makes either act—commission or omission—ethically justifiable are the physician’s obligations to the patient.⁹ If there is no clear duty to provide an intervention (such as a tracheostomy), then withholding or withdrawing treatments could be permissible.⁹ Therefore, key to allaying the anesthesiologist’s fears of culpability would be a clarification of her obligations to Kelly in the setting of this procedure.

Although adult patients have a legal right to refuse medical treatment, as established by the Patient Self-Determination Act of 1990,²¹ questions about how to handle advance directives often come up in the setting of anesthesia and surgery. In a seminal paper on the topic, Robert Truog stated, “With the increasing recognition of the autonomy of the competent patient in medical decision-making, it would be inappropriate not to seek the patient’s guidance and provide as much latitude as possible within the constraints of the physician’s own ethical standards.”²² Subsequently, the American Society of Anesthesiologists (ASA), the American College of Surgeons, and the American Academy of Pediatrics have recommended a process of “required reconsideration” of advance directives in the perioperative period.²³⁻²⁵ This process entails a thoughtful discussion

involving the patient, family, and treating physicians to identify and develop plans to support the patient's goals of care while allowing the team enough latitude to perform the indicated procedures. If such a discussion occurred with Kelly and her family, it would likely become clear to the medical team that Kelly has the capacity to assent or dissent, and that she and her parents concur on the goals of care. Ideally, the team would develop a consensus about the method for the planned intubation, the limits framing the attempt, a range of back-up plans that exclude tracheostomy, and a communication strategy if all attempts are failing and Kelly's death is imminent. The team should be challenged to consider the entire range of management options available for this patient including a completely awake fiberoptic intubation with topical anesthesia, which carries a very low risk of airway compromise or death, or placement of a laryngeal mask airway if intubation is impossible in order to provide ventilation until sedation drugs wear off.

The anesthesiologist could also recommend that Kelly accept a tracheostomy for the short term and defer the decision to continue or withdraw respiratory support until she is back in the ICU supported by her parents. This alternative should only be offered alongside the option of no tracheostomy in order to allow Kelly and her family the opportunity to make a decision consistent with their goals of care.

Honoring Limitations on Resuscitation

Anesthesiologists strive simultaneously to ensure patient comfort while maintaining normal circulation and respiration, and, in most crisis situations, acts of rescue to maintain life take precedence over comfort. However, for patients with terminal conditions who request limitations on resuscitation, the physician's obligations may shift towards ensuring comfort at the expense of sustaining life. Being asked to refrain from rescuing a patient is understandably difficult, but we would urge anesthesiologists to view this scenario similarly to situations in which terminally ill patients request discontinuation of life-sustaining treatments. Honoring an adult patient's or guardian's request for limitations on resuscitation in an operative setting supports the patient's right of self-determination and respects her ability to understand and consider the risks of mortality in a manner consistent with her version of the good. The cause underlying a need for resuscitation, physician induced or otherwise, might be irrelevant to the patient if the patient has considered the potential outcomes and explicitly stated a goal of care.

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

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CASE AND COMMENTARY

How Should Physicians Care for Dying Patients with Amyotrophic Lateral Sclerosis?

Commentary by Alexander Craig, MPhil and Elizabeth Dzung, MD, PhD, MPH

Abstract

We discuss physician aid in dying, euthanasia, and other dimensions of palliative care decision making and define relevant terms raised by this case of a dying patient with amyotrophic lateral sclerosis in Washington State who is unable to self-administer a lethal prescription. We then present a concrete framework that clinicians can directly apply when faced with difficult cases such as this one. We outline how exploring motivations, obtaining informed consent, defining goals, and examining alternatives can help guide physicians like the one in this case. We conclude by summarizing one way in which physicians might balance these issues while still remaining within the constraints of the law.

Case

Dr. S is a palliative care physician in Washington State. He follows a panel of patients longitudinally through their various disease courses. Today in clinic, Dr. S meets with Donald, a patient he's taken care of for a year and has been seeing about once per month. Donald was diagnosed with amyotrophic lateral sclerosis (ALS) last year at the age of 49. Prior to diagnosis, Donald's livelihood was completely dependent on optimal physical fitness and dexterity; as a marathon runner and professional violinist, ALS was profoundly devastating. Over the past year, his disease has been progressing rapidly. Initially presenting with right foot weakness, he now gets around in a wheelchair and health aides help him bathe, use the bathroom, dress, and eat. He has developed mild bilateral upper extremity contractures and is unable to use his hands to carry out even simple tasks. So far, his respiratory function, though declining, has remained intact, but his swallowing function is beginning to deteriorate. He was recently started on a dysphagia diet of pureed food and thickened liquids.

During his appointment, Donald tells Dr. S that, after giving it much thought, he has decided that he wishes to end his life. He explains that his illness has robbed him of everything that has defined him and created meaning in his life—he can no longer run or play his violin, and he is not comfortable being dependent on others for all his basic needs. He knows the disease will inevitably progress to the point at which he will become ventilator dependent, and he is certain that living this way would never be

acceptable to him. "Right now, I can eat. I can talk. I can breathe. I want to die before I lose anything else of importance to me." He asks Dr. S to help him end his life, acknowledging that he is no longer physically able to do so.

For Dr. S, having cared for countless patients suffering from terminal illnesses and practicing in a state that recently passed a death with dignity law, this request is not a new one. Dr. S agrees, in certain circumstances, that physician assistance in dying is appropriate. However, in Donald's case, due to his physical inability to actually take any medications prescribed to hasten his death, Dr. S realizes that his role in Donald's dying process would, at this point, have to be more than "assistance," which he finds troubling. Legally, if Donald passed through the rigorous psychological testing approved by the state, then he would be entitled to a prescription of the needed medication, but Donald's physical inability to voluntarily administer it himself means that he can't actually exercise the right this law grants him. Dr. S regrets that Donald cannot take advantage of this law, which was passed specifically to help terminally ill patients like him in nearly every way except in his incapacity to self-administer a lethal prescription. Dr. S worries that if he does not offer medical assistance to Donald, Donald could feel abandoned, desperate, and helpless and become pressed into a situation in which he pursues a path to death that is isolated, protracted, or violent. Dr. S wonders how to respond to Donald's request for help.

Commentary

Donald's case presents a challenging ethical dilemma that asks us to reflect on the ways in which a physician can act as healer at the end of life. Also relevant are legal issues related to physician aid in dying (PAD), which are important to consider separately from the ethical issues. In this essay, we focus specifically on an ethical framework for physicians faced with difficult end-of-life situations such as Donald's. We offer some ways in which Dr. S can honor Donald's wishes while still remaining on solid ethical footing; we will also discuss the legal implications of Donald's request in the context of acting ethically. Here, we assume that PAD is morally acceptable to Dr. S but that he is troubled by this extension of PAD, which would require him to assume a more active role in Donald's death.

PAD vs Euthanasia

Donald's request highlights the defining line between PAD and euthanasia. Because PAD and euthanasia assign agency very differently to patients and physicians, and because euthanasia would be categorically prohibited under all PAD laws in the US, it is critical to differentiate between the two in this case.

Legally, PAD and euthanasia are differentiated by the degree of physician involvement. In PAD, physicians prescribe lethal drugs that their patients self-administer, whereas in voluntary active euthanasia, physicians themselves administer lethal drugs upon request

by the patient.^{1,2} In the United States, debates over PAD and euthanasia were highlighted in *People v Kevorkian* (2001), a case in which the physician Jack Kevorkian appealed his conviction for second-degree murder in the death of a patient with ALS. In this case, the Michigan Court of Appeals ruled that physician-assisted suicide was tantamount to murder.³ Because the Court indicated that recognizing “a right to be free from intolerable and irremediable suffering” was better left to the state legislatures,³ it is notable that, since the decision, multiple US states have chosen to enact legislation legalizing PAD.^{4,5} Death with dignity (DWD) legislation in Washington and in other states appears to explicitly exclude patients such as Donald since the drug must be self-ingested⁴ and the alternative, euthanasia, is illegal in all US states,⁶ although it is [legal in Belgium and the Netherlands](#) provided patients give their explicit consent.⁷

Due to patients’ inability to self-ingest lethal drugs, ALS is a disease that lies at the center of ethical debates surrounding PAD. In Washington State, eligibility criteria based on a “reasonable medical judgment”⁴ include a capacity to make decisions, a prognosis of 6 months or less, and an ability to self-ingest the lethal drug. In contrast, the Oregon law is less clear in its requirement for patients to self-administer.⁵ People might assume that the disease trajectory of ALS bars them from utilizing death with dignity laws, but some Washington State clinicians note that patients occasionally “needed to compress a syringe to ‘self-administer’ the medication,”⁸ which is technically legal because it represents “a qualified patient’s act of ingesting medication to end his or her life.”⁴

Steps to Honoring PAD

When patients ask physicians for assistance in ending their lives and state laws include PAD as an option, it is helpful to consider the following steps to honor these requests. While there are clearly legal issues to consider, here we focus on the ethical issues inherent in the case.

Explore motivations. First, before offering a response, the physician should explore the patient’s reasons for the request. The physician should also identify, treat, or refer for any psychiatric conditions that might be relevant. In this case, Donald’s motivations are relatively clear. Loss of ability to engage in activities that make life meaningful is a common reason for terminally ill patients to pursue PAD, as is desire for control over the way their death arrives.⁹ Merely having the drug available might help strengthen patients’ feelings of self-determination. It is also important that physicians be mindful of their own personal responses to requests like Donald’s, as PAD is an issue that can evoke strong reactions from many physicians.¹⁰ Because exploring motivations is required for physicians to do right by their patients, it is at this point that the framework of principlism becomes relevant.¹¹ Applying principlism, the physician identifies and weighs harms and benefits, seeking to maximize beneficence, nonmaleficence, respect for autonomy, and justice as relevant to the case.

Physicians should invest time and energy in conversations devoted to exploring patients' motivations for their goals at the end of life in order to consider what is in their best interests and to maximize beneficence. The challenge is that it is often unclear what constitutes "beneficial." In pursuing beneficence, Dr. S should consider Donald's positive right to a "[good death](#)" as he defines it. Importantly, this right requires Dr. S to explore what Donald considers a "good life" and how the quality of his life has been affected by ALS. Dr. S must be mindful of the fact that the meaning—ie, the subjectively perceived existential value—of one's own life is not static but rather changes over one's lifetime, sometimes very quickly as death approaches. Additionally, he needs to consider Donald's negative right to be free from existential suffering—from loss of what makes him a whole person, of the ability to do the things that sustain meaning in his life, and of his independence.

While physicians are obligated to explore what a good life and good death mean for their patients, it is crucial that the patients define these terms for themselves, lest physicians not only fail to maximize beneficence but also jeopardize respect for autonomy.

Obtain informed consent. Once Donald's motivations have been thoroughly explored and determined to be genuinely his own, Dr. S should next secure informed consent from Donald. This is an ethical requirement for respecting Donald's autonomy¹² as well as a formal legal requirement for accessing the death with dignity law.⁴ Donald has already articulated an understanding of his situation and expressed a coherent choice through sound reasoning, but no discussion of consent is complete without eliciting patient understanding of the alternatives. Dr. S should discuss with Donald what living with his disease could look like with palliative care (loss of function and symptom management) and without palliative care (loss of function and progressively worsening symptoms). Donald should be made aware of the wide spectrum of palliative care options (discussed below in more detail) and that he does not have to accept additional life-sustaining treatments that are inconsistent with his goals and values.

Additionally, although Donald seems to clearly have capacity in this case, physicians in general should consider the [decision-making capacity](#) of their patients in such situations. Surrogates should be aware of and participate in these discussions so that they can continue to advocate for the patient when the patient loses capacity.

Finally, negative autonomy, or "freedom from," is also relevant. Donald as well as future patients should be free from potential abuse from active physician involvement without patient consent, and Dr. S should likewise be free from being forced to prescribe against his own ethical convictions.¹³

Define goals. After learning what brings meaning to the patient's life, the physician should discuss the prognosis and goals of care with the patient to avoid treatments that could

do the patient more harm than good. Dr. S needs to specify what nonmaleficence or to “do no harm” means, which includes accounting for both potential and actual harms to Donald. However, specifying what constitutes nonmaleficence is not always easy, and physicians often have strong opinions on what is appropriate. It is important to recognize that, for many physicians, PAD entails an actual harm *ipso facto* to the patient. On this view, engaging in PAD would violate the physician’s oath, and it would therefore be categorically impossible to respect the principle of nonmaleficence through PAD.¹⁴⁻¹⁷ Others may believe that by not honoring Donald’s request and allowing his natural disease course to continue, Dr. S would be bringing about significant actual harm to the patient-physician relationship or a potentially painful, isolated, or otherwise problematic death, including suicide.

Significant harm can come to patients when clinicians deny patients’ agency, choice, or autonomy. Therefore, Dr. S needs to find out what Donald hopes to get from health care. It is wrong to assume that death per se is Donald’s only goal. In fact, implicit in the case description is that Donald wants freedom from suffering further decline in his ability to engage in meaningful pursuits. Other possible goals could be maintaining self-determination, having a peaceful death, preserving dignity, or avoiding an isolated state in which he is unable to interact with loved ones in a meaningful way. When considering nonmaleficence, all physicians need to weigh the inherent harms they attribute to PAD against the potential harms of refusing to prescribe lethal drugs. This particular balance will vary for each physician, patient, and situation.

Examine alternatives. Finally, the physician should discuss alternative management options. Apart from PAD, Donald might not be aware of the spectrum of end-of-life interventions, any one of which might be at least as well aligned with his goals and wishes as PAD. In addition to aggressive palliative care support, these interventions include voluntarily stopping eating and drinking, withdrawal of respiratory support and life-sustaining treatments, pain medications that are known to hasten death, and [palliative sedation](#). Although in this case Donald has actively sought out PAD on his own initiative, in general physicians should be careful never to present PAD as the only option. Furthermore, Dr. S should ensure that Donald’s palliative care needs are being adequately addressed and that he is aware of hospice as an option, since inadequate symptom management could be a motivation for Donald to pursue PAD.¹⁸

In addition to exploring Donald’s motivations related to his personal experience, Dr. S should explore other potential motivations for Donald’s seeking PAD. In particular, Dr. S should ensure that Donald is not seeking lethal drugs due to lack of financial resources to pursue other palliative care options. Despite the high cost of PAD drugs (approximately \$3 000),¹⁹ they are still significantly less expensive than many life-sustaining treatments, especially when a complex disease approaches its terminus. It would be an injustice to offer PAD in the setting of inadequate palliative care services, a concern that

disproportionally harms patients of lower socioeconomic status. The case of Barbara Wagner in Oregon is perhaps the best example of this injustice: her insurance provider refused to pay for erlotinib, an expensive chemotherapy treatment, but did offer to reimburse PAD drugs; her case is unfortunately not isolated.²⁰ PAD must not become a preferentially attractive option for the poor; instead, the physician should make every attempt to connect the patient with other resources.

It is also important for physicians to be mindful of how race can affect choice or discussion of PAD. African-American patients are less likely than white patients to enroll in palliative care,²¹ possibly due to medicine's history of marginalizing this population and existing structural injustices. There has been concern that PAD could negatively affect vulnerable populations.¹⁸ Discussions of PAD might pose particular challenges for minorities, whose attitudes surrounding death and dying might reflect mistrust in health care professionals in part due to personal and historical experiences.²¹

Reflections

This concrete framework would help Dr. S understand Donald's request and also allow Donald to consider other options that might be better aligned with his motivations and goals. If Donald still wants Dr. S to help him end his life, Dr. S could consider one approach that has been used in Washington State: family members preparing the drug and assisting with its placement in the patient's mouth or feeding tube. If this approach were used with Donald, Donald would then subsequently self-administer by moving his head or by pushing the syringe with the lethal drug into his mouth or feeding tube.²² If Dr. S feels this option would be appropriate for him and his patient, it would allow Donald to exercise his autonomy while enabling Dr. S to minimize nonmaleficence by maintaining the patient-physician relationship. Ethically it could be permissible and, in Washington State, compressing a syringe to self-administer has been found to be legally acceptable, as discussed above. However, legally there is controversy surrounding this option in some US states,²² given that it could be seen to constitute euthanasia. Currently, this option resides in a legal and ethical gray zone.

PAD presents significant ethical challenges, especially when patients are unable to self-administer the drugs. Physicians should plan for in-depth conversations exploring motivations, determining capacity, defining goals, and elaborating alternatives. Throughout this process, it is vital that physicians remain aware of their own personal reactions to the patient's request and be mindful of strong views on this issue. Physicians should also seek the support of their colleagues in palliative care for both symptom management and goals-of-care conversations.

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CASE AND COMMENTARY

Should Physicians New to a Case Counsel Patients and Their Families to Change Course at the End of Life?

Commentary by Shyoko Honiden MD, MSc and Jennifer Possick, MD

Abstract

Although new cancer therapies have changed the prognosis for some patients with advanced malignancies, the potential benefit for an individual patient remains difficult to predict. This uncertainty has impacted goals-of-care discussions for oncology patients during critical illness. Physicians need to have transparent discussions about end-of-life care options that explore different perspectives and acknowledge uncertainty. Considering a case of a new physician's objections to an established care plan that prioritizes comfort measures, we review physician practice variation, clinical momentum, and possible moral objections. We explore how to approach such conflict and discuss whether and when it is appropriate for physicians new to a case to challenge established goals of care.

Case

Dr. T is a medical intensivist who has been an attending physician on the intensive care unit (ICU) service for the past week and will hand off her patients' care to another intensivist, Dr. B. While signing over her patients, Dr. T took great care to relay each patient's case details, gathered in part from meeting time with each patient's family.

John is a 65-year-old man with stage IV non-small cell lung cancer. Previously healthy and active, he was diagnosed 6 months ago and underwent several rounds of palliative chemotherapy and radiation. Despite aggressive treatment, his disease and symptoms continued to progress; due to his previously very high level of functioning, however, he was considered a good candidate for a new clinical trial with a novel regimen that has some positive preliminary results in refractory Stage IV disease. Unfortunately, right before starting this treatment, John became critically ill. Two weeks ago, he was admitted to the ICU with acute respiratory distress syndrome (ARDS) and septic shock from pneumonia requiring multiple medications to stabilize his blood pressure.

Despite the long hospital course, within 2 weeks, John had stabilized. He was on minimal ventilator settings, had weaned off vasopressors, and no longer required antibiotics. However, John remained intermittently delirious, and any time a nurse would try to

lighten his sedation he became severely agitated, attempting to pull at lines and his breathing tube. Although spontaneous breathing trials had been attempted daily, John continued to fail them due to severe agitation and an increased respiratory rate.

Although now medically stable overall, John was nearing a point of requiring a tracheostomy due to the prolonged duration of intubation. In light of his advanced disease and protracted hospital course, Dr. T and John's wife, Lisa, had discussed goals of care on multiple occasions. Because John is currently incapacitated, he has been unable to participate in any decision making. Lisa, having never discussed John's wishes with him in the past and feeling overwhelmed by the situation, turned to Dr. T for guidance. Considering the combination of widely metastatic disease, severe deconditioning, and inability to wean from the ventilator, Dr. T reasoned that John's chance of achieving any kind of meaningful recovery was extremely unlikely. Importantly, it seemed unlikely that he would ultimately become well enough to enroll in the clinical trial. Instead, she thought in John's case that more interventions were likely to inflict harm and increase complications. Dr. T recommended against the tracheostomy in favor of transition to hospice care. After giving it much thought and discussing it with her children, Lisa agreed with Dr. T's recommendation and decided on terminal extubation with transition to comfort measures only. To give time for family to arrive from out of town, the plan was for John to be extubated Saturday, the day that Dr. B would be taking over John's care.

As Dr. B listened to Dr. T review the case, he became increasingly uneasy with the plan that he was signed out to implement. Dr. B did not feel comfortable with terminal extubation for John. He felt that his respiratory prognosis remained uncertain and that transition to tracheostomy might facilitate decrease in sedation and improvement in mental status. He could not rule out the possibility that John might eventually become a candidate for clinical trial entry. Dr. B offered, "John has an advanced malignancy, but two weeks ago, was deemed a good candidate for a clinical trial with promising preliminary results—why not keep going and try to give him the best shot we can?" Although he realized the chances of John making a recovery to baseline were small, he had seen some dramatic recoveries by similar patients, so he did not deem terminal extubation appropriate at this time. Dr. B was inclined to advocate for tracheostomy in hopes that John could recover enough to allow potentially life-saving therapy.

Dr. T, a colleague for whom he had great respect, had established a relationship with the family, knew them well, and had developed a comfort care-oriented plan that the family felt comfortable with and seemed ready to implement. Tomorrow he would come to work and be expected to take over where Dr. T had left off. Perhaps he should leave things the way they were, but now that John was under his care, Dr. B wondered whether he should help John pursue a different, more aggressive acute care-oriented plan.

Commentary

This case highlights how rapidly evolving cancer therapeutics challenge our understanding of “advanced-stage” disease and lend new nuance to end-of-life (EOL) decision making. According to the National Cancer Institute, the overall 5-year survival rate for those diagnosed with stage IV non-small cell lung cancer (NSCLC) remains around 5%.¹ However, thanks to mutation-specific agents and immunotherapies, long-term survivorship has become a possibility for some patients.² [Conversations about prognosis](#), critical illness, and EOL are understandably influenced by these advances and can yield divergent recommendations from different physicians. Here we will focus on physician-centered and systems-based forces that impact EOL decision making and explore whether it is ever appropriate for physicians assuming care at a critical juncture to counsel patients (and families) to revisit decisions.

Physician Practice Variation as a Force in Decision Making

Surveys suggest that most patients prefer to die without aggressive life-sustaining therapies,³ yet roughly 25% of Medicare beneficiaries die in the hospital.⁴ Although this issue is complex and reflects many factors, some studies have highlighted the influence of physician practice variation. A recent study of nearly 200 000 patients with metastatic cancer found that the single most influential factor in determining whether a patient died in hospice care was the lead physician’s prior referral frequency to hospice.⁵ Another study of nearly 22 000 Medicare patients with advanced NSCLC found that 43% received chemotherapy within 30 days of death and that after adjusting for other patient and physician characteristics, physician practice in a smaller independent office was a predictor of more aggressive care.⁶ What motivates physicians to pursue or reject aggressive care is not known but could include factors such as personal beliefs, personality, knowledge deficits, and cognitive biases.

Practice variation as a potential problem in decision making. Such heterogeneity in physician practice raises a question about whether [practice variation](#) is inherently bad. The notion of a second opinion arises from patients’ recognition that different clinicians approach cases differently and that they can seek such opinions to either elicit other perspectives or confirm a prior decision. This process has value independent of the outcome. Most patients with cancer seeking a second opinion at crucial junctures in care report that the process is helpful and reassuring, regardless of whether such consultations yield a divergent diagnosis or alternative therapies.^{7,8} Within established parameters of best practice, nuanced recommendations are expected and encouraged in the pursuit of personalized, patient-centered care, and informed decision making is supported by the clinician community. As an example, the American Cancer Society provides detailed patient resources on this topic and encourages patients to solicit a variety of perspectives to inform their decision making.⁹

In the shared decision-making model, respect for patient autonomy is tempered by physician expertise and judgment, and decisions are neither solely vested with the patient nor paternalistically with any one clinician. Confronting uncertainty and acknowledging differing opinions are important aspects of effective communication in this model.¹⁰ Rather than undermining clinician credibility, such actions are more likely to foster trust and respect provided a clear recommendation is conveyed. For example, family members who were surveyed after the patient's death reported that they would have wanted more communication regarding *prognostic uncertainty*, including knowledge that death was possible or probable, to help inform decision making.¹¹ Withholding divergent opinions, particularly at critical decision points, can undermine effective partnerships. Thus, physician practice variation is not inherently bad—but recommendations must be conveyed carefully and effectively in a dialogue including many perspectives. That medicine is both an art and a science is widely accepted.

Exploring physician variation in the clinical vignette. In the present case, Dr. T and Dr. B have a difference of opinion regarding John's prognosis. Dr. T viewed John's chance of achieving ventilator liberation and eventually receiving further treatment as infinitesimally small, while the risks of ongoing harm and suffering were great. Dr. B similarly acknowledged that chances were slim but framed the prognosis differently. He saw John as "stable" with the possibility of further improvement and, given his good premorbid functional status, wanted to give him the benefit of the doubt. The vignette also suggests that Dr. B's recollection of dramatic recoveries by other patients is an instance of confirmation bias, which is a tendency to interpret or recall information in a way that confirms one's own hypothesis. The pertinent question here is how likely these recoveries are, how relevant these anecdotal cases are to John's current situation, and what the risks and benefits of further aggressive treatment might be.

If Dr. T did not acknowledge prognostic uncertainty when Lisa solicited an opinion from him to guide her decisions, Dr. B's discomfort might be justified. Assuming Dr. T was transparent about prognostic uncertainty, his recommendation for conservative management seems reasonable, given that John had entered a phase of chronic critical illness with low likelihood of a good outcome (a perspective shared by Dr. B). Importantly, Lisa was given time to consider this information and discuss it with her children. With all in agreement, she elected comfort measures and the family was given sufficient time to execute that decision in a meaningful way (ie, waiting for family to arrive from out of town). Ultimately, if risks, benefits, and alternatives were reasonably discussed and patient values and goals were elicited, Dr. T's recommendation sufficiently balances respect for autonomy with an informed physician perspective, thereby adhering to the principles of shared decision making.

Clinical Momentum as an Underappreciated Force

Clinical momentum is a systems-level force that can propagate unwanted aggressive care during critical illness or at EOL.¹² Akin to a biologic cascade like hemostasis, an initial clinical circumstance prompts therapeutic actions that in turn propagate more interventions, even when clinical circumstances have changed. Frequent hand-offs of care in the critical care setting make it even more challenging for clinicians to be cognizant of the power of clinical momentum. Physicians covering a complex and critically ill patient over a weekend or during a 12-hour night shift, for example, might find it comparatively more difficult to appreciate a larger, longer context of a patient's care than physicians taking care of that patient over a longer duration. They might be more likely to make decisions—even significant ones—based on impressions formed in narrower timeframes.

As in John's case, tracheostomy frequently signifies a pivotal turning point in the management of persistent respiratory failure, as it represents a commitment to a plan of chronic ventilatory support or long-term weaning.¹² And yet, for patients and families, this distinction might seem artificial and difficult to distinguish from the myriad of critical decisions favoring aggressive care that have already been made, such as vasopressor support and mechanical ventilation. Families might acquiesce to a series of smaller decisions that, in aggregate, are not aligned with patient preferences and fail to appreciate that certain choices, like tracheostomy, contribute to the [momentum of aggressive care](#). Indeed, clinical momentum is often unrecognized in the moment and hinders patients, families, and clinicians from pausing to consider alternatives and long-term outcomes.¹²

In the present vignette, there is no apparent conflict between Lisa and Dr. T about transitioning John to comfort measures. In fact, the shift from aggressive to comfort-focused care signifies a willingness to disrupt preexisting clinical momentum and can motivate appropriate realignment with patient goals, given the prognostic information available. However, one might wonder whether Dr. B is unconsciously influenced by clinical momentum. Dr. B perceives John to be stable (because he is now on minimal ventilator settings and weaned off vasopressors) after a rocky ICU course with severe ARDS and septic shock. He hopes that with a tracheostomy in place, John might become less delirious and agitated, weaned from the ventilator, and ultimately a candidate for future chemotherapy. But how likely is this?

Acute respiratory failure is a leading diagnosis among patients with cancer admitted to the ICU and a significant source of mortality.^{13,14} In a cohort of 5 000 cancer patients requiring ventilator support for more than 21 days, median 1-year survival was 14.3%.¹⁵ Subgroup analysis of those with lung cancer revealed a dismal 1-year survival rate of 6.6%.¹⁵ One could postulate that, among patients requiring ventilator support for several weeks like John, achieving a sufficient performance status to receive investigational

therapy would be unusual. Such discouraging data support the hypothesis that Dr. B might have succumbed to clinical momentum in advocating for ongoing aggressive measures in a cancer patient with respiratory failure. In upholding the principles of beneficence and maleficence, it is important for physicians to be able to navigate a medical environment primed to propagate clinical momentum and to avoid imposing unwanted aggressive care upon patients and their families.

Dr. B's Potential Moral Objections

Dr. B's discomfort with the current plan of care might be broken down into concerns regarding respect for autonomy, beneficence, and, finally, personal objection. Is Dr. B concerned that Lisa was inappropriately counseled by Dr. T? If there is evidence that information Dr. T provided about the prognosis was incorrect or that communication was ineffective or coercive, Dr. B is obligated to revisit the goals-of-care discussion, framing all the facts of John's case in an objective manner to ensure that Lisa would be able to make decisions based on her representation of John's best interests. However, if no such concern exists, placing a grieving family at the center of an intellectual conflict is unnecessarily destructive. Professional disagreements about inappropriate care must be distinguished from moral objections to valid care decisions. Our obligation as physicians, first and foremost, is to help patients and families through effective peer-to-peer communication during patient care transfers. Dr. T. could frame the present plan of care by outlining a summary of John's overall course, his evidence-based prognosis, and his proxy-represented wishes based on this information, while Dr. B could raise his concerns at the time of transfer of care to facilitate a collegial discussion.

A good next question is whether Dr. B is required to execute a plan that he does not fully endorse. Does his objection rise to the level of moral objection—such as being asked to terminate a pregnancy in the face of a religious or spiritual objection? Dr. B's objection is unlikely to reach that threshold. Physicians sometimes support decisions made by patients that they do not agree with—for example, a fully informed decision made by a patient to [forgo intubation](#) even when there is significant chance of benefit and meaningful recovery. This decision might not be one that the physician would personally elect, but that does not preclude another reasonable person from suggesting or selecting an alternate course, and thus patient autonomy should be respected. While not often talked about in the context of another clinician's decision, the professional autonomy of a clinician should be accorded respect much like the patient's personal autonomy, especially in view of the reality of physician practice variation previously explored.

There is very little in the literature about how to resolve treatment conflict among clinicians. Some concepts can be borrowed from futility disputes, although such disputes typically pertain to conflict between physicians and families. And while futile care is an extreme scenario not illustrated in this case, resolving concerns related to potentially inappropriate care can draw upon similar interprofessional communication strategies for

conflict resolution.^{16,17} While no single approach can be recommended, effective communication and trust building are necessary for treatment conflict resolution. If Dr. B cannot accept Dr. T's plan as outlined, an open discussion between the two physicians is an excellent start. The involvement of another impartial physician, much like a second medical opinion sought in futility disputes between a clinician and patient, might be helpful. If deemed necessary to reinvolve family, both physicians should be present to facilitate discussion in a way that does not jeopardize the existing trust and the relationship between Dr. T and the family and avoids undue emotional distress. If the family remains comfortable with the original decision, but Dr. B remains troubled, reassigning John and his family to another ICU team who can execute the plan could be the best course of action.

Fostering Dialogue about EOL Care

In summary, physician practice variation is common and reflects prognostic uncertainty, particularly in fields of evolving therapeutic options. In the shared decision-making model, respect for patient (or surrogate) autonomy and well-informed and well-communicated physician judgment are both considered in aligning difficult care decisions with patients' values and preferences. Verbalizing prognostic uncertainty or differences in opinion could strengthen trust between physicians, patients, and families by acknowledging that such gray areas exist. We should embrace and invite differing perspectives from our peers and encourage dialogue about critical decisions at transfers of care, neither yielding to inappropriate clinical momentum nor unnecessarily derailing care plans that are thoughtful, supported by available data, and appropriately communicated to patients and families.

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CASE AND COMMENTARY

How Should Physicians Manage Organ Donation after the Circulatory Determination of Death in Patients with Extremely Poor Neurological Prognosis?

Commentary by James L. Bernat, MD and Nathaniel M. Robbins, MD

Abstract

Organ donation after the circulatory determination of death (DCDD) accounts for a growing percentage of deceased organ donations. Although hospital DCDD protocols stipulate donor death determination, some do not adhere to national guidelines that require mechanical, not electrical, asystole. Surrogate decisions to withdraw life-sustaining therapy should be separated from decisions to donate organs. Donor families should be given sufficient information about the DCDD protocol and its impact on the dying process to provide informed consent, and donors should be given proper palliative care during dying. An unresolved ethical question is whether and how donor consent should be seen as authorizing manipulation of a living donor during the dying process solely for to benefit of the organ recipient.

Case

Jenna is a 21-year-old woman involved in a motor vehicle accident. She suffers severe head trauma and is emergently intubated at the scene by emergency medical services personnel who immediately transport her to the nearest level I trauma center. Jenna remains comatose for several days in the intensive care unit (ICU) without any signs of neurologic recovery. Scans of her brain revealed signs of severe cortical injury, but a neurologic exam suggests that some brain stem reflexes still remain. Her devastated family members understand her very poor prognosis and inquire about organ donation, as Jenna was listed as an organ donor and had been very active in promoting organ donation. They feel strongly that donation is what she would want.

Because Jenna does not meet criteria for brain death, the medical team members discuss cardiac death with her family and review the specifics of the protocol with them. In order to meet criteria for cardiac death, Jenna would be taken to the operating room where she would be extubated and her vital signs monitored and timed closely for the next hour. If, within that hour, her heart were to stop beating and remain stopped for 5 minutes, it would be considered irreversible cardiac death and thus organ procurement would begin immediately. If, however, after an hour Jenna's heart continued to beat, she would no

longer be eligible to be an organ donor as prolonged ischemia would render her organs unusable, and instead she would be taken back to the ICU and receive hospice care. Her family members do not want her to suffer, and they are reassured by her physicians that regardless of whether her organs can be procured and donated, her comfort will be their highest priority. That being said, they are hopeful that she will be able to donate her organs, both so that something hopeful might come from such an immense tragedy and to honor and uphold Jenna's own very clear wishes to be an organ donor.

In the operating room, Jenna is extubated with Dr. K, the medical intensivist overseeing the process. Her breathing continues initially for about 25 minutes and then becomes progressively slower. The team watches as her oxygen saturations begin to dwindle. At about 45 minutes postextubation, Jenna's oxygen saturations drop dramatically. Her heart continues to beat, though slowly. At 52 minutes and 35 seconds, the monitors show asystole, the complete cessation of electrical activity of the heart. A timer is started. One minute passes followed by 2, then 3, then, "What was that?" one of the technicians asks, staring at the heart monitor. A small blip on the rhythm strip had appeared on the screen for less than 1 second. "I think I might have bumped the table," says a nurse. "It's probably just artifact," she adds, turning to Dr. K. Staring at the clock, Dr. K knows that if he counts that small quiver on the screen as a heartbeat, then there will not be enough time left to restart the clock and for Jenna to remain asystolic for the designated 5 minutes. In other words, if it's counted as a heartbeat, Jenna would be sent to the ICU, likely die within minutes of leaving the operating room, and her organs would no longer be viable for donation.

Dr. K considers whether to count it.

Commentary

The practice of organ donation after the circulatory determination of death (DCDD) is increasing in frequency throughout the United States, Canada, and many European countries. This increase results from a greater interest of families of dying patients in donating organs and from the spread of hospital DCDD programs.¹ In the United States, Canada, and the United Kingdom, only "controlled" DCDD is practiced. In controlled DCDD, potential donors are ICU patients dependent on tracheal positive-pressure ventilation, usually because of profound brain damage, whose lawful surrogate decision makers have decided to withdraw life-sustaining therapy (LST) to allow them to die but have requested that they be organ donors after death. By aligning the timing of withdrawal of LST and subsequent circulatory death determination with the readiness of the transplantation surgical staff, the DCDD protocol allows for rapid recovery of organs, usually the kidneys and liver, and occasionally others, before the onset of ischemic organ injury.²

In several European countries, the accepted practice is “uncontrolled” DCDD, in which prospective donors are patients who sustained a sudden primary cardiac or respiratory arrest from which they could not be resuscitated. These patients are declared dead and, if deemed to be suitable organ donors, are then intubated, ventilated, and placed on a mechanical chest compression device to maintain oxygenation and circulation prior to organ donation.³ Trials of these protocols in the United States have failed largely because of the inability to obtain informed consent for donation from a lawful surrogate decision maker in the setting of a sudden unexpected death, usually occurring outside the hospital.^{4,5} Uncontrolled DCDD protocols have been conducted most successfully in Spain where the prevailing presumed consent law provides [automatic consent](#) for organ donation unless the potential donor previously had opted out.⁶

This case offers several discussion points centered on the proper management of a prospective DCDD donor, informed consent for DCDD, and the death determination of the donor. In the United States, individual medical centers and organ procurement organizations draft their own DCDD protocols, including the standards for death determination, which often vary, sometimes significantly.² Nevertheless, there are accepted general principles⁷ and national guidelines⁸ that should inform the design of DCDD protocols and improve the uniformity of death determination procedures. In our commentary, we show how the management of the case departs in several ways from established DCDD principles and guidelines, and we discuss several practical and ethical challenges posed by the case.

Determining Prognosis and Appropriate Treatment

The 21-year-old-woman in coma several days following a severe traumatic brain injury (TBI) was said to have a very poor prognosis. However, this prognosis could be overstated because young TBI patients with some brain stem function can occasionally make significant functional recovery.⁹ Neurointensivists caring for her must be careful to pronounce a rigorous evidence-based prognosis. The absence of brain stem functioning is an important element in an early prognostic score, often indicating if the patient had undergone uncal transtentorial herniation, which heralds irreversible brain stem damage. It is incumbent on neurointensivists to be confident of a poor prognosis when making decisions to withdraw LST after the first several days following a TBI in a young person to avoid creating a self-fulfilling prophecy.¹⁰ Clarity of [physician communication](#) is essential and a numeric estimate of prognosis on the basis of outcome studies is helpful to avoid family members understanding a different account than physicians think they have presented.¹¹

In this case, we were surprised to note that family members began discussing organ donation before discussing their level of certainty that, because of her poor prognosis, Jenna would wish to have LST discontinued and die. Although withdrawal of LST is a prerequisite for controlled DCDD, there is a strong consensus in the medical, ethics, and

organ donation communities that the decision to be an organ donor should be uncoupled from and never drive the decision to withdraw LST.¹² The obvious reason for uncoupling the two considerations is that the instrumental benefit of organ donation should not determine the treatment of the potential donor. The decision to withdraw LST must be made on the basis of determining and following the patient's personal values and preferences to the extent that they can be known. Advance directives can be useful to provide first-person expressed wishes but are unlikely to have been executed by a previously healthy 21-year-old woman and are not mentioned in the case report.

The lawful surrogate first must determine what type of treatment Jenna would have wished to have in this circumstance and then follow it. If the surrogate does not know Jenna's expressed wishes but knows something about Jenna's values and treatment preferences, the surrogate can apply the [substituted judgment standard](#) to try to reproduce a decision that Jenna would have made were she capable of deciding. If the surrogate does not know Jenna's values and treatment preferences or expressed wishes, he or she can use the best interest standard to try to weigh prospective benefits against prospective burdens of therapy. Given the family members' claim that Jenna wanted to be an organ donor, perhaps they assumed that, in this situation, she also would have wanted withdrawal of LST to allow her to die. But this omitted step is absolutely essential and should not be glossed over. Ideally, Jenna's physicians first should have asked her lawful surrogate decision maker if Jenna would have wished to receive further life-sustaining therapy given her prognosis. If she would not, then they could raise the option of her serving as an organ donor after the circulatory determination of death.

Determination of Death

The case repeatedly uses the outmoded phrase "cardiac death." Although this phrase, like "nonheart-beating" organ donor, was formerly accepted, over the past 12 years or so it has been replaced by the phrase "circulatory death." The rationale for this change in terminology is that all death statutes in the United States, which are modeled after the Uniform Determination of Death Act (approved by the National Conference of Commissioners on Uniform State Laws in 1981) use the phrase "cessation of circulatory and respiratory functions" to underscore that the absence of circulation determines death, not the absence of cardiac function.⁸ Although the heart usually is the source of circulation, other sources include cardiopulmonary resuscitation (CPR), heart-lung machines, and extracorporeal membrane oxygenation (ECMO). These technologies can provide circulation and support life when the heart is stopped or even surgically absent. What counts in a death determination therefore is the cessation of circulation. That is why the word "cardiac" has been replaced by "circulatory" in the acronym DCDD.^{2,9,13}

The physicians declaring death in this case apparently required electrical asystole as proof of circulatory death, which is why the presence of the questionable blip on the electrocardiographic monitor created such a problem. But in 2005, a national consensus

was reached within the DCDD community of intensivists and organ donation professionals that electrical asystole, while establishing complete cessation of circulation, is unnecessary, and mechanical asystole constitutes sufficient evidence of circulatory cessation.⁷ Thus, pulseless electrical cardiac activity, a common type of mechanical asystole, is considered circulatory cessation. The consensus holds that DCDD protocols for donor death determination should require only mechanical asystole and not electrical asystole as was demanded in this case. Residual electrical activity within the cardiac conduction system that does not generate a cardiac contraction producing circulation therefore is irrelevant to death determination. There might be a few hospitals whose DCDD protocols require electrical asystole for death determination, but the majority do not. If Dr. K.'s hospital protocol complies with currently accepted standards for circulatory death determination, the presence of the questionable electrocardiographic blip in this case would not have been an issue.

The protocol in this case describes a strict adherence to a 60-minute interval after death declaration in which DCDD is permitted. Although it is true that many planned cases of DCDD cannot be conducted because the patient does not die within the time interval after death declaration permitted by the protocol, there are no national guidelines on this time limit and it varies among transplant centers.⁷ Many centers respect a 60-minute limit,⁷ but some use 90 minutes and others even longer depending upon the preferences of the organ transplantation team. The time limit is stipulated not simply because transplanted organ health declines with longer dying intervals. Rather, it exists because the surgical staff members in the operating room remain scrubbed, gowned, gloved, and ready to procure organs and, as a logistical matter, they cannot wait indefinitely for the potential donor to die. Therefore, each medical center delineates a time limit after extubation based on its own resources such that, if the prospective donor remains alive, the donation is cancelled.⁷ In any event, the time limit is not an absolute cutoff (as suggested in this case) and can be negotiated in each case with the transplantation team. If Dr. K.'s hospital still followed an electrical asystole death determination standard, a longer observation period would be necessary in the presence of uncertainty about death determination, as in this case.

Palliative Care of the Organ Donor

The case does not mention donor palliative care during dying from LST withdrawal. There is a clear consensus among critical care and organ donor professionals that, during dying, DCDD donors should receive the same type of palliative care that nondonors receive after LST is withdrawn.⁸ Typically, DCDD donor palliative care in dying includes the judicious administration of opioid and benzodiazepine drugs to prevent possible suffering.¹⁴ Only when this palliative care is ordered and administered can Jenna's critical care physicians remain confident that they have fulfilled their promise that "her comfort will be their highest priority." The process of organ retrieval should not interfere with the

dying patient's medical care unless premortem interventions using catheters or drugs are prescribed for organ survival benefit.

Informed Consent for Organ Donation

Additional ethical issues raised in this case include the standards of informed consent for organ donation, including the permissible manipulation of the dying donor for the health of the procured organ. The consent issue encompasses 2 questions that physicians should explain to surrogates: how death occurs in prospective DCDD donors and how organ procurement impacts the dying process. There is evidence that surrogate consent for DCDD currently is inadequate because surveyed surrogates lack an understanding of the process of dying and the impact of donation.¹⁵ Surrogates and other family members deserve to know that withdrawal of LST will be conducted by the patient's critical care physician in the same way as he or she would do in a nondonation situation.¹⁶ But, in this case, for efficiency of donation, the withdrawal of LST will be performed in or near the operating room. In some centers, it is performed in the ICU and immediately following death declaration, the deceased patient is rushed to the operating room for organ procurement. In either location, many DCDD programs permit family members to remain present during extubation and death determination if they wish.

During the consent process, surrogates and family members need to be reassured that the same palliative measures during dying will be ordered as in withdrawal of LST in nondonation circumstances. They should be told that, after extubation, the patient's inadequate respiratory drive will produce respiratory failure, which will induce cardiac arrest within a relatively short time because of progressive hypoxemia. To allow the patient to die, no CPR or other circulatory or respiratory support will be attempted and, by protocol, death will be declared after a full 5 minutes of circulatory and respiratory arrest. Family members also need to be told that there is a reasonable chance that the patient will not die during the prescribed time interval after withdrawal of LST and, if that happens, donation will be cancelled for logistical reasons and the patient returned to the ICU.²

The consent process also should include the issue of permissible manipulation of the dying donor for the health of the procured organ. Permissible interventions vary among DCDD programs and remain a controversial subject with wide practice variations.^{2,17} Proponents of allowing donor interventions for the health of the organ argue that the donor will die anyway and therefore cannot be harmed significantly and that, furthermore, premortem treatment with catheters, drugs, and fluids might improve donor organ health and therefore the chances of normal functioning of the organ once transplanted.¹⁸ Advocates further claim that because the organ donor wishes to donate and these techniques will lead to more successful transplantation, their use is thereby following the donor's wishes. Opponents argue that it is wrong, even with donor or surrogate consent, to manipulate the living donor or to interfere with the donor's dying

process because it violates the principle of nonmaleficence; although the organ recipient might benefit, the donor does not.¹⁹

One national guideline proscribes the use of systemic ECMO on the recently deceased donor both because of the invasiveness of ECMO catheter insertion into the living donor and because ECMO in the deceased donor could retroactively negate the preceding death determination by re-establishing circulation to the brain, thereby preventing brain infarction.⁸ Some scholars believe that valid donor or surrogate informed consent for premortem interventions adequately resolves the issue of harm from donor manipulation, but others disagree.¹⁷ In any event, it is incumbent on physicians following DCDD protocols to fully explain to surrogates what, if any, premortem and postmortem interventions are planned and to seek surrogates' informed consent.

Summary

The determination of death of DCDD organ donors is an important element in DCDD protocols that requires scrupulous compliance by physicians declaring death. Hospitals should institute DCDD protocols that follow current terminology and accepted technical guidelines, unlike those depicted in several aspects of this case. Physicians should prescribe proper palliative care to the donor during dying. Patients or surrogates should provide valid informed consent for organ donation based on an understanding of the exact plan and procedure for terminal palliative care, donor organ support intervention, death determination, and organ donation.

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MEDICAL EDUCATION

Four Communication Skills from Psychiatry Useful in Palliative Care and How to Teach Them

Indrany Datta-Barua, MD and Joshua Hauser, MD

Abstract

Palliative care and psychiatry share a number of the same priorities, including careful attention to communication skill development. In this article, we identify 4 communication skills helpful in both fields: (1) attending to countertransference, (2) practicing active listening and active reflection, (3) remaining silent and neutral, and (4) naming the emotion. We then describe strategies for teaching these skills.

Parallels between Palliative Care and Psychiatry

Two primary skill sets in palliative care are complex symptom management and communication on difficult topics. Expert communication in palliative care is not only vital for patients and families but also can be a challenge for clinicians of all levels.^{1,2} In considering the communication skills needed in palliative care, we have noticed parallels with psychiatric training. Palliative care has always been interdisciplinary in perspective and practice, as reflected not only in its team approach to care but also in its recruitment of physicians from diverse specialties, including psychiatry. We propose that these similarities exist due to the intimacy of the clinical relationship in palliative care and psychiatry, the affectively charged clinical situation in which care occurs, and the primary role of patient-clinician relationships in decision making and treatment. In this article, we identify communication skills for difficult conversations common to palliative care and psychiatry, describe the theoretical underpinnings for these skills as taught in psychiatry, and discuss pedagogic practices that operationalize these skills in palliative medicine. Our goal is to help palliative care clinicians of all disciplines deepen their knowledge of and skills in communication by recognizing these contributions from psychiatry.

Important Skills for Conversations in Palliative Care

Attending to countertransference. Goals-of-care conversations are central to the work of palliative care clinicians. Clinicians might struggle with discussions about goals of care for many reasons, including prognostic uncertainty, fear of negatively affecting patients, and feelings of inadequacy or hopelessness.³ These limitations often lie within the clinician, which leads to the first communication skill that palliative care shares with psychiatry: recognition of countertransference.

Briefly, *transference* involves feelings that the patient has about the clinician, including those “transferred” from other significant relationships in his or her life.⁴

Countertransference encompasses the feelings and fantasies that the clinician has about the patient. Like transference, *countertransference* includes feelings that resonate with the clinician’s past as well as feelings evoked by the patient.⁵ In psychiatry, these phenomena are among the greatest sources of diagnostic information.⁶

How might countertransference be manifested in palliative care? Consider the clinician of a patient facing a diagnosis of metastatic lung cancer who confesses to a colleague, “I don’t want to bring up palliative care because I worry it will rob the patient of hope.” The clinician has little way of actually knowing what effect bringing up palliative care will have. However, she might have feelings that could be expressed as, *I am afraid*, and maybe, *I will lose hope*, perhaps followed by, *I won’t know what to do after that*. She fantasizes that the patient will feel the same, possibly due to her identification with the patient and perhaps to avoid the discomfort of her own fear and hopelessness.

These concerns are part of the countertransference that the clinician brings to the encounter. The patient, of course, might share these fears; perhaps the clinician feels them strongly because the patient is contributing them to the countertransference. Teasing out transference reactions that emanate from the clinician and from the patient is one way that palliative care clinicians navigate transference and countertransference. The goal is to draw out the patient’s underlying concerns and preferences—without the clinician imposing his or her own. This process is necessary for understanding patients’ and families’ goals and necessitates another skill: practicing active listening and reflection.

Practicing active listening and active reflection. In psychiatry, active reflection means developing awareness not only of our feelings of countertransference but also of our decisions and behaviors during clinical encounters in order to understand the influence that the clinician–patient relationship has on us and on our clinical decision making. Reflection does not free us from this influence but rather allows us to analyze and discuss it with the patient or change our behavior when indicated.

Similarly, in palliative care, active reflection enables us to observe ourselves in an encounter and ask, “Why am I having this reaction at this time with this patient?” such that we can separate our needs from those of the patient. While this skill of reflection is not specific to palliative care, it is highly important in the context of palliative care where decisions about preferences and goals of care are highly complex and often rapidly changing. For example, suppose a palliative physician is consulted for pain management of a woman with high-risk myelodysplastic syndrome. She had delivered a baby 2 days previously and her husband is at her bedside holding the infant. Upon meeting them, the physician becomes caught up in memories of his own child and has the impulse to say, “I

remember when my youngest was born in this very hospital." Active reflection might lead him to wonder, *Why do I feel the need to say that right now? Does it demonstrate empathy because I am away from my own children? Or that I feel guilty for being away? What is the benefit, if any, of my disclosing this to the patient and family?*

Active reflection is essential for active listening. True active listening, which builds and conveys empathy, requires not only the outward behaviors of attending and responding to the speaker but also the cognitive and affective process of wondering, *Why is the speaker saying that in that way at this moment?* By going through this internal process, verbally reflecting its results back to the patient (eg, "I'm hearing you say..."), and giving the patient the opportunity to correct or add data to our analysis of his or her experience, we begin to develop and convey empathy and we clarify patients' preferences and goals.⁷

Remaining silent and neutral. Constant reflection can be daunting and exhausting. Luckily, silence—another skill necessary for difficult conversations in palliative care and psychiatry—allows the time and mental space for the clinician to reflect while also producing clinically useful information. The therapeutic use of silence has its origins in Sigmund Freud's psychoanalytic technique. After attempts at hypnosis, Freud found that free association could produce the same preconscious and unconscious material.⁸ In palliative care, the surfacing of insights from a patient following a pause can lead to further elucidation of the patient's preferences and values. Although goals in difficult conversations in the palliative care setting are different than those in psychoanalysis, in both situations, [deliberate silence](#) can often allow the patient (or family) to reveal herself in ways that more immediate verbal reactions might impede.

These uninterrupted glimpses into our patients' inner lives that silence can afford are vital in conversations about dying and end-of-life care, because, as in psychoanalysis, it is our intention to remain neutral and facilitative. The psychoanalyst Roy Schafer wrote in *The Analytic Attitude*, "The analyst does not crusade for or against ... is not judgmental ... remains neutral ... attempting to allow all the conflictual material to be fully represented ... to avoid ... the imposition of his or her own personal values."⁹ Analogously, a clinician's goal in discussing end-of-life wishes is not to impose her own values, such as personal ideas of a "good death" or the "right" decision about a certain treatment, but to elucidate the patient's values and wishes.

For example, suppose a physician is seeing a woman with heart failure and progressive dependency who is considering moving in with her daughter and entering hospice. The physician, patient, and daughter are all meeting together. "Can we talk about my daughter?" the patient asks. "Sure," the physician responds. "We go to the grocery store, and I want to push my own cart, and she insists on pushing the cart, and we go back and forth. 'I can push my own cart!' 'No, Mom. I'll push the cart.'" The physician remains silent. The patient continues, "You know what's happened? She's become the mom, and

I'm the child. And the truth is that I might not have much time left, so there are things I need to do to make sure my daughters are taken care of." The daughter starts crying.

In this example, the use of silence (and not offering a specific question or answer) allowed the patient to express the pain of losing her autonomy and to mourn the losses associated with her illness while also recognizing her daughter's motivations. In his silence, the physician remained neutral to the interpersonal conflict, which facilitated the patient's revealing her underlying fear for her daughter's future well-being, and, hopefully, would allow her daughter to connect with her. Moreover, now that the physician better understands the patient's changing relationship with her daughter in the setting of her illness, he could make a recommendation for involving social work to help support them emotionally and interpersonally through the transition of moving in together. He could also affirm the recommendation of hospice in order both to assist the patient in her goal of completing practical matters and to relieve some of the strain of the patient's and daughter's growing interdependency.

Palliative care clinicians often describe a part of their role as getting to know the patient and family in order to make recommendations consistent with their values. Asking both general and specific questions of patients and their families helps us get to know them, and these questions are traditional tools of medical interviewing. But so is silence. Intentional silence allows patients to elaborate on thoughts and feelings that communicate important values that guide treatments.

Naming the emotion. A companion to silence is naming the emotion. Before she can translate values into a recommendation, the clinician must first demonstrate an understanding of the emotional motivation(s) behind the values. Naming the emotion is one way of conveying understanding. Importantly, it will often follow silence; when it precedes silence, it could lead to premature closure of an interaction.

For example, suppose a patient with metastatic colon cancer has been waiting for a palliative care clinician who is running late. When the clinician walks into the room, the patient's wife says, "You're all incompetent! We got here last night and had to wait all day to see palliative care. Aren't you supposed to be helping? He laid here in pain all day. We might as well have been home." The palliative care clinician pauses a moment before saying, "I can see you're angry. It must have been scary to see him in so much pain." In this case, **demonstrating understanding** of the family member by naming the emotion underlying her attack rather than reacting defensively assures her that she is being heard and may begin to restore trust, such that she will be more receptive to the clinician's recommendations. Furthermore, naming helps to contain (ie, make sense of) the overwhelming affect she might be feeling.^{10,11}

Pedagogical Practices for Teaching the 4 Communication Skills in Palliative Care

How do we teach these skills—attending to countertransference, practicing active listening and reflection, remaining silent, and naming the emotion—to palliative specialists of all levels? Since all clinicians in palliative care will encounter scenarios such as we have described, these skills are necessary for predoctoral (eg, medical, nursing) students and for residents, fellows, attending physicians, practicing nurses, and so on. In what follows, we describe basic approaches to teaching these skills to learners of multiple levels of experience. The complexity of the cases and the material can be varied depending on level of experience, but the overall approach is appropriate for all levels and disciplines.

As with many skills in palliative care, these communication skills are learned formally in the classroom and at the bedside. In the classroom, role play and [simulation](#) are approaches to teaching these skills. Role play allows clinicians to “try on” a role, drill down on a communication technique, and receive specific feedback.^{12,13} Role plays are most effective when they have focused communication objectives.¹⁴ And though role plays will sometimes have general objectives, such as practicing delivering a new diagnosis of breast cancer, the skills we described above can be objectives of role plays. Learners and teachers can focus on these skills in the development of a role play case, its enactment, and its debriefing. At the bedside, role modeling of these skills is a goal for experienced educators in palliative care.¹⁵ Role modeling itself is a skill that is more than just having trainees shadow a more experienced clinician. Physicians’ role modeling active reflection and listening with patients requires active listening and reflecting with *each other as colleagues*. As a teacher, it is not enough to “do” these skills in front of a learner and expect him or her to recognize them; we need to attend to situations in which these skills are applied, actively listening to patients, reflecting back what we hear them saying, and debriefing with learners on what they saw and how they would enact these skills. Role modeling parallels the clinical skill of naming the emotion; as we name the emotion with patients, so we can also name the emotion (and name the skill) with each other as clinicians. We identify points of tension and difficulty—as the clinician did in the above example by waiting for the wife’s emotion when accused of ignoring her—because these are areas of skill development that require more attention from us as teachers.

As we are describing them, these two educational approaches—the use of role play and careful attention to role modeling—are appropriate for teaching communication skills to clinicians of multiple levels of experience. Finally, we offer another idea from psychiatry that we believe palliative care can learn from: psychiatric supervision.¹⁶ In classic psychiatric supervision, trainees bring cases to a senior clinician and discuss not only clinical aspects of the case but also, more importantly, the trainee’s experience of the patient (eg, transference and countertransference). We have begun to experiment with this approach at Northwestern University Feinberg School of Medicine with our faculty

and palliative care fellows. In this type of regular sharing of difficult and meaningful cases between two clinicians, the communication issues we have described can be modeled in order to deepen subsequent patient interactions.

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MEDICAL EDUCATION

Which Critical Communication Skills Are Essential for Interdisciplinary End-of-Life Discussions?

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Abstract

Conversations about dying and end-of-life (EOL) care are the most challenging of all communication scenarios. These conversations include discussions about diagnosis and prognosis, treatment goals, and EOL wishes, goals of care, and plans for the future. Research has identified critically important skills involved in holding such conversations, and protocols have been established that can assist those discussing these important issues. Often several discussions and professionals from multiple disciplines are needed to ensure that EOL conversations are effective and comprehensive. In this article, we review what is known about the skills and strategies necessary for meaningful and effective EOL conversations and emphasize the valuable role of interdisciplinary approaches to these discussions. Advance care planning (ACP), which refers to patient decisions about desired care should the patient lose decisional capacity, is included as a type of EOL discussion in this article.

Skills and Approaches Needed for End-of-Life Conversations

In the last 30 years, numerous strategies and frameworks for end-of-life (EOL) discussions have been developed and used with success. Triggers for, methods of, barriers to, and issues in EOL discussion have been well described.¹⁻³ Some approaches that are widely referenced and accepted are the SPIKES 6-step protocol,⁴ the ABCDE plan,⁵ and VitalTalk.⁶ Others are described in Robert Buckman's 1992 seminal book, *How to Break Bad News: A Guide for Health Care Professionals*,⁷ and "The Serious Illness Conversation Guide."⁸ Several of these approaches focus on informing the patient and family about the patient's condition and prognosis and are therefore directed at physician skills, while VitalTalk provides resources for all clinicians involved in serious communication scenarios. Recently, the literature has supported collaborative models in which communication is rooted in teams rather than in the physician-patient dyad and conversations are ongoing rather than singular.⁹⁻¹¹

Elaborating on the principles of this work and realizing that there is more to EOL discussions than the relaying of difficult information, we offer associated clinical advice to professionals from all disciplines regarding conversational skills and team-based

approaches that can facilitate EOL discussions. Clinicians have the responsibility to provide opportunities for discussion and information to patients, caregivers, and surrogates throughout the trajectory of serious illness¹²; such conversations occur in the context of an uncertain, emotional environment¹³ and require core communication skills of sensitivity and empathy—skills that professionals in all disciplines should cultivate.¹⁴

It Takes a Team

Dying involves much more than medical concerns and decisions—there are psychological, social, spiritual, and financial concerns that require the efforts of an interdisciplinary team. The ideal team would include professionals from medicine, nursing, chaplaincy, and social work or similar fields to address the medical and psychosocial and spiritual needs of the patient and family. Institutional protocol may assign responsibility for completion of advance care planning (ACP) forms to the chaplain or social worker. A systematic review of social workers' ACP responsibilities identified a number of duties, including initiating discussions, advocating for patients' rights, providing patient or family education or counseling, facilitating communication, conflict resolution, and documentation.¹⁵ The team nurse can provide ongoing medical monitoring, evaluate treatment effectiveness, and instruct patients about treatments and medications. The [chaplain](#) is charged with addressing the spiritual implications and significance of the prognosis and with meeting patients' spiritual needs.

At least two team members should be present during discussions with the patient and family about goals of care, prognosis, treatment options, and ACP. The physician might be assigned to share information while the social worker or chaplain attends to emotions and ensures that everyone's voice is heard. Physicians can draw from the expertise of colleagues from other disciplines (eg, social work, psychology) in motivational interviewing, solution-focused brief therapy, and cognitive behavioral therapy to help the patient or family to make behavioral or attitudinal changes and medical decisions.¹⁶ Optimally, a "family" meeting involving the patient, others the patient wants present, and the full interdisciplinary team is held soon after the determination of a life-threatening illness to share information and develop a patient-centered plan. Often multiple follow-up conversations are required.¹⁷ Indeed, time limitations have been cited as a major barrier to ACP; a study at Brigham and Women's Hospital in Boston found that these conversations can require 22–26 minutes.⁸ Thus interdisciplinary teams offer great value by dividing responsibilities among team members to alleviate the pressure on the physician to "do it all."

Effective teams work together to communicate information and provide support to the patient and family. These goals are accomplished through synergistic and interdependent interaction of team members.¹⁸ Leadership is task dependent, with tasks determined by the patient's individual situation.^{18,19} Intra-team communication of people

to contact, new information, and plans is essential and must be timely. The team must be a united front in addressing and advocating for holistic, patient-centered goals.

Strategies for Successful EOL Communication

Being well-informed about the patient's medical history and present situation before holding any discussions related to serious illness is not just a good practice; it is crucial for successful EOL communication. The patient and family must have complete confidence that opinions and recommendations given in a setting often characterized by extreme emotions and conflicting perspectives are supported in every detail. Securing the patient's and family's confidence is key, especially when there is no long-term relationship. Knowing in advance what other involved clinicians think and recommend, what therapies have been attempted, the known results and side effects, and the social and emotional environment for care is critical for success. Patient preferences, values, quality of life factors, coping abilities, and cultural determinants are also crucial information. Such preparedness can also help avoid misinformation and misunderstanding between the patient and family. When planning a conversation related to the EOL, using a *who, what, when, where, and how* structure can be helpful.

Who? Ask who the patient wants present at this conversation and plan for any psychosocial or family issues that might affect the discussion. Family members may have differing attitudes towards the patient's wishes, and it is easy for conversations to be derailed by their opinions, conflicts, needs, and emotions. EOL situations bring prior family issues and conflicts to the surface, creating a dangerous oil slick of angst and emotion that must be navigated. As clinicians, we have responsibility both to acknowledge such issues and conflicts and to continually and patiently bring the focus back to the patient and the current situation. Family members obviously feel loss at these moments and should be comforted while not distracting from the patient's needs. Interdisciplinary care is at its best at these moments because the unique contributions of each profession enable the team to address the complexity of the situation.¹⁸ However, it may be necessary for the social worker or chaplain to address family conflict outside of a meeting or to make referrals for more intensive counseling.

Clinicians often know the inevitable outcomes of advanced illness and are tempted to "go there" early. Patience is a key skill in holding these conversations. If possible, "arriving" at the prognosis together brings peace and understanding. Laying out care options helps engage the patient and family, but we must avoid misleading them by characterizing each option with expected outcomes and side effects.

What? Clinicians should have a goal in mind prior to the conversation. Goals might be delivering serious news, clarifying the prognosis, establishing goals of care, or communicating the patient's goals and wishes for the EOL to those in attendance. Often some [discussion of prognosis](#) is important in the first meeting, but how much is said on

this topic should be based on the patient's preferences. Two questions are important when opening a meeting at which information about the illness will be shared. First ask, "Tell me what you understand about your illness and your prognosis?" Then ask, "How much information do you want?" The latter question can be challenging because patients and families will not know what information we have to share. Ascertain whether they prefer all the details or just the summary and bottom line recommendations. Often at this point a warning statement is appropriate: "John, I think we need to have a serious discussion. I'm afraid there is some serious news." Watching the reaction to that statement can help establish the pace, tone, and content of the rest of the discussion.

When? Time constraints are often cited as a barrier to EOL communication.^{1,20} EOL discussions are challenging to integrate into routine hospital rounds or office visits. Therefore, they should be scheduled when there is time to patiently listen, reflect what you hear, seek understanding, make suggestions, and talk about next steps. A squeezed-in conversation, usually driven by urgency, is rarely efficacious or time effective. When incomplete, other conversations will be required, and ground is often lost.

Where? Ideally, EOL conversations are held in a quiet room without interruptions. Realistically, such conversations are often held at the bedside due to the patient's condition or lack of space. Regardless, it is important somehow to sit down. Standing above an ill person adds to his or her feelings of vulnerability. Sitting means that we care and that we will not exit as soon as possible.

How? Semistructured discussion plans usually work best. Begin with some goals for this discussion as described above but be flexible depending on the dynamics and the patient's needs. It is important to remember that the patient is the most important team member and that his or her preferences and informational needs guide the meeting. Communication should be adapted based on what is acceptable to the patient.¹⁰ Surgeon and author Atul Gawande popularized the term "explain-aholics,"²¹ and, indeed, clinicians often assume this role. We know so many things from lab details to CT scan results to treatment options to prognosis.

To avoid taking charge of the conversation, even when it is approached with a set agenda and information to be shared, several strategies are useful. One is the "listen first" approach. The clinician makes herself actively listen by asking an open-ended question and responds to what is heard rather than controlling the conversation. Another strategy is to keep in mind the "20% rule"—that patients might remember about 20% of what is said in the first serious illness or EOL discussion because their minds are reeling with emotions, impairing their memory. Silence can be golden in these conversations. Allow time for the patient to truly hear what is said and to react emotionally. Emotions should be acknowledged, whether manifest in tears, anger, or sad withdrawal. Normalize patients' feelings and encourage them to share more about what they are feeling.

Finally, being direct, confident, and calm can be comforting. (“Mary, there are no more treatments that we can expect to extend to your life.”) Wait, listen, and respond. Only so much can be processed in a single conversation; therefore, serial conversations are usually needed to allow processing time and present aliquots of digestible information. (“Let’s both think about what we just discussed and talk again on Tuesday.”) This approach does not have to require more time overall.

Postconversation hallway conversations with family and friends are to be avoided. If appropriate, return to the room with everyone to address those questions. If not, words could be interpreted through someone else’s lens. “Well, I talked to Dr. Jones, and she told me...” This is known as “splitting” and allows others’ agendas to take hold.

Incorporating EOL Communication Skills Training into Medical Education

It is common to hear that some clinicians are “naturals” at EOL conversations. However, caring, empathy, and communication can be learned like any other clinical skill. As mentioned earlier, numerous training programs are available. Skills training programs ranging from seminars to workshops have been augmented by online training.²² Ariadne Labs has developed a serious illness community of practice (a social platform supporting practitioners caring for patients with serious illnesses) and a “Serious Illness Conversation Guide.”²³ The [Conversation Project](#) offers a free basic skills course for health care professionals and numerous resources for both patients and professionals wanting to have conversations about EOL care.²⁴

Studies have found that structured communication tools when used in EOL conversations can increase the frequency and documentation of such discussions and contribute to concordance between the care desired and the care received.^{25,26} Unfortunately, evidence related to the value of skills training is limited by poor reporting and weak methodology.²⁷ Chung and colleagues found consistent but very low-to-low quality evidence that training in EOL communication improved self-efficacy, knowledge, and communication scores compared to no formal training.²⁸ While training has shown to be somewhat beneficial, experience appears to be the best teacher. Drawing from the core established principles of EOL communication and the experiences of those around us (including team members from other disciplines), we can consciously and continuously improve our own skills.

Conclusion

Communicating with patients and families facing the EOL is challenging and time consuming. Clinicians can draw from multiple models and mentors as they develop their communication skills. Team-based efforts hold the most promise for facilitating the communication needed to provide information, explore options, develop plans and goals, and ultimately provide holistic, patient-centered care. Honing the essential skills for

these common yet critical conversations has tremendous ability to influence the lives and well-being of our patients and their families.

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IN THE LITERATURE

Clinical Momentum as One Reason Dying Patients Are Underserved in Acute Care Settings

Helen Stanton Chapple, PhD, RN, MA, MSN, CT

Abstract

“Clinical momentum” refers to the curious expansion of interventions applied to patients in the intensive care unit (ICU) without pause or design, leading to extensions of care that can violate patient wishes and distress clinicians. In this article, clinical momentum is placed in a wider context that includes ritual, reimbursement patterns, and actor network theory. These contextual features help motivate understanding of one way in which dying patients are underserved in intensive care settings. Suggestions are made for clinician interaction with families under these circumstances.

Clinical Momentum

In “Clinical Momentum in the Intensive Care Unit,”¹ Kruser, Cox, and Schwarze point to occurrences already well described in medical social science.^{2,3} They notice that, despite evidence of patients’ preferences for emphasis on quality of life, patient care interventions for older adults mount up in the intensive care unit (ICU) and that a perplexing, almost unstoppable energy expands and multiplies them.

Kruser, Cox, and Schwarze offer an example of clinical momentum for discussion.¹ They describe a patient with chronic obstructive pulmonary disease in the ICU who initially requires intubation and mechanical ventilation but experiences complications over an 11-day period, at which point, an endotracheal tube needs to be replaced by a tracheostomy tube. The authors imply that this procedure transforms her—and other patients like her—from acutely ill to chronically critically ill, signified by the clinicians’ decision to pursue tracheostomy tube placement. The clinicians know that placing a trach is the gateway to long-term ventilation. The patient had previously indicated her unwillingness to be on the vent “for a long time.”¹ Enacting this option would confirm the troubling fact that she has traveled into the territory of unwanted care. The clinicians are complicit in this turn of events because they have been unable to explain the significance of this particular decision in a way that the husband understands. The trach, then, becomes key not only to the unwelcome treatment plan but also to the clinicians’ moral unease.

The authors offer 4 concepts to support their argument that the trajectory of clinical momentum illustrated by this example exists and is potent. I contend that clinical momentum does not exist in isolation. Its power derives from forces much broader and more elaborated than the article's authors imply. In fact, "clinical momentum" operates within social forces that include both ritual and the reimbursement patterns in acute care. Actor network theory also provides explanatory benefit.

The 4 Concepts

Kruser, Cox, and Schwarze buttress their argument for clinical momentum by relating it to 4 disparate patterns of behavior: the *cascade effect*,^{1,4} such that a triggering event brings about a procession of interventions; the *fix-it model*,^{1,5} that addresses each discrete complication in isolation, without considering the big picture; *recognition-primed decision making*^{1,5} that clinicians use to match symptoms with a familiar pattern of action; and *sunk cost effects*^{1,5} that discourage departure from a course of treatment that required major investment. The first 3 patterns address clinician practice especially in intensive care, and the fourth adds to the mix the patient and family, who, in this case, voice reluctance "to give up" on the time and energy already expended on the patient's survival.¹

It is not clear exactly how these patterns relate to each other or to clinical momentum itself. They seem descriptive rather than explanatory. They belong within the larger contexts of ritual, reimbursement patterns, and actor network theory, each described below, but my few comments here cannot fully trace these connections. Yet with them I wish to show that clinical momentum is housed within sets of powerful cultural forces at work in the US health care system. It is not an independent development. Rich context conveys its own urgency to clinical momentum. Without appreciating these energies, we cannot explain why this momentum is so inexorable.

Ritual. Rituals are repeated social or communal actions that can acquire meaning and transformative power. The first 3 clinical practice patterns—the cascade effect, the fix-it model, and recognition-primed decision making—can be seen as manifestations of the ritual of intensification.² US society feels a cultural obligation to demonstrate its commitment to equitable treatment in extremis, and "rescue" is a central feature of the health care system. The ritual of intensification serves to transform patients from "rescuable" to "unrescuable," even "dying," if they do not respond in a positive way to interventions. If initial interventions fail, the patient is stabilized and treated aggressively over a period of time, with careful attention to every untoward change in lab values or fluid balance (demonstrating recognition-primed decision making and the fix-it model). As the patient's outcome remains unclear, patterned responses and interventions pile up in a cascade effect.

But clock time is also a significant factor. A critical mass of [technology](#) must accrue over

an unspecified amount of time, providing clear evidence of insufficient or declining patient response. Eventually the team may be ready to call the patient “dying.” At this point the transformation enacted by the ritual is complete. The arrival of the decision point about the trach in the case example indicates the team’s growing consensus that the patient cannot be delivered from unwanted long-term ventilation unless she is acknowledged to be dying.

Reimbursement patterns. The amassing of discrete interventions relates to the fourth phenomenon, sunk cost effects. Health care in the US is delivered and paid for by means of what Gawande calls “piecework.”⁶ Discrete devices, procedures, drugs, and levels of care are categorized and tagged as they attach themselves to the patient. Less boxable interventions such as nursing care, family meetings, and preventive instruction are not specifically charged for, so they carry much less weight in the capitalistic health care system. The tangible stuff of intervention such as lines, machines, and monitors also validates the worth of the patient attached to them. Being readily [reimbursable](#), this “stuff” stands in for and signifies patient care in the US. It is both pricey and priceless. Daniel Callahan refers to technology-driven health care in the US as “the beloved beast.”⁴ It both drives and is fed by clinical momentum, forming a perfect positive feedback loop.

Actor network theory. Sunk cost effects point to yet another frame for the network of forces fueling clinical momentum: actor network theory. A story helps explain this theoretical construct. When I attended my first critical care conference as a new ICU nurse, I was astonished at the enormity of the exhibit hall and what filled it. I roamed the aisles taking in the panorama of competing technologies, watching industry reps energetically demonstrating their latest designs to endless clusters of conference attendees. The scales dropped from my eyes. For the first time I realized that every single item I touched at work, from the alcohol wipes in my pocket to the monitors on the wall, the poles holding the IV pumps, the devices strapped around my patient’s calves preventing blood clots, and the bed itself had been made by someone. Someone else had sold the product to my hospital, and a third someone had delivered it. The power, the capitalistic urgency, and the unfathomable size of the supply chains fueling the ICU project that I enacted were laid bare to me for the first time in that convention hall.

I was viewing the bounty produced by a complex network of forces including ingenuity, compassion, avarice, and competition that routinely converge and transform themselves into tangible pieces of equipment, required as a part of my patient’s critical care. Once there, the drivers that produced them are obscured but still present and active. They enable the fabulous rescue modalities, populating the ICU with tools clinicians must manage and payers must reimburse. The material products appear inert. But, once on site, they seem to compel their own deployment. The new and exciting interventions quickly become part of routine care.⁵

This interaction between humans and objects in networks is an example of actor network theory. John Law explains: “the social and the technical are embedded in each other. This means that it simply isn’t possible to explore the social without at the same time studying the hows of relational materiality.”⁷ In order for us to unpack the meaning behind human patterns of behavior such as clinical momentum, it is necessary to include the roles of physical objects. Those roles intertwine with human actors and their actions. Certainly clinical momentum in the ICU is partly defined by the layering of technological interventions, sunk costs, and the management of all this “stuff.”

Viewed through the lens of actor network theory, the momentum comes not just from the clinicians’ habits of practice but also from the forces embodied by the technology they have at their fingertips. Using it to snatch patients back from the brink of death is expected. Keeping patients suspended between life and death until they can rally is technology’s purpose. Turning it off is not. Its very existence, along with the supply chain behind it, provides impetus for its use. In some way the machines themselves seem to resist being taken out of service. New cars are made to be driven. The momentum is built in.

In the case example, clinicians see the trach decision as a key turning point for the patient’s plan of care, and they try to impress this fact on the patient’s husband. But by now, 11 days in, it is no wonder that the husband sees this decision as no different from the other consents for this or that intervention that he’s been asked to give. The sunk cost effects make him reluctant to change course. The machines, validating both their own presence and value of the patient herself through her association with them, seem also to drive things forward.

But there is yet another force at work: the desire for a tangible “something” versus the alternative, which resembles “nothing.” The husband sees forgoing the trach as giving up—as nothing.¹ Left unstated is his fear of abandonment, his imagining of his wife’s room unpopulated by machines or staff, as just emptiness. Placing the trach guarantees ongoing relationship for him. To make its case for avoiding unwanted care, the team must fill that imaginary void with positive significance and meaning rather than absence. Honoring his wife’s wishes not to be on the vent for a long time is a start. Reassurance of the team’s continued involvement, descriptions of specific interventions to manage her symptoms, possibilities for visitors, and life review activities all can be helpful. Palliative care can provide additional suggestions. To embrace the critical present is an act of courage, and the husband should not be expected to do it alone. Dying appears to be a “personal trouble,”⁸ but it requires [communal solidarity](#) as palpable as the technology it replaces.

The 4 concepts used to buttress clinical momentum are fairly linear and devoid of

context. Neither they nor the phenomenon of clinical momentum exist in two dimensions—at least not in the ways the authors of this article imply. The passage of time brings mounting pressure to make a definitive decision on behalf of the chronically, critically ill. Its urgency combines with the ritual of intensification, health care reimbursement patterns, and the actor networks of influence created by humans interacting with technology. All these forces surround clinical momentum, and it rides on their combined power. When we meet with families, we need to remember that tangible interventions usually require little elaboration and carry great cogency. The alternatives to technology have their own promise and meaning, but we have to work harder to bring them to life so that they can compete.

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AMA CODE SAYS

AMA Code of Medical Ethics' Opinions Related to End-of-Life Care

Rajadhar Reddy and Danielle Hahn Chaet, MSB

Abstract

Caring for patients at the end of life (EOL) can be emotionally and ethically challenging for patients, families, and physicians and other health professionals. In accordance with the principle of respect for patient autonomy, patients should feel comfortable expressing their preferences for the EOL care they would like to receive, setting goals for treatment, and choosing surrogate decision makers as appropriate. Physicians are responsible for assisting patients in creating plans for EOL care, encouraging discussion of this subject with sensitivity to patients' situations, and respecting patients' preferences for EOL care. In many cases, compassion and clear communication are important in providing optimal EOL care, as discussed in Chapter 5 of the *Code of Medical Ethics*, "Opinions on Caring for Patients at the End of Life."

Advance Care Planning

Opinion 5.1, "Advance Care Planning," encourages physicians and patients to plan "in advance for decisions about care in the event of a life-threatening illness or injury."¹ [Advance care planning](#) is an effective way to engender discussions among patients, health professionals, surrogate decision makers, family members, and other close contacts about end-of-life (EOL) care. These discussions can support patients in determining their values and preferences regarding the goals of care and the types of services they want to receive as they approach death. Physicians can also take this opportunity "to address patients' concerns and expectations and clarify misunderstandings individuals may have about specific medical conditions or interventions."¹ However, such discussions should not begin only after a potentially fatal illness or injury has befallen a patient. Physicians should "regularly encourage all patients, regardless of age or health status" to consider these issues, "periodically review" with them their "goals, preferences, and chosen decision maker," and include notes from these conversations in medical records.¹ Physicians should make an effort to discuss advance care planning with patients across the age spectrum, encouraging them to think proactively about issues in EOL care, as any patient can find himself or herself afflicted with a potentially fatal condition. For example, medical literature indicates that young adults, who may become caregivers for aging family members, and adolescent oncology patients in particular need to be engaged in advance care planning.²⁻⁴ However,

whenever physicians approach the topic of EOL care, they “should be sensitive to each patient’s individual situations and preferences,” considering the various factors that might affect patients’ decision making, such as “culture, faith traditions, and life experience.”¹

Opinion 5.2, “Advance Directives,”⁵ discusses the importance of documenting advance care planning discussions. **Advance directives**, “whether oral or written, advisory or a formal statutory document,” allow patients to “express their values, goals for care, and treatment preferences to guide future decisions about health care” and to select their surrogate decision makers.⁵ These directives can be changed by patients or created with the help of surrogates. When patients maintain decision-making capacity, their opinions expressed at the time of care supersede any preferences listed in their advance directive, and, as patients continue to make treatment decisions, advance directives and other medical records should be updated accordingly.⁵ When patients lose **decision-making capacity**, physicians and surrogate decision makers, if available, can use advance directives “to make good-faith efforts” to understand patients’ treatment preferences, uphold their values, and—if there is enough information available—make decisions similar to those the patients might have made on their own.⁵ If a surrogate’s wishes contravene an advance directive or if a surrogate is unavailable, physicians should consult “an ethics committee or other appropriate resource” to help resolve the issue.⁵ When an advance directive is not readily available in an emergent situation, “physicians should provide medically appropriate interventions when urgently needed to meet the patient’s immediate clinical needs.”⁵ Once a patient’s preferences can be ascertained, ongoing interventions that violate those preferences can be withdrawn at that time.⁵

Refusal or Removal of Life-Saving Care

Opinion 5.3, “Withholding or Withdrawing Life-Sustaining Treatment,”⁶ discusses cases in which patients (or their surrogates) may refuse or ask to stop life-sustaining treatment. These decisions can be made “even when that decision is expected to lead to [the patient’s] death and regardless of whether or not the individual is terminally ill.”⁶ Such decisions can be applicable to situations of withholding certain life-sustaining treatment altogether or starting and then withdrawing such treatment if certain outcomes (predetermined by the patient or surrogate) are not achieved.

A do-not-attempt-resuscitation (DNAR) order, as detailed in Opinion 5.4, “Orders Not to Attempt Resuscitation (DNAR),”⁷ specifies that no resuscitative measures can be used on patients if they enter cardiopulmonary arrest “in any care setting.” Such orders “can be appropriate for any patient medically at risk of cardiopulmonary arrest, regardless of the patient’s age or whether or not the patient is terminally ill.”⁷ **DNAR orders**, like advance directives, should be included in a patient’s medical record to facilitate use by health professionals.⁷ If there is no DNAR order in the health record, “resuscitation should be attempted if it is medically appropriate.”⁷ If a DNAR order is found after resuscitative

measures have already begun, “the attending physician should order that resuscitative efforts be stopped.”⁷

When discussing the creation of DNAR orders, physicians should clearly explain to patients the resuscitative procedures that might be used, their probability of clinical benefit, and the possible quality of life that may result after such measures are taken. Physicians should also clarify that DNAR orders do not apply to other medical interventions, such as “antibiotics, dialysis, or appropriate symptom management” that, if appropriate, would be “provided or withheld in accordance with the patient’s wishes.”⁷ If a DNAR order is appropriate to the situation of a patient with no DNAR order on record and the patient loses decision-making capacity or cannot express his or her preferences, physicians should “candidly and compassionately” work with surrogates, if available, and “consult with an ethics committee or other appropriate institutional resource” to decide on the best course of action.⁷ Physicians should ensure that the patient or surrogate understands that, beyond the interventions declined, “all other medically appropriate care will be provided, including aggressive palliative care [and] appropriate symptom management if that is what the patient wishes.”⁶

Other Issues in EOL Care

According to Opinion 5.6, “Sedation to Unconsciousness in End-of-Life Care,” when “aggressive, symptom-specific palliation” does not relieve severe pain and distress, the physician can “offer sedation to unconsciousness as an intervention of last resort.”⁸ “Sedation to unconsciousness” refers to the palliative practice of controlling a patient’s symptoms through the continuous administration of a sedative to keep a patient unconscious until death, differentiating it from other forms of palliative sedation that do not result in unconsciousness.⁹ However, these measures “must never be used to intentionally cause a patient’s death,” should be limited to “patients in the final stages of terminal illness,” and should be used after “consult[ation] with a multi-disciplinary team (if available), including an expert in ... palliative care” to ensure that such care is “the most appropriate course of treatment.”⁸ Sedation to unconsciousness can only be used to “address refractory clinical symptoms, not ... existential suffering arising from ... death anxiety, isolation, or loss of control,” which “should be addressed through appropriate social, psychological or spiritual support.”⁸ The patient or surrogate should be educated on the plan of care and give informed consent, and the patient should be closely monitored after sedation.⁷

Opinions 5.7, “Physician-Assisted Suicide,” and 5.8, “Euthanasia,” acknowledge that patients in severe distress may unfortunately “come to decide that death is preferable to life.”^{10,11} However, according to the *Code*, both physician-assisted suicide and euthanasia are “fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.”^{10,11}

Summary

The *Code* recognizes the paramount importance of respect for patient autonomy in making decisions about EOL care. Physicians play a crucial role in helping patients and their families to plan in advance for possible life-threatening situations by assisting patients and surrogates with potentially difficult choices and respecting and upholding patient values with compassion and sensitivity. Despite the challenging nature of EOL care, physicians can work together with patients, families, surrogates, and members of the health care team to provide quality care to patients at the end of life.

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POLICY FORUM: PEER-REVIEWED ARTICLE

Should There Be a Disclosure Mandate for Physicians Caring for Perinatally Infected Adolescents Who Don't Know Their HIV Serostatus?

Sabhyta Sabharwal, MPH, Jason W. Mitchell, PhD, MPH, and Victoria Y. Fan, ScD, SM

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Abstract

With advances in antiretroviral therapies, perinatally infected children are now living with HIV well beyond adolescence. Parents and health care practitioners thus face the challenge of deciding how best to disclose positive serostatus to children living with HIV. Although many adolescents living with HIV are sexually active, parents often delay disclosure, which presents US physicians with an ethical dilemma because there is no legal requirement to follow clinical guidelines recommending disclosure prior to adolescence. When they become adults, US adolescents could face criminal penalties if they fail to disclose their positive serostatus to needle-sharing or sex partners despite there being no legal mandates to ensure that adolescents are first properly informed of their own diagnoses. We argue that there is an urgent need to bridge this gap between adolescent and adult HIV serostatus disclosure policies.

Critical Decisions about When to Disclose a Child's HIV Serostatus

Approximately 36.7 million people live with HIV globally, including 1.8 million children under the age of 15.¹ Despite clinical advances in HIV prevention and management, nearly 5700 new cases of HIV arise daily, including roughly 400 children under the age of 15.¹ The majority of these children have been perinatally infected with HIV via maternal transmission during pregnancy or breastfeeding.² Thanks to the advent of antiretroviral therapies (ART), HIV transmission from mother to child is preventable.³ Indeed, the number of new HIV infections among children has declined almost 70% from 2000 to 2015.¹ Moreover, HIV has evolved from a terminal illness to a chronic disease that can be managed well into adulthood with advances in ART and care.³

As perinatally infected children mature to adolescence, their parents, caregivers, and health care practitioners now face critical decisions about how best to disclose the child's HIV serostatus within and outside of the health care system. Prior to the development of ART, children infected with HIV rarely survived past their fifth birthday.⁴ Thus, the question of how and when to disclose a child's diagnosis at that age was not a long-lasting concern for parents or health care practitioners.^{5,6} However, clinical guidelines and legal policies regarding [HIV serostatus disclosure](#) must now be reconsidered within pediatric and adolescent contexts.

Within the United States, the contrast between HIV disclosure policies for adolescents and adults is stark. For nearly 2 decades, clinical pediatric guidelines have recommended, but not required, that disclosure take place prior to adolescence, a time when children transition towards maturity and are more likely to engage in risky behaviors.⁷ Yet physicians and caregivers are neither clinically nor legally mandated to inform adolescents of their serostatus. This lack of enforcement carries clinical implications, as adolescents living with HIV are having unprotected sex, often without disclosing their HIV serostatus to their sex partners.^{8,9} In order to protect the health of adolescents living with HIV, as well as that of their sex partners, physicians and caregivers ought to be legally required to inform adolescents of their serostatus. In contrast to the lack of legal policies concerning HIV disclosure to adolescents, adults living with HIV are subjected to controversial federal and state laws concerning disclosure of HIV exposure to sexual and needle-sharing partners.⁸ Many laws criminalize nondisclosure of positive HIV serostatus among adult partners, but none of them enforce clinical disclosure to adolescents living with HIV.⁸ Criminalizing behaviors based on HIV status, rather than criminal intent or actual risk of transmission, has been recognized not only as controversial but also as ineffective in preventing HIV transmission.¹⁰ Although current HIV criminalization laws are largely in need of reform, legal mandates can still have an important role to play in HIV prevention. Rather than criminalize, legal policies should be used to promote HIV management and prevention, which begins with patients learning of their own serostatus. For perinatally infected patients, this disclosure process must happen before adulthood, during adolescence.

Serostatus disclosure policies are complicated by adolescents' minor legal status, as parents often delay the disclosure process and request that physicians follow suit, commonly out of fear that disclosure will psychologically distress or socially isolate their child.^{5,11} For example, some parents delay disclosure by lying to their children regarding the reason they take medication.⁵ Given the [stigmatized nature of HIV](#),^{5,12} these parental fears are understandable, yet delaying disclosure introduces a new set of risks to both adolescents living with HIV and their potential sex partners. If parents choose to delay disclosure, then health care practitioners, who are not legally mandated to inform a child about his or her HIV-positive serostatus, are faced with an ethical and clinical dilemma.¹³

From an HIV-prevention standpoint, if adolescents are unaware of their own diagnosis, they will be unable to inform their sex partners, might not take their medication, and might engage in behaviors that they might not otherwise have chosen. On average, adolescents in the United States begin engaging in sexual intercourse as legal minors, with over 30% reporting sexual debut by age 16.^{8,14} Serostatus disclosure to sex partners and condom usage are important factors in preventing the transmission of HIV.⁹ In addition to preventing disease transmission, evidence suggests that disclosure can positively impact physical and psychological health by improving ART adherence, clinical care retention, and social relationships, as one no longer has to hide medications or doctor's appointments.^{12,15,16}

Adolescents living with HIV have an ethical right to know their serostatus. Given the health and social benefits and ethical value of disclosing HIV serostatus—and the potential negative implications of not disclosing—this article outlines and provides justification for bridging the current gap between adolescent and adult HIV serostatus disclosure policies in the United States.

Benefits of HIV Serostatus Disclosure

Despite parental hesitation to disclose a child's HIV diagnosis, disclosure has been associated with positive outcomes such as higher self-esteem, clearer understanding of HIV, and better coping skills.^{7,12,17} Disclosure of serostatus is also positively associated with engaging in fewer acts of unprotected anal and vaginal sex, facilitating partner [HIV testing](#), and improving ART adherence by reducing the need to hide medications from partners.^{18,19} The link between disclosure and adherence to ART is vital, as adherence is critical to maximizing the clinical benefits of ART and is the most reliable determinant of patient survival.²⁰

Despite clinical recommendations to encourage HIV disclosure by adolescence, global disclosure rates remain low among children and adolescents, including in the United States, where consistent disclosure policies and legal mandates to inform adolescents are lacking.¹⁷ While parents earnestly attempt to protect their children by delaying disclosure, delayed disclosure has been associated with increased anxiety, depression, and social exclusion among adolescents living with HIV/AIDS.¹⁷ Rather than mitigating HIV-associated stigma, delaying disclosure could simply reinforce the implicit feelings of shame and secrecy that have historically characterized HIV/AIDS.

By facilitating an appropriate and open disclosure process, clinicians and caregivers can help normalize a child's diagnosis. In this way, they can set a positive example that adolescents can follow as they develop the skills to disclose their serostatus to future sex partners and others throughout their lives. With the potential to improve the health outcomes of adolescents living with HIV, as well as those of their future partners, serostatus disclosure ought to be more strongly and consistently implemented.

Current HIV Serostatus Disclosure Policies

Following recommendations established in 1999 by the American Academy of Pediatrics (AAP) to encourage HIV disclosure by adolescence, the World Health Organization (WHO) created guidelines in 2011 for initiating the disclosure process when a child reaches age 6, recommending full disclosure by age 12.¹¹ As Wiener et al. note in their review of the literature, however, the prevalence of pediatric disclosure reported by previous studies ranges from below 10% to over 75%.²¹ Many studies have published low rates of full serostatus disclosure, suggesting that nondisclosure and partial disclosure (in which children are given only some information about their illness) are more prevalent.²¹ As suggested by the inconsistent patterns of pediatric serostatus disclosure across the United States, the AAP and WHO recommendations are not being used and would benefit from clinical enforcement.

Without clinical enforcement and legal mandates, how can adolescents properly inform or protect their partners if they remain uninformed themselves? In a study of 146 youth living with HIV in the United States, 47% reported having unprotected sexual intercourse in the past 3 months, and 44% of these youth did not disclose their HIV serostatus to their sex partner.⁹ Data regarding how many of these adolescents fully understood their own diagnosis were not reported. These findings, among others, nonetheless highlight the urgent need to prioritize adolescent HIV policy to improve rates of condom use and partner disclosure.²² Before adolescent partner disclosure can take place, adolescents must first be properly informed of their own serostatus. For adolescents living with HIV, the way in which they are first informed of their own diagnosis might influence their patterns of disclosure to others. And adolescents who are properly informed of their own diagnosis are more likely to receive emotional support from HIV counseling and follow preventive practices to reduce risks for themselves and others.²³

Although the urgent issue of pediatric HIV disclosure has begun to reverberate within the health promotion field,^{7,11} it is clear that recommendations alone are not enough to encourage disclosure. With consideration of their emotional, psychological, and cognitive development, adolescents must be informed of their own HIV serostatus, regardless of their parents' desire to delay disclosure. To help physicians navigate this ethical dilemma, legal policies ought to be established in tandem with current evidence-based disclosure guidelines, interventions, and educational efforts.

In the United States, 67 laws concerning HIV disclosure existed in 33 states by 2011, pertaining exclusively to adults.⁸ It seems incongruous to criminalize partner nondisclosure once an adolescent reaches adulthood without ever mandating that adolescents be informed of their own diagnosis prior to adulthood, let alone be given the opportunity to acquire skills in and practice disclosure before reaching adulthood. Legal policies need to bolster educational interventions to improve pediatric HIV disclosure by caregivers and physicians. It should not merely be recommended that, as they near

adolescence, HIV-positive youth be informed of their diagnosis: it should be required. Ideally, parents and health care practitioners would work as a team to facilitate a supportive disclosure process for adolescents. If parents are unwilling to disclose, physicians ought to be granted legal authority to begin the disclosure process without parental consent.

Prioritizing Disclosure for Adolescents Living with HIV

As evidenced by high rates of nondisclosure and unprotected sex among HIV-positive adolescents both within the United States and abroad, current clinical guidelines concerning disclosure lack enforcement. Globally, the number of adolescent HIV-related deaths increased by 50% from 2005 to 2012, while overall HIV-related deaths decreased by 30%.²³ The WHO acknowledges that adolescents living with HIV have not yet been prioritized in global or national policies.²³ Along with investigating ways to bolster ART adherence and community support among adolescents, HIV serostatus disclosure is recognized as a critically underresearched issue, warranting urgent attention.²³ The current recommendation for disclosure to occur by adolescence needs to be enforced with legal policy—not to criminalize or stigmatize youth living with HIV but to help ensure that they are fully informed of their diagnosis. Rather than “protect” HIV-positive children from news of their serostatus, health care practitioners have the potential to empower these children with knowledge of their condition and equip them and their families with skills to improve clinical outcomes and develop health-promoting practices. Legal policies to encourage and enforce timely disclosure are needed to protect and motivate physicians as they educate and care for adolescent patients living with HIV.

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POLICY FORUM

For People Dying to Talk, It Finally Pays to Listen with Reimbursable Advance Care Planning

Carin van Zyl, MD and Dawn M. Gross, MD, PhD

Abstract

Whether at the beginning, middle, or end of life, health care delivery choices abound. Yet only recently have conversations specifically regarding preferences for care at the end of life become a reimbursable intervention, deemed equivalent in importance to a medical procedure. Quite distinct from other procedures, in which expectations for outcomes are explicit and measurable, outcomes have been left intentionally vague for advance care planning (ACP) conversations. This article will explore the inherent challenges of and opportunities for developing formalized outcomes, methods of measurement, and training to ensure excellence in the performance of ACP conversation procedures.

Background

When Medicare's reimbursement mechanism for end-of-life (EOL) planning became effective on January 1, 2016, it was implicit recognition of both the necessity and the value of an explicit physician-patient conversation on this topic.¹ Advance care planning (ACP) involves exploring a patient's health-related values, discussing EOL treatment options that could help honor those values, and then developing an appropriate plan and communicating it to loved ones and the medical system. The 2014 Institute of Medicine report, *Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life*, detailed the clinician's imperative to help Americans navigate their EOL health care choices.² As of 2012, about a quarter of Medicare dollars were spent on beneficiaries in the last year of life for care that was sometimes ineffective and even unwanted.³ Much of this low-value, high-cost treatment could be avoided if patients had more opportunities to tell their physicians and families what mattered most to them if they were seriously ill. A 2015 Kaiser Health Foundation survey of the general public found that while 89% of patients thought a discussion with their physician about EOL treatment choices was important, only 17% had actually had one.⁴

There are many barriers to these conversations, but one major obstacle is practical: finances. An already overextended practitioner can spend hours over several appointments having these sensitive discussions, which, prior to 2016, were all unbillable. A proposal to reimburse physicians for valuable time spent on voluntary ACP

was introduced during drafting of the Affordable Care Act in 2009.⁵ Prominent conservative politicians used the provision to create opposition to the bill by falsely equating reimbursement for EOL discussions with “death panels.” The ACP provision was quickly dropped from the original bill to avoid the perception that the government would limit funding of potentially life-prolonging care to save money,⁶ but it was quietly reintroduced with strong public support in 2015. New billing codes were issued for these conversations, treating them like other medical procedures.¹ The Centers for Medicare and Medicaid Services (CMS) data for 2016, the first year that these billing codes were in effect, showed that 22 000 clinicians billed for these conversations on behalf of 570 000 Medicare beneficiaries.⁷

As is the case for any new billable procedure, well-defined measurable outcomes and formalized training must be developed. This article will explore some of the unique challenges and opportunities specific to the ACP conversation procedure that are beginning to be addressed. To begin, we first define ACP and distinguish ACP conversation as a procedure. We then discuss how we go about defining and measuring outcomes for an inherently individualized, though practically shared and somewhat unpredictable, procedure. Finally, we explore training paradigms that can support the delivery and reproducibility of high-quality ACP procedures.

What Is ACP?

ACP is the opportunity to communicate our values related to our quality of life to the people who might be put in a position to speak on our behalf should we lose the ability to speak for ourselves. Ideally, this conversation is started while we are healthy, well before any serious illness has set in. In the broadest sense, we are asking, “What makes life meaningful? What is most essential to making you who you are?” Thinking more specifically about ACP for purposes of directing medical care, it can be helpful to contextualize the question in 1 of 2 ways. For those capable of describing what matters most to them in life, a clinician might ask, “If your health were to become compromised or if time were undeniably short, what physical, spiritual, and psychosocial experiences are essential in order to preserve your uniquely defined quality of life?” Alternatively, if patients are having a hard time finding ways to describe the qualities that have meaning for them, it can be helpful to ask a different question, such as, “What is the minimum acceptable quality of life or function with which you are willing to live?”

Why is this conversation important? Because of the ever-growing number of medical interventions available, it is increasingly difficult to discern when death is approaching. As a result, people living with life-limiting illnesses often face choices between treatments that might extend time or improve quality of life but that can rarely achieve both. Therefore, rather than assuming that the ever-elusive and impossible-to-quantify “more time” is what is motivating a person to seek medical care, it is imperative that clinicians discover what defines quality of life for a patient so that they can then make

recommendations regarding treatment options that honor and support the patient's stated values. If one value is more time, for example, it becomes essential to discover what actual time the patient is imagining and why. For example, is the patient hoping to see the birth of a child or reach an important event? Such questions then ground the desire for more time in the context of quality of life, allowing medical care to be tailored to support what specifically matters most to the patient.

A clear objective of an ACP conversation is for the patient to select and formally [name a trusted surrogate](#) health care decision maker. The role of the surrogate health care decision maker (also known as the durable power of attorney or DPOA for medical decisions) is to be willing and able to advocate for the patient's wishes in the event that a serious illness precludes the patient from being able to articulate them herself. While often assumed that a patient's legal partner or family member will be the DPOA for medical decisions, this default approach might not actually serve the patient's best interests. Many family members, whether because of love or strife, become so emotionally compromised when a loved one becomes seriously ill that they lose the ability to distinguish their own wishes from those the patient had previously articulated. Facilitating [goals-of-care conversations](#) between the patient and the patient's selected surrogate is ideal for providing insight into the patient's hopes, fears, and values, so that the selected surrogate can attest to his or her ability to advocate accurately for the patient if called upon to do so.⁸ This task is far more complex than, and quite distinct from, asking the patient to simply list the abstract procedural "do's and don'ts" found in a common do-not-resuscitate (DNR) form.

Alternatively, a description of a patient's minimum acceptable quality of life or function could be an anchor point for decision making; treatment options that could not meet or improve upon that minimum would trigger a reconsideration of the balance between more time and quality time. Importantly, these discussions can serve to strengthen the patient-physician bond not only by soliciting and articulating a patient's wishes but also by reaffirming the physician's commitment to nonabandonment at a deeply stressful stage of life.

Formal documentation of ACP in the form of an [advance directive](#) (AD) can be valuable, particularly when a DPOA cannot be identified. And while no universal AD form or portability platform currently exists for medical personnel to access ADs across settings, [physician orders for life-sustaining treatment](#) (POLST) registries in several states have shown promise as a tool to both implement and measure patient-centered EOL care delivery.⁹

Measuring Outcomes of ACP Conversation Procedures: Opportunities and Challenges

Superficially, the outcome of the ACP conversation procedure seems well-defined and easily measured; a patient's values are solicited, documented, and then matched to the

appropriate health care choices when the time comes. Process measures, such as frequency or timeliness of these conversations, can be monitored. Outcome measures, such as concordance between a patient's wishes and the care received and whether the care met a patient's goals, could also be tracked. However, unlike other procedures, the outcomes of which are generally binary, the outcomes of ACP conversations are intentionally fluid. Furthermore, these discussions, which embrace the inherent uncertainty in medicine and in life, assume that treatment preferences and judgments about acceptable quality of life will change over time throughout a patient's illness trajectory. Rarely, though, do we revisit the dusty document sitting in a drawer or a safe each time our circumstances or feelings change. As much of medical care remains fragmented across settings and clinicians, it will be difficult to assign accountability for a successful ACP outcome, as no one person has absolute agency. Perhaps an even more obvious challenge to measuring the ultimate outcome (ie, did the patient die the way he or she wished?) is that the person most directly affected by the procedure is ultimately unable to comment on its accuracy. Surrogate feedback, by definition, will therefore need to be a key measure of success, and we would argue it should include clinician reflection and input for quality control, as discussed below.

Measuring the quality of the ACP conversation, as opposed to the outcome, is a nuanced process. A patient or family—or, for that matter, a physician—might never have engaged in such a discussion and therefore have little expectation as to the content and experience of it. In our experience, the difference between an excellent and an inadequate conversation has to do with the degree of connection it engenders among its participants. Meaningful engagement engenders empowerment and relief, which in turn fosters the trust that nourishes the relationship—trust that can be drawn on when an imagined health crisis arrives. The quality of a discussion is, therefore, less about how many or how thoroughly options are discussed than about how deeply and meaningfully the conversation engages participants. Sometimes the end product can speak for itself, in that a document that provides only the barest outlines of a patient's wishes might reflect an unskilled or superficial conversation. However, given that talking about death is taboo, even a highly skilled practitioner might not be able to draw much from a reluctant partner.

Next Steps: Incorporating Communication Training into Standard Practice

While community conversations are shifting social and cultural views on having ACP conversations, as evidenced by several bestselling books addressing EOL care,^{10,11} comprehensive training of medical professionals is, as yet, untapped. By assigning Current Procedural Terminology (CPT®) codes to ACP conversations, CMS implied that they are indeed procedures with indications, contraindications, and complications like any other procedure. Therefore, as with other procedures, they require skills that necessitate instruction and practice to master. As Diane Meier, who heads the Center to Advance Palliative Care, has stated, "People are not born knowing how to have these

conversations any more than they're born knowing how to do an appendectomy."¹² Approaching ACP communication training as a procedure represents a wonderful opportunity for improving its teaching while also elevating the importance of all nuanced communication skills in the medical culture.

Most procedural skills in medicine are learned through a training sequence involving didactic teaching followed by observation of a skilled clinician performing the procedure and coached practice of and by the trainee, resulting in the trainee's graduated independence. Or, more simply, the learning of most procedural skills in medicine accords the familiar mantra from medical school, "see one, do one, teach one." Learners should actively observe ACP conversations by a skilled practitioner, then engage in coached practice of how to manage conversations of increasing complexity.¹³ Structured feedback from experienced teachers, as well as real patients and families, could be used to coach both trainees and practicing clinicians on how to hold more effective ACP conversations.¹⁴ These complex communication skills should be considered so foundational that they become part of graduation and licensure requirements, just as simulations and certain types of continuing medical education already are. One could argue for ACP discussions being proctored as we do for other procedures before graduating from residency programs or when applying for privileges at new hospitals. Hands-on, experiential training is standard for cardiopulmonary resuscitation training, but not for more cognitively complex tasks such as navigating a family meeting in which complicated treatment choices and their consequences need to be matched to a patient's values. The authors as well as many of their palliative care colleagues recognize the need for additional communication training and have sought such training throughout their careers. Given the ubiquitous nature of death as part of life and therefore as part of all medical care, it would benefit our profession greatly if a life-long learning ethic concerning ACP communication skills were adopted universally.

In the End, It Pays to Start with the End in Mind

CMS reimbursement for ACP conversation procedures signifies it is time to banish the myth that talking is somehow less complex and powerful than the other things we do for patients. When caring for the seriously ill, discovering what matters most to them is central to the patient-physician relationship. Fully integrating whole person ACP into standard practice and normalizing it in our medical culture and training are key to ensuring that the care that matters to those we serve is the only thing delivered. By fully developing ACP conversations as a skilled procedure, we significantly enhance our capacity to restore the heart of medicine to a sinus rhythm.

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MEDICINE AND SOCIETY

How Should We Enhance the Process and Purpose of Prognostic Communication in Oncology?

Bryan A. Sisk, MD and Jennifer W. Mack, MD, MPH

Abstract

We propose that effective prognostic communication requires attention to the process and purpose of communication, where purpose represents the will and process the ability to communicate. Prognostic communication has historically challenged clinicians and patients. Few interventions have been developed to improve prognostic communication, and those that have been developed largely target the process of communication. We argue that more work is needed to address the purpose of prognostic communication, because the first step in all effective communication is desiring to communicate well. In developing communication interventions, investigators should be thoughtful about the audience they are targeting, the goals of the intervention, and the feasibility of disseminating and implementing the intervention in busy health care systems with limited resources.

The Challenge of Prognostic Communication in Oncology

Effective prognostic communication in oncology is essential for informed decision making, and the majority of adult patients and parents of children with cancer prefer honest disclosure.^{1,2} High-quality prognostic communication has been shown to support hope,³ trust,⁴ satisfaction with medical care,⁵ and peace of mind.⁶ Honest communication also allows patients to focus hopes on attainable goals.^{7,8} However, patients who receive explicit prognostic communication tend to interpret this communication as less compassionate.⁹

Given the challenges of maintaining this delicate balance of hope and honesty, it is not surprising that many clinicians have historically avoided discussions of prognosis.^{10,11} Starting in the 1970s, clinicians developed an appreciation for the value of honest communication with patients about a cancer diagnosis.¹² Prior to that time, cancer diagnosis and prognosis were largely synonymous due to limited treatment options. Over time, advancing technology has divided diagnosis from prognosis, but prognostic discussions remain challenging, and many deficiencies in this process persist. For example, many physicians avoid discussions of life expectancy unless initiated by patients.¹³ When prognosis is discussed, few physicians use quantitative terms or check

the patient's understanding.¹⁴ As a result, many physicians and patients with cancer hold discordant views of prognosis.¹⁵⁻¹⁷

In considering how to improve prognostic communication, we propose to define communication as the interplay of *purpose* and *process*. Purpose is the reason for which something is done or created, expressed in a person's will or desire to communicate. Process is the specific series of actions taken to reach a desired end, manifest in a person's ability to communicate effectively. When miscommunication occurs, it is related to a deficiency in one or both of these components. In this article, we will first explore impediments to the process and purpose of prognostic communication, and then we will make recommendations to guide the future development of communication interventions. Although communication is a bidirectional interaction, we will largely focus on clinicians' role in communication because clinicians possess prognostic information and thus have the onus to initiate prognostic discussions.

Barriers to the Process of Prognostic Communication

The process of prognostic communication in oncology can be impeded in many ways, some related to knowledge deficits. In some instances, clinicians might fail to understand what their patients want or need to know.^{18,19} Additionally, some patients might not want to hear poor prognostic information, or they might want to receive the information in specific ways that are not clear to the clinician. Other patients might not know how they prefer to hear this information since they have never had similar experiences before. In addition, prognostic disclosure can be overwhelming, making it challenging for some patients to absorb information while emotionally distressed.²⁰ Compounding this emotional distress, most patients have a limited understanding of complex medical information and statistics, necessitating effort and skill on the part of the clinician to satisfactorily explain pertinent information.²⁰

Another impediment is the misconception that diagnostic and prognostic communication is mostly about talking, explaining, and sharing information. In reality, providing information is only one of several functions of communication in cancer care.²¹ Active listening, for example, is equally essential for effective communication. Similarly, [responding to emotions](#) is another function of communication that is often overlooked. Scrimin et al. found that many physicians avoid discussions of emotion, even when patients use emotional statements, indicating either a lack of physician awareness or discomfort with addressing emotion.²²

Cultural differences can also make it difficult for even experienced communicators to appropriately understand and interpret the meaning behind the patient's words. Language differences alone can be a significant barrier to physicians' information sharing, contributing to suboptimal communication along with feelings of frustration, anger, and sadness for patients and parents.²³ True cultural competence starts with

cultural curiosity, which relies on asking questions, actively listening, and acknowledging when additional resources (such as translators) are necessary. This cultural curiosity should be manifest from the onset of the physician-patient relationship, thus serving as a foundation for all communication, not just difficult conversations.

Given these challenges to the process of prognostic communication, clinicians require a robust skill set to satisfactorily fulfill their role. However, there is evidence that trainees might have limited exposure to difficult communications during their training,²⁴ resulting in some clinicians' lack of confidence in their communication skills²⁵ or, conversely, a lack of awareness of their own deficiencies in communication skills.²⁶ Despite the development of educational curricula to promote communication skills during medical training, much of a trainee's communication education relies on role modeling, which is often insufficient for honing communication skills.²⁷ These challenges to the process of communication are largely related to lack of knowledge or lack of skill, making them amenable to improvement with [skill building](#) sessions of various sorts. As we discuss next, challenges to the purpose of prognostic communication involve lack of motivation, and might not be so easily addressed.

Barriers to the Purpose of Prognostic Communication

The first step in communicating well is actively intending to communicate well. Effective prognostic communication with patients is an intensive process that requires humility, taking risks, absorbing the emotional trauma of others, attentive listening, and investment of time. Even with a well-honed skill set, the most determined efforts at communication can be hampered by the clinician's time constraints and workload. This fast-paced clinical environment necessitates active, dedicated effort by clinicians to spend time developing relationships that support patient communication. Given the power dynamics in the clinical relationship, many patients might feel discouraged from pursuing prognostic discussions if not initiated by their clinician.²⁰ Therefore, most impediments to the purpose of prognostic communication originate with the clinician.

Many clinicians avoid discussion of life expectancy unless the patient initiates the discussion.^{28,29} Such avoidance might be related to the clinician's perceived challenge in balancing hope and reality or to the clinician's fear of diminishing hope.²⁰ Fostering hope is viewed by many physicians as an essential part of their professional role.^{30,31} In conveying poor prognoses to patients, some clinicians might feel like they are "hitting" patients "over the head" with [bad news](#).³² We acknowledge that some patients truly do not desire prognostic information, and in these situations avoiding prognostic disclosure when such conversations are not clinically urgent may be the appropriate approach. (At times, urgent clinical situations such as acute decompensation requiring resuscitation decisions might require clinicians to address prognosis whether or not the patient and family desire these conversations.) More often, however, such avoidance of prognostic communication represents a misguided attempt by the clinician to protect the patient or

a manifestation of the clinician's personal discomfort with sharing bad news. This discomfort can lead physicians to frame discussions more optimistically,³³ or it can dissuade them from discussing prognosis at all. In one study of patients with terminal cancer, 28.3% of physicians reported that they would communicate an overly optimistic survival estimate to their patients, and another 22.7% of physicians stated that they would not communicate any survival estimate at all.³⁴

This avoidance of prognostic communication might also result from clinician discomfort with responding to the patient's emotions. Patients often drop hints about their emotional state, waiting for clinicians to signal their openness to further discussion. Physicians, however, often miss these emotional cues, whether intentionally or not.²² Taylor et al. studied the interactions between cancer patients and oncologists, finding that 50% of clinicians reported that they had "often" or "almost always" discussed emotional issues, whereas only 18% of patients felt the same way.³⁵ Given these discrepant perceptions, hesitance to engage with patients' challenging emotions creates a barrier to effective prognostic communication.

Lastly, **uncertainty** can deter clinicians from discussing prognosis. Clinicians generally desire certainty before discussing death or life expectancy,³⁶ but such certainty is largely elusive until late in the course of disease. Such lack of certainty can lead clinicians to withhold prognoses or frame discussions with overly optimistic phrases and euphemisms.³⁷ Although discussions of uncertainty can be challenging for clinicians and frustrating for patients, most patients want physicians to discuss uncertainty because uncertainty is unavoidable, and they believe physicians are the best source of accurate prognostic information.³⁸ The clinician's desire for certainty is understandable, but it could lead to worse communication and therefore worse support of ill and dying patients.

Targeting the purpose of prognostic conversations, however, is not just about motivating clinicians. By conveying the importance of considering prognosis, these conversations can also implicitly reinforce the purpose of prognostic communication for patients and their families. These conversations can also remind patients that their lives are valued and their wishes are fundamentally important. Finally, clinicians who are willing to talk about a difficult future also model this behavior for patients, who might themselves be contemplating how to address these issues with loved ones. Engaging with the purpose of communication, we would argue, is therefore an important act of communication in itself.

Interventions—Past, Present, and Future

Given these impediments to the purpose and process of prognostic communication, several investigators have developed interventions in recent years that aim to support and improve difficult communications.²⁷ However, these interventions have focused

mainly on skill building and educational sessions that seek to bolster the process rather than the purpose of communication.³⁹⁻⁴¹ While we value this important work, we maintain that purpose is a critical element for effective communication. If a clinician has insufficient motivation to engage in prognostic communication, then educational sessions are unlikely to change the outcome. To maximize the effect of communication interventions in the future, investigators should seek out ways to motivate clinicians to engage in these conversations with patients and families. Future interventions to support prognostic communication could also benefit from attempts to leverage the roles of other clinicians or patients. Currently, because physicians largely serve as gatekeepers of prognostic information in the medical hierarchy, other clinicians might feel limited in their ability to address prognosis without the support of the primary physician. Some investigators have begun to address this issue by encouraging nurses and patients to use question prompt lists to initiate conversations.⁴²⁻⁴⁴

Targeting motivation, however, is a difficult venture. First, not all clinicians are willing to communicate about prognosis. We conceptualize 3 groups of clinicians: those highly motivated to communicate about prognosis, those conditionally motivated, and those unmotivated. Each group is likely to respond differently to interventions, and no single intervention is likely to effectively support all 3 groups. Second, health care budgets are limited and capital will likely be scarce to support longitudinal communication interventions. Therefore, investigators will need to make difficult decisions about the aims and scope of proposed interventions. For example, should interventions aim to maximize the quality of prognostic communication for highly motivated communicators, or should they aim to increase motivation for prognostic communication among unmotivated clinicians? Lastly, any intervention that requires clinicians' time or effort will likely be viewed as burdensome and onerous, even for those motivated to improve communication. Every moment spent engaged in an intervention has an opportunity cost. To maximize chances of success, future communication interventions should be integrated into clinicians' workflow as best as possible.

Effective prognostic communication requires that clinicians (and patients) have the will and ability to communicate about prognosis. As we have highlighted in this article, there are many impediments to prognostic communication. However, each impediment provides an opportunity in the form of a potential target for future communication interventions. By taking honest measure of the current challenges to communication and the limitations of clinicians, investigators can develop interventions that will meet the needs of clinicians and patients, paving the way to better communication and better care.

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MEDICINE AND SOCIETY

How Do Medicalization and Rescue Fantasy Prevent Healthy Dying?

Peter T. Hetzler III and Lydia S. Dugdale, MD, MAR

Abstract

Before antibiotics, cardiopulmonary resuscitation (CPR), and life-sustaining technologies, humans had little choice about the timing and manner of their deaths. Today, the medicalization of death has enabled patients to delay death, prolonging their living and dying. New technology, the influence of the media, and medical professionals themselves have together transformed dying from a natural part of the human experience into a medical crisis from which a patient must be rescued, often through the aggressive extension of life or through its premature termination. In this paper, we examine problematic forms of rescue medicine and suggest the need to rethink medicalized dying within the context of medicine's orientation to health and wholeness.

*[O]n callow, lumpish, and selfish youth
peril, sorrow, and the shadow of death
can bestow dignity, and even sometimes wisdom.*

J.R.R. Tolkien, *On Fairy Stories*

Finding the Proper Place for Medicalized Dying

In J.R.R. Tolkien's famous lecture on the power of storytelling, "On Fairy Stories," he suggests that children's stories should not avoid the topic of death. Rather, they should explore "the shadow of death" to help children begin to understand death's inevitability. This is a lesson from which most adults also stand to benefit.

Today our societal avoidance of death has led, in part, to "medicalized" dying, by which we mean a dying process facilitated or prolonged by medical intervention. Dying has been removed from the home and community and transplanted in the hospital or institution in an attempt to rescue dying patients from death. Medicalization can violate the bodies of dying patients with tubes, restraints, mechanical hums, and beeps—all efforts to control what remains of life and to stave off death as long as possible. It has enabled patients, their families, and physicians to delay death without necessarily promoting the health and healing of patients.

Medicalized dying is not categorically bad. Most generally, the term could apply to anyone receiving any health care (eg, oral pain medications) during the dying process. But our critique concerns the [forms of medicalized dying](#)—aggressive extension or premature termination of life—that both exemplify and perpetuate the belief that dying is a medical crisis from which patients must be rescued. The patient with terminal lung cancer whose mechanical ventilation simply staves off death, for example, experiences this sort of medicalized dying. Such dying prompts the question: What is the proper place of medicalized dying within the context of the aims of medicine?

To answer this question, we will first explore medicalized dying as a crisis from which patients must be rescued. We will then consider current practices that attempt to rescue patients. Finally, we will examine the role for medicalized dying as rescue within the broader context of the goals of medicine.

The Crises of Unhealthy Approaches to Death and Dying

In 2014, 37.3% of patients died in hospitals, approximately 23% died in nursing homes or long-term care facilities, and approximately 29% died at home.¹ In 2016, 48% of all Medicare patients received some hospice care, but roughly 28% of patients enrolled in hospice a mere 1 to 7 days.² Furthermore, in 2014, the national average for intensive care unit (ICU) mortality was 14.7%, with individual state averages reaching as high as 21.6%.³ Taken together, these data suggest that the vast majority of patients experience highly medicalized dying and deaths, the antithesis of what most patients prefer. In fact, approximately 80% of Americans indicate that they would prefer to die at home.¹

It is common to hear the public characterize the role of physicians as “saving lives.” It is no coincidence that this exalted depiction of the physician’s role exists, because the media routinely portray physicians as lifesavers or rescuers. Consider, for example, how cardiopulmonary resuscitation (CPR) has been romanticized. One study found that the immediate survival rate for television CPR was about 70%, which is much higher than the immediate survival rate of 37%–61% in reality.⁴ Of adult patients who are revived with CPR, only about a quarter survive to hospital discharge.⁵ Indeed, one study suggests that depictions of trauma patients in the television show *Grey’s Anatomy* might create false expectations among a general audience. The show typically depicts trauma patients either dying or being “fixed” and discharged from the hospital following a single surgery, which is far from reality.⁶ These portrayals contribute to a misguided belief among the general public that medicine always has the ability to cure, fix, and save lives, regardless of the type of injury or illness—precisely the sort of medicine that makes for exciting television.

Medicine’s misrepresentation is not solely the fault of the media, however; the culture of the medical profession is to blame as well. Physicians can feel ill prepared to discuss dying and death.⁷ As a result, patients, families, and physicians often address difficult

end-of-life decisions when it is too late—when patients are dying in the hospital and receiving useless interventions—in short, when death has become a medical crisis.⁸ These circumstances lead to inferior end-of-life decision making and create a culture in which both physicians and patients are ill prepared for death. When physician and patient alike avoid goals-of-care conversations, death comes as a surprise, and patients can make health care decisions out of fear or confusion. By contrast, when the goals and values of patient and family are explored deliberately over the course of an illness, the patient is empowered to make informed health decisions as death approaches.

Rescuing the Dying

The miasma of fear, confusion, and uncertainty surrounding this unpreparedness for death forces patients and families to ask physicians to do everything possible to rescue the dying. When disaster strikes, victims look to be rescued, and the disaster of death offers no exception. The bioethicist Albert Jonsen calls this the “rule of rescue”:

Our moral response to the imminence of death demands that we rescue the doomed. We throw a rope to the drowning, rush into burning buildings to snatch the entrapped, dispatch teams to search for the snowbound. This rescue morality spills over into medical care, where our ropes are artificial hearts, our rush is the mobile critical care unit, our teams the transplant services.⁹

Jonsen suggests that the imperative to rescue becomes, in the face of death, a compulsion that overrides rationality. When death looms, the utilitarian ethic of doing the most good for the greatest number of people fails, and physicians adopt a deontological or duty-based ethic to save life no matter the cost.

More recently, the philosopher Nancy Jecker has claimed that the rule of rescue has no moral imperative and that it can in fact work in opposition to the principle of justice.⁹ By attempting to rescue patients from situations in which the prospect of any benefit with treatment is minimal or poor, she writes that:

One is trying something, but it is not rescue. A more honest telling might be: harming the patient, wasting resources, feeding false hope, disregarding professional standards, failing to show courage, being seduced by technology, neglecting to focus on palliative care, being coopted by the family, refusing to acknowledge medicine’s limits, denying a patient’s impending death. Characterizing the use of futile interventions as rescue, or attempted rescue, clouds our moral perception, making it difficult to identify the morally egregious features of what we are doing.¹⁰

Jecker suggests that physicians should avoid such “dubious” and “farcical” rescue attempts.¹⁰

We agree with Jonsen and Jecker that the threat of death sometimes causes physicians to go to great lengths to avert it. But we want to push the notion of rescue further. It is true that sometimes rescuers throw ropes to the drowning, but it is equally true that

sometimes the more rational course is to abandon ship—to jump overboard hoping that some good might come of a bad situation. Jonsen and Jecker do not describe this sort of rescue morality, but we here suggest that an additional way that physicians rescue patients from medicalized dying is by helping them to abandon ship. Physicians do this by intentionally hastening death.

By “hastening death,” we mean a direct action with the aim of causing death. Although withdrawal of life support or withholding life-sustaining treatment can result in death, we do not define these acts as hastening death. The intent in these cases is not to make the patient dead but simply to remove or withhold treatments deemed to have more burdens than benefits. A number of cases, including Karen Ann Quinlan’s, demonstrate that removing life support does not necessarily lead to death. Quinlan lived a decade past removal of the ventilator.¹¹

Perhaps the most controversial method of intentionally hastening death in the United States is through the practice of physician-assisted suicide, also called [physician aid in dying](#). According to the American Medical Association (AMA), “Physician-assisted suicide occurs when a physician facilitates a patient’s death by providing the necessary means and/or information to enable the patient to perform the life-ending act.”¹² The AMA does not currently support aid in dying,¹² and the practice is now legal in 6 states.¹³ It will also become legal in Hawaii in 2019,¹⁴ and it has been decriminalized in Montana through a 2009 state Supreme Court ruling.¹⁵

The physician-writer Haider Warraich offers physician aid in dying as a possible antidote to modern medicalized dying. After describing the “de facto mode of modern death” as an “acute escalation of medical interventions” for patients who are close to death, he notes that “a select few patients don’t want to go down this trodden path.”¹⁶ Instead, he says, they choose death by “physician-assisted suicide.” Warraich suggests that because we physicians have complicated modern dying, we should not stand between patients and their wish to jump overboard to avoid the burdensome application of life-sustaining treatments. He acknowledges that many physicians oppose the practice of aid in dying and that only a minority of patients will request it. Still, he implies that physician aid in dying is, in fact, a deontological or duty-based ethic. Instead of a duty to save life, however, the duty shifts to respecting patient autonomy by facilitating patients’ choice to end their lives.

But implicit in Warraich’s assertion lies what the bioethicist Howard Brody calls a “rescue fantasy.” Building on Jonsen’s thesis, Brody asserts, “The rescue fantasy is a power trip: it envisions the physician having the power to snatch the patient from the jaws of death.”¹⁷ This rescue fantasy is not just held by physicians; patients likewise subscribe to the image of a “powerful physician” who can save them from “the harm that threatens.”¹⁷ The harm that threatens here is a prolonged, medicalized, “unhealthy”

dying process.^{18,19} Thus, by offering aid in dying, the physician can “snatch the patient from the jaws” of an undesirable, highly medicalized death.

Most often physicians realize the rescue fantasy when they overestimate how medicine might help a dying patient and apply all available medical technology to thwart death—precisely the problem with medicalized dying. Brody insists, however, that physicians can also err by *underestimating* what medicine can do to relieve patients’ disquieting symptoms and to support them until death. He explores this assertion by addressing the subject of voluntary active euthanasia, illegal in the United States,¹⁷ which occurs when a physician administers a lethal agent directly to the patient. Brody wonders whether euthanasia is not simply taking the easy way out. He notes that physicians have the ability to relieve almost any distressing symptom experienced by the dying and thus should be able to decline administering euthanasia. “But to do this the physician has to be willing to listen carefully to the patient’s view of his predicament and indeed to share in the patient’s anguish.”¹⁷ This is an enormous undertaking—as much work as patching a sinking ship. Although Brody discusses the temptation to take the easy way out with regard to euthanasia, it can be applied to the practice of aid in dying. It is far easier for physicians to help patients “jump” to their deaths than it is to sit with them, listen, and coordinate the help of ancillary staff like social workers and chaplains to address patients’ concerns—existential, spiritual, familial, personal—at the end of life.

Medicalized Dying and the Goals of Medicine

Perhaps medicalized dying and the rescue fantasy would be compatible with medicine if medicine were oriented solely toward the control of death and the indefinite extension of life. But it is not. Death control and delay are not medicine’s ends; they are subject to its broader aim.

What, then, is the aim of medicine? In a classic essay, the bioethicist Leon Kass suggests that the goal of medicine is promoting health, which he describes as “wholeness.” He writes, “The English word health literally means ‘wholeness,’ and to heal means ‘to make whole..... To be whole is to be healthy, and to be healthy is to be whole.”²⁰ Health is not simply physical health, however. The psychiatrist George Engel declared in the 1970s that a reductionist, strictly biomedical view of the patient was insufficient. He proposed instead a new model—the biopsychosocial model—to replace the disease model of illness.²¹ Since then, other scholars have expanded the model further, calling for a biopsychosociospiritual approach to medicine.²²

A medicine that aims at health or wholeness, then, is a medicine that strives toward robust, biopsychosociospiritual care of the patient. It attends not merely to the physical but also to the psychological, spiritual, and communal. It often entails a multidisciplinary team. This robust sort of care can be thwarted by the application of aggressive life support to hopelessly dying patients. In such instances, technology becomes an excuse

not to work toward a patient's health or wholeness and can prevent deep engagement with the patient by the physician, chaplain, or family. Rescue technology prevents the possibility of a patient's intimacy with loved ones, and it prevents the patient's dying at home. In the case of physician aid in dying, facilitating a patient's death by lethal ingestion also thwarts efforts at biopsychosocialspiritual care, but, in such instances, it does so by elimination of the one who suffers.

Conclusion

The rule of rescue is a pervasive, insidious force that has drawn physicians toward highly medicalized dying practices: aggressive life-sustaining treatment in futile cases and physician aid in dying. By uncovering and addressing the rescue fantasy, however, physicians can begin to improve health by promoting wholeness, even at the end of life. They, with the cooperative help of social workers and chaplains, can address each component of the patient's experience near life's end—biological, psychological, social, spiritual. By actively engaging with patients about the "peril, sorrow, and the shadow of death," physicians could help "bestow dignity, and even sometimes wisdom," on patients who are approaching the end.

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Lydia S. Dugdale, MD, MAR is an associate professor and the associate director of the Program for Biomedical Ethics at Yale School of Medicine in New Haven, Connecticut. She is editor of the volume, *Dying in the Twenty-First Century: Toward a New Ethical Framework for the Art of Dying Well* (MIT Press, 2015).

Editor's Note

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August 2018, Volume 20, Number 8: E774-775

ART OF MEDICINE

Do No Harm

Artwork and caption by Tracy A. Brader, MD

Figure. *Do No Harm*



Media

Acrylic paint on canvas.

Caption

After a goals-of-care conversation, this patient's chart listed his status as "full-code." As shown in this image, resuscitation was initiated for a 92-year-old man with metastatic malignancy after being found pulseless by the rounding team.

Tracy A. Brader, MD is a third-year resident in emergency medicine at Christiana Care in Newark, Delaware. She completed medical school at UNC School of Medicine. Tracy first started painting during her second year of medical school and has used this as a creative outlet ever since.

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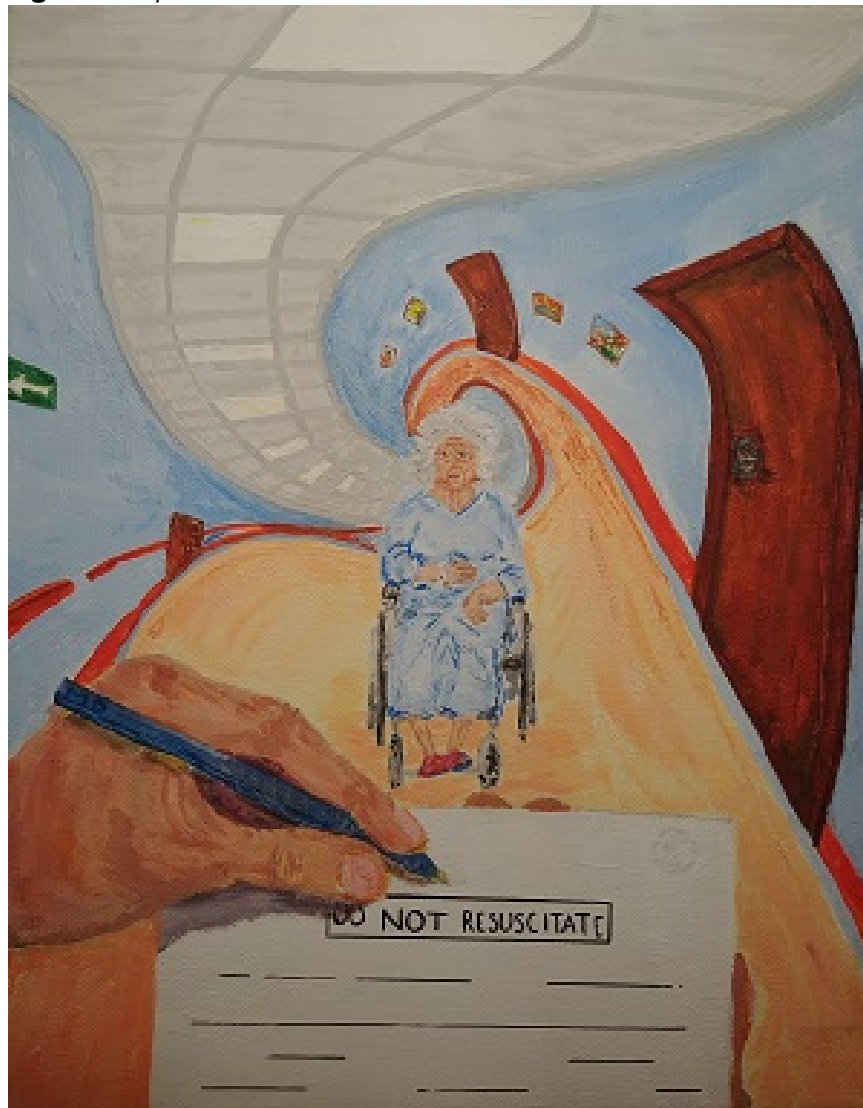
August 2018, Volume 20, Number 8: E776-777

ART OF MEDICINE

Unrepresent

Artwork and caption by Munir H. Buhaya

Figure. *Unrepresent*



Media

Acrylic on canvas.

Caption

This image represents a physician unilaterally completing a do-not-resuscitate order for an unrepresented patient.

Munir H. Buhaya is a first-year medical student at McGovern Medical School in Houston, Texas.

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ART OF MEDICINE

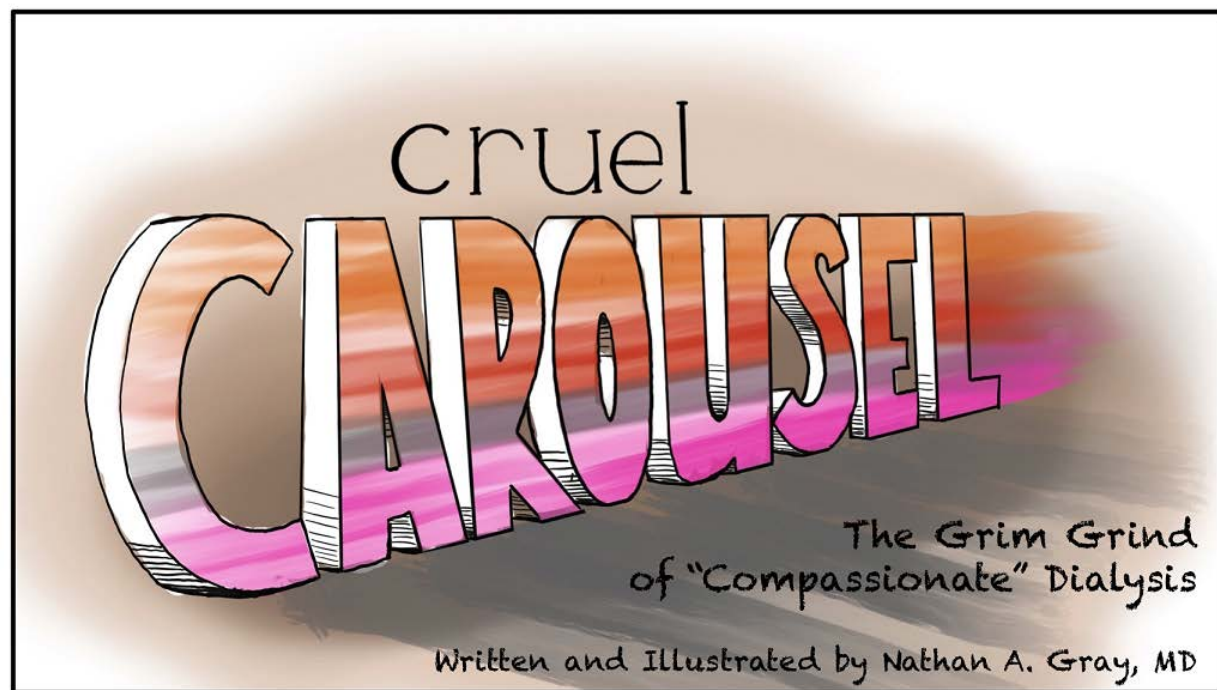
Cruel Carousel: The Grim Grind of “Compassionate” Dialysis

Artwork and caption by Nathan A. Gray, MD

Abstract

In this graphic narrative, a clinician illustrates an experience of caring for an undocumented patient suffering from end-stage renal disease (ESRD). *Cruel Carousel* tells one of the stories that most profoundly shaped the author’s own views on health care for undocumented immigrants. Graphic narrative was chosen to tell this story because words alone couldn’t capture the patient’s experience or the author’s distress about what happened to him.

Figure. Detail from *Cruel Carousel: The Grim Grind of “Compassionate” Dialysis*



[\(Click image to view the entire graphic narrative, and then click again to enlarge.\)](#)

Media

The illustrations in this piece were created using Paper version 4.1.2 and Procreate version 4.0.10 for iPad.

Caption

More than 6000 undocumented immigrants living in the United States suffer from end-stage renal disease (ESRD); those who live in locations where funding is not provided for scheduled dialysis face a recurring cycle of critical illness experiences as they wait for emergency sessions of dialysis through hospitals and emergency departments. This approach to dialysis treatment results in tragic patient outcomes and distress for clinicians, who are left to provide undocumented patients with care that is dramatically different from standard dialysis delivery. Patients oscillate between being marginally well and “ill enough” to receive dialysis, while clinicians wrestle with complicity in a system that both offers and withholds life-saving therapy.

Nathan A. Gray, MD is a physician in palliative medicine for Duke University Health System and an assistant professor at Duke University School of Medicine in Durham, North Carolina. His interests include supportive care for those with serious illness, medical education, and disparities in health care access. When not caring for patients, Dr. Gray spends time cartooning, and his work can be found online at inkvessel.com.

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ART OF MEDICINE

Resilience

Artwork and caption by Cheyanne Silver

Figure. *Resilience*



Media

Acrylic paint on wood panel.

Caption

When I told people I was pursuing a career in medicine, the statistics of female physician suicide were mentioned. When I professed an interest in surgery, I was told to choose a specialty for lifestyle, because as a woman I would need a career that would allow me to

raise my future children. All around me, I have been assaulted by doubt, as senior physicians whisper to students of my generation to turn away while we still can.

This painting represents how I see students among physician mentors, who seem to feel smothered, trapped, and grabbed at by hands of outside influencers: patients' reviews, fellow colleagues' exhaustion, society's expectations, and administrative demands for shortened patient encounters. In the middle of this painting is the eye of a student, representing where I sit today. While we observe and try to learn, despite bearing the weight of burned-out professionals' negativity, we are keenly seeking answers—to how to respond to crises, lower our rates of suicide, support our patients, and be home for dinner. This painting also conveys my hope for a future in which we can have it all and not fall into the quagmire of disappointment where so many of our mentors struggle. This painting comes from my personal art show exploring visual art as a means of promoting reflection about how to build resilience in future physicians.

Cheyenne Silver is a third-year medical student at Loyola Stritch School of Medicine in Maywood, Illinois. She has always had an interest in the fine arts, which has continued through her medical education.

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PERSONAL NARRATIVE

The Role of Hope, Compassion, and Uncertainty in Physicians' Reluctance to Initiate Palliative Care

Nora W. Wong, PhD

Abstract

This article addresses whether physicians' close ties to their patients might play an unexamined role in their reluctance to initiate palliative care. In cases characterized by uncertainty, physicians' emotional investment in their patients and patients' families might unduly promote decisions to continue aggressive treatment rather than transition to comfort care. Continued evaluation and communication of patient status, including scheduled objective consultations, can align compassionate actions with patients' best interests. This argument and analysis are based on a case of new onset refractory status epilepticus (NORSE).

A Recommendation to Withdraw Treatment at the Eleventh Hour

When my son Daniel, age 22, was struck by prolonged seizures in September 2013, he was sent to one of the finest US hospitals and cared for by a skilled and devoted medical staff. After 78 days in a medically induced coma, Daniel died. My family and Daniel's medical teams were devastated. Only after reading his autopsy report—which found extensive, global brain damage—and thinking back to Daniel's last days did I begin to realize that the fight to save his life went on too long.

In the last weeks of his life, Daniel's abdomen was sliced open to clean the aftermath of a displaced feeding tube. His bedsores grew; he had blood clots, kidney failure, and sepsis. His body was distorted by hydration, diuresis, and rehydration. He was ravaged by tubes in orifices both natural and surgically created. Until the last two days of his life, my family and I believed Daniel would walk out of that hospital the same person he was before. No one told us otherwise.

Daniel's diagnosis and prognosis were not discussed during our first 3 formal conferences with his epilepsy and intensive care unit (ICU) teams. The focus was on the crisis of the moment—the next test, drug modification, or procedure. It was only at the fourth and final conference that Daniel's prognosis was abruptly summarized for us. His physicians finally spoke to us in one voice to recommend we [discontinue aggressive treatment](#) the day before he died.

The catalyst for their abrupt, unified recommendation to stop treatment was an epilepsy physician who had never seen Daniel before. She was covering for a colleague on his epilepsy team who was about to attend a 5-day conference. After reviewing Daniel's records, she asked my husband and me gently, "Did anyone ever talk to you about function?" She left us to confer with her ICU colleagues. Her question reverberated throughout Daniel's teams. The next day, Daniel's ICU and epilepsy physicians assembled before us to give their recommendation to stop aggressive treatment. They believed it unlikely Daniel would survive. If he did, he would probably not be able to make new memories, recall old ones, speak, or move. He would suffer unremitting seizures.

The physicians were haggard and miserable; one was weeping. My husband and I were dumbfounded. My husband rejected their assessment since Daniel's first two brain magnetic resonance images (MRIs) were normal and unremarkable. The third suggested only small signs of brain atrophy. This atrophy caused concern in an epilepsy fellow, but an ICU attending physician with a neurology background was not worried. We chose to believe the more optimistic view of the senior physician and never asked for anyone else's. We didn't want to look for bad news. At that last conference, my husband insisted on a new MRI since weeks had passed since the last one. Confronted with their unified recommendation and the final MRI that suggested global, extensive brain atrophy, we decided to stop aggressive treatment. The next morning, Daniel died less than one hour after we stopped aggressive treatment.

It has taken me a few years to think beyond the pain of my son's death. I now question why Daniel's physicians waited so long to tell us that the quality of his life upon his unlikely survival would be questionable and that his death was imminent. Ongoing communication of his status would have given us time to think and to discuss with his physicians how Daniel, my husband, and I valued life and viewed death. I considered the possible explanations for the physicians' silence: they didn't know his prognosis, they knew but they were too busy to involve themselves in end-of-life discussions, and they didn't care enough about him or us to say.

I immediately rejected the last two explanations. His physicians were very involved in Daniel's case. They cared deeply about Daniel and about us. With perspective that only hindsight can give, I believe it was the uncertainty that pervaded his illness—combined with their compassion—that made Daniel's physicians reluctant to initiate end-of-life discussions.

NORSE: A Worst-Case Scenario for Communication

One ICU physician told me a few weeks after Daniel's admission that she thought Daniel had new onset refractory status epilepticus, commonly referred to by its acronym NORSE. But she abruptly left Daniel's team due to her own illness before she communicated that diagnosis to others. When I asked one of Daniel's epilepsy physicians

if Daniel had NORSE, he was reluctant to give any formal diagnosis. The diagnosis of NORSE was confirmed only indirectly after Daniel's death, when one of his epilepsy physicians referred me to other physicians investigating NORSE. When speaking with Daniel's medical teams after this confirmation, I learned that some members of his ICU team had never heard of the term NORSE.

Physicians currently have an incomplete understanding of NORSE, and their understanding was even more deficient when my son was hospitalized almost 5 years ago. It is easy to jump to conclusions about the physicians' behavior without understanding the pervasive uncertainty that characterized Daniel's case and NORSE cases today. A proposed consensus definition for NORSE was published only in April 2018. The international group of experts stated: "NORSE is a *clinical presentation*, not a specific diagnosis, in a patient without active epilepsy or other preexisting relevant neurological disorder, with new onset of refractory status epilepticus without a clear acute or active structural, toxic or metabolic cause."¹ Recent reviews find no confirmed etiology in more than half the cases of NORSE and no established effective treatment protocol. Cases that remain cryptogenic often result in significant brain damage and death.^{2,3} A common lexicon for NORSE is just beginning to coalesce, although the term NORSE was first posed in 2005 to describe the syndrome of sudden seizures in healthy people that results in "catastrophic outcome."⁴

The hospital rotation schedule and organizational structure further impaired physicians' understanding and communication of Daniel's condition. In Daniel's case, there was a division of responsibility by specialty: the epilepsy team focused on his brain, the ICU team, on his body. The two teams saw him at different times of the day. Other specialists from cardiology, neurology, infectious diseases, and nephrology consulted, creating many separate opinions. There was no single physician responsible for integrating these [silos of information](#) from the various specialties. The uncertainties of NORSE were compounded by the lack of integration of the information that did exist.

When Daniel was first admitted to the ICU, it seemed no one knew what was happening to him. As time progressed and all tests returned negative, Daniel's physicians understood more about his condition by learning the diagnoses that had been eliminated and the complications that had accrued. Even without consensus terms or a body of evidence for NORSE, physicians developed their own expectations for Daniel's outcome. Because communication among them was not integrated, each physician's understanding was incomplete. And because the physicians did not apprise us of their changing prognoses, my husband and I were the least informed.

Hope as a Humane Response to Uncertainty

No one wanted to predict devastating brain injury without certainty, which no procedure can guarantee. No one wanted to make the call to stop aggressive treatment without

clear evidence such treatment would be futile. The only certainty was that any deviation from aggressive treatment of NORSE would likely result in worse outcomes, including greater likelihood of death. Hope grew in this void left by uncertainty, a hope based on emotion since there were so few facts. And no one wanted to quash hope when hope was the only good thing that remained.

Daniel's physicians and nurses fought to save his life. They stayed beyond their shifts. They checked on him while on different rotations and even on their days off. Their devotion was profound. The staff never spoke to Daniel directly. He was initially unresponsive upon admission to the hospital and then placed in a medically induced coma to stop his seizures, a common treatment for NORSE. Perhaps the staff could not resist our endless, unspoken plea to save our son. Perhaps the sight of him lying there so vulnerable and beautiful in his youth compelled the physicians to action.

The medical teams' emotional investment in Daniel and in us might have led his physicians to believe Daniel must live not only for Daniel's sake but also for ours—and perhaps for theirs as well. Everyone desperately wanted Daniel to live. Almost no one focused on what his life would be like when he survived. It took the covering physician with no emotional tie to us to jolt Daniel's physicians into reassessing his condition. Compelling evidence to support the recommendation to withdraw aggressive treatment must have existed in his records—and who knows for how long. Because when Daniel's teams did reassess his condition, they quickly concluded that aggressive treatment should end.

The hope and compassion that fueled the medical teams' drive to save my son is what makes medicine humane. Without compassion, medicine is heartless. But compassion needs checks and balances.

Recommendations to Balance Hope and Action

NORSE is not the only acute illness characterized by uncertainty. In cases of [uncertain diagnosis](#) and prognosis, there must be one person responsible for integrating the silos of information from various specialists and teams. What remains unknown among some staff members should be articulated. The physician overseeing the unit where the patient spends the most time can be the leader who gathers the medical teams and family together as one decision-making unit to ask, What should we hope for, given what we know and expect? Discussions should be held as soon as the situation is deemed highly unpredictable, life-threatening, or grievously life-changing so that families have time to think and plan. The formal inclusion of an objective assessment can counterbalance the emotional involvement of the staff. Without complete information, physicians and families might hope for and work towards a recovery that is not possible and thereby delay end-of-life decisions.

Periodic and candid discussions of the relevant knowns and unknowns in a given case would help the medical teams and the family navigate the murky waters together. Only with eyes and hearts wide open can physicians and families align care to the changing best interests of the patient.

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Nora W. Wong, PhD is the founder and executive director of the [NORSE Institute](#).

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PERSONAL NARRATIVE

Specialized Palliative and Hospice Care and the Importance of Mourning Our Nation's Veterans

Tracy Shamas, MSN, APRN and Sarah Gillespie-Heyman, MSN, APRN

Abstract

One aspect of palliative medicine that has been underexplored is the perspective of veterans either facing critical life-limiting illness or at the end of life. The needs of veterans differ not only because military culture affects how veterans cope with their illness but also because exposure-related factors (combat and environmental) differ between military branches. In this paper, we describe two cases involving end-of-life care for veterans with combat trauma and describe individualized approaches to their care.

End-of-Life Care for Veterans with Histories of Combat Trauma

Palliative and hospice care in any setting pose opportunities for tailoring care to unique patient populations. In Veterans Affairs health care facilities, the influence of military culture is felt throughout the delivery of care. One particularly striking challenge is caring for veterans who have a history of combat trauma. This challenge is especially poignant as these same veterans might be facing an illness that is likely to shorten their lifespan. Therefore, it is of paramount importance to assess for traumatic memories associated with the time spent in the service and adapt plans of care appropriately. In the cases below, we elucidate these challenges in the hopes of increasing awareness and understanding of this patient population.

Case 1

W.D. was in his 60s when he was admitted to our hospice unit with end-stage liver disease due to alcohol intake. He was a Vietnam veteran who had served 6 consecutive, 1-year active combat deployments. Following his military service, he became a member of the Ku Klux Klan (KKK) and neo-Nazi organizations. W.D. had acknowledged difficulty reacquainting himself into civilian life, and it is possible that he joined these organizations to experience a sense of belonging and validation after the war-related atrocities he had committed. When he arrived, it was clear that he was angry, was minimally interactive with all staff, and had great difficulty allowing any physical care by a person of color. On a nearly daily basis over the first weeks of his admission, he described in graphic detail his combat experiences, telling staff regularly that because of his life choices he was evil. He

made these revelations not only to horrify staff members but also to push them away and avoid developing a more meaningful response to the care team.

Following these exchanges, boundaries were set for acceptable behavior, the violation of which entailed immediate disengagement and cessation of the visit. Simultaneously, W.D. was consistently reminded that he would continue to be cared for and would not be abandoned. His resistance to trusting the clinicians around him stemmed largely from combat trauma over his 6 years of active duty. He vacillated between begging for symptom management and refusing to take medications. The rationale for this refusal originated from his belief that, as a soldier, showing pain equated with weakness. Furthermore, he felt his symptoms were retribution and necessary suffering for the atrocities he had committed during and after his military service. He experienced great existential distress, as he could not reconcile the love he felt from the people around him with his previously held prejudiced ideas and thoughts, which he clung to because they had formed the basis of his identity. Over the months that he was cared for on our hospice unit, his attitude towards the staff changed from one of contempt to one of care and acceptance. As staff members showed him respect, demonstrated compassion despite his hostility, and displayed consistency in their approach to care, his behavioral outbursts lessened in frequency and intensity and eventually disappeared altogether. Over time, he was able to recognize his own capacity for love and to be loved by others, including the people he was initially prejudiced against. When he was nearing the end of life, he expressed to the [chaplain](#) that while he was grateful to the staff, he felt deep regret that his life had no value and felt that no one would remember him after his death. Our chaplain eloquently responded, "We will mourn you." This simple sentiment—and all the care he had received beforehand—allowed a peaceful death for this tortured soul.

Case 2

G.A., an Operation Iraqi Freedom veteran, was only 50 years old when he was diagnosed with stage IV adenocarcinoma. At initial diagnosis, he received a colonic stent for obstruction and multiple rounds of chemotherapy. Our team met him for an initial palliative care consultation approximately 5 months after his diagnosis. Unfortunately, by this time his cancer had already metastasized to his liver despite aggressive treatment regimens. Much of our initial visit did not focus on G.A.'s terminal cancer diagnosis but rather on his military experience, as it was clear that G.A. was struggling with another major health problem that had never fully been addressed. G.A. was a commander in the Army and was deployed to Iraq from 2004 to 2005. Like many veterans with combat exposure, G.A. suffered from severe [posttraumatic stress disorder](#) (PTSD) that had been ongoing since he returned from his deployment. He was very candid with us in sharing his experiences and quickly became tearful during our interaction in his hospital room. He disclosed that because his PTSD made him claustrophobic and unable to cope with reality, he often could not reside in his own home with his wife and son but rather lived in a tent in the backyard. G.A. prided himself on his

strength in battle and life, but it was clear that he never fully reassimilated into civilian life. He also described himself as “thick headed,” with a high tolerance for pain. Our team knew that as this particular veteran progressed in his illness, both PTSD and potential underreporting of symptoms were likely to become obstacles in his care.

G.A. was again hospitalized for an obstructed colon and stent replacement. During this admission, he became delirious, believing that medical staff members were holding him in the hospital against his will. Because of the severity of his agitation, he required physical and pharmacological restraints to ensure his safety and that of the staff around him. Afterwards, he poignantly described this experience as being like “an animal in a cage ... with no escape.” Eventually, G.A. stabilized and was discharged home to his wife and teenage son, but he soon developed refractory ascites and required paracentesis repeatedly. G.A. was never forthcoming in sharing his symptoms and required much prompting and encouragement from our team and the home care nurses to disclose his symptoms. It was a continuous balancing act to respect G.A.’s need for independence in his care, allowing him the space he needed to process and cope with his illness, and to feel that we were still adequately managing distressing symptoms. Because of the severity of G.A.’s symptom burden, he eventually required admission on our inpatient hospice unit. But because this veteran had been able to work with our team in the outpatient setting, by the time he came to the unit he was accepting that he was nearing the end of life and allowed all aspects of care provision in the inpatient setting.

Palliative Care for Veterans with Combat Trauma

As civilians working at a Veterans Affairs hospital, we needed time to acclimate to the military culture; adjusting to the language (“tour” vs “shift,” “leave time” vs “vacation”) seemed the most challenging initially. However, it became quickly apparent that our care of veterans was affected by much more striking features than language, and these features changed our approach to care. Developing an understanding of the nuances of the different military branches and of how veteran characteristics vary from one war era to the next is paramount to ensuring each veteran receives individualized care. For instance, a veteran with an Army or Marine Corps background has a greater likelihood of having experienced face-to-face ground combat than a Navy or Air Force veteran. Killing one person who is in front of you has a greater psychological impact than dropping a bomb on a faceless population. In the field of palliative care, the emotional response seen in veterans who have just received a life-limiting diagnosis makes formulating an individualized plan of care even more challenging, just as the emotional challenge of taking care of dying persons on a regular basis adds to palliative care practitioners’ burden.

Ascertaining a veteran’s military experience in order to adapt care must be approached sensitively yet directly, with awareness of nuances. One particular ethical challenge is helping the family to understand how military experience might impact the veteran’s

ability to cope with illness. Here we will focus on another ethical challenge: determining how the experience of military service has shaped the individual patient without undermining the veteran's trust in his or her clinicians. In our cases, the impact of PTSD on both W.D. and G.A. overshadowed their medical illnesses. In particular, W.D.'s illness was a result of alcoholism, which developed in response to his traumatic combat experiences. An additional ethical consideration is that the life-limiting illness that occurs might actually have been caused, directly or indirectly, by being in the service. For example, direct causal relationships have been established between illnesses such as lung cancer and Agent Orange exposure in Vietnam and between Gulf War Syndrome and exposure to burning oil pits in the Middle East.^{1,2} Learning that one's illness was caused by military service can lead to a myriad of emotional responses—anger, sadness, regret, or difficulties in processing the diagnosis and its implications. Finally, while the focus of palliation is alleviation of symptoms, veterans' underreporting of their symptoms stems from military culture and emphasis on stoicism or "fighting" through hardship. Conversely, overreporting or exaggeration of symptoms is also seen, which could be related to concern that [pain might be ignored](#), as it might have been upon return from war, especially for Vietnam veterans. Furthermore, comorbid substance use disorders in this population are a common problem often stemming from undiagnosed mental illness or self-treatment for PTSD that can make treatment with opioids or anxiolytics even more complicated.

These factors not only make assessment and intervention particularly complex but also could result in unnecessary emergency department visits or acute hospitalizations. Extensive and broad efforts have been made within the Veterans Health Administration to offer palliative care services. Notably, at VA Connecticut, the focus has been on delivery of palliative care in the outpatient setting to assess for military trauma, build rapport, and provide continuity across all care settings to minimize veteran distress in living with an illness that will be life shortening.

Challenges for Veterans at End of Life

All enrolled veterans with a life-limiting diagnosis who meet qualifications for hospice-level care are eligible for VA hospice benefits regardless of their service connection.³ However, use of these services might not facilitate achieving a "[good death](#)" outside of an inpatient facility. Lack of social support, challenges with substance use disorders, and combat trauma impeding appropriate interventions for distressing symptoms are only some of the limitations. If a veteran lives alone and has no discernable support network, death at home might not be possible. Notably, community hospice agencies might be unable to enroll a dying person in home hospice without 24/7 support at home. Likewise, the staff of a community agency might not have been exposed to military culture or know how military-related training, combat exposures, or past traumatic experiences can impact care. What is seen clinically on a regular basis, although its prevalence is not easily measurable, is PTSD at end of life. Veterans in the final stages of life who have

been affected by PTSD might experience existential distress during the dying process, which poses unique challenges in symptom control. Lack of appropriate assessment early in the course of advanced illness could limit opportunities to assess for military-related trauma and could potentially lead to families being inadequately prepared for the death of a loved one.

Implications of Care for Veterans with Life-Limiting Illness

Of the estimated 20 million veterans in the United States, just under half are currently enrolled in the VA system.⁴ What can be extrapolated from these data is that, while a significant portion of veterans die within the VA health care system, a significant number die in the community where their veteran status might be unknown or the influence of their military experience not fully appreciated. This circumstance limits effective delivery of veteran-specific outpatient palliative services over the course of a life-limiting illness by failing to ensure that caregivers of veterans at the end of life are sensitive to military culture and aware of PTSD and its effects. The most immediate implication of limited veteran-specific outpatient palliative care is the inability of veterans with life-limiting illness to achieve a reasonable quality of life. A more far-reaching implication is the long-term impact on families throughout the course of the disease as well as family distress during the period of active dying, which could cause protracted or complicated grief. Assessing patients at the end of life for military-related factors can greatly improve the care of veterans and members of their support network. Our veterans have taught us, and continue to teach us daily, how to be better practitioners in this field and to provide compassion, care, and comfort to those who have sacrificed so much for us. To W.D., G.A. and all the rest.... We will mourn you.

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