INNOVATIONS AND PROVOCATIONS

Recognizing a Patient Is Acutely Dying

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In bed 40 is a gentleman in his 60s. He had been electively admitted for an expedited liver transplant evaluation, but on hospital day 4, he started vomiting blood. He became hypotensive and was emergently intubated owing to active hematemesis. Because bedside endoscopy could not control his bleeding, an emergent transjugular intrahepatic portosystemic shunt insertion was performed. His bleeding nearly, but not completely, stopped. He developed substantial agitated delirium from hepatic encephalopathy. Despite antibiotic prophylaxis, he developed a distributive shock. Yet he was quickly resuscitated and weaned off norepinephrine; his creatinine remained normal and his fraction of inspired oxygen was only 0.3. The Hepatology Consultant believed that he remained a viable candidate for liver transplantation, although no commitment could be made until he was cleared by Cardiology owing to evidence of reversible ischemia just prior to the episode of hematemesis. As he thrashed in bed during our efforts to liberate him from the ventilator via sedation reduction, his wife asked me, “Is he dying?”

Two doors down is a woman in her early 30s. She had chronic myelogenous leukemia refractory to standard treatment and had undergone hematopoietic stem cell transplantation 3 months ago. Her course was complicated by substantial graft-versus-host disease and she had never reconstituted her immune system. Eight days before intensive care unit (ICU) admission, she had chosen to repeat stem cell transplantation, and begun fludarabine-melphalan conditioning. Midway through Flu-Mel, she was found to have new vancomycin-resistant enterococcal bacteremia. Her counts nadired as planned, and she underwent peripheral stem cell infusion 2 days before ICU admission. She developed progressive delirium, respiratory failure, and renal failure and was admitted to the ICU and promptly intubated. Now on day 9 after stem cell infusion, her intern and her father both asked me, “What are we doing? Isn’t she dying?”

In each case, I was not being asked for an itemization of the individual organ dysfunctions—those asking often knew lab values and trends better than I did. I believe these family members are really asking, “What should I do?”

Why Recognize a Patient Is Acutely Dying?

Families play an important role in patient recovery; family are there to support the patient, to offer hope and inspiration.

They keep the home fires burning, marshal family and friends for encouraging visits and video calls, and help the patient summon the strength to get out of bed for physical therapy one more time.

Families also know that there are a distinct set of tasks related to the dying patient. They must bring the relatives together, and often hold vigil at the bedside so that no one dies alone. They must grieve and do the mundane tasks of bringing closure to a dying life. Sometimes, they fear, they must also prevent inappropriate invasion of the dying body by a health system that defaults to intervention (1). There are things that must be done to prepare for a death, and to bear witness to the life it ends, and families know that only a tiny subset of those things are medical.

What they do not know is: which role are they supposed to be playing? The task lists and emotional burdens are quite distinct for the patient likely to recover versus the patient likely to die. These families are asking for permission to grieve, or for permission to hope (R. Barbaro, personal communication).

In the increasingly multidisciplinary, highly consultative world of the modern hospital, the many clinicians interacting with the patient need to act in a coordinated fashion. As an ICU doctor, I need to know my role—whether to push for one more biopsy, invasive line, or higher-risk imaging study; or to orient my team’s care to a suite of services in the acute care of the dying

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Table 1. A systems approach to the intensive care of the acutely dying patient

Classics:
Pain
Dyspnea
Anxiety
Stopping*
Alimentary:
Desire to eat
Secretions
Nausea
Constipation
Diarrhea
Urinary retention
Devices:
Lines, can they come out?
Access for giving i.v. palliative medications
Fans†
Social:
Loved ones and kinfolk at bedside as desired, or connected via virtual presence
Loved ones and kinfolk being supported physically (e.g., food, showers, and sleep) and emotionally (e.g., grief counseling, feelings of responsibility, and managing echoes in current care of past trauma)
Spiritual or religious rituals
Pets
Music
Paperwork‡
Organ donation
Team care:
Self-care
Team debrief and support
Plan for a pause after death
Planning time to grieve

Definition of abbreviation: i.v. = intravenous. This list is curated from multiple teachers, and no claim to originality is made. See, for example, the 3 Wishes Project for a related approach and framework for execution (2), and, recalling that families will grieve in their own ways, incorporate the principles of Trauma-Informed Care as outlined by Ashana and colleagues (7).

*Stopping treatment and monitoring that is no longer beneficial.

†Fans prevent the room from feeling stagnant and anecdotally may help relieve air hunger.

‡Offering support to family in any medical leave paperwork or transportation arrangements for family, and assuring them that they will be helped with death paperwork and funeral home when the time comes, so that they can be emotionally present with their loved ones now.

(Table 1 for my own strategy, as an example, or the 3 Wishes Project for a related approach [2]).

A Definition

An acutely dying patient, I propose, is a patient whose death is inevitable in a reasonably short period of time and would

be even if they received all acceptable medical care. The acutely dying patient is common in the ICU and hospital and must be distinguished from the “sick patient,” as the term “sick” is colloquially used in inpatient medicine. A “sick” patient is one whose physiology is so deranged that they will die in a short time. The category of “sick” patients also includes those who would die *unless* they receive medical care, but who can benefit from life-saving interventions; I propose those patients who are sick, but could be saved by acceptable interventions, should be distinguished from the “acutely dying” patient in the sense I wish to discuss here. Although the growth in hospice and palliative care have substantially expanded the recognition and appropriate care of dying patients in the outpatient setting, there remains room for improvement in the recognition and naming of the acutely dying patient in the inpatient setting.

Ways to Be Acutely Dying

There are at least three ways in which a patient may be acutely and inevitably dying. It may be that their body has suffered irreversible tissue damage to the extent that, even if given time to heal, recovery of function to support homeostasis is not possible. At some point, a patient will have too few cardiac myocytes to pump blood, too few alveoli to exchange gas, or too few hepatocytes to detoxify the blood. Although it may be possible using certain heroic technologies to delay the precise moment of cardiopulmonary arrest (e.g., by using extracorporeal life support), for such physiologically unsupportable patients, there is no reasonable expectation of a return to a self-regulated homeostasis supportable by conventional outpatient-available technologies. Such a patient is acutely dying by virtue of physiology both irreparable and, over the longer term, unsustainable. (Note that such unsustainability may be because of the local unavailability of a technology that is available elsewhere but cannot or will not be brought to bear on this patient.)

A patient may be supportable with acceptable and available technology, but the state of homeostasis to which they likely would be returned is unacceptable to them—or perhaps to us. For example, many would refuse a treatment that would lead to

dementia, even if it saved their own life painlessly (3). Other conventional examples include the quadriplegic patient who would find a life of ventilator dependence and total care to be unacceptable, or the patient who has sustained a massive stroke. Such patients are acutely dying because there is no medical treatment that can reverse their physiologic derangement to produce an outpatient homeostasis of sufficient quality to them.

Finally, it may also be that a patient can be returned to a life they would find consistent with their values, but only after a prolonged or onerous ICU course. That is, there may be resuscitative technologies available, but they are unacceptable to the patient. For example, a devout Jehovah’s Witness may be dying of exsanguinating hemorrhage because they will not accept packed red blood cell transfusion that would, in other cases, be sufficient to allow time for hemostasis to be achieved. For others, the path of prolonged rehabilitation, as after debridement for necrotizing fasciitis or a Whipple procedure, may be infeasible, even though such a procedure would be “curative” in a conventional sense. More disquieting to me, I have had patients and families tell me they find the confusion and loss of control over bodily functions associated with hepatic encephalopathy or prolonged agitated delirium unacceptable, even if they believe it is potentially reversible at a least for a time. For some patients, a given life-support technology (intubation, or a feeding tube) may cross a personal line about avoiding dependence on machines and be inconsistent with their values. Such a patient is acutely dying because there is no *acceptable* and feasible medical treatment that can reverse their physiologic derangement, even though such treatments might be acceptable in other contexts for other patients.

It is useful to pose three questions in deciding if a patient is acutely dying: Is the condition survivable for anyone? Would the outcome be worthwhile to this patient? Would this patient tolerate the treatment?

It may have been simpler in the past. Critical care, when it was a young and brash profession, fixated on the prolongation of life at any cost. The SUPPORT trial suggested that, in the 1980s to 1990s, once admitted to the ICU, patient preferences were ignored, as was any outcome beyond ICU discharge (4). No matter how painful or diminished, a life prolonged was a life; there are rich ethical traditions within which that is still true, but they are uncommon where I practice.

Instead, we must face uncomfortable uncertainties, weighing a death that

Table 2. Challenges

Concern	Explanation/Elaboration	Management Approach
Can't one both treat for survival and plan for death at the same time?	Is there a false dichotomy being created between curative and palliative care, which often coexist in contemporary best practice?	Often both can be done. But I believe that there does come a time when further treating for survival is inappropriate, perhaps even wrong. When such a time comes, it often is in the patient's and family's interests for us to name it as "acutely dying".
What is "inevitable"? How small a probability? How short a time frame?	It is currently impossible to reliably quantitate the probability of death under alternative treatment strategies. Can one accept ever being wrong in this situation?	I tend to use the framing of a "reasonable probability," with "reasonable" titrated in part based on what I know of the patients' values. I believe one should strive for ever-improved accuracy, but that there is real harm to errors in either direction. The balance of those harms should be done with the patient's and family's preferences in mind, not just the clinician.
Whose perspective on suffering should be definitive?	What if the patient believes something to be unacceptable suffering that the clinical team thinks should be fine, or vice versa?	These problems are no worse here than in every part of medicine that incorporates patient preferences, and the same tools can be used.
Aren't I just being ableist?	Does such a framework risk naming some lives as not worth living, and therefore recapitulating long histories of discrimination, and of medicine's refusal to see people with disabilities in their full humanity, entitled to the same dignity as others?	These problems of implicit and explicit bias are no worse here than in every part of medicine that incorporates patient preferences, and the same tools can be used.
Future selves and adaptation	Does choosing death deny one's future self the ability to find a meaningful experience after adaptation (8)? People are often far more able to adapt to situations than they expect to be able to	This may be true. However, we are not obliged to force people to suffer pain and indignity in order to see if their future self could adapt to it.
But ICU doctors can't be expected to know what outpatient treatment options are available!	Outpatient quality of life depends on the treatment and support options that the patient will have access to	Intensivists have an obligation to maintain an up-to-date understanding of what is feasible in the outpatient setting and to seek expert consultation where necessary.
How is this different than a goals-of-care conversation?	Goals-of-care conversations often include transmitting prognostic estimates to patients and surrogates	Goals-of-care conversations, in modern best practice, are about eliciting patient preferences and values—an essential input into the physician task of deciding if a patient is acutely dying at a given moment. This article seeks to improve the process of formulating a relevant prognostic estimate for acutely dying patients, rather than focus on the specific skills of communicating that prognosis.
Isn't this just paternalism?	Is declaring someone "acutely dying" just a way to end-run around patient and family preferences?	What I am proposing is meant to encourage physicians to step into the full obligation of truly shared decision-making and share their expert judgement on survivability under different scenarios.
Who is experienced enough to do this?	Can any physician do this? If interns start doing this in their first week on the ICU service, won't that cause harm?	I think this is a task that should always be done by attending physicians at this point, with input from all members of the multidisciplinary team, and seeking advice from other senior clinicians as appropriate and the situation permits.*

Definition of abbreviation: ICU = intensive care unit.

*There is a critical role of nursing in this, as partners, but for this forum I write to an audience of physicians about physicians' responsibility.

might have been avoided against pain and indignity that offered no benefit. There is, I suggest, no good way to avoid this responsibility that comes with the honor of being an ICU physician. If I say a patient

is dying, and based on that expert clinical judgement the family and I move to full comfort-oriented care, ceasing life support, then the patient will die. They will die at that time because of my judgment.

If I am wrong, I have in some sense wrongly sentenced that patient to death. But if I too greatly fear that error—and it is an error to be feared—then I fail in the ancient injunction to "first, do not harm."

If I refuse to acknowledge a patient is dying and therefore prolong their critical care, I cause that patient and their family needless suffering. Our inability—despite the best of modern palliative care and pain-relief practices—to remove all suffering from curative-intent critical care is the crux of the patient-centered obligation to diagnose patients as acutely dying.

Improving the Recognition That a Patient Is Acutely Dying

Given the stakes, I believe we need a professional discussion of how to improve our diagnostic acumen in recognizing a patient is acutely dying.

There are clearly challenges to diagnosing a patient as acutely dying. It requires acquisition and integration of several kinds of data, and careful counterfactual reasoning, often in a time-pressured situation. Specifically, data are needed on the patient's acute physiology (incorporating premorbid frailty, disability, and comorbidity—what is colloquially referred to as the patient's "substrate" or "protoplasm"); the available treatment options, both in the acute setting and for underlying derangements; and the patient's judgment (or substituted judgment of proxies, if necessary) on treatment burden and outcome under those treatment, or at least some guiding values. These must be integrated by counterfactual reasoning that incorporates probabilistic outcomes of the same patient under various different treatments—reasoning for which reliable population average effect size estimates, let alone individualized estimates, are often not readily available.

This problem is hard, but I fear the continued growth of life support and

organ support technology—usually support without cure—will only make this problem more pressing. Sometimes families will have prepared in advance, or the fact that the patient is dying will be obvious to everyone and everyone will have the courage to say so. Oftentimes it falls on the ICU physician to lead that conversation, especially as our profession's skills in communicating bad news have improved. But communication skills without diagnostic acumen are insufficient.

If this is true, then I think we need to have professional discussions to align our collective sense of what it means to say someone is acutely dying. Wide variation in how physicians define this is unacceptable. Although there are challenges in recognizing any given patient as acutely dying, as outlined in Table 2, I believe those challenges can be managed.

I propose that we use the same strategy that has helped us with other cases. First, we need to begin within our institutions, sharing tough cases and talking through them—just like we learn to recognize interstitial lung disease or acute respiratory distress syndrome (5, 6). These conversations must be held within an environment of unconditional positive regard for our partners (R. Awdish, M.D., oral communication, 2020), seeking to understand the extent to which differences lie in differences in facts, in values, or in judgment. Under what circumstances would you consider either of the two patients described at the beginning of this manuscript to be dying? Why or why not?

Ideally, such discussions would then extend into teaching conferences across institutions. Only after such discussions have occurred, rooted in real cases at the bedside, should there be consensus conferences to articulate general principles and the extent to which those principles can be reproducibly

and reliably applied to individual cases. Finally, electronic decision support might be feasible, incorporating estimates of what would happen under alternative treatment plans, not just aggregating risk.

Closing Thought

A mentor of mine told me a story years ago. When he was a medical student, his mother was dying of cancer. He had identified a promising new therapy undergoing early-stage trials at a top-tier university hospital. The animal and phase I data looked good. He made an appointment for her and proposed to her that they fly there together. She told him, "no." He raged against that decision, asking how she could give up hope. She said to him, in words that have stayed with me, "Son, a dying person needs to die like an exhausted person needs to sleep." She asked that he recognize it was time for that, and he was able to give her that, and be with her as she did. ■

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