

MEDICINE AND SOCIETY

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Falling Together — Empathetic Care for the Dying

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In February 2014, after not having spoken to him for more than a decade, I got an e-mail from my friend Paul Kalanithi asking for writing advice. A chief neurosurgical resident at Stanford who, at 36, had already conducted award-winning basic science research, Paul was trying to piece together a job as a physician-scientist and writer. But there was a hitch: he had just been diagnosed with terminal lung cancer.

“I no longer know what the hell I’m doing,” he wrote. Though he’d had job offers, they’d arrived when he was too sick to take them. “It’s only in the last couple of weeks that I felt well enough to envision having a career. . . . I had always envisioned spending the last 10–20 years of life as a writer, and in all probability, I am there now.”

Probability, insofar as it underlies the question that obsessed him — “How long have I got left?”¹ — figures prominently in Kalanithi’s posthumously published memoir, *When Breath Becomes Air*.² But the memoir reads more like a panel discussion among Enlightenment philosophers at a modern-day medical conference than like a litany of the probabilities that might chart the average patient’s journey through disease. Kalanithi is interested in why humans cling to these numbers and whether survival statistics, with their imprimatur of scientific rigor, distract us from the deeper meanings of life.

Early in the book, he describes a moment, before his diagnosis, when he lies on the grass with his wife, Lucy, an internist, still hoping that the previous months of weight loss, drenching night sweats, and intractable back pain are attributable to his grueling work schedule. But even denial has a half-life, and soon Lucy glimpses the medical database displayed on his phone screen: “frequency of cancers in thirty to forty year olds.” Paul seeks the reassurance of rarity, as if the unlikelihood of his fate could

render false what they both already know to be true. In his book, he explores this truth, this certainty of death, through the eyes of both physician and patient. How does one live knowing one will soon die? How can a physician ease this transition between life and death? What is the relationship between empathy and hope?

He raises these questions but pushes beyond them, peeling back the layers of discourse about dying as if performing a surgical dissection. Long a student of literature and philosophy, he understands that neurosurgeons “work in the crucible of identity.” When a patient’s mind could not be saved, when a meaningful life was not possible, the neurosurgeon was no longer “death’s enemy” but its “ambassador.” Paul knows he should similarly prioritize a meaningful existence for himself. But he finds it isn’t easy to figure out what such an existence entails. Poetry, philosophy, religion — each helps. But in a way that he could not have anticipated, he finds himself turning to something else: his doctor. The voice of Emma Hayward (not her real name but the one used in the book), Paul’s oncologist, is constantly in his head, alongside those of T.S. Eliot and Montaigne, telling him, “You have to figure out what’s most important to you.”

This mantra is not novel. Most basic instruction in end-of-life care emphasizes helping patients clarify their wishes and tailoring care in ways that preserve whatever gives them meaning or comfort. So we give patients choices. A 90-year-old woman opts for an aortic valvuloplasty so she can make it to her granddaughter’s wedding. A man whose failing glottal function leads to repeated episodes of respiratory compromise chooses to live his remaining days eating the food he loves rather than subsisting on nectar-thick liquids. A morphine drip. A beer. BiPAP at home. The choices are as varied as the people who make them.

And yet the promise of choice can ring hollow. I recently cared for a man who was dying from a rapidly progressive cancer. Every day when I asked him how he was, he could only speak of how he used to be — of his life of art and theater and fine dining. Above all, he fixated on his athleticism: weeks earlier, he had been kickboxing and running miles on a treadmill. As much as I wanted to ask him what would be meaningful in his remaining days, the more honest question was the one I could not ask: How would you like to spend your days now that you are no longer you?

What apparently distinguishes Hayward in this arena is her tacit recognition that autonomy can be like a surrogate marker for meaning: sometimes heralding success, other times obscuring what we ultimately care about. Paul's ability to find meaning depends, in no small part, on Hayward's assuming control. When he first receives his diagnosis and sees his tumor burden on his scans, he prepares to die. Hayward won't let him. In their first meeting, she tells him she prefers carboplatin over cisplatin for his first-line chemotherapy; cisplatin may be part of the traditional chemotherapy combination but is more neurotoxic. He's a surgeon, she reminds him, so they must protect his nerves. Though at first he thinks she's delusional and presses her for statistics on his prognosis ("Absolutely not," she says), soon he's operating again at a full load.

When he relapses, Hayward tells him she welcomes his input on next steps but that if he ever wants her to just "be the doctor," she's happy to do that. When he's admitted to the ICU with multiorgan failure during a week when she's away, he surveys the many specialists involved and longs for someone to be in charge. Hayward suddenly appears, and his relief is immediate. Recalling their earlier conversation, he tells her he wants to be her patient. He's read the scientific literature, he says, and yet he can't find the right perspective. She replies, "I'm not sure that is something you can find by reading about it."

How do we learn the right perspective to care for the dying? It seems there is no aspect of medicine that's more personal and therefore more difficult to teach. A 36-year-old neurosurgeon differs from a 94-year-old who feels he's had a good run. Sepsis differs from pancreatic cancer. The prospect of aggressive measures

elicits shudders in some people; others shudder at the prospect of being denied them. These sorts of divergences defy the guideline-driven approach we often rely on. More fundamentally, the very nature of death — the fact that we can't compare different approaches and then ask people about the experience — defies basic empiricism. So we are left to help the dying using the qualities we value in care for the living, such as empathy and respect for patients' preferences and goals. The current emphasis on reducing pain and suffering is a welcome shift away from an approach that seemed to prioritize the disease over the patient. But can such "person-centered" and "family-oriented" care be taught?³

Though there is a shortage of palliative care doctors, leaders in the field emphasize the importance of teaching basic skills to doctors of all specialties. Among other guiding principles, we learn to ask patients what they understand about what's going on before we tell them. We develop the expectation that end-of-life conversations are typically not single conversations, but many. We acknowledge pain and emotional distress. Now that undergraduate medical education must include some attention to end-of-life care, there is increased focus on these skills, but as a recent Institute of Medicine report, *Dying in America*, noted, there are still deficiencies, including a general inattention to "developing clinicians' ability to talk effectively to patients about dying."³

Just as caring effectively for the dying, like the development of any procedural skill, depends on careful instruction and practice, so too is it critical that we learn from our mistakes. I recently cared for a 65-year-old man with end-stage valvular disease. The only cure was surgery, but his surgical risk was extremely high, and even if he survived the operation, he was unlikely to have a meaningful recovery. Though we spent days conducting tests to clarify his risk level, I knew we were clinging to the possible rather than the probable. Possibly his newly discovered cancer was curable, and possibly his pulmonary reserve, as his family insisted, was better gauged by his capacity to garden last month than by the dismal results on pulmonary-function tests. But at some point the possible yields to the certain: we could not fix him.

And so one morning, I walked in and told him: there would be no surgery. I waited for him to respond. I suspected he wasn't much of a

talker at baseline, but for days his dyspnea had made it difficult to speak even if he wanted to. When he looked at me, saying nothing, I grasped at a straw: “Well, this might sound like a terrible thing to say, but I hope you have a good day.” “Yes,” he said. “That is a terrible thing to say.”

The word “empathy” was coined in 1908 from the German word *Einfühlung*, which means “feeling into.” But the concept is much older, according to Paul Bloom, a cognitive psychologist at Yale who studies empathy; it was described, for instance, by the Enlightenment philosopher and economist Adam Smith, who wrote, “We enter as it were into [another’s] body, and become in some measure the same person with him.”⁴ This definition suggests an obvious reason for the empathy lapses among physicians: we see a lot of pain, and in order to function and make rational decisions, we have to filter some of it out. Indeed, given this risk of impaired rationality, Bloom challenges the characterization of empathy as an unalloyed good.

But empathy for the dying is different from, say, empathy for a patient who has frequent headaches or newly diagnosed but possibly treatable cancer. To feel the patient’s pain under the latter circumstances may be unpleasant, but it is tempered by a hope, or even certainty, that we might offer relief or cure. It is thus an empathy that is identity-affirming. To empathize with a dying person, by contrast, is to feel a pain that we can’t fix. To some physicians, death inevitability feels like a failure. In that sense, I suspect that my insensitivity to my dying patient had less to do with not wanting to feel his pain than with not wanting to feel my own.

Paul Kalanithi recognized the danger of this mentality. He tells the story of his friend Jeff, who, as a fellow in vascular surgery, committed suicide after one of his patients died from a surgical complication. Paul wishes he could have shared with Jeff something he’s learned: “Our patients’ lives and identities may be in our hands, yet death always wins. . . . The secret is to know that the deck is stacked, that you will lose, that your hands or judgment will slip, and yet still struggle to win for your patients. You can’t ever reach perfection, but you can believe in an asymptote toward which you are ceaselessly striving.”

Much current discourse regarding end-of-life

care envisions that asymptote curving toward meaning and comfort. But at times, Paul’s story also calls to mind the literal meaning of the Greek word *asumptōtos* — “not falling together.” After he undergoes second-line chemotherapy and begins mourning all he has lost and will soon lose, Hayward tells him, “You have five good years left.” He realizes this statement is more plea than data-driven prognostication. But he understands: “There we were, doctor and patient, in a relationship that sometimes carries a magisterial air and other times, like now, was no more, and no less, than two people huddled together, as one faces the abyss. Doctors, it turns out, need hope too.”

It is in this moment that the depth of human connection is most palpable. But it’s also the moment when the physician turns out to be the most wrong. We want to believe that empathy and realism are compatible. We must believe that if we are to open our mouths and have these difficult conversations. But perhaps the greatest challenge of caring empathetically for the dying arises from this question: what does empathy look like when it has been stripped of hope?

Some people would argue that the question is based on a false premise: there is never no hope. One need not hope for more life to hope for a good death. But since patients want empathy from their physicians even if they can find it in other people in their lives, I wonder to what extent we conflate empathy and hope. Indeed, it’s hard to ignore the evidence that patients are more satisfied with physicians when they have less of a grasp of the direness of their prognosis.⁵ That doesn’t mean we should be dishonest with our patients about their disease; rather, it suggests that we should be honest with ourselves as we derive the asymptote for end-of-life care that draws closest to the values to which we aspire.

When Paul wrote me that e-mail contemplating devoting his remaining life to writing, I desperately wanted to be helpful. He had already published an essay in the *New York Times* that seemed to have touched the lives of people around the globe. So I told him sincerely that his writing had the power to change the world. But I also hedged, terrified to tell him what to do. “I can’t imagine what you are going through,” I wrote. “Who am I to tell you what to do or how to spend your time?”

In his book *How We Die*, Sherwin Nuland explored ways in which physicians may nurture hope among the dying. Though he recognized the diverse manifestations of hope, Nuland noted, “Of the many kinds of hope a doctor can help his patient find at the very end of life, the one that encompasses all the rest is the belief that one final success may yet be achieved whose promise vanquishes the immediacy of suffering and sorrow.”⁶

Although few of our patients can achieve the final act that Paul Kalanithi has, all of them can leave a legacy. The nature of prognostication means we will sometimes be wrong. And the nature of disease means we will often have no cure to offer. But the nature of hope requires a sort of empathy that is not about feeling what our patients feel, but instead about seeing in them what they can be. Sometimes that means refusing to fall, but sometimes it means falling a bit together.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org

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