A PIECE OF MY MIND

On Death and Courtship

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Dear Doctor,

Several years ago, my brother experienced a coronary artery dissection, and you tried very hard to save him. After your efforts to surgically repair his grievously torn heart, he lingered for another 18 days in the cardiac intensive care unit, mostly unresponsive, on every possible type of support. Some physician friends even speculate that Steve's ultimate outcome was known within those first 2 hours, having experienced a cardiac arrest twice before surgery and having sustained substantial heart damage. Decisions must get made, quickly, and maybe yours was a borderline call, even to attempt an aggressive approach. But it's not treatment decisions or even the death itself that haunt me years later. Words do and, in particular, the *D word*. As Steve was dying, death was not mentioned. An advance directive was forgotten. This is about something that needed to be said but wasn't—either "Steve is dying" (by you), or "Is Steve dying?" (by me) and the consequences of our collective silence.

Maybe communication between us was inherently compromised right from the start. The terms of our relationship are ferociously unequal. This is your job; this is my crisis. This is your ordinary day; this is one of the worst days of my life. For you this is clinical; for me this is impossible. The out-of-order death is an existential insult, and that's how trauma feels to the family: It *can't happen* but then, it does. The big moment is always out there, waiting to ambush us. Then, suddenly…the cars collide, the plane crashes, the gas line explodes, the gun is fired, the vertebrae shatter, the heart fails, and in that second everything changes.

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And when this moment happened to my brother and our family, we were asked to navigate the most intimate drama—of life and death—with you and medical staff but as strangers to each other, which must be the oddest intimacy imaginable, bordering on an oxymoron. It makes me think of victims of a plane crash whose fates are tied forever but randomly to a fellow passenger who just happened to be seated in row 9.

Much has been written on the patient-physician relationship in the decades since patients' rights, "shared decision-making," and more "transparent" and "honest" communication became goals in medicine. Scores of conversational protocols instruct physicians in the delivery of terrible news such as, "Your Brother is a salvage CABG"—the SAFER, CONES, SPIKES, HARD, and EVE (Explore the Emotion; Validate the Emotion; Empathic Response) protocols, to name a handful—and yet our relationship was still one of well-intentioned mutual incomprehension. Or, perhaps, considerately deceptive.

Doctor, some have called our silence about death a "conspiracy" or a "loving lie." The likelihood of death is suspected and denied; known and not known, which leaves family members in a surreal state that was once described as a *double bind*: verbal and controllable nonverbal cues convey, "You will live," while other nonverbal cues and the evidence of the patient's own body convey, "You will die." This delicately improvised collusion is pervasive enough that medical literature has cataloged nonverbal intimations, like gamblers' tells, of pending demise. I experienced firsthand some of the others. A favorite nurse avoided eye contact; doctors invited us to sit down; a liver specialist alluded to having been "in the same position" with a relative not too long ago but left the "position" unelaborated; a specialist subtly inflected that Steve's "*kidneys* [not the rest of him] were fine"; doctors fidgeted with stethoscopes and pens; others glanced frequently out into the hallway, perhaps seeking relief through flight.

Simultaneously, to send the "you will live" message, doctors do any number of things, sometimes instinctively. They might downplay or minimize symptoms, limit conversational topics, focus entirely on the present; order lots of expensive procedures and pursue special treatments; or simply emphasize the most optimistic of possible outcomes.

I've thought many times since about what realistically you might have said that would have helped us do better with Steve's final days. What could be said without the benefit of hindsight—and within the circumscriptions of clinical uncertainty, conflicting medical opinions, chance, and our own lingering hope, riding on the back of our sturdier capacity for self-delusion. Just as importantly, what could I have *heard*, under these circumstances? It seems this was the scenario: My family thought that Steve was in a process of recovery with a chance of death. But all that time he was in a process of death with a chance of recovery. This might have been possible for you to say. It might have been possible for me to hear. It might have been an excellent death icebreaker.

What happened between us wasn't exactly a conspiracy of silence. Or, if it was, then like most conspiracies it was an ineptly kept one. The relationship with trauma is more a convention of coded messages, duplicity, nonverbal signals, and coy efforts to speak about momentous and terrifying things indirectly. In this relationship, every silent gesture is parsed. Every

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Section Editor: Preeti Malani, MD, MSJ, Deputy Editor.

utterance mined for deeper meaning. Truths are implied more than stated.

There are other forms of communication that resemble this encryption and innuendo among doctor, family, and patient. Diplomacy would be one. But the most kindred style of communication is courtship between potential lovers. In courtship, our meanings are urgent, intimate, passionate, and perhaps life-changing and world-shattering. Yet by convention, they are conveyed indirectly, seductively, and coyly, with mannered evasion and through a filter of imprecision. As in courtship, no conversations are more ruthlessly cherry-picked for just the phrases and gestures that one prefers to believe. As in courtship, much of the communication, verbal or nonverbal, is a double bind of revelation and obfuscation; truth and disguise; passion and distance.

Love and death are both too large and seditious to be stated outright or looked in the eye. If we think of courtship as the strategic and exquisite delay of a very pleasant truth of love, then we can think of this patient-physician relationship as the strategic and heartbreaking delay of a very unpleasant truth of death.

When a death is sudden, survivors are left with odd chimeras: grief and guilt; grief and second-guessing; grief and existential terror, because you can never trust the ordinary again. In these cases, it matters deeply how the last days unfold—for survivors, they are indelibly etched in memory and conscience. The grief mellows over time, but I still wish this had been a better death. "We did the best we could," my sister replies. People say this a lot, but how many of us really believe it? Steve had a couple of promising days after surgery when he was conscious, still himself, and off the ventilator. This was our chance. Vital feelings might have been shared, information gathered, truths revealed, forgiveness offered, goodbyes exchanged, and ambiguities resolved. I might have asked him, "How do you want to be remembered?" "What do you have to say about your life?" "How should I tell your story?"

In courtship, the conversational goal isn't candor but seduction, and desire: we present—and promise—the best version of reality—and ourselves—that we can. With critical illness that best version of reality is hope, and death—being perceived as irreconcilable with hope—is banished from conversations. For the D word to get said more freely after a trauma, hope has to be made conjugable with dying, as it already has been to a larger extent with advanced age and terminal illness. But this will require that patients and doctors collaborate to change the perspective on medical heroism and longevity. One can love life—and being alive—and still be comfortable with its end.

In her essay "The White Album,"[1] Joan Didion famously wrote that "we tell ourselves stories in order to live." It turns out we must tell stories in order to die or to die as we wish, but telling that story has to begin with someone, somewhere, saying the word *death*.

Published Online: February 2, 2024. doi:10.1001/jama.2024.0221

Conflict of Interest Disclosures: None reported.

Additional Contributions: I thank my sister for allowing me to share our brother's story.

1. Didion J. *The White Album*. Straus and Giroux; 2009:11.