The New York Times

DOCTORS

At the End of Life, What Would Doctors Do?

By IRA BYOCK, M.D. JUNE 30, 2016 6:00 AM Comment

Americans have long been chided as the only people on earth who believe death is optional. But the quip is losing its premise. A recent profusion of personal narratives, best-selling books and social entrepreneurs' projects suggest that, as a culture, we are finally starting to come to terms with our mortality. Nationally, the Conversation Project is engaging people to discuss their wishes for end-of-life care. Death Cafes and Death Over Dinner events are popping up across the country, reflecting an appetite for exploring these matters. So too, the Dinner Party and the Kitchen Widow are using meals as a communal space to explore life after loss.

Admittedly, contemplating mortality is not (yet) a national strong suit. That's why these cultural stirrings are so significant. At a minimum, our heightened awareness and willingness to talk about illness, dying, caregiving and grieving will lead to much better end-of-life care. However, the impact on American culture needn't stop there. Like individuals who grow wiser with age, collectively, in turning toward death, we stand to learn a lot about living.

Doctors can be valuable guides in this process. In matters of illness, people are fascinated by the question, what would doctors do? Consider the social phenomenon of Dr. Ken Murray's online essay, "How Doctors Die." Dr. Murray wrote that doctors he knew tended to die differently than most people, often eschewing the same late-stage treatments they prescribed for patients. The article went viral, being read by millions, and reprinted in multiple languages in magazines, newspapers and websites across the globe.

Dr. Murray's observation even engendered studies of doctors' preferences for care near the end of life. So far, results are mixed. In a Stanford survey, 88 percent of responding physicians said they would avoid invasive procedures and life-prolonging machines. But a newly released comparative study of Medicare recipients, as well as a longitudinal study and separate analysis of Medicare data published in January, suggest that the actual differences between end-of-life treatments that doctors and nondoctors receive are slight. Perhaps like nearly everyone else, when life is fleeting, physicians find it difficult to follow their previous wishes to avoid aggressive life-prolonging treatments.

For what it's worth, the terminally ill colleagues I've known, including those I've been privileged to care for, have usually been willing to use medical treatments aplenty as long as life was worth living, and took great pains to avoid medicalizing their waning days. In any event, the public's interest in the medical treatments that doctors choose must not be allowed to reinforce our culture's tendency to see dying solely through medical lenses. More to the point is the question, how do dying doctors *live*?

What dying doctors do with their time and limited energy, and what they say, are deeply personal, sometimes raw and often tender. Like everyone else, doctors experience pain and suffering – yet many speak of a deepening moment-to-moment sense of life and connection to the people who matter most.

Listen to a few.

Dr. Jane Poulson lost her sight to diabetes while still in medical school. After years of successful internal medicine practice, Dr. Poulson developed inflammatory breast cancer and knew it would claim her life. Writing in the Canadian Medical Journal she said:

> "In a paradoxical way, I think I can say that I feel more alive now than ever before in my life…When you presume to have infinity before you the value of each person, each relationship, all knowledge you possess is diluted."
>
> "I have found my Holy Grail: it is surrounding myself with my dear friends and family and enjoying sharing my fragile and precious time with them as I have never done before.

> I wonder wistfully why it took a disaster of such proportions before I could see so clearly what was truly important and uniquely mine."

About a year after being diagnosed with incurable esophageal cancer, Dr. Bill Bartholome, a pediatrician and ethicist at the University of Kansas, wrote:

> "I like the person I am now more than I have ever liked myself before. There is a kind of spontaneity and joyfulness in my life that I had rarely known before. I am free of the tyranny of all the things that need to get done. I realize now more than ever before that I exist in a 'web' of relationships that support and nourish me, that clinging to each other here 'against the dark beyond' is what makes us human...I have come to know more about what it means to receive and give love unconditionally."

Bartholome referred to this period before his death as "a gift."

> "It has given me the opportunity of tying up the 'loose ends' that all our lives have. I have been provided the opportunity of reconnecting with those who have taught me, who have shared their lives with me, who have 'touched' my life. I have been able… to apologize for past wrongs, to seek forgiveness for past failings."

A healthy defiance is often palpable within the personal decisions of doctors who are living in the growing shadow of death. My friends, Herbert Maurer and Letha Mills, long-married oncologists, boldly renewed their vows before a crowd of family and friends during the months Herb was dying of cancer. In "When Breath Becomes Air," the neurosurgeon Paul Kalanithi relates the decision he and his wife, the internist Lucy Kalanithi, made to have a child, while knowing full well that he was unlikely to see their daughter grow up. Such affirmations of couplehood in the face of death are not denial; but rather insubordination, eyes-wide-open commitments to living fully despite the *force majeure*.

Gratitude also commonly emerges in the experiences of dying clinicians. In one of our last email exchanges, my friend, the clinical psychologist Peter Rodis, wrote:

> "The shock of knowing I'll die has passed. And the sorrow of it comes only at moments. Mostly, deep underneath, there is quiet, joyous anticipation and curiosity; gratitude for the days that remain; love all around. I am fortunate."

The neurologist Oliver Sacks concluded his essay "My Own Life" in exaltation.

> "Above all, I have been a sentient being, a thinking animal, on this beautiful planet, and that in itself has been an enormous privilege and adventure."

These experiences are like dabs of paint on an Impressionist's canvas. Taking in this contemporary *ars morendi* we can appreciate how dying and well-being can coexist. For all the sadness and suffering that dying entails, our human potential for love, gratitude and joy persists.

How fitting would it be for a corrective to the medicalization of dying to come from the medical profession itself? The general public's interest in what doctors do can teach all of us about living fully for whatever time we each have.

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