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Commentary

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To Life! Reflections on Spirituality, Palliative Practice, and Politics

Ira R. Byock, MD

Driving home from the medical center through spring rain on a dreary Sunday afternoon, I was struck, once again, by the stunning beauty and imperfect perfection of the world. There was something within the wet shades of green and brown of the trees and forest loam. There was life, hunkered and healthy within the gloom.

Weekends are quieter at the hospital and rounds that day mostly comprised sitting with people who were approaching the ends of lengthy illnesses. Somehow, in every room, we wound up talking about life.

Alice (not her real name) was a 47-year-old woman with advanced intraperitoneal cancer and ascites who was admitted the previous week when her leg suddenly turned cold and blue. After the successful removal of an arterial clot restored circulation to the limb, she developed kidney failure. When I visited Alice in her hospital room, after the requisite pain and bowel update, we indulged in musings about illness, healing, God, and love. The conversation began when I asked about the collection of Rumi poems on her bedside table. We read a few and then I shared a favorite poem and asked her to guess who wrote it.

You do not need to leave your room,
Remain sitting at your table and listen.
Do not even listen, simply wait.
Do not even wait, be quiet still and solitary.
The world will freely offer itself to you to be unmasked.
It has no choice.
It will roll in ecstasy at your feet.

She correctly surmised it wasn't Rumi, but was surprised to learn the poet was Franz Kafka, the quintessential existentialist. Existentialism sees the universe as cold and impersonal, leaving each individual exposed to circumstance and happenstance, ultimately reliant only on him or herself. Yet Kafka recognized an esthetic intelligence within the very stuff of reality. This led Alice and me to talk about chaos theory, fractals, patterns within randomness, and of God within us all and all that is. She spoke about healing and well-being in the face of loss.

Alice's husband arrived from their home in time to witness, bemused, the crescendo of this brief reverie. Knowing from our previous discussions the remarkable story of their mid-life romance, 3-year marriage, and expanding love through her illness, I said that I've come to believe that love is stronger than death. For one thing, love outlasts death to live on within others. But the love of 2 people can also be a fiercely defiant act, for love affirms life in the face of death. Looking though my windshield and the rain that day, I had the image in my mind of Alice and her husband holding hands, beaming into each other's eyes.

Mortality teaches us a lot about life, if we let it. One thing it teaches is that human life is inherently spiritual, whether or not a person has a religion. Recently, I asked a gruff elderly Vermont farmer, whom I saw in clinic, whether he had a sense of what comes after this life. He chuckled and replied, "The worms go in; the worms go out."

Half-expecting such a response, I asked. "And where will the worms go in and out of *your* bones?"

"Oh, we have a family cemetery on a hill in Thetford. We Gradys (not his real name) have been buried there for over a century and I suspect my grandchildren and their grandchildren will be there, too."

Mr Grady doesn't pray, attend church, or believe in God, but he has a strong sense of connection to the land and to his family, ancestors who preceded him and relatives who will be born into generations to come. The meaning and value he derives from being part of something that is larger and more enduring

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than his own life seems authentically, unassumingly spiritual to me.

In fact, the confrontation with death lays bare the spiritual core of the human condition. Human spirituality arises in response to the awe-inspiring and terrifying mystery of life and the universe. We reflexively seek to make meaning of our experience in the world and make or strengthen our connections to others.

Hospice and palliative care clinicians recognize this anthropologic truth. Reverence for life resonates within our field and we are generally recognized for attending to these inherently human dimensions of suffering and well-being.

Political Context of Our Practice

Yet we live and practice in nonordinary times. And not everyone trusts our motives or approves of our practices.

On one end of the spectrum, a few ardent proponents of legalizing physician-assisted suicide accuse us of forcing people to suffer by refusing to prescribe lethal medications. Recently an elderly physician committed (unassisted) suicide in an assisted-living center in the Upper Connecticut Valley. I was called by a reporter to comment on the phenomenon of elder suicides and was subsequently quoted in a local newspaper saying that it seems tragic when someone of any age feels that life is not worth living and takes his or her own life. The next day a reader sent an e-mail suggesting that I, and my colleagues in palliative care, secretly harbor a religious agenda.

Interesting thought. I don't think of myself as religious. But in full disclosure, I was raised by Jewish parents, and although I am not particularly observant of holidays or rituals, my sense of the inherent value of life has roots deep within my ancestry and upbringing. Life is an absolute value for Jews. Many Jews wear the Hebrew symbol for life, *Chai* as pendants around their necks. We toast *La Chaichim!* (to life) as we raise glasses in celebration. If reverence for life constitutes a religious agenda, I suppose I have one.

On the other extreme, a fringe element of the right-to-life movement regularly accuses hospice, palliative care, and even intensivists of killing innocent victims each time we write or honor a do-not-resuscitate (DNR) order or permit a person to die without a feeding tube. Think I'm exaggerating? Consider the recent saga of New Hampshire House Bill 656.

The bill began in 2004 as a prosaic effort by concerned citizens to update the state's advance directive law, removing the antiquated requirement to have the document signed in front of a notary public and creating a consistent way for emergency medical technicians to honor DNR orders outside of hospitals. But in the wake of Terri Schaivo's death, the far Right hijacked the bill for political purposes. They inserted statutory language requiring anyone without an advance directive to undergo medically administered nutrition and hydration and cardiopulmonary resuscitation (CPR) before death. These provisions were designed to be symbolically potent and inflammatory, but they made no biologic sense and, therefore, no legal sense.

Respectful efforts by the citizens committee who had crafted the original bill to explain the pragmatically and medically troubling aspects of the proposed requirements and reach a constructive understanding were ignored or turned aside. In hearings in both chambers of the New Hampshire legislature, I and other medical professionals testified that, while we agreed with the presumption of performing CPR in most circumstances, exemptions were needed for situations in which death is imminent and CPR is not medically indicated or would cause unnecessary harm. Similarly, while accepting the presumption of sustaining life through medically administered nutrition and hydration, we extended an amendment encompassing situations, such as advanced, multisystem failure, in which persisting in administering intravenous or enteral nutrients would cause unnecessary suffering or hasten a patient's death.

Opposing testimony from the far Right made it seem as if death was always optional, in each case the result of a doctor's DNR order or an alleged decision "to starve an innocent victim," rather than the inevitable consequence of aging, diseases, or injuries. On March 15, 2006, the health care community's amendment was defeated in the New Hampshire House of Representatives by a vote of 286 to 57. One gleeful opponent referred to it as "the angel of death clause."

Thankfully, the Senate Judiciary Committee later reinstated rational exemptions which permit clinicians to discontinue artificial nutrition and hydration when it would hasten death or cause suffering and to write DNR orders when death was expected or efforts to resuscitate a person would be useless and merely cause harm. After contentious

debates and rancorous parliamentary maneuvering, the bill was passed and signed into law with those provisions intact. A crisis was averted, but an acrimonious cultural chasm remains.

Having stood personally with faith-based organizations, including fundamentalist Christian groups, in opposing proposals to legalize physician-assisted suicide, this all feels highly ironic and disheartening. The uncivil war over abortion has long threatened to engulf rational debate over assisted suicide, and by extension, polarize any discussion of how we die. Still, I have always thought that providing medically excellent, unabashedly tender, loving care was bedrock common ground—a tangible expression of the values that unite people on the far Left and the far Right. Apparently, I was naïve. On the Internet and, indeed, on the floor of the New Hampshire legislature, doctors who allow people to die without inflicting unwanted or useless medical treatments are accused of promoting a "culture of death." The practices they decry are epitomized by hospice and palliative care.

These invectives are couched in the name of religion, but they have nothing to do with authentic religious teaching. Although I was raised Jewish, I've often been well guided in my practice by the teachings of other great religions, including Catholicism. In his final months, the late Chicago Cardinal Bernadin wrote an open letter to the Supreme Court opposing the legalization of physician-assisted suicide. He observed:

> I am at the end of my earthly life. There is much that I have contemplated these last few months of my illness, but as one who is dying I have especially come to appreciate the gift of life. I know from my own experience that patients often face difficult and deeply personal decisions about their care. However, I also know that even a person who decides to forgo treatment does not necessarily choose death. Rather, he chooses life without the burden of disproportionate medical intervention.

Cardinal Bernardin's words do not express a culture of death but, rather, describe the proper relationship of medical treatment to human life. Whatever our politics, clinicians who practice hospice and palliative care comprise the most ardent pro-life group in America. To be a true proponent of life, one has to affirm *all* of life—and that means not only helping people to live fully but also to die well.