Making Sense of Bioethics
November, 2010

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Facing Terminal Illnesses Realistically

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In modern times, dying is more and more often portrayed as a cold, clinical reality to be kept at arm's length, relegated to the closed doors of a hospital, almost hermetically sealed from the rest of our lives. When it comes to the event itself, we diligently work to avoid confronting it, addressing it, or acknowledging it. Because of this cultural backdrop, patients receiving a diagnosis of a terminal illness can be tempted to indulge in unrealistic expectations about what lies ahead, clinging to unreasonable treatment options and hoping for highly improbable outcomes.

The patient-survival curve for various terminal diseases often shows patients clustered around a median survival time of perhaps several months or a year or two, with survivability extending out along a more slender tail into the future for an ever smaller number of people. Yet rather often, that long tail seems to become the focus, even the obsession, of so many patients and doctors. As Dr. Atul Gawande once put it in a thought-provoking 2010 essay in *The New Yorker*:

> "There is almost always a long tail of possibility, however thin. What's wrong with looking for it? Nothing, it seems to me, unless it means we have failed to prepare for the outcome that's vastly more probable. The trouble is that we've built our medical system and culture around the long tail. We've created a multi-trillion-dollar edifice for dispensing the medical equivalent of lottery tickets — and have only the rudiments of a system to prepare patients for the near-certainty that those tickets will not win."

One is reminded of the words of the old platitude: "No one gets out of this life alive." Because clinicians tend to view death in terms of failure, and because our medical system generally values doing something over doing nothing, even when it may be futile to do so, rational, measured decision-making at the end of life can become difficult, as Dr. Gawande emphasizes:

> "The simple view is that medicine exists to fight death and disease, and that is, of course, its most basic task. Death is the enemy. But the enemy has superior forces. Eventually, it wins. And, in a war that you can-

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> not win, you don't want a general who fights to the point of total annihilation. You don't want Custer. You want Robert E. Lee, someone who knew how to fight for territory when he could and how to surrender when he couldn't, someone who understood that the damage is greatest if all you do is fight to the bitter end."

Trying every option in the face of terminal illness, pursuing all medical possibilities no matter how unlikely to succeed, and raging against death can easily become the default position in a culture that hesitates to acknowledge or discuss death openly. Yet approaching our own mortality with a greater dose of realism helps us make better decisions about when to roll back the medical interventions and focus our energies on preparing for death. Hospice and palliative care can be important and helpful adjuncts in this process. When done well, these approaches allow us to focus on improving the remaining time for those with a terminal illness. Pain management, comfort care, acknowledgement of the coming death, family support and an opportunity for spiritual reconciliation are essential elements in these approaches. Far from abandoning the needs of patients, hospice and palliative care seek to properly acknowledge that in some cases, efforts at curing should be scaled back while efforts at caring for the patient should be scaled up.

Terminally ill patients who choose to discuss end of life treatments with their families and doctors more often opt for palliative care or hospice care, leading to more appropriate medical care near death, and better overall outcomes and satisfaction. They also tend to spend less money and do not die significantly earlier. Rather they often die more peacefully than those receiving aggressive interventions, which tend to be associated with a poorer standard of life and a worse bereavement adjustment.

Our instincts so often tell us that facing death means facing fears about loss of control and dignity, increasing dependence on others, intractable pain, dying too soon (or not soon enough), increasing costs, being alone and fear of the unknown. Because we die only once, we have little or no experience to draw upon when these matters come upon us in the first person. Yet when doctors and nurses are willing to have the hard discussions and say what they have seen, when families become willing to acknowledge death and mortality, and when spiritual preparations are allowed to hold priority of place, patients can better and more peacefully prepare for what lies ahead when they receive the summons of approaching death in the form of a terminal illness.

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