Bioethics Book Club

Being Mortal: Medicine and What Matters in the End
by Atul Gawande

Metropolitan Books, 2014

Summary[1]

When it comes to the inescapable realities of aging and death, what medicine can do often runs counter to what it should. Through eye-opening research and gripping stories of his own patients and family, Gawande reveals the suffering this dynamic has produced. Nursing homes, devoted above all to safety, battle with residents over the food they are allowed to eat and the choices they are allowed to make. Doctors, uncomfortable discussing patients' anxieties about death, fall back on false hopes and treatments that are actually shortening lives instead of improving them. Gawande follows a hospice nurse on her rounds, a geriatrician in his clinic, and reformers turning nursing homes upside down. He finds people who show us how to have the hard conversations and how to ensure we never sacrifice what people really care about.

Ethics Issues

- Quality of life
- Dignity
- Palliative care
- Long-term care and home care
- Family relationships
- Living at risk
- Advance care planning
- Futility
- Resource allocation
- End of life decision-making

Discussion Questions

1. Is a preoccupation with risk stultifying the quality of life for those nearing the end of their lives? Do we prioritize patient safety over values of dignity and respect for autonomy?
2. This book combines discussions about senior living arrangements and aging with autonomy and self-respect, with insights about palliative care and dying with grace. What is the relationship between these two?
3. Is helping patients to have a "good death" as important as helping them to flourish while alive?
4. Gawande reflects on the end of his father's life and his roles/ experiences in this process as both a son and a physician. How does this compare with your own life experience with death and dying – what is the relationship between your experience as a health care provider and your family/ friend relationship with a dying patient?
5. What do you think about Gawande's assertion that the role of health care providers is not to ensure health and survival, but to enable well-being?

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[1] Adapted from the publisher's summary

6. Some critics of this book believe that Gawande does not give enough attention to our economic structures; what influence/ role does the economy, resource allocation, health system funding play in these discussions?
7. Discuss reasons why a patient may decide to begin or continue burdensome treatment even when it is futile and causes suffering.
8. Gawande discusses pervasive shortcomings in physician-patient communication about terminal illness. Discuss the advice he receives from a palliative physician to "ask, tell, ask": Ask what patients what to hear, tell them, then ask what they understand.
9. *Being Mortal* discusses the state of continuing care in the US – how do Gawande's observations compare to your own here in Nova Scotia.
10. Discuss the following passages in the book:
    a. "Our ultimate goal, after all, is not a good death but a good life right to the very end."
    b. "Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need."
    c. "We end up with institutions that address any number of societal goals – from freeing up hospital beds to taking burdens off families' hands to coping with poverty among the elderly – but never the goal that matters to the people who reside in them: how to make life worth living when we're weak and frail and can't fend for ourselves anymore."
    d. "A few conclusions become clear when we understand this: that our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives."
    e. "Your chances of avoiding the nursing home are directly related to the number of children you have."
    f. "Sometimes we can offer a cure, sometimes only a salve, sometimes not even that. But whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person's life. When we forget that, the suffering we inflict can be barbaric. When we remember it the good we do can be breathtaking."
    g. "The problem with medicine and the institutions it has spawned for the care of the sick and the old is not that they have had an incorrect view of what makes life significant. The problem is that they have had almost no view at all. Medicine's focus is narrow. Medical professionals concentrate on repair of health, not sustenance of the soul. Yet—and this is the painful paradox—we have decided that they should be the ones who largely define how we live in our waning days."
    h. At least two kinds of courage are required in aging and sickness. The first is the courage to confront the reality of mortality—the courage to seek out the truth of what is to be feared and what is to be hoped. Such courage is difficult enough. We have many reasons to shrink from it. But even more daunting is the second kind of courage—the courage to act on the truth we find."