Coming to grips with an end

In his new book on his father’s final days, Atul Gawande unravels why our health care system so often misses the mark for patients at the end of their lives.

REVIEW BY CHARLES R. MEYER, MD

What should I do with mom?” The daughter’s voice was urgent, almost pleading. Her 90-year-old mother had been admitted to the hospital with a bowel obstruction. Having weathered lung cancer with what proved to be curative radiation 10 years before, her strong-willed mother insisted that she had seen the last of aggressive medical care as she settled into her self-imposed vigil, waiting for her own death. On her rare visits to my office, she reiterated, “I don’t know why I’m alive.” So now she had an unrelenting bowel obstruction, resistant to medical therapy. Her choice was surgery or hospice. She looked at the surgeons circling her bed and said “no.” She was sure about her choice; her daughter wasn’t.

Physicians today need to decide about doing things to people at ages unimagined 30 years ago. Those decisions involve not only the precise medical calculus of determining the right treatment for a given disease but also the slipperier consideration of what is right for the old elderly. That is the conundrum tackled by surgeon and New Yorker contributor Atul Gawande in his recent book Being Mortal.

Gawande terms this approach “making mortality a medical experience” and points out “it is just decades old. It is young. And the evidence is it is failing.”

Gawande argues that the ice-pick view of a patient as a medical problem without social or psychological considerations leads to care that results in the “waning days of our lives … given over to treatments that addle our brains and sap our bodies for a sliver’s chance of benefit. They are spent in institutions—nursing homes and intensive care units—where regimented, anonymous routines cut us off from all the things that matter to us in life.”

In addition to recounting numerous stories of his own patients, Gawande’s analysis most poignantly contrasts the final days of his grandfather and his father. A farmer in a small town in India, his grandfather lived to 100. In his later years he became infirm, walking with a cane and giving up his work in the fields. Rather than suffering the American solution of nursing home placement, he was surrounded by a large extended family that cared for him until his death. Modernization in American society, according to Gawande, has not demoted the elderly. “It demoted the family. It gave people—the young and the old—a way of life with more liberty and control, including the liberty to be less beholden to other generations. The veneration of elders may be gone, but not because it has been replaced by veneration of youth. It’s been replaced by veneration of the independent self.” Without a family cocoon, “our elderly are left with a controlled and supervised institutional existence, a medically designed answer to unfixable problems, a life designed to be safe but empty of anything they care about.”

In Gawande’s opinion, our health care system needs to be redesigned, not only because it costs too much but also because it doesn’t provide humane solutions to end-of-life problems. Our challenge, he says, is to “build a health care system that will actually help people achieve what’s most important to them at the end of their lives.” And he confronted that challenge when his father neared the end.

A vital, athletic surgeon practicing into his 70s in Athens, Ohio, Gawande’s father, Atmaram, began having weakness and numbness in his extremities. Evaluation revealed a cervical spinal astrocytoma. The diagnosis triggered a cascade of difficult decisions over the ensuing years—surgery, radiation, chemo, hospice and whether to treat pneumonia at the end. Each decision involved the complex interplay between
Gawande’s father, the family and Gawande. None of the decisions were clear-cut, and Gawande does a masterful job of painting the uncertainties they encountered and the unpredictability that befuddled even a medically trained mind like his. He concludes, “At root, the debate is about what mistakes we fear most—the mistake of prolonging suffering or the mistake of shortening valued life.” He and his family recurrently asked whether the father was, at the end, sensing that further treatment was futile but fearing “the mistake that loomed largest … the possibility of failing to preserve his life long enough.”

His father’s death was neither tidy nor idyllic. Deaths rarely are. But Gawande hopes we can change our health care system to ease the last days of patients’ lives. Achieving that goal requires acknowledging our human limits. “Being mortal is about the struggle to cope with the constraints of our biology, with the limits set by genes and cells and flesh and bone,” he writes. “Medical science has given us remarkable power to push against these limits, and the potential value of this power was a central reason I became a doctor. But again and again, I have seen the damage we in medicine do when we fail to acknowledge that such power is finite and always will be.” Finding where the finite stops is a hazardous journey that must be informed both by medical training and the sage voices of the patient and family. MM

Charles Meyer is editor in chief of Minnesota Medicine.

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