THE TOTAL PATIENT





"Letting go," and why it's so hard to do: Atul Gawande on end-of-life care challenges

Bette Weinstein Kaplan

he subject of end-of-life care came up in The New Yorker magazine recently in an article entitled "Letting Go," by Atul Gawande. A surgeon and writer, Dr. Gawande is on staff at Boston's Brigham and Women's Hospital, the Dana Farber Cancer Institute, and The New Yorker magazine. He is also an associate professor of surgery at Harvard Medical School, an associate professor in the Department of Health Policy and Management at the Harvard School of Public Health, and the associate director of the Brigham and Women's Hospital Center for Surgery and Public Health.

In his article Dr. Gawande explains that expense is the reason that end-oflife medical care has become a topic of discussion. Health costs continue to escalate, especially for patients in their final months of life, which accounts for 25% of Medicare's total spending.¹ The cost pattern of treating patients with cancer is higher in the beginning and levels off as treatment is effective. However, if the disease worsens, treatment escalates, and cancer-related expenses create a U-shaped curve.²

THINGS MONEY CAN'T BUY

The discussion of end-of-life care should go far beyond money. As Dr. Gawande writes, "Our medical system is excellent at trying to stave off death with eight-thousand-dollar-a-month chemotherapy, three-thousand-dollara-day intensive care, five-thousanddollar-an-hour surgery. But, ultimately, death comes, and no one is good at knowing when to stop."

In 2008, the national Coping with Cancer project published a study showing that terminally ill cancer patients who were put on a mechanical ven-

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tilator, given electrical defibrillation or chest compressions, or admitted to intensive care as they neared death had a substantially worse quality of life in their last week of life than those who received palliative care and no such interventions. And, 6 months after they died, their caregivers were three times as likely to suffer major depression.³

ARE WE GOING TOO FAR?

This was not a concern years ago, when people died quickly because there were no medical interventions. But now there are many things that can be done in the end stages of illness or in very old age; there are IVs, of course, and ventilators, dialysis, surgery, and all sorts of intubation. If one chemotherapy agent fails to work, maybe the next level or an experimental drug would work. When the patient's side effects escalate, the physician prescribes new drugs to counteract them. All of this is done with the best intentions of helping the patient, but does it enhance the patient's quality of life? Does it address the dying patient's concerns? Does the patient even know that he or she is dying? Has anyone broached the subject?

Dr. Gawande believes there should be more instruction for medical staff to talk to patients, to help them in the art of dying. "We train and retrain for surgical skills. We probably need to do so for these discussions with terminally ill patients, as well—especially given the stakes."

PALLIATIVE CARE SPECIALIST, SUSAN D. BLOCK

Dr. Gawande consulted Susan D. Block, MD, a nationally recognized palliative care specialist at Peter Bent Brigham who trains medical staff in the art of end-of-life discussions. She said, "A large part of the task is helping people negotiate the overwhelming anxiety anxiety about death, anxiety about suffering, anxiety about loved ones, anxiety about finances. There are many worries and real terrors."⁴

Dr. Block explained that it is important to sit down with the patient, try

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Letting Go, by Atul Gawande www.newyorker.com/reporting/2010/08/02/100802fa_fact_gawande

to ascertain what is most important to the patient at this time, and then help the patient achieve it. This should not be a discussion about medical or surgical treatment. She cautioned that at least half of this sit-down should be devoted to listening to the patient.

The actual words the practitioner uses in what Dr. Block calls a *breakpoint discussion* are important. Palliative care experts advise saying something such as, "I wish things were different," instead of, "I'm sorry things turned out this way," which can sound like pity. Instead of asking, "What do you want when you are dying?" the practitioner should ask instead, "If time becomes short, what is most important to you?"

Dr. Gawande wrote that Dr. Block "keeps a list of items that she aims to cover with terminal patients in the time before decisions have to be made: what they understand their prognosis to be; what their concerns are about what lies ahead; whom they want to make decisions when they can't; how they want to spend their time as options become limited; what kinds of trade-offs they are willing to make."

MEETING THE NEEDS OF THE TERMINALLY ILL

Patients who are terminally ill are concerned with more than simply surviving. When surveyed, they cited concerns such as not suffering, spending time with family, feeling the caring touch of someone else, being cognitively aware, and not being burdensome to others.⁵ However, according to Dr. Gawande:

Our system of technological medical care has utterly failed to meet these needs, and the cost of this failure is measured in far more than dollars. The hard question we face, then, is not how we can afford this system's expense. It is how we can build a health care system that will actually help dying patients achieve what's most important to them at the end of their lives.

We need to become more effective in using the techniques that experts already have for walking people through these moments in their lives. The failure of our system is that we are not good at helping people sort out what is most important to them when they are dying and then helping them achieve it.

The complete article is available in *The New Yorker*: August 2, 2010, and online.

Bette Kaplan is a medical writer in Tenafly, New Jersey.

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