How to improve dying in America

By many measures, how people die in America has plenty of room for improvement, whether it's boosting quality of life at the end for the individuals and their families, reducing costs or even extending life. That was a panel's consensus after an address at Stanford University earlier this week by Dr. Atul Gawande, a surgeon and author of the bestselling book Being Mortal: Medicine and What Matters at the End.

According to Dr. Gawande, what most people want at the end of their life is to say goodbye to loved ones, give away keepsakes, take care of unfinished business, make sure loved ones will be taken care of and make peace with their spiritual beliefs. In other words, to construct a good ending to their life's story. But it's very hard to do that in the intensive care unit of a hospital with tubes down your throat and a mind clouded by drugs, even if those interventions might extend your life by a few days, weeks or months.

What gets in the way of better endings? The usual suspects: money, politics and human nature, according to a panel of distinguished experts that followed Dr. Gawande's talk. The panel included Charles Munger, vice chair of Berkshire Hathaway (BRK.A) and chair of the Good Samaritan Hospital of Los Angeles; Dr. Laura Carstensen, director of the Stanford Center on Longevity; Dr. Robert Pearl, president and CEO of the Permanente Medical Group; and Dr. Arnold Milstein, director of the Stanford Clinical Excellence Research Center.

Munger placed much of the blame on the financial incentives inherent in the U.S. medical system. Doctors and health care providers are often paid per procedure. As a result, they earn a lot of money for surgeries and other complex, expensive procedures whose exclusive focus is extending life at any cost, no matter how slim the odds of recovery and without regard to what the patient really wants at the end of life.

Munger praised the Kaiser Permanente model, which instead pays a salary to doctors and rewards them based on outcomes and patient satisfaction, which reduces health care costs in the process.

Dr. Carstensen contended that in an age of longevity, many challenges facing individuals and families are due to behavioral factors. As she explained, before the 20th century, individuals often died quickly of acute diseases and accidents. Today, many chronic diseases result from a lifetime of unhealthy choices about exercise and nutrition, and individuals might live with such diseases for many years.
Healthy lifestyle choices could increase the odds of delaying or even preventing chronic disease in a person's last few decades of life. Near the end, individuals and families often shy away from facing the reality that life is almost over, and they don't have the vitally important conversations necessary to understand the patient's desires for how to spend the last weeks and months of life.

Dr. Gawande told the touching yet insightful story of his daughter’s piano teacher, who had terminal cancer and contacted him after "a year in hell" undergoing various treatments aimed at prolonging her life and spending a considerable amount of time in her hospital's ICU. The teacher eventually realized and accepted that she was dying.

Dr. Gawande asked her a few key questions that guided her course of treatment: What do you really want in the next few weeks and months? What are you most afraid of?

What she really wanted was to have just a few good days, and she was most afraid of dying at the hospital. The doctors recommended hospice care to manage her pain and give her those good days she desired. She returned home to hold a few more piano lessons with her close students, who responded by performing two piano recitals for her during her final days.

Everyone involved had experiences they'll remember to the end of their own days. This was a much more fulfilling -- and much less expensive -- end to her life, compared to living out her days hooked up to machines in a hospital.

Unfortunately, societal conversations about end of life can get politicized. Remember when hospice care was given the ridiculous "death panel" label? Hospice care has demonstrated repeatedly to be a godsend to individuals and families facing the end of life.

Frank discussions with doctors about the truth of the patient's odds of survival and treatment options that have the goal not necessarily of extending life but relieving pain and enabling patients to finish their lives on their own terms have been demonstrated to considerably relieve the anxieties of both patients and their families.

Research can help inform policymakers and decision-makers. For example, Dr. Gawande shared the results of one study of two groups of patients with stage IV lung cancer. Half of these patients -- the control group -- received usual oncology care. The other half -- the treatment group -- received the usual oncology care plus parallel visits with a palliative care specialist, whose focus is preventing and relieving suffering.

The patients in the treatment group discussed their goals and priorities with the specialists if and when their condition worsened. The treatment group stopped chemotherapy sooner, entered hospice far earlier, experienced less suffering at the end of their lives -- and they lived 25 percent longer than the control group!

Dr. Gawande made the point that if such care were a drug with such results, the Food & Drug Administration would approve it, leading to celebrations in the medical community.

Dr. Gawande and the panelists shared essential recommendations that can help us all address these tough issues, whether we're the stewards at the end of life for our parents, close friends or relatives, or whether we're contemplating our own ending.

Each of the panelists recommended having frank conversations with family and medical care providers to express what's most important for our final phase of life and also what we're most afraid of. In addition, we should learn about treatment
options that can address these goals, which may not be the expensive treatments that would extend a painful life for a few extra weeks or months.

When you think about it, dying is a very important event in your life. You may want to devote considerable time and attention to designing your ending on your own terms.

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Steve Vernon
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Steve Vernon helped large employers design and manage their retirement programs for more than 35 years as a consulting actuary. Now he’s a research scholar for the Stanford Center on Longevity, where he helps collect, direct and disseminate research that will improve the financial security of seniors. He’s also president of Rest-of-Life Communications, delivers retirement planning workshops and authored Money for Life: Turn Your IRA and 401(k) Into a Lifetime Retirement Paycheck and Recession-Proof Your Retirement Years.

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