

End-of-Life Care and Choice: The Looming Crisis of Suffering in the U.S.

The U.S. is facing an end-of-life crisis. Americans approaching death increasingly find themselves on a conveyer belt of unnecessary, unwanted and painful medical treatment. These treatments often prolong the dying process at the expense of quality time with loved ones and dying at home peacefully. Challenges within our medical system hinder honest discussions between doctors, patients and their loved ones about end-of-life care priorities and all available options.

The Growing Need

Many of the more than 75 million baby boomers² in America provide care for aging parents at the end of life or already have witnessed their parents die, in many cases suffering needlessly due to futile, invasive treatment. Every day, 10,000 people turn 65.³ And forty-nine times more people reach age 85 now than did a century ago.⁴ Unless things change, we'll face a tsunami of needless human suffering in the coming years.

This increase in life expectancy also brings increased healthcare challenges and puts incredible demands on our health system. As people who have long endured chronic or progressive diseases or conditions near the end of life, they face myriad difficult, sometimes debilitating symptoms. Medical advances that help people survive serious illness or injury put tremendous strain on the healthcare system at every level, and call for a more humane and sustainable approach to end-of-life care.

Unwanted or Unnecessary Care

The Medical System

The present medical system prioritizes saving and prolonging lives at any cost. As Dr. Atul Gawande

A landmark study showed almost 90 percent of doctors would choose to forgo aggressive end-of-life treatment for themselves, and most would opt to die gently with few interventions.¹

says in his groundbreaking book *Being Mortal*, "Doctors, uncomfortable discussing patient's anxieties about death, fall back on false hopes and treatments that are actually shortening lives instead of improving them."⁵ Moreover, studies show doctors often overestimate survival not just slightly, but by a factor of five. This false optimism leads to doctors recommending inappropriate treatments and delaying referrals to palliative or hospice care.^{6,7}

However genuinely doctors believe they want the best for patients, our healthcare payment system discourages change, rewarding the volume of medical treatments provided rather than comfort measures that would better support people with advanced illness.⁸ While numerous professional guidelines and resources encourage healthcare providers to counsel their patients about palliative care, adoption of this practice is slow, as it's still commonly conflated with euthanasia or murder.^{9,10,11} In fact a University of Pittsburgh study of critically ill patients showed that physicians informed their surrogates about comfort care options in only half of the cases.¹²

The Individual

Studies indicate most Americans want to die on their own terms. A recent Gallup survey shows that 7 in 10 Americans (70%) believe that doctors should be able to help terminally ill individuals end their lives "by some painless means."¹³ Furthermore, while baby boomers express a desire to die at home, nearly 40 percent of patients die in the hospital.

Almost 60 percent of these deaths follow an admission to the intensive care unit (ICU), where one out of every five U.S. adults will die.¹⁴

Beyond not getting what they DO want, Americans are getting a lot of what they DON'T want. Recent research indicates people prefer care that enhances their quality of life over extending life through interventions that could reduce its quality.¹⁵ Yet, accounts of unwanted treatment -- treatment that is in direct conflict with stated patient preferences -- are reported regularly.^{16,17}

A 2014 Compassion & Choices poll shows that nearly one out of four older Americans (24%) say that either they or a family member have experienced excessive or unwanted medical treatment, the equivalent of about 25 million people.¹⁸ And they want adequate information about treatment for advanced illness.¹⁹ Furthermore, people want their doctors to be forthcoming about the potential downsides of treatment.²⁰

The Need for Improved Communication

While Americans today want to die on their own terms, many have no idea how to accomplish that. And until people face serious health challenges, it is often hard for them to explore and consider all the options. Most Americans want adequate information about treatment for advanced illness. According to a recent Kaiser Family Foundation survey, about 9 in 10 people (89 percent) say doctors should discuss end-of-life care issues with their patients. But relatively few (17 percent) say they've had such discussions with a doctor or other healthcare provider.²¹ While advance directives can help, they're not always effective depending on circumstances.²²

Today's Options

Americans today have several options on the palliative care spectrum: pain and symptom management, hospice, voluntarily stopping eating and drinking (VSED), refusing life-sustaining treatment, palliative sedation, and medical aid in

dying. But too often, patients are not informed of these choices. Furthermore, medical aid and dying, which has widespread public support, is not routinely offered by providers as an end-of-life care option -- even in the states where it is authorized. Policymakers and the medical establishment have been slow to respond to the strong demand for this option.

In addition, religiously affiliated hospitals and nursing homes often impose restrictions that interfere with a person's ability to direct their end-of-life care based on specific doctrines. For example, Catholic hospitals, which care for one in six American patients,²³ are governed by the Ethical and Religious Directives for Catholic Health Care Services, which are issued by the United States Conference of Catholic Bishops. These specify that patients' end-of-life decisions will not be honored if they conflict with Catholic moral teaching.²⁴

This has dire implications for people admitted to the more than 600 Catholic hospitals in the U.S. each year.²⁵ These patients cannot access medical aid in dying -- even in states that authorize the practice. Depending on the facility, other palliative care options may also be withheld. Furthermore, the problem is getting worse. Between 2001 and 2011, the number of Catholic sponsored or affiliated acute-care hospitals increased by 16%, while all other types of nonprofit hospitals declined in numbers.²⁶

The Solution

Despite progress in improving end-of-life-care, there is still much work to be done. Compassion & Choices, with its more than 450,000 supporters, continues to build momentum. Aid in dying is key to this movement because it clearly puts the patient in charge of end-of-life decisions. However, the movement to transform end-of-life care goes beyond providing the option of aid in dying, and includes personal advocacy and a host of policy solutions with the ultimate goal of ensuring all Americans have the power to make decisions about their end-of-life care based on their own values and priorities.

Resources

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