

End of Life Care and Issues

Key Takeaways:

- End-of-life care in America is suboptimal: Patients typically receive more intensive treatment than they would choose if properly informed about burdens and benefits; much care delivered has little or no likelihood of benefit; and both patients and their families report relatively low levels of satisfaction with their experience.
- Americans tend to believe that more treatment is better, especially at end of life. However, most medically intensive care to dying patients causes needless suffering and increases healthcare expenditures without corresponding benefit.
- Palliative care services have increased substantially in recent years, often employing not only skilled physicians but interdisciplinary teams that managed both physical symptoms and emotional/spiritual needs.
- Use of hospice services in the US has soared in recent years, and that industry has grown dramatically. However, average length of stay in hospice remains much shorter than generally recommended, reducing its benefit.
- Medical aid in dying now is legal in several states. While very few Americans avail themselves of this option, it is highly visible and controversial, causing challenges for healthcare providers.
- Recently Medicare began reimbursing physicians for having advanced care planning discussions with patients; however, most physicians lack the appropriate skills and are uncomfortable with these discussions.
- The high cost of end-of-life care coupled with its relative lack of benefit and low satisfaction levels combine to provide a rare opportunity within US healthcare to improve care and satisfy patients while saving money.

Background

Medical expenditures on individuals in the last year of their life account for 8.5 percent of all US healthcare spending (French EB). 25 percent (Riley, G.) of Medicare spending came in the last year of life. Yet patient satisfaction with end-of-life care is remarkably low, with just 14 percent saying it is excellent or very good. Many experts believe that end-of-life care is the “low-hanging fruit” of medical spending, where both treatment and spending are excessive. Yet the issue is politically fraught, with accusations of “death panels” looming

over decisions. Here we explore the issues facing end-of-life care in the US from medical, economic, and human perspectives.

Dying in America

The Patients' Experience

The average life expectancy in the US is 79 years. Approximately 2.75 million Americans die each year - about one out of every 118 of us. Around 60 percent of Americans die in acute care hospitals, 20 percent in nursing homes, and 20 percent at home. This is in spite of data that show that 70-80 percent of Americans wish to die at home. In addition, ICU use in the last month of life reached 29.2 percent in 2009.

Patients' overall experiences with dying and the commonly associated symptoms of pain and depression are often dependent on their ability to cope with advanced illnesses. In cases in which the patient has positive coping skills they may demonstrate attitudes of optimism and be practical, aware, resourceful and flexible. However, those who are unable to cope can respond defensively to their diagnoses and resort to suppression or isolation, projection, noncompliance, avoidance, and denial-- behaviors that can result in delay of treatment or disagreement about the disease. (Cannon B. et al) When an inability to cope is associated with a patient's noncompliance, behaviors of avoidance and denial can become dangerous and threaten the wellbeing of the patient. (Weiden et al)

Patients receiving end-of-life care wish to die with dignity, a sense that is related to the level of autonomy and independence retained throughout the course of illness. (Woo et al) A 50-patient case series conducted in an urban hospital revealed that for patients diagnosed with advanced-stage cancers a variety of factors including functional capacity, cognitive acuity, symptom management and alleviation of psychological distress were necessary for preserving dignity. (Hack T and McClement S) The loss of dignity has been associated with loss of independence and a sense of being burdensome to others, common experiences of individuals with terminal illness. (Hack T and Hassard T.) The compounding effect of heightened depression, hopelessness and the loss of dignity can lessen a terminally ill patients desire to continue living (Hack T and Hassard T.).

A terminally ill patient's sense of dignity and willingness to continue living can be linked to their ability to maintain control throughout their dying process. According to a survey of 2649 Oregon physicians, the most common reasons for patients to request Physician Assisted Suicide, a practice that has been legal in Oregon since 1997, were "a loss of independence, a desire to control the circumstances of death, readiness to die, and poor quality of life". In addition to these reasons, not wanting to be a burden on others was reported to be important for many dying patients. (Ganzini et al) In an effort to support varying coping styles of terminally ill patients and help them maintain their dignity, some researchers suggest that providers strive to provide such individuals with as much control over their end-of-life care as possible. (Woo et al)

Cost

Another aspect of the patient's end-of-life care experience is the cost of care and its impact on their financial well-being and that of their families. A study used prospective data from interviews of 336 patients with advanced cancer and their caregivers estimated the mean cost of care in only the last week of life to be \$8,110 with a range of \$1,022-\$38,819. (Garrido et al) This cost has an impact on household income and serves as a financial burden for many families. One study estimated that for patients with substantial end-of-life care needs, 10 percent of household income has to be spent on healthcare costs; these expenses can result in families having to take out loans or a second mortgage, deplete savings, or work an additional job to make ends meet. (Emanuel, FE et al)

On a larger scale, it is estimated that medical expenditures on individuals in the last year of their life account for 8.5 percent of all US healthcare spending (French, EB) and 25 percent of Medicare spending. (Riley, G.) The annual expenditures for hospice and home care - two healthcare segments that are closely involved in the provision of end-of-life care—are about \$ 3.5 billion and \$29 billion, respectively. (Levit et al) A significant proportion of the coverage for end-of-life care is provided by public programs such as Medicare, which covers about two-thirds of all hospice costs (National Hospice and Palliative Care Organization), the remainder coming

from private insurance (12 percent), other (11 percent), Medicaid (8 percent) and indigent care programs (4 percent).

The financial cost of end-of-life care can be a significant barrier to patients because most insurance plans do not cover services that are necessary for good-quality end-of-life care. When coverage is available, it is typically tied to a specific site rather than the individual, and payment for most services is limited to a certain amount of time and not by the amount of service necessary for comprehensive treatment. This payment structure leaves patients under-served after they exhaust their benefits. (Raphael et al)

Controversies

End-of-life care, though an important aspect of terminally ill patient's process, is not without controversy, political debate and legislative tension.

In 2009, former GOP vice presidential candidate and Alaska governor, Sarah Palin, and several Republicans representatives "accused the Obama administration and Democrats in Congress for creating 'death panels'." (Forbes) This claim was proven false by several organizations, but it contributed to lawmakers' decision to remove Medicare reimbursement of physicians who provided end-of-life consultations from the preliminary legislation that became the Affordable Care Act. (Forbes)

In 2017, Senator Ted Cruz of Texas attacked the palliative care movement, which aims to enhance communication between the healthcare team and patients by paying physicians to discuss the range of options available to patients at the ends of their lives. Cruz suggested that the practice shortens the lives of elders and argued that full ICU care for the sick elderly was instead the right approach. (Houston Chronicle) The same year, Representative Steve King of Iowa introduced a HR410, The Protecting Life Until Natural Death Act, a bill which aimed to amend "title XVIII (Medicare) of the Social Security Act to exclude from Medicare coverage advanced planning services, with the exception of certain hospice-related services that may include advising on end-of-life or advanced care planning" (Congress.gov)

Medical aid in dying now is legal in several states. While very few Americans avail themselves of this option, it is highly visible and controversial, causing challenges for healthcare providers. The debate over end-of-life care and physician-assisted-suicide continue in the United States, with advocates arguing that “mentally competent people who are suffering and have no chance of long-term survival, should have the right to die if and when they choose” and opponents contending that “Medical prognoses are often inaccurate... people who have been told they will soon die sometimes live for many months or even years longer”. (NPR)

Potential Solutions

Explore Established Models: Several models are being piloted with the aim of improving end-of-life care. These programs should be evaluated successes, challenges and best practices. Learning from models that have already been established can help inform promising approaches for the healthcare field and solutions for common issues facing the terminally ill and aging populations.

- The Conversation Project a program that encourages families to establish an actionable plan for end-of-life care (Health Affairs)
- The Cambia Health Foundation’s “Sojourns” program provides funding for projects that focus on workforce development and increasing awareness of and access to end-of-life care options.
- Regence adapted its health insurance policies to include a palliative support benefit for its 1.7 million members.
- Cigna is piloting a collaboration project with Aspire Health to provide in-home palliative care services to members in Baltimore, Washington, D.C. and Richmond, Va.
- Blue Shield of California expanded its home-based palliative care program statewide. As a result of this expansion, 90 percent of those enrolled in palliative care who passed away did so at home, according to their wishes. (AHIP)

Improve Communication by Training Providers: Medical care providers are often in the position of providing a diagnosis to patients explaining the necessary course of treatment and available options. Improving communication between physicians and their patients about these difficult topics can help reduce the rate of inappropriate end-of-life care. (Health Affairs) In order to improve communication providers should be trained to have better awareness of cultural and ethnic preferences and of beliefs related to death and dying. Such awareness can help provider gain patients' trust, confidence, and acceptance of appropriate end-of-life care. In turn this can also result in improved quality of life, and reduced healthcare expenditure. (AJMC)

Increased Access to Palliative Care: Expanding patients' access to palliative care that is aligned with disease modifying treatment can allow for gradual transition from costly, aggressive treatments that are of low value and have a low probability of arresting disease progression. (Health Affairs) Palliative care services have increased substantially in recent years, often employing not only skilled physicians but interdisciplinary teams that managed both physical symptoms and emotional/spiritual needs. Recently Medicare began reimbursing physicians for having advanced care planning discussions with patients; however, most physicians lack the appropriate skills and are uncomfortable with these discussions. Use of hospice services in the US has soared in recent years, and that industry has grown dramatically. However, average length of stay in hospice remains much shorter than generally recommended, reducing its benefit.

Conclusion

End-of-life care is a challenging and controversial field of medical care that can have a psychological impact patients, families and providers who give and receive support throughout the dying process. The taboo nature of dying can make it difficult for providers to be successful agents to their patients and differences in moral opinions of what services should and should not be accessible to patients complicates the issue further. Despite these challenges, it is crucial that the US healthcare system develop policies to frame provider practices to ensure that patients receive appropriate and affordable care that allows them to die with a sense of dignity and control. The high cost of end-of-life care

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coupled with its relative lack of benefit and low satisfaction levels combine to provide a rare opportunity within US healthcare to improve care and satisfy patients while saving money.

An honest conversation about death and dying could play an important role in enhancing treatment quality, improving patient satisfaction and lowering the cost of end-of-life care in the United States.

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