

BREAKING THE TABOO

Addressing Barriers to Effective End-of-Life Care Planning and Hospice Utilization

A White Paper

By Jocelyn D. Campbell
June 2022



"We have to talk about death in order to live life to the fullest. In order to face our fears, we have to shine a light on them." - Dr. Atul Gawande, author of "Being Mortal: Medicine and What Matters in the End"

INTRODUCTION

Death and dying are universal experiences, yet many Americans have an aversion to discussing and planning for the end of life. This cultural taboo has significant consequences for patients' quality of care at the end of their lives. In particular, hospice care, a specialized form of care that focuses on symptom management and improving the quality of life for patients with life-limiting illnesses, is underutilized in the United States. Despite the proven benefits of hospice care, such as improved quality of life and decreased hospitalizations, patients often delay enrollment until very late in their illness, and many receive care for far less time than is recommended. This paper will explore the reasons for this cultural aversion to death and dying and its impact on hospice utilization. We will also discuss potential solutions, including education and awareness initiatives, policy changes, and research efforts to improve end-of-life care for all patients.

DISCUSSION

The culture of aversion to death and dying in the United States has long been recognized as a barrier to effective end-of-life care planning, particularly concerning hospice care. Hospice care is a specialized form of care for patients with life-limiting illnesses, focused on relieving symptoms and improving quality of life. Despite the benefits of hospice care, studies have consistently shown that Americans are hesitant to discuss end-of-life care and often delay hospice enrollment until very late in the course of their illness.

The National Hospice and Palliative Care Organization (NHPCO) reports that in 2019, 1.55 million patients received hospice care in the United States, with an average length of stay of 24 days. However, research shows that patients often receive hospice care for far less time than is recommended for optimal symptom management and psychosocial support.

- 2018 study in the Journal of Palliative Medicine found that only 26.3% of hospice patients received care for more than 30 days, despite guidelines recommending a minimum of 60 days.
- Racial and ethnic disparities exist in hospice utilization, with non-white patients receiving hospice care at lower rates than white patients.
- The reluctance to engage in end-of-life care planning and hospice enrollment is wider than patients; healthcare providers also play a significant role. A 2019 Journal of General Internal

Medicine study found that only 20% of primary care providers consistently discussed end-of-life care with their patients. Providers who reported discomfort with end-of-life discussions were less likely to engage in these conversations.

One potential reason for this cultural aversion to death and dying is the American healthcare system's emphasis on curative treatments and prolonging life at all costs. A 2020 study in the American Journal of Hospice and Palliative Medicine found that patients with life-limiting illnesses often receive aggressive, invasive treatments in the last month of life, despite evidence that these interventions do not improve quality of life or prolong survival. This "medicalization" of death can lead to unrealistic expectations and a lack of understanding about the benefits of hospice care. Other factors that may contribute to the reluctance to engage in end-of-life care planning include:

- fear of losing control
- fear of death
- unresolved emotional/family trauma
- lack of knowledge about advanced care planning
- lack of knowledge about hospice care

A 2018 study in the Journal of Pain and Symptom Management found that patients who received hospice care reported improved quality of life, lower rates of depression, and higher rates of satisfaction with care compared to patients who did not receive hospice care. To address these issues, there is a need for increased education and awareness about hospice care and end-of-life planning. Healthcare providers must be trained in communication skills and get comfortable discussing end-of-life care with their patients. Patients and families must be educated about the benefits of hospice care and encouraged to discuss their wishes with their healthcare providers.

OPPORTUNITIES

The Centers for Medicare and Medicaid Services (CMS) has also recognized the need for increased access to hospice care and offers a range of resources and guidelines to improve hospice utilization. For example, CMS implemented the Hospice Quality Reporting Program in 2014, which requires hospices to report on specific quality measures. In addition, CMS has expanded the availability of hospice services through the Medicare Hospice Benefit. Despite the proven benefits of hospice care, Americans often delay enrollment and receive care for shorter periods than recommended.

- Healthcare providers must be trained in communication skills and encouraged to engage in end-of-life discussions with their patients.
- Patients and families must be educated about the benefits of hospice care.

- The government can also play a role in improving hospice utilization through policy changes and funding support. For example, the Affordable Care Act (ACA) included provisions to expand hospice care and promote its use among Medicare beneficiaries. The ACA has created the Medicare Care Choices Model, which allows eligible patients to receive both curative treatments and hospice care simultaneously, and the Centers for Medicare and Medicaid Services (CMS) provides reimbursement for hospice services, making it a viable option for many patients.
- The government can invest in research to better understand the barriers to hospice utilization and develop interventions to address them. This can include funding studies on the attitudes and beliefs of patients and healthcare providers towards hospice and testing different strategies to increase awareness and education about hospice care.
- Improve access to hospice care for underserved populations, such as rural communities and minority groups. This can involve initiatives to increase the number of hospice providers in these areas and cultural competency training for hospice staff to ensure they are equipped to meet the unique needs of diverse patients and families.

CONCLUSION

Improving hospice utilization requires a multi-faceted approach involving healthcare providers, patients, families, and policymakers. By working together to overcome the barriers to hospice care, we can ensure that all patients receive the support and comfort they need at the end of life. This is a holistic effort. We were not born with ingrained DNA on how or even when we will die; so Americans must close this healthcare gap that too often leaves the bereaved family members with negative death experiences.