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Transforming the American experience of death: What dreams may come?

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Abstract

There is no means to evaluate the death experience in the US healthcare system. Other countries have established population-wide measures to evaluate and improve the dying experience for patients and their families. With an increasing population of advanced-age persons, changes in sites of death, and a continually fractured healthcare delivery system, there is a need to establish a universal assessment of the quality of death in the US. In this commentary, we outline the need for such an assessment and build off of previous literature on the various existing assessments of the quality of death that have typically been reserved for end-of-life care specialties. Based on the aforementioned reasons and poor performance relative to other nations, there is a need for political attention to assessing the quality of American death experiences for patients and for their families. Absent such a measure, there will never be an incentive to improve the quality of death for patients and their families and the US healthcare system will continue to neglect this important aspect of American life.

Keywords

End-of-life care, family caregivers, quality of care, patient experience, patient- and family-centered care

“Even though death is very much part of the cycle of life and the journey to physical dying begins with the inception of living, thinking and talking about one’s own death usually remains in the background, at least until its prospect becomes more probable or imminent.” (Preface to the 2015 Report on Dying in America)

The United States needs a population level assessment of death and dying from patients, families, and caregivers. In the wake of a global pandemic and having confronted a mass death event, which revealed deficiencies in the US healthcare system’s response to the dying and bereavement process for individuals and their families and caregivers, now is the time to address this national healthcare need. At the time of this publication, it is estimated that more than 1.1 million people in the United States have died from Covid-19. The increase in deaths related to the US Health Emergency has prompted a new awareness of the need for the US healthcare system to be more proficient throughout the dying process. Establishing the quality of death in the US healthcare system is an essential requirement to evaluate healthcare quality—It is imperative for patients, it is imperative for families, and it is imperative for society at large to address these issues with urgency.

The Institute of Medicine’s report on the experience of dying in the United States calls for an approach that emphasizes deep engagement with patient preferences.¹ The Committee on Approaching Death draws attention to the lack of patient knowledge regarding end-of-life

decisions, stating that the health community and other leaders have yet to sufficiently use public engagement and education strategies in making this information available. There is a pressing need for this engagement to occur at the societal, community/family, and individual levels.

In addition to the social and cultural reluctance to talk about death and dying, the medical system has a historic and documented aversion to managing death and dying.^{2,3} Factors relating to clinician reluctance including a lack of skill in or discomfort with having conversations regarding serious illness have been identified as a prominent barrier to hospice utilization.⁴ As outlined by Gawande in *Being Mortal*, “The simple view is that Medicine exists to fight against death and disease... Death is the enemy. ...Eventually, it wins.⁵” The pervasive delusion, that medicine is capable of and encouraged to fight death without regard to either patient preferences or economic constraints, is costly. The evidence for costs of medical services at the time of death is well examined in the literature.⁶ Increasingly, US citizens and patients can expect to die across a variety of settings, inclusive of inpatient hospitals, but also including nursing homes, hospice facilities, hospice at home, and other home healthcare models as the population, specifically Baby Boomers, continues to age.⁷ The increased fracturing of the US healthcare systems in this country translates to an increasingly fractured death and dying experience, and, furthermore, the movement of death and dying into new

settings will make assessment of the quality of the dying experience all the more challenging.

Some medical specialties frequently provide care for seriously ill or near end-of-life patients, for example, Geriatric Medicine. Critical Care Medicine and Hematology-Oncology now incorporate some training pertaining the management of death and dying into their graduate medical education curriculums. However, the medical subspecialty of Hospice and Palliative Medicine (HPM) is the only specialty dedicated to an evidence-based approach to the care for patients and their families at the end of life. Because these few specialties have established practices regarding death and dying, those few with training in end-of-life care have become the de facto specialties for dealing with issues surrounding death and dying in America. Other physicians call these specialists in when they have exhausted all of their curative care options, and calling in a palliativist or referring to hospice is often viewed by many care providers as an admission of failure to death rather than an acceptance of what is imminent and inevitable. However, when curative treatments run out, healthcare does not stop, it makes an important transition to ensure that each patient has a good death.

It is difficult to improve the patient's experience of death without confronting our cultural, professional, and economic challenges in managing care at end-of-life. Important conversations germane to patient death and dying often occur within specific specialties, however, assessment and evaluation of the quality of death across these specialties seldom occurs. Further, death and dying across all care settings and care delivery processes beyond these specialties is not evaluated, making determinations about the quality of death in the US health system nearly impossible. With an increasingly fragmented healthcare system and the professionalization of care providers, there is a need to have a universal assessment of the quality of death in America.⁸ Universal access to a standardized metric evaluating the quality of death for patients and their families would allow for comparison across settings. Furthermore, for those dying, such an assessment would inform the integration of care across settings and care transitions that impact the death experience at the end-of-life.

Existing assessments of the quality of death have been developed which evaluate end-of-life experiences. A recent systematic review includes 51 family assessments that capture the experiences of death, dying, and end-of-life care.⁹ Among these assessments, 14 domains of the dying experience were categorized: bereavement support, caregiver support, environment, financial needs, information and care planning, overall experience, personal care, provider care, psychosocial care, quality of death, responsiveness and timing,

spiritual/religious/existential care, symptom management, and other. Table 1 lists the Family Experience of Death domains in the order of the most frequently used to the least. The second column provides a question example from each of the twelve most frequently used assessments while the third column indicates the specific surveys that included the particular domain. Although these existing instruments measure the family experience at the end of life, no assessment encompasses all 14 domains.

While end-of-life, hospice, and palliative care experts continue to improve our means for reducing suffering and improving quality of care during dying by focusing on a "person-centered, family-oriented, and evidence-based" approach, most individuals and family caregivers find the experience of death extremely painful, difficult to discuss, and a topic to be avoided if possible.^{1,10,11} Within the United States, in particular, costs for healthcare continue to be highest during the last year and final days of life and, yet, [quality of care](#) during that period ranks extremely poor relative to other developed nations.^{6,12,13} One recent study found the percentage of family members rating their loved ones' care at end-of-life as excellent has declined since the turn of the century, and the rankings from [a 2021 article](#) on cross-national comparisons of the quality of death ranks the United States below the top 40 countries for the quality of death experience.^{13,14} Countries rated the best for the quality of death experience include the United Kingdom, Ireland, Taiwan, Australia, and the Republic of South Korea. These countries have improved the dying experience by implementing broad-scale changes in healthcare, and the United States has lagged in its implementation of the best end-of-life care practices. The relative performance to other developed nations may be due in part to other developed nations having either established quality of death assessments such as the National Survey of Bereaved People (VOICES) in England or having such measures in stages of either development or implementation.¹⁵ Because, unlike other national systems, the American health system is a collection of fractured systems, and the transformation of the death and the dying experience in America requires an ability to assess these experiences at the population level.

As healthcare in America has become increasingly complex due to an aging and comorbid population and an increasingly fragmented care delivery system, so too, care for the dying has become increasingly complex with numerous barriers to quality care. End-of-life care and dying in America is impacted by many of the same barriers to high-value and quality healthcare (e.g., social determinants of health, provider shortages, inequitable access, etc.). However, absent any means to evaluate the death and dying experiences across care sites and across care delivery processes, the quality of death and dying experiences will never be known. Adopting measures for

Table 1. Survey Domains for Family Experiences of Death (with question examples)

Family Experience of Death Domains	Question Example	Assessments that Include Domain
<p>Information and Care planning:</p> <p>Related to advance care planning, communication, and decision-making between patient, family and providers, discussing goals and preferences for care</p>	<p>How satisfied are you with family conferences to discuss the patient's illness?</p> <p>(FAMCARE)</p>	<ul style="list-style-type: none"> • FAMCARE • FEHC • ADI • QODD • FATE • VOICES • EOLD-SWC/CAD • FS-ICU • End of Life Care in Acute... • Sat-Fam-IPC
<p>Provider Care:</p> <p>Related to quality and satisfaction with care given by specified provider</p>	<p>How satisfied are you with the doctor's attention to patient's description of symptoms?</p> <p>(FAMCARE)</p>	<ul style="list-style-type: none"> • FEHC • ADI • FATE • VOICES • EOLD-SWC/CAD • QUEST • FS-ICU • End of Life Care in Acute... • Sat-Fam-IPC
<p>Symptom Management:</p> <p>Related to experience and management of symptoms</p>	<p>In that last week/While under care of the nursing home, did [PATIENT] receive too much, too little, or just the right amount of medication for his/her pain?</p> <p>(ADI)</p>	<ul style="list-style-type: none"> • FAMCARE • FEHC • ADI • QODD • FATE • VOICES • EOLD-SWC/CAD • End of Life Care in Acute... • Sat-Fam-IPC
<p>Spiritual, Religious, and Existential Care:</p> <p>Related to religious aspects of care and/or patients' spiritual and existential needs and well-being</p>	<p>Did _____ have a spiritual service or ceremony before his/her death?</p> <p>(QODD)</p>	<ul style="list-style-type: none"> • EHC • ADI • QODD • FATE • EOLD-SWC/CAD • QUEST • FS-ICU • End of Life Care in Acute... • Sat-Fam-IPC
<p>Psychosocial Care:</p> <p>Related to emotional well-being, social support, and social needs</p>	<p>How much help in dealing with these feelings [sadness] did [PATIENT] receive- less than was needed or about the right amount?</p> <p>(ADI)</p>	<ul style="list-style-type: none"> • FAMCARE • FEHC • ADI • QODD • FATE • EOLD-SWC/CAD • QUEST • End of Life Care in Acute... • Sat-Fam-IPC

Table 1. Survey Domains for Family Experiences of Death (with question examples), cont'd.

Family Experience of Death Domains	Question Example	Assessments that Include Domain
<p>Caregiver Support: Related to support and services provided to the caregiver</p>	<p>How supported did you feel throughout the decision making process? (FS-ICU)</p>	<ul style="list-style-type: none"> • FAMCARE • FEHC • ADI • FS-ICU • End of Life Care in acute... • Sat-Fam-IPC
<p>Responsiveness and Timing: Related to responsiveness to needs of patient and caregiver</p>	<p>How satisfied are you with the availability of the doctor to the patient? (FAMCARE)</p>	<ul style="list-style-type: none"> • FAMCARE • FEHC • ADI • QUEST • Sat-Fam-IPC
<p>Personal Care: Related to quality of personal care provided (bathing, eating)</p>	<p>(In that last week/while under care of the nursing home), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom? (ADI)</p>	<ul style="list-style-type: none"> • FAMCARE • FEHC • ADI • QODD • FATE • VOICES • EOLD-SWC/CAD • Sat-Fam-IPC
<p>Bereavement Support: Related to support and services provided to family after patient's death</p>	<p>Providers gave the family enough emotional support after the patient's death. (FATE)</p>	<ul style="list-style-type: none"> • FEHC • ADI • FATE • VOICES • Sat-Fam-IPC
<p>Environment: Related to room, noise, and comfort of facility</p>	<p>How satisfied are you with the atmosphere (mood) of the ICU? (FS-ICU)</p>	<ul style="list-style-type: none"> • FATE • FS-ICU • End of Life Care in Acute... • Sat-Fam-IPC
<p>Financial Needs: Related to patient's financial needs, health care costs, and funeral planning</p>	<p>Were all of _____'s health care costs taken care of? (QODD)</p>	<ul style="list-style-type: none"> • FEHC • QODD • FATE • End of Life Care in Acute... • Sat-Fam-IPC
<p>Quality of Death: Related to experience of care received immediately before dying for patient/family</p>	<p>During the final hours of your family member's life which of the following best describes your views: - I felt that he/she was very uncomfortable - I felt that he/she was slightly uncomfortable - I felt that he/she was mostly comfortable - I felt that he/she was very comfortable - I felt that he/she was totally comfortable (FS-ICU)</p>	<ul style="list-style-type: none"> • ADI • QODD • FS-ICU

Table 1. Survey Domains for Family Experiences of Death (with question examples), cont'd.

Family Experience of Death Domains	Question Example	Assessments that Include Domain
Overall Experience: General assessments of care received	On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that [PATIENT] received in [PATIENT'S] last week of life/white [PATIENT] was under care of the nursing home? (ADI)	<ul style="list-style-type: none"> • FEHC • ADI • FATE • VOICES • EOLD-SWC/CAD • QUEST • FS-ICU • RSCD
Other: Demographic information about patient or type of facility	What was the highest level of schooling [PATIENT] completed? (ADI)	<ul style="list-style-type: none"> • FEHC • ADI • QODD • FATE • Sat-Fam-IPC
Surveys		
<ul style="list-style-type: none"> • Family Satisfaction with Advanced Cancer Care (FAMCARE) • Family Evaluation of Hospice Care (FEHC) • After-death Bereaved Family Member Interview (ADI) • Quality of Dying and Death (QODD) • Family Assessment of Treatment of End-of-life (FATE) • Views of Informal Carers– Evaluation of Services (VOICES) • End of Life in Dementia- Satisfaction with Care, Symptom Management, & Comfort Assessment in Dying (EOLD- SWC & EOLD- CAD) • Quality of End-of-Life Care and Satisfaction with Treatment (QUEST) • Family Satisfaction in the ICU (FS-ICU) • Region Study of Care for the Dying (RSCD) • End of Life Care in Acute Care Hospitals- Caregiver and Patient Versions • Satisfaction scale for family members receiving inpatient palliative care (Sat-Fam-IPC) 		

death can be transformational for the patient and family experience of care and inform healthcare systems on how they can improve their dying experiential offerings. Just as healthcare quality initiatives have improved care processes through the implementation of assessments, so too could the quality of the dying process be improved. This would also allow for knowledge creation and scholarship regarding the quality of the American death and dying experience. As the “Silver Tsunami” advances, there is an urgent need to recognize that there is no policy that addresses the dying experience in America. In other countries as well, there is a need to develop culturally sensitive assessments of the dying experience. Absent such a policy or relevant metric, there is neither an incentive to evaluate the dying experience. Thus, improvement of the dying experience will remain as much a dream as that which lies beyond the veil.

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