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TIME TO SAY GOODBYE: HISTORICAL PERSPECTIVES AND CONTEMPORARY APPROACHES TO PALLIATIVE CARE AT THE END OF LIFE

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About Notable Grand Rounds

These assembled papers are edited transcripts of didactic lectures given by mainly senior residents, but also some distinguished attending and guests, at the Grand Rounds of the Michael and Marian Ilitch Department of Surgery at the Wayne State University School of Medicine.

Every week, approximately 50 faculty attending surgeons and surgical residents meet to conduct postmortems on cases that did not go well. That “Mortality and Morbidity” conference is followed immediately by Grand Rounds.

This collection is not intended as a scholarly journal, but in a significant way it is a peer reviewed publication by virtue of the fact that every presentation is examined in great detail by those 50 or so surgeons.

It serves to honor the presenters for their effort, to potentially serve as first draft for an article for submission to a medical journal, to let residents and potential residents see the high standard achieved by their peers and expected of them, and by no means least, to contribute to better patient care.

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Time to Say Goodbye: Historical Perspectives and Contemporary Approaches to Palliative Care at the End of Life

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“You matter because you are you and you matter to the last moment of your life.” —Cicely Saunders

Introduction

End-of-life care, encompassing palliative and hospice care, represents a critical aspect of medical practice deeply impacting patients, healthcare providers, and society at large. Despite its significance, this subject often receives insufficient attention in medical education and training. This paper aims to address this gap by exploring the evolution of end-of-life care, examining current practices in the United States, and discussing the concept of a "good death."

Historical Overview

The trajectory of end-of-life care has undergone a profound transformation over the centuries. To contextualize this evolution, one might consider the reflections of Michel de Montaigne, a French Renaissance philosopher. Montaigne observed that in his era, the majority succumbed to death before reaching the age of fifty, typically from rapid-onset conditions like trauma or communicable diseases, with the dying

Fig. 1. Michel de Montalgne, 1570s. Source: Unknown author - http://www.archivio.-formazione.unimib.it/DATA/Insegnamenti/11_2349/materiale/2.pdf

process occurring swiftly and at home (Montaigne, 1580). He noted, "To die of old age is a rare, extraordinary, and singular death, much less natural than other kinds" (Montaigne, 1580). This historical observation underscores the stark contrast between past and present death experiences, with the latter now often occurring in medicalized settings.

The modern hospice movement, which laid the groundwork for contemporary palliative care, emerged in the 1960s and 1970s, epitomized by the establishment of the first hospice in London by Dame Cicely Saunders. Saunders, a nurse with a privileged background, was deeply influenced by personal experiences with terminally ill patients, including two whom she loved (Clark, 2005). Motivated by these encounters, Saunders sought to improve the quality of life for those at the end of life. She founded St. Christopher's Hospice as a pioneering institution that integrated clinical research, education, and holistic care, addressing the physical, social, psychological, and spiritual needs of patients and their families (Saunders, 1967). Saunders' philosophy that "you matter because you are you, and you matter to the last moment of your life" encapsulates the ethos of palliative care, emphasizing dignity, compassion, and individualized care (Saunders, 1976).

Transition to Modern Palliative Care

The hospice movement spearheaded by Saunders catalyzed the development of palliative care as a specialized field. Today, palliative care aims to enhance the quality of life for patients facing life-threatening illnesses, focusing on symptom management, psychosocial support, and assistance in making complex healthcare decisions. This shift reflects a broader understanding of the multifaceted needs of terminally ill patients and their families, moving beyond the traditional focus on physical symptoms to encompass a more comprehensive approach to care.

Following Cicely Saunders' establishment of the hospice movement in the United Kingdom, the concept of specialized end-of-life care began to gain traction internationally. A pivotal moment in the transatlantic exchange of hospice philosophies occurred when Florence Wald, an American nurse and later the Dean of the Yale School of Nursing, attended a lecture by Saunders. Inspired by Saunders' pioneering work, Wald visited St. Christopher's Hospice in London, absorbing its foundational principles. This experience catalyzed the hospice care movement in the United States, with Wald establishing the first American hospice institution in Connecticut (Stoddard, 1992). This marked a significant milestone in the integration of hospice care within the American healthcare system, laying the groundwork for the broader field of palliative care.

The 1970s witnessed a burgeoning discourse around end-of-life care, prompted in part by legislative developments in Oregon concerning physician-assisted suicide and a growing recognition of the changing dynamics of death in America. Policymakers and medical professionals observed a shift towards prolonged life expectancies and an increase in hospital deaths, sparking a national conversation on the quality and locus of end-of-life care (Meier, 2011).

In 1980, a landmark policy change occurred when the federal government began covering hospice care under Medicaid, facilitating the expansion of hospice services and, indirectly, the growth of nursing homes. This period also saw the World Health Organization's recognition of palliative care as a distinct medical specialty in 1990, emphasizing its goal to "relieve suffering and improve the quality of life for patients with life-limiting illnesses" (quoted in Connor & Sepluveda Bermedo 2014).

Elisabeth Kübler-Ross and the Psychosocial Dimensions of Dying

Elisabeth Kübler-Ross, a psychiatrist, significantly contributed to the understanding of the emotional and psychological aspects of dying. Her identification of the five stages of grief—denial, anger, bargaining, depression, and acceptance—provided a framework for comprehending the emotional responses to terminal illness and loss (Kübler-Ross, 1969). Though initially met with skepticism, her work gained traction, influencing not only the field of psychology but also the general public's perception of grief and dying.

Kübler-Ross's interest in death and dying was shaped by her personal experiences with health challenges in early childhood and her observations of the dying process. Her later years, marked by a series of strokes and a reflective period in a nursing home, offered her unique insights into the experiences she had previously studied. An interview with Oprah Winfrey revealed Kübler-Ross's contemplations on her own stages of grief, highlighting her readiness for death and her perception of divine timing in her life's end (Kübler-Ross, 2002).

Analyzing End-of-Life Care: The Institute of Medicine's Findings

In 1997, the Institute of Medicine conducted a comprehensive study on the prevailing patterns of death and dying in America, culminating in a revealing report about the realities of end-of-life care. This report not only shed light on the existing practices and gaps in care but also highlighted the divergence between the manner in which Americans die and how they wish to die (Institute of Medicine, 1997). A critical insight from the report is the misalignment between clinical interventions and patient desires, emphasizing a widespread need for reform in end-of-life care strategies.

The IOM report set forth several recommendations aimed at enhancing the quality of end-of-life care, notably:

- **Early Diagnosis and Communication:** Emphasizing the importance of promptly diagnosing life-limiting conditions and effectively communicating these diagnoses to patients and their families. This recommendation underscores the need for transparency and clarity in discussions about prognosis and available care options.
- **Goal Alignment:** Advocating for the establishment of clear care goals that are in harmony with the patient's values and wishes. This involves a collaborative approach where the healthcare provider's recommendations are aligned with the patient's personal values, cultural background, socioeconomic status, and religious beliefs.
- **Guidelines for Modern Dying:** Recognizing the changing landscape of death in contemporary society, the report calls for the creation of guidelines that address the needs and preferences of individuals dying in the modern age. This reflects an acknowledgment of the shift away from traditional settings of death towards more medicalized contexts.
- **Relationship Building:** Highlighting the importance of fostering strong relationships between patients, families, and caregivers. Such relationships are pivotal for ensuring that end-of-life care is compassionate, respectful, and attuned to the emotional and psychological needs of all involved.
- **Healthcare Community Responsibility:** Stating that the healthcare community bears a special responsibility to educate itself on effective end-of-life care practices. This includes learning how to have constructive conversations with families about death and dying, ensuring that end-of-life

care is both humane and consistent with patient wishes.

The Changing Landscape of Death in America

Historically, most Americans died at home, with death often occurring swiftly due to acute illnesses such as pneumonia. This traditional experience of dying surrounded by family and friends starkly contrasts with the contemporary reality, where death frequently takes place in medicalized settings such as hospitals and nursing homes. The IOM report's insights into this shift highlight a critical gap between preferred and actual contexts of death, indicating a need for systemic changes in end-of-life care practices.

The report revealed a dissonance between preferred and actual places of death, indicating that while many Americans expressed a desire to die at home, the majority were dying in institutional settings (Institute of Medicine, 1997). To bridge this gap, the IOM recommended early diagnosis, clear communication of prognosis and care options to patients and families, and alignment of care goals with patients' values and cultural, socioeconomic, and religious backgrounds. These guidelines underscored the need for a patient-centered approach in end-of-life care, emphasizing the importance of dignity, respect, and shared decision-making (Institute of Medicine, 1997).

Shifts in Life Expectancy and Causes of Death

By the early 2000s, significant shifts in life expectancy and predominant causes of death were observable. Despite a slight decline attributed to the COVID-19 pandemic, the average American life expectancy had increased markedly from the mid-20th century, with heart disease, cancer, and stroke being the leading causes of death, pre-COVID. The pandemic, however, introduced a new variable, briefly making COVID-19 the third leading cause of death in the United States. These shifts reflect broader trends in public health and medicine, where advancements have transformed once-fatal conditions into manageable chronic illnesses, thereby extending life but also altering the landscape of terminal care (National Center for Health Statistics, 2021).

The Evolution of Death Settings

The 20th century witnessed a significant transition in the settings of death. While home was once the primary site of death, the latter half of the century saw a marked increase in institutional deaths. By 1949, approximately half of all American deaths occurred in institutions, with hospitals accounting for 40% of these (Lunney et al., 2003). This trend intensified by 1980, with nearly three-quarters of deaths occurring in institutional settings, underscoring a societal shift towards medicalized end-of-life care (Institute of Medicine 1997; National Academies 1997)

However, the reliability of data regarding the exact location of death (e.g., hospital vs. nursing home) remains a challenge, due to factors such as transfers between care settings and reporting inconsistencies.

The Medicaid Act

The increase in institutional deaths during the 1980s can be partially attributed to the Medicaid Act, which expanded coverage for palliative care and nursing home facilities. This legislative change facilitated access to institutional care for terminally ill patients, leading to a notable shift in the settings of death. By the 1990s, only 20% of Americans died at home, a significant decrease from previous decades (Hogan et al., 2001). This shift underscores the impact of healthcare policy on end-of-life care practices and preferences.

Americans' Preferences for End-of-Life Care

Despite the growing trend of institutional deaths, surveys from the period reveal a persistent preference among Americans to die at home, conditional upon the certainty of terminal illness and the absence of curative options (Teno et al., 2004). This reflects an intrinsic optimism and a desire for aggressive treatment until all hope is exhausted, at which point the preference shifts towards comfort and palliation. The complexity of accurately predicting disease trajectories complicates this preference, as it challenges healthcare providers to balance hope with realism in care planning.

The changing social fabric of America, characterized by increased mobility and the dispersal of families(making family-based decision-making logistically more difficult), has influenced end-of-life experiences. The emergence of available medical interventions for previously life-threatening disease and end-of-life interventions have further complicated end-of-life care for American families. A study in 1996 highlighted generational differences in attitudes towards life-sustaining treatments, with younger individuals more likely to reject measures that compromise independence, compared to older generations who may be more accepting of dependence in their final years (Emanuel et al., 1996).

The reliance on survey data from predominantly middle-class, white respondents raises questions about the generalizability of these findings across America's diverse population. With projections indicating that by 2050 the United States will be a majority-minority country, the heterogeneity of cultural, religious, and ethical perspectives on death and dying suggests a need for a more nuanced understanding of end-of-life care preferences (Passel & Cohn, 2008).

Confronting Death in Medical Practice: Challenges and Perspectives

The prevailing culture within the medical profession, characterized by a focus on intervention and cure, reflects broader societal attitudes towards death. This cultural inclination towards seeing death as a failure presents significant challenges in end-of-life care, driving an increase in healthcare interventions in the final stages of life (Smith & Fisher, 2015). The difficulty that healthcare providers face in accepting the inevitability of death complicates the pursuit of a balanced approach to end-of-life care, one that emphasizes quality of life and comfort over aggressive treatments.

Good vs. Bad Death

The concept of a "good death" is complex and varies widely among individuals, influenced by their values, beliefs, and experiences. A good death is generally understood to be free from avoidable distress and suffering for patients, families, and caregivers, aligning with their wishes and cultural, ethical, and religious standards (Meier et al., 2016). This definition expands the focus from the patient and family to include the well-being of caregivers, acknowledging the emotional and psychological toll of end-of-life care on healthcare providers.

Moreover, the notion of a "good death" transcends physical considerations to encompass philosophical and existential dimensions. For some, a dignified death involves maintaining control over the dying process, including decisions related to life-sustaining treatments and palliative care options. Cultural and religious beliefs significantly influence these preferences, highlighting the importance of a personalized and respectful approach to end-of-life care (Emanuel, 1998).

Cultural, religious, and personal values play a crucial role in shaping individuals' preferences for end-of-life care. For some, dignity at the end of life may involve minimizing dependence on others and controlling pain and symptoms. For others, it may mean being surrounded by family and dying in a familiar environment. The variability in what constitutes a dignified and comfortable death underscores the necessity for healthcare providers to engage in open, empathetic discussions with patients and their families about their end-of-life wishes (Chochinov, 2006).

While consensus on a universally "good death" remains elusive, there is a clearer agreement on what constitutes a "bad death." A "bad death" is characterized by needless suffering, the disregard of patient and family wishes, a perceived loss of dignity, and the provision of unnecessary or non-beneficial medical interventions. An example often cited is the aggressive treatment of a patient with terminal illness, such as metastatic lung cancer, with high-intensity interventions like extracorporeal membrane oxygenation (ECMO), which may not align with the patient's preferences for end-of-life care (Truog et al., 2008).

Quality of Dying

The quality of dying introduces further complexities in end-of-life care discourse. While quality of life metrics are relatively well-established, encompassing aspects such as autonomy and functional capacity, the quality of dying is more difficult to define and measure. The challenge lies in the subjective nature of pain and suffering and their distinction from one another. Suffering can occur in the absence of physical pain and can have philosophical dimensions that extend beyond the physical realm. This distinction underscores the need for a nuanced approach to end-of-life care, recognizing that individual experiences of dying are shaped by a myriad of factors beyond mere physical symptoms (Cassell, 1991).

The legal and medical communities strive to delineate end-of-life through definitions that can guide care and decision-making. For instance, end-of-life care in the United States is often associated with a prognosis of a progressive illness expected to result in death within a specific timeframe, commonly six months, in the absence of life-prolonging treatments. However, this timeframe can be arbitrary and does not easily apply to all conditions, highlighting the challenges in setting parameters around what constitutes terminal illness (Gomez-Batiste et al., 2014).

Furthermore, the definition of death itself has evolved, encompassing both cardiopulmonary and brain death criteria. The American Association of Neurologists, among others, has updated criteria for death, reflecting ongoing debates and advancements in medical science and technology that challenge traditional conceptions of death (Bernat, 2006).

The consensus on what constitutes a "bad death"—characterized by needless suffering, disregard for patient and family wishes, and unnecessary medical interventions—highlights the medical community's struggle with end-of-life care decisions. This perspective underscores the importance of respecting patient autonomy and ensuring that care aligns with the individual's values and preferences, particularly in cases of terminal illness where the focus should shift from curative efforts to comfort and quality of life (Callahan, 2000).

The concept of quality of dying remains challenging to define, encapsulating more than the physical experience of pain and suffering. The differentiation between pain and suffering, with the latter potentially existing without physical discomfort, introduces a philosophical layer to end-of-life care that necessitates a holistic approach addressing emotional, spiritual, and existential needs (Cassell, 2004). This complexity underscores the importance of a nuanced approach to end-of-life discussions, recognizing the diverse experiences and interpretations of suffering and dignity among individuals.

Legal and Medical Definitions of Death

The evolving legal and medical definitions of death, including the distinctions between cardiopulmonary and brain death, reflect ongoing debates within the medical and ethical communities. These definitions bear significant implications for end-of-life care, particularly in determining when to transition from curative to palliative care strategies. The recent updates to criteria for death by medical associations illustrate the dynamic nature of these definitions and their impact on end-of-life decision-making (President's Council on Bioethics, 2008).

The Importance of Early End-of-Life Discussions

Early conversations about end-of-life preferences and care goals are crucial in preventing surprises and conflicts during the advanced stages of illness. Such discussions enable a comprehensive understanding of the patient's values and wishes, facilitating care that honors these preferences and supports a dignified end-of-life experience. This approach emphasizes the need for patient-centered care planning that encompasses physical, emotional, and spiritual dimensions of end-of-life care (Wright et al., 2008).

Educational Advances in End-of-Life Care

The incorporation of end-of-life care education in medical training represents a significant shift towards improving care quality at life's end. By embedding these discussions within clinical rotations, future healthcare providers are better prepared to engage in meaningful end-of-life conversations and advocate for care that aligns with patient values and preferences. This educational evolution, coupled with self-directed learning and mentorship, is essential in cultivating a healthcare workforce adept in delivering compassionate and competent end-of-life care (Billings & Block, 1997).

Innovative Approaches to End-of-Life Care Conversations: Insights from Practice and Public Education

Angelo Volandes, a Harvard-trained internal medicine and palliative care physician, offers valuable insights into facilitating end-of-life discussions through his concise and accessible book. Volandes emphasizes the importance of two critical questions aimed at understanding the patient's values and ~~preferences~~ end-of-life goals: what activities or experiences are most important to the patient, and what the patient would choose regarding their care if they could communicate their wishes directly. These questions serve to center the conversation around the patient's desires, thereby alleviating the decision-making burden from family members and ensuring that care aligns with the patient's values (Volandes, 2016).

The Role of Humor and Social Media in Public Education

The utilization of humor and social media represents a novel approach to educating the public about end-of-life care. ZDoggMD, also known as Dr. Zubin Damania, leverages his platform as a medical influencer to demystify aspects of palliative care through engaging and humorous content (see, for example, the examples provided below). His skits provide a relatable and accessible means for the public to understand complex medical interventions like CPR, intubation, and tracheostomy, fostering a more informed and comfortable dialogue about end-of-life choices. (Those reading this paper online may click on the arrows in the images below to see examples on YouTube; the website itself is accessible at https://zdoggmd.com/).

Z-DOGG Videos

Hospice Care and the Concept of Hospitality

The etymology of "hospice" from the Latin "hospitium," meaning a place of rest or protection for the weary, reflects the foundational principle of hospice care as a sanctuary that prioritizes comfort, dignity, and support for patients and their families at the end of life. This historical perspective underscores the hospice movement's goal of reversing the trend of institutional death by offering a more compassionate and patient-centered approach to end-of-life care (Saunders, 1967).

Volandes underscores the importance of facilitating end-of-life discussions through targeted questions that reflect the patient's values and desires. By asking what activities give the patient joy and how they would view invasive treatments in the context of their quality of life, healthcare providers can shift the decision-making process to align with the patient's wishes, easing the burden on family members (Volandes, 2016). This approach exemplifies the patient-centered care ethos, crucial in end-of-life care planning.

Hospice care, derived from the Latin word "hospitium" meaning hospitality, emphasizes a comprehensive approach to end-of-life care, addressing the social, spiritual, physical, psychological, and emotional needs of patients and their families. The field of palliative care has seen significant growth, with over 8,000 certified specialists as of recent years, reflecting its increasing recognition as a vital medical specialty. This growth is supported by a structured certification process through various medical boards, demonstrating the multidisciplinary nature of palliative care (Certification Board, Year).

Hospice and Palliative Care: Beyond Healthcare Costs

While the financial implications of end-of-life care are significant, with a substantial portion of healthcare dollars spent in the last year of life, the value of hospice and palliative care transcends economic considerations. These services embody the medical profession's commitment to compassion, dignity, and supportive care, extending the physician's role to encompass the final stages of a patient's journey (Healthcare Finance Administration, Year). This perspective reinforces the ethical foundation of medical practice, highlighting the responsibility to ensure quality of life until the end.

Conclusion

The complexities of end-of-life care, encompassing communication strategies, the development of hospice and palliative care specialties, and their ethical and economic implications, highlight the evolving landscape of healthcare at life's end. Effective end-of-life discussions, rooted in understanding and respecting patient values, along with the holistic support provided by hospice and palliative care, represent essential components of compassionate medical care. As the healthcare system continues to grapple with these challenges, the commitment to patient-centered, ethical care remains paramount in navigating the journey towards a dignified and meaningful end of life.

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Andrea and Matteo Bocelli singing *Time to Say Goodbye* (courtesy YouTube)

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