

# Palliative Care Public Education





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## Paper Submission for Presentation at the Society of Actuaries, Living to 100 Symposia

Palliative Care Public Education

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#### Introduction

The American Academy of Actuaries, as a professional organization, have committed to addressing the challenge of Aging in America. In 2015, then Academy President Mary Miller, said "The aging of America calls for a new shared commitment to raise awareness of the needs of the aging population and to seek creative solutions to address those needs" (Mendes, 2015). Areas of importance, at that time, included solvency of public welfare programs, income security, and health care costs.

The Society of Actuaries (SOA) 2017-2021 strategic plan had a focus on longevity and mortality. They jointly published (with the American Academy of Actuaries) a 'Longevity Illustrator' (*Actuaries Longevity Illustrator*, 2017) to aid in public education and decision making regarding how long one might actually live. The focus in both organizations is advancement of knowledge and expert advice regarding societal and financial challenges and risk management. One important aspect not yet fully addressed by these professional organizations are the drivers of and public education regarding end-of-life health care costs and decisions given that that palliative care has the potential to drive down health care costs and improve quality of life of an aging population

#### Longevity and Cost

Particularly concerning are the overlapping issues of increased longevity around the globe and the impact of longevity on health care costs. The world was home to nearly half a million centenarians in 2015, more than four times as many as in 1990, according to United Nations estimates. Projections suggest there will be 3.7 million

centenarians across the globe in 2050. In the United States the number of citizens aged 65 or above is projected to more than double by 2060, amounting to 24% of the total population; the number of people aged 85 or older will have more than tripled up to nearly 20 million. The percentage of U.S. residents ages 65 and older is increasing at the fastest pace in U.S. history, with significant implications for public spending on programs for older adults (Mather, 2019). In the European Union, the percentage of people aged 65 or above relative to those aged 15 to 64 is projected to rise from 29.6% (2016) to 51.2% in 2070 (*The 2018 Aging Report: Underlying Assumptions and Projection Methodologies*, 2018). In Japan, the proportion of inhabitants aged 65 or older is estimated to increase from 26.6% (2015) to 30.0% in 2025 (IPSS, 2015).

Increasing longevity impacts cost of health care. Patterns of disease in the last years of life are changing along with the demographics, with more people dying from chronic debilitating conditions, such as cardiovascular disease, chronic obstructive pulmonary disease, diabetes, cancer, and dementia. Since many of these illnesses often occur together among older people, this group frequently experiences multiple health problems and disabilities. In the last year of life, they may have symptoms such as pain, anorexia, low mood, mental confusion, constipation, insomnia or problems with bladder and bowel control (Matzo & Sherman, 2019).

Models for redesigning care for older adults have focused on the last month or two of life, whereas late-life care typically begins one to three years before that. The Congressional Budget Office has estimated that spending for health care, especially for older Medicare beneficiaries, will be the single largest source of federal budget growth over the next 20 years (CBO, 2021). Regarding older adults end-of-life care wishes,

although 71% of Americans say they'd prefer to die at home, 73% of people who are 65 or older die in a hospital and more than 25% of Medicare spending is incurred in a patient's last year of life (Rinaldo et al., 2020).

Within the traditional medical model of care lies a perceived dichotomy between curative/death-defying care and palliative care. It is almost as though the goal of care is first and only cure; and then, only if unable to cure, to relieve suffering. Often, this perceived dichotomy prevents or delays the introduction of palliative care measures for patients and their families. Health care practitioners struggle with decisions about appropriate care for patients who are near death. Predicting how long someone will live with an incurable illness is a difficult and complex task. For provision of quality, comprehensive, and whole-person care, the goals of curative and palliative care are woven together concurrently (Matzo & Sherman, 2019).

#### Site of Death

In previous centuries most people died at home. By the mid-seventies, more than 70% of deaths were occurring in hospitals and other institutional settings. The shift in the location of dying had a dramatic impact on the nature of dying. Patients dying at home were usually cared for by family members with little or no high technology equipment.

The institutionalization of death raised a new set of challenges and problems for caregivers. Challenges included increased decision making about the extent of aggressive treatments; how to support and provide proper care for the dying; how to deal with the isolation and depersonalization of institutions; and how to best meet the

nonphysical but critically important sociological, spiritual, and emotional needs of patients and family members. Additional regulations placed on institutions from managed care organizations often resulted in earlier discharges, shortened lengths of stay and follow-up home care needs far greater than previously experienced.

From 2003 to 2017, the proportion of home deaths in the United States grew by 29% and accounted for 30.7% of deaths. Death at home has now exceeded dying in the hospital as the most common place of death in the United States for the first time since the early 20th century (Cross & Warraich, 2019). The home death rate of 30.7% is still much lower than in Canada, which has a rate of 59.9%, and England, where the rate is 46.0% (Cross & Warraich, 2019).

Hospital deaths during the same period declined by 25%, accounting for 29.8% of American place of death in 2017. Hospital deaths were still common in 2017 (Figure I), and the percentage in the United States was lower than in Canada (59.9%) and England (46.0%). Nursing facility deaths have also been decreasing, going from 23.6% to 20.8%. The greatest increase was in deaths in hospice facilities which accounted for 0.2% of deaths in 2003 and 8.3% in 2017, reflecting more than a 41-fold increase.

#### Palliative Care

Palliative care is becoming a universally available approach in health care which addresses both the needs of patients and families experiencing serious, progressive, and life-threatening illness, and the costs of delivering such services. Palliative care and hospice are part of a continuum of care with palliative care provided at any time during the illness trajectory, while hospice care is offered at the end of life. Palliative care is

becoming a universally accepted approach to health care with the imperative of improving quality of life and of dying across the illness/dying trajectory and into the bereavement period of families (Matzo & Sherman, 2019; Sherman & Cheon, 2012).

Palliative care roots are from the hospice movement. The World Health Organization (WHO, 2020) defines palliative care as an approach that improves the quality of life of patients and families who face life-threatening illness by providing pain and symptom relief, spiritual and psychosocial support to from diagnosis to the end of life and bereavement. Specifically, palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling. It facilitates quality of life and may also positively influence the course of an illness. It is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life (e.g. chemotherapy or radiation therapy), and includes research studies needed to better understand and manage distressing clinical complications (Matzo & Sherman, 2019).

Access to hospice is limited to people who have a life expectancy of less than six months and are no longer pursuing active treatment. Palliative care, however, can begin from the time a patient is diagnosed with a life-threatening illness. Due to a typically late referral to hospice, the median length of stay for hospice patients is

relatively short and averages only about 18 days and has changed little in the last fifteen years (NHPCO, 2020).

Physicians are less reluctant to refer patients to the palliative care (rather than hospice) because it does not carry the absolute association with death that hospice care does. Hospice programs typically require a Do Not Resuscitate order, insurers may not allow high-tech life-prolonging therapies, or they may limit access to medical specialists. While palliative care programs also strive to relieve the pain and suffering associated with any life-threatening illness, they do not mandate foregoing of life-prolonging therapies. The goal of treatment remains achieving the optimal quality of life for patients and families (Matzo & Sherman, 2019).

Palliative care has evolved based on work of the National Consensus Project for Palliative Care (Ferrell, 2017). Palliative care and hospice programs have grown in the United States in response to a population living with chronic, debilitating, and lifethreatening illness and to clinician interest in effective approaches to providing care. Quality palliative care should be available for all in need, regardless of setting, diagnosis, prognosis, or age. Palliative care is provided for patients and their families in a variety of care settings, including, but not limited to, acute care hospital units, longterm care facilities, assisted-living facilities, inpatient, home or residential hospices, palliative care clinics or ambulatory settings, private practices, and prisons (Matzo & Sherman, 2019).

Factors that have contributed to the palliative care movement in the United States include the: growing aging population; assisted suicide debate; reduced patient autonomy; and inappropriate end-of-life care (i.e., over-treatment of medical care and

undertreatment of pain and depression). Quality outcomes of good palliative care ensure that: patients' values and decisions are respected; comfort is a priority; psychosocial, spiritual, and practical needs will be addressed, and opportunities for growth and completion of unfinished business (Ferrell, 2017; Matzo & Sherman, 2019).

A framework for the delivery of PC throughout the disease continuum can be most visualized as an "umbrella of care." Palliative care starts with the initial diagnosis of an illness, at which time the management of symptoms and the psychosocial stressors of the disease upon the patient and family are vigorously addressed with active curative-focused therapy. Although this scope may be considered ideal, most palliative care practitioners emphasize the maximization of function and quality of life in those with far-advanced disease. For all practitioners, palliative care culminates in the management of complex physical, psychological, social, and spiritual issues that patients and members of their families will experience during the final phase of life and includes bereavement care for the family (Dy et al., 2012; Teoli D & VB., 2022).

By providing a continuum of care, patients with advanced progressive disease and their families have access to palliative care expertise in all settings, which is coordinated and collaborative manner to achieve mutually established goals. With a comprehensive palliative care program, the interprofessional team utilizes the same philosophy and model of care as they work throughout the continuum with the patient and family in a coordinated and collaborative manner to achieve mutually established goals (Matzo & Sherman, 2019).

Palliative care not only lowers the cost of health care but also improves healthrelated outcomes for patients and families (Temel et al., 2010). As more and more

individuals express their desire to remain at home during an illness and to die at home, palliative and hospice care allows the shift of care from hospital to home (Landers et al., 2016). The result is fewer hospital days, fewer emergency department or physician office visits, and fewer days in a skilled nursing facility. End-of-life care is primarily funded through Medicare, Medicaid, the Veterans Administration, and other public programs, with 50.7 percent of Medicare decedents enrolled in hospice at the time of death (NHPCO, 2020). Palliative care/hospice partnerships create a commonsense allocation of health care resources as patients move across the illness trajectory and approach the end of life (Matzo & Sherman, 2019; Temel et al., 2010).

Morrison et al., reported that palliative care, when compared to usual care, reduced the total costs of ICU admissions by \$2,642, lowered the cost per day by \$279, lowered the direct costs per admission by \$1,696, and also reduced laboratory costs (Morrison et al., 2011). It was further indicated that for a hospital with 400 beds, annual cost savings from palliative care was more than \$1.3 million per year. Based on a report by the Institute of Medicine, if PC were fully integrated into the nation's hospitals, there would be a projected total cost savings of greater than \$6 billion per year (Morrison et al., 2011). These levels of cost savings have continued to be studied and reported worldwide (Bird et al., 2018; Yadav et al., 2020; Yu et al., 2020; Zemplényi et al., 2021).

The Society of Actuaries (ASA) executed a retrospective analysis of the cost of care for deceased cancer patients over the last six months of life and compared the average cost difference between patients who enrolled in hospice versus their non-hospice counterparts (Bednar et al., 2018). This study then estimated potential savings (at both a national and a regional level) based on two variables, 1) increasing hospice

participation and 2) earlier hospice enrollment. They estimated that there were potential Medicare fee-for-service medical cost savings (excluding prescription drugs) of about \$200 million annually (Bednar et al., 2018).

Additionally, non-hospice patients had 25% higher medical costs (excluding prescription drugs) than their hospice-enrolled counterparts over their last six months of life. Based on the assumption that 50% of those people could have benefited from hospice, the estimated medical cost reduction was \$120–\$170 million annually. The per patient savings was approximately \$5,000–\$7,000, or 7%–9% of the total cost of care over the six-month period (Bednar et al., 2018).

Fear and misconceptions from both the public and health care practitioners regarding palliative and hospice care drive avoidance of their utilization. A study by Temel, et.al., documented that among patients with metastatic non-small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival (Temel et al., 2010). Despite the availability of hospice services, many people do not receive their benefit because of inadequate end-of-life discussions with their health care practitioners (Bergenholtz et al., 2019; Chuang et al., 2021; Knutzen et al., 2021; Sutherland, 2019) and a low level of awareness and misinformation about these services (Hoerger et al., 2017; Shalev et al., 2018; Temel et al., 2010).

#### Call to Action

Thus far, this paper has discussed issues related to the aging of global populations, corresponding chronic co-morbid health issues, associated costs, and the role of palliative and hospice care in addressing, among other factors, health care costs for the end of life. The Congressional Budget office has documented that a significant contributor to growing deficits is the increase in spending for Social Security (mainly owing to the aging of the population) and for Medicare and the other major health care programs (because of rising health care costs per person and the aging of the population) (CBO, 2021). The National Hospice and Palliative Care Organization has data documenting that only about half of Medicare decedents are enrolled in hospice at the time of death (NHPCO, 2020). Lastly, the ASA study estimated medical cost savings of about \$200 million annually through informing the public about the benefits of hospice care when receiving a qualifying diagnosis to increase earlier hospice participation rates (Bednar et al., 2018).

Health promotion and public education have a key role to play in end-of-life care for older people (Fulmer et al., 2021; Hoerger et al., 2017; Shalev et al., 2018). While palliative care does not replace medical care for either the treatment of acute diseases or for acute flare-ups of chronic illness, this approach can reduce symptom burden and improve quality of life in situations of serious, life-limiting illnesses (Matzo & Sherman, 2019; Schroeder & Lorenz, 2018; Temel et al., 2010). Health promotion and palliative care have much in common.

Health promotion aims to build public policies that sustain health, create supportive environments, strengthen community action, develop personal skills, and reorient health services, especially toward partnerships with the community. This

approach enhances collaboration and participatory relationships; recognizes the social character of health, illness and dying; emphasizes education and information-sharing; and requires the understanding that all health policies must be designed for both ill and well individuals and that health is everyone's responsibility. These principles underpin the WHO public health strategy to integrate palliative care into existing health care systems and at all levels throughout the society (WHO, 2020).

Palliative care health promotion activities involve educational programs in partnerships with communities to foster understanding of health care needs, the acceptance of loss and dying and encouraging personal and social support at the end of life. Other aspects include recognizing the social character at the core of care and loss and reorienting health services (such as palliative care, care for older people or bereavement care) towards community engagement (WHO, 2011).

One ambitious example of public education and engagement in palliative care has been the learning initiative *Everyone Dies* which focuses on public education related to serious illness, dying, death, and bereavement. This educational endeavor offers a weekly podcast, resources, and public engagement via social networking platforms. Podcasts have been published weekly since April 2020 with 29,000+ downloads and over 19,000 social media followers. Seventy-five percent of the podcasts are listened to in the United States and the other 25% are listeners from 122 countries. The average listener age is 60 years, and engagement focusses on options and decisions for the end of life. This novel educational model has not previously been utilized for health promotion as it relates to palliative care at the end of life.

The *Everyone Dies* resources and podcast offers a source that is available for listeners whenever they are ready and in need of information related to serious illness, dying, death, and bereavement. Professionals can also make use of this information to inform their advice regarding financial security issues on the population level and related solutions for financial, business, and societal issues.

Populations around the world are aging, and more people are living with the effects of serious chronic illness towards the end of life. Meeting their needs presents a public health challenge. Multi-disciplinary policy teams working on health-related economic issues should include actuaries to address quantitative and qualitative predictions of likely future conditions, development of agreed-upon goals/strategies/quality measures for the seriously ill population and the delivery of palliative care. These teams are necessary to fund for sustainability and delivery of high-quality end-of-life medical care in an aging society.

Research studies have documented the cost–effectiveness and generalizability of palliative care programs utilizing both an individual person and a health systems approach with outcomes to improve care and quality of life of older people (Bird et al., 2018; Morrison et al., 2011; Temel et al., 2010; WHO, 2011; Yadav et al., 2020; Yu et al., 2020; Zemplényi et al., 2021). The current health care system does not yet consistently support access to palliative care services that follow nationally recognized standards (Author, 2020). All individuals with serious illness, along with their caregivers, deserve high-quality health care that relieves their suffering and maximizes their qualityof-life. Actuaries have the education and skill to make significant contributions to the

development of financially sustainable palliative care services which has the potential to improve quality of life for an aging population.

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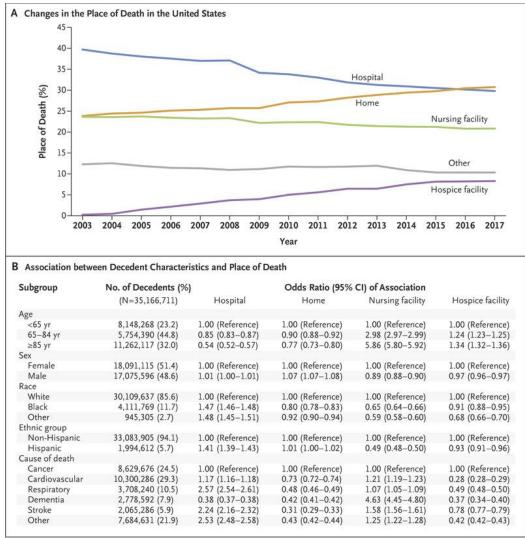


Figure I Changes in the Place of Death in the United States (Cross & Warraich, 2019)

- (A) shows the changes in the place of death (hospital, home, nursing facility, hospice facility, or other) in the United States from 2003 through 2017.
- (B) shows the number of decedents from 2003 through 2017 and the odds ratio of the association between decedent characteristics and place of death from 2013 through 2017, adjusted for year of death.

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