Post-Millennial

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The Millennials in an Aging Society: Improving End-of-Life Care by Public Health Policy

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We examine the theory and practice of end-of-life care in relation to the Millennial Generation as surrogate, informal caregivers for their aging parents. Utilizing a uniquely combined public health and human rights-based approach, we conducted a content analysis comparing theory to practice, i.e. how laws and regulations compare to the application of policy at the service level. Accordingly, we identified ten relevant areas: end-of-life care, palliative care, hospice care, Medicare, long-term care, advance directives, well-being, spirituality, bereavement counseling, and dignity. We found that some key concepts, including patient well-being, spirituality, and quality of care, while being legally required, are not legally defined, creating ambiguity that impacts all people. We also observed disparities in availability, accessibility, acceptability, and quality of end-of-life care that present barriers to such care and may result in consequences to the Millennial Generation as caregivers and future patients. Health disparities were associated with race, culture, language, the public’s beliefs, treatment cost, the payment system, and a shortage of health care providers. In aging societies, high quality end-of-life care can be assured through standardized service and strong public health systems. A combined public health and human rights approach to this problem can work to change individual behaviors to reduce the incidence of ‘preventable’ diseases, improve health literacy, and advance end-of-life care. High-cost medical events may also be minimized through
behavioral or life-style change. By establishing a universally available, accessible, acceptable and high quality care infrastructure, the key aspect of preventative care in public health policy can be strengthened.

Introduction

The reality of death presents unprecedented challenges to quality of life requirements and ideals. While end-of-life care, including hospice and palliative care, has rapidly evolved in the past decades, millennials will be dramatically affected by demographic and healthcare trends in a rapidly aging United States society. To ensure millennials are mentally, physically, and financially prepared for the burdens of either their parent's, or their own, end-of-life processes, especially considering the current lack of health infrastructure surrounding this, we need to examine these issues though both a public health and human rights lens.

The Public Health Approach

The 1946 Constitution of the World Health Organization (WHO) defined “health” as, “complete physical, social and mental well-being” (World Health Organization 1946, United Nations 1948). Public health refers to the targeted care and the promotion of health aimed towards a population, or particular group within the population. While public health does not directly involve the provision of medical care to individuals, it is intrinsically linked to the success of both individual health and the greater health care system as a whole (World Medical Association 2016).

The public health approach is comprised of key components that make it well-suited to studying both end-of-life-care and its impacts on the Millennial Generation. These components include: 1) a prevention-oriented focus; 2) a population-based
perspective; 3) a focus on the social, structural and environmental determinants of health; 4) an evidence-base that incorporates fact-based program decisions, in agreement with community expectations; and 5) a focus on health disparities, including vulnerabilities caused by poverty, discrimination, health illiteracy and inadequate education (Neff, 2014) (Brownson, Ross, Baker, Elizabeth, Leet, Terry, Gillespie, Kathleen, True, 2011) (Hess, Jeremy, Eidson, Millicent, Tlumak, Jennifer, Raab, Kristen, Luber, George, 2014).

Human Rights in Public Health Policies

Human rights are fundamental freedoms and entitlements that support human dignity. Health is one of these fundamental human rights, as stated in the World Health Organization (WHO) Constitution of 1946. The universality principle of human rights is the cornerstone of international human rights law (United Nations, 2016). The central subject of this article, end-of-life care, profoundly relates to human rights issues.

Millennials and Baby Boomers

Millennials, born between 1982 and 2000, became the largest demographic cohort in the history of the United States in 2015. That year, the 83.1 million millennials living in the United States outnumbered baby boomers, the previous largest demographic cohort, by 7.7 million individuals (United States Census Bureau 2015b). When baby boomers were near the age of today’s millennials, Medicare was established by Congress (in 1965) to provide health insurance for all Americans 65 and older, making it the first federal health insurance program for the aged.

“Approximately one in every four caregivers in the United States are between 18 and 34.”
Maturing Millennials in an Aging Society

End-of-life care encompasses the special support and attention given to an individual during the period leading up to death (National Institute of Health 2014). Though this life stage may appear too distant for millennials to appreciate, given their relative youth, many millennials already serve as informal caregivers. Approximately one in every four caregivers in the United States are between 18 and 34 (The Editors 2015).

While millennials may not yet consider long-term care for themselves, many may join the ‘informal care’ workforce to offset the costs of care for their elderly parents or grandparents. A 2015 Rand study found that the opportunity cost of informal care (cash not earned by the caregiver due to lost time) is $522 billion annually in the U.S. (Chari, Amalavoyal, Engberg, John, Ray, Kristin, Mehrotra, 2015). Forty-seven percent of informal caregivers are older children or grandchildren, otherwise known as “working-age adults” (Chari, Amalavoyal, Engberg, John, Ray, Kristin, Mehrotra, 2015). If the informal services were replaced by professional nursing staff service, the cost of replacement would be $642 billion annually (Chari, Amalavoyal, Engberg, John, Ray, Kristin, Mehrotra, 2015).

To understand the relationship between millennials and the challenges posed by current and future end-of-life care responsibilities and demands, we examined the following research questions from public health and human rights perspectives:

a. What are the chasms separating end-of-life care theory (laws, regulations, policies, and guidelines) and practice (the application of policy at the service level) in the United States, and how do they impact maturing millennials?
b. What are the actions needed to protect both current and future patients’ right to end-of-life care, in a resource-scarce era of a rapidly aging society?

Methods and Materials

We conducted a content analysis of end-of-life care by comparing theory to practice. More specifically, we compared laws, regulations, and guidelines to their policy application at the service level. We first abstracted the primary terminologies from sources including the Federal Register, Code of Federal Regulations, state law, regulatory bodies, professional trade organizations and other concerned entities. Second, we explored the practice of end-of-life care by examining terminologies from scientific articles, reports, guideline recommendations, surveys, newspaper articles, and online information. To better understand the translation and evolution of the regulatory intent to practice, we conducted policy interviews with experts from relevant trade organizations and professional institutions for cross verification of data.

To examine the theory and practice regarding end-of-life care, aiming to investigate solutions to improve the current public health policy, we used a combination of public health and human rights-based approaches, which are normally separated by professional boundaries.

The public health approach focuses on prevention, population-based perspectives, evidence-based principals, and the impact of social, structural, and environmental determinants of health. This approach also focuses on the elimination of health disparities, which are vulnerabilities caused by poverty, discrimination, health illiteracy and inadequate education (Neff, 2014). A public health approach aims to
increase community involvement by including health promotion activities that focus on education and empowerment, for individuals and their overall communities (Libby Sallnow et al. 2016, Betty R Ferrell and Coyle 2010).

We also used a human rights-based approach that aims to realize human rights by improving policies and programs. The approach has been developed and widely used by the United Nations (UN) and its member countries (United Nations HRBA, 2016). We employed the following essential elements of a human rights-based approach to our analysis of end-of-life care: availability accessibility, acceptability, and quality of health care; universality (non-discrimination); and accountability of the government and health care providers (UN Development Group 2011).

While we recognize the importance of tangential issues, such as end-of-life care for children and young adults, as well as physician-assisted suicide laws, this article does not include these topics due to space limitation.

Findings

Analysis: Theory and Practice in End-of-life Care

Our combined public health and human rights-based approach to end-of-life care presented both theoretical and practical accomplishments and concerns. We focused on specific populations, universality of care, and opportunity for prevention. We identified ten primary areas related to our research questions: end-of-life care, palliative care, hospice care, Medicare, long-term care, advance directives, well-being, spirituality, bereavement counseling, and dignity. The definitions and the synthesis of our analysis of the primary terminologies, theory, and practice in end-of-life care, are discussed and are presented in the Tables.
Achievements in End-of-Life Care

From a human rights lens, we observed great achievement in the availability, accessibility, acceptability, and quality of end-of-life care in past decades. Progress in accountability government and health care providers was noted, as well as the universality in end-of-life care.

Progress in these areas has contributed to an increase in overall accountability of health care providers. Both government and industry increased transparency of operations and health systems outcomes by publishing data that promoted the universality, or participation of the patients and their family, in decision making processes (Table 1.2. Palliative Care, 1.3. Hospice Care, 1.4. Medicare, 1.5. Long-Term Care, and 1.6 Advance Directives).

Expansion of end-of-life care

Patient-centered end-of-life care has spread in the United States. A knowledge survey on “hospice” found that 86 percent of respondents stated that they had heard of the term (Cagle et al. 2014), suggesting that grassroots movements by health care providers in the United States have been successful in building awareness of hospice care as an option. Since the establishment of the first American hospice in Connecticut in 1974, the number of hospice care providers has increased to 6,100 (National Hospice and Palliative Care Organization 2015a; The Connecticut Hospice, 2014). Almost two-thirds of hospice care is provided at the patient’s residence (National Hospice and Palliative Care Organization 2015a), indicating that the availability of hospice care to those who are in need has also increased (Table 1.3. Hospice Care). Financial accessibility of hospice, palliative and long-term care for eligible persons has also been supported by the Medicare
program (Tax Equity and Fiscal Responsibility Act 1982), the largest health insurance program in the country (Table 1. 4. Medicare).

Palliative care is one of the fastest growing health care fields in the United States (Mark T. Hughes and Smith. 2014). Although it was originally provided in the hospice setting, palliative care gradually became available to patients in hospitals around the country. A number of resources indicate the positive effects of palliative care, such as prolonging life (Diane E Meier 2011) and increasing the quality of life (Table 1. 2. Palliative Care). Those positive effects were encouraging, not only for the patients, but also for the palliative care providers. As quality of life is one of the main focal points of palliative care, the dedicated institutions and health professionals endeavored to reduce patient discomfort.

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Widening the scope of End-of-Life care

Treatment and therapies for both physical and non-physical (e.g., psychological, social and spiritual) discomfort have been available and accessible through the provision of palliative care within and outside end-of-life care practice. For instance, opioid therapy to reduce physical pain became more available and accessible (e.g., self-injection or skin patches) for patients who receive palliative care at medical institutions and/or at home (U.S. Food and Drug Administration 2015). To reduce spiritual suffering, an interdisciplinary approach (religious or non-religious initiatives) has produced widely available spirituality measurement tools (Table 1.8. Spirituality). In addition to providing psychological, emotional, social and spiritual comfort,
bereavement counseling must be provided by qualified professionals before and after the patient’s death (Table 1. 9. Bereavement Counseling). This is to assure that the patient, family, and caregivers are able to adjust appropriately for the patient’s approaching death (Department of Health & Human and Services. 2011).

The advance directives (part of the advance care planning process) are typically documents prepared by a patient, in the form of a living will, that contains the specific description of their wishes for treatment if one becomes unable to make medical decisions (Editorial Staff 2012). A recent change regarding end-of-life care regulation (effective January 1, 2016) requires Medicare to pay for advance care planning (including advance directives discussions) provided by physicians and other health professionals (Centers for Medicare & Medicaid Services 2015). While the effect of this new coverage has not yet manifested, it aims to incentivize more physicians to discuss advance care planning, at earlier stages with their patients (House of Representatives 2015).

*Concerns in End-of-Life Care*

Terms without clear definition

Our analysis showed that some key terminologies used in end-of-life care lack clear definition. Acknowledged by the Code of Federal Register’s Hospice Conditions of Operation, quality assurance in the health care environment is driven by standards recognized by the industry. However, the term “standard of care” is not used in the language of the law. “Quality of care” is required, though not directly defined, leaving the hospice care providers to develop internal methods for quality assurance. This has compelled overseeing organizations to develop recommended guidelines for quality care in hospices (National Hospice and Palliative Care Organization).
Traditionally, regulations for quality of care were primarily developed in institutionalized medicine environments, such as hospitals. Thus, these standards may not be appropriate for hospice care, which largely grew out of non-institutionalized grassroots movements. Though many states govern hospice entitlements directly, hospice care is most frequently delivered at the patients’ residence. In addition, the definition of “quality” may not be consistent across health care and end-of-life care practice spectrums. Quality Palliative Care, for example, requires eight domains of clinical guidance, including social, spiritual, religious, existential, and cultural aspects (National Concensus Project for Palliative Care). Some components of these domains may be unfamiliar to traditional health care providers.

“Only 20 to 30 percent of surveyed respondents had heard of the term palliative care.”

Public’s Misconception and Mistrust

Undefined or unclear definitions in key end-of-life care terminologies confuse patients and families (Table 1.2 Palliative Care, 1.3. Hospice Care, 1.6 Advance Directives, 1.7. Well-being and 1.8. Spirituality).

Hospice care, for instance, is in principle provided to the individuals whose “prognosis is for a life expectancy of six months or less if the terminal illness runs its normal course” (Department of Health and Human Services and Services. 2015). On the contrary, palliative care is provided “throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice” (Federal Register
Those without life-threatening diseases are also eligible for palliative care (Table 1.2 Palliative Care). Similarly, any person, who may or may not suffer from a life-threatening disease, can use long-term care services; adult day services centers, home health agencies, hospices, nursing homes, and assisted living/residential care communities (Table 1.5 Long-Term Care). Notably, 36.4 percent of users of adult day service centers, and 17.5 percent of users of home health agencies, are under the age of 65. This indicates that the younger populations, who may not be at their end of life, also turn to these services (Center for Disease Control and Prevention 2015).

Each year, there are approximately 1.5 to 1.6 million hospice patients (National Hospice and Palliative Care Organization 2015b) and 1.4 million residents in nursing homes. Despite the large number of Americans receiving end-of-life care, the key terminologies appear to be confusing among the general public. Even though a majority of aged Americans were aware of the term hospice, misconceptions of end-of-life care are still common (Cagle et al. 2014). Only 20 to 30 percent of surveyed respondents had heard of the term palliative care (National Academy of Sciences 2015). Multiple sources report that the general public often confuses hospice care with palliative care (Anne Arundel Medical Center 2015, National Caregivers Library 2015, WebMD 2015). The Public Opinion Strategies survey revealed that the concept of palliative care was not well understood and that low health literacy existed as a barrier to patients receiving high quality health care (William F. Benson and Aldrich. 2012).

In terms of long term care, a survey supported by the Department of Health and Human Services was conducted with 15,298 non-institutionalized adults (40-70 years old). It revealed that only 15.3 percent respondents knew the hourly cost of a
home health aide care and 20.2 percent had correct knowledge of the cost of monthly nursing home care (Wiener, Joshua, Khatutsky, Galina, Greene, Angela, Thach, Trini, Allaire, Benjamin, Brown, 2015).

Health Disparities

While the availability of overall end-of-life care has expanded, there are still disparities in the care provided. In palliative care, for instance, a primary barrier is the lack of health care providers in the current workforce. Across the United States, there is one palliative care physician for every 1,200 patients with a serious or life-threatening illness (R. Sean Morrison and Meier 2015). This creates regional disparities by negatively impacting remote areas, such as Alaska where the availability of palliative care at medical institutions is only 25 percent. In contrast, New Hampshire has 100 percent availability of palliative care (Table 1.2. Palliative Care).

Racial, linguistic and cultural barriers also create health care disparities. For example, only four percent of physicians in California are Hispanic, even though Hispanics represent approximately one third of the state population (Margaret R. McLean and Graham. 2014). According to Cerminara, asking Hispanic patients to choose comfort care over another option of a life-prolonging treatment, may be incongruent with their culture and beliefs (Cerminara, 2010). Given the current demographic shifts in the US population, including the growth of the Hispanic population, concerns of availability and accessibility of end-of-life care with cultural sensitivity arise.

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population, concerns of availability and accessibility of end-of-life care with cultural sensitivity arise.”

Furthermore, even in facilities adequately staffed with palliative care physicians and related health care providers, there is an inadequate knowledge of pain management techniques (National Cancer Institute 2015). Palliative care often involves opioid therapy for physical pain management. Prescription errors and inappropriate use of opioid analgesics, for instance, increase risk and can lead to death. This may in turn result in an arguable violation of one’s right to life according to the UN (United Nations, 1948b)(United Nations, 1948a)(United Nations, 2010), given that the situation is often preventable (U.S. Food and Drug Administration, 2015). Bruera and Kim (2003) state that financial barriers, such as non-reimbursement, inadequate reimbursement, or costly treatment, can also lead to disparities in access to palliative care (Table 1.2. Palliative Care).

WHO clearly states that palliative care is recognized under human rights (World Health Organization, 2015). Patients denied palliative care can be considered to have possibly been denied of their rights (FBX Center, 2013). Thus, recognizing the significance of end-of-life services to the patient’s right to life, health, liberty, and freedom (United Nations 1948), solutions from public health and human rights perspectives are necessary (Wiener, Joshua, Khatutsky, Galina, Greene, Angela, Thach, Trini, Allaire, Benjamin, Brown, 2015).

Discussion of Findings

Achievements and Concerns in End-of-Life Care

A public health and human rights “two-pronged approach” enabled us to analyze
today’s challenges, extract possible solutions, and strengthen public health policies for both the Baby Boomer and Millennial Generations (Box 1). Despite some of these areas of improvement, we found that confusing and undefined terminologies are used in end-of-life care. From a human rights perspective, this lack of clarity, along with the broader problem of health illiteracy, creates concerns for both the right to information and the accessibility to information for patients and their families (World Health Organization 2015b). Insufficient information can interfere patients from accessing healthcare services while they are available. The lack of terminological clarity may prevent the development of standardized measures to evaluate these key concepts. It also impacts the human right to health, which the WHO asserts is a fundamental right (World Health Organization 1946, United Nations 1948).

Issues in health disparities and health illiteracy relate to racial, cultural, and religious insensitivity and barriers. They may result in the public’s mistrust of end-of-life care, and can be associated with the lack of financial accessibility of care, and impact quality of care. This may further influence human dignity and freedom of the patients.

We found other hurdles preventing the realization of human rights in end-of-life care. These include: the shortage and lack of training of health care providers; concerns regarding the objective to respect, protect and fulfill patients’ human rights in end-of-life care; and the payment system. These factors form barriers to access end-of-life care.

To increase the availability of palliative care, the report “Dying in America,” emphasized the need for training, certification, and/or licensure requirements for palliative care clinician knowledge building and skill development (Institute of
State and Congressional legislation has been introduced to support the provision of increased palliative care (R. Sean Morrison and Meier 2015) and in 2015, the Palliative Care and Hospice Education and Training Act was amended to enable enhanced education and training opportunities for the workforce (House of Representatives 2015). In terms of next steps, a nationwide effort to expand the accessibility of palliative care is necessary. Examples include outreach to affected populations to support increasing health literacy.

**Box 1. End-of-Life Care Influences on the Millennials**

**Immediate**

**Caregiving for parents:** Approximately one in every four caregivers in the United States is aged 18-34, the age cohort of the Millennials (The Editors 2015).
- Millennials may become the Informal Caregivers (any person who provides long-term care services without pay) to offset the costs of care for their parents or grandparents (DHHS).
- Informal Care services are defined as “services that include medical and non-medical care for people with a chronic illness or disability” (DHHS).
- Total opportunity costs of informal elder-care amount to $522 billion annually, while the costs of replacing this care by unskilled and skilled paid care are $221 billion and $642 billion, respectively (Anawaltayal V, Chari et al. 2015).

**Long-term care use by younger cohort:** 36.3% users of adult day service centers and 17.5% users of home health agencies are under age 65 (Harris-Kojetin L, Sengupta M, and Park-Lee E 2016).

**Shortage of specialists:** Only 1 palliative care physician is available for every 1,200 patients living with serious or life-threatening illness across the United States (Morrison and Meier 2015).

**Disparity in palliative care:** Availability in New Hampshire is 100% while availability in Alaska is 25.0% (Morrison and Meier 2015).

**Untrained professionals:** Doctors and nurses are not trained to discuss patients’ (and family’s) critical questions regarding prognosis, expectations, options for treatment, and tradeoffs (Alves and Meier 2015).

**Long-term**

**Increase of the elderly population:** The population aged 65+ will account for 21.7% (81.2 million) by 2040 (U.S. Department of Health and Human Services 2015a, b).

**Federal fund at risk:** The Hospital Insurance trust fund for Medicare Part A is estimated to deplete in 2030 (Davis 2015).

**Shortage of doctors:** There were fewer than 7,500 geriatricians in 2014, although 25,000 are needed in order to provide high quality care. Of 124 academic medical centers, 8 have “full” geriatric departments: less than 1/2 of nationally-available positions (< 350) are staffed (Banuchin 2015).

**Shortage of nurses:** Nursing shortage is projected to grow to 260,000 registered nurses (RNs) by 2025 in the United States.
- RNs aged 50+ will be the largest age group in the nursing workforce and their retirement will lead to a projected shortfall by 2018 (American Association of Colleges of Nursing 2016).

**‘Burnout’ of the professionals:** Although hospice care nurses traditionally enjoyed personal, one-on-one contact with patients to provide intimate patient care, the current shortage of nurses, complications of “managed care,” and other financial constraints, have limited this opportunity for patient care (Betty R Ferrell and Coyle 2010).
- If new community-based trends in service (such as patient family interaction) are not implemented, the nursing shortage will negatively affect the quality of care (Betty R Ferrell and Coyle 2010).
Recommendations

Our unique combination of a public health and human rights-based approach to end-of-life care illustrates how these methods can help professionals collaborate to improve public health policies related to end-of-life care.

Public Health Policy to Improve End-of-Life Care

In anticipation of the demographic shifts expected in the United States, as well as millennials further encountering the caregiving burden of the older generations, we recommend the following solutions from a public health and human rights-based approach. The combined approach will contribute to the improvement of public health policies related to end-of-life care.

Raising Availability, Accessibility, and Quality of Care

The public health community should collaborate to educate and train the necessary workforce in order to remove hurdles to availability, accessibility, and quality of end-of-life care. Currently, there are 167 accredited schools or programs of public health offering advanced degrees (master’s or doctorate) in the field (Council on Education for Public Health 2015). They have already collaborated with related disciplines and groups, such as nursing and medical schools, public policy schools, law schools, faith-based communities, and government agencies. Increasing this powerful alignment of resources will continue to build common understanding and promote an infrastructure for end-of-life care that highlights its linkage to human rights.

Population-based health, a public health core competency that utilizes systems of statistical measurement, should also be used as a tool in end-of-life care. Public
health experts are equipped with knowledge and research capacity to study populations to better understand their dynamics. This research can then be used to establish policy to intervene in observed community health concerns, which can include how best to take care of an aging population and their care burden on millennials. The recommended policy approach can then be utilized to train health care providers to better serve their patients. This will increase the availability, accessibility, acceptability, and quality of care by enhancing the accountability of government and health care providers to evidence-based analysis.

Information technology is another useful tool for health promotion that enhances health illiteracy, thereby promoting greater universality of care. With the help of the internet, health, diet and exercise websites, millennials have the resources to increase their own health prevention capacity exceeding that of previous generations (Karen B. DeSalvo 2016) by simply being more informed about health, health outcomes, and care. Technology supported healthcare, such as telemedicine, can contribute to the reduction of health disparities caused by the lack of availability, accessibility, acceptability, and quality of care, which occurs particularly in rural areas.

*Eliminating Health Disparities*

From our analysis, gaps in the availability of and accessibility to information on end-of-life care exist in racial, cultural and linguistically segmented populations. Cultural sensitivity of health care providers also arose as a key health disparity concern. Outreach to affected populations must be increased or initiated in order to eliminate these disparities. Furthermore, health literacy is necessary for patients and their families in order to make informed decisions. They need to know medical, financial, and insurance terminology, and understand the possible costs and benefits of
relevant options (National Academy of Sciences 2015).

Millennials became the first “majority-minority” cohort in the United States in 2014, with 50.2 percent belonging to a minority race or ethnic group. The racial demographics of millennials are quite different from those of baby boomers who are 72 percent white, 10 percent Hispanic, and 11 percent black (United States Census Bureau 2015a). Today, at least 350 languages are spoken in the United States. For example, 26 percent of Washington D.C. residents over the age of five speak a language other than English. These rates are higher in other metropolitan areas, with 38 percent of residents in New York, 40 percent in San Francisco, and more than 50 percent in Miami speaking a language other than English. (US Census Bureau 2015).

![Language Diversity in Major Urban Regions](image)

The high rates of non-English speaking populations reiterate the need to eliminate
health disparities due to language barriers in end-of-life care. The Office of Minority Health in the United States Department of Health and Human Services developed the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (The National CLAS Standards) in 2000. Its primary objective aims at advancing health care quality and health equity through a framework for organizations to serve increasingly diverse communities. Linguistic assistance is one of the 15 National Standards (Office of Minority Health 2015). These standards can and should be applied to end-of-life care institutions (Interpreters, 2005).

In addition to racial and linguistic diversity, millennials have also shown lower levels of religious affiliation than older generations. Less than six-in-ten millennials self-identify as Christian (compared with more than seven-in-ten among older generations). Approximately one-third of millennials are religiously unaffiliated - the so-called religious “nones” (Pew Research Center 2015). Currently, hospice care aims to deliver “medical, social, physical, emotional, and spiritual services through the use of a broad spectrum of caregivers” by an interdisciplinary approach (Centers for Medicare & Medicaid Services, 2008). This interdisciplinary group includes a chaplain to provide spiritual services to hospice patients. Some modifications in the designation of this individual may be required on a case-by-case basis, given recent changes in religious beliefs and non-beliefs among the growing millennial population.
Due to changes in United States demographics, accurately targeted outreach to affected populations is a key to enhancing access to correct information and quality of care. It is also important to respect patients’ preferences and rights in this process. This requires education and cultural sensitivity training for health care providers. These remedies may eliminate health disparities caused by racial, cultural, and language barriers to health care and end-of-life care as presented in this article. The public health community can support these efforts through increased outreach targeting minority groups to inform them of their options and where they can find more information. Educating diverse populations through collaboration with medical, nursing, non-profit and for-profit, community-oriented, and faith-based communities should be emphasized.
Supporting Financial Accessibility Through Health Literacy & Prevention

In addition to health literacy, financial accessibility is also crucial in end-of-life care. Since hospice care costs for those aged over 65 are covered by Medicare in the United States, securing both national and personal spending capacities is important.

Americans aged over 65 represented 14.1 percent of the total population in 2013 and are expected to comprise 21.7 percent of the population by 2040 (U.S. Department of Health and Human Services 2015a, b). As of May 2015, more than 55 million Americans were already enrolled in Medicare, with enrollment expected to continue increasing as the rest of the Baby Boomer Generation turns 65 (Center for Medicare & Medicaid Services 2015b).
In terms of one of the key areas in end-of-life care, palliative care, the Quality of Death Index measures its quality in 80 countries. It ranked the United States as sixth overall. However, the United States dropped to eighteenth in financial accessibility to care measures, below Cuba and Panama (The Economist Group 2015). According to a panel of experts, Americans’ palliative care needs “can’t be met through traditional funding models” (Institute of Medicine 2014).

At a personal level, a survey result presented Americans’ concerns about financial access and quality of care in long-term care, as well as human dignity and freedom. With regards to financing long-term care, 17.4 percent of the respondents regarded children and family as responsible, in comparison to 58.7 percent of respondents who believed that individuals were responsible for paying for their own care. The respondents were most concerned about losing independence (90.6 percent), as well as being a burden on family (83.5 percent). They were also anxious about
being unable to afford high quality care (82.0 percent) or using up all of their savings and/or income in financing care (81.1 percent). It is notable that 37.1 percent respondents expected the government to help pay for long-term care (Wiener, Joshua, Khatutsky, Galina, Greene, Angela, Thach, Trini, Allaire, Benjamin, Brown, 2015).

Long-term care insurance serves as an option in ensuring financial stability for current baby boomers. It is specifically designed to “assist individuals with some or all of the costs of medical and personal care” (Virginia State Corporation Commission, 2014) for not less than 12 months. Yet, the current long-term care insurance is far from a panacea. The state of Virginia’s website cautions readers that they should carefully weigh the tradeoffs between ability to afford expensive long-term insurance premiums against the advantages that insurance may provide: “depending on your level of income and the value of your assets, long-term care insurance may or may not be the most appropriate option for your long-term care financing” (Virginia State Corporation Commission, 2014).

In fact, 71.2 percent of the above respondents agreed that it is important to prepare for the future long-term care, nonetheless, only one in ten respondents owned a private long-term care policy (Wiener, Joshua, Khatutsky, Galina, Greene, Angela, Thach, Trini, Allaire, Benjamin, Brown, 2015). Although we find that the millennials may be increasingly impacted by the financial inaccessibility and practical limitations of long-term care insurance, even those that are most economically capable to afford the additional costs, may be forced over time, due to changing life situations, to relinquish the additional and expensive insurance policy premiums before they are utilized.
It is important to pay attention to the characteristics of current Medicare enrollees to understand the dynamics of not only Medicare expenditures, but the general landscape of health costs in the United States. Only seven percent of the Medicare enrollees had ‘no’ chronic conditions (e.g., heart disease, stroke, cancer, and obesity). This group accounted for only two percent of total Medicare expenditures, averaging $2,245 per person. In comparison, the 63 percent of Medicare enrollees who had three or more chronic conditions (plus functional limitations) spent 83 percent of the total Medicare expenditures. Annually, those who had three or more chronic conditions spent $7,926 per person, while those who had chronic conditions (plus functional limitations) spent $15,833 per person (Harriet L. Komisar and Feder. 2011).

A public health approach to the reduction of health expenditures (Figure 2) can play
a key role in securing financial accessibility, both at a personal and national level for end-of-life care. This approach can help suppress health expenditures by ‘preventing’ acute diseases (e.g., injuries and infectious diseases), chronic diseases, or chronic conditions, from which over half of adults in the United States currently suffer (Center for Disease Control and Prevention 2015). Tobacco control serves as a successful example of public health policy that changed societal behaviors (Koh and Sebelius 2012, Cabrera and Carballo 2013, World Health Organization 2015a). Historical evidence points to the accomplishment of regulatory mandates in reducing risky behaviors, such as smoking, that are a cause of life-threatening diseases (Crystal E. Tan and Glantz. 2012, Rusanen et al. 2011, Siegel et al. 2015, Johnson et al. 2014). This suggests that public health policies reduce ‘preventable’ diseases and high-cost medical events by incentivizing or promoting behavioral (life-style) change, e.g., proper diet, adequate exercise, and reduced distress. It follows that collective improvements in health, such as a reduction in preventable diseases and associated costs, will contribute to the sustainability of the Medicare fund, as well as savings on the individual level, thus improving financial accessibility for end-of-life care. The support of public health strategies in this effort, particularly in prevention and outreach, can also immeasurably improve the quality of care.

**Public Health Approach to Reduction of National Health Expenditures**
Conclusion

By 2025, the proportion of the United State population aged 65 and older will increase by 46 percent. As life expectancy increases, and medical and scientific advances further this trend, no one can avoid the need for appropriate end-of-life care (Association of American Medical Colleges 2015). The Centers for Disease Control and Prevention advocate for the benefits of advance care planning and the prevention of patient suffering, while supporting patient's preferences through end-of-life (William F. Benson and Aldrich. 2012). We advanced these goals through a unique combined human rights public health approach to end-of-life care for improving public health policy to equally serve all the populations, including millennials who will not only have to care for their aging parents, but themselves rely on end-of-life care one-day.

This article has demonstrated how the increase in aging populations, and the partial transferal of the associated financial burden to older millennials, emphasizes the urgent need to modernize traditional methodologies in end-of-life care.

“As life expectancy increases, and medical and scientific advances further this trend, no one can avoid the need for appropriate end-of-life care.”

Not only should millennials be concerned about their parents’ and grandparents’ ability to approach end-of-life with the security of their health, rights, finances, and well-being, but they must also consider their own potential role as informal caregivers and the lost opportunity costs that many in their cohort have already, or
will endure. Millennials may also be personally affected by the relative unaffordability of long-term care insurance, coupled with the shift towards chronic, debilitating disease that is a consequence of increasing lifespans and lifestyles.

A holistic approach to human health (Christina Puchalski and Ferrell. 2010) is needed in end-of-life care. The holistic approach is also a public health approach: one that carefully measures the outcomes of the success of interventions mitigated through population-based assessment with cultural sensitivity.

To aid in the success of other recommendations noted in this article, we suggest the update of federal regulatory drivers to include specific definitions for key terminologies in end-of-life care (e.g., well-being, spirituality, and quality of care). These key terms should also be recognized at state and local levels with clarity and precision that enables the successful establishment and provision of end-of-life care in the United State.

The public health approach, as we describe it, aims to reduce preventable diseases and medical events through behavioral or life-style changes, as enabled and empowered by outreach delivered by public health agencies to specific populations. Coupled with a human rights-based approach, the gap between theory and practice is further reduced. The right to universally available, accessible, acceptable and high-quality end-of-life care that respects human dignity can be realized.
### Tables:

#### Table 1.1

<table>
<thead>
<tr>
<th>Terminology</th>
<th>Theory</th>
<th>Practice</th>
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<tbody>
<tr>
<td><strong>End-of-Life Care</strong></td>
<td>End-of-life care (EOL) is used to describe the care required in the days or years leading up to time of death; the goals of EOL care are comfort and quality of life. (National Institute of Health; 2014). The American Psychological Association defines EOL care as when healthcare providers expect death within approx. six months (Joint Commission 2015).</td>
<td>Older Americans want a “good death” without pain, symptoms, and technology, and most patients prefer to avoid being hospitalized at EOL (Joint Commission 2015). The most common causes of failure in EOL care include poor teamwork, lack of safety culture, poor communication, and lack of standardized protocols. (Joint Commission 2015). Doctors and nurses also receive little training in how to talk to patients about prognosis, what to expect in the future, and the benefits and drawbacks of different treatment options. (Alais B. and Meier D. 2015).</td>
</tr>
<tr>
<td><strong>Clinical practice of EOL care should:</strong></td>
<td>- the respect of the patient's and family's wishes;</td>
<td>- Use appropriate measures that are consistent with patient choices;</td>
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<td></td>
<td>- Encompass alleviation of pain and other physical symptoms;</td>
<td>- Assess and manage psychological, social, and spiritual/religious problems;</td>
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<td></td>
<td>- Offer continuity of care that should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers;</td>
<td>- Other continuity of the patient's health team should be able to continue to be cared for;</td>
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<td></td>
<td>- Provide access to any therapy which may be expected to improve the patient's quality of life, including alternative or nontraditional treatments;</td>
<td>- Provide access to palliative care and hospice care;</td>
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<td>- Respect the right to refuse treatment;</td>
<td>- Respect the right to refuse treatment;</td>
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<tr>
<td></td>
<td>- Respect the physician’s professional responsibility to discontinue some treatments, with consideration for patient and family preferences.</td>
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#### Table 1.2

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<tr>
<th>Terminology</th>
<th>Theory</th>
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<tbody>
<tr>
<td><strong>Palliative Care</strong></td>
<td>Palliative care (PC) refers to patient and family-centered care that optimizes quality of life by anticipating treatment, and prevention of physical and emotional suffering. PC can begin at diagnosis, or at the same time as treatment, and involves addressing physical, psychological, social, and spiritual needs, and bolstering patient autonomy, access to information, and choice (Kilk TW and Makary 2010, World Health Organizations, 2015, US National Library of Medicine, US Department of Health and Human Services, and Health 2015).</td>
<td>A 2011 Public Opinion Strategies survey found that most Americans believe PC should be made available at all hospitals (CAPC 2011). The concept of “palliative care” is not well understood (CAPC 2011). Only 1 PC physician is available for every 1,200 patients living with serious or life-threatening illness across the United States (Moor and Weir 2015). Barriers to PC related to healthcare professionals include: - Insufficient knowledge of pain management. - Poor assessment of pain (Browne and Ke 2003). - Concerns about regulation of controlled substances. - Concern about side effects of medications and tolerance to analgesics. Problems related to patients: - Resistance to report pain. - Concerns about dying physicians from treatment of underlying disease. - Lack of knowledge about basic pain management. - Resistance to take pain medications due to fear of addiction oroverdose. - Concern about not being a “good” patient. - Worry about severe side effects (e.g., constipation, nausea, or slowing of thought). - Poor adherence to the prescribed analgesic regimen. - Financial barriers to treatment and medicationation (Browne and Ke 2003) (NH National Cancer Institute, 2015). Problems related to the health care system: - Up to 50 percent of severely ill patients don’t receive adequate pain management (December et al 2008, Fantlch A. 2010). - Treatment is too costly for patients and families. - Too low priority given to cancer pain treatment. - Restrictive regulation of controlled substances. - Problems of availability of treatment or access. - Unavailable or unaffordable medication. - Failure of the availability of PC services to keep pace with the growing demand (National Institute of Medicine 2014).</td>
</tr>
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<td></td>
<td>World Health Organization (WHO) defines that PC:</td>
<td>- Provides relief from pain and other distressing symptoms;</td>
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<td>- Aims neither to hasten or postpone death;</td>
<td>- Integrates the psychological and spiritual aspects;</td>
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<td></td>
<td>- Offers a support system to help patients live as actively as possible until death, and to help the family cope during the patient’s illness; and in their own bereavement;</td>
<td>- Offers support system to help patients live as actively as possible until death, and to help the family cope during the patient’s illness; and in their own bereavement;</td>
</tr>
<tr>
<td></td>
<td>- Will enhance quality of life, and may also positively influence the course of illness;</td>
<td>- Will enhance quality of life, and may also positively influence the course of illness;</td>
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<tr>
<td></td>
<td>- Is applicable early in the course of illness, in conjunction with other therapies intended to prolong life, such as chemotherapy or radiation therapy (World Health Organization 2005).</td>
<td>- Is applicable early in the course of illness, in conjunction with other therapies intended to prolong life, such as chemotherapy or radiation therapy (World Health Organization 2005).</td>
</tr>
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Table 1.3

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<th>Terminology</th>
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<th>Practice</th>
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</table>
| Hospice Care | Hospice care (HC) provides PC for patients with limited life expectancy and who require comprehensive biologic, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition (National Quality Forum 2004). It also supports family members coping with the complex consequences of illness, disability, and aging (National Quality Forum 2004). | There are an estimated: 8 1.6 - 1.7 million hospice patients in the US 9 An estimated 6,100 HC providers operating in the US  
Where is hospice care provided?  
- Patient residences: 65%  
- Inpatient facilities: 7%  
- Acute care facilities: 4%  
Who are the hospice providers?  
- Free standing: 8%  
- Home health: 14%  
- Other: 78%  
- For profit: 70%  
- Not for profit: 20%  
- Other: 10% |

Note: Data Source: National Hospice and Palliative Care Organizations (2015).

Table 1.4

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<thead>
<tr>
<th>Terminology</th>
<th>Theory</th>
<th>Practice</th>
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</thead>
</table>
| Medicare     | Medicare is a health insurance program for people aged 65 or older, people aged younger than 65 with certain disabilities, and people of all ages with End-Stage Renal Disease (permanent kidney failure requiring dialysis or a kidney transplant) (Centers for Medicare & Medicaid Services 2014b). The Medicare program, established in 1965, was enacted by Congress to tax and spend for the general welfare (Centers for Medicare & Medicaid Services 2014b). To be eligible for Medicare hospice services, the individual’s prognosis is for a life expectancy of 6 months or less if the terminal illness runs its normal course (Centers for Medicare & Medicaid Services 2015a). | Overall Medicare Beneficiaries’ Out-of-Pocket Yearly Spending  
- Under 65: $2,015  
- 65 - 64: $2,495  
- 65 - 74: $5,400  
- 75 - 84: $8,600  
- 85+: $14,100  
Medicare reimburses $159.34 per patient per day to the hospice provider for inpatient home care. |

Note: Data Source: US Department of Health & Human Services and Centers for Medicare & Medicaid Services, Kaiser Family Foundation.
Table 1.5

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<tr>
<th>Terminology</th>
<th>Theory</th>
<th>Practice</th>
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<tr>
<td>Long-Term Care</td>
<td>Long-term care (LTC) services (or “long-term services and supports”) include a broad range of health, personal care, and supportive services that meet the needs of frail older people and other adults whose capability for self-care is limited because of in chronic illness, injury, physical, cognitive, or mental disability, or other health-related conditions (U.S. Department of Health and Human Services). The need for long-term care services is generally defined based on functional limitations (need for assistance with or expansion in activities of daily living: ADLs; e.g., dressing, bathing, and toileting), instrumental activities of daily living (IADLs; e.g., medication management and housework), and health maintenance tasks (Harris-Kojetin L, Sengupta M, and Park-Lee E 2016). Long-term care services include assistance with activities of daily living (ADLs; e.g., dressing, bathing, and toileting), instrumental activities of daily living (IADLs; e.g., medication management and housework), and health maintenance tasks (Harris-Kojetin L, Sengupta M, and Park-Lee E 2016).</td>
<td>Types of Providers:</td>
</tr>
<tr>
<td>Hospital</td>
<td>4000</td>
<td></td>
</tr>
<tr>
<td>Adult Day Services</td>
<td>4000</td>
<td></td>
</tr>
<tr>
<td>Home Health</td>
<td>3460</td>
<td></td>
</tr>
<tr>
<td>Skilled Nursing Homes</td>
<td>1400</td>
<td></td>
</tr>
<tr>
<td>Assisted Living</td>
<td>1,345</td>
<td></td>
</tr>
<tr>
<td>Breakdown of Long-Term Services Users (Participants) Served by Providers:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Day Services</td>
<td>282,850</td>
<td></td>
</tr>
<tr>
<td>Assisted Living</td>
<td>93,300</td>
<td></td>
</tr>
<tr>
<td>Nursing Homes</td>
<td>38,040</td>
<td>80,000</td>
</tr>
</tbody>
</table>

Users Over 65 by Provider:
92.9% of users of residential care communities are over age 65, while 36.3% of users of adult day service centers and 17.5% of users of home health agencies are under age 65 (Harris-Kojetin L, Sengupta M, and Park-Lee E 2016).

Nature of Providers:
66% = home health agencies, hosptals, nursing homes, and residential care communities were for-profit, while about 40% of adult day services centers were for-profit (Harris-Kojetin L, Sengupta M, and Park-Lee E 2016).

Employees:
Over 1.5 million working employees (full-time and part-time) in the five sectors (Harris-Kojetin L, Sengupta M, and Park-Lee E 2016).

Recent estimates for the amount spent annually on post-acute care services are approximately $210.9 billion (O’Shaughnessy, 2014) and $137.1 billion (Callef, Maloney, & Takagi, 2013).

Table 1.6

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<tr>
<th>Terminology</th>
<th>Theory</th>
<th>Practice</th>
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<tbody>
<tr>
<td>Advance Directives</td>
<td>The federal law defines an advance directive (AD) as “written instructions, such as a living will, or durable power of attorney for health care, recognized and accepted under state law, relating to the provision of health care when the individual is incapacitated” (U.S. Department of Health &amp; Human Services and Centers for Medicare &amp; Medicaid Services 2011). An AD tells the doctor what kind of care the individual wants to have if/when she becomes unable to make medical decisions (Harley, Doctor.org 2012).</td>
<td>Impacted unable to make a treatment decision</td>
</tr>
<tr>
<td></td>
<td></td>
<td>46%</td>
</tr>
<tr>
<td></td>
<td>Five Wishes is America’s most popular living will: 25 million plus people have used it (Aging with Dignity 2015). Planning for the EOL is increasing being viewed as a public health issue, given its potential to prevent unnecessary suffering and to support an individual’s decisions and preferences related to the EOL (Centers for Disease Control and Prevention 2013). Although Informed Consent and Advance Care Planning laws are driven by 38 CFR 17.12 (US Government Publishing Office 2011), states may also control the form and content of the advance care directive.</td>
<td></td>
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### Table 1.7

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<tr>
<th>Terminology</th>
<th>Theory</th>
<th>Practice</th>
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<tbody>
<tr>
<td>Well-being</td>
<td>Well-being is a positive outcome that is meaningful for people and for many sectors of society. Good living conditions (e.g., housing, employment) are fundamental to well-being. Tracking these conditions is important for public policy (Centers for Disease Control and Prevention 2013).</td>
<td>The comprehensive assessment must identify the physical, psychological, emotional, and spiritual needs related to the terminal illness that must be addressed in order to promote the hospice patient’s well-being, comfort, and dignity throughout the dying process (Federal Register 2010).</td>
</tr>
<tr>
<td>Constructs of meaning or a sense of life’s purpose have been suggested as primary components of well-being (Michaletz and G. 998).</td>
<td>The NHPCO also states that “outcome measures must be collected consistently and in the same manner for every patient,” but does not provide specific measurements of well-being (National Hospice and Palliative Care Organization).</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>The term “physical, psychological, emotional, and spiritual” needs ... “to promote the patient’s well-being, comfort, and dignity,” are not defined in the CFR (National Hospice and Palliative Care Organization).</td>
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### Table 1.8

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<th>Terminology</th>
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<tbody>
<tr>
<td>Spirituality</td>
<td>Spirituality is expressed in an individual’s search for ultimate meaning through participation in religion and/or belief in God, family, nature, rationalism, humanism, and the arts. All these factors can influence how patients perceive health and illness (Association of American Medical Colleges 1999).</td>
<td>Religion and spirituality potentially can mediate quality of life by enhancing patient subjective well-being through social support and stress coping strategies (Drolet and Wade 2000).</td>
</tr>
<tr>
<td></td>
<td>A discussion with the patient or caregiver about spiritual or existential concerns can be initiated by any member of the hospice staff or interdisciplinary group (Centers for Medicare &amp; Medicaid Services 2015c).</td>
<td>Spiritual counseling must be provided by the hospice program as a core service. It requires cultivating an ongoing relationship with local faith communities and the need for education about EOL issues (National Hospice and Palliative Care Organization).</td>
</tr>
<tr>
<td></td>
<td>This comes through training and experience and should be available in the professional providing that service (Fletcher Hospital and Palliative Care Organization).</td>
<td>A discussion with the patient or caregiver about spiritual or existential concerns can be initiated by any member of the hospice staff or interdisciplinary group (Centers for Medicare &amp; Medicaid Services 2015c).</td>
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### Table 1.9

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<tr>
<th>Terminology</th>
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<th>Practice</th>
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<tbody>
<tr>
<td>Bereavement Counseling</td>
<td>Bereavement counseling includes “emotional, psychological, and spiritual support.” Coordination with the spiritual counselor may be necessary to achieve compliance with bereavement scope of practice (National Hospice and Palliative Care Organization).</td>
<td>Bereavement counseling is available to the patient and his or her immediate family before and 1 year after the death of the patient and to assist with issues related to grief, loss, and adjustment (Centers for Medicare &amp; Medicaid Services 2015b, Kaiser Family Foundation 2015c).</td>
</tr>
<tr>
<td></td>
<td>Bereavement counseling is available to the patient and his or her immediate family before and 1 year after the death of the patient and to assist with issues related to grief, loss, and adjustment (Centers for Medicare &amp; Medicaid Services 2015b, Kaiser Family Foundation 2015c).</td>
<td>An initial bereavement assessment of the needs of the patient’s family and other individuals focusing on the social, spiritual, and cultural factors that may impact their ability to cope with the patient’s death. The information gathered must be incorporated into the plan of care and considered in the bereavement plan of care (Federal Register 2010).</td>
</tr>
<tr>
<td>Bereaved family members were more likely to rate overall satisfaction with hospice services as “excellent” if they felt:</td>
<td>Bereaved family members were more likely to rate overall satisfaction with hospice services as “excellent” if they felt:</td>
<td>Bereaved family members were more likely to rate overall satisfaction with hospice services as “excellent” if they felt:</td>
</tr>
<tr>
<td>- they were regularly informed about their loved one’s condition and received accurate information about his/her medical treatment;</td>
<td>- the hospice team provided the right amount of emotional support; and</td>
<td>- they could identify one nurse as being in charge (Rhodes et al. 2008).</td>
</tr>
</tbody>
</table>

![Chart showing Belief in the positive impact of spiritual care](image-url)

Some patients want physicians to address religious belief more: 39%

A number of measurement tools exist. Four of the most widely used tools are: FICA, FAMHS, SPIRITual and HOPE (Becker, 2015).

Education at medical school, primary care residency, and psychiatry residency programs has been delivered since 2001 (The George Washington Institute on Spirituality & Health 2015).

There is no comprehensive list of spiritual or existential concerns, although new guidance in V.1.2 of the Hospice Item Set Manual lists some basic examples (Centers for Medicare & Medicaid Services 2015c).
Acknowledgement

We would like to thank Pamela Cook, RN, M.B.A. for her valuable comments on the earlier version of the Tables, and interviewees from the end-of-life care institutions for sharing their significant insights in the early stage of this research project. We would also like to thank the faculty reviewers and the editors of the journal for their guidance and helpful process. We are also thankful to the artists that constructed the excellent visual data that highlight our research.

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www.nhpco.org/research.

http://nihseniorhealth.gov/endoflife/preparingfortheendoflife/01.html.


The Georgetown Public Policy Review


A informal caregiver is, “any person who provides long-term care services without pay,” and informal care services are defined by the Department of Health and Human Services (HHS) as, “services that include medical and non-medical care for people with a chronic illness or disability.


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