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Curative and Palliative Care: The Ethical and Economic Considerations of a Person-Centered Health Care Paradigm

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When a patient receives a diagnosis, treatment options essentially fall under two, but not mutually exclusive, main categories: 1. Curative Care, treatment aimed at curing a disease, and 2. Palliative Care, which focuses on symptom management. In the case of (some) chronic and terminal diseases, curative treatments will provide quantity of days, where palliative care focuses on providing quality of days. Why is the current health care paradigm biased in favor of promoting curative care?

The Issue: The United States has benefited from advancements in science and evolutions in medical equipment, which have contributed to the current life expectancy of 78.8 years¹. The current health care paradigm is one which is disease-focused and promotes curative treatments. This raises serious ethical concerns about a patient's end of life preferences and experience. Additionally, cultural attitudes and societal perspectives struggle with accepting that death is unavoidable, which prevents patients from planning for a good death experience. Americans overwhelmingly report that they would prefer to die at home, however less than 20 percent do. The majority (over 50 percent) of American deaths occur in an acute hospital, followed by 30 percent in a nursing facility¹.

Under the classification of palliative care is hospice, which is end of life care for patients facing a life limiting disease. This type of end of life care: provides relief

from pain and other symptoms, allows for a comfortable natural death progression, addresses the psychological and spiritual needs of patients, informs patients and families about advance care planning, and provides a holistic team to help patients and families cope³.

We generally consider that all medical treatment and therapies are aimed at providing a "cure." There are several types of therapies that fall under the classification of curative care: chemotherapy, surgery, and antibiotics are common examples. There is less known and understood about palliative care, which is another classification of medical care that aims at symptom control and pain management that result from serious illness. While curative and palliative care have varying goals, there is a push to integrate them. However, the current health care paradigm is skewed towards focusing on curative care, and less so on the promotion and integration of palliative care, even though palliative care can be conducive to achieving patient goals.

The discussion surrounding palliative end of life care also includes economic implications. Medicare Trustees forecast that by 2030, the Hospital Insurance portion of Medicare Part A will become insolvent. While we are the beneficiaries of medical innovations, this does not translate to providing patient options. A health care system that heavily promotes curative

treatments carries hefty costs implication that may not be congruent with person-centered care.

This paper seeks to explore key systemic and endemic contributing factors that lead to the disconnect between patient preferences and realities when it comes to end of life care. To enhance the conversations and policy considerations that have began to increase regarding end of life care, this paper will look at national trends and include implications for Latino populations.

In 2010, 13 percent of Americans were over 65 years; in 2014 that population grew by 2 percent, and it is projected that by 2040, it will grow to 22 percent⁴. The share of the total U.S. population that is age 65 and older has more than tripled over the last century.⁵ This "graying of America," fueled by Baby Boomers, is forcing healthcare professionals and leaders to put End of Life Care (EOLC) in the forefront. Latinos are the fastest growing minority group and comprise 17 percent of the U.S. population⁶. There is an immediate need to address EOLC due to the influx of Americans over 65 years. In looking forward, it is imperative that health policy makers and industry understand the uniqueness of Latinos as patients, and preemptively create a health care system that is malleable to the uniqueness of this population.

Death is inevitable, but remains one of the most difficult topics to discuss. While the promotion and perpetuation of EOLC has been slowly and steadily increasing, preparing for this important phase in life has negative nomenclature and stigma, and for some, is taboo and physically discomfoting to have these discussions.

It is ethically fundamental that health care and clinicians are providing care that is culturally equitable and competent, that patients are provided information and options, and that all efforts are exhausted to deliver care in accordance with patients' wishes. This person-centered approach to care is especially crucial for patients that need to consider EOLC. Americans are expressing the desire for a different EOLC experience than they are receiving, and it is necessary to be critical of the role of the physician.

End of life care is a multi-faceted issue, and another key point in this discussion is to understand that there are economic considerations for both patients and families, and health care systems. Patients are entitled to make EOLC decisions that accommodate their wishes, goals, and cost. Similarly, the U.S. health care system has take into account the spending on treatments that don't accommodate patient preferences. Approximately one-fourth of total Medicare spending is allocated for a person's last year of life⁷. It is projected that healthcare expenditures, including Medicare spending, will outpace the growth in the gross domestic product (GDP)⁸. The current paradigm of promoting aggressive treatments may not be in line with a patient wishes, and it is not fiscally responsible.

End of Life Care Services

End of Life Care (EOLC) refers to services that one receives in the preparation of their death. Fortunately, the health care system in the U.S. is more than adequate to serve patients with complex medical conditions that want to pursue curative treatments, palliative care, or a medical plan that integrates both.

When a patient chooses aggressive curative treatment (such as surgery at a hos-

pital), there is accompanying post-treatment care involving restorative therapy. This therapy can be given at a patient's home, as is the case with home health-care, or at a skilled nursing facility. Here, the goal is to rehabilitate the patient to a restored condition. This process is physically taxing, and acute patients dealing with a terminal illness should be allowed to consider if this treatment is in accordance with their wishes. While public perspectives on nursing homes are not favorable, these institutions represent a prominent component of EOLC.

Home healthcare and skilled care (from skilled nursing facilities) represent two common types of care for terminally ill patients. Hospice care is another option for patients with a prognosis of six months or less. Hospice services can be given to a patient at any location they deem as their home (their residence, a nursing home, residential facility), a hospice inpatient unit, or in some cases at an acute hospital. It addresses symptom management and focuses on quality of life in the patient's remaining days as opposed to extending the patient's life. It is covered 100% by Medicare and entitles patients to a holistic team (physician, nurses, social workers, certified nursing assistants, a chaplain), medications prescribed for illness, durable medical equipment, and other covered items. In 2014, nearly 60 percent of deaths by hospice patients were at home, and only 9 percent were at an acute hospital⁹.

Nursing Homes A nursing home resident must have a health situation which medically necessitates admission as they provide crucial care for short term and long term acute patients. Nursing homes are not particularly meant to serve patients that are dying; however almost two thirds of nursing home residents have 3 or more chronic conditions, and hospital

patients are increasingly transferred to nursing homes in the last weeks of life. Even though many individuals are admitted with a terminal diagnosis, the majority of residents died after a long and slow decline in function.

The 1987 Nursing Home Reform Act gives nursing home residents the opportunity to achieve maximal functional independence, but can be counter with the palliative care needs of residents who are nearing the end of their lives. For example, if a nursing home patient faces a medical episode (a fall) that requires hospitalization, the nursing home will be able to receive the patient back from the hospital and bill their Medicare plan for skilled care (a higher rate than the Medicaid reimbursable rate that covers nursing home care), and thus provides a financial incentive.

A recent survey illustrated that symptoms, needs, and illness trajectories of dying nursing home residents are insufficiently recognized by nursing home staff, resulting in missed opportunities for advance care planning and palliative intervention. Furthermore, family members reported that they rarely saw a physician in the nursing home, and others reported dissatisfaction with the quality of interaction with the physician. There was similar dissatisfaction with other nursing home medical staff, and family members of residents reported that the staff of the nursing home lacked compassion¹⁰.

Nursing home residents that receive hospice services: experience fewer hospitalizations and invasive treatments near the end of life, and they receive better analgesic management for daily pain. Hospice staff is independent from the nursing home staff and therefore have specialized training in this type of care. Hospice services often enhance the care of dying persons in nurs-

In the dialogue of end of life care, it is equally important to not only look at the human side of this issue, but also the fiscal impact in regards to the patient, the family, and societal costs. In 2014, approximately 30 percent of Medicare benefit payment expenditures— \$183.3 billion— went to hospital services.¹⁰

ing homes. In this way, there is wide variation in experience of EOLC in nursing home settings.

Endemic Facets of End of Life Care: Societal and Cultural Attitudes

Death is inevitable, but remains one of the most difficult topics to discuss. While the promotion and perpetuation of EOLC has been slowly and steadily increasing, preparing for this important phase in life has negative nomenclature and stigma, and for some, is taboo and physically discomforting to have these discussions. Pursuing aggressive treatments is related to notions of being strong, and this makes conversations about palliative care difficult. Further, death is commonly associated with aging, but many younger people are facing serious life limiting and complex medical situations. Physicians and health-care providers, and patients and families alike all struggle in approaching EOLC discussions.

Latinos Attitudes and the Manifestations in Patient Care: Since 2005, Hispanics have increased their belief in opting for aggressive medical treatments in situations which they have an incurable disease. Fifty five percent of Hispanics report they would want their medical staff to do everything possible to save their lives, versus 65 percent of whites, which would ask their doctor to stop medical treatment¹¹.

According to the Medicare Payment Advisory Commission, in 2014 approximately 48 percent of Medicare patients used the hospice benefit under the Medicare program, significantly up from 27 percent in 2000¹². However, the rates are notably different in Latinos. In 2007 approximately 20 percent of all patients receiving hospice care were minorities, and only 5 percent of those patients reported being of His-

panic or Latino origin. This clearly illustrates that understanding cultural reluctance in discussing EOLC, and being able to navigate around cultural resistance is key in facilitating the communication of EOLC wishes.

Communicating End of Life Care Wishes in Latino Populations:

In general Hispanics are less likely, as compared to the approximately two-thirds of Americans, to have done some sort of behavior to communicate their EOLC wishes. An Advance Directive (AD) is a written statement by a competent person indicating his or her wishes regarding medical treatment. There are two types: a Living Will that informs health care providers about the type of medical care they would want, and a Health/Medical Power of Attorney (Durable Power of Attorney) that identifies a health care proxy or decision maker. It is important to note that these documents become “active” only when a patient becomes incapacitated and cannot verbalize their wishes.

The demographics for patients more likely to have communicated their EOLC wishes include¹³:

- Having a chronic illness¹⁴.
- Older adults (>65 years), as opposed to younger adults (<30), are more likely to have communicated in writing their EOLC wishes.
- 74 percent of whites, as opposed to 50 percent of Hispanics, have communicated their EOLC wishes either verbally or in writing.
- Americans with more years of formal education are more likely than those with less education to have written down or talked with someone about their EOLC wishes.
- Adults with higher incomes are more likely than lower-income adults to say they have communicated their EOLC wishes.

Health care has to consider perspectives and attitudes that are endemic to Latinos that may be contra to discussing EOLC wishes. Providers are hesitant, and in some cases don't have the training or skills, to approach such sensitive topics with cultural sensitivity. Other factors to consider are language barriers and health literacy (being able to understand health information) issues. Latinos face difficulty communicating with their physician or other healthcare provider¹⁵. If there is a Spanish-speaking patient in front of an English-only speaking provider, the patient is likely to underreport symptoms, and less likely to seek further information from the provider. Additionally, older Latino adults are less likely to access preventative programs and services, and they don't know how to navigate the U.S. medical system¹⁶. The complexity of information can be too much for a low literacy patient. According to the National Assessment of Adult Literacy—an initiative overseen by the U.S. Department of Education—14 percent of adults have below basic health literacy, many of whom are Latino.

The Interplay of Religion on Health Care In Latino Populations:

Fifty seven percent of adult Latinos identify as Catholic, which comprises approximately thirty eight percent of all adult Catholics in the U.S. Religion, specifically Catholicism, is a pronounced characteristic of Latino culture and is perpetuated from generation to generation. Seven in ten Latinos raised Catholic remain in the faith as adults, while six of ten non-Latinos raised Catholic remain in the faith¹⁷. Religious views manifest themselves in health care behaviors in Latino patients.

Sixty five percent of white Catholics say they would stop their medical treatment if they had an incurable disease and were suffering with a lot of pain, as opposed to

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57 percent of Hispanic Catholics. Blacks and Hispanics are less likely than whites to say they would halt medical treatment if they faced an incurable disease with a lot of pain. Blacks and Hispanics are more likely than whites to say they would tell their doctors to do everything possible to save their lives¹⁸.

Understanding Providers Play a Significant Role in Promoting EOLC

Dr. Ira Byock notes that we “are the benefactors and victims of scientific success.” The current model of medical training instills in physicians that there is always a cure or treatment, and physicians approach diagnosing with the mentality that it is a personal failure to not find a remedy. In Dr. Atul Gawande’s book, *Being Mortal*, he explains that one of the most “uncomfortable difficulties” for physicians is working with the cases where there is no fixable or treatment solution. Dr. Gawande says that this type of thinking doesn’t apply to the “two big unfixables” which are aging and dying.

A U.S. Government Accountability Office report¹⁹ found that while approaches to inform individuals about advance directives can vary by provider, similar challenges existed across settings, including provider discomfort in talking about end of life issues as well as lack of staff time for such discussion²⁰. There are misunderstandings about the coverage of the Hospice Benefit and a referral is frequently made late in the progression of an illness or not at all, preventing full benefit from such services²¹. These dynamics support the fact that so many deaths are occurring in hospitals. Studies show end of life conversations between patient and physician are associated with fewer life-sustaining procedures and lower rates of Intensive Care Unit admission, and thus lower end of life care cost²². Promoting healthy dia-

logue between provider and patient is critical in promoting EOLC and ensuring that patients are planning for the type of EOLC they would want.

Doctors as Patients: Physicians have started to enter the national forum on EOLC and they are painting a different picture on the type of health care they want for themselves in comparison to the experiences of their patients. In a 2015 NPR interview, Dr. Kendra Fleagle Gorlitsky talks about the distress giving an elderly person CPR and resuscitation because of the physical trauma that is a bi-product. Her colleague, Dr. Ken Murray mentions how doctors die differently; at home and also forgoing some types of aggressive treatments, which is more in line with palliative care options.

A Fiscal Approach to End of Life Care

In the dialogue of end of life care, it is important to holistically discuss this issue by also addressing the fiscal impact in regards to the patient, the family, and societal costs. In 2014, approximately 30 percent of Medicare benefit payment expenditures —\$183.3 billion—went to hospital services²³. In dealing with this issue, we focus on older Americans, and the U.S. population is aging quickly, specifically due to the Baby Boomers. In 2000, the U.S. population age 65 and older was 12.3 percent. Current trends project that, by 2030,

19.6 percent will be age 65 and older, with the majority of people being approximately 85 years old²⁴. This indicates the urgency for Congress to promote policies that address end of life care.

What these population trends translate to is a great deal of expenditure by the Centers of Medicare and Medicaid Services. Much analysis has been done regarding the cost of end of life care and what the last two years, last year, and the last month of life translates to in terms of patient care costs.

Medicare is crucial in getting 53.8 million of Americans, most are patients over 65 and with disabilities, benefits that in 2014 totaled \$613 billion³¹. From 1990–2000, total Medicare expenditures rose from 1.8 percent to 2.4 percent, and in 2001, Medicare spending accounted for 17 percent of total national health expenditure²⁹. In 2014, spending on Medicare accounted for 14 percent of the federal budget, and 22 percent of total national health spending³⁰.

Medicare is comprised of four parts: Part A covers skilled nursing care, hospice care, and inpatient hospital services, Part B covers physician services, Part C is a private plan that covers Part A and B, and Part D covers outpatient prescription drugs. Medicare spending is heavily skewed in Part A derived from increased hospital visits, complexity of hospital treatments, and longer

Last 2 Years of Life	In 2009, Medicare paid \$55 billion in doctor and hospital expenses ²⁵
Last Year of Life	In 1999, 27.9% of total Medicare expenditure was attributed to expense relating to end of life care. The percentage has been steadily increasing every year ²⁶ . ~1/4 of Medicare expenditures are for the last year of life, which is about 6 times higher than a living Medicare beneficiary ²⁷ .
Last Month of Life	30% of Medicare expenditures are attributed to 5% of beneficiaries who die each year, and ~1/3 is spent in the last month ²⁸

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length of stays. The Hospital Insurance Fund (HI) is funded primarily from payroll tax of 2.9 percent of current workers earnings with the purpose to cover Part A³². Some providers and healthcare models will look at, with the exception of planned procedures, hospitalizations as a failure outcome of outpatient care. Providers are not talking to their patients about all of their options when it comes to EOLC, and this is particularly problematic for the highly acute patients (the most severe and complex) as they tend to have the highest hospitalization rates and those visits tend to be costly. Medicare Trustees forecast that the HI will be depleted in 2030. This means that there will not be sufficient funds to fully cover Part A expenditures from taxed income, unless there is an increase in payroll taxes to 3.58 percent, or alternatively, an immediate decrease in expenditures by 15 percent³³. Palliative Care via hospice services could be an essential key factor in decreasing healthcare expenditures if practices are used to increase its utilization. Currently only 5 percent of hospice patients are Hispanic. Increasing the utilization among Latinos could be in line with person-centered care, and have a secondary benefit of having an impact in decreasing system spending.

Prevalence of hospital palliative care programs in the United States has steadily increased since 2000, with 53 percent of hospitals reporting a palliative care program in 2006 compared to 25 percent in 2000³⁴. The National Hospice and Palliative Care Organization (NHPCO) estimated that 4 million patients received services from hospice care providers in 2007, and increased to 1.65 million in 2011³⁵. This is indicative of a shift in the healthcare industry from a paradigm of promoting only aggressive treatment, to one that approaches patients with the option to focus on symptom management.

In addition, patients are realizing cost savings as more are benefiting from end of life care. In 2008, medical costs for patients that benefited from palliative end of life care were \$1,876, compared with \$2,917 for patients who pursued aggressive treatments. Costs were 35.7 percent lower for patients that had palliative end of life care than those who did not.³⁶ The expenses associated with hospital stays, treatment options, rehab facilities, and skilled healthcare workers contributed to the higher costs, but mostly are allocated to services that are not always consistent with patient wishes. There is a push in the industry to reallocate this spending into providing services that support person-centered care in their communities.

While CMS is bearing the brunt of the expenses related to end of care costs, there are costs that patients and families incur. Health care is intrinsic to a person's values, and personalized. Unlike other spending in a person's life, health care costs are ambiguous and complex, leaving patients unable to plan and understand. Hispanics live on average two years longer than non-Hispanic whites despite more poverty and health disparities, underscoring the importance of conversations with providers regarding all facets of health care. Of the 65 and over U.S. population, 20 percent are minority, and 6.9 percent are Hispanic. This is expected to dramatically increase over the next two decades: the population of older non-Hispanic whites is projected to increase by 59 percent, whereas the growth rate of Hispanics that will be over 65 is projected to increase by 202 percent (160 percent for all minorities) in twenty years³⁷.

Policy Recommendations

In order to address this multi-faceted issue, policies must aim at remedying systemic shortcomings and work in accordance with endemic characteristics of all communities, including Latino communities.

Systemically, the political climate understands the movement of the health care pendulum to a more patient focused approach. There have been innovative policies and programs recently that address different facets of ELOC and that are culturally inclusive to Latino attitudes.

- The industry is advocating for a more integrated partnership with concurrent delivery of curative care and palliative end of life care.
- Dr. Lena Wen is an Emergency Physician that believes that there should be total transparency in regards to physician's disclosures on possible conflicts of interests. She created an
- H.R. 2208 Hospice Commitment to Accurate and Relevant Encounters Act (Hospice CARE) would allow providers to have face-to-face discussions with patients to determine their eligibility for hospice services³⁸.
- H.R. 3119 Palliative Care and Hospice Education and Training Act includes components that would allow for workforce training, education and awareness initiatives, and enhance research by the National Institutes of Health³⁹. A survey by family members of nursing homes residents recommend providing incentives under General Medical Education (GME) funding to support physician training in palliative care in an effort to improve the death experience of nursing home residents⁴⁰.
- S. 1549 Care Planning Act of 2015 would ensure that advance care planning is being done with patients at hospitals before discharging, skilled nursing facilities, home health agencies, and hospice programs (although this is already an incorporated component of many hospices). The Secretary of Health and Human Services would be able to offer grants for the purposes of educating the public, providing

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online training and materials, and the development of assessment tools on effectiveness and accuracy of care plans.

- The U.S. Department of Health and Human Services Office of Minority Health has Promotores De Salud (Community Health Workers) that are para-professionals and experts in understanding the unique dynamics of their communities, and are responsible for disseminating health information⁴¹.
- Money Follows the Person (MFP) is a Medicaid Demonstration Program that targets traditional long-term care with the goal of increasing the use of home and community-based services in lieu of remaining at a nursing home⁴².
- S.1719 & H.R. 3099 Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2015 (RAISE) focuses on providing support for the many family members that are caregivers to loved ones. Latino's have lower admission rates into nursing homes, and prefer to take care of loved ones at home⁴³.

Advance Directive (AD) and Care Planning: An Institute of Medicine 2014 *Dying in America* Report showed that 47 percent of adults over the age of 40 had an AD. Additionally, a 2011 National Center of Health Statistics study found that 88 percent of discharged hospice patients had an AD, compared to 65 percent of nursing home residents, and 28 percent of homecare patients. Historically there have been policies that encourage providers to promote advance care planning, and recently, incentives for providers to ensure these conversations are happening.

The Patient Self-Determination Act of 1990 requires certain Medicare and Medicaid covered providers to promote advanced care planning, and those that are not in compliance can have payments

withheld by the Secretary of HHS. The Act requires that clinicians: provide patients with written information regarding their rights under state law concerning medical care (including advance directives), document advance directives in the patients' medical record, and provide education for staff and the community on issues regarding ADs.

In 2010, CMS received comments encouraging the inclusion of advance care planning (ACP) at the Annual Wellness Visit in an effort to remedy the missed communications among providers and patients and families. Starting in 2016, CMS physician payment regulations now allow for ACP under two new Current Procedure Terminology (CPT) codes⁴⁴:

99497/99498⁴⁵ – advance care planning including the explanation and discussion of advance directives such as standard forms (with the completion of such forms) by the physician or other qualified health professional (first 30 minutes, face-to-face with the patient, family member (s) and/or surrogate, with an add-on code for each additional 30 minutes).

Conclusion

Perspectives on EOLC can be generated from a patient-centered goal: ethically we should allow patients to have the death experience that they want. An ancillary bi-product of this conversation regards economic considerations for the patient and their families, and health care system costs. For policy makers, spending on end of life care at the current rate is not sustainable, and there are efforts to address this and to be fiscally aware of the implications that stem from a health care system that favors curative treatment. Savings in system costs can be better utilized to match patient's wishes with parallel health care services. The U.S. is well

equipped to handle the breadth of end of life care options: from seeking purely curative options or solely palliative care, to an integration of both.

The goal of this paper is to empower individuals to understand that they have options for the most vulnerable time of their lives, and to alleviate some of the stigma attached with planning for a good death experience. While there may be systemic shortfalls (many out of the scope of this paper), perhaps one of the most challenging issue is overcoming cultural reluctance. There are imminent factors forcing health care and policy to address the incongruence between patient's wishes with patient-centered end of life care. The Latino community now is young, but the lessons learned and implications that evolve over the next years will be pertinent to an aging Latino population.

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