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IMPROVING THE CULTURE OF DEATH DENIAL ACROSS THE UNITED STATES

Christopher Blake Hales (Joseph R. Horton, Thesis Mentor)
Department of Operations and Information Systems

IMPROVING THE CULTURE OF DEATH DENIAL ACROSS THE UNITED STATES

by

Christopher Hales

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Approved:

Joseph R Horton

Joseph Richards Horton
Thesis Faculty Supervisor

Glen M. Schmidt
Chair, Department of Operations and
Information Systems

Jessica Taverna
Honors Faculty Advisor

Sylvia D. Torti, PhD
Dean, Honors College

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Abstract

The culture of death denial in the United States has been a problem for many years, resulting in significant consequences for individuals, families, and society. Death is inevitable, yet society lacks the preparation needed to deal with death when it comes. The societal default has been to fight death and its reality. In fighting death, vast amounts of medical spending occur at the end-of-life, some of which is considered “medical waste”. Research was performed focused on discovering whether a change in our current culture of death denial is key to the minimization of medical waste at the end-of-life in the United States. During the end-of-life, in an attempt to improve the quality of life, care, and the humanity of patients; methods have been developed that can significantly transform the healthcare system of the United States. Improving the culture of death denial is essential if the people of the United States hope for an improved death experience with honor, dignity and ultimately save costs and utilize resources where they matter most.

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Improving the Culture of Death Denial Across the United States

For humans, life is a finite experience. As a biological function, the time will come for every individual human being alive, to die. Yet despite the daunting thoughts that arise regarding death or what comes after, it is an inescapable reality. Thus, the subject of death in the United States has become uncomfortable to think or speak about and as a result, receives rare acknowledgement and few discussions. With the integration of personal knowledge, beliefs, and experiences, the actual meaning and significance of old age and death varies widely among individuals. All of these factors contribute to what is now the current societal culture of death denial.

Commonly known as "death denial", death denial in the United States can be considered as a sum total of ways to prolong life. Or rather an emotional, intellectual, and physical manifestation to our basic human survival mechanisms. As an aggregate, these responses built by human behavior and beliefs have created a culture that has propagated across generations. Though death is certain, its reality has often been avoided or not accepted. Therefore, many at the end-of-life have lost the significant opportunity to prepare for the final phase of human life. Current behaviors and beliefs have put tremendous focus on ensuring health and survival. Also, the capabilities of modern medicine have aided in reducing physical decay and minimizing the possibility of death. Individuals then, at the end-of-life repeatedly go through medical procedures and interventions seeking personal medical benefit. Whether that benefit be a greater quality of life or a cure for an illness and disability, sometimes these medical procedures and interventions do not provide the significant benefit that patients seek, leaving them worse off than before. Consequently, medical costs at the end-of-life are staggering, leading to what is considered “medical waste”. In this context, “medical waste” denotes medical spending for services and goods that are unnecessarily spent and provide minimal or no health benefit. Medical waste in the United States has increased considerably over the years and more importantly, has costed many people meaningful final years of life and ultimately a good death. To minimize medical waste at the end-of-life, the societal perspective and culture of death denial must change. A change in the culture of death denial will improve the end-of-life experience for all, while reducing costs, saving resources, and allocating those resources to better means.

Culture of Death Denial

To begin implementing an effective change to the American culture of death denial, it is critical to understand the specific elements establishing the current culture of death denial and the effects thereof. These specific elements are the history of old age in the United States, the rise of individual independence, and the societal consequences derived from society’s extreme focus on maintaining individual independence till the end-of-life.

History of Old Age in the United States

Early recollections of how old age and death were perceived in the United States has altered within the last few centuries. Therefore, it is significant to recognize the history and change in perspectives of old age in the United States. The transformation of the perspectives of old age are a result of the variation in the family dynamic, the societal significance of old age, and the increase of life expectancy.

Life expectancy has gradually improved over the course of human history, especially in the last few centuries. Then it is no surprise that, “Before the twentieth century, life expectancy was short but generations were long" (Ruggles, 2003, p. 145). At the time, it was quite uncommon for parents to reach old age and still have their children living with them. However, when a parent did live to reach old age, often times one or more of their children would remain to live with them. Although these situations were infrequent, circumstances such as these would necessitate what would be considered as a multi-generational family dynamic. In most cases, this system was created out of necessity because the parent(s) were too weak to perform the work and take care of themselves. Typically, the child that remained would aid the parent by contributing effort, time, and work. As repayment for the effort, time, and work given, the child could expect to inherit the parent's money, land, or business. Ruggles (2003) stated that, "This multigenerational phase nevertheless played an essential role in the functioning of the pre-industrial family economy. It ensured continuity of the labour supply on farms and for other traditional livelihoods and provided economic security in old age" (p. 149). Meanwhile, in the 19th century, the multigenerational family dynamic began to decline, allowing the nuclear family dynamic to replace the multigenerational family in the early 20th century. Unlike the multigenerational family, the nuclear family dynamic was different. In this regard, Kertzer (1995, as cited in Ruggles, 2003) describes that the nuclear family emerged as children left the house to marry and when large numbers of older, elderly parents would move into the house of one of their children (p. 150). The nuclear family dynamic benefited many because if the parent(s) could not afford a place of their own, a child who was more financially stable and had extra space, could provide the parent(s) a place to live. Gawande (2017) expressed that the system of the multi-generational family and the nuclear family, "…shared the advantage of easily resolving the question of care for the elderly” (p. 17). Nevertheless, the creation and arrangement of the multigenerational and nuclear family allowed for a system of care that was accepted and functional during the mid-19th and early 20th century.

Currently, in the 21st century, many of the old and elderly are not treated the same. In the United States, a significant portion of the older population live alone either at home, on a hospital bed, or secluded in medical institutions. This shift in lifestyle can be attributed to the way old age was viewed and understood in the United States during the 20th century. More specifically, through the different popular press perceptions toward the significance of old age. Hirshbein (2001) indicates that in the early half of the 20th century, there were three overlapping phases in the ideas about old age represented in the popular press and mass media.

The first phase of ideas occurred from 1900 to 1920. The popular press during these two decades was primarily focused on the experiences and memories of the individuals approaching or already at old age. Many of these popular press sources were the general public and society’s source of information regarding old age. At the time, there had been no societal standard as to what age constituted “old age” and no designated list of characteristics that qualified as “old age”. Old age was viewed positively and “…there were no negative features necessarily associated with old age” (Hirshbein, 2001, p. 1556). In addition, the popular press instilled a broader cultural significance for those who were of old age. Rather than solely focusing on the experiences and memories of older people, the popular press also provided the opportunity for older people to represent history and the past. As Hirshbein (2001) states, “Whether or not these images of older people corresponded to real culture or events from the 19th century, they seemed to embody the memories that people in the 20th century wanted to have about the past" (p. 1557). It wasn't until 1920 when the societal idea of old age began to change.

The second phase of ideas represented in the popular press received a significant transformation from the first phase. From 1920 to 1930, information and resources on how to prolong youth and staying healthy were receiving greater emphasis. Depictions of feebleness, frailty, and infirmity among the old became commonplace. Soon, the societal idea of old age providing an opportunity to remember the past changed. "As Americans became aware of their nation's position as a new national power in the 1920s, many encouraged a look to the future rather than the past" (Hirshbein, 2001, p. 1557). It wasn't until the 1930s and 40s when the American society began to group the older population and separate the idea of remembering the past from the memories of old age. Then between 1930 to the 1950s, the popular press went through its third phase of ideas regarding old age.

Before 1930, many of the older population did not retire once reaching old age. Almost all stayed working until the financial funds to successfully retire were obtained. In the early years of this time frame, the Great Depression pushed for dire economic decisions. As a result, retirement for those of old age became more desirable among the American society. Many at this time viewed that retirement of older individuals would enable economic opportunity for those who were younger. However, Hirshbein (2001) revealed that, "During this time, the increasing numbers of older people came to be seen as adding a burden to American society" (p. 1558). This "burden" that old age presented was due to the ever-increasing opportunity for the older population to reach retirement age. Longer life expectancy enabled adults to reach the age of 65, therefore having more individualism, independence, and self-reliance. But with a greater population of older individuals, the indications of old age such as weakness, pain, and death became much more public. That’s when society began to question the value and significance of old age. Over the next two decades, old age in the United States became widely regarded as a medical problem needing a solution. In regard to how this was expressed in the popular press, Hirshbein (2001) specifies that, “…Old age within popular literature had become a topic for medical and other professional intervention, rather than a way to explain people’s lives or their position in the national order” (p. 1555). By the beginning of the 21st century, old age had become depicted as unwanted, undesirable, and less valuable.

Rise of Individual Independence

Coupled with these events, as family dynamics and societal perceptions of old age changed, so did economic and financial resources. Economic and financial resources such as Social Security, Medicare, and Medicaid, enabled a rise in income, pensions, and retirement. By means of these resources, the idea for individual independence and the pursuit of it, emanated for both young and old.

The search for individual independence in the United States came as a result of the ever-changing social spheres. As observed, the culture and social meanings of old age, growing old, and dying changed. Fleming et al. (2003), revealed that “This history has been shaped largely by the search for economic security” (p. 914). One aspect of this search for economic security was through the means of retirement. Back in 1790, many states began to make it mandatory for individuals in public office to retire at the age of 60 (Fleming et. al, 2003). Especially with increased life expectancy, numerous adults were able to maintain their connection to the work force well into their older years. Lee (2014) added that, "Rising US life expectancy has added years of life not only in old age but also in the current working ages of 20 to 65" (p. 234). Not only has the proportion of workers increased, but so has the actual population of older Americans. "Nonetheless, the proportion age 65 and over in the United States rose from 8 percent in 1950 to 13 percent in 2010 and is expected to rise above 20 percent by 2030 as the baby boom moves into old age" (Lee, 2014, p. 234). This is significant because more and more is the older population growing, playing an immense effect on how older individuals will choose to live their lives. Additionally, McFall et al. (2015, as cited in, Dong et al.,2017) stated:

> Ideally, those who are near or at retirement age who want to keep working and are able to do so, would have opportunities to work. Those in poor health, or with stressful or physically demanding jobs, would be able to retire or have the option to transition gradually to retirement through part-time or bridge work. (p. 325)

Rather than working till death or total disability, adults started to gain the opportunity to choose either to work well past retirement age or to retire and spend the remaining years of life doing whatever they wanted. Others, unfortunately faced disability and illness either from old age or from the physical jobs they spent decades performing, forcing them to retire. Regardless, the concept of retirement drastically changed the economic environment for the old and helped demonstration that it was possible to have an enjoyable old age experience. The difficulty for some however, was obtaining and living off of the necessary means during that period of retirement.

To accomplish those means, pensions became the second aspect of this search for economic security. Pensions began in the late 19th century but at that time, the pension system was unlike what it is today. Having been historically created for military purposes, "…the military pension was transformed into a rudimentary old-age system of social insurance for the working class" (Fleming et al., 2003, p. 916). After this change, the implementation of pensions both in the private and public sector became more common. Typically, working adults would expect to work till a certain age, retire, and acquire financial support dependent upon these pensions. Pensions as well began to influence how long individuals would work and when they would retire, transforming society's behavior. By the 20th century, retirement became a more viable option for many older Americans.

Besides pensions, the creation and implementation of the United States Social Security Act of 1935 is by far most important and influential aspect of this search for economic security. It wasn't until 1933 during the Great Depression, that it became clear that there was a need for a more supportive system to keep the elderly and retired out of poverty. Before 1935, pensions were the means that helped cushion the transition out of the workforce for the older American population. Now, the American population became fully dependent upon benefits from Social Security. The Social Security legislation helped improve and provide relief to the lives of many Americans and sought to offer safety for future downturns. In 1965, the Social Security Act was amended to implement the public programs of Medicare and Medicaid. This new amendment allowed for financial coverage for older and low-income individuals in regard to medical and health expenses. Fleming et al. (2003) explained that, "The combination of income assistance in the form of Social Security and health insurance through Medicare made retirement increasingly attractive and, for the first time, financially feasible for most elderly people"

(p. 917). Finally, numerous adults and elderly in the United States had the means to live through their final stage of life. Even today, Social Security still continues to provides pensions, securities, and benefits to the elderly, disabled, unemployed and their dependents. The elderly experienced and witnessed "…first-hand the demise of elder pauperism, the poorhouse, and the rise of pensions and retirement (Fleming et al., 2003, p. 918). Retirement ultimately became a period of higher wealth and greater ability of leisure.

At this point, the search for individual independence had finally been found for many adults and older individuals. In comparison, from the beginning of the 20th century to the beginning of the 21st century, "The economic wellbeing of the elderly has improved dramatically since World War II" (Arno et al., 2011, p. 236). This newly improved economic wellbeing allowed for a greater sense of financial freedom and control well into old age. Parents were the ones that provided economic security and when the time came, passed down their financial resources to their children and families. But as life expectancy increased, parents began to live longer and maintain control of their personal livelihood, without help or support. This continual control increased financial tension between children and parents, resulting in children leaving the house earlier in life, as seen in the nuclear family dynamic. Surprisingly, parents were content and became used to living alone through old age. With their children moving out earlier, parents weren't necessarily unhappy to see their children go. Parents now had the ability to choose how they wanted to live their lives. Many of which chose to continue living autonomously.

Putting this into perspective, in the United States "There are over 12 million Americans aged 65 and older who live alone—about a trifold increase compared to the mid-20th century (Klinenberg, 2013; Stepler, 2016, as cited in Mudrazija, 2020). With welfare programs and social supports currently present in the United States, living alone has become much more feasible, making it a common choice among older adults. Fleming et al. (2003) observed that:

> The desire to live independently as long as possible has gained increasing importance since the 18th century. Rather than representing a weakening of family bonds or kin responsibility, the gradual decline of the extended-family dwelling was welcomed across generations. The rise of the middle class made this long-desired goal a reality for more and more of the elderly population. (p. 920)

More than ever, the 21st century has become a unique time for the elderly to live. Though the preference to preserve individual independence and autonomy has enabled many to live a life they choose, there are resulting consequences.

Societal Consequences

For two centuries, society focused on how to maintain one's independence. Yet, during the 18th to 20th centuries, society lost precious time focusing on a more central and vital idea, such as the subject of death. All the while, the population of independent elderly continued to grow and the symptoms of old age and death became a closer reality for all. Thus, several societal consequences began to develop, two of which society currently faces. These consequences are the formation of the culture of death denial and an institutional existence designed to medically answer many of the unfixable problems encountered in old age.

Death Denial

Unsurprisingly, the topic of death can be a sensitive and frightful topic to internalize. Not many individuals want to ponder on the ultimate moment of their finite life, much less the stage in which it comes. There are times where patients or even family members never accept the outcome of death, especially if nothing more can be done for the patient. Zimmerman (2007) said, "Our society is death-denying, so it is not unexpected that patients and families are reluctant to acknowledge the finality of a terminal diagnosis" (p. 301). The idea of death is disconcerting; no one likes to be told they are dying. As a response, thoughts of death and its reality are repressed to hide the unpleasant truth. Expounding on this, Scott (1994, as cited in Zimmermann, 2007) stated:

> This fear and denial within our society has led us to ignore or minimize the huge and rapidly growing burden of suffering imposed by terminal illness. Our fear of death has dictated our society's massive expenditure on high-technology resources in the last months of life in frantic, futile attempts to prolong life. (p. 305)

Over time, this fear and denial have led to the ignorance and minimization of the approaching reality of death. In the past, the societal focus was primarily on managing the everyday aspect of life; however, death denial began to negatively impact choices regarding care, causing greater detriment to quality of life for many. According to Zimmermann (2007):

> Denial was perceived to be standing in the way of several components of palliative care: (1) open discussion of dying, (2) dying at home, (3) advance care

> planning, (4) symptom management and (5) stopping ‘futile’ treatments. These components of care form what may be considered a proper ‘way to die’". (p. 299)

Especially with increased life expectancy, people in the United States have had a greater chance of living a longer life. Unfortunately, many have failed to realize that independence will ultimately be lost, one way or another. All this time, rather than questioning what is needed to preserve and manage life for a long time, society should have asked the question, “If independence is what we live for, what do we do when it can no longer be sustained?” (Gawande, 2017, p. 23). Previous contemplation and attention of this question have occurred but not in the way or means necessary, leaving this question unanswered. One solution aimed to address this question resulted in the conception of medical institutions, such as nursing homes and hospitals.

Institutional Existence

Early in the United States, many of those who were dependent had the help of family. For those who did not have family, they found themselves in what was called a “poorhouse”. These poorhouses gave dependent individuals shelter, sustenance, but care was poor and basic needs were not met. As technology and infrastructure grew, hospitals were substituted for poorhouses and presented places of healing and health. “Focus shifted to medical and scientific advances and to big business, leading to a devaluation of the elderly population, whose remaining years were now bounded by dependency, decay, and dementia” (Fleming et al., 2013, p. 915). New ways were discovered to improve or remove the problems that life brought, making the prolongation of life possible. It was not long till the capabilities of modern medicine changed the way the United States practiced medicine. As Gawande (2017) observed, “…the advances of modern medicine have given us two revolutions: we’ve undergone a biological transformation of the course of our lives and also a cultural transformation of how we think about that course” (p. 29). This was especially true for the elderly and those at end-of-life. Elderly individuals with sickness, symptoms of aging, and chronic illness who had access to a hospital, flocked to them thinking that these conditions could be cured or fixed. Hospitals started to fill up and beds became occupied with patients requiring constant care, leaving not enough room for those desperately needing attention or immediate care. Soon, hospitals couldn’t meet the needs or demands required by both the young and old. That’s when, society began to regard old age as a problematic medical situation requiring a solution. As Fleming et al. (2013) said:

> With the Passage of Medicare and Medicaid legislation resulted in the rapid development of commercial nursing homes, accelerating the trend away from nonprofit and government facilities. Congress had intended the nursing home benefit as a mechanism to shorten hospital stays, thereby hoping to reduce costs. (p. 918)

Rather than utilizing the vast amounts of resources and time demanded from medical providers, nursing homes were the solution used to relocate the dependent individuals who occupied hospital beds. Nursing homes, just like hospitals years before, became another new place for a majority of the elderly, dependent, and sick.

The End Result

With the help of legislation and technology, nursing homes began to evolve into a place that would allow for elderly, dependent, and sick patients to receive expert care in a low-risk environment. Besides the special situations where an individual would be admitted into a nursing home out of necessity, families began to send their loved ones and elderly to these nursing homes for the sake of “safety”. Individual independence was still an expectation for families and their loved ones but as it turns out, individual independence and safety are mutually exclusive desires. For many, once independence was lost, a life of freedom and worth was unattainable. Gawande (2017) mentioned:

> We end up with institutions that address any number of societal goals—from feeing up hospital beds to taking burdens off families’ hands to coping with poverty among the elderly—but never the goal that matters to the people who reside in them: how to make life worth living when we’re weak and frail and can’t fend for ourselves anymore. (p. 77)

Not only were the elderly left in a controlled and supervised institutional existence, but for those at the end-of-life, the ability to control their quality of life diminished. In a sense, the culture of death denial led to an aggregate effect that significantly decreased the quality of life and death among many. Thus, as a consequence for a society that tries not to think about the final phase of life and not prepare for it, the medical costs at the end-of-life have increased, and ultimately leading to medical waste.

Medical Waste at End-of-Life

The healthcare industry in the United States is one of the most sophisticated, advanced, and finest healthcare systems in the world. Yet, the United States generally also has the highest mortality rate, lower life spans, lower recovery rates, a higher disease burden, the least access, the greatest cost, and the most health spending (as a % of GDP or “Gross Domestic Product”) as compared to other countries. Of the total healthcare spending in the United States, a significant portion is the end-of-life healthcare spending, whether it be privately or publicly funded. In the United States, the central public financier for healthcare among the elderly and chronically ill is Medicare. Recently, various articles and research have observed that end-of-life costs are a large proportion of Medicare spending. Two of the main institutions for the elderly and chronically ill, hospitals and nursing homes, receive Medicare reimbursements for the beneficiaries within. But with the existence of a culture of death denial, elderly and sick individuals opt for medical interventions and procedures that seek to cure or reduce the possibility of death, which are then generally paid for by Medicare or private insurance. Oftentimes, these interventions and procedures do not always succeed or provide significant benefit to the patient and their family. Currently, society's perception is that higher spending equals greater results. Unfortunately, this is not always the case. Especially in regard to medical procedures and outcomes, higher spending can frequently result in worse outcomes. Because of these perspectives and choices, this has led to a widespread amount of medical waste.

Although the attention of rising costs and medical waste is necessary, the greater concern and primary focus should be that medical waste is costing people their lives, quality of care, and death experience. This excess of spending not only affects those at end-of-life but other stakeholders such as families, the current population, medical providers, insurances, and future generations. Therefore, it is essential to address the medical costs commonly found at the end-of-life in both nursing homes and hospitals. Then when addressing the effect on the quality of life, we must ask the question, "Is prolonging life humane?".

Costs and Spending

Before analyzing the actual cost and spending of healthcare for the elderly, it is beneficial to recognize how the United States healthcare system functions and the influential players within it. Primarily, the United States healthcare system is not a universally accessible system like the United Kingdom, Switzerland, or other countries are. Rather it is a mix of both private and public programs and organizations. Of the two, the private sector is the main source of health insurance coverage for many Americans. Private health insurance has had continuous growth since the early 20th century. The Congressional Research Service (2021) measured that private health insurance accounted for $1,195 billion (33% of total health consumption expenditures) in 2019. To obtain private health insurance in the United States, the common method is either through employer-sponsored plans (group market) or individually purchased insurance plans (non-group market). However, for those who have employer-sponsored plans, once that individual reached retirement age, they lost their ability to retain their employer-sponsored plans. For many of those 65 and older, there needed to be some system or program to cover the health costs and spending. Thus, the use of Medicare and Medicaid. The Congressional Research Service (2021) found that as of 2019, not only were 58 million individuals enrolled in Medicare, but the total spending measured $799 billion (22% of total health consumption expenditures). At the same time, there were 64 million individuals who received Medicaid in 2019 (17.6% of total health consumption expenditures). Combined, Medicare and Medicaid comprised 39% of total health consumption expenditures, 6% more than that of private health insurance.

With Medicare and Medicaid covering health care expenditures for many of Americans 65 and over, large portions of spending are for care given at end-of-life. End-of-life care, as defined by the National Cancer Institute, is care that includes physical, emotional, social, and spiritual support given to both patients and/or their families. End-of-life is generally defined as a period ranging from the last two years or 6 months of life. In the United States, nursing homes have become one of the primary healthcare settings for those at the end-of-life. This is important because nursing homes are an institution that have an effect on the medical spending and care observed at the end-of-life.

Nursing Homes

Before death, nursing homes are the first stop for many of the elderly. After retirement and the loss of independence, many are brought to some kind of institutional setting for care, either of their own volition or by their family. The term “Nursing homes” is an umbrella term for institutional settings of care such as independent living, assisted living and skilled nursing. Regardless, the services and care provided by the nursing homes are not inexpensive. De Nardi et al. (2016) observed that in 2014, a typical nursing home stay estimated $77,000-88,000 a year (p. 722). If the role of gender were to affect the actual cost of nursing homes for an individual, De Nardi et al. (2016) stated that, “…women spend nearly twice as much on nursing home care as men” (p. 730). As age increases so does the private and public medical spending for those in nursing homes. In that regard, De Nardi et al. (2016) found that “In 2013, 29[%] of nursing home costs were paid out-of-pocket, while around 30[%] were covered by Medicaid” (p. 722). Within a few years, it is typical for a majority of those living in nursing homes to deplete all of their personal financial funds in order to pay for necessary care. requiring Medicare and Medicaid then would reimburse the nursing home on the patient’s behalf for the care performed. With nursing home stays and care demanding high such costs, it is no surprise that increased expenditures were the result. Overall, this contributed to a higher increase in the total Medicare and Medicaid spending.

When measuring and reporting the statistical data associated with Medicare and Medicaid spending, The Dartmouth Atlas Project created by The Dartmouth Atlas of Health Care can be a key resource. The Dartmouth Atlas Project intends to measure and document the variations of how medical resources are distributed and used in the United States. Use of this data can provide insightful information and analysis about national, regional, and local medical spending. Of the various data sets that are measured, one includes the Medicare reimbursements for Skilled Nursing Facilities (SNF) and Long-Term Care. The Dartmouth Atlas Project (2017a) indicates that Medicare reimbursements in 2017 ranged from a minimum of $1,062 to a maximum of $66,194. These reimbursements included payments to the facility or agency, and to physicians for services performed. From these results, it appears the Medicare spending within the last two years of life has maintained similarity to previous years. But within the last year and months leading up to death, both the medical expenditures and healthcare setting change.

Hospitals

Like nursing homes, hospitals are one of the many institutions in which end-of-life care is provided. Since hospitals account for a large part of total Medicare reimbursements for end-of-life care it can be perceived that many Americans find themselves in a hospital rather than a nursing home at the end-of-life. Consequently, hospital use has increased dramatically, especially for those in the last year to months of life. Hospitals in the United States experience one of the highest medical spending costs for those in the last year of life, confirming the exponential increase in costs as death approaches.

A primary cause for the high medical spending in hospitals is the underlying culture of death denial existing in the hospital setting. This uncomfortable relationship with death contributes to many Americans wanting to utilize immense hospital resources and high-tech interventions. Gawande (2015) mentioned, “In just a single year, the researchers reported, [25% to 42%] of Medicare patients received at least one of the twenty-six useless tests and treatments” (p. 2). The most common consequences that patients experience are repeated hospitalizations, poor care, unnecessary tests, painful interventions, and a death inconsistent with the patient’s wishes. Hence, “Dying in a hospital has been associated with high rates of unwanted aggressive treatment, underuse or late use of palliative care and poorer symptom management” (Waller et al., 2017, p. 1).

Today, much of the United States healthcare system still continues to concentrate medical spending at the end-of-life on patients who are terminally ill, sick, and over diagnosed. “In 2010, the Institute of Medicine issued a report stating that [medical] waste accounted for [30%] of health-care spending, or some [$750] billion dollars a year, which was more than our nation’s entire budget for K-12 education” (Gawande, 2015, p. 2). Researchers, medical providers, and policymakers consider unnecessary end-of-life care to be a major source of medical waste. More recently, Einav et al. (2018) expressed that “…one-quarter of Medicare spending in the United States occurs in the last year of life is commonly interpreted as waste” (p. 1). Statistical data showcasing this can be observed through “Hospital Care Intensity”. Created by the Dartmouth Atlas Project (2017b), Hospital Care Intensity demonstrates the intensity of care either by state, region, or hospital and is defined as, "…the number of days patients spent in the hospital and the number of physician encounters (visits) they experienced as inpatients". Throughout the United States different states had varying percentages of hospital intensity and showed fascinating results. The states that were the least intensive or aggressive in their hospital care were Utah, Idaho and Montana. The states with most intensive and aggressive hospital care were New Jersey, New York, and Florida. These results however, do not necessarily correlate with high medical spending.

Besides Hospital Care Intensity, the Dartmouth Atlas Project (2017a) also measured and recorded the total Medicare reimbursement across all states in the United States. The average reimbursement amounted to $68,844 with a range between $53,439 to $92,870. When comparing the total reimbursement data by hospitals, the low was $52,840 to an astounding high of $237,500. When narrowing the parameters for inpatient hospital Medicare reimbursement, the data showed a similar pattern. The average Medicare reimbursement cost for inpatient care was $30,353 with a low of $21,051 and a high of $46,087. Since 2003, inpatient spending for the last six months of life has gradually increased. Data has shown, especially in earlier decades, that high-cost and high-use regions tend to stay the same over time, suggesting that spending patterns in these regions play an important role in overall Medicare spending. Gawande (2009) illustrated that a variation in physicians' chosen practice patterns can create a difference in Medicare costs. In addition, "Health care expenditures are affected by Medicare reimbursement rules, which pay providers differently based on their geographic location" (Chicklis et al., 2015, p. 1576). More importantly, when looking towards the future, "The *Dartmouth Atlas* investigators estimate that the United States could save 40[%] of the resources spent on chronic illness if all regions adopted the practice patterns of high-quality, low-cost regions" (Chicklis et al., 2015, p. 1585). In the end, it is critical that the United States understands not only the statistical data and research but the overall significance these findings provide. The data and research show that the majority of medical spending is at the end-of-life. Yet, even despite these numbers, it is not enough to identify and focus solely on crude data and averages. The culture of death denial has a tremendous effect on the medical spending seen in hospital settings and the care performed. Unfortunately, denial has left many individuals waiting until death to begin preparing for the death they want, which has become not only costly but unrealistic.

Is Prolonging Death Humane?

The effect of the culture of death denial goes beyond just the medical costs in the United States. The immense end-of-life medical expenditures and rising medical costs are only one of many problems faced by those at the end-of-life. The other more significant problem is the quality of care and life for patients. For many patients and their families, a prolonged and painful death can be an overwhelming and terrifying thought. The general behavior and belief have been that in order to extend life, one must receive numerous medical interventions. This leads to a greater societal cost and a depletion of resources from the healthcare system. Rather, the behavior and belief should change to understand that often times, not everything technologically possible should be done. Although efforts have been made to make this change possible, outcomes show that futile attempts are still being made. Thus, the question is begged to be asked, "Is prolonging life humane"?

Ethically, this question provokes a serious and necessary examination of our societal behavior and mindset. When at the end-of-life, is the goal to prolong life or hasten death? How about neither? Rather, shouldn’t the goal be to have a meaningful life worth living till the very end? Possibly, the greatest honor that can be given is to enable and give an individual at the end-of-life the right to choose and shape their death in the most humane and dignified way. However, the ever-existent culture of death denial permits the notion that death is defeat, but this is not true. If unnecessary medical interventions for people who cannot be cured are stopped, these individuals can have a peaceful, comfortable, dignified, and humane death. To provide greater dignity and make death more humane, society can begin to implement greater end-of-life discussions through stronger doctor-patient relationships and earlier use of palliative services and hospice care.

Doctor-Patient Relationship

The doctor-patient relationship plays a significant role in the delivery of any services or health care for patients in need. Since the death experience for every individual is unique, the doctor-patient relationship is especially important as this relationship affects the care provided and ultimately, the death experience of the patient. Given the uniqueness of these situations, death happens in numerous settings and timelines. Oftentimes there are those who die suddenly and those who die after a prolonged period. Thus, the process by which end-of-life discussions occur are also unique. Glogowska et al. (2016) said in this regard:

> The first of these [discussions] was how death and dying are brought to the attention of patients and their families. Secondly, professionals discussed the issue of recogni[z]ing when patients might be at their [end-of-life]. Thirdly, the professionals’ attention was focused on the frequent hospital admissions of

> patients at the end of their lives, and their experience of working with services which might provide alternatives to admission (p. 3).

The role of the patient is created starting from the moment when an individual resorts to the advice and knowledge of a doctor for certain circumstances; however, the quality of this service ultimately rests upon the form of relationship created between the doctor and patient. Other possible stakeholders in the doctor-patient relationship are medical providers such as nurses, aids, and healthcare administrators. Unfortunately, medical providers have a difficult time engaging in these conversations. To showcase how often end-of-life discussions occur, Keary and Moorman (2015) observed that, "These conversations were quite rare, with less than 1% of our large sample reporting them" (p. 996). It is vital that stakeholders become more active and engaged in leading end-of-life discussions to comfort the patient and make their preferences, wishes, and values known. One method to encourage this change may be to ponder again and introduce Medicare reimbursements to physicians who engage in end-of-life discussions with their patients.

Apart from the passing of the Medicare and Medicaid legislation as part of the Social Securities act, potentially beneficial legislation that could have changed end-of-life care revolved around the 2010 Affordable Care Act. At the time, several politicians aimed to create a legislative bill that would allow and extend Medicare reimbursements every five years for physicians. The intent was to implement a method to provide greater cost savings for end-of-life care. Essentially, if the physicians participated in end-of-life care planning with the patient, they would receive Medicare reimbursements. However, the decision was made to remove this bill and provision from the Affordable Care Act.

It is necessary for the patient and their family, to have a clear understanding of end-of-life and death. This is important because, "...few patients will have discussed the place of death or wishes for end-of-life care in advance" (Glogowska et al, 2016, p. 8). Yet, patients and even doctors find it difficult to talk about the serious nature of death and the pain and disability that precede it. The Hartford Foundation (2016, as cited in Gerard 2017) indicated that "Most physicians say they have not received formal training on how to have end-of-life conversations" (p. 38). Thus, it is imperative that both the patient and their family work alongside medical providers to enable the patient a peaceful, comfortable, dignified, and humane death.

For doctors to continue this goal of providing a dying patient the best possible care and a comfortable and honorable death, the subject of death must be addressed in a timely fashion. It is no secret that America has had an uneasy, uncomfortable, and unwilling perception of death. Elizabeth's Kubler-Ross's book *On Death and Dying* demonstrated this exact notion in the late 20th century. As a result of her book, there has been positive change in policy and attitude about death and dying but it alone has not been enough (Guseva, 2019). That is why, certain skills must be learned and acted upon to create better patient engagement regarding the subject of death, especially when involving heightened emotions. Branch (2014) points out that one of the most, if not most, important skill with handling emotions is expressing empathy. Getting the right emotion at the right time in order to express genuine care is essential for connecting to the patient (p. 69). A lot of emphasis is focused on harnessing the power of medicine, but medicine has its limitations and capabilities. When medicine falls short, empathy is there to draw upon. When our bodies are weak and frail, we as humans still need reassurance, hope and love. Empathy provides the chance for doctors and care providers to draw on personal experiences and to better engage with the patient. By focusing on the human element of medicine and harnessing empathy, patients can experience better outcomes.

But as Walczak et al., (2014) stated, “Doctors’ avoidance of life-expectancy discussions is common, often for fear of destroying hope or the therapeutic relationship” (p. 2). In 2014, in an effort to make end-of-life discussions more common, the Institute of Medicine published recommendations that would enable medical providers to address end-of-life care preferences with patients and families. Two years later, Medicare and Medicaid billing codes designated to reimburse medical providers for engaging in end-of-life discussions were approved (Sullivan et al., 2017). With these additional methods and incentives, discussions about death and end-of-life are still difficult to have. For many patients, it was a possibility that “death anxiety” would also trigger defense mechanisms in order to deny, avoid, and essentially minimize the anxiety produced by the threat of mortality. (Walczak et al., 2014). By addressing these worries, fears, and questions, patients then are able to put trust and confidence in the capabilities of the doctor, leading to healthier outcomes. Thoughtful care from the doctor enables patients to participate in healthier and more active self-care that ensures the care is consistent with patient’s values. Gawande (2016) acknowledged:

> These patients have fears and worries about what is to come; they have goals and priorities for how they wish to live their lives; they have aspects of their lives they are willing to sacrifice, and aspects they are not willing to sacrifice, for the sake of more time; they have certain functions they consider essential for life to be

> worth preserving; and they want and need their caregivers and families to understand and support these concerns as a central part of their care. (p. 2)

Promoting closer, empathetic relations between the doctor and patient can allow for more comfortable and understanding end-of-life discussions. By encompassing more open-ended communication, this type of communication can aid in providing detailed information to the patient, by which doctors can listen and discuss the patient’s concerns. Branch (2014) notes that actual active and mindful listening plays a significant role in the value of the doctor-patient relationship. This type of listening means hearing every word spoken, noting the emotion behind what is said, hearing the tone of voice, observing facial expressions, dress, posture, reactions, and being able to follow the patient’s story while knowing the underlying theme (p. 69). Listening is an essential part of communication. Without listening, doctors become unaware of any thoughts, concerns, or questions the patient may have. Paying attention to the needs of the patients can assist doctors in helping the patient and their families to accurately understand the situation. As well as to encourage patients to define their goals and expectations for medical care and become more involved with end-of-life medical decisions. In the end, better communication and development of the doctor-patient relationship offers more opportunity for patients and their families to achieve greater diagnosis/prognosis understanding, medical literacy, and personal perception of care. Which in turn reduces the chance of choosing potentially futile care and increases the likelihood for earlier use of palliative services and hospice care.

Palliative and Hospice Care

In recent years, palliative services and hospice care in the United States have grown in popularity. Among high income countries, data and research show an increasing majority volume of deaths in institutional settings such as hospitals and nursing homes which has consequently led to fewer home deaths (Kasleth & Halvorsen, 2020). Due to poor experiences of dying in an institutional setting, this would drive the idea that people would rather die at home as compared to a hospital or nursing home. Waller et al., (2017) stated, “Between one-third and two thirds of people in developed world countries will die in hospital, and approximately 20% of people will die in an intensive care unit” (p. 1). With patients experiencing poor care, rising medical costs, and ultimately their deaths in these institutional settings, there has been a need to create a system with available resources to effectively reduce these numbers. In the United States, two of these systems, palliative and hospice care are designed to better enable patients and families with the ability to choose personal preferences about comfort, pain, end-of-life care, and place of death.

As a result, both palliative and hospice care have brought patients out of hospitals and nursing homes, providing them the life and death experience they need and want. Though palliative and hospice care provide greater patient comfort, these systems are different in regard to the focus of care, individual eligibility, actual services provided, and the method of payment for services. A key difference is mainly timing. Typically, palliative care can begin at diagnosis and at the same time as treatment. Hospice care, however, begins after treatment of the disease is stopped and when it is clear that the person is not going to survive the illness. Guseva (2019) states, “More than 66% of American Hospitals with 50 or more beds now have formal palliative treatment programs, ranging from 90% of larger hospitals to 56% of smaller ones" (p. 472). Besides palliative hospital programs, palliative care can also be found at home or other non-institutional settings. Evidence shows that care given in these settings is often performed by family or paid caregivers. Gardiner et al., (2019) explained that, "It is estimated that family caregivers provide 75% to 90% of home-based care for people who are near the end-of-life" (p. 1190). Unfortunately, "The United States is notable for its lack of national strategy or policy in palliative care" (Gardiner et al., 2019, p. 1191). Because of this, it has been difficult for family caregivers to receive the financial support needed due to the substantial end-of-life medical costs, making the use of palliative resources much more difficult to use and maintain. In comparison, hospice care has taken the brunt and burden off the families themselves by providing care through For-profit, Not-for-profit, and government organizations. With the United States program of Medicare and Medicaid incorporating a hospice benefit scheme, this has proven to be the main proponent for designing a system to help dying individuals the ability to avoid futile care and provide holistic care at the end-of-life.

To better understand the aspects of hospice, the National Hospice and Palliative Care Organization (2020) defines hospice care as the following:

> Considered the model for quality compassionate care for people facing a life-limiting illness, hospice provides expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's family as well. Hospice focuses on caring, not curing. In most cases, care is provided in the patient's home but may also be provided in freestanding hospice facilities, hospitals, and nursing homes

> and other long-term care facilities. Hospice services are available to patients with any terminal illness or of any age, religion, or race. (p. 2)

Hospice has indeed become a model of end-of-life care for various individuals and programs which has contributed to significant improvements in various aspects of the end-of-life. These improvements can be witnessed through:

1) Better communication about disease prognosis
2) Benefits and burdens of treatments
3) Costs of care
4) Psychological support
5) Tailoring of end-of life care to patient's needs, values, and preferences, and
6) The provision of coordinated team-based care.

In addition, hospice care has shown to decrease medical costs as well. With the rapid expansion of now, "more than 6,000 hospice programs across the United States" (Guseva, 2019, p. 471), hospice has become a high-value intervention for many because of its ability to affect end-of-life expenditures.

Last year, the National Hospice and Palliative Care Organization (2020) published its *Facts and Figures on Hospice Care in America*. This article contains primary data obtained in 2018. The article gives information necessary in understanding hospice patient characteristics, hospice provider characteristics, and Medicare hospice spending. Medicare, serving as the main source of funding and reimbursement for hospice care has covered upwards of 1.55 million Americans. Of those 1.55 Medicare decedents, 50.7% received one day or more of hospice care with the average Lifetime

Length of Stay (LLOS) being 89.6 days. In total, hospice patients received 114.0 million days of care coverage and reimbursement from Medicare. More than half (55.1%) of the hospice Medicare beneficiaries were female as compared to (46.1%) who were male. Since 2014, there has been steady growth in the percentage of Medicare Advantage enrollment, beginning at 30.2% with an increase of 6.7%, resulting in a 36.9% enrollment of a Medicare Advantage plan in 2018. Across the entire United States, each state has a different proportion of Medicare decedents enrolled in hospice. Leading with the highest hospice enrollment was the state of Utah, with a high of 60.5%. The lowest percentage of enrollment was “other” at 14.3% and Alaska at 22.8%. By focusing on end-of-life care, at the time of death, hospice contributed to a big change in bringing deaths from outside the hospital to individual homes. Of the 1.55 million Medicare beneficiaries, 1.1 million died at home which represents 51.5% of total deaths (those who died while enrolled in hospice). Although the other 48.5% of deaths occurred in other facilities such as nursing homes, assisted living, and in-patient settings, there has been a significant difference when compared to deaths in the past.

In terms of the total Medicare reimbursements and costs paid out to hospice, in 2018, the total Medicare spending for hospice care was $19.2 billion dollars. When measuring average spending per patient, in 2018 the average was $12,200. Especially in hospice, medical spending per patient can differ due to principal diagnosis. For the years 2017 and 2018, a majority of the diagnoses were cancer, with heart disease and dementia as the next leading diagnoses. As for actual hospice spending for terminal illnesses, various studies have shown that hospice has helped or can save end-of-life medical costs. Even when comparing hospice care and spending among different countries such as the

United Kingdom, Canada, Australia, Japan, Korea, and Taiwan, Obermeyer et al. (2014, as cited in, Huang et al., 2020) found that hospice care can save $8,697 per person in the United States for the cost of terminal medical expenses in the year before death. Hospice manages to reduce costs because not only are is hospice focused on limiting care but by not performing unnecessary treatments, healthcare costs are lower. Guseva (2019) said, "…hospices manage to seamlessly align morality with money: limiting care assures a 'good death', while also helping to reduce healthcare costs. And both help sustain the hospice economy and a largely for-profit industry in the United States" (p. 472). To increase cost savings even more, hospice can utilize a provider reimbursement policy. Chen et al., (2018) demonstrated that when patients used hospice, by expanding hospice care benefits through the use of provider payments and reimbursement policies, the cost savings can increase an estimated 7%. Despite the study performed in Taiwan, the United States might receive benefit if it were to take the principles from the study and apply it, making hospice more available. Right now, a lot of hospice services can be found in more populated areas in the country. Surprisingly, "In the United States, hospice services are unavailable in 24% of the rural communities versus only 1.3% of the urban communities" (Wang et al., 2016, p. 354). There is no doubt that these individuals, families, and communities deserve hospice services just as much as those who already have access. In the long term, by providing hospice services to greater portions of the country, medical costs should decrease. Ultimately, to save on end-of-life medical costs, patients should be referred to hospice care earlier to achieve greater quality of end-of-life care and a dignified and comfortable death. In the words of Gawande (2017), "The question therefore is not how we can afford this system's expense. It is how we can build a healthcare system that will actually help people achieve what’s most important to them at the end of their lives” (p. 155). This is the hope for the future.

Hope for the Future

I believe, that as human beings, we fundamentally deserve to die in an honorable, peaceful, and loving way. Family, friends, and ultimately ourselves, will all have to come to terms with death, its reality, and its experience. In the United States, studies have shown that medical care expenditures at the end-of-life are an excellent target for cost containment and change, but this on its own will not be enough. That’s why, Gawande (2017) asks the noteworthy question, “How can we build a healthcare system that actually works and achieves the goals for those at the end-of-life?” (p. 155). To accomplish this essential goal, I believe three things must be done: (1) Change culture of death denial, (2) Reduce costs effectively, and (3) Improve the end-of-life experience. By changing the culture of death denial in the United States, the end-of-life experience would improve for patients and their families, and as a result, cut down on unnecessary costs which will help allocate those savings to where it is needed.

Change the Culture

The first and most important thing that can be done is to change society’s perception of death. It is beneficial to acknowledge that such an immense change may seem like an impossible feat but if such a change can happen, death may not be a source of fear or denial. The work will be hard but when looking at how the perception of old age and death has changed over time, change is definitely possible.

In the past, death was viewed as the final step to the natural course of life. Life and death were intertwined; two parts to a whole. In a sense, death was stoic, without need of intervention, fear, and denial. This has drastically changed, to where now in the United States, the subject of death is often avoided or not thought about. Nor are discussions being had, which are necessary preparations for the final phase of human life. The use of modern medicine has tremendously blessed human life but has also negatively impacted society's approach to death, making death full of interventions and commonly experienced after a long course of struggle and pain. The problem has become a matter of going through the process of how to die and when.

Gerard (2017) has mentioned that we must begin to have open conversations about death in order to sincerely improve end-of-life care in the United States. "Overall, end-of-life care is an ongoing, dynamic process involving the interplay of clinicians, patients, and families, and is moderated by religion, culture, and personal preferences (among other factors)" (p. 28). This effort is not limited to patients and medical providers but applies to individuals, families, and communities. These conversations and improvements have the opportunity to positively control the way that death and end-of-life care is addressed, which can effectively change the way the culture of death denial affects our healthcare.

In addition to these conversations, healthcare administrators can work together to prioritize advanced care planning and end-of-life care. One consideration might be through implementing better training among doctors and other medical providers. Emphasizing better training on advanced care planning and end-of-life discussion, will allow healthcare providers to better serve as a conduit for conversation regarding death. This is especially important because priorities for the sick and elderly have been often misunderstood and misdirected. Families and medical providers must recognize that there are desires and values besides just wanting to live longer and in a safe manner. Examples of these desires are wanting to live at home with loved ones and having more control over everyday lives. As Gawande (2017) said, “We want these choices. But that doesn’t mean we are eager to make the choices ourselves. Instead, most often, we make no choice at all. We fall back on the default, and the default is: Do Something. Fix Something” (p. 174). To prevent falling back on the default, we can acknowledge and accept the different priorities patients may have. Doing this will provide greater control to the patient, allowing the patients to dictate how they live through engaging in whatever brings them joy and meaning. With patients having the agency to live their life in whatsoever manner they choose, the result will create a drastic change in the ways patients receive their end-of-life care. We must also search and discover a way to strike a balance between our fear of dying and our hope for a long, healthy life. To do this, we can begin involving society in conversations by asking questions like, “What is your attitude toward old age?”, “Is it something to avoid thinking about, or a stage of life to be honored?” and “Do you think most people are in denial about their own aging?”. Promoting greater discussions about death will help society contribute to a greater end-of-life for all.

Save Money and Reallocate

Data and research have shown that a significant percentage of Medicare spending goes to the patients in the last stages of life. Thus, medical waste at end-of-life has drawn attention over the years, especially when trying to cut expenditures and create greater savings. Modern medicine has allowed us to go farther than we ever have before and we have been fortunate to witness those capabilities and powers of modern medicine. In contrast, we have seen the damage of what too much medicine can do and when medicine falls short of its desired expectations. Although lives have been tremendously blessed in terms of ensuring health and survival, society still favors attempts to “fix” health problems, no matter the odds of their success. Which perhaps may be a reason why it has been so difficult for patients, their families, and doctors to curtail unnecessary treatment.

To curtail unnecessary treatment, one method would be to approach this in a “Lean” fashion. Typically, the more money thrown at the problem, the quality of the solution is diminished. Higher spending equals worse outcomes. Which is exactly what has been observed for those in institutional care settings. “Lean” as an operating model is just the opposite. Rather, attempts should be made to lower the amount of spending and focus on the quality of the outcome by eliminating waste and using as few resources as possible. This effort of controlling costs and outcomes would help patients tremendously improve their death experience. Money wouldn’t be wasted trying to expect better results and society can better understand on when to stop intervening on people who can't be helped or cured. In the end, a reduction in medical waste can aid in making more resources available to areas that need it. The main goal is not to eliminate unnecessary care altogether but rather find valuable, positive, and necessary care for all who find themselves at the end-of-life.

Improve End-of-Life Experience for All

Within the last two years, I have worked directly in the medical field as a Certified Nursing Assistant (CNA). Many of the patients I served were geriatric patients in a skilled nursing facility with either disability, chronic illness, or lack of support or resources to live independently thus requiring long-term care. As a CNA, it was my responsibility to support and help these patients do the things they couldn’t do themselves

There were days that had tremendous joy and feelings of value from being able to heal and help those in need while other days had high levels of stress, physical exhaustion, and emotional drainage. Day after day, I began to witness first-hand the situation and environment our sick and elderly lived in. I would see these patients void of anything that enabled them to live a meaningful life. Quite frankly, the focus of care I performed was directed to keeping the patient’s well-being preserved. Thus, in my work and efforts, I had to be intentional with everyday conversations. More importantly, outside my regular training and education, I had to learn to recognize these patients as individuals with passions, dreams, hope, love, sadness, pain, and fear.

There was a time during one of my shifts, I was asked by a co-worker to aid in changing the brief and transfer of their patient in order for the patient to be ready for their medical appointment two hours away. Walking into the room and addressing the patient by name, I introduced myself and my coworker and explained to the patient that both of us were there to change their brief, get them dressed, and help transfer into their wheelchair. I quickly began to read the patient report and I observed that the patient fell at home where broke her left femur and hip. Ever since then, she has been bed bound and declined progressively. Now, here was this patient in front of me, attached to a feeding tube, her body thin and fragile, laying on bed with a hospital gown draped across her body. I mentioned to the patient the steps that I was taking while removing her soiled brief. I quickly started to place a clean brief under her but needed to disconnect the patient from the feeding tube before doing so. Shortly after, the nurse arrived to disconnect and flush out the feeding tube. Once the patient was disconnected, both my coworker and I began to roll the patient again. No more than three seconds into the roll, the patient began to moan and scream. We immediately stopped and asked the patient what was wrong. She confirmed that it was her hip and leg that hurt. After a brief pause, I told her we would go slower and gentler, but it was necessary to roll her to correctly place the brief and get her ready. We were able to roll her farther than before but halfway through, the patient screamed again, much more intensely this time. By now, it had been at least 30 minutes and hardly any progress had been made. Unannounced, the speech therapist arrived along with a physical therapy aid with the patient's family on video call. At this point, the room was filled with at least 4 other medical workers, myself not included. With all of us in the room, we were able to work together to help get the patient ready. Unfortunately, no matter what we did, we could not help the patient get ready without the presence of pain. Towards the end, the patient was in excruciating pain, constantly moaning, and screaming to the point of crying. I remember pausing, allowing the patient to breathe and rest. In that quiet moment, that's when I heard the patient say, "Please, just let me die. I want to die". It wasn't until this encounter that my outlook on the end-of-life completely transformed and I became aware of the reality these patients faced.

Ever since then, I have both seen and heard numerous patients whose wishes were to die because of their pain and poor quality of life. When this would happen, I had family members express different wishes, hoping to keep their relative alive and to help them get stronger and better, disregarding their loved one's wishes, thinking that they are "giving up" if they allow for their loved one to pass away. Gawande (2017) voiced that:

> Our responsibility, in medicine, is to deal with human beings as they are. People die only once. They have no experience to draw on. They need doctors and nurses

> who are willing to have the hard discussions, and say what they have seen, who will help people prepare for what is to come, and escape a warehoused oblivion that few really want. (p. 188)

It should be obvious, but it’s not. We can see what’s missing. What is missing are these first-hand accounts as to what truly goes on and the life experiences for those at the end-of-life. Whether it be from the patient themselves, family, or medical providers. My personal experience has enabled me to learn that as a society and as medical workers, we must ask and listen to the wishes of the patient, especially the wishes that go beyond mere survival. Gawande (2017) asserted that the vital questions we can begin to ask ourselves, our loved ones, and any who encounter any sickness, injury, or possibility of death, are the following:

1. What is your understanding of the situation and its potential outcomes?
2. What are your fears and what are your hopes?
3. What are the trade-offs you are willing to make and not willing to make?
4. And what is the course of action that best services this understanding? (p. 259)

Promoting these honest discussions will help ourselves and loved ones experience a death truly honorable and memorable. Putting value on reasons to be alive not just at end-of-life but actually throughout life itself, will allow society to observe the transformation in the mindset and culture of death denial. By being realistic and intentional in our care and lives, medical waste would be diminished and reduced, thus gaining the opportunity to save costs and allocate resources to other areas in the United States that need it. When the time comes to appropriately decide where the saved costs and resources are allocated to, ideas could be greater hospice resources and availability, other medical resources, education, and any necessary area to be further decided upon.

Conclusion

In the United States, the history of old age and perception of death has taken a unique course. Changes to the family dynamic and economic resources have somehow led to an unsustainable focus and search for individual independence. Soon society began to avoid death and its existence, in order to maintain independence until the end of life. Consequently, a societal culture of death denial began to form, creating an ongoing problem for the United States. Although death is inevitable, society lacks the preparedness needed for the final phase of human and death when it comes. As aggregate choices were made to preserve life and autonomy for as long as possible, society needed a medical solution to solve the individuals who faced chronic illness and advancing age. This led to the creation of institutional existences but unfortunately this environment prevented those inside to have a meaningful life besides the goals of safety from dependency.

With countless improvements in technology, modern medicine has proven to be a valuable resource when aiming to preserve health and fix things when possible, but the capabilities of medicine only go so far. Oftentimes, these medical procedures do not provide any benefit, leading to medical waste at the end-of-life. This is because the societal default has been to fight death, but eventually death wins. Therefore, research was performed to discover to what extent medical waste occurs at the end-of-life. Research suggested that the large amounts of spending occur at the end-of-life in the United States. Hospitals, nursing homes, and other care settings are the major settings in which end-of-life care is performed, and subsequently the settings that contained the highest medical spending. Even despite great amounts of spending, patient care was poor and the quality of life was negatively affected. To improve the quality of life, care, and humanity of patients, attention has been given to increasing the likelihood of engaging earlier in discussions meant to be had at the end-of-life. Methods to accomplish this can be through improving doctor-patient relationships and enrolling individuals in palliative and hospice care earlier when applicable. If all of this were to be implemented, society would be better able to provide patients the wishes and preferences they want and need at the end-of-life.

There is no doubt that much more effort and research still needs to be had to provide greater understanding about this subject matter. In fact, this will be an ongoing effort requiring constant discussion and collaboration. With a focus on end-of-life costs, the culture of death denial has shown that there is a very real opportunity to change this culture, reduce end-of-life costs, and improve the end-of-life experience. I know that on the surface, as a society, we want to do what’s right. However, the hard part is finding how to do exactly that. If anything is to be achieved by this thesis, is to bring a general awareness and to become an advocate in making this necessary and fundamental change. By becoming more aware and educated as a society, we will more easily be able to find the discussion points, dialogue, and details necessary for true, effective change. The time is now. Addressing and effectively changing the culture of death denial can give society hope for a greater end-of-life experience; not only for ourselves, our loved ones, but ultimately for all.

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Name of Candidate: Christopher Hales

Birth date: June 6, 1998

Birth place: Salt Lake City, Utah

Address: 870 E Utah Highlands Dr.
Lehi, Utah, 84043