End-of-Life Healthcare in the U.S.

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction & Problem Frame

The United States has the world's most expensive but least effective healthcare system, and a disproportionate amount of our healthcare resources are spent on older patients (Kumar et al., 2011; Marik, 2015). As shown in Figure 1, the U.S. spends almost twice as much on healthcare as other comparable high-income countries. However, as seen in Figure 2, the U.S. has the worst medical outcomes compared to other countries. For instance, the U.S. has the lowest life expectancy, highest infant mortality, and highest obesity rate.

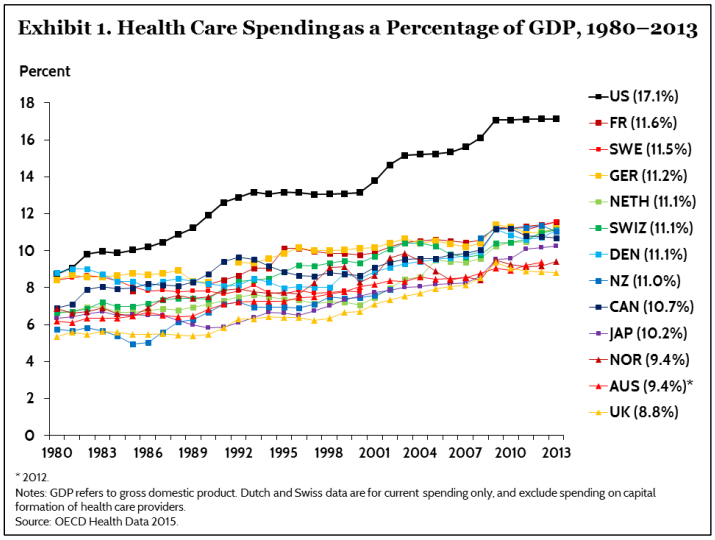

Figure 1: Healthcare spending as a percentage of gross domestic product (GDP) by country. The U.S. is represented as the upper black line (Squires & Anderson, 2015).

Though elderly patients (65 years of age and older) only make up 11% of the U.S. population, they account for 34% of health care expenditure. As shown in Figure 3, compared to other countries, the United States uses a significant amount of healthcare resources on the older population (Marik,

Exhibit 9. Select Population Health Outcomes and Risk Factors

	Life exp. at birth, 2013[a]	Infant mortality, per 1,000 live births, 2013[a]	Percent of pop. age 65+ with two or more chronic conditions, 2014[b]	Obesity rate (BMI>30), 2013[a,c]	Percent of pop. (age 15+) who are daily smokers, 2013[a]	Percent of pop. age 65+
Australia	82.2	3.6	54	28.3[e]	12.8	14.4
Canada	81.5[e]	4.8[e]	56	25.8	14.9	15.2
Denmark	80.4	3.5	–	14.2	17.0	17.8
France	82.3	3.6	43	14.5[d]	24.1[d]	17.7
Germany	80.9	3.3	49	23.6	20.9	21.1
Japan	83.4	2.1	–	3.7	19.3	25.1
Netherlands	81.4	3.8	46	11.8	18.5	16.8
New Zealand	81.4	5.2[e]	37	30.6	15.5	14.2
Norway	81.8	2.4	43	10.0[d]	15.0	15.6
Sweden	82.0	2.7	42	11.7	10.7	19.0
Switzerland	82.9	3.9	44	10.3[d]	20.4[d]	17.3
United Kingdom	81.1	3.8	33	24.9	20.0[d]	17.1
United States	78.8	6.1[e]	68	35.3[d]	13.7	14.1
OECD median	81.2	3.5	–	28.3	18.9	17.0

[a] Source: OECD Health Data 2015.
[b] Includes: hypertension or high blood pressure, heart disease, diabetes, lung problems, mental health problems, cancer, and joint pain/arthritis. Source: Commonwealth Fund International Health Policy Survey of Older Adults, 2014.
[c] DEN, FR, NETH, NOR, SWE, and SWIZ based on self-reported data; all other countries based on measured data.
[d] 2012. [e] 2011.

Figure 2: Medical outcomes by country. The U.S. is highlighted in orange (Squires & Anderson, 2015).

2015). America is aging and our current healthcare system cannot sustain the aging population. By 2034, older adults will outnumber children for the first time in U.S. history (Figure 4) (*An Aging Nation*, 2018). Along with an aging population or more older adults is a rise in health problems. Figure 5 shows how the rates of chronic diseases, diabetes, arthritis, and obesity are all projected to rise in the coming years (*When I'm 64: How Boomers Will Change Health Care*, 2007).

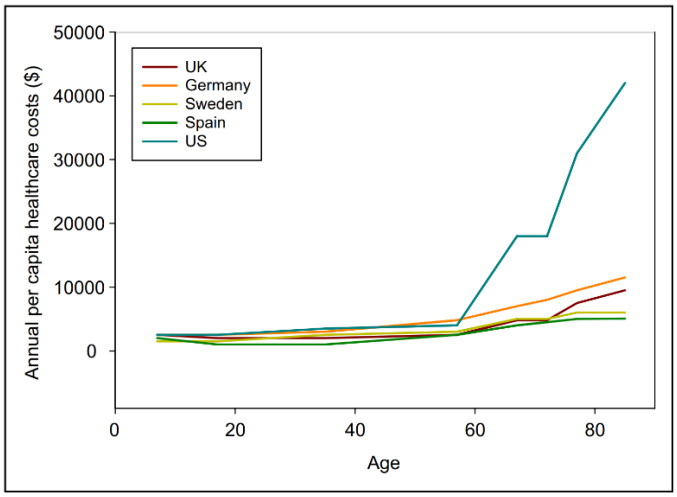

Figure 3: Annual per capita healthcare costs as a function of age. The U.S. is represented as the upper teal line (Marik, 2015).

Our current healthcare system is unsustainable both in terms of healthcare resources and economically. In Figure 6, from the 2020 Congressional Budget Outlook, the blue curves show how our spending on Social Security and healthcare programs like Medicare and Medicaid are increasing due to the aging population. The red line represents total federal revenue. Federal programs like Medicaid are funded by federal revenue. And as illustrated in Figure 6, the blue and red lines cross in 2036, meaning the United States is projected to consume all federal funding by 2036 (*The 2020 Long-Term Budget Outlook*,

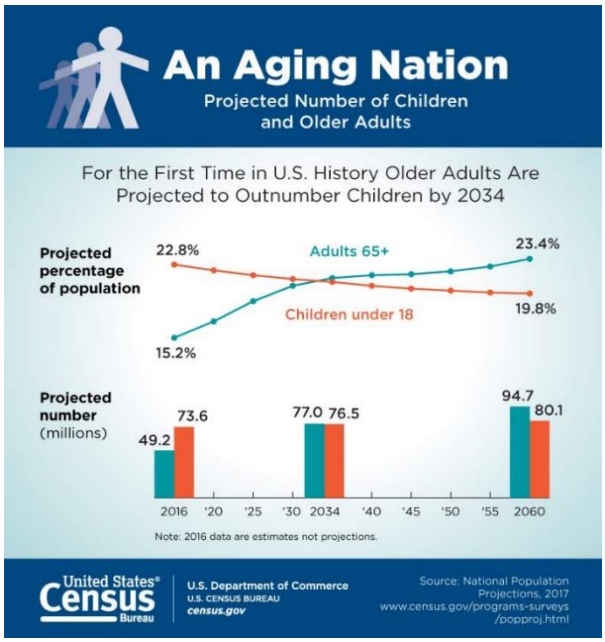

Figure 4: Projected population of children and older adults from the United States Census Bureau (*An Aging Nation*, 2018).

2020; *What Is Devouring Our Taxes?*, 2021). The U.S. essentially has infinite demand for healthcare but finite economic resources.

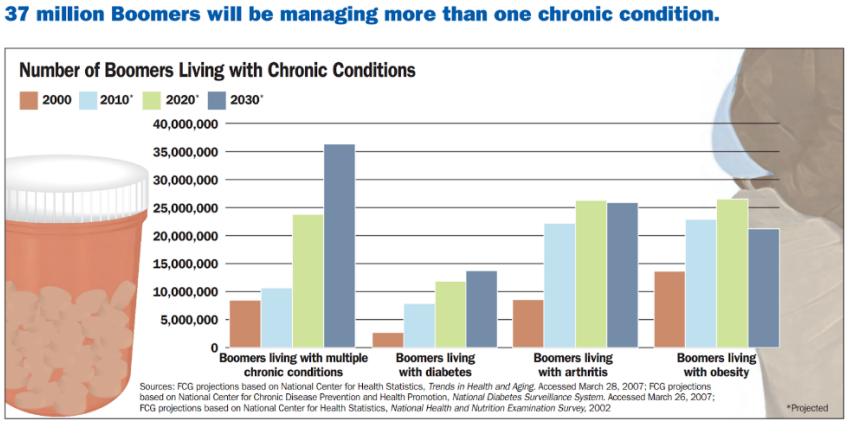

Figure 5: Projected number of older adults with chronic conditions (*When I'm 64: How Boomers Will Change Health Care*, 2007).

The aging American population will result in an increase in demand for health care as well as palliative care (PC) due to longer life expectancy and more chronic disease (*When I'm 64: How Boomers Will Change Health Care*, 2007). Additionally, the structure of our current healthcare system often does not act according to patient preferences. By reviewing scholarly literature and research from the fields of healthcare, economics, and philosophy through an ethics of care theoretical framework, this research paper aims to demonstrate that our healthcare system can and needs to be more cost effective by shifting our notion of care from treatment to prevention. End-of-life care in the U.S. has much room for improvement and needs to change, as the current healthcare system is unsustainable.

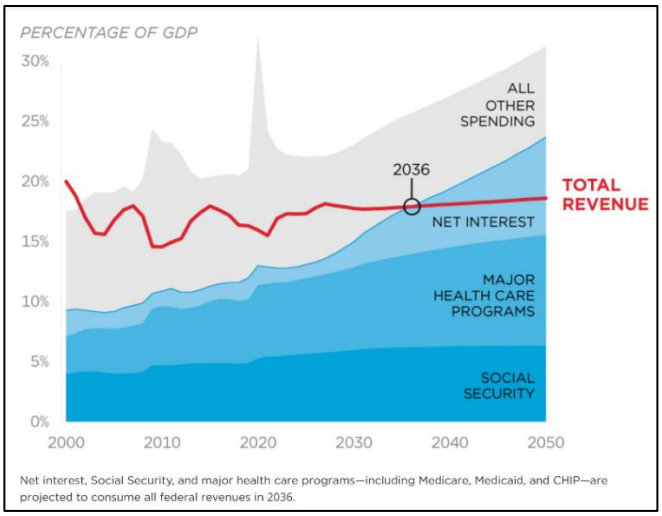

Figure 6: Federal outlays for net interest, Social Security, and major health care programs from the 2020 Congressional Budget Outlook (*The 2020 Long-Term Budget Outlook*, 2020; *What Is Devouring Our Taxes?*, 2021).

High Expenditures

Compared to other high-income countries, the United States spends nearly twice as much on health care yet has worse medical outcomes and the lowest life expectancy (Squires & Anderson, 2015; Tikkanen & Abrams, 2020). Hospitalization and using high technology health care resources at the end of life likely account for the U.S.'s uniquely high healthcare spending (Marik, 2015). The U.S. has eight times more intensive care unit (ICU) beds per capita than other Western Nations, again with a disproportionate number of elderly patients using these ICU beds. Not all elderly patients benefit from ICU use, and despite the Society of Critical Care Medicine's guidelines to reserve ICUs for patients with "a reasonable prospect of substantial recovery," almost all patients with serious illnesses are admitted to ICUs regardless of their prognosis (Marik, 2015).

Chronic diseases – such as heart disease, cancer, stroke, diabetes, osteoarthritis, and Alzheimer's – are the primary health care costs in the U.S., with over $1 trillion of total direct costs for treatment of chronic diseases in 2016. By 2030, more than 80 million people are predicted to have at least three chronic diseases. (Levine, 2019).

Against the Patient's Wishes

Surgery often does not help elderly patients live longer, nor does it guarantee the same quality of life they had pre-operation. Some contributing factors include our aggressive and invasive attitude towards healthcare and difficulty translating the value of the quality of life into surgical decisions. Seniors who hold a life-or-death framework feel obliged to choose life and therefore surgery, reporting that declining any life prolonging measures would disappoint others. They expressed how it would be better to die while attempting to prolong life, as they believed

that death in the operating room to be painless, out of their control, and satisfy their obligation to pursue life – despite being informed that perioperative death occurs later in the ICU. Seniors also have a hard time believing that modern medicine sometimes has nothing more to offer. In their peer-reviewed study, Nabozny et al. concluded that misunderstandings and false expectations dictate high-stakes surgical decisions and that it's difficult to align personal preferences with treatment decisions (Nabozny et al., 2016; News, n.d.).

Another reason why patient preferences may not be followed is because of death anxiety. Assistant professor and geriatrician Gary Sinoff found that while the elderly had low levels of death anxiety, their children had high death anxiety. While the elderly usually fear suffering and the process of dying, their children fear death and often project onto their parents. This can cause children to not tell their parents relevant medical information (even if that contradicts the patient's preferences), highlighting the need for honest communication between elderly patients, their children, and medical staff (Sinoff, 2017). We are essentially making older people die slower, sometimes against their wishes.

Instead of focusing on treatment and pressuring older patients to undergo treatment, we should shift our focus to preventive and PC services. Preventing disease is much more favorable to treating people after they get sick, especially for chronic diseases, which have increasing numbers of deaths and health care costs in America due to the aging population. In their peer-reviewed article, Levine et al. found that most providers do not prioritize preventive care services – although they know how such services can reduce the incidence of chronic diseases, hospitals and physicians alike are currently paid more to treat disease rather than prevent them (Levine, 2019).

The Economics of Healthcare

Our current healthcare policies are predicted to not be able to support the aging American population (*Population Aging Will Have Long-Term Implications for Economy; Major Policy Changes Needed*, 2012; *The 2020 Long-Term Budget Outlook*, 2020). Longer life expectancy and lower birth rates means that programs like Medicare and Medicaid will have more beneficiaries but less contributing workers in the near future (*Population Aging Will Have Long-Term Implications for Economy*, 2012). A leading ethical question of modern medicine is: how much money should be spent on keeping sick patients alive? Scarcity is intrinsic to market economies, and the U.S. healthcare system is no exception. Despite general acknowledgment of the current unsustainable spending trends and criticism of over-treatment, end-of-life spending continues to increase. Moral decisions become intertwined with economics as life, often perceived as priceless, encounters finite economic resources. Finite financial resources exist to pay for the excess of life-prolonging interventions, in other words, the demand far exceeds the supply.

Assistant Professor of Sociology Roi Livne argues this scarcity of money and resources can be moralized in a positive way through the hospice ethic perspective. Hospices' and hospitals' financial interests and the overall goal to reduce end-of-life care spending converge with the hospice ethic, which gives new connotations to the dying process by emphasizing virtues of acceptance and limited treatment. Deciding to limit spending helps people come to terms with their approaching death and avoids prolonging unnecessary suffering from aggressive treatments (Livne, 2014). We often say that money is no object when it comes to keeping someone we care about alive, but we are not taking into account the suffering that someone has to endure by receiving life prolonging treatments like surgery or chemotherapy.

In the current era of rapid advances in technological medicine driven by profit, dying has a high price in terms of suffering and personal economic loss. Terminal care is essential to health care, but comprehensive PC can be very expensive. Despite remarkable advances in medicine, serious flaws remain with a system that is majorly influenced by the marketplace, such as the ever-increasing cost of drugs and treatments (Rizzo, 2000).

Alternative Approaches

Two problems people face at the end of life are, one, lack of quality care, and two, the ever-increasing cost of health care. Both may be mitigated with earlier and increased PC. Increasing PC intervention achieves the primary clinical effects (reducing symptom burden, increasing inter-team communication, better alignment between treatment and patients' goals) but also the secondary and unintended outcome of reducing cost due to terminating unwanted or ineffective treatments and decreasing hospital services (Dalal & Bruera, 2017).

Paul E. Marik, a Professor of Medicine at Eastern Virginia Medical School, offers other suggestions of more realistic treatment plans for elderly patients such as time-limited trials in the ICU for patients with uncertain prognoses and considering PC and an ethics consult rather than ICU admission or ongoing care for patients with irreversible diseases (Marik, 2015). Hospitals, patients, and patients' families spend tremendous amounts of money trying to prolong patients' death (sometimes despite patient preferences); this money may be better spent trying to promote health and well-being and thus preventing the need for treatment in the first place (Nabozny et al., 2016; Sinoff, 2017). The reason Americans are willing to go to such extensive lengths for medical care may be because of unrealistic expectations of modern medicine perpetuated by the media, a strongly individualistic culture, and the inability to accept death (Marik, 2015).

Analogous to Birth Doulas, who help women throughout their pregnancies, Death Doulas are now emerging in end-of-life care. Death Doulas work with people at the end of life and have similar responsibilities as PC nurses, but they notably offer the possibility of personalized care directed by the dying person either in addition to other health services or without other oversight. They can serve as a mediator and communicator between patients, families, and medical staff for better communication and more alignment with the patient's preferences (Rawlings et al., 2019).

In the past, death may have meant the end of life, but we think about death very differently now. Much of what we associate with death is constructed and would not exist without us. Berger and Luckmann's now famous thesis from 1966 on the social construction of reality is based on two fundamental concepts: reality and knowledge. Reality refers to phenomena we cannot control; knowledge refers to the certainty of how real phenomena are. Sociology Professor Sarah Brabant claims that the construction of death – which involves the moment of death and bereavement for example – is consistent with Berger and Luckmann's social construction of reality. Each construct is experienced while one is awake, exists apart from the individual, is organized around the present "here and now," and is thought to be shared with others (Brabant, 2011). Other than the medical death itself, everything else associated with death – including healthcare and our attitudes regarding death – is constructed and can thus be changed.

STS Framework: Ethics of Care

The ethics of care theoretical framework is a feminist, contextual approach that emphasizes "human connectedness" and "communal relationships." American feminist philosopher Rosemarie Tong argues that ethics of care is an appropriate approach for healthcare

that highlights the importance of emotion and care in health morale. A person can not genuinely care for someone if they are forced to economically, socially, and/or psychologically – however, this increasingly characterizes the world of healthcare and medicine. Tong states that healthcare practitioners must try to become more caring, conscientious, and empathetic people and that healthcare cannot just be another commodity marketed to consumers. In their most vulnerable times, patients probably do not just want a doctor who can do surgery, they want a doctor that cares for their well-being as a human being, a sentiment Tong herself expressed (Tong, 1998). A system driven by capitalism leaves little room for care and compassion, which leads to medical miscommunication and mistranslation. At the heart of it, ethics of care focuses on the person, which would be the patient in this context.

Conclusion

The current healthcare system in the U.S. is inefficient, expensive, unsustainable, and often does not align with patient preferences. A disproportionate amount of healthcare resources is spent on the elderly, and considering the aging American population, there is expected to be an increase in demand for palliative care (*When I'm 64: How Boomers Will Change Health Care*, 2007). This research paper illustrates why our healthcare system should shift our notion of care from treatment to prevention and focus on preventive and palliative care. Such a shift would not only align better with patient preferences but also benefit the healthcare system by becoming more sustainable and cost effective.

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