Palliative Care and Dementia:

An Underutilized Method in the Fight Against a Health Crisis

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Acknowledgments

There are many people I need to thank, as without each of them this project would not have been possible, and I cannot fully express my gratitude for each person's thoughtfulness, patience, and kindness when it came to helping me complete my thesis. First and foremost, I would like to thank Professor Jo Hardin for the immense amount of support she has given me over the course of the past year. Professor Hardin single-handedly taught me how to use R studio, and has dedicated an incredible amount of her time and mental energy assisting me in this project. Throughout the entire process, she met every setback, pivot, and challenge with grace, patience, and astounding intelligence. I would also like to thank Professor David Menefee-Libey for overseeing my project, providing constant feedback, encouragement, and reassurance. The Public Policy Analysis department is incredible, owing much to the leadership and energy of DML, and I have been very lucky to have majored in the program. I also owe a huge amount of gratitude to Hilary LaConte, who is the backbone of the PPA program. Without her, I would have never figured out which classes to take, when to take them, and I would have been lost at Pomona without her. I would also like to give an enormous thanks to Professor Elizabeth Glater, who graciously agreed to be my second thesis reader despite having minimal information regarding my project. Although our work together was brief, it was an absolute pleasure to work with her and I am incredibly lucky to have had her input on my thesis. Tons of credit must also be given to Dr. Julien Cobert, who provided the idea for this project and an immense amount of guidance throughout its completion, and selflessly mentored me throughout last summer and this past fall. Finally, I would like to thank my parents, Penny and Peter, as I owe absolutely everything to them. Not only would this project be impossible without them, but I never would have been able to attend Pomona without their constant support in all areas of my life. I love you both so much and I am the luckiest kid in the entire world!

Introduction

In an age where people are living longer, the ability to provide specialized care to an aging population has become more important than ever. One way that healthcare practitioners are improving the way they treat aging patients is by treating based on the patient's priorities, rather than exclusively on what the doctor thinks is best for the patient's health. This type of patient-oriented care is called palliative care and it is a newer yet rapidly growing field in the medical world.

Palliative care is defined as specialized care for people living with a serious illness, whether it be a chronic or terminal disease, or in the context of patients receiving high risk surgeries.[1] Palliative care can be delivered in the hospital (e.g., ICU) or in a hospice setting and is focused on treating the pain and stress that is typically associated with serious illnesses. The ultimate goal of palliative care is to make the patient as comfortable and happy as possible, while also considering the needs and comfort of the patient's family. There are many different metrics used to determine whether palliative care is appropriate for a certain patient, as well as many metrics for evaluating whether the treatment is successful. Multiple studies have looked at specific outcomes of patients that received palliative care and compared them to outcomes of patients with similar illnesses and comorbidities (other factors that affect the health of the patient, such as age, family history, other health risks, etc.) who did not receive palliative care. Outcomes that have been investigated include aggressiveness of interventions, utilization of hospice, length of stay in the hospital/ICU, length of survival, whether or not the patient has an

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[1] "What Is Palliative Care? | Definition of Palliative Care | Get Palliative Care," accessed October 30, 2020, https://getpalliativecare.org/whatis/.https://getpalliativecare.org/whatis/"What Is Palliative Care?"

advanced directive, and quality of life.[2,3] Quality of life is evaluated using a variety of methods, such as patient questionnaires (both for the patient and the patient's family), physical mobility, level of independence, and severity of treatments/medication.[4]

Another result of people living longer is that the prevalence of dementia is rapidly increasing. As people live longer, the odds of developing dementia increases drastically, resulting in many more people suffering from the serious consequences associated with all different types of dementia. From 2000 to 2018, deaths from Alzheimer's disease, which is the most common type of dementia, increased by 146%, while over the same period of time, deaths from heart disease decreased by 7.8%.[5] Alzheimer's disease, which is only one type of dementia, is the 6th leading cause of death in the United States, and death is far from the only detrimental consequence associated with Alzheimer's and other forms of dementia. The different forms of dementia all have detrimental effects on the patient as well as the patient's family, as well as being very costly and difficult for doctors to treat.[6]

"Dementia" is defined using many different metrics, and is not a single disease, but rather a term that encapsulates a wide range of medical conditions that involve abnormal brain changes.[7] The changes cause a decrease in cognitive ability, such as thinking skills, memory, and other functions that are imperative to living independently. Decline in brain function affects the

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[2] Koji Amano et al., "Association between Early Palliative Care Referrals, Inpatient Hospice Utilization, and Aggressiveness of Care at the End of Life," *Journal of Palliative Medicine* 18, no. 3 (September 11, 2014): 270–73, https://doi.org/10.1089/jpm.2014.0132.

[3] Jennifer S. Temel et al., "Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer," *New England Journal of Medicine* 363, no. 8 (August 19, 2010): 733–42, https://doi.org/10.1056/NEJMoa1000678.

[4] Koji Amano et al., "Association between Early Palliative Care Referrals, Inpatient Hospice Utilization, and Aggressiveness of Care at the End of Life," *Journal of Palliative Medicine* 18, no. 3 (September 11, 2014): 270–73, https://doi.org/10.1089/jpm.2014.0132.

[5] "Facts and Figures," Alzheimer's Disease and Dementia, accessed February 26, 2021, https://www.alz.org/alzheimers-dementia/facts-figures.

[6] "Facts and Figures," Alzheimer's Disease and Dementia, accessed February 26, 2021, https://www.alz.org/alzheimers-dementia/facts-figures.

[7] "What Is Dementia?," Alzheimer's Disease and Dementia, accessed November 2, 2020, https://alz.org/alzheimers-dementia/what-is-dementia.

patient's feelings and behaviors, making it difficult for families to care for the patient without professional help. Diseases that fall under the broad category of "dementia" include, among others, Alzheimer's, vascular dementia, and Lewy body dementia. The wide variety of how cognitive diseases present themselves in different people makes it difficult for doctors to correctly diagnose the patient, which in turn makes it complicated to treat them effectively and efficiently.

It is important to note that while terribly physiologically debilitating for the patient, Alzheimer's and other dementias are equally, if not more so, psychologically devastating for the patient and the patient's family. Due to its currently untreatable nature, the diagnosis of Alzheimer's alone often has devastating effects on the patient's mental state, especially because the progression of the disease is so debilitating both physically and mentally. The progression of the disease is described by family and friends of the patient as terrible to witness, and by the end, makes the patient's loved-ones unrecognizable, and can transform the patient into an entirely different person. Joel Shurkin, a professor of writing who taught at Stanford and UC Santa Cruz, lost his wife to Alzheimer's. In an article he wrote detailing his experience with the disease, he describes the hopelessness he felt watching the woman he loved forget entirely who he was, as well as her transformation from a kind, brilliant and cunning researcher at Johns Hopkins to a shell of a human who would exhibit fierce aggression that he never felt was possible from her.[8]

Once a patient is diagnosed with dementia, they are assigned an International Classification of Disease (ICD) code that corresponds to that specific disease. ICD codes are used so that healthcare practitioners can quickly, easily and ideally, consistently, assign a diagnosis to a patient, and that diagnosis can then be used (through ICD coding) to secure proper treatment from different specialties, as well as ensure insurance coverage and reimbursement for

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[8] Joel Shurkin, "The Human Toll" (Scientific American, May 2020).

the patient and the practitioner. However, the ambiguity that surrounds different kinds of dementia makes it difficult for practitioners to assign the proper ICD code to the patient. Without the correct ICD coding, neither patients nor practitioners will receive insurance coverage, and will thus be denied adequate treatment.[9] In order to ensure that patients are receiving appropriate care for serious illnesses, it is essential that the coding system in place can be easily, consistently, and correctly implemented.

As if the physical and psychological tolls of dementia are not challenging enough, the cost of treating dementia is incredibly burdensome, and is quite difficult to overcome by itself. Following his wife's diagnosis of Alzheimer's, Shurkin had to pay over $12,000 in legal fees, and $80,000 per year for a nursing home once his wife was no longer able to live at home. In the state of Maryland where they lived, in order to qualify for Medicaid, he needed to have less than $2,500 in his bank account. Over the course of this tragedy, Shurkin lost all his retirement funds, and even had to sell his home and move into an apartment.[10] While working towards better treatments and eventually a cure for Alzheimer's is incredibly urgent, ensuring that patients and their families do not have to go bankrupt due to their diagnosis is equally important, especially while a cure for the disease does not currently exist.

The cost of treating dementia patients is also quite burdensome for the healthcare system as a whole. In 2020, Alzheimer's and other dementias cost the nation $305 billion, and by 2050 these costs are projected to rise as high as $1.1 trillion.[11] These costs include $206 billion in Medicare and Medicaid payments, indicating the additional costs borne by taxpayers. The total

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[9] Julie Clements, "Proper Documentation Essential for Dementia Coding in ICD-10," *Outsource Strategies International* (blog), September 2, 2019, https://www.outsourcestrategies.com/blog/proper-documentation-essential-for-dementia-coding-icd-10.html.

[10] Joel Shurkin, "The Human Toll" (Scientific American, May 2020).

[11] "Facts and Figures," Alzheimer's Disease and Dementia, accessed February 26, 2021, https://www.alz.org/alzheimers-dementia/facts-figures.

lifetime cost of caring for someone with dementia is very high due to the constant level of care that dementia patients need, usually over the course of a long period of time. Of the total cost involved in caring for a patient with dementia, 70% is covered directly by families of the patients, either in the form of out-of-pocket costs, long-term care expenses, or from the value of unpaid care for family members.[12]

In addition to the cost placed upon individual families and the overall healthcare system, dementia patients can also burden healthcare practitioners, largely due to the amount of care they require and the complexity of the diseases themselves. This burden of care mostly falls upon primary care physicians, who often have not received sufficient training on how to treat dementia patients. In a 2020 report done by the Alzheimer's Association, 82% of primary care physicians said that they are the main care providers for dementia patients, but many of them also stated they are not confident in their ability to care for patients with Alzheimer’s and other dementias.[13] Almost 2 in 5 (39%) primary care physicians responded they are “never” or only “sometimes” comfortable making a diagnosis of Alzheimer’s or other dementias. When faced with patient questions regarding Alzheimer’s or other dementias, 27% report they are “never” or only “sometimes” comfortable when answering questions about the disease treatment and trajectory. This lack of confidence is based in the fact that most physicians have very limited training, and some receive no training at all on the diagnosis and treatment of dementia. Of the primary care practitioners who reported having received training in residency about dementia diagnosis and

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[12] “Facts and Figures,” Alzheimer’s Disease and Dementia, accessed February 26, 2021, https://www.alz.org/alzheimers-dementia/facts-figures.

[13] “Facts and Figures,” Alzheimer’s Disease and Dementia, accessed February 26, 2021, https://www.alz.org/alzheimers-dementia/facts-figures.

care, 65% felt that the amount of training they received was “very little,” while 22% of all primary care physicians had no residency training at all.[14]

The growing rate and prevalence of dementia in tandem with the lack of education and preparation for treating dementia patients are creating the potential for a medical emergency. Over 50% of primary care physicians believe that the medical profession is not ready for the growing number of people with Alzheimer's or other dementias, and 51% believe there are too few options for continuing education and training on dementia care.[15] Just below a third (31%) say that current options for continuing education and training for dementia care are difficult to access, and 37% of primary care physicians say they learned the most about dementia care from their own experiences treating patients.[16] While learning from experience is a great way to hone skills and identify the best methods of care, it is an unacceptable standard when it comes to such a serious and common group of diseases. Dr. Joanne Pike, PhD, an expert in the study of dementia, believes the importance of this problem must be addressed, claiming that “we’re heading toward a medical emergency, when it comes to ensuring dementia care will be available for all who need it.”[17]

Beyond the increasing prevalence of dementia, its burdensome costs and the lack of preparation for this disease in the healthcare system, there are also disparities between different groups of people in terms of who develops dementia and who has access to sufficient care. These

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[14] “Primary Care Physicians on the Front Lines of Diagnosing and Providing Alzheimer’s and Dementia Care,” Alzheimer’s Disease and Dementia, accessed February 26, 2021, https://alz.org/news/2020/primary-care-physicians-on-the-front-lines-of-diag.

[15] “Primary Care Physicians on the Front Lines of Diagnosing and Providing Alzheimer’s and Dementia Care,” Alzheimer’s Disease and Dementia, accessed February 26, 2021, https://alz.org/news/2020/primary-care-physicians-on-the-front-lines-of-diag.

[16] “Primary Care Physicians on the Front Lines of Diagnosing and Providing Alzheimer’s and Dementia Care,” Alzheimer’s Disease and Dementia, accessed February 26, 2021, https://alz.org/news/2020/primary-care-physicians-on-the-front-lines-of-diag.

[17] “Primary Care Physicians on the Front Lines of Diagnosing and Providing Alzheimer’s and Dementia Care,” Alzheimer’s Disease and Dementia, accessed February 26, 2021, https://alz.org/news/2020/primary-care-physicians-on-the-front-lines-of-diag.

disparities exist largely between different ethnic groups and socioeconomic groups. One study found that even when controlling for risk-factors of dementia, such as heart disease, history of stroke, education level, and literacy, African-Americans are twice as likely to have Alzheimer's or other dementias as whites.[18] Older Hispanics were found to be one and a half times more likely to have Alzheimer's or other dementias as older whites. And, despite this higher prevalence, African Americans and Latinos with Alzheimer's are, on average, less likely than white Americans to be diagnosed by a healthcare professional, meaning that true rates are even higher.[19] Furthermore, due to higher prevalence and lack of proper coverage, African Americans bear a disproportionate amount of the costs of dementia. While African Americans make up only 13.6% of the U.S. population, they pay for almost 33% of the costs of Alzheimer's disease and other dementias. In total, the economic burden of Alzheimer's and other dementias for African Americans was $71.6 billion in 2012, and has only increased more recently.[20]

One way that disparities appear in the treatment of patients with Alzheimer's or other dementias is in how frequently patients are prescribed with medication used to treat dementia. In a study done by Hernandez et al. which looked at how often different ethical groups were prescribed dementia-medications, the researchers found a significant difference between white patients and minorities. The study showed that whites were much more likely to be prescribed AChEI or memantine, which in 2010 when the study was conducted, were the two FDA-approved medications for moderate to severe dementia. The researchers found that 59% of white patients were prescribed one or both medications, while only 43% of non-white patients

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[18] Alexander L. Chin, Selamawit Negash, and Roy Hamilton, "Diversity and Disparity in Dementia: The Impact of Ethnoracial Differences in Alzheimer's Disease," *Alzheimer Disease and Associated Disorders* 25, no. 3 (2011): 187–95, https://doi.org/10.1097/WAD.0b013e318211c6c9.

[19] Ilene H. Zuckerman et al., "Racial and Ethnic Disparities in the Treatment of Dementia Among Medicare Beneficiaries," *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences* 63, no. 5 (September 2008): S328–33.

[20] "Disparities," UsAgainstAlzheimer's, accessed March 16, 2021, https://www.usagainstalzheimers.org/learn/disparities.

received these treatments.[21] Furthermore, in a similar study that focused only on Medicare patients with dementia, Zuckerman et al. found that when controlling for demographics, socioeconomics, health care access and utilization, comorbidities, and service year, anti-dementia medication was used 30% more frequently among non-Hispanic whites compared to other ethnic groups.[22] These findings suggest that the observed differences in treatments between racial groups are not due to demographic, economic, health status, or access, but rather may result from deeper biases ingrained within our healthcare system and within healthcare practitioners.

In contrast, a prospective cohort study by Yaffe et al. that tracked a group of elderly (60 or older) people in order to compare the dementia rates between white and black people, found little difference between ethnicities. Initially, the study found that 20.7% black participants developed dementia, while only 16.6% of white participants developed dementia.[23] However, once the results were adjusted by grouping the participants by socioeconomic status, the difference between black participants and white participants was no longer significant, suggesting that differences in risk factors, specifically socioeconomic status, likely play a large role in the higher rates of dementia seen among older black people compared with older white people. Yaffe et al. concluded that an effective way to lower dementia rates would be to mitigate risk factors, such as socioeconomic status.[24]

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[21] Santiago Hernandez et al., "Pharmacological Treatment of Alzheimer's Disease: Effect of Race and Demographic Variables," *Journal of Alzheimer's Disease : JAD* 19, no. 2 (2010): 665–72, https://doi.org/10.3233/JAD-2010-1269.

[22] Ilene H. Zuckerman et al., "Racial and Ethnic Disparities in the Treatment of Dementia Among Medicare Beneficiaries," *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences* 63, no. 5 (September 2008): S328–33.

[23] Kristine Yaffe et al., "Effect of Socioeconomic Disparities on Incidence of Dementia among Biracial Older Adults: Prospective Study," *BMJ* 347 (December 19, 2013): f7051, https://doi.org/10.1136/bmj.f7051.

[24] Kristine Yaffe et al., "Effect of Socioeconomic Disparities on Incidence of Dementia among Biracial Older Adults: Prospective Study," *BMJ* 347 (December 19, 2013): f7051, https://doi.org/10.1136/bmj.f7051.

In tandem, the studies outlined above reveal that the reason for the higher rates of dementia among African-Americans is not a singular thing, but rather a combination of factors that include lack of access to care, inherent biases among healthcare practitioners, and prevalence of risk factors such as socioeconomic status.

With the growing number of dementia patients and the lack of adequate care that is available, it is imperative that the current practices and policies surrounding dementia care are evaluated and improved. Furthermore, the disparities that exist between people of different ethnicities and socioeconomic statuses in terms of who develops dementia and who has access to sufficient care make dementia treatment an issue of equality, as well as a general inadequacy of our healthcare system. While there is no simple fix for the problems that dementia presents, it is essential that the problems are addressed and acted upon.

Research Goals

The goal of this thesis is to examine the use of palliative care, focusing on the use in the context of dementia, and to identify the policy barriers that prevent palliative care from being utilized more, as well as the issues surrounding proper care for all dementia patients, regardless of ethnical or socioeconomic factors. Once the barriers have been identified, I will make recommendations of ways to overcome the barriers, and, based on my research, what changes I believe must occur in order to make palliative care widely accessible. To illustrate potential discrepancies in who receives palliative care using real-life examples, I will use a dataset with patient information to examine how the demographics of dementia patients who receive palliative care differ from those who do not, as well as looking at a variety of different characteristics of these dementia patients, such as race, insurance, gender, and socioeconomic class. Finally, I will also delve into the biological processes behind the mental degradation of dementia, examining how these diseases affect the brain and human body.

The support for my assertions will largely be provided through literature reviews, looking into both palliative care, dementia, and how the two intersect. I will also examine literature to look at policies and policy issues that surround palliative care and dementia, and will use sources and my own research to make recommendations for policies moving forward.

The data aspect of this project will examine data from forty thousand patients who stayed in critical care units between 2001 and 2012, specifically looking at patients who had dementia, and then examining the characteristics of the patients as well as which of them were treated using palliative care. Using the dataset and R, which is a computer program that enables manipulation of large data sets in order to examine different parameters within the data set, I isolated a cohort of patients who were coded for dementia, Alzheimer's, or other similar cognitive degenerative diseases. An immense amount of data wrangling was necessary before I was able to examine the data itself, such as merging files based on values, renaming and manipulating certain rows and columns within the dataset, removing duplicate entries, and organizing the patient data into a usable format. The group of dementia patients was isolated using ICD codes associated with dementia which were identified from existing literature.

Once I isolated the group of dementia patients, I also created a second cohort of patients using free-text notes written by nurses, doctors, technicians, etc. in the ICU. The second cohort included all patients whose note contained a reference to the patient receiving palliative care or a palliative care consult. Using the two cohorts of patients, I generated a master-cohort, with columns identifying whether patients were ICD coded for dementia or not, as well as if a patient received palliative care or not. This master-cohort also contains all the pertinent information for each patient, such as age, gender, insurance, ethnicity, religion, and free-text notes. I then examined the characteristics of the patients in order to evaluate the sociodemographic characteristics of the patients that have dementia, receive palliative care, or both.

I expect to see results that match the larger trends that exist within the demographics of dementia patients and palliative care patients. Certain groups are more at risk of developing dementia, specifically older people, women, and racial and ethnic minorities.[25,26] The risk of dementia increases greatly as age increases, especially after the age of 65 and again after the age of 85. The prevalence of dementia among different ethnicities varies largely as well: the probability of developing dementia at the age of 70 or older is 8.4% for non-Hispanic whites, 12.7% for non-Hispanic blacks, and 17% for Hispanics.[27] In accordance with these trends, I expect to see a higher rate of dementia among patients of increasing age, patients who are gendered as women, and patients who are racial and ethnic minorities.

The way dementia patients are treated also varies based on demographics, especially when it comes to socioeconomic status. Middle-income people (annual financial resources of $25,001–$60,000 dollars) with dementia are less likely to receive paid care, meaning that most care provided to middle-income dementia patients is either unpaid by family members or out of pocket.[28] Similarly, the chances of receiving palliative care greatly increases as income increases, as usually only private insurances will cover the costs of the care, and the only other option for families to access the care is oftentimes to pay out of pocket.[29] Due to the difficulty in receiving

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[25] “Demography of Dementia and Dementia Caregiving,” accessed April 27, 2021, https://www.prb.org/the-demography-of-dementia-and-dementia-caregiving/.
[26] C. A. Lane, J. Hardy, and J. M. Schott, “Alzheimer’s Disease,” *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.
[27] “Demography of Dementia and Dementia Caregiving,” accessed April 27, 2021, https://www.prb.org/the-demography-of-dementia-and-dementia-caregiving/.
[28] “Demography of Dementia and Dementia Caregiving,” accessed April 27, 2021, https://www.prb.org/the-demography-of-dementia-and-dementia-caregiving/.
[29] “Palliative Care, Report Card,” Palliative Care, Report Card, accessed October 14, 2020, https://reportcard.capc.org/.

dementia care as a middle-income person, I predict that a vast majority of the dementia patients will either be insured privately or by Medicaid/Medicare. Furthermore, I predict that the rates of dementia patients who receive palliative care will be much higher among patients who have private insurance as opposed to those with Medicaid or Medicare.

This research has the potential to change the way patients are treated both within and outside the ICU. By drawing attention to the disparities in which patients are diagnosed and treated for dementia, as well as how patients receive palliative care based on their sociodemographic characteristics, such as ethnicity, gender, etc., doctors and policy-makers who read this paper will be better equipped to make the right decisions surrounding dementia-care. By examining their own biases and having access to effective and continued training, healthcare practitioners can be more equitable, accurate and consistent in the way they treat their patients. With the help of new policies, requirements can be made to ensure that patients receive proper treatment regardless of their ethnicity or other characteristics, and to ensure that the healthcare system is ready and well-equipped to fight the battle against the surging cases of dementia.

Dementia Biology

As mentioned previously, “dementia” does not refer to a specific disease, but rather is used as an umbrella-term for many different kinds of neurological degenerative diseases. These diseases include Alzheimer's, vascular dementia, frontotemporal dementia and Lewy body dementia. While these diseases can present in similar ways, they are each different in their own unique way. Of all different disease types, Alzheimer's is by far the most common form of the disease, accounting for 50%–75% of all dementias, and it is the most well-known and researched. It is also a very deadly disease, killing the patient on average 8.5 years after initial presentation.[30] Because of this, I will review the biological mechanisms behind Alzheimer's, looking at what is currently understood about the disease, what is still left to be discovered, and how patients are currently treated as well as potential future therapies.

Biology of Alzheimer's

Alzheimer's, along with most dementias, is a condition that is primarily developed later in life, with its prevalence doubling every 5 years after age 65.[31] While the exact cause of Alzheimer's is not fully understood, its development is closely linked to clumps of misshapen protein fragments located in the brain. The clumps consist either of β-amyloid protein or pathologic tau protein, and are thought to cause neurodegeneration. Pathologic tau, β-amyloid and neurodegeneration are the three biomarkers most often used to diagnose Alzheimer’s. The accumulation of the specific proteins β-amyloid and tau result in pathological processes that cause lesions to form in the brain, leading to neurodegeneration with synaptic and neuronal loss.[32] This process culminates in macroscopic atrophy, or the death of brain cells on a large scale.

Mechanistically, β-amyloid builds up and clusters in between neurons, while tau clusters inside the neuron. More is currently known about the effects of β-amyloid deposits, which have been shown to activate microglia, although there are other theories about what β-amyloid does at a molecular level. Microglia, which account for 10–15% of all cells found within the brain, are a type of immune cell located throughout the brain and spinal cord, and act as the first and main

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[30] C. A. Lane, J. Hardy, and J. M. Schott, “Alzheimer’s Disease,” *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.

[31] C. A. Lane, J. Hardy, and J. M. Schott, “Alzheimer’s Disease,” *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.

[32] Clifford R. Jack et al., “NIA-AA Research Framework: Toward a Biological Definition of Alzheimer’s Disease,” *Alzheimer’s & Dementia* 14, no. 4 (April 1, 2018): 535–62, https://doi.org/10.1016/j.jalz.2018.02.018.

form of immune defense in the central nervous system.[33] Unfortunately, the microglia immune response, unlike other more specific immune responses in the body, is not targeted to the entity that triggered the response, but rather generates a broad assault on the area. The sweeping immune response of the microglia often results in the damage or destruction of healthy brain-cells in addition to the harmful clusters.[34]

The accumulation of β-amyloid deposits is something that has been deemed necessary, but not sufficient, for diagnosing Alzheimer's.[35] Many individuals die with significant β-amyloid deposits, and yet, show no symptoms of Alzheimer's during their lifetime.[36] There are other clinical symptoms that doctors rely on to make a definitive diagnosis, which include both cognitive assessments and physiological tests. Blood tests, including full blood count, renal function, and thyroid function are often performed as an initial step, primarily to exclude other conditions which may cause or contribute to common symptoms of Alzheimer's. If the blood tests do not pinpoint abnormalities that could explain the symptoms the patient is experiencing, the next step is to take images of the brain. Magnetic resonance imaging (MRI) identifies possible harmful protein deposits as well as ruling out the other neurodegenerative diseases that could be the culprit of dementia symptoms (Figure 1).[37]

Cognitive assessments are performed alongside a detailed description of symptoms in order to observe the possible indicators of Alzheimer's disease. The most common symptom of Alzheimer's is forgetfulness, specifically centred on episodic memory. Other cognitive indicators

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[33] Sara Bachiller et al., "Microglia in Neurological Diseases: A Road Map to Brain-Disease Dependent-Inflammatory Response," *Frontiers in Cellular Neuroscience* 12 (2018), https://doi.org/10.3389/fncel.2018.00488.
[34] Kenneth Kosik, "The Way Forward" (Scientific American, May 2020).
[35] C. A. Lane, J. Hardy, and J. M. Schott, "Alzheimer's Disease," *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.
[36] C. A. Lane, J. Hardy, and J. M. Schott, "Alzheimer's Disease," *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.
[37] C. A. Lane, J. Hardy, and J. M. Schott, "Alzheimer's Disease," *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.

of the disease are difficulties with multitasking and loss of confidence. However, it is not until the issues begin to interfere with activities of daily living that the patient can be diagnosed with Alzheimer's. In severe cases, typically later on in the advancement of the disease and close to death, substantial behavioral changes, impaired mobility, hallucinations and seizures may all occur.[38]

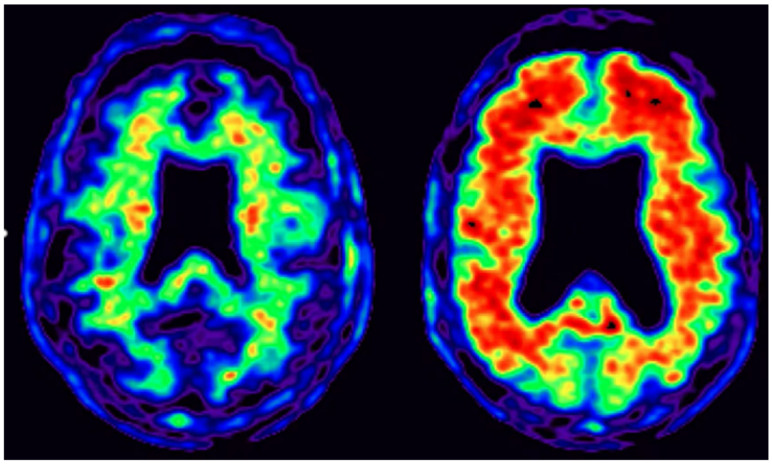

Figure 1: Imaging of a healthy brain (left) and an Alzheimer's disease patient (right). The red coloring indicates high amyloid accumulation, which leads to neurodegeneration.[39]

Current Treatments

Although there is currently no cure for Alzheimer's or even a way to effectively combat the disease, there are treatments available that help to slow its progression. The most common class of drugs used to treat the disease are acetyl-cholinesterase inhibitors, such as donepezil, galantamine and rivastigmine. These inhibitors increase the availability of acetylcholine, which is a neurotransmitter that affects learning, memory, and other cognitive functions, thus making it

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[38] C. A. Lane, J. Hardy, and J. M. Schott, "Alzheimer's Disease," *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.

[39] C. A. Lane, J. Hardy, and J. M. Schott, "Alzheimer's Disease," *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.

a useful tool to slow the progression of the disease.[40] The other commonly used pharmaceutical is a N-methyl D-aspartate receptor antagonist called memantine, which is only used in patients with moderate to severe Alzheimer's. Memantine works by reducing L-glutamate, which is the most abundant excitatory neurotransmitter in the central nervous system.[41] While the promotion of neurotransmitter activity may sound like a desired outcome, this subtype of glutamate receptors, actually causes over-activation of the transmitters, which is believed to contribute to the neurotoxicity in Alzheimer's disease. Memantine prevents the overactivation of glutamine receptors while allowing normal levels of activity to continue.[42]

The current list of medications available to dementia patients is short, and unfortunately, even the ones that are approved by the FDA are not very effective. On average, acetyl-cholinesterase inhibitors and memantine have been shown to slow the progression of Alzheimer's disease by around six months.[43] Some patients experience benefits for a longer time, while others for shorter periods. Both medications help patients by improving their performance of activities of daily living, and contributing to the management of some non-cognitive behavioral disturbances. Unfortunately, both medications also come with a host of adverse side-effects, including disruption of sleep, enhanced risk for bleeding, and even potentially deadly side-effects, such as slowing of the heart rate to the point of danger.[44]

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[40] "Cholinesterase Inhibitors for Alzheimer's, Side Effects, and Uses," MedicineNet, accessed March 26, 2021, https://www.medicinenet.com/cholinesterase_inhibitors/article.htm.

[41] Anil Kumar, Arti Singh, and null Ekavali, "A Review on Alzheimer's Disease Pathophysiology and Its Management: An Update," *Pharmacological Reports: PR* 67, no. 2 (April 2015): 195–203, https://doi.org/10.1016/j.pharep.2014.09.004.

[42] Brianne Kuns, Alan Rosani, and Dona Varghese, "Memantine," in *StatPearls* (Treasure Island (FL): StatPearls Publishing, 2021), http://www.ncbi.nlm.nih.gov/books/NBK500025/.

[43] "Do Alzheimer's Medications Really Help?," BrightFocus Foundation, May 26, 2015, https://www.brightfocus.org/alzheimers/article/do-alzheimers-medications-really-help.

[44] "Do Alzheimer's Medications Really Help?," BrightFocus Foundation, May 26, 2015, https://www.brightfocus.org/alzheimers/article/do-alzheimers-medications-really-help.

Future Research

While the current treatments for Alzheimer's are clearly insufficient, there are many areas of research that have immense potential when it comes to developing a cure for the disease. For starters, the inability to properly rid the brain of β-amyloid and tau clusters, as well as the key components behind the inflammatory response to these proteins, are just some of many unknowns surrounding the causes, mechanisms, and potential treatments for Alzheimer's. These proteins pose additional questions beyond why they cannot be destroyed, such as why they cluster in the way that they do, and what exactly the clusters look like. If researchers were able to identify the reason the accumulation of these proteins, technically described as "conformations," are harmful to the brain, and how those conformations occur, it would be possible to create drugs to target and destroy the harmful clusters. In recent years, researchers have gotten closer to identifying the mechanisms behind the formation of harmful tau clusters. In 2017, a photo of an abnormal tau cluster inside of a cell was recorded in great detail, revealing thousands of tau proteins interlocked into a c-shape.[45] While this discovery is by no means a cure within itself, this type of fundamental research is a step in the right direction.

Beyond the specific shapes of folded proteins, another potential method of treatment involves investigating how and why the folding processes occur. If the reason and conditions under which the proteins fold into harmful conformations can be elucidated, there is potential to prevent this process from ever beginning. Current research projects are examining the phase transition of tau, which refers to the protein changing from a liquid into a solid, as the protein can only congregate into its harmful c-shape when it is in solid form.[46] Phase changes require a change in energy state, and if tau's energy state drops too low, which is something that occurs in

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[45] Kenneth Kosik, "The Way Forward" (Scientific American, May 2020).
[46] Kenneth Kosik, "The Way Forward" (Scientific American, May 2020).

its solid state, the protein cannot shift back. A phase change increases the rigidity of the protein, transforming the protein into its potentially harmful state.[47] If the conditions behind a phase change can be identified, it could be possible to stop the transformation from happening by controlling the environment of tau's location in the brain.

Unfortunately, although there have been drugs developed that target and destroy protein clusters, none of the clinical trials on those drugs have demonstrated a meaningful slowing of cognitive decline. However, it is important to note that most studies that have examined the potential drugs have used subjects with late stage Alzheimer's. Some researchers believe that at late stages in the disease, β-amyloid and tau may no longer be the most appropriate target, and destroying or preventing the clusters is something that must occur early in the development of the disease.[48] Of course, the issue then becomes identifying the disease early enough in order to treat it effectively. Unfortunately, early detection is not something that is possible at this point in time, although progress is being made in developing screening protocols based on genetic analysis and identification of risk factors that will allow for early identification of Alzheimer's.[49]

In addition to the β-amyloid and tau proteins, the microglia immune response is an area of extreme interest for researchers, who have hopes of halting or preventing the harmful effects of the broad microglia attack. Unfortunately, there are many steps that need to be taken before scientists can directly mitigate the response and the damage that it causes, such as understanding the effects of activated microglia. Mapping out exactly how the microglia immune response works, the mechanisms involved, and the specific molecules that play a role in this defense

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[47] Kenneth Kosik, "The Way Forward" (Scientific American, May 2020).

[48] C. A. Lane, J. Hardy, and J. M. Schott, "Alzheimer's Disease," *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.

[49] C. A. Lane, J. Hardy, and J. M. Schott, "Alzheimer's Disease," *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.

system are key to being able to better understand the pathological progression of the disease, and ultimately how to treat it.[50]

Other inflammatory factors, such as systemic inflammation in other locations of the body, including the digestive tract and joints, as well as risk factors such as obesity and traumatic brain injury, are also likely to play a role in the promotion of neuroinflammation. While few studies have looked specifically at other risk factors and how they affect the immunological processes of the brain and whether they promote disease progression or development, systemic inflammation, obesity, and brain injury are all variables of interest when it comes to the topic of neuroinflammation.[51]

Genetic components have also been linked to Alzheimer's, both to the development of the disease as a whole, as well as connections to the specific immune response. Genome-wide analysis has identified several genes that increase the risk for Alzheimer's, many of which are genes that regulate the microglia clearance of misfolded proteins, and the subsequent inflammatory response. Figure 1 shows a variety of genes that have been linked to the development of Alzheimer’s. While most genes present a low risk of developing Alzheimer’s, three genes, APP, PSEN1 and PSEN2, all are incredibly correlated to the development of early-onset Alzheimer’s. All three of these genes are thought to influence amyloid metabolism, which supports the notion that amyloid accumulation is closely related to the development of Alzheimer’s. Two other genes that have captured immense interest are two receptors of these microglia immune cells, which are TREM2 and CD33.[52] TREM2 promotes phagocytosis, which

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[50] Sara Bachiller et al., “Microglia in Neurological Diseases: A Road Map to Brain-Disease Dependent-Inflammatory Response,” *Frontiers in Cellular Neuroscience* 12 (2018), https://doi.org/10.3389/fncel.2018.00488.

[51] Michael T Heneka et al., “Neuroinflammation in Alzheimer’s Disease,” *The Lancet Neurology* 14, no. 4 (April 2015): 388–405, https://doi.org/10.1016/S1474-4422(15)70016-5.

[52] Michael T Heneka et al., “Neuroinflammation in Alzheimer’s Disease,” *The Lancet Neurology* 14, no. 4 (April 2015): 388–405, https://doi.org/10.1016/S1474-4422(15)70016-5.

is the ingestion of foreign or harmful cells by immune cells in order to destroy them. However, variants of TREM2 have been identified that impair the proper function of the microglia cells, affecting the ability of the microglia to perform phagocytosis and generate the desired inflammatory response, among other things.[53] CD33 is a transmembrane receptor also found in microglial cells. Studies have shown that individuals with higher levels of this receptor have slower microglial phagocytosis and clearance of β-amyloid cells, which results in an increased risk of developing Alzheimer's disease.[54]

Overall, early detection of Alzheimer’s disease using a combination of risk factors appears to be the first step along the path to successfully treating the disease. Genetic studies have already revealed a myriad of gene pathways that are important to the development of Alzheimer's, which are illustrated in Figure 2. By learning more about genetic risk factors and how they contribute to the development and progression of the disease, there will be an increased number of ways to potentially prevent or treat Alzheimer’s by targeting specific genes. The more understood these risk factors are, the easier it will be to screen individuals for their chance of developing the disease, which will also increase the opportunities to successfully combat the disease by intervening earlier, hopefully allowing drugs that target the harmful protein clusters to be more effective. Researchers have already begun to plan for and develop tests that combine genetic risk scores with other factors that have been proven to be hazardous. This test would allow for at-risk patients to be identified, and subsequently given more invasive tests such as

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[53] Sara Bachiller et al., “Microglia in Neurological Diseases: A Road Map to Brain-Disease Dependent-Inflammatory Response,” *Frontiers in Cellular Neuroscience* 12 (2018), https://doi.org/10.3389/fncel.2018.00488.

[54] Sara Bachiller et al., “Microglia in Neurological Diseases: A Road Map to Brain-Disease Dependent-Inflammatory Response,” *Frontiers in Cellular Neuroscience* 12 (2018), https://doi.org/10.3389/fncel.2018.00488.

β-amyloid and tau imaging, and given treatments tailored to that individual's stage and nature of disease.[55]

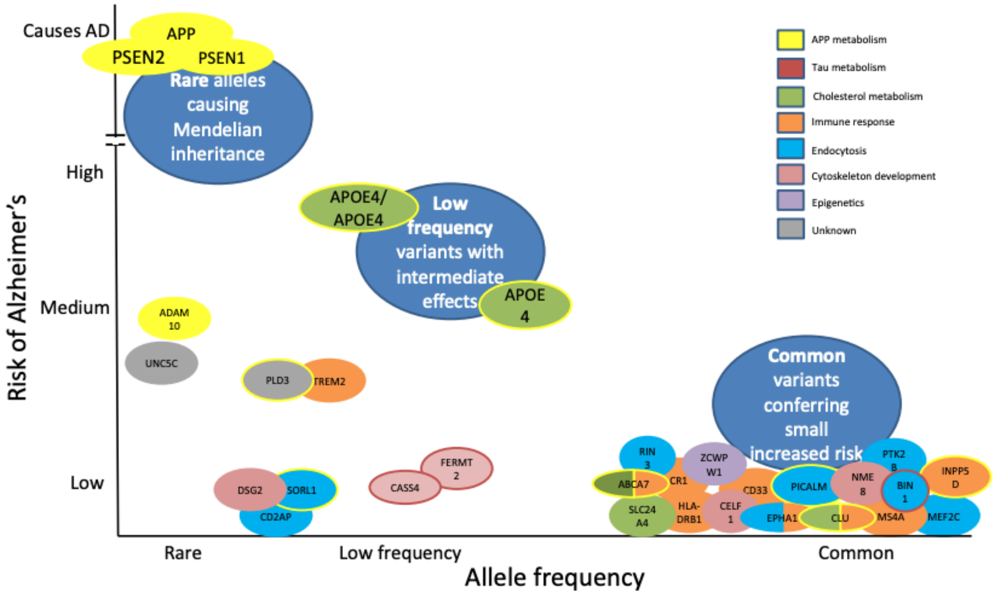

Figure 2: An overview of genes which have been implicated in Alzheimer's disease, with color corresponding to their function. The yellow colored genes are also thought to influence amyloid metabolism, while the red colored genes are thought to influence tau metabolism. As you move along the Y-axis, the correlation between the presence of the gene and developing Alzheimer's increases, and as you move along the X-axis, the frequency of the gene increases.[56]

With the current difficulties associated with treating Alzheimer's disease, its grave symptoms, and a cure likely far in the future, along with the arduous difficulties placed on the patient and the patient's family, it is essential that resources are available for Alzheimer's patients to alleviate some of the burden. Optimal management should be tailored to a patient's individual circumstances, and should include engagement with the patient's family, as well. Both the patient and caregivers should be involved in decision-making, with efforts made to include the patient as much as possible even after cognition declines. Researchers Lane et al. state that a

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[55] C. A. Lane, J. Hardy, and J. M. Schott, "Alzheimer's Disease," *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.
[56] C. A. Lane, J. Hardy, and J. M. Schott, "Alzheimer's Disease," *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.

"multidisciplinary approach including medical professionals, nurses, social services and charities/support services is vital" to proper treatment, and also state that "referral to palliative care to discuss end-of-life planning can be particularly valuable."[57] While they are spot on with their initial assertion, the notion that palliative care is only valuable for end of life care is flawed, as their description of the care services they state as "vital" is really just a description of palliative care. Palliative care has immense value for chronically and terminally ill patients, no matter the stage of the disease.

Palliative Care

In many different areas of medicine, studies have been conducted which look at the efficacy and importance of palliative care for patients with serious illnesses in different settings. Yefimova et al. (2020) explored the relationship between whether or not a patient receives palliative care following major surgeries and that patient's outcome, specifically looking at family-reported ratings of overall care, communication, and support for the patient. The researchers retrospectively analyzed 227 patients who underwent high-risk operations and died within 90 days after the operation. The authors found that the patients who received palliative care performed better when it came to quality of life, satisfaction of care, and aggressiveness of treatments than those that did not. This difference, primarily identified through family-reporting and patient charts, demonstrates the importance of palliative care for critically ill patients.[58]

There is also research done that demonstrates how the implementation of palliative care soon after the diagnosis of a serious illness results in notably improved outcomes for patients. In

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[57] C. A. Lane, J. Hardy, and J. M. Schott, "Alzheimer's Disease," *European Journal of Neurology* 25, no. 1 (2018): 59–70, https://doi.org/10.1111/ene.13439.

[58] Maria Yefimova et al., "Palliative Care and End-of-Life Outcomes Following High-Risk Surgery," *JAMA Surgery* 155, no. 2 (February 1, 2020): 138–46, https://doi.org/10.1001/jamasurg.2019.5083.

2010, Temel, et al. found that early palliative care consults result in better outcomes for patients with lung cancer compared to patients who did not receive consults.[59] Among the 151 patients in the study, the researchers found that those who received palliative care had "significant improvements in both quality of life and mood," including decreased length of stay and longer survival than patients who did not receive consults. These improvements are incredibly important to the comfort and overall quality of life for the patient as well as the patient's family, establishing the positive influence of palliative care, especially when implemented early-on in the patient's treatment.[60]

Similar results were reported in a study done by Amano et. al. in 2014 that looked at the association between early palliative care referrals and "aggressiveness" of care for patients in the ICU. "Aggressiveness" of care refers to the treatments that patients receive, with more aggressive treatments including major surgeries, intubation, and medications that potentially have severe side-effects. The authors retrospectively studied 265 patients in the ICU to compare the outcomes of patients who received palliative care consults early on in their hospitalization against those who did not receive early consults, finding that early palliative care consults resulted in less aggressive interventions due to the patient or the patient's family opting out of treatment when given all options, as well as increased utilization of inpatient hospice. Less aggressive interventions and inpatient hospice have been linked to the alleviation of stress

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[59] Jennifer S. Temel et al., "Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer," *New England Journal of Medicine* 363, no. 8 (August 19, 2010): 733–42, https://doi.org/10.1056/NEJMoa1000678.

[60] Jennifer S. Temel et al., "Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer," *New England Journal of Medicine* 363, no. 8 (August 19, 2010): 733–42, https://doi.org/10.1056/NEJMoa1000678.

associated with serious illness for the patient and the patient's family, demonstrating the utility of palliative care consults in the ICU.[61]

Researchers Lilley, Cooper, Schwarze, and Mosenthal also found that palliative care should be given to patients undergoing high risk surgeries immediately upon their admission to the hospital. The authors conducted a literature review of existing studies surrounding the use of palliative care in relation to high-risk surgeries, as well as evaluated the current standards and outcome metrics for patients who received palliative care. Lilley et. al. found that if patients are given palliative care, it is often administered only after undergoing surgery, and utility of palliative care decreases when given post-surgery due to the prospective nature of palliative care and how it enables the patient to have more control over the way their disease is treated. Early use of palliative care allows the patient to explore all treatment options and offers a more holistic view of all the different possible outcomes based upon treatments. This result is consistent with the studies discussed above, once again showing that earlier palliative interventions are important and effective for patients with serious illnesses in allowing the patient to have more control and satisfaction regarding their treatment.[62]

A study done by DiMartino et. al. in 2019 looked specifically at different methods of implementing palliative care. The researchers investigated two types of triggered palliative care consultation (TPCC) to evaluate their effects of the consistency and quality of consults for inpatient oncology. The study was completed over the course of six years and assessed two types of TPCC to determine which type was more effective. The first type of TPCC was a written guideline for practitioners to follow, while the second TPCC utilized a multiple-strategy

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[61] Koji Amano et al., “Association between Early Palliative Care Referrals, Inpatient Hospice Utilization, and Aggressiveness of Care at the End of Life,” *Journal of Palliative Medicine* 18, no. 3 (September 11, 2014): 270–73, https://doi.org/10.1089/jpm.2014.0132.

[62] Elizabeth J. Lilley et al., “Palliative Care in Surgery: Defining the Research Priorities,” *Journal of Palliative Medicine* 20, no. 7 (March 24, 2017): 702–9, https://doi.org/10.1089/jpm.2017.0079.

approach, including training, chart review, and written guidelines. The single approach of TPCC was also compared against "usual care," which did specifically prompt practitioners to include palliative care. The results showed that in order to increase consistent implementation of palliative care, TPCC supported by multiple strategies was the most successful. This is an interesting source because it examines palliative care through a new lens (that of oncology), which although is not directly related to the ICU, further supports the importance and utility of palliative care.[63]

Finally, there is also research surrounding the prevalence of palliative care among severely ill patients, specifically looking at how many patients are actually receiving palliative care. In 2017, Rayburn et. al. researched the effect of palliative care on ICU patients with lung cancer through a retrospective study of pre-existing data. The researchers concluded that "end of life care" in the ICU is an underutilized tool, especially in the context of increasing rates of aggressive ICU interventions by physicians, finding that only 32% of patients studied received a palliative care consult. This small percentage of patients who received palliative care was the major finding of this study, and when considered in tandem with other studies that demonstrate the effectiveness of palliative care, clearly shows that palliative care is an underutilized tool.[64]

Palliative Care in the Management of Dementia

Although there is not the same depth of research into the utility of palliative care when used to treat dementia patients, there have been numerous studies that have looked into the

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[63] Lisa D. DiMartino et al., "The Impact of Two Triggered Palliative Care Consultation Approaches on Consult Implementation in Oncology," *Healthcare (Amsterdam, Netherlands)* 7, no. 1 (March 2019): 38–43, https://doi.org/10.1016/j.hjdsi.2017.12.001.

[64] Joshua R. Rayburn et al., "Underutilization of End of Life Care Plans and Palliative Care Resources in Lung Cancer Patients Admitted to Intensive Care Units," in *D22. THE COURSE OF CRITICAL ILLNESS: ADMISSION TO FOLLOW-UP*, 313 vols., American Thoracic Society International Conference Abstracts (American Thoracic Society, 2017), A7098–A7098, https://doi.org/10.1164/ajrccm-conference.2017.195.1_MeetingAbstracts.A7098.

delivery of palliative care to patients with dementia and its benefits, as well as into the barriers that prevent it from being utilized more frequently. Many of the articles I analyzed were review articles, meaning that they were not actual studies, but rather a synthesis of multiple studies that examined the effect of palliative care on dementia patients. While primary sources also gave good insight into the delivery of palliative care to treat dementia patients, the review articles were helpful for identifying general trends of how palliative care is used for dementia patients, the effect that it had on the patient and the patient's family, as well as how caregivers view the practice and what they believe are the barriers to better implementation.

Overall, the vast majority of the literature that exists on using palliative care as a treatment for dementia is very supportive of the practice. Many different benefits of employing palliative care have been identified, all centered around an improved quality of life for the patient. Positive results also extend to the family of the patient, including family satisfaction in the treatment given to the patient as well as improved relationships between professional caregivers and the family.[65]

One of the most important ways that improvement for the patient, the family, and even the doctor occurs is through the creation and implementation of an advanced directive. An advanced directive allows the patient to express how they wish to be treated in the case that they are unable to advocate for themselves, a situation which almost all dementia patients find themselves in eventually due to cognitive decline. Such a directive usually consists of the patient's wishes when it comes to the utilization of life-prolonging treatments, and allows the patient to prioritize quality of life over length of life. With an advanced directive in place,

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[65] Ruth Piers et al., "Advance Care Planning in Dementia: Recommendations for Healthcare Professionals," *BMC Palliative Care* 17, no. 1 (December 2018): 88, https://doi.org/10.1186/s12904-018-0332-2.

patients can indicate their desire for a palliative approach to their care, resulting in fewer hospitalizations, fewer unwanted and burdensome treatments, and less emotional distress.[66]

The existence of a plan in place allows the patient to be treated the way they wish to be treated, allowing for greater satisfaction for both the patient and the patient's family. A plan also removes an immense burden from the healthcare practitioners who are charged with caring for the patient, who are often tasked with making hard decisions on behalf of the patient. A palliative approach with an advanced directive in place limits the need to make difficult decisions, such as whether or not to conduct an arduous treatment with the primary goal of prolonging the patient's life.[67]

While it is incredibly important for the patient to be treated the way they wish to be treated regardless of their ability to express their desires in the moment, the relief that an advanced directive provides for caregivers is also greatly beneficial. In a study conducted by Hirshman et al. that interviewed over 35 different people who acted as caregivers for a family member with dementia, 43% of the caregivers said they were "emotionally exhausted" in coping with their family member's illness.[68] Furthermore, in a longitudinal study conducted by Sachs et al., researchers found that caregivers who were categorized as "strained" based on verbal interviews had a 63% increased mortality rate compared to family members who were not acting as a caregiver for the patient.[69] Considering the immense emotional and financial burden placed

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[66] Ruth Piers et al., "Advance Care Planning in Dementia: Recommendations for Healthcare Professionals," *BMC Palliative Care* 17, no. 1 (December 2018): 88, https://doi.org/10.1186/s12904-018-0332-2.

[67] Josie Dixon, Maria Karagiannidou, and Martin Knapp, "The Effectiveness of Advance Care Planning in Improving End-of-Life Outcomes for People With Dementia and Their Carers: A Systematic Review and Critical Discussion," *Journal of Pain and Symptom Management* 55, no. 1 (January 2018): 132-150.e1, https://doi.org/10.1016/j.jpainsymman.2017.04.009.

[68] Karen B. Hirschman et al., "P-143: Family Members' Perceptions of Palliative Care Service Needs of Advanced Dementia Patients," *Alzheimer's & Dementia* 3, no. 3S_Part_2 (2007): S144–45, https://doi.org/10.1016/j.jalz.2007.04.207.

[69] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

on caregivers, it is quite common for those caring for a dementia patient to feel overwhelmed, exhausted, and even hopeless, which in turn significantly increases that person's own chance of dying.

Fortunately, palliative care can drastically reduce the risks and burdens placed on caregivers. In their study "Steps to H.O.P.E: Building Health, Optimism, Purpose, and Endurance in Palliative Care for Family Caregivers of Persons with Dementia," researchers Susan Favaro and Carol Long investigated the effects of palliative care on caregivers for dementia patients, with the study yielding encouraging results. The project, which was conducted at the Banner Alzheimer's Institute in Arizona, had four groups of 8 to 10 caregivers of people with dementia meet with a palliative care specialist once a week for four weeks. The groups discussed loss, grief, and the difficulties of caring for a family member with dementia, with the palliative care specialist offering encouragement and methods of coping with these emotions. The outcome of these four week counseling sessions showed a significant reduction in both caregiver stress and strain, defined using response surveys.[70] Qualitative findings also indicated numerous strategies and program tools that were identified by caregivers as helpful in managing the stress, burden and grief associated with caring for a family member with dementia, which included physical exercise, self‑talk, asking for help, and taking breaks throughout the day.[71]

Furthermore, although more research needs to be done into the quantitative outcomes associated with palliative care for dementia patients, there is evidence that shows palliative care has the potential to reduce unnecessary hospital admissions as well as overall healthcare costs,

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[70] Susan C. Favaro and Carol O. Long, "[P3–499]: Steps to H.o.p.e.: Building Health, Optimism, Purpose, and Endurance in Palliative Care for Family Caregivers of Persons with Dementia," *Alzheimer's & Dementia* 13, no. 7S_Part_24 (2017): P1167–68, https://doi.org/10.1016/j.jalz.2017.06.1718.

[71] Susan C. Favaro and Carol O. Long, "[P3–499]: Steps to H.o.p.e.: Building Health, Optimism, Purpose, and Endurance in Palliative Care for Family Caregivers of Persons with Dementia," *Alzheimer's & Dementia* 13, no. 7S_Part_24 (2017): P1167–68, https://doi.org/10.1016/j.jalz.2017.06.1718.

especially in nursing homes where costs associated with end-of-life care are high.[72] Unfortunately, generating reliable data regarding the quantitative outcomes of palliative care is very difficult to do, as it is very complicated to prove cause and effect between the delivery of palliative care and patient outcomes, as there are many confounding variables that must be controlled for before patients in different treatment groups can be compared.

Despite the clear benefits of palliative care, there are many barriers that prevent it from being utilized often and effectively. As mentioned earlier, most physicians who diagnose and treat dementia patients have limited training when it comes to treating dementia patients, and most have no training in palliative care at all.[73] Even when doctors are sufficiently trained and experienced in treating dementia patients, and even doctors who have experience delivering care with a palliative approach, it is very difficult to initiate conversations surrounding the possibility of the patient losing autonomy and dying. The timing of discussions surrounding these topics is complicated, as the patient is usually overwhelmed by the diagnosis alone, let alone conversations about their death. However, if the discussion is delayed for too long, the risk of the patient losing the ability to make important decisions and participate meaningfully in the trajectory of their care increases.[74] The tendency to delay these difficult conversations is a dangerous one, as a study done by Lopez-Tourres et al. found that 70.6% of demented patients do not want aggressive intervention during the terminal phase of their illness.[75] The terminal

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[72] Ruth Piers et al., “Advance Care Planning in Dementia: Recommendations for Healthcare Professionals,” *BMC Palliative Care* 17, no. 1 (December 2018): 88, https://doi.org/10.1186/s12904-018-0332-2.

[73] “Primary Care Physicians on the Front Lines of Diagnosing and Providing Alzheimer’s and Dementia Care,” Alzheimer’s Disease and Dementia, accessed February 26, 2021, https://alz.org/news/2020/primary-care-physicians-on-the-front-lines-of-diag.

[74] Josie Dixon, Maria Karagiannidou, and Martin Knapp, “The Effectiveness of Advance Care Planning in Improving End-of-Life Outcomes for People With Dementia and Their Carers: A Systematic Review and Critical Discussion,” *Journal of Pain and Symptom Management* 55, no. 1 (January 2018): 132-150.e1, https://doi.org/10.1016/j.jpainsymman.2017.04.009.

[75] F. Lopez-Tourres et al., “Soins palliatifs et maladie d’Alzheimer,” *La Revue de Médecine Interne* 30, no. 6 (June 1, 2009): 501–7, https://doi.org/10.1016/j.revmed.2008.09.010.

phase refers to a period of time when death is imminent, and there is no longer any hope for a cure or significant improvement of the disease. The majority of patients from Lopez-Tourres' study who wished not to receive aggressive treatment demonstrates the importance of having conversations about the latter-part of the patient's disease, and the importance of having those conversations early.

Furthermore, there is a large portion of both professionals and family members that believe dementia is not terminal. Although many experts in the field categorize Alzheimer's and other dementias as terminal illnesses, many families and clinicians have the perception that the terminal event, whether it be pneumonia, cardiac disease, or a urinary tract infection, is the actual cause of death in someone with dementia, even though it is almost always the dementia that initiates the chain of events leading to death. People with dementia in its advanced stages develop apraxia, dysphagia, and decreased mobility that drastically increase the risk of infection, malnutrition, blood clotting, and other adverse medical outcomes.[76] In a series of interviews conducted with medical and nursing care teams who treat dementia patients, one doctor stated "I think people with dementia are not considered often in the same league as somebody with heart failure, COPD or cancer. That is what happens to elderly people isn't it? They get confused."[77] While dementia patients should not be treated the same as cancer patients, it is vital that they receive the same level of care and consideration as other patients with seemingly more "serious" diseases, and many dementia patients have similar needs as other terminally-ill patients.

Cultural differences and expectations surrounding the role of medicine can also play a part in preventing patients from receiving palliative care, both on the side of the patient and the

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[76] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

[77] Tony Ryan et al., "Barriers and Facilitators to the Receipt of Palliative Care for People with Dementia: The Views of Medical and Nursing Staff:," *Palliative Medicine*, October 3, 2011, https://doi.org/10.1177/0269216311423443.

healthcare practitioner. In some cases, families can be confused or even offended by the idea of palliative care, as some people view the function of medicine as purely a way to treat the disease at hand, rather than a way to address the emotional desires of a patient and their family.[78] Feelings of distrust and displeasure are often exacerbated by the notion of relinquishing care of a family member when discussions surrounding hospice are initiated, which is commonly suggested when it comes to late-stage dementia patients. Furthermore, professionals from different upbringings and backgrounds can share the same sentiments about the role of medicine, and can also have difficulties communicating clearly with a patient and their family members in order to figure out exactly what course of treatment is desired by the patient.[79]

Another barrier against delivering care centered around comfort and quality of life is the guilt and pressure that family members feel surrounding the treatment of a relative with dementia. When palliative care is implemented, the family of the patient will be forced to consider certain treatments, including some that can even seem ordinary, minimally invasive, and relatively painless in the short run.[80] Withholding treatments such as antibiotics can be incredibly emotionally and psychologically challenging, and can create the feeling for families that they are responsible for the life and death of the patient. Support and skillful communication from a trained professional is needed for the family in order for them to be relieved of such feelings of guilt.[81] It is imperative that the family of the patient understands that the evolution of the disease,

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[78] Mareeni Raymond et al., "Palliative Care Services for People with Dementia: A Synthesis of the Literature Reporting the Views and Experiences of Professionals and Family Carers," *Dementia* 13, no. 1 (January 1, 2014): 96–110, https://doi.org/10.1177/1471301212450538.

[79] Mareeni Raymond et al., "Palliative Care Services for People with Dementia: A Synthesis of the Literature Reporting the Views and Experiences of Professionals and Family Carers," *Dementia* 13, no. 1 (January 1, 2014): 96–110, https://doi.org/10.1177/1471301212450538.

[80] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

[81] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

the associated nutritional and behavioral problems, are all due to the dementia itself and not poor care. When family members lack this vital understanding, the guilt from the issues associated with dementia can lead to requests for aggressive treatment, as this is often for a way for them to show their love and care for the patient and serves as a way to rid themselves of the feeling that they are not doing enough to support their loved one.[82] As a result, many people with late-stage dementia have numerous emergency hospital admissions and can be subject to burdensome medical treatments, even if such treatments do not have high chances of positive outcomes.[83] Because these feelings of guilt can often only be alleviated by the support of a trained professional, it is essential for such a professional to be a member of the patient's care team.

Healthcare professionals are not exempt from these same feelings of guilt and pressure to keep their patient alive. Many practitioners feel that they have a duty to do everything they can to treat whatever ailments that affect their patients. In the same series of interviews conducted with medical and nursing care teams that treat dementia patients, another doctor reflected on the challenges of choosing whether or not to treat late-stage dementia patients, stating "the [patients] I've had [which] have been quite aggressive towards the end of their life are quite difficult... you end up giving them lots of chemicals that you're not sure if it's a good idea or not, but they're so upset... you want to help."[84] In another series of interviews conducted with dementia-caretakers, an intern recalled an instance where he felt that the patient's wishes were not followed due to the doctor's desire to treat the patient in the way that the physician saw fit, despite there being a

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[82] F. Lopez-Tourres et al., "Soins palliatifs et maladie d'Alzheimer," *La Revue de Médecine Interne* 30, no. 6 (June 1, 2009): 501–7, https://doi.org/10.1016/j.revmed.2008.09.010.

[83] Josie Dixon, Maria Karagiannidou, and Martin Knapp, "The Effectiveness of Advance Care Planning in Improving End-of-Life Outcomes for People With Dementia and Their Carers: A Systematic Review and Critical Discussion," *Journal of Pain and Symptom Management* 55, no. 1 (January 2018): 132-150.e1, https://doi.org/10.1016/j.jpainsymman.2017.04.009.

[84] Tony Ryan et al., "Barriers and Facilitators to the Receipt of Palliative Care for People with Dementia: The Views of Medical and Nursing Staff:," *Palliative Medicine*, October 3, 2011, https://doi.org/10.1177/0269216311423443.

hand-typed statement from the patient stating that she wished for a peaceful ending. In this instance, the intern witnessed the patient's family members being convinced over the phone that certain invasive and painful procedures, such as chest tube insertions, were in the best wishes of the patient.[85] This example of a patient's wishes being overridden by the treating physician in tandem with permission from the patient's family demonstrates the importance of having an official advanced directive. While the opinions of trusted family members are important, they should not be able to override the wishes of the patient.

Furthermore, despite the pressure that doctors and family caregivers feel to treat the patient aggressively, it is important to note that more aggressive treatment does not always equate to better treatment. During the later stages of dementia, it becomes difficult to keep the patient sufficiently fed and hydrated, as oftentimes the patient will stop eating and drinking.[86] Frequently, the treating physician will choose to use a nasogastric tube, which is inserted through the nose and connected to the stomach, in order to get nutrients into the patient's system. However, studies show that despite the painful and involved process of inserting a nasogastric tube into a patient's nose, these tubes do not increase the survival rate among dementia patients, and up to 44% of dementia patients die with a tube in place.[87] Decisions regarding treatments such as feeding tubes can make a big difference in a patient's conditions at the end of their life. For example, two patients with advanced dementia had drastically different courses due to the decisions of their families and physicians. When one patient suffered a dramatic decline in oral intake and developed pneumonia, the patient's wife decided against antibiotics and a feeding

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[85] Mareeni Raymond et al., "Palliative Care Services for People with Dementia: A Synthesis of the Literature Reporting the Views and Experiences of Professionals and Family Carers," *Dementia* 13, no. 1 (January 1, 2014): 96–110, https://doi.org/10.1177/1471301212450538.

[86] F. Lopez-Tourres et al., "Soins palliatifs et maladie d'Alzheimer," *La Revue de Médecine Interne* 30, no. 6 (June 1, 2009): 501–7, https://doi.org/10.1016/j.revmed.2008.09.010.

[87] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

tube, and instead chose hospice care, which resulted in that dying peacefully at home. At a similar juncture, the other patient's family opted for hospitalization, intravenous antibiotics, and tube feeding. The patient was rehospitalized seven times over the next 18 months for subsequent complications before her family opted for home hospice care.[88] While this is not to say that every intervention given to a late-stage dementia patient is a bad idea, it is important for families and physicians to fully understand every option available to the patient, and to understand that aggressive treatments are not always the best course of action.

Another barrier that prevents palliative care from being administered more frequently is the belief that palliative care is something that is solely used for pain management. While not all physicians have this perception, there is a significant number of professionals who believe palliative care is for pain management, likely due to the lack of education about palliative care that many physicians have.[89] In the conversations that researchers had with dementia caretakers, participants articulated a reluctance to refer people with dementia to palliative care specialists, citing the fact that the difficulties of dementia patients are not the same as cancer patients, particularly in terms of pain management.[90] Contrary to this belief, studies show that demented patients are typically under-treated for pain, especially in contrast to older people with intact cognitive functions.[91] The inability to communicate verbally reduces the recognition and treatment of pain, and while dementia itself may not cause physical pain, patients with dementia

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[88] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

[89] Tony Ryan et al., "Barriers and Facilitators to the Receipt of Palliative Care for People with Dementia: The Views of Medical and Nursing Staff:," *Palliative Medicine*, October 3, 2011, https://doi.org/10.1177/0269216311423443.

[90] Tony Ryan et al., "Barriers and Facilitators to the Receipt of Palliative Care for People with Dementia: The Views of Medical and Nursing Staff:," *Palliative Medicine*, October 3, 2011, https://doi.org/10.1177/0269216311423443.

[91] Josie Dixon, Maria Karagiannidou, and Martin Knapp, "The Effectiveness of Advance Care Planning in Improving End-of-Life Outcomes for People With Dementia and Their Carers: A Systematic Review and Critical Discussion," *Journal of Pain and Symptom Management* 55, no. 1 (January 2018): 132-150.e1, https://doi.org/10.1016/j.jpainsymman.2017.04.009.

are likely suffering from arthritis, osteoporosis, or a variety of other painful conditions that increase in prevalence with advanced age.[92]

As with many issues in the healthcare system, policy plays a vital role in if, how and when patients receive palliative care. Unfortunately, the current policies in the United States regarding palliative care are insufficient. While certain states have legislation that incentivize the use of palliative care, such as reimbursement for care given, many do not, and there is no federal legislation in place that guarantees that practitioners will be reimbursed for delivering palliative care.[93] Because of this, access to palliative care is dependent on a variety of factors, including which state a patient is in, geographical location within a particular state, socioeconomic status and insurance (the last two factors being tightly correlated). Individuals are much less likely to have access to palliative care if they have substandard insurance or reside in a rural area, and in extreme cases, the patient will be unable to receive care at all.[94]

An example of a state that lacks sufficient palliative care coverage is Alaska, as with the exception of specific palliative care clinics, access to palliative care is scarce. Additionally, there are no laws in Alaska that require healthcare reimbursements for palliative care, making it economically unfavorable for healthcare practitioners to offer palliative care services to patients. Effectively, if a patient wants to take advantage of the numerous benefits of palliative care, they must seek it out on their own, and it is likely that their insurance will not cover the costs, meaning the patient will likely have to pay out of pocket. The difficulty of receiving palliative care leads to a huge disparity of health care in Alaska, as only the wealthy have the ability to

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[92] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, “Barriers to Excellent End-of-Life Care for Patients with Dementia,” *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

[93] “Palliative Care, Report Card,” Palliative Care, Report Card, accessed October 14, 2020, https://reportcard.capc.org/.

[94] “Palliative Care, Report Card,” Palliative Care, Report Card, accessed October 14, 2020, https://reportcard.capc.org/.

explore palliative care options, while those who are of lower socioeconomic status or who live in more rural areas will not have any ability to receive palliative care.[95] Without laws that mandate insurance coverage for palliative care, especially for governmental insurance plans, many patients and their families will not experience the immense benefits that palliative care offers.

Generally, if a patient is insured under Medicaid, Medicare, or an HMO provider (meaning patients can only receive care from a specific network of facilities and caretakers), the patient can only be enrolled in hospice care if their physician certifies that the patient has a six month life expectancy.[96] Furthermore, the patient and the patient's family must forgo rehospitalization for conditions related to the primary diagnosis, which in the case of dementia, is practically everything. As mentioned previously, the timeline of dementia is incredibly varied and unpredictable, making it challenging for a physician to clearly identify a point in time when the patient will likely be dead within six months. The inability to determine that specific point in time, in tandem with the requirement to forgo future treatment, makes it extremely difficult for dementia patients to be placed into hospice and have the costs associated with that treatment covered by their insurance. The importance of insurance coverage cannot be understated — one caretaker for dementia patients in a hospital admitted that decisions made about care were dependent on the finances of the Medicare system, recalling a patient that was "on a costly staff-intensive, acute care ward and Medicare/insurance rules would no longer allow payment. Because of this, he was discharged."[97]

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[95] "Palliative Care, Report Card," Palliative Care, Report Card, accessed October 14, 2020, https://reportcard.capc.org/.

[96] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

[97] Mareeni Raymond et al., "Palliative Care Services for People with Dementia: A Synthesis of the Literature Reporting the Views and Experiences of Professionals and Family Carers," *Dementia* 13, no. 1 (January 1, 2014): 96–110, https://doi.org/10.1177/1471301212450538.

In addition to lack of coverage for palliative care, current policies in the US create monetary incentives that encourage physicians to transfer dementia patients to different facilities or areas in the hospital. As dementia patients reach the later stages of their disease, they require more time from caretakers to manage symptoms and provide comfort, the care facility housing the patient ends up bearing the increased cost of care, without receiving additional reimbursement. However, if the facility transfers the patient to the hospital for acute care, the facility not only avoids the cost associated with the increased staff time, but can also be paid a "bed hold" while the patient is gone if the patient's stay is under Medicaid.[98] A transfer to the hospital also decreases the facility's liability for "allowing a patient to die," which family members sometimes claim. Furthermore, there is the possibility of regulatory citations for weight loss or dehydration that occur as death approaches.[99] The treating physician is also incentivized to have the patient readmitted to the hospital, as the Medicare reimbursement for a treatment of a hospitalized patient greatly exceeds that of a visit to a nursing home. All of the healthcare professionals and institutions involved with the treatment of dementia patients have financial incentives to admit dying dementia patients to the hospital, which actively decreases the chances of the patient receiving palliative care.[100]

The process of being transferred between different facilities that dementia patients undergo has a clear sequence that results in the cycling between facilities. The patient experiences an acute injury or illness (typically associated with their dementia) that lands them in

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[98] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

[99] "Measuring Quality of Care for Nursing Home Residents — Considering Unintended Consequences," Population Health Learning Network, accessed April 14, 2021, https://www.managedhealthcareconnect.com/article/measuring-quality-care-nursing-home-residents-considering-unintended-consequences.

[100] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

the hospital, followed by a decline in cognition and function. The patient is then transferred to a permanent care facility, where they remain until they plateau at a new baseline below that of their pre-hospitalization, which usually coincides with the discontinuation of Medicare-covered therapy, nursing and other services. The gradual decline in function due to the underlying dementia progresses until the next acute illness or injury sparks the repetition of the cycle.[101] If the lack of coverage for consistent care that the dementia patient receives is not enough, the process itself of moving from one place to the next contributes to the deterioration of the patient's disease. These frequent moves are stressful for the patient, and the changing surroundings and caretakers can increase the patient's confusion, resulting in a worsening of their symptoms.[102]

Unfortunately, the negative consequences from the process of constant transfers do not end with lack of care or a worsening of symptoms. Moving between different care facilities also means that the patient is moving between different physicians and caretakers, creating a discontinuity in care. While some healthcare systems are synced and have reliable channels of communication, oftentimes there is no established system for caretakers and doctors of the different facilities to communicate with one another beyond a recap of treatments via a chart note.[103] Bouncing around between different care facilities can also create a disconnect in the scope of a patient's treatments, with some physicians focusing on acute care while others act in accordance with a long-term plan. A common example of a disconnect between acute and

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[101] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

[102] Mareeni Raymond et al., "Palliative Care Services for People with Dementia: A Synthesis of the Literature Reporting the Views and Experiences of Professionals and Family Carers," *Dementia* 13, no. 1 (January 1, 2014): 96–110, https://doi.org/10.1177/1471301212450538.

[103] Tony Ryan et al., "Barriers and Facilitators to the Receipt of Palliative Care for People with Dementia: The Views of Medical and Nursing Staff:," *Palliative Medicine*, October 3, 2011, https://doi.org/10.1177/0269216311423443.

long-term care that harms dementia patients occurs when a patient's acute care team makes the decision to place a feeding tube in the patient without properly discussing the decision with the patient's long-term caretakers. While the placement of a feeding tube may seem like the right move for the patient immediately, the patient will eventually go home or go to a nursing home, where there oftentimes is no support in place for patients with a feeding tube if something goes wrong or the patient deteriorates further.[104] Without the presence of a support team that can properly care for a patient with a feeding tube, the patient must return to the hospital for any complications that might arise with the tube, further reinforcing the cycle of transfers and confusion for the patient. The cycle of transfers, which is well recognized in the literature, is unfortunately the consequence of poor healthcare policies in the United States.

Although numerous barriers exist that prevent palliative care from being utilized more frequently, there are also many ways that have been identified that can increase palliative care usage, mainly centered around changes in healthcare policies. However, in addition to changing policies so that incentives are better aligned towards proper care for dementia patients, there are also changes that can be made on an institutional and individual level in order to increase the use of palliative care.

First and foremost, all physicians should receive training in the use of palliative care in the relation to end of life care, not just those who specialize in hospice care. As mentioned previously, general practitioners receive very little training when it comes to treating dementia patients, and even less training when it comes to understanding how to implement palliative

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[104] Tony Ryan et al., "Barriers and Facilitators to the Receipt of Palliative Care for People with Dementia: The Views of Medical and Nursing Staff:," *Palliative Medicine*, October 3, 2011, https://doi.org/10.1177/0269216311423443.

care.[105] One very important skill for caretakers to have, yet also one that is not common among practitioners, is the ability to identify non-verbal cues in patients with advanced dementia who can no longer express their wishes verbally.[106] Identifying non-verbal cues becomes vital when it comes to pain management for late stage dementia patients, as the patient cannot accurately express their pains verbally, which leads to dementia patients being chronically undertreated for pain.[107] In addition to trying their best to understand what the patient is expressing, caregivers should also receive input from other members of the patient's care team, including the patient's family, as well as using other metrics such as aggression or behavioral changes in order to identify pain.[108] Despite the importance of being able to identify a range of indicators and different signs in order to correctly assess a dementia patient's needs, a majority of the respondents in the study that interviewed dementia clinicians reported that they "did not feel confident," in using a myriad of criteria to identify their patient's needs.[109]

Fortunately, steps have already been made in an attempt to address the lack of education and training that many clinicians receive. The Feinberg School of Medicine at Northwestern University has implemented an "EPEC" program, which stands for Educating Physicians in End-of-Life Care, and has the goal of improving training surrounding end of life care for

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[105] "Primary Care Physicians on the Front Lines of Diagnosing and Providing Alzheimer's and Dementia Care," Alzheimer's Disease and Dementia, accessed February 26, 2021, https://alz.org/news/2020/primary-care-physicians-on-the-front-lines-of-diag.

[106] Ruth Piers et al., "Advance Care Planning in Dementia: Recommendations for Healthcare Professionals," *BMC Palliative Care* 17, no. 1 (December 2018): 88, https://doi.org/10.1186/s12904-018-0332-2.

[107] Josie Dixon, Maria Karagiannidou, and Martin Knapp, "The Effectiveness of Advance Care Planning in Improving End-of-Life Outcomes for People With Dementia and Their Carers: A Systematic Review and Critical Discussion," *Journal of Pain and Symptom Management* 55, no. 1 (January 2018): 132-150.e1, https://doi.org/10.1016/j.jpainsymman.2017.04.009.

[108] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

[109] Tony Ryan et al., "Barriers and Facilitators to the Receipt of Palliative Care for People with Dementia: The Views of Medical and Nursing Staff:," *Palliative Medicine*, October 3, 2011, https://doi.org/10.1177/0269216311423443.

students in medical school, as well as providing continued education for established physicians.[110] The program has reached a large number of practicing physicians, but its current curriculum contains little on dementia. The American Geriatrics Society is working in tandem with the Feinberg School of Medicine on a revised version of EPEC that expands on areas that address geriatric diseases, specifically dementia.[111] However, although it is not yet perfect, the EPEC program has already made a significant difference in the abilities of clinicians who have been taught under the program. In an independent evaluation of the program and its effectiveness, researchers found that physicians who were trained to use the curriculum (meaning the physicians received training not only on the content of the program, but also on how to teach it to other physicians), responded very positively to the program. Out of the 200 physicians who received the training, 62% responded that EPEC "greatly improved" their knowledge of end-of-life care, and 72% responded that the program "greatly improved" their ability to teach end-of-life care.[112]

In addition to the EPEC program, there is a bill that attempts to address the gap in end-of-life training for physicians. The Bill is titled "Palliative Care and Hospice Education and Training Act" (S. 2080), and it has passed the House but has not yet been voted on in the Senate. The Bill, if passed, would establish a variety of tools that would enhance palliative care training, including grants to medical schools and teaching hospitals, as well as fellowship programs through the new Palliative Care and Hospice Education Centers to provide intensive courses

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[110] "Curricula," accessed April 25, 2021, https://www.bioethics.northwestern.edu/programs/epec/curricula/index.html.

[111] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

[112] "Assessment of the Education for Physicians on End-of-Life Care (EPEC™) Project | Journal of Palliative Medicine," accessed April 25, 2021, https://www.liebertpub.com/doi/10.1089/jpm.2004.7.637?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub++0pubmed&.

focused on a team-approach to palliative care. These fellowship programs would aim to provide supplemental training for a variety of different caretakers, including pharmacy, nursing, social work, physician assistants, and other allied health disciplines. The bill would also create special preferences that would incentivize nurses to have background training in hospice and palliative nursing, mainly through education, practice, quality grants, workforce development, and nurse retention projects.[113,114]

Another key step to increasing the availability of palliative care at an institutional level is the development of a culture that values and believes in the utility of palliative care. If a clinic can set the expectation that palliative care is something to be valued, a standard surrounding the use of palliative care will be set. Such a standard would have huge impacts on the way that patients are treated at the clinic, not only by having physicians and caretakers that have experience using palliative care and can teach newer members of the organization but also by creating cohesive and team-oriented care throughout different departments.[115] Even if there are gaps within the organization of what caretakers can provide patients, both patients and their families can benefit immensely from physicians knowing outside resources that patients can be directed to, such as social workers, a local chapter of the Alzheimer's Association, or other community resources.[116]

The largest change that needs to be made in order to increase the availability and use of palliative care and to ensure proper treatment for dementia patients lies within the realm of

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[113] "PCHETA Action Center - What We Do | Patient Quality of Life Coalition," accessed April 25, 2021, http://patientqualityoflife.org/pcheta-action-center/.

[114] "Palliative Care, Report Card," Palliative Care, Report Card, accessed October 14, 2020, https://reportcard.capc.org/.

[115] Ruth Piers et al., "Advance Care Planning in Dementia: Recommendations for Healthcare Professionals," *BMC Palliative Care* 17, no. 1 (December 2018): 88, https://doi.org/10.1186/s12904-018-0332-2.

[116] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

healthcare policy. As outlined previously, the current policies do not encourage optimal care for dementia patients, but rather influence both short and long-term healthcare facilities to transfer the patient back and forth between institutions, prioritizing profits for the organizations rather than optimal care for the patient. Efforts must be made to align financial incentives with practices that also lead to superior treatment for patients.

Time and time again, continuity of care has been linked to superior care for dementia patients, reflected by physicians, the patient's family, and the patient themself. During an interview regarding care practices for dementia patients, one primary care physician asserted that care for dementia patients was all about "having some sort of relationship, some sort of a background, a shared history with that patient... I don't think it is something that we do and probably something that we should."[117] A similar sentiment was expressed by the daughter of a dementia patient who was subjected to multiple trips back and forth between the hospital and her primary place of care. The daughter of the patient reflected on the last time that her mother returned from the hospital to her nursing home, recalling "her soul and comfort were not addressed or nurtured [in the hospital]. The night she returned to her nursing home bed, with its attendant feel and smells, she immediately relaxed, became more responsive, and her grimace transmuted into a smile.[118] While a nursing home may not be able to provide as complex and aggressive treatments as a hospital can, the comfort and consistency that a long-term care facility can provide is often superior in supporting quality of life than anything that an acute care facility can offer.

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[117] Tony Ryan et al., "Barriers and Facilitators to the Receipt of Palliative Care for People with Dementia: The Views of Medical and Nursing Staff:," *Palliative Medicine*, October 3, 2011, https://doi.org/10.1177/0269216311423443.

[118] Mareeni Raymond et al., "Palliative Care Services for People with Dementia: A Synthesis of the Literature Reporting the Views and Experiences of Professionals and Family Carers," *Dementia* 13, no. 1 (January 1, 2014): 96–110, https://doi.org/10.1177/1471301212450538.

Beyond changing the reimbursement policies that encourage the transferring of severely-ill patients, these payment policies could also be modified to reflect a slightly higher rate of reimbursement for patients who are identified as having primarily palliative care goals, meaning that they choose to forgo certain invasive treatments in order to prioritize comfort.[119] A reimbursement system that encourages palliative care would not only allow for coverage of the costs associated with palliative care that a facility might have, but it would also be favorable for insurance companies who would not have to cover other more invasive and expensive treatments. Aligning financial incentives for both insurance companies and healthcare facilities is essential for encouraging the use of palliative care, as one of the largest barriers to increased use of palliative care is funding.[120]

Inadequacies of funding and coverage surrounding palliative care for dementia patients is also a result of the perception of dementia and what treatments are typically associated with it. For example, although cancer patients can also experience trouble when seeking insurance coverage for palliative care, cancer charities provide a much larger source of funding when compared to charities and organizations centered around dementia.[121] Although modifying policies to align financial incentives in favor of palliative care would likely help dementia patients the most, changes to increase coverage of palliative care would make a huge difference in the lives of many different severely-ill patients.

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[119] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

[120] Mareeni Raymond et al., "Palliative Care Services for People with Dementia: A Synthesis of the Literature Reporting the Views and Experiences of Professionals and Family Carers," *Dementia* 13, no. 1 (January 1, 2014): 96–110, https://doi.org/10.1177/1471301212450538.

[121] Tony Ryan et al., "Barriers and Facilitators to the Receipt of Palliative Care for People with Dementia: The Views of Medical and Nursing Staff:," *Palliative Medicine*, October 3, 2011, https://doi.org/10.1177/0269216311423443.

Furthermore, the firm six-month timeline that serves as the entry criteria for hospice should be relaxed in the case of dementia patients, allowing for earlier referral of patients with dementia. Earlier referrals, or even consults from palliative care specialists working in a hospice setting, would allow for smoother transitions into palliative-focused care, and would allow patients to better understand their treatment options before they lose autonomy.[122] However, the ideal model of care-delivery should still be an integrative system that incorporates palliative care into the ongoing primary care of patients, with patient-focused care and advanced planning delivered over the course of years rather than months.[123]

Even if policies can be changed to incentivize care that is centered around the patient rather than around profits for healthcare facilities, it is still up to the individual facilities and healthcare practitioners to ensure that palliative care is available for patients. While other countries have passed laws that encourage the use of palliative care through insurance coverage and requirements that palliative care to be available to patients, these places still struggle immensely with the implementation of these policies. For example, France passed the Léonetti law in 2005, which mandated that health professionals must do everything in their power to limit suffering and to guarantee their patients have the least difficult life possible until death.[124] The main intent of this law was to ensure that the doctor informs their patients of all different options and trajectories of treatment, and so that the patient can set up an advanced directive while they still have the cognitive capabilities to make decisions for themselves. Unfortunately, a study showed that years after the passing of the Léonetti law, as many as 90% of severe dementia

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[122] Greg A Sachs, Joseph W Shega, and Deon Cox-Hayley, "Barriers to Excellent End-of-Life Care for Patients with Dementia," *Journal of General Internal Medicine* 19, no. 10 (October 2004): 1057–63, https://doi.org/10.1111/j.1525-1497.2004.30329.x.

[123] Tony Ryan et al., "Barriers and Facilitators to the Receipt of Palliative Care for People with Dementia: The Views of Medical and Nursing Staff:," *Palliative Medicine*, October 3, 2011, https://doi.org/10.1177/0269216311423443.

[124] F. Lopez-Tourres et al., "Soins palliatifs et maladie d'Alzheimer," *La Revue de Médecine Interne* 30, no. 6 (June 1, 2009): 501–7, https://doi.org/10.1016/j.revmed.2008.09.010.

patients had no notes in their file referring to a discussion regarding the goals of treatment or reference to an advanced directive.[125]

Another similar example of encouraging policy and disappointing implementation is the National Guidelines for Palliative Care in Residential Aged Care Settings that Australia introduced in 2006. The guidelines mandate that physicians in residential care facilities incorporate a palliative approach to their treatments, including early identification and treatment of physical, cultural, psychological, social and spiritual needs. The guidelines aim to support continuous improvement in the quality of all palliative care services across Australia, and contribute to Palliative Care Australia's mission to make palliative care options available to all Australians.[126] However, like the Léonetti law, there is little evidence that the guidelines have been widely implemented. In a study that examined the awareness, attitudes, confidence and knowledge of palliative care for people with dementia in six Australian residential aged care facilities, researchers found that as recently as 2015, there remain wide gaps in the abilities of caregivers to deliver palliative care.[127] Only 46% of all staff indicated that their facility used the Palliative Care Guidelines in care settings, and observations by the researchers indicated that even in cases where staff claimed to implement the guidelines, many practices did not reflect the care standards set by the guidelines, such as a lack of individualized care and discontinuity of care. When asked to explain the guidelines and what they required, 55% of the staff exhibited a good "general knowledge" of the guidelines. Nevertheless, the majority of staff identified

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[125] F. Lopez-Tourres et al., "Soins palliatifs et maladie d'Alzheimer," *La Revue de Médecine Interne* 30, no. 6 (June 1, 2009): 501–7, https://doi.org/10.1016/j.revmed.2008.09.010.

[126] National Palliative Care Program (Australia), Edith Cowan University, and National Health and Medical Research Council (Australia), *Guidelines for a Palliative Approach in Residential Aged Care* (Canberra: National Health and Medical Research Council, 2006).

[127] Vanessa Nolasco, "Palliative Care in Residential Care," *Centre for Health Economics Research and Evaluation (CHERE)*, April 2018.

conversations surrounding death as difficult, and did not feel confident when answering questions about dying or adhering to resident preferences for end of life care.[128]

Fortunately, similar efforts to draft legislation that provides coverage of palliative care are being made in the United States, at least at a state-level. In contrast to the state of Alaska, California has made good strides in creating policies that encourage the use and coverage of palliative care for residents of the state. Senate Bill 1004, which was approved by the Governor of California in 2014, requires that people insured by Medi-Cal, which is California's Medicaid health care program, are entitled to palliative care.[129] SB 1004 was the first bill of its kind signed into law, however other states have since passed similar legislation or are currently proposing similar legislation.

While action taken by states like the passing of SB 1004 is a great step in the right direction, there is more to be done in order to ensure that the policy is successfully implemented so that palliative care is truly accessible to patients who need it. In order to put legislation like SB 1004 into practice, it is essential that there are adequate government resources, such as funding and trained personnel. For example, SB 1004 was passed in 2014, but implementation of the Bill was not even addressed until 2018 due to lack of government resources.[130] While it has been shown that this type of legislation increases access and quality of palliative care, which has been demonstrated to be valuable for improved patient care, these programs are expensive. As a consequence, this type of legislation is difficult to pass and fund, particularly with the pandemic reducing state budgets. Despite high costs, when looking at the benefits for seriously-ill patients,

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[128] Vanessa Nolasco, “Palliative Care in Residential Care,” *Centre for Health Economics Research and Evaluation (CHERE)*, April 2018.
[129] “Bill Text - SB-1004 Health Care: Palliative Care.,” accessed October 15, 2020, http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=201320140SB1004.
[130] Stacie Sinclair, “Reflections from a Palliative Care Champion – California’s Kate O’Malley,” accessed October 16, 2020, https://www.capc.org/blog/palliative-pulse-palliative-pulse-may-2017-palliative-care-champion-kate-omalley/.

it is clear that funding and supporting palliative care is a worthy expense. Beyond legislation surrounding insurance coverage of palliative care, states can also increase the quality and accessibility of palliative care through laws that require the continuation of education in areas like pain management, safe opioid prescribing, and other important aspects of end-of-life care.[131]

When it comes to access to excellent palliative care for dementia patients, significant change will only occur once both policies change and individual institutions make a conscious effort to promote this form of care. While increased education, training and coverage are all necessary for making palliative care available to all dementia patients, as seen with the Léonetti law in France and the National Guidelines for Palliative Care in Residential Aged Care Settings in Australia, change will not occur without pressure from within individual care facilities. As mentioned previously, institutions must build a culture from within that values the use of palliative care, and sets the expectation that palliative care is to be made available to all patients. Such a culture, in tandem with policies that allow for coverage and reimbursement for palliative care as well as increased opportunities for ongoing training and education, will allow for palliative care to become available for all, and hopefully, will become the standard when treating dementia patients.

Results

The results from my data analysis were varied, with some of my predictions holding true while others were incorrect. I predicted that I would see results that match the larger trends that exist within the demographics of dementia patients and palliative care patients. I predicted I would see a higher rate of dementia among patients of increasing age, patients who are gendered

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[131] Stacie Sinclair, "Reflections from a Palliative Care Champion – California's Kate O'Malley," accessed October 16, 2020, https://www.capc.org/blog/palliative-pulse-palliative-pulse-may-2017-palliative-care-champion-kate-omalley/.

as women, and patients who are racial and ethnic minorities. Additionally, I predicted that a majority of the dementia patients will either be insured privately or by Medicaid/Medicare, and that the rates of dementia patients who receive palliative care will be much higher among patients who have private insurance as opposed to those with Medicaid or Medicare.

The results of my data research largely went against my predictions when it came to ethnic breakdowns. The demographic breakdowns of the ethnicities of the dementia patients matched the overall trends of the data set. While the vast majority of dementia patients were white (figure 3), the proportion of the dementia patients by ethnicity were very similar to the proportions of each ethnicity in relation to the entire dataset (table 1). The data I reviewed did not reflect the higher rates of dementia among Hispanic and black ethnicities that I expected.

The breakdowns of which insurance coverages the dementia patients had were slightly closer to my predictions, with the vast majority of dementia patients being insured by Medicare (figure 4). While Medicare patients accounted for 56.59% of all the patients in the dataset, 91.17% of dementia patients were covered by Medicare (table 1). Furthermore, while 30.80% of patients paid out of pocket for their treatments, only 5.67% of dementia patients were self-pay (table 1).

My prediction regarding the higher prevalence of dementia among patients who were categorized as women compared to those who were labeled as men was also correct (figure 5). There was a significantly higher proportion of women that had dementia than men, with women making up 58.40% of dementia cases despite only representing 44.28% of the entire dataset (table 1).

Conversely, my predictions surrounding the demographic breakdowns of palliative care patients were incorrect. The proportions of each demographic when it came to ethnicity, insurance, and gender matched the overall proportions of the data set. While patients of white ethnicity accounted for by far the largest number of patients that received palliative care (figure 6), patients received palliative care at similar rates, regardless of ethnicity (figure 15). My hypotheses regarding the breakdown of insurance coverage of patients who received palliative care was mostly correct, with the largest number of patients who received palliative care being insured by Medicare (figure 7), and the highest proportions of insurances that had patients treated with palliative care being Medicare, Medicaid, and private insurance (figure 16). While I did not make any predictions about the gender breakdown of patients who received palliative care, it was interesting to see that while around the same amount of each gender received palliative care (figure 8), patients gendered as women were slightly more likely to receive the treatment, making up 50.43% of palliative care treatments but only representing 44.28% of the entire population (table 1).

When it came to patients that both had dementia and received palliative care, the results were largely unremarkable, with the proportional demographics of dementia patients that received palliative care matching the proportional demographics of the entire dataset. Looking at the ethnic breakdown of patients that had dementia and received palliative care, although white dementia patients received palliative care the most (figure 9), Asian and black patients had the highest proportions of dementia patients to receive palliative care (figure 12). The breakdown of insurances that covered dementia patients who received palliative care was dominated by Medicare (figure 10), although proportionally, most dementia patients who received palliative care were covered by Medicaid (figure 13).

The difference between Medicaid and Medicare is that medicaid is controlled by individual states accessible based on income, while Medicare is managed by the federal government and is primarily based on age. I did not have the opportunity to take a deeper look into the difference between Medicare and Medicaid and how the coverage they offer differs, but it seems intuitive that the vast majority of dementia patients were insured by Medicare, considering that it is a federal program that covers elderly people. It is very interesting that a larger proportion of dementia patients who were insured by Medicaid received palliative care compared to those insured by Medicare. While I did not have time to look into the Medicaid policies in the state of Massachusetts (the location of the hospitals from which the data came from), I would guess that Medicaid in Massachusetts likely offers greater coverage for treatments than other states. Further research should look into the Medicaid system in Massachusetts, as it could offer insight into how to increase coverage for dementia patients and encourage the use of palliative care.

Finally, it also made sense that the data reflects that no dementia patients who had to pay out of pocket received palliative care, as it is very unlikely to seek palliative care if it is not covered by insurance (figure 10). When it came to the gender of dementia patients that received palliative care, a significantly higher number of dementia patients who were gendered as women received palliative care (figure 11), along with a higher proportion as well (figure 14).

It is important to note that the results that I found, specifically the results surrounding the palliative care patients, may not be very accurate. It is very possible that the methodology I used to identify patients who received palliative care did not accurately capture the population that I hoped to isolate. I used word-matching to identify patients that had the words “palliative care” or some form of that phrase in their free-text notes, which although I was able to do successfully, I think some of these patients never actually received palliative care. While some patients had a note that made reference to a specific palliative care consult or reference to the patient’s palliative care team, many patients only had a mention or recommendation of palliative care in their note. For this second category of patient that did not have a specific reference, it is possible that these patients did not ever actually receive palliative care. I was not able to read through each note individually and select only the patients that had a specific reference to a consult or a palliative care team, so it is likely that my cohort of dementia patients that received palliative care contained patients that never received palliative care despite a recommendation from a doctor for this care to be delivered.

Demographic and Clinical Characteristics	**All Patients (n=651047)**	**Dementia Patients (n=1993)**	**Palliative Care Patients (n=936)**	**Dementia and Palliative Care Patients(n=128)**
Race, n(%)				
Black/African	65930 (10.13)	202 (10.14)	95 (10.15)	18 (14.06)
White	466043 (71.58)	1495 (75.01)	690 (73.72)	93 (72.66)
Asian	14392 (2.21)	47 (2.36)	31 (3.31)	7 (5.47)
Unknown	104682 (16.08)	249 (12.49)	120 (12.82)	10 (7.81)
Insurance, n(%)				
Government	15942 (2.45)	3 (0.15)	13 (1.39)	0 (0)
Medicaid	61290 (9.41)	57 (2.86)	68 (7.26)	4 (3.12)
Medicare	368442 (56.59)	1817 (91.17)	675 (72.12)	118 (92.19)
Self-Pay	200528 (30.80)	113 (5.67)	176 (18.70)	6 (4.69)
Private	4845 (0.44)	3 (0.15)	4 (0.43)	0 (0)
Sex, n(%)				
Male	362773 (55.72)	829 (41.60)	464 (49.57)	41 (32.03)
Female	288274 (44.28)	1164 (58.40)	472 (50.43)	87 (67.97)

Table 1: Breakdown of patients included in the study and their characteristics

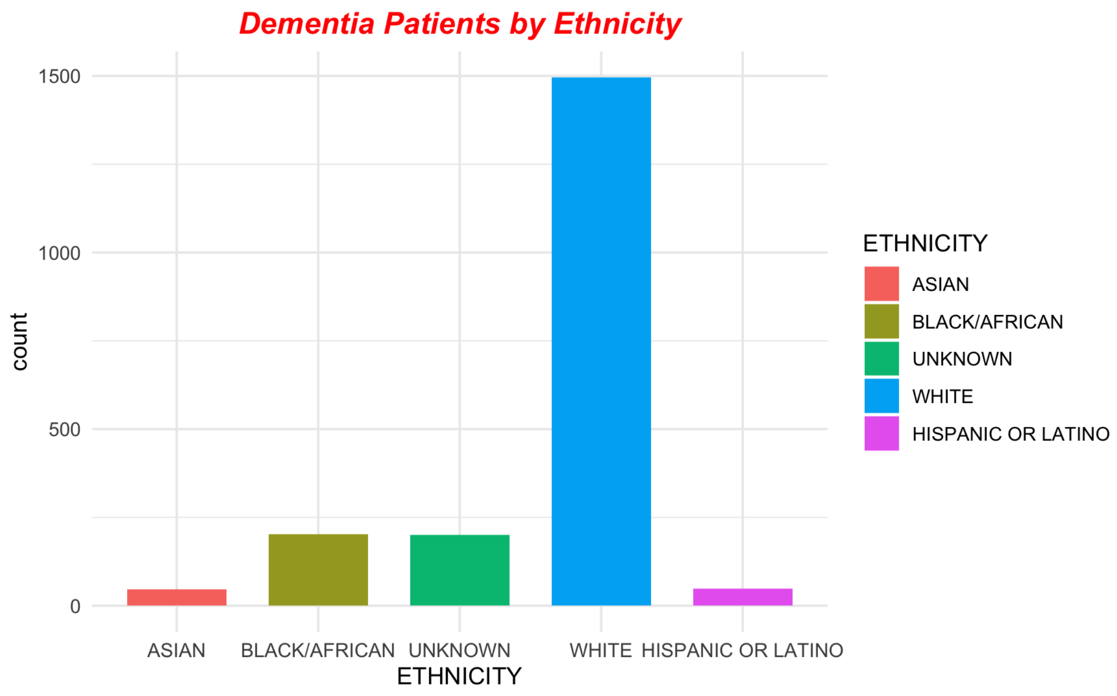

Figure 3: Ethnicities of all dementia patients

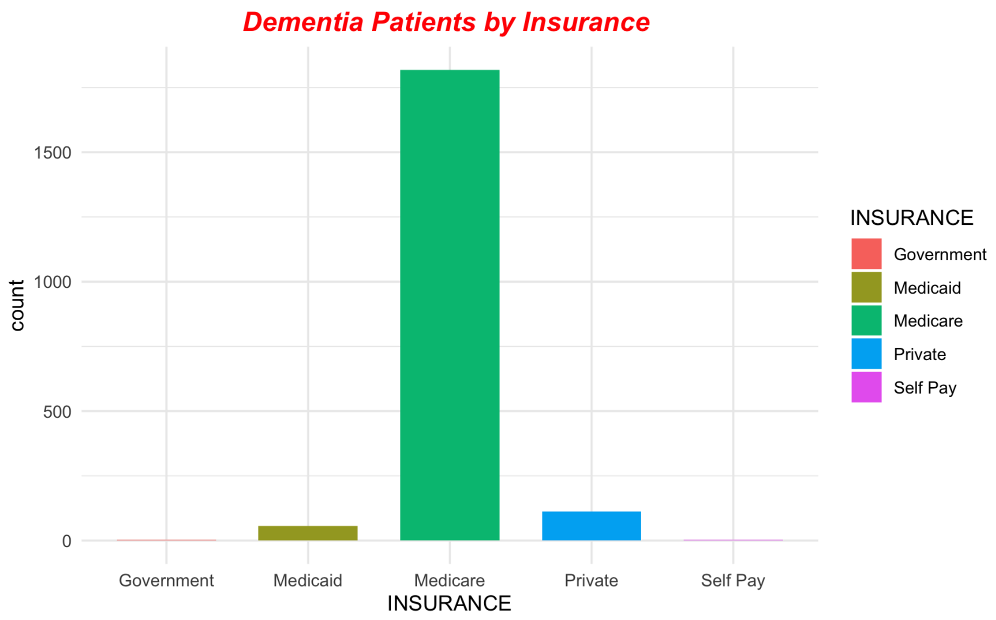

Figure 4: Insurance of all dementia patients

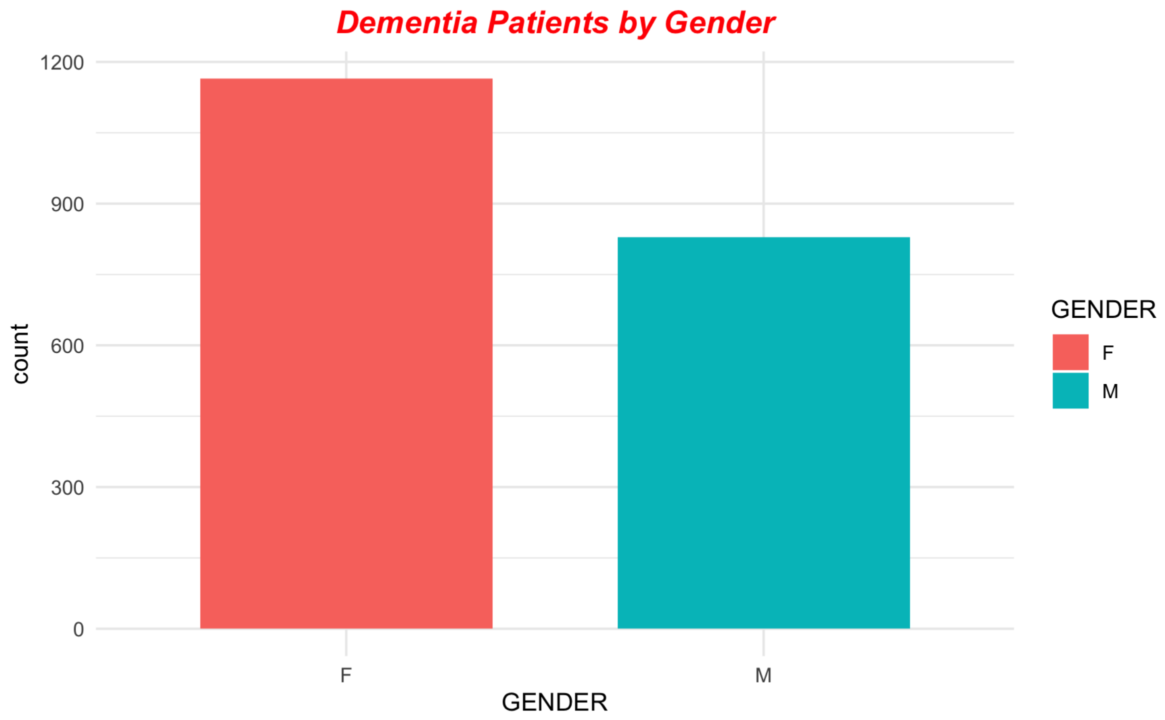

Figure 5: Gender of all dementia patients

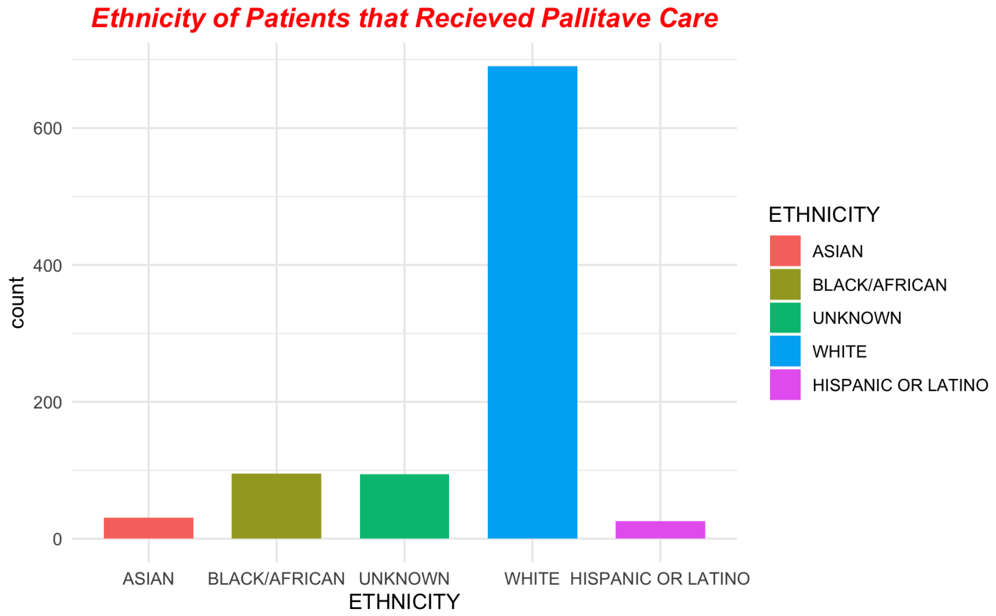

Figure 6: Ethnicity of all patients that received palliative care

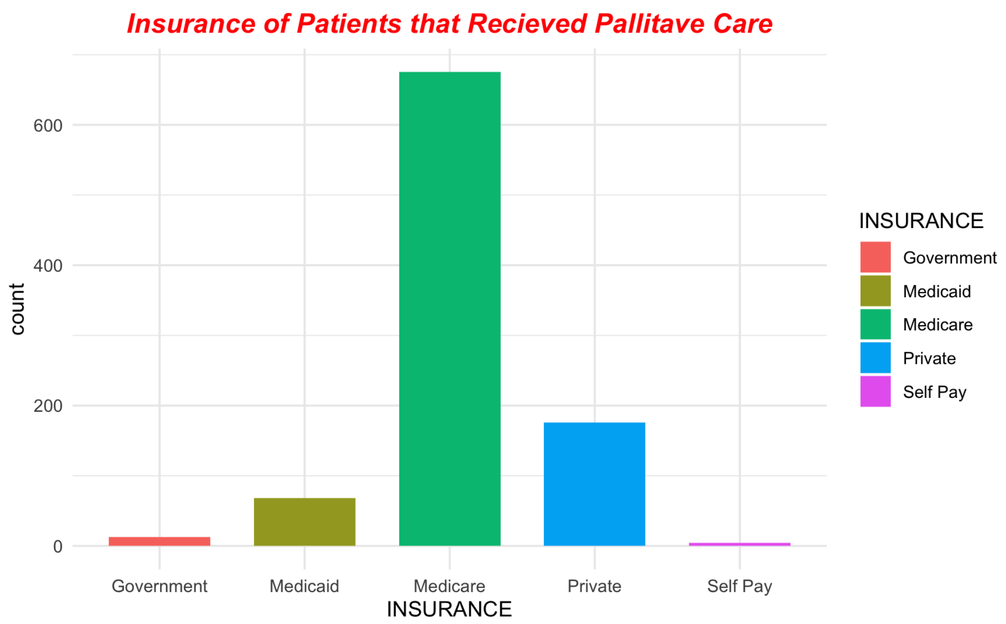

Figure 7: Insurance of all patients that received palliative care

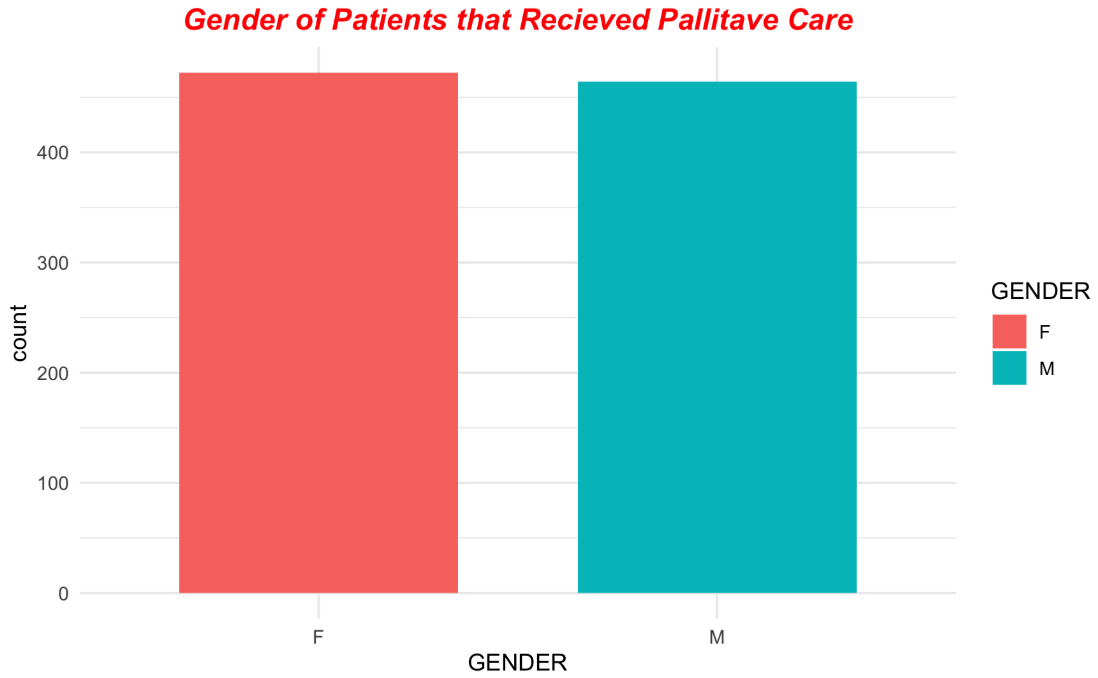

Figure 8: Gender of all patients that received palliative care

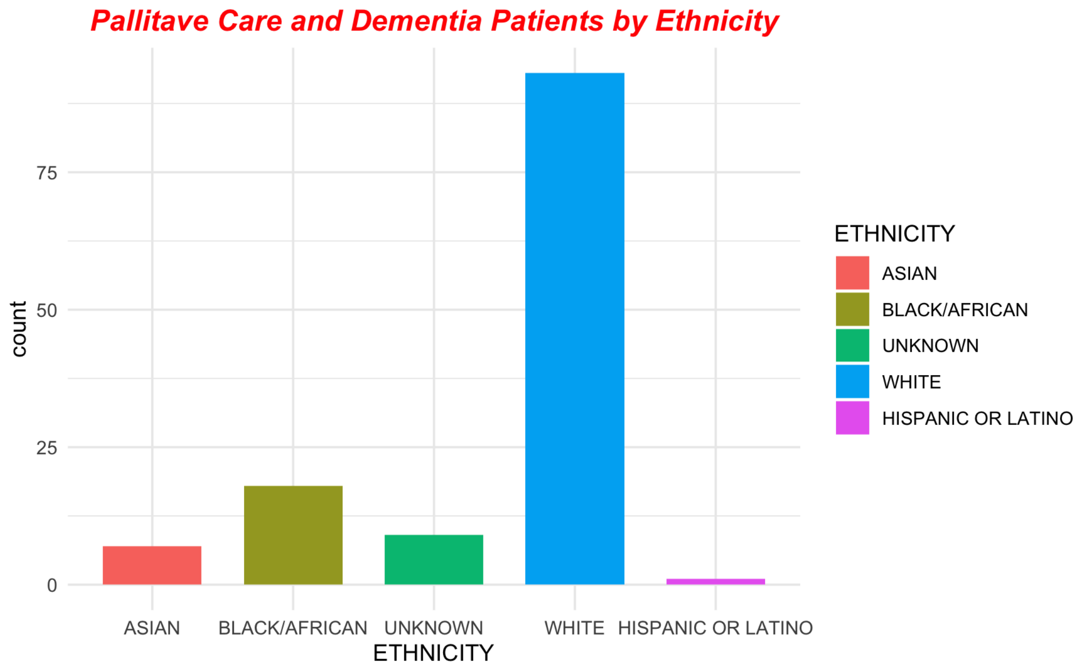

Figure 9: Ethnicity of all dementia patients that received palliative care

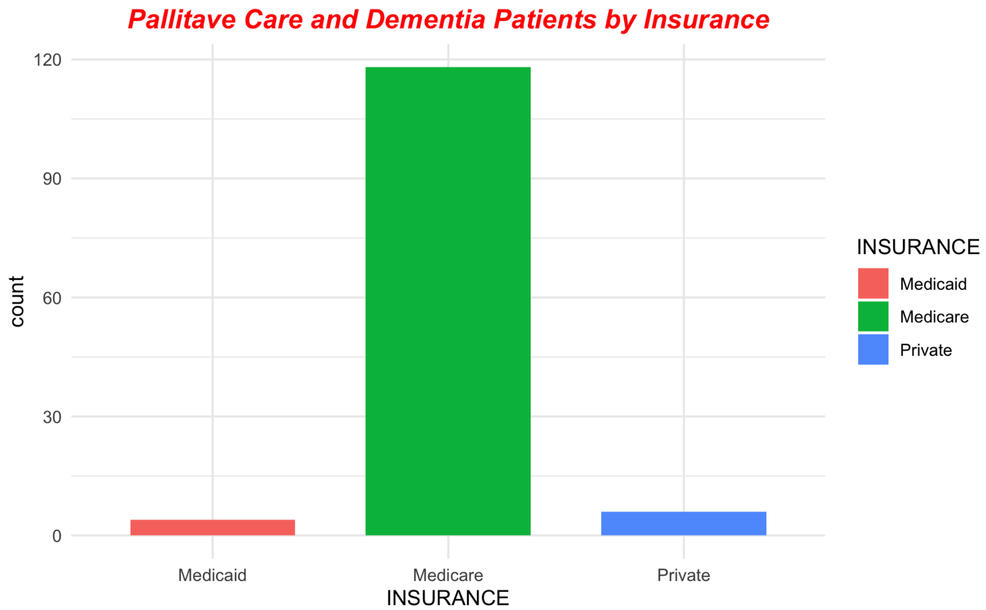

Figure 10: Insurance of all dementia patients that received palliative care

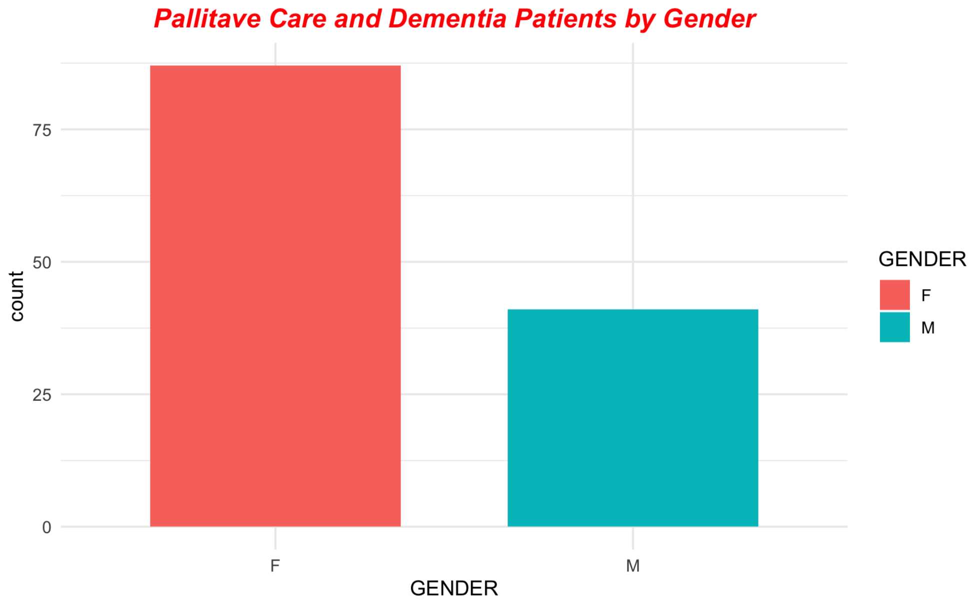

Figure 11: Gender of all dementia patients that received palliative care

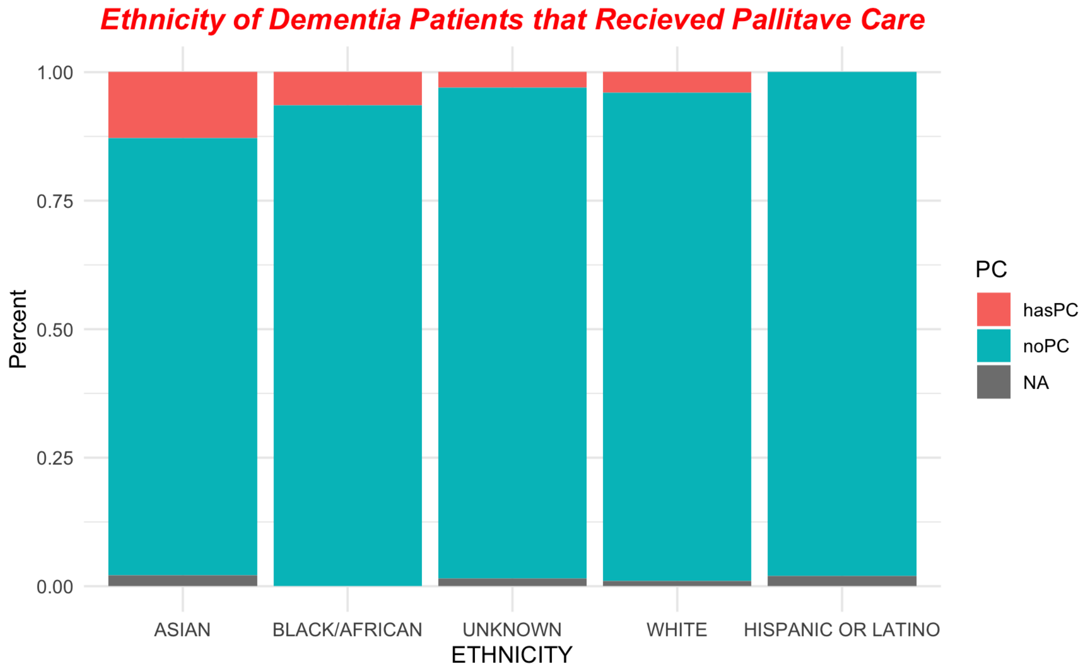

Figure 12: Percentage of dementia patients that received palliative care, segregated by ethnicity

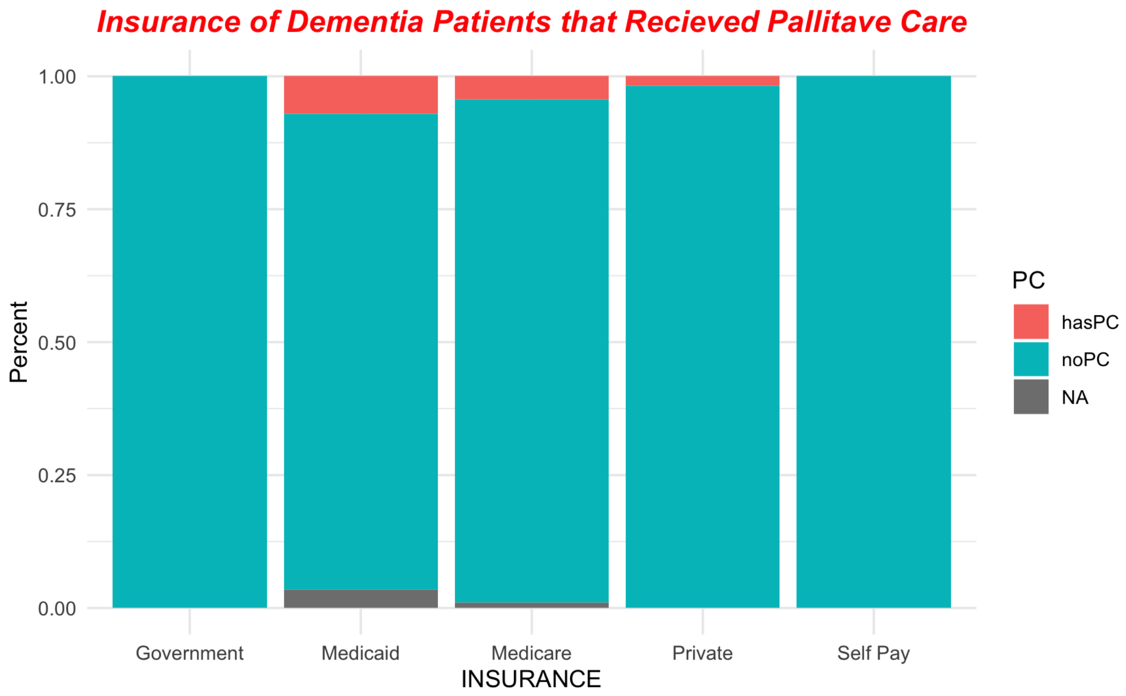

Figure 13: Percentage of dementia patients that received palliative care, segregated by insurance

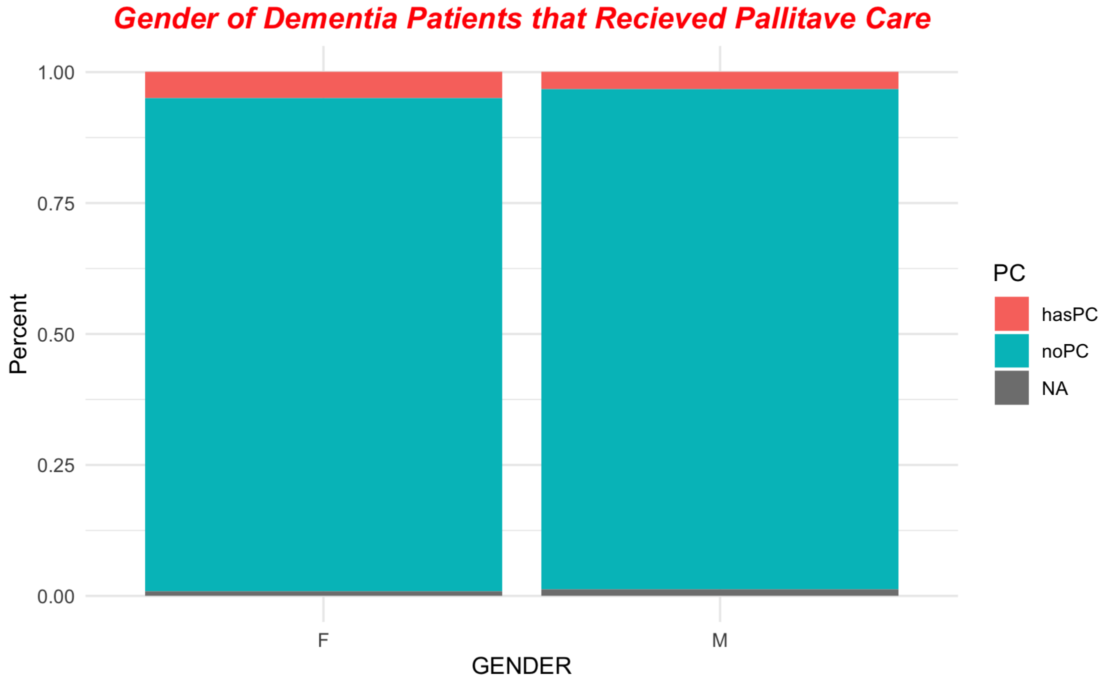

Figure 14: Percentage of dementia patients that received palliative care, segregated by gender

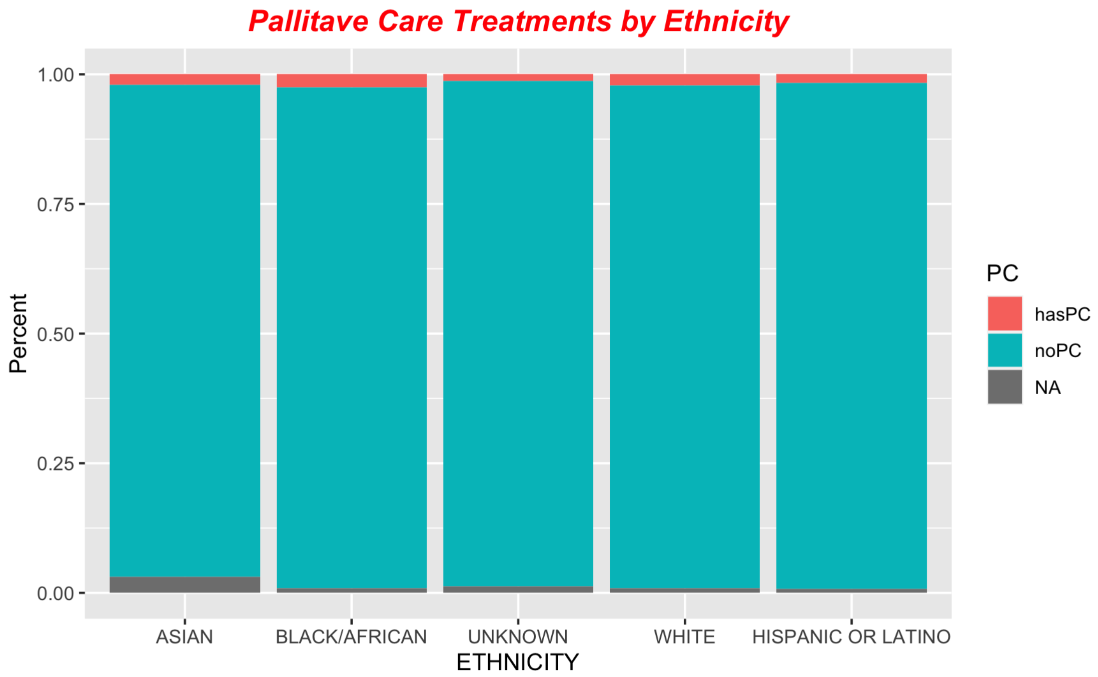

Figure 15: Percentage patients that received palliative care, segregated by ethnicity

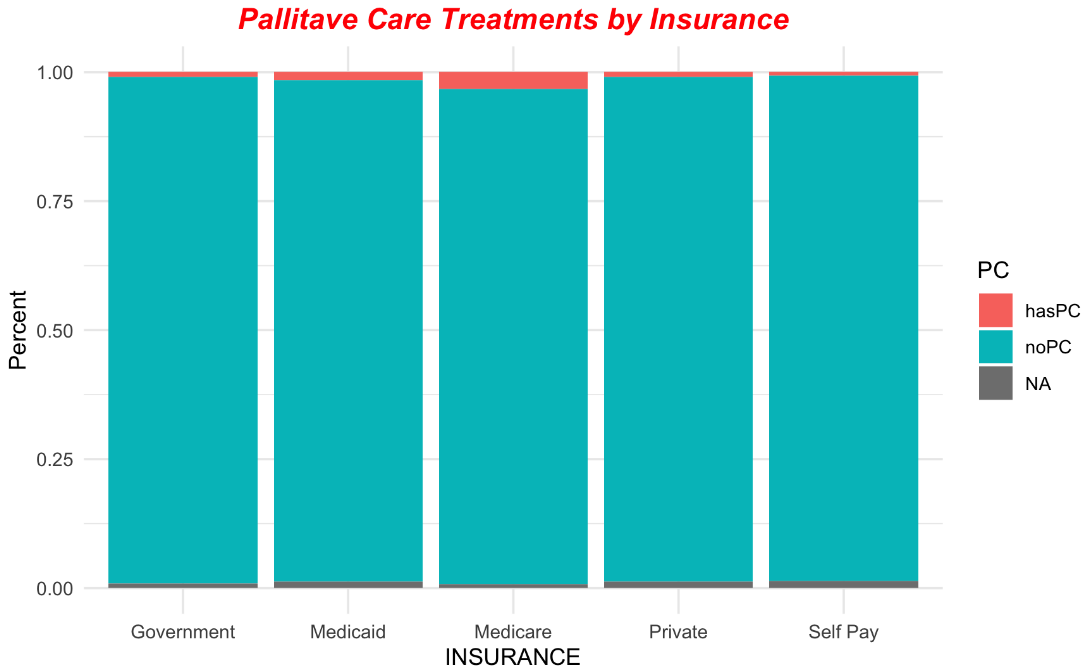

Figure 16: Percentage of patients that received palliative care, segregated by insurance

Conclusion

Before beginning this nearly year-long project, I had no idea what palliative care was, much less had an appreciation for its utility and the many benefits it offered. Now, nine months later, I feel passionate that palliative care is an incredibly valuable form of treatment, and is something that should be available to all seriously ill patients, particularly patients with dementia. The benefits of palliative care are abundantly clear: not only does a palliative approach allow for more cohesive care between specialists when implemented correctly, it empowers the patient to be treated in the manner they wish to be treated, allowing the patient to maximize their quality of life as they see fit in the face of a serious illness. Furthermore, it offers the patient's family a system of support, not only by potentially relieving the family from making challenging and emotional decisions on behalf of the patient, but also by considering the emotional needs of the family, who are affected deeply by the illness of their loved one. The patient and the patient's family can particularly benefit from palliative care in the case of a patient with dementia, as it allows for the patient to set advanced directives to ensure that once the patient loses autonomy, the patient's family will not have to make decisions regarding potentially expensive, invasive, and painful treatments — treatments that oftentimes do not improve the patient's quality of life. Finally, it has been demonstrated that palliative care can save money for the patient and the patient's family, taxpayers, and the healthcare system as a whole by avoiding expensive treatments that often result in complications and the frequent transfer of the patient between long-term and acute care facilities.

Despite the clear benefits that palliative care offers, it is inaccessible to many people who could be helped greatly by receiving the treatment. These barriers consist of a variety of factors, but are mainly centered around gaps in policy that disincentivize the use of palliative care. For starters, many insurance companies do not cover palliative care, meaning that patients who wish to be treated using palliative care must pay out of pocket to do so, making the care largely available only to those who have the financial means to cover the costs of care. Furthermore, current policies make it so that healthcare facilities are incentivized from a monetary standpoint to transfer patients back and forth between long and short-term care facilities, and to treat patients with aggressive and expensive interventions that will be reimbursed substantially by almost all insurances. While the current system benefits the bottom line for these facilities, it results in inferior care for the patients themselves. Finally, the lack of education and understanding surrounding palliative care also serves as a large barrier to widespread accessibility of palliative care. Unless a healthcare student chooses to specialize in palliative care, very little (if any) teaching is done in medical schools regarding palliative care, end of life care, or, even fundamentally, how to properly care for dementia patients. Furthermore, once a student graduates, their opportunities to learn about palliative care are even more limited, as programs that provide ongoing training and education on palliative care are quite scarce. The combination of these barriers have led to a healthcare system that immensely underappreciates and underutilizes palliative care.

Fortunately, each barrier that lies in the way of palliative care being made available to all who need it can be surmounted. First and foremost, changes need to be made to existing policies to guarantee reimbursement of palliative care, and to alter financial incentives in the healthcare system so that facilities are encouraged to use a palliative approach instead of treating patients aggressively and transferring them back and forth between care facilities. The education and awareness surrounding palliative care is something that can be accomplished through policy changes and modifications to the ways that doctors are taught and trained. Pushes are being made to make these changes, and some schools are changing their curriculums to include more on palliative care and end-of-life care.[132] Finally, in tandem with understanding and awareness, institutions must try to make a shift in culture that emphasizes the importance of palliative care. Once an expectation surrounding knowledge of palliative care is cultivated within a healthcare facility, it will become the norm to take a team-oriented approach to patient care, and to make palliative care available to those who need it.

While suggesting that policy should be drafted to guarantee coverage of palliative care is wonderful in theory, the lack of awareness in policy-makers and lack of available funding will prevent such a change from occurring anytime soon. Thus, it is important to take a closer look into more attainable policies that can encourage and increase the use of palliative care. A great place to start would be to do deeper case studies into the different policies that different states have in place, such as looking at what coverage is offered by Medicaid in Massachusetts, who can qualify for Medicaid, and which particular policies lead to increases in palliative care.

There is no better time to make pushes for these changes than right now. The COVID-19 pandemic has brought an increased amount of attention toward the healthcare system, and while the virus has been nothing short of horrible, a possible silver lining is that it has drawn attention to the terrible way that our healthcare system is centered around profit, rather than helping those who need it. There is enormous pressure on doctors and healthcare workers to treat patients as fast as possible, using services that are well reimbursed. The pandemic turned this system on its head, as the major sources of income for hospitals and other healthcare facilities were elective surgical and other interventions, but these procedures were halted due to the risk of spreading the virus and the need to repurpose health systems to treat massive amounts of COVID patients.[133]

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[132] "Curricula," accessed April 25, 2021, https://www.bioethics.northwestern.edu/programs/epec/curricula/index.html.

[133] David Marchese, "Covid Has Traumatized America. A Doctor Explains What We Need to Heal.," *The New York Times*, March 22, 2021, sec. Magazine, https://www.nytimes.com/interactive/2021/03/22/magazine/diane-e-meier-interview.html.

As a consequence, more institutions are looking at how previously unreimbursed healthcare can be paid for.

In an interview with the New York Times, Dr. Diane E. Meier drew attention to this strange situation that the healthcare system is now in, and how now is the perfect time to realign the incentives of the healthcare system to benefit patients instead of benefitting a hospital's profits. Dr Meier is the longtime director of the Center to Advance Palliative Care, which is part of New York City's renowned Mount Sinai Hospital, and is a passionate advocate and pioneer in the realm of palliative care. In the interview, she discusses how most doctors look to palliative care specialists to provide the "human side" of medicine, and laments the fact that the main motivators behind medical treatment have become getting paid rather than helping people who are suffering.[134] "There's more than a kernel of truth in the perceptions of people feeling as if they or their loved one is being put through a marketplace of M.R.I.s and P.E.T. scans and specialists and subspecialists," Dr. Meier says, adding "the extraction mind-set in the practice of medicine is not subtle, and the public knows it."[135] Fortunately, the scope of the medical world does not have to be this way. Changes can be made to encourage care based on the patient's needs rather than reimbursement, and to prioritize quality of life, comfort and happiness over the bottom dollar. Once incentives can be realigned to support doing the right thing rather than the profitable thing, every patient, especially dementia patients, will be able to receive the quality of care that they deserve.

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[134] David Marchese, "Covid Has Traumatized America. A Doctor Explains What We Need to Heal.," *The New York Times*, March 22, 2021, sec. Magazine, https://www.nytimes.com/interactive/2021/03/22/magazine/diane-e-meier-interview.html.

[135] David Marchese, "Covid Has Traumatized America. A Doctor Explains What We Need to Heal.," *The New York Times*, March 22, 2021, sec. Magazine, https://www.nytimes.com/interactive/2021/03/22/magazine/diane-e-meier-interview.html.

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