# HOSPICE CARE IN THE MODERN DAY AFRICAN AMERICAN COMMUNITY: BELIEFS AND INEQUALITY

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# ABSTRACT

## Hospice Care in the African American Community: Beliefs and Inequality

Doctor of Medical Humanities Dissertation by

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The purpose of this dissertation is as follows: What are the underlying issues pertaining to the discrepancy in hospice care utilization rates between African Americans and Caucasians?

The study's methodology is different from other studies due to the utilization of a more creative process. The data collection method involves analyzing secondary sources to investigate the research problem of this dissertation. The background of this study is as follows.

One major reason why African Americans mistrust the hospice care field is due to cultural differences, but also decades of abuse and mistreatment at the hands of the medical field. However, the rationale for mistrust also includes gaps in insurance access, persistent inequities in healthcare, and a taboo attitude towards death and suicide. Throughout this study, I will explain the numerous factors that have led to the low African American hospice enrollment rates, from medical mistrust to religion to insurance rates. Furthermore, I will also explain the early history of hospice care in

Ireland and the United States. Lastly, I will offer some suggestions for alleviating the medical racism problem at the heart of the low African American hospice care enrollment rate crisis.

This dissertation is my attempt to solve a decades-old problem that needs to be addressed for a better tomorrow.

# DEDICATION

I would like to dedicate this dissertation to my family, my professors, my dissertation committee, The Drew U Library, The Apple Computer Company,  caffeine, melatonin, and -Fi for getting me to this point.

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# INTRODUCTION

End-of-life care is not just the specialized care one receives at the end of life; it also encompasses funeral care, palliative care, and decisions about when and how to end curative care. The problem statement of this dissertation is to identify the underlying issues that are responsible for the discrepancy in hospice care utilization rates between African Americans and Caucasians. Controversial issues that surround end-of-life care include quality of care at the end of life, whether or not to utilize a physician's help with dying, and lastly, how to be culturally sensitive. Everyone deserves a peaceful death that is free of drama and unnecessary suffering. One good way to achieve a somewhat peaceful death is to enroll in hospice. However, there are different hospice utilization rates for African Americans and Caucasians due to misunderstandings about what hospice care does, being more attuned to curative care rather than the comfort of hospice care.

Hospice care is defined as, according to *Magill's Medical Guide*, "A philosophy of care directed toward persons who are dying. Hospice care uses a family-oriented, holistic approach to assist these individuals in making the transition from life to death in a manner that preserves their dignity and comfort." (Zukowski, 2023, 1)

This specific form of care differs from more normalized curative care and focuses on alleviating illness and disease. The goal of hospice care is to make terminal care patients comfortable. The St. Christopher's Hospice Care Center was founded in 1908 in Ireland. Later in 1908, Cicely Saunders founded the first hospice center in America at Yale University. While there is a set of principles guiding the missions of numerous modern-day hospice care centers, there is one overarching theory that aims to provide terminal patients with a good death.

One must ask how we can define a good death. There are various ways to answer this question. One way to answer this question is to distinguish between a death in a hospital and a death at home. Deaths at hospitals or nursing homes conjure up images of cold, sterile, and desolate hospital corridors and patient rooms. Dying in a hospital also conjures up images of being in bed while on countless medications and intravenous fluids or life support machines.

It also evokes inescapable feelings of having the most vulnerable parts of one's life and one's illness exposed to physicians, nurses, and healthcare workers whom people do not know. There is an immense amount of uncertainty, limited contact with family members, and worrying involved with any illness, disease, or injury, especially a terminal disease or illness. Alternatively, dying at home is an entirely different experience. Unlike dying at a hospital, dying at home allows a terminal patient to be surrounded by the people and things they cherish. Moreover, the cost of dying at home is less expensive, as payments of all these costs depend on access to health insurance, which will be discussed in the fourth chapter of this dissertation. Having a comfortable death at home also depends on the availability of family members who can take time off from their own busy lives at work, school, or home.

One also needs to consider that some people do not have familial or spousal support at the end of their lives. For some of these people, their deaths do not happen in a hospital but in a nursing home, which can be just as alienating as dying in a hospital.

While nursing homes attempt to make the lives of the elderly better, they so often fall short. One rationale for this is insurance costs and how much care and attention terminal patients can afford at this crucial time. Another factor that affects the comfort level of a nursing home is the amount of funding available for the individual nursing home. Lastly, having access to their spouses and family members is also a crucial factor in whether or not the elderly can have comfort at the end of life. For some elderly people, this is not a concern as they have access to these essential resources as well as a support system and resources such as music and art therapy.

A good example of this dichotomy in care between well-funded nursing homes and underfunded nursing homes comes from a story of when my grandfather moved from the house he had lived in for years (and also the house that was the sight of countless Thanksgiving/Christmas dinners, barbeques, and a single family reunion). After living in the home he loved, he took the drastic step of moving to a nursing home; thankfully, this was a pleasant, nice nursing home with clean, modern, and inviting interiors and a meeting room for the residents. All the patient rooms were reminiscent of normal hospital rooms; instead, they were small apartments with household items that the residents cherished. There were also activities and outings for the residents, which helped all the residents feel a sense of belonging and comfort after moving from the homes they loved. Unfortunately, my grandfather had a second stroke and had to move to another nursing home. This particular nursing home was not as lovely as the other nursing homes and could be mistaken for a hospital. The hallways were dark and alienating, and the patient rooms were not cozy apartments with the residents' belongings. An animal therapy program had been put in place to help the residents, but that did not help with the cold and isolating feeling of being far away from any true sense of comfort. Another thing missing from the nursing home atmosphere was a sense of camaraderie among the residents. Outings consisted of the residents sitting in their wheelchairs around the nursing station. There were no more field trips or bingo nights.

Many more factors go into whether or not someone can have a good death. These factors will be analyzed in this dissertation, including how music and art therapy can alleviate the excruciating symptoms that so often accompany death, which will be analyzed in the second chapter. The long-lasting and brutal impact of medical racism, not just on patients but also on access to necessary hospice care, will be explored in the third chapter of this dissertation. In the literature review of this dissertation (the first chapter), there will be an overview of not just the history and significance of hospice care but also the primary reasons why African-Americans are skeptical of hospice care, the reasons for hospice care inequality, and the history and development of African-American funeral homes and memorials. Originally, the section on African-American funeral homes and memorials was going to be its own ArcGIS (Geographic Information System)  website through Drew University Digital Humanities Initiative.

However, grant funding and allotted time to develop this project into a more substantial project ran out. As a result, this project will, for the time being, be a section in the literature review rather than the groundbreaking project it could have been if given the time, energy, and grant funding. The distinct differences between palliative and hospice care will be explained in more detail. These two forms of care may seem alike, but the goals are quite different: Palliative care is more of a form of curative care, while hospice care can be considered more of a form of comfort care.

The severity of suicide in the African-American community will be addressed within the literature review. As this topic relates to the discussion within this dissertation, it needs to be analyzed. Also, since it is a serious issue, it will not be analyzed in great depth beyond the literature review. African-American funeral homes and notable African-American cemeteries will be analyzed towards the end of the literature review as they relate to the earlier discussion of the ill-fated ARC GIS website/storymap. The last chapter of this dissertation will focus on the intricate and highly regulated details of health insurance. The conclusion of this dissertation will be the final argument as to why hospice and end-of-life care need to be made more equitable.

# CHAPTER ONE

# LITERATURE REVIEW

## Part One: Introduction

The actual history of hospice care in the United States starts with a movement to replicate the hospice care that was starting to be revolutionized in Europe over to America. The history of hospice care in America started with Dr. Cicely Saunders being invited to Yale University, as Stephen K. Connors explains:

> In 1963, Florence Wald, then Dean of the School of Nursing at Yale, invited Dr. Cicely Saunders, matriarch of the worldwide hospice movement, had developed approaches to managing pain and total needs of the dying patients based on the philosophy of using a team to treat the whole person. (Connors, 2008, 90)

Cicely Saunders' actions launched the global movement to improve hospice care and care for the dying as a whole. In fact, the American hospice movement took place in the United States at the same time as the American movement to "Take back control of various institutions, including churches, community services, and health care, from birth to death." (Connors, 2008, 90)

The hospice movement took off at Yale University, with Florence Wald leading the charge and in doing so:

> Launching the Nurses Study of Dying Patients and Their Families soon after returning from London in 1968. In 1974, Hospice Inc. (later the Connecticut Hospice) opened in New Haven, Connecticut, providing home care services to people with a limited life expectancy, a primary caregiver at home, and a cancer diagnosis. (Abel, 2018, 2)

Now, years later, the hospice movement that Florence Wald started at Yale University in 1974 continues to help countless dying patients, although the necessary care that hospice provides is not distributed evenly among all races, which is the focus of this dissertation. The hospice care movement would not be able to accelerate in the United States without a supportive community of volunteers. During the early days of hospice care, "Everyone was essentially a volunteer, either lay or professional." (Connors, 2008, 90).

The book *On Death and Dying* by Elizabeth Kubler-Ross was also published around this time (this book was published by the MacMillian Company in 1969), and Kubler-Ross sought to de-mystify the five stages of dying. In her book, Kubler-Ross not only explained the five stages of dying, but she also attempted to explain America's aversion to talking about dying. The five stages of dying are "Denial and isolation, anger, bargaining, depression, and acceptance." (Ross, 1969). However, when Kubler-Ross initially published her book, there was an immediate backlash that stemmed from not only the content of the book but also Kubler-Ross's research method as well, specifically her research method of interviewing dying patients.

Rothweiler and Ross reviewed the book *On Death and Dying* and further explained that at the time of the book being published:

> Dying patients were not informed about the nature of their illnesses. Family members were not allowed to visit their dying loved ones, unless it was during predesignated visiting hours. Children were forbidden to visit their dying parents and siblings entirely. She fought against these practices at significant cost to her career and reputation. (Rothweiler and Ross, 2019, 3)

After reading the above quote, one should be able to summarize the theory that the dying process was devoid of dignity until Elizabeth Kubler-Ross thought of a better and newer way for people to die. Kubler-Ross' goal was to not only revolutionize the level of care but also to bring some dignity back to the dying process.

While hospice care has become a major and successful industry in America, Rothweiler and Ross further explain that there are still barriers to hospice care that exist today:

> Some providers continue to be hesitant to involve hospice or involve hospice care so late that patients and their families do not share in the needed resources that would be available to them. Many patients continue to be afraid to plan for end-of-life care. (Rothweiler et al., 2019, 3-4)

The aforementioned quote shows just how far the United States still has to go to provide adequate hospice care to everyone, especially minorities. African Americans, in particular, have a skeptical view of hospice care due to mistreatment in medical research. Another reason that African Americans do not fully approve of hospice care is that they see switching from curative treatment to hospice care as giving up, and prefer to continue treatment. This is where Elizabeth Kubler-Ross comes in, as she was essential in starting serious conversations about death in hospitals and other care centers. Elizabeth Kubler-Ross's own journey to hospice care is an interesting one. In her article, Barbara Blaylcok mentions, in regard to Kubler-Ross:

> Her childhood experiences with death taught her that a death at home, surrounded by family and friends, was far better than one shut away in a sickroom. Her earliest work, as a teenager with survivors of the horrors of World War 2, left lasting impressions of the power of compassion and the resilience and strength of the human spirit. (Blaylock, 2005, 108)

Even before Kubler-Ross started working to improve hospice care, she was already thinking of ways to improve care for patients that would also improve the care they received when they were dying. Later in her life, specifically in the 1960s and 1970s, Kubler-Ross wrote her groundbreaking book *On Death and Dying* and also worked at a children's hospital. Furthermore, "She also began giving workshops on dying, grieving, dealing with serious illness, and loss." (Blaylock, 2005, 109)

In addition to the work she was already doing, Kubler-Ross also began to:

> Investigate near-death experiences at a time when no one else was doing so. She also began to talk about her experiences with spiritual guides and her belief in an afterlife. She persevered in this controversial work even though it led, in part, to the loss of her marriage. In 1994, her home in Virginia was burned, and arson was suspected. (Blaylock, 2005, 109)

In conclusion, Elizabeth Kubler-Ross sought to not only talk about hospice care but also to talk about taboo topics about death in an effort to de-mystify the death process and make people less afraid of dying as a whole.

## Part Two: Inequities in Hospice Care

Regardless of the kind of care provided- palliative or hospice- African Americans are receiving care that is disproportionate to the care of patients of other races, according to the data/literature. Multi-faceted barriers are related to the disproportion of care. One of the barriers is broken trust in the system, which results from heinous medical experiments from the past, namely the Tuskegee Experiment and the Henrietta Lacks experiment. In later sections of this chapter, there will be more on the history of the level of distrust within the medical field from African Americans. More barriers to equal care include: "Unequal distribution of health determinants, including people's physical environments, social support networks, income or social status, and access to health services." (Aker et al., 2023, 2).

In their study, Elizabeth Luth and Holly G. Prigerson exclaim:

> Dying patients tend to receive aggressive, burdensome, and potentially futile care, as evidenced by the fact that over 40% of hospitalized [patients] are admitted to an intensive care unit during their last six months of life. This trend is disproportionately borne out among black patients, who consistently receive more aggressive, burdensome, and potentially futile care than white patients. (Luth et al., 2018, 752-753)

The quote above shows even more proof of the disturbing fact that African Americans are enrolling less often in hospice care.

Luth et al. also conclude:

> Black patients desiring less aggressive care may complete ACP [Advance Care Planning] but still receive aggressive care at EOL, resulting in increased psychological distress. Rather, in these data, caregivers report that black descendants received unwanted care at similar, low rates, regardless of ACP completion and as white descendants. (Luth et al. 2018, 757)

In agreement with the Luth et al. quote above, Noh et al. state in their own study that encouraging African-Americans to talk about EOL (end-of-life) issues can be quite a challenge. Noh et al. explain:

> Although end-of-life discussions have the aforementioned benefits, many Americans still do not engage in the conversation. A 2018 national survey of nationally representative Americans age 18+ reported most participants viewed family discussion around end-of-life as important to talk about them (95%); yet less than one-third (32%) indicated they had discussed them. (Noh et al. 2022, 1763)

A possible reason for the negative attitude in the aforementioned quote toward end-of-life discussions includes a general avoidance of the topic of death. Death itself is generally not something people want to think about; therefore, they do not prepare beforehand until they have a fatal diagnosis.

This fact was proven in Noh et al.'s study. Noh et al.'s study also revealed:

> Blacks/African Americans and Hispanics were less likely to document their wishes than Whites. Prior research pointed to several factors for the disparities: lower socioeconomic status, lack of ACP knowledge, mistrust in the healthcare system, and spiritual/religious beliefs not in line with ACP. (Noh et al. 2022, 1764)

There is more than one barrier that needs to be addressed from the aforementioned quote in terms of prompting African Americans to change their mindsets about end-of-life care. One reason why disparities in hospice care exist is that people in America are particularly averse to talking about death. Carolyn Jaffe and Carol E. Ehrlich state: "Talking about death is taboo in our society; no one wants to hear about it. Maybe we hope that avoiding the words will invoke magic of some strange sort, putting off one's dying indefinitely. Whatever the reasons, we do not want to think about it." (Jaffe & Ehrlich, 2016)

However, going to great lengths to circumvent conversations about death does not make the topic of death go away, since everyone will die at some point. Moreover, Jaffe and Ehrlich exclaim, "Older people, those who are reminded of their own mortality by the loss of one friend after another and by their own visible aging, will sometimes reveal their feelings haltingly, perhaps, in fragments of conversation." (Jaffe & Ehrlich, 2016, 41)

When it comes to the African-American community, as Patrick J. Dillion and Ambar Basu proclaim:

> Although a variety of factors potentially contribute to differences in the cost and quality of end-of-life care, many scholars argue that such disparities largely result from the underuse of hospice care by African American patients and their loved ones. (Dillion & Basu, 2016, 1385)

The rationale for the underutilization of hospice care by the African-American community could be due to an incomplete comprehension of the concept of palliative care or not having complete faith in the medical system.

Significant events from history, including slavery and the Tuskegee Experiments from 1932-1972 (which involved the public health service starting a years-long operation to transmit a syphilis infection to Alabama sharecroppers and disprove any treatment of the disease to study how the disease progresses) and the Henrietta Lacks experiments (which involved Henrietta's cells being harvested from her body without her permission after she was diagnosed with a form of gynecological cancer at Johns Hopkins Hospital in the 1950s), have played a role in the high level of distrust felt by the African-American community.

All of these injustices have led to African Americans losing trust in the healthcare system and not receiving the dignified care they deserve.

## Part Three: Solutions

The question becomes what to do about the low enrollment and low hospice utilization by African Americans. One solution to this problem is to enforce the use of advance directives and DNRs (Do Not Resuscitate Orders) within the African American community.

A second solution lies in simply removing the numerous barriers that exist to hospice care in the African American community. A third solution comes from Apollo Townsend et al., who claim:

> Repeated hospitalizations for aggressive treatments are likely to be traumatic for patients, detrimental to their quality of life, financially draining for the patient and health care system, and are frequently futile. Fortunately, another option exists that, when chosen, offers comprehensive support to patients and families and allows patients to receive that support at home at a lower cost. (Townsend et al., 2017, 32)

Lowering the number of hospitalizations at the end of a chronic disease can also help reduce the risk and need for aggressive care. More comprehensive preventive care can also reduce the risk explained in the previous quote. Moreover, the solution mentioned in the aforementioned quote involves working with the African American church (regardless of denomination) to expand knowledge and access to hospice care in the African American community. The benefits of the hospice community working with the African-American church are that "The partnerships between health care providers and African-American church congregation positively affect the social and health status of the African-American community." (Townsend et al., 2017, 33)

In addition, working with the African-American church to expand education regarding hospice care can help improve the level of health literacy of the African-American community about hospice care. Lastly, reaching out to African-American churches can also help with the low African-American hospice enrollment rate. Although one major distinction that is universal among all of these articles is that cultural competency is a major factor when it comes to medical care for African Americans. Improving cultural competency starts with educating healthcare workers before they start working to improve patient-physician relations. In agreement with this theory, Townsend et al. state: “African-Americans may expect physicians to care for spiritual as well as physical needs at the end of life. Even the spiritual and religious-based care decisions for pediatric patients may be affected by these cultural beliefs.” (Townsend et al. 2017, 33)

In addition to the above theory of the benefits of improving cultural competency, Townsend exclaims the results of a major survey from their recent study. The major themes that emerged from the Townsend et al. study were:

> Spirituality, cultural competency, lack of knowledge, hospice is synonymous with death and elicits fear of death, hospice prepares families for patient’s death, hospice provides comfort and support for patients and families. (Townsend et al. 2017, 35-36)

In conclusion, health literacy and cultural competency would go a long way in greatly improving end-of-life outcomes for African Americans. Additionally, learning more about history can also go a long way toward improving cultural competency.

## Part Four: History and Development of African American Cemeteries and Memorials

This section will analyze the history and analysis of African-American cemeteries. My interest in this topic started after reading the book *Grave* by Allison Meier, which was published on February 9th, 2023. The book *Grave by* Alison Meier is instrumental in explaining the history of notable cemeteries around the world, which includes the African Burial Ground in New York City. One notable cemetery is the African Burial Ground in New York City, which originally operated as a burial ground for enslaved Africans to ensure they would be buried separately from Caucasians.

The site itself is now a memorial that functions as a tribute to the African Americans who have passed on. Erick Kessel Jr. further explains in the next quote:

> A structure that takes up about a quarter of a small block enclosed by Duane and Reade Streets in New York City amid a towering complex of federal administrative buildings. The monument sits atop a larger span of land that, following a 1697 law in the recently established Province of New York, became a burial plot for slaves and free slaves and free blacks who had been banned from being interred alongside white parishioners. (Kessel, 2022, 47)

Aside from operating as a burial ground for enslaved Africans, the burial ground also functions as a form of preservation for the controversial history of slavery in New York City.

The African Burial Ground is of importance because:

> From the 1690s until 1794, an estimated 15,000 enslaved and free Africans were laid to rest in the African Burial Ground. In 1991, during construction of the Ted Weiss Federal Building, 419 human skeletal humans were exhumed. (Kessel, 2022, 51)

The next memorial to be analyzed within this paper is the National Memorial for Peace and Justice in Montgomery, Alabama. The National Memorial is a museum that traces the United States' dark history of slavery within the United States. The National Memorial is a separate, albeit dark and meaningful memorial that takes viewers on a journey through the dark legacy of lynching in America.

Although the National Memorial has been recently expanded to include a Freedom Monument Sculpture Park to honor the countless victims of slavery, it also includes a wall that lists every surname of the formerly enslaved in the United States, just after the end of slavery. During a recent conversation with my aunt, I found out my surname is one of the names on the wall. My surname, which is located on the wall at the Freedom Monument Sculpture Park, can only mean that my ancestors' lineage can be traced to the history of slavery. Tragically, that is the extent of my knowledge about my ancestors' lives during the times of slavery. I do not know which part of Africa they were living in before they were forced to travel to America. I also don't know what their lives were like before and during slavery, which further encapsulates the need for better and sustained historical education.

Memorials like the National Memorial are sorrowful and harrowing, and reminders that the lessons and consequences of history are never far away from us. A similarly profound memorial can be found across the country in Tulsa, Oklahoma. This particular memorial is a testament to the dark day in 1921 when the city known as Black Wall Street was leveled to the ground after a gruesomely violent riot.

According to Konstantinos Karatzas, this violent day started when Rowland:

> Entered an elevator, the door opened, he ran away, and Page screamed that the black man had assaulted her. There were no eyewitnesses in the elevator; the most logical explanation was that Rowland stepped on her by accident. (Karatzas, 2018, 128)

The singular event that was analyzed in the aforementioned quote, despite not being an actual assault as it was portrayed in the newspapers at the time, led to one of the most violent and deadly assaults on an African-American community, more formally known as the Tulsa 1921 Massacre.

The effects of the riot on the town of Tulsa were extraordinarily destructive and still have lasting effects today, as the town was never rebuilt.

Karatzas states:

> The Tulsa Race Riot and War came to an end, with more than 1256 houses burned and 314 residences looted and robbed by the rioters. The actual damage to the 199 recorded cases was calculated between 1.5 and 1.8 million dollars. (Karatzas, 2018, 130).

Henrietta Lacks never received her own memorial, but her surviving family members did finally receive a settlement from the company that stole her cancer cells without her approval for their own benefit and profit. Rebecca Skloot, author of the book *The Immortal Life of Henrietta Lacks,* proclaimed:

> Her [Henrietta's] cells would survive her and proliferate wildly in Gey's lab, with 'mythological intensity.' Over time, for-profit cell banks and biotech companies would enter the picture and launch a multi-billion dollar industry from a dime-sized sample of Henrietta's cervix. (Scannell, 2010, 496)

Henrietta's story portrays a clear contradiction within the field of medical science. Specifically, the area of the scientific community that is preoccupied with advancement and progress, and the field of science that will also stop at nothing to get there. Henrietta's story should be held as a cautionary tale not only for gynecology and oncology but for science as a whole.

Around the same time as the Henrietta Lacks experiments, the Tuskegee Syphilis Study was taking place in Macon County, Alabama. The experiment lasted from 1932 to

1973 and caused an untold amount of suffering. The men who were experimented on during the Tuskegee Experiment were never treated for their illness.

They were only told that they had bad blood. Initially, the Public Health Service was going to have a “Syphilitic group and a control group and wanted to monitor health differences between the two groups.” (Barrett, 2019, 12).

The Public Health Service used deceptive practices in their fliers that stated there would be “Free blood tests and free treatments for ‘bad blood’ in addition to free meals, free physicals, and free burial insurance.” (Barrett, 2019, 12)

Some participants in the study, “That were enrolled in the control group at the beginning of the study also contracted the disease during the study.” (Barrett, 2019, 12) To add insult to injury:

> The men were never told that they would not receive adequate treatment for syphilis, and were not given the option of leaving the study. This practice continued even when it was discovered in the 1940s, Penicillin was a safe and effective treatment centers for syphilis but made sure that participants were not treated. (Barrett, 2019, 12)

The Tuskegee Experiment was not the only unspeakable medical experiment conducted on African Americans.

The most unspeakable medical history story is a story of gynecological experimentation on African Americans that did not just start with Henrietta’s stolen cells. In fact, the dark history of gynecology started with a doctor named J. Marion Sims. Portrayed as the ‘Father of Modern Gynecology,’ he has been so exalted that he has his own statue near Central Park and the New York Academy of Medicine. However, when the horror of how truly awful and contradictory his early experiments were on the plantation, his statue was taken down. In the book *Medical Bondage: Race, Gender, and the Origins of American Gynecology,* Deirdre Cooper Owens traces the history of the first preliminary gynecological surgeries. Often, these gynecological surgeries were performed without anesthesia on the enslaved women who were working and living on the plantation with Dr. Marion Sims. Sims' ultimate goal was to find a way to treat a common but deadly problem that was plaguing many plantations at the time, and that was "Vesicovaginal fistulae, a common obstetrical condition that caused incontinence, and that was brought on by trauma and by the vaginal and anal tearing of women suffered in childbirth." (Owens, 2018, 1)

Sims achieved this goal and received a statue near Central Park that has been recently torn down. His treatment is still being used today throughout the medical community, but that was not without the sacrifice and experimentation of enslaved women.

The effects of the heinous medical experimentation on African-American bodies in the past have effects today. The profound book *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present,* written by Harriet Washington, shows the progression of medical experimentation throughout history within the African-American community. Washington proclaims:

> Mounting evidence of the racial health divide confronts us everywhere we look, from doubled black infant death rates to African-American life expectancies that fall years behind black babies born in more racially segregated cities have higher rates of mortality. The life expectancy of African Americans is as much as six years less than that of whites. (Washington, 2006, 3)

Furthermore, the healthcare disparities even extend to cancer diagnosis and survival rates, as Washington explains in the next quote:

> Eighty-six percent of white women with breast cancer are alive five years later; only 71 percent of black women survive that long. A black woman is 2.2 times as likely as a white woman to die of breast cancer. Black women have been undergoing mammograms at the same rate as white women but are more likely to receive poorer-quality screening which may not detect a cancer in time for a cure. A black woman is also more likely to develop her cancer before age forty, too early for recommended mammograms to catch it. Black breast cancer patients have a worse overall prognosis and a worse prognosis at each stage. (Washington, 2006, 4)

Washington further supports her claim by stating that medical experimentation is still an issue that is being dealt with today, and this is another particular issue that has led to the high level of mistrust between African Americans and the medical field.

## Part Five: Differences Between Hospice and Palliative Care

Palliative care is another form of end-of-life care that is usually grouped together with hospice care, although these two forms of care are quite different. The definition of Palliative care is "A medical specialty that aims to maximize the quality of life in people with life-threatening illnesses. Palliative care focuses on symptom control, pain management, and psychosocial support for patients and their families." (Weng, 2022, 1). The thing to remember with palliative care is that its primary goal is to focus on "Symptom management, psychosocial support, and assistance in decision making." (Davis et al, 2015, 569)

Although it goes deeper than a specific definition and there are certain instances when a palliative care consult is appropriate.

Also, according to Mellar P. Davis et al., the following situations are the most appropriate for a palliative care consult:

> A life-limiting illness in a patient who is not terminally ill, a life-threatening illness in a patient who has symptoms but with the potential to recover., a chronic illness such as heart failure or chronic obstructive pulmonary disease in a patient who is on disease-modifying therapy but has sypmtoms and will eventually succumb to the illness, but is expected to live longer than someone with advanced cancer. (Davis et al., 2016, 569)

Unlike hospice care, when someone is receiving palliative care, “The patient does not need to stop the primary curative treatment. Instead, palliative care is like another layer of support on top of the original medical treatment plan.” (Weng, 2022, 1) Hospice care on the other hand is solely focused on “Provid [ing] quality of life and comfort and to avoid overly aggressive, expensive, and futile care at the end of life. The focus is on intensive, hands-on, personalized symptom care and family support at home. The goal is to provide a comfortable and dignified death among family and support at home.” (Davis et al., 2015, 570).

An important to note that relating to the medicare payment is that:

> The Medicare per diem payment limits what hospices can afford, so they must be fiscally responsible. Hospice agencies are capitation and are responsible for providing medications and durable equipment necessary to treat symptoms related to terminal illness. They also provide bereavement services for family at no charge.
> (Davis et al., 2015, 571)

## Part Six: More Background on Rationale for Low African American Hospice Enrollment Rate.

Throughout their research, Ramona L. Rhodes, Simon C. Lee, and Ethan A. Halm uncovered more reasons for the low hospice care enrollment rate.

They state there is an:

> Overall lack of knowledge or misunderstanding about advance care planning, palliative care, and hospice may play a role. Others suggest completion of an advance directive or enrollment in hospice can be constructed as losing faith in God or conflict with patients' and family members' spiritual or religious beliefs. (Rhodes et al, 2017, 510)

These discoveries are not new or extraordinary, as this opinion has been seen in other studies as well. In addition, when the participants were questioned about their opinions, the participants stated:

> Making decisions and being involved in EOL [End of Life] discussions about their own loved ones was difficult, but they understood the importance of focusing on their loved ones' experiences instead of their own feelings about their loved ones care and, ultimately, their passing. (Rhodes et al. 2017, 512)

Again, these beliefs are not extraordinary as they were also proven and shown in other studies and articles within this literature review, such as the overwhelming proof from Harriet Washington's book *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present.*

The similarity between multiple studies within these studies shows that there are universal experiences within the African-American community when it comes to maneuvering end-of-life care policies.

## Part Seven: Suicide in America and in the African-American community

Suicide rates are an aspect of death that needs to be mentioned; suicide rates in the African-American community, specifically men, have seen an expansion. The current suicide rate in America, according to the CDC, is "[Forty-eight thousand one hundred forty-three] suicides between the years 2021 and 2022." (CDC Suicide Prevention).

Family support plays an important role in whether or not an African-American experiences any form of suicidal ideation. Throughout their 2012 study, Lincoln et al. found that certain factors impact suicidal thoughts in African Americans: “Low levels of social support from family predicts adolescents’ suicide behavior and ideation in the 6 months following psychiatric hospitalization, predicts suicidality into adulthood and is associated with poor treatment adherence.” (Lincoln et al. 2012, 1949). Although even with high levels of family and social support, racism is still an ever-present threat in the community that African-Americans have to deal with on a daily basis. Systemic racism is defined as “The oppression of a racial group to the advantage of another perpetuated by inequity within interconnected systems (such as political, economic, and social systems.)” (Merriam-Webster)

The systems are in place all over certain communities, so there is no way to escape, which leads to high rates of depression and suicide. Robinson et al. wrote *African-American adolescent suicidal ideation and Behavior: The Racism and Prevention,* explain:

> It is likely that suicidal ideation and behavior, among African-American adolescents, have different etiological risk factors than those for adolescents with different cultural and ethnic backgrounds and experiences and as, such, prevention and intervention strategies must address these distinctive risk factors, to be effective. (Robinson et al. 2020, 1284)

In terms of suicide in the African-American community, emotional support is a buffer against suicidal ideation in the African American community.

Karen D. Lincoln, Robert Joseph Taylor, Linda M. Chatters, and Sean Joe stated in their article, “Suicide, Negative Interaction and Emotional Support among Black Americans,”:

> Higher levels of family cohesion and family support, for example, are associated with lower levels of suicide behaviors among African-American college students and adults. Studies of black Americans’s suicide risk that include measures of social support are limited and the few available studies use nonrepresentative or clinical samples. (Lincoln et al., 2012, 1948)

In summary, there are some protective measures for young African Americans who may be suicidal, yet not all young people have access to these vital protective measures. Amanda Calhoun and Andres Martin state that in the year 2020, “Suicide rates increased each year throughout the observation period, with the starkest finding having to do with gender differences: the annual increase among Black Girls was more than twice that for Black boys (6.6% or 2.8%, p. < .001.).” (Calhoun et al., 2022, 601)

The perplexing suicide statistics show just how much racism and other negative factors impact adolescent African Americans. Anti-black racism is the one factor that ties together all the other factors involved in the high suicide rate among African Americans. Physician-Assisted Suicide can be defined as “Suicide by a patient facilitated by means (such as drug prescription) or by information (such as an indication of a lethal dosage) provided by a physician aware of the patient’s intent.” (Merriam-Webster)

In America, physician-assisted suicide has been legalized in Oregon, where “Around 130 terminally ill persons take their life yearly with the help of physician-prescribed drugs.” (Ahlzen, 2020, 354)

African-Americans, on the other hand, are “Prominently more opposed to the legalization of voluntary euthanasia than are whites.” (Macdonald, 1999, 411)

These beliefs among African Americans toward voluntary euthanasia are similar to the feelings many African Americans have about enrolling in hospice care and palliative care programs. Macdonald further states, “One view is that the greater opposition toward legalizing voluntary euthanasia found among blacks is a result of a greater fear among blacks of giving others the power to end one’s life.” (Macdonald, 1999, 412)

Macdonald further explains their theory in the following quote:

> Perhaps then, the difference between blacks’ and whites’ levels of fundamentalism is due to previously existing structural conditions. (e.g., slavery) that once governed race relations in the United States. These norms and values are also consistent with religious beliefs that grew out of blacks’ experiences with slavery. (Macdonald, 1999, 413)

In summary, religion is still considered another protective factor against suicide, but also deep reflections on traumatic and important events from history are something else to think about in the context of protective factors against suicidal ideation. Another important factor to consider when contemplating the disparity between African Americans and other races when it comes to voluntary euthanasia is socioeconomic status factors. Macdonald also explains this theory in the next quote: “The cultural differences that grew out of the institution of slavery are consistent with the cultural differences that some see as responsible for this race difference. The relevance of current structural disadvantages that blacks continue to experience.” (Macdonald, 1999, 413)

Lastly, history also plays a huge part in why African Americans are not too fond of voluntary euthanasia, specifically the dark history of experimentation.

Once again, Macdonald states: “The black experience in American history, characterized by the brutally controlling nature of slave laws and Jim Crow laws, certainly supports the prediction that blacks would be more likely than would whites to express such trepidations.” (Macdonald, 1999, 413)

The quote above proves that there is a connection between the past and the present, not only through history but also in terms of obliging medical autonomy at all levels of care, from diagnosis to the final breath. Analyzing suicide from an African-American woman’s perspective is completely different from analyzing suicide for all African Americans, as stated by Michelle Marion and Lillian M. Range. For starters, “African-American women commit suicide less than other U.S. women and men, perhaps due to strong anti-suicide attitudes.” (Marion et al., 2003,44)

A rationale from Marion et al. offers an explanation for the suicide disparities between African Americans and other races, specifically Caucasians:

> One reason for African-American women low suicide rates is this group’s possession of strong anti-suicide beliefs. In one qualitative study, African-American pastors asserted that African Americans have developed a ‘culture of resilience as a response to constant historical and present-day struggles. (Marion et al., 2003, 44)

Marion and Range have a theory that explains how resilience has been a protective factor against self-injury, specifically suicide: “A strong sense of resiliency and survival has particular relevance to African-American women, as they have been the backbones of their communities. Consequently, African-American women, condemn suicide which is contradictory to their value system.” (Marion et al. 2003, 44-45)

One sees the theory of religiosity in tandem with the theory of extending life and repudiating suicide, as is seen in the next quote from Marion and Range, "In two other studies of African-American women, greater religiosity correlated with decreased suicide acceptability. Therefore, African American women may be particularly influenced by religiosity in developing attitudes toward suicide." (Marion et al., 2003, 45)

In the Caribbean, views on suicide are similar to African-American views about suicide in America. There is also a strong sense of using religion for emotional relief. Robert Joseph Taylor, Linda M. Chatters, and Sean Joe all proclaim that: "Religious involvement measured as public behaviors (e.g., service attendance), self-ratings of religiosity, and stated importance of religion in life, are suicide attempts, lower rates of ideation, and more negative views of toward suicide." (Taylor et al. 2011, 6)

The earlier quote shows that there is some documented proof that regular church attendance was protective against suicide. Alternatively, "African Americans who attended religious services less than once per year were significantly more likely to have suicidal ideation than those who attended services nearly every day, at least once per week, a few times per month, or never." (Taylor et al., 2011, 6)

However, a research gap has been presented within Taylor et al.'s study that shows that for some Black Caribbeans:

> Denomination and subjective religiosity were significantly associated with both suicidal attempts and ideation. Our analysis indicates that although both groups have high levels of religiosity, it is important to examine the impact of religious involvement on suicidal behavior separately for each group. (Taylor et al. 2011, 7)

Moreover, Taylor et al. noticed in their study that “African-American service attendance was significantly associated with both attempts and ideation. The protective effect of service attendance on suicidal behavior is consistent with numerous previous studies in this area.” (Taylor et al., 2007, 7)

In terms of the elderly population, regardless of race or religion, one needs to think deeply about suicide risk, specifically suicide pacts, in their study of a nursing home in the United Kingdom. Kelvin Tran, Pauline Chen, and Tessy Korah found a suicide pact involving a 93-year-old man at a nursing home. As they explain in the following quote:

> A 93-year-old man developed dementia and moved into a memory unit at an assisted living facility (ALF) with his 92-year-old wife. The wife brought medications and a knife to her husband’s room and they both attempted suicide by overdosing and cutting their wrists. After medical stabilization, the wife reported that she had not wanted to die but went along with her husband’s desire to die together. (Tran et al. 2021, 1)

The particular case study in the aforementioned quote presents an intriguing case because the 93-year-old man had a DNR in place, and the nursing home staff found this ethically conflicting. Tran et al. concluded,

> With proper treatment and in the setting of an individual without [a] terminal illness desire to die can be treated and extinguished. Findings from an analysis of people who died in suicide pacts in England and Wales reveal that improved management of illness, both mental and medical disorders, would likely help avoid suicide pacts. (Tran et al., 2021, 2)

In conclusion, improved care can help people avoid early death and have a better life expectancy.

According to Beverly Bunch-Lyons, the African-American funeral home “Has a unique place in African-American communities. They comfort the living while burying the dead. As business owners, they are necessarily concerned with profit, yet their business demands compassion.” (Lyons, 2015, 58)

The African-American funeral home has a dual purpose that involves more than just providing death care services; they also furnish deaths and burials with dignity.

Furthermore, according to Lyons, “There are over two thousand. The vast majority are concentrated in the eight Southern states of Georgia, South Carolina, North Carolina, Florida, Alabama, Mississippi, Virginia, and Louisana (Purple Directory).” (Lyons, 2015, 59)

The necessity for more African-American funeral homes started with a general:

> Concerns about the manner in which black bodies were laid to rest by white undertakers fueled the desire among African Americans to have their family members buried by black undertakers whom they believed would bury their dead with care and dignity. A desire to meet this community need, while also earning a comfortable, stable living led would-be-entreprenuers to be undertaking business. (Lyons, 2015, 61)

Candi K. Cann, who is the author of the article “Black Deaths Matter Earning the Right to Live: Death and the African-American Funeral Home*,*” traces the history of the Birmingham Church Bombing to the history of African-American funeral homes.

In her article, she proclaims:

> At 10:22 a.m. on Sunday, 15 September 1963, a bomb exploded in the basement of the Sixteenth Street Baptist Church in Birmingham, Alabama. Afterward, at the funeral, the caskets were kept closed as the mourners grieved the continuing violence against people of color-even children, and "Claude Wesley's refusal to open his daughter's casket to the public reflected a deeper shift in the psyche of the national civil rights movement. The price of the non-violent struggle was getting too high and the deaths (and closed caskets) of Wesley, McNair, Collins, and Robertson symbolized that cost as nothing else have. (Cann, 2020, 1)

Ashley Lemke, the author of the article "Missing Cemeteries and Structural Racism: Historical Maps and Endangered African/American and Hispanic Mortuary Customs in Texas," pronounces:

> Cemeteries of historically oppressed groups, specifically African, African-American, and Hispanic populations, are even more susceptible to destruction or damage due to systematic, institutionalized racism; neglect; segregation; and unique mortuary patterns that often result in these cemeteries being ignored, damaged, or lost. (Lemke, 2020, 605)

Another factor in the destruction and loss of cemeteries is the "Overall combination of systematic, institutionalized racism, neglect, segregation, and unique mortuary patterns often results in minority cemeteries becoming systematically lost and essentially erased from the historical and archaeological records." (Lemke, 2020, 606)

A team effort was launched to preserve the history of the cemeteries. Lemke explains this project in the following quote:

> The Missing Cemeteries Project was undertaken in the state historical preservation office at the Texas Historical Commission (THC), Archaeology Division, in response to these incidents. The project sought to explore historical maps of Texas to preemptively locate cemeteries that were missing on modern maps in order to add to their locations to a geographic information system (GIS) database used by professional archaeologists and cultural resource management (CRM) companies in the state, and the additions were made in order to limit further damage to historical cemeteries. (Lemke, 2020, 607)

It is likely that the lost cemeteries project will unearth not only hidden cemeteries but also decades, if not centuries, of history just waiting to be told. Moreover, due to the history being told, the Missing Cemeteries project will also raise uncomfortable questions about the origins and purposes of the cemeteries.

The actual history of jazz funerals in New Orleans is both complex and wondrous. In accordance with Brenda Marie Osbey, the tradition of jazz funerals started in the 1970s.

Osbey explains this history in the quote below:

> The 1970s, however, set in motion one set of changes to this particular celebration of the dead. No doubt future generations also will coin it anew. In recent years there has been a tendency for the second line to start all but immediately from the church and proceed to the cemetery, dancing and blasting right up to the holy ground gates. (Osbey, 1996, 98)

Angelo P. Coclanis and Peter A. Coclanis state in regard to jazz funerals:

> The roots of this musical mortuary tradition go way back, originating early in the city's history within the African American community. Funerals involving parades and bands of one type or another became more frequent in the decades after the Civil War as the growing number of black benevolent and burial societies in New Orleans honored deceased members- musicians or otherwise- with properly rousing send-offs into the hereafter. (Coclainis et al., 2005, 86)

In the book *Hidden History: African American Cemeteries in Central Virginia,* Lynn Rainville, who is a "Research professor in the humanities at Sweet Briar College, where she also serves as the Director of the Tusculum Institute." (Rainville, 2014) traces the history of African-American cemeteries in Virginia; Rainville explains that during the time of slavery, funerals were controlled to prevent slave uprisings. Due to these strict laws, many slave funerals were the opposite of a mourning ritual and were actually quite painful. Rainville illustrates this fact in the following quote:

Rainville also commented on the atmosphere that was present at the time of the secretive and restricted funerals at the time of slavery, and that the funerals did not always go well. Rainville declares:

> African Americans needed passes for travel at night, many would-be-mourners were accosted and often beaten by slave patrols. Dr. Randolph lived at the Roundtop Plantation and owned fifty-eight slaves in 1860. That same year he wrote a letter in which he discussed a funeral held by the enslaved population. (Rainville, 2014, 59)

In conclusion, unfortunately, some of these practices are still in practice today around the country, but instead of slave patrols, it’s aggressive policing policies that sometimes mimic slave patrols from centuries ago.

## Part Eight: Notable African-American Cemeteries in Virginia

This next section will focus on the history and significance of African American cemeteries in the state of Virginia. The cemeteries that will be covered in this section will include various notable cemeteries from around the state of Virginia, such as the Bowles Family Cemetery, the Brown Family Cemetery, the Lewis/Terrell Cemetery, the Jackson Family Cemetery, and lastly, the University of Virginia Slave Cemetery.

What made the Bowles cemetery so significant was the fact that, after conducting an archeological dig at the site where the cemetery was found, archeologists found:

> Several stone grave markers, but only one inscribed. Fortunately, that one stone solidified the connection of the cemetery to the African American residents of Free State. The marker, plain with a painted top, read Mary Bowles, Died December 6, 1882. Mary was married to Edward Bowles, who had purchased land here in the 1830s. The gravestone that was found in the Blue Ridge

> Mountains of Virginia led the new residents of the housing development to take some time to think about having a small family cemetery within their midst. This unusual development feature is certainly not highlighted in any developers' promotional materials. (Rainville, 2014, 91)

The next cemetery to be analyzed is in the same neighborhood as the Bowles Cemetery. The Brown, Lewis, and Terrell family cemeteries are all close to each other. Rainville exclaims:

> Three other black families, the Browns and the Lewis and Terrell families, created their own cemeteries in the early twentieth century…The Brown family cemetery lies about two hundred feet south of the Bowles Cemetery and is one of the few in Albemarle County that has remarkably increased its deceased population without the benefit of any additional deaths. (Rainville, 2014, 91)

One particular cemetery looms particularly large in the context of African-American history in the state of Virginia, and that cemetery is East End Cemetery.

That cemetery is the East End Cemetery, which is located in the city of Richmond.

Brian Palmer, who wrote *The Lives of East End: Recovering African American Burial Grounds,* states:

> In the nineteenth century, cemeteries like East End rose all over the South, even as Jim Crow legislation rapidly hardened the color line. Barred from white cemeteries, Black families buried loved ones in small churchyards and in their own backyards. Like white families, Black elders carved epitaphs and raised funerary monuments, using donations from neighbors to do so. (Palmer, 2020, 66)

The fact that cemetery funds were mostly given to white cemeteries shows the complete disregard for black death and black lives during colonial times in the state of Virginia.

The level of disregard for the cemetery continues today:

> Decades of segregation, discrimination, and institutional racism have worked their way like creeping vines, prising basic infrastructure and financial resources from local areas. Throughout the twentieth century, as families departed the South for opportunities in the industrialized North and Midwest, untold numbers of ancestral cemeteries fell into obscurity. (Palmer, 2020, 66)

The stories from the section show the necessity and importance of the care of vital African American cemeteries. However, the Palmer 2020 quote also shows the brutality of slavery that needs to be honored and taught the right way. Proper conservation of the cemeteries is one way to memorialize this vital African-American history. These cemeteries hold so much knowledge and history from the time of slavery that it is necessary to understand our present time and the future. To memorialize and maintain these cemeteries is also important to the comprehension of family and community history.

## Chapter Breakdown For the Rest of the Dissertation

Chapter two of this dissertation will examine the role of art and music therapy in the care of hospice and palliative care patients to heal from the most intense emotional and physical symptoms of their various diseases. Moreover, this chapter will also examine the role of music and art therapy in reducing physical pain.

Chapter three will examine the role that medical racism and discrimination play in the low African-American hospice enrollment rate.

Chapter four will examine the intersectional role of health insurance access and inequalities in hospice care. Furthermore, this section on health insurance will also examine how a lack of health insurance contributes to inequities in health care.

Chapter four will explain the ties between health insurance and inequalities in healthcare. Inequalities in healthcare greatly contribute to the death and disease burden in the African-American community. So, it will be important to do an in-depth analysis of these factors.

The conclusion of this dissertation will be devoted to not only concluding the entire dissertation but also explaining how advanced care planning and advanced directives can ensure more African Americans enroll in hospice care.

# CHAPTER TWO

# MUSIC THERAPY, ART THERAPY, AND HOSPICE CARE

## Part One: Introduction

This section of my dissertation will focus on the connections between music and art therapy and hospice care. More specifically, the role that music and art therapy can play in helping the terminally ill process their intense emotions. Music can also help people express what cannot be put into words, and music is an integral part of our society. Music powers our morning routines/commutes, workdays, walks, flights, train rides, long drives, work and study sessions, parties, special events, nights out, and eating out. There is no part of our society that music has not touched. We have almost turned into a society that is music-obsessed, so it makes sense that we would turn to the rehabilitation powers of music to power us through the most challenging times of our lives, specifically the end of our lives and grieving the loss of a loved one.

The theory of music and art therapy as beneficial to hospice patients was certainly the idea that Bob Heath and Jane Lings had when they wrote their article investigating the role that music and songwriting therapy played in helping the patients at a hospice center in the U.K. Within their article, they recorded a story that is as follows that shows the power of music therapy.

The patient's name was Carl, and he had been diagnosed with:

> A rare form of cancer and had been given a prognosis of weeks. He described the songwriting process as being all to do with feelings and stuff…if you look at it purely from the therapy side, that's good because it gets it all out it's better to talk about things than not to. (Heath et al, 2012, 108)

Another patient from the article included Mary, who had been given a:Short prognosis; however, she was still alive and was trying to make sense of this. Questions such as Why am I here? Why is it that I'm meant to be doing? Although, she struggled to express herself using some of the musical instruments, she responded warmly to the idea of songwriting. (Heath et al., 2012, 111)

In short, music therapy and songwriting helped Mary untangle the detrimental and scary feelings she was having in terms of her own death.

During her sessions, she described intense feelings of:

> Anger and frustration that [was] resulting from her emotional and physical needs not being understood or met appropriately. I suggested that despite her profound physical difficulties, she could be involved in active music-making by writing a song. (Heath et al. 2012, 113)

Russell E. Hillard, a professor in the music department at the University at the State University of New York at New Paltz, states, "Music therapy is a growing service provided in end-of-life care, with music therapists gaining employment opportunities in hospices and as members of palliative care teams in hospitals each year." (Hillard, 2005, 173)

However, art therapy is not the only avenue used to help people who are either facing terminal illness or dealing with grief.

Music therapy can also be another avenue that can be used for healing for people in the palliative or hospice care stages of their lives. Lisa Graham-Wisener et al. state:

> Music therapy aligns to the holistic approach of palliative and end-of-life care (PEOLC) as the active total care of patients and involves the use of sounds and music within an evolving relationship between client and therapist to support and encourage physical, mental, social, spiritual, and emotional well-being (Wisener et al., 2018, 282).

The quote above shows that music therapy can be just as valuable to end-of-life care as receiving adequate pain medication. Moreover, music therapy can offer an avenue for hospice and end-of-life care patients to escape their current worries about treatment and the last days/weeks, and months of their lives. Wisener et al. further elaborate on the theory of music therapy being healing in the following quote. Throughout the course of their survey study, Wisener et al. discovered:

> The most common therapeutic goal in working with PEOLC clients as cited by all respondents was supporting psychological needs (100%), followed by supporting quality of life (93%). The least common therapeutic goal was helping people to be as active until death (34%) (Wisener et al. 2018, 283).

Only people who are dying know the psychological toll that facing death can bring to someone's life. People in Germany also agree that music therapy can be quite helpful for easing the psychological symptoms faced by end-of-life patients.

In the case of terminally ill patients with cancer in Germany, a study conducted by Marco Warth et al. proved, through their study, that music therapy was "A powerful, feasible, and accepted intervention in this study addresses emotional and spiritual needs of patients approaching the end of their lives" (Warth et al. 2018, 170).

In conclusion, music therapy can be a wonderful tool for expressing what can't be put into words, but music therapy sessions must be done in the right way so the patients can get the full benefits of music therapy. Art therapy can also be very powerful for end-of-life patients who are seeking psychological relief from end-of-life symptoms. The full benefits and testimonials of art therapy will be explained later in the chapter. Art therapy is so powerful that it not only helps patients but also helps art therapists themselves.

In the quote above, the six themes of art therapy similarly lead to the same health benefits as music therapy. It comes down to what the patient prefers- either a music session or an art session. Music therapy has a very interesting history and background,  as is documented and examined in the next section of this dissertation.

## Part Two: Background of Music Therapy

Music therapy can be categorized as “The clinical and evidence-based use of music, including playing instruments and singing, in therapeutic practice.” (Apello, 2022, 1)

A more expansive definition of music therapy is in the following quote: “ It was initially used to distract patients from the monotony of a hospital stay, but the utility of music therapy in now being investigated as knowledge of the human brain increases.” (Apello, 2022, 1)

In fact, music therapy had therapeutic benefits long before the year 2024. As Jogie Ann Contreas states:  “Florence Nightingale used music as an intervention to improve patient outcomes and healing.” (Contreas, 2022, 234)

Music therapy can also be used for psychological relief. The effectiveness of music therapy also has a lot to do with how music affects the human brain. Apello explains this phenomenon in the next quote. According to Apello, there is a very specific part of the human brain that is responsible for processing music, and Apello explains the way the brain processes music in the next sentence, “Processing of music is located in the right hemisphere. Other structures involved in experiencing music include the frontal lobe, limbic system, and imagery-related cortical regions of the temporal, parietal, and occipital lobes.” (Apello, 2022, 2)

Music therapy would not be so effective if it were not for the way that music affects the brain. The music itself, as explained in the introduction of this chapter, can be very powerful within the human brain and either lead to calm feelings or happy feelings, depending not only on the song that is playing but also on the intricate ways that music therapy affects the brain. Music has other benefits that extend far beyond end-of-life care and dementia. Specifically, the effect of "Combining music with singing may help children with autism develop language skills." (Appello, 2022, 3)

In addition to the benefits mentioned in the quotes above, music therapy can also be useful for "Persons with neurological disorders suffering from shaking or spasms may be able to regain some control over their movements using rhythm to help them focus on regulating their movements." (Apello, 2022, 3)

With the benefits of the past quote in mind, one of the most beneficial effects of music therapy lies in its effect on hospice care patients. These benefits can be explained in the following quote: "A study of patients in hospice care suggested that pain control, the ability to relax, and overall comfort increased in those receiving music therapy compared to those that did not." (Apello, 2022, 4)

Music therapists are highly effective for all kinds of patients because they have the dual ability to work in public and private medical settings and can reach more patients by being able to work in various environments. One should note that there are discrepancies regarding who can access music and art therapy in terms of affordability and cost.

## Part Three: Music Therapy and Hospice Care

If music therapy can be helpful for dementia patients who face the loss of their mental capacities, then music therapy can be helpful for hospice patients who are facing death.

The statistics of the number of people who received hospice care in 2013 are important because, according to Liu et al., "The delivery of hospice care to NH residents doubled from 14% in 1999 to 33% in 2006." (Liu et al. 2015, 377)

Within the United States, according to Jenny Yang and the website Statista, "In 2021, 1.71 million Medicare beneficiaries were enrolled in hospice services for one day or more in the United States." (Yang, 2024, 1)

Not surprisingly, music therapy has become a significant part of the care framework in hospice care, as was noted by Liu et al:

> Music therapy has become one of the most widely used discretionary services within hospice care, with a growing number of music therapists being employed in hospices and hospital-based palliative care programs each year.
> (Liu et al, 2015, 378).

The research method utilized within Liu's study was the analysis of various sets of electronic medical data records from a regional hospice center. The results show that the majority of the people living in nursing homes were more likely to be: "Female, Caucasian, with a diagnosis of dementia." (Liu et al., 2015, 383)

Across other forms of care, such as pediatric hospice care, the benefits of music therapy are extraordinary, as reported by Sarah Hodkinson et al. from the University of Southampton University in the U.K., the University of West England, and the Shooting Star Chase Children's Hospice in Hampton, United Kingdom. The diseases or disorders that were most prominent within the children's hospice included "Congenital and chromosomal disorders or static encephalopathy, for example, severe cerebral palsy were the most common diagnoses for children with life-limiting or life-threatening disorders." (Hodkinson et al. 2014, 570)

In various children's hospices, there are already some beneficial music therapy programs for children. Hodkinson et al. further elaborate on the point above in the quote: "Children's hospices in the UK are fortunate enough to benefit from Jessie's Fund, a charity that supports the design, implementation, and development of the provision of music therapy for children." (Hodkinson et al, 2014, 570)

However, not everyone was on board, which was due to a number of considerations, which are explained in the quote below:

> Lack of funding, potential costs to the organisation. Two respondents were concerned about potential demands on existing services that the provision of additional specialist services might place, including demands for support and supervision. Other respondents felt that music therapy provision might be over and above standard service or would not fit with their existing service. (Hodkinson et al. 2014, 573).

Hodkinson et al. highlight the various problems that arise with the implementation of effective music therapy programs at pediatric hospice centers that could potentially help scores of sick children. However, Porter et al. still found valuable benefits of music therapy despite the barriers to program implementation. Throughout the course of their research study, Porter et al. discovered that a "Cochrane systematic review and a meta-analysis indicates improved mood and sense of wellbeing, along with reduced nausea, anxiety, and depression." (Porter et al. 2017, 1)

At a hospice care center in Australia, Clare O'Callaghan, who is a music therapist at the Peter MacCallum Cancer Institute at the University of Melbourne in Australia, conducted a research study into music therapy for cancer patients. O'Callaghan's rationale for conducting the research study was to “Try and understand the breadth of people’s music therapy experiences over a specific three-month time frame.” (O’Callaghan, 2001, 156)

O’Callaghan found even more benefits of music therapy within the results of their study:

> The results of O’Callaghan’s study showed that “all 128 patients who participated in music therapy in the three months at PMCI, and who took a questionnaire and anonymously responded, indicated that music therapy was a positive experience. (O’Callaghn, 2001, 157)

The commentary from the patients in O’Callaghan’s research study shows the beneficial effect of music therapy on cancer patients in Australia. In an article titled *Music Dying*, the chief executive officer of the Hospice [Center] of Crawford County Inc., Meadville, Pennsylvania, Brown, shares his experience of going to nursing homes with his mother to play music for some of the bedbound residents. One resident who has had a particular impact on Brown was a patient named Mr. Green. According to Mr. Brown, Mr. Green had: “Bone cancer that had metastasized to the bone. Surprisingly, in spite of bone involvement, he did not evidence much discomfort except that of the spirit. The songs continued and so did the conversation.” (Brown, 1992, 17)

The aforementioned quote further proves the effectiveness of music therapy not just on psychological symptoms but also on the universal phenomenon of pain. The ability of music therapy to improve chronic end-of-life pain is a phenomenon to uphold, and also a phenomenon that needs to be shared with all end-of-life patients.

The next resident who had an impact on Brown was a patient named Frank. As Brown states: “Frank was a hospice patient. He dozed all day, thumbed and prowled all night, was non-compliant, drove his family up the wall and terrorized our hospice staff with either menacing silence or verbal hostility.” (Brown, 1992, 18)

However, Frank’s mood improved once the Christmas holidays rolled around and the Christmas caroling started in the nursing home. As Brown states, “Frank sang every song. We were in shock. I asked him if I might come back another time and do some of the old songs with him. He said he’d be delighted.” (Brown, 1992, 18) The patients at the hospice center are not the only people benefiting from the use of music therapy. The healthcare workers at the hospice also greatly benefited from the music therapy sessions. As Brown proclaimed: “Our hospice nurses have used music to exceptional effect. One sang as the moment at a patient’s death neared and family members gently joined in. It was very good medicine.” (Brown, 1992, 20)

It is not only the elderly and the hospice nurses who can benefit greatly from music therapy. Brown recounts a case study with a fourteen-year-old with a fatal condition. When Brown visited him in the hospital:

> Fred’s parents approached and told me that he was critical and in the ICU. They asked if I would sing to him because he so enjoyed our times together. I found him on a ventilator, with other life support measures in place. His mother asked me to [Play] ‘Love Me Tender’. Doubtless [,] the last thing Fred heard in his life was our meager rendition of ‘Love Me Tender.’ (Brown, 1992, 20)

Aside from music therapy leading to tender moments like what happened with Fred, it is also prior knowledge that music can be quite beneficial to the brain. Later on in his career as a music therapist, Brown encountered his own medicine and music therapy moment while recovering from open heart surgery. Sensing how much pain and anxiety he was dealing with at the time, he suggested to his family, “When you come back tonight, bring your guitar and play for your dad. This she did to my comfort. After all, doctor’s orders are doctor’s orders.” (Brown, 1992, 20)

When it comes to hospice care, pain is a common but tricky-to-manage phenomenon.

Lauren Dimaio, the author of *Music Therapy Entertainment: A Humanistic Music Therapist's Perspective of Using Music Therapy Entrapment with Hospice Clients Experiencing Pain,* states:

> The concept of total pain created by Dame Cicely Saunders, founder of the hospice movement in the 1960s following her work with terminally ill clients. In her concept of total pain, Saunders discussed pain as an experience needing multiple interventions and that pain related to other problems in the patients' lives. (Dimaio, 2010, 106)

While music powers our lives, it can also power the ability to ease the pain at the end of one's life and help us heal from the things we do not talk about in the last days of our lives. Luckily, music exists to help us express what cannot be said. Art therapy also has powerful relief properties, and trips to art museums are now being used in medical education to teach empathy. If art can be used to educate, surely it can also be used to heal. The ability of art therapy to heal is the focus of the next section of this chapter.

Noah Potvin, who is a certified music therapist from Drexel University, conducted his own case study by interviewing and conducting a music therapy session with a "47-year-old Caucasian woman who, at the time I began working with her, had been battling her second bout of breast cancer in a decade long with the disease." (Potvin, 2015, 53)

The reason that Mitzi decided to attend music therapy sessions, according to Potvin, was due to her "Rapid decline over the past several weeks, including decreased food and fluid intake, increased disorientation, and an inability to independently ambulate." (Potvin, 2015, 53)

Moreover, at the start of the music therapy sessions, Mitzi seemed to be approaching the last days of her life and death. Potvin explains Mitzi's condition in the following quote: "Shallow breaths, mouth in an open and fixed position, eyes glazed and unfocused, and minimal movement that, when occurring, was largely sporadic in nature." (Potvin, 2015, 53)

The main themes that emerged from Potvin's case study with Mitzi include:

> Control/Resistance, Contact/Release, and Permission. Concurrently, three emergent cultural, spiritual, and historical contexts informed these themes: cancer (in America) and Survival, Judaism and Survival, and Judaism and Death. These contexts weaved in and out of these themes, shaping them and infusing them with meaning. (Potvin, 2015, 56)

The song that was chosen for Mitzi's music therapy sessions was "You Are My Sunshine," and this song was requested by her father, Ed. The reason that this song was chosen was because the song embodied the themes of being able to "Express their deepest values namely the desire for Mitzi to survive and persist as Jews always have." (Potvin, 2015, 58)

In the *International Handbook of Art Therapy in Palliative and Bereavement Care*, Michèle Wood and Hannah Cridford declare:

> Portrait therapy plays a helping role in helping living with life-threatening or chronic illnesses to heal unresolved grief and loss. I examine the therapeutic implications of building 'continuing bonds' within the portraits and argue that through a process of mirroring and attunement portrait therapy enables people to bring closure to painful experiences and find a sense of peace at [the] end of life. (Wood et al, 2019, 95)

A more expansive definition of portrait therapy is in the following Ashwell quote: "By definition. Portrait therapy is a collaborative process within which the art therapist and patient co-design the portraits and the art therapist then paints them for the patient, becoming their 'third hand." (Ashwell et al., 2019, 95)

Portrait Therapy can help patients with opportunities to have their artwork reach a wider audience, as explained in the next quote: The two hospice centers involved in this art project are both located in the UK but are different geographically; one hospice center is located in a rural environment, while the other hospice center is located in a suburban environment.

The premise of this essay, written by Gill Thomas, chronicles the art therapy sessions conducted at the Marie Curie Centre in London. The Marie Curie Hospice Center is a: "Thirty-two-bed unit with a very active out-patients department and day centre. There is a very strong medical lead within the unit, which provides excellent palliative care." (Thomas, 1998, 64)

Despite the wonderful palliative care within the palliative care center, patients can still feel immense emotional pain in the face of chronic disease and, ultimately, their deaths. The next few patient stories illustrate the point that having a creative outlet can be as beneficial as medical care.

The individual patient stories from this particular hospice center include stories from Sarah and Jane. Starting with the story of Sarah, a: "[Fifty-seven] year old lady with advanced cancer of the ovary. She was first admitted to the hospice for a period of symptom control, and her general state of health was to be addressed." (Thomas, 1998, 68) Sarah's journey with art therapy helped her have the:

> Confidence to grow, she became fired up with an enthusiasm about her drawing, and she was able to add more of herself into these images. She began to draw at home and would bring things in with her each week. (Thomas, 1998, 68)

Art therapy was useful in helping Sarah open up and express some of the heavier feelings that she was feeling due to her serious diagnosis of ovarian cancer. Another ovarian cancer patient named Jane also greatly benefited from the art therapy sessions at the hospice center.

Jane did not specifically request to be in art therapy sessions; she was referred to art therapy by one of her nurses, as Gill explains in the following quote. Gill explains:

> Jane was a lady with an abdominal carcinoma of unknown origin, possibly ovarian. My first contact with Jane was following a referral from the nursing staff, and she seemed questionably wary of me, questioning me at length about art therapy. She told me of art projects that she was working on that seemed to be very ambitious. (Thomas, 1998, 70)

Jane was initially referred to art therapy because of her negative and angry demeanor that was getting in the way of her medical treatments. Although by attending the art therapy sessions: “Jane was able to express some of her fears within the sessions, and had been feeling a little about the physical contact with the medical and nursing staff.” (Pratt et al., 1998, 71)

What made the difference in the stories of Sarah and Jane was not a diagnosis of similar diseases but also there is another avenue for conveying themselves and the ability to express what might have been too difficult or challenging to express themselves through the written word. Pratt and Wood agree as they state in the next quote:

> For Jane, the sharing of her work with the staff had shifted her from at times being a lady who was difficult to approach to being an accomplished artist in her own right. Staff had been right to be wary of how to approach her; she had acted out huge amounts of anger. (Pratt, 1998, 73)

Just like Jane, Sarah was also able to have her own breakthrough art therapy that led to not just psychological healing but also the ability to heal from the things she was not able to initially talk about with the other healthcare workers or professionals. Sarah, in the next quote, is able to talk about the things she does not talk about.

As a result of the intensive art therapy Sarah received, Sarah was able to:

> Engage with the ‘well’ part of herself and allowed her to be viewed in a more rounded way. Sarah’s standing within her family changed. She became the artist, not just the sister who was dying of cancer. For Sarah using the found images not only acted as a bridge to her own creativity, it allowed her to step over to a place where she was in touch with herself in a new way. (Pratt, 1998, 72)

However, these are not the only impactful art therapy stories included in *Art Therapy in Palliative Care: The Creative Response.* Many other stories have been included within this volume that show the immense power of music therapy in not only hospice care but also palliative care. Another cancer patient named Eileen, “Who is [Fifty-Two] with motor neuron disease, was referred to art therapy. The referral had come from nursing staff aware of her increasing depression since her admission to hospice.” (Coote, 1998, 55)

Throughout the course of art therapy sessions, she was able to articulate the feelings she had about estrangement from her family, as is explained in the next quote:

> None of her family was able to acknowledge her illness and imminent death. All this left her feeling abandoned, neglected, and empty. Like the house with the curtains drawn, she had been unable to let anyone outside know what was really going on inside. (Coote, 1998, 56)

Through the art therapy sessions, Eileen was able to de-stress from the heavy emotions she had been dealing with during the course of her disease. Moreover, she was able to gain the confidence to “step over the boundary and the danger.” (Coote, 1998, 57) Another patient at the hospice center, Teresa, was also recommended to attend music therapy by the hospice staff.

The rationale for recommending Teresa to music therapy was due to the fact that she was:

> Very poorly and deteriorating rapidly. The nursing staff had found her very needy for some time. She wanted constant attention, yet they had trouble meeting her needs, as it was never really clear what the problem was. Nothing was ever quite right. (Coote,  1998, 59)

Teresa's first approach to art therapy was very different from the other hospice patient participants in the essay since she had prior art experience. Once the art therapy session started, she got sick, as noted in the following quote: "She was also suffering from nausea and vomiting and was concerned that the small bowl she had brought with her should be within reach." (Coote, et al., 1998, 59)

Teresa's discomfort can be attributed to her own illness, or it can be attributed to nerves about a new therapy regimen. Either way, through the art therapy sessions, Teresa was able to recognize her own feelings about facing death, as is explained in the next quote:

> She went on to express the bitterness and resentment she felt towards anyone she came into contact with because, basically, they weren't about to die. She was. She expressed the desperate unfairness she felt in that she had spent much of her life being health-conscious.  (Coote, 1998, 60)

Art therapy, just like music therapy, can also help with expressing feelings that can be related to dying and serious illnesses. The Coote quote above also displays the ability of art therapy and music therapy to put some emotions into words that sometimes cannot be put into words, such as dying. Coote further expands on the healing ability in the context of a phone call in the next quote.

The author of this particular essay is Jackie Coote:

> Received a phone call to say there seemed to have been a massive breakthrough with Teresa, and already she was much more relaxed and approachable. I was asked if I might call in and see her very soon, as she had found the session so helpful that she wanted a further meeting and knew she had little time left. (Coote, 1998, 60)

Another patient named Ben had hoped to have his own breakthrough in the power of art therapy. Although Ben's journey through art therapy is quite different since he is facing a serious illness, he is not facing the end of life like the other case study participants in Coote's essay. Ben, who is a ten-year-old. However, his childhood has been drastically altered due to having to take time off to be treated for leukemia. Ben was not able to participate in the things other ten-year-olds get to participate in due to his illness.

Ben was quite different from all of the other hospice patients included in this chapter since he was only ten years old. He was placed in the children's ward because he was "Attending the hospital for yet more treatment. [due to his progressing leukemia]." (Pratt, 1998, 61)

During his art therapy session, he drew a:

> Dragon's head [that] became decapitated- a sword and slayer were added-the sword became more bloodied [,] the dragon grew [,] and the fire from its mouth increased. Whilst Ben continued to work I felt strongly that he was expressing his anger about his situation and all that went with it. He wanted to 'mark' the nurse with the dragon's colours, which he had in his hand. (Pratt et al, 1998, 61)

The vivid description of Ben's drawing shows that Ben's cancer had led to serious feelings of despair and hopelessness, which is understandable. '

Due to the art therapy session, Ben had a safe outlet for expressing his resentful feelings about dealing with a serious illness.

The last patient story that was chronicled within Coote's essay is Bob. Bob was diagnosed with a terminal illness and decided to sign up for art therapy.

During the art therapy session,

> Bob was constantly brimming with tears and having to wipe his eyes. He said that since he had come to hospice, he had been like a leaking tap. Always weeping. He felt sad-grief stricken at leaving his wife, whom he loved dearly. (Coote, 1998, 58)

During the time that Ben conducted art projects in the art therapy session, he was able to recall an incident in his own life that happened years before, as is explained: "He told me he used to be a bus driver, and enjoyed his job. [However] some problems arose, and a judgment had been made on him which was unjust and underserved." (Coote, 1998, 58)

Not only was Bob able to share his complex feelings about facing a terminal illness, but he was also able to connect his current terminal illness to a prior incident in his own life. A mental breakthrough like what Bob experienced is akin to what happens in cognitive behavioral therapy and shows the power of art therapy to not only heal feelings about facing serious, terminal illness, but also the power of art therapy to heal traumatic events from one's past. Robert E. Krout states in his paper, *Music Therapy with the Imminently Dying Hospice Patients and Their Families: Facilitating Release Near the Time of Death,* that "Single-session music therapy interventions appeared highly successful in increasing observed and self-reported pain control, physical comfort, and relaxation." (Krout, 2001, 384)

In his study, Krout conducted a case study with “[Eighty] patients receiving regularly scheduled music therapy services from Hospice of Palm County, Florida, from June to August 2000.” (Krout, 2001, 384) The most prevalent diseases within the study were: “Cancer, renal failure, encephalopathy, dementia, coronary obstructive, pulmonary disease, cardiovascular disease, congestive heart failure, and others.” (Krout, 2001, 385). The music therapy sessions helped the terminal patients with “Self-reported pain control, physical comfort, and relaxation.” (Krout, 2001, 388) Once again, Krout has proved that music therapy is valued and helpful for terminal patients, as it has been proven to help with the often serious symptoms one faces at the end of life.

## Part Three: The Connections Between Art, Music Therapy, and Hospice Care

Fine art has the power to evoke our deepest emotions, but also our emotions that we cannot convey or explain. Art therapy can be defined as:

> The use of art materials for self-expression and reflection in the presence of a trained art therapist. The creation of an image or artefact provides the client and therapist with a concrete form depicting something of the client’s experiences, with which both client and therapist can engage. (Wood, 1998, 1)

Art therapy can be utilized as a way to help people heal from the most traumatic and challenging events in one’s lives.

Megan Robb, who is an assistant professor in graduate art therapy, proclaims that at the National Institute of Health:

> Art therapy was purely a research pursuit in the intial years of the National Institute of Health, (NIH), a U.S. government agency with a long history of groundbreaking research. Due to a shift in funding, art therapy faded in interest until it returned in NIH’s clinical arena. (Robb, 2012, 33)

The benefits of art therapy extend past research theories at the National Institutes of Health. Also, according to Robb, art therapy proved beneficial at a mental hospital in

Washington, D.C. As recounted by Robb: "Thanks to the leadership of Bowen and Wynne, art therapy research was funded for inclusion in the psychodynamic family research agenda and led to the development of a standard evaluation technique." (Robb, 2012, 33)

One pivotal example of the power of art therapy in a hospice setting is the Hope Tree Art Installation at the Peace Arch Hospice Center located in White Rock, British Columbia. The purpose of this project was to help patients through the heavy emotions they can feel at the end of life, such as "Depression, anger, hopelessness, and anxiety, while family members often contend with distress, poor health, financial problems, and disruption in their work." (Collins et al., 2018, 1274)

The intense and heavy emotions associated with hospice care can also extend to the healthcare workers at the hospice center, who, according to Collins, are "Caring for terminally ill patients and can experience stress, various trauma, and/or compassion fatigue." (Collins, 2018, 1274)

Throughout their study, Collins et al. hope to offer a creative outlet to patients, families, and healthcare workers. The questions within the survey that were dispersed to the study participants asked three questions:

> Did the Hope Tree have a negative impact on the hospice? Did the Hope Tree interfere with the day-to-day operations of the hospice? Do creative art projects like the Hope Tree have a role in a hospice environment? (Collins et al, 2018, 1274)

The patients at Peach Arch Hospice state that certain feelings emanated from the Hope Tree Project, including "Peace, dreams, total wellbeing, acknowledgment of loss, relationships, hospice care, spirituality, [and] dichotomies." (Collins et al., 2018, 1276)

Mary B. Safrai, who is an art therapist affiliated with the Visiting Nurse Service of New York Hospice and Palliative Care, states:

> In the process, they may be motivated to become active in taking leave of their families and friends. A heartfelt goodbye can be a source of sustained comfort for loved ones. Art therapy in hospice offers healing and life-enhancing benefits for patients, families, and staff. (Safrai, 2013, 122)

Safrai states in the aforementioned quote that art therapy can also help people heal from one of the most distressing symptoms of dying, which is loneliness. Safrai continues her argument of the valuable benefits of art therapy within the next quote: “Art therapy in hospice care is an intimate encounter. During an art therapy session, the therapist and hospice patient enter into and share a space where the creative spirit can flourish.” (Safrai, 2013, 123)

One of the participants in Safrai’s study, Eli, was more attuned to the benefits of art due to an actual background in art:

> Entered a nursing facility in a large metropolitan city for the last two months of life because he could no longer function independently. I met him a few days after his arrival. He was delighted, he said, to hear that I was an art therapist-’ whatever that is.’ More recently he had painted in an artist-run studio at the hospital where he was undergoing cancer treatment. (Safrai, 2013, 123)

Over the course of the next few art therapy sessions, Eli was able to fully express himself and re-tell and remember important moments of his life through art. Closer to the end of his life, he had requested more art therapy sessions during the week, as noted by Safrai. As the art therapy sessions continued, Eli noticed the art therapy sessions were actually beneficial to his recuperation.

Eli was able to express more of his feelings and more about his own life. Throughout the course of the study:

> Eli valued routine; he ate a tuna fish sandwich every night for dinner. He habitually accumulated piles of papers and struggled to keep track of them. 'You have no idea how much of my life I've spent checking and rechecking things', he told me. His extended family was small and distant, but he maintained a connection with his brother until his death. (Safrai, 2013, 125)

Eli's art therapy sessions eventually inspired one of the volunteers to reach out to Eli with a suggestion. This suggestion involved:

> A pamphlet about the work of Gustav Klimt, and he felt attracted to the peacock pattern on the woman's cape depicted in *The Kiss*. He worked hunched over the paper and carefully dabbed paint into the outline of his design. When he finished, he said that he liked it, but that it was 'not him.' (Safrai, 2013, 126)

One thing that Eli noticed during his art therapy sessions was:

> He was sometimes incapacitated by fear as he watched his body decline, yet he was able to take action through art-making and in forming relationships with me and with others on the hospice team. The struggle of integrity versus despair played out on a daily basis; however Eli remained engaged to the end. (Safrai, 2013, 127)

In terms of hospice patients encountering severe pain, music therapy can benefit their healing. Lauren Dimaio, who wrote *Music Therapy Entrainment Music Therapists Perspective of Using Music Therapy Entrainment with Hospice Clients Experiencing Pain,* proclaims that a common refrain from her hospice clients is "I'm not afraid of dying, I'm afraid of pain." (Dimaio, 2010, 106) Over the course of a set of case studies, Dimaio examines the role of music therapy in easing the pain that dying people uniformly experience when facing death and terminal illness. Once again, according to Dimaio, "The American Cancer Society described pain as a sensation that hurts." (Dimaio, 2010, 106).

Music Therapy Entrainment was founded on three principles, which are as follows:

> The principle, the Concept of Resonance Vibration, and the Entrainment Principle. This technique has been facilitated in group and individual sessions, and clients have been either active in making their sounds or passive by listening to others or the therapist creating the music.
> (Dimaio, 2010, 107)

The individual stages of music therapy entrainment involve "Assessment, goal formulation, creating auditory images, externalization of pain and therapeutic resonance, and finally, ISO Continued Application and Evaluation." (Dimaio, 2010, 107)

The following stories are case studies and testimonials from Dimaio's research from Robert, Meredith, Walter, and Patricia.

Robert had a "Hospice diagnosis of debility, a broad diagnosis used when a client has multiple symptoms and is generally declining without one specific disease causing the decline." (Dimaio, 2010, 109)

Before Robert started receiving music therapy:

> He had never played any instruments, but his wife played hymns on the piano. He described himself as Protestant but offered no insight into the role of music in his spirituality. He made song choices during the assessment session but declined the offer to play any instruments with assistance. (Dimaio, 2010, 109)

Over the course of the next few months, Robert still reported pain during these therapy sessions and repeatedly said that he did not want additional support.

Robert's therapy sessions were not like the therapy sessions for other patients due to his paralysis, which left him:

> I interpreted his descriptions musically and requested his feedback. I feel that I was able to do this well because of the time I had to get to know him with his copy at our next scheduled session. He never permitted another entertainment session, but he did begin requesting relaxation techniques during regular music therapy sessions. (Dimaio, 2010, 110)

Over time, the music therapy sessions helped Robert have better communication with his wife and his caregiver.

Meredith is another participant in the research study who is an:

> [Eighty-Eight] year-old Caucasian woman with a primary diagnosis of Parkinson's disease and a secondary diagnosis of dementia. Meredith was a widow and had one son who lived out of state. Her husband had died five years earlier. She resided in a private room at a local nursing home and was Protestant. She participated in one MTE session. (Dimaio, 2010, 110)

Dimaio once again shows that music therapy can help one ease physical pain, which can be beneficial to helping hospice patients either use less or ease off of pain medications during a time when physical pain is at an all-time high.

Noah Potvin, who is a certified music therapist from Drexel University, conducted his own case study by interviewing and conducting a music therapy session with a "[Forty-Seven] year old patient Caucasian woman who, at the time I began working with her, had been battling her second bout of breast cancer in a decade long with the disease." (Potvin, 2015, 53)

The reason that Mitzi decided to attend music therapy sessions, according to Potvin, was her "Rapid decline over the past several weeks, including decreased food and fluid intake, increased disorientation, and an inability to independently ambulate." (Potvin, 2015, 53)

Moreover, at the start of the music therapy sessions, Mitzi seemed to be approaching the last days of her life and death.

Potvin explains Mitzi's condition in the following quote: "Shallow breaths, mouth in an open and fixed position, eyes glazed and unfocused, and minimal movement that, when occurring, was largely sporadic in nature." (Potvin, 2015, 53)

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Portrait Therapy can help patients with opportunities to have their artwork reach a wider audience, as  explained in the next quote:

> Art Therapy, Community Engagement, and Living and Dying" written by Annalie Ashwell examines an art project "that offered individuals connected to a hospice the opportunity to create a piece of artwork and contribute it to a public exhibition. Exhibition art creativity, thoughts, and feelings of people in touch with illness, hospices and mainstream society. (Wood et al, 2019, 95)

The two hospice centers involved in this art project are both located in the UK but are different geographically:

> One of the Hospice centers is located in a rural environment and is “more purpose-built and located in large rural grounds, on the outskirts of a largely affluent small town; the other, an historic building in the centre of a multicultural town. Each hospice has developed services in response to the needs of their local community, and together have established a partnership to deliver a range of innovative outpatient services. (Wood et al., 2019, 149)

The premise of this essay, written by Gill Thomas, chronicles the art therapy sessions conducted at the Marie Curie Centre in London. The Marie Curie Hospice Center is a “Thirty-two bed unit with a very active out-patients department and day centre. There is a very strong medical lead within the unit, which provides excellent palliative care.” (Thomas, 1998, 64)

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Throughout the course of art therapy sessions, she was able to articulate the feelings she had about estrangement from her family, as is explained in the next quote:

> None of her family was able to acknowledge her illness and imminent death. All this left her feeling abandoned, neglected, and empty. Like the house with the curtains drawn, she had been unable to let anyone outside know what was really going on inside. (Coote, 1998, 56)

Through the art therapy sessions, Eileen was able to de-stress from the heavy emotions she had been dealing with during the course of her disease. Moreover, she was able to gain the confidence to "Step over the boundary and the danger." (Coote, 1998, 57) Teresa, another patient within the hospice center, was also recommended to attend music therapy by the hospice staff. The rationale for recommending Teresa to music therapy was due to the fact that she was "Very poorly and deteriorating rapidly. The nursing staff had found her very needy for some time. She wanted constant attention, yet they had trouble meeting her needs, as it was never really clear what the problem was. Nothing was ever quite right." (Coote,  1998, 59)

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Either way, through the art therapy sessions, Teresa was able to recognize her own feelings about facing death, as is explained in the next quote:

> She went on to express the bitterness and resentment she felt towards anyone she came into contact with because, basically, they weren't about to die. She was. She expressed the desperate unfairness she felt in that she had spent much of her life being health conscious.  (Coote, 1998, 60)

Art therapy, just like music therapy, can also help with expressing repressed feelings that can be related to either facing death or dealing with serious illness. The aforementioned Coote quote also displays the ability of art therapy and music therapy to put some emotions into words that sometimes cannot be put into words, such as dying. Coote further expands on the healing ability in the context of a phone call in the next quote.

The author of this particular essay, Jackie Coote:

> Received a phone call to say there seemed to have been a massive breakthrough with Teresa, and already she was much more relaxed and approachable. I was asked if I might call in and see her very soon, as she had found the session so helpful that she wanted a further meeting and knew she had little time left. (Coote, 1998, 60)

Ben was another patient who had hoped to have his own breakthrough in the power of art therapy. Although Ben's journey through art therapy is quite different since he is facing a serious illness, he is not facing the end of life like the other case study participants in Coote's essay. Ben is actually a kid. However, his childhood has been drastically altered due to having to take time off to be treated for leukemia. Ben was not able to participate in the things healthy kids get to participate in due to his illness.

Ben was quite different from all of the other hospice patients included in this chapter since he was only ten years old. He was placed in the children's ward because he was "Attending the hospital for yet more treatment [due to his progressing leukemia.]" (Pratt, 1998, 61)

During his art therapy session, he drew a:

> Dragon's head [that] became decapitated- a sword and slayer were added-the sword became more bloodied [,] the dragon grew [,] and the fire from its mouth increased. Whilst Ben continued to work I felt strongly that he was expressing his anger about his situation and all that went with it. He wanted to 'mark' the nurse with the dragon's colours, which he had in his hand. (Pratt et al, 1998, 61)

The vivid description of Ben's drawing shows that Ben's cancer had led to serious feelings of despair and hopelessness, which is understandable. Due to the art therapy session, Ben had a safe outlet for expressing his resentful feelings about dealing with a serious illness.

The last patient story that was chronicled within Coote's essay is Bob. Bob was diagnosed with a terminal illness and decided to sign up for art therapy.

During the art therapy session:

> Bob was constantly brimming with tears and having to wipe his eyes. He said that since he had come to hospice, he had been like a leaking tap. Always weeping. He felt sad-grief stricken at leaving his wife, whom he loved dearly. (Coote, 1998, 58)

During the time that Ben conducted art projects in the art therapy session, he was able to recall an incident in his own life that happened years before.

Ben's success in art therapy is explained in the next quote:

> It was an occasion where he had been treated badly at work. He told me he used to be a bus driver, and enjoyed his job. [However] some problems arose, and a judgment had been made on him which was unjust and underserved. He described the fury he had felt toward the person who had made the accusation and had ultimately returned to tackle him about it. (Coote, 1998, 58)

Not only was Bob able to share his complex feelings about facing a terminal illness, but he was also able to connect his current terminal illness to a prior incident in his own life. A mental breakthrough like what Bob experienced is akin to what happens in cognitive behavioral therapy and shows the power of art therapy to not only heal feelings about facing serious, terminal illness, but also the power of art therapy to heal traumatic events from one's past. Robert E. Krout states in his paper that "Single-session music therapy interventions appeared highly successful in increasing observed and self-reported pain control, physical comfort, and relaxation." (Krout, 2001, 384)

In his study, Krout conducted a case study with "[Eighy] patients receiving regularly scheduled music therapy services from Hospice of Palm County, Florida, from June to August 2000." (Krout, 2001, 384) The most prevalent diseases within the study were: "Cancer, renal failure, encephalopathy, dementia, coronary obstructive, pulmonary disease, cardiovascular disease, congestive heart failure, and others." (Krout, 2001, 385).

The music therapy sessions helped the terminal patients with “Self-reported pain control, physical comfort, and relaxation.” (Krout, 2001, 388).

Once again, Krout has proved that music therapy is valued and helpful for terminal patients, as it has been proven to help with the often serious symptoms one faces at the end of life.

## Conclusion

Everyone will die; it’s just a matter of when. When we do die, we will not only be dealing with our own imminent mortality, but we will also be grappling with the flood of emotions that accompany a terminal diagnosis or simply dying. There are two ways to face the end of life; the usual five stages of death, popularized by Elizabeth Kubler-Ross, include denial and isolation, anger, bargaining, depression, and acceptance. These five stages would inevitably lead to even more anger and lashing out. Or one could use music and art therapy sessions, which operate as an outlet for current negative feelings and some repressed feelings from the past, which can all make the transition to the afterlife a little easier. Furthermore, the connection between art and music therapy and the initial theories of this dissertation include the ability to make dying less intense while memorials are connected to the initial theories of this dissertation and to the theories of art and music therapy due to the innate human need to be remembered after death, especially if one’s death happened at the turning points of history. There is nothing worse than dying and then having one’s death be neglected and ignored, which will be examined in the next chapter of this dissertation.

# CHAPTER THREE

# MEDICAL RACISM, AFRICAN AMERICANS, & HOSPICE

## Part One: Introduction

The focal point of this chapter is understanding the factors that are instrumental to the low hospice care enrollment rate among African Americans, specifically the factor of medical racism. However, some of the factors are already known, including medical mistrust. The main issues that will be addressed within this chapter will be a brief connection between the history of medicine and medical mistrust, the factors leading to medical mistrust, religious divides between patients and physicians, sickle cell and racism, heart disease, and racism, racism in medical education, and solutions to this systematic problem.

Medical mistrust stems from historical unwarranted medical experiments, such as the Henrietta Lacks Experiment, which involved Johns Hopkins University stealing cervical cancer cells from Henrietta Lacks against her will after a diagnosis of cervical cancer in the 1950s. After a biopsy, the physicians at Johns Hopkins learned that Henrietta's cells could grow indefinitely, meaning the cells would be a great contributor to scientific research. The cells were instrumental to scientific research, generating millions in profits. Moreover, the cells did not contribute anything to the Lacks as they continued to live in poverty even while the cells were generating record profits for the sciences and healthcare.

The second crucial factor in medical mistrust that African Americans felt toward the medical community was the Tuskegee Experiment, which started from the 1930s  to the 1970s. The Public Health Service ran this particular experiment. Impoverished Alabama sharecroppers were infected with syphilis and then refused treatment so the

Public Health Service could get more accurate data for their study. According to the esteemed writer Harriet Washington, the lasting effects of the experiment included: “The death rate of the infected men [that] was twice that of the control subjects, prompting Wenger to boast smugly in 1950, ‘we now know, where we could only surmise before, that we have contributed to their ailments and shortened their lives.” (Washington, 2006, 166)

Washington further states: “On May 16, 1997, a quarter of a century after the Tuskegee Syphilis Study ended, President William Jefferson Clinton formally apologized for the study in a dignified White House ceremony.” (Washington, 2006, 184) Another factor that contributes to medical mistrust within the African American community is the high level of racism and disparities in the medical community. In the quote above, Washington shows how deep and pervasive the disparities are within the United States medical system.

Even cancer patients are not immune to the high levels of medical racism that have claimed too many African American lives. In their article, “A Review of Race and Ethnicity in Hospice and Palliative Medicine Research: Representation Matters,” Rhodes et al. examine theories and the presence of racism in hospice and palliative care. Additionally, they proclaim:

> Accounting for race and ethnicity and improving the representation of diverse and racial and ethnic groups in hospice and palliative medicine research are essential to addressing disparities and facilitating equitable access to benefits of palliative care for all. To date, there has been no rigorous examination of racial and ethnic representation and categorization in a large [,]diverse sample of published hospice and palliative medicine research. (Rhodes et al., 2022, 290)

The extraordinary findings in the quote mentioned above regarding race and medicine from the previous quote are quite astounding when one considers the fact that the death rates in this country are breathtaking. Areeba Jawed and Amber R. Comer state in their article: “Disparities in End-of-Life Care for Racial Minorities: A Narrative Review” that the “Racial and ethnic makeup of the U.S. population facing end-of-life (EOL) is also shifting and it is estimated that by 2050, the U.S. population will include 33 million Black, Hispanic, Asian, American Indian, or Alaskan Native individuals aged 65 years and older.” (Jawed, 2024, 310)

Jawed et al. affirm that health literacy, access to care, social determinants of health, cultural and religious values of patients, and communication between providers and patients are all contributing to the low hospice care utilization rate and medical racism as a whole.  The definition of health literacy is, according to Huang et al., “The ability to read, understand, evaluate and use some health information to make reasoned, health-related decisions.” (Huang et al., 2019, 725)

When it comes to hospice care, health literacy can also mean the difference between an EOL (end-of-life) patient fully understanding the role and importance of their hospice care and dying in the hospital and still obtaining curative or life-sustaining treatment, whether that is the type of care they wanted at the end of life.

Liu et al. expand on the theory of the significance of health literacy in their article, “What is the Meaning of Health Literacy? A Systematic Review and Qualitative Synthesis,” that “Inadequate health literacy is associated with difficulties in comprehension of health information, limited knowledge of diseases [,]  and lower medication adherence, which contribute to poor health, high-risk mortality, insufficient and ineffective use of healthcare.” (Liu et al, 2020, 1)

All of the disparities that were explained in the Liu et al. quote definitely contribute to a higher mortality rate among African Americans, and this higher mortality rate contributes to even more disparities at the end of life. Poor health literacy contributes to a vicious cycle that does not put quality health care at the center. These individual tenets of health literacy include, according to Liu et al.: "Identifying a health issue (knowing when and where to find health information), engaging in information exchange (verbal communication skills, assertiveness and literacy skills) and acting on health information (capacity to process and retain information, and application skills)."  (Liu et al, 2020, 4)

Another factor that influences medical racism and the ability of African Americans to enroll in hospice care is actual access to hospice care. Access to hospice care is the great divide between religious beliefs and practices of patients and healthcare workers, as noted in Robert A. Neimeyer's article, "Confronting Suffering and Death at the End of Life: The Impact of Religiosity, Psychosocial Factors, and Life Regret Among Hospice Patients." Neimeyer et al. state, "As the percentage of the U.S. population over the age of 65 is expected to increase from 12% in 2010 to over 20% in 2040 (U.S. Census Bureau, 2008), it becomes increasingly important to understand factors that shape the attitudes of this cohort toward mortality." (R.A. Neimeyer et al., 2010, 778) The rise in the population of elderly adults in the United States shows just how great the need for geriatric care has become within the United States in recent years. Additionally, the rising population of elderly adults also shows the need for improved end-of-life and comfort care for terminal patients. Just like music and art therapy can be a balm against the scary experience of death. For some non-religious people,  the availability of religion can also be a balm against the experiences of death. R.A. Neimeyer also explains this in the following quote:

> Moreover [,] although little evidence suggests that atheist or agnostic patients with serious illnesses turn to religion to deal with the challenges posed by their mortality, it does seem that existing beliefs among those with a spiritual orientation function as a critical resource for both the orientation function for both of the dying and the bereaved (R.A. Neimeyer et al., 2010, 779)

The quote above from R.A. Neimeyer is significant to consider within the context of the African American death experience since a large number of African Americans are religious, and many African Americans see religion as part of their treatment plan. As stated by Brian C. Dunlop in the article, "Demystifying African American Spirituality: Exploring the Measurement of Spirituality in the Context of Medical Decision-Making,": "As a result, many African Americans, [Ninety-Seven Percent] of whom believe in God or a higher power that is intimately involved in their lives, rely on their faith or spirituality to navigate the toxic stress produced by inadequate access to timely and responsive care." (Dunlop, 2024, 376) However, these beliefs are at odds with the views and beliefs of healthcare workers and physicians, which creates conflict and hinders the level of care that African American patients receive at this crucial time in their lives. Within the context of his study, Dunlop was able to utilize two beneficial research methods for this study, specifically, the Duke University Research Religion Index, which is: "The [five]-item questionnaire [that] was developed to measure three different dimensions of religious involvement activity an individual participates in as an expression or celebration [of] what they consider sacred or diving." (Dunlop, 2024, 378)

The second research tool that was utilized for Dunlop's study was the Religious Beliefs in EOL [End of Life] Medical Care (RBEC), which is a "Proxy tool administered by trained interviewers to measure religious beliefs within the context of EOL medical care." (Dunlop, 2024, 379)

The last research tool that was utilized for this particular research study was the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being 12-Item Scale, which is a "[Five]-point Likert-type, self-administration[,] and interview tool used to measure three subdomains of spiritual well-being, peace, meaning [,] and faith." (Dunlop, 2014, 380) The results of Dunlop's study were inconclusive in getting to a final consensus and proving whether or not religion and spirituality played a role in improving end-of-life care for African Americans. Yet, Dunlop was still able to show the gaping disparity between patients and physicians/healthcare workers when it comes to belief in a higher power.

One thing that will always be true is that racism will always play a role in whether or not African Americans receive adequate care. As mentioned earlier in this chapter, medical experimentation and medical racism have a long history in America, yet this dark history has only just now been addressed despite being a prevalent and serious problem. The long history of medical racism started in the times of slavery and endures until today. In his article, Joe Feagin, a professor from Texas A&M University, states:

> The first [Sixty] of our [Four hundred ten] years involved a slavery/genocide system; then 23% more of our history involved the near-slavery of legal and de jure segregation of a blatant type followed by current widespread patterns of white racial framing and discriminatory practices in most institutions. (Feagin, 2017, 54)

Feagin further states that medical racism also extends to the field of medical education, which explains the extensive amount of racism within the medical field itself. Numerous scholars and medical professionals have documented the existence of medical racism throughout the country. One of those scholars was the widely respected writer Harriet A. Washington. The other widely admired scholar is a physician and Harvard Medical School Graduate and author of *Legacy: A Black Physician Reckons with Racism in Medicine,* Uche Blackstock, M.D. In this book, she chronicles her autobiography and journey to Harvard Medical School, Racism, and growing up in New York City during contentious times in American history.

Moreover, Blackstock explains the micro and not-so-micro aggressions she experienced during her education and employment at Yale University Medical School as an educator of future physicians. As explained in the book, Blackstock explains that the lack of regard for diversity and overt racism at Yale University Medical School led to her leaving her highly acclaimed career and setting out on her chartered course regarding post-ivory tower employment. Someone else who adequately explained and chronicled the vast amount of medical racism within the United States is Walela Nehanda, who narrated her experiences with cancer in the book *Bless The Blood: A Cancer Memoir.* Nehanda's book flows differently by combining well-crafted poetry and short narratives; Nehanda narrates the tale of navigating the United States healthcare system and the insurance industry either by herself or only with the help of her fiancé or fiancée's family. One pervasive theme within the context of her book was either dealing with unreliable people or feeling befuddled about the United States' healthcare system and having to depend on a system that is not fully understandable.

The reason why the stories of the chronically and seriously ill matter is that their lives, abilities, and rights matter. The experiences of people with sickle cell will be examined in the next section of this chapter.

## Part Two: Sickle Cell Disease Racism

Two diseases prevalent in the context of medical racism are sickle cell disease and heart disease. According to Wakefield et al., the triggers of a sickle cell crisis include: "Stress, cold climates, dehydration, and infections may predispose an individual to have a pain crisis that can further trigger complications including acute chest syndrome, a painful and life-threatening vaso-occlusive crisis of the pulmonary vasculature." (Wakefield et al, 2018, 779)

Sickle cell disease attracts so much negative attention not only because the disease causes inordinate amounts of pain and blood cell crises that can lead to hospitalizations and the necessity for specialized medicine that can only be distributed in a trusted medical setting. These known factors about the disease have led some medical providers to believe that their serious illnesses are not crises. The definition of sickle cell disease is, as stated by Alexandria Power Hays, M.D.  and Patrick T. McGann, M.D., "A life-threatening, inherited blood disorder, affecting more than 100,00 Americans. Painful vaso-occlusive crises, the hallmark of SC, result in substantial suffering and lead to associated stigma. SCD affects all organs." (Hays et al. 2020, 1902)

Moreover, as claimed by Hays et al., the reason that sickle cell anemia primarily affects African Americans is that "In the United States as a direct result of the transatlantic slave trade, nearly all patients with SCD are black. This fact would be mere medical trivia if we did not live in such a highly racialized society." (Hays et al., 2020, 1902) In a recent study, Stephen Nelson explains that when it comes to physician opinions, "Race and gender influence physicians' management decisions. Concerning provider bias, patients with SCD are perceived as being opioid-dependent at twice the rate of other patients with pain.” (Nelson, 2016, 163)

Moreover, Nelson explained that after conducting a study with:

> [Two hundred] providers in a sickle cell center showed differing perceptions of the effect of race on the quality of health care delivery. Providers of color and women providers perceived race as an issue, whereas White male providers tended not to see race as a factor in health care delivery. (Nelson, 2016, 163)

Nelson interviewed a wide range of physicians to examine them for biased opinions. The biased opinions of the providers in this study assuredly describe why critical care for African Americans is lacking. However, there is room for attitude improvement in regard to the treatment of sickle cell patients. However, one should note that the effects of racism on young patients can be intense and long-lasting, especially with so many hospital visits and treatments. As a result, the self-confidence and self-esteem of young patients can affect other areas of their lives, such as school, extracurricular, and finding friends.

Additionally, biased or racist treatments can influence whether or not younger patients feel enthused about the course of their future treatments. In their article, “The Influence of Perceived Racial Bias and Health-Related Stigma on Quality of Life Among Children With Sickle Cell Disease,” A.M. Hood et al. explain that “Studies of adolescents with SCD have found that most adolescents report moderate to high levels of health-related stigma, which is negatively associated with health-related quality of life.” (A.M. Hood et al. 2022, 834) Other factors that influence the experiences of young patients with SCD include perceived racial bias and health-related quality of life.

Health-related stigma can be especially acute for African-American girls who are forced to:

> Deal with harmful perceptions that they are more mature and less in need of protection. These negative stereotypes, such as not being ‘feminine’ or ‘ladylike,’ may make them feel that they are being held to a different standard compared to their white counterparts. (A.M. Hood et al. 2016, 841)

The language that physicians use in the context of sickle disease patients can also considerably affect patient well-being: “Additionally, children with SCD may overhear pejorative terms used by medical providers such as ‘sicklers,’ ‘frequent flyers,’ or ‘clock watchers’ when they seek treatment for pain.” (A.M. Hood et al., 2016, 841).

In a separate article, “Describing Perceived Racial Bias Among Youth With Sickle Cell Diseases,” Wakefield et al. describe data from their study that echoes previous results from similar studies within the chapter of this dissertation. Wakefield et al. proclaim: “[Eighty-eight point four percent] of the sample reported at least one incident of racism, and about one-third of the children reported that the event happened in school.” (Wakefield et al., 2018, 781)

Facing racism and also being in treatment for a chronic disease is not a problem that a chronically ill youth needs to face. The only thing a chronically ill youth needs to handle is getting better and being a young person. Handling a high amount of bias and perceived bias can lead to unusually high levels of stress and serious heart problems, which will be examined in the next section of this paper.

## Part Three: Heart Disease

Adults are also not immune to the effects of discrimination and racism, as numerous African-American adults can recall their experience of medical discrimination during treatment for heart disease. The widely admired writer Harriet Washington, who wrote the book *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present,* states has veritable proof that medical discrimination against African Americans exists. Washington explains her theory in the following quote: “Despite its image as a disease that affects middle-aged white men, heart disease claims 50 percent more African-Americans than whites and African-Americans die from heart attacks at a higher rate than whites.” (Washington, 2006, 4)

The symptoms of heart disease include, according to Richard C. Falcon, “Pain, sweating, shortness of breath, inability to exercise, irregular heartbeat, and loss of consciousness.” (Falcon, 2024, 1) The causes of heart disease include “Pulmonary problems, atherosclerosis, smoking, diabetes, hypertension, infection, high-fat diet and obesity, and stress.” (Falcon, 2024, 1) The first such quote demonstrates evidence of medical racism: “African-Americans less likely than Whites to be admitted had lower coronary artery bypass procedures, were less likely to be triaged for CHD, and were more likely to delay seeking care.” (Fincher et al. 2004, 362) Moreover, they also found that “African Americans were less likely to receive thrombolysis for AMI when clinically indicated; no difference in the use of beta-blockers or aspirin; African-Americans least likely to receive pharmacological treatments.” (Fincher et al. 2004, 362)

In addition, Fincher et al.’s extensive literature review proved that “Physicians perceived African-Americans and low and middle SES groups on a number of measures.” (Fincher et al., 2004, 362)

In summary, the quotes above show that there are serious issues that affect the level of care that African Americans with heart conditions receive, either at the time of a severe cardiac event or a routine care appointment. However, one should also note one across-the-board factor that contributes to the level of care that African Americans receive: systematic racism. About the presence of systematic racism within the United States medical system, Fincher et al. proclaim, “When comparing black and white differences in seeking medical care for chest pain, in seeking medical care for chest pain, Strogatz documented ‘structural access’ issues for Blacks, such as affordability and accommodation. Racist beliefs embedded in an institution also present barriers.” (Fincher et al. 2004, 367-368) Providing improved community access to healthcare centers can go a long way toward ending this disparity.

Some of the beliefs about race and heart disease are changing; as far back as the 1950s, there was a common belief within the medical community that “Myocardial infarction and the presence of angina were rare among African-Americans.” (Fincher et al. 2004, 368) All opinions on heart disease and medical racism should not just come from physicians; patients should also share their opinions on this contentious matter. Providing a patient opinion was the goal of Felicia York and Lu Tang when they wrote their 2021 article,  “Picture Me Heart Disease Free: Understanding African-Americans’ Cardiovascular Disease Experiences Through a Culture-Centered Approach.”  During their research process, York et al. found that “Between 2013 and 2016, [fifty-eight point six Percent]  of non-Hispanic African-American men and [fifty-six point six] of non-Hispanic African-American women had high blood pressure compared to [forty-eight point two percent] of Caucasian men and 41.3 Caucasian women.” (York et al., 2021, 247).

Moreover, in the course of their research, York et al.'s research proved that "African-Americans are more likely to have CVDs [Cardiovascular Diseases] and associated risk factors than Caucasians. They are also more likely to die of heart-related illnesses than other racial groups. Such disparities have been attributed to structural and cultural determinants." (York et al. 2021, 248)

Nevertheless, some factors are more prevalent factors for CVD[Cardio-Vascular Disease], and those include, according to York et al., "Education and income, disproportionally disadvantage African Americans. The experience of racism and discrimination affects African Americans' cardiovascular health through medical professionals' bias,  low-quality clinician-patient communication, and stereotype threats." (York et al, 2021, 248)

However, one factor that has not been thoroughly assessed is the effect of:

> Psychological determinants such as depression, anxiety, and stress all negatively affect CVD-related morbidity and mortality rates. These psychological determinants mediate the relationship between socioeconomic status and CVD-related health outcomes in that those with lower SEP tend to be more stressed or depressed. (York et al., 2021, 249)

To offer a solution, York et al. proposed utilizing a CCA approach, which calls "For community-centered, participatory health communication research among marginalized populations and spaces."  (York et al. 2004, 250) Medical racism in cardiology even extends to the Precision Medicine Initiative. The precision medicine initiative is defined in accordance with Genevieve et al.; "Precision medicine is defined as an approach to disease treatment and prevention that seeks to maximize effectiveness by taking into account individual variability in genes, environment, and lifestyle." (Genevieve et al. 2020 1) Precision medicine is generally utilized for "Advanc[ing] medical and scientific discoveries and still offering more tailored, precise and accurate health interventions, which will maximize the health benefits for patients." (Genevieve et al. 2020, 1)

Although this medical innovation seems promising for people who have to endure the symptoms and effects of dangerous chronic diseases, there are still serious risks involved with this new technique. As stated by Genevieve et al., there are three tiers of structural racism involved with the field of precision medicine, and they include "The quality of health data collected; the integration of these data in PM initiatives; and the development of new therapeutics, diagnostics or disease prevention strategies." (Genevieve et al., 2020, 3) The first tier of structural racism involved with precision medicine involves the very first encounter that a patient has with a healthcare provider or researcher. Thus, the reason for more thorough education of healthcare professionals and providers is to hopefully end medical racism, which will be addressed in the next section of this chapter.

## Part Four: Medical Racism and Medical Education

One must be sure to acknowledge that medical education plays a predominant role in preventing and remedying medical racism. It is paramount to acknowledge the fact that history is and has been a crucial factor; however, training the next round of race-aware and competent healthcare professionals is also crucial for ending medical racism. As it stands, there are current beliefs within the field of medical education where many medical students and medical educators still hold racist beliefs from the past.

In recorded and transcribed interviews, numerous medical students from various ethnic groups stated that they had frequently overheard racist and insensitive jokes while conducting rounds during their clinical rotations, and even more disturbing, these jokes were accepted by everyone and seen as normal, which shows the necessity of more race-aware education. In her article, Brenda L. Beagan interviewed medical students currently studying in Canada. The responses and results from the study show that "Everyday racism consists of inequitable 'practices that infiltrate everyday life and become part of what is seen as normal by the dominant group, even in the context of formal commitment to equality." (Beagan, 2003, 853) In summary, the mostly white medical student stated: "I don't know…it is so easy when you are not the minority to not notice things. So I am not sure." (Beagan, 2003, 855)

The quote above is in contrast to what some of the minority medical students stated during their interviews:

> I think it's tougher to gain respect from people than if I was a 30-year-old white male walking into the room, and they see you, and they think you're a doctor. Whereas if you walk into the room, and you look like you're 18, you're Chinese, you're a girl, they automatically assume you're a nurse or a volunteer, a candy striper. (Beagan, 2003, 855)

A medical student from the Caribbean stated regarding the ever-present racism in medical schools:

> And he was like, 'Sing the Banana Boat song and then he started singing it, and okay, that's not appropriate. And I'm thinking, 'I don't really know how to get you to shut up, because you're still singing!'... Later he said, "If you send me on a free trip to the Caribbean, I'll let you do the next procedure…Then he said, 'Oh, do some Island speak. I said, "No, I don't think so.' He starts, mimicking a Caribbean accent, 'Eh, mon." and I'm thinking, "That's not right. I don't think you understand why I'm not laughing at you." (Beagan, 2003, 857)

Other students within the medical school stated that having to adhere to authority made it harder to stand up to offensive displays of racism, as is explained in the next quote:

> We had a native man come in and told us he wasn't feeling well or whatever. And we went into the other room and the doctor said, "So, do you think this is a dumb Indian or a smart Indian?' And I went, 'What'... This is a person I'm supposed to be learning from so I can't say, "What kind of stupid question are you asking me here?' I've got to be with him for another 3 weeks and try to get a reference letter out of him, so I can't cut him down. (Beagan, 2003, 857)

Another student involved in the study stated in regard to Beagan's questions regarding everyday racism and fitting in:

> Furthermore, [twenty-four percent] of students who identified as members of minority groups indicated that their racialised or cultural background had a negative effect on their experiences of medical school, compared to non-minority students. Interestingly, minority students were also more likely to indicate that their 'race'/culture had a positive impact, which may reflect the consensus that familiarity with a second language was advantageous. In contrast [,] [eighty four percent] of non-minority students experienced the impact of their 'race'/culture as neutral. (Beagan, 2003, 858)

Despite the detrimental effects of medical racism on both the U.S. healthcare system and medical schools alike, there are some medical schools and medical centers that are trying to help improve the equity and justice landscape for American medical students and future doctors. For example, the Beth Israel Deaconess Medical Center, which is located in Newark, New Jersey, according to Afolabi et al., "Has removed the racial correction factor from the electronic medical record. In June 2020, Mass General Brigham [which is located in Boston] followed suit by removing the eGFR racial multiplier from the Epic medical record." (Afolabi, 2021, 803) Taking action to remove the eGFR racial multiplier recently led to the reclassification of numerous transplant records and patients, which has led to the ability of numerous patients to receive long-awaited and much-needed kidney transplants. Elsewhere, the  University of California at San Francisco organized a new initiative called:

> White Coats For Black Lives (WC4BL). W4CBL, which now has chapters at over 50 medical schools, formed as a national organization in 2014 when students at the U.S. Medical Schools staged a 'die-in' lying on ground in their white coats to recognize the deaths of black men Eric Garner and Micheal Brown.  (Afolabi, 2021, 803)

The University of California took it one step further by announcing a "[Nine point six million] Differences Matter Initiative, which included a new orientation curriculum that immediately introduced incoming students to race-based health inequities." (Afolabi, 2021, 804)

Samuel C. Bullock, MD, and Earline Houston, MD [who passed away in 1981] conducted their interviews with:

> Thirty-one black medical students attending five white medical schools were seen in individual interviews of one to two hours to evaluate their perceptions of racism in their medical school education. The interviews focused on racism experienced in high school, college, and medical school.  (Bullock et al., 1987, 601)

What Bullock et al. found within the context of their study showed that the students utilize "A variety of methods of coping with racist experiences and emphasized the importance of fellow minority students, faculty, and the minority office in coping with the stresses of racist experiences." (Bullock et al. 1987, 601) Bullock et al.'s interview process involved a fixed method set of questions that focused on: "Perceptions of issues of discrimination and prejudice in their school experience for several reasons: 1. Experiences of prejudice and discrimination and frequent topics of discussion by black medical students 2. Racial discrimination has been mentioned as one of the stresses in the medical school experience." (Bullock et al., 1987, 602)

The results of their study showed that a portion of the thirty-one study participants had experienced racist experiences prior to enrolling in medical school.

Bullock et al. proclaim:

> Fifteen students reported experiences of racism in high school, nine of which were described as subtle. The experiences ranged from difficulty in obtaining recognition and support from teachers to being actively discouraged from taking science courses by counselors and from making applications to prestigious colleges. Three students reported conflicts between black and white students.(Bullock et al., 1987, 603)

Moreover, Bullock et al. noted that there is a notable amount of racism in the admissions process and the preclinical years. During their study, Bullock et al. revealed that:

> In the admission process, approximately one-half of the 31 students had an experience that varied from abruptness in the interview with the subjective impression that the student was not wanted, to the loss of the application and transcript and letters, with the statement by one dean that no minority student had applied. One student was told the tale that students from her state were not being accepted by a certain school. (Bullock et al., 1987, 604)

Despite the fact that Bullock et al.'s study may have taken place in 1987, it is still quite relevant today, as the same issues that were examined in Bullock et al.'s article are still present in the healthcare system. Another example of medical racism in the United States comes from a study conducted by Rebecca Dodd et al., "The Impact of Patient Skin Color on Diagnostic Ability and Confidence of Medical Students." Within the article, they examine "Whether or not patient skin color can affect the diagnostic ability and confidence of medical students, and their cognitive reasoning processes." (R.V. Dodd et al., 2023, 1171)

To examine their theory within their study, Dodd et al:

> Presented students with 12 different clinical presentations on both white skin and non-white skin. A think- aloud study (TA) study was conducted where students submitted a diagnosis and confidence level for each clinical presentation. In the TA interviews, students used similar levels of information gathering and analytical reasoning for each skin type but appeared to display uncertainty and reduced non-analytical reasoning methods for the NWS images compared to the WS images. (R.V. Dodd et al., 2023, 1171)

Through the course of their interviews, Dodd et al. found extraordinary research results based on a certain set of themes that are shared in the following set of quotes. The first quote delves into the next quote:

> Lack of exposure on dermatology rotations, 'I think it's in terms of exposure. [Hesitates] probably especially for [hesitates] my year group and the year group above, because our dermatology placements have been quite impacted by COVID. And they also they're not that long, and they're mostly in the outpatient setting.(R.V. Dodd et al., 2023, 1180)

The quote also delves into the topic of:

> Ethnically diverse presentations only being shown in resources in certain circumstances: So, I think that, especially in, like, medical school textbooks and online resources, we often see images, of, white Caucasian people with skin conditions, unless it's something that's very…Sorry [laughs], just trying to think of the right word.Unless it's a [hesitates], skin condition that we only see in a certain, like ethnic group, for example. (R.V. Dodd et al., 2023, 1180)

On the topic of "Pairing images of different skin types during teaching, to demonstrate different presentations: I think every time I'm shown a diagnosis on a lighter skin tone, if I was shown the exact same diagnosis on a darker skin tone." (Dodd et al, 2023, 1180) On the subject of increased studying, the participant stated: "So, I think it's a bit of a mixture. I think, on one hand, more revision on my own part would improve some of the confidence over some of the presentations." (R.V. Dodd et al., 2023, 1180)

Another perspective comes from the next quote:

> Topic of Questioning first instinct/diagnosis: ‘So, yes, I like this, like, rapid-fire thing, but also thinking, can I just do a spot diagnosis and can I then question myself, because, like, sometimes I realise what I thought was completely different to what the history suggested. [Hesitates]. So, then, just understanding that, yes, it is, [stammers], you can get to a point where you’re quite good at spotting things, but also you need to always have that voice at the back of your head, saying, [hesitates], just double check, you might be wrong, you might have missed something. (R.V. Dodd et al., 2023, 1180)

The results of this study focused on the efficiency of diagnosing skin conditions in African-American versus Caucasian patients, showing just how much work still needs to be done not just to treat African Americans but to treat and heal African-American patients with the dignity they deserve. Of course, the issue of medical racism is a multi-pronged issue that will require a multi-faceted approach from everyone involved in the healthcare field, not just patients and advocates. One good way to do that is to fully understand the history and origins of medical racism to fully understand how to move forward to a better future.

## Part Five: Origins & Solutions to Medical Racism

One question that needs to be answered is how the systems of medical racism started in the United States healthcare system in the first place. This question can be answered by asking what the origins of scientific racism are. In her article, “Racism and Medicine in the United States,” Sarah L. Berry proclaims that the origin of medical racism is rooted in the Enlightenment period.

There are layers to Berry’s theory of medical racism, and they include both the history of racial bias in medicine, which has been well documented within this chapter, and the history of the United States, which extends from the “Early republic and nineteenth century [to the] twin legacies: twentieth century.” (Berry, 2021, 2)

One must also ask what should be done to fix this monumental, systematic healthcare problem. It will take more than reforming the medical education curriculum, as this problem requires a system-wide level solution and participation from everyone in the healthcare system as a whole-doctors/physicians, nurses, administrators, physician assistants, community healthcare workers, chaplains, and EMTS. It will also take more than one training session. A true solution would require challenging stereotypes and changing people's minds, which is a difficult thing to do and actually takes time.

Stephen Nelson, the author of the article "Race, Racism, and Health Disparities: What Can I Do About it?", states in regard to diversity training: "Although they have been to be successful in fostering an appreciation and awareness of difference as well as developing the tools necessary for cross-cultural communication, they have not addressed the core of racism." (Nelson, 2016, 163-164) One thing to note is that Nelson does propose his own workshop module for healthcare workers.

The core components of the workshop module include the following:

> Addresses the definitions of race and racism and the history of the social construction of race, differentiates among diversity, cultural competency, and social justice, explores our current health care system (racial make-up of providers, how insurance became tied to employment, what we're taught and not taught in school, evidence-based medicine, and racial disparities). (Nelson, 2001, 164)

Nelson's proposed course goes one step further:

> [Examining] racism and whiteness in our society, including examples of racism and whiteness in medicine, examines how race affects each of the IOM's six measures of quality care (safe, effective, patient-centered, timely, efficient, and equitable; Committee on Quality of Health Care in America, Introduces critical thinking tools for improving medical providers' comfort and skills in caring for patients of color, introduces a 'critical race lens' and tools for addressing our unconscious biases. (Nelson, 2001, 164)

Notwithstanding the fact that the core problems of systematic racism. The author of the article “Racism in Medicine: Planning For the Future” suggests that a solution to hopefully ending racism in medicine also involves the realization that: “Only [three point six percent] of all practicing physicians in America are African American, representing only a slight increase over the past decade.” (Dennis, 2000, 15) Today, the number of African American doctors is only five point seven percent, and this disparity can be directly related to the still lingering effects of the Flexner Report.

Moreover, Dennis states that current anti-racism efforts must extend further “Beyond medical education to the practice of medicine. Although black physicians have historically cared for the nation’s poorest patients, the current system of health care is not serving African-American physicians or patients well.” (Dennis, 2001, 25)

To achieve this goal, Dennis suggests enforcing “Increased numbers of African-American students in pipeline programs for entry into medical schools; more African-American medical students; postgraduate trainees in all specialties, African medical school faculty as well as more African American practicing physicians.” (Dennis, 2001, 45) A couple more of Dennis’ suggestions also include: “Active opposition to anti-affirmative action ballot initiatives in collaboration with other organizations to highlight their negative impact on the medical education of African Americans and other minorities.” (Dennis, 2001, 45) Education of the next generation of American doctors is pivotal for ending medical racism, but making sure future physicians and healthcare workers are dedicated to being fully anti-racist is also vitally important for the eradication of medical racism.

In terms of medical education, Dennis suggests drastically improving the medical school curriculum:

> All U.S. medical school curricula incorporate a course on the healthcare of racial and ethnic minorities. Every medical school design a course which helps students to identify their own intrinsic racial and ethnic biases and sensitizes them to the negative effects of such biases on health outcomes. [and] provide an understanding of how issues of racial attitudes, study how African Americans have not been helpless victims in the face of oppression but have developed strategies and institutions to care for themselves, provide a forum for students to talk about racism. (Dennis, 2001, 45)

More suggestions for eradicating the health disparities that have been presented in this article. Some of those suggestions come from Nuridddin et al. as they recommend and proclaim that “The killing of Eric Garner in 2014 at the hands of the New York Police Department and the footage that circulated of his death after he was put in a chokehold elevated the phrase ‘I can’t breathe’ to a protest chant for those in the fight against structural racism worldwide.” (Nuriddin et al., 2020, 949) There was a similar uprising in the Summer of 2020 during the COVID-19 Pandemic, as Keisha Ray, Faith E. Fletcher, Daphne O. Martschenko, and Jennifer E. James exclaim in their article, “Black Bioethics in the Age of Black Lives Matter.” In the Summer of 2020, many people awoke to the troubling realities that many African Americans face on a daily basis. Consequently, the:

> #BlackLivesMatter protests that occurred over the past [ten] years were their first introduction to anti-Black racism and racially motivated violence. Similarly, the COVID-19 Pandemic introduced many people to systematic racial inequalities in healthcare due to poor access to vital resources like access to transportation, healthy foods, and clean air.  (Ray et al., 2023, 251)

In a separate essay within the same article, Faith E. Fletcher, Ph.D., M.A., recounts a particularly harrowing healthcare experience from her own childhood.

The story is as follows:

> One of my early encounters with the healthcare system as a pre-adolescent left me feeling ashamed, demoralized, and self-conscious. When the provider (a White male) initiated my physical examination, he fully lifted my medical gown without warning and embarrassed me. Still, making sense of my rapid physical development, I was deeply troubled by that interaction. (Ray, 2023, 256)

Keisha Ray, the author of "Black Bioethics in the Age of Black Lives Matter," further stated in her article that there is a reason for the systems of injustice that are in place at the current moment. The reason is as follows: "One reason for this perpetual cycle of racial injustice is a lack of institutional reckoning with the idea that anti-Black racism continues to be ingrained in all aspects of medicine and public health and that, as this is a systematic problem, the solution itself must also be systemic." (Ray, 2022, S46)

In a list of initiatives within the article, the American Public Health Association declares:

> In 2020, the APHA released the policy statement: "Structural Racism is a Public Health Crisis: Impact on the Black Community. The policy calls on the APHA to fund research that focuses on structural racism in institutions like education, health care, environmental issues, criminal justice, and economics that harm Black People. This policy statement supports current APHA policies that already aim to address structural racism, such as policies that approach law enforcement policies and housing insecurity as public health issues." (Ray, 2022, S43)

Within the same article, the American Medical Association pledged in 2020, "The AMA made the rare move of acknowledging its contributions to anti-Black racism in Medicine have been among the causes of racial inequities in healthcare and of the low numbers of Black Physicians." (Ray, 2023, S47)

The Centers for Disease Control and Prevention further stated that:

> The CDC has therefore made a commitment to address racism's effects on health equity. They have created the web portal 'Racism and Health' to demonstrate their efforts to be a leader in helping people be healthier by ending racism in the systems and policies that created racial disparities in health. (Ray, 2023, S48)

Other efforts to improve the outlook on medical racism come from a new push to improve the concept of health equity. Health Equity can be defined as, according to Trudy Mercadal from the Salem Press Encyclopedia, "Studying the differences in access to and resources of health care among different populations. Health in equity is often used as equivalent to inequality." (Mercadal, 2021, 1) The goal of health equity is to "Improve both equity and equality, including ideas of the common good, and secure fair access to resources." (Mercadal, 2021, 2) In regard to the healthcare field, Ashley Ottwell et al., who wrote *Leveraging Science to Advance Health Equity: Preliminary Considerations for Implementing Health Equity Science at State and Local Health Departments,* states: "Addressing social and structural drivers of health such as structural racism and social determinants of health has the potential to decrease health disparities and inequities, more research is necessary to understand their real-world success or failure." (Ottwell, 2024, 468)

Moreover, in light of the uprisings in 2020 over the police killing of George Floyd, "The CDC declared racism a public health threat and recognized it as a fundamental driver of racial and ethnic inequities in the United States." (Ottwell et al. 2024, 468)  At the same time, the CDC launched another new initiative called "CORE, an agency-wide strategy to embed health equity as a foundational component across all areas of the agency's work to address underlying issues of structural racism, discrimination, stigma, and disenfranchisement that drive health inequities." (Ottwell, 2024, 468)

Health Equity can also be used to measure patient experiences, as noted by Annette J. Browne et al. in their article, "Using a Health Equity Lens to Measure Patient Experiences of Health Care in Diverse Health Care Settings."  In the article, Browne et al. explained a vitally important concept in terms of health inequities: "People who are structurally disadvantaged experience poorer outcomes on many measures of health and report poorer health care experiences. Research also shows that people's healthcare experiences influence their timely access to health care and their overall people's health." (Browne et al., 2024, 1).

Their proposal within the article is to utilize a program called:

> Equity-oriented health care (EOHC). Grounded in a critical theoretical conceptualization of health equity, the notion of EOHC explicitly aims to: (a) address the frequent mismatches between usual approaches to care and the needs of people most impacted by health and social inequalities, (b) mitigate the impacts of multiple. Interesting forms of discrimination, racism, and stigma, and (c) take into account the health effects of social and structural inequities. (Browne, 2024, 3)

This eradicates medical racism because we should be able to fully trust physicians and healthcare workers at our local hospitals during the most vulnerable and challenging times of our lives.

## Conclusion

In conclusion to this chapter, which has presented a plethora of reasons to invest in health equity and end medical racism, I would also like to present one last and essential reason to completely invest in the eradication of medical racism. This reason has not yet been explained or listed in this chapter. However, it is still vitally important since it is a contributing factor to a high death rate among African-American women with a dark history. The person behind this dark history is a gynecologist named James Marion Sims, who used to have a statue in New York City near Central Park.

Sims is widely regarded as one of the fathers of American Gynecology, along with John Archer, a physician from Maryland [who] became the first American granted a medical degree from the College of Philadelphia." (Cooper-Owens, 2021, 29) Another so-called father of modern gynecology, Ephraim McDowell, was:

> A frontier doctor who would become lauded decades later as the 'Father of the Ovariectomy' much better known in the history of medicine. His story exemplifies how challenging life could be for those who were innovators in the field of reproductive medicine. (Cooper-Owens, 2021, 30)

The next and last so-called father of modern gynecology is Peter Mettauer, who: "Performed the country's first successful vesicovaginal fistula operation on a local white woman. Intellectually curious and ambitious, he performed experimental surgery on two additional local women to repair their obstetrical fistulae." (Cooper-Owens, 2021, 33) What ties all three of these men together is the fact that they all experimented without consent on enslaved women for medical discoveries that are still being celebrated today. This matters because we are only now learning the back stories of the enslaved women who were experimented on without their consent, with consequences that reverberate to today. These women and everyone else who suffered from not only medical experiments but also biased care deserve equitable treatment so they can get back to their lives, even if there are personal responsibility consequences at stake.

# CHAPTER FOUR

# HOW DOES HEALTH INSURANCE, OR LACK THEREOF, CONTRIBUTE TO THE UNDERUTILIZATION OF HOSPICE SERVICES AND HEALTH EQUITY?

## Part One: Introduction

This chapter will be broken into three separate sections: the first section will explain the details of health insurance. The second section will focus on how access to health insurance impacts health equity. The third section will describe how health insurance impacts access to hospice care. The fourth and last section will focus on how young people are affected by the lack of access to health insurance, and also how young people feel about health insurance access in general.

*The Salem Press Encyclopedia* defines health insurance as “Insurance against bodily injury, disablement, or death by accident or accidental means, or the expense thereof, or against disablement or expense resulting from sickness, is available in the United States through government and private providers.” (Flynn, 2023, 1) There are two health insurance industries: “The commercial (or private) health insurance industry and the government (or public) health insurance.” (Flynn, 2023, 1) An example of a commercial health insurance plan includes: “Fee-for-service plan, managed fee-for-service plan, health maintenance organizations (HMO), preferred provider organizations (PPO), and point-of-service plans (POS).” (Flynn, S.I., 2023, 1)

In 2008, when President Obama took office, “Forty-six million individuals in the United States did not have health insurance coverage.” (Kirby et al., 2010, 1035) The Affordable Care Act, which was passed in 2010, eased the burden of the uninsured. However, instituting the Affordable Care Act was a burden within itself as the website faced technological hurdles when it was first introduced to the American public. The health policy website KFF proclaims that “[Eight] Percent of the population is uninsured.” (Tolbert et al., 2024, 1) The factors that affect the uninsured rate include: “Economic conditions, federal and state policy changes, and significant health crises, such as the Covid-19 Pandemic.” (Tolbert et al., 2024, 1) Other factors that influence the current uninsured rate include: “Coverage not affordable (64.2%), not eligible for coverage (28.4%), Do not Need or Want (26.1%), signing up was too difficult (22.2%), cannot find a plan that meets needs (18.5%), lost job (4.5%).” (Tolbert et al., 2024, 1)

Health insurance itself may be bureaucratic and hard to understand, but multiple threads relate to it. This chapter will explore these threads.

## Part Two: How Does Health Insurance Affect Health Equity

It is known that access to health insurance affects someone’s ability to see a physician or get urgent medical help when they are experiencing a medical emergency. Choosing between paying a healthcare bill and paying a utility bill is a brutal reality that too many people are facing right now. This reality, coupled with the reality of not having adequate access to health insurance, can lead to dire health consequences for African Americans who need quality hospice care. In their article, “Race/Ethnicity, Insurance, Income and Access to Care: Influence of Health Status,” Tze-Fang Wang et al. note:

> In Healthy People 2020, relevant goals included increasing the proportion of persons with a usual primary care provider, increasing the proportion of persons who have a specific source of ongoing care, reducing the proportion of individuals who are unable to obtain or delay obtaining necessary medical care, dental care, or prescription medicines, etc.
> (Wang et al., 2013, 1)

The goals of the Wang et al. article, which were laid out in the aforementioned quote, have long-term health effects on the uninsured.

Wang et al., notes “People of racial/ethnic minorities and low-income typically also have worse health status than their counterparts. Without adjusting for health status, it is not clear whether observed racial and income-related disparities are stand-alone or a reflection of health disparities.” (Wang et al., 2013, 2) Wang et al.’s study concluded that “Respondents with fair or poor health status were less likely than those with good or better health to have no usual place of care. (33.7% vs. 5.74%) However, income level is not the only indicator of whether or not a person will have access to health insurance and, therefore, health equity.

David Satcher and George Rust, the authors of “Achieving Health Equity in America,” explain that other environmental factors are also important for health equity, such as:

> Poverty and homelessness among teens and young adults can drive unhealthy behaviors such as smoking or violence or risky sexual behaviors. Impoverished neighborhoods can also feed a sense of powerlessness or external locus of control that directly conflicts with efforts to achieve empowered self-management of various diseases. (Satcher et al., 2006, S3-8)

Naomi Zewede from the Department of Health Policy and Management, Fielding School of Public Health, at the University of California and the author of “Racial Wealth Inequality and Access to Care with High-Deductible Health Insurance” states, “Black consumers may be harmed particularly by the trend in the design health care benefits. Under stricter income constraints, Black consumers may be drawn to less generous coverage for upfront cost reduction.” (Zewede, 2024, 180) In the conclusion of her study, Zewede concluded that: “A greater share of Black Consumers with high-deductible health insurance are among those drawn from lower in the income distribution” (Zewede, 2024, 3). Zewede also notes that “Black high-deductible enrollees are no more likely to own a home or derive income from financial assets than Black enrollees in conventional plans. By contrast, more Whites with high deductibles hold these assets than Whites with conventional coverage, and more of both groups do Blacks of either coverage type." (Zewede, 2024, 4)

The Centers for Disease Control publishes an annual report called *Healthy People* that is focused on:

> Attain[ing] high-quality; longer lives free of preventable disease, disability, injury, and premature death; achieve health equity, eliminate disparities, and improve the health of all groups; create social and physical environments that promote good health for all, promote quality of life, healthy development, and healthy behaviors across all life stages (CDC, 2020)

Healthy People 2020 was one of the main sources that were utilized for Tze-Fang Wang et al.'s study, "Race, Ethnicity, Insurance, Income, and Access to Care: The Influence of Health Status." Within the study, Wang et al. examined the connection between race and health care. Wang et al. explain: "Uninsured adults were less likely to get preventive care and physician care, and therefore, more likely to have unmet needs than insured individuals, which ultimately result in fundamental differences in health outcomes and overall life experiences." (Wang et al., 2013, 2) The high cost of prescription drugs and being forced to delay care when facing a serious health crisis are not the only problems that exist when uninsured. Simply getting to a physician's office can also be a challenge, as noted by Marsha Lillie-Blanton and Catherine Hoffman in their article "The Role of Health Insurance Coverage in Reducing Racial/Ethnic Disparities in Health Care."

Blanton et al. proclaim: The most widely promoted initiative by the U.S. Department of Health and Human Services (HHS), 'Take a Loved One to the Doctor Day,' focuses on

> changing consumers' behavior by encouraging people to go to a doctor or other health professional for a health screening. Also underway are a number of public and private sector efforts to improve the cultural competence of providers, increase the racial/ethnic diversity of the health workforce, and collect and monitor data on use of health services by race/ethnicity. (Blanton et al., 2005, 1)

Blanton et al. state that while assisting or taking a loved one to the doctor may seem like a great idea, it's not an effective solution for "People who cycle between being insured and uninsured because of changes in employment, family structure, or health status." (Blanton et al., 2005, 1) Blanton et al. also explained the current uninsured rates in 2005: "Uninsured blacks are less likely than Whites or Hispanics to come from working families…racial/ethnic minority Americans have lower rates of health insurance than whites largely because they are less likely to have employer-sponsored coverage." (Blanton et al., 2005, 2) With regard to income level, Blanton et al. explained: "Uninsured blacks are also poorer than uninsured whites. In 2003, three-fourths of uninsured blacks had incomes below 200 percent of the federal poverty level, compared with 56 percent of uninsured whites." (Blanton et al., 2005, 2)

In their article, Vimbainshe Dihwa, Hannah Shadowen, and Andrew J. Barnes, Ph.D., state that in terms of advancing health equity, the national Medicaid program should do more to fix health equity.

In their article, they claim that:

> As the United States grapples with its racist history and present, policymakers, researchers, and communities are searching for pathways to meaningfully redress and eradicate centuries of structural disparities. Medicaid, as a state-federal partnership focused on low-income families, offers a unique set of policy tools to improve health and social needs equitably. (Dihwa, 2022, 167)

However, Dihwa et al. acknowledge that some significant gains have been made since the national Medicaid program was implemented around the country. Dihwa et al. explain, “After Medicaid expansion, Black and Latino populations experienced larger reductions in uninsurance rates compared to White populations but remained more likely to be uninsured White populations.” (Dihwa et al., 2022, 167) Furthermore, Dihwa et al. add another layer to the extensive amounts of research on health inequality and health equity as they state that the co-morbidities of disability and immigration are important factors of health equity. According to Paul M. Lantz from the University of Michigan and Sara Rosenbaum from George Washington University:

> The ACA, however, also reached beyond health care coverage to address health status disparities related to race/ethnicity, socioeconomic status, geography, and other social factors. Indeed, the ACA refers multiple times to the need to address underserved and “health disparities populations,” defined as identifiable social groups with significant differences in disease incidence/prevalence, morbidity, mortality, or survival compared to the general population. (Lantz, 2020, 832)

Dr. Patrick Dillion, an assistant professor from the University of South Florida, and Dr. Ambar Basu, who is also an assistant professor from Purdue University, have done research into effective ways to eliminate the enrollment disparities for African-Americans states:

> Of particular concern is the care that African American patients receive as they near the end of life, as recent studies indicate that their care is generally more expensive and of lower quality than comparable non-Hispanic White patients. (Dillion et al., 2016, 219)

Steven H. Woolf, who is the director of the Center on Society and Health at Virginia Commonwealth University in Richmond, states very matter-of-factly that “Health care is a necessary but insufficient prerequisite for health equity. Health care is, of course, indispensable: Good health requires access to preventive and therapeutic health care services, from immunizations to treatments for chronic diseases." (Woolf, 2017, 986) Woolf also suggested that actual solutions to improving health equity need to go further than just providing improved access to providers. Woolf suggests that "Meaningful process in addressing health inequities, complementary policies to reduce inequities in education, employment, housing, transportation, and public safety." (Woolf, 2017, 986) Woolf's theory differs from other theories about improving health equity in the sense that Woolf focuses on structural problems in society that are leading to serious health disparities. Woolf concludes, "Health equity is achieved not only by treating illnesses but also by addressing the physical and social environments that shape health behavior and produce disease and by creating opportunity." (Woolf, 2017, 989)

The Affordable Care Act, which was addressed in the introduction of this chapter, made great strides in improving healthcare access for millions of people around the country. As Paul M. Lantz and Sara Rosenbaum exclaim: "There is significant evidence that the ACA has reduced social disparities in key health disparities in key outcomes, including insurance coverage, health care access, and the use of primary care." (Lantz et al., 2020, 831)

However, the ACA greatly upgraded existing healthcare programs that were already working, such as the "ACA's reauthorization of the Children's Health Insurance Program or CHIP (first enacted in 1997) and the Indian Health Care Improvement Act (first enacted in 1976). The ACA also provided major expansions of Medicaid, community health centers, legal protections against health care discrimination, and public health prevention." (Lantz et al., 2020, 832) The Affordable Care Act also made "Gains in coverage [that] were greater for minority groups and people with incomes below 139%

of the federal poverty level, social disparities in health insurance coverage have been significantly reduced.” (Lantz, 2020, 833)

Colleen M. Grogan expands on the theory of the effectiveness of the Affordable Care Act for numerous Americans around the country. First, Grogan notes the actual length of the Affordable Care Act, which is “906 pages long” (Grogan, 2017, 985) Throughout those 906 pages, according to Grogan, “There are thirty-five explicit mentions of ‘health disparities’ in the Act specifying a particular effort to reduce or eliminate health disparities. Title 1 focuses primarily on reforms to the individual and group health insurance markets. There are numerous sections of Title 1 that deal explicitly with prohibiting various forms of discrimination.” (Grogan, 2017, 987)

Grogan further explains that “Title [two] deals primarily with specifications for improving access to the Medicaid Program is now known as Medicaid expansion. However, also included in this title is Section 2951-which details goals to improve maternal, infant and early childhood home visiting programs for at-risk communities.” (Grogan, 2017, 987)

The next section of the Affordable Care Act, or “Title [Three] specifies a set of programs and principles for improving the quality and efficiency of health care where the goal of attempting to achieve health equity is clearly specified.” (Grogan, 2017, 987)

The fourth section of the Affordable Care Act “Also created community transformation grants administered by the CDC, with the expressed purpose of creating healthy communities that would prioritize strategies to reduce ethnic disparities, including social, economic, and geographic determinants of health.” (Grogan, 2017, 987) The fifth section of the Affordable Care Act is “Devoted to improving cultural competency and public health proficiency training to reduce health disparities. The Patient-Centered Outcomes Research Institute (PCORI) was established under Title VI of the ACA." (Grogan, 2017, 988)

The last section of the Affordable Care Act, or section 7, is focused on "Improving access to innovative medical therapies- contains three sections devoted to improving access to affordable medicines for children and underserved communities. And finally, Section 10334 is devoted to issues pertaining to 'Minority Health' under Title X." (Grogan, 2017, 988)

The suggestions that were mentioned in this section are all achievable goals and can go a long way toward implementing full health equity for the most vulnerable and deserving among us.

## Part Three: Health Insurance and Hospice Care

It is no secret that any extended stay in the hospital comes with a rehabilitation process for regaining normalcy.

According to Melissa D. Aldridge et al., "Hospice use was found to save Medicare money across a huge range of hospice enrollment durations primarily owing to lower rates of hospital admission and in-hospital death for hospice users." (Aldridge et al., 2022, 2) Hospice care can greatly benefit anyone who would much prefer to die at home and avoid the isolation, vulnerability, and uncertainty of dying at a hospital. Moreover, dying at home can be beneficial for the hospice patient as they will be surrounded by the people and the things that they love rather than a cold, unfamiliar, and stressful hospital room.

Lengthy hospital stays can be quite expensive. Bradley Chen et al. affirmed this theory in their article "Reducing Costs at the End of Life Through Provider Incentives For Hospice Care: A Retrospective Cohort Study." Chen et al. explained the following: "The costs of medical care have been found to be highest in the last year of one's life and especially in the last 6 months of life" (Chen et al., 2018, 1390). For African Americans who are already facing barriers to health equity or health insurance, the high costs of end-of-life care can be another burden. As previously noted in other chapters of this dissertation, hospice care benefits patients who utilize its services. Just to reiterate, the benefits of hospice care include: "Higher quality pain management, better quality of life, increased survival times, congruence between preferred and actual place of death, and a reduction in medical expenditures." (Noh et al., 2015, 286) Noh et al. also affirmed that there are barriers that impact whether or not African Americans can access hospice care, and that burden includes "Lack of health insurance and limited income." (Noh et al., 2015, 286)

The newly realized theory of health insurance as a hindrance to access to hospice care clashes with earlier theories in this dissertation, which stated that the main hindrance to hospice care for African Americans was a difference in beliefs regarding curative care at the end of life.

Although Noh et al. did acknowledge this very theory in their article,

> Even when African Americans have access to hospice care, however, researchers have found evidence that they may not use it. Previous studies have shown that African Americans' philosophy of nonaggressive treatment discourages them from using hospice care even when they have access to it. (Noh et al., 2015, 286)

The results of Noh et al.'s study explained that: "Some respondents viewed hospice care as provided by God, some believed the decision to choose hospice care allowed for the practice of their spiritual and religious beliefs." (Noh et al., 2015, 293)

Physician referrals to hospice care programs can play a big role in whether or not someone enrolls in a hospice care program. Mark J. Stillman, MD, and Karen L. Syrjala, in their article "Differences in Physician Access Patterns," analyzed the aforementioned theory. Stillman et al. analyzed this theory by "We hypothe[sized] that length would be shorter when referrals were received from oncologists, or from academically placed physicians as compared with community-based physicians. Further, we hypothesized that family caregiver satisfaction would be better with length of stay." (Stillman et al., 1999, 158) The fact that this study was conducted in 1999 has no impact on the fact that this study is still relevant today. The study was carried out at the Fred Hutchinson Cancer Research Center, and Stillman et al. concluded there were "Measurable differences in patterns of referral to hospice, but the differences are less than expected and can be better explained by factors other than physician specialty." (Stillman et al., 1999, 160) There is more than one factor that impacts whether or not a hospice patient stays enrolled at a hospice care center long enough to receive adequate care. Stillman et al. proclaim that one of these factors was the medicare hospice benefit.

The medicare hospice benefit can be defined, according to The Center for Medicare and Medicaid Services, as:

> Includ[ing] these items and services to reduce pain or disease severity and manage terminal illness and related conditions: services from a hospice-employed physician, nurse practitioner, or other physicians chosen by the patient, nursing care, medical equipment, medical supplies, drugs to manage pain and symptoms, hospice aide and homemaker services, physical therapy, occupational therapy, speech-language pathology services, medical social services, dietary counseling, spiritual counseling, individual and family or just family grief and loss counseling before and after the patient's death, short term inpatient pain and control and symptom management and respite care (CMS.Gov).

Another factor that impacted the length of stay for hospice patients was the level of:

> Caregiver satisfaction with the hospice experience was significantly related to LOS [length of stay].To provide greater caregiver satisfaction with hospice care, these data support the importance of providing care for a long enough period of time, which in this study appears to be about 30 days. (Stillman et al., 1999, 161)

The determination of how long one stays in the ICU depends on numerous factors. David A. Gruenberg et al. state in their article, "Factors Influencing Length of Stay in the Intensive Care Unit" that the main factors include: "Institutional factors, medical factors, social factors, psychological factors and nonmedical interventions to reduce length of stay." (Gruenberg et al., 2006, 502-509)

Lastly, Stillman et al. noted that there is a high cost associated with the care of a hospice patient in the following quote: "Estimated costs of admitting a patient to the Medicare hospice benefit currently running as high as $2000. It serves the best interests of a hospice to admit patients earlier than later in the patient's illness so as to increase the chances that the 'upfront' admission costs can be recouped." (Stillman et al., 1999, 162)

Melissa D. Aldrige et al. hypothesized in their article whether or not "Hospice enrollment saves money across all payers including families and does hospice shift costs from Medicare to families?" (Aldridge et al., 2022, 1)

Over a multi-year span of sixteen years from 2002-2018,  Aldridge et al. executed a research study where they examined the following:

> Total health care costs, across all payers, including spending by patients and families. Use of hospice may shift economic burden onto families through higher out-of-pocket spending that may be required to care for patients at home. To the extent that hospice is not meeting patient needs adequately, families may face increased pressure to pay for supplemental care, services, medication, or other healthcare expenditures as has been found outside the hospice setting. (Aldridge, 2022, 2)

At the conclusion of their study, Aldridge et al. inferred that there was a significant discrepancy between the costs between people who enrolled in hospice care and people who did not enroll in hospice care. Aldridge et al. explain, "Private insurance expenditures were lower for those who enrolled in hospice compared with those who did not enroll with hospice for all periods examined. Unlike Medicare and families, private insurance and all other payers combined (Medicare Advantage, Medicaid, private HMOs, Veterans Administration, and other)." (Aldridge, 2022, 6)

Additionally, Aldridge et al. concluded:

> Use of hospice did not shift costs from Medicare to families through higher family out-of-pocket spending. Health Care Costs were lower for patients and families receiving hospice care for each time period examined up to 1 month prior to death compared with health care costs of patients and families who did not receive hospice. (Aldridge et al., 2022, 7)

According to Aldridge et al., "Hospice use was associated with lower total health care costs in the last three days to 3 months of life." (Aldridge, 2022, 7) Aldridge et al.'s final conclusion was that hospice "Improves the quality of end-of-life care and is associated with lower health care costs. Moreover, unlike many other aspects of our health care system, cost reductions to insurers in the present study did not translate into higher costs for patients and families." (Aldridge et al., 2022, 8)

Dr. Patrick Dillion, an assistant professor from the University of South Florida, and Dr. Ambar Basu, who is also an assistant professor from Purdue University, have done research into effective ways to eliminate the enrollment disparities for African-American states:

> Of particular concern is the care that African American patients receive as they near the end of life, as recent studies indicate that their care is generally more expensive and of lower quality than comparable non-Hispanic White patients. As Melhado and Bushy note, 'the health needs of African American older adults are the same as those for any other group at the end of life, yet services provided to older African Americans…are less than optimal. (Dillion et al. 2016 219)

Moreover, Dillion et al. exclaim conclusions about structural barriers that have been echoed and repeated in other research studies within this dissertation, such as: "Insufficient knowledge of hospice care, lack of health insurance/financial concerns, mistrust of the health care system and individual health care providers, mistrust of the health care system and individual health care and individual health care providers." (Dillion and Basu, 2016, 220)

In their research process of interviewing hospice patients and their caregivers, Dillion et al. found worrisome stories about the direct impact of a lack of health insurance on the quality of healthcare. Healthcare, such as the personal example:

> My mom actually had cancer, pancreatic cancer. And she was doing pretty good up until a year, maybe about 10 months before her surgery. She stopped eating and just seemed to have less energy. She had Medicare, but I think she still had that idea that she couldn't afford to go. It was a few weeks before I finally convinced her to go. Then, we found out that she had three masses on her abdomen. So she was lucky she lived long enough for us to consider hospice. She was in her 70s, she had Medicare, but it [going to the doctor] was not something she had been able to do. (Dillion et al., 2016, 223)

Other African-American patient stories included themes of distrust, which is documented in the following quote:

> If you're not seeing a doctor regularly, how can you trust that this person is looking out for your best interest? It's one of those things where you are putting an immense amount of faith in that person. You have to trust that there is nothing better that can be done and that it is your best option. That's a tough pill if you don't know that person well or have questions about them… I think you have a lot of Black folks who wouldn't have a doctor they trusted enough to allow that person to put them in hospice. (Dillion et al., 2016, 223)

Other patients within the study mentioned that health insurance also plays a major role in the following:

> Increasing health insurance rates among African-Americans, reducing out-of-pocket medical costs for those with insurance, and eliminating racial prejudice and discrimination within the health system would facilitate increased access to hospice care and, thus, should be incorporated into efforts to reduce enrollment differences. (Dillion et al., 2016, 230)

In conclusion to this section, if there were actual reform to the health insurance industry, it would actually help with reducing African-American mortality rates and helping people live longer and healthier lives.

Another theory that needs to be considered here is the theory of health literacy, which goes a long way in terms of whether or not someone can fully understand their treatment and care options. Not understanding one's own health or payment can have very dire consequences that could greatly endanger one's own health. Asking multiple questions at the end of an appointment can be stressful when one is trying to absorb a lot of information at once, or there are only a few minutes allotted for a primary care appointment. Yet, not asking seriously important questions could also mean the difference between life and death. The same thing applies to not fully understanding health insurance options. The ability to pay for the necessary health care one would need could also mean the difference between life and death. How can one get the treatment one needs for a chronic disease or injury if one cannot afford the vital treatment one needs?

Some physicians and hospitals/medical care centers also only accept certain insurance payments, which can make finding necessary care more of a challenge. In their article, Edward et al. proclaim that in the context of health insurance, “Improving HIL is essential to supporting consumer health insurance decision-making by increasing their likelihood of being insured. Having health coverage results in timely access to needed health care services.” (Edward et al., 2019, e251)

Edward et al. do acknowledge that there is a caveat in implementing health literacy programs around the country as they state, “Despite growing research in the area of HIL after the implementation of the Affordable Care Act and subsequent changes in health care reform policies, few studies have been able to establish national socio-demographic trends in HIL.” (Edward et al., 2019, e251) Throughout their study, Edward et al. “Conducted a secondary analysis of data from the Health Reform Monitoring Survey (HRMS) cross-sectional, probability-based, nationally representative Internet Survey.” (Edward et al., 2019, e251) The results of their study showed that there were a few themes that surfaced from their study, and those themes include: “Knowledge of personal deductibles and out-of-pocket costs.” (Edward et al., 2019, e252

The participants in the Edward et al. study stated that they:

> Were unsure about their family’s out-of-pocket costs in the past year, and more than one-half of those with insurance coverage were unsure about their health insurance deductibles amounts. For both, those with only public insurance plans had the most uncertainty. People who were uninsured had the least uncertainty about out-of-pocket costs. (Edward et al., 2019, e252)

The young people in the study, “Those with less education, and those who are unemployed had a higher prevalence of having inadequate knowledge of both deductibles and out-of-pocket costs. Risk of inadequate knowledge of deductibles was elevated for females and non-Hispanic Blacks (relative Hispanics).” (Edward et al., 2019, e252)

Edward et al. found more discrepancies within their study, including “Non-US citizens are among the most at-risk groups for low HIL; this group generally has less experience with the unique characteristics of the American health system and has limited options for health insurance coverage when compared to U.S. citizens.” (Edward et al., 2019, e254) This specific discrepancy within the immigrant community with regard to HIL is completely understandable. There is a certain level of fear and trepidation in the immigrant population about being undocumented and facing larger consequences. Women and non-Hispanic Blacks also face an inappropriate level of discrimination when seeking healthcare, so this could be an explanation for their low amount of HIL. Nonetheless, one can conclude that understanding health insurance and health literacy is especially important.

Health Insurance also has a clear impact on one’s health status, as Abigail R. Barker and Linda Li from the Brown School, Washington University in St. Louis, Missouri, explain in their article: “The Cumulative Impact of Health Insurance on Health Status,”

The opening sentence of their article states:

> While it is a compelling narrative that health insurance, by ensuring uninterrupted access to health care and in particular early access to preventive care, is likely to have a positive impact on health, much of the available evidence is unable to directly answer this question. (Barker et al., 2020)

The individual costs associated with end-of-life care can be quite costly, as noted by Kimberly Johnson et al. in their article, “Are Hospice Admission Practices Associated with Hospice Enrollment for Older African-Americans and Whites?” As stated by

Johnson et al., “Between 2000 and 2011, the proportion of Medicare beneficiaries who enrolled in hospice nearly doubled from [Twenty-Three Percent]to [Forty-Five Percent]. However, despite this growth, African Americans continue to use hospice at lower rates than Whites.” (Johnson et al., 2016, 697) The theory of disparities between African-American and White hospice patients is well known and also well documented within this dissertation. However, what has not been well documented regarding the hospice disparities is the regional or geographic differences that contribute to the disparities. Johnson et al. explained the geographic disparity in the following quote: “For example, in 2002, the proportion of African-American Medicare beneficiaries who used hospice ranged from 10% in New York to [Forty-Nine Percent] in Arizona.” (Johnson et al., 2016, 698)

Furthermore, Johnson et al. further noted that: “A larger proportion of generalist physicians (vs specialists) also was associated with a greater proportion of African-Americans served by a hospice in the HSA. These findings have implications for efforts to increase hospice use among diverse groups of older adults.” (Johnson et al., 2016, 702) This finding from Johnson et al. firmly proves earlier theories and findings within this dissertation in the sense that African Americans would rather have curative care at the end of their lives rather than hospice care, which would also be greatly beneficial for their illnesses at the end of life.

Access to physicians at the end of life was not the only factor that needed to be considered when thinking about African Americans and disparities in hospice care. Shi-Yi Wang et al. stated in their article: “Continuous Home Care Reduces Hospice Enrollment and Hospitalization After Hospice Enrollment” that “Previous literature has indicated that about [Forty-Five Percent] of hospice programs provide CHC services, and CHC constitutes approximately [One Percent] of hospice enrollee days, with African-American or unmarried descendants being less likely to use CHC than white or married descendants.” (Wang et al., 2016, 814)

Health insurance is quite important for minorities who face the steepest barriers in not just attaining health insurance, but also barriers to health insurance in general.

## Part Three: Insurance Status, Health Equity, and Cancer

The severe effects of being uninsured also extend to cancer care, especially if there are wide-ranging disparities. Micheal T. Halpern, MD, PhD from the University of Arizona Mel and Enid Zuckerman College of Public Health and Otis W. Brawley from the American Cancer Society and Emory University proclaim in their article, “Insurance Status, Health Equity, and the Cancer Care Continuum that “Patient sociodemographic and cultural characteristics are often associated with barriers to receipt of high-quality and timely care.” (Halpern et al., 2016, 2) Moreover, Halpern et al. note that “Uninsured patients are more likely to present with advanced disease, are less likely to receive definitive treatment, and are more likely to die of their disease.” (Halpern et al., 2016, 2)

The disparities in care related to insurance status also relate to the type of insurance status someone has as well, as noted by Halpern et al. in the following quote: “Rong et al., noted that individuals with Medicaid insurance were less likely to receive surgical treatment, while both Medicaid insurance, while both Medicaid insurance and uninsured status were associated with lower likelihood of receiving adjuvant radiotherapy.” (Halpern et al., 2016, 4)

The disparities in cancer care also greatly affect when cancer is diagnosed and at what stage, as is explained in the following quote: “Being uninsured or having Medicaid coverage, compared with those having other forms of insurance, is associated with disparities throughout the cancer care continuum, including stage at diagnosis, treatment plans, and survival.” (Halpern et al., 2016, 5) Halpern further notes that “In states that have expanded Medicaid, those with incomes up to 138% of the federal poverty level can enroll in Medicaid and get better access to a number of preventive and primary care services when needed.” (Halpern et al. 2016, 6)

## Part Four: Young People and Health Insurance

In her article, Kim Nichols Dauner and Jack Thompson, from the University of Minnesota Duluth, state that when it comes to health insurance, “Young adults between the ages of 18-34 are most likely to lack health insurance in the United States.” (Dauner, 2014, 1)

The rationale for younger people being so uninsured is that “Young people tend[ing] to have lower wages even in full-time jobs and face hurdles imposed by employers (e.g., having to work for a certain period of time before becoming eligible.” (Dauner et al., 2014, 1) Lastly, Dauner et al., proclaim that more barriers exist for young people obtaining health insurance: “In addition to eligibility, other barriers to using government-sponsored include a lack of knowledge about eligibility, how, and where to apply; concerns about welfare eligibility; and barriers to related income documentation and the application process.” (Dauner et al., 2014, 2)

As part of her research, Dauner et al. collaborated with a healthcare organization in Minnesota regarding young uninsured people. However, one pervasive theme emerged from the Dauner et al. study conducted with her students, and that theme was health literacy. It is understandable that not having an understanding of the US healthcare system and healthcare bureaucracy can be quite confusing and almost bewildering.

The constant bafflement at trying to understand the United States' healthcare system can lead to an aversion to the healthcare system and the necessary preventive check-ups and scans that prevent early deaths. However, the participants in Dauner et al.'s study have a different view. One study participant shared their opinions in the following quote: “I really don't feel like I need it. I don't take any prescriptions, I don't go to the hospital, and do doctor appointments or check-ups or anything like that. I feel fine, and if an illness does come down, I'll just go through the motions and let it pass.” (Dauner et al., 2014, 8)

Another study participant explained their confusion regarding health insurance and the United States healthcare system itself; “See, I'm not quite sure how it works, see if they do a dollar a day or something, or is it like every time you go on or …?.” (Dauner et al., 2014, 8) Alternatively, one study participant stated a differing opinion of knowing that health insurance is important but not knowing where to go to find it: “Everybody needs insurance-I guess could go to the government building or wherever they're giving it out at I don't know. I guess I don't need it at the time so when I need it then I can just go figure out where I can get it from.” (Dauner et al., 2014, 8)

Another participant in Dauner et al.'s study described a traumatic experience of not having the right experience in the past and being worried about the future: “At first when I had health insurance it didn't mean much but then now that I don't have it and I have asthma and I have to pay for my asthma stuff-and it's like [Two Hundred Twenty Dollars]- and then I realized how important it is." (Dauner et al., 2014, 9)

Even if obtaining insurance through an employer seems like a good idea, it's still not enough for some participants, as is explained in the following quote:

> If you buy your own health insurance they'll reimburse you up to $150 a month for it. So you're still paying this huge sum out of pocket- I mean they'll reimburse you for it, but you got to start somewhere, it's like I don't have even $150 to even start. (Dauner et al., 2014, 9)

Dauner ascertains the participant's ambivalence towards their workplace-sponsored healthcare to feelings of scarcity in their healthcare plan. Dauner et al. explain these feelings: "Some participants felt that health insurance offered by their employers was inadequate due to certain treatments and procedures not being covered or high-cost sharing." (Dauner et al., 2014, 9)

The beliefs of the young people in this study are understandable but worrying in the sense that these young people do not know when they will have a medical emergency. Hopefully, their parents have health insurance or enough funds to cover the high costs of a sudden medical emergency. However, the suddenness of a medical emergency just shows the importance of attaining an adequate health insurance policy. As demonstrated within this chapter of this dissertation, there are numerous barriers and misunderstandings to actively obtaining a decent health insurance policy. Providing more information for people would be a good place to start to make sure young people not only sign up but also understand everything when they get health insurance, as one participant explained within Dauner's study: "I do wish there were more health insurance options for people in their mid to late 20s. A lot of us are starting out and with the economy these days it's really difficult to find jobs right out of college." (Dauner et al., 2014, 11)

In conclusion, everyone needs health insurance, including young people who sometimes engage in risky behaviors that can lead to the very health crises that require sufficient health insurance plans. Along with age, it may depend on the line of work/employer.

## Conclusion

There is no other consequence to inadequate health insurance than going completely bankrupt, and going bankrupt due to a sudden medical emergency, which too many Americans contend with in this country. It does not have to be this way; people should be able to afford groceries, gasoline, healthcare, and their monthly bills. If the Affordable Care Act did not adequately cover everyone, then Medicare for All is something to consider in addition to the Affordable Care Act. While some people do not fully understand the necessity of Medicare for All, they would understand the difference between life and death. Everyone also understands surviving the worst or scariest night/ medical emergency of your life and going home and not having to spend weeks, months, or years being constantly reminded of the worst night of their lives, and just appreciating being alive.

# CONCLUSION CHAPTER

## Part One-Introduction

Over the past four chapters, I have explained the breadth and depth of systematic healthcare inequalities and how they relate to hospice care. I have also presented a brief history of death care within the United States in the literature review. The topics covered in the fourth chapter of my dissertation include the complexities of health insurance and how they relate to health inequality, low hospice enrollment rates, low health insurance enrollment rates among young people, and the effects of cancer on insured/uninsured rates. This dissertation also explained the history and development of African-American cemeteries and memorials, and the important differences between hospice and palliative care. Suicide in America and African American attitudes towards suicide were also briefly discussed within the literature review, as well as the evolution of African-American funeral homes and notable African-American funeral homes in Virginia. The previously mentioned chapters were included in this dissertation to answer the original question of why there is a discrepancy between African Americans and Caucasians when it comes to hospice enrollment rates. Answering this question has proved to be difficult because multiple factors influence the answer to this question, as discussed numerous times in this dissertation. The horrendous Henrietta Lacks and Tuskegee experiments and their implications for racism and mistrust in healthcare were also covered. The impact of religion on the decision to enroll in hospice care and pursue more curative care at the end of life, and the differences between the beliefs of African-American patients and physicians were also discussed in the third chapter, although one could agree that more research is needed in this area. Sickle cell disease and racism were also briefly discussed in the third chapter. Sickle cell disease can be defined as a blood disorder that primarily affects African Americans and has received negative attention. The necessity of pain meds intertwined with racism can make finding necessary medications quite challenging. More research is being done into the treatment of this disease, which involves CRISPR and other promising therapies.

Further into chapter three, the implications of racism and heart disease are discussed. Just like with numerous other topics in this dissertation, more research is needed into the high amount of discrimination African Americans face during the treatment of their disease. The intersectionality of medical racism and medical education was briefly discussed near the conclusion of the third chapter. There are broader implications here, and hope for change within the realms of medical education. Since the backbone of the U.S. healthcare system starts in medical schools, it only makes sense that serious anti-racism discussions take place before medical students become medical professionals. Suggestions and advice for the future of anti-racist healthcare are concluded in the third chapter.

The data collection method was more unconventional in terms of typical research methods for dissertations, instead of utilizing interviews, ethnographies, case studies, numerical data collection, narrative inquiry, phenomenological analysis, and surveys. The rationale for utilizing a more creative research method was due to the approval issues with the Drew University Institutional Review Board. The specific issue with the Institutional Review Board was that too many questions were required for approval. Nonetheless, I decided to embrace a more creative approach to my dissertation. The creative approach involved secondary sources and primary sources. These sources were researched not only at the Drew University Library but also at Amazon and Google Scholar. As no traditional quantitative or qualitative research was conducted, this conclusion chapter will look different from other conclusion chapters in other dissertations.

Nevertheless, it will still present the necessary conclusions and recommendations for this dissertation. First, the sources and research presented in this dissertation accurately reflect the original research question and inquiry. However, more research is needed to determine the research gaps.

The recommendations for future research include expanding the original question to include expanding Medicaid, African-American cemeteries and memorials, heat waves and the impact on African-Americans, and health inequality, more research into solutions for health inequality, and the evolution of African-American funeral homes. More research is needed into these areas because the aforementioned issues are all problems that are directly related to African Americans and health inequality, yet these issues are under-researched. Moreover, housing inequality and financial instability/inequality can impact not only someone's health and livelihood but also their ability to afford the care, especially the hospice care they need. When it comes to health inequality, it's never just one issue.

Health Literacy is another avenue that needs to be further researched in terms of health inequality and hospice care. Health Literacy was touched upon within the health insurance chapter, but health literacy is an underrated issue. Fully understanding what is going on with one's healthcare and one's end-of-life would go a long way in ensuring that more African Americans sign up for hospice care and feel empowered and in control of their healthcare.

Could the solution to this problem lie in expanding the social networks that vulnerable African Americans have at the end of their lives? One could assume that nobody wants to die alone. Despite this fact, one needs to assume that there are numerous African Americans who may not have social networks they can depend on during such vulnerable times in their lives. It has already been mentioned that there is a strong aversion to ending curative care during treatment for terminal illnesses and a strong inclination towards family care at the end of one's life. However, this theory may be an anomaly. Surging rates of medical racism and racism, in general, can lead to disastrous consequences that were examined within the chapters of this dissertation.

Also, racism, in general, can lead to mental health issues, specifically anxiety and depression. Higher rates of anxiety and depression can lead to avoiding certain places or avoiding preventive care, and also hospice care, which will only lead to more racism. One could postulate that providing essential hospice services with the added benefit of music and art therapy would be enough to help a terminal African-American patient with the dying process. However, if a terminal patient does not have the occasional or persistent support of their family members, spouses, or friends, no other comfort measures will matter. Nobody knows what it's like to die. Many movies and books have tried to answer this question, such as the 2023 film *After Death,* which chronicles the lived experiences of people who faced near-death experiences and lived to share their experiences. Likewise, numerous books  have attempted to explain the near-death experience, including *After* by Bruce Greyson, M.D., *In My Time of Dying* by Sebastian Junger, *Proof of Heaven: A Neurosurgeon's Journey into the Afterlife* by Eben Alexander, *Nothing to Fear* by Julie McFadden, RN, *Journey of Souls: Case Studies of Life Between Lives* by Michael Newton, Ph.D., *Evidence of the Afterlife* by Jeffrey Long, Ph.D. Between all the theories and patient stories, one can have bits and pieces of theories about what it's like to die, but no one who is alive will know what it is actually like to die and what life is like in the great unknown of death and the afterlife. Film after film has stated that one supposedly lifts up above one's body and floats above one's own body. Astral projection can be defined as "hallucinatory visual experiences that involve seeing the physical body placed in an external visual space." (Mugdal, 2021, 1)

## Part Two: More Recommendations

As a final conclusion, more in-depth research needs to be conducted into the hospice care discrepancies between African Americans and Caucasians in terms of end-of-life care.

Other socioeconomic factors and other social determinants of health, such as extreme heat, mental health concerns, women's health, drugs/drug addiction, housing inequality, financial inequality, and homelessness, also affect whether or not someone, specifically African Americans, can access adequate hospice care that they need. With these considerations in mind, one can only imagine the countless implications for the United States' healthcare system. More specifically, anyone interested in hospice care, healthcare inequality, African-American history, African-American funerals/cemetery and memorial history, medical racism, chronic diseases, medical education, medical experimentation, CRISPR, palliative care, health insurance, religion, and health care will be greatly interested in pursuing this dissertation from start to finish.

An advance directive is another important conclusion and recommendation to take away from this dissertation.

These documents can be quite beneficial for anyone with chronic diseases that require extended hospitalization. Advance directives are also great for anyone who wants to be prepared for the uncertainties of a medical emergency. There are notable benefits intertwined with advanced care planning and hospice care. Before advance directives were widely utilized and accepted by the medical world, the healthcare power of attorney form was more widely utilized. The purpose of this form is to assign someone as a medical guardian in case someone is not able to either voice or share their medical wishes. In the 21st century, advance directives are more widely used and accepted not only by the medical world but also by every single U.S. state. ADs (Advance Directives) also face steep barriers in enforcement from African-American communities due to African Americans not having a full understanding or not being fully trustworthy of the process of drafting an advance directive.

The power of an advanced directive for an African American who is dying is having their voice and their end-of-life wishes heard. Already knowing the end-of-life wishes of a terminal patient goes a long way toward avoiding the ethical issues that arise when healthcare workers do not know someone’s end-of-life wishes. If healthcare workers do not know someone’s wishes at the end of life, they will have to resort to consulting family members. If the family members do not know what a terminal patient wants at the end of life, their case will be reported to the best wishes of the ethics committee. This is not a good way to ensure that someone can have a death with dignity. Leaving medical decisions in the hands of an ethics committee can also lead to serious ethical issues that can spill out to the legal and political, sometimes with disastrous consequences. Terri Schiavo's family dealt with these ethical issues and dilemmas after their daughter fell into a coma.

Even so, the Schiavos decided to keep Terri alive on a machine in a case that eventually ended up at the Florida Supreme Court. The case of Nancy Cruzan is a bit different but still directly relevant to the necessity of advance directives. Cruzan's case eventually ended up at the Supreme Court in 1990. Nancy Cruzan's feeding tube was eventually removed in December 1990.

The two previously presented medical ethics cases present why an advance directive is so important because if there is no advance directive, the final decisions in medical cases get murky, confusing, and arduous to figure out. These complexities are so important for African Americans because, as a minority group of people who already face the barriers presented in this dissertation. The NIH (National Institute of Health) proclaims that there is a discrepancy between African Americans and Caucasians in terms of advance directives. Hopefully, research into advance directives will help African Americans achieve the right to die with dignity that they deserve.

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