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## A History of Pain: Ensuring the Utilization of Palliative and Hospice Care for African-Americans

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**A HISTORY OF PAIN: ENSURING THE  
UTILIZATION OF PALLIATIVE AND HOSPICE  
CARE FOR AFRICAN-AMERICANS**

Melissa G Walker

M. Walker

# TABLE OF CONTENT

<b>INTRODUCTION.....</b>	<b>1</b>
<b>OVERVIEW: THE BUILDING BLOCKS OF PALLIATIVE AND HOSPICE CARE.....</b>	<b>4</b>
A.    Historical Setting .....	4
1. <i>The pitfalls of pain management: Opiophobia</i> .....	6
B.    Where the law stands on palliative care.....	7
1. <i>The usages of Tort Law for inadequate pain management</i> .....	7
2. <i>Palliative and Hospice care in the state of New Jersey</i> .....	9
<b>THE DISPARATE TREATMENT OF AFRICAN-AMERICAN IN THE MEDICAL FIELD AND UNDERUTILIZATION OF HOSPICE AND PALLIATIVE CARE... 9</b>	<b>9</b>
A.    The Historic distrust of Medical Providers .....	11
B.    Cultural and false physiological differences affect the level of palliative and Hospice care for African-Americans .....	14
1. <i>Spirituality and religion</i> .....	14
2. <i>Misdiagnosis</i> .....	15
C.    Outside socioeconomic pressures reduce African-American’s access to Palliative and Hospice care due to barriers to access and knowledge .....	16
1. <i>Lack of Access to palliative and Hospice Care</i> .....	17
2. <i>Lack of knowledge</i> .....	18
<b>CURRENT PALLIATIVE AND HOSPICE PROCEDURE IN THE STATE OF NEW JERSEY .....</b>	<b>18</b>
A.    Hospice care in New Jersey .....	19
B.    Palliative care.....	21
C.    New Jersey Palliative and Hospice Care Act.....	22
<b>INCREASING THE UTILIZATION OF PALLIATIVE AND HOSPICE CARE FOR AFRICAN-AMERICANS IN NEW JERSEY .....</b>	<b>22</b>
A.    Developing trust in the Medical system for African-Americans .....	23
B.    Using Cultural Competency to combat concerns of religion, spirituality, misdiagnosis, and lack of knowledge .....	24
1. <i>Religion and Spirituality</i> .....	26
2. <i>Misdiagnosis: Combating racial stereotypes in medicine</i> .....	27
3. <i>Lack of Knowledge</i> .....	27
C.    Assessing the lack of access .....	28
<b>CONCLUSION .....</b>	<b>29</b>

## INTRODUCTION

Studies have shown that African–Americans<sup>1</sup> are less likely to receive proper hospice or palliative care in the United States when compared with White<sup>2</sup> counterparts. Hospice and palliative care are important steps to dying with dignity. Both types of care improve a patient’s quality of life by lessening suffering and providing psychological assistance. Palliative care is the process of improving the quality of life of patients who have a serious or life-threatening disease through the prevention and relief of suffering. “The goal of palliative care is to prevent or treat, as early as possible, the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment.”<sup>3</sup> Palliative care can start at any time for anyone living with a serious illness, it is not limited to a terminal diagnosis. Hospice care

[is a] program that gives special care to people who are near the end of life and have stopped treatment to cure or control their disease... The main goal of hospice care is to control pain and other symptoms of illness so patients can be as comfortable and alert as possible. It is usually given at home, but may also be given in a hospice center, hospital, or nursing home.<sup>4</sup>

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<sup>1</sup> For the Duration of this article, African-Americans are defined as person who identify as African-American and are classified in the skin group-based classification used for specific people with a mid to dark pigmentation. This differs from term “Black” which is strictly classified by the skin group-based classification.

<sup>2</sup> White, for the purpose of this article, is based on the skin group-based classification of light to medium skin tone of, typically, European decent.

<sup>3</sup> Palliative care is defined as. *NCI Dictionary of Cancer Terms*, NAT. CANCER INST., (last visited Oct. 18, 2019), <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/palliative-care>.

<sup>4</sup> *NCI Dictionary of Cancer Terms*, NAT. CANCER INST., (last visited Oct. 18, 2019), <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/hospice>.

Hospice care is limited to patients with a terminal diagnosis, by a physician, with the life expectancy of six months or less.

Hospice care and palliative care are under-utilized in the United States and in the State of New Jersey. In 2019, 25.3% of Medicare decedents aged 65 and over died in a hospital, rather than in a setting where they could receive hospice care. New Jersey ranks 47<sup>th</sup> in the country for hospital deaths. By comparison, the top ten states reported hospital deaths of Medicare decedents under 18%. New Jersey's shortage of palliative and hospice services is one reason for its high hospital death rate.<sup>5</sup>

While the shortages of palliative and hospice services affect everyone, the African-American communities in the United States are less likely to be offered or utilize palliative and hospice care than white counterparts. In 2009, 33% of African-American decedents used hospice services prior to death, versus 44% of white decedents.<sup>6</sup> In 2013, only 8.5% of hospice patients identified as African-Americans.<sup>7</sup> This phenomenon can be attributed both to the behavior of providers, and the fears and preferences of African-American patients. This behavior, fear, and preference come from a multitude of sources, including African-American's distrust of health care providers, the lack of compassion and unbiased care from health care providers, misdiagnosis of African-American Patients, the lack of access to care, and inadequate usages of cultural competency in health care settings.

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<sup>5</sup> N.J. GOVERNOR'S ADVISORY COUNCIL ON END-OF-CARE, REPORT & RECOMMENDATIONS, [https://www.state.nj.us/health/advancedirective/documents/NJAdvisoryCouncil\\_EOL\\_FinalReport.pdf](https://www.state.nj.us/health/advancedirective/documents/NJAdvisoryCouncil_EOL_FinalReport.pdf).

<sup>6</sup> Cheryl Arenella, *Hospice and Palliative Care for African Americans: Overcoming Disparities*, 19 J. PALLIATIVE MED 126, 126 (2016).

<sup>7</sup> Ramona L. Rhodes, Kim Batchelor & Ethan A. Halm, *Barriers to End-of-Life Care for African Americans From the Providers' Perspective: Opportunity for Intervention Development*, AM. J HOSPICE & PALLIATIVE CARE, 137, 137 (2015).

African-Americans express greater levels of mistrust towards health care providers and establishments than Whites due to the historic abuse African-Americans suffered from physicians, the existence of widespread racism in the medical field, and a person's belief of discrimination when seeking medical help.<sup>8</sup> One study found that 27% of African-Americans age 54 +, suffering from a chronic illness experienced discrimination in the health care system.<sup>9</sup> The racial discrimination in the health care system stems from health care providers harboring their own racial bias through falsely held beliefs about the differences between Whites and African-Americans.<sup>10</sup> Those beliefs, which include addiction stereotypes, prevent health care providers from providing African-American's with unbiased and compassionate care. The historical treatment of slaves that fostered incorrect medical treatment for African-Americans which leads to misdiagnosis<sup>11</sup>. In addition to racial stereotypes and biases in the medical field, African-Americans are more likely to physically lack access to care, due to lack of health care infrastructure, poverty, and transportation.<sup>12</sup> Finally, cultural competency can be utilized to lessen the challenges stated above. "Cultural competency in health care describes the ability of systems to provide care to patients with diverse values, beliefs, and behaviors, including tailoring delivery to meet patients' social, cultural, and linguistic needs."<sup>13</sup> The main challenge of

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<sup>8</sup> BRIAN D SMEDLEY ET AL., UNEQUAL TREATMENT : CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE 135-136 (National Academy Press) (2003).

<sup>9</sup> Thu T Nguyen et al., *Trends for Reported Discrimination in Health Care in a National Sample of Older Adults with Chronic Conditions*. 33 J. GEN. INTERNAL MED. 291, 291 (2018).

<sup>10</sup> See Kelly M. Hoffman et al., *Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs about Biological Differences Between Blacks and Whites*, PROC. OF THE NAT'L ACAD. OF SCI., 4296 (2016).

<sup>11</sup> See generally HARRIET A. WASHINGTON, MEDICAL APARTHEID: THE DARK HISTORY OF MEDICAL EXPERIMENTATION ON BLACK AMERICANS FROM COLONIAL TIMES TO THE PRESENT (New York: Doubleday) (2006).

<sup>12</sup> See Allan S. Noonan, Hector Eduardo Velasco-Mondragon & Fernando A. Wagner, *Improving the health of African Americans in the USA: an overdue opportunity for social justice*, 37 PUB. HEALTH REV. 12 (2016).

<sup>13</sup> JOSEPH R. BETANCOURT, ALEXANDER R. GREEN & EMILIO CARRILLO, CULTURAL COMPETENCE IN HEALTH CARE: EMERGING FRAMEWORKS AND PRACTICAL APPROACHES, (The Commonwealth Fund 2002).

expanding hospice palliative care is how to increase cultural competency of healthcare establishments, while providing minorities with dignified end-life care.

This article will explore the concerns of African-Americans pertaining to palliative and hospice care, and explore solution for current issues. First, the articles will explore the historical setting and purpose of palliative care and hospice care, then leading into the disparate treatment suffered by African-Americans. The under-utilization of palliative and hospice care will be examined under African-American's distrust of medical professionals, spiritual concerns, lack of access and knowledge of care, and the misdiagnosis of African-American illnesses. Finally, the article will discuss the current palliative and hospice care procedures and how to apply the previous finding to increase the usages of palliative and hospice care in African-American communities.

## **OVERVIEW: THE BUILDING BLOCKS OF PALLIATIVE AND HOSPICE CARE**

### ***A. Historical Setting***

Hospice care and palliative care evolved throughout the centuries, first providing help to ill travelers<sup>14</sup> and then becoming a medical specialty meant to ease the pain and suffering of the ill and terminally ill. While the care of terminally ill patients has roots in religious organizations, it slowly progressed into the modern hospice movement, cumulating in the 1960s with the help of Dame Cicely Saunders. She discovered that patients with terminal diagnoses needed a distinctive approach to care; they needed specific mental, physical and emotional needs for

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<sup>14</sup> The word hospice originates from the Latin word *Hospes*, a term referring to either a traveling guest or a traveler's host. Stephen Lutz, *The History of Hospice and Palliative Care*, 35 *CURRENT PROBS. IN CANCER* 304, 304 (2011).

care.<sup>15</sup> In 1974, the first bill proposing Medicare coverage for hospice was introduced to but ultimately rejected by Congress.<sup>16</sup> Eight years later, following a pilot hospice program, Congress created the Medicare Hospice Benefit which provides persons with Medicare Parts A and B payment for hospice care. The benefit was a part of the Tax Equity and Fiscal Responsibility Act of 1982, and it provided the first requirements to receive hospice care, which is that the patient must be certified as terminally ill with a life expectancy of 6 months or less to receive the benefit.<sup>17</sup> While hospice care and, on a different level, palliative care, are currently supported by Congress and the medical literature, a blind spot exists when it comes to administering that care.

Evidence of physicians and nurses not treating pain adequately has appeared in medical literature since before the creation of the Medicare Hospice Benefit, and continues to be written about today.<sup>18</sup> Socially and morally, adequate pain treatment should be available to those who need it because inadequate pain management can lead to a low quality of life.<sup>19</sup> Inadequate pain management, for patients with chronic pain or suffering a terminal illness, can cause immune impairment, increases the chance of depression and anxiety, interferes with sleep and concentration, and harms work life.<sup>20</sup> Socially, families have used tort law to rectify the suffering

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<sup>15</sup> Nicole Fisher, *The History of Hospice: A Different Kind Of Health 'Care'*, FORBES (Jun. 22, 2018), <https://www.forbes.com/sites/nicolefisher/2018/06/22/the-history-of-hospice-a-different-kind-of-health-care/#790ef29660ce>.

<sup>16</sup> Lutz, *supra* note 6, at 305.

<sup>17</sup> Tax Equity and Fiscal Responsibility Act of 1982, Pub .L. No. 97-248, § 122, (1982).

<sup>18</sup> See R.M. Marks & E.J. Sachar, *Undertreatment of Medical Inpatients with Narcotic Analgesics*, ANN. INTERN. MED. (1973).

<sup>19</sup> See Frank Brennan, Daniel B. Carr & Michael Cousins, Pain Management: A Fundamental Human Right, 105 ANESTHESIA & ANALGESIA 205, 206 (2007). See generally Diederik Lohman, Rebecca Schleifer & Joseph J Amon, *Access to Pain Treatment as a Human Right*, BMC MED. 8 (2010).

<sup>20</sup> Frank Brennan, Daniel B. Carr & Michael Cousins, Pain Management: A Fundamental Human Right, 105 ANESTHESIA & ANALGESIA 205, 206 (2007).

of their loved ones, and it seems that juries understand the moral need of a dignified painless death.<sup>21</sup>

In the federal sphere, The Supreme Court has danced around the idea of whether there is a constitutional right for pain relief.<sup>22</sup> The Supreme Court referenced palliative care in two<sup>23</sup> cases regarding assisted-suicide, however, “there [was] no need to address the question whether suffering patients have a constitutionally cognizable interest in obtaining relief from the suffering that they may experience in the last days of their lives,”<sup>24</sup>

### 1. *The pitfalls of pain management: Opiophobia*<sup>25</sup>

While the need for palliative and hospice care is understandable in a social and moral sense, the major reason for inadequate pain relief in the U.S. is the fear of addiction. Not necessarily the fear of the patient becoming addicted to the substance, but the substances themselves. Opioid analgesics are very useful in managing moderate to severe pain, however, it is also a Schedule II<sup>26</sup> controlled substance. In tandem with the known addictive properties of opioids, the U.S. is experiencing an opioid epidemic that has claimed many lives, and continues

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<sup>21</sup> See Ben Rich, *Physicians' Legal Duty to Relieve Suffering*, 175(3) WEST J. OF MED., 151 (2001).

<sup>22</sup> *Vacco v. Quill*, 521 U.S. 793, 117 S. Ct. 2293, 2303 (1997). Stating “there is no need to address the question whether suffering patients have a constitutionally cognizable interest in obtaining relief from the suffering that they may experience in the last days of their lives.”

<sup>23</sup> See *Wash. v. Glucksberg*, 521 U.S. 702, 737; *Vacco v. Quill*, 521 U.S. 793, 809. (Both cases focused on statutes banning suicide *Wash.* was action against state of Washington for declaratory judgment that statute banning assisted suicide violated due process clause. *Vacco* had New York statutes making it crime to aid person in committing suicide or attempting to commit suicide. In both, the majority failed recognize pain management as a fundamental right. The Concurrences expressed the importance of palliative, ending with Justice Breyer stating “were state law to prevent the provision of palliative care, including the administration of drugs as needed to avoid pain at the end of life--then the law's impact upon serious and otherwise unavoidable physical pain (accompanying death) would be more directly at issue. And as Justice O'Connor suggests, the Court might have to revisit its conclusions in these case,” *Wash.*, 521 U.S. at 792.

<sup>24</sup> *Vacco*, 521 U.S. 809, (O'Connor, J., concurring).

<sup>25</sup> The fear of opioids.

<sup>26</sup> Schedule II drugs, substances, or chemicals are defined as drugs with a high potential for abuse, with use potentially leading to severe psychological or physical dependence.

to.<sup>27</sup> In recent years, pain management guidelines for opioids “highlight the importance of carefully screening patients to identify those who are at high risk of opioid use disorder.”<sup>28</sup> This places the onus on the medical providers to look-out for patients they assume will have addictive behaviors. Physicians prescribing opioids risk disciplinary actions by state medical board if they failed to keep proper record of pertinent medical history and complete pertinent physical examinations.<sup>29</sup> In *Armstrong v. La. State Bd. Of Med. Examiners*, a physician was given a two-year suspension for violating a controlled substance regulation, referenced to as the “pain rules”. The court found in conditions where controlled substances are used as pain relief and “when such practice is unaccompanied by appropriate testing, diagnosis, oversight and monitoring... the physician falls below generally accepted standards of care, constituting the practice of bad medicine.”<sup>30</sup> While there is a need to address opiophilia, opiophobia tends to harm patients suffering from chronic and terminal illnesses. Physicians can be either too afraid to prescribe the appropriate amount of pain medication for a patient or the physician may lose their practice.<sup>31</sup>

## ***B. Where the law stands on palliative care.***

### *1. The usages of Tort Law for inadequate pain management*

“The primary purpose of tort law is to compensate plaintiffs for the injuries they have suffered wrongfully at the hands of others”<sup>32</sup> through compensatory and punitive damages. Tort

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<sup>27</sup> *Opioid Overdose Crisis*, NAT’L INST. ON DRUG ABUSE, <https://www.drugabuse.gov/drugs-abuse/opioids/opioid-overdose-crisis>. (last visited Nov. 27).

<sup>28</sup> Evan Wood et al., Pain Management With Opioids in 2019-2020, 322 JAMA 1912, 1912 (2019).

<sup>29</sup> See Jack Richard & Marcus M. Reidenberg, The Risk of Disciplinary Action by State Medical Boards Against Physicians Prescribing Opioids, 29 J. PAIN & SYMPTOM MGMT. 206, 206 (2005).

<sup>30</sup> *Armstrong v. La. State Bd. of Med. Exam’rs*, 868 So. 2d 830, 840 (La. Ct. App. 2004) (quoting *Holladay v. La. State Bd. of Med. Exam’rs*, 689 So. 2d 718, 727 (La. Ct. App. 1997)).

<sup>31</sup> Jayne O’Donnell & Ken Alltucker, Feds Issue New Warning to Doctors: Don’t Skimp too Much on Opioid Pain Pills, U.S.A. Today, Apr. 24, 2009, (<https://www.usatoday.com/story/news/health/2019/04/24/opioid-pain-pills-crackdown-doctors-prescriptions-cdc-fda/3562373002/>).

<sup>32</sup> *Wolkenhauer v. Smith*, 822 F.2d 711, 714 (7th Cir. 1987), (quoting *Goldberg v. Ruskin*, 128 Ill. App. 3d 1029, 471).

law is meant to put a person, or their family, back into a position before the negligent or intentional act happened, while trying to deter the conduct of the defendant.

Two state-level jury cases, *Estate of Henry James v. Hillhaven Corp.*,<sup>33</sup> and *Bergman v. Wing Chin, Md and Eden Medical Center*,<sup>34</sup> demonstrated that socially there is a recognized duty that physicians have to relieve pain and suffering. The inadequate pain management provided for the patients in each case lead to a painful death, that the families felt could have been circumvented with proper care and pain management. The cases recognized the dissatisfaction of families and bystanders, here being the jury, of a person suffering through severe, yet manageable pain. The families of the decedents used the tort law as a way to hold the physicians liable for inadequate pain management, this type of liability is more of a knee-jerk reaction, as with most of tort law. However, tort law is not appropriate in changing the medical field when it comes to inadequate pain management, because pain management is a complex issue that cannot be easily tested. Also,

[t]here is no evidence that the deterrence effect of tort liability can overcome or even mitigate the deterrence effect of imprisonment or loss of medical license that has deterred so many physicians into playing it safe—and, in effect, undertreating pain.<sup>35</sup>

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<sup>33</sup> Ben Rich, *Physicians' Legal Duty to Relieve Suffering*, 175(3) WEST J. OF MED., 151 (2001). In the *Estate of Henry James*, a NC jury found that a nurse's refusal to administer the opioid analgesics necessary to relieve Mr. James's pain, on the rationale that he would become addicted, constituted a gross departure from acceptable care. The estate was awarded \$15 million.

<sup>34</sup> *Supra* note 19 at 152. In *Bergman*, an action brought under California's elder abuse statute, found the defendants grossly negligent or reckless when providing inadequate pain management for the plaintiff, who rates a pain intensity as 10 on a 10 point scale. The jury awarded the plaintiff's estate \$1.5 Million.

<sup>35</sup> James R. Blaufuss, Comment, *Note: A Painful Catch-22: Why Tort Liability for Inadequate Pain Management Will Make for Bad Medicine*, 31 WILLIAM MITCHEL LAW REV. 1093, 1109 (2005).

## 2. Palliative and Hospice care in the state of New Jersey.

In August 2019, the New Jersey state legislature passed an act is meant to increase access to palliative care. This act will create the “Palliative Care and Hospice Care Consumer and Professional Information and Education Program” in the Department of Health. The program will develop and implement initiatives to further palliative and hospice education. The act can also bring an action against facilities who do not inform patients with serious illness about palliative and hospice care. This “bare-bones” act is meant to develop into a comprehensive palliative and hospice education plan.

### **THE DISPARATE TREATMENT OF AFRICAN-AMERICAN IN THE MEDICAL FIELD AND UNDERUTILIZATION OF HOSPICE AND PALLIATIVE CARE**

The historical adverse treatment of African-Americans is still evident in contemporary medical care. Due to the legal status of slaves, African-Americans in the historic U.S. were used as medical test subjects. African Slaves were believed to have thicker skin and a high pain tolerance than Whites. Through time, African-Americans were stereotypes with addiction seeking behavior and, due to the stereotyping, are less likely to be prescribed opioid analgesics.<sup>36</sup> The case study on Tammie Robinson demonstrates a contemporary problem face by African-Americans seeking palliative care.

*Robinson v. St. John Med. Ctr.*<sup>37</sup> is about the wrongful termination of Tammie Robinson<sup>38</sup>, an African-American Registered Nurse Case Manager who was fired for interfering

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<sup>36</sup> Joshua H. Tamayo-Sarver et al., *Racial and Ethnic Disparities in Emergency Department Analgesic Prescription*, 93 AM. J. PUB. HEALTH 2067, 2071 (2003) (finding that Blacks and Latinos were less likely than Whites to receive opioid analgesics for migraines, back pain, and bone fractures in an emergency room).

<sup>37</sup> *Robinson v. St. John Med. Ctr., Inc.*, 645 F. App'x 644 (10th Cir. 2016).

<sup>38</sup> The Hospital is located in Tulsa, Ok, a town with historical inequities. See Meagan Day, *The history of the Tulsa race massacre that destroyed America's wealthiest black neighborhood*, Timeline, Sep. 21, 2016, <https://timeline.com/history-tulsa-race-massacre-a92bb2356a69>.

with a patient's care, after becoming concerned that the physician was undertreating the patient's pain. The patient, an African-American, was admitted for complications of Sickle Cell Disease<sup>39</sup> ("SCD"). The Palliative team assigned to the patient were concerned about the patient's potential opioid abuse<sup>40</sup> and a need for better pain management.<sup>41</sup> The palliative care team rejected the use of IV pain medication due to the concerns of said potential opioid abuse.<sup>42</sup> Robinson, the only African-American medical professional, was concerned because the palliative care team and physician did not consult a hematologist, start the patient on antibiotics, or effectively manage the patient's pain.<sup>43</sup> She was afraid that the patient was receiving inadequate medical care and pain management. Robinson advocated for the patient, notifying her supervisor and pushing the physician on the issue of the IV pain pump. Ultimately, her supervisor and the physician saw her actions as disruptive; her employment was terminated on March 15<sup>th</sup> for undermining a physician. There are multiple concerns regarding Robinson's case, first, SCD pain is immeasurable, complex and intense, which is often misunderstood by medical providers.<sup>44</sup> Second, SCD patients, primarily being African-American, are faced with bias from medical providers. The nurse's behavior is not a random well-intended occurrence, it is a consequence of

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<sup>39</sup> William T. Zempsky, *Evaluation and Treatment of Sickle Cell Pain in the Emergency Department: Paths to a Better Future*, 11 CLIN. PEDIATR. EMERG. MED. 265, 265-266 (2011). Sickle cell is the most common genetic disease of African-Americans, with 90% of the children in the U.S. affected by it being African-American. SCD patients can experience painful episodes, with over 70% of emergency visit for SCD in a single year for pain management.

<sup>40</sup> The case did not provide evidence of actual opioid abuse by the patient.

<sup>41</sup> *Robinson*, 645 F. App'x at 646.

<sup>42</sup> Allan Geller & Kevin O'Connor, *The Sickle Cell Crisis: A Dilemma in Pain Relief*, 83 MAYO CLINIC PROCEEDINGS, 320 (2008). The article found that a large percentage of nurses (63%) and physicians (53%) believe that patients with SCD have a substance abuse disorder. Only 23% of Hematologists believe their patients are using drug seeking behavior. Roughly 0.2% to 2.0% of patients experience drug addiction. The racial factor also attributes to the misconception of drug seeking behavior in SCD patients.

<sup>43</sup> Geller and O'Connor, *supra* note 15 at 321. "The initial management of a sickle cell crisis should be aimed at providing rapid pain control. Once the pain is controlled, treatment guidelines recommend addressing underlying complications, including infection and severe anemia; providing adequate hydration; administering supplemental oxygen; and employing narcotic analgesics for pain relief."

<sup>44</sup> William T. Zempsky *supra* note 39 at 2.

the inequities in medical care. SCD causes painful episodes that require adequate pain medications, however, African-Americans are less likely to receive adequate medication for pain and more likely to receive low-value healthcare.<sup>45</sup>

African-Americans are subjected to inadequate palliative and Hospice care for a number of reasons. First of all, African-American communities harbor distrust towards medical professionals due to historical mistreatment, such as the Tuskegee Experiment. Second, medical providers lack proper knowledge of African-American culture and spirituality, this leads to confusion when acknowledging spirituality for palliative and hospice care. African-Americans are being misdiagnosed as drug-seeking or suffering from less pain due to physicians believing in outdated stereotypes. Finally, medical providers are not aware of the racial inequalities African-American face day-to-day, which makes them more likely to lack medical knowledge and lack access to proper pain management. The following sections will discuss the above concerns.

#### ***A. The Historic distrust of Medical Providers***

The abuse African-Americans suffered through left long lasting scars of distrust towards medical providers. The general distrust toward medical providers in the context of saving life also affects African-Americans who are seeking a dignified death. Racial injustice has existed in the U.S. for centuries, African Slaves were bought, sold, and forced to work for White slavers. The slave trade didn't limit itself to labor, but soon it spread to the medical field for human

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<sup>45</sup> See William L. Schpero et al., *For Selected Services, Blacks And Hispanics More Likely To Receive Low-Value Care Than Whites*, 36 HEALTH AFFAIRS 1065 (2011).

testing, and after that eugenics. In recent times, African-Americans still face low-quality care<sup>46</sup> that directly contributes to inadequate palliative and hospice care.<sup>47</sup>

Enslaved African-Americans were used for medical experimentations - as property that could be bought, sold, and experimented on. Typically, medical schools and physicians found live specimens by opening clinics for the poor, however, in the South a few schools “encouraged slave owners to send their sick and injured slaves to the infirmary for treatment.”<sup>48</sup> Medical experimentation was also used to test racial stereotypes. Dr. Thomas Hamilton, a respected southern gentleman, experimented on John Brown, an enslaved man, to determine the depth of black skin.<sup>49</sup> The Doctor believed that black skin was thicker than white skin and that African-Americans had larger sex organs, small skulls, and a higher tolerance for heat. These fallacies were presented as fact and legitimized in medical journals.<sup>50</sup>

Prior to Dr. Hamilton’s experimentations, the 1787 manual “A Treatise on Tropical Diseases; and on The Climate of the West-Indies,”<sup>51</sup> claimed that Blacks<sup>52</sup> could bear surgical operations more easily than whites, thusly creating a misrepresentation of high pain tolerance for Blacks. This misrepresentation of pain tolerance allowed for Dr. J. Marion Sims to use enslaved Black women in unconscionable experimentation to develop a surgical technique to repair

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<sup>46</sup> William L. Schpero et al., *supra* note 45.

<sup>47</sup> See Generally Kelly M. Hoffman et al., *supra* note 10.

<sup>48</sup> Todd L. Savitt, *The Use of Blacks for Medical Experimentation and Demonstration in the Old South*, 48 J. S. HIST. 331, 334 (1982).

<sup>49</sup> Linda Villarosa, *Myths About Physical Racial Differences Were Used to Justify Slavery — and are Still Believed by Doctors Today*, N.Y. TIMES, Aug. 14, 2019, (discussing Samuel A. Cartwright, *Report on the Diseases and Physical Peculiarities of the Negro Race*, NEW ORLEANS MED. & SURGICAL J., May 1851, at 691.).

<sup>50</sup> See Lundy Braun, *Race, ethnicity and lung function: A Brief History*, 51 Can. J. Respir. Ther. 99 (2015) (the author discussed the dilemma on lung function research that tried to tie lung capacity to race. The research persisted past 1970).

<sup>51</sup> BENJAMIN MOSELEY, A TREATISE ON TROPICAL DIEASES; AND ON THE CLIMATE OF THE WEST-INDIES (1787).

<sup>52</sup> I shift to the usages of the word Black because the manual was based in the East and West Indies, not the United States.

vesico-vaginal fistula.<sup>53</sup> These medical beliefs prevail today; in 2016, a survey of 222 white medical students showed that half endorsed false beliefs about biological differences between African-Americans and Whites.<sup>54</sup> This translates into African-Americans being prescribed lower amounts of pain medication in the emergency room for higher levels of pain than white counterparts.<sup>55</sup>

Experimentation on African-American bodies did not end with slavery – it continued well into the 20<sup>th</sup> century. In 1932, The Tuskegee experiment was a study on syphilis that initially involved 600 African-American men – the majority, 399, were already infected with syphilis.<sup>56</sup> The study was expected to last six months and provide the subjects with free medical exams, free meals, and burial insurance. The experiment actually went on for 40 years and did not provide the African-American subjects with adequate treatment, even after Penicillin was discovered and became the drug of choice for syphilis. The study came to a halt in July 1972 when the Associated Press published a story on the Tuskegee Study.<sup>57</sup>

There are many more examples of African-Americans being unwittingly experimented on, such as, racial eugenics that sterilized thousands of poor black Southern women without their knowledge or consent until the 1970s<sup>58</sup> and the extraction and use of Henrietta Lacks' cells without her permission.<sup>59</sup> African-Americans, unlike Whites, did not have control or authority

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<sup>53</sup> L.L. Wall, *The Medical Ethics of Dr. J Marion Sims: A Fresh Look at the Historical Record*, 32 J. MED. ETHICS 346, 346 (2006),

<sup>54</sup> See Generally Kelly M. Hoffman et al., *supra* note 10.

<sup>55</sup> Joshua H. Tamayo-Sarver et al. *supra* note 36 at 2069. (Showing that African-Americans are less likely to receive Opioids for pain relief than Whites for Bone fractures, Migraines, and back pain during emergency visits.

<sup>56</sup> HARRIET A WASHINGTON, *MEDICAL APARTHEID : THE DARK HISTORY OF MEDICAL EXPERIMENTATION ON BLACK AMERICANS FROM COLONIAL TIMES TO THE PRESENT* 157 (Doubleday 1st) (2006)

<sup>57</sup> CDC, U.S. Public Health Service Syphilis Study at Tuskegee, (last visited Nov. 30, 2019), <https://www.cdc.gov/tuskegee/timeline.htm>.

<sup>58</sup> HARRIET A WASHINGTON, *supra* note 56 at 189.

<sup>59</sup> Laura M. Beskow, *Lessons from HeLa Cells: The Ethics and Policy of Biospecimens*, 17 ANN. REV. GENOMICS HUM. GENETICS 395, 396 (2016).

over their own bodies. The distrust in medical professionals results in African-Americans feeling that they receive a lower quality of health care services<sup>60</sup>, which can make African-American suspicious at the suggestion of hospice care since it focuses on comfort rather than the more costly treatment.<sup>61</sup>

***B. Cultural and false physiological differences affect the level of palliative and Hospice care for African-Americans***

Barriers to palliative and hospice care include culture and false physiological differences between African-American patients and non-African-American medical professionals, who make up a majority of the healthcare field.<sup>62</sup> The failure to integrate and understand a patient's culture "may contribute to disparities in palliative [and hospice] care across the care continuum."<sup>63</sup> In addition to the lack of cultural understanding, the medical profession suffers from false physiological beliefs which attribute to misdiagnosing African-American as addicts.<sup>64</sup> Misdiagnosing African-American patients as drug-seeking can prevent them from starting appropriate pain management care.

***1. Spirituality and religion***

African-American communities are rich in spiritual beliefs; death can be viewed as a "welcomed friend," there to assist the decedent in the transition from an earthly to a heavenly

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<sup>60</sup> William L. Schpero, *supra* note 45. (The article demonstrates that African-American do receive low-quality healthcare).

<sup>61</sup> Kimberly S. Johnson, Maragatha Kuchibhatla & James A. Tulsky, *What explains racial differences in the use of advance directives and attitudes toward hospice care?*, 56 J. Am. Geriatrics Soc. 1953, 1957 (2008).

<sup>62</sup> U.S. DEP'T OF HEALTH AND HUM. SERV. ET AL., *SEX, RACE, AND ETHNIC DIVERSITY OF U.S. HEALTH OCCUPATIONS (2011-2015)* 5 (2017). (Finding that Whites make up roughly 67% working physicians).

<sup>63</sup> Cindy L. Cain et al., *Culture and Palliative Care: Preferences, Communication, Meaning, and Mutual Decision Making*, 55 J. PAIN & SYMPTOM MGMT. 1408, 1410 (2018).

<sup>64</sup> Taylor N. Santoro & Jonathan D. Santoro, *Racial Bias in the US Opioid Epidemic: A Review of the History of Systemic Bias and Implications for Care*, 10 CUREUS 3733, 3735 (2018).

existence.”<sup>65</sup> It isn’t uncommon for African-Americans to reference the deceased as “going home”.<sup>66</sup> These spiritual beliefs equate to wanting the patient to be “right” with God and have a good death experience. African-Americans prefer to be in a place where their “traditions are embraced and not just tolerated, meaning the inclusion of a time of prayer, Bible reading, spiritual counseling, and singing religious hymns.”<sup>67</sup>

African-Americans patients may feel that entering hospice care was “giving up”, or against God’s plan.<sup>68</sup> Individuals are more hopeful for a miracle healing and will continue with aggressive, curative treatment.<sup>69</sup> While Palliative and hospice care does try to encompass religion and spirituality in treatment, the issue seems to be that the hospice staff fails to “understand and support the spiritual beliefs of African-American patients and families.”<sup>70</sup>

## 2. *Misdiagnosis.*

Access to palliative care requires a diagnosis of a chronic, painful illness or a terminal-illness, and a proper palliative care plan requires a team to assess a patient's pain. Cultural insensitivity and deep-rooted prejudices cause physicians to focus on the patient’s race when making a diagnosis.<sup>71</sup> These biases are readily seen between African-American patients and Non-African-American medical professionals.<sup>72</sup> Many African-Americans are misdiagnosed as

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<sup>65</sup> LaVera Crawley, Richard Payne,; James Bolden et al., *Palliative and End-of-Life Care in the African American Community*, 284 JAMA 2518, 2518 (2000).

<sup>66</sup> *Id.*

<sup>67</sup> Sheronda Drisdorn, *Barriers to Using Palliative Care: Insight Into African American Culture*, 17 CLINICAL J. ONCOLOGY NURSING 376, 377 (2013).

<sup>68</sup> Angela D. Spruill, Deborah K Mayer & Jill B. Hamilton, *Barriers in Hospice Use Among African Americans With Cancer*, 15 J. HOSPICE & PALLIATIVE NURSING 136, 142 (2013).

<sup>69</sup> *Id.* (citing A. Tork, *Medical care at the end of life: views of African American patients in an urban hospital*, 8 J. PALLIATIVE MED., 593 (2005).

<sup>70</sup> Apollo Townsend, Alice L. March & Jan Kimball, *Can Faith and Hospice Coexist: Is the African American Church the Key to Increased Hospice Utilization for African Americans?*, 28 SAGE PUB. 32, 37 (2017).

<sup>71</sup> See Elizabeth N. Chapman, Anna Kaatz & Molly Carnes, *Physicians and Implicit Bias: How Doctors May Unwittingly Perpetuate Health Care Disparities*, 28 J. GEN. INTERNAL MED. 1504 (2013).

<sup>72</sup> Janice A. Sabin et al., *Physicians’ Implicit and Explicit Attitudes About Race by MD Race, Ethnicity, and Gender*, 20 J. HEALTH Care Poor Underserved 896, 897 (2012).

suffering from substance use disorders or as a drug dealer when seeking palliative care due to racial stereotyping.<sup>73</sup> Hospice and palliative care may be delayed due the lack of empathy non-African-American physicians show African-American patients; physicians tend to show more empathy for their own race.<sup>74</sup>

One study showed the African-Americans are diagnosed with Cancer at more advanced stages, even though they exhibited the same or similar screening behavior or risk factors as their White counterparts.<sup>75</sup> African-Americans are more likely to be unstaged<sup>76</sup> at the initial diagnosis than white counterpart, and then later on diagnosed with advanced stage cancer.<sup>77</sup>

***C. Outside socioeconomic pressures reduce African-American's access to Palliative and Hospice care due to barriers to access and knowledge***

In addition to the above factors, palliative and hospice care is underutilized in African-American Communities due to socioeconomic factors. Those factors include a lack of access to proper care and a lack of knowledge. The lack of access serves as a physical barrier to palliative and hospice care, while the lack of knowledge prevents African-Americans from making complete health care decisions. Both factors are expanded on below.

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<sup>73</sup> Heather Lindsey, *Disparities Found in Opioid-Prescribing Patterns in African Americans with Cancer*, 36 ONCOLOGY TIMES 31, 31(2014).

<sup>74</sup> David R. Williams & Lisa Cooper, *Reducing Racial Inequities in Health: Using What We Already Know to Take Action*, 16 INT'L J. ENV'T RES. PUB. HEALTH 606, 620 (2019).

<sup>75</sup> Beth A. Virnig et al., *A Matter Of Race: Early- Versus Late-Stage Cancer Diagnosis*, 28 HEALTH AFF. (MILLWOOD) 160, 162 (2009).

<sup>76</sup> Unstaged cancer is cancer for which there is not enough information to indicate a stage.

<sup>77</sup> *Id.*

### 1. *Lack of Access to palliative and Hospice Care*

In 2011, about 63% of all hospitals reporting the presence of a palliative care team.<sup>78</sup> Unfortunately, only 54% of public hospitals, which disproportionately serve minorities, have a palliative care team.<sup>79</sup> African-Americans tend to live in communities that lack the infrastructure to support hospice care outside of hospitals.<sup>80</sup> Hospice and palliative care outside of hospitals required pharmacies to have an availability of analgesic medications, pharmacies located in minority areas tend to have inadequate opioid stock.<sup>81</sup> Pharmacist in New York City cited a few reasons for a reduced opioid supply:

Ninety-five pharmacists (54 percent) reported that they had little demand for these medications, 78 (44 percent) cited concern about disposal, 35 (20 percent) cited fear of fraud and illicit drug use that might result in investigations by the Drug Enforcement Administration, 34 (19 percent) cited fear of robbery, and 13 (7 percent) cited other reasons (e.g., problems with reimbursement by health plans and Medicaid).<sup>82</sup>

African-Americans are more likely to lack reliable transportation than Whites for medical care.<sup>83</sup> The cost of travel can be a burden on the patient, and relatives, to access proper care and medication.

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<sup>78</sup> R. Sean Morrison, Rachel Augustin, Phomdaen Souvanna & Diane E. Meier, *America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals*, 14 J. PALLIATIVE MED. 1094, 1094 (2011).

<sup>79</sup> *Id.* at 1095.

<sup>80</sup> Angela D. Spruill, *supra* note 68 at 142.

<sup>81</sup> See Carmen R. Green et al., *Differences in Prescription Opioid Analgesic Availability: Comparing Minority and White Pharmacies Across Michigan*, 6 J. OF PAIN 689 (2005). See generally Jessica Rizzuto & Melissa D. Aldridge, *Racial Disparities in Hospice Outcomes: A Race or Hospice Level Effect?*, 66 J. AM. GERIATRIC SOC. 407, 412 (2018).

<sup>82</sup> R. Sean Morrison et al., “*We Don't Carry That*” — *Failure of Pharmacies in Predominantly Nonwhite Neighborhoods to Stock Opioid Analgesics*, 342 NEW ENG. 1023, 1025 (2000).

<sup>83</sup> Samina T. Syed, Ben S. Gerber & Lisa K. Sharp, *Traveling Towards Disease: Transportation Barriers to Health*, 38 J. COMMUNITY HEALTH 976, 978 (2014).

## 2. *Lack of knowledge*

Physicians frequently fail to inform African-American Patients of access or need for palliative and hospice care. Studies revealed that many African-American assumed that hospice care was only available via private insurance and others assumed that Hospice was a location.<sup>84</sup> Medical Providers' personal bias has an impact on their ability to discuss end-of-life issues with African-American patients.<sup>85</sup> The lack of proper medical attention from racial biases is an indication of a lack of empathy towards minorities. Without empathy, medical providers can feel less motivated to meet the needs of African-American patients.<sup>86</sup> The lack of empathy from non-African-American medical providers means that they cannot meaningfully convey critical information to African-American patients.<sup>87</sup>

In addition to the lack of information on hospice, African-American are more likely to have lower health literacy.<sup>88</sup> Individuals with lower health literacy tend to favor more aggressive treatment over palliative care.<sup>89</sup>

## **CURRENT PALLIATIVE AND HOSPICE PROCEDURE IN THE STATE OF NEW JERSEY**

Improving end-of-life care has been a priority of the State of New Jersey, especially since medical costs are, on average, 20% more in New Jersey per person than other states.<sup>90</sup> In 2016,

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<sup>84</sup> Sheronda Drisdorn, *Barriers to Using Palliative Care: Insight Into African American Culture*, 17 CLINICAL J. ONCOLOGY NURSING 376, 377 (2013).

<sup>85</sup> *Id.*

<sup>86</sup> David R. Williams, *supra* note 74.

<sup>87</sup> Sheronda Drisdorn, *supra* note 84 at 378 (On top of racial bias towards African-Americans, Many healthcare providers also are inefficiently educated about hospice programs and palliative care).

<sup>88</sup> Sheronda Drisdorn, *supra* note 84, at 377.

<sup>89</sup> Sheronda Drisdorn, *supra* note 84, at 377.

<sup>90</sup> Schwimmer, *Exclusive Look at Rising Health Care Spending in New Jersey*, NEW JERSEY HEALTHCARE QUALITY INSTITUTE (Oct. 10, 2018) <https://www.njhqci.org/exclusive-look-at-rising-health-care-spending-in-new-jersey/> (using this data from the HCCI report found here: [http://www.njhqci.org/wp-content/uploads/2018/10/NJ-HCCI-Charts\\_10.8.2018-1.pdf](http://www.njhqci.org/wp-content/uploads/2018/10/NJ-HCCI-Charts_10.8.2018-1.pdf)).

the federal Medicare program extended benefits to pay for end-of-life planning.<sup>91</sup> That same year, New Jersey established the advisory council on end-of-life care.<sup>92</sup> Every year since 2016, the council issued a report detailing issues with end-of-life care in New Jersey. The New Jersey Governor's advisory council on End-of-Life Care released a report with 26 recommendations on improving the care.<sup>93</sup> The suggestions include education and training programs, culturally appropriate public awareness, allowing for chronically ill patients to be treated at home by intensive-care paramedics, and creating an advisory council.

This year, Governor Phil Murphy signed Assembly Bill 312<sup>94</sup> to set up a program to improve access to existing palliative and hospice care programs.<sup>95</sup> The act tasks state officials with “ensuring that hospitals, nursing homes and rehabilitation facilities give accurate and comprehensive information about these services to patients with serious illnesses.”<sup>96</sup> The program will be overseen by 11 appointed members and will go into effect December 2019.

#### ***A. Hospice care in New Jersey***

New Jersey codified its hospice guidelines under the Hospice Services Manual.<sup>97</sup> This guideline was originally adopted in 1992 and has been re-adopted multiple times.<sup>98</sup> Hospice

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<sup>91</sup> See Generally Nancy K. Zeitoun, *New Medicare Rule Will Reimburse Physicians for Advance Care Planning*, THE HOSPITALIST Nov. 2015 at 11, <https://www.the-hospitalist.org/hospitalist/article/122030/health-policy/new-medicare-rule-will-reimburse-physicians-advance-care>.

<sup>92</sup> Jim Parker, *New Jersey Enacts Law to Expand Palliative Care*, HOSPICE NEWS (Aug. 12, 2019), <https://hospicenews.com/2019/08/12/new-jersey-enacts-law-to-expand-palliative-care/>.

<sup>93</sup> Shereef Elnahal, *New Jersey Governor's Advisory Council on End-of-Life Care Submits Recommendations to the Governor and Legislature*, STATE OF N.J. DEP'T OF HEALTH (Nov. 21, 2018), <https://nj.gov/health/news/2018/approved/20181121a.shtml>.

<sup>94</sup> Lilo H. Stainton, *New Measure Aims to Strengthen Patient Access to Palliative Care in NJ*, NJSPOTLIGHT (Aug. 12, 2019), <https://www.njspotlight.com/2019/08/19-08-11-new-measure-aims-to-strengthen-patient-access-to-palliative-care-in-nj/>.

<sup>95</sup> N.J.S.A. 26:2H-5o - 26:2H-5r (An Act concerning palliative care and hospice care and supplementing Title 26 of the Revised Statutes).

<sup>96</sup> Id.

<sup>97</sup> N.J.A.C. 10:53A

<sup>98</sup> This manual is current since 2015 and is due to expire on December 21, 2022

services through the NJ code include: durable medical equipment and supplies including drugs and biologicals, homemaker/home health aide services, physical therapy, occupational therapy and speech-language pathology services.<sup>99</sup>

Hospice providers must be licensed by the Department of Health and Senior Services and be enrolled as a Medicare (Title V XIII) Hospice provider.<sup>100</sup> In New Jersey, Hospice providers are no longer required to provide all physician services, they are allowed to contract with other physicians.<sup>101</sup> Individuals are allowed to change hospices once each benefit period, without the revocation of hospice services and providers have to, at minimum, have an interdisciplinary group (“IDG”) with at least a physician, registered professional nurse, a medical social worker, and pastoral or other social worker either employed or contracted. The IDG is responsible for establishing the plan of care, coordinate with the patient’s attending physician, periodically review the plans of care for patients, and establish day-to-day provisions of services. The patient, family members, or significant others shall participate in the formulation of the final plan of care.<sup>102</sup>

Patients must voluntarily elect hospice services, and here physician must certify... that the patient must be certified or recertified as terminally ill<sup>103</sup> by an attending physician, and the attending physician must certify that hospice services are reasonably necessary. The patient must

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<sup>99</sup> N.J. Admin. Code § 10:53A-3.4(b)(1) (Lexis Advance through the New Jersey Register, Vol. 51 No. 19, October 7, 2019)

<sup>100</sup> N.J. Admin. Code § 10:53A-2.1 (Lexis Advance through the New Jersey Register, Vol. 51 No. 19, October 7, 2019)

<sup>101</sup> N.J. Admin. Code § 10:53A-1.3 (Lexis Advance through the New Jersey Register, Vol. 51 No. 19, October 7, 2019)

<sup>102</sup> N.J. Admin. Code § 10:53A-2.4 (Lexis Advance through the New Jersey Register, Vol. 51 No. 19, October 7, 2019)

<sup>103</sup> Normally, terminally illness for hospice patients means there is roughly six months left to live.

also waive services that are related to the treatment of terminal conditions certified for hospice services.<sup>104</sup> Patients are allowed to revoke the waiver of treatment

### ***B. Palliative care***

The New Jersey Hospital Association created a Palliative care tool kit for clinicians. While it does state that “culture, religion and spiritual beliefs... should be taken into consideration,” it does not provide exact guidelines on how or why. It separates palliative care from hospice care by specifying that a palliative care “program helps to prevent and relieve suffering and supports the best possible quality of life for patients and their families through communication, shared decision making, holistic care and continuity of care.”<sup>105</sup> Palliative care can happen at any age and does not require a terminal diagnosis, it is for anyone diagnosed with a chronic, progressive, or serious illness. Palliative care utilizes an interdisciplinary team, quality of life treatment, bereavement support, social support, psychosocial support, curative treatment, symptom management, and treatment to improve function. The palliative care team will define goals, coordinate care, and much more. Patients can be referred to palliative care through many sources, such as a physician, nurse, relatives, social worker, or anyone with information on palliative care; permission from a physician isn’t always required to start the process.<sup>106</sup>

Palliative care isn’t only pain management; it also helps the patient improve their quality of life. This means that the palliative care team should have open communication with patients and their families about the seriousness of the illnesses and create reasonable goals. Palliative

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<sup>104</sup> *Id.* at § 10:53A-3.1 (c)

<sup>105</sup> 2011 New Jersey Hospital Association, *Comfort Care and Compassion at the End of Life*, INST. FOR QUALITY & PATIENT SAFETY, 3, [http://www.njha.com/media/44544/pc\\_guide\\_full.pdf](http://www.njha.com/media/44544/pc_guide_full.pdf).

<sup>106</sup> 2011 New Jersey Hospital Association, *supra* note 112, at 4.

care can be a lifelong program, especially for people with SCD, a temporary stop, or utilized with Hospice. Importantly, palliative care gives back dignity to those who are suffering.

### *C. New Jersey Palliative and Hospice Care Act*

In December, the bare-bones palliative care and hospice care act will become effective. This act is meant to expand public and clinician awareness of palliative and hospice care, while building a system that will identify patients who will need the type of care.<sup>107</sup> The bill is to maximize the effectiveness of palliative and hospice care initiatives by the state.<sup>108</sup> Every hospital, nursing home, extended care facility, and any other appropriate facility identified by the commissioner of health must provide information about appropriate palliative and hospice care to patients with serious illness, or their family members if the patient lacks the capacity to make health care decisions.<sup>109</sup> If facilities fail to comply with the information requirements, the bill states “the Commissioner of Health may require the hospital, nursing home, or facility to provide a plan of action to bring the hospital, nursing home, or facility into compliance.”<sup>110</sup>

## **INCREASING THE UTILIZATION OF PALLIATIVE AND HOSPICE CARE FOR AFRICAN-AMERICANS IN NEW JERSEY**

The previous section describes the hospice and palliative care process in the state of New Jersey. On paper, the process feels seamless, however, there are many concerns that affect African-Americans that were not taken into account. This section will discuss the reasons why African-Americans under-utilize palliative and hospice care and explore ways to combat those issues.

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<sup>107</sup> Jim Parker, *supra* note 99.

<sup>108</sup> N.J.S.A. 26:2H-5p(b).

<sup>109</sup> N.J.S.A. 26:2H-5p(a).

<sup>110</sup> N.J.S.A. 26:2H-5p(b).

### *A. Developing trust in the Medical system for African-Americans*

Trust between African-Americans and non-African-American medical providers is essential for obtaining the appropriate provisions of care.

Trustworthy, health care providers need to show competence, caring behaviors, good interpersonal skills, and a desire to promote the health of the patients they serve. Likewise, trustworthy patients need to be honest, adhere to the treatment regimen, and perform self-care behaviors.<sup>111</sup>

Due to historic inequalities and treatment, trust does not readily exist between many African-American patients and physicians. Research has shown that African-Americans are less likely to receive needed medical services for common health problems compared to Whites,<sup>112</sup> which hinders trust building. Building trust may require physicians to demonstrate interpersonal and technical competence.<sup>113</sup> “Interpersonal Competence included the common themes of physician caring and empathy, taking the time to listen, honesty, and keeping the patient’s best interest at heart.”<sup>114</sup> This can be achieved by talking with and listening to patient before beginning an exam. Technical competency is when the physicians make the “right diagnosis, gave the appropriate treatment, and provided the correct follow-up care.”<sup>115</sup>

African-Americans also show distrust towards physicians with language and culture differences, physician’s focused on profit, physicians who are perceived as treating patients

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<sup>111</sup> Willie M. Abel & Jimmy T. Efirid, *The association between trust in health care providers and medication adherence among Black women with hypertension*, 1 FRONTIERS IN PUB. HEALTH (Art. 66) 1, 1 (2013).

<sup>112</sup> See generally BRIAN D SMEDLEY, *supra* note 8.

<sup>113</sup> Elizabeth A. Jacobs et al., *Understanding African Americans’ Views of the Trustworthiness of Physicians*, 21 J. GEN. INTERNAL MED. 642, 643 (2006) (A small study where participants indicated that they trusted physicians who demonstrated interpersonal and technical competence).

<sup>114</sup> *Id.* At 644

<sup>115</sup> *Id.*

differently based on their race, and a distrust towards experimentation.<sup>116</sup> Building trust with African-American patients starts with a friendly conversation; physicians can utilize empathy for all patients.<sup>117</sup> Achieving the goal of trust with African-American patients starts with empathy and grows into interpersonal competence. Medical school can apply those factors to cultural competency classes.

***B. Using Cultural Competency to combat concerns of religion, spirituality, misdiagnosis, and lack of knowledge***

Health care organizations have strived to become culturally competent facilities. A culturally competent organization has the ability to provide for patients with diverse values, beliefs and behavior, including the “tailoring of health care delivery to meet patients' social, cultural and linguistic needs.”<sup>118</sup> Cultural competency can be used to bridge barriers in spirituality, religion, and communication when it comes to African-American patients. Unfortunately, physicians and nurses still subscribe to outdated and incorrect medical methodology when dealing with African-American patients. A majority of studies found an implicit preference for white patients, especially among white physicians.<sup>119</sup> That correlation is relevant when it comes to the treatment and communication provided by physicians. In addition to the “color” preference, African-Americans are more likely to be diagnosed with drug seeking behavior when it comes to palliative care treatment. Proper cultural competency training should

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<sup>116</sup> *Id.* at 644-655.

<sup>117</sup> David R. Williams, *supra* note 74, at 620.

<sup>118</sup> Health Research & Educational Trust, *Becoming a culturally competent health care organization*, HEALTH RESEARCH & EDUCATIONAL TRUST, 3 (2013).

<sup>119</sup> Erin Dehon et al., *A Systematic Review of the Impact of Physician Implicit Racial Bias on Clinical Decision Making*, 24 ACAD. EMERGENCY MED. 895, (2017).

reduce the issue of implicit bias and cultural communication between African-Americans and physicians.

Bias behaviors of physicians can be mitigated by requiring continuing medical education classes to include cultural competency training. This can be achieved by tying individual licensure requirements to certain Continuing Medical Education (“CME”) classes, or allowing private parties or the government to bring a suit if cultural competency education isn’t adhered to by the facilities’ staff, or by restricting funding to facilities that lack cultural competency training. Currently in New Jersey, there are no requirements on how often physicians have to comply with culturally competency CME classes after medical school.<sup>120</sup> CME classes are known to be beneficial for physicians, it correlates with improved physician care and notifies physicians of changes in practice.

Physicians play a critical role in the lives of terminally ill patients; almost 70% of physicians and white and roughly 5% of doctors identify themselves as Black/African-American.<sup>121</sup> There are consequences to cultural incompetency and the lack of African-American physicians available, one is that White doctors are less empathetic to African-American patients near the end of their lives, despite experiencing the same symptoms as white patients.<sup>122</sup> CME classes for cultural competency should be required by the New Jersey medical board to be a part of 100 CME credits every two years.<sup>123</sup>

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<sup>120</sup> N.J.S.A. 45:9-7.3. (Only physicians who graduated from schools without cultural competency requirements were required to take the CME classes)

<sup>121</sup> Physicians & Surgeons, DATA USA (last accessed Dec. 2, 2018), <https://datausa.io/profile/soc/291060/#demographics>.

<sup>122</sup> Andrea M. Elliott et al., *Differences in Physicians' Verbal and Nonverbal Communication With Black and White Patients at the End of Life*, 51 J. PAIN & SYMPTOM MGMT 1, (2016). (A study of 33 hospital-based physicians, it showed that there were fewer positive, rapport-building nonverbal cues with black patients).

<sup>123</sup> BoardVitals, *Continuing Medical Education: CME State Requirements*, (Dec. 17, 2018), <https://www.boardvitals.com/blog/cme-requirements-by-state/>.

### 1. Religion and Spirituality

African-American culture has many religious sects in the United States. While many African-Americans are mainly involved with Christianity or Islam, the individual sects of these religious groups can vary widely. Christian religious beliefs of African-Americans can depict pain and suffering as a part of death, and something to be endured. African-American Muslims, who adhere to traditional Islamic teachings, believe that “pain, sent by God to test one's faith, is to be endured.”<sup>124</sup> The belief of enduring pain and suffering as a part of death, and other spiritual beliefs, are ways to cope with illness.<sup>125</sup> Physicians can be expected to be a part of the coping process by providing spiritual care,<sup>126</sup> being part of the spiritual care may help the patient come to terms palliative and hospice care.<sup>127</sup> Physicians should regard their work as provided a death with dignity and a proper “going home”.

Cultural competency credits can teach physicians about spiritually coping with illness, how to utilize religious figures in the community, and using staff to consult on religious matters. Incredibly, Physicians don't have to share the same believe structure as African-American patients, pretending to understand and believe a patient's religious and spiritual needs is enough.<sup>128</sup> Ultimately, if physicians cannot adhere to a patient's religion, showing deference and empathy when administering palliative and hospice care will go a long way.

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<sup>124</sup> LaVera Crawley, *supra* note 64, at 2519. (Enduarce does not men to give up

<sup>125</sup> See Kimberly S. Johnson, Katja I. Elbert-Avila & James A. Tulsy, *The Influence of Spiritual Beliefs and Practices on the Treatment Preferences of African Americans: A Review of the Literature*, 53 J. AM GERIATRICS SOC. 711

<sup>126</sup> Apollo Townsend, *supra* note 70, at 33.

<sup>127</sup> Kimberly S. Johnson, *supra* note 125.

<sup>128</sup> Apollo Townsend, *supra* note 70, at 33. (quoting a patient “I don't need that physical comfort anymore. I need someone who, I may not be aware of it, but I need someone who believes in the living God”).

## 2. *Misdiagnosis: Combating racial stereotypes in medicine*

Palliative care is used to treat chronic pain from a serious illness, regardless of age and severity. Cultural insensitivity and deep-rooted prejudices cause physicians to focus on the patient's race when making a diagnosis.<sup>129</sup> White physicians tend to misdiagnose African-American with drug seeking behavior<sup>130</sup> or underestimate and undertreat their pain due to outdated stereotypes.<sup>131</sup> New evidence suggests that African-Americans have a biological predisposition for lower pain tolerances and thresholds which causes them to be more sensitive to pain.<sup>132</sup> CME classes can be utilized to combat the negative stereotypes that plague the medical community. Physicians and medical staff need to combat their own biases in a positive environment to help them provide the best standards of care. Cultural Competency CME class can address the bias that cause misdiagnosis of palliative patients as drug seeking. Proper cultural competency CME classes can help reshape decades of false biological assumption and help African-Americans get adequate pain care.

## 3. *Lack of Knowledge*

African-American communities are less likely to receive information on end-of-life care. African-Americans tend to worry about financial barriers, forfeiting treatment for the terminal illness, and how to care for the patient at home. While medical providers can provide information on palliative and hospice care, their personal bias impacts their ability to discuss those issues with African-American patients.<sup>133</sup> “Most physicians are not explicitly racist or

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<sup>129</sup> Elizabeth N. Chapman, *supra* note 71.

<sup>130</sup> Heather Lindsey, *supra* note 73.

<sup>131</sup> Kelly M. Hoffman, *supra* note 10, at 4298.

<sup>132</sup> Claudia M. Campbell, Robert R. Edwards & Roger B. Fillingim, *Ethnic differences in responses to multiple experimental pain stimuli*, 113 PAIN 20, 22-21 (2005), (African-Americans display lower tolerances to ischemic pain tolerance and cold pressor tolerance than Whites, while all other pain thresholds were similar.).

<sup>133</sup> Sheronda Drisdorn, *supra* note 84, at 377.

prejudiced, [but] studies show that physicians manifest the same implicit biases and stereotypes found in the general public.<sup>134</sup> Cultural Competency classes on implicit bias<sup>135</sup> can help physicians identify their own biases and reduce the harm it has on all populations. Currently, cultural competency classes are primarily taught in medical school, in a safe environment,<sup>136</sup> it should be expanded to CME licensure requirements to provide physicians with updated training biennially.

New Jersey's palliative care act circumvents individualized training by requiring health facilities to provide prospective patients with information regarding appropriate palliative and hospice care.<sup>137</sup> Requiring medical providers to provide information may not reduce the disparity in medicine because it doesn't address the positive treatment white patients<sup>138</sup> experience due to implicit bias and will not tackle the negative treatment faced by African-Americans.

### **C. Assessing the lack of access**

African-Americans lack access to palliative care teams<sup>139</sup>, opioid stocked pharmacies<sup>140</sup>, and can have difficulty traveling to appointment.<sup>141</sup> Visiting Nurses can help palliative care<sup>142</sup>

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<sup>134</sup> Augustus A. White et al., *Self-Awareness and Cultural Identity as an Effort to Reduce Bias in Medicine*, 5 J. RACIAL & ETHNIC HEALTH DISPARITIES 34, 34 (2018). (citing M. van Ryn & J. Burke, *The effect of patient race and socio-economic status on physicians' perceptions of patients*, 50 SOC. SCI. 813 (2000)).

<sup>135</sup> *Understanding Implicit Bias*, KIRWAN INST. FOR STUDY OF RACE & ETHNICITY, (last accessed Dec. 2, 2018) (“Implicit bias refers to the attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner. These biases, which encompass both favorable and unfavorable assessments, are activated involuntarily and without an individual’s awareness or intentional control.”)

<sup>136</sup> Augustus A. White, *supra* note 130, at 41.

<sup>137</sup> N.J.S.A. 26:2H-5q(a).

<sup>138</sup> I Helena Hansen & Julie Netherland, *Is the Prescription Opioid Epidemic a White Problem?*, 106 K. Am. J. Pub. Health 2127, 2127 (2016) (The positive bias lead to over prescribing opioids. “In the United States, where insurance coverage and access to physicians are racially stratified, opioid prescriptions disproportionately went to White patients, whereas non-White patients, even those with access to a physician, were less likely to be prescribed opioids, which increased racial differences in opioid use.”).

<sup>139</sup> R. Sean Morrison, *supra* note 78.

<sup>140</sup> Carmen R. Green, *supra* note 81.

<sup>141</sup> Samina T. Syed, *supra* note 83.

<sup>142</sup> 42 C.F.R. § 418.64(b) (Hospice care already utilizes visiting nurses and health aides).

patients by providing at home assessments and bringing patients' medication. Visiting nurses are different from home health aides; home health aides provide services such as grooming, light housekeeping, meal prepping, and medication reminders.<sup>143</sup> A visiting palliative care nurse can assess pain and address issues, such as bed sores and constipation, without a costly trip to the doctor's office. Patients are more comfortable at home and more nuances that indicate pain and discomfort can be readily seen in the home environment. This can help mitigate inadequate pain assessments made by physicians, ultimately providing the patient with the correct level of pain management. The visiting nurse can also provide patients with proper medical dosages, provide all relevant parties with pertinent information, identify signs of depression and anxiety, and nausea. This also provides the patient with a sense of independence and relief from the confusing health care system.

## CONCLUSION

Palliative and hospice care is underutilized by African-Americans, this means that many African-Americans are not getting the support they need for pain management and dying with dignity. The State of New Jersey has taken the first step to help African-Americans learn about their ability to receive proper pain management, and to demystify hospice care by introducing the Palliative care and hospice care act. Soon medical staff will be required to inform patients of their access to palliative and hospice care. The act is a great start; however, the appointed council will have to create guidelines for health care facilities.

The state should try to increase cultural competency by requiring physicians to complete cultural competency CMEs biennially. Cultural competency can help address the concerns of

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<sup>143</sup> *Home Health Aide*, VNA Care (last access Dec. 2, 2019), <https://vnacare.org/patients/by-caregiver/home-health-aide>.

medical distrust, social and cultural differences, and reduce implicit biases portrayed by medical providers. In addition to cultural competency, empathy is a valuable currency in creating trustful relationships and providing proper care for African-American patients. Palliative and hospice care has the potential to improve the quality of life for African-American patients. Without the proper information and treatment, African-Americans and their families suffer more during times of chronic illness and death. Death is the great equalizer and the care before it should be meaningful and dignified.