

SYSTEMIC AND RACIAL BARRIERS TO PALLIATIVE CARE

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ABSTRACT

Those who have known an individual with a chronic medical condition or someone that has been diagnosed with a terminal illness have experienced the physical and emotional toll these diagnoses have on both patients and their loved ones. Medical providers encounter these situations daily and are often responsible for assisting the patient and their family in the decision-making process. The specialty of Hospice and Palliative Medicine was created specifically with these difficult, but very common, situations in mind. Even though the concept of palliative care has become mainstream and its practice is considered standard of care in many situations, it continues to be misunderstood, misrepresented, and underutilized, despite providing measurable benefits to patients, families and the healthcare system. This paper explores two systemic barriers to palliative care that contribute to this problem and highlights how race, cultural mistrust, and a long history of racial disparities in health care work together to undermine the effective delivery of palliative care.

Keywords: palliative care, hospice, quality of care, race, barriers, education, communication

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CHAPTER 1

INTRODUCTION

The most basic definition of Hospice and Palliative Medicine is that it is a medical specialty dedicated to relieving suffering and improving quality of life for patients. This includes patients with terminal illnesses where the progression of their disease is well known and relatively easy to predict, as well as individuals with manageable chronic conditions where the progression of their disease is less well known. Hospice and Palliative Medicine physicians provide hospice care, which is limited to individuals that likely have fewer than six months to live, as well as palliative care, which is available to any patient suffering from an illness regardless of whether or not it can be cured.

The term palliative is derived from the Latin term *palliare* which means “to cloak” or surround, and so the concept of palliative care revolves around “cloaking” the patient and family with support. The palliative care teams help patients and families navigate chronic illnesses and the variety of side effects associated with these conditions. They utilize a team-based approach to better understand the goals of the patient and their families, provide additional emotional and spiritual support that primary care teams may not have time or training to provide, and have been shown in various studies to enhance the quality of life for patients and their families (Beernaert et al., 2014; Brousseau et al., 2012; Gelfman, Meier, & Morrison, 2008; Temel et al., 2016; Temel et al., 2010). If a patient’s condition is terminal, these teams can facilitate communication to ensure that the wishes of the patient are honored and that their symptoms are effectively managed.

The goal of Hospice and Palliative Medicine physicians is to provide a valuable supportive service to patients with very complex problems, both emotional and physical.

While these goals make sense in the context of improving the wellbeing of patients, its promise is often compromised. Hospice and palliative care is not as widely used as it could be, and of those patients who do utilize these services, the vast majority are white. Lower use, as well as disparities in use, are fostered by two types of barriers: systemic and racial. The systemic barriers are those that exist within the healthcare system – how we train medical providers and how that care is delivered - and adversely affect the medical provider's ability to understand and integrate palliative care into everyday practice. The racial barriers are impediments to effective palliative care that are experienced by people of color in general, but specifically by black patients due to a unique combination of cultural mistrust in the medical system and racial biases from medical providers.¹

In terms of structural barriers, one key barrier to effective palliative care is the adequacy of the education our medical providers receive. Studies show that the individuals responsible for connecting patients to appropriate resources often do not have a good understanding of Hospice and Palliative Medicine, even to the extent that a significant number of physicians cannot accurately describe the difference between palliative care and hospice care. They lack an adequate understanding of the breadth of palliative care services, receive sub-optimal clinical exposure to end of life discussions, and are often unprepared to fully support patients and family members with chronic or life threatening conditions.

¹ Cultural mistrust refers specifically to African American's mistrust of white Americans and/or traditional American institutions, such as health care or criminal justice (Terrell & Terrell, 1981).

The second barrier involves the way providers communicate with patients, as illustrated by studies showing a disconnect between what physicians perceive and what patients perceive. Patients often have pre-conceived notions regarding palliative care, hospice care, and supportive care in general and it is the responsibility of a well-informed, well-trained medical provider to ensure the information they receive is accurate and complete. A significant barrier occurs when those medical providers do not exhibit the ability to effectively communicate the benefits of palliative care or communicate incorrect or misleading information to the patient.

In addition to these systemic barriers explored throughout this paper, racial differences of patients and how these differences are perceived by medical providers represents a second type of barrier that has a profound influence in medicine in general and in palliative care specifically. Physician biases, incorrect assumptions regarding patient preferences, historical oppression in medicine leading to cultural mistrust, and a lack of racial diversity in medicine all strengthen the systemic barriers and undermine effective delivery of palliative care.

Traditional medical education utilizes a system-based approach that allows learners to focus on one area at a time to ensure complete understanding of the subject, but this often has the unintended effect of compartmentalizing subjects that are intimately related. In medical school, for instance, the social determinants of health are typically discussed during different sessions than the treatments for heart failure or the pharmacology of blood pressure medications. This separation gives young learners the ability to compartmentalize and prioritize the information they deem most important, since the volume of information is often overwhelming. The downside of this segmented

approach is it divides topics into silos, despite their significant interconnectedness. Race, for instance, is not a single stand-alone variable that can be separated from all the other variables it influences. Thus, a key goal of this paper is to explore structural barriers to effective palliative care while simultaneously discussing how race can also inform these decisions.

For trainees and medical providers, this paper aims to provide a broad overview of the history of Hospice and Palliative Medicine as a specialty and explicitly define the scope of practice. It will provide historical context for the cultural mistrust that exists between black patients and the health care system. By acknowledging this historical context that contributes to these differences, and highlighting some of the existing research, medical providers can better understand how a specialty meant to improve the lives of patients and their families can be so difficult to effectively implement.

Hospice and Palliative Medicine: Defining the Specialty

Hospice and Palliative Medicine is a relatively new subspecialty in medicine, officially recognized by the American Board of Medical Subspecialties (ABMS) in 2006. However, while the recognition as a subspecialty is more recent, the history of its practice can be traced back over 60 years to the early 1950's (Loscalzo, 2008). Cicely Saunders, an English nurse, physician, and social worker is credited with championing the idea of adequate symptom management and "proper relief of suffering without the hastening of death" (Saunders, 1975). The idea that patients could experience quality of life in the face of death was a novel concept in the early days of palliative and hospice care. Dr. Saunders' leadership, dedication to terminally ill patients, and her quest to constantly relieve patient's suffering were instrumental in founding St. Christopher's Hospice in

London, the first academic institution focused on end-of-life care (Emanuel & Lawrence Librach, 2011). Cancer was becoming an increasingly common diagnosis and during this time, medicine was sharply focused on curative treatments for cancer, often to the neglect of patients who could not be cured. Dr. Saunders, while not specifically an oncology physician or nurse, recognized the need for palliative therapy in these individuals and focused on providing additional support to these patients with end-stage cancer (Clark, 2007). Since that time, cancer treatment and the specialty of Hospice and Palliative Medicine have been closely related. One of the major reason for this is due to the diseases' predictability, the known trajectory of its adverse effects across all types of cancers, and the high number of patients affected by this disease relative to other terminal conditions.

The founding organization of hospice services in the United States emerged after Dr. Saunders visited Yale and lectured on the benefits of hospice care in the early 1970's. In 1973, the first US hospice group began treating patients utilizing home hospice care in Branford, Connecticut. Several national meetings followed this, and ultimately interest was significant enough to create the National Hospice Organization (NHO) in 1978. Shortly after the creation of the NHO, after one of these meetings in 1979, the first US guidelines for hospice care were created (Connor, 2007). In 1982, Medicare, the dominant medical insurer for individuals over the age of 65, officially acknowledged the work of hospice care by funding several programs (Clark, 2007). The gradual progress and increased recognition of hospice and palliative care continued until several events in the 1990's accelerated the growth of Hospice and Palliative Care. The Last Acts initiative, a national communications campaign comprised of over 800 national health

and consumer groups created by the Robert Wood Johnson Foundation in 1995, focused on improving end of life care with a specific goal of creating change to the culture of health care institutions. The organization acted as an educational resource for end of life issues and was successful in raising professional awareness for improving end of life care (Karani & Meier, 2003). There were also two influential Institute of Medicine reports, in 1997 and in 2001, the later titled *Crossing the Quality Chasm: A New Health System for the 21st Century*, which established a list of recommendations for the promotion of the specialty (Clark, 2007).

Hospice and Palliative Medicine, while officially one subspecialty, has distinctly different responsibilities when providing palliative care and providing hospice care. Confusion over these terms will be explored in detail below as it contributes to one of the primary barriers to effective use of palliative care. In brief, the confusion for both providers and patients is essentially that these individuals believe the terms “palliative care” and “hospice care” are synonyms, which prevents providers from offering palliative care services to patients with life-limiting, but not terminal, conditions who could benefit from these interventions.

Palliative care is broadly defined by the World Health Organization (WHO) as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (Emanuel & Lawrence Librach, 2011). While all physicians regardless of specialty receive some training in these domains and are encouraged to provide counseling to patients whenever

appropriate, the term palliative care usually refers to an interdisciplinary specialty that often includes nurses, social workers, and/or spiritual and emotional support staff (Gelfman et al., 2008). These teams help patients and their families with difficult decisions like goals of care, advanced directives, code status, and can also assist the primary team for improved symptom management.

There is one important aspect of palliative care that must be emphasized repeatedly: patients can continue to receive curative therapies while taking advantage of the symptom management expertise of the palliative care team. Palliative care consultation is not equivalent to withdrawal of care, comfort directed care, or “giving up.” Despite not having terminal diagnoses, patients with any chronic life-limiting illness such as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), Alzheimer’s disease, multiple sclerosis (MS), and many others can receive benefits from palliative care services.

Hospice care, on the other hand, aims to provide the same support as palliative care but without any curative intent. The key difference between palliative care and hospice care is that the former is used alongside therapies intended to cure diseases whereas the latter is only used when curative treatments have been stopped. This distinction is best illustrated when looking at how this condition is covered through Medicare, which provides most of the hospice benefits in the US since it is the public insurance payer for those over 65 years old (Taylor, 2009). Patients must be terminally ill with a life expectancy of 6 months (in Pennsylvania) or less and accept comfort directed care instead of any curative therapies to qualify for hospice care (Centers for Medicare and Medicaid Services (CMS), 2016). When patients and physicians use the term

“palliative care” they often confuse it with the more commonly used term “hospice care”, however it is vital to understand the differences between the two terms.

In addition to differences in purpose, there are important differences in the delivery of palliative and hospice care as well. In the United States, palliative care is often delivered through inpatient palliative care teams. These can be integrated with other care teams that frequently deal with life threatening illnesses such as Oncology or Heart Failure, or they can be stand-alone consult services. Outpatient palliative care services are also available, however this service and its unique barriers to implementation are beyond the scope of this analysis.

In the United States, hospice care is provided in two ways. First, a patient can be admitted to an inpatient hospice facility. These facilities specialize in comfort directed care for the patient and provide convenient features to make the family feel as welcome as possible. Often these facilities have extended visiting hours, more comfortable single patient rooms, and specialized staff trained in symptom recognition and management. The second option is home hospice care, where a hospice team provides hospice expertise in the patient’s home. This requires family members to play an active role in patient care with nursing support to help with any issues that arise and there is usually not constant care like an inpatient hospice facility. Hospice care is an important option for people with terminal conditions to consider and the decision to choose hospice care often requires multiple conversations between physicians, patients, and family members. Figure 1 provides a summary of the key differences between hospice and palliative care (Centers for Medicare and Medicaid Services, 2015).

Palliative Care	Hospice
<ul style="list-style-type: none"> • Focuses on relief from physical suffering. The patient may be being treated for a disease or may be living with a chronic disease, and may or may not be terminally ill. • Addresses the patient’s physical, mental, social, and spiritual well-being, is appropriate for patients in all disease stages, and accompanies the patient from diagnosis to cure • Uses life-prolonging medications • Uses a multi-disciplinary approach using highly trained professionals. Is usually offered where the patient first sought treatment. 	<ul style="list-style-type: none"> • Available to terminally ill Medicaid participants. Each State decides the length of the life expectancy a patient must have to receive hospice care under Medicaid. In some States up to 6 months; in other States up to 12 months. • Makes the patient comfortable and prepares the patient and the patient’s family for the patient’s end of life when it is determined treatment for the illness will no longer be pursued • Does not use life-prolonging medications • Home hospice relies on a family caregiver and a visiting hospice nurse

Figure 1. Key differences between palliative and hospice care

The Benefits of Palliative Care

In the United States, almost 50% of individuals spend the last moments of their life in an acute care hospital (Angus et al., 2004). These patients can be unhappy with the amount of symptom relief they receive and many are exposed to treatment, and intervention, that are unlikely to improve their current prognosis (Temel et al., 2010). When patients express a desire to die at home these preferences are met less than half of the time (Agar et al., 2008). Palliative care services, particularly in the setting of end of life and acute hospital care, have been shown to benefit patients and their families in multiple ways.

For patients, there are many benefits to palliative care. The concept of quality of life, in addition to quality of dying, is important for advocates of palliative care. In terminally-ill patients, the questions of where to die, how much treatment will be sought at the end of life, and code status are often critical discussions. There is a risk that many or all of these questions will never be asked by physicians and thus never be answered by patients, resulting in treatments and outcomes that are discordant with patient’s desires.

Just one example of this discrepancy is that a majority of cancer patients facing terminal diagnoses prefer to die at home when in practice most deaths actually occur in a hospital (Chen et al., 2016). When Temel et al., a multi-centered group of oncologists and palliative care specialists, looked at palliative care's effect on metastatic lung cancer patients, they found improved quality of life, improved mood, increased incidence of documentation of code status, and less aggressive treatment at the end of life. The palliative care arm of this study also had half as many patients report clinically documented depressive symptoms on a validated depression scale. Surprisingly, palliative care patients in this study also had longer survival than those that did not, suggesting that there could be a life span benefit to comfort directed strategies (Temel et al., 2010). A more recent study by a similar group of researchers illustrated that early palliative care had a positive impact on communicating end of life preferences; patients were twice as likely to report having discussions regarding their end of life wishes if they had palliative care involvement (Temel et al., 2016). These patient issues are not limited to cancer or other terminal illnesses and can be more broadly applied to chronic, life-limiting illnesses that significantly alter an individual's quality of life. The focus of palliative care providers and their ability to dedicate time to integrate the psychosocial, spiritual, and physical needs of these patients brings additional value. Life-limiting diseases can have similar adverse effects on these domains as terminal diagnoses, and patients could benefit from the same palliative care integration shown to improve outcomes for terminal diagnosis (Beernaert et al., 2014).

Families are also placed in difficult situations caring for loved ones with terminal or life-limiting diseases. Families of patients receiving high level ICU care report

experiencing grief, depression, and symptoms of post-traumatic stress (Brousseau et al., 2012). Palliative care teams not only improve patient outcomes but can improve family outcomes as well. Families that received palliative care consultation have an increased likelihood of reporting enough support with their feelings as well as satisfaction with the extent to which their religious and spiritual beliefs were addressed. This same study also showed palliative care positively influenced family member's self-efficacy, defined as "the competence perceived by family members in participating in the care of the dying person" (Gelfman et al., 2008, p. 4). These studies indicate that palliative care consultation can help family members cope with the responsibilities inherent in taking care of loved ones and it can give them a better opportunity to recover both emotionally and spiritually after their loved one dies.

In addition to providing benefits to the patient and the family while not negatively impacting life expectancy, an ancillary benefit of palliative care is that it has been shown to have a positive effect on cost savings. End of life care is incredibly expensive: in the last two years of life, Medicare recipients with chronic medical conditions account for over 30% of the Medicare spending over that same timeframe (Institute of Medicine, 2001). According to a 2008 study, palliative care was associated with significant cost savings for both those patients who were discharged alive and those who died in the hospital (Morrison et al., 2008). This implies that not only can palliative care improve patient outcomes and family satisfaction but has the added benefit of reducing health care expenditures. However, despite these benefits to patients and families, palliative care is still underutilized due to numerous barriers.

The focus of this paper is two-fold. One area of focus is on educational and communication deficiencies, two of the most obstinate structural barriers to palliative care delivery. Second and intimately related, the fact that race has a pervasive effect on how palliative care is delivered in the United States and will be explored as a third barrier, one that when combined with the structural barriers, creates complex and unique barriers to effective palliative care for black patients. I start with addressing this third barrier, as it provides a foundational backdrop to the other two. As a group, black patients are the least likely minority group to discuss palliative care in the hospice setting, as well as organ donation and withdrawal of life-prolonging therapy (Cort, 2004). However, there is no concrete evidence to connect this disparity to one thing specifically. Most likely it is a combination of many factors across many different aspects of health care that combine to result in this disparity. Nonetheless, the disparity exists, and it is important to explore the concept of cultural mistrust as a contributing factor.

Cultural Mistrust in Health Care

In the context of palliative care, there are many variables as to why individuals make the end of life treatment decisions they do. These variables are frequently studied and some of them will be discussed later; however, to have an informed discussion regarding palliative care in any area with a high volume of black patients, the concept of cultural mistrust must be introduced and explored. Cultural mistrust within the African-American community can be a significant confounding variable when trying to understand why patients make certain decisions, and more importantly, how those decisions affect the type of care a patient receives.² An early definition of cultural

² Some researchers used “African American”, some used “black”, and others used both, so for consistency the terms “African-American” and “black” are used interchangeably throughout this paper.

mistrust is a response to oppression, both historical and personal, that results in a mistrust of whites and traditional institutional systems, including health care (Terrell & Terrell, 1981). Some more recent research also suggests that cultural mistrust is not experienced to the same extent by all minority populations and is specific to black patients (Welch, Teno, & Mor, 2005). When looking at research that uncovers racial and cultural differences among patients, particularly differences between African Americans and whites, there is an obligation to explore the deep historical atrocities that contribute, at least partially, to cultural mistrust within this community. This context can also help when looking at the barriers to palliative care as it relates to black patients.

The most widely publicized reason for cultural mistrust is the Tuskegee Syphilis Study, a 40-year study funded by the United States government, where young black men were unethically enrolled in a research study without their knowledge or consent, and intentionally denied treatment known to cure syphilis so that the course of the untreated disease could be witnessed firsthand (Gamble, 1997). This experiment was so egregious and universally condemned as a human rights violation that President Bill Clinton issued a formal apology for the government's involvement. The history of experimentation on black patients, however, dates to the beginning of slavery. Slaves were often subject to medical procedures because they were considered property, and thus had no legal right to refuse participation, and society lacked legal protections to prevent these events from occurring (Cort, 2004). There were undoubtedly countless examples of this mistreatment occurring on a regular basis, but one of the most impactful involves a physician whose statue still stands in Central Park and who was one of the founders of the first hospital for women in 1855 (Gamble, 1997). Dr. J Marion Sims, considered one of the pioneers of

gynecology, an early inventor of the speculum and the father of modern vesicovaginal fistula repair, experimented on at least three female slaves over the course of his career. These women had developed fistulas after childbirth, a stigmatizing and incurable condition at the time, and he operated on them using experimental techniques in attempts to perfect his procedure. Each of the slaves received no anesthesia, although it was recently available, and one of the women underwent 30 separate procedures (Gamble, 1997).

The experimentation and exploitation of black men and women did not stop at the end of slavery. Philadelphia medical schools stole the bodies from black cemeteries for use in their anatomy labs. Black patients in the south were placed in segregated hospital wards and received inferior medical care and experimental treatments (Gamble, 1997). More recently, there are studies that highlight underuse of potentially lifesaving procedures for heart attacks and strokes in African Americans when compared to whites, disparities in organ transplantation, and under-prescribing of pain medication (Dula & Williams, 2005). While these studies have not always conclusively shown overt racial biases, and some subsequent studies have shown different results, the racial disparities were stark enough that in 2002, the United States Congress requested that the Institute of Medicine (IOM) issue a comprehensive paper evaluating the racial and ethnic disparities in health care (Nelson, 2002).

Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care is the IOM's in-depth report on the state of discrimination within the healthcare system of the United States. One of the overarching conclusions was that there are still significant racial and ethnic disparities within the health care system even after other variables such

as insurance status, income, and age are considered. Furthermore, mortality from several common conditions such as heart disease, cancer, and diabetes are all higher in racial and ethnic minorities. The report also suggested that bias and prejudice from health care providers could directly contribute to the disparities seen in the research. Lastly, while there are clear reported differences in the preferences of racial and ethnic minorities such as increased rates of refusal of treatment, poorer adherence to treatment regimens, and delay in seeking care, these differences cannot account for all the disparities (Nelson, 2002). Considering the conclusions of this report, along with the historical precedent described above and taking into account the negative experiences in the healthcare system African-American patients can have throughout their lives, it is unsurprising that this cultural mistrust exists.

Cultural mistrust has broad implications for the delivery of a variety of health care services. For palliative care services, the history of oppression and experimentation along with recent examples of exploitation of individual's rights and privileges, can create additional barriers to what is already an incredibly challenging topic. Conversations regarding death, end of life planning, code status, and goals of care are often difficult to have with any patients and these become even more so when considering the additional complexity that cultural mistrust can add. Integrating attention to these racial barriers into analyses of the structural barriers to the provision of effective quality palliative care illuminates in a more complex way the true breadth of these challenges.

CHAPTER 2
PROVIDER AND PATIENT EDUCATION – STRUCTURAL
AND RACIAL BARRIERS TO PALLIATIVE CARE

The process of educating students so that they can become competent physicians is time consuming and challenging. The volume of information that medical students and residents are expected to learn and retain is vast and takes years to master. Subjects that are critical to the practice of medicine are taught repeatedly during the training process to ensure retention of the information. There are some aspects of medicine, such as palliative care, that continue to receive inadequate focus in medical education despite being highlighted by licensing bodies and public health organizations as critically important. No matter what specialty physicians choose, they will care for patients with life-threatening illnesses, and learning how to support patients and their families is just as important as knowing how to identify and treat these conditions. In addition, there are distinct racial differences in the utilization of palliative care services as well as research that shows palliative care delivery to racial minorities is distinct in several ways. Considering that palliative care in general is a poorly understood topic amongst physicians, it is unsurprising that palliative care regarding minorities receives even less attention. This section will explore the research that highlights how the educational barriers, compounded by racial bias, impede effective palliative care.

Medical school serves a critical first step in preparing future physicians as much as possible to overcome the challenges they will face as a doctor. Residency is the next step in education, where these doctors will often be the first point of contact for patients and families and as such play important roles in their care. They will be responsible for

delivering information to patients and families in addition to creating diagnoses and treatment plans. Despite it being critical that these care providers have an understanding and comfort level with palliative care because of how often they communicate with patients, a 2003 study showed there were glaring inadequacies in this training. Most of the residents surveyed reported having minimal end-of-life communication teaching (which included classroom teaching and clinical observation). In addition, they had a low level of comfort in dealing with end-of-life conversations and their level of comfort was found to be associated with how many clinical experiences they had as a medical student (Ury, Berkman, Weber, Pignotti, & Leipzig, 2003). Despite the fact that the licensing body for medical schools, the Liaison Committee on Medical Education (LCME), mandates that end-of-life is a required aspect of the curriculum, there is evidence that while required, this aspect of medical education is overlooked (Case, Orrange, & Weissman, 2013).

Part of the issue could be culture-driven since medical schools have a substantial emphasis on diagnosing and treating illnesses with little time devoted to supportive care and pain management. For example, there are formal assessment tools that medical schools use to determine satisfactory comprehension of competencies. These observed structured clinical examinations (OSCE's) test a variety of subjects and attempt to objectively evaluate a student's understanding of disease processes, their mastery of treatment options, and how well they can communicate with patients. However, there are currently no OSCE's in use to assess medical students' competency in palliative care (Ellman, Putnam, Green, Pfeiffer, & Bia, 2016). Some data suggest that clinical palliative care experience is more effective than classroom work for both medical

students and for residents, which would require medical schools and residencies not only to devote didactic time to the subject but also have palliative care teams in place to provide clinical experience (Aldridge et al., 2016). The increase of palliative care teams across the country in the inpatient setting potentially gives students and residents more opportunities to experience palliative care instead of just reading about it (Case et al., 2013). More recent analysis of medical school education shows that as of 2015, more than 90% of programs surveyed now expose their students to the principles of palliative care (Dickinson, 2016).

Perhaps the most obvious example of why physician education is still lacking: physicians must know what palliative care is, when it should be utilized, and know the difference between palliative care and hospice care. In a 2014 study, a mixed group of heart failure specialists and primary care providers were interviewed to determine their level of knowledge and their attitudes regarding palliative care and hospice services. It is important to note that heart failure is a life-threatening illness, with a 50% mortality rate five years after diagnosis, and doctors who specialize in heart failure understand it has a profound effect on quality of life for patients and their families (Mozaffarian et al., 2016). While all the providers indicated that they understood the concepts of palliative care and hospice medicine, almost all of them did not understand that palliative care could be given in addition to life-prolonging therapy. These providers frequently referred to patients' insistence on life-prolonging therapy as a barrier to obtaining palliative care consults because they mistakenly thought that in order to be reimbursed, patients must stop treatment and pursue comfort care measures. Figure 2 provides a graphic representation of when palliative care is appropriate and how it should be utilized

alongside curative treatments (Connor, 2007). This misunderstanding amongst specialized physicians that have frequent interactions with patients dealing with life limiting conditions highlights the inability of providers to differentiate palliative care from hospice care (Kavalieratos et al., 2014).

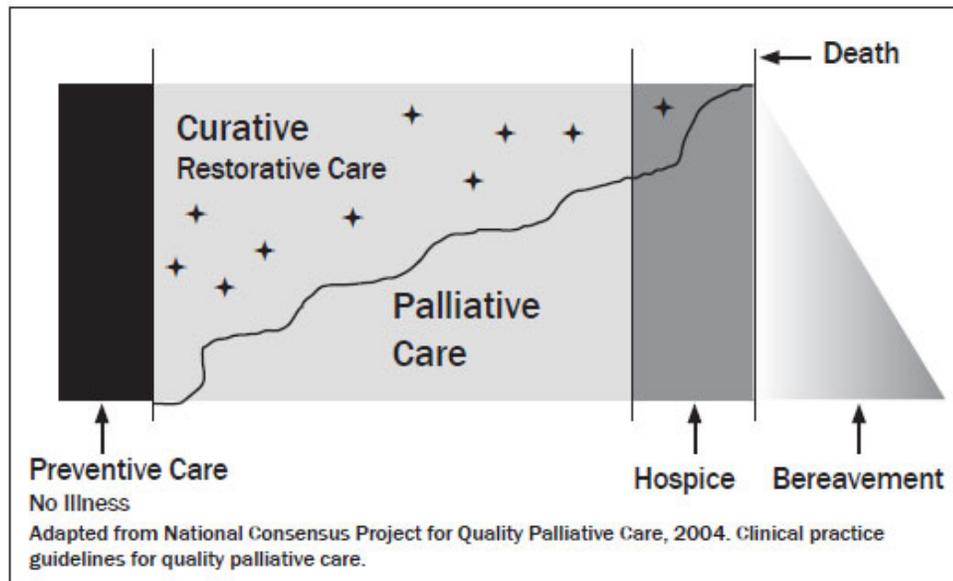


Figure 2. Illustration of appropriate timing for palliative and hospice care

If the problem was only limited to providers misunderstanding these concepts it would be more straightforward to fix. The problem is compounded, however, by poor patient understanding of palliative care. A 2013 study looked at patient attitudes towards the terms themselves and tested whether changing the wording would have any impact on patients' feelings towards palliative care services. When they compared using the term "supportive care" versus the term "palliative care", they found that patients with advanced cancer had more favorable impressions and a higher perceived need for services than those that were labeled "palliative care" (Maciasz et al., 2013).

In addition to these problems of patient and provider misunderstanding regarding palliative care and the specialties scope of practice, low utilization of palliative care

services is also partially due to physician biases. A 2012 study looked at over 150 lung cancer specialists in New York City, who like heart failure specialists must deal with life threatening prognosis daily, and found that half of the respondents referred fewer than 25% of their patients for palliative care consultation. This means that over 75% of patients who obtained their oncologic care from that subset of physicians were never given the option of a palliative care consultation. One of the physicians' main reasons for this low referral rate is that they felt that even mentioning palliative care would alarm patients and families, so they declined to discuss this option with patients (C. B. Smith et al., 2012) One example of the lack of evidence for this opinion is found in the 2010 New England Journal of Medicine study, referenced earlier in this paper, that specifically looked at palliative care for patients with lung cancer and showed the exact opposite conclusion: that early palliative care consultation showed significant improvement in the quality of life in patients and families (Temel et al., 2010). It is imperative that all physicians develop a better understanding of palliative care, especially those in specialties that have patients with life limiting conditions, and thus education of these physicians is a large barrier to effective palliative care delivery.

In addition to some of the more concrete educational deficiencies, there are multiple issues regarding racial differences that are lightly discussed in both medical school and residency programs. Some of the assumptions regarding certain racial preferences can compound existing barriers to palliative care like those mentioned above and create even more challenging environments. Particularly in areas with a high concentration of racial diversity it is crucial to highlight this research to improve physician understanding.

There are several assumptions regarding racial minorities amongst physicians that have the possibility of negatively impacting use of palliative care. As mentioned previously, African Americans have been shown to have a lower percentage of completed advanced directives, lower hospice utilization, and a higher propensity to want invasive treatments at the end of life (K. S. Johnson, Kuchibhatla, & Tulsky, 2008; Lee, Long, Curtis, & Engelberg, 2016). Keeping these studies in mind, as well as the historical context explored earlier, health care personnel can unintentionally contribute to worsening these barriers by perpetuating these assumptions regarding African-American patients. While cultural mistrust could be a contributing factor to these statistics, patients themselves are individuals and not defined by the statistics of their race. In a 2016 paper, minority patients and their families had lower quality of life ratings in the intensive care unit than their white counterparts, even after adjusting for education level. Researchers also found that lower quality of life ratings were associated with an absence of advanced directives and death in the setting of full supportive therapy (Lee et al., 2016). It is possible that because of an existing bias, physicians assumed these patients were not interested in palliative care or advanced directives and thus the options were not discussed. The reason for these disparities is likely multifactorial, but in the context of this section highlighting education, physician misunderstanding regarding preferences amongst African-American patients is something that should be considered.

A 2011 study attempted to identify whether racial biases affected physician decision-making processes with terminally ill patients by looking at two identical clinical scenarios featuring either a Caucasian actor or an African-American actor. Both patients had identical clinical findings and the result of the study showed that as far as decision-

making, the patients received identical treatment. What was more relevant was that physicians in this study, despite delivering identical treatment, believed that African-American patients would prefer life prolonging therapies over palliative care, would be less amenable to a Do Not Resuscitate Order (DNR), and would be more likely to request mechanical ventilation than their white counterparts. More broadly, they significantly overestimated patient preference across both races for life saving treatment (Barnato et al., 2011). This study indicates how complicated the topic is and how difficult it is to come to any firm conclusions regarding causality. Do physicians' biases regarding African-American patients' perspectives, which have been supported by previous studies, perpetuate a stereotype, or is the cultural mistrust amongst African Americans the leading driver for some of these findings? Or described differently by Malcom Cort in his 2004 paper *Cultural Mistrust and Use of Hospice Care: Challenges and Remedies*, it is possible that the "collective attitude of the African-American community towards a social system that they define as discriminatory, promoting doubt rather than inspiring confidence, is powerful enough to dictate their attitude toward end-of-life issues" (page 66).

One way the community of medical educators and providers can attempt to counteract cultural mistrust, specifically in education, is ensuring that there is adequate representation of minority students in the medical profession. Research suggests that by improving racial and ethnic diversity in health care systems there can be improvements in the acceptability of programs like palliative care and hospice care (Cort, 2004). Even attempting to achieve this goal, however, is fraught with racial bias and cultural mistrust that can be difficult to overcome. A 2016 report on one medical school's experience was

released recently, showing that at this institution there was significant evidence of implicit racial bias amongst a significant number of members of the admissions committee. After these members were made aware of the results, a majority of them thought knowing this result would be helpful in reducing bias. Consequently the year after this study the school had its most racially diverse class in its history (Capers, Clinchot, McDougle, & Greenwald, 2016).

While this study shows how difficult it can be to improve the racial diversity of our medical professionals and thus take steps to heal the cultural mistrust that exists in medicine, it also shows how an awareness of these biases can result in positive impacts. Similarly, the goal of this section is to systematically review some of the educational barriers to palliative care and to bring awareness to the racial biases of physicians and the cultural mistrust of patients that can contribute additional layers of complexity to this topic.

CHAPTER 3

PROVIDER AND PATIENT COMMUNICATION – STRUCTURAL AND RACIAL BARRIERS TO PALLIATIVE CARE

Effective communication is an important aspect of medicine and has been increasingly seen as a critical component to the relationship between physicians and their patients. In other areas of medicine, particularly highly technical specialties that have large information gaps between patients and doctors, communication is often less important than knowledge or technical expertise. For a cardiothoracic surgeon, while their ability to connect with patients is valued, above all else their skill as a surgeon and the quality of their outcomes are more important. For palliative care, communication is at the center of the specialty; Hospice and Palliative Medicine specialists are required to have extensive knowledge about life threatening illnesses and their treatments, and they receive additional training on effective communication techniques that focus on ways to improve their relationships with patients. This section will explore ways in which ineffective communication can adversely affect outcomes and present a substantial barrier to palliative care. In addition, it will look at studies that show distinct racial differences in how physicians communicate, how minority patients respond to different types of communication, and how race can be an additional barrier to palliative care.

In 1995, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients; the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments* (SUPPORT) trial was published in the Journal of the American Medical Association (JAMA) and its findings shown a very unfavorable light on the state of communication between physicians and patients at the end of life. The study was a

prospective study that initially enrolled 4301 patients (during phase I) who were in the end stages of various diseases and had a predicted survival of 52% at six months (with an actual survival of 48%). The purpose of the study, in addition to several other outcomes, was to assess timing of DNR orders, whether patients and physicians agreed on DNR orders, and the effectiveness of symptom control. In this cohort, almost a third of patients (31%) indicated to investigators that they preferred to not receive CPR. However, among these same patients less than half (47%) of their physicians could relay this preference accurately to investigators. Even more concerning was that 49% of those patients did not have a DNR order recorded during their hospitalization despite a verbalized preference to not have CPR, implying that they would have received treatment that was contrary to their wishes. Ultimately, almost 80% of patients who died during their hospitalization had DNR orders at their time of death, but 46% of these were initiated in the last two days of the patient's life. As for pain control and symptom management, surrogates for patients reported that half of the patients (50%) suffered with moderate or severe pain at least half of the time in the final three days of life (Connors, Jr, Dawson, Desbiens, & et al., 1995). The unsettling realization that emerged from this study was that in a subset of patients where doctors could accurately predict their mortality, those same physicians had relatively little communication with their patients regarding end of life preferences and even when they did, those preferences were not reflected in hospital documentation. While this study is now over twenty years old and the hope would be that conditions have improved, there is compelling data from more recent studies that indicate physicians still do a poor job communicating with patients and successfully translating patient wishes into care those patients receive in the hospital.

Several notable changes have occurred since the SUPPORT trial was published in 1995. Hospice and Palliative Medicine was officially recognized as a subspecialty in 2006 and has seen increasing numbers of physicians enter the field. A majority of hospitals with over fifty beds now have palliative inpatient care services and 84.5% of medical schools have exposure to at least one palliative care program (Goldsmith, Dietrich, Du, & Morrison, 2008). Also, patient centered medicine, or the practice of medicine that centers around the patient's wishes for medical care, is now firmly established as the standard of care. However, communication barriers continue to exist, especially regarding end of life care and life limiting illnesses. A 2015 study *Is Care for the Dying Improving in the United States?* continued to show that patients were not receiving the care they wanted. 20.9% of family members of patients who died in the ICU responded that decisions were made that were contradictory to the patient's wishes. Also, one in five family members expressed concerns over communication with medical providers and indicated they were not kept adequately informed of the patient's condition. While this study was not specifically focused on assessing palliative and hospice care, they did note that when hospice was involved respondents were over twice as likely to say their care was excellent as those who did not receive hospice care (Teno, Freedman, Kasper, Gozalo, & Mor, 2015).

Other studies that attempt to identify the specific challenges to effective communication have come up with several possibilities. First, physicians indicate that uncertainty of diagnosis is a significant barrier to both conversations about end of life care and getting a palliative care consult for patients (Oishi & Murtagh, 2014). Second, what physicians believe is important to patients during end-of-life care is different than

what patients think is important. A 2000 study interviewed groups of patients, physicians, and bereaved family members to assess what they felt were important attributes in end-of-life care. While the top three choices were the same for patients and physicians, patients and families valued mental awareness and having their finances in order much higher than physicians, who tended to value more of the physical and biological aspects of dying (Steinhauser et al., 2000). Communication between patients and physicians has been improving incrementally over the years and even though it is still woefully ineffective across all groups, the challenges facing this communication when you include race are even greater.

As previously mentioned, studies have consistently demonstrated a difference in end-of-life preferences between black patients and white patients. Black patients are less likely to have DNR orders, more likely to desire invasive procedures at the end-of-life, and are more likely to die in a hospital than white patients (K. S. Johnson et al., 2008; R. W. Johnson et al., 2010). Cultural mistrust plays a prominent role in contributing to this disparity, however to identify this as a primary issue would be to ignore evidence that supports there is provider bias and physician communication deficiencies that contribute to this issue. Moreover, with palliative care consultation, some studies have shown an equalizing of some of these issues once thought to be intractable.

These issues were illustrated in a 2010 study and echo the findings of the 1995 SUPPORT trial but specifically for minority patients. When looking at racial disparities and the effect of communication on end-of-life decisions, they continued to find that black patients had preferences that were different than white patients. They continued to have higher incidence of life-prolonging care along with fewer documented DNR orders

despite having the same amount of end-of-life counseling, which would support that an underlying cultural mistrust or other factors not related to the provider could be contributing to this phenomenon. However, when the investigators looked at black patients with DNR orders and those without, they found that both groups were receiving the same amount of invasive treatments at the end of life including intubation, mechanical ventilation, and CPR (Mack, Paulk, Viswanath, & Prigerson, 2010). Like the SUPPORT trial before it, this study had important implications. While white patients and black patients received the same amount of end-of-life counseling and white patients benefited from this by receiving care that was concordant with their wishes, black patients did not benefit and continued to receive care that differed from their stated preferences. This study provides empirical evidence to support the cultural mistrust black patients exhibit; they continue to receive care that is different from white patients. In addition, when researchers interview black patients and ask questions about their healthcare experiences they find this sentiment to be true.

In the study *Delivering palliative care to patients and caregivers in inner-city communities: Challenges and opportunities*, investigators interviewed patients, healthcare workers, and other community members to see what they perceived as barriers. The topic of cultural mistrust was again brought up and participants felt “disempowered by healthcare providers” that stemmed from their difficulty in accessing care and their sense of inadequate medical knowledge. Additionally, there were multiple mentions of communication as a central reason for strained relationships with healthcare providers (Kayser, DeMarco, Stokes, DeSanto-Madeya, & Higgins, 2014). This is similar to studies that have found lower satisfaction amongst African-American patients

with regard to end-of-life care in the intensive care unit (Lee et al., 2016) and lower reported quality of patient-physician relationships (A. K. Smith, Davis, & Krakauer, 2007). One analysis suggested that due to this unique combination of cultural and racial factors, family-based communication (similar to what is provided with palliative care consultations) should be highlighted to help alleviate the communication gap that is often reported amongst black patients (Welch et al., 2005).

More recently, research has supported the concept that improved communication, family meetings, and palliative care involvement can improve the communication gap reported by black patients and possibly affect some of the differences that were once firmly attributed to racial preferences. The most general study looked at palliative care in an urban hospital with mostly non-white patients and found that palliative care consults had a positive effect on several factors. Opiate use at the end of life, existence of a DNR order at the time of death, and the chance of dying in the ICU were all positively impacted by palliative care consults, despite a majority of patients representing minority groups (Bhatraju, Friedenber, Uppal, & Evans, 2014). More impressively, there were three studies completed in the last three years that all showed a near reversal of several tendencies previously seen in black patients and occasionally attributed to cultural mistrust. A study including only patients in California found that after palliative care consultations the rate of hospice enrollment for minority groups was equal to that of white patients, whereas previous data suggested that minority patients were less likely to accept hospice care (Enguidanos, Vesper, & Goldstein, 2013). Another large, retrospective study from Georgia found that prior to palliative consultation, black patients were more likely to be full code and less likely to have chosen comfort directed care or

have a DNR order. The percentage of black patients who chose to be full code prior to consultation was a large majority, 78.8%. However, after consultation that percentage dropped to 22.2%, and the number of patients choosing to utilize comfort directed care increased from 3.5% to 34.7% (Benton et al., 2015). A third study looked specifically at advanced directives, which have historically been completed at lower rates by African-American patients. The investigators found a significant increase in completion of advanced directives after palliative care consultation amongst black patients, from 11.3% completion prior to consultation to 28.9% after (Zaide et al., 2013).

While these studies may indicate that improved communication along with palliative care services can assist in narrowing the gap between black and white patients specifically for end of life discussions and care planning, the actual implementation and dissemination of these programs in the areas that need them most is still very much a work in progress.

CHAPTER 4

CONCLUSION

The doctor-patient relationship is unlike any other professional relationship. Doctors are responsible for keeping patients well and maintaining their health, but they are also given the privilege of ensuring that patients can die in a way that is consistent with their values. Hospice and Palliative Medicine was founded on the principle that every patient with a chronic illness has the right to comprehensive team based care that can help patients and families cope with the physical, psychological, and spiritual sequelae of these conditions. When patients are given access to palliative care services they exhibit less depressive symptoms, receive fewer unwanted medical interventions, achieve better levels of pain and symptom management, and are more likely to die in ways that agree with their stated desires. Their families also feel more supported, both spiritually and emotionally, and report that palliative care improves communication that ultimately leads to greater satisfaction.

There are multiple barriers that prevent these services from being utilized effectively and in this review two systemic barriers, along with a third racial barrier that augments their strength, are explored in depth. There are serious educational deficiencies, both in medical school and residency as well as in post-graduate education, that result in physicians who poorly understand the scope of palliative care and the benefits it has conferred to patients and families. In addition, aspiring physicians and residents receive little relevant exposure to palliative care, resulting in discomfort with end of life discussions and initiating goals of care discussions. Despite having several landmark studies showing the inadequacy of current communication practices there

continues to be disparities in the way physicians perceive end of life care and what their patients desire. Lastly, the impact of cultural mistrust and racial prejudice on palliative care has profound effects on both education and communication. When there are recent studies that show ongoing unequal treatment of black patients by the medical community, it is easy to understand that the terms “comfort directed care”, “hospice”, or “do not resuscitate” to that same population are all synonymous for an unwillingness to do everything possible to stay alive.

In every medical specialty, doctors will experience death and dying. Some patients will want to die in a hospital surrounded by the most technologically advanced treatments possible while others would prefer to die in their home with minimal intervention. Understanding that often times death is not a failing of the physician or the medical system but a natural part of life is difficult, especially for people trained specifically to diagnose and to cure. Palliative care is one of the specialties that has embraced this idea and has been shown to benefit patients and families because of it. More powerfully, it can shift patient’s and physician’s perspectives on these conditions and can empower patients and their families to seek treatments that fully align with their wishes. As baby boomers are aging and the number of individuals requiring palliative care services subsequently increases every day, the barriers to palliative care will continue to limit access to this valuable service. With improved education, training, and increased exposure to the ways in which race can inform medical decision making and provider biases, future medical providers can identify patients with life limiting illnesses earlier and be more comfortable with what options are available for these individuals so that their wishes may be honored.

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