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Physician Perceptions on Treating Patients of Color at the End-of-life

Madeline de Leon
Pacific University
A thesis submitted in partial satisfaction of the requirements for the degree of Bachelor of Science in Sociology and Public Health

May 4th, 2015
Dr. Daniel Eisen
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Research questions and objectives

Death is a universal experience and the way that people are treated and cared for at the end of life is a concern for everyone. As the United States continues to experience demographic changes such as increased life expectancy and a wider range of ethnicities due to immigration, the likelihood of U.S. physicians caring for patients from a different cultural background of their own will increase (Crawley, Marshall, and Koenig 2002). The patient-provider relationship can be complicated by cultural differences and may ultimately impact the patient’s quality of care. Tensions often arise between patients and physicians when the patient’s cultural beliefs, values, and the conceptualizations of dying do not coincide with Western medical practices.

Additionally, dying has become increasingly institutionalized and the use of hospitals, hospice, and palliative care in the last stages of life has become more common. In 2012, an estimated 1.5 to 1.6 million patients received services from hospice in the United States (National Hospice and Palliative Care Organization [NHPCO] 2012). Hospice care is critical when it comes to improving the quality of life of patients in the dying process; however, the utilization of these services by minority patients is extremely low. In 2012, approximately 85.1% of hospice patients identified as White or Caucasian, 8.6% were African American, 2.8% were Asian/Hawaiian/Pacific Islander, 0.3% were American Indian/Alaskan Native, and 6.7% identified as other (NHPCO 2012). These numbers demonstrate that non-white patients are not utilizing end-of-life care, which can be attributed to cultural insensitivity, stigmatized views of Western medicine, and other factors pertaining to race. This may also be explained by lack of access, misunderstandings about end-of-life care, language barriers, and fear of cultural insensitivity by physicians and other healthcare providers. There are structural inequalities present where disadvantaged social groups, such as ethnic minorities, and groups who
continuously experience social disadvantage experience worse health or at greater health risk than advantaged social groups. Christakis (1999:26) states that the small proportion of minorities utilizing this form of care can also be attributed to the fact that “dying in modern American society has been characterized as highly professionalized, institutionalized, mechanized, secularized, and dehumanized”. Discussing death and the experience of dying is stigmatized and it is important to address these topics to ensure patients are treated effectively during this intimate stage in life.

The aim of this study is to highlight common experiences of physicians currently practicing in the hospice and palliative specialty when working with patients of color. These experiences showcase instances when physicians subconsciously engage in culturally insensitive practices. Interviews with physicians will allow us to speculate how they conceptualize methods of treatment when caring for patients of color and will help us to better understand what methods they take when differences arise. In doing so, I hope to provide insight into the following research questions: How do providers talk about race without implicitly talking about race? And in doing so, how do providers construct themselves as non-racist? The data suggests urgency for structural change within the health care system and for physicians to be better prepared to treat patients of color with respect and dignity. If physicians are able and willing to acknowledge that their patients’ treatment preferences are built upon a lifetime of cultural experiences, this will allow them to view their patients as autonomous agents. My hypothesis is that providers within end-of-life care settings bring generalized assumptions about patients of color into their interactions, even when they believe they are making a conscious effort to be culturally sensitive. The interviews may shed light on the possibility that current end-of-life policies and lack of cultural training by medical personnel contributes to the small population of minority patients’
utilization of end-of-life care. The data collected at the end of the study will illustrate that physicians are ill equipped to treat minority patients and often generalize these groups causing poor communication and less effective treatment.

This proposed research will contribute to the recent surge of interest in end-of-life care and the importance of cultural competency and sensitivity of health care providers. As the United States population continues to experience demographic changes, increased immigrations rates, and the aging ‘baby boomer generation’, this data will support the formation of guidelines and policies that promote the respect of minority patients. The proposed research will also contribute to the gerontology, sociology, and public health academic literature. As an interdisciplinary topic, the research may impact the implementation of programs within hospice and palliative organizations that focus on cultural competency. It is important that patients of color can be sure they are receiving respectful and thoughtful care as they enter an extremely intimate and sensitive stage in their lives. In order to receive this type of care, physicians must be trained in communication skills that will create a trusting relationship.

The overall goal is to determine the barriers that prevent minority groups from utilizing this care and propose guidelines and other policies that would assure that physicians and health providers act with cultural sensitivity, while delivering effective care. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments documented that patients’ emotional suffering at the end of life can be profound, yet physicians are too frequently ill equipped to address this suffering. “In response, medical societies, health care organizations, and the public have identified improved end-of-life care as a high national priority” (Steinhauser et al. 2000:2476). These findings call for an individualized approach to end-of-life care where physicians acknowledge the influence of culture on values and behaviors in order to respect and
protect the rights of patients and their families. End-of-life care and the dying process is a concern for everyone as death is a universal experience. Attention to the cultural differences of patient’s in this crucial point in life is important, as it is a very emotional and vulnerable time. Physicians should recognize that there is no one good definition of death and patients and families tend to view the end of life with broader psychosocial and spiritual meaning, shaped by a lifetime of experiences” (Steinhauser et al. 2000:2482).

**Literature review**

Examining the relationship between patients of color and physicians within hospice and palliative care is critical to improving the utilization of care and quality of life for minority groups. Although the literature about the effects of culture and race on end-of-life care is limited there are sociological theories and concepts that are relative. The Critical Race Theory is vital to this discussion and can help us to draw connections between the experiences of care by patient’s of color in a Westernized health care system. Current patient-provider interactions often result in misunderstandings and subtle forms of racism, negatively impacting patient satisfaction and effectiveness of care. The rather new concept of colorblind racism discusses theses subtle forms of racism and explains how racism can go unnoticed within every day interactions. Theories and concepts will help us to examine how physician’s act in these cross-cultural interactions. Moreover, acknowledging that mistrust and fear of providers by patients of color is deep-rooted within the history of the United States showcases the need for change and demonstrates the complexities of the topic. By exploring Critical Race Theory and concept of colorblind racism, discussing the evolution of the patient-provider relationship in the US, and referring to studies
highlighting gaps within cross-cultural interactions, we will come to understand the ways race permeates the health care system, specifically in physicians’ approach to care.

The Critical Race Theory is a collection of texts and perspectives that challenge dominant ideologies and cultural capital. These theorists believe that racism is deeply embedded in all of American society, including our institutions like the US health care system. It often provides explanations for the complex relationship between racism, race itself, and power struggles. The theory acknowledges individuals as racist because they are a product of a racist society and that racism is institutionalized within power structures that perpetuate the marginalization of certain groups. Critical Race Theory asserts that race is a social construction and recognizes the ways in which our [people of color] struggles for social justice are limited by discourses that omit and thereby silence the multiple experiences of People of Color (Yosso 2005:73). People and patients of color are often robbed of the opportunity to represent themselves and are forced to adopt the beliefs that society labels them with. Race is often thought of in terms of genetic endowment, however, according to this theory, race is created and perpetuated in our interactions and through social constructions. This phenomenon happens often, especially “when we consider racial, cultural, or ethnic factors, we shift our focus from the individual patient to that of group membership or populations” (Crawley 2005: S-60).

The Westernized health care system marginalizes patients of color and negatively impacts their health outcomes. Patients are marginalized when physicians disregard their cultural diversity and their attitudes about choices and attitudes about their health. The system in place may acknowledge that diverse populations are being served, however, the formation and regulation of policies to provide appropriate care is either absent or not present. “As a result of both the proliferation of medical technology and the even-greater contact of dying patients with
physicians and hospitals, contemporary American physicians influence the timing, rapidity, and nature of patients’ death,” therefore there is a direct correlation between the experience of dying by patients and the care given by their physicians (Christakis 1999:24). White physicians are capable of unknowingly acting as authoritative figures that have a direct impact on the health behaviors of his or her patients. A power struggle often takes place and is worsened by the fact that minorities have experienced exploitation in regards to their health throughout history. If the health care provider is not culturally competent and does not engage in culturally sensitive practices, this relationship will not have positive results and autonomy will not be respected.

Bonilla-Silva (2014) asserts that the problem of racism is not limited to controversial to groups like the Ku Klux Klan or the Republic Party. Racism is a collective process that all members of society contribute to in some way. Bonilla-Silva (2014:3) argues that, “contemporary racial inequality is reproduced through ‘new racism’ practices that are subtle, institutional, and apparently nonracial,” all of which are apparent in the healthcare setting.

Examples of racist behavior between patients and providers are not limited to verbal messages but also non-verbal cues such as lack of eye contact and other forms of body language. “Thus, a doctor’s non-verbal behavior has both immediate consequences at a patient’s first visit and longer-term consequences for the patient’s eventual recovery and well-being,” therefore, the negative impact of culturally insensitive interactions is not fleeting (Levine and Ambady 2013:870). According to Bonilla-Silva (2014:36), microaggressions can serve as a way to “overt racial appeals” and remain neutral in any given situation. Microaggressions are commonly defined as daily verbal or behavioral actions, both unintentional and intentional, that communicate derogatory messages towards people of color (Sue, Capodilupo, and Torino 2007). Unfortunately, these can present themselves in interactions within providers and their patients,
which may help to explain minority groups’ mistrust against medicine in the US. He further argues that racism is an extremely emotional topic for most people due to the fact that society has convinced itself that race is a thing of the past.

Not only does Bonilla-Silva give a vivid description of the colorblind racism that takes place in modern America, he also provides four central frames of this type of racism. The first is abstract liberalism, which involves using political and economic liberalism in an abstract way when discussing racial matters. In this way, individuals are able to present themselves as moral and reasonable when ignoring or opposing racial inequality. Naturalization is the second frame that individual’s may use by stating that racial occurrences are simply natural occurrences. When it is suggested that all individuals in one particular racial group act in the same way, it is rationalized as non-racial because “they do it too” (Bonilla-Silva 2014:28). The third frame is cultural racism that utilizes culturally based arguments to explain the standing of minority groups in society. White individuals are quick to argue that inequalities experienced by minorities are due to their lack of financial resources and poor education. Minimization of racism is the fourth frame that suggest that racism and discrimination no longer a central factor affecting minorities. Bonilla-Silva explains that these frames of colorblind racism are flexible and they are often used in combination. In doing so, it can be said that an person’s level of sympathy for certain minority groups impacts the frames they choose to use.

Bush (2011) also examines colorblind racism in her book arguing that the achievement of the American Dream by hard work is not as plausible as one might think. Minority groups are depicted as lazy, incapable, and even unworthy of acknowledgement and the root of the problems of those around them. Non-whites can say that they are not racist and condemn those who are, yet there is little done to change the structures that sustain white dominance in politics,
medicine, and education. While exposure to minority groups or groups from a different culture may positively affect people’s perceptions of those different from them, this is not sufficient to ending racism. Bush (2011:51) illustrates this when she says that, “However superficial of noninteractive, daily contact provides a space in which whites can assert their own perceptions and interpretations as ‘truths’ to justify broad-sweeping generalizations about Blacks, Latinos, and Asians because they feel they ‘know.’” There must be social awareness and education programs in order to listen and reflect on history and people’s experiences in order to make a difference. The history of mistreatment of minority groups within medical research and the contribution of social theory to this topic of cultural insensitivity in America is central to the prominence of racial and cultural tensions in medicine.

The United States’ participation in culturally insensitive research throughout history has contributed to the mistrust of non-white patients towards Western medicine. In fact, American physicians profited both financially and professionally from slavery. African Americans were claimed to have possessed physiological and anatomical features, such as thicker skin, higher pain tolerance, less susceptibility to pain, which made them ideal candidates for research. In the 19th century United States, “medical research was used to justify racial domination and support the prevailing ideology of racial inferiority” (Williams 1994:272). One of the most severe instances of exploitation in medical research was the Tuskegee Syphilis Study where 399 poor African American sharecroppers were deceived into participating in a study that resulted in approximately 100 deaths due to untreated syphilis. While these examples illustrate exploitation of African American groups, other racial groups can relate to this mistreatment in medical settings. “The history of American medicine includes torturous exploitation, deception, withholding of needed treatment, experimentation without consent, coerced treatment, and
stigmatization, perpetrated by health care institutions and physicians upon African American and other minority patients,” which explains the mistrust of health care providers by these groups (Krakauer, Crenner, and Fox 2002:186). It is suggested that knowledge of unethical and racist practices throughout US history by patients affects the patient-provider relationship and demonstrates the social structures that contribute to culturally insensitive care in today’s society. The sociological discourse regarding the marginalization of patients of color is vast and the issues regarding the effects of the field of Public Health has noted this within medical settings. Therefore, there have been previous interventions relating to cultural competency that can be applied to hospice and palliative care settings.

In the discussion of culture, ethnicity, and race, generalizations are made about whole populations, disregarding subcultures and individual beliefs and values. Health care providers often tailor treatment toward patients based on physical appearance and “most decision-making theories reflect biases of Western cultural and ignore the influence of family members and the larger social networks” (Kwak and Haley 2005:640). Providers often base their treatment of patients off of generalized beliefs about specific minority groups. Westernized medical practice is still considered foreign to minority patients, especially those who are immigrants. A self-administered questionnaire was given to Japanese American and Japanese patients from Japan to determine how immigration affects perceptions and satisfaction of care in the United States. The study determined that “controversy may develop when a minority patient or family acts on culturally-based values that are at variance with the U.S. norm” (Matsumura, Bito, Liu, Kahn, and Fukuhara 2002:536). Patients bring cultural beliefs with them as they enter relationships with health care providers often causing conflict when approaches to good medical care are not in alignment. Additionally, a web-based survey of hospice directors found that directors often
overestimated how well programs in general are doing in terms of providing culturally sensitive care. Hospice services tend to “reflect the traditional paradigm of the dominant culture” which can further oppress minority populations (Beckwith and Reece 2013:2). Although the study of Japanese and Japanese American patients concluded that Westernized practice of medicine relies on stereotypes in their provision of care, the results of this web-based survey illustrates colorblind racism in practice. In overlooking the organization’s failure to provide culturally competent care, with a belief that their care is sufficient enough, it proves that hospice organizations are still not culturally sensitive.

There have been many studies conducted in order to collect the perspective of minority patients in end-of life care. In a study of terminally ill patients in ICU’s, Sprung et al. (2000:1738), found significant differences associated with religious affiliation and culture and observed end-of-life decisions, times to therapy limitation and death, and discussion of decisions with patient families. This highlights the individualized relationships between culture and religion, socioeconomic status, education, income, etc. A lack of communication amongst physicians and their patients is an ongoing concern for minorities who feel misunderstood by healthcare providers. Such misunderstandings soon lead to mistrust and, “even in the absence of overt bias, subtler differences in the doctor-patient interactions experienced by White and minority group patients, respectively, may produce discrepancies in trust and satisfaction” (Levine and Ambady 2013: 868). A case study of a Hispanic woman illustrated how physicians must understand the cultural context behind forms of communication. The patient would often nod to be polite, but the physician would accept this as a form of agreement. There was also miscommunication between an African American patient and his physician who felt he was being discriminated against when he did not receive maximal care, a common perception of
Black minorities who have experienced discrimination in the past (Crawley et al., 2002). In both cases, patients experienced less than optimal care because the providers failed to consider their cultural and generational differences. This is another example of colorblind racism in that by treating all patients the same, providers may unknowingly participate in culturally insensitive practices. Recognizing cultural background and its effects on decision-making and end-of-life treatments is important for physicians who will ultimately decide how to care for patients.

This calls for a new definition of end-of-life care that strays away from solely Western ideals and recognizes that the dying process is conceptualized differently by diverse cultural backgrounds and shaped by life experiences. In most studies, patients communicated common preferences about the type of care they sought from physicians. Bosma et al. determined in their review of several qualitative studies that patients value health care providers that are compassionate, respectful, and do not talk about “dying” necessarily. They promote an individual approach to care where “patients and families emerge more readily as the experts of their own culture, while health care providers (HCP) shift their focus to seeking an understanding of what it means in the context of HCP” (Bosma et al., 2010, p. 520). Born et al. conducted two focus groups in order to assess the attitudes and beliefs of hospice services and found that common to all cultural groups was the “view of hospitals as being sterile, rigid places where routines and procedures often take precedence over an individual’s needs” (Born et al., 2004, p. 251). There must be a shift in the way patients are treated in this vulnerable time in life and a cultural sensitivity must be adopted to assure quality care. High-quality end-of-life care results when healthcare professionals: ensure desired physical comfort and emotional support, promote shared decision making, treat the dying person with respect, provide information and emotional support to family members, and coordinate care across settings (Teno et al., 2004, p.
Improving end-of-life care for patients of color is a difficult task as the theories discussed validate how deeply embedded cultural insensitivity is within US society.

Broader end-of-life research is still in its infancy and greater researcher is required to gather more perceptions and experience of minority patients in hospice and palliative care. Many projects and guidelines have been provided in order to ensure programs are providing quality care to diverse populations. One approach to the scrutiny of current programs should include: *availability, awareness, acceptability, and accessibility of services* (Gelfand 2003:135).

Providers must recognize that there are many factors that contribute to the inaccessibility and stigma of end-of-life care by minorities. Barriers to optimum end-of-life care are institutional, cultural, and individual and the complexity of these barriers is increased by the dying process itself (Krakauer et al. 2002). “Teaching doctors to approach interracial interactions with the goal of learning could open them to learning more about race and cultural differences,” while reducing their anxiety and hesitant about having these type of interactions (Levine and Ambady 2013:873). Project Implicit, a collaboration between Harvard University, University of Washington, and University of Virginia, provides a series of well-designed virtual activities where visitors can explore their underlying preferences and prejudices in a safe, secure environment. Projects like this can contribute to the future of culturally sensitive end-of-life care.

**Methods**

**Introduction to Method**

This qualitative research study focuses primarily on the ways in which colorblind racism enables providers to engage in non-culturally competent practices. A qualitative study will allow for the detailed understanding of the human experience and how a physician’s background and
personal beliefs influence their treatment and communication methods when treating patients of color. Critical Race Theory and other sociological concepts, such as colorblind racism, will be used to further explain the actions and approaches to care by providers. In this way, deductive reasoning will be utilized as we are using theories and other premises to make conclusions about how providers engage in culturally insensitive practices. Such sociological theories are important to this discussion as they provide insight into the microaggressions and other forms of culturally insensitive practices by providers. Very seldom has someone been able to capture the feelings and experiences providers have had in treating patients from a different race and culture of their own. In-depth semi-structured interviews with providers for end-of-life patient of color will be used to illustrate the point-of-view of providers. This study is aimed at uncovering the causes or what leads providers to engage in non-culturally competent care and from these findings, we may be able to determine the most effective strategies and interventions to encourage and allow for more culturally sensitive practices within end-of-life care.

**Recruitment and Sampling**

A snowball sampling technique was used to recruit 7 participants in the Portland Metro Area. These individuals are currently practicing hospice and palliative physicians, some of which are also medical directors of hospices. They represent larger health care organizations in the state of Oregon such as Compass Oncology, Kaiser Permanente, and Providence Health and Services (St. Vincent’s) and all physicians have been practicing in the field for 5 years or more. The sample size of 7 allowed for a wide range of varied experiences and perspectives. In a demographic survey given to participants following their interviewer, I was able to capture their age, place of birth, gender identification, ethnicity, and religion (These characteristics did not affect their eligibility). Their ages range from 49 to 69 and the two oldest participants are retired
hospice physicians who are currently active in the end-of-life care community. When recruiting participants, I attempted to recruit individual’s who were younger than 55. The purpose of this was to speak to generational differences that may occur when younger providers treat older, end-of-life patients. In the study, 5 participants identified as Anglo or White and the remaining 2 participants identified as Multiethnic. With permission, all interviews were audio recorded and later transcribed.

**Research Technique and Instrument**

The use of in-depth semi-structured interviews was an appropriate technique for this research question because they provided detailed narratives and feelings by physicians that may not have been captured through observation. While ethnographic research may have illustrated examples of culturally incompetent practices by providers, there would not have been an opportunity to discuss with the provider why they acted in certain ways or said certain things. The interviews gave the opportunity for physicians to demonstrate how race impacts treatment methods and communication tools when caring for patients of color. Physicians were able to discuss controversial topics like racism within medical settings, in a confidential space. I situated myself in the field as a Sociology and Public Health student concerned with the low utilization of hospice and palliative care by minorities in the United States. End-of-life services are essential to all dying patients in order to improve their quality of life and patient satisfaction during an extremely intimate and sensitive time.

Interviews with physicians took place either at the personal work office of the participant or over the phone as a consideration of their time. The interviews lasted between 45 and 60 minutes giving enough time for physicians to answer all questions and providing insight on the topic. Physicians were asked open-ended questions in order to provide opportunities for them to
describe detailed narratives and elaborate on real-life patient experiences. The interview schedule was divided into three sections: importance of cultural sensitivity within end-of-life care, cultural consideration in conversations, and challenges within cross-cultural interactions. The first section asked providers to discuss if and why they believe cultural sensitivity is important within care. They were also asked to explain why they believe there are a low number of minorities utilizing end-of-life care. The second section directly asked if they infer about culturally significant details that may ultimately contribute to culturally insensitive care (i.e. if patients speak a language other than English at home, if they have a preferences towards who will handle their care, and if there are procedures their culture prohibits). The purpose of this section was to determine what culturally related characteristics they believe is important to one’s health care. The third section asked providers to describe, in detail, experiences they have had working when working with patients from different cultural backgrounds. This section was the most important in order to understand how physicians deal with cultural conflict and how they conceptualize such events in retrospect.

**Data Analysis**

The data collected from the interviews with physicians was analyzed using a specific coding scheme to pinpoint instances when physicians may have engaged in racist practices. The two main areas of focus were how physicians cover-up racism and also how they construct themselves as non-racist. Physicians engaged in racism when they used a variety of cover-up tactics and narratives to explain the reasons why patients of color choose not to access end-of-life care. These tactics included blaming the patients, that is, their blatant distrust stemming from the Tuskegee Syphilis Study and blaming the U.S. Health Care System. Continuing to blame
financial burdens and other related things experienced by patients of color to explain the low number of minorities utilizing and accessing end-of-life care ultimately contributes to the view physicians uphold of themselves as non-racists. The following section contains excerpts and key quotes from the 7 practicing and retired hospice and palliative physicians and medical directors. The data suggests that physicians believe they negate racism and while also fighting racism, which are combined to support the false perception they hold of themselves that they are culturally competent.

Covering-up racism

Blaming patients of color

Physicians used a number of techniques to cover-up racism in their medical practice and one of most apparent ways was by blaming patients of color. In all seven interviews, physicians made statements that clearly blamed the patients of color for either their dissatisfaction of care or not accessing hospice or palliative care services. By using phrases like “they feel”, “they don’t understand”, or “they don’t know” physicians actively undermine and devalue individual beliefs. Referring back to the literature, Bonilla-Silva (2014) would refer to this as the frame of minimization of racism in action because using these phrases implies that their feelings are not real, they are just an interpretation. Physicians claimed they knew how the patients were experiencing treatment and how they felt towards end-of-life care, however, these claims were much different than what the patients were attempting to express in their own ways. An example of this came from a narrative about a patient shared by Dr. Katrina, a multiethnic, 49-year-old hospice physician working within Providence Health and Services. She told the story of a female patient with mild dementia who only spoke her native language of Polish and Russian as a
second language. Her daughter was her primary caregiver and said her mother would regularly lie in her bed and say, “bring me the candle”, an act she interpreted as telling her daughter that she would soon pass. Dr. Katrina put the patient on several medications but was never fully sure if they were effective in treating the pain since they could not truly communicate. With the added frustration of the daughter’s constant calls when her mother would ask for the candle, Dr. Katrina and her colleagues became irritated. It was not until the patient was transferred into a skilled nursing facility where the nurse coincidentally spoke Polish, that the patient “blossomed”. Dr. Katrina expressed the frustration when she said, “I mean we were driving ourselves nuts trying to figure this out. But she was a fairly demanding patient, she was demented, and she didn’t understand, she always wanted that nurse to come in and talk to her.” This is a prime example of how physicians view their patients when cultural misunderstandings occur. In a way, Dr. Katrina was blaming the patient’s disease for her actions and focused on everything except her culture.

**Blaming history**

Dr. Brenda, a 49-year-old, White, Hospice and Palliative Physician used a scapegoat tactic to blame her African American patients for not utilizing hospice and palliative care. She said, “But I have been in circumstances where there has been a lot of anger and mistrust and it can happen in cases where, say African Americans, where the feel the medical system isn’t giving me what I deserve and I’ve been subjected to humiliation in the past and don’t trust you.” In this statement, she is referring to the Tuskegee Syphilis Study where hundreds of African American sharecroppers in Alabama were exposed to and withheld treatment from Syphilis. Dr. Katrina shared this same sentiment by saying, “And it’s so hard…so I think there are some barriers [to end-of-life care], some shaming within families but also some well-recognized fears
of the medical profession in the African American community probably as a result of historic precedence.” In both cases, the physicians are not acknowledging that the fears of the African American community are legitimate and their distrust could possibly be resolved by their acknowledgement of the mistreatment their profession is partly responsible for.

In these instances, it is clear that physicians are quick to blame the Tuskegee Syphilis Study when asked to explain their reasons for the low numbers of minority patients utilizing end-of-life care in the United States. They are implicitly saying that the system is not biased and that there are historical occurrences that can be blamed for their feelings towards current health systems. In blaming history, physicians are showcasing the frame of cultural racism by claiming that minority groups, the African American community in this particular case, maintain a cultural of creating mistrust. Physicians also minimize racism by speaking as though our system is not racist, thus re-creating mistrust and marginalizing these groups.

**Blaming the system**

While physicians blame patients of color for not accessing end-of-life care and often undermine their anxiety and fear of hospice, and the health care system as a whole, physicians also blame the system itself. Firstly, many physicians stated that the lack of diversity in Portland can explain the under utilization of hospice and palliative care. This may be partly true, however, the problem is not that there is a vast majority of Caucasian people dying in the area therefore they simply outnumber patients of color; the problem is that this health system is not reaching out to diverse populations. Dr. Sophia, a 65-year-old, Multiethnic, retired hospice and palliative physician spoke to this in our interview when I asked if there was a general consensus within the end-of-life care community about cultural competency. When asked if providers truly think they are culturally competent, she said that it was remarkable how many providers did not consider it
an issue. Dr. Sophia asked one of her colleagues how his organization accesses the Latino population in his community and they responded with, “Oh! It hasn’t really been a problem we don’t have Latino patients.” Appalled by what she heard, Dr. Sophia expressed her belief that the hospice and palliative care system has the tendency of being “cultish” and that the philosophy does not want to be moved much.

Physicians will also blame the way the end-of-life system is organized and managed. I asked Dr. Steve, a 51-year-old, Caucasian, palliative physician and medical director, to describe how his experience has been working with medical interpreters in patient interactions. His response was, “So they [interpreters] are obligated to be there, but no one ever uses them…I mean, what do you do with interpreters when they aren’t interpreting?” Imagine that you are a patient who does not speak English and your only way of communicating with your physician is through a medical interpreter. Dr. Steve disempowers his patients by withholding a vital communicative resource. As a result, his patients are unable to express concerns or make autonomous decisions, further marginalizing them. The question at the end of his response suggests that he is blaming the system creating obstacles towards using various resources patients of color need. Dr. Steve feels inconvenienced by these interpreters and blames the system for not utilizing them. Overall, physicians made statements that gave the impression that they are situated in a space that does not have room some minority groups and may behave in culturally insensitive ways.

**Self-perception as non-racists**

Fighting racism while simultaneously negating it ultimately contributes to the false self-perceptions that physicians hold of themselves as non-racists. Evidence of physicians viewing themselves as non-racists is through their self-management of race. Throughout the interviews,
physicians used self-victimization and gave me the impression they wanted me to sympathize with them when hearing their narratives about interacting within diverse populations. Dr. Michelle, a 57-year-old oncologist and palliative care medical director told me the story of a female, Hispanic patient who had a complicated family dynamic. The patient took a more passive role in her care, leaving her husband and son the primary decision-makers, and her sisters were quick to interject whenever they saw fit. The intricacies within her family and the added complication of language barriers caused Dr. Michelle to feel uneasy about the care they had given her, after all, they hadn’t seen the patient even crack a smile until the end of her life when she told the translator, “tell my family that I will be okay.” Dr. Michelle went on to say:

I always felt like there was so much more beneath the surface that I just didn’t know and it wasn’t for lack of trying, but I felt like there were things I just didn’t know and I think all of it made it hard for me to build the kind of rapport I wished I could have had, you know, the language, the different family beliefs, the religious stuff, it all stacked up to making it really hard, even though the whole team was trying. I don’t know, I think maybe having a primary Spanish speaking physician could have been helpful too and we didn’t one, so…we were just trying to do our best but it was clearly a situation where I was well-aware that we were not providing everything that was needed and I felt bad, I really did feel bad.

Not only does this quote highlight a physician actively seeking sympathy in dealing with this Hispanic patient, it sends the message that hospice providers are poorly equipped to handle these types of cross-cultural interactions. Dr. Michelle recognized that there were many cultural layers present when treating this patient that she felt she could not uncover. Despite this, it is concerning to know that many other minority patients share this family dynamic and feeling bad for the care given as a physician thinks in retrospect is not effective practice. In going back to the Polish- and Russian-speaking patient of Dr. Katrina, it was clear to me that this physician wanted me to know that she did everything she thought she could to ease the cultural tension. Dr. Katrina said, “And we did everything we could. We tried to arrange for her to have the financial
resources, we got her in Medicaid, and we got her set up so she could go back and live there [Poland] permanently.” While these financial aspects of a patient’s life are important, what about their quality of life or satisfaction of care? Losing sight of the proper care a patient is receiving can perpetuate the culturally insensitivity of physicians and negatively impact the patient’s already deteriorating health.

Included in the discussion of self-management is when physicians discuss their own race critically in order to buffer or downplay comments made or microagressions acted out when treating patients of color. An example of this came from Dr. Steve when asked if he could speak to the diversity of the patients he treats:

And it’s not for lack of trying, and I’ve been trying to get more diversity in our population of caregivers in end-of-life care and it’s a barrier we have not figured out how to get around and bring people on board to do and I think part of it’s that…because here I am a pasty, white boy coming in and I’m taking care of somebody who I can’t really understand their culture and especially in my job as a physician, like we talked about in the beginning the intimacy of this; I’m a stranger who walks in and transgressed those boundaries into the most intimate component of ones existence that can be really intimidating if there’s an element of distrust or there’s a lack of understanding of the intent and the boundary difference.

By referring to himself as a pasty, white boy Dr. Steve is acknowledging that his patients are physically different than him. Not only does he point out this difference, he goes on to label himself as a stranger who is intruding on this person’s life, an act of blaming the patient. Dr. Steve is recognizing his privilege and is distancing himself from the structures of inequality. When telling these narratives, physicians construct themselves outside of the system and call attention to whiteness, particularly within the medical system. By discussing their self-management to race and being critical of their own race, they give themselves a free-pass to engage in non-culturally competent practices.
Looking forward

Although physicians shared narratives that demonstrated moments of cultural insensitivity and failure to treat patients of color with complete respect, some stories provided a positive outlook on race within hospice and palliative settings. Dr. Courtney, a 57-year-old, Caucasian, physician and palliative care specialist, described the story of a 57-year-old, male patient suffering from diabetes, heart failure, and possible kidney failure. He had been going in for kidney dialysis at Providence Hospice (St. Vincent’s) for two days at a time, always rushing to go back home. His nephrologist was frustrated at what he considered to be patient that did not want his condition to get better. Dr. Courtney was soon called, as the only fluently Spanish-speaking physician, and she sat with this patient for three days explaining to him that there was such thing as a “silent disease”; one that is effecting your body but may not always cause physical pain. She said to him:

…You know when you bring water up from the river, that if you have a strong pump, you get a big output of water. You call it a chorro. And if your pump isn’t working well, you get a chorrito, a little chorro. And I said that’s what happening with your heart, your heart is not a good pump and it’s giving a little chorrito of blood going forward. Then he said, ‘Oh! Well why didn’t they tell me that?

This is an example of a physician meeting a patient where they are and recognizing that there is much more going on behind a language barrier. Dr. Courtney patiently sat with this man and asked appropriate questions that allowed her to gain cultural context. She not only discovered that he was from the mountain of Guatemala where illness is only treated if it causes pain, but that he had never heard of a disease that did not hurt. Although not all physicians have the travel experience in Latin America like Dr. Courtney, it illustrates how important it is to have cultural consultations with patients and ask about where they are from, what they value, and who they are
as a person. Knowing these things can guide conversations about treatment plans and preferences.

The interviews I conducted in this study and the data collected from it provided insight into the design of a Public Health intervention for a local, non-profit hospice and palliative care organization. The program will begin by procuring the funds necessary to hire an employee essential to achieving the intended outcomes. This employee will be responsible for communicating the program objectives to the organization’s staff and volunteers. The identifiable personnel will facilitate cultural competency trainings and presentations with knowledge on how to effectively present relevant topics. They will facilitate discussions about cultural sensitivity and draft the questions and main points to be offered at the patient-provider consultation. The employee will identify benchmarks to measure the program’s success and determine what changes need to be made in order to keep the program sustainable. Benchmarks may include a certain percentage of providers reporting less anxiety in cross-cultural interactions or an increase in the number of providers who participate in the cultural competency committee, which is introduced later in this section.

The second activity is a cultural consultation between patients and providers after they are admitted into a hospice or palliative service. The purpose of this consultation is to give providers the opportunity to gain cultural context and ask questions about their patients’ cultural preferences towards treatment. Questions might include the following: Where did you grow up? How have you dealt with illness throughout your life? Who do you want to be involved in your care? In the interviews I conducted in my Sociological study, all physicians spoke to the positive impacts of having providers sit down with patients, and interpreters, if necessary, for a lengthy
period of time. This is a good time to build rapport and trust between parties and to acknowledge that it is a two-way street and both providers and patients have much to learn about each other.

The third activity is the formation of a cultural competency committee that will meet monthly to discuss dilemmas providers are faced with when working with patients of color. The cultural competency committee will talk about controversial topics and experience of employees regarding race, culture, and related topics. These meetings are crucial to the program’s success because they will create common goals between providers in ensuring culturally sensitive care and a support system will be created that will facilitate effective conversations.

Intended short-term goals of the program include increased frequency of discussion about culture and its affect on health, positive changes in approach by health care providers and employees towards patients of color, and a 50% increase in comfort by providers when treating patients of color. This will be measured through a survey by the end of year two of the program. Intended long-term outcomes include a 25% increase of patients of color by year five, decreased anxiety about interactions by providers, thus making them more likely to engage in culturally sensitive conversations. Specifically the program aims to:

- Employ identifiable personnel to measure cultural competency success and oversee educational training programs by year two.
- Require a consultation between patient and provider regarding cultural preferences towards treatment by year one.
- Lead to the formation of a cultural competency committee to meet and discuss ethical dilemmas and issues regarding race, cultural, or ethnicity by year one.
- There will be a 25% increase in the amount of minority patients that choose to utilize hospice and palliative care through this organization after five years.
- There will be a 50% increase in staff comfort in engaging with patients of color by the end of year two and will be measured by survey.
Conclusion and discussion

Death and dying in the United States has become increasingly stigmatized and institutionalized. Adding race and culture to this discourse about death and dying only demonstrates the complexities within this stage of the life course. Hospice and palliative care provides vital services for patients and their families in the dying process. These services can immensely improve the quality of life of patients and families at the end-of-life; however, the utilization of services by minority groups is extremely low. Minority groups may not be accessing these services due to fear of mistreatment within a Westernized health care system. Additionally, mistrust of physicians by patients of color is not uncommon, as they have been subjected to medical malpractice throughout our country’s history.

The Critical Race Theory provides insight into this topic regarding the impacts of race on the human experience. Racism is embedded without power structures and certainly within the health system in our country. Patients of color are marginalized within this system when they are deprived of care that is respectful of their cultural background. In addition to this, the concept of colorblind racism asserts that modern racism involves subtle, every day microaggressions that perpetuate the marginalization of minority groups. Microaggressions can take place in every day interactions, becoming passive to the extent that people believe we live in a post-racial society. History also tells us that mistreatment of patients of color is deep-rooted in the United States medical system. The Tuskegee Syphilis Study provides an example of unethical behavior by medical professionals that may result in mistrust of the system by patients of color. Such topics came into play during interviews with hospice and palliative physicians.

Very few researchers have been able to record personal anecdotes from physicians in regards to treating diverse populations. My interviews with them suggested that they come from a Westernized health care system that may enable them to engage in non-culturally competent
practices. In the data analysis, it was clear that they covered up racism by blaming the patient, blaming history, or blaming the system. Physicians also constructed themselves as non-racist by being self-critical and discussing their self-relation to race. Modern racism can be extremely subtle, however, their narratives gave examples of what these newer forms may look like today. In all cases, physicians provided narratives and shared experiences illustrating that there is a lack of cultural competency within end-of-life care settings.

This study can contribute to the academic literature in gerontology, sociology, and public health. Further research should evaluate the quality of medical interpreters and determine if interpreters are educated on cultural context behind language. We should also study the effectiveness of community health workers in hospice and palliative settings. The use of community health workers is on the rise as they provide invaluable insight to health care providers who are working with their community members. Lastly, future research should study the impacts of gender and religion on treatment styles towards patients of color.
Appendix A

Interview Guide:

Can you tell me your name and about the work that you do and the type of patients you treat?

Importance of cultural sensitivity within end-of-life care
- Why do you think the end-of-life is such an intimate stage in the life course?
- Do you find you have a lot of diversity in the patients you treat?
- Why do you think more Caucasians utilize end-of-life care versus non-white patients?
- In what ways do you believe cultural sensitivity is important in hospice and palliative care settings?

Cultural considerations in conversations
- How important do you think it is to ask patients if they speak a language other than English in their homes?
  - Rephrased: Do you have experience working with individuals with Limited English Proficiency?
- How important do you think it is to ask patients what their usual diet is like?
- How important do you think it is to ask if their are certain procedures or treatments that their culture prohibits?
- How important do you think it is to ask patients what their healthcare experience was like in their native country (if applicable)? Or how their experiences have been in the United States?
- Are there instances when you ask the patient if they have anyone else they would like you to share medical information with?

Challenges within cross-cultural interactions
- Please share any experiences you have in working with individuals from backgrounds different from yours.
  - Describe instances in which a patient’s cultural background conflicted with a proposed treatment plan.
- How would you go about building rapport with a patient who is from a background different from yours?
  - Would you do research on your own?
  - Would you talk to family members and friends?
- If you suspected a patient was experiencing challenges (not following treatment plan, missing appointments, etc.) due to cultural preferences, what steps would you take to understand their preferences?
- What are some of the challenges you have encountered in working with patients from diverse populations?

General
- Have you ever participated in cultural competency training (in medical school or within the office that you provide treatment/care)? Please describe the experience.
• Do you have any colleagues or know of anyone else who may be interested in participating in this study?
• Thank you and contact information for possible follow-up and study results.
Appendix B

Demographic Questions

- What do you identify your gender as?
- What is your age?
- Where were you born?
- Please specify your ethnicity.
- What is your religion? (If applicable)
- What type of health care provider are you?
Appendix C

Coding Scheme

**Category 1: Colorblind racism**
- **Code:** Socioeconomic status
- **Code:** Education
- **Code:** Income
- **Code:** Access to health care
- **Code:** Geographic location

**Category 2: Culturally insensitive patient-provider interactions**
- **Code:** Verbal (By provider)
  - **Subcode:** Title provider gives to patient
  - **Subcode:** Tone or verbal message by patient to provider
- **Code:** Non-verbal (Expressed by provider about patients)
  - **Subcode:** No eye contact
  - **Subcode:** Inexpressive
  - **Subcode:** Closed body language
  - **Subcode:** No communication

**Category 3: Provider discomfort**
- **Code:** Hesitancy
- **Code:** Nervousness/anxiety
- **Code:** No connection/rapport
- **Code:** Back tracking

**Category 4: Provider solutions**
- **Code:** Outside help
- **Code:** Self-education
- **Code:** Seek assistance from family/friends of patient

**Category 5: Acknowledging structures of racism (Race-conscious)**
- **Code:** Structural barriers
- **Code:** Refer to statistics
- **Code:** Mention of false post-racial society
References


