THE PERCEIVED BARRIERS TO HEALTH CARE ADVANCE DIRECTIVE POSSESSION IN THE BLACK AMERICAN COMMUNITY—SHOULD WE ADDRESS IT AS A RACIAL DISPARITY OR A CULTURAL DIFFERENCE?

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ABSTRACT

Death is an inevitable part of life, yet many Americans fail to plan for this final part of life. Only about 1/3 of our country has an advance directive (Off White Papers, 2014). This underutilization of advance directives is reflected in our health care spending. It is estimated that 30% of all Medicare spending occurs during the last six months of a patient's life.

The numbers are even lower when broken down into sub-categories. Only 24% of older Black Americans possess an advance directive versus 44% of their older White counterparts (Huang, Neuhaus, & Chiong, 2016). Some studies found that African Americans were more likely to "express discomfort discussing death, want aggressive care at the end of life, have spiritual beliefs which conflict with the goals of palliative care, and distrust the healthcare system" (Johnson, Kuchibhatla, & Tulsky, 2008). Other studies have even concluded that Black race is an independent predictor of lack of advance directive possession (Huang et al., 2016). This paper further explores the possibility that race and ethnicity may simply be proxies for cultural values that impact advance directive possession. We'll discuss the barriers, for both Black patients and health care providers, to advance directive possession as well as investigate culturally mindful interventions to combat the barriers.

This thesis is dedicated to my family, my patients, The Center for Bioethics, Urban Health, and Policy at Lewis Katz School of Medicine at Temple University, and the Student National Medical Association. All of which continually inspire me to advocate for culturally competent and clinically excellent care to the underserved.

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CHAPTER 1: BACKGROUND

Death is the greatest inevitability of life. Greater than 2.74 million Americans die each year ("FastStats - Deaths and Mortality", 2017). Despite this, many Americans fail to plan for this ultimate event. Only about one third of our nation has advance directives in place (Andrews, 2017). This results in health care providers being left in the dark regarding patients' end of life wishes. The result of this is seen in our end of life health care spending, where it is estimated that nearly 30% of all Medicare spending occurs during the last six months of a patient's life" (Off White Papers, 2014). Based on extrapolations, the future is not promising. Often times, end of life care is incongruent with the patient's actual wishes because life-sustaining measures are taken when an advance directive is not in possession. Many families live with the mental, economic, and emotional burden left behind from this lack of planning. This is what led me to explore the topic further.

In 2014, the Institute of Medicine published a report called *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. The report revealed that we had end of life health care delivery all wrong. For Americans, most of our health care spending happens in the last six months of life. The lack of end of life planning, advance directive possession, and provider-patient communication were major contributors to patients, particularly from underserved communities, receiving expensive and low-quality care that is often misaligned with patients' actual wishes (Huang et al., 2016). This care includes CPR, ventilators, invasive tube feedings, blood products, dialysis, blood drawing, surgery, and invasive diagnostic tests.

As stated before, lack of end of life care planning is a problem for all Americans. But, Black older Americans are far less likely than their older white counterparts to possess an advance directive. Even when controlling for possible confounding factors such as "gender, age, retired or disabled employment status, educational attainment, religious affiliation, internet access, preferences for physician-centered decision making, and desiring longevity regardless of functional status," black race was an independent predictor of advance directive possession. A modest 24% of Black older Americans have advance directives, whereas 44% of older white Americans possess them. In a survey of 205 older adult Americans, "African Americans were more likely to express discomfort discussing death, want aggressive care at the end of life, have spiritual beliefs which conflict with the goals of palliative care, and distrust the healthcare system" (Johnson et al., 2008)

Advance directives are a relatively new concept. In 1967, human-rights lawyer Luis Kutner, who represented the Euthanasia Society of America, proposed the first advance directive (Sabatino, 2010). He was tasked with the challenge on how to proceed with care when a patient no longer had the capacity to make their own decisions. He suggested that the patient plan out their course of care prior to the point of incapacitation. He called it a living will, or a "testament permitting death". The purpose of this tool was to prevent the patient from being subjected to any unwanted treatments without their own consent. Physicians just started advocating for them about fifty years ago (Andrews, 2017). In 1992, the Patient Self-Determination Act was enacted. One of its purposes was to encourage patient utilization of advance directives in order to preserve their dignity at end of life. An advance health care directive is a term that is used to describe the different options you have for making health-care related decisions in times when you're deemed

to be medically “incompetent”. It’s all to help relay to physicians what the patient’s wishes are regarding end of life care. Any physician can determine a patient to be incompetent, or unable to give informed consent, if despite educating them on a healthcare topic they must make a decision about, they are still unable to understand the potential benefits, risks and alternatives to a proposed health care decision; make that health care decision on their own; or communicate that health care decision to any other person. This definition is very dynamic. It must be noted that an intellectual or developmental disability does not exclude one from having capacity to give informed consent. Even if an individual does not have capacity, they should be included in their own health care decision making to the greatest capability possible.

In 2006, a law was enacted in Pennsylvania called ACT 169 that breaks down the specifics of advance directives and gives a framework for governing such ("Facts on Act 169 Advance Directives", 2013). It described some of the main tenets of an advance directive such as assigning a healthcare power of attorney and drafting a living will. It also detailed what happens in the event that you do not have a healthcare agent assigned prior to incompetency. One option for end of life planning is drafting a living will. “Living wills focus on life-sustaining treatment and other end-of-life care. The Act generally defines life-sustaining treatment as treatment that merely prolongs the process of dying or maintains the patient in a permanently unconscious state. A living will is not even operative (i.e., in effect) unless the patient is incompetent, and the patient has an end-stage medical condition or is permanently unconscious.” So, we as physicians would just follow the rules that you outlined in your living will when it comes time for end of life.

A healthcare POA (power of attorney) is selected by you and can withdraw (take off life support) or withhold (Do not resuscitate orders to allow for a natural death) care regardless of whether you're in a persistent vegetative state, have an end stage medical condition, or not. You've given them that decision making power and trust that they will fulfill their duty of doing what is best for you. Of note, withholding or withdrawing life sustaining treatment does not mean that you cannot get comfort (palliative) care or hospice care.

A healthcare representative is not selected by you. It is assigned to the patient in the event that they do not have a living will, healthcare POA, or guardian. This person only has decision making power if you're in a persistent vegetative state or have an end stage medical condition. They, too, can make Do Not Resuscitate (DNR) orders. In Pennsylvania, health care agent is assigned by a statutory list in the following order of priority:

1. spouse and adult children who are not the children of the spouse
2. adult child
3. parent
4. adult sibling
5. adult grandchild
6. close friend

This means that if you are at the end of life and find yourself in a situation where you have not chosen a healthcare power of attorney, decision making power defaults to these people going down the list in priority order. So, say you have been in a relationship with someone you trust more than anyone with making your health care decisions. You fall gravely ill and are no longer competent to make decisions. Your treatment team

determines that you have an end stage medical condition and would like to have a goals of care meeting. It is discovered that although in a loving relationship, you and your partner are not married. You have no children and you have been estranged from your parents and siblings for some years now. According to Pennsylvania law, your treatment team would be obligated to assign your parents as your health care agents, leaving your end of life decisions up to people who may not even know your wishes or what exactly is in your best interest. Unfortunately, I've seen this situation play out more than my fair share of times—both in the hospital and in my own community.

Barriers the possession of advance directives such as the aforementioned include ethnic differences in knowledge about advance directives, differences in access to health care associated opportunities to complete advance directives, absence of appropriate surrogates, concerns about placing undue burden on surrogates, mistrust of the medical system, miseducation, discomfort, and technological barriers.

In this paper we'll explore some of the perceived barriers to end of life planning on both the patient and the healthcare providers' part and brainstorm some possible interventions to help mitigate the problem.

CHAPTER 2: PATIENT BARRIERS

1. Religion

Religion may be the link between Black race and the perception that we prefer more aggressive end of life care. Black patients are more likely to belong to conservative Protestant denominations and are generally less likely to participate in formal advance care planning. Black patients are also more likely to believe that the timing of death is within the hands of God. People who highly value life extending treatment and view it as consistent with the will of God in end of life decision making may incorrectly view advance care planning as a means of withholding end of life care, leading to lower rates of end of life planning in religious communities (Garrido, Idler, Leventhal, & Carr, 2013).

The National Association of Evangelicals approves of withdrawal of life support that unnaturally extends life. Yet, "self-identified religious importance, religious service attendance, and positive religious spiritual coping" are all negatively associated with advance care planning. The concept is actually paradoxical in nature. To explain this phenomenon, some use the Common-Sense Model as a theoretical framework. Personal perception of our own health affects our decision making when it comes to seeking care. If someone thinks their illness is able to be controlled with medications, then they seek out that help. If they feel that it can not be controlled with such interventions, then they don't seek out help. You can relate this concept to death and dying as well. If people do not believe death is something they have control over, but instead feel that it is controlled by a higher power, then they do not participate in planning for such.

Literature over the years has suggested that the underutilization of advance directives in the black community reflects disparities in both access to healthcare and

health literacy, but an alternative hypothesis has been proposed suggesting that the racial disparities we see in advance care planning are actually based on cultural differences (Huang et al., 2016). Race and ethnicity are simply "proxies" for the black community's cultural beliefs and religious values that impact their inclination to participate in advance care planning.

This alternate hypothesis is supported by research showing that black Americans are more likely to endorse the belief set that their health is in the hands of God and outcomes, too, are determined by His will (Huang et al., 2016). The black community is also more likely than their white counterparts to want life-sustaining treatment, regardless of prognosis and quality of life thereafter. These beliefs were also echoed in another study finding that Blacks were more likely to be uncomfortable discussing the topic of death and more likely to say that believers in God do not have to participate in end of life planning (Johnson et al., 2008).

To get a better understanding of the role of religion in influencing advance care planning, I interviewed Reverend Leroy Miles, an associate pastor of Enon Tabernacle Baptist Church of Philadelphia, Pennsylvania (L. Miles, personal communication, February, 2019). As part of the clergy of Enon, Reverend Miles' responsibilities include chaplaincy work at local hospitals and preaching funerals for church members. His background also includes owning a life insurance agency. In short, Reverend Miles is no stranger to the concept of end of life planning. When I sat down with Reverend Miles, he immediately began a narrative recalling his mother's death. It was a busy week for him last year where he had to preach three funerals in one week. His mother had been driving in from Pittsburgh with his sister when she suffered a heart attack while getting off the exit close to Reverend Miles' home. Although his mother was a Licensed Practical

Nurse, his mother did not have an advance directive and his family had never discussed end of life wishes with her. After a short discussion with his friend, who was also a cardiologist at the hospital, Reverend Miles decided to go and let his mother "receive her reward". He gave the okay to withdraw care. When I asked if he'd had any regrets or reservations in that moment, he replied, "no". "I never looked back. Not at all. In that moment, everything that I said to the five funeral families that week, I believed". When I asked why he thought that his mother had not possessed an advance directive he said that it went back to conversations. He felt that both practitioners and black patients needed to start having those "honest and transparent" conversations. We just don't talk about it enough culturally. Those of us in positions of influence should be working to figure out creative ways to start the conversation. It should be done at the dinner table when talking to family. It should also be done at the very first primary care visit and included in new patient packets. Practitioners cannot assume that spouses have already had that "pillow talk" about what they'd like at the end of life. Reverend Miles did not feel that religion was a primary influence in advance directive possession since Christianity is not monolithic, but he agreed that the possession of an advance directive was important. He felt that "preparation will cut back on the trauma involved" just from his own personal and work experiences.

Members of these religious communities may have other established plans for advance care that preclude needing advance directives or may perceive that advance directive possession is inconsistent with their religious beliefs. Along these lines, Garrido and colleagues have reported that conservative Protestants, including Baptists and other Evangelicals, were most likely to report that religious beliefs would influence their

medical decisions and to endorse the claim that the length of one's life is determined by God (Huang et al., 2016).

2. Cultural Considerations

It is true that advance directives can be a great tool for "protecting autonomy and reducing distress among surrogate decision-makers" (Huang et al., 2016). In fact, as I sat in on a meeting for Temple University Hospital's Advance Directive Steering Committee, improving patient autonomy was one of the advantages of advance care planning that was mentioned. We do have to consider the value of autonomy in certain cultures though. Often times in American medical culture, we take a patriarchal approach. We try to impart our own values onto patients. When patients are unwilling to accept, we pass judgement. Medical trainees are taught that truth-telling is one of the basic values of ethics. We are taught that if we do not explicitly disclose a diagnosis to a patient, then we are not telling them the truth and are therefore being unethical. But, this concept of explicit disclosure of prognosis and planning for the end of life may not be as heavily valued in the black culture (Candib, 2002). It may actually make patients uncomfortable. Along the same lines of thinking, many Black patients could be shamed for autonomous thinking in their families and even be labeled as selfish. While at the Student National Medical Association's Annual Medical Education Conference of 2019, I had an opportunity to sit down with Dr. Brooke Mobley, a Black Philadelphia-native woman who is the Lead Physician over Skilled Nursing Care in Tampa Bay, Florida for DaVita Medical Group (B. Mobley, personal communication, April, 2019). She stated that she felt some family members guilt their dying loved ones into discomfort with the subject of death. They tell their dying family members that they can not leave them or to keep fighting. This results in "aggressive" of life care.

Another value in advance directives that is widely expressed in Western medicine is quality of life. Many healthcare professionals feel that the withdrawal of care in seemingly futile situations is the right thing to do because quality of life will never be regained. After spending some time on the Respiratory Intensive Care Unit, I often saw patients' families harshly judged for their inability to promptly bring themselves to withdrawal care in poor prognostic situations such as brain death after drug overdose. We must be careful not to reflect our own "value judgements" because patients and families pick up on this and it could result in frank conflict. It could be interpreted as putting pressure on minority families to submit to majority values.

When you break down older Americans into employment status subgroups such as employed, unemployed, and disabled, it is interesting to find that disabled Americans have the lowest rates of advance directive possession. It's even more interesting to find that disabled Blacks (24%) have much higher rates when compared to Whites (6.6%) and Hispanics (12.1%) (Huang et al., 2016). You may ask yourself why that is and the answer, in short, may be culture. As stated before, autonomy and quality of life are highly valued in the Western world. Majority patients who are disabled may feel hopeless; therefore, having difficulty finding worth in completing an advance directive. When older Black Americans were surveyed along with White and Hispanic people, it was found that Black older Americans were the least likely group to be afraid of becoming dependent on family or a nursing home for daily needs and most likely to desire a long life, regardless of how healthy or independent they would be. This is all in line with one of the overarching themes of Blackness, and that is family connectedness. The black communities sometimes-contradictory view of death as defeat also plays into this. Life, by any means necessary, is valued over an easy death. It was because Reverend Miles

was able to take a step back and realize that dying and going on to be with the Lord was a reward, that he was able to make the decision to peacefully withdraw care for his mother.

Western medicine follows the belief that autonomy translates to control over end of life. We, as health care providers, offer the unique perspective of seeing desperately ill patients be kept alive using machines. We emphasize the importance quality of life in end of life planning because of this (Candib, 2002).

"The U.S. Patient Self-Determination Act (1991) was born out of this concern, which mandated that facilities getting Medicare and Medicaid funding must provide patients their rights regarding EOL planning and give patients a pamphlet about it, asking for their preferences regarding resuscitation at the time of admission to the hospital". It was not until the recent decade that it occurred to some that the insistence upon such advance directives could be culturally inappropriate and even viewed as hostile or racist.

Another cultural value in the Black community is the idea of our elders, matriarchs and patriarchs, deserving the utmost respect. The idea of respect was also a common theme in the responses of a qualitative study examining thoughts on the utility of advance directives in a small sample of Black Americans (Dupree, 2001). Participants shared stories about care instances where they felt they were disrespected by health care providers, along with being ignored and disregarded. I, too, have witnessed this treatment of Black patients and experienced it myself, as a patient. I've found myself going back to patient rooms after rounds to try to alleviate some of their fears and explain any concepts that were left misunderstood. One participant recalled her first-time hearing about advance directives, upon hospital admission:

> Well, the way the nurse explained it to me I had to do it [submit a directive]. And, I hate for somebody to tell me I got to do it. Just ask me if I want to do it, and I probably would do it. So, when they pushed and pushed and said I had to, I said no, I don't have to do anything. I can take care of my own business.

It's considered disrespectful to *tell* a black elder what he or she *should* do. Although it is possible that the nurse was trying to suggest advance directive completion, rather than tell the patient what to do, that is how it was interpreted. Conversations, especially with elders, must be mindful of this. If an elder feels disrespected, that may dissolve rapport and you may be met with resistance.

Although some data suggests better quality of life with advance directives, including better pain management, emotional support, and satisfication with provided care, other studies suggest that advance directives are not aligned with the major cultural value set of Black Americans (Johnson et al., 2008).

3. Surrogate Decision Maker

A surrogate decision maker is someone you designate as your primary decision maker in the event that you become incapacitated. This can be a friend or a loved one, but a health care provider directly involved in patient care can not serve in this capacity. Some may have difficulty identifying a suitable surrogate decision maker. They may not have someone in their life that they trust to make this decison. Or, they may not be able to fairly identify just one surrogate decision maker. It could also be that they do not want to place undue burden on a surrogate decison maker. All lines of thinking are understandable. This dilemma becomes a double edged sword when patients become incapacitated. Because health care providers can not make this decision for patients, we

have to, then, designate a health care representative using the default list I presented earlier. This, ultimately, places that burden on family members or friends. Many times, before patients have even had the opportunity to discuss their wishes with this representative. It is a huge responsibility to place on a loved one at such a difficult time. The hope is that advance directives can cut back on some of the burden, but if we are being honest, there are decisions, such as timing, that the advance directive does not account for. Without an advance directive, the health care representative may clash with those who actually knew the patient best. The family may not all agree. Undue burden and stress become inevitable**.**

When surveryed, White, Black and Hispanic patients all agreed that health care proxy designation was a potential burden for the agent (Morrison, Zayas, Mulvihill, Baskin, & Meier, 2003). Echoing the same sentiments that many of my other interviewees expressed, Dr. Mobley felt that the hospital setting was inappropriate for first mention of advance care planning. When faced with death, many families have not yet coped with the possibility of losing their loved one, so they can not fathom the thought of letting go. Dr. Mobley felt that, as a whole, the Black community often times has great difficulty in letting go of loved ones. Sometimes, family can even guilt patients into “fighting” or “holding on”.

I also spoke with Audrey Pinera-Tanner, a black woman Pharmacist who serves as the Pharmacy Supervisor at Temple University Hospital, and is also a student in the Masters in Urban Bioethics program who is currently exploring what shapes the thoughts of Black seniors’ attitudes toward advance directives (A. Pinera-Tanner, personal communication, January, 2019). Mrs. Pinera-Tanner and I sat for hours swapping family stories about end of life. We both recalled drama and discord surrounding death in our

own families, but also peaceful transitions as well. We also shared common themes we saw in both of our families, hers—a black Southern Family with strong roots in New Orleans, Louisiana and distant roots in Cuba. Mine—a black Philadelphia based family with distant roots in Costa Rica. Both families with strong Baptist ties who believed in "fighting until the end [of life]" and "leaving it up to God" thereafter. When we sat down, she had just lost her brother, whom she had been assigned as a surrogate decision maker. Her brother, who had been disabled for quite some years, trust Mrs. Pinera-Tanner with this duty of decision maker. They had legal documents to solidify this trust and she was designated as his health care agent. When the time came, she was confident in her brothers' wishes for end of life.

4. Mistrust

To approach a community that has been largely rejected and abused by American medicine with advocacy for end of life planning is risky. Blacks may believe that if they possess a living will, the doctor may not try their hardest exhausting resources to save them or may withdraw care prematurely. It could surely result in further mistrust between patients and their medical providers. It has the potential to hurt the rapport before you even get a chance to build it. It must be done with caution and care. This is why I, along with all of my interviewees, believe that the first conversation about end of life planning should not be done in the critical care setting. In fact, it is culturally insensitive. Only about half as many black people as white will agree to DNR status and it is usually late in the hospital course after a prolonged period of discomfort for the patient.

Patients should be having these conversations with their primary care providers as soon as they establish care so that the trust can be built. It can also help with reiterating the importance of advance directives since primary care providers often know their

patients more than hospitalists and specialists and have more of a long-term relationship with them. This is reflected in the fact that black patients typically desire more life-sustaining measure, regardless of health outcome, when compared to their white peers. Black patients may reject end of life planning efforts from their physicians because as advocacy of advance directives was emerging, Black people were slowly starting to come out of a place of rejection, malpractice, and ethical violations by the medical field. For black people, wanting "everything done" is our way of pushing back at the mainstream white culture of medicine. Minority cultures typically prefer family control and no disclosure. Because overt discussion is rare between patients and their providers about racism or inequities in healthcare, conflict may initially be masked in situations where individuals and families prefer aggressive intervention while the largely white medical culture opposes intervention for an apparently futile condition.

As Dr. Justin Sanders, an Instructor in Medicine at Harvard Medical School and an attending physician in the Psychosocial Oncology and Palliative Care department at the Dana-Farber Cancer Institute and the Brigham and Women's Hospital, pointed out, the literature may actually be misinterpreting reality (Gaitan, 2016) . Do more Blacks prefer aggressive end of life care or life-sustaining care than whites? Yes. But, do Blacks as a whole prefer aggressive end of life care over comfort-focused care and dying at home? No. We have to ask ourselves why someone would even prefer aggressive care at the end of their life. In my own experiences as a black woman who has seen death in my own family since a very young age, and a long-term care charge Registered Nurse turned M.D., I'd say that we simply do not want to be killed or withheld from equitable care. We feel that aggressive treatment is a form of self-advocacy. The fear of medical malpractice at, largely, the hands of our oppressors, is real.

5. Health literacy

As Dr. Mobley and I were on the elevator headed to her room to conduct the interview, we were accompanied by a hotel bellhop. When Dr. Mobley began going over some of the common misconceptions in the Black community regarding end of life care in general, the gentleman chimed in (B. Mobley, personal communication, April, 2019).

He actually followed us off of the elevator to express his beliefs that Black people are only put on hospice to speed up the process of dying with morphine and then left to die. When Dr. Mobley and I attempted to dispel this myth by having an honest conversation with him about end of life care, the gentleman was very appreciative of the information and thanked us for trying to make a difference in the Black community, as he knew we were attendees of the Black student doctor conference.

Dr. Mobley told me that one of her biggest challenges is educating the elderly on what can happen if you *do not* have an advance directive, rather than convincing people to complete an advance directive. There's less than a 2% chance of recovery from CPR in normal patients and an even lower chance of survival in elderly patients with comorbidities. Many patients do not realize the outcomes are this grim. Dr. Mobley spends a lot of time dispelling myths in the black community as well. She finds that many Black patients have beliefs that medical professionals will just let them die or possibly even harvest their organs or expedite their death if they have an advance directive.

People with less than a high school diploma have the lowest rates of advance directive possession (Huang et al., 2016). This is statistically significant for all races. People who have completed high school have highest rates in White and Black patient populations. Hispanic populations with some college have the highest rates of advance directive possession in their cohort. This data suggests that there may be an association

with education and literacy, but many factors, such as socioeconomic status, contribute to education level as well.

In a study done by the American Academy of Family Physicians, they found that many patients felt that the terminology in advance directive documents was vague. They were unsure of how to interpret terms such as "terminal", "no hope of recovery", "life support", and "no heroics" (Spoelhof & Elliot, 2012). These terms required further clarification for many.

6. Socioeconomic Status

When I sat down with John O'Donnell, the Senior Legal Counsel for Healthcare Delivery at Temple University Health System, he explained that most of the cases he sees presented to the Ethics committee are related to lack of advance directive possession and assigning a health care representative (J. O'Donell, personal communication, January, 2019). Being a Philadelphia native himself, he felt that the issue of underutilization of advance directives in the Black community was related to class but guised as race-related. He stated that if he went to South Philadelphia, which is a predominately white poverty-stricken part of Philadelphia, he would see the same rate of end of life planning as we do here in North Philadelphia. Simply put, the lack of advance directive possession in the black community was due to low socioeconomic status and not unique to the Black community. Several studies over the years have found this not to be true. The Black community not largely participating in end of life planning with their physicians can not solely be attributed to socioeconomic status. Many were surprised to learn that Black Physicians, obviously of higher socioeconomic status, had end of life wishes that were in line with the rest of the Black community. When surveyed through the National Medical Association and American Medical Association databases, it was found that Black

physicians were more likely to desire “aggressive” end of life treatments and refuse DNR status. When discussing physicians’ attitudes toward care preferences, 58% of White physicians felt that tube-feeding in terminally ill patients is "heroic,” while only 28% of Black physicians felt this way (Mebane, Oman, Kroonen, & Goldstein, 1999). These thoughts showed that this end of life value set prevalent in the black community spans the socioeconomic spectrum.

Another demographic to consider is employment status. “The effects of retirement and disability on advance directive possession are as strong as that of black race, suggesting that employment transitions prompt many older adults to complete advance directives as part of comprehensive estate or disability planning” (Huang et al., 2016).

When examining the trends in advance directive completion in a recently deceased population of people, positive demographic predictors of advance directive completion were older age, female gender, second quartile income, and a diagnosis of chronic disease such as lung disease, heart disease, neurological disease, or mental illness (Portanova et al., 2016).

I also sat down with Spencer Rand, a clinical professor of law at Temple University, Beasley School of Law, who is accompanied by his students each week in the Cancer Center at Temple University Hospital for a community lawyering clinic. Students assist patients with filling out advance directive forms (S. Rand, personal communication, February, 2019). Mr. Rand felt that trust was at the center of the disparity he sees in advance directive possession in our community. Although he and his students’ volunteer program dates back over 25 years ago, he still sees major underutilization of advance directives, even in the cancer patient population. He felt that learning about end of life

care planning at the end of life was “strange”. In his experience working with impoverished communities and largely Black clients he’d come to realize three common beliefs regarding end of life planning. 1) Some clients feel that the law is not the answer. Something (perhaps God) else dictates end of life. 2) Some clients feel that the advance directive documents do not make a difference anyway. 3) It’ll all work out in the end, regardless. All family and loved ones will be in the room when it comes time for death and they will work together to figure things out. He found that often times, people did not go that second step in thinking to realize that this could be an incredibly difficult decision for family members to make in that moment. Mr. Rand felt that the best place for advance care planning was in social service centers, hence his clinic. He believed that outside of the hospital, it may be easier for families to see the mortality of life. It may be easier to think things through without the pressures of the inpatient hospital setting.

7. Insurance and Reimbursement

Insurance restraints impose time limits on patient interactions and affect reimbursement. Physician barriers to facilitating end of life care are often related to lack of time and incentive (Spoelhof & Elliott, 2012) Reviewing advance directives in the office setting may require greater than thirty minutes, especially if the physician meets with the potential health care proxies and family members. Billing for this service may also be problematic. Temple University health care providers confirmed this with ~25% of participants slightly agreeing and ~12% agreeing that it takes too much time to discuss advance care planning with patients ("Healthcare Provider and Support Staff Knowledge, Attitude, and Experience with Advance Directives", 2018).

When polled on what their biggest barriers were to having patients complete advance directives, Temple University Hospital health care providers felt that time was their biggest barrier, with family disagreements and the patient not being ready to discuss end of life planning coming just behind time ("Healthcare Provider and Support Staff Knowledge, Attitude, and Experience with Advance Directives", 2018). Health care providers also felt that patients not knowing what an advance directive entails is a significant barrier to possession as well as health care providers themselves not being ready to discuss end of life care and patient/family mistrust of medical professionals also playing a role in underutilization.

Of note, Medicare began reimbursing physicians in January of 2016 for counseling beneficiaries on advance care planning (Andrews, 2017). Many providers are not even aware of this information. When I interviewed Dr. Mobley, she was unaware that you could bill for end of life counseling in patients. Perhaps, educating health

systems on the financial benefits of participating in end of life care planning with their patients could be helpful in helping providers to see the incentive.

8. Knowledge
   When speaking with a Black male PGY4 Psychiatry Resident at Temple University Hospital, Dr. Datrell Ward, he stated that we do not educate physicians-in-training on the topic enough (D. Ward, personal communication, January, 2019). Many student doctors leave medical school without proper education on the topic. In his medical school, Rutger's New Jersey Medical School, students were able to practice end of life counseling by making their own advance directives. This, however, is not the standard in medical education.

9. Comfort Level
   The American Academy of Family Physicians (AAFP) noted physician discomfort as a barrier. Some physicians prefer to wait for their patients to raise the issue because of they are uncomfortable bringing it up to patients themselves (Spoelhof & Elliott, 2012).

Dr. Mobley pointed out that some physicians sense that they are culturally distant from patients and are fearful of this so they do not address end of life planning (B. Mobley, personal communication, April, 2019). A strong rapport between patients and their health care providers could help reduce discomfort for both parties.

Dr. Ward stated that, not specific to the black community, the topics of death and dying were taboo and uncomfortable in general (D. Ward, personal communication, January, 2019). No one wants to talk about. It's almost counterintuitive to physicians because the emphasis of our training is to keep people from dying, not facilitate the process. In the Temple Advance Directive Community Engagement cohort's survey monkey, ~32% of health care providers felt that advance care planning was too upsetting

for families ("Healthcare Provider and Support Staff Knowledge, Attitude, and Experience with Advance Directives", 2018).

10. Accessibility

End of life care often requires that decisions be made urgently (24). This requires easy access to a patient's advance directives if we are going to honor their wishes. Even when patients have advance directives, many do not distribute to their health care providers, surrogate decision maker, or loved ones. This can be problematic in those critical times of decision making. Also, the document may get lost in transmit from facility to facility. Without an advance directive on file, the team may default to life-sustaining measures or feel pressured into providing care based on the wishes of vocal family members, not necessarily in line with the wishes of the patient.

11. Bias

As health care providers, it is important that we identify and reflect on our own biases and the root of them to be sure we do not let them impact patient care. In a study of seventeen Black Americans ranging from 23-74 years old, it was found that participants felt that advance directives did little to alleviate their concern about dying without dignity (13). One participant shared their experience with end of life planning and felt that people with advance directives are treated with more respect than those who don't possess them:

> Having an advance directive [is equated with] having a plan and when doctors and nurses see that you have a plan, it commands respect. They will respect you more because you have made a plan.

Beliefs such as these convey a sad reality that I've seen both in and out of the hospital, the thought that Black American patients have to actually *do* something to earn the respect of their white physicians because they are not intrinsically respected.

12. Improve Accessibility of Medical and Social Services

Racial disparities in access to advance care planning is one barrier we can not afford to leave in the way (Huang et al., 2016).

In the Institute of Medicine report referenced earlier, the committee of experts found that improvements in the accessibility of medical and social services for patients and their loved ones during the end of life could potentially help us provide them with higher quality care and also cut health care costs, leading to a more sustainable health care infrastructure ("Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life", 2014).

Low adoption of advance directives among Black older Americans (as compared with white older Americans) is not fully explained by other demographic factors, religious characteristics, or personal health values. Race remains important.

13. End of Life Committee

Another intervention I have seen come together while working on this thesis is the formation of an End of Life Committee. Ideally, the individuals comprising this committee would come from diverse ethnic, racial, religious, and professional backgrounds. Their mission would be to provide education to nurses, physicians, case management, social workers, chaplains, and other care providers about advance directives and other end of life care topics. They would also be tasked with providing patients with educational resources. One effort I saw emphasized at Temple University Hospital was National Health Care Decisions Day (NHDD). This day, which is April 16th each year, is creatively centered around the two things that people recognize as the only certainties in life—taxes (due on April 15th) and death. This day “exists to inspire,

educate and empower the public and providers about the importance of advance care planning. NHDD is an initiative to encourage patients to express their wishes regarding healthcare and for providers and facilities to respect those wishes, whatever they may be" ("About Us", 2019). This can be instrumental in starting the conversation with both patients and providers.

When exploring longitudinal trends in advance directive completion, we find that although Blacks and Hispanics had similar rates of advance directive completion overall (~16%), Blacks exlusively saw increasing rates of advance directive completion between 1998 and 2012. This trend, at least in part, may be associated with educational efforts being targeted primarily at Blacks (Portanova et al., 2016).

14. Community-based Initiatives

The "community", both figurartely and physically, is central to Black culture. Community sites such as churches, barbershops, and hair salons, are staples. They are excellent places to start the conversation of end of life planning and build trust. "Congregation could be a nonclinical setting in which advance care planning discussions could help as individuals with similar attitudes toward the end of life could discuss their treatment preferences with those who share their views" (Garrido et al., 2013).

In an effort to normalize the conversation, Enon Tabernacle Baptist Church has end of life planning built into their pre-marital counseling model. They also emphasize end of life planning at Caregivers' Day every November. The Legal Ministry has also conducted advance directive workshops free to church members in which they help them to fill out the paperwork. Reverend Miles recalled that last year had a large turnout.

It is important to have end of life care planning discussions in community settings before medical crises occur, without the stressful context of immediate life and death decision making.

15. Target Career Transitions

Employment transitions may be useful targets for promoting advance care planning in underserved groups. This could be an intervention to help reduce end of life planning disparities and promote other things such as will drafting and life insurance and estate planning. In terms of policy, data suggests targeting employment transitions and access to information (such as through the Internet) for promotion of advance care planning and, ultimately, closer adherence to older adults' wishes near the end of life.

In terms of policy for promotion of end of life care planning, targeting employment transitions and access to information, particularly via the internet, is promising in terms of helping us to provide care aligned with our patients' wishes for end of life.

Per Rev. Miles, when working in the insurance industry, client transitions through life's phases were key opportunities to have those end of life plans discussions. He also pointed out that the Financial Ministry at church also does occasional classes on end of life planning and talks about the paperwork involved and where to find them.

16. Table 1: Integrate into the Primary Care Setting (Spoelhof & Elliott, 2012).

Table 4. Suggested Approach for Including Advance Directives in Primary Care

Stage	*Discussion points*	*Actions*
Routine patient visit, patient 50 to 65 years of age	"If you were to get very sick, who would you trust to make medical decisions for you?" "Have you thought of completing an advance directive?" "How would you like to be cared for if you had a devastating injury or illness?"	Provide advance directive forms Review forms, and offer to answer questions (review again at later meeting) If possible, offer a group session to introduce advance directive topics to multiple patients
Diagnosis of progressive chronic disease (e.g., heart failure, cancer, dementia, chronic obstructive pulmonary disease)	"Your health has changed. What is your understanding of your condition?" "Do you have any feelings about what you have experienced so far?" "Have your goals for care changed?" "Have you discussed your feelings with your loved ones?"	Offer to meet with patient, proxy, and family members Discuss how changes in health may have changed advance directive goals, and update forms
Increasing frailty and dependency (e.g., patient admitted to nursing home)	"If time becomes short, what is most important to you?" "Have you spoken to your proxy about any changes in your care goals?"	Meet with patient, proxy, and family members Discuss prognosis and personal goals Review life support and resuscitation options in detail, and update advance directive forms

Information from reference 6.

17. Improve Accessibility of Documents in Electronic Medical Record

Dr. Mobley felt that one barrier she faces often in advance care planning is a disconnect in communication among care providers. Here is a point where the electronic medical record can serve as a tool to knocking down this barrier and increasing accessibility to patients' advance directives that may physically be elsewhere. I remember being on the Respiratory Intensive Care Unit and having a patient who was sedated and intubated. In report, it was passed along by both physicians and nurses that the patient stated that he had an advance directive prior to becoming unconscious. When we checked the chart, both paper and electronic, there was no advance directive on file. So, we treated him as if he had no advance directive and continued with life-sustaining measures.

Because of the continuity of care that they provide, primary care physicians are well suited to make sure the advance directive is available to all members of a care team and implemented properly. Office clerks and unit secretaries should also have advance

directive forms on hand at all times and be aware of office/hospital procedures for re-ordering forms.

18. Making Efforts Patient-centered, but Family-Oriented

End of life care planning should be patient centered, but family-oriented with the understanding that the patient is a part of a larger extension. The one patient narrative I came across, the attending physician stated “I believe that it is important for people to be in charge of their healthcare and only wanted to provide you with that opportunity" (Candib, 2002). This is unfairly pushes an agenda based on personal values and biases on to a patient. Instead, we can encourage a family conversation. “If instead of seeing illness as happening to an individual, we view it as happening to a family, then we can make sense of the viewpoint that each member has a duty to protect the family and honor each other within the family roles”. America is largely an individualistic society. Minorities usually are not, as we tend to depend on one another and make collective decisions. The family unit is key. Elders are also treated with the utmost respect and some elders even feel that they’ve earned the right to pass along the hard work of decision making to their adult kids with the belief that they know and will act in the patient’s best interest. Death is scary to most and no one wants to die alone. When you consider this thought, it is not unreasonable for a person to wish to involve their loved ones in this decision-making process. If we can show families that end of life planning can be a family thing and could potentially cut back on family discord upon death, maybe we can show the value in it.

19. Take a More Informal Approach

For Black Americans, providers should consider the value of informal ways of expressing preferences, including oral and written instructions or even deferral of decisions to family. Greater emphasis should be placed on understanding and respecting

whatever care preferences patients may have and whatever form they choose to communicate these values and goals.

Less focus on the completion of documents and more emphasis on the process of advance care planning for those who are willing to do that may be necessary. Before accepting formal advance directives as the only legal standard by which medical decisions are to be made for patients lacking decisional capacity, it is important to understand why such a large segment of society has not completed these documents (Morrison et al., 2003). Philadelphia, the sixth most populated city in the United States of America, has ~1.58 million people living within our city limits ("U.S. Census Bureau QuickFacts: Philadelphia County, Pennsylvania", 2018). About 44% of those people are Black or African American.

"While considerable variability across the states still remains, changes in law and policy over time suggest a gradual paradigm shift from what is described as a "legal transactional approach" to a "communications approach," the most recent extension of which is the emergence of Physician Orders for Life-Sustaining Treatment, or POLST. The communications approach helps translate patients' goals into visible and portable medical orders" (Sabatino, 2010).

In a study done involving older black nursing home residents, it was found that patients thought that discussions with their physicians about treatment restrictions was helpful (Rich, Gruber-Baldini, Quinn, & Zimmerman, 2009). It was also discovered that their significant others felt that discussions about treatment restrictions were helpful.

Because formal advance care planning has limitations, such as problems with physical access in critical times of need, it should be encouraged that people supplement a formal advance directive with informal discussions with family members and care

providers. It's not legally binding, but at least your folks will know what you want in the end and they may end up being the people who make decisions for you in the future if you do not have a formal advance directive. If you start the conversation with informal discussions (rather than formal advance care planning), they may better reflect patients' values and beliefs. Informal discussions may also be best for people of strong religious faith because it may make them less uncomfortable with the language of Living Wills (Garrido et al., 2013)

CHAPTER 5: CONCLUSION

Many barriers exist to explain the disparity in advance directive possession in the Black community. Through literature review and narratives, we see that the barriers on the patient end exist due to both racial/ethnic health disparities from a history institutional racism, but also cultural differences. On the provider side, we see that both provider competency and the infrastructure of medicine have served as barriers to providing patients with appropriate opportunity for end of life care planning. We, as providers, must be advocates for our patients every day. We must work to eliminate the barriers with some of the aforementioned interventions we have discussed, with strong focus on community. Most importantly, we must talk with our patients. Developing a rapport and trust with our patients is paramount. We must hear their wishes for end of life care out. If they wish to share, find out the why behind their wishes. We work to eliminate racial/ethnic disparities so that patients that wish to utilize the advance directives can. But, we must also recognize that formal advance directives may be culturally inappropriate for the Black American community. In the event that our patients wish to simply discuss their wishes with us and/or family members and not fill out any formal paperwork, we must also give that choice the same amount of respect. If we shift our focus to having honest conversations with our patients about their "goals, values, and priorities" early on, we stand a much better chance at providing quality end of life care than currently (Gaitan, 2011). As with many other aspects of American medical culture, we have to get back to the basics. We must address the whys before we can jump to the solution. We can not simply assume that Black patients will not be receptive to end of life planning. We have to work with our patients to develop a culturally appropriate model for end of life planning.

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