

The Barriers to Hospice Care for African Americans

A COMPREHENSIVE PROJECT

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THE BARRIERS TO HOSPICE CARE FOR AFRICAN AMERICANS

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DEDICATION

As a memorial to all the families I have served in hospice care over the years, this project is dedicated to them. It was a pleasure to be invited into your home during one of your most difficult times. I am deeply grateful for the opportunity.

ACKNOWLEDGEMENTS

My appreciation and thanks extend to the Highest God for His faithfulness, love, steadfastness, and dedication over the years. My work aims to bring light to those who suffer unnecessarily. I sincerely want to thank you for being a God who faithfully keeps His Word. You have never changed your pursuit, and I am eternally grateful for the people you provided me with during my doctoral studies. Your divine support has been a cornerstone in my journey, guiding me through every challenge and triumph. It is through your unwavering presence that I have found the strength to persevere and make a meaningful impact on the lives of those I serve. I am deeply humbled and grateful for the continuous blessings and wisdom you have bestowed upon me.

ABSTRACT

THE BARRIERS TO HOSPICE CARE FOR AFRICAN AMERICANS

A comprehensive overview of research on The Barriers to Hospice Care for African Americans. As part of the Doctor Social Work requirements at California Baptist University, a comprehensive overview of the Community Engagement and Social Innovation Process Model (CESI Model) equips the ability to provide critical input on the pressing problem of Barriers to Hospice Care for African Americans. Innovative strategies include creating educational training modules through The Barriers to Hospice Care for African Americans website. A series of modules that align with the Continuous Quality Improvement Project has been developed to make end-of-life care more accessible to African Americans. A comprehensive project was conducted to identify barriers to hospice care for African Americans.

A critical understanding of the social problems surrounding African Americans not electing hospice care reveals a complex interplay of factors that influence end-of-life healthcare decisions within this community. The comprehensive project utilized a quantitative approach to gather data on barriers to hospice care for African Americans. The Barriers to Hospice Care for African Americans Website was created with quantitative surveys administered to a diverse sample of congregational individuals. This was done in collaboration with Hilltop Assembly of God Church. In contrast, quantitative surveys were distributed to healthcare providers and community leaders. This methodology allowed for an in-depth understanding of the unique challenges faced by this population in accessing end-of-life care.

Executive Summary

Observe

In my role as a hospice social worker, I had the opportunity to walk with terminally ill patients and their families through some of the most challenging times in their lives. I learned that African Americans need critical awareness regarding hospice care acceptance and dignity of death. Concerning dying with dignity, this issue extends beyond a focus on physical comfort and pain management. It is also about preserving personal values, autonomy, and agency. I observed that having culturally sensitive and equitable hospice services that support the unique needs and experiences of African Americans means having the right to make end-of-life care decisions, being treated with respect, and being treated with compassion.

Identification

The research literature suggests that African Americans continue to face health disparities and barriers to hospice care. Specific health disparities faced by African Americans in hospice care include lower rates of hospice utilization, delayed referrals to hospice, and limited access to culturally sensitive care. These disparities can result in inadequate pain management, unmet emotional and spiritual needs, and a lack of support for family caregivers, further exacerbating the challenges faced by African American patients and their families during end-of-life care. African Americans face specific barriers to hospice care, including a lack of awareness and education about hospice services. These barriers can contribute to disparities in end-of-life care experiences and outcomes for African American patients and their families.

Integration

Both theology and theory provide with a lens to better understand the social problem of lack of hospice care utilization among African Americans. The Bible provides examples for end-of-life planning through the stories of characters like Jacob. In the Bible, Jacob experienced a peaceful death. This is when he instructed his son to prepare him for burial. In parallel, a quiet death in hospice care is surrounded by family and friends who accept that their loved one is transitioning to the end of their life. Further sociological theory helps us understand how racism and systemic barriers continue to play a role in the social problem. Namely, comparing structural functionalism theory and conflict theory, both focus on oppression and the power that aligns to help the systems remain in power. Moreover, structural functionalism theory analyzes the healthcare system's structuralist functions that continue to dominate healthcare outcomes by creating the systems that allow African American to continue to be at the disadvantage of health care.

The goal of conflict theory is to understand how racism impacts societal norms that create oppressive systems against other groups of people. The conflict theory explains how racial disparities affect hospice care at an institutional level and systematically. Conflict theory aim to understand the issues of racism, discrimination, and the use of power to oppress minority groups within hospice care through a practical, explanatory, and normative approach. Additionally, for decades African American churches have advocated for justice reforms. The African American church has been at the forefront of equality, from civil rights to contemporary social justice movements. It has fought against systemic racism and advocated for marginalized communities' rights. Its influence and leadership have been instrumental in shaping policies and bringing about positive change in society.

Engagement

It is the primary responsibility of hospice professionals to provide quality end-of-life care to terminally ill patients. By using community-based participatory research (CBPR) methods, several key professionals were interviewed regarding the health services in hospice care and the barriers African Americans face at the end of life. According to one provider, the church has played a pivotal role in the African American experience. Despite this, the doctor believes that the biggest challenge at the end of life is the lack of advance care planning. However, African Americans struggle with end-of-life care for several reasons, including lack of advance care planning. African American community members continue to discuss barriers they face. As a result, it is evident that the church and its members can play a significant role in improving the care provided to African Americans at the end of their lives.

Assessment

An analysis of barriers to hospice care for African Americans was conducted. The objective of this study was to identify the reasons why African Americans are not electing hospice care. A significant number of African Americans die in emergency rooms and intensive care units. It is important to experience end-of-life care in a peaceful and dignified manner. The focus of this study was on African American barriers to hospice care since African Americans are unwilling to seek advance care planning and end-of-life care.

Based on the scoping review, all articles that discuss African Americans' experiences at the end of life were identified. Utilizing the Prisma Diagram as a tool for data extraction. During the scoping review, all articles were subjected to inclusion and exclusion criteria. Following this process, 16 articles were collected with the objective of creating a literature review that provides an evaluation of and future implications for serving the African American community. All people, regardless of their race or ethnicity, should be treated with dignity, respect, and comfort at the end of their lives.

Innovation

This project focuses on Barriers to Hospice Care for African Americans. As part of this effort, a website has been developed with three educational training modules offering information about barriers to hospice care for African Americans. The purpose of this program is to provide education to individuals who have been recently diagnosed with a terminal illness and are unsure what to do next. The website is designed to provide African American families with a better understanding of the end-of-life journey and how to proceed after being informed that a loved one is terminal.

Evaluation

In this continuous quality improvement project, participants were encouraged to complete beginning and ending after engaging on the website. The evaluation objectives were provided via Qualtrics, obtaining quantitative data. These questions were asked at the beginning and end of the website. Engagement on the website will increase hospice care knowledge. Engagement on the website will reduce negative beliefs regarding hospice care. Engagement on the website will increase willingness to utilization of hospice care. Additional questions were asked about demographics such as ethnicity, job title, hospice care pursuit, and whether the website had been helpful after engaging with it.

Dissemination

The following steps for the Barriers to Hospice Care for African Americans website include strengthening the website, adding additional resources, engaging more churches as partners, and applying for non-profit and grant funding. Some specific ways to enhance the Barriers to Hospice Care for African Americans website and improve user experience could include strengthening the website's design and user interface to make it more visually appealing and user-friendly, regularly updating and adding new content to keep it relevant and informative, incorporating interactive features such as quizzes or forums to promote engagement and interaction, and ensuring that the website is accessible and mobile-friendly to reach a wider audience. Engaging community partners, such as churches, in developing and promoting the Barriers to Hospice Care for African Americans website can significantly enhance its impact. By collaborating with these partners, the website can reach a larger audience and benefit from their existing networks and trust within the community. This will increase awareness and utilization of hospice care among African Americans.

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CHAPTER 1: OBSERVE

Introduction

The beginning of my career as a professional and practicing social worker was in 2015. Upon earning my Master of Social Work (MSW), I began my career as a hospice social worker. In the following years, I worked with patients who were not experiencing the same economic hardships as those living in more disadvantaged areas; as a result, I transitioned to working with terminally ill patients and their families faced with such barriers as poverty, unemployment, and socio-demographics. When I moved to the more impoverished areas, I often encountered African Americans who were facing the end of their lives. In my experience, I have walked with many families who benefit from hospice care. But would find it challenging to explain the need for quality end-of-life care. Having begun to realize that there are barriers to hospice care for African Americans, I was determined to raise awareness of these barriers.

Social Problem

In analyzing the social problem surrounding African Americans not electing hospice care, it becomes evident that a variety of factors influence end-of-life healthcare decisions within this community. The underutilization of hospice care among African Americans is attributed to several key factors. As a result of these issues, systemic disparities and cultural considerations are brought to light that impact access to quality end-of-life services. There is a historical legacy of medical mistrust and mistreatment suffered by African Americans. As a result of events such as the Tuskegee syphilis study and racial inequalities within the healthcare system, there is a legacy left behind. As a result of this history of exploitation and discrimination, African Americans have developed a deep skepticism toward hospice care and healthcare institutions.

Additionally, cultural beliefs, values, and family dynamics are crucial in end-of-life decision-making within the African American community. Strong familial bonds, religious beliefs, and cultural traditions may influence preferences for care at the end of life, with some individuals opting for home-based or spiritual care over formal hospice services.

Furthermore, disparities in access to healthcare resources, including palliative care education and outreach, affordability of services, and geographical barriers, contribute to the underrepresentation of African Americans in hospice care. Limited awareness of hospice benefits, lack of culturally sensitive care options, and communication challenges with healthcare providers further hinder African American individuals' decision-making when considering end-of-life care.

Increasing awareness of hospice benefits, enhancing cultural competency training for healthcare professionals, fostering trust and transparency in healthcare relationships, as well as increasing access to equitable end-of-life care resources in underserved communities, are essential in addressing these social problems and increasing utilization of hospice care among African Americans. Promoting inclusive and culturally competent hospice services can reduce disparities by cultivating a critical consciousness. Further, this can help ensure that all individuals, regardless of race, are treated with compassion and dignity at the end of their lives.

Observation

Observations of societal events for African Americans receiving hospice care reveal several important issues and challenges. Black Americans are more often adversely affected by hospice care inaccessibility than other races or ethnicities. Many factors may contribute to this, including socioeconomic barriers, cultural differences, and intercultural difficulties. Numerous studies have shown that African Americans are less likely than White Americans to enter hospice care, which results in disparities in end-of-life care. African American hospice patients may suffer from inadequate pain management, limited palliative care access, and diminished quality of life due to these disparities. As part of the hospice care process, culturally sensitive and inclusive care must be provided to African American patients and their families. This initiative ensures that all individuals have access to quality end-of-life care, regardless of their race or ethnicity. In hospice care, African Americans have experienced complex interactions between social, economic, and cultural factors. Several factors have contributed to healthcare disparities among African Americans. In addition to the lack of access to quality healthcare, African Americans also face systemic barriers to hospice care. Furthermore, racism, discrimination, socioeconomic inequality, and unequal access to resources contribute to the problem. Mistrust of the healthcare system, a lack of health literacy, cultural beliefs and practices, and historical trauma play a significant role in shaping African Americans' attitudes toward hospice care. African Americans have a deep-seated distrust of healthcare institutions because of historical injustices, including the Tuskegee syphilis study and other unethical medical practices, resulting in a low willingness to seek hospice care.

Environmental

The availability of community resources, the health care infrastructure, the geographic location, and social determinants of health all contribute to the health of African Americans. As a result of these factors, their access to and utilization of hospice care is significantly impacted. Disparities in end-of-life care for African Americans are further compounded when they lack access to quality healthcare facilities, palliative care services, and hospice programs within underserved communities. The historical intersections of individual and environmental factors that have affected African Americans in hospice care require an integrated approach that identifies and eliminates systemic racism, promotes cultural humility and sensitivity among healthcare providers, enhances community engagement and outreach efforts, and advocates for policies that prioritize equitable access to hospice care for all individuals, regardless of race or ethnicity.

To reduce disparities and improve hospice care quality for African Americans, we must address these historical factors and promote culturally competent end-of-life care. A constant observation of social behavior, social ills, injustices, and inequities associated with African American hospice patients reveals persistent disparities and challenges that affect the quality of end-of-life care for this population. Racism and injustice are often prevalent among African Americans receiving hospice care.

As a result of unequal access to health care resources and historical behavior within the healthcare system, African American hospice patients have experienced disparities in hospice care. Additionally, African American patients are more likely to receive suboptimal care, suffer inadequate pain management, and lack access to palliative care due to prejudices, stereotypes, and a lack of cultural competence among healthcare providers (Hospice 2018). In hospice care, African Americans are likely to experience lower quality of life and poorer health outcomes because of these systemic issues.

Limitations

In African American communities, social ills such as poverty, lack of education, and limited access to health care are disproportionately prevalent. It is these ills that affect the quality of their hospice care. As a result of social determinants of health, African Americans often have difficulty accessing quality end-of-life care as well as experiencing disparities in hospice services.

Moreover, African Americans' hospice care challenges are compounded by additional injustices and inequities within the healthcare system. As a result of structural barriers such as unequal distribution of resources, racial discrimination, and disparities in health care financing, African American patients at the end of their lives receive unequal treatment and outcomes.

These social behaviors, social ills, injustices, and inequities require a multifaceted approach in order to be addressed, including promoting cultural humility and diversity in healthcare settings, increasing the availability of palliative care and hospice services in underserved communities, promoting policies that eliminate systemic racism and healthcare disparities, and empowering African American patients and their families to advocate for their rights and preferences when receiving hospice care. It is critical that we continue to pay attention and address these issues to ensure equity and justice in the care provided to African Americans at the end of their lives (Huskamp, 2019).

Conclusion

As a result, African Americans will be able to receive dignified and equitable end-of-life care. To empower African American patients and families to advocate for their rights, culturally competent education and resources regarding their rights and options in hospice care may be provided. The provision of information on advance care planning, patient rights, and navigation of the healthcare system can be provided through workshops or support groups. Moreover, healthcare providers should actively involve patients and their families in decision-making, ensuring their voices are heard and respected throughout the end-of-life process. In this way, healthcare providers can help to ensure that patients and their families are able to make informed choices about end-of-life care.

CHAPTER 2: IDENTIFY

Introduction

Historically, African Americans have held a negative view of the healthcare system due to racial discrimination and mistreatment. It has been established that there is a profound mistrust of medical research because of past examples of medical experimentation without informed consent, such as the Tuskegee Syphilis Study. Healthcare disparities between races reinforce this mistrust and contribute to reluctance to seek hospice care.

Impact

There is considerable evidence that cultural practices and beliefs about death and dying can greatly influence end-of-life care decisions among African Americans. There may be a great deal of emphasis placed on the involvement of the family and caregiving in some African American communities. It is therefore possible for individuals to receive hospice care at home rather than in a hospice facility. The acceptance of hospice services may also be influenced by spiritual and religious beliefs, which might influence perceptions of death and dying. Providing effective end-of-life care requires a comprehensive understanding of African American cultural practices and beliefs.

In addition, historical experiences of discrimination and mistreatment within the health care system may contribute to a reluctance to seek hospice care. A variety of factors contribute to the difficulty African Americans face in obtaining quality healthcare services. Among these factors are institutional racism, socioeconomic inequality, and geographic isolation. Despite these barriers, African Americans may not be able to access and receive timely, equitable, and culturally appropriate healthcare. This may result in a difficulty in accessing hospice care for

many African Americans. In consequence, these services are underutilized at the end of life, contributing to their overall underutilization.

Comparison with other racial and ethnic groups, African Americans significantly underutilize hospice care at the end of life. Several factors may contribute to this disparity in utilization, including cultural beliefs and practices regarding death and dying, a lack of awareness and understanding of hospice care, a distrust of the healthcare system, disparities in access to quality healthcare services, and historical experiences with discrimination and mistreatment within the healthcare system. Considering these factors, African Americans are often unable to access and receive hospice care in a timely, equitable, and culturally appropriate manner.

Grand Challenge

Our role as social workers is to act as activists against racism. The oppressive legacy of racism and white supremacy in the United States has left African Americans in a position of power and oppression (Barth et al., 2022). Despite racist policies, healthcare systems, the judicial system, and biases, African Americans are still denied the dignity of death. Numerous examples of racist policies can be found within the healthcare system, such as racial segregation in hospitals. Several unethical experiments were conducted on African Americans without their consent. Furthermore, there is a continuing disparity in access to high-quality healthcare services based on racial factors.

In the judicial system, racism has resulted in racial profiling and harsher sentences for whites who commit the same offenses. A disproportionate number of African Americans are affected by discriminatory legal practices (Barth et al., 2022). The inequity of end-of-life care is

perpetuated by systemic injustices that deprive African Americans of equitable care at the end of their lives.

Experimental Trials

A sense of mistrust has been created between African Americans and the healthcare system because of the historical trauma caused by systematic racism, particularly the study of the Tuskegee Syphilis Trial. This unethical study has led to a deep-seated fear and skepticism towards medical institutions among African Americans. Many individuals in the community are still reluctant to participate in medical research or seek timely medical care. Consequently, this mistrust has contributed to poorer health outcomes and disparities in healthcare access. In the wake of this historical trauma, African Americans have developed a profound mistrust of the healthcare system (Jaiswal 2019). This mistrust often leads to African Americans avoiding hospice services that could provide comfort and support during their final days. Without access to these resources, patients may experience unmanaged pain and emotional distress. Consequently, the quality of life in their final days is significantly diminished, further exacerbating health disparities.

Furthermore, African Americans are less likely to receive hospice care when in need. The consequences of such a situation can be profound. Hospice care provides essential support for patients and their families during end-of-life situations, focusing on comfort and quality of life rather than curative treatment. It offers medical, emotional, and spiritual care tailored to terminal illnesses. Without hospice care, patients may experience unnecessary pain and distress. Families may lack the necessary support to cope with their loved ones' final days. In the absence of hospice care, African Americans are more likely to suffer from physical, emotional, and financial hardships at the end of their lives (Jaiswal, 2019).

African Americans underutilize hospice care due to several barriers, including lack of access to information and resources. Moreover, they have cultural beliefs and practices, as well as disparities in healthcare quality and delivery. Individuals may be hesitant to seek hospice care in certain cultures, religions, and practices, such as cultures that place a higher value on home-based care or those that rely on religious or spiritual beliefs. Moreover, African American communities are underserved when it comes to information and resources, and outreach efforts are insufficient to increase awareness of hospice services. Furthermore, disparities in healthcare quality and delivery, such as unequal access to palliative care and racial bias in healthcare decision-making, create systemic barriers that prevent African Americans from receiving appropriate end-of-life care (Jaiswal, 2019).

It is likely that African Americans who do not seek hospice care will suffer devastating consequences. These include unmanaged pain, reduced quality of life, and higher levels of stress for both patients and their families. In addition, the absence of hospice care may lead to increased hospitalizations and medical interventions that might have been avoided. Consequently, medical costs may increase and loved ones will be subjected to an emotional strain. The risks of physical, emotional, and financial hardship increase if appropriate end-of-life care is not provided to them. Considering this, it is imperative that barriers that contribute to the underutilization of hospice care be addressed and that all communities have access to hospice care on an equal basis.

To eliminate underutilization of hospice services among African Americans, culturally sensitive end-of-life care is essential. Providers of healthcare must acknowledge and respect cultural beliefs and practices to build trust with patients. To address the disparities in healthcare quality and delivery, they should provide targeted outreach efforts. Specific outreach strategies

could include partnering with community leaders and faith-based organizations to raise awareness about hospice care. Additionally, hosting informational workshops and health fairs in predominantly African American neighborhoods can help educate the community. Providing resources and materials in a culturally relevant manner, including testimonials from African American families who have benefited from hospice care, can also build trust and encourage utilization. As a result, African Americans will have access to the resources and support that they require to obtain hospice care.

It is recommended that the following measures be implemented to address these concerns transparently and empathically, ensuring that families fully participate in hospice decision-making and care planning. It is imperative to encourage open communication and support networks to alleviate fears and concerns. Access to hospice care should be available to all individuals, regardless of race or socio-economic status. Ensure that African Americans have equal access to high-quality end-of-life care by addressing disparities in healthcare access. As a result of implementing these strategies and fostering open dialogue within the African American community, negative beliefs regarding hospice care can be reduced. Consequently, these valuable services can also be promoted for acceptance and utilization.

Problematic Integration Theory

Barrow believes communication is essential to death and dying, first discussed in 1992, as stated in the article. Barlow addressed the importance of communication during death and dying in his article by Kuang and Barrow (2021). According to Chatterjee & Kozar, five central concepts are considered probabilistic: beliefs, expectations, uncertainties, and evaluative, which refer to values, desires, hopes, and fears. Identifying the gold standard for end-of-life care after a patient dies is paramount. Staff members of hospices refer to it as a "good death."

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Expectations and beliefs can be better understood by analyzing the problematic integration theory. As outlined in the "good death" standard, the patient should die peacefully in their home surrounded by their family members. During their illness, it is essential that their wishes are met and that they receive adequate pain management and palliative care. An individual must receive emotional, spiritual, and religious support during the final moments of his or her life. A good death standard recognizes the importance of effective communication between healthcare providers, patients, and their families. By doing so, everyone will be on the same page and respecting the patient's preferences and values will be ensured. Patients who are dying can present several challenges when it comes to hospice care. The reason for this is that different families have different expectations and understandings of death. Families fear death and dying (Rafferty et al., 2014).

Conclusion

In the social problem section, African Americans are provided with an insight into the barriers they face when seeking hospice care. Furthermore, there is a strong emphasis on death and dying, as well as a discussion of the dying process. The statistics provided illustrate not only who benefits from hospice care, but also how many African Americans die in hospitals rather than at home with their families. This disparity can lead to increased emotional distress among African American families, who may feel a sense of loss and regret not being able to provide a peaceful home environment for their loved ones. The lack of access to hospice care also exacerbates the grief process, as families struggle with the trauma of hospital deaths. Moreover, the emotional burden of navigating these systemic barriers can deepen the sense of disenfranchisement and isolation within the community. By investigating how communication affects death and dying outcomes, a problematized integration can be achieved. Also, it provides a valuable opportunity for families to be heard and educated regarding their loved one's death. The provision of quality end-of-life care should be available to all; no one should feel alone in caring for their loved ones, and everyone should be able to die in dignity, peace, and with respect.

CHAPTER 3: INTEGRATION

Introduction

In addressing barriers to hospice care for African Americans from a Christ-centered justice perspective, several models and principles can serve as guiding frameworks for promoting equity, compassion, and dignity in end-of-life care. Four models emphasize the values of justice, love, and solidarity rooted in Christian principles. In addressing barriers to hospice care for African Americans from a Christ-centered justice perspective, Christ-centered justice emphasizes the inherent worth of every individual, advocating for compassionate care that respects the dignity of all patients. These frameworks encourage the provision of hospice care that is inclusive and sensitive to cultural needs, ensuring that African American patients receive respectful and equitable treatment. By focusing on love, service, and justice as taught by Christ, these models aim to dismantle systemic barriers and foster an environment of trust and support.

Justice Model

By embracing these Christ-centered justice models and principles, healthcare providers, community leaders, and stakeholders can work collaboratively to address barriers to hospice care for African Americans, promote equity and inclusion in end-of-life services, and uphold the values of justice, compassion, and love in providing care to those in need.

- 1.) The compassionate care model focuses on providing care guided by love, empathy, and deep compassion for needy individuals. In hospice care for African Americans, this model emphasizes the importance of meeting patients and families with understanding, kindness, and support, ensuring that their physical, emotional, and spiritual needs are addressed with care and sensitivity.

2.) The social justice model emphasizes equity, fairness, and advocacy for marginalized communities, aligning with Christ's call toward justice and righteousness. In the context of addressing barriers to hospice care for African Americans, this model calls for challenging systemic inequalities, addressing social determinants of health, and advocating for policies and practices that promote equitable access to end-of-life care services.

3.) The community engagement model emphasizes the importance of involving community members, churches, and faith-based organizations in addressing healthcare disparities and promoting wellness within vulnerable populations. In the context of hospice care for African Americans, this model encourages partnerships with local churches, community leaders, and support networks to raise awareness, provide education, and offer spiritual and emotional support to individuals facing end-of-life challenges.

4.) The healing ministry model centers on healing, restoration, and wholeness, mirroring Christ's ministry of compassion and restoration. In the context of hospice care, this model calls for providing holistic care that addresses not only physical symptoms but also emotional, psychological, and spiritual well-being, recognizing the dignity and sacredness of everyone's journey at the end of life.

Our social work values are for the person's dignity and worth. Dignity in social work means recognizing and respecting the inherent worth and individuality of each person. It involves treating clients with compassion, empathy, and fairness, regardless of their circumstances. By upholding dignity, social workers empower individuals to feel valued and

capable of making their own choices. Our code of ethics and the importance of human dignity and respect are correlated with Christ-centered justice models.

Biblical Theology

The purpose of this section is to emphasize the importance of Biblical theology in death and dying, as well as to point out the racial disparities and barriers African Americans will experience during death and dying. Hospice care has been the leading specialized medicine for terminal illness patients, those struggling with underlying diseases, and those experiencing unmanageable pain. (Buss et al., 2017). The patient is introduced to end-of-life care, preferably by their physicians, who discuss treatment planning and long-term health goals. Patients want to pursue every avenue of treatment options before electing hospice care. Opting into hospice care can be overwhelming for patients due to the fear death can bring. This paper acknowledges death and dying from the Old and New Testament theological perspectives. While merging social work theories that provide evidence and understanding of the disproportionality African Americans will experience with death and dying, despite this acknowledgment, the barriers and access to end-of-life care are profound, particularly for African Americans and those in disadvantaged communities.

It has been found that minority, cultural, and ethnic groups face deficiencies in hospice care and pain management across all medical settings. African Americans have some of the highest rates of terminal diagnoses, such as heart disease and cancer (Rosa et al., 2022). Interventions that can improve access to end-of-life care for African Americans and those in disadvantaged communities include increasing awareness and education about end-of-life options, providing culturally sensitive and linguistically appropriate care, addressing systemic

barriers such as lack of health insurance or transportation, and ensuring equitable distribution of resources and services in underserved areas.

Additionally, fostering partnerships between healthcare providers, community organizations, and faith-based institutions can help create a comprehensive support network for individuals and families navigating the complexities of death and dying. This leads to them seeking resources from the emergency room for end-of-life care. (Rosa et al., 2022). African Americans continue to distrust healthcare professionals due to the health-related racial disparities they experience. (Rosa et al., 2022). Research supports that African American communities struggle to gain quality care and health services. Acquiring health insurance is a particular challenge African Americans experience. One out of four African Americans does not have health insurance, leading to the inability to obtain quality care on the death and dying journey (Dillon & Basu, 2016).

With these proven facts, African Americans and their families experience death and dying differently from other cultures. They receive discrimination and subpar care compared to whites. We should take note of the racial biases and discrimination in the health care system. Physicians report that African American patients are less intelligent, educated, and more likely to abuse substances and likely not to participate in treatment recommendations and plans than white patients (Dillon & Basu, 2016). Another known fact is that physicians feel that African Americans will not follow treatment recommendations and providing them with appropriate therapies is unimportant. This contributes to high mortality rates among African Americans due to racial and ethnic health disparities. Moreover, without end-of-life care or hospice benefits, African American patients suffering from a terminal diagnosis do not have the peace that different cultures may feel and experience in death. (Buss et al., 2017)

Barriers

To understand dying with dignity, the importance of a biblical approach, and the barriers faced and continue to be within the healthcare system. This includes African Americans' barriers to accessing hospice and palliative care services. It is vital to understand that the care provided at the end of life reflects the values and ethics of the helping professionals. It is also essential to recognize and resolve existing implicit biases. Helping professionals are trained medical providers, doctors, nurses, clinicians, social workers, chaplains, and medical personnel. The Helping professionals mirror how society responds to end-of-life care, and more significant disparities in end-of-life care result in African Americans continuing to be underserved by hospice (Reglan & Bradley, 2021).

Nonphysicians and medical providers also create a space when African Americans do not continue their hospice journey. The percentage of people who elected to receive hospice benefits was 76%. Compared to nonminority, such as black and brown patients who only elect hospice at 7.6%. The proven data compared has shown that 47% of whites are dying on hospice care, while only 31% percent of blacks are dying with hospice care; in contrast, reviewing a qualitative study on hospital usage examined hospice disenrollment for blacks and whites (Rizzuto & Aldridge, 2017). This qualitative study shows that terminally ill whites are admitted to the hospital at 8.7%, in contrast to terminally ill blacks at 19.8%. After admitting to the hospital, both no longer receive hospice care (Rizzuto & Aldridge, 2017).

The data shows that many African Americans are not seeking end-of-life care and are admitted to hospitals to die. African Americans experience barriers from physicians, nurses, and social workers. Academic curriculum and professional development of nurses and social workers provide an understanding of the limitations that minorities will experience because of the

minimum training nurses and social workers receive (Reglan & Bradley, 2021)—recognizing that education is essential for all medical professionals to understand African Americans who continue to face the disproportionate burden of hospice care that minorities receive (Belisomo, 2018).

Preparing for Death

The Old Testament of Jacob provides insight into death and dying from a theological viewpoint. Through Jacob, we see his anticipation of being with his ancestors and his instruction to his children about burial. “Then Jacob instructed them, “Soon I will die and join my ancestors.” (Genesis 49:29 New Living Translation) When patients are nearing death, they can comfort their families and prepare them for leaving this earth. His sons surrounded Jacob at the end; this relates to when families could see their loved ones take their last breath at the bedside. “When Jacob finished this charge to his sons, he drew his feet into the bed, breathed his last, and joined his ancestors in death.” (Genesis 49:33 New Living Translation)

All cultures want to be surrounded by loved ones in death. The family has peace when they are present when their loved one transitions to death as a family. Jacob’s death provides an accurate assessment of death in hospice. There is a sense of letting go from everyone, a peace in knowing that this is not the end of the story. If every race and ethnicity is not experiencing this kind of peace at the bedside, are they experiencing death and dying the way God intended? There is peace in death, and families should be provided with education at the end of life, but Joseph responded like most families. He threw himself at his father, wept over him, and kissed him.

Following the death of a loved one, this response is expected. Despite knowing death is imminent, families experience anticipatory grief when losing a dear one. After Joseph calmed himself, he told the physicians to take his father and prepare for his burial. (Genesis 50:1-2 New

Living Translation) Jacob's death correlates with the same response families have to hospice care. They can tell hospice to call the funeral home and allow their loved ones to leave and be prepared for burial, and the grieving process begins. The Death of Jacob models how hospice patients' families surround the patient at the end.

In the story of David and Bathsheba, we see another account of death and the response to death. "After Nathan returned to his home, the Lord sent a deadly illness to David and Uriah's child. David begged God to spare the child. He slept without food and lay all night on the bare ground." (2 Samuel 15-18 New Living Translation) They account for how quickly a terminal diagnosis can affect the patient and family. This account can appear in all cultures; families pleaded for healing for their loved ones. For Christians, the typical response is to start with the church asking for prayer, fasting, and a miracle. "Then, on the seventh day, the child died. David's advisers were afraid to tell him." (2 Samuel 12:15-18 New Living Translation)

David highlighted the importance of prayer during death and dying. Cultural comfort through prayer can offer meaning and comfort to people experiencing anticipatory grief for themselves or others. David exhibited the spiritual suffering a patient may endure when facing death and experiencing death. Prayer provides a sense of identity and control during a crisis by giving structure and guidance (Anderson & Souza, 2021). Not all people believe in prayers like David did or seek guidance when facing death. Everyone dies, but not all cultures will have the same spiritual response that David accounted for at his child's death. After the death of David's child, the advisors were scared to tell David of the child's death. (2 Samuel 12:15-18)

Grief is inevitable for all experiencing a terminal illness; these scripture stories point to death's pain. Grief is a social emotion and part of human nature. At the end of life, it can sometimes appear like you are making decisions no one ever wanted to make. It can be painful to

realize that your loved one will not have the shared experiences you discussed. It can look like an out-of-order death, parents burying their children. It can look like dying of a terminal illness that a patient was told about that same day (Bandini, 2022). However, God understands the pain death brings, the sorrow families feel, and the abandonment death produces. He still comforts, provides peace, and understands when a community hurts.” For the Lord never abandons anyone forever. Though He brings grief, He also shows compassion because of His unfailing love. For he does not enjoy hurting people or causing them pain.” (Lamentations 3:31-33).

Scripture shows God’s love and compassion for death and dying. He continues to meet the needs of those hurt by the death of a loved one. He promises He will never abandon those He adores; this displays His love for humanity, as discussed in Genesis. Death of a loved one can feel empty, but God will never leave anyone in grief. Lamentation shows that. In conclusion, God walked with those experiencing grief through death and dying. Solomon concludes, “There is a time to be born and die, but also a time to heal.” (Ecclesiastes 3:1-3).

Hope Amid Death

Like the Old Testament, the New Testament also guides us in facing death. Jesus’ death and resurrection is a pivotal story and foundation for a Christian theology of death and dying. It emphasizes the importance of the resurrection hope. From a Christian perspective, the family hopes for Heaven after a patient passes, and as stated earlier, Jesus provides hope through the resurrection. In Heaven, God prepares a place for everyone so that He will come and get you. John helps patients cope with their grief and sorrow through their death and dying journey. The passage that provides this hope is, “Do not let your hearts be troubled.” Trust in God, and trust also in me. My father’s home has more than enough room. If this were not so, would I have told you I would prepare a place for you? (John 14:1-4 New Living Translation) Faith is instrumental

in Christian culture while also significant for those questioning their approach to death and dying. Faith helps some terminally ill patients believe in peace in death.

At the same time, some patients seek out pastors for answers on their death and dying journey. To have the faith experience Christians hope to feel at the end of their lives (Waters, 2022). Provides peace through Jesus' resurrection. The whole Gospel message is the antidote to despair over death. Jesus is the propitiation for sin and allows hope that death will never be final or the end. Jesus is rich in mercy and offers hope for resurrection. (Ephesians 2:4-6 New Living Translation) Death on earth is final, but death in Jesus Christ lives for eternity, as written: "Oh death, where is your victory? Oh, death, where is your sting?" (1 Corinthians 15:55-58 American Standard Version) These passages point to the plan God has for creation. That everyone would spend eternity with Him, without sin, without death. The book of Revelation gives a better picture of God's plan for the future of Heaven and Earth. Where the things of this world fade away, there will be no more pain or suffering, and there will be complete Shalom.

Cultural and Spiritual Beliefs

Addition to the African American churches have been the most enduring and multifaceted institutions. The African American church provides a vital place of refuge, spiritual, economic, educational, cultural, and political support for black and brown communities. Breaking down barriers to social policy and change has been essential to social justice movements with the support of the African American church. According to King & Carson (2010), the bus protest in Birmingham, Alabama, exemplifies the influence African American culture's fundamental beliefs can have on society. As a result of protesting, the power of spiritual movements and church support was demonstrated.

Through history, the African American church has been crucial to social justice movements. From the bus protest in Birmingham, Alabama, to Dr. Martin Luther King Jr.'s civil rights movement, the church has provided a foundational space for African Americans to unite, organize, and fight for equality. In addition to breaking down barriers, it has contributed to advancing social policies that promote justice and equality. The Birmingham bus protest can provide African American churches with a foundation for conversation about death. As well as encouraging discussion about death. It is a complex understanding of black culture to bridge the gap between spiritual belief and preparing for death. Providing hospice care, this can be regarded as a hindrance. As a result, they and their families cannot prepare for burial. In African American culture, freedom will eventually come.

The purpose of this research is to gain an understanding of the African American belief system in America. During the era of slavery and segregation in America, African Americans suffered immense oppression and looked to their faith for comfort and hope. Considering Jesus to be a liberator and deliverer, they prayed for freedom and looked to spiritual leaders like James Johnson for guidance. An analysis of the historical context of African American faith in Jesus is the purpose of this research. Moreover, it sheds light on the profound effects it has had on their collective consciousness and their fight for equality. For society to recognize the pain experienced by African Americans and the hope that they have in Jesus' freedom, it must understand the pain they have suffered.

In recognition of the known racial disparities in health care, African Americans can enhance and sustain the importance of advanced care planning for death and dying (McDonnell & Ellen, 2020). It is important to understand that trust has a direct relationship to advanced care planning within the African American community, as trust is essential for effective communication and decision-making. Those who trust their healthcare providers and institutions are more likely to discuss advanced care planning with them. As a result, their preferences and wishes regarding their end-of-life care are respected and honored. Moreover, this trust enables the community to advocate for equitable access to quality health care and to address racial disparities in end-of-life care. According to Reverend Tyrone Pitts, "living well until the end" promotes the existence of humans and recognizes the presence of God and spirituality within human communities (Grant, 2017).

In this paper, we discuss the need for health professionals, clinicians, and healthcare systems to alter society's narratives to emphasize the community perspective. In addition to providing quality medical care, understanding different cultures, and honoring dying with dignity, Grant also provides a space for emotional and spiritual healing (Grant, 2017). According to Reverend Tyrone Pitts, it is imperative that one live a meaningful and purposeful life until the end. True well-being encompasses more than just physical health and medical care. It also includes an understanding of the emotional, spiritual, and social aspects of well-being. The purpose of this project is to encourage individuals to find joy, fulfillment, and connection in their remaining years. By embracing spirituality and higher power as sources of strength and comfort, this can be achieved.

Structural Functionalism

Moreover, structural functionalism theory analyzes the healthcare system's structuralist functions that continue to dominate healthcare outcomes. This is done by creating systems that continue to put African Americans at a disadvantage. Moreover, the inability to experience death and dying as God intended. (Potts et al. 2016) Structural Functionalism was created to renovate and restore the comprehensive historical belief system due to the involvement of the economic, social, cultural, demographic, and structural issues America faces (Izadi et al., 2020). The impact of structural Functionalism on healthcare outcomes is significant. By analyzing the structuralist functions of the healthcare system, it becomes clear how certain groups, like African Americans, are consistently put at a disadvantage. This perpetuates healthcare disparities and hinders equal access to quality care for marginalized communities.

Structural functionalism theory recognizes the influence of economic, social, cultural, and demographic factors on the healthcare system. These factors shape the structuralist functions that perpetuate healthcare disparities, particularly for marginalized communities such as African Americans, hindering their access to quality care and exacerbating health inequities. As discussed, end-of-life care is essential for terminally ill patients and contributes to a society that understands everyone should receive quality care. From the perspective of medical professionals, the healthcare system structure facilitates institutionalized racism, as discussed in the barriers section of the paper.

Apart from the structure of the health care system and the laws and regulations that have allowed these structures to remain in power, it is the enforcement and politicization of practices that have ruled on racial disparities. It is necessary to break these barriers by becoming interactive and socially committed to changing the laws that promote discrimination and racism (Izadi et al., 2020). Perpetuating healthcare disparities not only leads to unequal access to quality

care for marginalized communities like African Americans, but it also exacerbates health inequities and contributes to poorer health outcomes overall. It is crucial to address and dismantle the structuralist functions that perpetuate these disparities to create a healthcare system that provides equitable care for all individuals, regardless of their race or socioeconomic status.

In contrast, breaking down barriers means understanding Medicare hospice benefits and end-of-life care costs. Hospice care is a Medicare fee-for-service benefit and can average around \$15.1 billion in a year, depending upon the number of patients and the average length of time a patient remains in hospice care (Obermeyer et al., 2014). As stated, hospice is the leading specialized medicine for end-of-life care in the United States. With the knowledge that the cost of hospice care changes depending on the terminal diagnosis and the number of days a patient will remain in hospice care (Fine & Davis, 2017). Medicare hospice benefits can have a significant impact on marginalized communities, such as African Americans, by providing them with access to end-of-life care that they might otherwise not be able to afford. By covering the costs of hospice care, Medicare helps to ensure that individuals from marginalized communities can receive the necessary support and services during their final stages of life, reducing disparities in access to quality end-of-life care. What does not change are the racial barriers African Americans face to hospice care. Hospice care can provide excellent care for all, regardless of ethnicity or race. Nevertheless, systematic reviews and methods show that non-minorities benefit more from end-of-life care than other races.

Who benefits from hospice care outside of the medical provider? Medicare Payment Advisory Commission received data on Medicare decedents between 2000 and 2015. Only 17% of African Americans chose hospice care, compared to 23.8% of whites and 24.1% of Hispanics. It should be noted the difference in hospice benefits election for African Americans. This is to

understand that 8.4% identified as African American while 7.4% described themselves as multiracial or another race. Compared to 80.9% who identified as white or Caucasian (Payne, 2016). In addition to the research, there is extensive data that supports African Americans' excessive mortality rate from almost all causes of death. As a group with the highest mortality rate, African Americans might opt for end-of-life care sooner than any other group, but they continue to choose to die in hospitals (Payne, 2016).

There are several possible reasons why African Americans have a higher mortality rate. These include systemic racism and discrimination in healthcare, limited access to quality healthcare services, higher rates of chronic illnesses, socioeconomic disparities, and cultural beliefs and attitudes toward end-of-life care. These factors can contribute to African Americans choosing end-of-life care in hospitals rather than hospice care. To have the top mortality rate and not opt for hospice care, the belief would be that more African Americans would be given more avenues to seek out more treatments to survive a terminal diagnosis or help care professionals would educate African Americans on the avenues to receive more end-of-life care.

Healthcare professionals need discussion, but are healthcare professionals willing to address implicit biases and racial disparities? Implicit biases can significantly affect healthcare decision-making, particularly regarding end-of-life care. Studies have shown that healthcare professionals may have biases influencing their treatment recommendations and patient discussions, even unintentionally. These biases can contribute to the lower utilization of hospice care among African Americans, as healthcare providers may not adequately address their specific needs or provide sufficient education about available options.

Critical Race Theory

Comparing Structural Functionalism Theory and Critical Race Theory, both focus on oppression and the power that aligns to help systems remain in control. Additionally, understand that Critical Race Theory is not allowed in local schools in Oklahoma. The purpose of discussing Critical Race Theory is not a political stance but an understanding of how racism impacts societal norms that create the system that continues to oppress another people group. Critical Race Theory examines the impact of racism by analyzing how it is embedded in laws, policies, and institutions, perpetuating systemic inequalities. It recognizes that racism is not just individual acts of prejudice but a systematic and structural issue that disadvantages marginalized communities. By foregrounding the experiences and voices of people of color, Critical Race Theory seeks to challenge and dismantle these oppressive systems.

This section of the paper is not to debate the biblical perspective or create problems. This theory explains how hospice care has been affected by racial disparities at the institutional level and systematically. Equally important is to acknowledge African Americans' barriers to access to hospice care and the emphasis on death and dying; it is necessary to discuss Critical Race Theories aim to understand in a practical, explanatory, normative approach to address racism, discrimination, and the ability to use power to oppress minority groups within hospice care the hope is to dismantle racial desegregation efforts (Wright et al., 2023)

Critical race theory first believes that race is not biological but socially constructed, which means that it is socially significant to understand that perspective; there is a need to define race from a societal lens. Race can be defined as the idea of the human species, which is a distinct group yet divided based on inherited physical and behavioral differences (Wright et al., 2023). By applying Critical Race Theory to the study of hospice care, researchers and

practitioners can gain a deeper understanding of how racism operates within the system and perpetuates disparities in access and quality of care. This analysis allows for targeted interventions and policy changes that aim to dismantle racial segregation and ensure equitable and compassionate end-of-life care for all individuals, irrespective of their race or ethnicity.

Intuitively or inherited, race is enmeshed in societal institutions and must be dismantled, regardless of underlying conditioning. As a society, we must reject the notation that surrounds racism based on the belief that racism was dismantled during the Civil Rights movement. Societal conditioning plays a significant role in shaping how individuals perceive and understand race. From a young age, people are socialized to internalize certain beliefs, biases, and stereotypes about different racial groups. This conditioning can perpetuate systemic racism and contribute to the marginalization and discrimination experienced by minority communities. We must also reject the instinct to report using the colorblind framework to overcome racism (Wright et al., 2023). Colorblind is the belief that “I see people, not colors,” which is a typical response from those questioned about race.

This type of racism is subtle and expressed indirectly compared to blatant and direct. While blatant racism is more overt and easily recognizable, subtle racism can be equally damaging, if not more so. Subtle racism operates through unconscious biases and microaggressions, which can be more insidious and more complicated to confront. It perpetuates systemic inequalities and can have long-lasting effects on marginalized communities, often going unnoticed or dismissed by those who perpetrate it. The response is the belief system that racism no longer exists and should not be addressed while believing everyone is equal. This is neither helpful nor true because racism is robust and institutionalized (Mitchell, 2020).

A belief system that understands African American stories, as well as non-minorities, needs to connect with African Americans who have lived experiences to be able to believe racism still exists in institutions and society. Lastly, the discussion continues to be vital to how society views hospice care. Unconscious biases are deeply ingrained attitudes and stereotypes people hold without being aware of them. These biases can influence our thoughts, perceptions, and actions, often leading to discriminatory behavior.

Microaggressions, on the other hand, are subtle, everyday acts of discrimination that may seem harmless on the surface but can have a cumulative and damaging effect on marginalized individuals. They can manifest as dismissive comments, invalidating experiences, or making assumptions based on stereotypes. Both unconscious biases and microaggressions contribute to the perpetuation of systemic racism and the marginalization of minority communities. Suppose African Americans are considered challenging to care for by physicians or difficult to trust in their shared racism experiences. The effects of dismantling systemic racism will always be an uphill battle.

Conclusion

In conclusion, the social work code of ethnicity serves as a guide for professionals. Analyzing the importance of theoretical belief systems of death and dying in addressing barriers to hospice care for African Americans. Understanding these aspects is crucial for social workers to provide culturally sensitive care and address hospice utilization disparities among African American communities. It helps professionals navigate and dismantle barriers that prevent equitable access to end-of-life care. As well as utilizing structural functionalism and conflict theory to maintain the necessity for God to restore humanity into

complete harmony with Him. In this way, social workers can create a more equitable and effective hospice system to better serve African American communities.

CHAPTER 4: ENGAGEMENT

Introduction

Community-based participatory research (CBPR) methods have proven to be effective in identifying and addressing the unique needs and challenges faced by specific communities, such as the African American community in this case. By involving key professionals and stakeholders in the research process, CBPR helps to ensure that the end-of-life care provided is culturally sensitive, inclusive, and tailored to the specific needs and values of the community. This approach can lead to improved communication, access to care, and overall quality of end-of-life experiences for terminally ill patients.

Community

It is important to note that hospice care is provided by a multidisciplinary team of trained professionals. This approach ensures that patients receive comprehensive care tailored to their individual needs. It allows for better coordination among healthcare providers, resulting in more effective symptom management and emotional support. Additionally, it addresses various aspects of a patient's well-being, including medical, psychological, and spiritual needs. Hospice care professionals undergo specialized training to equip them with the skills necessary to handle complex end-of-life issues (Noh et al 2022 & Noh et al 2022). This training includes pain management, emotional counseling, and ethical decision-making. Such comprehensive education ensures that they can provide compassionate and competent care to patients and their families during challenging times.

Hospice Administer

A key component of the CESI Model engagement process was interviewing key stakeholders. In an interview with Hospice administrator, Donna, it was discussed the barriers to

hospice care for African Americans. As Donna pointed out, there were several barriers to hospice care, including cultural mistrust of the healthcare system and lack of awareness of hospice services. Additionally, she stated that financial constraints and limited access to healthcare resources were significant obstacles. Upon being asked what innovative solutions could be developed to overcome hospice care barriers for African Americans, Donna suggested developing targeted outreach programs that would build trust within African American communities. To reflect better the needs of the communities in which hospice care is provided, she also recommended increasing the diversity of the hospice care workforce. As well as offering sliding-scale payment options and enhancing mobile healthcare services, can address financial and access barriers by implementing these measures.

Medical Professional

A vital component of the hospice team is the medical director. The medical director plays a crucial role in overseeing the medical care provided to patients, ensuring that it aligns with the highest standards of quality and compassion (Gillett et al., 2016). They collaborate with other healthcare professionals to develop comprehensive care plans tailored to each patient's needs. Additionally, the medical director provides vital support and guidance to the team and the patient's family. In the engagement process, we interviewed an African American male physician who had experience with a loved one in hospice care (Mack et al., 2016). His personal experience profoundly influences his approach, allowing him to empathize deeply with patients and their families.

Furthermore, unique perspective enables him to advocate for compassionate care that addresses medical and emotional needs. His firsthand understanding of the hospice journey enriches his ability to lead the team with sensitivity and dedication. Having diverse perspectives

in hospice care enriches the team's ability to address patients' and their families varied cultural, emotional, and spiritual needs. It ensures that care plans are more inclusive and respectful of different backgrounds, fostering a more comforting and supportive environment. Moreover, diverse viewpoints can lead to innovative solutions and improvements in care practices, ultimately enhancing the overall quality of hospice services (Lycette, 2016).

Conclusion

To address African Americans' barriers to accessing hospice care, a collaborative effort involving various community members and stakeholders is required (Noh et al. 2022 & Noh et al. 2022). The goal is to dismantle barriers to hospice care for African Americans by engaging these community members and stakeholders in a collaborative effort, which could include hosting community forums to discuss hospice care needs and concerns, establishing partnerships with local churches and advocacy groups, and providing culturally competent training for healthcare providers. Creating educational materials tailored to the African American community can also raise awareness and understanding of hospice services. Building trust through consistent and transparent communication is equally essential. The provision of quality end-of-life services can also be enhanced, as well as equitable healthcare outcomes for all people. Therefore, providing culturally competent hospice services is essential for the African American community (Mack et al. 2016).

CHAPTER 5: ASSESSMENT

Introduction

An assessment of African Americans' hospice care barriers was conducted via a scoping review. The purpose of the study was to determine why African Americans are not electing hospice care. African Americans die in emergency rooms and intensive care units more often than any other group. This is instead of passing away with dignity and experiencing peace during the end-of-life process. African Americans' unwillingness to seek advance care planning and end-of-life care leads us to focus on African American barriers to hospice care. All articles about African Americans' end-of-life journeys were scoping reviewed using Prisma diagram. Data was extracted, articles were screened for inclusion, and articles were excluded during the scoping review. In the scoping review, 16 papers were reviewed to create a literature review to assist African Americans in their journey to the end of life. This will have implications for future research. No matter the race or ethnicity, every person who dies deserves dignity, respect, and comfort.

Methodology

This scoping review follows the Prisma 2020 flow diagram for a scoping review. This study addresses African Americans' barriers to hospice care while introducing the barriers AAs experience at the end of life. Six search engines were utilized in the search: Google Scholar, PubMed, APA, PsycINFO, Medline, and Academic Search Premier, which are all search engines that have access to the diagram. The data base was collected from credible sources to determine hospice care barriers. Each database allowed for a thorough literature search and adequate data to acknowledge the obstacles to accessing hospice care benefits for AAs

Search Methods

The purpose of completing a scoping review was to address all the identified barriers to hospice care for AAs. The initial search created was end-of-life care, which did not address the existing cultural variations in hospice care and provided too broad of a scope to obtain data to be able to answer the research question, the known racial disparities in hospice care—creating a new search method that only provided the existing barriers to hospice care for AAs, by narrowing this search method to include only data that obtained keywords such as known barriers in hospice care, AAs, lack of knowledge, 65+, trauma, palliative care, and resources.

Moreover, changing the search method allowed further research to screen quantitative and qualitative studies using the practitioners of evidence-based practice specialized framework called the PICO (Methley et al., 2014). Filtering peer-reviewed articles using advanced search keywords with the year criteria 2013-2023. This literature review was compiled when changes were made. Table 1 in the appendix *Scoping Review Articles* will include the PICO model addressing the population, intervention, comparison, and outcomes, allowing articles to be screened and selected.

Each article had to have (a) AA being the population, (b) an intervention theory or strategy to address known barriers, (c) a comparison between the known racial variation of selections of hospice care and the common barriers shown throughout the articles, and (d) the outcomes or results of the studies that led to an innovative opportunity to address the barriers to hospice care benefits (Collins et al., 2018). See Table 1 in the Appendix.

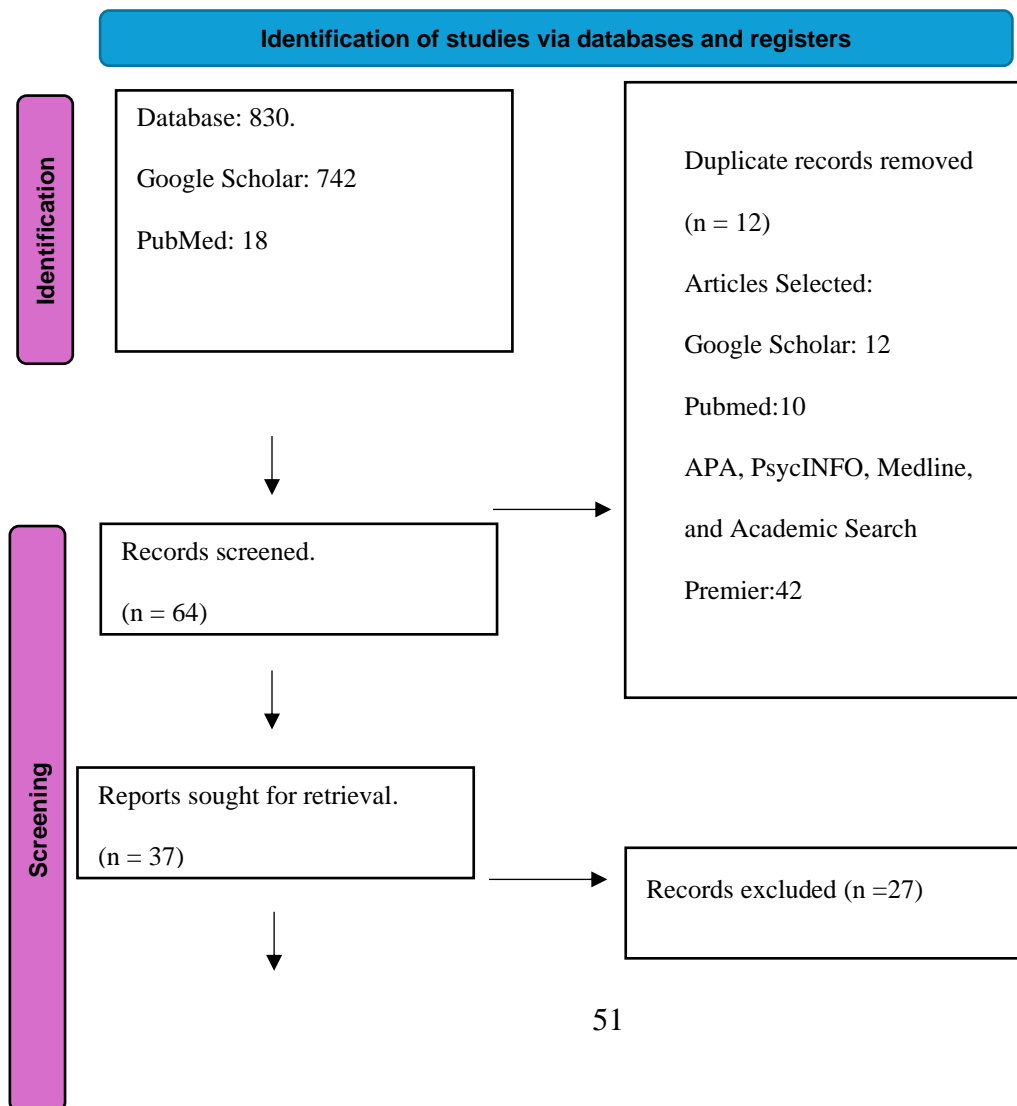
Screening

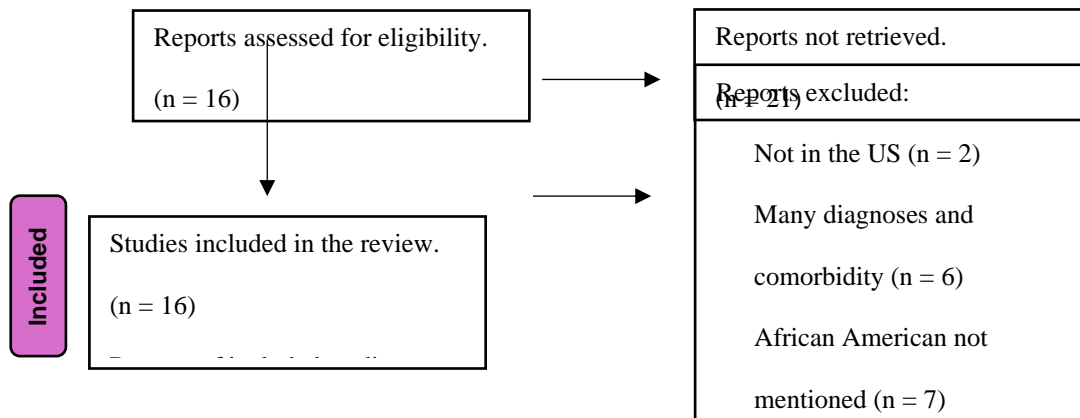
Data extraction was completed on all articles that met inclusion and exclusion criteria. Each piece selected was reviewed to include information about the AA population, the known

barriers to hospice care, the racial disparities in hospice care, the senior population, identifying social work theories, lack of knowledge, trauma, and resources. Exclusion criteria consisted of outside of the United States, no mention of AAs, pediatrics, the broad scope of diagnosis and comorbidity, caregiver-driven support, specific diagnosis of Alzheimer's, discussion of only advance care planning, racial variation not clear, and singular debate of social workers at the end of life. Table 2 (see Appendix) demonstrates the exact method of searching databases. It will also follow the screening process, the exclusion and inclusion criteria, and the results after the data extraction.

Figure 1

PRISMA Diagram





Level of Evidence

The articles selected for scoping review included studies that were examined through multiple assessment tools; these assessments included the National Quality Framework for Palliative Care: Clinical Practice Guidelines for Palliative Care, Palliative Care Patient Self-Determination (PSDA), National Hospice and Palliative Care Organization (Sedhom et al., 2020), Crowe Critical Appraisal Tool, Edmonton Symptom Assessment, Family Inpatient Communication Survey (FICS), (NA et al., 2022) and Functional Assessment of Chronic Illness Therapy-Palliative Care.

These assessment tools examined and answered research questions about hospice care barriers. The intervention and outcomes examined each article chronologically for known bias, shortcomings, lack of discussion of AAs, outliers, and information that could better explain why AAs are not electing hospice care. While reviewing this study procedure, known outcomes were established to highlight each significant barrier to hospice care for AA. Each article was screened for a positive or negative response to research questions and identified obstacles. If such articles

received a “no,” they were not added to this scoping review; interventions and outcomes were not deemed to be reviewed for the scoping study. The articles that received a “yes” were examined for interventions and results to be selected for further review.

Methods

The first database search was Google Scholar, and (742) articles were obtained to be reviewed; the keywords in the search were AAs, hospice care, palliative care, known racial disparities, trauma, resources, lack of knowledge, and 65+/. Furthermore, excluding articles on titles alone due to not defining AAs as the population and no discussion of end-of-life care. Upon reviewing titles independently, (13) papers were selected, and one was duplicated, leaving (12) reports to be chosen. The following database searched was PubMed with advanced search including keywords AA, hospice care, and barriers allotted for collecting (18) reports, no duplicates, and ten articles selected from the database while excluding criteria of peer-reviewed journals and no mention of palliative or hospice care and lastly, obtaining articles from APA PsycINFO, Medline, and Academic Search Premier. The keywords in the advanced search were AA, palliative care, and hospice care; (70) articles were obtained from the database search, and exclusion criteria included not being peer-reviewed, articles selected before 2013, caregiver-driven support, and specific diagnosis of caring for an AA with Alzheimer’s. The total of articles after the exclusion criteria was (48); six were duplicated, leaving (42) to be screened for further research.

Moreover, selecting a total of (64) articles to be screened for systematic review, all papers were reviewed, and a selection of (27) articles did not meet inclusion criteria due to studies not being in the United States, mental health intervention, specific diagnosis of cancer, dementia, and Alzheimer’s, advance care planning focused, end of life for caregivers and cultural

humility being too broad of a scope to collect data and leading to (37) articles being extracted for full-text review with exclusion criteria constant with previous data extraction mentioned with a total of (16) articles to be added to the scoping evaluation due to all of them meeting inclusion criteria ongoing with barriers to hospice care benefits for AA, while also answering research questions over the known barriers to hospice care for African American.

Results

In the appendix table 1 *Scoping Review Articles* will provide the results from articles. The data obtained three significant barriers: spirituality, lack of trust in medical professionals, and lack of knowledge to complete advance care planning, including a discussion of do-not-resuscitate, advance directives, and living wills. Upon analyzing data from articles, the barriers that need to be addressed are the beliefs that using medications leads to death. In addition, AAs trust that their families will offer the care that hospice will and the lack of communication with healthcare professionals about end-of-life care. All results acknowledge that AAs experience barriers to hospice care benefits or death differently than their white counterparts. The table 1 *Scoping Review Articles* below provides more details from the articles reviewed to select the barriers to hospice care benefits for AAs. It also provides the known racial disparities in hospice care.

The data obtained three significant barriers: spirituality, lack of trust in medical professionals, and lack of knowledge to complete advance care planning, including a discussion of do-not-resuscitate, advance directives, and living wills. Upon analyzing data from articles, the barriers that need to be addressed are the beliefs that using medications leads to death. In addition, AAs trust that their families will offer the care that hospice will and the lack of communication with healthcare professionals about end-of-life care. All results acknowledge that

AAs experience barriers to hospice care benefits or death differently than their white counterparts. The table below provides more details from the articles reviewed to select the barriers to hospice care benefits for AA. It also provides the known racial disparities in hospice care.

SWOT Analysis

A SWOT analysis can provide a structured way to examine African Americans' barriers to hospice care, identifying strengths, weaknesses, opportunities, and threats within this context. Here's a detailed breakdown:

Strengths

1. **Community and Family Support:** Strong familial bonds and community networks can offer significant emotional and logistical support in hospice care.
2. **Cultural Competence of Hospice Providers:** Some hospice care providers are increasingly becoming culturally competent, which can help address specific needs and preferences.
3. **Faith-Based Organizations:** Many African American communities have strong ties to religious institutions that can support hospice care through pastoral care and community outreach.

Weaknesses

1. **Mistrust of Medical System:** Historical and ongoing disparities in healthcare contribute to a deep-seated mistrust of the medical system among African Americans.
2. **Lack of Awareness:** There is often a lack of knowledge about what hospice care entails and its benefits.

3. Economic Barriers: Financial constraints can limit access to hospice care, particularly in underinsured or uninsured populations.
4. Underrepresentation in Healthcare Workforce: A lack of African American healthcare providers can lead to a feeling of disconnect and lack of cultural understanding in patient care.

Opportunities

1. Education and Outreach: Increasing awareness and understanding of hospice care through targeted educational campaigns.
2. Policy Changes: Advocating for healthcare policies that improve access to hospice care for underserved communities.
3. Training Programs: Implementing training programs for healthcare providers to enhance cultural competence.
4. Partnerships with Community Organizations Collaborating with faith-based and community organizations to improve outreach and support.

Threats

1. Healthcare Disparities: Persistent disparities in healthcare access and quality can hinder the effectiveness of hospice care.
2. Economic Inequality: Widening economic inequality can exacerbate financial barriers to accessing hospice care.
3. Policy Limitations: Existing healthcare policies may not adequately address the specific needs of African American communities in accessing hospice care.
4. Cultural Stigma: There may be cultural stigmas associated with hospice care, viewed as giving up on the patient or a lack of faith.

Addressing the barriers to hospice care for African Americans requires a multifaceted approach that includes enhancing community outreach, building trust within the healthcare system, improving economic access, and fostering cultural competence among providers. By leveraging strengths and opportunities while addressing weaknesses and threats, the accessibility and quality of hospice care for African American communities can be significantly improved.

Conclusion

According to the current literature examining the barriers to hospice care for African Americans, these barriers will be ongoing struggles that the African American community must face (Drisdom, 2013). In the literature review, none of the outcome's prior were known regarding how to bring about change and the barriers to providing hospice care to African Americans. In providing end-of-life care, palliative care, and hospice care to African American patients, the innovation consists of having more conversations and demonstrating cultural humility. It continues to be evident that the African American community possesses a robust spiritual belief system and remains resilient. As a result, African American communities tend to receive more aggressive treatment, and hospital deaths remain a common occurrence.

Despite their efforts, African Americans still face challenges when it comes to dying peacefully and comfortably. To maintain rapport and trust with the African American community, an innovative strategy is developing solutions. A significant part of building trust is asking challenging questions about biases and racism from healthcare providers and professionals. These professionals engage with African American culture at the time of death as part of their work. As difficult as it is to discuss death, whether it is hospice care or an unexpected passing, the truth remains that it is a difficult conversation. It is challenging for society to have realistic views about end-of-life care and to prepare for end-of-life journeys.

CHAPTER 6: INNOVATION

Quality Improvement

According to my quality improvement project with Hilltop Assembly of God Church, the following barriers have been identified: the willingness of African Americans to choose hospice care over other medical options. A recent literature review informs us that African Americans experience limitations and barriers to hospice care, including (a) mistrust of medical professionals and (b) culture and spiritual beliefs, (c) inadequate planning of care, (d) inadequate understanding of end-of-life care, families, and medication management.

The provision of quality end-of-life care to racial minorities has historically been disparate for African Americans. Furthermore, African Americans lack knowledge about hospice care. Historically, the community has struggled for quality end-of-life care and services. Based on the literature review, African Americans are less likely to utilize, consider, and obtain hospice care due to these underlying problems. To reach our goals, we must acknowledge limitations and barriers. African Americans need to receive dignity and quality end-of-life care. In collaboration with Hilltop Assembly of God Church, identified barriers will be addressed by creating “The Barriers to Hospice Care” website to acknowledge, inform, educate, and teach church members about the African American community and its obstacles.

Community Engagement

The key personnel at my partnering organization, Hilltop Assembly of God are Martin Gossett, Hospice Chaplain, and Associate Pastor at Hilltop Assembly of God. Martin has spent 15+ years being an invested, compassionate, and dedicated professional. As a spiritual care and support provider, he has provided spiritual support to individuals and their families during their

end-of-life journeys. A deep understanding of various religious and spiritual beliefs is necessary for this role.

As well as comforting and guiding people from different backgrounds, it involves providing them with guidance and support. Martin has witnessed the effects of grieving on individuals from diverse backgrounds. With many years of experience offering advice and resources, he has helped individuals find solace in their faith or spirituality by navigating their emotions. Provide a detailed description of your interactions with the organization within your regular responsibilities or area of expertise. During our five plus years working in hospice care, Martin and I gained extensive experience in this field. We observed discrepancies within hospice care when we began to serve the Northeast of Oklahoma City.

As a hospice chaplain, Martin provides quality end-of-life care to people in the Oklahoma City metro area. His goal is to eliminate African Americans' barriers to end-of-life care through his role as Associate Pastor with Hilltop Assembly of God. Being active at Hilltop Assembly of God, interacting with a diverse population, partnering with Martin as a stakeholder and leader within the hospice community, and engaging with Martin create a space for these barriers to be acknowledged and addressed to bring about positive changes in the African American community.

Social Innovation

Collaborating with community partners to launch a social innovation called “The Barriers to Hospice Care” as part of the continuous quality improvement project. For this continuous quality improvement project, I created and published a publicly accessible website in collaboration and interaction with Hilltop Assembly of God Church. Addressing the barriers African American patients, face to hospice care, a website named “Barriers to Hospice Care”

was created. A few of the website's features include three different video modules, additional resources, and a frequently asked question section. These modules offered educational discussions to increase African Americans' understanding of hospice care. The programs improved African Americans' acceptance of hospice care and reduce their negative beliefs.

Initially published in early May, the Barriers to Hospice Care for African Americans educational website received approval from the Institutional Review Board (IRB). Surveys were administered at the beginning and end of the website to assess the level of engagement of African American community members and church members in hospice care. Additionally, the website offers access to a variety of resources. In addition, a local resource site provided access to additional resources besides the fact sheet about hospice companies in Oklahoma.

The first video module acknowledged, taught, and educated on the importance of quality hospice care and how to bridge the gap African Americans experience at the end of life. The second video module discussed the negative beliefs and barriers of hospice care perspective from the African American population. The final video module discussed the lack of utilization African Americans have regarding hospice care at the end of life and how to provide education on how to utilize hospice care to the African American population and church members.

The innovation's primary goal is quality end-of-life care. Moreover, African American cultural values, traditions, and beliefs must be considered, respected, and honored at the end of life. Ensuring that African Americans with terminal diagnoses admitted to hospice care receive cultural competence, healthcare professionals, and church members recognize the significance of African American practices, spiritual beliefs, and meanings at the end of life is essential for delivering effective and empathetic hospice care to the African American population. The overarching goal long term goal of the innovation was the ability for African Americans to

experience quality care at the end of life with the hopes of increasing knowledge of hospice care, reducing African Americans' negative beliefs regarding hospice care, and growing the willingness African Americans have to the utilization of hospice care through the barriers to hospice care website.

Implementation

The website "Barrier to Hospice Care" published by May, and approved by the IRB. It was shared through word-of-mouth, emailed, and presented to Martin Chaplain with Hilltop Assembly of God. It also had a 4x4 flyer with a quick response code to be distributed to local community and church members. These cards were distributed to educate people on hospice care barriers.

Module One

The first video module acknowledges, teaches, and educates on the importance of quality hospice care and how to bridge the gap African Americans experience at the end of life. In hospice care, the learning objective is to provide compassionate care and support for terminally ill individuals. It focuses on improving quality of life, managing symptoms, and offering emotional and spiritual support to the patient and their family. Hospice care requires an interdisciplinary team to provide holistic care.

- 1.) This team, consisting of healthcare professionals from various disciplines, such as doctors, nurses, social workers, counselors, and chaplains, collaborates to address patients and their families' physical, emotional, social, and spiritual needs. By working together, they ensure that all aspects of the patient's well-being are addressed, providing comprehensive and compassionate care. Hospice care aims to ensure end-of-life comfort and dignity.

- 2.) African Americans use hospice services less than white individuals, which results in untreated pain at the end of life for many. A comprehensive approach involving healthcare professionals is needed to improve access to hospice and palliative care among African Americans. Studies indicate that increasing hospice enrollment among African Americans can enhance end-of-life care within this community.
- 3.) However, there is still a gap in understanding the reasons behind the disparity between white and black families. Some experts cite a lack of clear explanations for hospice usage differences. Healthcare professionals play a crucial role in improving access to hospice care for African Americans. Healthcare professionals can educate and reach the community by addressing cultural and systemic barriers, debunking misconceptions, and raising awareness about hospice care benefits.
- 4.) Additionally, healthcare professionals can communicate culturally sensitively and actively listen to patients and their families. They can also tailor their care plans to meet their needs and preferences. By actively working to bridge the gap in understanding and providing equitable access to hospice care, healthcare professionals can help ensure that African Americans receive the comprehensive and compassionate end-of-life care they deserve. Factors such as family dynamics, fear, and faith play significant roles in end-of-life decisions for African American patients. Black patients' palliative care needs may vary.

Research suggests that family members are less likely to express concerns about unmet pain needs when receiving care from hospices with higher proportions of Black patients.

Enhancing knowledge about hospices, addressing cultural beliefs, and providing tailored support are crucial steps in improving hospice experiences for African Americans. Resources and studies

explore hospice challenges and opportunities and palliative care for African Americans. By highlighting these disparities and addressing systemic issues, healthcare providers can work towards ensuring that African Americans receive equitable and culturally sensitive end-of-life care.

Module Two

The second objective is to reduce negative beliefs regarding hospice care. To mitigate negative beliefs about hospice care within the African American community, it is necessary to address historical mistrust, ethnic differences, and a lack of awareness. Listed below are some strategies for overcoming these obstacles. Educating and acquainting the public about hospice care, eliminating misconceptions, and raising awareness. Highlight hospice benefits, such as pain management, emotional support, and spiritual care.

1. Community Engagement: Develop workshops, seminars, and information sessions to promote hospice care among community leaders, churches, and organizations. Please engage with trusted individuals in the community to encourage acceptance and understanding.
2. Raise awareness of the needs and beliefs of African American patients and families by ensuring hospice providers are racially and culturally competent.
3. Acknowledge the historical distrust in the healthcare system among African Americans due to past injustices and discrimination. With empathy and openness, address these concerns.
4. 5. Family Involvement: Encourage families to participate in hospice decision-making and care planning. To alleviate fears and concerns, encourage open communication and support networks.

5. 6) Access and Equity: Ensure hospice care is available to all individuals regardless of race or socioeconomic status. Equal access to quality end-of-life care for African Americans and address disparities in healthcare access.

Family involvement in hospice decision-making can immensely benefit patients and their loved ones. By actively participating in the care planning process, families can ensure that the patient's wishes and preferences are respected and followed. Additionally, family involvement can help alleviate fears and concerns, foster open communication, and create a strong support network during this challenging time. We can reduce negative beliefs surrounding hospice care by implementing these strategies and encouraging open dialogue within the African American community. We can also promote increased acceptance and utilization of these valuable services. Ultimately, these efforts can help to ensure that African American patients receive the best possible end-of-life care.

Module Three

The third objective increased willingness to utilize hospice care. Cultural beliefs, historical experiences, and access to information must be addressed when increasing hospice care utilization among African Americans. Cultural beliefs, such as the importance of family support and the desire for spiritual healing, can play a significant role in the utilization of hospice care among African Americans. Understanding and respecting these cultural values can help develop strategies that effectively promote the benefits of hospice care within the community. Here are some strategies for you to consider.

1. Provide culturally sensitive education about hospice care to address misconceptions or fears within the African American community. Highlight the benefits of hospice care, such as improved quality of life and support for the patient and their loved ones.

2. **Community Engagement:** Collaborate with community leaders, churches, and organizations to spread awareness about hospice care and its benefits. Engage in dialogues that address cultural beliefs and concerns about end-of-life care.
3. **Representation:** Ensure healthcare providers and hospice care staff reflect community diversity. Having African American healthcare professionals who relate to patients and families can increase trust and comfort in considering hospice care.
4. **Tailored Support:** Provide culturally competent care that respects African American traditions; this includes honoring family roles, spirituality, and rituals during end-of-life care.
5. **Accessibility:** Ensure hospice care services are accessible and affordable for all community members. Address any barriers, such as lack of information, transportation issues, or financial concerns.
6. **Promote Early Discussions:** Encourage open conversations about end-of-life planning within families and communities. Starting these discussions early can help individuals make informed decisions about hospice care when the time comes.

The willingness to utilize hospice care in the African American community can be increased by implementing these strategies and fostering a supportive environment that values cultural diversity. In this way, communities can become stronger and more resilient.

CHAPTER 7: EVALUATION

Objectives

In this quality improvement project in collaboration with Hilltop Assembly of God, the institutional review board approved the concept of a published website that evaluates barriers to hospice care for African Americans. The Barriers to Hospice Care for African Americans website employs quantitative and qualitative data combining three modules of 3 to 5 minutes each, with the first objective being to increase hospice care knowledge. The second objective is measuring the outcome of reduced negative beliefs regarding hospice care. The final objective is to increase willingness to access hospice care. The website ultimately was intended to reduce disparities in hospice care for African Americans. Including qualitative and quantitative methods for data analysis. This quality improvement project evaluated the outcomes to assess whether the goals were met.

In addition to the modules, the website provides a detailed description of the barriers African Americans, and their families face when accessing hospice care. The website was distributed through word of mouth, email, and presentations at Hilltop Assembly of God. Additionally, contained note cards with programmatic information on how to participate. These cards were distributed to local community and church members to raise awareness of hospice care barriers. Ultimately, the website and cards are designed to inform and motivate African Americans and their families to access hospice care.

Methodology

Quantitative data was used to collect data via beginning and ending surveys. The survey used to gather the data for analysis was created using Qualtrics, (Lewis, 2024) a robust platform offering various survey creation and analysis features. It provides a user-friendly interface, customizable design options, and efficient data collection and management tools. This allows researchers to gather quantitative data, providing a more comprehensive understanding of the research topic.

By combining closed and open-ended questions, researching barriers to hospice care for African Americans yielded numerical data and rich, descriptive insights from participants. Ultimately, this combination of qualitative and quantitative data provided a more comprehensive understanding of the research question: “What are the known barriers to hospice care for African Americans?” This approach also enhances the validity and reliability of the findings.

Participants were encouraged to submit the beginning survey before watching the modules. After completing the modules, participants were encouraged to fill out the end-of-course survey. The beginning survey aimed to establish a baseline of participants’ knowledge, attitudes, and beliefs regarding hospice care for African Americans. This allowed an assessment of any changes in these factors after participants completed the modules. The end-of-course surveys aimed to gather feedback on the effectiveness of the modules, participants’ perceptions of hospice care barriers, and any additional insights gained from the educational content. Overall, the surveys were successful in providing a comprehensive evaluation of the impact of the hospice care educational modules.

In this continuous quality improvement project, quantitative data were used to examine if the three objectives were met. A survey was conducted at the beginning of a visit to the website

using Qualtrics, via a link at the top of the website. Website participants also received a survey invitation after interacting with the modules. The surveys evaluated if the continuous quality improvement project objectives were met. Collected and original data were analyzed. In addition, responses to the surveys at the beginning and end of website visits were averaged and compared. The first objective was to increase knowledge of hospice care, as measured by the question: “How would you describe your level of knowledge about hospice care before participating in this website?” The ending survey asked: “How would you describe your knowledge of hospice care after visiting the website?” (Taber et al., 2019).

The second objective was to measure the outcome of reducing negative beliefs regarding hospice care (after participating on the website), determined by the Negative Beliefs About Hospice Care measure (Center to Advance Palliative Care, 2011; Taber et al., 2019). Questions from the measure were adapted to include “Before participating on the website” and “After participating on the website” to evaluate if the website decreased negative beliefs regarding hospice care. The final objective was to increase willingness to take advantage of hospice care. Before participants interacted with the website, the beginning survey question was: “How likely, if at all, would you be to consider hospice care for a loved one?” Answer options were 1 = *very likely*, 2 = *somewhat possible*, 3 = *not too likely or not at all likely*, and 4 = *do not know*. This measure has been used in the literature to examine willingness to use hospice care (Shalev et al., 2018) was used for all surveys.

As part of the initial survey, participants were asked to provide demographic information such as their race and ethnicity and occupation, along with knowledge of hospice care, negative beliefs regarding hospice, whether their loved ones had sought hospice care. The survey allowed participants to remain anonymous. The statistical analysis techniques used in the study included

descriptive statistics to summarize the demographic information provided by the participants. Overall, the survey provided valuable insight into the participants' opinions.

Results

The first measure collected from 15 participants related to race and ethnicity: 42.86% were African American; 14.29% were First American, Native Indian, or Native Alaskan; 7.14% indicated another race or ethnicity; and 35.71% considered themselves White. The second question on the survey addressed job title, and 53% of participants reported being social workers. The remaining 47% reported other job roles, including construction worker and chiropractor.

Regarding how participants would describe their level of knowledge about hospice care before engaging on the website, 40% stated they were very knowledgeable, 3% responded that they were somewhat knowledgeable, and 27% reported having no knowledge of the topic.

Regarding whether participants had negative beliefs about hospice care before visiting the site, 40% reported that they strongly disagreed, 7% indicated that they somewhat disagreed, 20% indicated that they neither agreed nor disagreed, 13% indicated that they somewhat agreed, and 20% responded that they agreed.

The next question before engaging on the website addressed the likelihood that participants would consider using hospice care. In this sample, 54% said they were very likely, 23% said they were somewhat likely, 8% stated not at all likely, and 15% stated they did not know. The final question addressed whether the participant or a loved one was pursuing end-of-life care; all participants responded no.

Thirteen participants completed the ending survey. Asked how they would describe their level of knowledge about hospice care after engaging on the website, 75% said very knowledgeable, 25% stated somewhat knowledgeable, and no participants selected not

knowledgeable. For the question about negative beliefs regarding hospice care, 38% strongly disagreed, 8% strongly agreed, 38% neither agreed nor disagreed, 8% somewhat agreed, and 8% strongly agreed. After engaging on the website, participants indicated how likely they would be to consider using hospice care; 88% stated very likely and 13% stated somewhat likely. Asked what they found most beneficial after engaging on the website, participants provided various responses.

Participants were also asked: “What is your understanding of hospice?” After engaging in the website, the 13 participants responded with answers such as: “to promote comfort and dignity with the end of life” and “the modules just confirmed my experience and working hospice care for over two decades.” See Table 4 for more responses to this question.

Asked whether they would recommend this website to others, all participants stated yes and provided various explanations: “People from the black community are in mind, and they can greatly benefit from it” and “Education is important.” Table 5 features all reply to this open-ended question.

The final question was: “What did you like most about the website?” As shown in Table 6, participants provided answers such as: “The website is easy to navigate” and “The modules! They made me more knowledgeable regarding hospice care!”

Conclusion

Based on the results of this analysis of the Barriers to Hospice Care for African Americans website, African Americans constituted the largest racial and ethnic group among respondents. This finding highlights the critical need to overcome specific cultural, social, and systemic barriers African Americans face in accessing hospice care. It suggests that tailored interventions and resources are necessary to ensure equitable hospice care services for this

community. Understanding these unique challenges can improve healthcare outcomes and satisfaction for African American patients and their families. Addressing hospice care barriers for African Americans requires a multifaceted approach that includes enhancing community outreach, building trust within the healthcare system, improving economic access, and fostering cultural competence among providers. By leveraging strengths and opportunities while addressing weaknesses and threats, hospice care accessibility and quality can be significantly enhanced. Through this, African Americans can receive equitable hospice care services. African Americans constituted the largest racial and ethnic group among respondents, according to this analysis of the Barriers to Hospice Care for African Americans website.

CHAPTER 8: DISSEMINATION

Introduction

This research project explored multiple barriers to hospice care for African Americans. However, it is worth noting that various successful initiatives have sought to improve access to hospice care for African American communities. For example, organizations such as the African American Hospice Foundation and the National Black Nurses Association have worked tirelessly to raise awareness, provide education, and advocate for culturally sensitive end-of-life care for African Americans.

These efforts have helped bridge the gap and ensure that more individuals in these communities have access to the support and services they need during such a critical time. Analysis of the modules and other information on the Barriers to Hospice Care for African Americans website indicated a successful response that suggests this site can be used to promote outreach to communities and education for healthcare professionals. The African American Hospice Foundation has implemented programs that focus on community outreach and education, providing resources and support to African American families facing end-of-life care decisions. Similarly, the National Black Nurses Association has developed training programs for healthcare professionals to promote culturally sensitive care and address the unique needs of African American patients seeking hospice services.

These initiatives have played a crucial role in breaking down barriers and ensuring equitable access to hospice care for African American communities. Based on the feedback of those who participated in the beginning and ending surveys, ongoing research remains necessary to promote hospice care among African Americans. Collecting feedback from participants who have experienced barriers to hospice care for African Americans is crucial for informing future

research and interventions. By understanding their perspectives and experiences, researchers can gain valuable insights into the specific challenges faced by this community. They can also develop targeted strategies to address them. This feedback also ensures that future studies and initiatives are culturally sensitive, relevant, and effective in improving access to hospice care for African American individuals and their families.

Next Steps

The next goal is to create a proposal to present this research and data to colleagues and other healthcare professionals. With this information, African Americans can access hospice care effectively. The proposal should be completed within two weeks to allow for thorough review and revisions. A draft presentation is scheduled for the end of the month, followed by a final presentation to stakeholders in the first week of next month. In the next year, additional information will be applied to the data received from stakeholders. Healthcare professionals will enhance the ability to create more modules and establish more curriculum. By creating more modules and strengthening the curriculum, healthcare professionals will have access to a wider range of resources and educational materials.

This will enable them to better understand the unique needs and challenges faced by African Americans when it comes to accessing hospice care. Ultimately, this increased knowledge and awareness could lead to more effective and targeted interventions, resulting in improved access and quality of care for this population. It could also generate more research and data so that African Americans can die with dignity and respect at the end of their lives. In addition, the next step is to involve African American communities in the research to jointly develop solutions for medical professionals. Involving African American communities in the research process is crucial for several reasons.

First, it will ensure that the research is culturally sensitive and considers the unique perspectives and experiences of the community. Second, it can foster trust and collaboration between researchers and the community, which can lead to more accurate and meaningful data collection. Finally, involving community members in the research process will empower them to participate in shaping solutions and interventions that are tailored to their specific needs and challenges in accessing hospice care. Ultimately, this collaborative approach can build trust and foster meaningful change.

Conclusion

This quality improvement project has demonstrated that the initiative to ensure that African Americans receive quality end-of-life care is achievable. Although the next steps for addressing these barriers are still being developed, it is hoped that all African Americans will be able to access quality end-of-life care in the future. Achieving equitable end-of-life care for African Americans would not only improve health outcomes but also address long-standing disparities in healthcare.

Achieving this goal would promote social justice and ensure that every individual, regardless of their race or ethnicity, receives dignified and compassionate care during their final stages of life. Most people strive to arrange their affairs in such a way that their loved ones die in a good and dignified manner. Ensuring equitable end-of-life care for African Americans is not only essential for improving health outcomes and addressing healthcare disparities, but also a crucial step toward achieving social justice in healthcare.

By providing dignified and compassionate care to every individual, regardless of their race or ethnicity, we can create a more fair and inclusive healthcare system that upholds the principles of equality and human rights. It is our responsibility to arrange our affairs in a manner

that promotes the well-being and dignity of our loved ones during their final stages of life.

Equitable end-of-life care for African Americans can promote social justice by addressing the systemic barriers and biases that have historically led to disparities in healthcare.

By ensuring that every individual, regardless of their race or ethnicity, receives dignified and compassionate care during their final stages of life, we work toward dismantling the structures of inequality that have perpetuated these disparities. This not only improves health outcomes but also sends a powerful message that every life deserves respect, fairness, and equal access to quality care. Ultimately, this will lead to a more equitable healthcare system.

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APPENDIX

Table 2

Methods

Methods

This study aims to address the barriers in hospice care for AA while introducing the barriers AAs experience at the end of life.

Keywords and information about the AA population, the known barriers to hospice care, the geriatric population, trauma, hospice care, and palliative care.

Exclusion Criteria included caregiver driven, not in the US, focused on dementia, pediatrics, not peer-reviewed, and social work.

Inclusion Criteria included AA, 65+, hospice care, palliative care, U.S, barriers, lack of resources and knowledge.

Spirituality was chosen as a keyword because of the support the AA church has had on the community.

Table 1
Description of Search Process and Results by Database Source

Source	Search Terms	Other Parameters	Results
PubMed	African Americans, known racial disparities, hospice care, palliative care, barriers, aging, 65+, end of life care.	MeSH terms	18 articles
Google Scholar	"African Americans" "known racial disparities" "barriers" "hospice care" "resources" "lack of knowledge" "trauma" "65+"	All fields	742 articles
CBU Library APA PsycINFO, MEDLINE, and Academic Search Premier	African American and hospice care and barriers and palliative care, barriers, aging, end of life care, 65+	Peer-reviewed Journals only	70 articles

Table 3

Q4: What Did You Find Most Beneficial after Engaging on the Website?

All of it.

The information on each page was clear and consistent.

The information was thorough yet concise.

Resources provided at end of page.

The knowledge of help that is involved through hospice.

Na

After looking through your website, I found the links for more resources helpful and beneficial.

The short clips of information!

Table 4

Q5: What is Your Understanding of Hospice after Engaging in the Website?

To promote comfort and dignity with end of life

The modules just confirmed my experience and working in hospice for over two decades

That the stereotypes about it are completely false.

Na

More knowledgeable than I was before listening.

I knew a lot going into your survey, and watching the videos helped confirm my knowledge of the process. I learned that each background of humans may have a different ritual about death.

How it can be very beneficial for families during that time.

Hospice is about supporting individuals and family! Education is very important!

Table 5

Q6: Would You Recommend This Website to Others? If So, Please Explain Why

Very knowledgeable website.

People from the Black community are in mind, and they can greatly benefit from it.

It was informative. I worked in hospice for over 20 years and owned a hospice agency for over 10 years. Being an African American woman, and having such a passion for the industry, I always openly discussed cultural competency, diversity, etc. my staff understood the sensitivity that it took to sign an African American family onto services. Hospice is truly ministry and thank you for these three modules.

Explained the importance of educating individuals and families. Also dealing maybe with our own beliefs about hospice and end of life care.

Because it is beneficial explaining the care during that time.

Give them knowledge on hospice

Everyone needs to have at least the basic knowledge of what hospice is and you need numbers for your survey.

Education is important.

Table 6

Q7: What Did You Like Most About the Website?

The website is easy to navigate.

The modules! They made me more knowledgeable regarding hospice care!

The informative information regarding hospice.

The flow was great!

Speaker

I found it easy to navigate through the modules

Easy access

Details on hospice

Figure 2

Ethnicity

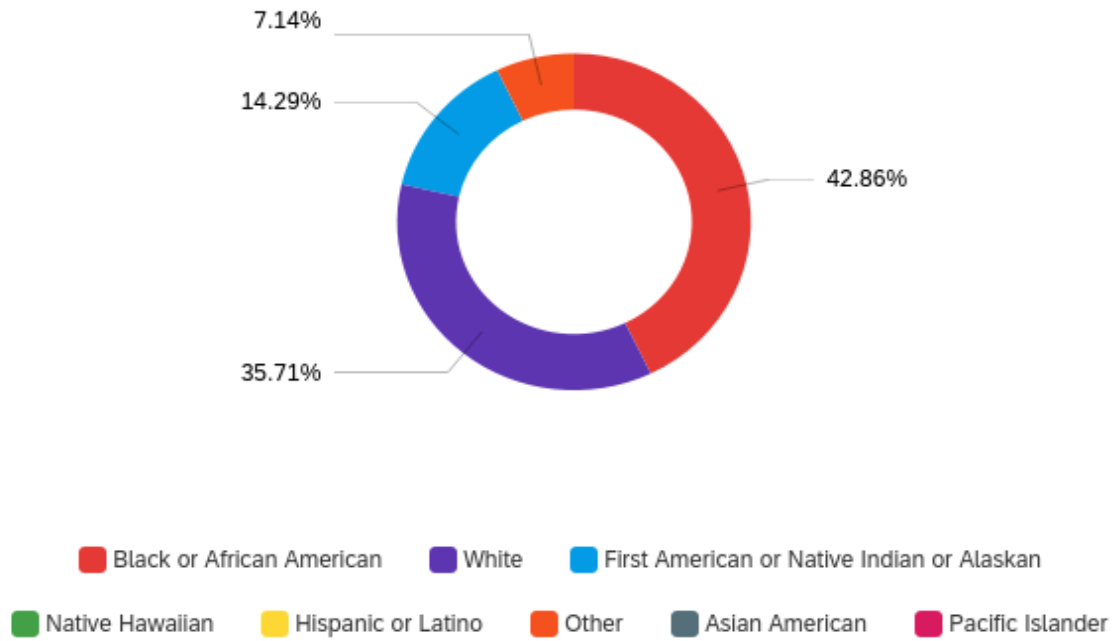


Figure 3

Job Title

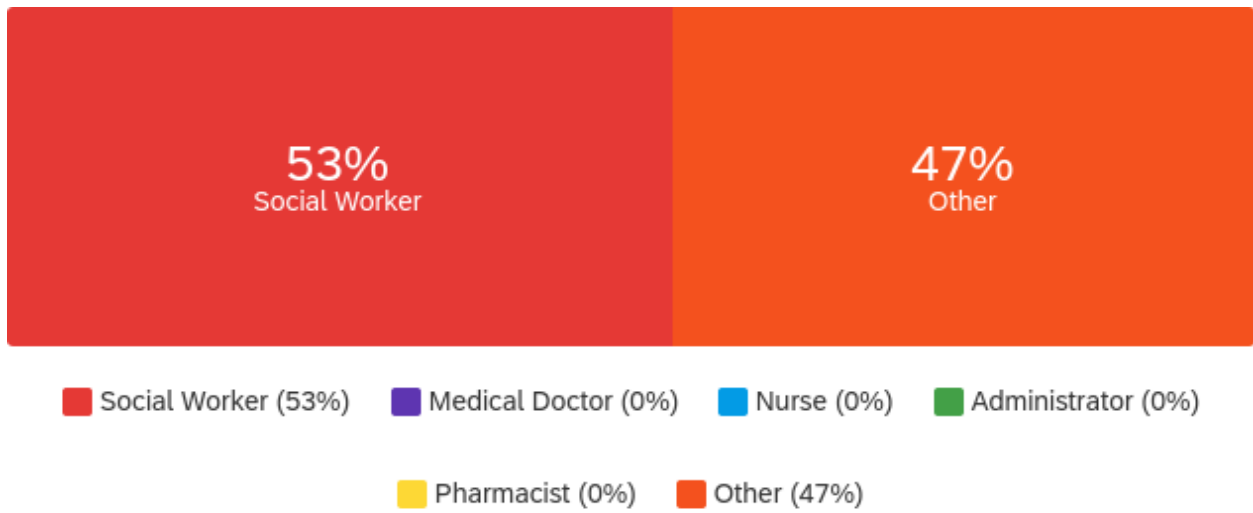


Figure 4

Level of Knowledge About Hospice Care before and after Engaging in This Website

	Before Engaging	After Engaging
Very Knowledgeable	40.00%	75%
Somewhat Knowledgeable	33.33%	25%
Not Knowledgeable	26.67%	0.00%

Figure 5

Negative Beliefs Regarding Hospice Care before and after Engaging in This Website

	Before Engaging	After Engaging
Strongly disagree	40.00%	38.46%
Somewhat disagree	6.67%	7.69%
Neither agree nor disagree	20.00%	38.46%
Somewhat agree	13.33%	7.69%
Strongly agree	20.00%	7.69%

Figure 6

Likelihood of Considering Hospice before and After Engaging on the Website

	Before Engaging	After Engaging
Do not know	15.38%	0.00%
Not at all likely	7.69%	0.00%
Somewhat possible	23.08%	12.50%
Very Likely	53.85%	87.50%

Figure 7

Pursuing End-of-Life Care



Figure 8

Barriers to Hospice Care for African American Website



Note. See <https://sites.google.com/view/hospicebarriers/home>

Figure 9

Barriers to Hospice Care for African American Introduction



Welcome to Barriers to Hospice Care for African Americans

Welcome to Barriers To Hospice Care for African Americans

Every human community, regardless of time and culture, has faced the seriousness and fear of death. Some cultures respond with cultivated acceptance, some with dismissive humor, and some with words of comfort, but all are aware of the magnitude of facing death. Every culture has traditions and practices that help individuals and families prepare for active dying and death. Defining hospice care would be beneficial to understanding why African Americans seek out intensive care units and emergency rooms for care.

①

Hospice care is palliative care, which means that a patient has a terminal diagnosis that's incurable and has elected not to have

Figure 10

Barriers to Hospice Care for African American Training Module

Below are three training modules regarding Barriers to Hospice Care for African Americans.

Please scan the QR code or click the link.

https://calbaptist.az1.qualtrics.com/jfe/form/SV_6nYmGdpcmuFppGK

Taking the survey allows for data to be collected regarding the knowledge of hospice care.




Barriers to Hospice Care for African American Modules



Figure 11

Barriers to Hospice Care for African American Resources



Hospice Resources in Oklahoma





 <p>TRINITY HOSPICE <i>"Caring When It Matters Most"</i></p>		 <p>OKLAHOMA Palliative & Hospice Care</p>	
<p>Trinity Hospice https://trinityhospice.com/about-us</p>	<p>Crossroad Hospice https://www.crossroadshospice.com/</p>	<p>Oklahoma Palliative and Hospice Care</p>	<p>Integris Hospice House https://integrishealth.org/locations/hospice-and-home-care/hospice-house</p>

Figure 12

Brochure Provided to Participants

Join My doctoral study Comprehensive Project in Collaboration with Hilltop Assembly of God Church on The Barriers to Hospice Care for African Americans.

The primary focus of this Comprehensive Project in Collaboration with Hilltop Assembly of God Church is for African Americans to have quality end-of-life care to be able to die with dignity in hospice.

HOW TO PARTICIPATE:
SIMPLY SCAN THE QR CODE TO GET STARTED!
<https://sites.google.com/view/hospicebarriers/home>

Please watch three modules. It will take less than 10 mins to complete.

Please take beginning and ending survey. All information shared is confidential.

Please reach out for any additional questions at shamicam.lewis@calbapist.edu

Let's work together to address and bridge the gap African Americans experience at the end of life with the hopes of increasing knowledge of hospice care, reducing negative beliefs regarding hospice, and growing the willingness of African Americans to utilize hospice care.

THANK YOU!