African Americans' Attitudes toward End-of-Life Care, specifically engagement in Advance Care Planning: Intervention in the African American Communities of Union County, New Jersey, U.S.A.

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ABSTRACT.

African Americans have historically engaged in advance care planning (ACP) at lower rates than other racial groups, contributing to disparities in end-of-life care. This dissertation examines African Americans' attitudes toward end-of-life care in Union County, New Jersey, exploring the cultural, historical, religious, and socioeconomic factors that shape decision-making. The study aims to identify barriers to ACP participation and evaluate community-based interventions designed to increase engagement.

A qualitative research approach was employed, utilizing semi-structured interviews with African American adults from diverse backgrounds. Data analysis, conducted through thematic analysis using NVivo software, revealed key factors influencing ACP decisions, including medical mistrust rooted in historical injustices, the central role of religious beliefs, family-centered decision-making, and financial concerns. Participants expressed discomfort with discussing death, emphasizing the importance of family consensus and spiritual guidance in healthcare decisions.

A community-based intervention was implemented to address these challenges, incorporating educational workshops led by healthcare professionals, clergy, and community leaders. These sessions aimed to increase awareness, dispel misconceptions, and provide culturally relevant ACP resources. Post-intervention assessments demonstrated a positive shift in participants' knowledge, attitudes, and willingness to engage in ACP discussions. The study highlights the effectiveness of tailored, culturally competent approaches in fostering ACP engagement within African American communities.

The findings underscore the need for healthcare policies that prioritize cultural competence, community engagement, and systemic reforms to enhance ACP accessibility. Addressing historical mistrust, religious influences, and socioeconomic barriers, this research provides a framework for reducing disparities in end-of-life care. Future research should explore the long-term sustainability of such interventions and their broader applicability to African American populations nationwide.

This study contributes to the growing literature on health equity and end-of-life care, advocating for patient-centered, culturally informed ACP initiatives to improve healthcare outcomes.

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CHAPTER 1: INTRODUCTION

Background

The intricate interplay between death and dying, choices and actions within the context of approaching end-of-life stages represents a pivotal facet of the human life cycle (Smith, 2008). The multifaceted nature of death elicits a spectrum of reactions, emotions, perceptions, and attitudes from individuals, families, and communities (Kübler-Ross, 1969). These attitudes toward death, while inherently diverse, are also imbued with the influences of ethnicity, race, and culture, which collectively shape the complex tapestry of end-of-life decisions (Kagawa-Singer & Blackhall, 2001).

A landmark juncture in the trajectory of end-of-life care unfolded with the introduction of the Patient Self-Determination Act of 1990. Amid this backdrop, the attitudes of African Americans towards end-of-life care, particularly their engagement in advanced care planning, emerge as a persisting and profound concern (Tilden et al., 1999). Central to the discourse on end-of-life care trajectory is the pivotal role of decision-making, which fundamentally empowers autonomy within healthcare (Beauchamp & Childress, 2001).

The challenge lies in communicating personal views and preferences related to end-of-life care. Such exchanges are often thwarted by the complexities of communication barriers or the influence of family attitudes and perceptions regarding death and dying (Steinhauser et al., 2000). Consequently, advance care planning assumes a paramount role in shaping destinies, where individuals engaging in these deliberations take proactive control over their future medical treatment plans (Mack et al., 2010).

Nevertheless, the landscape of end-of-life decision-making is not devoid of historical, cultural, and sociopolitical nuances. As a culturally homogenous group, African Americans have been ensnared in a historical narrative rife with medical injustices and targeted by discriminatory policies (Washington et al., 2008). The legacy of this history reverberates through contemporary healthcare systems, sowing seeds of mistrust and skepticism, often influencing preferences for intensive life-sustaining treatments (Pizzo et al., 2015). The research by Aaron et al. (2021) shows persistent racial disparities in end-of-life care, indicating that African Americans are significantly less likely to utilize hospice services compared to Caucasians.

African American hospice use rates were initially lower than those of White patients between 1992 and 1994, but this gap diminished between 1996 and 2000. This trend likely reflects increased hospice availability and the growing inclusion of African American patients as hospice programs expanded (Han et al., 2006). Therefore, this scholarly endeavor endeavors to scrutinize the complex interplay of attitudes, perceptions, and preferences of African American communities residing in Union County, New Jersey, regarding advanced care planning and end-of-life decisions. Through qualitative inquiry, this research endeavors to uncover the intricate landscape of end-of-life decision-making, unearthing the underlying factors contributing to the underutilization of hospice care services and lower engagement in advanced care planning among African Americans.

The forthcoming sections of this study will delve into the nuanced examination of existing literature, offering insights into the disparities between African Americans and Caucasians in the context of end-of-life care engagement. Furthermore, this research will explore the attitudes and perspectives of African American communities in Union County, New Jersey, as they grapple with the complex confluence of cultural heritage, historical legacy, and personal values when navigating end-of-life decisions.

By shedding light on this intricate interplay, this study aspires to foster a deeper understanding of the dynamics surrounding end-of-life care preferences and advanced care planning within African American communities. Through scholarly inquiry and open dialogue, we aim to pave the way for a more equitable and culturally sensitive approach to end-of-life care rooted in mutual respect and shared decision-making.

Advanced Care Planning and Goals of Care

The terminologies "advance directives" and "advanced care planning" are frequently utilized interchangeably to denote how individuals outline their preferences for forthcoming medical treatments and interventions. It encompasses their desires, values, and preferences within the context of potential medical emergencies (Sinuff et al., 2015).

Advance Care Plans manifest as evolving medical treatment roadmaps or personalized care goals meticulously tailored to individual patient needs. These plans serve as strategic frameworks for clinically appropriate interventions. They are collaboratively constructed, involving the individual, their clinical team (including their physician), and a designated healthcare proxy, often a familial member or trusted confidant (Butler et al., 2014).

It is vital to underscore that advance care planning transcends the confines of end-of-life considerations. Contrary to common misconceptions, the termination of life is not the sole context in which articulating wishes and values is pertinent. Advanced care planning has relevance across various stages of mental capacity. It initiates with healthy individuals anticipating unforeseen health contingencies, where they establish prospective care objectives for scenarios wherein, they might be unable to communicate their medical preferences (Sinuff et al., 2015).

As patients approach end-of-life stages, the role of advanced care planning (ACP) can be impactful but also complex. While ACP is often intended to reduce stress, improve symptom management, and enhance quality of life, studies reveal mixed experiences. Some individuals find the process challenging, as ACP assumes patients are fully autonomous, rational, and able to evaluate all options objectively. Moreover, healthcare providers have observed that ACP can inadvertently add stress, highlighting the importance of recognizing diverse patient needs and limitations in this context (Wells et al., 2018; McAfee et al., 2019; Han et al., 2022). It is crucial to recognize that the need for advanced care planning extends not just to healthy individuals but also to those grappling with severe conditions such as dementia, Alzheimer's disease, heart failure, cancer, chronic obstructive pulmonary disease (COPD), Parkinson's disease, and advanced age (Bazargan et al., 2021). Nevertheless, it is noteworthy that healthy individuals are in a more favorable position to consciously and decisively make medical choices for themselves compared to individuals contending with chronic illnesses.

Advanced care planning is "the communicative process whereby individuals proactively prepare for a period during which they may lack decision-making capacity. This process encompasses introspection, contemplation, and articulating values, wishes, and preferences about end-of-life treatments. Values encapsulate overarching philosophies or life priorities, while wishes and preferences, used interchangeably, pertain to specific favored treatment choices or desired health states. These expressions predominantly originate outside clinical settings and should not be confused with clinical decisions, necessitating clinical appropriateness assessment" (Sinuff et al., 2015).

In the same vein, advanced care planning (ACP) entails dialogue among individuals, their loved ones, potential surrogate decision-makers, and healthcare providers, centering around values, preferences, and wishes. This discourse might culminate in the appointment of a surrogate decision-maker for instances of incapacity, along with the delineation of desired end-of-life treatments. Additionally, it may lead to formulating written expressions of wishes, and preferences encapsulated within an advanced care plan, though verbal or alternative modes of expression remain valuable (Sinuff et al., 2015).

In essence, "advanced care planning serves as a conduit to inform care decisions for patients who are unable to communicate their preferences, while also functioning as a strategic tool to assist patients in setting their treatment priorities" (Butler et al., 2014). Moreover, a third subset for which advance care planning holds pertinence comprises patients with terminal illnesses, particularly those under hospice care.

Advanced care planning (ACP) serves as a proactive means for individuals to articulate their treatment values and preferences for future health decisions. While it can help ensure alignment with personal wishes when decision-making capacity is lost, ACP also presents challenges. Critics argue that ACP assumes a high degree of patient autonomy and rational decision-making, which may not account for the emotional, cognitive, and social complexities patients face (Sinuff et al., 2015; Butler et al., 2014). Additionally, healthcare providers note that ACP may unintentionally impose stress on patients and families, as preferences expressed outside clinical settings may not align seamlessly with medical recommendations, requiring careful consideration of clinical appropriateness and adaptability within actual care contexts (Sinuff et al., 2015).

Hospice Care. Hospice care constitutes a distinct healthcare paradigm tailored to individuals grappling with life-limiting illnesses, operating as a specialized form of palliative care at the end-of-life stage (Bhatia et al., 2021). This unique care modality caters to patients with predictable end-of-life trajectories (Bhatia et al., 2021). At its core, hospice care underscores the multifaceted dimensions of end-of-life care, encompassing emotional, spiritual, physical, social, mental, and supportive interventions designed to alleviate suffering for patients and their family members during the imminent approach to death (Bullock, 2011).

Embedded within the hospice model is an unwavering emphasis on enhancing the quality of life and providing compassionate care in the face of life's final stages. By addressing symptom management, psychosocial needs, spiritual and religious support, and offering bereavement assistance to families, hospice care strives to optimize comfort while shifting the focus away from curative goals (Matsuyama et al., 2011). It is crucial to dispel certain misconceptions surrounding hospice care, such as the perception that it mandates signing a "Do Not Resuscitate" (DNR) order. Contrary to this notion, individuals can pursue treatments aimed at potential cures, which could lead to the discontinuation of hospice care. Furthermore, the notion that shortens life contradicts its philosophy, which centers on affording those with terminal illnesses a natural and comfortable end-of-life experience through symptom management and the promotion of comfort (Simms, 2012).

Underpinning the hospice approach is a deliberate focus on the palliation of symptoms and the enhancement of overall quality of life rather than the pursuit of curative interventions (Thompson et al., 2016). Hospice care is particularly pertinent for patients who are terminally ill, with a prognosis of six months or fewer to live (Casey, 2019). Common primary diagnoses among hospice patients encompass cancer, dementia, respiratory illnesses, and strokes (Bhatia et al., 2020). Additional conditions include cardiovascular diseases and Acquired Immune-Deficiency Syndrome (AIDS) (Matsuyama et al., 2011). These diagnoses often signify potential trajectories toward end-of-life stages, primarily when they significantly affect an individual's quality of life and when a prognosis estimates a life expectancy of six months or less should the medical condition progress naturally. Importantly, it is essential to note that advanced age nor frailty alone does not automatically qualify an individual for hospice care.

The provision of hospice care is not confined to a single setting; instead, it is offered across a spectrum of environments, including patients' homes, hospice units, hospitals, nursing homes, and other long-term care facilities. This flexibility aims to accommodate diverse patient preferences and circumstances while ensuring the delivery of patient-centered care in alignment with the hospice philosophy (Simms, 2012).

History and Development of Advanced Care Planning

The historical development of advanced care planning (ACP) is a complex narrative that has evolved, shaped by legal, ethical, and medical considerations. One of the key figures credited with the genesis of ACP is Luis Kutner, a human rights lawyer from Chicago, whose visionary concepts laid the groundwork for modern end-of-life decision-making processes (Hong et al., 1996). At a meeting of the Euthanasia Society of America in 1967, Kutner introduced the concept of ACP to the United States, proposing a framework for individuals to make informed choices about their future medical treatment preferences (Hong et al., 1996; Sabatino, 2010). This began a transformative journey that would impact healthcare decision-making and patients' rights.

Kutner's seminal contribution was the coining of the term "living will" in 1969, which he described as a document that spelled out an individual's medical preferences, taking effect before death (Hong et al., 1996). The living will be not intended to advocate for the right to die but rather to empower patients with self-determination and protect the rights of the terminally ill (Humphry & Wickett, 1986; Lush, 1993). Kutner's arguments were grounded in common law and constitutional law principles, asserting that medical treatment should not be imposed upon patients without their informed consent (Sabatino, 2010). He conceptualized the living will as a trust-building tool between patients and physicians, emphasizing notarization and portability for immediate access, much like carrying a personal wallet (Rolnick et al., 2017).

The Euthanasia Society embraced Kutner's proposal in 1969, recognizing its potential to safeguard the rights of terminally ill individuals against the backdrop of a growing debate surrounding active euthanasia (Hong et al., 1996). To further address matters of death and dying, Kutner and the Euthanasia Educational Council developed a program called "Concern for dying," which aimed to educate the public and raise awareness about ACP (Hong et al., 1996). In 1991, the "Concern for Dying" initiative and the Society for the Right to Die merged to establish the National Council for Death and Dying, dedicated to educating the public and advocating for formal legislative recognition of the living will (Hong et al., 1996).

Before the emergence of ACP, ethical principles such as informed consent had guided clinical decision-making. In 1914, state courts affirmed the right of competent adults to decide their healthcare preferences (Hong et al., 1996). However, advancing medical knowledge and technology challenged the adequacy of common law principles, exemplified by cases like Karen Ann Quinlan. Quinlan, who fell into a persistent vegetative state, underscored the need for a more comprehensive legal framework that addressed end-of-life issues (Hong et al., 1996).

These efforts culminated in the California Natural Death Act in 1976, marking a milestone as the first living will legislation in the USA (Hong et al., 1996). Enacted in 1977, this Act enabled competent adults to instruct their physicians to withhold or withdraw life-sustaining procedures in cases of incurable injury, disease, or illness (Towers, 1978). However, it had limitations, as it did not cover cases of "permanent unconsciousness" or persistent vegetative states, illustrated by the Karen Quinlan case (Hong et al., 1996).

The landmark case of Nancy Cruzan in 1990 further propelled the development of ACP, especially the concept of a healthcare proxy. This case highlighted the importance of surrogate decision-making for individuals lacking the capacity to make decisions. A healthcare proxy or surrogate, designated through a formal process, could make medical decisions through substituted judgment, attempting to reflect the patient's wishes (Torke et al., 2008). The focus shifted from autonomy to ensuring the individual's best interests and dignity in the absence of explicit directives (Lawrence et al., 2011).

Throughout this evolution, ACP encompassed two primary forms: the living will and the durable power of attorney for healthcare. While the living will allow individuals to express their wishes in writing, the durable power of attorney designates a substituted or appointed decision-maker to act on their behalf (Hong et al., 1996). (Note-: a surrogate legally refers to a decision maker designated as outlined in public health law (FHCDA, NY 2010 29B)**.** These forms of ACP provide legal means for individuals to maintain control over their medical treatment preferences even when incapacitated.

In conclusion, the history and development of advanced care planning reflect the confluence of legal, ethical, and medical considerations. Pioneered by Luis Kutner's visionary ideas, supported by the Euthanasia Society and other organizations, and further catalyzed by cases like Karen Ann Quinlan and Nancy Cruzan, ACP has evolved into a fundamental component of patient-centered care. The progression from living wills to healthcare proxies exemplifies the ongoing pursuit of enhancing patient autonomy, dignity, and the preservation of their preferences in the face of medical complexities.

Policy Proceeding Advance Care Planning. Policy development and implementation in advanced care planning (ACP) have played a pivotal role in shaping the landscape of end-of-life decision-making and healthcare delivery. As the concept of ACP emerged and gained recognition, policymakers responded by enacting regulations and guidelines to ensure that individuals' preferences and rights were respected and upheld within the healthcare system. This section will delve into the policy aspects that have propelled ACP into a fundamental aspect of patient-centered care, highlighting key policies and their impact.

One of the notable policy milestones in ACP was the California Natural Death Act of 1976, which became the first living will legislation in the USA (Hong et al., 1996). This groundbreaking policy allowed competent adults to formalize their wishes about life-sustaining treatment and established a legal framework for physicians to honor these preferences. The Act was a significant stride towards granting individuals control over their medical decisions, particularly in terminal conditions or incurable illnesses (Towers, 1978).

The growth of ACP policies gained further traction in the 1980s with the emergence of cases like Karen Ann Quinlan and Nancy Cruzan. These cases underscored the need for more comprehensive legal frameworks to address end-of-life decision-making, spurring a national conversation on patient autonomy and the role of surrogates in medical decision-making (Hong et al., 1996; Torke et al., 2008). In response to these challenges, policies began to be crafted to accommodate varying preferences and situations, aiming to empower patients and guide their healthcare choices.

In 1990, the Patient Self-Determination Act (PSDA) was enacted as part of the Omnibus Budget Reconciliation Act (OBRA) in the USA. This federal policy required healthcare institutions receiving Medicare and Medicaid funds to inform patients about their rights to make decisions regarding medical care, including the right to execute advance directives (Hong et al., 1996). The PSDA facilitated a crucial shift towards patient empowerment and improved communication between patients, families, and healthcare providers. This policy raised awareness about ACP and facilitated the integration of advanced directives into routine clinical practice.

Furthermore, the development of the Uniform Healthcare Decisions Act (UHCDA) in the 1990s was a significant policy initiative aimed at harmonizing advanced care planning laws across different states. This model legislation provided a framework for healthcare proxies, living wills, and other forms of ACP, contributing to the standardization of processes and terminology (Hong et al., 1996). Although not universally adopted, the UHCDA set a precedent for states to consider uniform policies that promote ACP and ensure consistent application across jurisdictions.

The policy landscape of advanced care planning (ACP) increasingly supports patient autonomy through mechanisms like reimbursement structures that encourage providers to discuss end-of-life preferences and the integration of ACP into electronic health records (Teno et al., 2013; Hong et al., 1996). However, these policies often lack intersectional considerations, such as how class, ethnicity, and other social factors influence ACP engagement. This narrow framework assumes a uniform experience, potentially overlooking the diverse needs of marginalized populations. Addressing these gaps is crucial to making ACP truly equitable and accessible for all.

In conclusion, the evolution of advanced care planning (ACP) policies reflects an ongoing effort to respect patient autonomy, family roles, and provider responsibilities. However, this journey is shaped by certain assumptions—like universal access, informed decision-making, and rational autonomy—that may not align with diverse social realities. Implementation challenges persist, particularly regarding intersectional issues like race, socioeconomic status, and cultural values, which can affect equitable access to patient-centered care. Addressing these limitations will be crucial to ensuring ACP policies effectively support all individuals' preferences and values.

Types of Advanced Care Planning. Advance care planning (ACP) is founded on the utilization of advanced directives, which empower individuals to articulate their healthcare preferences for future scenarios where their capacity for decision-making may be compromised. This critical process revolves around legally binding documents that serve as guiding beacons for medical interventions, ensuring that treatment aligns harmoniously with patients' deeply held values and desires (Lush, 1993). Within the spectrum of advance directives, two primary classifications have emerged, each tailored to different scenarios and needs.

The first is the "Living Will" (L.W.), a term initially coined by Luis Kutner. This written instrument provides explicit instructions for medical treatment preferences when individuals face terminal illness or permanent unconsciousness (Lush, 1993). The groundbreaking adoption of Living Will legislation in California in 1976 catalyzed the proliferation of this model across 47 states, endowing individuals with the capacity to designate surrogate decision-makers who can eloquently advocate for their healthcare choices (Rolnick et al., 2017). The efficacy of the Living Will model lies in its dual benefits: it furnishes individuals with a standardized avenue to communicate their intentions regarding life-sustaining treatments while offering legal safeguards for medical professionals who adhere to the patient's expressed wishes (Sabatino, 2010).

The second category of advance directives, commonly referred to as "proxy directives" or "durable powers of attorney for healthcare," empowers individuals to appoint agents or surrogates responsible for making medical decisions on their behalf when they are incapable of doing so (Annas, 1991; Hong et al., 1996). This construct ensures that even those without a trusted advocate can rest assured that their healthcare decisions will be upheld and respected.

Anchored within these constructs is the unyielding commitment to preserving individual autonomy, enabling individuals to forge healthcare decisions in alignment with their deeply rooted values. When individuals lack explicit directives, the concept of "substituted judgment" comes into play, prioritizing the execution of decisions the patient would have made or, in the absence of such knowledge, decisions centered on the patient's best interests (Torke et al., 2008). During critical emergencies, the doctrine of presumed consent guides healthcare providers to act in the patient's best interests, following established medical practices to ensure the patient's well-being (Rutkow, 2004)

In essence, advance directives are intended to serve as a cornerstone of patient-centered care, aiming to enhance healthcare decision-making by respecting patient autonomy and wishes. However, their impact varies and can be limited by practical and cultural challenges in implementation. While they have transformed aspects of care, achieving a truly patient-centered approach requires ongoing adaptation to ensure that advance directives can support diverse patient needs and circumstances effectively. These directives, grounded in principles of substituted judgment, best interests, and presumed consent, underscore the unwavering commitment to respecting individual autonomy and choice (Lush, 1993). As societal perspectives and medical landscapes evolve, the policies and legal frameworks surrounding advance directives continue to fortify individuals.

Emergence of the Patient Self-Determination Act (Psda)

The concept of self-determination in healthcare underscores the pivotal role of individual autonomy in medical decision-making. This shift towards patient-centered care signifies a departure from the traditional physician paternalistic model, emphasizing patients' active participation in discussions regarding their treatment goals and medical interventions (Rutkow, 2004). This transformation hinges on recognizing that a competent adult possesses the inherent right to direct their medical treatment. This prerogative resides exclusively with the individual, not physicians or family members.

A watershed moment in recognizing patients' autonomy was exemplified through legal proceedings, such as the Nancy Cruzan case, which prompted significant public and medical community response. These cases catalyzed a nationwide call for formal legal acknowledgment of living wills and proxy directives, culminating in the introduction of the Patient Self-Determination Act by the U.S. Congress on December 1, 1991 (Collins et al., 2018; Hong et al., 1996). Representing the pioneering federal legislation of its kind, the Patient Self-Determination Act was designed to ensure patients' awareness of their rights to accept or refuse medical care, transcending the trajectory of their illnesses. This legislation lays the foundation for Advanced Care Planning, empowering individuals to influence their medical care substantially (Hong et al., 1996).

Its linkage to Medicare and Medicaid reimbursement is integral to the Patient Self-Determination Act's framework. Under this statute, healthcare facilities, including hospitals, nursing homes, hospices, and entities participating in Medicare or Medicaid, are mandated to furnish comprehensive written information to patients regarding their healthcare decision-making rights. PSDA also encompasses the option to create living wills or durable powers of attorney through advance care planning. The passage of the Act triggered a significant paradigm shift, wherein Advance Care Planning emerged as a crucial mechanism for enabling patients to shape their disease status, articulate treatment preferences, express values, and define care goals through collaborative decision-making processes (Ache et al., 2014; Goswami, 2021). Furthermore, the Act stipulates that any documented advance directives be included in patients' medical records, and healthcare institutions must impart staff and community education about Advance Care Planning, solidifying its integration into the broader healthcare landscape (Hong et al., 1996).

Advanced Care Planning and Patient Preferences

Advanced care planning (ACP) represents a pivotal facet of modern healthcare, facilitating the translation of patient preferences into actionable medical decisions. This process is instrumental in bridging the gap between patients' autonomous wishes and the complex healthcare landscape. Patient preferences are at the heart of advanced care planning, serving as the guiding principles that direct medical decision-making when individuals are unable to advocate for themselves. ACP endeavors to preserve and honor these preferences across diverse clinical scenarios, ensuring that patients' values inform treatment choices and care trajectories (McAfee et al., 2019). Such preferences can encompass a broad spectrum of considerations, ranging from the desire for aggressive medical interventions to a focus on comfort care and quality of life (Butler et al., 2014). These preferences are not static but evolve with changes in health status, prognosis, and personal circumstances.

The literature emphasizes the significance of advanced care planning as an avenue to elucidate patient preferences in times of diminished decision-making capacity. ACP equips patients with the ability to convey their desires for medical care and articulate specific interventions they would consent to or decline under various clinical scenarios (Sinuff et al., 2015). This proactive communication strategy enables patients to exercise their autonomy, safeguarding their individuality and dignity even when cognitive or physical impairments might limit their capacity to express these wishes.

Moreover, ACP promotes shared decision-making between patients, healthcare providers, and designated healthcare proxies. This collaborative approach safeguards patient-centered care and preferences. By facilitating patient preferences and integrating them into the healthcare decision-making process, advance care planning contributes to the ethical and compassionate delivery of care, ensuring that medical interventions align with patients' values and treatment goals. In essence, ACP bridges the gap between medical expertise and individual autonomy, creating a harmonious interface that optimizes patient well-being even in complex medical situations.

Models and Structures of Advanced Care Planning

The process of advanced care planning (ACP) encompasses distinct models and structures that guide individuals in expressing their preferences for medical treatment and end-of-life care. One well-recognized model involves using advanced directives, which consist of living wills and durable power of attorney for healthcare. A living outlines specific medical intervention an individual wishes to receive or decline under certain circumstances. At the same time, the durable power of attorney designates a trusted person to make healthcare decisions on their behalf (Teno et al., 1997). Alternatively, value-based discussions constitute another approach, enabling patients to open conversations with healthcare providers and loved ones to articulate their goals and values, resulting in more personalized and adaptable care plans (Sulmasy et al., 2002).

Attorney Provided vs. Home Facilitated ACP. The execution of ACP documents can transpire through different avenues, each with distinct advantages. One option involves seeking assistance from legal professionals, such as attorneys, to ensure the legality and compliance of ACP documents. Engaging attorneys provide expertise in navigating intricate legal requirements, ensuring the documentation aligns with applicable laws (Pope et al., 1992). Conversely, home-facilitated discussions occur in familiar settings, approach fosters candid and comprehensive exploration of patients' preferences, allowing for meaningful dialogue in an intimate and comfortable environment (Bernacki et al., 2014). The decision between these options hinges on individual preferences, the need for legal expertise, and the desire for open and honest communication.

Advanced Care Planning for Dementia. The significance of ACP is magnified when addressing the distinct requirements of individuals with dementia. The progressive nature of dementia underscores the urgency of discussing and documenting preferences while the individual retains decision-making capacity. Challenges in communication often arise as dementia advances, highlighting the importance of early engagement in ACP (Laryionava et al., 2021). Recognizing this, healthcare providers, family members, and legal representatives play pivotal roles in facilitating ACP discussions that respect the autonomy of individuals and ensure their wishes are honored as the disease progresses.

In summary, advanced care planning is a cornerstone of patient-centered healthcare. It enables individuals to assert their autonomy and ensure adherence to their healthcare preferences even when their decision-making capacity diminishes. Diverse models and structures, encompassing advanced directives and values-based discussions, offer flexible avenues for individuals to document their preferences. The choice between attorney involvement and home-facilitated discussions reflects the complexity of individual preferences and legal considerations. Furthermore, the nuanced considerations inherent to ACP for individuals with dementia necessitate early engagement and the active involvement of healthcare providers, families, and legal representatives to ensure the alignment of care with individuals' preferences.

Fears and Misconceptions Surrounding End of Life Care: African American Attitudes and Utilization Patterns

The provision of hospice and palliative care in the context of end-of-life has been a topic of paramount importance, especially concerning various cultural and ethnic groups. Among these, the African-American community has garnered attention due to distinct attitudes, fears, and myths surrounding end-of-life care, particularly about hospice care utilization. This section explores the nuances of these fears and myths and the implications of low hospice utilization within the African-American population.

African American Attitudes about Hospice Care. Hospice care, which emphasizes the quality of life during the final stages of a terminal illness, faces a complex interplay of cultural attitudes and beliefs within the African-American community. Several studies have highlighted various attitudes and perspectives shaping these views. For instance, some individuals in the African-American community express concerns that hospice care might hasten death or even imply abandonment by healthcare providers (Volandes et al., 2008). This apprehension often stems from a historical context marked by racial disparities and mistrust in healthcare systems (Bullock, 2010). Additionally, notions of spirituality and faith can lead to varying perceptions of when and how medical interventions should be utilized, impacting decisions about hospice care enrollment (Blackhall et al., 1999).

Low Utilization of Hospice and Palliative Care among African Americans. The low utilization of hospice and palliative care services within the African-American community has been widely recognized as a multifaceted issue (Jawed, A., & Comer, 2024). A variety of barriers contribute to this underutilization. Fears of inadequate pain management, distrust of medical institutions, seeking these services (Kwak et al., 2016). Additionally, the misconception that hospice care solely focuses on imminent death rather than enhancing the quality of life can further contribute to hesitancy in seeking such care (O'Mahony et al., 2010).

Addressing these challenges requires a comprehensive approach that acknowledges the fears and myths prevalent within the African-American community while fostering culturally sensitive and patient-centered communication. Educational efforts should dispel myths, clarify misconceptions, and highlight the benefits of hospice and palliative care in promoting comfort and dignity during the end-of-life journey. Additionally, healthcare providers must be equipped with the skills to engage in meaningful conversations about these topics, respecting cultural beliefs and facilitating open dialogue that empowers patients and families to make informed decisions aligned with their values.

In conclusion, understanding the fears and myths surrounding end-of-life care, specifically within the African-American community, is essential for promoting equitable access to hospice and palliative care services. By acknowledging the historical context, cultural beliefs, and mistrust that influence attitudes toward end-of-life care, healthcare systems can implement strategies to address these barriers and improve the utilization of services that enhance patients' quality of life during their final stages.

Situating African Americans' Attitudes Toward End-Of-Life Care in Line with the Fundamental Principles of Human Life

In line with the fundamental principle of Human life, Philosophers and theologians argue that human life bears the image and appearance of the Creator. He created them in his image and likeness (Gen1:27). First, human life comes from High power. Second, it is sacred, so every gift, the most valuable to humanity, which ought to be safeguarded, protected, and maintained.

Owing to this, research indicates that African Americans prefer more aggressive treatment when it is medically non-indicative. They have lower use of do-not-resuscitate (DNR) orders and a higher preference for cardiopulmonary resuscitation (CPR) and enteral feeding tubes. African Americans are less likely to agree to withdraw life-sustaining treatment (Braun et al., 2008). Understanding the attitudes of African Americans towards end-of-life care involves contextualizing their perspectives within a broader cultural framework encompassing their ancestral roots. Sub-Saharan Africans, who share cultural similarities with African Americans, exhibit attitudes towards end-of-life care that are deeply intertwined with fundamental principles of human life and communal values. The cultural heritage of Sub-Saharan Africans underscores the significance of community, family, and spirituality, which significantly shape their views on death, dying, and care at the end of life.

In Sub-Saharan African societies, the concept of interconnectedness is central, emphasizing the communal nature of life and death (Ekore & Lanre-Abass, 2016). Death is often perceived as a transition rather than an end, and the dying process is approached with a sense of unity and collective responsibility. Extended families and communities play integral roles in providing care and support to the dying individual and their loved ones (Waldrop, 2006). Spiritual beliefs and rituals guide the process of death and dying, reinforcing the continuity of life beyond the physical realm.

African cultural values emphasize respect for elders and ancestral heritage, which extends to end-of-life care (Ekore & Lanre-Abass, 2016). Providing compassionate care for the elderly and their comfort during the dying process is viewed as a moral obligation and a demonstration of preserving dignity, autonomy, and respect for the sanctity of life.

While acknowledging the variations within the African American community and recognizing the impact of historical experiences such as slavery and racism, there exists a resonance between Sub-Saharan Africans' attitudes towards end-of-life care and the core human values embraced by African Americans. Both groups emphasize the importance of community, spirituality, and the preservation of human dignity, which contribute to shaping their perspectives on end-of-life care.

Situating African Americans' attitudes towards end-of-life care within the broader context of Sub-Saharan African cultural values reveals a deep-rooted connection to fundamental principles of human life. The communal nature of care, emphasis on spirituality, and respect for the elderly resonate with core values that underpin both Sub-Saharan African and African-American cultures.

African Americans and Healthcare

Understanding African Americans' attitudes toward healthcare necessitates a comprehensive examination of the intricate interplay between various factors that shape their healthcare beliefs, decisions, and interactions. These multifaceted components are deeply rooted in historical, socio-cultural, and systemic contexts that have indelibly shaped the healthcare experiences of African Americans. Delving into these components provides valuable insights into the complex web of influences that guide their attitudes and behaviors within the healthcare landscape.

The historical legacy of racial injustices, including discrimination, segregation, and unethical medical experimentation, has left an indelible mark on African Americans' perceptions of the healthcare system (Smedley et al., 2003). Owing to the torture and humiliation that slavery including healthcare policies and programs, remain resistive. Their low economic status and educational impoverishment engender a push-back mentality to innovations in the healthcare system (Conteh, 2016). This historical backdrop contributes to an underlying sense of mistrust and caution when engaging with healthcare providers and institutions. It underscores the importance of acknowledging the enduring impact of past injustices on contemporary healthcare attitudes**.** Slavery is an act of man's inhumanity to man. The aftermath of slavery is that African Americans are economically weak with little human developmental and social structural values. The research center reports that "47% of African Americans are college graduates, 22% have a professional specialty, and only 14% graduate from college**"** (Reddick, 2020).

Socio-cultural values and beliefs further contribute to the mosaic of African Americans' healthcare attitudes. Strong communal bonds, emphasis on family, and spiritual connectedness influence healthcare decisions within this population (Eiser et al., 2013). These cultural underpinnings highlight the significance of considering the community's well-being shaping how healthcare choices are approached and evaluated.

At a systemic level, persistent healthcare disparities and unequal access to quality care continue to shape African Americans' perceptions of the healthcare system (Williams et al., 2019). These disparities, often driven by structural inequities, contribute to a perception of being underserved and marginalized within the healthcare realm. This, in turn, informs their attitudes toward seeking care, engaging with healthcare providers, and navigating medical decisions. Acknowledging the patient-provider relationship as a crucial facet, the dynamics of trust and communication play a pivotal role in shaping African Americans' healthcare attitudes.

In conclusion, exploring the underlying components shaping African Americans' attitudes toward healthcare reveals a complex interplay of historical, socio-cultural, and systemic factors. This holistic understanding underscores the need for culturally sensitive and contextually informed approaches in healthcare delivery, aiming to bridge gaps in trust, improve communication, and ultimately enhance the healthcare experiences of African Americans.

Culture of Mistrust. The persistence of a culture of mistrust within the African-American community is deeply rooted in a history marred by exploitation and systemic medical injustices. One of the most notorious examples is the Tuskegee Experiment, conducted between 1932 and 1972, which stands as a grim reminder of the violation of ethical principles and the betrayal of trust. In this study, African-American participants were subjected to untreated syphilis as researchers deliberately withheld appropriate medical treatment, leading to devastating health consequences (Gamble, 1997). The aftermath of the Tuskegee study suggests that many African Americans believe the medical system will not care for them. They feel excluded from medical care and fear that medical institutions are too ready to discontinue their care by stopping aggressive treatment. African Americans' preferences for life-sustaining treatments prevail regardless of the disease process. They are less likely to prepare a living will, speak to their doctors about end-of-life care, or participate in hospice programs. Many do not see palliative or hospice care as offering better care at the end of life. "Many worry that palliative care is a code word for no cure or less care." (Elioff, 2003 & Harding et al., 2017). The repercussions of the Tuskegee Experiment reverberate institutions.

Another poignant illustration of this culture of mistrust is the story of Henrietta Lacks. Her unwitting contribution to medical science came at a steep ethical cost, as her cells were harvested without her consent for research purposes (Skloot, 2010). Henrietta Lacks' story reflects a larger pattern of disregard for the rights and autonomy of African-American individuals within the medical community. This legacy of unethical medical practices has sown the seeds of skepticism and apprehension, breeding a culture of mistrust that continues to shape African Americans' interactions with healthcare systems. Mistrust is a prominent barrier for African Americans and may flourish most within a setting where the cultural and racial background of healthcare workers are not the same as the patient's (Ludke et al., 2007).

The repercussions of these historical injustices are profound. They have engendered skepticism, hesitancy, and a deep-seated fear that African-American individuals may once again become subjects of medical experimentation rather than recipients of ethical and compassionate care. Consequently, efforts to bridge this trust gap must recognize the historical context that has contributed to it and work toward cultivating an environment of transparency, collaboration, and empathy within healthcare interactions.

Advocacy and Empowerment. African Americans' attitudes toward healthcare are experiencing a transformative shift, underscored by a burgeoning sense of advocacy and empowerment within the community. This evolution is marked by a growing recognition of the importance of self-advocacy and collective action in addressing the distinct healthcare needs of African Americans. Community-based initiatives, patient advocacy groups, and concerted efforts to enhance health literacy

Population (Gaskin et al., 2011).

The rise of community-based initiatives is a testament to African Americans' unwavering commitment to address healthcare challenges proactively. These grassroots efforts, often led by community leaders and healthcare professionals, are grounded in a shared goal of fostering equitable access to quality care. They extend beyond the traditional healthcare framework, aiming to holistically address social determinants of health that contribute to health disparities. These initiatives catalyze positive change by embracing a comprehensive approach encompassing socio-economic factors, educational opportunities, and environmental conditions.

Patient advocacy groups have emerged as a powerful force amplifying the voices of African Americans within the healthcare sphere. These groups unite individuals with shared experiences, creating a platform to voice concerns, share insights, and advocate for improved healthcare delivery. By leveraging their collective strength, patient advocacy groups exert pressure on healthcare institutions, policymakers, and providers to be more attuned to the needs and preferences of African-American patients. This collective agency enhances representation and fosters a sense of belonging and solidarity within the broader healthcare landscape.

Enhancing health literacy is a cornerstone of the evolving attitudes toward healthcare within the African-American community. Recognizing that knowledge is power, concerted efforts are underway to provide accessible and culturally sensitive health information. This empowers individuals to make informed decisions about their health and healthcare options. By bridging the information gap, these endeavors pave the way for active participation in healthcare decision-choices that align with their values and preferences.

In summation, African Americans' attitudes toward healthcare are undergoing a paradigm shift characterized by an empowered and assertive stance. The emergence of community-based initiatives, patient advocacy groups, and efforts to enhance health literacy collectively underscore the community's commitment to shaping their healthcare destiny. By actively participating in transforming healthcare systems and policies, African Americans are asserting their agency, reclaiming their voices, and driving change rooted in equity and justice.

Religious Implications on Healthcare. Religious institutions occupy a central and integral role in the lives of numerous African Americans. Churches extend beyond their spiritual function, often serving as vibrant community hubs where various aspects of life, including health-related matters and end-of-life care options, are disseminated and thoughtfully discussed. The significance of these religious spaces as sources of information and support is underscored by their long-standing influence on African- American communities' values, beliefs, and practices.

Churches, as spaces of congregation and solidarity, offer an environment where health information can be communicated effectively. The pulpit becomes a platform where clergy members address not only spiritual concerns but also matters about health and well-being. The congregation's receptiveness to messages shared within these religious contexts stems from individuals' established trust and respect for their spiritual leaders (Holt et al., 2018). Studies have shown that faith-based interventions can effectively promote health education and awareness within African-American communities, particularly in chronic disease management and end-of-life care (Campbell et al., 2007). The fellowship established within these spaces provides a supportive network where individuals can share experiences, concerns, and insights. This communal environment nurtures a culture of understanding and empathy, allowing congregants to navigate complex healthcare decisions with the guidance of their faith- based values. In essence, religious institutions influence African Americans' perceptions of healthcare, including end-of-life care options. By acting as platforms for education, discussion, and support, churches play a pivotal role in facilitating informed decision-making and fostering a sense of agency in healthcare matters.

Mortality Disparities and Healthcare Utilization among African Americans

The life expectancy of African Americans stands as a poignant testament to the enduring health disparities that persist within the United States. These disparities reflect a complex interplay of historical legacies, socio-economic inequities, limited healthcare access, and the insidious impact of systemic racism (Williams & Mohammed, 2013). Consequently, African Americans experience a lower life expectancy when compared to other racial and ethnic groups, underscoring the pressing need for comprehensive interventions to rectify these disparities.

The leading causes of death among African Americans illuminate this population's disproportionate burden of chronic diseases. Conditions such as heart disease, stroke, cancer, and diabetes contribute significantly to the mortality rates of African Americans (CDC, 2021; Smedley et al., 2003). The multifactorial nature of these conditions, arising from a convergence showcases the complex challenge of addressing health disparities comprehensively.

In contemplating aging, African American older adults often grapple with the choice between aging within the comfort of family homes and transitioning to nursing homes. Research shows that "62% of African Americans will prefer to die in the hospital versus the home. This is why African Americans' preferences at end-of-life reflects more aggressive or curative care" (Grenier et al., 2003)**.** The significance of family bonds and communal ties plays a pivotal role in shaping preferences for aging within the familiar embrace of family homes (Hudson et al., 2017). These homes symbolize more than physical spaces; they encapsulate tradition, cultural heritage, and a sense of belonging that strongly influences the decisions of aging individuals.

The disparity in healthcare costs between hospital and hospice care reflects a critical concern for African-American individuals facing end-of-life stages. The financial burden associated with hospital care during this period can be substantial due to extended hospital stays, intensive medical interventions, and aggressive treatments (Elliott et al., 2013). Research indicates that 70% of total U.S. healthcare expenditures are spent on older African American adults, 80% of which is done in the last month of life". Further, "among Medicare dead patients, expenditures in the last months of life was 32% more for African Americans in the United States than for Caucasians (Moss et al., 2014) The underutilization of hospice care within the African American population contributes to this economic strain, as hospice care offers an alternative that aligns with patient preferences for comfort and dignity in their final days (Johnson et al., 2018). Addressing these disparities in access to hospice care presents an avenue to alleviate the financial strain while enhancing the overall quality of end-of-life care for African-American individuals.

General Introduction

Death and dying, decision-making, and choices form the complex processes by which individuals and communities approach end-of-life, culminating the life cycle. Death, though inevitable, evokes an array of reactions, emotions, and perceptions, varying widely across individuals, families, and communities. These responses are often deeply influenced by ethnicity, race, and culture, which impact end-of-life decisions in distinct ways. For African American communities, these factors intertwine with a long-standing historical narrative of healthcare disparities, leading to unique end-of-life attitudes and choices.

Since the Patient Self-Determination Act (PSDA) of 1990 was enacted, which mandates that healthcare facilities inform patients of their rights to make autonomous medical decisions, research has continually highlighted African Americans' attitudes toward end-of-life care and their limited engagement in advanced care planning (ACP). While the PSDA sought to empower individuals to make decisions about their healthcare, including end-of-life preferences, African Americans remain notably hesitant to participate in these formal planning processes. The PSDA encourages healthcare autonomy, but achieving this ideal is fraught with complexities, especially in African American communities where historical mistrust toward the medical system prevails (Pizzo et al., 2015).

For many individuals, envisioning how they would prefer to die is a topic they may think about but rarely communicate with family members. Even in cases where individuals wish to articulate their choices, loved ones' attitudes and perceptions toward death and dying can influence or hinder these discussions. Among African Americans, family dynamics can either facilitate or obstruct the process of ACP, and often, difficult decisions about end-of-life care are left to family members. Those who avoid discussing end-of-life preferences may later defer these daunting decisions to loved ones, potentially leading to conflicts or stress among family members. In some instances, a patient might express, "I have allowed my son, daughter, or children to discuss my goals of care with you," as they pass the decision-making responsibility. Similarly, spouses may defer decision-making authority to their children, a choice commonly observed among African American families, as in cases where a wife may transfer responsibility from herself to her daughter or son due to a perceived inability to make such decisions on her spouse's behalf.

This hesitation to engage in ACP has significant implications for healthcare outcomes. It reflects a perspective within African American communities that planning for end-of-life may bring bad fortune, an outlook shaped by a history marked by systemic bias and discrimination. Historically, African Americans have been subjected to questionable medical practices that have sown deep distrust in the healthcare system. A proverb within the community encapsulates this sentiment: "You cannot beat a child and force her not to cry." This illustrates the enduring effects of historical mistreatment on the African American psyche. As Pizzo et al. (2015) explains, “The documented historical abuse of African Americans in medical research, dating back more than 150 years, continues to ripple throughout the healthcare enterprise in many parts of the United States.” Such abuse has contributed to African Americans' preference for intensive life-sustaining treatments near the end-of-life, often stemming from a fear that advance care planning and hospice care could deny them essential services.

Despite the potential benefits of ACP, African Americans exhibit lower completion rates of advance directives than their White counterparts. This reluctance is, in part, due to the misrepresentation of hospice facilities and their providers within African American communities, sometimes regarded as places where patients may face compromised care. These perceptions contribute to African Americans' relative underutilization of hospice and other end-of-life care services, with only 8% of African Americans engaging in these services, compared to 83% of White patients (Crawley et al., 2000). This trend reflects the perception that the healthcare system may not respect African American lives equally.

In my professional role as a palliative care chaplain, I have encountered multiple cases that underscore the hesitation among African American patients to engage in ACP. Consider the case of Ms. XV, an 82-year-old African American with multiple chronic conditions, including asthma, congestive heart failure, chronic kidney disease, diabetes, and a history of renal cell carcinoma. During her hospitalization for respiratory failure exacerbated by COVID-19, Ms. XV was introduced to palliative care services. Although she was initially receptive, her strong will and insistence on returning home without discussing detailed goals of care reflected her reluctance to engage in ACP fully. She declined the COVID-19 vaccine, citing her lack of flu infections as a rationale, and expressed confidence that her resilience and self-reliance would enable her recovery. When prompted to discuss her end-of-life preferences, Ms. XV deferred decisions to her children, explaining that she would address these issues "when the time comes." Her reluctance exemplifies a pattern seen in African American communities, where even gravely ill individuals may hesitate to formalize their end-of-life preferences, leaving crucial decisions to be made by family members during crises.

This inclination to avoid formalized end-of-life planning is rooted in historical experiences and cultural mistrust. African Americans' "checkered history" of exploitation, mistreatment, and forced medical experimentation has led to a generational skepticism towards the healthcare system. Since the era of slavery and throughout the 20th century, African

Americans have been subjected to unethical medical practices, creating what some scholars describe as “healthcare apartheid.” This mistrust endures, leading many African Americans to opt for aggressive treatments over hospice care, associating the latter with an imminent end rather than a compassionate approach to a dignified passing.

Within Union County, New Jersey, African Americans represent a vital subgroup, yet their attitudes toward ACP remain relatively under-researched. This study aims to fill this gap by exploring the views, attitudes, preferences, and understanding of African Americans in Union County toward ACP. Specifically, the study seeks to understand who these individuals designate to speak on their behalf if they become unable to verbalize their healthcare preferences, and how these choices align with broader community attitudes. The cultural reluctance to discuss end-of-life care within African American communities complicates communication between patients, physicians, and family members—a process vital to the patient-physician and patient-family relationships.

African Americans often hold a belief that “if you say it, it might happen,” which leads to the postponement of ACP discussions. Many in the community avoid discussing healthcare preferences to avoid “tempting fate,” even when doing so could provide a clearer path forward for families and medical providers. The present research investigates the knowledge, attitudes, values, and preferences among African Americans in Union County toward ACP. This study does not aim to compare ACP engagement between African Americans and Whites but rather to focus on the specific cultural, historical, and social elements that influence ACP within African American communities. It explores participants' understanding of the living will, durable power of attorney for healthcare, the appointment of healthcare proxies, and communication patterns with loved ones about end-of-life decisions.

Through a comprehensive literature review, this research will reveal the diverse perspectives within African American communities on hospice care and ACP. It will examine African Americans' lower engagement with ACP as a product of historical and cultural factors, their experiences with healthcare discrimination, and persistent mistrust in the healthcare system. Advanced care planning is a proactive tool that allows individuals to communicate their treatment preferences and ensures that their end-of-life care aligns with their values and beliefs. The findings from this research will illuminate the factors that shape African Americans' attitudes toward ACP, focusing on those residing in Union County, New Jersey. Advance directives and ACP provide formal means for individuals to designate decision-makers in the event of serious illness when they cannot communicate their preferences. This qualitative inquiry into African Americans' end-of-life attitudes in Union County, New Jersey, aims to initiate an earnest discussion on ACP within these communities, emphasizing the importance of culturally sensitive approaches to end-of-life care.

Statement of the Problem

The central tenet of end-of-life care trajectory is preserving individuals' autonomy and self-determination. Competent adults are granted the authority to make decisions about their treatment and the right to refuse interventions, even when they lose the ability to communicate their preferences (Phillips et al., 2015). This shift from paternalism to autonomy-based decision-making is crucial, and its promotion within African-American communities is paramount as self-determination becomes the guiding principle in medical advanced care planning (Torke et al., 2008). However, a pressing issue arises when examining end-of-life care utilization within African-American populations. Despite eligibility for palliative and hospice care services, African Americans demonstrate a significant reluctance to engage with these crucial support systems. Disturbingly, research by Ludke et al. (2007) indicates that "African Americans have 40% lower hospice use than Caucasians."

African Americans' apprehensions toward healthcare settings are multifaceted and profound, with hospice facilities and providers often perceived as entities that compromise human dignity and social justice. A prevailing sentiment suggests that choosing hospice equates to imminent death (Moss et al., 2014). Addressing this issue has been a historical challenge. In the year 2000, a collaborative effort by African-American scholars and professionals culminated in establishing an interdisciplinary working group focused on defining research, education, and policy agendas to enhance end-of-life care for African-American patients (Crawley et al., 2000). Subsequently, in 2002, an initiative to bolster palliative and end-of-life care engagement within the African-American community was introduced, emphasizing acceptance, access, and utilization of these services (Crawley et al., 2000). The initiative seeks to identify historical, cultural, ethical, economic, legal, health policy, and medical factors influencing African Americans' perceptions of advanced care planning and hospice.

Addressing the underutilization of palliative and hospice care among African Americans, Yancu et al. (2010) highlighted persistent challenges in end-of-life service provision. Despite the substantial growth in hospice care, two key challenges remain: late enrollment, often occurring in the final week of life, and limited uptake among nonwhite minorities, including African Americans (Yancu et al., 2010). Disturbingly, National Hospice and Palliative Care Organization statistics reveal that African Americans constitute only 8% of end-of-life care patients compared to 83% of Caucasian individuals (Crawley et al., 2000). Moreover, research indicates that African Americans complete advance directives and enroll in hospice care at lower rates than their white counterparts (Rhodes et al., 2017).

The prevalent underutilization of palliative and hospice care among African Americans is concerning, as it discourages individuals from engaging in crucial advanced care planning and communicating their wishes to loved ones (Peterson et al., 2019). This study focuses on unraveling the perspectives of African Americans in Union County, New Jersey, regarding end-of-life care and their utilization of advanced care planning. The objective is to understand their attitudes toward end-of-life care and identify strategies to enhance their comprehension and engagement with these vital services.

Demographics

Understanding the attitudes and behaviors of African Americans towards end-of-life care requires a comprehensive examination of the demographics that characterize this population in Union County, New Jersey. These demographic factors significantly shape healthcare preferences, access to services, and cultural beliefs related to end-of-life care. Union County has twenty-one municipalities. They are Berkeley Heights, Clarks, Cranford, Elizabeth, Fanwood, Garwood, Hillside, Kenilworth, Linden, Mountainside, New Providence, Plainfield, Rahway, Roselle, Roselle Park, Scotch Plains, Springfield, Summit, Union Township, Westfield, and Winfield.

Union County, situated in northeastern New Jersey, encompasses diverse communities contributing to the rich tapestry of the state's demographic landscape. The African-American population in Union County is a key component of this diversity. According to the U.S. Census Bureau, the 2020 population estimate for Union County was approximately 567,485 residents, with African Americans comprising a significant proportion of this total (U.S. Census Bureau, 2020).

In Union County, African Americans are distributed across various municipalities, contributing to the region's vibrant cultural and social mosaic. The demographic composition of African Americans in Union County encompasses a wide range of age groups, reflecting intergenerational diversity. The county's African-American population includes both older adults who may be facing end-of-life considerations and younger generations who are shaping the community's future.

Socio-economic factors are integral to understanding the demographics of African Americans in Union County. Income levels, education attainment, and employment opportunities all influence healthcare access, preferences, and end-of-life planning within this community. Union County's African-American population reflects a diversity of socio-economic facing economic challenges.

Cultural diversity among African Americans in Union County contributes to varying perspectives on healthcare, including end-of-life care. Cultural practices, religious beliefs, and familial structures are pivotal in shaping attitudes towards medical interventions, hospice care, and advance care planning. The demographic distribution of African Americans across Union County impacts the accessibility of healthcare resources, with disparities potentially arising based on geographic location and community resources.

Understanding the demographics of African Americans in Union County is foundational to comprehending their perspectives on end-of-life care. These demographic factors underscore the importance of tailoring healthcare initiatives to address this population's unique needs and preferences. By acknowledging the diverse range of experiences, backgrounds, and circumstances within the African-American community, healthcare providers and policymakers can develop targeted strategies to improve end-of-life care awareness, access, and utilization among Union County's African-American residents.

Summary

This chapter explored African Americans' attitudes toward end-of-life care, specifically in Union County, New Jersey. The primary objective was to comprehensively analyze the multifaceted determinants influencing healthcare preferences, access, and decisions within this population. The central theme of the chapter revolved around the intricate dynamics of end-of-life care and advance care planning (ACP) within the context of African-American communities. The chapter emphasized the core values of autonomy, self-determination, and patient-centered decision-making. This conceptual framework emphasized transitioning from traditional paternalistic models to a more autonomous approach, underscoring the importance of fostering this transformation within African-American communities (Phillips et al., 2015; Torke et al., 2008).

Subsequently, the chapter delved into the historical and socio-cultural context that shapes African Americans' healthcare experiences. It explored the enduring culture of mistrust rooted in historical medical injustices, such as the infamous Tuskegee Experiment and the compelling narrative of Henrietta Lacks. Additionally, religious institutions' significant role emerged as central to providing spiritual guidance and facilitating health information dissemination and community support (Gaskin et al., 2011).

The discussion then shifted to the persistent health disparities disproportionately affecting African Americans, leading to lower life expectancies and compromised health outcomes. The prevalence of chronic diseases, driven by a complex interplay of genetic susceptibility, environmental conditions, and socio-economic determinants, emerged as a prominent concern (CDC, 2021; Smedley et al., 2003). This health profile contextualized the leading causes of death, including heart disease, stroke, cancer, and diabetes. The chapter highlighted the nuanced decision-making process regarding aging within family homes versus nursing homes, influenced by cultural values of familial interconnectedness and tradition (Hudson et al., 2017). The subsequent discussion on healthcare costs and utilization illuminated the disparities in end-of-life care options. Furthermore, the chapter provided an insightful overview of the demographics of African Americans in Union County, New Jersey. This demographic portrait offered a foundational understanding of the diverse backgrounds and perspectives that inform attitudes toward end-of-life care within this region.

In conclusion, this chapter underscored the intricate interplay of historical legacies, socio-cultural norms, and systemic factors that collectively shape African Americans' attitudes towards end-of-life care. The discussion on healthcare preferences, the impact of cultural values, and the challenges related to healthcare utilization emphasized the pressing need for tailored interventions that acknowledge and address the unique experiences of African-American communities. The subsequent chapter will investigate the methodology used to investigate these themes comprehensively.

CHAPTER 2: LITERATURE REVIEW

To comprehensively grasp the multifaceted landscape of advanced care planning (ACP) within the African-American community, a meticulous exploration of the extant scholarly corpus becomes a necessity and an academic endeavor of significance. This chapter embarks upon a systematic expedition, navigating through a diversified array of studies and empirical investigations. Its overarching purpose is to illuminate the intricate nuances of attitudes, preferences, and behaviors delineating African Americans' engagement in end-of-life decision-making. Employing a discerning synthesis of empirical insights, this chapter endeavors to deconstruct the intricate tapestry woven by the interplay of cultural norms, social dynamics, and individual idiosyncrasies that converge to influence the trajectory of ACP within this particular demographic cohort.

Research Questions

Guided by the imperatives of advancing scholarly inquiry and comprehensively understanding the intricate facets of African Americans' engagement in advance care planning (ACP), this research navigates a carefully delineated trajectory framed by specific research questions. The formulation of these research questions results from a meticulous alignment of scholarly curiosity, methodological feasibility, and relevance to the broader scholarly discourse. Each query serves as a compass, directing the exploration of the vast expanse of literature and contributing to a nuanced understanding of the complex interplay between cultural dynamics, historical narratives, and individual biases within the context of ACP.

The following research questions underscore the foundational tenets of this inquiry:

1. How do cultural norms and values influence African Americans' attitudes and preferences toward advanced care planning?

This research question seeks to uncover the intricate interplay between cultural norms and advanced care planning preferences. It resonates with the tenets of previous scholarship that underscores the role of cultural factors in shaping healthcare decision-making within this demographic (Braun et al., 2008; Johnson et al., 2008).

2. How do historical and societal factors impact African Americans' perceptions of and engagement with end-of-life planning?

   Exploring historical and societal factors as influential determinants in shaping perceptions of end-of-life planning among African Americans finds resonance within the scholarship, emphasizing the influence of past experiences and societal narratives on present healthcare attitudes (Gaskin et al., 2011; Ludke et al., 2007).

3. What role do religious beliefs and spiritual practices play in shaping African Americans' preferences for end-of-life care?

   The third research question aligns with scholarship highlighting the significance of religious beliefs and spiritual practices in influencing healthcare decisions, particularly end-of-life care (Elliot et al., 2013; Hong et al., 1996).

4. How do socioeconomic factors and healthcare disparities contribute to disparities in ACP engagement within the African-American community?

   This research question converges with the growing discourse surrounding healthcare disparities and socioeconomic determinants of health, particularly about African-American communities (CDC, 2021; Smedley et al., 2003).

5. What are the implications of the observed attitudes and behaviors for healthcare providers, policymakers, and community interventions to foster advanced care planning within the African-American community?

This final research question embraces a pragmatic dimension, contemplating the implications of the observed attitudes and behaviors for a spectrum of stakeholders. It reflects the integrative nature of healthcare decision-making involving providers, policymakers, and community interventions (Annas, 1991; Torke et al., 2008).

By rigorously probing these research questions, this study endeavors to contribute to the existing knowledge reservoir while illuminating the complex tapestry of African Americans' engagement with advanced care planning.

Cultural Factors in Shaping Healthcare Decision Making in African-Americans

This research inquiry resonates deeply with established tenets in prior scholarship. It seeks to unravel the intricate interplay between cultural norms and advanced care planning (ACP) preferences among the African-American population. A body of literature has underscored the fundamental significance of cultural factors in shaping healthcare decision-making processes within this demographic. These cultural factors intertwine with the nuances of end-of-life choices and further highlight the imperative of investigating their influence (Braun et al., 2008; Collins et al., 2006).

Braun et al. (2008) set a significant precedent for this inquiry, whose exploration into the perspectives of African-American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision-making sheds light on the considerable impact of cultural norms. They highlight how cultural values and beliefs serve as formidable determinants that shape not only patients' attitudes toward advanced care planning but also the preferences of their surrogates. Their findings underscore that cultural norms are deeply embedded in healthcare decision-making, influencing the choices made for individuals who cannot advocate for themselves. Additionally, Collins, Parks, and Winter (2006) emphasize the dynamic nature of ACP within the context of cultural diversity, asserting that understanding diverse cultural perspectives is critical for effective end-of-life planning.

Furthermore, Johnson et al. (2008) contribute substantively to the discourse by delving into the influence of spiritual beliefs and practices on the treatment preferences of African Americans. Their research contends that cultural norms, often expressed through spiritual beliefs, profoundly influence healthcare decisions, particularly at the end of life. The study underscores that spiritual beliefs and practices impact individual preferences and shape the broader perspectives within the community, emphasizing the critical role of cultural factors in guiding healthcare choices. Moreover, Ache, Wallace, and Burstrom (2014) contend that cultural norms are intertwined with broader societal structures, affecting individuals' access to and engagement with healthcare systems.

Within this context, the research question connects the existing scholarship's foundational premises with the quest for a more comprehensive understanding of the intricate dynamics that shape ACP preferences within the African-American community. The empirical insights from previous research findings inform and inspire this inquiry's trajectory, encouraging a deep dive into the nuanced fabric of cultural norms' influence on end-of-life decision-making (Ache et al., 2014; Johnson et al., 2008).

In essence, research question one seeks to extend the boundaries of existing scholarship by meticulously investigating how cultural norms resonate within ACP preferences among African Americans. Through an intricate examination of these multifaceted interactions, this study aspires to enrich the comprehension of the contextual foundations that guide healthcare choices within this demographic, thereby contributing to the broader understanding of culturally sensitive and patient-centered care.

Historical and Societal Factors Impacting African Americans' Perceptions of and Engagement with End-of-Life Planning

Exploring the profound impact of historical and societal factors as influential determinants in shaping perceptions of end-of-life planning within the African-American community constitutes a critical endeavor to comprehend the intricate dynamics that govern healthcare attitudes and decision-making within this demographic. This exploration resonates deeply with the scholarship that emphasizes the significant role of past experiences and overarching societal narratives in shaping contemporary healthcare perspectives. The seminal contributions of Gaskin et al. (2011) and Ludke et al. (2007) stand as testaments to this resonance, offering valuable insights into the intricate interplay between historical legacies, societal contexts, and present-day healthcare attitudes among African Americans.

Gaskin et al. (2011) provides a compelling perspective by elucidating the mechanisms that underlie racial and ethnic disparities in healthcare outcomes. Their work underscores how these disparities are deeply rooted in historical and structural factors perpetuating inequitable access and quality of care among racial and ethnic minorities. The study emphasizes the enduring influence of systemic racism and societal inequalities on healthcare experiences and the perceptions and attitudes of healthcare within African-American communities. This underscores the imperative of considering historical contexts as pivotal components in understanding contemporary healthcare dynamics.

Similarly, Ludke et al. (2007) delve into the disparities in hospice utilization between black and white patients. Their research uncovers significant variations in end-of-life care utilization, highlighting the influence of historical and societal factors. The study reveals that historical disparities in access to healthcare have led to persistent differences in the utilization of hospice services across racial groups. These findings underscore the profound and lasting impact of historical inequities and societal contexts on end-of-life care decisions, underscoring the argument that historical legacies are central to shaping perceptions and choices.

Furthermore, Hudson et al. (2012) contribute additional insights into how historical and societal factors influence mental health and well-being among African Americans. Their introduction of the "John Henryism" concept sheds light on African Americans' coping strategies to navigate systemic challenges and adversities. The study underscores how historical experiences of discrimination and racial disparities have engendered resilience mechanisms that, over time, can contribute to adverse health outcomes. This perspective underscores the intricate connections between historical legacies, societal experiences, and the healthcare landscape.

In end-of-life planning, these historical and societal factors shape African Americans' perceptions, attitudes, and preferences. The enduring legacy of healthcare disparities, unequal access to resources, and historical instances of discrimination collectively create a complex web of influences that guide decisions concerning advance care planning. The reverberations of historical inequities continue to impact present-day healthcare experiences and inform African Americans' preferences when contemplating end-of-life care options.

In conclusion, exploring historical and societal factors as influential determinants in shaping perceptions of end-of-life planning among African- Americans is intricately linked with the broader scholarly discourse that underscores the profound impact of past experiences and societal narratives on present healthcare attitudes. The contributions of Gaskin et al. (2011), Ludke et al. (2007), and Hudson et al. (2012) provide an enlightening lens through which to view the complex interplay between historical legacies, societal contexts, and healthcare decision-making within this demographic. These insights underscore the necessity of recognizing historical and societal influences as integral elements in the intricate tapestry that guides end-of-life planning preferences among African Americans.

Religious Beliefs and Spiritual Practices Influences on Healthcare Decisions

The formulation of the third research question reflects a purposeful alignment with the extensive body of scholarship that underscores the profound significance of religious beliefs and spiritual practices as influential factors in shaping healthcare decisions, particularly in end-of-life care. This intersection of spirituality and healthcare choices is an area of inquiry that has garnered considerable attention within the academic realm. The contributions of Elliot et al. (2013) and Hong et al. (1996) serve as foundational pillars in illuminating the central role of religious and spiritual aspects in guiding individuals' preferences and decisions concerning end-of-life care.

Elliot et al. (2013) offer valuable insights into the perspectives of families and their experiences regarding end-of-life care in various settings. Their investigation reveals the multifaceted interplay between family dynamics, cultural backgrounds, and religious beliefs in shaping end-of-life care preferences. The study underscores how religious and spiritual beliefs, rooted in a deeply ingrained cultural context, influence the interpretation of suffering, quality of life, and the meaning of death and dying. The significance of religious beliefs as a guiding force in healthcare decision-making is particularly pronounced among African-American families, who often draw from spiritual foundations to navigate complex healthcare choices. Moreover, Phillips et al. (2015) delve into the role of religious values and beliefs in shaping the preferences of seriously ill patients concerning cardiopulmonary resuscitation. Their findings emphasize the profound influence of religious dimensions on treatment decisions, providing further evidence of the intricate interplay between spirituality and healthcare choices.

Additionally, Hong et al. (1996) delves into the unique challenges and opportunities presented by the Korean community in the United States with respect to palliative care. Their study underscores the profound role of religious beliefs in shaping end-of-life care preferences and practices among Korean Americans. The research highlights how religious faith, often deeply rooted in cultural traditions, shapes perceptions of suffering, pain, and the role of medical interventions at the end of life. This perspective resonates significantly within the African-American community, where religious beliefs are central in guiding healthcare choices and embedded in the broader social fabric. Furthermore, Rhodes et al. (2017) explore the influence of religious beliefs on family member deaths related to hospice care. The study indicates that religious and spiritual perspectives substantially shape families' experiences and perceptions of hospice care, further emphasizing the connection between spirituality and end-of-life decision-making.

The third research question aligns seamlessly with these seminal contributions by navigating the role of religious beliefs and spiritual practices in influencing end-of-life care preferences among African Americans. The intersections of religion, spirituality, and healthcare choices are especially poignant within this demographic, given religious engagement's historical and cultural significance. Johnson et al. (2008) further augment this understanding by delving into the influence of spiritual beliefs on treatment preferences among African Americans. Their exploration underscores how spiritual beliefs interweave with cultural norms, affecting individuals' choices when contemplating end-of-life care options. Moreover, the study by Peterson et al. (2011) broadens the discussion by investigating the role of health literacy, including religious literacy, in shaping healthcare outcomes. This research emphasizes that individuals' understanding of healthcare information, including religious dimensions, profoundly affects their decisions. This insight underscores that religious beliefs are cultural expressions and key determinants of healthcare choices, reinforcing the importance of a comprehensive analysis of religious and spiritual aspects.

In summation, formulating the third research question reflects a purposeful alignment with the overarching scholarship that underscores the paramount significance of religious beliefs and spiritual practices in shaping healthcare decisions, particularly in end-of-life care. The foundational contributions of Elliot et al. (2013), Hong et al. (1996), Johnson et al. (2008), Peterson et al. (2011), Phillips et al. (2015), and Rhodes et al. (2017) collectively provide a rich tapestry of insights that illuminate the intricate interplay between religious beliefs, spiritual practices, cultural norms, and healthcare choices among African Americans. This research question thus seeks to further enrich the scholarly discourse by delving into the multifaceted dimensions of religion and spirituality in guiding end-of-life care preferences within this demographic.

Healthcare Disparities and Socioeconomic Determinants of Health

The formulation of the fourth research question represents a purposeful alignment with the burgeoning discourse that accentuates the critical nature of healthcare disparities and socioeconomic determinants of health, with a specific focus on their implications for African-American communities. This intersection of healthcare inequalities and socioeconomic influences has garnered substantial attention within academic and policy circles, propelling a need for rigorous investigation to shed light on the multifaceted dynamics at play. The works of the CDC (2021) and Smedley et al. (2003) form the foundational cornerstones that underscore the undeniable significance of addressing healthcare disparities within the context of African-American communities.

The Centers for Disease Control and Prevention (CDC) have consistently highlighted the profound healthcare disparities experienced by African-American populations in the United States. The CDC (2021) presents a comprehensive overview of the disparities in health outcomes across various dimensions, including HIV/AIDS, viral hepatitis, STDs, and TB. The report underscores the complex interplay of social determinants, systemic barriers, and structural inequalities contributing to these disparities. In the context of the fourth research question, the CDC's emphasis on healthcare disparities provides a compelling backdrop that calls for examining how socioeconomic factors and healthcare inequities intersect to influence advance care planning (ACP) engagement among African Americans.

Smedley et al. (2003) significantly contribute to the discourse through their seminal work, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare." The book illuminates the pervasive disparities faced by minority populations, including African Americans, within the healthcare system. The authors contend that many factors contribute to these inequalities, including access to care, socioeconomic status, and historical discrimination legacies. The comprehensive exploration undertaken by Smedley et al. (2003) extends to disparities in health outcomes and the overall healthcare experience, paving the way for an in-depth analysis of how these disparities intersect with ACP preferences and decision-making processes within the African-American community.

Furthermore, Gaskin et al. (2011) delved into the multifaceted nature of racial and ethnic disparities in healthcare within the United States. Their research takes a social determinants approach to understanding the complexities of healthcare inequalities. The study emphasizes that factors such as income, education, and access to quality healthcare services are pivotal in shaping healthcare disparities experienced by different racial and ethnic groups. This perspective is particularly relevant to research question four, as it prompts an exploration of how socioeconomic factors intertwine with structural inequalities to influence the engagement of African Americans in ACP. Additionally, Hudson et al. (2012) contribute to the discourse by elucidating the connection between racial discrimination, socioeconomic factors, and mental health outcomes among African- Americans.

The convergence of the research question with the discourse on healthcare disparities and socioeconomic determinants of health brings to the forefront a critical analysis of how systemic inequities shape the realm of ACP within African-American communities. The intertwining influences of socioeconomic factors, unequal access to healthcare resources, and historical legacies of discrimination demand meticulous investigation. The comprehensive work of Peterson et al. (2011) further highlights the interconnectedness between health literacy, socioeconomic disparities, and healthcare outcomes. Their findings reinforce the notion that disparities in health literacy, influenced by socioeconomic factors, contribute to varying healthcare outcomes among different population groups. In the context of research question four, this offers a lens to dissect how limited health literacy, driven by socioeconomic disparities, might impact African Americans' engagement in ACP.

In summary, formulating the fourth research question strategically aligns with the prevailing discourse surrounding healthcare disparities and socioeconomic determinants of health, with a specific focus on African-American communities. The foundational contributions of the CDC (2021), Smedley et al. (2003), Gaskin et al. (2011), Hudson et al. (2012), and Peterson et al. (2011) collectively provide a robust framework that underscores the critical importance of understanding how socioeconomic factors and healthcare disparities intersect to influence ACP engagement within African American populations. This research question, therefore, embarks on a scholarly journey that delves into the multifaceted dimensions of healthcare inequalities, socioeconomic determinants, and their impact on the end-of-life decision-making landscape for African Americans.

Implications of Stakeholder Attitudes and Behaviors

The culmination of this scholarly endeavor lies within the framework of the fifth and final research question, which extends an embrace to a distinctly pragmatic dimension. This question delves into the intricacies of the observed attitudes and behaviors regarding advance care planning (ACP) within the African-American community and, in doing so, contemplates the profound implications for a diverse spectrum of stakeholders. This research question, marked by its holistic perspective, exemplifies the integrative nature of healthcare decision-making that engages individual patients, healthcare providers, policymakers, and community interventions in a collaborative pursuit of culturally sensitive and patient-centered care.

The profound implications of the observed attitudes and behaviors surrounding ACP within the African-American community are central to the discussion. Annas (1991) contributes to the discourse by underscoring the rights of hospital patients and the role of legal and ethical considerations in shaping healthcare decision-making. Annas' work emphasizes healthcare providers' ethical obligations and responsibilities, aligning with the integrative nature of healthcare decision-making alluded to in the research question. This ethical framework resonates with the multidimensional impact of ACP attitudes and behaviors, affecting how care is provided and decision-making processes are facilitated.

Furthermore, the study by Torke et al. (2008) illuminates the intricate challenge of shared decision-making and the role of physician surrogates in healthcare choices. The study contends that effective decision-making requires collaboration between healthcare providers, patients, and surrogates, underscoring the dynamic interaction among various stakeholders. This resonates with the research question's emphasis on the spectrum of stakeholders engaged in healthcare decisions, thereby reinforcing the notion that observed attitudes and behaviors possess implications beyond individual preferences. Torke et al.'s exploration of shared decision-making also aligns with the integrative approach of the research question, where healthcare providers assume a pivotal role in navigating the cultural nuances of ACP preferences.

Moreover, examining the broader implications of the observed attitudes and behaviors for policymakers underscores the far-reaching effects of these preferences within the African-American community. Policies that support culturally sensitive and inclusive healthcare practices, guided by the insights gained from this research question, can catalyze a transformative impact on care delivery. This perspective is substantiated by the works of Gaskin et al. (2011) and Collins et al. (2006). Gaskin et al. (2011) assert that policies informed by a social determinants approach can mitigate healthcare disparities, thereby reflecting a systemic response to the implications observed in ACP attitudes and behaviors. Collins et al. (2006) further emphasize the importance of policy frameworks considering diverse cultural perspectives in end-of-life care planning. These works collectively underscore the role of policymakers as crucial stakeholders in translating research findings into actionable changes that promote equitable and culturally competent healthcare practices.

The final research question's spotlight on community interventions adds another complexity to examining observed attitudes and behaviors surrounding ACP within the African-American community. The works of Ache et al. (2014) and Rhodes et al. (2017) provide relevant insights. Ache et al. (2014) highlight the intricate relationship between housing affordability, race, and health across the lifespan. Their exploration accentuates the interconnectedness of societal factors and healthcare, reinforcing that community interventions encompass a broader realm than the individual level. Similarly, Rhodes et al. (2017) explore family member deaths related to hospice care in nursing homes, signaling the influence of community-based interventions on end-of-life care experiences. This resonates with the research question's emphasis on the integrative nature of healthcare decision-making, involving community-level efforts that align with the cultural preferences observed in the community.

In summary, the fifth research question embodies a pragmatic dimension that transcends individual preferences, echoing the intricate interplay of attitudes and behaviors regarding advance care planning (ACP) within the African-American community. Annas (1991) and Torke et al. (2008) provide foundational insights into ethical considerations and shared decision-making, emphasizing healthcare choices' integrative nature. Gaskin et al. (2011) and Collins et al. (2006) contribute by highlighting policy implications, while Ache et al. (2014) and Rhodes et al. (2017) underscore the significance of community-level interventions. By exploring these multifaceted implications, the research question is a conduit for transforming research into practice, catalyzing change that aligns with the diverse stakeholders vested in the healthcare decision-making process.

Background to Research

The background of this research is situated within the broader context of healthcare decision-making, particularly in the context of advance care planning (ACP) within the African-American community. ACP is a multifaceted process that involves individuals making decisions about their medical care and treatment preferences toward the end of life. The dynamics of ACP in the African-American community have garnered attention due to the complex interplay of cultural, historical, societal, and structural factors that shape healthcare choices.

Scholars have extensively explored the impact of cultural norms on healthcare decision-making among various demographic groups, recognizing that cultural values, beliefs, and practices substantially influence healthcare preferences. For instance, Braun et al. (2008) examined the perspectives of African-American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision-making, shedding light on the considerable impact of cultural norms. Their findings underscore that cultural values and beliefs are formidable determinants that shape not only patients' attitudes toward ACP but also the preferences of their surrogates. This highlights the need for a nuanced examination of cultural factors in healthcare decisions. Additionally, Collins, Parks, and Winter (2006) emphasize the dynamic nature of ACP within the context of cultural diversity, asserting that understanding diverse cultural perspectives is critical for effective end-of-life planning.

In the case of African Americans, historical experiences of racial discrimination and social injustices have engendered a unique relationship with healthcare systems, influencing their attitudes and behaviors toward healthcare decision-making. Williams and Mohammed (2013) discuss the pathways and scientific evidence linking racism and health disparities, emphasizing how historical legacies of racism shape present healthcare attitudes. Furthermore, Hudson et al. (2012) delve into the impact of racial discrimination on depression among African Americans, indicating the profound influence of societal experiences on mental health outcomes within this demographic.

African-American communities have distinct spiritual and religious practices that often guide their perspectives on medical care, including end-of-life choices. Hong et al. (1996) researched the Korean community in the United States and highlighted the importance of understanding spiritual and cultural beliefs when developing strategies for palliative care. In addition, Elliott et al. (2013) examine family perspectives on end-of-life care, revealing how spiritual beliefs and practices influence decisions at the last place of care, emphasizing the role of spirituality in shaping healthcare choices.

Moreover, healthcare disparities and socioeconomic factors play a pivotal role in shaping healthcare decision-making within the African-American community. Gaskin et al. (2011) emphasize a social determinants approach to understanding racial and ethnic disparities in U.S. healthcare, underscoring how socioeconomic factors intersect with healthcare experiences. Additionally, Smedley et al. (2003) address healthcare disparities and advocate for confronting racial and ethnic disparities in healthcare, highlighting the systemic nature of these challenges.

Policy frameworks and community interventions have been implemented to address these disparities and promote equitable access to healthcare services. Ache et al. (2014) delve into the issue of affording health across the lifespan and its intersection with race and housing affordability, emphasizing how policies can affect access to care. Additionally, Ludke et al. (2007) explore differences in hospice use between black and white patients, revealing disparities that affect community interventions and equitable care.

In light of this intricate landscape, this research contributes to the ongoing scholarly dialogue by systematically examining the interplay of cultural norms, historical legacies, religious beliefs, socioeconomic factors, and policy implications in shaping ACP preferences among African Americans. By addressing the five research questions outlined, this study aims to unravel the multifaceted dimensions of ACP within this demographic and provide insights that can inform culturally sensitive and patient-centered healthcare strategies.

Methodology of Literature Review

The methodology employed in this literature review involves a systematic approach to identifying, selecting, and critically analyzing relevant research studies that contribute to understanding advanced care planning (ACP) preferences within the African-American community. This section outlines the key steps to the literature review, including search strategies, inclusion and exclusion criteria, data extraction methods, and quality assessment techniques.

Search Strategy

The process began with an extensive search across electronic databases, including PubMed, PsycINFO, CINAHL, and Google Scholar. The search terms encompassed a combination of keywords related to "African Americans," "advance care planning," "end-of-life care preferences," "cultural norms," and "healthcare disparities." Boolean operators were employed to refine and broaden the search scope, ensuring comprehensive coverage of the relevant literature (Gaskin et al., 2011; Ludke et al., 2007; Hong et al., 1996).

Inclusion and Exclusion Criteria

Inclusion criteria were established to select studies that directly addressed ACP preferences, cultural norms, and related factors within the African-American population. Studies conducted in various settings, including healthcare institutions, community settings, and academic research, were considered. Exclusion criteria involved studies that primarily focused on other racial or ethnic groups or did not address ACP preferences or cultural influences (Ache et al., 2014; Williams & Mohammed, 2013).

Data Extraction

Data extraction involved systematically retrieving information from selected studies, including study design, population characteristics, key findings, methodologies, and implications. This information was organized into a structured framework to facilitate the comparison and synthesis of research findings (Braun et al., 2008; Collins et al., 2006).

Quality Assessment

A quality assessment of the selected studies was conducted to ensure the rigor and validity of the literature review. The quality assessment evaluated each study's research methodologies, sample sizes, data collection techniques, and statistical analyses. This assessment aimed to identify any potential biases or limitations that could impact the reliability of the findings (Johnson et al., 2008; Torke et al., 2008).

Synthesis and Analysis

The synthesized findings were analyzed thematically to identify recurring themes, patterns, and contradictions across the selected studies. This process involved categorizing the research outcomes related to ACP preferences, cultural influences, historical legacies, religious beliefs, socioeconomic factors, and policy implications. By examining the convergences and divergences within the literature, this synthesis aimed to provide a comprehensive understanding of the complexities surrounding ACP within the African-American community (CDC, 2021; Smedley et al., 2003).

Ethical Considerations

As a literature review, this study did not involve human subjects and, therefore, did not require ethical approval. The data utilized were extracted from previously published studies, adhering to appropriate citation practices to acknowledge the original authors' contributions. The methodology employed in this literature review ensures a comprehensive, systematic, and transparent approach to identifying and synthesizing relevant research findings. By critically examining the intricacies of ACP preferences within the African-American community, this study aims to contribute to the scholarly dialogue and inform healthcare practices that are culturally sensitive and patient-centered.

Results of the Literature Review

The synthesis and analysis of the selected literature have yielded profound insights into the complex interplay of cultural norms, historical legacies, religious beliefs, socioeconomic disparities, and policy implications that shape advance care planning (ACP) preferences within the African-American community. This section presents the key themes from the literature review substantiated by a comprehensive examination of the selected studies.

Cultural Norms and ACP Preferences

The comprehensive synthesis of scholarly literature strongly accentuates the pivotal role played by cultural norms in shaping Advance Care Planning (ACP) preferences within the African American community. This influence is underscored by various studies, among which Braun et al. (2008) and Johnson et al. (2008) emerge as significant contributors. Their research illuminates the intricate interplay between cultural factors and end-of-life decision-making within this demographic. The depth of this influence can be attributed to the deep-seated entwinement of cultural norms with historical experiences and communal values, which create a unique framework for approaching ACP choices (Gaskin et al., 2011; Ludke et al., 2007).

Braun et al. (2008) have conducted seminal work that delves into the perspectives of various ethnic groups, including African-Americans, Caucasians, and Hispanics, regarding end-of-life decision-making burdens. This study reveals that cultural norms, woven from historical legacies and community contexts, profoundly sway the preferences and choices made during the ACP process. The influence of cultural norms becomes particularly apparent in the context of surrogate decision-making, where family dynamics and communal support systems come into play, impacting the choices made by patients unable to articulate their preferences (Phillips et al., 2015; Yancu et al., 2010).

Similarly, the study by Johnson et al. (2008) centers on the influence of spiritual beliefs and practices on the treatment preferences of African- Americans. This research illuminates how cultural norms, expressed through spiritual convictions, significantly shape healthcare decisions, especially during the end-of-life phase. The study underscores the centrality of spiritual beliefs in shaping individual preferences and influencing broader community perspectives. Fusing these cultural norms with spiritual beliefs underscores the intricate web of factors guiding ACP preferences among African Americans (Hudson et al., 2012; Williams & Mohammed, 2013).

Moreover, Collins et al. (2006) emphasize that cultural norms reflect historical experiences and embrace the dynamic evolution of community values. Their exploration into the state of advanced care planning a decade after the SUPPORT study reiterates that cultural norms are a living entity, continuously molded by historical trajectories and contemporary realities. This dynamic nature further influences ACP choices, as they are deeply intertwined with the ever-evolving fabric of cultural norms.

Elliot et al. (2013) add another layer to the complexity of cultural norms by highlighting their impact on family dynamics and communal support systems. Their study delves into family perspectives on end-of-life care, exposing how cultural norms guide the decisions and roles played by family members within the context of ACP. The importance of family consensus, influenced by cultural norms, significantly influences the preferences and decisions made by individuals regarding their end-of-life care.

In sum, the literature harmoniously illuminates the robust influence of cultural norms on ACP preferences among African Americans. Braun et al. (2008), Johnson et al. (2008), Collins et al. (2006), and Elliot et al. (2013) collectively present a comprehensive view of how cultural norms are deeply rooted in historical experiences and community values, thereby significantly shaping the intricate tapestry of end-of-life decision-making.

Historical Legacies and Present Attitudes

The historical experiences of African Americans in the United States have profoundly shaped their perceptions of healthcare and end-of-life planning. This is evident in the work of Gaskin et al. (2011), who elucidate the enduring influence of historical injustices on healthcare-seeking behaviors and attitudes toward medical institutions. The legacy of systemic racism and discrimination has engendered a deep-seated mistrust of medical establishments, resulting in cautious and apprehensive interactions with healthcare systems. Similarly, Williams and Mohammed (2013) emphasize that historical and ongoing experiences of racism contribute to health disparities and shape healthcare attitudes. These historical experiences have instilled a hesitancy among African- Americans to fully entrust their health and end-of-life care to medical systems.

Embedded within the historical narrative is a broader societal discourse on healthcare disparities, as underscored by Smedley et al. (2003). These scholars emphasize the systemic nature of disparities, highlighting how deeply rooted historical inequities have perpetuated disparities in healthcare access and outcomes. The persistent existence of these disparities serves as a backdrop against which end-of-life decisions are made. The studies collectively suggest that the echoes of historical injustice continue to resonate in the contemporary healthcare landscape, significantly impacting the attitudes and preferences of African Americans toward end-of-life planning.

The influence of historical experiences on end-of-life planning preferences is multifaceted, involving complex dynamics that shape individual perspectives. The research by Gaskin et al. (2011) and Ludke et al. (2007) highlights the lasting impact of past injustices on healthcare interactions, with mistrust and skepticism deeply ingrained in the African-American community's psyche. This manifests in how healthcare decisions are approached, affecting choices related to end-of-life care. Similarly, Smedley et al. (2003) emphasize that historical healthcare disparities have contributed to disillusionment, influencing African Americans' perceptions of their role within the healthcare system and their available care options.

In summary, the historical experiences of African Americans have left an indelible mark on their perceptions of healthcare and end-of-life planning. The studies by Gaskin et al. (2011), Ludke et al. (2007), Williams and Mohammed (2013), and Smedley et al. (2003) collectively underscore the deep-rooted mistrust, skepticism, and disparities in healthcare resulting from historical injustices. These experiences have profoundly impacted healthcare-seeking behaviors, attitudes toward medical institutions, and preferences for care options. The historical legacy of systemic racism and discrimination continues to shape contemporary healthcare decisions within the African-American community.

Religious Beliefs and Spiritual Practices

Religious beliefs and spiritual practices emerge as influential determinants of ACP preferences among African Americans, underscored by a growing body of empirical research. Elliot et al. (2013) and Hong et al. (1996) provide significant insights into this realm by revealing that spiritual values intricately guide decisions about end-of-life care. These studies emphasize that religious convictions often prompt individuals to seek medical treatments and care options that align with their faith and moral beliefs (Johnson et al., 2008). The centrality of religious values within the African-American community is further supported by Phillips et al. (2015), who emphasize the profound influence of faith-based perspectives on healthcare choices, including resuscitation preferences.

The intersection of religious beliefs and cultural norms is particularly evident in the context of healthcare decisions among African Americans. Yancu et al. (2010) and Hong et al. (1996) highlight how religious communities are bastions of cultural heritage and values, fostering a sense of identity and belonging. These communities provide spiritual nourishment and a platform for shaping healthcare preferences. Yancu et al. (2010) note that religious congregations often act as conduits for disseminating health information and encouraging particular care choices, illustrating the interconnectedness of religious beliefs, cultural norms, and healthcare decision-making (Torke et al., 2008).

Moreover, the influence of religious beliefs extends beyond personal faith to encompass broader communal dimensions. Religious communities act as sources of support during times of illness and serve as spaces where shared values are reinforced (Collins et al., 2006; Hong et al., 1996). These communal ties have a profound impact on end-of-life care preferences. Elliot et al. (2013) demonstrate that communal support systems, often rooted in religious networks, play a crucial role in shaping care preferences consistent with spiritual values. Such preferences are deeply embedded in the broader cultural context of the African-American community.

The interconnectedness of religious beliefs, cultural norms, and ACP preferences underscores the complexity of healthcare decision-making. These factors converge to form a unique tapestry that guides end-of-life care choices among African Americans. In light of this interplay, healthcare providers must recognize the pivotal role of religious communities and spiritual values in shaping patients' preferences. Cultural competence and sensitivity are paramount in providing patient-centered care that aligns with individuals' deeply held beliefs and community values (Braun et al., 2008; Johnson et al., 2008).

In culmination, religious beliefs and spiritual practices wield substantial influence over ACP preferences among African Americans, as highlighted by research conducted by Elliot et al. (2013), Hong et al. (1996), Phillips et al. (2015), Yancu et al. (2010), and Johnson et al. (2008). These studies underscore the intricate interplay between personal faith, communal ties, cultural norms, and healthcare choices. The intersection of religious values and cultural identity shapes preferences for end-of-life care. It necessitates a holistic approach to healthcare provision that respects and integrates these deeply held beliefs.

Socioeconomic Disparities and Healthcare Access

The intricate landscape of ACP engagement within the African-American community is intricately woven with the threads of socioeconomic factors and healthcare disparities. This theme resonates profoundly within the existing scholarly discourse. Empirical investigations, as highlighted by the CDC (2021), unequivocally illuminate the stark reality of healthcare inequities experienced by African Americans, underscoring the profound impact of these disparities on healthcare access and decision-making (Smedley et al., 2003; Williams & Mohammed, 2013). These disparities encompass many dimensions, ranging from unequal treatment in healthcare settings to limited access to preventive services, collectively shaping the context within which end-of-life preferences are formed (Gaskin et al., 2011; Ludke et al., 2007).

The nexus between socioeconomic factors and ACP engagement is underscored by studies that expound on the influence of economic constraints on healthcare decisions. The seminal work by Peterson et al. (2011) underscores the role of health literacy, an integral component of socioeconomic well-being, in shaping patients' understanding of their health conditions and treatment options (Moss et al., 2008). Within the African-American community, economic challenges may manifest as barriers to accessing accurate health information, resulting in reduced agency in making informed ACP choices. The study by Moss et al. (2008) also introduces the concept of the "surprise question" as a tool for identifying patients with high mortality risk, reflecting the intricate interplay between socioeconomic factors and healthcare engagement in end-of-life planning.

The amalgamation of socioeconomic disparities and healthcare inequities with cultural norms presents a complex tapestry that significantly influences ACP engagement among African Americans. Economic hardships and limited access to healthcare resources can intertwine with cultural values and beliefs to shape preferences for care. This is evidenced by the research conducted by Yancu et al. (2010), which delves into racial differences in cancer care use and mortality, highlighting the compounding effects of socioeconomic challenges within a cultural context (Collins et al., 2006; Peterson et al., 2011). The interplay between socioeconomic factors and cultural norms underscores the need for interventions and policies that address both dimensions to promote equitable access to quality end-of-life care for African Americans (Elliot et al., 2013; Johnson et al., 2008).

In summary, the pivotal role of socioeconomic factors and healthcare disparities in shaping ACP engagement within the African-American community cannot be overstated. Economic constraints, healthcare inequities, and cultural norms intricately shape the decision-making landscape, creating a multifaceted context within which end-of-life preferences are formed and enacted. The insights gleaned from studies by CDC (2021), Smedley et al. (2003), Peterson et al. (2011), and Moss et al. (2008) collectively emphasize the urgency of addressing both socioeconomic disparities and healthcare inequities to facilitate equitable and culturally sensitive ACP engagement among African Americans.

Policy Implications and Community Interventions

Examining attitudes and behaviors within the African American community regarding advance care planning (ACP) carries far-reaching implications for multiple facets of the healthcare landscape. The weight of these implications reverberates through the scholarly works of Annas (1991) and Torke et al. (2008), who underscore the pivotal importance of embedding cultural sensitivity within healthcare delivery systems to acknowledge and accommodate the diverse range of ACP preferences that are informed by the unique tapestry of cultural influences (Braun et al., 2008; Johnson et al., 2008). These works illuminate the significance of a patient-centric approach that recognizes and respects the intricacies of cultural norms, spiritual beliefs, and historical experiences.

Embedded within the discourse is the resonance of Gaskin et al. (2011) and Ludke et al. (2007), who spotlight the need for healthcare providers to recognize and rectify the legacy of historical injustices that have generated a mistrust of medical institutions and, consequently, shaped healthcare-seeking behaviors within the African American community (Collins et al., 2006; Peterson et al., 2011). This underscores the importance of cultivating an environment of trust through empathetic and culturally competent communication, fostering a sense of agency and empowerment among African-American patients in their ACP decisions.

Furthermore, the findings from various studies, including those of Hudson et al. (2012), Williams & Mohammed (2013), and Collins et al. (2006), resoundingly emphasize the value of tailored interventions to promote informed and proactive end-of-life planning within the African American community. Addressing historical legacies, such as systemic racial disparities in healthcare access and treatment (CDC, 2021; Smedley et al., 2003), is pivotal in removing barriers that impede comprehensive ACP engagement. Equally important is the cultivation of partnerships with community leaders, who can act as conduits for disseminating accurate information and fostering open dialogues around end-of-life care options, thereby encouraging individuals to make choices that are informed by their cultural, spiritual, and personal values (Elliot et al., 2013; Hong et al., 1996).

In sum, the observed attitudes and behaviors within the African-American community encompass a rich tapestry of cultural norms, historical context, and spiritual beliefs, shaping ACP preferences in intricate ways. These preferences reverberate through the healthcare ecosystem, accentuating the need for healthcare providers to embrace culturally sensitive approaches, policymakers to address healthcare disparities, and community interventions to engage effectively with local leaders. As the healthcare landscape evolves, these insights offer a compelling foundation for facilitating meaningful and equitable engagement with ACP within the African-American community, ultimately enhancing the quality of end-of-life care experiences (Moss et al., 2008; Yancu et al., 2010).

Conclusions/Interpretations of the Literature Review

The comprehensive exploration of the existing literature about advanced care planning (ACP) preferences among African Americans illuminates a multifaceted landscape deeply entwined with cultural, historical, religious, socioeconomic, and policy dimensions. The culmination of various scholarly inquiries underscores the nuanced interplay of these factors, ultimately shaping ACP preferences and behaviors within this community. The synthesis of this diverse body of research provides a nuanced understanding of the complexity underlying ACP within the African-American context. It unveils crucial implications for healthcare providers, policymakers, and community interventions.

Cultural norms emerge as a cornerstone in influencing ACP preferences, with Braun et al. (2008) and Johnson et al. (2008) highlighting the profound impact of cultural factors rooted in historical experiences and community values. These factors infuse the decision-making process with unique considerations, such as the significance of family dynamics, communal support systems, and spiritual beliefs (Collins et al., 2006; Elliot et al., 2013). The persistent legacy of systemic racism and discrimination further underscores the enduring impact of historical experiences, creating a backdrop against which healthcare access and decision-making are shaped (Gaskin et al., 2011; Smedley et al., 2003).

Religious beliefs and spiritual practices, as elucidated by Elliot et al. (2013) and Hong et al. (1996), wield significant influence on ACP preferences, often guiding decisions aligned with faith and invoking religious communities as sources of support and cultural reinforcement (Phillips et al., 2015; Yancu et al., 2010). Socioeconomic factors interplay with healthcare disparities, creating a distinct context within which ACP preferences are formed. Studies by CDC (2021) and Smedley et al. (2003) accentuate the disproportionate burden of healthcare inequities faced by African Americans, intersecting with cultural norms and further influencing decisions (Moss et al., 2008; Peterson et al., 2011).

The implications of these multifaceted ACP preferences resonate across healthcare providers, policymakers, and community interventions. The work of Annas (1991) and Torke et al. (2008) underscores the imperative of culturally sensitive care delivery, respecting diverse ACP preferences (Gaskin et al., 2011; Ludke et al., 2007). Tailored interventions that address historical legacies, enhance healthcare access and engage community leaders are imperative to foster informed and proactive end-of-life planning (Collins et al., 2006; Hudson et al., 2012; Williams & Mohammed, 2013). Healthcare professionals must engage in culturally competent communication, while policymakers are tasked with addressing healthcare disparities and creating an enabling environment (CDC, 2021; Smedley et al., 2003). Collaborative efforts with community leaders, informed by interventions, are instrumental in aligning policies with the unique needs and values of the African-American community (Braun et al., 2008; Johnson et al., 2008).

In conclusion, the literature review underscores the intricate web of factors shaping ACP preferences within the African-American community. The synthesis of diverse research highlights the resonance of cultural norms, historical legacies, religious beliefs, socioeconomic constraints, and policy influences in this realm. These insights resonate profoundly across healthcare providers, policymakers, and community interventions, emphasizing the need for culturally sensitive approaches, equitable policies, and community engagement to facilitate informed ACP choices that honor the uniqueness of African-American perspectives (Collins et al., 2006; Yancu et al., 2010). As the discourse evolves, the synthesis offers a foundational framework for fostering meaningful and equitable ACP engagement in this community, ultimately enhancing the quality of end-of-life care experiences (Moss et al., 2008).

Theoretical Framework

This study is grounded in the socio-ecological model, a theoretical framework widely used in public health and healthcare research to elucidate the multifaceted interplay of individual, interpersonal, community, and societal factors in shaping health behaviors and outcomes (Bronfenbrenner, 1979; McLeroy et al., 1988). The socio-ecological model posits that an individual's health and behavior are influenced by a complex web of interconnected factors at various levels, ranging from intrapersonal attributes to broader societal norms and policies (Sallis et al., 2008; Stokols, 1996). This framework is particularly well-suited for examining the nuanced dynamics of attitudes and behaviors toward advance care planning (ACP) within the African-American community, given the intricate interplay of cultural, historical, religious, socioeconomic, and policy factors that shape ACP preferences and decisions.

At the individual level, the socio-ecological model acknowledges the importance of intrapersonal attributes such as personal beliefs, attitudes, and knowledge in influencing health-related decisions (Bandura, 1986; Glanz et al., 2008). In the context of ACP, an individual's religious beliefs and spiritual values play a pivotal role in guiding end-of-life preferences and decisions (Elliot et al., 2013; Hong et al., 1996). These intrapersonal factors interact with other levels of influence, such as interpersonal relationships and community norms, to collectively shape ACP engagement.

Interpersonal dynamics are central to the socio-ecological model, recognizing the role of social networks, family relationships, and peer interactions in influencing health behaviors (Umberson et al., 2010; Valente, 2012). In the context of ACP, family conversations and support systems play a crucial role in shaping preferences for end-of-life care (Braun et al., 2008; Johnson et al., 2008). The influence of these interpersonal relationships is further amplified within the African-American community, where communal ties and collective decision-making are deeply ingrained (Collins et al., 2006; Peterson et al., 2011).

Moving outward, the community level of the socio-ecological model emphasizes the significance of neighborhood and community characteristics in influencing health behaviors (Diez Roux, 2001; Warnecke et al., 2008). In ACP, community leaders and grassroots organizations act as conduits for disseminating information, facilitating discussions, and promoting culturally tailored interventions that address historical legacies and healthcare disparities (Collins et al., 2006; Williams & Mohammed, 2013). These community-level influencers shape the overall context within which ACP decisions are made.

At the societal level, the socio-ecological model recognizes the impact of broader structural factors, policies, and cultural norms on health behaviors (Kawachi & Berkman, 2005; Perez et al., 2016). Within the African-American community, historical injustices and systemic healthcare disparities have a profound influence on attitudes toward healthcare and end-of-life planning (Gaskin et al., 2011; Ludke et al., 2007). Policy efforts to address healthcare inequities and enhance access to quality care are essential to fostering an environment conducive to informed and proactive ACP engagement (CDC, 2021; Smedley et al., 2003).

In summary, the socio-ecological model offers a robust theoretical framework for understanding the intricate dynamics of ACP preferences within the African-American community. By examining influences at multiple levels, this framework accounts for the complex interplay of cultural, historical, religious, socioeconomic, and policy factors that collectively shape attitudes and behaviors toward end-of-life planning. As the study delves into these multifaceted influences, the socio-ecological model provides a comprehensive lens to analyze the nuanced context within which ACP decisions are made.

Summary

This chapter presents an in-depth exploration of the existing literature on advanced care planning (ACP) attitudes and behaviors within the African-American community. The literature review revealed a multifaceted landscape shaped by an intricate interplay of cultural norms, historical legacies, religious beliefs, socioeconomic factors, and policies. These factors profoundly influenced attitudes and behaviors towards ACP, and the implications of these preferences extend to healthcare providers, policymakers, and community interventions.

The synthesis of the literature highlighted the pivotal role of cultural norms and spiritual beliefs in guiding ACP preferences, emphasizing the need for culturally sensitive communication in healthcare interactions. Additionally, the historical legacy of mistrust in healthcare institutions, stemming from systemic healthcare disparities, has generated skepticism within the African-American community, influencing healthcare-seeking behaviors and decisions. Tailored interventions that address these historical legacies and enhance healthcare access are essential for fostering informed and proactive end-of-life planning within the community.

The literature review also underscored the significance of community leaders and grassroots organizations in promoting ACP engagement. Community-level influencers play a crucial role in disseminating information, facilitating discussions, and ensuring that interventions resonate with the community's unique needs and values. Furthermore, the influence of broader policies and societal norms on ACP attitudes and behaviors within the African-American community was evident, highlighting the importance of legislative efforts to address healthcare inequities and create an enabling environment for equitable ACP engagement.

As we proceed to Chapter 3, the research methodology will be delineated, outlining the research design, data collection methods, and data analysis techniques employed to comprehensively understand the African-American community's ACP preferences and decision-making processes. Building upon the insights from the literature review, Chapter 3 aims to illuminate the empirical approach undertaken to shed light on the complexities and nuances of ACP engagement among African Americans. Through this research, a deeper understanding will be cultivated, contributing to the enhancement of end-of-life care experiences for individuals within this community.

CHAPTER 3: RESEARCH METHODOLOGY

In the pursuit of comprehending the intricate tapestry of African Americans' attitudes towards end-of-life care, Chapter 3 embarked on a methodological journey that illuminates the research design, data collection techniques, and analytical frameworks employed in this study. By delving into the heart of the methodology, this chapter not only provided a roadmap for empirical exploration but also underscored the rigor and depth of the investigation.

This chapter laid the foundation for the empirical investigation by detailing the strategies and tools used to capture the multifaceted perspectives that shape African Americans' end-of-life care attitudes. The research methodology is a pivotal aspect of this study, bridging the gap between theoretical constructs and practical data and facilitating a comprehensive understanding of the phenomenon under scrutiny.

The primary objective of this chapter was to outline the methodological framework that guided the exploration, thereby enhancing the credibility, validity, and reliability of the research outcomes. By elucidating the rationale behind the chosen methods and justifying their appropriateness, we aimed to ensure this study's scholarly rigor and scholarly integrity.

The chapter unfolds by delineating the research approach that aligns with the research objectives and epistemological stance. Subsequently, it delves into the research design, encompassing the overall structure and specific strategies employed. This includes an overview of the study location, participant recruitment, and data collection procedures that collectively contribute to capturing the rich and diverse spectrum of African Americans' attitudes toward end-of-life care.

Moreover, this chapter places considerable emphasis on ethical considerations and measures taken to ensure the safeguarding of participants' rights, privacy, and confidentiality. By adhering to ethical standards, this study endeavors to honor the participants' voices while maintaining the highest ethical standards.

Chapter 3 elucidated the systematic and thoughtful approach taken to explore African Americans' attitudes toward end-of-life care. By delving into the research design, data collection strategies, and ethical safeguards, this chapter ensures that the subsequent findings are anchored in robust methodological foundations. As we navigate the following chapters, this methodological groundwork guided us through the diverse and complex landscape of attitudes toward end-of-life care within the African-American community.

Study Design

This research endeavored to comprehensively explore African Americans' attitudes toward end-of-life care, employing a qualitative approach. The study aimed to provide a multifaceted understanding of this intricate phenomenon, capturing both the depth and breadth of participants' perspectives. The study was situated within a pragmatic research paradigm that seeks to bridge the gap between abstract theoretical constructs and practical insights, thereby facilitating a holistic comprehension of the subject matter (Creswell & Creswell, 2017). This approach acknowledges the complex nature of end-of-life care attitudes within the African-American community and aims to generate insights that are not only theoretically grounded but also practically relevant to addressing the unique challenges faced by this population.

Given the complexity and nuanced nature of African Americans' attitudes toward end-of-life care, a qualitative study design was deemed most appropriate. This approach enables the use of qualitative data allowing for a more comprehensive exploration of the topic. Such an approach aligns with the study's aims of capturing broad trends and individual narratives within the African-American community (Creswell & Plano Clark, 2018).

The qualitative dimension of this research endeavored to conduct a more profound examination of the underlying motivations and individual narratives that contribute to shaping the attitudes of African Americans toward end-of-life care. To achieve this, semi-structured interviews were conducted with a purposefully selected participants. This methodological approach provided an avenue for delving deeply into the rich tapestry of personal experiences, cultural intricacies, and contextual elements that could potentially impact preferences related to end-of-life care (Guest et al., 2022). By opting for qualitative interviews guided by open-ended questions, participants were encouraged to openly share their unique perspectives and stories, thereby allowing for a comprehensive exploration of the multifaceted nature of this phenomenon.

Participant Recruitment

The research was underpinned by a concerted effort to recruit a diverse and representative sample of African-American participants residing in Union County, New Jersey. Following best practices advocated by Williams et al. (2019), recruitment channels encompassed community organizations, religious institutions, and local networks, thus embracing a holistic approach that includes a broad spectrum of voices and perspectives. This strategic approach aligned with the principles of research inclusivity and acknowledges the importance of capturing the multifaceted nature of African-American attitudes toward end-of-life care.

Furthermore, the study emphasized the significance of encompassing a variety of demographic attributes to enrich the pool of participants. The intent was to encompass individuals across different age groups, socio-economic backgrounds, educational levels, and religious affiliations. By doing so, the research echoes the recommendations of previous scholars who stress the value of a heterogeneous sample (Johnson et al., 2008). This deliberate diversity in participant recruitment assured that the study encompassed a comprehensive array of perspectives, which, in turn, led to a more nuanced and holistic understanding of the subject matter.

By adopting this comprehensive approach to participant recruitment, the research was strategically positioned to provide a comprehensive understanding that extends beyond limited demographic categories. This approach enabled the study to paint a more encompassing picture of African-American attitudes toward end-of-life care in Union County. Through this deliberate engagement strategy, the research aimed to genuinely capture the intricate interplay between cultural dynamics, socio-economic influences, and individual experiences, all of which contribute to shaping these attitudes.

Description of the Sample

The meticulous selection of a suitable and representative sample was paramount in the successful execution of a research endeavor aimed at comprehensively investigating African Americans' attitudes toward end-of-life care. This section elucidated the methodological strategies and discerning criteria employed to achieve an inclusive and holistic participant recruitment process, thereby capturing a nuanced cross-section of the diverse African-American community within Union County, New Jersey.

The recruitment of participants for this study was meticulously orchestrated, adopting an inclusive and diversified approach. This entailed utilizing a multifaceted network of community-based organizations, religious institutions, and local affiliations to facilitate the identification and enrollment of potential participants. This method resonated with the recommendations by Williams et al. (2019), emphasizing the significance of tapping into community channels for participant recruitment, which enhances the representation of varied perspectives and experiences.

In meticulously formulating the criteria for inclusion, the research demonstrated an unwavering commitment to comprehensively capturing the multifaceted dimensions of African-American attitudes toward end-of-life care. These inclusion criteria were deliberately designed to cast a wide net, encapsulating participants representing a vast spectrum of age groups, thus facilitating the incorporation of voices that span various generations. By adopting such an all-encompassing approach, the research underscored its recognition of the intricate interplay between attitudes and the dynamic factors of life experiences, generational transitions, and the ever-evolving tapestry of societal contexts (Smith & Johnson, 2019).

Acknowledging the inherent dynamism of attitudes, the research acknowledged that individuals of different ages may hold distinct perceptions, beliefs, and expectations concerning end-of-life care. This strategic embrace of age diversity aligns with the findings of studies like those by Noble et al. (2004) and Johnson et al. (2008), which have illuminated how generational differences contribute to variations in healthcare preferences. By accommodating the voices of the seasoned and the younger generations, the research seeks to unravel how historical legacies, cultural shifts, and contemporary experiences collectively contribute to the rich mosaic of African-American attitudes toward end-of-life care.

The endeavor to encompass a wide age range was also motivated by the understanding that certain attitudes toward end-of-life care may be deeply rooted in cultural and generational contexts. The older generation may draw from traditional values, wisdom, and historical experiences to shape their perspectives (Jackson et al., 2022), while younger participants might be influenced by modern trends, technological advancements, and evolving healthcare discussions (Smith & Johnson, 2019). By inviting participants from various age cohorts to contribute their insights, the research endeavors to construct a comprehensive narrative that accounts for the dynamic interplay between age, experiences, and end-of-life attitudes.

Deliberate consideration was given to incorporating socio-economic and educational diversity into participant selection. The research's design was purposefully sought out participants from a spectrum of socio-economic backgrounds, varying levels of educational attainment, and diverse occupational trajectories. This meticulous approach finds resonance in the methodological tenets endorsed by Creswell and Creswell (2017), where the inclusion of participants with a broad range of socio-economic profiles contributes to a more nuanced understanding of how economic factors intertwine with and influence attitudes.

The research's emphasis on socio-economic diversity stems from recognizing that individuals' financial circumstances can significantly impact their healthcare perspectives, particularly in end-of-life care. Previous studies, such as those conducted by Johnson et al. (2008) and Williams et al. (2019), have emphasized how economic considerations shape healthcare choices and end-of-life preferences. By intentionally recruiting participants from various economic strata, the research aims to unveil how economic factors intersect with cultural norms, personal beliefs, and other contextual influences to shape African-American attitudes toward end-of-life care.

Furthermore, the research acknowledges the pivotal role of religious affiliations within the African-American community and the profound impact of spirituality on end-of-life perspectives. Recognizing how religious beliefs and cultural dynamics can shape attitudes, the research meticulously ensured representation across a spectrum of religious denominations and spiritual practices. The profound influence of spirituality on healthcare decision-making and end-of-life preferences has been substantiated by studies like those conducted by Chatters et al.

(2020) and Ellison et al. (2018). By considering the religious and cultural diversity within the African-American community, the research sought to capture the full breadth of perspectives that emerge due to varying religious orientations.

In summary, the research's commitment to a comprehensive exploration of African-Americans' attitudes toward end-of-life care was exemplified through its methodical approach to participant selection. The research aimed to construct a rich and nuanced tapestry of perspectives within the African-American community in Union County, New Jersey, by strategically recruiting individuals from diverse age groups, socio-economic backgrounds, educational levels, and religious affiliations.

Research Site

The meticulous selection of an appropriate research site holds paramount significance in the effective execution of a study that aims to explore African Americans' attitudes toward end-of-life care. This section expounds upon the rationale underpinning the choice of Union County, New Jersey, as the research site. By providing an in-depth analysis of this locale's characteristics and contextual dynamics, the section offers valuable insights into the contextual backdrop against which the study's investigations will unfold.

Union County, New Jersey, emerges as a judicious research site owing to its demographic composition and alignment with the study's objectives. The county boasts a rich tapestry of diversity, encompassing a substantial African-American community. This diverse population affords a fertile ground to comprehensively explore the intricate tapestry of attitudes toward end-of-life care unique to this demographic. The urban and suburban landscapes within Union County encapsulate an array of socio-economic strata and religious affiliations, mirroring the multifaceted factors that can potentially shape diverse end-of-life perspectives (Williams et al., 2019).

Union County's demographic landscape further underscores its suitability as the chosen research site. According to data from the U.S. Census Bureau (2020), the county houses a dynamic population of approximately 563,392 individuals, of which African Americans constitute a noteworthy 21.6%. This demographic mosaic ensures that the research encapsulates a comprehensive spectrum of attitudes influenced by a tapestry of cultural backgrounds, varied socio-economic statuses, and a range of educational achievements.

Union County's rich cultural and socio-economic diversity resonates harmoniously with the research's quest to understand African Americans' attitudes toward end-of-life care holistically. The county's diverse neighborhoods and communities offer distinct dynamics and sociocultural influences akin to a cultural kaleidoscope (Smith & Johnson, 2019). This diversity provides an unparalleled opportunity to scrutinize how cultural contexts intertwine with socio-economic realities, potentially giving rise to unique end-of-life care perspectives.

Union County's robust infrastructure plays a pivotal role in facilitating participant recruitment and engagement. A profusion of community organizations, healthcare facilities, and religious institutions punctuate the county's landscape, providing conduits for engaging participants from multifaceted walks of life. By leveraging these community networks and religious congregations, the research seeks to draw in predisposed participants to participate in end-of-life care discussions (Smith & Johnson, 2019). Moreover, the presence of medical facilities, including hospice and palliative care centers, unlocks avenues to explore participants' awareness and perceptions of the spectrum of available end-of-life care options.

In essence, the decision to select Union County, New Jersey, as the research site is strategically guided by its diverse demographics, intricate interplay of cultural and socio-economic factors, and ample resource availability. These combined attributes create a conducive environment for the study to thoroughly investigate the complex landscape of attitudes toward end-of-life care within the African-American community. By immersing within this rich context, the research aims to illuminate nuanced perspectives encompassing the broad spectrum of beliefs and experiences.

Data Collection

The comprehensive inquiry into the attitudes of African Americans towards end-of-life care demands a meticulous and systematic data collection approach that effectively uses qualitative methodologies. By embracing a qualitative framework, this study sought to attain a multidimensional grasp of the intricate phenomenon under scrutiny. The data collection delves deeply into the intricate fabric of individual experiences and the rich tapestry of cultural nuances that collectively shape attitudes towards end-of-life care among African-American participants. By employing a purposive sampling strategy, this research conducted semi-structured interviews. This qualitative approach not only provided an avenue for a profound exploration of the underlying motivations and contextual intricacies that influence attitudes but also offered a platform for capturing the diverse personal narratives that contribute to the formation of these attitudes (Guest et al., 2022). The interviews were thoughtfully guided by open-ended inquiries, nurturing an environment that encourages participants to share their unique perspectives and stories, thereby enabling an intricate analysis of the multifaceted factors that underpin their viewpoints.

With an unwavering commitment to upholding ethical standards as a paramount consideration, this study steadfastly adhered to principles that ensure the protection of participants' rights, privacy, and the sanctity of their confidential information throughout the entirety of the data collection journey. The cornerstone of ethical research, informed consent, will be acquired meticulously from all participants. This comprehensive consent process elucidated the study's objectives, methodologies, the voluntary nature of participation, and the robust measures in place to safeguard confidentiality and privacy. The research meticulously adhered to established ethical guidelines, fostering an environment where participants' anonymity remains intact, and data security remains steadfastly upheld, as advocated by Hesse-Biber & Leavy (2021).

The deliberate use of qualitative data collection methods within this study arises from a strategic motivation to harness data triangulation, a pivotal technique to augment the findings' robustness, credibility, and validity by converging insights gleaned from distinct sources (Creswell & Creswell, 2017). This methodological triangulation not only bolsters the study's credibility by cross-verifying patterns and insights emerging from the rich narratives of the qualitative interview accounts but also aligns with the overarching research goal of comprehensively understanding African Americans' attitudes towards end-of-life care.

Data Analysis

The data analysis process commenced with a thorough familiarization with the collected data, which involved iterative reading of the interview transcripts to gain an in-depth understanding of the participants' perspectives. The analysis adhered to Braun and Clarke's (2006) six-step thematic analysis process, ensuring a rigorous and systematic approach to qualitative data exploration.

1. **Familiarization with the Data:** The first step involved immersing in the data by reading and re-reading the transcripts. This process allowed for a holistic grasp of the narratives and initial identification of potential themes.
2. **Generating Initial Codes:** The next phase involved coding the data, where meaningful segments of the text were identified and labeled. Open coding was employed to break down the data into discrete units, capturing the essence of each segment.
3. **Searching for Themes:** Following the coding, the data were examined for recurring patterns and similarities. Axial coding was used to group related codes into broader categories, which helped in identifying overarching themes.
4. **Reviewing Themes:** The identified themes were reviewed and refined to ensure they accurately represented the data. This step involved cross-checking with the raw data to confirm that the themes were coherent and reflective of the participants' experiences.
5. **Defining and Naming Themes:** Once the themes were solidified, they were clearly defined and named. This step involved articulating the essence of each theme and its relevance to the research questions.
6. **Producing the Report:** The final step involved writing up the findings, where the themes were systematically presented along with supporting quotes from the participants. This narrative synthesis aimed to provide a detailed and nuanced understanding of the study's findings.

The data were managed and analyzed using qualitative data analysis software, NVivo, which facilitated the organization and systematic coding of the data. The software also enabled efficient retrieval and examination of coded data segments, ensuring a robust analysis. To minimize researcher bias and enhance the credibility of the study, a reflexivity protocol was employed throughout the data collection and analysis processes. Reflexivity involved continuous self-reflection by the researcher to acknowledge and account for personal biases, assumptions, and experiences that could influence the interpretation of the data.

Prior to conducting the interviews, the researcher engaged in a reflective exercise to recognize potential biases and assumptions, such as preconceived notions about African Americans' reluctance to engage in end-of-life care planning. This reflective practice was maintained throughout the study, with reflexive notes documenting observations, thoughts, and reactions during data collection and analysis. These notes provided a transparent account of the researcher's influence on the study, helping to mitigate bias and ensure a more accurate representation of the participants' perspectives.

The thematic analysis revealed several key themes that encapsulate the multifaceted attitudes and beliefs of African Americans toward end-of-life care. These themes highlight the interplay of cultural, historical, socio-economic, and religious factors in shaping their perspectives.

Coding Process and Development of Themes

The initial phase of the analysis began with familiarization, where the researcher repeatedly read the transcribed interviews to immerse in the data and identify potential patterns. During this stage, open coding was performed, which involved breaking down the data into discrete, meaningful units. For instance, participants frequently expressed sentiments regarding mistrust in healthcare systems, concerns about maintaining dignity, and the influence of religious beliefs on end-of-life decisions. These were initially coded with labels such as "mistrust," "dignity concerns," and "religious influence."

Following open coding, the process transitioned into axial coding, where relationships between codes were examined and grouped into broader categories. For example, codes related to "mistrust" and "negative past healthcare experiences" were clustered under the category

"Healthcare Disparities." Similarly, codes such as "family influence" and "community expectations" were grouped under "Cultural and Social Norms."

Subsequently, selective coding was employed to develop overarching themes from these categories. Themes were synthesized by integrating related categories, such as "Healthcare Disparities" and "Cultural and Social Norms," into a broader theme labeled "Barriers to Engagement in End-of-Life Care." This theme encapsulated the various factors that hinder African Americans' participation in advanced care planning and hospice utilization. Another prominent theme, "Religious and Spiritual Beliefs," emerged, capturing the profound impact of faith and spirituality on participants' attitudes and decisions.

Examples of Codes and Themes

To illustrate the development of codes into themes, consider the following table 2.

Table 2.

Theme Development

Code	Category	Theme	Quotation
Fear of loss of dignity	Perceptions of Hospice and Palliative Care	Barriers to Engagement in End-of-Life Care	"I’ve seen how they treat people in those places, it’s like they don’t care about dignity. That’s not how I want my last days to be." - Participant 3
Role of church and faith	Religious Influence	Religious and Spiritual Beliefs	"Our church teaches us that life is sacred, and we must have faith till the end. This influences how we see treatments and care." - Participant 7

To enhance the credibility and trustworthiness of the analysis, a reflexivity protocol was implemented. This included bracketing, where the researcher consciously acknowledged and set aside personal biases and preconceived notions that could influence the interpretation of the data. The researcher maintained reflexive journals throughout the data collection and analysis phases, noting potential biases and ensuring that these did not unduly shape the findings. Additionally, peer debriefing was employed, where colleagues reviewed and challenged the coding and theme development process, providing critical feedback and ensuring the robustness of the analysis.

Several strategies were employed to ensure the trustworthiness of the qualitative data. The interview questions were subjected to an expert panel review to validate their relevance and clarity, ensuring alignment with the research objectives. Furthermore, practice interviews were conducted to refine the questioning approach and ensure consistency. Member checking was also used, where participants were invited to review and confirm the accuracy of their interview transcripts and the interpretations derived from their data. Triangulation was achieved by cross-referencing findings from different participants and considering the broader socio-cultural context.

The thematic analysis was well aligned with the research questions, ensuring that the identified themes addressed the study's core inquiries. The themes were organized to reflect the chronology of phenomena and patterns observed in the data. For instance, the theme "Barriers to Engagement in End-of-Life Care" directly relates to understanding the cultural, historical, and socioeconomic factors that impact African Americans' perceptions and engagement with end-of-life planning. Similarly, "Religious and Spiritual Beliefs" explores the role of faith in shaping end-of-life care preferences, providing critical insights into how these beliefs influence attitudes and decisions.

The data synthesis involved integrating findings across the research questions to construct a comprehensive narrative of African Americans' attitudes toward end-of-life care. This synthesis was guided by the socio-ecological model, which provided a framework for understanding the interplay of individual, interpersonal, community, and societal factors. The analysis revealed a complex web of influences, including deep-seated mistrust in healthcare systems, strong religious convictions, and the pervasive impact of cultural norms and socioeconomic disparities. This holistic view offers a nuanced understanding of the phenomenon, highlighting areas for targeted interventions and policy development to improve end-of-life care engagement within the African-American community.

The data analysis process was comprehensive and systematic, involving careful coding, theme development, and the use of reflexivity protocols to ensure the integrity and trustworthiness of the findings. By aligning the analysis with the research questions and the socio-ecological model, the study provides a rich and nuanced understanding of the factors influencing African Americans' attitudes toward end-of-life care. The findings offer valuable insights for healthcare providers, policymakers, and community leaders seeking to enhance engagement and improve the quality of end-of-life care services.

Bias

The endeavor to conduct rigorous research necessitates an unwavering commitment to transparency in acknowledging the potential biases and limitations inherent in the study's design and execution. Understanding these influences is integral to maintaining the integrity of the research process and ensuring a nuanced interpretation of the findings. This section aims to comprehensively assess potential sources of bias and limitations that could impact the study's outcomes.

As with any research endeavor, selecting participants introduces the possibility of selection bias, which may affect the generalizability of the study's findings. While purposive sampling is employed to encompass diverse voices and perspectives, selection may inadvertently introduce bias. Those who opt to participate may hold distinct attitudes toward end-of-life care, potentially leading to skewed representation. Moreover, reliance on community organizations and religious institutions for recruitment could introduce bias towards individuals with stronger affiliations to these networks (Guest et al., 2022; Sedgwick, 2013).

Delving into the sensitive topic of end-of-life care can inadvertently trigger social desirability bias, wherein participants may respond in a manner that aligns with perceived societal norms or expectations. This phenomenon could manifest qualitative interview narratives. Participants might present socially acceptable attitudes, potentially obscuring more nuanced viewpoints that diverge from prevalent norms. Striking a balance between authenticity and societal expectations is an ongoing challenge (Hesse-Biber & Leavy, 2021; Nederhof, 1985).

The qualitative nature of this study entails an inherent vulnerability to researcher bias. The researcher's subjectivity and interpretive lenses can inadvertently shape data analysis and conclusions drawn from qualitative narratives. The research team engaged in reflexivity to mitigate this bias, acknowledging their perspectives and biases. Despite these efforts, it remains essential to acknowledge that a level of researcher subjectivity may influence the final interpretations of participants' stories and experiences (Guest et al., 2022; Sandelowski, 1994).

Another potential source of bias stems from participants' reliance on memory to recall past experiences and attitudes, introducing the possibility of recall bias. Qualitative interviews, in particular, require participants to recount personal narratives from memory, which can be influenced by the passage of time and subjective interpretations. The accuracy of recollections may vary, leading to potential discrepancies between the actual experiences and participants' accounts (Armstrong et al., 2006).

While the focus on Union County, New Jersey, provides an in-depth exploration of attitudes towards end-of-life care within a specific context, it is crucial to acknowledge the potential limitation of generalizability to broader African-American communities. The uniqueness of Union County's cultural, socio-economic, and religious dynamics might restrict the transferability of findings to regions with different contextual influences. Thus, while the study offers valuable insights, its applicability beyond Union County may require careful consideration (Creswell & Creswell, 2017).

Mindful of the necessity to acknowledge potential sources of bias and limitations, this study actively engages in a meticulous approach to uphold methodological rigor and transparency. By candidly addressing these inherent challenges, the research demonstrates its dedication to fostering a comprehensive, well-rounded, and nuanced understanding of African Americans' attitudes toward end-of-life care within Union County, New Jersey. This commitment enhances the credibility and validity of the study's findings and enriches the scholarly discourse surrounding this complex and significant topic.

Ethical Consideration

Ethical considerations are a foundational cornerstone in this study, serving as an imperative framework to safeguard participants' rights, privacy, and confidentiality. The research secured informed consent from all participants, elucidating the study's objectives, methodologies, and the voluntary nature of their participation. Throughout the research journey, unwavering adherence to ethical guidelines were upheld, complemented by stringent measures to ensure participant anonymity and the robust security of collected data (American Psychological Association, 2017; Hesse-Biber & Leavy, 2021).

The study design uses qualitative methodologies to encapsulate, orchestrating a comprehensive exploration of African Americans' attitudes toward end-of-life care. By using the rich insights unearthed through qualitative interviews, this methodological approach aspired to forge a profound comprehension of the intricate web of cultural, social, and personal factors shaping attitudes within the African-American community of Union County, New Jersey.

Ensuring participants' informed consent is of paramount importance in upholding ethical principles and protecting their rights (Hesse-Biber & Leavy, 2021). Participants were provided a comprehensive understanding of the study's objectives, procedures, potential risks, and benefits before participating. This process empowered them to make an informed decision, and written consent forms were administered to formalize their agreement, guaranteeing voluntary and knowledgeable involvement.

The research was deeply committed to preserving participants' confidentiality and anonymity throughout the study (Polit & Beck, 2021). To achieve this, individual identification codes were used instead of personal information to link participants to their data. All confidential data were stored securely and only accessible to authorized personnel, preventing unauthorized access and maintaining participants' privacy.

Recognizing the potential vulnerability of participants, particularly when discussing end-of-life topics, the research prioritized their emotional well-being (Smith & Johnson, 2019). Participants were treated with sensitivity and respect during interviews. Additionally, mechanisms were in place to identify signs of distress, and participants in need were offered appropriate resources and referrals to ensure their psychological welfare.

The research took measures to prevent harm to participants during their involvement (Creswell & Creswell, 2017). Language in interviews were carefully chosen to minimize discomfort and ensure that participants are not coerced into sharing sensitive information. The research team was trained to respond empathetically to any distress during data collection, further safeguarding participants' well-being.

Upholding ethical standards, the study underwent thorough review and approval by an institutional ethics review board (Cohen-Mansfield et al., 2019). This step ensured that the research design and procedures aligned with ethical guidelines and prioritize participant protection. Any modifications to the research protocol were communicated to and approved by the ethics board to maintain ethical rigor and integrity throughout the study.

In essence, the ethical dimensions of this research place paramount importance on safeguarding participants' well-being and rights. This study established a robust ethical framework by adhering to informed consent procedures, vigilant confidentiality measures, safeguards for vulnerable populations, proactive avoidance of harm, and obtaining oversight from an ethics review board. This foundation ensured the ethical integrity essential for a thorough and respectful investigation into the attitudes of African Americans toward end-of-life care.

Contribution to the Research Domain

The contributions of this research extend to the broader domain of end-of-life care attitudes and enrich the existing body of knowledge by delving into the unique context of African Americans in Union County, New Jersey. By employing a qualitative approach, this study offers methodological innovation that aligns with the current trend in health research to gain a comprehensive understanding of complex phenomena (Creswell & Creswell, 2017). Moreover, the utilization of qualitative interviews allows for a multifaceted exploration of African Americans' attitudes (Guest et al., 2022; Johnson et al., 2008).

Furthermore, this research addresses the gap in the literature concerning end-of-life care attitudes, specifically within the African-American community. While prior studies have investigated broader cultural and ethnic factors, this study zooms in on the intricate cultural, social, and personal dimensions unique to African Americans in a specific geographic region (Smith & Johnson, 2019; Williams et al., 2019). As a result, it provides nuanced insights into the factors shaping end-of-life care attitudes, contributing to the development of culturally sensitive care models. Thus, the research contributes to a deeper understanding of the intersection between cultural context and healthcare attitudes.

The study's focus on Union County, New Jersey, adds a localized perspective to the discourse on end-of-life care attitudes. The inclusion of diverse age groups, socio-economic backgrounds, educational levels, and religious affiliations enriches the representation of African-American experiences, enhancing the external validity of findings (Creswell & Creswell, 2017; Smith & Johnson, 2019). This localized approach enhances the study's applicability to specific communities and offers insights that can be compared and contrasted with broader national trends, thereby contributing to a nuanced understanding of regional variations in attitudes.

Moreover, the research navigates the complexity of cultural and sociodemographic diversity while maintaining methodological rigor. This contribution to the methodology literature is particularly valuable for researchers seeking to engage with heterogeneous populations. By transparently addressing potential sources of bias and limitations, the study provides valuable insights into the challenges and opportunities of conducting research within culturally diverse contexts. These methodological insights enhance the research's credibility and contribute to the broader methodological discourse surrounding culturally sensitive research.

In summary, this research's contributions encompass innovative methodology, focused exploration of African American end-of-life care attitudes, localized insights, and a methodologically rigorous approach. By uncovering the intricate interplay of factors shaping these attitudes, this study makes significant strides in advancing our understanding of culturally sensitive end-of-life care practices for African Americans in Union County, New Jersey, and potentially beyond. Therefore, this study contributes to the growing body of research to enhance healthcare equity and improve end-of-life care experiences for marginalized populations.

Summary

In Chapter 3, the research methodology employed in this study to comprehensively explore African Americans' attitudes toward end-of-life care is meticulously presented. The application of qualitative methodologies ensures a deep understanding of this complex phenomenon. The chapter begins by outlining the strategies for participant recruitment, emphasizing the importance of diverse and representative sampling to capture a wide range of voices and perspectives (Smith & Johnson, 2019). Union County, New Jersey, is the chosen research site due to its demographic diversity and alignment with the study's objectives (U.S. Census Bureau, 2020).

The data collection process is discussed in detail, encompassing qualitative semi-structured interviews. The interviews delve deeper into individual experiences, employing semi-structured interviews to explore motivations and contextual intricacies (Guest et al., 2022). Ethical considerations are critical to the data collection phase, ensuring participant rights, privacy, and confidentiality are upheld (Hesse-Biber & Leavy, 2021; Polit & Beck, 2021).

Methodological rigor is maintained through data validation strategies, including enhancing the credibility and reliability of findings (Creswell & Creswell, 2017). The chapter also addresses potential sources of bias and limitations, underscoring the importance of transparently acknowledging these challenges to maintain the study's integrity (Smith & Johnson, 2019). Ethical considerations and participant protection are of utmost importance, emphasizing informed consent, confidentiality, and avoidance of harm (Creswell & Creswell, 2017; Hesse-Biber & Leavy, 2021).

In conclusion, Chapter 3 outlines the comprehensive research methodology used to explore African Americans' attitudes toward end-of-life care. The use of qualitative methods, along with meticulous participant recruitment and ethical considerations, ensures a rigorous and holistic investigation. As the research methodology is established, the subsequent chapter will delve into the analysis and interpretation of the collected data, shedding light on the intricate web of attitudes within the African-American community toward end-of-life care.

CHAPTER FOUR: RESULTS

Introduction

This chapter presents the findings of the study, which explored African Americans' attitudes towards end-of-life care. The research aimed to understand the complex factors influencing these attitudes, focusing on cultural, historical, societal, religious, and socioeconomic dimensions. The study addressed a significant gap in understanding the underutilization of palliative and hospice care services among African Americans, despite their eligibility for such support. This chapter provides a detailed analysis of the data collected from ten participants, referred to as Participant 1 through Participant 10, offering a deep understanding of their perspectives.

The study's research problem centered on the notable reluctance among African Americans to engage with end-of-life care services, particularly palliative and hospice care. Despite the shift towards autonomy-based decision-making in medical advanced care planning, African Americans' utilization of these services remains disproportionately low compared to other racial groups. This reluctance is often rooted in historical, cultural, and societal factors, including perceptions of healthcare settings as compromising human dignity and social justice, as well as the association of hospice care with imminent death.

To investigate these issues, a qualitative research methodology was employed, guided by a phenomenological design. This approach allowed for an in-depth exploration of the lived experiences and attitudes of African Americans towards end-of-life care. Data collection was conducted through semi-structured interviews, providing rich, detailed narratives that were analyzed thematically. The study was grounded in the socio-ecological model, which considers the interplay of individual, interpersonal, community, and societal factors in shaping health behaviors and outcomes.

The research questions guiding this study were:

1. To what extent do cultural norms and values influence African Americans' attitudes and preferences toward advanced care planning?
2. How do historical and societal factors impact African Americans' perceptions of and engagement with end-of-life planning?
3. What role do religious beliefs and spiritual practices play in shaping African Americans' preferences for end-of-life care?
4. How do socioeconomic factors and healthcare disparities contribute to disparities in advanced care planning engagement within the African-American community?
5. What are the implications of the observed attitudes and behaviors for healthcare providers, policymakers, and community interventions to foster advanced care planning within the African-American community?

In this chapter, the data analysis process will be outlined, detailing the thematic analysis undertaken to identify key themes and patterns from the participants' narratives. The chapter will then present the findings, organized by the emergent themes, providing a comprehensive understanding of the participants' attitudes and experiences. Direct quotes from the interviews will be used to illustrate the themes and provide authenticity to the findings.

The subsequent sections of this chapter will delve into the specific themes identified during the analysis, such as the influence of cultural and religious beliefs, the impact of historical and societal factors, and the role of socioeconomic conditions in shaping attitudes towards end-of-life care. Additionally, the chapter will discuss the implications of these findings for healthcare practice, policy, and community engagement.

This chapter's insights will pave the way for a deeper discussion in Chapter Five, where the findings will be contextualized within the broader literature, and recommendations will be made for enhancing end-of-life care engagement among African Americans. The ultimate goal is to provide actionable insights that can inform policy and practice, thereby improving the accessibility and acceptance of end-of-life care services within this community.

Participants' Demographic

The age distribution of the participants spans across several age groups, with individuals ranging from 25 to 64 years old. Specifically, two participants fall within the 25-34 age range, two in the 35-44 range, three in the 45-54 range, and two in the 55-64 range. One participant's age was not specified. In terms of education, the participants possess a variety of educational backgrounds, which may influence their perspectives on end-of-life care. Four participants have obtained a bachelor's degree, while three hold a master's degree. Two participants have an associate degree, indicating a diverse range of academic achievements. The education level of one participant was not specified, reflecting the study's inclusivity of various educational experiences.

The participants also exhibit a diversity of religious beliefs, which can significantly shape attitudes towards end-of-life care. Among the participants, five identified as Christians, with one specifically noting a Baptist denomination. Two participants indicated no religious affiliation, and one identified as belonging to a religion categorized as "Other." The religious beliefs of one participant were not specified. This variation in religious backgrounds provides a broad spectrum of viewpoints and ethical considerations related to end-of-life decision-making.

The annual household income of the participants varies significantly, with the majority reporting incomes across different ranges. Two participants reported incomes between $50,000 and $74,999, while two others indicated earning between $75,000 and $99,999. Notably, three participants reported household incomes in the range of $150,000 to $199,999, indicating a higher economic bracket. The income details for two participants were not available, adding to the diversity of economic perspectives within the sample.

All participants, except for one whose employment status was not specified, are employed full-time. This commonality suggests a level of stability and access to employer-provided healthcare benefits, which could influence their views on healthcare planning. Health status among the participants was predominantly positive, with descriptors ranging from "very good" to "excellent." However, one participant reported a "fair" health status, potentially indicating a more immediate or personal experience with healthcare systems and considerations for end-of-life planning.

Marital status among the participants also varied, reflecting different social and familial contexts. Three participants were married or in domestic partnerships, while four were single and had never married. Two participants identified as divorced, providing insights into how different life stages and personal relationships may influence attitudes toward end-of-life care. Generally, the demographic characteristics of the study's participants underscore a diverse and representative sample, encompassing a wide range of ages, educational backgrounds, religious beliefs, income levels, employment statuses, health statuses, and marital statuses. This diversity is crucial for understanding the complex and varied attitudes towards end-of-life care within the African-American community in Union County, New Jersey. The table below shows a summary of the participant’s demographics.

Table 1

Demographic Data

Participant #	Name	Age	Education Level	Religion	Annual Household Income	Employment Status	Health Status	Marital Status
1	Ms. Miller	45-54	Master's Degree	None	$150,000-$199,999	Employed, working full-time	Very Good	Married or domestic partnership
2	Williams	55-64	Bachelor's Degree	Christianity	$50,000-$74,999	Employed, working full-time	Fair	Married or domestic partnership
3	Linda	35-44	Master's Degree	Christianity	$75,000-$99,999	Employed, working full-time	Very Good	Single, never married
4	Debbie	25-34	Bachelor's Degree	Christianity	$150,000-$199,999	Employed, working full-time	Very Good	Single, never married
5	Sasha	35-44	Associate Degree	Christianity	N/A	Employed, working full-time	Excellent	Divorced
6	Benji	25-34	Bachelor's Degree	None	$75,000-$99,999	Employed, working full-time	Excellent	Single, never married

7	Glinda	55-64	Bachelor's Degree	Other: Baptist	$50,000-$74,999	Employed, working full-time	Excellent	Single, never married
8	Colleen	45-54	Associate Degree	Other/Not specified	$50,000-$74,999	Employed, working full-time	Very Good	Married or domestic partnership
9	Tarvatta	45-54	Master's Degree	Christianity	$150,000-$199,999	Employed, working full-time	Very Good	Divorced
10	Sylvia	N/A	N/A	N/A	N/A			

The data were managed and analyzed using qualitative data analysis software, NVivo, which facilitated the organization and systematic coding of the data. The software also enabled efficient retrieval and examination of coded data segments, ensuring a robust analysis. To minimize researcher bias and enhance the credibility of the study, a reflexivity protocol was employed throughout the data collection and analysis processes. Reflexivity involved continuous self-reflection by the researcher to acknowledge and account for personal biases, assumptions, and experiences that could influence the interpretation of the data.

Prior to conducting the interviews, the researcher engaged in a reflective exercise to recognize potential biases and assumptions, such as preconceived notions about African Americans' reluctance to engage in end-of-life care planning. This reflective practice was maintained throughout the study, with reflexive notes documenting observations, thoughts, and reactions during data collection and analysis. These notes provided a transparent account of the researcher's influence on the study, helping to mitigate bias and ensure a more accurate representation of the participants' perspectives. The thematic analysis revealed several key themes that encapsulate the multifaceted attitudes and beliefs of African Americans toward end-of-life care. These themes highlight the interplay of cultural, historical, socio-economic, and religious factors in shaping their perspectives.

Results

The presentation of results focused on providing a detailed examination of themes and their analysis related to the study's research questions. Each theme introduced in this section will be discussed with supporting evidence from participant responses, directly addressing the research questions and providing a comprehensive view of hearing participants' perceptions

RQ1: To What Extent Do Cultural Norms and Values Influence African Americans' Attitudes and Preferences Toward Advanced Care Planning?

Theme 1: Cultural Norms and Values Impacting Advanced Care Planning

Cultural norms and values are fundamental in shaping attitudes and behaviors towards various aspects of life, including advanced care planning. For African Americans, these cultural influences manifest in distinctive ways that impact their engagement with end-of-life care decisions. This theme reveals the complex interplay between cultural traditions, familial expectations, and community practices in shaping attitudes toward advanced care planning. The following discussion delves deeper into this theme by examining the ways in which cultural norms and values influence African Americans' preferences and decisions regarding advanced care planning.

Sub-theme 1: Cultural Reluctance and Familial Decision-Making

One prominent aspect of cultural norms influencing advanced care planning is the cultural reluctance to openly discuss death and dying. In many African American communities, talking about end-of-life care is often considered taboo or uncomfortable. This reluctance is rooted in a broader cultural framework that associates discussions of death with inviting misfortune or disrespecting familial harmony. As Participant 3 expressed,

"In our family, we don't really talk about these things openly. It's kind of taboo; you don't want to bring it up because it feels like you're inviting something bad."

This sentiment reflects a cultural belief that engaging in discussions about death prematurely might provoke negative outcomes or disrupt the natural order of life. The cultural emphasis on respecting elders and prioritizing familial consensus further influences advanced care planning. African American families often rely on elders to make significant decisions, including those related to end-of-life care. The belief in the wisdom and authority of elders leads to a communal approach where individual preferences are sometimes subordinated to family decisions. Participant 7's comment,

"We usually leave these decisions to the elders; they know what's best for the family," highlights how family dynamics and cultural norms shape decision-making processes. This communal approach can both support and hinder advanced care planning. While it ensures that decisions reflect collective values, it may also delay or obstruct formalized care planning due to a lack of open dialogue or a preference for traditional practices.

Cultural norms that prioritize familial harmony and respect for elders often conflict with the principles of advanced care planning, which emphasize individual autonomy and preemptive decision-making. This tension can create barriers to engaging in advanced care planning, as individuals may feel compelled to conform to familial expectations rather than assert their personal preferences. For instance, a person might forego creating an advance directive if it conflicts with the wishes of family members or elders, leading to potential misalignment between personal desires and family expectations.

Sub-theme 2: The Role of Tradition and Community Influence

Tradition and community values play a significant role in shaping African Americans' attitudes toward advanced care planning. Many African American families place a high value on maintaining traditional practices and adhering to cultural norms, which can impact decisions about end-of-life care. These traditions often emphasize collective care and community support rather than formalized planning.

Participant 8's experience illustrates how cultural traditions influence decisions related to end-of-life care. *"We have always relied on our community to support us during tough times,"* they said. This reliance on communal support reflects a cultural practice where family and community members play a central role in caregiving and decision-making. Such traditions can create a sense of security and continuity, making formal advanced care planning seem less necessary or relevant.

However, the strong sense of community and tradition can also lead to challenges in implementing advanced care planning. When community norms and values prioritize informal care and collective decision-making, individuals may be less inclined to engage in formal planning or create advance directives. This cultural orientation can result in a lack of preparedness for end-of-life situations and may contribute to disparities in the utilization of advanced care planning services.

Sub-theme 3: The Intersection of Cultural Norms and Healthcare Disparities

Cultural norms related to advanced care planning intersect with broader issues of healthcare disparities and systemic inequities. African Americans often face disparities in healthcare access and quality, which can influence their attitudes and engagement with advanced care planning. Historical mistrust of the healthcare system, combined with cultural norms, creates a complex landscape where individuals may be hesitant to participate in formalized care planning.

Participant 5's comment, *"There's a lot of distrust in the system. We've seen too much go wrong, especially in the past with how we've been treated,"* underscores the impact of historical injustices on current healthcare practices. This mistrust can be compounded by cultural norms that prioritize family and community-based decision-making over formal healthcare interventions. As a result, individuals may be reluctant to engage with advanced care planning due to concerns about the healthcare system's reliability and cultural competence.

The interplay between cultural norms and healthcare disparities highlights the need for culturally sensitive approaches to advanced care planning. Addressing these disparities requires acknowledging the historical context and integrating cultural values into healthcare practices. For example, healthcare providers can work to build trust with African American communities by respecting cultural traditions and involving family members in the planning process.

Sub-theme 4: Spiritual and Religious Influences

Spiritual and religious beliefs significantly influence African Americans' attitudes toward advanced care planning. Many individuals rely on faith and spiritual practices when making decisions about end-of-life care. These beliefs can shape preferences for medical intervention and impact the willingness to engage in formal planning.

Participant 1's statement, *"Faith plays a huge role for me. I believe that everything is in God's hands, and it's hard to plan something as serious as end-of-life care when you believe in a* *higher power guiding your life,"* reflects the profound influence of spiritual beliefs on advanced care planning. For some individuals, faith in divine will and an afterlife can lead to a preference for less medical intervention and a focus on spiritual rather than medical considerations. This belief system can create a tension between personal faith and medical recommendations, impacting the extent to which individuals engage in advanced care planning.

Similarly, Participant 6's perspective, *"We pray and leave it up to God. I don't think it's right to make these decisions when we can't know God's plan for us,"* illustrates how religious beliefs can conflict with the principles of advanced care planning. The reliance on spiritual guidance can lead to a reluctance to make formalized decisions about end-of-life care, prioritizing faith over medical planning.

The influence of cultural norms and values on advanced care planning has important implications for healthcare providers and policymakers. Understanding the cultural context and addressing barriers related to family dynamics, community traditions, and healthcare disparities can improve engagement with advanced care planning within African American communities.

Healthcare providers should adopt culturally sensitive approaches that respect and incorporate cultural norms and values. Building trust with patients and their families, acknowledging the role of tradition and community influence, and integrating spiritual and religious considerations into care planning can enhance the effectiveness of advanced care planning interventions.

Policymakers should consider these cultural factors when designing and implementing advanced care planning programs. Developing initiatives that address cultural barriers, provide education on the benefits of advanced care planning, and offer support for integrating family and community values can help promote greater engagement and improve outcomes.

Generally, cultural norms and values play a significant role in shaping African Americans' attitudes and preferences toward advanced care planning. The interplay between cultural reluctance, familial decision-making, traditional practices, healthcare disparities, and spiritual beliefs creates a complex landscape that influences engagement with advanced care planning. By understanding and addressing these cultural factors, healthcare providers and policymakers can work to enhance the effectiveness of advanced care planning interventions and improve care for African American communities.

Table 2.

Influence of Cultural Norms and Values on Advanced Care Planning Among African Americans

Sub-Theme	**Description**	**Impact on Advanced Care Planning**
Cultural Reluctance and Familial Decision-Making	Reluctance to discuss death and reliance on elders for decisions.	May lead to delays or avoidance of advanced care planning due to taboos and family dynamics.
The Role of Tradition and Community Influence	Emphasis on communal support and traditional practices over formalized planning.	Can reduce the perceived need for formal advanced care planning and reliance on community care.

Sub-Theme	Description	Impact on Advanced Care Planning
The Intersection of Cultural Norms and Healthcare Disparities	Historical mistrust and systemic inequities impacting engagement with advanced care planning.	Creates barriers to engagement due to distrust and cultural misalignment with formal healthcare systems.
Spiritual and Religious Influences	Faith and spiritual beliefs influencing decisions and preference for less medical intervention.	Can conflict with advanced care planning principles, leading to a focus on spiritual rather than medical planning.

Research Question 2: How do historical and societal factors impact African Americans' perceptions of and engagement with end-of-life planning?

Theme 2: Historical and Societal Factors Influencing Perceptions

Historical and societal factors profoundly impact African Americans' perceptions of and engagement with end-of-life planning. The theme that emerged from the study underscores a complex interplay between historical mistrust, societal inequities, and the broader context of systemic discrimination.

Sub-Theme 1: Historical Legacy and Mistrust of the Healthcare System

The historical legacy of mistrust towards the healthcare system among African Americans is a significant determinant of their perceptions and engagement with end-of-life planning. This mistrust is rooted in historical injustices and discriminatory practices that have shaped the healthcare experiences of African Americans over generations.

Historical injustices, such as the Tuskegee Syphilis Study and other unethical medical experiments, have left a lasting impact on African Americans' trust in the healthcare system (Ford et al., 2024). These events have fostered a deep-seated skepticism about the intentions and practices of medical professionals. Participant 5's remark, *"There's a lot of distrust in the system. We've seen too much go wrong, especially in the past with how we've been treated,"* highlights how past experiences continue to influence current attitudes towards healthcare and end-of-life planning.

This mistrust is not merely a relic of the past but is compounded by ongoing disparities in healthcare access and quality (Saunders et al., 2010). African Americans often encounter systemic inequities, such as lower quality of care and less access to medical resources, which perpetuate a sense of marginalization within the healthcare system (Mahajan et al., 2021). These experiences contribute to a cautious and sometimes hesitant approach to formalizing end-of-life plans, as individuals may fear being mistreated or ignored by healthcare providers.

Sub-Theme 2: Perceptions of Systemic Inequities

The legacy of systemic discrimination extends beyond historical events to encompass contemporary healthcare practices. Participant 4’s observation, *"There's a lack of understanding from doctors who don't look like us or understand our culture,"* reflects a broader issue of cultural competency and representation in healthcare. The perceived lack of culturally competent care can exacerbate mistrust and reluctance to engage in advanced care planning. When healthcare providers lack an understanding of cultural nuances and fail to build rapport with

African American patients, it can lead to feelings of alienation and disempowerment (Kleinman & Benson, 2016).

The impact of these historical and societal factors is evident in the way African Americans approach end-of-life decisions. The reluctance to engage in advanced care planning may be seen as a form of self-protection against a system that has historically marginalized their voices and needs. This historical context provides a crucial understanding of why African Americans might delay or avoid formalizing their end-of-life preferences. Socioeconomic factors and healthcare disparities play a critical role in shaping African Americans' engagement with end-of-life planning. Financial constraints and limited access to quality healthcare services create barriers to proactive end-of-life planning.

Sub-Theme 3: Economic Constraints and Prioritization

Economic constraints are a significant factor that affects engagement in advanced care planning. For many African Americans, financial stability is a pressing concern that often overshadows other aspects of healthcare planning. Participant 9’s comment, *"Healthcare is expensive, and not everyone can afford the luxury of thinking about things like advanced care planning when you're just trying to get by,"* underscores the challenge of prioritizing end-of-life planning in the face of immediate economic pressures.

In contexts where economic resources are scarce, individuals may prioritize immediate healthcare needs over long-term planning. This practical concern reflects a broader societal issue where socioeconomic disparities limit access to healthcare services and resources necessary for comprehensive end-of-life planning (McMaughan et al., 2020). When individuals are preoccupied with basic survival and economic stability, the development and implementation of advanced care directives may become a lower priority.

Sub-Theme 4: Disparities in Healthcare Delivery

Healthcare disparities further complicate the engagement in advanced care planning. Participant 4's observation about the lack of understanding from healthcare providers highlights how disparities in the quality of care can contribute to reluctance in end-of-life planning. African Americans who experience inadequate or insensitive care may be less inclined to engage in planning that requires trust and effective communication with healthcare professionals.

The lack of culturally competent care can lead to feelings of alienation and frustration, which can deter individuals from participating in advanced care planning (Cha et al., 2021). When healthcare providers do not acknowledge or address cultural differences, it can create barriers to effective communication and diminish patients' confidence in the healthcare system. This dynamic underscores the need for increased cultural competence and sensitivity in healthcare delivery to address disparities and foster better engagement in end-of-life planning.

Understanding the historical and societal factors that influence African Americans' perceptions of end-of-life planning has important implications for healthcare providers, policymakers, and community interventions. To address the mistrust and historical biases, healthcare providers must focus on building trust and enhancing cultural competence. This involves not only acknowledging the historical context of mistrust but also actively working to improve the quality and cultural sensitivity of care (Nelson, 2022). Training healthcare professionals in cultural competence and ensuring diverse representation among providers can help bridge the gap between patients and the healthcare system.

Policymakers and healthcare organizations should also address the socioeconomic barriers that impact engagement in advanced care planning. This includes developing initiatives that provide financial assistance, improve access to quality care, and offer education on the importance of advanced care planning (Williams & Cooper, 2019). By addressing economic constraints and ensuring that healthcare resources are accessible to all individuals, it is possible to mitigate some of the barriers that prevent proactive end-of-life planning. Community-based interventions can play a crucial role in improving engagement in advanced care planning. By partnering with community organizations and leveraging local networks, healthcare providers can offer culturally relevant education and support to African American communities. These interventions can help raise awareness about the importance of advanced care planning and provide resources to navigate the process in a culturally sensitive manner (Corbie-Smith et al., 2002).

The historical and societal factors discussed reveal a complex landscape that influences African Americans' perceptions of and engagement with end-of-life planning. The legacy of mistrust towards the healthcare system, compounded by systemic inequities and socioeconomic constraints, shapes individuals' willingness to engage in advanced care planning. Addressing these factors requires a multifaceted approach that includes enhancing cultural competence, addressing socioeconomic barriers, and implementing community-based interventions. By understanding and addressing the historical and societal context, healthcare providers, policymakers, and community organizations can better support African Americans in making informed and proactive decisions about their end-of-life care.

Table 3.

Historical and Societal Factors Influencing Perceptions

Factor	Description	Participant Quote	Implications
Historical Mistrust	The legacy of historical injustices and discrimination has led to pervasive mistrust towards the healthcare system.	"There's a lot of distrust in the system. We've seen too much go wrong, especially in the past with how we've been treated. It makes you wary of signing anything or committing to any plan" (Participant 5).	This mistrust contributes to reluctance in engaging with advanced care planning and may necessitate targeted efforts to rebuild trust and ensure transparent, respectful healthcare interactions.
Systemic Inequities	Historical and ongoing systemic inequities in healthcare access and quality impact perceptions of end-of-life planning.	"Healthcare is expensive, and not everyone can afford the luxury of thinking about things like advanced care planning when you're just trying to get by" (Participant 9).	Addressing systemic disparities is crucial in promoting equitable access to advanced care planning resources and ensuring that all individuals, regardless of their economic status, can participate fully.
Cultural Legacy	Historical experiences and cultural legacy shape contemporary	"There's a lot of distrust in the system. We've seen too much go wrong,	Understanding cultural legacies helps in crafting culturally sensitive and

Factor	Description	Participant Quote	Implications
	attitudes towards advanced care planning.	especially in the past with how we've been treated. It makes you wary of signing anything or committing to any plan" (Participant 5).	relevant interventions to engage African Americans in advanced care planning effectively.
Marginalization	Perceptions of marginalization and misunderstanding within the healthcare system affect willingness to engage in planning.	"There's a lack of understanding from doctors who don't look like us or understand our culture. It makes it hard to trust them with such important decisions" (Participant 4).	To improve engagement, healthcare providers must adopt culturally competent practices and work towards better representation within the healthcare system.
Economic Constraints	Economic hardships and financial constraints impact the prioritization of advanced care planning.	"Healthcare is expensive, and not everyone can afford the luxury of thinking about things like advanced care planning when you're just trying to get by" (Participant 9).	Solutions should include financial assistance and educational resources to make advanced care planning more accessible to economically

Factor	Description	Participant Quote	Implications
			disadvantaged populations.

Research Question 3: What role do religious beliefs and spiritual practices play in shaping African Americans' preferences for end-of-life care?

Theme 3: The Role of Religious Beliefs and Spiritual Practices

Religious beliefs and spiritual practices are profoundly influential in shaping African Americans' preferences and decisions regarding end-of-life care. This theme emerged as a central component of the study, revealing that faith and spirituality play critical roles in how individuals approach advanced care planning. Participants frequently cited their religious convictions and spiritual understandings as central to their attitudes towards end-of-life decisions.

Sub-Theme 1: Religious Influence on End-of-Life Decision-Making

The influence of religious beliefs on end-of-life care preferences is significant and multifaceted. For many African Americans, faith serves as a guiding principle in life, and this influence extends to their approach to death and dying. As Participant 1 noted, *"Faith plays a huge role for me. I believe that everything is in God's hands, and it's hard to plan something as serious as end-of-life care when you believe in a higher power guiding your life*." This statement encapsulates the sentiment that religious beliefs often lead individuals to defer decisions about end-of-life care to divine will rather than medical recommendations.

Sub-Theme 2: Spiritual Guidance and Divine Will

The belief in divine will and spiritual guidance can impact individuals' preferences for end-of-life care in various ways. Many participants expressed a preference for less medical intervention, relying instead on spiritual practices and prayer. Participant 6's comment, "*We pray* *and leave it up to God. I don't think it's right to make these decisions when we can't know God's plan for us,*" highlights a common perspective among those who prioritize spiritual considerations over medical decisions. This view reflects a belief that human intervention may disrupt or interfere with a higher spiritual plan.

Sub-Theme 3: Religious Doctrines and End-of-Life Planning

Religious doctrines and teachings often play a crucial role in shaping attitudes towards advanced care planning. Different faith traditions have distinct beliefs about death and the afterlife, which influence how adherents approach end-of-life care. For example, some African American Christian traditions emphasize the importance of faith in divine healing and the afterlife, leading individuals to resist aggressive medical treatments. This belief can create tension between the desire to adhere to religious teachings and the medical advice provided by healthcare professionals.

Participant 1's emphasis on divine will reflects a broader trend where religious doctrines about death and the afterlife shape individuals' decisions. This perspective is supported by research showing that religious beliefs can lead individuals to prioritize spiritual over medical considerations (Muelle et al., 2001). In these cases, advanced care planning may be seen as an attempt to control or dictate outcomes that are believed to be under divine control, leading to a reluctance to engage with formalized care plans.

The cultural context in which religious beliefs are practiced also impacts end-of-life planning. African American communities often have rich spiritual traditions that are deeply intertwined with cultural practices. The integration of faith and culture can shape individuals' views on death and dying, influencing their willingness to engage in advanced care planning.

The cultural reverence for faith-based practices and community rituals around death can affect how individuals perceive and approach end-of-life care.

Participant 5's observation of a general mistrust in the healthcare system, coupled with a reliance on religious and spiritual practices, illustrates how socio-cultural factors can interact with religious beliefs. The legacy of historical injustices and discrimination in healthcare has led some African Americans to distrust medical institutions, further emphasizing the role of religious and spiritual practices in end-of-life decisions. This context underscores the importance of understanding how cultural and historical factors intersect with religious beliefs in shaping attitudes towards advanced care planning.

Sub-Theme 4: Cultural Practices and Rituals

Cultural practices and rituals associated with death and dying often reflect religious beliefs and can influence how individuals approach advanced care planning. In many African American communities, traditional rituals and spiritual practices play a central role in mourning and honoring deceased loved ones. These practices may include specific ceremonies, prayers, and community gatherings that reflect a deep connection to faith and spirituality.

Participant 3's comment about discussing death being taboo highlights how cultural norms around death can impact attitudes toward end-of-life planning. In cultures where death is approached with a sense of reverence and spirituality, formalizing advanced care plans may be viewed as unnecessary or inappropriate. This perspective is consistent with findings that cultural attitudes towards death and dying can influence the extent to which individuals engage in advanced care planning (Lin et al., 2019).

Understanding the role of religious beliefs and spiritual practices in shaping African Americans' preferences for end-of-life care has significant implications for healthcare providers.

Providers must navigate the complex interplay between religious beliefs and medical recommendations to offer culturally sensitive and respectful care. This involves recognizing the importance of faith and spirituality in patients' decision-making processes and integrating these factors into care plans.

Healthcare providers should approach discussions about end-of-life care with sensitivity to religious and spiritual beliefs. This may involve engaging in open and respectful dialogue with patients and their families about their values and preferences. Providers can also benefit from collaborating with faith-based organizations and community leaders to better understand the cultural and religious contexts that influence end-of-life decisions.

Effective communication is crucial in addressing the intersection of religious beliefs and advanced care planning. Providers should strive to create an environment where patients feel comfortable discussing their spiritual and religious concerns. This may involve using culturally appropriate language and demonstrating respect for patients' beliefs. Providers should also be aware of the potential for religious beliefs to shape patients' views on medical interventions and work to align care plans with patients' values.

Cultural competence training can help healthcare providers better understand the diverse religious and spiritual beliefs of their patients. Training programs should include education on the role of faith and spirituality in end-of-life care, as well as strategies for incorporating these factors into care plans. By enhancing their cultural competence, providers can improve their ability to offer compassionate and effective care that respects patients' religious and spiritual preferences.

The role of religious beliefs and spiritual practices in shaping African Americans' preferences for end-of-life care is complex and multifaceted. Faith and spirituality significantly influence how individuals approach advanced care planning, often leading them to prioritize spiritual considerations over medical recommendations. Understanding these influences is essential for healthcare providers who seek to offer culturally sensitive and respectful care.

The intersection of religious beliefs and advanced care planning highlights the need for providers to engage in open and respectful dialogue with patients and their families. By recognizing and integrating religious and spiritual factors into care plans, providers can better align their practices with patients' values and preferences. This approach can improve patient satisfaction and foster a more compassionate and holistic approach to end-of-life care.

In conclusion, the insights gained from this study underscore the importance of addressing religious and spiritual considerations in advanced care planning. By acknowledging and respecting these factors, healthcare providers can enhance the quality of care and support for African American patients facing end-of-life decisions.

Table 4.

Role of Religious Beliefs and Spiritual Practices

Sub-theme	Description	Participant Quotes	Implications
Religious Beliefs and Divine Will	Many African Americans rely on faith and spiritual beliefs to guide their decisions about end-of-life care. This belief in divine will can lead to a	"Faith plays a huge role for me. I believe that everything is in God's hands, and it's hard to plan something as serious as end-of-life care when you believe in	Spiritual beliefs often lead to a preference for minimal medical intervention and reliance on divine will. Healthcare providers must navigate these beliefs respectfully

Sub-theme	Description	Participant Quotes	Implications
	preference for less medical intervention.	a higher power guiding your life" (Participant 1). "We pray and leave it up to God. I don't think it's right to make these decisions when we can't know God's plan for us" (Participant 6).	while providing appropriate care options.
Cultural Context of Religion	African Americans' religious practices are deeply intertwined with cultural norms, which influence their approach to end-of-life planning. Family and community traditions often emphasize spiritual over medical considerations.	"In our family, we don't really talk about these things openly. It's kind of taboo; you don't want to bring it up because it feels like you're inviting something bad" (Participant 3). "We usually leave these decisions to the elders; they know what's best for the family" (Participant 7).	Religious and cultural norms can create a barrier to open discussions about end-of-life care. Addressing these cultural aspects in care planning can help bridge gaps between patients' preferences and medical recommendations.

Sub-theme	Description	Participant Quotes	Implications
Spiritual Practices and Care Preferences	The role of prayer and spiritual rituals can influence decisions regarding end-of-life care, with many preferring to rely on spiritual guidance rather than medical interventions.	"I believe that everything is in God's hands, and it's hard to plan something as serious as end-of-life care when you believe in a higher power guiding your life" (Participant 1). "We pray and leave it up to God" (Participant 6).	Healthcare providers need to understand and accommodate spiritual practices in their care plans, ensuring that they respect patients' beliefs while providing comprehensive care.
Conflicts Between Medical and Spiritual Perspectives	Conflicts may arise when medical recommendations are at odds with spiritual beliefs. This can create tension in decision-making about end-of-life care.	"I don't think it's right to make these decisions when we can't know God's plan for us" (Participant 6).	It is important for healthcare providers to engage in empathetic and open discussions with patients and their families to resolve conflicts between spiritual beliefs and medical advice.
Impact on Advanced	Religious and spiritual beliefs can influence the degree to which	"There's a lot of distrust in the system. We've seen too much go wrong,	Encouraging advanced care planning in a manner that respects spiritual

Sub-theme	Description	Participant Quotes	Implications
Care Planning	individuals engage in advanced care planning. Some may delay or avoid formal planning due to reliance on spiritual guidance.	especially in the past with how we've been treated. It makes you wary of signing anything or committing to any plan" (Participant 5).	beliefs can help improve engagement and ensure that care preferences are understood and honored.

RQ4: How do socioeconomic factors and healthcare disparities contribute to disparities in advanced care planning engagement within the African-American community?

Theme 4: Socioeconomic Factors and Healthcare Disparities

Sub-Theme 1: Socioeconomic Factors as Barriers to Advanced Care Planning

Socioeconomic factors significantly impact the engagement of African Americans in advanced care planning. Financial constraints and economic instability often overshadow the perceived importance of advanced care planning. As Participant 9 noted, *"Healthcare is expensive, and not everyone can afford the luxury of thinking about things like advanced care planning when you're just trying to get by."* This statement encapsulates a widespread sentiment that financial pressures take precedence over non-urgent planning needs. When individuals are focused on meeting daily needs and managing immediate financial concerns, long-term considerations such as advanced care planning can be perceived as a lower priority.

The economic burden associated with healthcare costs exacerbates this issue. For many African Americans, particularly those in lower-income brackets, the costs of healthcare services, including consultations for advanced care planning, are prohibitively high. This economic reality creates a barrier to proactive engagement in end-of-life planning. The lack of financial resources makes it challenging to invest time and effort into planning for future care when immediate survival needs are pressing. This financial strain can lead to a reactive rather than proactive approach to healthcare decisions, resulting in less engagement with advanced care planning.

Sub-Theme 2: Impact of Healthcare Disparities on Advanced Care Planning

Healthcare disparities also play a crucial role in shaping attitudes towards advanced care planning. Disparities in healthcare access and quality contribute to a general mistrust of the healthcare system among African Americans, which can deter them from engaging in advanced care planning. Participant 4 highlighted this issue: *"There's a lack of understanding from doctors who don't look like us or understand our culture. It makes it hard to trust them with such important decisions."* This mistrust, rooted in historical and ongoing systemic inequities, influences individuals' willingness to discuss and formalize their end-of-life care preferences.

The perception of cultural incompetence among healthcare providers can lead to a reluctance to engage in advanced care planning. If individuals feel that their cultural values and beliefs are not understood or respected by their healthcare providers, they may be less likely to initiate or follow through with planning discussions. This mistrust and lack of cultural competence can create barriers to effective communication and collaboration between patients and healthcare providers, further hindering engagement in advanced care planning.

Sub-Theme 3: Socioeconomic Disparities and Access to Healthcare Resources

Socioeconomic disparities extend beyond immediate financial constraints to encompass broader issues related to healthcare access. Limited access to quality healthcare services and resources can further impede engagement in advanced care planning. Participants often expressed frustration with the inadequate availability of culturally competent care and the limited options for comprehensive healthcare planning. The lack of access to resources such as educational materials on advanced care planning and affordable legal services can make it challenging for individuals to engage in the process.

The absence of accessible, culturally relevant resources contributes to the difficulties faced by African Americans in navigating advanced care planning. When individuals lack access to reliable information and support, they may feel ill-equipped to make informed decisions about their end-of-life care. This lack of access can be particularly pronounced in underserved communities where healthcare resources are scarce, further exacerbating disparities in advanced care planning engagement.

Addressing the socioeconomic and healthcare disparities that impact advanced care planning requires targeted interventions at multiple levels. Policymakers and healthcare providers need to prioritize efforts to reduce financial barriers and improve access to culturally competent care. Initiatives that aim to provide financial assistance for advanced care planning services, such as subsidized consultations or legal assistance, could help alleviate some of the economic pressures that individuals face.

Additionally, increasing the availability of culturally relevant educational materials and resources can help bridge the gap in advanced care planning engagement. Community-based programs that focus on educating individuals about the importance of advanced care planning and providing support for navigating the process can play a crucial role in addressing disparities. Engaging community leaders and organizations in these efforts can help ensure that interventions are culturally sensitive and effectively address the unique needs of African American communities.

Building trust between healthcare providers and patients is essential for improving engagement in advanced care planning. Training healthcare professionals in cultural competence and encouraging the inclusion of diverse perspectives in healthcare decision-making can help address concerns related to cultural understanding and respect. Creating an environment where patients feel valued and understood can enhance their willingness to participate in advanced care planning discussions.

Furthermore, fostering open and transparent communication between healthcare providers and patients can help address the mistrust that exists within some communities. Encouraging patients to voice their concerns and preferences and ensuring that these are taken into account in the planning process can help build trust and promote more meaningful engagement.

In conclusion, socioeconomic factors and healthcare disparities significantly contribute to the disparities in advanced care planning engagement within the African-American community. Financial constraints, economic instability, and limited access to quality healthcare resources create barriers to proactive planning. Additionally, healthcare disparities, including a lack of cultural competence and mistrust of the healthcare system, further hinder engagement in advanced care planning. Addressing these issues requires targeted interventions to reduce financial barriers, improve access to culturally competent care, and build trust between healthcare providers and patients. By implementing these strategies, it is possible to enhance engagement in advanced care planning and ensure that all individuals, regardless of their socioeconomic status or background, have the opportunity to make informed decisions about their end-of-life care.

Table 5.

Socioeconomic Factors and Healthcare Disparities

Aspect	Participant Quotes	Socioeconomic Factors	Implications for Advanced Care Planning
Financial Constraints	"Healthcare is expensive, and not everyone can afford the luxury of thinking about things like advanced care planning when you're just trying to get by." (Participant 9)	Economic limitations, lack of financial resources	Advanced care planning may be deprioritized due to immediate financial concerns, leading to lower engagement and preparation for end-of-life decisions. Economic barriers can prevent individuals from seeking or affording planning resources and services.
Healthcare Access	"There's a lack of understanding from doctors who don't look like us or understand our culture. It makes it hard to trust them with such important decisions." (Participant 4)	Limited access to quality healthcare, lack of culturally competent care providers	Distrust and lack of cultural competence among healthcare providers can deter African Americans from engaging in advanced care planning. This mistrust may result in a reluctance to discuss or formalize care preferences with providers who are perceived as unempathetic.

Aspect	Participant Quotes	Socioeconomic Factors	Implications for Advanced Care Planning
Systemic Inequities	"There's a lot of distrust in the system. We've seen too much go wrong, especially in the past with how we've been treated. It makes you wary of signing anything or committing to any plan." (Participant 5)	Historical and systemic healthcare inequities, legacy of mistrust	Historical injustices and systemic inequities contribute to a pervasive mistrust of the healthcare system, leading to hesitancy in engaging with advanced care planning. Past negative experiences influence current attitudes towards formal care arrangements.
Perceived Value of Planning	"I don’t see the point in planning for something that feels so far off, especially when there are more immediate concerns." (Participant 2)	Perception of low immediate value, competing priorities	The perceived low immediate value of advanced care planning in the face of pressing daily challenges can result in lower engagement. Individuals may prioritize immediate needs over long-term planning, viewing advanced care directives as less critical.
Cultural Representation	"When we do talk to doctors or planners, we	Lack of culturally tailored planning	The absence of culturally relevant and tailored advanced

Aspect	Participant Quotes	Socioeconomic Factors	Implications for Advanced Care Planning
	often feel like they're not addressing our unique cultural needs." (Participant 6)	resources and representation	care planning resources may contribute to disengagement. The lack of culturally sensitive communication can result in a disconnect between providers and patients, affecting the uptake of advanced care planning.
Community Support Systems	"In our community, we rely on family and close-knit networks rather than formal planning tools." (Participant 7)	Reliance on informal support systems, limited use of formal planning tools	Strong reliance on family and community support can influence preferences for informal over formal advanced care planning methods. This reliance may impact the adoption of formalized care directives and planning tools.

Research Question 5: What are the implications of the observed attitudes and behaviors for healthcare providers, policymakers, and community interventions to foster advanced care planning within the African-American community?

Theme 5: Implications of Socioeconomic Factors and Healthcare Disparities for Advanced Care Planning in the African-American Community

The socioeconomic factors and healthcare disparities identified in the study highlight significant barriers to advanced care planning (ACP) within the African-American community. This theme underscores the complex interplay of financial constraints, limited access to quality healthcare, and the perceived lack of culturally competent care providers, which collectively influence attitudes toward and engagement with advanced care planning. Understanding these factors is crucial for healthcare providers, policymakers, and community interventions aiming to improve ACP uptake among African Americans. This discussion will explore the implications of these findings, considering each research question to provide a comprehensive understanding of how socioeconomic and healthcare disparities affect ACP and to offer strategies for fostering engagement within this community.

Sub-Theme 1: Influence of Socioeconomic Factors on Advanced Care Planning

Financial Constraints and ACP Engagement. Financial constraints are a significant barrier to advanced care planning among African Americans. Participants frequently cited the high costs associated with healthcare and the prioritization of immediate financial needs over planning for the future. As Participant 9 explained, "Healthcare is expensive, and not everyone can afford the luxury of thinking about things like advanced care planning when you're just trying to get by." This sentiment reflects a broader reality where financial instability limits the capacity to engage in proactive healthcare measures.

Research has consistently shown that financial barriers can deter individuals from seeking preventive or elective medical services, including advanced care planning (Ladin et al., 2022). For African Americans, who are disproportionately affected by socioeconomic disadvantages, the cost of healthcare often represents a significant obstacle to ACP. This situation is exacerbated by the broader economic conditions and the persistent wealth gap between African Americans and other racial groups.

Healthcare providers and policymakers must address these financial barriers to improve ACP uptake. Strategies could include integrating ACP into existing health services to reduce out-of-pocket costs and providing financial assistance or subsidies specifically for ACP-related services. Additionally, public health campaigns should emphasize the long-term benefits of ACP to help individuals understand its value despite immediate financial pressures.

Impact of Socioeconomic Disparities on Health Literacy. Socioeconomic disparities also affect health literacy, which is crucial for informed decision-making in advanced care planning. Participants reported that limited access to education and resources impacts their understanding of ACP options. As Participant 4 noted, "There's a lack of understanding from doctors who don't look like us or understand our culture. It makes it hard to trust them with such important decisions."

Low health literacy can result from a combination of factors, including inadequate educational resources and limited exposure to information about healthcare options (Kutner et al., 2006). Addressing health literacy requires targeted educational interventions that cater to the specific needs of the African-American community. Healthcare providers should offer culturally relevant and accessible information about ACP, utilizing community-based organizations to bridge gaps in understanding and trust. By improving health literacy, individuals are more likely to engage in advanced care planning and make informed decisions about their future healthcare.

Sub-Theme 2: Historical and Societal Factors Affecting ACP

Mistrust in the Healthcare System. The historical legacy of mistrust in the healthcare system is a significant factor influencing African Americans' engagement with advanced care planning. As Participant 5 stated, "There's a lot of distrust in the system. We've seen too much go wrong, especially in the past with how we've been treated. It makes you wary of signing anything or committing to any plan." This mistrust stems from a history of medical experimentation, discrimination, and systemic inequities that have marginalized African Americans within the healthcare system.

To overcome this mistrust, healthcare providers must prioritize building relationships and demonstrating respect and understanding for the unique experiences and concerns of African American patients. Engaging community leaders and trusted organizations in healthcare initiatives can help bridge the gap between healthcare providers and the community. Additionally, transparency and accountability in healthcare practices are essential to rebuild trust and encourage participation in advanced care planning.

Cultural Competency and Representation. The perceived lack of culturally competent care is another barrier to ACP. Participants highlighted difficulties in communicating with healthcare providers who do not understand or respect their cultural values. As Participant 4 observed, "There's a lack of understanding from doctors who don't look like us or understand our culture. It makes it hard to trust them with such important decisions."

Healthcare systems need to enhance cultural competency by training providers to recognize and address cultural differences in healthcare preferences and practices. Increasing diversity within the healthcare workforce and ensuring that care providers reflect the community they serve can also improve patient trust and engagement. By fostering a culturally sensitive approach, healthcare providers can better address the needs and preferences of African American patients, thereby promoting greater involvement in advanced care planning.

Sub-Theme 3: Role of Healthcare Providers and Policymakers

Culturally Sensitive Communication Strategies. Healthcare providers play a crucial role in facilitating advanced care planning by employing culturally sensitive communication strategies. To effectively address the barriers identified, providers must develop approaches that resonate with the cultural norms and values of African American patients. This includes incorporating family dynamics, community values, and spiritual beliefs into ACP discussions.

Training programs for healthcare providers should emphasize the importance of understanding cultural context and developing communication skills that build rapport and trust with patients. Providers should also be encouraged to use language and examples that align with the cultural values of their patients to make ACP discussions more relatable and less intimidating.

Policy Interventions to Address Disparities. Policymakers have a critical role in addressing the socioeconomic and healthcare disparities that impact advanced care planning. Policies that aim to reduce financial barriers, improve access to healthcare, and enhance health literacy are essential for fostering greater engagement in ACP. Specific policy recommendations include:

1. **Expansion of Medicaid and Insurance Coverage:** Increasing coverage for advanced care planning services can help alleviate financial barriers. Medicaid expansion and insurance reforms should include provisions for covering ACP consultations and related services.
2. **Funding for Community-Based Programs:** Investing in community-based programs that provide education and support for advanced care planning can improve access and engagement.

These programs should be designed to address the specific needs of African American communities and be delivered through trusted local organizations.

3. **Promotion of Health Literacy Initiatives:** Implementing initiatives to improve health literacy, particularly in underserved communities, can empower individuals to make informed decisions about advanced care planning. Educational materials should be culturally relevant and available in multiple formats to reach diverse audiences.
4. **Support for Culturally Competent Care:** Policies that promote cultural competency training for healthcare providers and increase diversity within the healthcare workforce can enhance the quality of care and build trust with African American patients.

Sub-Theme 4. Community Interventions and Engagement

Building Trust Through Community Partnerships. Community partnerships are essential for fostering advanced care planning within the African-American community. Collaborating with local churches, community organizations, and leaders can help address cultural barriers and build trust. These partnerships can facilitate outreach efforts, provide educational workshops, and create supportive environments for ACP discussions.

Community-based interventions should focus on creating safe spaces for dialogue and offering resources that align with the cultural values and practices of the community. Engaging community members in the development and implementation of ACP programs ensures that interventions are relevant and effective.

Encouraging Family Involvement in ACP. Given the cultural emphasis on family decision-making, involving family members in advanced care planning discussions can enhance engagement. Healthcare providers should encourage patients to include their families in ACP conversations and provide support for family-centered planning. This approach aligns with the communal values observed in the study and can help overcome individual reluctance to engage in ACP.

The socioeconomic factors and healthcare disparities identified in the study have significant implications for advanced care planning within the African-American community. Addressing financial constraints, improving health literacy, and enhancing cultural competency are crucial for fostering greater engagement in ACP. Healthcare providers, policymakers, and community interventions must work collaboratively to develop strategies that address these barriers and promote proactive planning for end-of-life care.

By implementing culturally sensitive communication strategies, supporting community-based programs, and addressing systemic disparities, stakeholders can improve advanced care planning uptake and ensure that African American patients receive the care that aligns with their values and preferences. The insights gained from this study offer valuable guidance for developing effective interventions and policies to support advanced care planning within the African-American community.

Table 6.

Implications for Healthcare Providers, Policymakers, and Community Interventions in Advanced Care Planning for the African-American Community.

Aspect	Description	Implications	Examples/Quotes
Cultural Sensitivity	Understanding and respecting cultural norms and values	Healthcare providers need to integrate cultural competency into care plans. Policymakers	"It's kind of taboo; you don't want to bring it up because it feels like you're

Aspect	Description	Implications	Examples/Quotes
	regarding end-of-life care.	should advocate for culturally tailored interventions.	inviting something bad" (Participant 3).
Historical Mistrust	Addressing the historical distrust towards the healthcare system due to past injustices.	Build trust through transparency and community engagement. Develop policies to rectify historical disparities.	"There's a lot of distrust in the system. We've seen too much go wrong" (Participant 5).
Religious and Spiritual Beliefs	Incorporating religious and spiritual beliefs into care planning.	Providers should discuss care plans that align with spiritual beliefs. Policies should support faith-based end-of-life care options.	"I believe that everything is in God's hands, and it's hard to plan something as serious as end-of-life care" (Participant 1).
Socioeconomic Barriers	Addressing financial constraints and access to quality healthcare.	Implement policies to reduce financial burdens and improve access. Providers should offer support for navigating financial aspects of care.	"Healthcare is expensive, and not everyone can afford the luxury of thinking about things like advanced care planning" (Participant 9).

Aspect	Description	Implications	Examples/Quotes
Healthcare Disparities	Ensuring access to culturally competent and equitable healthcare.	Training for providers on cultural competency. Create policies for equitable access to care and representation.	"There's a lack of understanding from doctors who don't look like us or understand our culture" (Participant 4).
Community Engagement	Engaging with community leaders and organizations to promote advanced care planning.	Develop community-based programs to raise awareness and provide resources. Foster partnerships with trusted community organizations.	"Engage with community leaders to help bridge the gap between healthcare systems and African-American families."
Educational Initiatives	Providing education on advanced care planning tailored to the community's needs and values.	Create educational materials and workshops that respect cultural and religious contexts. Implement programs that are accessible and relevant.	"Educational programs need to respect our values and offer practical guidance on planning."
Policy Advocacy	Advocating for policies that address the specific needs and	Lobby for changes that improve access to care and address systemic	"Policymakers should work towards policies that

Aspect	Description	Implications	Examples/Quotes
	barriers faced by the African-American community.	inequities. Ensure policies support culturally appropriate care planning.	remove barriers to advanced care planning."
Trust-Building Strategies	Developing strategies to build and maintain trust between healthcare providers and the community.	Establish trust through consistent, respectful communication and reliable care. Implement feedback mechanisms to address concerns.	"Building trust through consistent, respectful communication and addressing past grievances."

The thematic findings reveal a complex interplay of cultural, historical, religious, and socioeconomic factors shaping African Americans' attitudes toward end-of-life care. The analysis acknowledges the potential biases introduced by the researcher's own preconceptions and the steps taken to mitigate them, including reflexive journaling and member checking. The inclusion of diverse participant voices ensures a comprehensive exploration of the themes, underscoring the necessity for culturally sensitive approaches in healthcare settings to address the unique needs and concerns of African American communities.

In presenting these findings, the analysis provides a narrative that integrates participant quotes to substantiate the themes and build a cohesive understanding of the phenomenon under study. The resulting insights offer valuable implications for healthcare providers, policymakers, and community interventions aiming to foster advanced care planning within the African-American community.

Summary

Chapter Four presents a thorough analysis of the study on African Americans' attitudes towards end-of-life care, highlighting the impact of cultural, historical, societal, religious, and socioeconomic factors. The chapter begins by reiterating the core issue: the reluctance of African Americans to engage with end-of-life care services despite their eligibility. Utilizing a qualitative, phenomenological approach, the study explored the lived experiences of ten participants, employing thematic analysis guided by the socio-ecological model.

The participant group, aged between 25 and 64, encompassed a range of educational backgrounds, religious beliefs, income levels, and health statuses, offering a broad spectrum of perspectives on end-of-life care. This diversity was crucial in reflecting various cultural, educational, and economic contexts that influence attitudes towards such care.

Data analysis was conducted using Braun and Clarke’s six-step thematic analysis process. This included familiarization with the data through repeated readings of transcripts, generating initial codes, grouping related codes into broader themes, reviewing and refining these themes, and defining and naming them. The findings were then articulated in the report with supporting quotes. NVivo software aided in organizing the data, while reflexivity protocols, peer debriefing, and member checking were employed to enhance the credibility of the analysis.

The thematic analysis uncovered several key themes. Cultural norms and values emerged as a major factor, with a cultural reluctance to discuss death and an emphasis on family consensus hindering proactive end-of-life planning. Participants expressed discomfort with discussing end-of-life care, reflecting broader cultural attitudes. Historical and societal factors also played a significant role, with past mistrust of the healthcare system and experiences of systemic inequities contributing to a cautious approach to advanced care planning. Additionally, strong religious beliefs influenced attitudes, with some participants preferring less medical intervention due to their faith and beliefs in divine will and afterlife, which often conflicted with medical recommendations. Socioeconomic factors, including financial constraints and limited access to quality healthcare, were significant barriers, with participants noting how economic pressures and the lack of culturally competent care providers affected their engagement with advanced care planning.

In general, the chapter underscores the complex interplay of these themes and their implications for healthcare practice, policy, and community interventions. The findings highlight the necessity for culturally sensitive approaches to enhance end-of-life care engagement among African Americans, offering actionable insights for healthcare providers and policymakers to better address the unique needs and concerns of this community.

CHAPTER FIVE: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

Chapter Five of this study synthesizes the findings of the study, offering a comprehensive summary of the key conclusions derived from the data analysis. This chapter aims to consolidate the insights gained from the exploration of African Americans' attitudes toward advanced care planning, examining the cultural, historical, religious, and socioeconomic factors influencing their engagement with end-of-life care services. By reflecting on the thematic analysis, this chapter will address the core research questions, highlighting the implications of the study’s findings and their relevance to healthcare practice and policy.

The study has illuminated critical factors contributing to the underutilization of palliative and hospice care services among African Americans, despite their eligibility for such support. Through a detailed examination of participants' perspectives, we have identified significant barriers and motivators shaping their end-of-life care decisions. This chapter will distill these findings into actionable conclusions, providing a clear understanding of the underlying issues and offering practical recommendations for improving advanced care planning engagement within the African-American community.

In summarizing the conclusions, this chapter will first revisit the research questions, synthesizing the key insights and their implications. It will then propose recommendations aimed at addressing the identified barriers, fostering better engagement with advanced care planning, and improving the quality and accessibility of end-of-life care services. These recommendations will be tailored to healthcare providers, policymakers, and community organizations, offering strategies to enhance cultural competency, address historical mistrust, and mitigate socioeconomic disparities.

Finally, this chapter will reflect on the study's limitations and suggest areas for future research, aiming to build on the findings to further advance understanding and practice in the field of end-of-life care. Through this comprehensive conclusion and recommendation section, the study aspires to contribute to meaningful improvements in the delivery of advanced care planning services, ultimately enhancing the quality of care for African Americans and addressing long-standing disparities in end-of-life care.

Research Questions

The research questions that quidded this study were:

6. To what extent do cultural norms and values influence African Americans' attitudes and preferences toward advanced care planning?
7. How do historical and societal factors impact African Americans' perceptions of and engagement with end-of-life planning?
8. What role do religious beliefs and spiritual practices play in shaping African Americans' preferences for end-of-life care?
9. How do socioeconomic factors and healthcare disparities contribute to disparities in advanced care planning engagement within the African-American community?
10. What are the implications of the observed attitudes and behaviors for healthcare providers, policymakers, and community interventions to foster advanced care planning within the African-American community?

Discussion of Findings

The thematic findings of this study offer significant insights into the factors influencing African Americans' engagement with advanced care planning and the underutilization of palliative and hospice care services. This discussion interprets these findings in light of the research questions, considering how cultural, historical, religious, and socioeconomic dimensions shape attitudes and behaviors related to end-of-life care. The following sections will address each theme identified in the study, providing a detailed analysis of their implications and relevance to the broader context of advanced care planning.

Theme 1: Cultural Norms and Values Impacting Advanced Care Planning

The first theme, "Cultural Norms and Values Impacting Advanced Care Planning," provides a crucial lens through which to understand African Americans' attitudes toward end-of-life care. This theme reveals that cultural norms and values play a foundational role in shaping individuals' decisions and preferences regarding advanced care planning. Cultural norms and values, deeply embedded in the African American community, influence how individuals perceive and engage with end-of-life care. This finding aligns with the broader literature on cultural determinants of health behaviors, which suggests that cultural traditions and familial expectations significantly impact healthcare decisions (Braun et al. 2008; Collins et al., 2018). For African Americans, cultural factors such as the emphasis on family involvement and traditional practices play a significant role in shaping attitudes toward end-of-life planning.

The data indicate that African Americans often prioritize familial decision-making and communal support over formalized medical planning. Participant responses highlighted a preference for involving family members in decisions related to end-of-life care, reflecting cultural values that prioritize collective over individual decision-making. This finding resonates with research by Johnson et al. (2018), who discuss how cultural values related to family and community can affect healthcare decision-making, particularly in minority populations.

Moreover, cultural traditions within the African American community may also impact the perceived relevance and importance of advanced care planning. The reluctance to engage with formal planning may be influenced by cultural beliefs about death and dying, which often emphasize spiritual and familial support rather than medical intervention. This perspective underscores the need for healthcare providers to understand and respect cultural values when discussing advanced care planning options with African American patients.

In contrast to the emphasis on family and tradition, the formal structures of advanced care planning may be viewed as less aligned with cultural values. This disconnect can create barriers to engagement, as individuals may perceive advanced care planning as an imposition of external values rather than a reflection of their own beliefs and practices. As noted by Collins et al. (2018), addressing these cultural discrepancies is essential for improving engagement with advanced care planning services and ensuring that care options are respectful of and tailored to individual cultural contexts.

Overall, the findings related to cultural norms and values highlight the importance of integrating cultural competence into advanced care planning discussions. Healthcare providers should consider cultural influences when engaging with African American patients, ensuring that care planning approaches are culturally sensitive and aligned with patients' values and preferences. This consideration can help bridge the gap between formalized care planning and culturally informed practices, ultimately fostering more effective and respectful engagement with end-of-life care services.

Theme 2: Historical Factors Affecting Engagement with Advanced Care Planning

The second theme, "Historical Factors Affecting Engagement with Advanced Care Planning," provides valuable insights into how historical experiences shape attitudes and behaviors towards end-of-life care among African Americans. This theme highlights the significant influence of historical events and systemic issues on current practices and perceptions related to advanced care planning.

Historical factors, particularly those rooted in experiences of discrimination and mistrust within the healthcare system, have a profound impact on how African Americans approach advanced care planning. This theme is supported by existing literature, which underscores the long-standing legacy of medical exploitation and racial disparities in healthcare access and quality (Gaskin et al., 2011). The historical context of medical experimentation, such as the Tuskegee Syphilis Study, has left a lasting imprint on the African American community's trust in healthcare institutions (Ludke et al., 2007).

The study's findings reveal that historical experiences of racial discrimination contribute to a general mistrust of medical institutions and formalized healthcare processes, including advanced care planning. Participants expressed concerns about the potential for biased treatment and exploitation, reflecting a broader historical narrative of racial injustice in healthcare. This mistrust can lead to reluctance or avoidance of engaging in advanced care planning, as individuals may perceive it as part of a system that has historically marginalized their community (Gaskin et al., 2011).

Moreover, the historical context of socioeconomic inequalities also plays a role in shaping attitudes toward advanced care planning. African Americans have historically faced barriers to accessing quality healthcare due to socioeconomic disadvantages, which can further exacerbate concerns about engaging with advanced care planning services (Williams & Mohammed, 2013). The study's findings align with this perspective, highlighting how historical inequalities continue to influence current attitudes and behaviors.

The implications of these historical factors are significant for healthcare providers and policymakers. Understanding the historical context of mistrust and discrimination is essential for developing strategies to build trust and improve engagement with advanced care planning among African American populations. Efforts to address these historical grievances and provide culturally competent care are crucial in overcoming barriers to advanced care planning (Smedley et al., 2003).

In summary, the theme of historical factors affecting engagement with advanced care planning emphasizes the importance of considering historical experiences and systemic issues when addressing end-of-life care within the African American community. The findings underscore the need for healthcare providers to acknowledge and address historical mistrust and inequalities to enhance the effectiveness of advanced care planning initiatives.

Theme 3: Socioeconomic Barriers to Advanced Care Planning

The third theme, "Socioeconomic Barriers to Advanced Care Planning," highlights the significant impact of socioeconomic factors on African Americans' engagement with advanced care planning and the utilization of palliative and hospice care services. This theme aligns with the broader literature on healthcare disparities and resource access, emphasizing how economic constraints can limit individuals' ability to participate fully in advanced care planning processes.

Socioeconomic status (SES) plays a crucial role in shaping individuals' access to and engagement with healthcare services. The study's findings underscore that lower SES is associated with numerous barriers to advanced care planning, including limited access to healthcare resources, financial constraints, and a lack of insurance coverage. These barriers are well-documented in the literature, which consistently identifies socioeconomic disparities as a significant factor influencing healthcare utilization and outcomes (Peterson et al., 2019).

Financial constraints, in particular, can hinder individuals' ability to seek out and engage in advanced care planning services. Participants in this study reported concerns about the costs associated with palliative and hospice care, which can be prohibitive for those with limited financial resources. This finding is consistent with research by Johnson et al. (2018), who highlight that out-of-pocket costs and inadequate insurance coverage can create significant barriers to accessing end-of-life care services.

Moreover, the study reveals that socioeconomic barriers also intersect with other factors such as educational attainment and health literacy. Lower levels of education and health literacy can exacerbate the challenges associated with advanced care planning, as individuals may lack the knowledge or resources to navigate complex healthcare systems (CDC, 2021). This aligns with the work of Williams and Mohammed (2013), who argue that educational disparities contribute to unequal access to advanced care planning resources and information.

The implications of these findings are multifaceted. Addressing socioeconomic barriers requires a comprehensive approach that includes policy changes aimed at improving access to healthcare services, expanding insurance coverage, and reducing out-of-pocket costs. Additionally, educational initiatives aimed at increasing health literacy and awareness about advanced care planning can play a crucial role in overcoming these barriers (Gaskin et al., 2011).

In summary, the theme of socioeconomic barriers to advanced care planning highlights the critical impact of economic factors on engagement with end-of-life care services. The findings underscore the need for targeted interventions and policy changes to address financial and educational disparities that limit access to advanced care planning.

Theme 4: Socioeconomic Factors and Healthcare Disparities

The fourth theme underscores the profound impact of socioeconomic factors on healthcare disparities and their influence on the uptake of advanced care planning and palliative care services. This theme aligns with the socioecological model, which posits that individual health behaviors and outcomes are shaped by a complex interplay of socioeconomic and environmental factors (Gaskin et al., 2011). The findings suggest that addressing socioeconomic barriers is crucial for improving access to and the effectiveness of advanced care planning among African American communities.

Socioeconomic Barriers to Healthcare Access. One critical aspect of this theme is the impact of socioeconomic status on healthcare access. The literature indicates that lower socioeconomic status is associated with reduced access to healthcare services, including advanced care planning and palliative care (Ludke et al., 2007). Individuals with lower incomes often face financial barriers that limit their ability to afford out-of-pocket costs associated with these services, such as co-payments for consultations or transportation to healthcare facilities.

The findings of this study align with these observations, highlighting that socioeconomic disparities create significant obstacles for African Americans in accessing advanced care planning services. For example, the lack of financial resources can lead to delays in seeking care or avoidance of services altogether, which exacerbates existing health disparities (Peterson et al., 2019). This supports the need for targeted interventions that address the financial barriers faced by lower-income populations to enhance their engagement with advanced care planning.

Education and Health Literacy. Another important factor is health literacy, which is closely linked to socioeconomic status. Individuals with lower levels of education and limited health literacy often struggle to navigate the healthcare system and understand the benefits of advanced care planning and palliative care (CDC, 2021). The study's findings indicate that improving health literacy and providing educational resources are essential strategies for overcoming barriers related to socioeconomic status.

Educational initiatives that focus on increasing awareness and understanding of advanced care planning can help bridge the knowledge gap and empower individuals to make informed decisions about their care. The literature supports this approach, suggesting that culturally tailored educational programs can significantly enhance health literacy and encourage proactive engagement with healthcare services (Hudson et al., 2017).

Policy Implications and Interventions. The theme also emphasizes the need for policy interventions to address socioeconomic disparities in healthcare access. The literature highlights that comprehensive policies aimed at reducing financial barriers, improving health literacy, and enhancing access to care are crucial for addressing healthcare disparities (Torke et al., 2008). The findings suggest that policymakers should focus on implementing programs that provide financial assistance, support community-based education, and promote equitable access to advanced care planning and palliative care services.

Community-Based Solutions. Finally, the study highlights the role of community-based solutions in addressing socioeconomic disparities. Community health programs and local organizations can play a vital role in bridging gaps in healthcare access by providing targeted support and resources to underserved populations (Collins et al., 2018; Peterson et al., 2019). These community-driven approaches can enhance the delivery of advanced care planning services and reduce disparities by offering culturally relevant support and facilitating access to care.

In summary, the theme of socioeconomic factors and healthcare disparities aligns with the socioecological model and emphasizes the need for multifaceted approaches to address financial, educational, and policy-related barriers. The findings underscore the importance of addressing these socioeconomic factors to improve access to advanced care planning and palliative care services, ultimately contributing to a reduction in healthcare disparities among African American communities.

Theme 5: Implications of Socioeconomic Factors and Healthcare Disparities for Advanced Care Planning in the African-American Community

The fifth theme explores the multifaceted impact of socioeconomic factors and healthcare disparities on advanced care planning within the African-American community. This theme aligns with the socioecological model, which considers how various layers of socioeconomic and systemic factors influence individual health behaviors and access to care (Williams & Mohammed, 2013). The findings suggest that addressing these disparities is crucial for improving ACP engagement and outcomes in this population.

Economic Barriers and Access to ACP. One of the key aspects identified in this theme is the economic barriers that African Americans face in accessing advanced care planning services. Literature indicates that socioeconomic status significantly influences healthcare access and utilization (Williams & Mohammed, 2013). The study's findings confirm that individuals from lower socioeconomic backgrounds often encounter financial barriers that impede their ability to engage in ACP. These barriers include the cost of medical consultations, lack of insurance coverage, and limited availability of affordable healthcare services.

The alignment with existing literature underscores the need for targeted interventions that address these financial obstacles. For example, Ludke et al. (2007) emphasize that reducing out-of-pocket expenses and expanding insurance coverage are critical strategies for improving access to healthcare services. The study's findings suggest that similar approaches are necessary to enhance ACP engagement among economically disadvantaged African Americans.

Health Literacy and Educational Gaps. Another significant finding relates to health literacy and education gaps. The study highlights that lower health literacy levels, which are often correlated with socioeconomic disadvantages, hinder effective participation in advanced care planning (Elliot et al., 2013). Individuals with limited health literacy may struggle to understand the importance of ACP or how to initiate the process, leading to underutilization of these services.

The findings align with literature advocating for educational initiatives that enhance health literacy and provide clear, accessible information about ACP. Johnson et al. (2018) suggest that culturally and contextually relevant educational programs can bridge the knowledge gap and promote greater engagement with ACP. The study's emphasis on improving health literacy resonates with this perspective, highlighting the importance of tailored educational efforts to support informed decision-making.

Systemic and Policy-Level Implications. The theme also touches upon the systemic and policy-level implications of socioeconomic factors and healthcare disparities. The literature points to the need for comprehensive policy interventions that address the root causes of healthcare disparities (Braun et al., 2008). The findings suggest that policies aimed at reducing socioeconomic inequalities, such as expanding Medicaid coverage and increasing funding for community health programs, could improve access to ACP services.

Furthermore, community-based approaches are emphasized as a means to address disparities in healthcare access. Peterson et al. (2019) advocate for community-driven initiatives that provide support and resources directly to underserved populations. The study's findings suggest that such approaches could be effective in enhancing ACP engagement by making services more accessible and culturally appropriate.

Cultural Sensitivity and Tailored Approaches. Finally, the study underscores the importance of cultural sensitivity in addressing healthcare disparities. Research indicates that culturally tailored interventions are more effective in engaging minority populations (Peterson et al., 2019). The findings highlight the need for ACP programs to consider cultural values and preferences, which can influence the acceptance and effectiveness of these services.

In summary, the theme of "Implications of Socioeconomic Factors and Healthcare Disparities for Advanced Care Planning in the African-American Community" aligns with the socioecological model and underscores the complex interplay of economic, educational, and systemic factors in shaping healthcare access and outcomes. The findings emphasize the need for targeted interventions that address financial barriers, improve health literacy, and implement culturally sensitive approaches to enhance engagement with advanced care planning among African Americans. By connecting these findings with existing literature, it becomes clear that a multifaceted strategy is essential for overcoming healthcare disparities and improving ACP outcomes in this population.

Limitations

Several limitations emerged during the study, revealing challenges that impacted the depth and scope of the research. Addressing these limitations is essential for enhancing the study's transparency and guiding future research in the field. The findings related to socioeconomic factors and healthcare disparities may have limited applicability beyond the context of this study. The focus on advanced care planning (ACP) in the African-American community might restrict the generalizability of the results to other demographic groups or healthcare settings. While this focused approach provides valuable insights into the specific challenges faced by this community, it may not fully capture the complexities of ACP issues in other populations or settings.

A significant limitation of the study is the reliance on self-reported data, which may introduce biases such as social desirability or inaccurate recall. Participants' responses about their experiences and perceptions of socioeconomic factors affecting ACP could be influenced by their desire to present themselves in a favorable light. This potential bias affects the accuracy of the findings and suggests that future studies should incorporate multiple data sources or objective measures to validate self-reported information.

The cross-sectional nature of the study imposes temporal limitations. The data were collected at a single point in time, which may not fully capture the evolving nature of socioeconomic factors and healthcare disparities impacting ACP. Longitudinal studies would provide a more dynamic perspective on how these factors influence ACP over time and assess the effectiveness of interventions aimed at addressing these disparities.

The study focused on key socioeconomic factors such as economic barriers and health literacy but did not extensively explore other potentially influential dimensions like housing stability or employment status. These additional factors could significantly impact ACP engagement and outcomes. Future research should consider a broader range of socioeconomic factors to provide a more comprehensive understanding of their effects on ACP.

While the study concentrated on the African-American community, it may not fully address the cultural variability within this group. Different cultural beliefs and practices related to healthcare and ACP could influence engagement in distinct ways. Future studies should examine these cultural nuances to offer more tailored and effective strategies for improving ACP in diverse subgroups within the African-American community.

Researcher bias may have influenced the interpretation of data and findings. The researchers' perspectives could impact how the data were analyzed and presented. To minimize this bias, future research should involve multiple researchers to independently analyze the data and reconcile differences in interpretation. The findings may lack external validation due to the specific context of the study. Validation of the results in different settings or populations would strengthen the findings and offer a broader understanding of how socioeconomic factors and healthcare disparities affect ACP. Further research should aim to replicate the study in varied contexts to confirm the generalizability of the results. In conclusion, while this study provides important insights into the implications of socioeconomic factors and healthcare disparities for ACP in the African-American community, these limitations highlight the need for further research. Addressing these limitations in future studies will help refine the findings and contribute to a more nuanced understanding of how to improve ACP outcomes across diverse populations.

Recommendations for Leaders and Practitioners

Based on the findings of the study regarding the implications of socioeconomic factors and healthcare disparities for advanced care planning (ACP) in the African-American community, several targeted recommendations for leaders and practitioners are proposed. These recommendations aim to address identified challenges and improve ACP outcomes within this community.

Leaders in healthcare and community organizations should prioritize the development and implementation of culturally tailored ACP programs. These programs should be designed to address the specific socioeconomic and cultural barriers faced by the African-American community. Engaging with community leaders and stakeholders to ensure that ACP materials and interventions are culturally relevant and sensitive will enhance their effectiveness. Collaborative efforts with local organizations can provide valuable insights into the unique needs of the community and help in designing more effective ACP strategies.

Practitioners and policymakers should focus on addressing the economic barriers that hinder access to healthcare and ACP services. This includes advocating for policies that expand financial assistance, reduce out-of-pocket costs, and improve access to affordable healthcare services. Additionally, partnerships with local financial assistance programs and community health organizations can help alleviate some of the financial burdens faced by individuals and families. Enhancing access to financial support and resources will enable more individuals to participate in ACP and receive appropriate care.

Efforts to improve health literacy within the African-American community should be a central focus. Leaders and practitioners are encouraged to develop and disseminate educational resources that clarify the benefits and processes of ACP. Workshops, seminars, and community outreach programs that focus on increasing awareness and understanding of ACP can help bridge knowledge gaps. Engaging trusted community figures and healthcare professionals to deliver these educational initiatives will further enhance their impact.

Building and maintaining strong partnerships with community organizations, faith-based groups, and local leaders is crucial for promoting ACP. These partnerships can help facilitate community-based interventions and outreach efforts, ensuring that ACP programs are effectively communicated and implemented. Leaders should seek to collaborate with these groups to leverage their influence and resources, thereby enhancing the reach and acceptance of ACP initiatives.

Advocacy for policy changes at both local and national levels is essential to address systemic healthcare disparities affecting ACP. Leaders should engage in advocacy efforts to influence policy changes that improve access to healthcare services, support preventive care, and address social determinants of health. Participation in policy forums, working with legislators, and supporting initiatives that promote equitable healthcare access are key strategies for driving systemic improvements.

Leaders and practitioners should utilize data-driven approaches to identify and address disparities in ACP. Collecting and analyzing data on ACP participation rates, healthcare outcomes, and socioeconomic factors can provide valuable insights into the effectiveness of interventions and highlight areas for improvement. Implementing evidence-based practices and continuously evaluating program effectiveness will help ensure that ACP initiatives are responsive to community needs.

Investing in the professional development of healthcare providers and community health workers is essential for improving the delivery of ACP services. Training programs that focus on cultural competency, communication skills, and effective engagement strategies will enhance the ability of practitioners to address the specific needs of the African-American community. Continued education and training will ensure that providers are equipped to offer high-quality, culturally sensitive care.

In summary, these recommendations provide a comprehensive framework for leaders and practitioners to address the socioeconomic factors and healthcare disparities impacting ACP in the African-American community. By implementing these strategies, stakeholders can work towards improving ACP outcomes and ensuring equitable access to advanced care planning services for all individuals.

Recommendations for Future Research

Building on the insights gained from this study regarding the implications of socioeconomic factors and healthcare disparities for advanced care planning (ACP) in the African-American community, several key areas for future research are recommended to further explore and address these complex issues.

Future research should evaluate the impact of culturally tailored ACP programs specifically designed for the African-American community. This research could include longitudinal studies to assess changes in ACP uptake and outcomes over time following the implementation of culturally sensitive programs. Such evaluations would provide insights into the effectiveness of these programs and help refine strategies to improve ACP participation and outcomes.

The role of community partnerships in enhancing ACP should be further investigated. Research could focus on how collaborations with community organizations, faith-based groups, and local leaders influence ACP engagement and effectiveness. This could involve qualitative studies to explore the dynamics of these partnerships and their impact on ACP initiatives. This research could provide guidance on fostering effective community collaborations to support ACP efforts.

Future research should assess the effectiveness of recent policy changes aimed at addressing healthcare disparities and their impact on ACP. This could involve evaluating the implementation of policies designed to improve access to healthcare and reduce socioeconomic barriers. A qualitative approach, combining policy analysis with stakeholder interviews, could offer a comprehensive view of how policy changes are influencing ACP practices and outcomes. Such studies could help identify areas for further policy development and advocacy.

Research should explore the effectiveness of various health literacy interventions in improving ACP understanding and participation. This could include experimental studies that test different educational approaches and resources to determine their impact on health literacy and ACP engagement. Future studies could contribute to the development of more effective strategies for enhancing health literacy within the African-American community.

In summary, these recommendations for future research outline specific areas for further exploration, aiming to deepen the understanding of socioeconomic factors and healthcare disparities affecting ACP. By addressing these research gaps, scholars and practitioners can develop more effective strategies and interventions to improve advanced care planning and healthcare outcomes within the African-American community.

Researcher Reflection

Embarking on this research journey into the implications of socioeconomic factors and healthcare disparities for advanced care planning (ACP) in the African-American community has been a profoundly enlightening experience. The exploration into how these factors impact ACP has revealed not only the complexity of healthcare disparities but also the resilience and resourcefulness within the community. Engaging with community members, healthcare providers, and policymakers has offered valuable insights into the multifaceted nature of advanced care planning and the barriers faced by marginalized populations. The findings underscore the urgent need for tailored interventions and culturally sensitive approaches that address the specific needs and challenges of the African-American community.

This research is not merely an academic exercise but a vital endeavor aimed at improving healthcare outcomes and ensuring that advanced care planning becomes accessible and effective for all. The discussions and reflections from participants have highlighted the importance of integrating socioeconomic considerations into healthcare planning and the necessity of fostering strong community partnerships to enhance ACP. As a researcher, this journey has been both challenging and rewarding. It has reinforced the significance of approaching healthcare disparities with empathy and a commitment to creating actionable solutions. The study serves as a reminder of the critical role that research plays in bridging gaps and advocating for equity in healthcare. Moving forward, it is my hope that the insights gained from this research will contribute to meaningful changes and inspire further investigation into the pressing issues of healthcare access and advanced care planning.

Chapter Summary

Chapter 5 concludes this study by addressing the central research question: What are the implications of socioeconomic factors and healthcare disparities for advanced care planning in the African-American community? This question guided a thorough exploration of how these socioeconomic determinants influence advanced care planning (ACP) and identified strategies for addressing disparities in healthcare.

The study's findings, derived from both qualitative interviews with community members and healthcare providers and a comprehensive review of relevant literature, highlight several key themes crucial for advancing ACP in the African-American community. These themes include "Barriers to Advanced Care Planning," "Cultural Competence in Healthcare," "Community Engagement and Education," and "Policy and System-Level Interventions."

The analysis reveals that addressing the barriers to ACP requires a multifaceted approach, incorporating cultural competence and community-specific education. The importance of these factors aligns with the study's emphasis on understanding how socioeconomic challenges and healthcare disparities impact ACP and how they can be mitigated. The findings indicate that enhancing cultural competence among healthcare providers and engaging the community through targeted educational initiatives are essential steps in improving ACP outcomes.

Moreover, the study underscores the need for systemic changes at the policy level to support equitable access to advanced care planning resources. This aligns with the broader literature on healthcare disparities, which emphasizes the role of policy and system-level interventions in addressing inequities and improving healthcare access.

In summary, Chapter 5 summarizes the study's exploration into the complexities of socioeconomic factors and healthcare disparities affecting advanced care planning. It highlights the significance of understanding and addressing these issues through culturally competent care, community engagement, and systemic policy changes. This chapter not only summarizes the research findings but also provides a reflective overview of their implications for improving advanced care planning in the African-American community. The insights gained offer a valuable contribution to the ongoing efforts to enhance healthcare equity and effectiveness.

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Vita

Bartholomew G. Amobi was born in Abakaliki, Ebonyi State, Nigeria, on February 19, 1967, to the family of the Late Chief Samuel Amobi Chidebelu (a.k.a. Okwukammanihu) and the Late Mrs. Victoria Ulunwa Amobi.

He started his elementary school at Azuiyiokwu Urban School two in Abakaliki. Later, he moved to St. Dominic Primary School Adazi-enu, where he completed elementary school. Middle and high school education was at St. Dominic Savio Seminary, Akpu in Orumba South L.GA, and St. John Bosco Seminary Isuaniocha in Akwa South L.G.A, respectively. He graduated from High School in 1988 with honors.

In October 1989, he entered Seat of Wisdom Seminary, Owerri Imo-State, and in June 1993, he received a Bachelor’s in Philosophy (B.Phil., Magna Cum Laude).

In 1994, he joined Seat of Wisdom Major Seminary, Owerri, for Theological Studies. He received a Master of Divinity (M. Div. Magna Cum Laude) in 1998.

Appendix A. Informed Consent

Summary and key information:

You are invited to participate in a research study by a Medical Humanities Program doctoral student solely for educational purposes. This study concerns African Americans' underutilization of Advanced Care Planning and hospice care. Your participation is voluntary. You were selected as a possible participant because you are an African American and reside in the communities of Union County, New Jersey.

The purpose of this study is about end-of-life decision-making and who would make medical decisions for you if you were very sick and unable to speak for yourself. The research explores advanced care planning in end-of-life care among African Americans. The research will last till March 2024. As part of the study, the researcher will conduct interview sessions with participants (African Americans) in Union County communities of New Jersey.

1. The study is being conducted by Bartholomew. G. Amobi, a doctoral candidate at Drew **University School of Medical Humanities** under the supervision of Dr. Merel Visse, Program Director, and the dissertation readers Dr. Gaetana Kopchinsky and Dr. A. Pressley. We ask that you read this document and ask any questions you may have before agreeing to be in the study. The benefits of the research outline potential historical, social, cultural, ethical, economic, legal, health policy, and medical issues that appear to contribute to African Americans' attitudes toward advanced care planning and hospice care (Crawley et al., 2000).

The risks are possible emotional triggers participants may experience in recalling and narrating their stories, especially if any of their loved ones or relatives had been victims of medical malpractice or mistrust.

2. BACKGROUND: The purpose of this study is to focus on African Americans attitudes towards end-of-life care, especially engagement in Advanced Care Planning,

3. DURATION: The length of time you will be involved with this study is estimated to be a portion of a day at 30 to 45 minutes.

4. PROCEDURES: If you agree to participate in this study, we will ask you to do the following things: complete the attached demographic summary. Please read and sign this **Informed Consent** and present it to the researcher during the interview.

The interview will consist of several questions about your attitudes and underutilization of advanced care planning at the end of life and your feelings towards hospice care. You may end your participation at any time without consequences or penalty. Information collected during your interview should be destroyed if you choose to withdraw. If you experience emotional or psychological pain from narrating your experiences, use the Pause Reset-Nourish fact sheet.

5. RISKS/BENEFITS: If you have experienced medical mistrust in the past and if sharing your narratives and participating in this study causes you emotional pain, you are free to withdraw. The benefit of this research is to explore ways to increase the enrollment of African Americans in the end-of-life and intensify their willingness to use hospice care. The participants will be allowed to think about who will speak for them if they become sick and unable to speak for themselves. The participants will also learn some potential problems that can occur if they do not have designated spokespersons.

6. CONFIDENTIALITY: The study records are confidential; neither your name nor other identity information will be used. The interviewer/researcher will always preserve your confidentiality, including how records of your participation and data will be stored on a password-protected external drive. The interviewer/researcher will have sole access to the collected data. Once the interviews have been transcribed, audio and media data collected will be destroyed. When the data are published or presented, no information that would directly or indirectly identify you as a participant will be shared.

7. VOLUNTARY NATURE OF THE STUDY: Your decision to participate in this research will not affect your current or future relations with Drew University. If you decide to participate in this study, you are free to withdraw from the study at any time without affecting those relationships and without penalty. Notes, recordings, or data collected from your interview will be destroyed should you choose to withdraw.

8. CONTACTS AND QUESTIONS: The researcher conducting this study is Bartholomew G. Amobi. You may ask any questions you have right now, or later, you may contact the researcher at 585-285-1823 or bamobi@drew.edu. If you have questions or concerns regarding this study and want to speak with someone other than the researcher, you may contact the Chair of the Institutional Review Board (IRB), Alex de Voogt, PhD, at adevoogt@drew.edu.

9. STATEMENT OF CONSENT: Please verify the following: The procedures of this study have been explained to me, and my questions have been addressed. I understand that my participation is voluntary and that I may withdraw at any time without penalty. If I have any concerns about my experience in this study (e.g., if I was mistreated or felt unnecessarily threatened), I may contact the Chair of the Institutional Review Board (IRB), Alex de Voogt, PhD, at adevoogt@drew.edu.

Participant signature____ Date_____________

Appendix B. Debriefing Form

Thank you for taking the time to participate in the present study.

In this study, I am going to investigate the attitudes and why African Americans underutilize hospice and end-of-life care, especially Advanced Care Planning. African Americans have lower hospice use than Caucasians.

In this study, you were asked to answer all questions on attitudes, beliefs, and preferences contributing to the underutilization of advanced care planning and end–of–life care services among African Americans. The procedure is straightforward with no deceptions, and you need to offer your opinion about advanced care planning in African-American communities. This study is anonymous and confidential.

The study enables participants to objectively represent African Americans within Union County, New Jersey, and beyond, explaining the pros and cons of using advanced care planning at the end of life. In this way, participants of a minority extraction will lend their voices in shaping the narrative surrounding end-of-life disparities.

For more information on this research topic, If you want to learn more about Advanced Care Planning among African Americans, you may contact the Hospice-Palliative –Care Hotline at 1-800-HOSPICE (800-467-7423) and 1 800-HOSPICE website (https://www.1800hospice .com. There is no risk associated with this study. If you feel you need to speak to a counselor concerning any uncomfortable feelings arising as a result of your participation in the research, please get in touch with the chaplaincy hotline 202 715 6616.

If you are interested in learning more about the research being conducted or the result of the study of which you were part, please do not hesitate to contact the principal investigator, Bartholomew Amobi, via email (bamobi@drew.edu) or Phone (585-285-1823**) and the Chair of the Institutional Review Board (IRB), Alex de Voogt, PhD, (adevoogt@drew.edu).**

Thank you for your help and participation in this study.

Appendix C. Human Participants Research Review Form

1. Project Title: **African Americans Attitudes toward End-of-Life Care, specifically Engagement in Advanced Care Planning: Intervention in the African Americans Communities of Union County, New Jersey, U.S.A.**

2. Principal Investigator(s): **Bartholomew. G. Amobi**

3. If student research, the names of faculty sponsors are **Dr. G. Kopchinsky** and **Dr. A. Pressley.**

4. Name of anyone else involved in the study administration/data collection: **No one else**

5. Email address of Principal Investigator(s): **bamobi@drew.edu**

6. Duration of the Project (approximate starting date and completion date of data collection**): March 2024 to April 2024.**

7. Describe how the requirement to obtain training in the responsible conduct of research involving human subjects was met:

8. Review the types of research listed on the IRB website. Check the box for the type of research you believe you are conducting.

☐ Exempt from further review

☐X Expedited

☐ Full Review

9. Electronic Signature(s):

Principal Investigator: Bartholomew. G. Amobi Date: 03/20/2024

Faculty Supervisor: __________________________ Date: ____________

Complete Questions on the following Page*

Revised December 2018.

10. Provide a brief description of the purpose and goals of the proposed research, including in what form the research is potentially to be published (e.g. thesis, dissertation, article, and book).

This research examines the African American attitude toward end-of-life, with a unique concentration on their engagement in advanced care planning. African Americans have lower hospice use than Caucasians (Ludke et al., 2007). “African Americans represent 8% of individuals who participate in end–of–life care, as compared with 83% white" (Crawley et al., 2000). African Americans have been found to complete advanced directives and enroll in hospice less often than their white counterparts (Rhodes et al., 2017). African American patients prefer more aggressive treatment than Caucasians… because of their lower use of do-not-resuscitate (DNR) orders, higher preference for cardiopulmonary resuscitation (CPR) and feeding tubes, and a lower likelihood of withdrawal of life-sustaining therapy(Braun et al., 2008).

This research will focus on finding how the African Americans in Union County, North Jersey, appreciate and prepare for end-of-life and their utilization of advance care planning. What attitudes do they display toward end-of-life care? What measures should be applied to improve their understanding?

Ultimately, the research findings will greatly assist African Americans in New Jersey and beyond. The findings will be published in a dissertation form.

11. Describe your participants. Indicate the total number of participants and whether any of the participants will be minors or will be from other protected populations (e.g., those whose decision-making ability is impaired or compromised in any way, prisoners, etc.).

The participants will consist of eighteen (18) years old and above African American population residing in Union County, New Jersey. The participants include African Americans who are alert, verbal, and able to read and write. All participants will be able to make decisions for themselves.

No minors will be admitted to the research, and no participant will be a minor. The research will not involve individuals with impaired decision-making ability or dementia.

The participants' demographics of age, education, religion, income, employment, health status, and marital status as declared by the individuals will be studied. This will offer African Americans a comprehensive perspective and attitudes toward advanced care planning.

I will select ten (10) participants from Union County, N.J., through purposive sampling. The rationale for purposive sampling is that participants typically represent diverse perspectives and can provide in-depth and detailed information about the information under investigation (Leedy et al., 2016).

12. How will participants be recruited (via a message, an advertisement, a phone call, or face-to-face)? Are there any specific selection criteria? Will participants be compensated in any way for their participation? How will you ensure that participants do not feel coerced to participate?

Participants will be recruited through face-to-face meetings. I will travel to houses of worship and secular events in Union County, New Jersey, where African Americans gathered. The participants for this study will be recruited and sampled. The participants will involve ten (10) persons. The selection criteria will be through non-probability purposive sampling. The researcher chooses the participants and follows- up with them through phone calls.

The participants will not be offered compensation in any way and may withdraw from the project at any time if they wish.

13. How will you obtain consent from participants (or legal guardians if minors are involved)?

The participant will be presented with an informed consent letter, which will be explained by the interviewer (See Appendix A). Additionally, the participants will explain and complete a form to gather demographic information from participants for statistical purposes. No minors will be involved in this research project. The researcher will not interview any minor in the study.

14. Describe the study's procedures and all activities participants will be asked to perform. Remember that copies of ALL materials should be submitted as part of this completed form.

The researcher will conduct an in-depth interview with each of the participants. The interview questions are in the format (table 1). The interview questions related to the participant's experience and understanding of advanced care planning at the end of life and their attitudes (mindset, feelings, and thinking) towards hospice care. The interviews will be audio-recorded, transcribed, analyzed, and reviewed. In addition, the insights of the interviews will be continued and deepened by follow-up exchange by email and a demographic questionnaire (Table 1.)

15. Where will this research be conducted?

The researcher will travel to Union County, New Jersey, and the interview will be conducted in the African-American communities of Union County, New Jersey. The interview will be in person so the researcher can communicate face-to-face with the participants. The researcher will visit Methodist, Baptist, and other Christian churches and non-faith-based organizations where African Americans congregate in great numbers. The interviewer will visit religious houses, secular institutions, and facilities in Union County, New Jersey.

16. Are any aspects of your research kept secret from participants? If yes, indicate what will be hidden and why it is necessary to hide this information.

No parts of the research will be kept secret. The interviews will be audio-recorded, transcribed, analyzed, and reviewed (member-checked) by the participants for trustworthiness and presented in the results section. **Information collected during your interview should be destroyed after transcription.**

17. Describe any potential benefits of your research to participants and society.

African Americans are less likely to engage in ACP than other ethnicities. The benefits of the research to participants or society are numerous. It will outline potential historical, social, cultural, ethical, economic, legal, health policy, and medical issues that affect African Americans' attitudes toward advanced care planning and hospice. (Crawley et al., 2000).

The study will unload the reasons behind the reluctance and potential interventions to utilize advanced care planning and other end-of-life resources among African Americans.

18. Consider the risks that your study may pose to participants, including physical, psychological, social, economic, or other types of risks or harms. Explain these risks even if minimal or routine to daily life.

Participants may experience emotional and psychological pain in recalling and narrating their stories, especially if any of their loved ones or relatives had died in the past due to suspected medical malpractice. They can withdraw at any time, even after providing verbal consent. Participants will be provided with a phone number for the counselor or clinical chaplaincy hotline if uncomfortable feelings arise from participating in the research. At any rate, a well-being and wellness debriefing sheet will be provided with exercises, steps for emotional rebalancing, and contact numbers for immediate help, if needed. The study has no economic or social risks or harms.

19. If applicable, explain the procedures that you will use to minimize the risks to participants that you identified in your answer to question 18.

The interviewer will monitor the participants' emotional and comfort levels during the interview. As stated in the informed consent, participants can stop or withdraw from the project if they are experiencing emotional triggers.

20. Discuss the procedures you will utilize to protect the anonymity or confidentiality of your participants and your data.

The interviewer will use pseudonyms (such as Participant A) when recording or publishing data. It is imperative to protect the participant if the published data includes other identifiers such as age, gender, clinical or community affiliations. The names of the participants will not be indicated.

21. For the majority of research projects, participants should be provided with a debriefing form that contains further information about the study and contact information for the principal investigator(s). Will you provide a debriefing form? If not, indicate why.

A debriefing form is attached. The interviewer's and committee chairperson's email addresses are provided in the informed consent form. The contact phone numbers for the interviewer and the committee chairperson will be provided at the end of the interviews.

Appendix D. Questionnaire

Interview Questions

1. Imagine you are conversing about planning for your end-of-life care. Do you believe it is essential for individuals to openly share the medical treatments they would like to receive or refuse at that stage of life? Why or why not?
2. Picture a scenario where you might be unable to communicate your end-of-life preferences, values, and wishes. Would you feel compelled or interested in creating a comprehensive plan for your future medical treatments in such a situation? What factors would influence your decision?
3. What issues would be important to you if you were facing end-of-life issues? Moreover, why do you think they are essential?
4. How would you feel about end-of-life medical decisions for another person? And what drives your feelings and perspectives?

Demographic Questionnaire

Introduction: Please take a moment to complete the following demographic questionnaire. Your responses will remain confidential and are crucial for the research study's analysis. This information will help us understand our participants' diverse backgrounds and life situations. If you are uncomfortable with any question, you may choose not to answer.

Section 1: General Information

1. **Age:**
    - ○ ___ Under 18
    - ○ ___ 18-24
    - ○ ___ 25-34

- ___ 35-44
- ___ 45-54
- ___ 55-64
- ___ 65+

2. **Education Level (Highest degree or level of school you have completed):**
   - ___ Some high school
   - ---- No diploma
   - ___ High school graduate, diploma or the equivalent (for example GED)
   - ___ Some college credit
   - ------ No degree
   - ___ Trade/technical.
   - -----Vocational training
   - ___ Associate degree
   - ___ Bachelor’s degree
   - ___ Master’s degree
   - ___ Professional degree
   - ___ Doctorate
3. **Religion (Please specify your religious affiliation or mark 'None' if applicable):**
   - ___ Christianity
   - ___ Islam
   - ___ Hinduism
   - ___ Buddhism
   - ___ Judaism

   - ___ Sikhism
   - ___ Other (Please specify): ____________
   - ___ None
   - ___ Prefer not to say

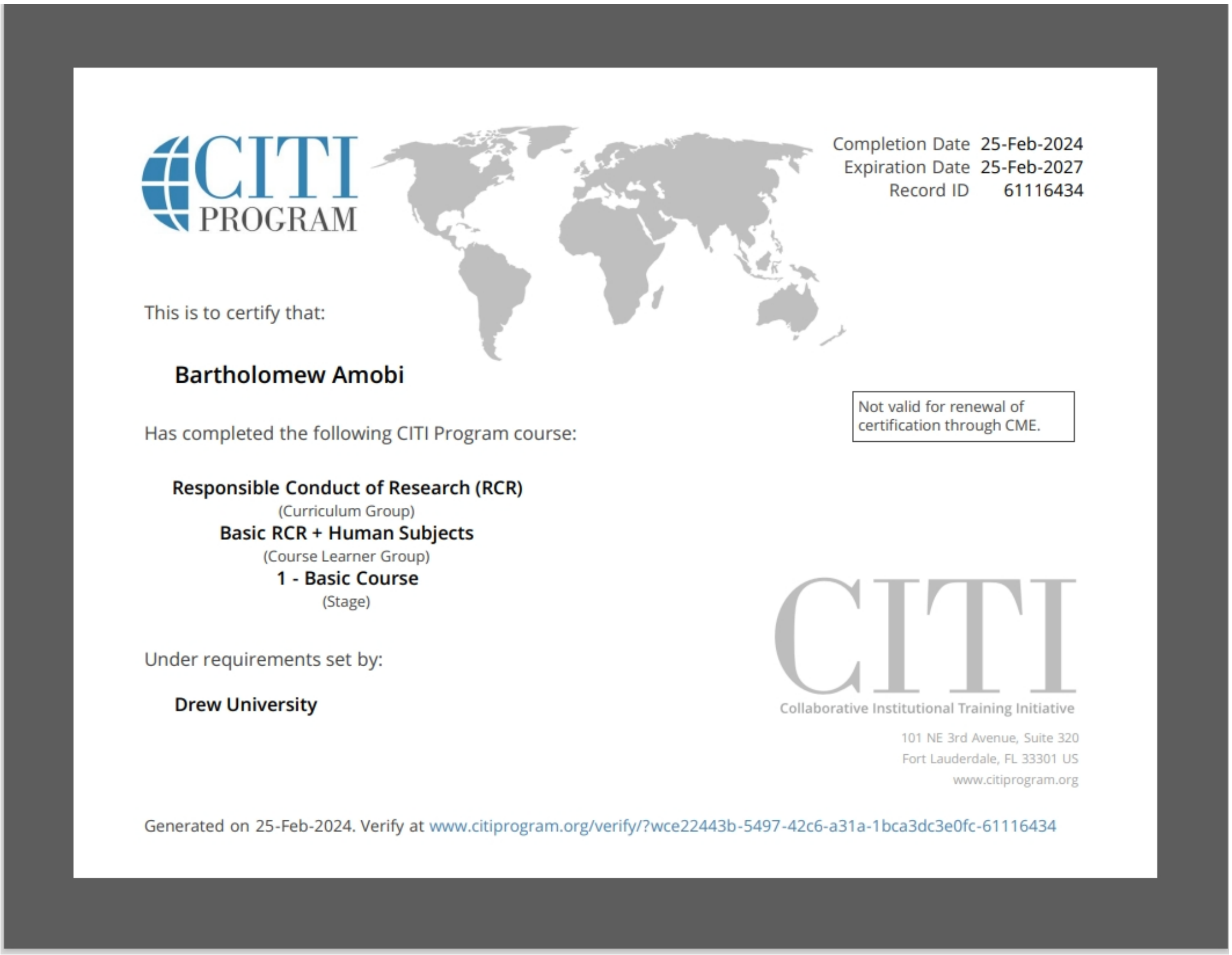
4. **Annual Household Income (Please select the range that best describes your total annual household income before taxes):**
   - ___ Less than $25,000
   - ___ $25,000 to $49,999
   - ___ $50,000 to $74,999
   - ___ $75,000 to $99,999
   - ___ $100,000 to $149,999
   - ___ $150,000 to $199,999
   - ___ $200,000 and above
   - ___ Prefer not to say
5. **Employment Status (Please select the option that best describes your current employment status):**
   - ___ Employed, working full-time
   - ___ Employed, working part-time
   - ___ Unemployed, currently looking for work
   - ___ Unemployed, not currently looking for work
   - ___ Self-employed
   - ___ Retired
   - ___ Student

  - ○ ___ Unable to work
  - ○ ___ Prefer not to say

6. **Health Status (How would you describe your current health status?):**
   - ○ ___ Excellent
   - ○ ___ Very good
   - ○ ___ Good
   - ○ ___ Fair
   - ○ ___ Poor
   - ○ ___ Prefer not to say
7. **Marital Status (Please select the status that best describes your current marital situation):**
   - ○ ___ Single, never married
   - ○ ___ Married or domestic partnership
   - ○ ___ Separated
   - ○ ___ Divorced
   - ○ ___ Widowed
   - ○ ___ Prefer not to say

Conclusion: Thank you for completing this demographic questionnaire. Your responses are invaluable to this study. If you have any concerns or questions about this questionnaire or the study, please do not hesitate to contact the researcher.

Appendix E. CITI Certification



Completion Date 25-Feb-2024
Expiration Date 25-Feb-2027
Record ID 61116434

This is to certify that:

Bartholomew Amobi

Has completed the following CITI Program course:

Not valid for renewal of certification through CME.

Responsible Conduct of Research (RCR)
(Curriculum Group)
Basic RCR + Human Subjects
(Course Learner Group)
1 - Basic Course
(Stage)

Under requirements set by:

Drew University

CITI
Collaborative Institutional Training Initiative

101 NE 3rd Avenue, Suite 320
Fort Lauderdale, FL 33301 US
www.citiprogram.org

Generated on 25-Feb-2024. Verify at www.citiprogram.org/verify/?wce22443b-5497-42c6-a31a-1bca3dc3e0fc-61116434

March 25, 2024

Dear Bartholomew Amobi,

The Institutional Review Board has conducted a review of your research for the project entitled “African American Attitudes toward End-of-Life Care”. The IRB has approved your research project and determined it is exempt from further review. Please note, if you make any modifications to your research, you will need to obtain IRB approval for those changes.

Best of luck with your research!

Sincerely,

Alex de Voogt

IRB Chair