

THE INTERSECTIONAL IMPACT OF RACE AND GENDER ON QUALITY OF LIFE AT
THE END OF LIFE

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A DISSERTATION

Submitted in partial fulfillment of the requirements

for the degree of Doctor of Philosophy

in the School of Social Work

in the Graduate School of

The University of Alabama

TUSCALOOSA, ALABAMA

2022

ABSTRACT

Racial and gender disparities at the end of life have been well-studied in the literature, but few studies have considered the impact of intersectionality on end-of-life outcomes. This study examined the intersectional impact of race and gender on eight indicators of quality of life at the end of life; hospice care, pain, anxiety/depression, dying alone, religious belief discussions, treatment with respect, having decisions made without the patient's input, and overall care rating.

In this study, data were derived from the combined 2013 (Round 3) to 2020 (Round 10) National Health and Aging Trends Study (NHATS). Chi-square tests were used for bivariate analyses, and two multivariate logistic regressions were used to assess the impact of race and gender on quality of life at the end of life. Model 1 included the main effects of race and gender, while Model 2 included the interaction term for race/gender.

The interaction models for all dependent variables were significant, except for the "treated with respect" variable. Regarding the gender effects of race, White women and Black women had worse outcomes compared to their male peers. For the race effects of gender, Black men and Black women had worse outcomes compared to their White peers. Black women had the worse outcomes for both race and gender effects, thus confirming the theory of intersectionality. Provider cultural humility training, early intervention, and culturally sensitive patient education may help in mitigating these disparities. Future research should consider primary data collection and include qualitative accounts to guide targeted interventions.

DEDICATION

This dissertation is dedicated to the person who gave me the opportunity to move to the United States, complete this Ph.D., and pursue my dream of being an educator for life. Danbaba Danfulani Suntai, you are my hero, my role model, and the best father I could have ever asked for. Though you are no longer here with me, you shall live in my heart forever, and I miss you every single day. This dissertation is inspired by you, for you, and because of you. I hope I have made you proud. Thank you for everything.

GLOSSARY

End of Life: The 12-month period before death

End-of-Life Care: The support and care provided to a person who is at the end of life

Palliative Care: Specialized medical care for people with serious illnesses, focused on pain and symptom management. Palliative care can be received at any stage of the disease trajectory, not just at the end of life.

Hospice Care: Hospice care provides physical, emotional, and spiritual support to individuals who are at the end of life. Under the Medicare Hospice Benefits which is the largest payer of hospice care services, the eligibility for hospice care includes a prognosis of around six months.

Critical Race Theory: Based on the core idea that race is a social construct, the critical race theory encourages the consideration of historical context to understand the relationship between race, power, and class in the United States

Intersectionality: Stemming from the critical race theory, the theory of intersectionality suggests that memberships in multiple vulnerable groups may result in increased hardships and stressors across the lifespan

ACKNOWLEDGEMENTS

Completing this dissertation has been one of the most challenging experiences of my life, an experience that tested my mental health beyond compare. As such, it would be inaccurate to say that I did this by myself, because I truly would not be at this stage without so many people around the world. First, I am eternally grateful and lucky to have had Dr. Hyunjin Noh as my dissertation chair and advisor. It wasn't just Dr. Noh's expertise in the field of palliative and end-of-life care that aided me, it was her compassion as a mentor that allowed me to overcome the challenges that I faced along the way. So many tears were shed during this process, and Dr. Noh was always there to listen and come up with a plan to make sure everything would be okay in the end. Thank you so much, Dr. Noh. Second, I would like to thank my dissertation co-chair, Dr. Lewis Lee, who took time out of his numerous responsibilities to make sure that my dissertation was accurately completed. Thank you so much, Dr. Lee. Third, I want to thank the remaining members of my committee, Dr. Hee Lee, Dr. Bell, and Dr. Lippe, who are all distinguished members of the scientific communities within their fields and yet, found the time to guide me throughout the dissertation process. I am so thankful for each one of you. Finally, I want to extend my love and appreciation to my family back home in Nigeria, and to the entire village of Suntai. This one is for all of us.

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INTRODUCTION

According to the National Council on Aging (2018), 80% of older adults (65 and older) in the United States have at least one chronic illness and 77% have at least two. Consequently, chronic illnesses are the leading causes of death among individuals aged 65 and older (Xu et al., 2020). Despite burgeoning advances in medical care, the impact of chronic illness on quality of life at the end of life has remained a dire area of focus in the field of palliative and end-of-life care (Rome et al., 2011). End-of-life care refers to the medical care and support provided in the last few months of life, typically around 12 months or less before death (National Institute on Aging [NIA], 2017). These include physical, psychological, social, and spiritual factors that undoubtedly moderate the experience of an older adult in the last months of life (LML; Neimeyer et al., 2011; Vazquez & Santone, 2011). Quality of life itself is an abstract concept that generally refers to an individual's perception of satisfaction with life domains such as health, social status, and overall well-being (World Health Organization [WHO], 2021). It specifically relates to personal satisfaction with end-of-life outcomes that reflect the person's preferences, values, and goals (Roscoe & Stockmen, 2010).

End-of-life care focuses primarily on improving the quality of life in the final moments of life, by providing supportive services in the aforementioned areas, through avenues like pain management, spiritual counseling, emotional support, comfort care, and other key areas of need for dying individuals (NIA, 2017). As end-of-life care has been acknowledged to be critical to the quality of life for individuals with chronic illnesses, the major barrier remains that of

accessibility to appropriate and quality care (Orlovic et al., 2018). Black individuals have historically experienced systemic injustices that have negatively influenced their health outcomes, including but not limited to the morbidity of chronic diseases, lack of access to quality health care, and interpersonal discrimination/stigma from medical providers (Johnson, 2013). While research in this area has proliferated over the past few decades, there is still an essential need to explore how intersectional identities impact the quality of life at the end of life among older adults living in the United States.

Rationale

In the 1948 Universal Declaration of Human Rights, the United Nations (UN) lists access to medical care, necessary social services, and overall health and well-being as basic human rights that should be accessible to all individuals (UN, 1948). More recently, the most updated Sustainable Development Goals from the UN prioritize the health and well-being of all individuals as its third aim (UN, 2018). These include equitable access to health care services, improving preventative/primary care, and achieving universal health coverage in all countries (UN, 2018). While health and well-being are universally recognized as priority areas, socioeconomic inequities create vast differences in the availability of quality care for individuals around the world as well as in the United States (U.S.; Baciu et al., 2017). Although the U.S. is one of the most developed countries in the world, many individuals are still unable to access health care, including those who are uninsured or underinsured and those who are undocumented (Kirzinger et al., 2020). About 9.2% of the U.S population is estimated to be uninsured, and the proportion of uninsured residents is as high as 18.4% in some states (Kaiser Family Foundation, 2020). Even among those who do have access to health insurance, differences exist in the quality of medical care available and the ease of access to care (Spencer et al., 2013). Similarly, there

are differences in the types of services covered under various insurance plans and the number of co-pays required, which may leave some individuals with out-of-pocket expenses that may not be affordable (Kirzinger et al., 2020). Although initiatives such as the Affordable Care Act have been enacted to address the toll of medical care, research shows that 58.5% of Americans who file for bankruptcy cite medical expenses as a contributor (Himmelstein et al., 2019).

While systemic/structural factors play a significant role in the quality of care among individuals with chronic illnesses, interpersonal interactions with providers and personal preferences also affect health outcomes (Hall et al., 2015). For example, Howe and colleagues (2019) identified that both patient perception of a provider's knowledge and skill, and their perception of a provider's warmth, engagement, connection, and care can boost health outcomes. The experience of interpersonal discrimination has also been found to adversely influence mental and physical health outcomes, including higher rates of psychological distress, anxiety, depression, hypertension, diabetes, cardiovascular disease, and poor self-rated health (Richman et al., 2018). Apart from the potential bias and prejudice from providers, the personal preferences of patients can also affect health outcomes. For instance, prior studies have found that Black older adults prefer providers that are of the same race, and when that is not possible, they prefer providers that make an effort to understand their culture, while also respecting their individuality (Hansen et al., 2016; Meghani et al., 2009). Research on the provider-patient concordance also shows that having a provider of the same race can indeed improve health outcomes (Meghani et al., 2009). Thus, in considering the interpersonal impact of care, it is important to consider both the influence of patient preferences/cultural background, as well as the provider's background.

Given the influence of both systemic/structural and interpersonal factors on health outcomes, the purpose of this study was to explore the intersectional impact of race and gender on quality of life at the end of life among older adults.

Relevance to Social Work

Central to social work is the value of social justice and the ethical principle that “social workers challenge social injustice” (National Association of Social Workers [NASW], 2008, para. 3). This pursuit of social change is particularly attributed to vulnerable and oppressed populations, groups of people that may otherwise be voiceless, underserved, and unrecognized. Black individuals in older adulthood, for example, are at risk of having adverse experiences and are in a state of “double jeopardy,” by being members of two vulnerable and discriminated groups due to their race and age (Bellizzi et al., 2012). As a result of these intersecting identities, older Black adults are afflicted with multiple stressors related to their age, related to their race, as well as other intersecting identities such as gender (Williams, 2018). While the social climate in the United States (U.S.) has changed significantly in the last few decades, many older adults in their 60s and above lived through traumatic times where the integrity of Blacks was exploited through avenues like the Tuskegee Study of Untreated Syphilis in the Negro Male, which has created distrust in the health care and legal systems (Scharff et al., 2010). The impact of these trying times remains evident today through structural, systemic, and interpersonal racism that creates persistent racial disparities in the availability, accessibility, and quality of health care among older adults.

Social workers in medical settings often work with families from diagnosis to the end of life. In the United States, 36% of masters-level social workers practice in medical settings, and although the characteristics of patients in those settings are diverse, 72% of masters-level social

workers in the United States are White (Salsberg et al., 2017). The disproportionate racial distribution of social workers to clients could result in adverse outcomes that may include cultural miscommunication, stigma toward clients based on stereotypes, and mistrust in the social worker from the client's perspective (Loya, 2012). As such, social workers of all backgrounds are expected to engage in educational initiatives that increase their understanding of diverse populations and cultural humility. The Council on Social Work Education (CSWE) lists the engagement of diversity and difference in practice as its second competency for accreditation standards (CSWE, 2008), thus highlighting the impact of diverse identities on the human experience. Due to this accreditation standard, most social work programs have at least one diversity-related class, but cultural humility requires lifelong learning (Loya, 2011).

One recommendation from the NASW (2015) is the engagement in continuous self-education beyond the classroom as a practitioner working with diverse populations, by consuming research and creating targeted service-delivery systems for clients, which is known as evidence-based practice (Rubin & Babbie, 2016). Researchers contribute to this initiative by describing, explaining, and predicting racial differences across multiple social and health outcomes. This, in turn, helps practitioners understand the needs and preferences of racially and culturally diverse clients (Rubin & Babbie, 2016). Disparities persist throughout the healthcare spectrum, and toward the end of the spectrum lies end-of-life care. With an increasingly aging and diverse population, research focused on end-of-life outcomes among diverse populations has been on an incline, aiming to improve the quality of life of dying patients and their families (Aziz et al., 2012; Johnson, 2013; Mather et al., 2019). While several studies have examined racial disparities at the end of life (Johnson, 2013), the impact of intersectional identities such as race and gender has not been well-studied. This study aimed to fill the gap in the literature by

examining the intersectional impact of race and gender on eight indicators of quality of life at the end of life, guided by the National Consensus Project (NCP) and the National Coalition for Hospice and Palliative Care (NCHPC). Specifically, this study examined the intersectional impact of race and gender on the following outcomes: being alone at death, hospice care at the end of life, the experience of pain at the end of life, depression, and anxiety at the end of life, decision-making involvement at the end of life, being treated with respect at the end of life, engaging in desired religious/spiritual discussions at the end of life, and overall care rating at the end of life. Notably, the study focused specifically on the cis-gendered experience due to limitations in secondary data.

Format

This study is in the form of a traditional monograph dissertation and is divided into five chapters: 1) Chapter 1 is an overall introduction to the dissertation, 2) Chapter 2 provides a detailed review of the existing literature, 3) Chapter 3 details the methods section of the dissertation, 4) Chapter 4 presents the results of the data analyses and 5) Chapter 5 provides a discussion of the results, implications, limitations, and overall conclusions.

LITERATURE REVIEW

Racial Disparities in Health Outcomes

Racial disparities in the prevalence of health problems and provision of health care in the United States are well-documented in the literature. While the health of Black and White persons has improved significantly throughout the 21st century, Black individuals persistently have higher rates of morbidity and mortality than their White peers (Crowley, 2010). These disparities exist at the organizational, structural, and clinical levels, ranging from the type of health insurance available to the one-on-one clinical encounter with a healthcare provider (Orsi et al., 2010). In a study analyzing the survival rates from cancer in the United States, Singh and Jemal (2017) found that mortality from cancer was higher among Black individuals and people from more deprived neighborhoods. Blacks have also been found to have a higher prevalence of diabetes (Heidemann et al., 2016) and higher rates of heart disease (Benjamins et al., 2017). In addition to these health outcomes, they are also more likely to go undiagnosed and untreated, and more likely to have a lower quality of treatment for their chronic illnesses (Frankenfield et al., 2020).

Gender Disparities in Health Outcomes

The historical placement of women over the span of time has resulted in vast disparities in health outcomes and health care access. Stemming from the classic role of women as homemakers, women have lagged behind men in acquiring wealth and having socioeconomic capital, which largely influences access to health care (Braveman & Gottlieb, 2014; Ortiz-Ospina & Roser, 2018). For example, Cameron and colleagues (2010) examined differences in health

outcomes and healthcare access among men and women in the Health and Retirement Study. They found that women had greater health needs than men, but were less likely to have hospital stays, and were less likely to engage in primary/preventative care compared to men, despite controlling for health insurance. Notably, women in the study also had fewer economic resources than men (Cameron et al., 2010). Similarly, Thakral and associates (2019) explored gender differences in health outcomes for individuals with long-term disabilities, finding that women reported more fatigue, more pain, and higher depressive symptoms compared to men. These disparities have also been noted in other countries, with findings showing that women in India have lower health-care expenditures than men (Saikia, 2019).

Intersectional Disparities in Health Outcomes

The importance of considering the intersectional impact on health outcomes is evident within the literature, with multiple studies including interaction terms that account for multiple identities/characteristics. Manuel (2018) for example, explored the intersectional impact of race and gender on health care access over time among adults aged 18 and older. The author discovered that Asian men had the greatest increase in health care access during the study period, while Black men and Black women experienced the least gains in health care access (Manuel, 2018). Hsieh and Ruther (2016) also used an intersectional approach to examine how race, gender, and sexual orientation affect self-rated health and functional limitations. They found that all intersectional groups except straight White women, gay White men, and bisexual non-White men were more likely to report worse self-rated health compared to White men. Additionally, all women in the study (regardless of race or gender) and non-White gay men were more likely to report having functional limitations compared to straight White men (Hsieh & Ruther, 2016).

Other studies indicate that membership in multiple minority groups may result in worse health outcomes (Assari, 2018; Budge et al., 2016).

Quality of Life at the End of Life

Quality of life, like many other concepts in the social sciences, is an abstract construct lacking uniformity in definition. Generally, quality of life refers to an individual's subjective perception of satisfaction with life domains, which may include physical, financial, psychological, social, and cognitive aspects of life (WHO, 2021). The challenge of measuring and defining quality of life also exists in end-of-life care, but prior studies have tried to determine the domains or aspects of end-of-life care that represent the quality of life at the end of life (Mistry et al., 2015; Zhang et al., 2012). Although variations exist across studies, some general themes are common across multiple research articles. The following paragraphs will provide evidence for why the eight dependent variables within this study are indicative of the quality of life at the end of life.

Hospice Care

The provider's role in the quality of life at the end of life is critical, as several studies have identified that how providers treat patients can greatly affect health outcomes (Cvengros et al., 2009). Research suggests that end-of-life care teams are more effective when they include individuals from different professions, each playing a critical role, while also coming together as an interdisciplinary team (Albers et al., 2018; Sagha Zadeh et al., 2018). Hospice care is designed with this standard in mind, typically including an interdisciplinary team of physicians, nurses, social workers, and religious professionals to address the physical, psychosocial, emotional, and spiritual needs of terminally ill patients and their families (Wittenberg-Lyles et al., 2010). Receipt of hospice care is often considered to be an indicator of the quality of life at

the end of life because the individual would have access to the specialized, quality care that is specifically designed to serve dying individuals and their families (Zhang et al., 2012). Research shows that individuals who receive hospice care are generally more likely to have positive end-of-life outcomes, including greater life expectancy, being free of pain, feeling content, and having psychosocial/emotional/spiritual support (Eichelberger & Shadiack, 2018; Kiely et al., 2010; Wajid et al., 2021; Zhang et al., 2012). Additionally, prior research shows that the family-rated quality of end-of-life care is higher for patients who received hospice care than for those who did not (Richards et al., 2019).

Pain at the end of Life

Pain is an often-subjective concept that can be dependent on the severity of an illness, access to pain management services, and a number of other factors (Hagarty et al., 2020). Pain is a common factor across most quality-of-life scales within end-of-life care measured as an indicator of the quality of life. This remains true regardless of the country in which the scale originated (Davis & Hui, 2017). In studies aiming to determine the preferences and wishes of dying individuals, researchers have also found that not being in pain is an important aspect of quality-of-life for patients (Sandsdalen et al., 2015; Waller et al., 2020; Winter, 2013). Additionally, studies show that experiencing pain can result in a number of adverse outcomes, including anxiety, substance use, and depression (Rosenstein, 2011; Starr et al., 2010; Woo, 2010). The experience of pain at the end of life has also been linked to suicide and the desire for hastened death among cancer patients (Rosenstein, 2011). The suffering from pain among individuals with chronic illnesses is also one of the factors that advocates of physician-assisted death present, arguing that such suffering diminishes the quality of life (Ahlzen, 2020).

Mental Health at the end of Life

Mental well-being at the end of life has been explored as an indicator of the quality of life among dying individuals. Similar to pain, most scales addressing quality of life at the end of life use one or more measures of mental well-being, often measuring anxiety and/or depression at the end of life (Davis & Hui, 2017). Research shows that not only do dying individuals experience sadness and anxiety in relation to their approaching death, but they also often experience a feeling of grief (Widera & Block, 2012). The grief experienced at the end of life may be attributed to the multitude of losses that occur in the final months of life, especially for older adults. These may include the loss of friends and family members, the loss of mental capacity, the loss of physical abilities, and the loss of joy in life (Widera & Block, 2021). In a report published by the Oregon Health Authority (2020), individuals who petitioned to end their lives through physician-assisted death listed the inability to engage in activities that make life enjoyable as the most common reason for requesting the life-ending medication. This points to the role pain may have on mental health, leading to lower quality of life among dying individuals (Tjakkes et al., 2010).

Dying Alone

Several studies support that dying in the presence of family or other close ones is one of the indicators of quality of life at the end of life (Sandsdalen et al., 2015). However, many factors may affect a patient's ability to be with family or other supportive individuals at the end of life, including personal preferences, location, and quality of relationship with family members (Bablitz et al., 2018). During the COVID-19 pandemic, for example, restrictions for visitors in hospitals and long-term care facilities meant that family members were unable to have physical, in-person interactions with their loved ones (Anderson-Shaw & Zar, 2020). Although health

providers used technology such as Facetime to improve the lack of social contact, critical patients in intensive care units (ICU) settings were largely unable to partake in this alternative option, especially those who were unconscious (Anderson-Shaw & Zar, 2020). While being alone does not necessarily equate to loneliness, research shows that many people have an inherent fear of dying alone and that family and friends often have a secondary fear of their loved ones dying alone (Frommer, 2016; Larsson et al., 2017). Additionally, research on preferences or wishes for individuals nearing the end of life suggests that most prefer to have the presence of another individual and human connection at death (Thompson et al., 2019).

Religion/Spirituality at the end of Life

The importance of religious/spiritual beliefs on the quality of life at the end of life is evident in a number of ways. Some research suggests, for example, that more religious individuals may have greater self-rated health, less depressive symptoms, more social participation, and greater excitement at the end of life compared to non-religious individuals (Idler et al., 2009). Across the life course, research shows that religiosity and spiritual beliefs may have a positive association with several quality-of-life domains, including physical and psychological domains (Counted et al., 2018). Prior studies have also found that religion/spirituality influences choices made at the end of life, which could affect quality-of-life outcomes (Gijsberts et al., 2019; Zhang et al., 2012). For example, one study found that fundamentalist Catholics and Protestants had a preference for life-prolonging treatment compared to non-fundamentalists, which was fully explained by differences in beliefs about religious control over medical decisions (Sharp et al., 2012). Prior studies have suggested that having providers with religious competency, engaging in self-reflection, and visibility of spiritual care through spiritual counselors were all important aspects of providing appropriate

religious care at the end of life (Gijsberts et al., 2019). Adhering to this standard, several scales that measure the quality of life at the end of life also include questions about religious/spiritual comfort (Davis & Hui, 2017).

Respect at the end of Life

In accordance with the idea that provider treatment/behavior affects health outcomes, research has shown that being treated with respect is an important factor for dying individuals at the end of life (Rodríguez-Prat et al., 2016). Depending on the nature of their illness, several aspects of life such as independence and dignity are severely impacted for many people with chronic illnesses (Kennedy, 2016). This change already causes a level of distress among dying individuals, which can be exacerbated by stigma and bias from external parties (Kennedy, 2016). Within care settings, it is important for dying individuals to feel comfortable and to have their wishes, beliefs, and values respected (Guo & Jacelon, 2014). Respect for dying individuals may be demonstrated by greeting the patient when a provider enters a room, showing gratitude, having empathy, engaging in active listening, asking patients how they would like to be addressed, and respecting their cultural beliefs (James, 2018). Research on preferences for care at the end of life shows that people want providers who are caring, who communicate with them, and who respect their individuality (Hansen et al., 2016; Meghani et al., 2009).. Rather, patients want a provider who is willing to learn directly from them, by asking them what they need, and respecting the choices that they make (Hansen et al., 2016; James, 2018; Meghani et al., 2009). Showing respect for a patient's culture may also involve providing alternative treatment options, involving family members in decision-making, providing patients with access to language/translation services, and other actions that demonstrate awareness of and respect for the person's heritage (Givler et al., 2020).

Patient/Family Involvement in Decision-Making

Autonomy at the end of life is a critical indicator of the quality of life at the end of life, especially in considering the loss of autonomy that may occur along a disease trajectory (Reach, 2014). For many patients, the ability to have control over their lives is a meaningful way to reclaim autonomy, especially when several other factors may be already out of their control (Reach, 2014). Research on the preferences of dying individuals shows that the ability to make decisions for themselves, and/or the ability to have their family members involved in the decision-making process is an important factor at the end of life (Houska & Loučka , 2012; Waller et al., 2020). Involving the patient in the decision-making process is not only an ethical expectation but also a legal requirement in all states within the U.S (Cerminara & Meisel, 2015). The Patient Self Determination Act of 1990 amended the Social Security Act to require that all medical facilities inform patients of their legal rights to make decisions for themselves, required facilities to respect the documented wishes of patients, and included other requirements that advocated for patient autonomy (Library of Congress, 1990). In most scales that measure the quality of life at the end of life, some aspects of patient autonomy or family decision-making involvement are often included, as it demonstrates the ethical, legal, and moral commitment to patient self-determination by the providers (Davis & Hui, 2017). Even from the provider perspective, one research study shows that providers and administrators within a palliative care setting perceive the respect for patients' wishes to be the most important indicator of the quality of life at the end of life (Mistry et al., 2015). Another study suggests that both caregivers and patients also regard patient and family involvement in decision-making as a critical factor in determining end-of-life care quality (Lewis et al., 2019).

Overall Care Rating

Overall care rating generally encompasses all the individual indicators of quality of life into one measure. Due to the comprehensive nature of the measure, the overall care rating provides the most conclusive picture of the quality of life at the end of life. In prior studies, researchers often measure singular indicators of quality of life at the end of life, such as pain and emotional well-being, and also include a question on overall care quality (Lendon et al., 2015; Xu et al., 2020). Including this measure is critical because patients/families may report having quality care within specific domains, but not in others, which may complicate the ability to conclude whether or not quality care was generally provided. For example, a family/proxy may report that their loved one had excellent pain management and mental health at the end of life but may still report that the overall care provided was not good. Additionally, research shows that the way in which patients cope with physical and mental symptoms may differ, leading providers and family members to misinterpret their experiences (Givler et al., 2020). In certain cultures, for example, the nature of a family member's disease may not be disclosed to all family members, and families may be shielded from observing the true nature of a loved one's disease progression (Coolen, 2012). Similarly, some individuals may have a higher tolerance for pain, which may result in an underestimating of pain experienced by family members or other proxies (Givler et al., 2020). Due to the potential for inconsistent results across the individual measures, adding an overall measure of care quality may allow for a more reliable examination of the quality of care at the end of life.

Racial Disparities at the end of Life

Racial disparities at the end of life have received increasing attention in the literature over the past few decades and include a diverse range of end-of-life outcomes.

Hospice Care

Ornstein et al. (2020) examined the use of hospice services for three or more days in the last six months of life among older adults using data linked with Medicare claims. They found that Black decedents were about 28% less likely to use hospice services compared to their White peers (Ornstein et al., 2020). This result mirrors that of several other studies that consistently found a lower likelihood of hospice usage among Black older adults (Hardy et al., 2014; Wasp et al., 2020). In addition, researchers have also found that Black older adults are less likely to receive hospice referrals from providers (Wasp et al., 2020) and that even when referrals were provided, it was often delayed when compared to Whites (Karanth et al., 2018). Other studies also show that even when Black older adults use hospice services, they are less likely to use it for a long period of time, are more likely to disenroll, and more likely to experience four or more hospice transitions (Laguna, 2014; Wang et al., 2019).

Pain

Prior research on the experience of pain at the end of life suggests a significant disparity in the level, assessment, and management of pain among adults at the end of life. Monroe and Carter (2010) found that Black residents in a nursing home had higher scores on the Discomfort Behavior Scale, which is used to assess pain among individuals with cognitive impairments. For Black older adults with access to pain management, research suggests that disparities may exist in both assessment and management. Booker et al. (2020), for instance, aimed to determine racial differences in the implementation of 11 cancer management approaches among patients receiving hospice care, finding that although most practices were the same regardless of race, the assessment and management of pain from opioid-induced constipation with a bowel regimen was lower among Black patients. Research also shows that adherence to pain medication among

Black patients is quite low, with concerns around nausea, changes in pain, and mistrust in providers explaining some of the variances in medication adherence (Yeager et al., 2019). Overall, prior studies consistently suggest that Black older adults may be more likely to experience pain at the end of life compared to Whites, and that their pain is less likely to be assessed and managed effectively (Hoffman et al., 2016; Montague & Green, 2009; Wyatt, 2013).

Mental Health

Research on racial differences among older adults, in general, suggests that Black/African Americans may have a lower prevalence of anxiety and depression but may experience both at a greater intensity compared to Whites (Asnaani et al., 2010; Bailey et al., 2019). For older adults who do have anxiety or depression, studies also show that they are less likely to seek mental health treatment and are less likely to have a positive attitude towards mental health treatment, largely due to internalized and public stigma (Conner et al., 2010). Additionally, research suggests that older Black/African Americans may be at greater risk of experiencing anxiety and depression at the end of life, despite engaging in protective measures such as advance care planning. In a study of Medicare beneficiaries who engaged in end-of-life care discussions, Luth and Prigerson (2018) discovered that Blacks were more likely to report having depression and anxiety at the end of life, compared to Whites. Another study by Alcalá (2014) found that, although cancer affected the mental health of most participants in the study, Blacks were more likely to experience negative mental health impacts of cancer compared to non-Hispanic Whites. Other studies support that Black individuals with chronic illnesses may experience more negative mental health outcomes compared to Whites. For example, Calhoun et al. (2015) found that Black breast cancer survivors who had aromatase inhibitor therapy were

more likely to have depressive symptoms compared to Whites, while Parikh et al. (2021) reported that African American veterans diagnosed with prostate cancer were more likely to be diagnosed with depression, but less likely to be prescribed an antidepressant compared to White veterans. According to these results, while the lifetime experience of depression and anxiety may be lower among Blacks, those with chronic illnesses may be more susceptible to adverse mental health outcomes at the end of life.

Being Alone at Death

Although dying in the presence of loved ones has been identified as an important indicator of the quality of life at the end of life, studies that examine retrospective racial differences in dying alone are surprisingly limited (Davis & Hui, 2017). However, some studies have explored preferences for end-of-life care among diverse populations, finding significant differences in the importance of social support/social presence at the end of life. Grill et al. (2021) identified two groups of end-of-life preferences within their study: the relational group prioritized family and friends, comfort from the church, and the presence of other individuals at the end of life, while the self-determination class prioritized advance care planning and honesty from their providers over relationships. The authors found that Blacks were three times more likely to be in the relational class and that Blacks who were also sexual minorities were more likely to be afraid of dying alone (Grill et al., 2021). An earlier study by Barnato et al. (2009) found that Black individuals were more likely to live alone compared to non-Hispanic Whites and that those who lived alone were more likely to prefer dying in a hospital, as opposed to dying at home. In another study, Thorpe et al. (2012) found that Blacks were more likely to live alone, were more likely to have low social contact, and lacked emotional support compared to Whites. These studies suggest that Black individuals may be more likely to be alone at the end of

life, even though studies in the general population of older adults point to greater social connectedness and preference for such connectedness among Blacks (Nguyen, 2017; Taylor et al., 2019; Udell et al., 2012).

Religious/Spiritual Beliefs

Studies in the field of end-of-life care suggest that religious/spiritual beliefs are most important to Black individuals, though no evident studies have aimed to identify racial differences in the provision of spiritual support at the end of life. Religious beliefs can affect several factors at the end of life, including preferences for medical treatment and perception of pain (Balboni et al., 2013; Brown, 2014; Givler et al., 2020). For instance, research shows that Black individuals are more likely to hold strong religious beliefs, viewing pain as a test of their religious faith, unwilling to engage in end-of-life planning, and hoping for the miracle of cure (Koffman et al., 2008; Sanders et al., 2016; Witcher & Meeker, 2012). However, the ability to integrate religious/spiritual beliefs may be limited by a lack of communication between patients, providers, and families. Johnson et al. (2016), for example, interviewed religious leaders and other church members within Black communities about their congregants' beliefs related to end-of-life care, finding that religious beliefs influenced feelings, perceptions, and beliefs about end-of-life care that were often not communicated to family members or medical providers. Research suggests that actively integrating religious/spiritual beliefs into end-of-life practices can actually result in positive outcomes for Black individuals. In a systematic review of faith-based initiatives to improve advance care planning and end-of-life discussions among Black older adults, Catlett and Campbell (2021) discovered that the integration of faith/religious initiatives increased advance care planning, advance directive completion, and the use of hospice services. Considering this, most studies suggest the inclusion of questions about religious beliefs by

providers and the importance of having religious-cultural competency (Fang et al., 2016; Givlet et al., 2020; Pentaris, & Thomsen, 2020; Swihart et al., 2021). However, Black individuals are still less likely to have religious support from their providers (Kutney-Lee et al., 2019).

Respect

Interaction based on respect for the patient is an important factor that affects the quality of life at the end of life; yet studies suggest significant disparities in how patients are treated by providers at the end of life. Kim et al. (2020) examined differences between Asian and White decedents in the San Francisco Bay area, finding that families of Asian decedents were more likely to report that their cultural traditions and religious beliefs were not respected, compared to White decedents. Language is also a critical factor in ensuring a patient's and family's culture and related preferences are communicated to and respected by providers (Givler et al., 2020). A systematic review by Silva et al. (2016) aimed to determine whether professional interpreters are effectively used to mitigate language barriers in palliative care settings, finding that the use of professional interpreters was inadequate. Studies within the review also concluded that patients who did not have access to professional interpreters were less likely to understand their diagnosis and prognosis, which led to worse end-of-life outcomes such as anxiety and pain (Silva et al., 2016). Research shows that Black individuals in particular experience poor communication from providers and also experience discrimination within end-of-life settings, which leads to mistrust in the health care system (Duffy et al., 2006; Gardner et al., 2018; Johnson, 2013; Koss & Baker, 2017). Evidently, this can have significant implications for the health and well-being of Black individuals. For instance, one study by Penner et al. (2009) found that when Blacks perceived discrimination from their provider, they were less likely to adhere to the health recommendations of the provider. The distrust in medical providers also contributes to lower usage of end-of-life

services, advance care planning, and other services that may improve health and psychosocial outcomes at the end of life (Johnson, 2013). Hence, providers' interaction with Blacks, when perceived as lacking respect for their culture and beliefs, may adversely affect their end-of-life outcomes.

Involvement in Decision-Making

Respecting a patient's autonomy and involving family members in the decision-making process is a critical indicator of quality care at the end of life, and studies generally suggest that Black individuals may be less likely to have their wishes honored, and less likely to have input in their care (Cain et al., 2018; Loggers et al., 2009). An early systematic review from Kwak and Haley (2005) found that non-White older adults were less likely to have knowledge of advance directives, less likely to support advance care planning, and were more likely to prefer family-centered decision making at the end of life. Research shows that positive relationships between providers and family members can have beneficial decision-making outcomes for all parties. One study, for example, found that family members who had a higher quality of communication with providers were less likely to have a decisional conflict (Smith-Howell et al., 2018). However, several barriers exist in the communication and decision-making between providers, families, and patients, including fear of legal consequences and family confrontation for providers, the inability to accept prognosis for patients, and decisional conflict among family members (Luna-Meza et al., 2021; Xie et al., 2018). Another barrier may manifest in the form of provider bias and discrimination, as one study found that even when Black individuals document advance directives, their wishes may not be honored (Loggers et al., 2009). This is also supported by research showing that Black individuals prefer to have discussions about end-of-life wishes with their family members but not as much with their providers (Wagner et al., 2010). Overall, a

combination of patient preference and provider bias/discrimination could exacerbate a lack of involvement in family decision-making and patient autonomy for Blacks in their end-of-life decisions (Cain et al., 2018).

Overall Care Rating

Overall care rating at the end of life provides an overarching picture of the quality of care provided to an individual at the end of life. Using chart reviews and data from the Bereaved Family Survey, Kutney-Lee et al., (2019) examined racial differences in the quality of care provided to veterans at the end of life. The authors found that Black veterans were less likely to have excellent or good care at the end of life, compared to White veterans. Another study by Lee et al. (2016) obtained data on the quality of life at the end of life from the perspectives of family members. Their results showed that families of Black individuals were more likely to provide low ratings on the quality of dying. Earlier studies also suggest that Black older adults may experience a lower quality of care at the end of life. Koffman and Higginson (2001) examined differences in care quality between the Black Caribbean and White decedents using interviews with family members or friends and found that a higher proportion of families of Black Caribbean decedents reported negative care quality. Similarly, Welch et al. (2005) found that family members of Black decedents were less likely to report excellent or good quality of care at the end of life.

Other End-of-Life Outcomes

Racial disparities have been explored across other end-of-life outcomes that will not be examined within this study despite being equally important. Some studies have found that Black older adults are less likely to use palliative care in any setting, despite controlling for medical diagnosis, geographic location, and other explanatory factors (Johnson, 2013; Wasp et al., 2020).

In addition to differences in the usage of end-of-life services, Black individuals have also been found to be more likely to experience financial hardships at the end of life (Karanth et al., 2019). Research has also shown that Blacks are disproportionately more likely to die in a hospital and less likely to engage in end-of-life planning activities before death (Carr, 2011; Laguna, 2014; Orlovic et al., 2018). Additionally, Blacks are more likely to have multiple hospitalizations, more likely to have emergency department visits, and more likely to end up in the ICU at the end of life (Karanth et al., 2018; Laguna, 2014; Wasp et al., 2020). Black individuals also tend to prefer a more aggressive care at the end of life, including an increased likelihood of using mechanical ventilation, cardiopulmonary resuscitation, artificial nutrition, aggressive chemotherapy, and other life-saving measures (Karanth et al., 2018; Laguna, 2014; Orlovic et al., 2018).

Gender Disparities at the End of Life

Surprisingly, gender differences at the end of life have not been as well-researched as racial differences. Gender is often used as a control or explanatory variable within studies and is rarely considered as a singular outcome in end-of-life research (Gott et al., 2020). However, some researchers have explored gender differences across a number of end-of-life outcomes. Sharma et al. (2015), for example, examined gender differences in the receipt of ICU care at the end of life, finding that men were more likely to receive ICU care at the end of life compared to women. Saphire et al. (2020) used Medicare data to examine gender differences in the pattern of medications received for symptom management at the end of life. According to their finding, women were more likely to receive medications for emotional distress, nausea /vomiting, dyspnea, and pain, compared to men (Saphire et al., 2020). In another study, Saeed et al. (2018) examined gender differences in attitudes towards palliative care among cancer patients, finding that women were more likely to prefer palliative care compared to men. Ullrich et al. (2019)

employed a qualitative approach to discover the specific needs of palliative care patients based on their gender, using qualitative interviews with both patients and providers. Both patients and providers concluded that women had more expressive coping mechanisms, had a more extended social network, and had a stronger desire for communication and support from providers (Ullrich et al., 2019).

Taking a different approach from the aforementioned studies, Seifart et al. (2020) focused on how gender differences affect preferences for end-of-life discussions among patients. Their findings revealed that men generally preferred not to engage in discussions about death and dying and preferred to discuss “hard” medical facts only. By contrast, women preferred to focus on “soft” topics such as emotions and religiosity/spirituality (Seifart et al., 2020). Overall, many studies acknowledge a significant gender difference across several end-of-life topics, with common themes around men preferring more aggressive care at the end of life, women preferring palliative/comfort care, and women experiencing more pain and depression at the end of life.

Intersectional Disparities at the End of Life

In an article entitled *Gender and Palliative Care: A Call to Arms*, Gott et al. (2020) highlight the numerous ways in which gender affects outcomes at the end of life. One key point related by the authors was that gender is never at play as a singular factor but must be considered in conjunction with other intersecting identities. Unfortunately, not many studies have accepted this call and explored the intersectional impact of gender and other identities, with most studies exploring different identities/characteristics individually. However, there is one prominent example that closely mirrors an intersectional approach. Gott et al. (2017) explored the end-of-life preferences of indigenous people in New Zealand and found intersectional differences by

gender. Specifically, indigenous female participants were more likely to prefer spiritual practices at the end of life compared to indigenous men, while non-indigenous men preferred to be resuscitated compared to non-indigenous women (Gott et al., 2017). Although this study explores intersectionality in some form, the two identities (gender and indigenous status) were not explicitly combined. Also, the study did not aim to actually examine intersectional differences.

The combination of two independent variables to examine a dependent variable is known as an interaction effect in statistical terms and allows the researcher to narrow down the impact of independent variables on the dependent variable (Lavrakas, 2008). When an interaction effect is not included, researchers can make general conclusions about a population that may be misrepresented. This may lead to inaccurate interventions by consumers of the research product (Lavrakas, 2008). For example, a research study may find that girls are more likely to graduate high school compared to boys but adding an interaction term for gender and race may reveal that only White girls are more likely to graduate high school. The needs of non-White girls will be ignored without the interaction effect. Similarly in end-of-life research, it is important to understand the specific needs of patients receiving care, which can be best accomplished by accounting for as many intersectional factors as possible, including race, gender, educational status, income, health, and several other factors that affect one's well-being in general (Gott et al., 2020). However, the combinations of intersectional identities are infinite in number, and researchers may take many more years to explore the true depth of individual needs at the end of life. Yet, it is still important to consider key identities that do impact quality of life at the end of life, within the scope/feasibility of a research study. As such, this study aimed to fill the significant gap in the use of intersectionality within end-of-life research, by examining the

intersectional impact of two major identities – race and gender - on quality of life at the end of life.

THEORETICAL FRAMEWORK

To achieve the primary purpose of the dissertation, this study drew from four theories that each play a critical role.

Critical Race Theory

The critical race theory is a movement of race scholars that challenge the fabric of race, power, and law in the U.S. (Delgado & Stefancic, 2017). Although emergent from the field of law, the critical race theory has burgeoned into a dominant force in the social sciences, informing advances in understanding racial disparities within the context of the U.S. The core assumption of the theory suggests that racial disparities are a result of historical, institutional, and structural/systemic racism that benefits from the oppression and marginalization of minority groups (George, 2021). The critical race theory has six main tenets identified by Delgado and Stefancic (2017). First, the critical race theory recognizes that racism is normalized and is ingrained into society in a way that is difficult to cure. Second, race itself does not objectively exist and is therefore socially constructed by society. Third, the system of oppression exists to serve the benefit of the oppressor. Fourth, society uses differential racialization whenever it benefits the most; in one era, minorities are depicted as simpletons while in another, they are depicted as dangerous and cunning. Fifth, different identities may combine to create increased hardships through a concept known as intersectionality. Finally, racial minorities are positioned to be ideal communicators to their White counterparts, and that minority status, therefore, has an assumed competence to speak about issues of race and racism.

In the context of research, the critical race theory encourages the critical examination of race and power structures, considering how historical factors may play a role in current outcomes (Delgado & Stefancic, 2017). The critical race theory has been used in various studies to understand the impact of race on everyday and lifetime experiences, using both quantitative and qualitative methods. In a study aiming to understand the lower use of health services along the human immunodeficiency virus (HIV) continuum of care among Blacks living with HIV, Freeman et al. (2017) found that the experiences of Blacks with HIV in receiving HIV care reflected the historical and cultural aspects of racism in the United States. The study participants often felt that decisions were made without their input, felt distrust for medical providers, and felt that the healthcare system was dehumanizing. These factors, therefore, affected their engagement with HIV care, leading to poor outcomes (Freeman et al., 2017).

Other studies have found that discrimination experienced in the healthcare system led to preferences for medication over talk therapy (Sonik et al., 2020), prompted minorities to forego care (Rivenbark & Ichou, 2020), and resulted in worse mental health and substance use treatment outcomes for minorities (Mays et al., 2017). The critical race theory has also been used to explore how segregation laws such as redlining continue to impact present-day outcomes, including the physical, mental, and behavioral health of adolescents (Hardeman & Medina, 2019). Using the critical race theory framework simply means using a social justice lens to examine experiences of systemic and interpersonal discrimination experienced among minorities (Delgado & Stefancic, 2017). As such, several studies actually employ this framework without explicitly saying so (Gott et al., 2017; Gott et al., 2020). However, the use of this theory or an overall exploration of discrimination within end-of-life research remains limited. The critical race theory serves as the overarching theory that guided the rationale/reason for this study.

Intersectionality

Stemming from the critical race theory movement, the theory of intersectionality was developed by Kimberlé Crenshaw, a critical race scholar who observed an intersection between racial and feminist movements (Carbado et al., 2013). In an article titled *Demarginalizing the Intersection of Race and Gender: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory, and Antiracist Politics*, Crenshaw presents three legal cases to demonstrate how the legal system treats Black women, and how Black women are “theoretically erased” (Crenshaw, 1989, para. 2). Crenshaw (1989) contends that Black women are not represented within feminist movements, nor are they represented within racial movements and that society often views them as either Black or a woman, but never as both simultaneously. Crenshaw concludes that the intersection of race and gender must be considered together, rather than separately. She argues that Black women are not simply women and are not simply Black, but a combination of both. As such, systems must consider how both identities combine to create unique experiences (Crenshaw, 1989). This forms the basic tenet of the theory of intersectionality, which posits that the combination of multiple identities culminates in exceptional experiences (Collins & Bilge, 2020).

While initially focused on Black women, the theory has expanded to include the considerations of multiple social and demographic identities. These include class, gender, race, sexuality, socioeconomic status, political views, and many others (Collins & Bilge, 2020). The core assumption of intersectionality suggests that individuals in multiple vulnerable groups may experience more hardships and stressors than others (Crenshaw, 1989). As such, being White, male, of higher income, heterosexual, cisgender, and a part of other mainstream groups comes with great advantages.

Despite being used implicitly, the theory of intersectionality has been used to understand differences in several end-of-life outcomes. Giesbrecht et al. (2018), for example, used an ethnographic approach to examine the complexities of access to end-of-life care for indigenous older adults living in Canada. According to the findings of this study, other hardships from poverty, mobility challenges, and existing mental and physical conditions further exacerbated the barriers and stressors associated with accessing needed care. Similarly, Gott et al. (2020) identified a critical need to consider intersectional factors that affect access to palliative care among women, including caregiving roles, poverty, and other factors that may add to the existing disparities in end-of-life care among women. While several studies have used intersectionality within end-of-life research, most studies are exploratory using qualitative methods or conceptual in nature. Few efforts have been made using quantitative methods to understand how gender and race interact to influence the quality of life at the end of life. Beyond end-of-life care, intersectionality has been used to explore the intersections of HIV stigma and demographic identities (Johnson Shen et al., 2019), the influence of education, gender, and region on health disparities (Roy et al., 2020), and the impact of race/ethnic identity and gender on disability trajectories (Warner & Brown, 2011). These studies; findings suggest that an individual's combined identities significantly influence health trajectories across the life course, but this has not been assessed within the context of race and gender at the end of life. Intersectionality was the main theory that was tested within this study and was therefore used to guide the study hypotheses.

Social Determinants of Health

Social determinants of health, which refer to the circumstances in which people live, have a direct or indirect impact on their health and well-being (Healthy People, 2020). The social

determinants of health encompass five key areas: economic stability, education, social and community context, health and healthcare, and finally, neighborhood and built environment (Healthy People, 2020). The basic tenet of the framework suggests that access to economic and social capital can influence health trajectories, which has been explored in end-of-life research. For example, Tzeng et al. (2019) examined the association between the demographic characteristics of older adults and the ability to perform four self-care activities at the end of life. The study found that place of residence, education, age, and marital status significantly predicted participants' ability to perform self-care activities at the end of life (Tseng et al., 2019). Similarly, Koroukian et al. (2017) assessed the role of social determinants and multimorbidity on end-of-life outcomes, with findings showing that income particularly predicted the location of death. Social determinants have also been found to influence preferences for place of death and treatment and many other end-of-life outcomes (Higginson et al., 2017). In this study, the social determinants of health were used to guide the selection of control variables to account for factors other than race and gender that may affect the quality of life at the end of life.

Clinical Practice Guidelines for Quality Palliative Care

The National Coalition for Hospice and Palliative Care (NCHPC) and the National Consensus Project (NCP) developed the Clinical Practice Guidelines for Quality Palliative Care. The guidelines provide baseline care standards that professionals should employ when working with patients who have serious illnesses and their families (NCP, 2018). The NCP guidelines were formulated as a collaborative effort between palliative care leaders across the United States, who gathered to develop standards of care that should be provided to patients with chronic illnesses (NCP, 2018). The first edition of these guidelines was published in 2004. Since then, these guidelines have been continually updated as the palliative care field evolves, with the

second edition published in 2009, the third edition published in 2013, and the most recent edition (4th) published in 2018 (NCP, 2018). The primary goal of the 4th edition, in particular, was to ensure equitable access to quality palliative care for all individuals, regardless of setting, age, illness trajectory, or other factors (Sullivan et al., 2018). The guidelines include eight key domains: 1) The structure and processes of care, 2) The physical aspects of care, 2) The psychological and psychiatric aspects of care, 4) The social aspects of care, 5) The spiritual, existential, and religious aspects of care, 6) The cultural aspects of care, 7) The care of the patient nearing the end of life, and 8) The ethical and legal aspects of care (NCP, 2018).

The structure and processes of care primarily focus on the role of the interdisciplinary team, which includes conducting assessment and screening, providing resources, and providing caregiving training and support before, during, and after death. The physical aspects of care emphasize the importance of symptom management, functional status, and quality of life for patients. This includes the use of both pharmacological as well as non-pharmacological interventions for enhancing the physical well-being of patients. The psychological and psychiatric aspects include screening and assessment for mental well-being, developing treatment plans, addressing family conflicts, providing grief support, and giving referrals for further mental health care when needed. The social aspects of care include providing support to address the environmental factors that affect treatment trajectory, including housing, food, transportation, family presence, and other social needs. The spiritual aspects of care include providing access to spiritual support for patients who want it and being respectful of patients' beliefs and values. The cultural aspects of care emphasize the importance of respecting different cultural backgrounds and encourage professionals to examine their own biases and perceptions. The care for the patient at the end of life specifically focuses on the last months or days leading

up to a patient's death, underscoring the importance of early hospice referral, appropriate patient education, assessment and management of symptoms, clear communication with family members, and other critical standards of care. The ethical and legal aspects of care emphasize the importance of honoring decisions made by patients and their families, understanding health care proxies, abiding by state and federal laws, and other legal considerations (NCP, 2018). In this study, the NCP guidelines aided the selection of dependent variables to represent the quality of life at the end of life.

Research Questions and Hypotheses

The following research questions were proposed, along with the hypotheses emanating from each research question to address the gap in prior research on the intersectional impact of race and gender on quality of life at the end of life among older adults:

- 1. Research Question Number 1:** Guided by the critical race theory (Delgado & Stefancic, 2017), the first research question seeks to simply understand the magnitude of racial disparities along the eight end-of-life domains explored within this study. *Research question Number 1 is: To what extent do racial disparities exist in the quality of life at the end of life?* The hypotheses under this research question were also guided by the critical race theory and findings from prior studies. Overall, there is consensus in the literature that Blacks are likely to have worse end-of-life outcomes compared to White older adults (Ornstein et al., 2020; Wasp et al., 2020). As such, the following hypotheses were formulated:
 - a. Hypothesis 1.1:** Black older adults will be less likely to have hospice care in the last month compared to White older adults.

- b. **Hypothesis 1.2:** Black older adults will be more likely to be in pain compared to White older adults.
 - c. **Hypothesis 1.3:** Black older adults will be more likely to have depression and anxiety compared to White older adults.
 - d. **Hypothesis 1.4:** Black older adults will be more likely to be alone at death compared to White older adults.
 - e. **Hypothesis 1.5:** Black older adults will be less likely to engage in talks about religious/spiritual beliefs compared to White older adults.
 - f. **Hypothesis 1.6:** Black older adults will be less likely to be treated with respect compared to White older adults.
 - g. **Hypothesis 1.7:** Black older adults will be more likely to have decisions were being made without their input compared to White older adults.
 - h. **Hypothesis 1.8:** Black older adults will be less likely to have good overall care compared to White older adults.
2. **Research Question Number 2:** The second research question specifically tests the theory of intersectionality, which suggests that different identities interact to influence outcomes across the lifespan (Crenshaw, 1989). *Research question Number 2 is: Does gender moderate the relationship between race and quality of life at the end of life?* Under this research question, hypotheses were formulated to reflect the premise of intersectionality, with gender predicted as a moderator for the relationship between race and all eight quality-of-life domains. The hypotheses for the second research question are as follows:

- a. **Hypothesis 2.1:** Gender will moderate the relationship between race and hospice care at the end of life.
- b. **Hypothesis 2.2:** Gender will moderate the relationship between race and pain at the end of life.
- c. **Hypothesis 2.3:** Gender will moderate the relationship between race and mental health at the end of life.
- d. **Hypothesis 2.4:** Gender will moderate the relationship between race and being alone at death at the end of life.
- e. **Hypothesis 2.5:** Gender will moderate the relationship between race and religious belief discussion at the end of life.
- f. **Hypothesis 2.6:** Gender will moderate the relationship between race and being treated with respect at the end of life.
- g. **Hypothesis 2.7:** Gender will moderate the relationship between race and autonomy at the end of life.
- h. **Hypothesis 2.8:** Gender will moderate the relationship between race and overall care quality at the end of life.
- i.

METHODS

Data Source

This study used death data from Round 3 (2013) to Round 10 (2020) of the National Health and Aging Trends Study (NHATS). The NHATS is an annual longitudinal panel survey of Medicare beneficiaries aged 65 and older living in the United States. Although the NHATS is collects repeated measures, this dissertation used data that was only collected once, after the individual died (“last-month-of-life interview”), thus making it a cross-sectional study. The first round of the NHATS was conducted in 2011 and a new sample was added in 2015 to ensure that the sample remained representative of the population. The NHATS was originally created as a source for studying health trends and reducing disability among older adults but has been used to study multiple aspects of aging. It oversamples individuals who are 85 and older, and those who identify as Black. Additionally, analytic weights are provided to ensure that the sample is proportionate to the general population of Medicare beneficiaries in the United States and to adjust for oversampling. Each year, detailed information about physical health, cognitive health, activities of daily living, social participation, and several other measures of day-to-day life are collected from each participant.

The NHATS is conducted by the Johns Hopkins School of Public Health, with data collection by Westat and funding from the NIA (Kasper & Freedman, 2021). For individuals who die between each round, a last-month-of-life (LML) interview is conducted with a proxy to determine the quality of life in the final month of the individual’s life. The proxy may be a family member, a friend, or another person familiar with the individual’s status in the last month

of life (Kasper & Freedman, 2021). For the LML interviews, the unweighted response rate was 94.4 in Round 2, 94.1 in Round 3, 94.8 in Round 4, 95.8 in Round 5, 96.4 in Round 6, 93.1 in Round 7, 96.4 in Round 8, 95.7 in Round 9, and 93.9 in Round 10 (Kasper & Freedman, 2021). Only individuals from round 3 (2013) onwards were included although the LML interviews began in Round 2 (2012) because one dependent variable of interest (hospice care in the last month) was not collected in Round 2. As such, all Round 2 decedents were excluded. The actual decedent is referred to as the sample person or SP, while the respondent is called the proxy.

NHATS Data Collection and Sampling Strategy

The primary data collection method for the NHATS is the sample-person interview. Trained data collectors from Westat conduct the interviews either in person or over the phone (NHATS, 2020). Prior to the interview, NHATS participants receive a letter thanking them for their previous participation and reminding them that they will be contacted the following year for another interview (NHATS, 2020). The interviewers are provided with scripts that can be used when calling or visiting a home. All answers are then recorded digitally within a computer software (NHATS, 2020). All NHATS participants received a \$50 check each round for their participation in the study (NHATS, 2020).

The NHATS sampling frame was the list of all living Medicare beneficiaries provided by the Centers for Medicare and Medicaid, from which NHATS researchers applied a probability sampling strategy to recruit participants (NHATS, 2020). The NHATS uses a stratified three-stage sample design that includes: 1) The selection of 95 counties to serve as primary sampling units, 2) The selection of 655 zip codes within the counties to serve as secondary sampling units, and 3) The selection of Medicare beneficiaries within each selected secondary sampling unit as well as the over-selection of individuals who are Black and age 85 plus (Kasper & Freedman,

2021). The same three-stage stratified sampling design was employed, and during each round for the sample replenishment in 2015, the study was designed in a way that would result in equal probability samples (Kasper & Freedman, 2021).

Strengths

The NHATS has several strengths, including a moderate sample size and analytic weights that allow for the estimation of the general population. In addition, it represents individuals that are often underreported in studies, including those who are Black and those over the age of 85. The NHATS also provides a foundation for a sister study called the National Study of Caregiving, which provides additional information about NHATS participants and their caregivers. Furthermore, it provides a comprehensive measure of several well-being indicators, including an extensive survey of activities of daily living (ADLs), functional limitations, social participation, and many other variables. The NHATS also collects one of the most comprehensive accounts of life in the final month, with a focus on the quality of the end-of-life experience (Freedman & Kasper, 2019). The NHATS uses measures from the Toolkit of Instruments to Measure End of Life Care, which was developed by the Center for Gerontology and Health Care Research at Brown University, with the purpose of providing health care institutions with a way to determine whether the care provided is patient-focused and family-centered (Teno et al., 2001). The toolkit includes assessment questions around physical comfort, spiritual comfort, emotional and social support, decision-making, and communication, closely mirroring the NCP guidelines that were used within this study (NCP, 2018; Teno et al., 2001).

Dependent Variables

Guided by the NCP clinical guidelines, the study examined eight individual dependent variables, representing the quality of life at the end of life. All dependent variables were derived

from the year after the individual died, which is when the LML interview is conducted. Each variable was selected specifically to align as closely as possible with NCP's eight domains, and the rationale for each dependent variable selection is provided below. The study variables are highlighted in bolded italics, while the corresponding NCP guidelines are emphasized in regular italics.

Hospice Care at the End of Life/The Structure and Processes of Care

The structure and processes of care refer to the role of the interdisciplinary team in providing care to individuals with chronic illnesses. These include providing comprehensive assessments, creating palliative care plans, coordinating care and care transitions, providing care in any setting, maintaining their education and their own emotional well-being, and various other considerations (NCP, 2018). Palliative care is an integral part of hospice care, including a focus on comfort, pain management, and psychosocial relief provided by the interdisciplinary team of hospice care at the end of life (Rome et al., 2011). As such, the best variable to assess the structure and processes of care was "hospice care", which determined whether the decedent received hospice care in the last month of life, regardless of their place of death. This was the best available variable because hospice care is truly an interdisciplinary team-based comfort care that can be provided in any setting, including the individual's home, a hospital, or an inpatient hospice facility, and addresses multiple aspects of the patient's well-being and quality of life as well as the family's (NIA, 2017).

The hospice care variable was determined by asking proxies "During the last month of {SP's} life, did {he/she} receive hospice care?" Responses included "yes," "no," "don't know," or "refused." The variable was recoded to reflect one of two options: "yes=1" or "no=0" with other responses excluded.

Pain in the Last Month/Physical Aspects of Care

The physical aspects of care focus on symptom relief at the end of life, particularly the relief of pain (NCP, 2018). As such, the best variable to represent this domain was “pain in the last month,” which determined whether an individual experienced pain in the last month before death. Experience of pain in the final months indicates poor quality of life at the end of life and can depend on the severity of the illness, the quality of medical care provided, and a plethora of other factors (Hagarty et al., 2020). This variable was chosen because it will assist in determining whether the individual experienced any pain at the end of life.

The pain variable was determined by asking proxies “During the last month of {SP}'s life, were there times when {he/she} experienced pain?” Responses included “yes,” “no,” “don't know.” or “refused.” The variable was recoded to be binary, with “yes=1” and “no=0,” and other responses will be excluded.

Anxiety/Sadness in the Last Month/Psychological Aspects of Care

The psychological aspects of care emphasize the importance of emotional well-being for individuals with a chronic illness (NCP, 2018). The best variable to represent this domain was “anxious or sad in the last month” determining whether an individual experienced depression or anxiety in their final months. Psychological well-being is another indicator of the quality of life at the end of life and may point to the experience of individuals suffering from depression or anxiety in their final months. Psychological well-being is another indicator of the quality of life at the end of life and may point to the experience of multiple stressors for the dying individual (Soto-Rubio et al., 2018). This variable was chosen because it will assist in determining the level of psychological stress experienced by individuals at the end of life.

The anxious/sad variable was determined by asking proxies “During the last month of {SP}’s life, did {he/she} have any feelings of anxiety or sadness?” Response choices were “yes,” “no,” “don’t know,” or “refused,” and were recoded as only “yes=1” or “no=0” options. All other responses were excluded.

Alone at Death/Social Aspects of Care

The social aspects of care focus on the experience of social well-being for individuals with chronic illnesses. This includes having access to social support and closeness with family members (NCP, 2018). The best variable to represent this domain was “alone at death”, which determined whether the individual was living alone at the time of death, or if family/friends/other supportive individuals were present. Research shows that most individuals prefer to die surrounded by family/friends or other supportive individuals, whereas people who die alone have been found to have worse end-of-life outcomes, including loneliness and death by suicide (Shaw et al., 2021; Thompson et al., 2019).

The alone at death variable was determined by asking proxies “At the time of {SP}’s death, was {he/she} living alone?” Responses included “yes,” “no,” “don’t know,” and “refused.” The variable was recoded to be “yes=1” and “no=0.” All other responses were excluded.

Talk Religious Beliefs/Spiritual Aspects of Care

The spiritual aspects of care highlight the importance of respecting spiritual/religious preferences and providing access to spiritual resources (NCP, 2018). The best variable to represent this domain was “talk religious beliefs”, which determined whether the care team discussed religious/spiritual needs with an individual. Several studies have identified the importance of asking questions regarding religious preferences as a standard of inclusive care.

The aforementioned variable indicates whether the providers are adhering to this standard (Choudry et al., 2018). This is important because conversations about religious and spiritual beliefs have been found to improve end-of-life quality for dying individuals and their families, but research also suggests that providers feel uncomfortable with religious discussions (Wittenberg et al., 2015).

The talk religious beliefs variable was determined by asking proxies “During the last month of life, did any doctors, nurses, or other health professional talk with {SP} about {his/her} religious beliefs?” Responses included “yes,” “no,” “does not apply/no care in the last month,” “don’t know,” and “refused.” The variable was recoded to “yes=1” and “no=0”, with other responses excluded.

Treated with Respect/Cultural Aspects of Care

The cultural aspects of care emphasize the importance of cultural considerations in all aspects of care provision, including respecting cultural beliefs (NCP, 2018). As such, the best variable to represent this domain was “treated with respect”, which determined whether the individual was treated with respect by providers at the end of life. Prior studies show that attentiveness and respect from providers are critical areas of satisfaction with care for dying individuals. This variable was chosen because it will assist in determining if providers are treating their patients with respect (Kennedy, 2016). Additionally, patients often report that they want providers who make an effort to understand and respect their cultural background while acknowledging their individuality (Hansen et al., 2016; James, 2018; Meghani et al., 2009).

The treated with respect variable was determined by asking “During the last month of {SP}’s life, how often were {he/she} treated with respect by those who were taking care of {him/her}: always, usually, sometimes, or never?” Responses included “always,” “usually,”

“sometimes,” “never,” “does not apply/no care in the last month,” “don’t know,” and “refused.” Responses of “always,” “usually,” and “sometimes” were combined and renamed to “always, usually, or sometimes=1”. The responses of “never” were coded as “never=0” and used as the reference group. All other responses were excluded.

Overall Care Rating/Care for the Patient Nearing the End of Life

The care for the patient nearing the end of life focuses specifically on the final days and weeks of life and includes a culmination of all other domains (NCP, 2018). Considering the comprehensive nature of this domain, the best variable to represent the care for the patient nearing the end of life was “overall care rating”, which determined the overall quality of care provided. While the individual aspects of care provide specific quality indicators, the overall care rating provides the most conclusive picture of the quality of care provided at the end of life (Lendon et al., 2015). The care rating variable was determined by asking “Overall, how would you rate {SP}’s care in the last month of life? Would you say it was, excellent, very good, good, fair, or poor?” Responses included “excellent,” “very good,” “good,” “fair,” “poor,” “does not apply/no care in the last month,” “don’t know,” and “refused.” Responses of “excellent,” “very good,” and “good” were combined and recoded as “Excellent, very good, or good =1”. Responses of “fair” and “poor” were combined into one and renamed to “fair or poor=0” and used as the reference group, as done in prior studies (Kuffman & Higginson, 2001; Welch et al., 2005).

Decisions without Input/Legal and Ethical Aspects of Care

The legal and ethical aspects of care focus on the importance of patient autonomy and involvement in all decision-making (NCP, 2018). As such, “decision about care without input”, which determined if the care team made decisions about the individual’s care without first asking

for his/her/their input or the family's input, was the best variable to represent this domain. Involving patients in decision-making is a critical indicator of quality care, and several studies refer to the importance of continuous communication and collaboration with the patient throughout the care process, as well as the respect for the patient's autonomy (Houska & Loučka, 2019). This variable was chosen because it will help determine whether providers are respecting patient autonomy by involving them and/or their families in the decision-making process.

The decision about care without input variable was determined by asking "During the last month of {SP}'s life, was there ever a decision made about {his/her} care or treatment without enough input from {him/her} or {his/her} family?" Response options were "yes," "no," "does not apply/no care in the last month," "don't know," and "refused." Responses were recoded to "yes=1" and "no=0" with other responses excluded.

Table 1 shows the original NHATS coding of each dependent variable.

Table 1*Original Coding of Dependent Variables*

Variable	Raw Variable Name	Variable Type	Variable Response Type	Variable Role in Analysis
Hospice care in the last month	Pd9hospcelml	Categorical	-9=Missing -1=Inapplicable 1=Yes 2=No	Outcome
Pain in the last month	lm9pain	Categorical	-8=Don't Know -1=Inapplicable 1=Yes 2=No	Outcome
Lived alone at death	re9alonedec	Categorical	-9=Missing -1=Inapplicable 1=Yes 2=No	Outcome
Anxious or sad in the last month	lm9sad	Categorical	-8=Don't Know -1=Inapplicable 1=Yes 2=No	Outcome
Talk religious beliefs	lm9relg	Categorical	-8=Don't Know -1=Inapplicable 1=Yes 2=No	Outcome
Treated with respect	lm9respect	Categorical	3=No LML Care 8=Don't Know -1=Inapplicable 1=Always 2=Usually 3=Sometimes 4=Never	Outcome
Overall care rating	lm9ratecare	Categorical	5=No LML Care -8=Don't Know -7=Refused -1=Inapplicable 1=Excellent 2=Very Good 3=Good 4=Fair 5=Poor	Outcome
Decision about care made without input	lm9caredecis	Categorical	6=No LML Care -8=Don't Know -1=Inapplicable	Outcome

1=Yes
2=No
3=No care in LML

Main Independent Variables

Race and gender were the main independent variables for the study. The specific racial groups considered were non-Hispanic Whites and non-Hispanic Blacks. In the United States, about 60.1% of the population are non-Hispanic Whites, 18.5% are Hispanic, 13.4% are Black, and the remaining 10% are from other racial/ethnic groups (United States Census Bureau, 2019). Due to limited sample sizes from racial/ethnic groups other than non-Hispanic Whites and non-Hispanic Blacks, coupled with the acknowledgment that each racial/ethnic group has specific cultural factors that should be considered separately, only non-Hispanic Black and non-Hispanic White older adults were examined within this study, focusing on the racial disparities between the two groups (Delgado & Stefancic, 2017). To accurately answer the research questions, White older adults were used as the reference group for comparison with Black older adults. The race variable was recoded so that “White=0” and “Black=1.” Within the NHATS, gender is collected as a binary measure with men and women only. The gender variable was recoded to “men=0” and “women=1”, with men as the reference group. Both these variables were derived from previous interview years when the decedent was still alive, as some demographic variables are not collected every year. For the interaction effect, the combination of race and gender resulted in four groups: White men, White women, Black men, and Black women. White men were compared to the other three groups, in accordance with the theory of intersectionality.

Control Variables

In addition to the main independent variables, control variables were considered in accordance with the social determinants of health. Figure 1 shows the link between each domain

of the social determinants of health and the control variables selected. The social determinants selected were age at death, annual income, education, social network size, living arrangement, geographic location, chronic illnesses, functional limitations, additional health insurance plans, self-rated health, pre-existing depression and anxiety, and a dummy variable to indicate the round or year when the participant had an LML interview done.

The control variables (except the new variable indicating round/year of LML interview) were taken from the previous year before the individual died, or whenever the particular variable was collected. Two particular variables, education, and income were only collected at first entry into the study (in Round 1 and Round 5). Table 2 shows the specific rounds wherefrom all variables will be derived, based on when the NHATS participant died.

Table 2*Location of NHATS Variables Based on Participant Death Year*

Year a Participant Died	Round of LML Interview and Age at Death	Round of Income and Education (Dependent on whether the participation entered the study at Round 1 or Round 5)	Round of all Other Independent Variables (Derived from the year before the participant died)
Between Round 2 and Round 3	Round 3	Round 1	Round 2
Between Round 3 and Round 4	Round 4	Round 1	Round 3
Between Round 4 and Round 5 (New sample added)	Round 5	Round 1	Round 4
Between Round 5 and Round 6	Round 6	Round 1 or Round 5	Round 5
Between Round 6 and Round 7	Round 7	Round 1 or Round 5	Round 6
Between Round 7 and Round 8	Round 8	Round 1 or Round 5	Round 7

Between Round 8 and	Round 9	Round 1 or Round 5	Round 8
Round 9			
Between Round 9 and		Round 1 or Round 5	Round 9
Round 10			

The age at death variable included the categories “65-69,” “70-74,” “75-79,” “80-84,” “85-90,” and “90+.” The youngest group (65 to 69) was chosen to be the reference group. Although collected continuously, the income variable was recoded into a categorical variable. Those with income under \$30,000 were classified as “low income=0”, those with income between \$30,001 and \$60,000 were classified as “moderate income=1”, and those with income greater than \$60,001 were classified as “high income=2.” These income categories were determined based on the average living expense of an older adult without any dependents (Senior Living, 2019). Older adults with low income were the reference group.

The education variable had the options “missing,” “inapplicable,” “1st to 8th grade,” “9th to 12th grade (no diploma),” “high school graduate,” “vocational, trade, or technical school certificate,” “some college but no degree,” “associate’s degree,” “bachelor’s degree,” and “masters, professional or doctoral degree.” Due to extremely small cases within some categories, the variable was recoded so that all categories below high school were marked as “Less than high school=0,” those with only a high school diploma were coded as “high school=1,” and those with the most than a high school education were coded as “post-secondary=2”. The “less than high school” group was the reference group.

The social network variable was a continuous variable ranging from 0 to 5 that identifies the number of individuals that a person talks to, who are considered members of the person’s

social network. The living arrangement variable included the options “inapplicable,” “alone,” “with spouse/partner only,” “with spouse/partner and with others,” and “with others only.” The variable was recoded so that “alone=0”, and all other living arrangements were combined into one and coded as “living with others=1”. Those living alone were compared to the other group. A decision was made to choose one of the two variables due to multicollinearity between living arrangement and marital status, and the living arrangement was chosen because it provides a more accurate measure of social contact in older adulthood (Cudjoe et al., 2020). This is because there is a higher risk of mortality in older adulthood, due to natural causes and chronic illnesses, which leads to a higher rate of widowhood among older adults (Xu et al., 2020). As such, marital status alone does not indicate social contact, and living arrangement allows for the inclusion of larger social networks such as friends, children, and extended family that an older adult may be living with (Cudjoe et al., 2020). The geographic location variable was binary and identified whether an individual lived in a metropolitan area or not. The variable was originally coded as “Metropolitan=1” and “non-Metropolitan=2.” The coding was changed to “Metropolitan=0” and “non-Metropolitan=1” to ensure consistency, with the former used as the reference group.

The chronic illness variable included eight different variables that asked whether the person had a particular chronic illness or not. These included heart disease, high blood pressure, osteoporosis, arthritis, cancer, diabetes, dementia/Alzheimer, and lung disease. Each variable included options of “missing,” “don’t know,” “inapplicable,” “yes,” “no,” or “previously reported.” All responses of “yes” or “previously reported” were combined as one category so that “yes=1”. All responses of “no” were recoded so that “no=0” and used as the reference group. All other responses were excluded. The eight chronic illness variables were then

combined into one continuous variable ranging from 0-8, which was labeled as the “number of chronic illnesses.”

The functional limitation variable included multiple variables combined into one. Measures of functional limitations in the NHATS have previously been tested for reliability, with a Cronbach’s alpha of 0.95, which delineates a high level of reliability (Marfeo et al., 2020). The first group of variables are referred to as activities of daily living (ADLs) and include functional skills that are required to take care of oneself (Edemekong et al., 2020). The NHATS asks participants or proxies if they are able to eat by themselves, bathe by themselves, toilet by themselves, and dress by themselves. The second group of variables are instrumental activities of daily living (IADLs), which are more complex activities that may require greater skill than regular activities of daily living (Assisted Living, 2020). The NHATS asks participants or proxies whether the person can do laundry by themselves, shop by themselves, prepare meals by themselves, and bank by themselves. For both ADLs and IADLs, the responses included options of “inapplicable,” “did not do by self in last month,” “did by self in last month with no difficulty,” “did by self in last month with difficulty,” “don’t know or refused,” and “not done in last month.” The responses were recoded as such; “Did by self in the last month=0,” “did by self in last month with difficulty=1,” and “did not do by self =2,” and the other responses were excluded. All eight variables were then combined into a continuous variable ranging from 0-16, where higher numbers indicated more functional limitations.

The self-rated health variable asked participants to rate their health and included the options “-9=missing,” -8=don’t know,” “-1=inapplicable,” “excellent=1” “very good=2,” “good=3,” “fair=4,” or “poor=5.” The variable was recoded so that the responses “excellent,” “very good,” and “good” were combined into one and coded as “excellent or good=1.” The

responses “fair” and “poor” were combined and coded as “fair or poor=0,” as researchers have done in prior studies (Giltay et al., 2012; Wuorela et al., 2020). The “fair or poor” category served as the reference group. The anxiety and depression variable used questions from the Patient Health Questionnaire-9 (Cronbach’s alpha=0.81) and the Generalized Anxiety Disorder Scale-2 (Cronbach’s alpha= 0.86; Ahn et al., 2019; Gelaye et al., 2013; Kasper & Friedman, 2021).

For depression, the participants or proxies were asked how often they felt little interest or pleasure in doing things, and how often they felt down, depressed, and hopeless in the last month. For anxiety, participants were asked how often they felt nervous, anxious, or on edge, and how often they felt unable to stop or control worrying in the last month. For all four questions, options included “missing,” “don’t know,” “refused,” “inapplicable,” “not at all,” “several days,” “more than half the days,” and “nearly every day.” For both depression and anxiety, all four variables were recoded so that “not at all=0,” “several days=1,” “more than half the days=2,” and “nearly every day=3.” The depression and anxiety variables were then made into continuous variables ranging from 0-3. Finally, the additional health insurance variable asked if participants had additional health insurance plans outside of Medicare. Medicaid, Medigap or Medicare Supplement, and Tricare were the three additional insurance plans. All three variables included the options “missing,” “don’t know,” “refused,” “inapplicable,” “yes,” or “no,” and were recoded so that “yes=1” and “no=0,” with all other options excluded. The three variables were then combined into a “Number of Additional Health Insurance” variable ranging from 0-3. A new variable was created particularly to control for the effect of history, and how the year an individual passes away may affect end-of-life outcomes. A drastic example is the COVID-19 pandemic, which made it difficult for individuals to interact with their families at

the end of life, likely affecting social interactions at the end of life (Ersek et al., 2021). The new “round of interview” variable was coded so that 0=Round 3, 1=Round 4, 2=Round 5, 3=Round 6, 4=Round 7, 5=Round 8, 6=Round 9, and 7=Round 10. The original NHATS coding of all independent variables is shown in Table 3. Additionally, Figure 1 depicts the conceptual framework for the entire study, which includes the link between all theories, dependent variables, the main independent variables, and the control variables.

Table 3*Original Coding of Independent Variables*

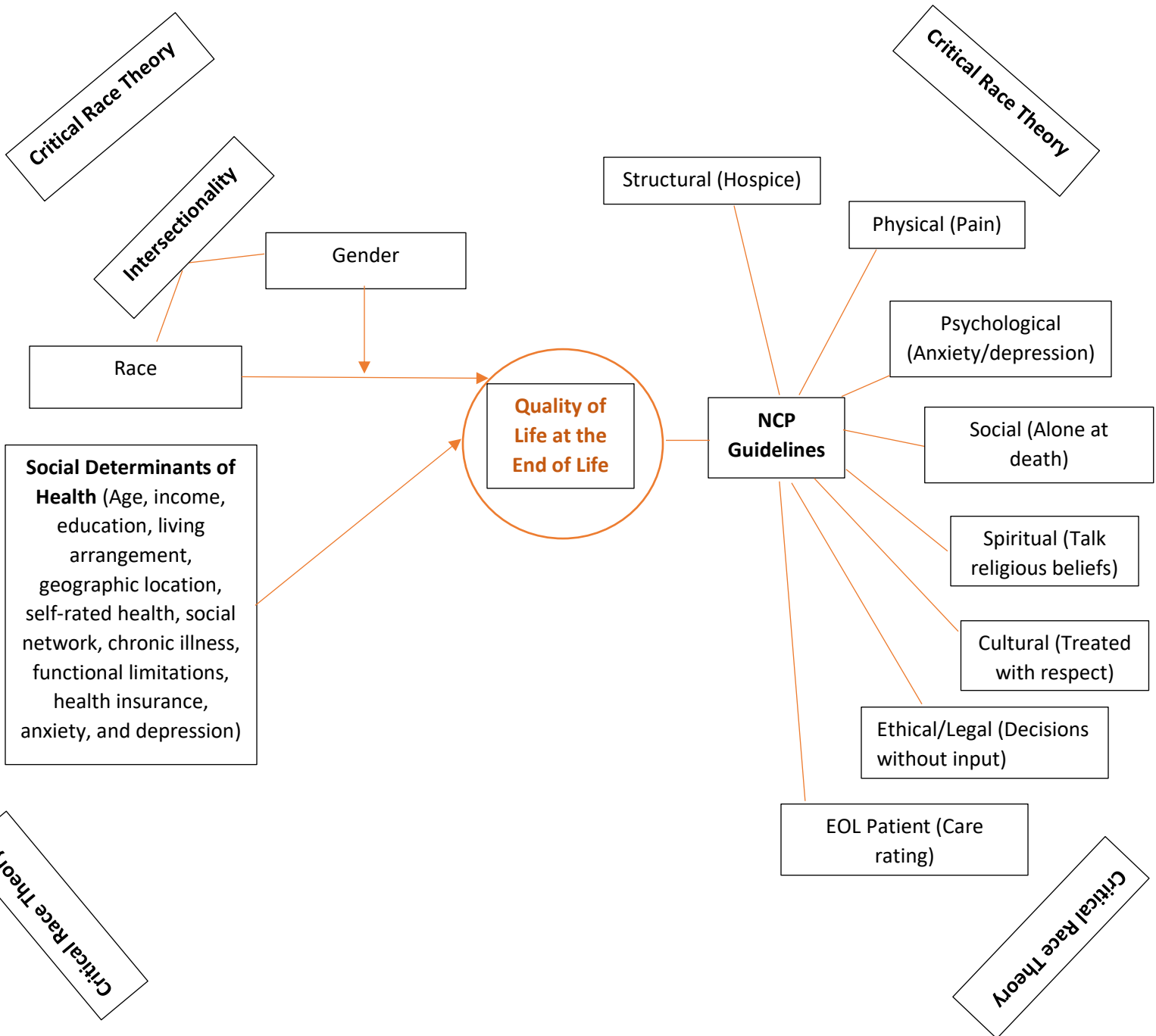
Variable Name	Raw Variable Name	Variable Type	Variable Response	Variable Role in Analysis
Age at death	r9d2deathage	Categorical	-8=Don't Know -1=Inapplicable 1=65-69 2=70-74 3=75-79 4=80-84 5=85-89 6=90+	Control
Gender	r5dgender	Categorical	1=Male 2=Female	Control and Main Independent Variable
Race/Ethnicity	r15dracehisp	Categorical	1=Non-Hispanic White 2=Non-Hispanic Black 3=Other (Non-Hispanic American Indian, Asian, Native Hawaiian, Pacific Islander, Other specific race) 4=Hispanic 5=More than one/Don't Know or Refused Primary Race/Ethnicity 6=Don't Know or Refused	Main Independent Variable
Income	ia9totinc	Continuous	-9=Missing -8=Don't Know -7=Refused -1=Inapplicable Mean=57,504.34 S.D= 70,538.43 Minimum=0 Maximum=1,485,923	Control
Education	el5higstschl	Categorical	-9=Missing -8=Don't Know -1=Inapplicable	Control

			1=No Schooling Completed 2=1 st to 8 th grade 3=9 th to 12 th grade (no diploma) 4=High School Graduate 5=Vocational, technical, business or trade school certificate 6=Some college but no degree 7=Associate's degree 8=Bachelor's degree 9=Masters, Professional or Doctoral Degree	
Number in Social Network	sn9dnumsn	Continuous	-1=Inapplicable 0=0 1=1 2=2 3=3 4=4 5=5	Control
Chronic Illnesses:	hc9disescn2	Categorical	-9=Missing	Control
Heart Disease	hc9disescn3		-8=Don't Know	
High Blood Pressure	hc9disescn4		-1=Inapplicable	
Arthritis	hc9disescn5		1=Yes	
Osteoporosis	hc9disescn6		2=No	
Diabetes	hc9disescn7		7=Previously Reported	
Lung Disease	hc9disescn8			
Dementia/Alzheimer's	hc9disescn9			
Cancer				
Functional Limitations	sc9deatsfdf	Categorical	-1=Inapplicable	Control
Eating by self	sc9ddressfdf		1= Did not do by self	
Dressing by self	sc9dbathsfdf		2= Did by self with no difficulty	
Bathing by self	sc9dtoilsfdf		3=Did by self with difficulty	
Toileting by self	ha9dbanksfdf		6=Don't know or refused	
Banking by self	ha9dlaunsfdf		8=Not done in the last month	
Laundry by self	ha9dmealsfdf			
Meals by self	ha9dshopsfdf			
Shopping by self				
Health Insurance: Medigap or Medicare Supp, Medicaid, and Tricare	ip9mgapmedsp ip9cmedicaid ip9covtricar	Categorical	-9=Missing -8=Don't Know -1=Inapplicable 1=Yes 2=No	Control

Geographic Residence	r9dmetnonmet	Categorical	1=Metropolitan 2=Non-Metropolitan	Control
Living Arrangement	hh9dlvngarrg	Categorical	-1=Inapplicable 1=Alone 2=With spouse/partner only 3=With spouse/partner and others 4=With others only	Control
Self-Rated Health	hc9health	Categorical	-9=Missing -8=Don't Know -1=Inapplicable 1=Excellent 2=Very Good 3=Good 4=Fair 5=Poor	Control
Depression: 1) Little interest and pleasure in doing things 2) Down, depressed, and hopeless	hc9depresan1 hc9depresan2	Categorical	-9=Missing -8=Don't Know -1=Inapplicable 1=Not at all 2=Several days 3=More than half the days 4=Nearly every day	Control
Anxiety: 1) Nervous and anxious 2) Unable to stop worry	hc9depresan3 hc9depresan4	Categorical	-9=Missing -8=Don't Know -1=Inapplicable 1=Not at all 2=Several days 3=More than half the days 4=Nearly every day	Control

Figure 1

Conceptual Framework



Note. Arrows represent causal relationships between the independent and dependent variables, while non-arrowed lines show how multiple variables within the study represent a particular construct.

Missing Data

A total of 3,264 LML interviews were conducted between Round 3 (2013) and Round 10 (2020). As many as 523 individuals had LML interviews in Round 3, 404 individuals had LML interviews in round 4, 296 individuals had LML interviews in round 5, 486 individuals had LML interviews in round 6, 459 individuals had LML interviews in round 7, 397 individuals had LML interviews in round 8, 374 individuals had LML interviews in round 9, and 325 individuals had LML interviews in Round 10. Missing data analysis was conducted using the missing data analysis function in SPSS, version 27 (IBM, 2020). The missing data analysis function examines how many participants have complete data on all variables of interest and excludes any person with missing values on even one variable. As such, the missing data analysis showed that only 5 variables of the 44 variables included in the study had complete data from all participants. Of the 3,264 participants, only 914 had complete data on all 44 variables. All variables had less than 33% missingness, with the hospice, social network, and religious belief variables having the most missingness, respectively. To preserve the integrity of the study, only cases with complete data on all variables were included, and no variables were removed from the study because each variable is critical to explaining differences in quality of life at the end of life. As such, a final sample of 914 was used for the study.

Calculating Sample Size

To ensure that a sample size of 914 was sufficient, a minimum guideline for the event per variable (EPV) formula was employed. The sample size's suitability is based on the EPV 50 and formula $n=100 +50(i)$, where i represents the number of independent variables within a study (Bujang et al., 2018; Peduzzi et al., 1996). Applied to this study, the result was $n=100 +50(15)$

=750. Based on the results, a minimum sample size of 850 is needed, meaning that a sample size of 914 is suitable for this study.

Analytic Weights

Due to the complex sampling design of the NHATS, analytic weights are provided to researchers, which can be used to adjust for the over and under-sampling of participants. The survey weights account for differential probabilities of selection and also adjust for nonresponse bias for all interviews conducted from Round 1 to Round 10 (DeMatteis et al., 2021). For each participant, a final analytic weight is calculated using a raking procedure, and the weights are applied based on the original entry point into the study (i.e., at round 1 or at round 5). The analytic weights from each round allow for the sample to represent all Medicare beneficiaries who would have been alive and eligible for participation in the NHATS in the year before the interview date (DeMatteis et al., 2021). This implies that the analytic weight in Round 10 (2020) would represent all Medicare Beneficiaries who would have been alive and eligible for the NHATS in Round 9 (2019; DeMatteis et al., 2021). Since the individuals in this study have died, their analytic weights were derived from the year right before they died, together with the independent and control variables.

Analytic Plan

For all levels of analyses, analytic weights were applied to ensure that the sample represented the population and the alpha level will be set at .05, which is a standard alpha level in social science research (Thron & Miller, 2015). All statistical analyses were conducted using SPSS, version 27. The analytic approach for each research question is provided below:

1. **Research Question Number 1:** To what extent do racial disparities exist in the quality of life at the end of life?

- a. *Univariate Analyses:* Unweighted descriptive statistics were calculated to describe the characteristics of each participant in the study, across all variables.
- b. *Bivariate Analyses:* Weighted Pearson Chi-Square tests were conducted to examine the association between each dependent variable and each independent/control variable, with the alpha level set at .05. To perform a Chi-square test, all variables must be measured at ordinal or nominal levels, and the proportion of cells with expected values less than 5 should be less than 20% (McHugh, 2013). The Chi-square tests included all variables measured at ordinal or nominal levels, and SPSS generates a data note within the Chi-square test result showing how many cells have expected values less than 5 to check for the expected count within each cell. For all continuous independent variables, bivariate logistic regression models were used to check the associations with the eight categorical dependent variables.
- c. *Multivariate Analyses:* To predict the likelihood of experiencing each of the eight end-of-life outcomes examined within this study, eight weighted multivariate logistic regression models were generated, one for each of the eight dependent variables. The assumptions for a logistic regression include: the dependent variable should be nominal, there should be one or more independent variables, the independent variables should also be independent of each other (i.e., not repeated data from the same person), there should be no multicollinearity between independent variables (i.e.,

all tolerance values should be less than 1, and Variance Inflation Factor (VIF) values should be less than 10), there should be linearity between the independent variables and the log odds, and there should be no logit outliers among the residuals (Osborne, 2008; Schreiber-Gregory, 2018). Within the study, all dependent variables are categorical, there is more than one independent variable, and the measures are not repeated. Multicollinearity was checked using the VIF, Tolerance, and Collinearity Diagnostic function within the logistic regression analysis (Schreiber-Gregory, 2018). Linearity between the independent variables and the log odds was checked using the Box-Tidwell test, and logit outliers were identified by obtaining the standardized residuals within the logistic regression analysis (Sarkar et al., 2011; Schreiber-Gregory, 2018).

2. **Research Question Number 2:** *Does gender moderate the relationship between race and quality of life at the end of life?*
 - a. *Univariate Analyses:* Unweighted descriptive statistics were calculated for each variable in the study, including the race/gender interaction term.
 - b. *Bivariate Analyses:* Weighted Chi-square tests were performed to determine the association between each dependent variable and all categorical independent/explanatory variables, including the race/gender intersectional term. Bivariate logistic regression models were used for the continuous predictors.
 - c. *Multivariate Analyses:* To determine the role of race and gender on quality of life at the end of life, a second block was created for the eight

multivariate logistic regression models used for answering research question 1, adding an interaction term for race and gender.

Institutional Review Board

The dataset used for this study is publicly available and de-identified (available at: <https://www.nhats.org/researcher/data-access>), which exempts this study from institutional board review (IRB), based on guidelines from the University of Alabama's Institutional Review Board (University of Alabama, 2016). Additional information on the University of Alabama's guidelines for using publicly available secondary can be found here:

<http://ovpred.ua.edu/files/2016/11/39-I3D-Public-Data-Sets-10-3-2011.pdf>.

RESULTS

Univariate

The final analytic sample included a total of 914 decedents who died between Round 3 and Round 10 of the NHATS. Table 4 shows the univariate results for all dependent variables. For the dependent variables, the majority of the decedents did not have hospice care (53.6%), were in pain during the last month of life (73.7%), had anxiety/depression at the end of life (58.1%), were not alone at death (74.0%), did not undertake religious belief discussions with their providers (52.3%), were treated with respect always, usually, or sometimes (99.9%), did not have decisions made without their input (93.4%), and had an overall care rating of excellent or good (84.4%).

Table 4

Univariate Results for Dependent Variables

Variable	Value	Count	Percent Within Sample
Hospice Care	Yes	424	46.4%
	No	490	53.6%
Pain	Yes	674	73.7%
	No	240	26.3%
Anxiety/Depression	Yes	531	58.1%
	No	383	41.9%
Alone at Death	Yes	238	26.0%
	No	676	74.0%

Talk Religious Beliefs	Yes	436	47.7%
	No	478	52.3%
Treated with Respect	Always, Usually, or Sometimes	913	99.9%
	Never	1	.1%
Decisions Without Input	Yes	60	6.6%
	No	854	93.4%
Overall Care Rating	Excellent or Good	771	84.4%
	Fair or Poor	143	15.6%

Table 5 shows univariate results for all categorical independent variables. For the categorical independent variables, the majority of the decedents were 80 and older at death (76.7%), over half were women (54.4%), and most were Whites (79.3%). For the race/gender intersection, the majority of decedents were White women (43.0%), followed by White men (36.3%), Black women (11.4%), and then Black men (9.3%). Most of these decedents had low income (i.e., < \$30,000) (79.2%), had no post-secondary education (73.2%), lived with other individuals (59.7%), lived in metropolitan areas (78.8%), and rated their health as fair or poor (53.5%). Round 6 (15.3%) had a higher proportion of decedents compared to all other rounds, with round 5 having the least proportion of decedents (8.4%).

Table 5

Univariate Results for Categorical Independent Variables

Variable	Value	Count	Percent Within Sample
Age at Death	65-69	14	1.5%
	75-79	129	14.1%
	80-84	181	19.8%
	85-89	226	24.7%
	90+	294	32.2%

Gender	Men	417	45.6%
	Women	497	54.4%
Race	White	725	79.3%
	Black	189	20.7%
Race × Gender	White Men	332	36.3%
	White Women	393	43.0%
	Black Men	85	9.3%
	Black Women	104	11.4%
Income	Low Income	724	79.2%
	Moderate Income	107	11.7%
	High Income	83	9.1%
Education	Less Than High School	392	42.9%
	High School	277	30.3%
	Post-Secondary	245	26.8%
Living Arrangement	Alone	368	40.3%
	With Others	546	59.7%
Geographic Location	Metropolitan	720	78.8%
	Non-Metropolitan	194	21.2%

Table 5 (continued)

Variable	Value	Count	Percent Within Sample
Self-Rated Health	Excellent or Good	425	46.5%
	Fair or Poor	489	53.5%
Round	Round 3	129	14.1%
	Round 4	104	11.4%
	Round 5	77	8.4%
	Round 6	140	15.3%
	Round 7	131	14.3%
	Round 8	130	14.2%
	Round 9	123	13.5%
	Round 10	80	8.8%

Table 6 illustrates the univariate results for all continuous independent variables. On average, the decedents in the sample had 1.9 people in their social network, had 3.2 chronic illnesses, had about 4.3 functional limitations, had .84 number of additional health insurance plans, had a depression score of 1.5, and had an anxiety score of 1.2.

Table 6

Univariate Results for Continuous Independent Variables

Variable	Range	Mean	Standard Deviation
Social Network Size	0-5	1.9	1.2
Number of Chronic Illnesses	0-8	3.2	1.5
Functional Limitations	0-16	4.3	3.4
Health Insurance	0-3	.84	.57
Depression	0-6	1.5	1.6
Anxiety	0-6	1.2	1.6

Bivariate

A Chi-square test of independence was used to examine the association between each categorical independent variable and each categorical dependent variable. In addition, a simple logistic regression model was used to test the association between each continuous independent variable and each categorical dependent variable. The Chi-square tests and simple logistic regressions for the association between all independent variables and all dependent variables were significant with an alpha level of less than .05.

Bivariate Results for Hospice Care and all Categorical Independent Variables

Table 7 shows the bivariate association between hospice care and all categorical independent variables. For the association between age at death and hospice care, decedents aged 65-69 were more likely to have hospice care (54.6%), followed by those in the age group of 90 and older (51.7%), 80-84 (50.9%), 85-89 (48.4%), 70-74 (44.9%), and 75-79 (43.7%). Similarly, in the association between gender and hospice care, women were more likely to receive hospice care at the end of life (51.5%), compared to men (45.1%). Meanwhile, the association between race and hospice care, White decedents were more likely to receive hospice care (49.9%) compared to Black decedents (35.0%). For the association between the race/gender intersection and hospice care, White women were the most likely to have received hospice care (53.2%), followed by White men (46.0%), Black men (36.3%), and then Black women (33.9%). For the association between income and hospice care, decedents with high income were more likely to receive hospice care (54.6%), followed by those with low income (48.1%), and those with moderate income (45.9%). For the association between education and hospice care, decedents with less than a high school education were more likely to receive hospice care (50.6%), followed by those with post-secondary education (49.3%), and those with only a high school diploma (46.0%).

For the association between living arrangements and hospice care, those living with others were more likely to receive hospice care (48.9%) than those living alone (47.9%). For the association between geographic location and hospice care, those living in non-metropolitan areas were more likely to receive hospice care (50.2%) than those in metropolitan areas (48.1%). For the association between self-rated health and hospice care, those with fair or poor health were more likely to receive hospice care (53.9%) than those with excellent or good health (41.9%). For the association between the round of interview and hospice care, decedents in round 10 were

most likely to receive hospice care (63.3%), followed by those in round 5 (50.1%), those in round 8 (48.8%), those in round 9 (48.2%), those in round 6 (47.5%), those in round 7 (47.4%), those in round 4 (45.6%), and those in round 3 (41.7%).

Table 7

Bivariate Association between Hospice Care and all Categorical Independent Variables

Variable	Value	Percent Received Hospice Care	Chi-Square
Age at Death	65-69	54.6%	17659.002 *
	70-74	44.9%	
	75-79	43.7%	
	80-84	50.9%	
	85-89	48.4%	
	90+	51.7%	

* $p < .05$

Table 7 (continued)

Variable	Value	Percent Received Hospice Care	Chi-Square
Gender	Men	45.1%	16665.982*
	Women	51.5%	
Race	White	49.9%	30152.272*

	Black	35.0%	
Race x Gender	White Men	46.0%	49800.900*
	White Women	53.2%	
	Black Men	36.3%	
	Black Women	33.9%	
Income	Low Income	48.1%	9023.328*
	Moderate Income	45.9%	
	High Income	54.6%	

* $p < .05$

Table 7 (continued)

Variable	Value	Percent Received Hospice Care		Chi-Square
Education	Less than High School	50.6%	5646.603*	
	High School	46.0%		
	Post-Secondary	49.3%		

Living Arrangement	Alone	47.9%	400.836*
	With Others	48.9%	
Geographic Location	Metropolitan	48.1%	1323.142*
	Non-Metropolitan	50.2%	
Self-Rated Health	Excellent or Good	41.9%	59731.098*
	Fair or Poor	53.9%	

* $p < .05$

Table 7 (continued)

Variable	Value	Percent Received Hospice Care	Chi-Square
Round	Round 3	41.7%	49257.176*
	Round 4	45.6%	
	Round 5	50.1%	
	Round 6	47.5%	
	Round 7	47.4%	
	Round 8	48.8%	

Round 9 48.2%

Round 10 63.3%

* $p < .05$

Bivariate Results for Hospice Care and all Continuous Independent Variables

Table 8 shows the bivariate association between hospice care and all continuous independent variables. For social network size, every one-unit increase in the number of people in a person's social network led to a higher likelihood of receiving hospice care ($OR=1.052$, $CI=1.051-1.054$). For chronic illnesses, every one-unit increase in the number of chronic illnesses resulted in a higher likelihood of receiving hospice care ($OR=1.106$, $CI=1.104-1.107$). For functional limitations, every one-unit increase in the number of functional limitations led to a higher likelihood of receiving hospice care ($OR=1.046$, $CI=1.046-1.047$). For health insurance, every one-unit increase in the number of additional health insurance plans resulted in a higher likelihood of receiving hospice care ($OR=1.031$, $CI=1.027-1.034$). For depression, every one-unit increase in the number of depressive symptoms resulted in a higher likelihood of receiving hospice care ($OR=1.170$, $CI=1.169-1.172$). For anxiety, every one-unit increase in the number of anxiety symptoms resulted in a higher likelihood of receiving hospice care ($OR=1.045$, $CI=1.044-1.046$). All of the hospice care odds ratios had a small effect size relative to Cohen's d (Chen et al., 2010), which indicated a weak association between hospice care and all the continuous independent variables.

Table 8*Bivariate Association between Hospice Care and all Continuous Independent Variables*

Variable	Range	Odds Ratio	Confidence Interval
Social Network Size	0-5	1.052 *	1.051-1.054
Number of Chronic Illnesses	0-8	1.106 *	1.104-1.107
Functional Limitations	0-16	1.046 *	1.046-1.047
Health Insurance	0-3	1.031 *	1.027-1.034
Depression	0-6	1.170 *	1.169-1.172
Anxiety	0-6	1.045 *	1.044-1.046

* $p < .05$

Bivariate Results for Pain and all Categorical Independent Variables

Table 9 shows the bivariate association between pain and all categorical independent variables. For the association between age at death and pain at the end of life, decedents aged 65-69 were more likely to be in pain (96.5%), followed by those aged 70-74 (81.4%), those aged 80-84 (75.7%), those aged 85-89 (73.3%), those aged 90 and older (72.2%), and finally those aged 75-79 (69.0%). Women were also more likely to have pain at the end of life (79.8%), compared

to men (68.1%). A higher proportion of Black decedents were in pain at the end of life (76.2%) than White decedents (74.5%). White women were more likely to be in pain (80.0%), followed by Black women (77.6%), Black men (74.5%), and then White men (68.1%). Decedents with low income were more likely to be in pain (76.2%), followed by those with moderate income (74.1%), and those with high income (65.2%). Decedents with less than a high school education were more likely to be in pain (78.4%), followed by those with only a high school diploma (76.0%), and then those with post-secondary education (71.8%). Those living alone were more likely to be in pain at the end of life (75.8%), than those living with others (73.9%). On the other hand, those living in non-metropolitan areas were also more likely to be in pain (76.8%) than those in metropolitan areas (74.1%). Those with fair or poor health were more likely to be in pain at the end of life (78.5%) than those in excellent or good health (69.9%). For the round of interview and pain at the end of life, those in round 10 were more likely to be in pain at the end of life (80.8%), followed by those in round 7 (80.4%), those in round 4 (76.0%), those in round 5 (74.7%), those in round 6 (74.4%), those in round 8 (73.7%), those in round 9 (72.1%), and those in round 3 (67.2%).

Table 9

Bivariate Association between Pain and all Categorical Independent Variables

Variable	Value	Percent in Pain	Chi-Square
Age at Death	65-69	96.5%	64858.149 *
	70-74	81.4%	

	75-79	69.0%	
	80-84	75.7%	
	85-89	73.3%	
	90+	72.2%	
Gender	Men	68.7%	67803.791*
	Women	79.8%	
Race	White	74.5%	488.923*
	Black	76.2%	
Race x Gender	White Men	68.1%	71738.443*
	White Women	80.0%	
	Black Men	74.5%	
	Black Women	77.6%	

* $p < .05$

Table 9 (continued)

Variable	Value	Percent in Pain	Chi-Square
Income	Low Income	76.2%	27391.491*
	Moderate Income	74.1%	
	High Income	65.2%	

Education	Less than High School	78.4%	16811.844 *
	High School	76.0%	
	Post-Secondary	71.8%	
Living Arrangement	Alone	75.8%	1839.410 *
	With Others	73.9%	
Geographic Location	Metropolitan	74.1%	2730.233 *
	Non-Metropolitan	76.8%	
Self-Rated Health	Excellent or Good	69.9%	40147.684 *
	Fair or Poor	78.5%	

* $p < .05$

Table 9 (continued)

Variable	Value	Percent in Pain	Chi-Square
Round Round 3	67.2%	37222.504 *	
Round 4	76.0%		
Round 5	74.7%		
Round 6	74.4%		

Round 7	80.4%
Round 8	73.7%
Round 9	72.1%
Round 10	80.8%

* $p < .05$

Bivariate Results for Pain and all Continuous Independent Variables

Table 10 depicts the bivariate association between pain and all continuous independent variables. For social network size, every one-unit increase in the number of people in a decedent’s social network resulted in a higher likelihood of being in pain ($OR=1.144$, $CI=1.142-1.146$). For chronic illness, every one unit-increase in the number of chronic illnesses a decedent resulted in a higher likelihood of being in pain ($OR=1.356$, $CI=1.354-1.359$). For functional limitations, every one-unit increase in the number of functional limitations a decedent led to a higher likelihood of being in pain ($OR=1.022$, $CI=1.021-1.022$). For health insurance, every one-unit increase in the number of additional health insurance plans a decedent resulted in a lower likelihood of being in pain ($OR=.876$, $CI=.873-.880$). For depression, every one-unit increase in the number of depressive symptoms led to a higher likelihood of being in pain ($OR=1.172$, $CI=1.170-1.173$). For anxiety, every one-unit increase in the number of anxiety symptoms resulted in a higher likelihood of being in pain ($OR=1.105$, $CI=1.103-1.106$). All of the pain odds ratios had a small effect size relative to Cohen’s d (Chen et al., 2010), indicating a weak association between pain and all the continuous independent variables.

Table 10*Bivariate Association between Pain and all Continuous Independent Variables*

Variable	Range	Odds Ratio	Confidence Interval
Social Network Size	0-5	1.144 *	1.142-1.146
Number of Chronic Illnesses	0-8	1.356 *	1.354-1.359
Functional Limitations	0-16	1.022 *	1.021-1.022
Health Insurance	0-3	.876 *	.873-.880
Depression	0-6	1.172 *	1.170-1.173
Anxiety	0-6	1.105 *	1.103-1.106

* $p < .05$

Bivariate Results for Anxiety/Depression and all Categorical Independent Variables

Table 11 shows the bivariate association between anxiety/depression and all categorical independent variables. For the association between age at death and anxiety/depression at the end of life, those aged 65-69 were more likely to have anxiety/depression at the end of life (63.4%), followed by those aged 80-84 (62.6%), those aged 85-89 (60.7%), those aged 90 and older

(60.0%), those aged 75-79 (59.3%), and then those aged 70-74 (54.6%). For the association between gender and anxiety/depression at the end of life, women were more likely to have anxiety/depression at the end of life (62.0%), compared to men (57.7%). For anxiety/depression, White decedents were more likely to experience anxiety/depression at the end of life (61.5%) than Black decedents (45.0%). For the association between the race/gender intersection and anxiety/depression, White women were the most likely to have anxiety/depression at the end of life (63.1%), followed by White men (59.5%), Black women (50.2%), and Black men (39.1%). Decedents with low income were more likely to have anxiety/depression at the end of life (27.0%), followed by those with moderate income (22.0%), and those with high income (10.9%). Those with only a high school diploma were more likely to have anxiety/depression at the end of life (63.5%), followed by those with post-secondary education (60.1%), and then those with less than a high school education (55.0%). Those living alone were more likely to have anxiety/depression at the end of life (53.3%) than those living with others (6.5%). Those in non-metropolitan areas were more likely to have anxiety/depression at the end of life (62.5%) than those in metropolitan areas (59.3%). Those with fair or poor health were also more likely to have anxiety/depression at the end of life (64.9%) than those with excellent or good health (53.8%). For the round of interview and anxiety/depression at the end of life, those in round 10 were the most likely to have anxiety/depression at the end of life (66.7%), followed by those in round 7 (64.0%), those in round 5 (64.2%), those in round 7 (64.0%), those in round 3 (61.4%), those in round 9 (58.4%), those in round 4 (58.1%), those in round 6 (55.0%), and those in round 8 (54.8%).

Table 11

Bivariate Association between Anxiety/Depression and all Categorical Independent Variables

Variable	Value	Percent with Anxiety/Depression	Chi-Square
Age at Death	65-69	63.4%	10543.598 *
	70-74	54.6%	
	75-79	59.3%	
	80-84	62.6%	
	85-89	60.7%	
	90+	60.0%	
Gender	Men	57.7%	8008.347
	Women	62.0%	
Race	White	61.5%	38397.120 *
	Black	45.0%	
Race x Gender	White Men	59.5%	48245.014 *
	White Women	63.1%	
	Black Men	39.1%	
	Black Women	50.2%	

* $p < .05$

Table 11 (continued)

Variable	Value	Percent with Anxiety/Depression	Chi-Square
Income	Low Income	59.0%	15412.453 *
	Moderate Income	67.5%	
	High Income	57.9%	
Education	Less than High School	55.0%	17171.161 *
	High School	63.5%	
	Post-Secondary	60.1%	
Living Arrangement	Alone	63.6%	14310.995 *
	With Others	57.7%	
Geographic Location	Metropolitan	59.3%	2877.905 *
	Non-Metropolitan	62.5%	
Self-Rated Health	Excellent or Good	53.8%	53329.489 *
	Fair or Poor	64.9%	

* $p < .05$

Table 11 (continued)

Variable	Value	Percent with Anxiety/Depression	Chi-Square
Round	Round 3	61.4%	27717.834 *
	Round 4	58.1%	
	Round 5	64.2%	
	Round 6	55.0%	
	Round 7	64.0%	
	Round 8	54.8%	
	Round 9	58.4%	
	Round 10	66.7%	

* $p < .05$

Bivariate Results for Anxiety/Depression and all Continuous Independent Variables

Table 12 shows the bivariate association between anxiety/depression and all continuous independent variables. For social network size, every one-unit increase in the number of people in a person's social network resulted in a higher likelihood of having anxiety/depression at the end of life ($OR=1.092$, $CI=1.094-1.098$). For chronic illnesses, every one-unit increase in the number of chronic illnesses resulted in a higher likelihood of having anxiety/depression at the end of life ($OR=1.193$, $CI=1.191-1.194$). For functional limitations, every one-unit increase in the number of functional limitations resulted in a higher likelihood of having anxiety/depression at the end of life ($OR=1.054$, $CI=1.054-1.055$). For health insurance, every one-unit increase in the number of additional health insurance plans resulted in a higher likelihood of having anxiety/depression at the end of life ($OR=1.157$, $CI=1.153-1.162$).

For depression, every one-unit increase in the number of depressive symptoms resulted in a higher likelihood of having anxiety/ depression at the end of life ($OR=1.169$, $CI=1.168-1.171$).

For anxiety, every one-unit increase in the number of anxiety symptoms resulted in a higher likelihood of having anxiety/depression at the end of life ($OR=1.246$, $CI=1.245-1.248$). All of the anxiety/depression odds ratios had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between anxiety/depression and all the continuous independent variables.

Table 12

Bivariate Association between Anxiety/Depression and all Continuous Independent Variables

Variable	Range	Odds Ratio	Confidence Interval
Social Network Size	0-5	1.092 *	1.094-1.098
Number of Chronic Illnesses	0-8	1.193 *	1.191-1.194
Functional Limitations	0-16	1.054 *	1.054-1.055
Health Insurance	0-3	1.157 *	1.153-1.162
Depression	0-6	1.169 *	1.168-1.171
Anxiety	0-6	1.246 *	1.245-1.248

* $p<.05$

Bivariate Results for Being Alone at Death and all Categorical Independent Variables

Table 13 shows the bivariate association between being alone at death and all categorical independent variables. For the association between age at death and being alone at death, decedents aged 90 and older were more likely to be alone at death (34.1%), followed by those aged 85-89 (26.5%), those aged 75-79 (25.6%), those aged 80-84 (20.2%), those aged 70-74

(14.3%), and then those aged 65-69 (11.9%). Women were more likely to be alone at death (27.0%) than men (21.6%). Black decedents were slightly more likely to be alone at death (25.3%) than White decedents (24.4%). Black men were more likely to be alone at death (32.5%), followed by White women (27.7%), White men (20.5%), and then Black women (19.0%). Decedents with moderate income were more likely to be alone at death (67.5%), followed by those with low income (59.0%), and those with high income (57.9%). Those with post-secondary education were more likely to be alone at death (26.3%), followed by those with only a high school diploma (25.8%), and those with less than a high school education (19.0%). Those living alone were also more likely to be alone at death (63.6%) than those living with others (57.7%).

Those in non-metropolitan areas were more likely to be alone at death (26.8%) than those in metropolitan areas (23.9%). Those with excellent or good health were more likely to be alone at death (26.5%) than those in fair or poor health (22.9%). Those in round 7 were the most likely to be alone at death (35.6%), followed by those in round 6 (28.6%), those in round 5 (28.0%), those in round 8 (26.0%), those in rounds 3 and 9 (21.5% each), those in round 10 (18.8%), and those in round 4 (16.8%).

Table 13*Bivariate Association between Being Alone at Death and all Categorical Independent Variables*

Variable	Value	Percent Alone at Death	Chi-Square
Age at Death	65-69	11.9%	100679.622
			*
	70-74	14.3%	
	75-79	25.6%	
	80-84	20.2%	
	85-89	26.5%	
	90+	34.1%	
Gender	Men	21.6%	16151.177 *
	Women	27.0%	
Race	White	24.4%	149.853 *
	Black	25.3%	
Race x Gender	White Men	20.5%	36002.253 *
	White Women	27.7%	
	Black Men	32.5%	

Black Women 19.0%

* $p < .05$

Table 13 (continued)

Variable	Value	Percent Alone at Death	Chi-Square
Income	Low Income	27.0%	61270.701 *
	Moderate Income	22.0%	
	High Income	10.9%	
Education	Less than High School	19.0%	20141.137 *
	High School	25.8%	
	Post-Secondary	26.3%	
Living Arrangement	Alone	53.3%	1183990.30 *
	With Others	6.5%	
Geographic Location	Metropolitan	23.9%	3276.285 *
	Non-Metropolitan	26.8%	
Self-Rated Health	Excellent or Good	26.5%	7027.999 *
	Fair or Poor	22.9%	

* $p < .05$

Table 13 (continued)

Variable	Value	Percent Alone at Death	Chi-Square
Round	Round 3	21.5%	75032.563 *
	Round 4	16.8%	
	Round 5	28.0%	
	Round 6	28.6%	
	Round 7	35.6%	
	Round 8	26.0%	
	Round 9	21.5%	
	Round 10	18.8%	

* $p < .05$

Bivariate Results for Being Alone at Death and all Continuous Independent Variables

Table 14 shows the bivariate association between being alone at death and all continuous independent variables. For social network size, every one-unit increase in the number of people in a person’s social network resulted in a higher likelihood of being alone at death ($OR=1.064$, $CI=1.063-1.066$). For chronic illnesses, every one-unit increase in the number of chronic illnesses resulted in a lower likelihood of being alone at death ($OR=.867$, $CI=.866-.869$). For functional limitations, every one-unit increase in the number of functional limitations resulted in a lower likelihood of being alone at death ($OR=.854$, $CI=.854-.855$). For health insurance, every

one-unit increase in the number of additional health insurance plans resulted in a lower likelihood of being alone at death ($OR=.914$, $CI=.910-.917$). For depression, every one-unit increase in the number of depressive symptoms resulted in a lower likelihood of being alone at death ($OR=.961$, $CI=.960-.963$). For anxiety, every one-unit increase in the number of anxiety symptoms resulted in a lower likelihood of being alone at death ($OR=.966$, $CI=.964-.967$). All of the alone at death odds ratios had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between being alone at death and all the continuous independent variables.

Table 14

Bivariate Association between Being Alone at Death and all Continuous Independent Variables

Variable	Range	Odds Ratio	Confidence Interval
Social Network Size	0-5	1.064 *	1.063-1.066
Number of Chronic Illnesses	0-8	.867 *	.866-.869
Functional Limitations	0-16	.854 *	.854-.855
Health Insurance	0-3	.914 *	.910-.917
Depression	0-6	.961 *	.960-.963
Anxiety	0-6	.966 *	.964-.967

* $p < .05$

Bivariate Results for Religious Belief Discussions and all Categorical Independent Variables

Table 15 depicts the bivariate association between religious belief discussions and all categorical independent variables. For the association between age at death and religious belief discussions, those aged 85-89 were more likely to have had religious belief discussions with their providers (55.2%), followed by those aged 80-84 (48.3%), those aged 90 and older (48.0%), those aged 65-69 (44.0%), those aged 75-79 (39.4%), and those aged 70-74 (38.0%). For the discussion of religious beliefs, more women had religious belief discussions with their providers (48.3%), than men (44.6%). Black decedents were also more likely to have had religious belief discussions with their providers (48.3%) than White decedents (46.4%). Black men were more likely to have religious belief discussions with their providers (49.6%), followed by White women (48.4%), Black women (47.2%), and then White men (44.1%). Decedents with moderate income were more likely to engage in religious belief discussions with their providers (50.7%), followed by those with low income (47.5%), and those with high income (36.1%). Decedents with less than a high school education were more likely to have religious belief discussions with their providers (47.2%), followed by those with post-secondary education (46.9%), and then those with only a high school diploma (45.7%). Those living alone were more likely to have religious belief discussions with their providers (49.2%) than those living with others (45.0%). Decedents in non-metropolitan areas were more likely to have religious belief discussions with their providers (52.8%) than those in metropolitan areas (44.9%). Those with excellent or good health were more likely to have religious belief discussions with their providers (52.6%) than those in fair or poor health (39.1%). Those in round 7 were more likely to have religious belief discussions with providers (54.0%), followed by those in round 5 (53.2%), those in round 10 (51.4%), those in round 3 (47.2%), those in round 4 (45.0%), those in round 8 (43.7%), and those in round 9 (43.5%).

Table 15*Bivariate Association between Religious Belief Discussions and all Categorical Independent**Variables*

Variable	Value	Percent who had Religious Belief Discussions	Chi-Square
Age at Death	65-69	44.0%	61314.595 *
	70-74	38.0%	
	75-79	39.4%	
	80-84	48.3%	
	85-89	55.2%	
	90+	48.0%	
Gender	Men	44.6%	5572.319 *
	Women	48.3%	
Race	White	46.4%	498.959 *
	Black	48.3%	
Race x Gender	White Men	44.1%	7590.211 *

White Women	48.4%
Black Men	49.6%
Black Women	47.2%

* $p < .05$

Table 15 (continued)

Variable	Value	Percent who had Religious Belief Discussions	Chi-Square
Income	Low Income	47.5%	26067.986 *
	Moderate Income	50.7%	
	High Income	36.1%	
Education	Less than High School	47.2%	631.070 *
	High School	45.7%	
	Post-Secondary	46.9%	
Living Arrangement	Alone	49.2%	6908.575 *
	With Others	45.0%	

Geographic Location	Metropolitan	44.9%	17318.550 *
	Non-Metropolitan	52.8%	

* $p < .05$

Table 15 (continued)

Variable	Value	Percent who had Religious Belief Discussions	Chi-Square
Self-Rated Health	Excellent or Good	52.6%	76171.554 *
	Fair or Poor	39.1%	
Round	Round 3	47.2%	45964.004 *
	Round 4	45.0%	
	Round 5	53.2%	
	Round 6	36.9%	
	Round 7	54.0%	
	Round 8	43.7%	
	Round 9	43.5%	
	Round 10	51.4%	

* $p < .05$

Bivariate Results for Religious Belief Discussions and all Continuous Independent Variables

Table 16 shows the bivariate association between religious belief discussions and all continuous independent variables. For social network size, every one-unit increase in the number of people in a person's social network resulted in a higher likelihood of having religious belief discussions ($OR=1.064$, $CI=1.062-1.065$). For chronic illnesses, every one-unit increase in the number of chronic illnesses resulted in a higher likelihood of having religious belief discussions with providers ($OR=1.105$, $CI=1.107$). For functional limitations, every one-unit increase in the number of functional limitations led to a higher likelihood of having religious belief discussions with their providers ($OR=1.021$, $CI=1.020-1.021$). For health insurance, every one-unit increase in the number of additional health insurance plans resulted in a lower likelihood of having religious belief discussions with their providers ($OR=.823$, $CI=.820-.836$).

For depression, every one-unit increase in the number of depressive symptoms resulted in a higher likelihood of having religious belief discussions with providers ($OR=1.079$, $CI=1.078-1.081$). For anxiety, every one-unit increase in the number of anxiety symptoms resulted in a higher likelihood of having religious belief discussions with providers ($OR=1.066$, $CI=1.065-1.067$). Each of these religious belief discussions odds ratios had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between religious belief discussions and all the continuous independent variables.

Table 16

Bivariate Association between Religious Belief Discussions and all Continuous Independent Variables

Variable	Range	Odds Ratio	Confidence Interval
Social Network Size	0-5	1.064 *	1.062-1.065
Number of Chronic Illnesses	0-8	1.105 *	1.104-1.107
Functional Limitations	0-16	1.021 *	1.020-1.021
Health Insurance	0-3	.823 *	.820-.836
Depression	0-6	1.079 *	1.078-1.081
Anxiety	0-6	1.066 *	1.065-1.067

* $p < .05$

Bivariate Results for Treated with Respect and all Categorical Independent Variables

Table 17 illustrates the bivariate association between being treated with respect and all categorical independent variables. For the association between age at death and being treated

with respect, 100% of decedents were treated with respect always, usually, or sometimes, across all age groups except those aged 75-79, among whom 99.2% were treated with respect always, usually, or sometimes. One hundred percent of men were treated with respect always, usually, or sometimes, while 99.7% of women were treated with respect always, usually, or sometimes. Similarly, one hundred percent of Black decedents were treated with respect always, usually, or sometimes, while 99.8% of White decedents had the same treatment. One hundred percent of all race/gender groups were also treated with respect always, usually, or sometimes, except for White women (99.7%). One hundred percent of decedents with moderate or high income were treated with respect always, usually, or sometimes, while 99.8% of those with low income had the same treatment. One hundred percent of those with less than a high school education and those with only a high school education were treated with respect always, usually, or sometimes, while 99.7% of those with post-secondary education had the same treatment. One hundred percent of those living alone were treated with respect always, usually, or sometimes, while 99.8% of those living with others had the same treatment. One hundred percent of metropolitan decedents were treated with respect always, usually, or sometimes, while 99.3% of non-metropolitan decedents had the same treatment. One hundred percent of those in excellent or good health were treated with respect always, usually, or sometimes, whereas 99.7% of those in poor or fair health had the same treatment., Except for those in round 8 (99.1%), and those in round 10 (99.9%), one hundred percent of decedents in all rounds were treated with respect always, usually, or sometimes.

Table 17*Bivariate Association between Treated with Respect and all Categorical Independent Variables*

Variable	Value	Percent Treated with Respect	Chi-Square
Age at Death	65-69	100%	26933.766 *
	70-74	100%	
	75-79	99.2%	
	80-84	100%	
	85-89	100%	
	90+	100%	
Gender	Men	100%	5151.545 *
	Women	99.7%	
Race	White	99.8%	584.848 *
	Black	100%	
Race x Gender	White Men	100%	6210.286 *

White Women 99.7%

Black Men 100%

Black Women 100%

* $p < .05$

Table 17 (continued)

Variable	Value	Percent Treated with	Chi-Square
		Respect	
Income	Low Income	99.8%	1984.311 *
	Moderate Income	100%	
	High Income	100%	
Education	Less than High School	100%	7271.310 *
	High School	100%	
	Post-Secondary	99.7%	
Living Arrangement	Alone	100%	3699.634
	With Others	99.8%	
Geographic Location	Metropolitan	100%	22210.024 *

	Non-Metropolitan	99.3%	
Self-Rated Health	Excellent or Good	100%	4764.338 *
	Fair or Poor	99.7%	

* $p < .05$

Table 17 (continued)

Variable	Value	Percent Treated with Respect	Chi-Square
Round	Round 3	100%	33484.315 *
	Round 4	100%	
	Round 5	100%	
	Round 6	100%	
	Round 7	100%	
	Round 8	99.1%	
	Round 9	100%	
	Round 10	99.9%	

* $p < .05$

Bivariate Results for Treated with Respect and all Continuous Independent Variables

Table 18 shows the bivariate association between treated with respect and all continuous independent variables. For social network size, no significant association was found between social network size and being treated with respect. For chronic illnesses, every one-unit increase in the number of chronic illnesses resulted in a lower likelihood of being treated with respect

($OR=.409$, $CI=.401-.417$). For functional limitations, every one-unit increase in the number of functional limitations resulted in a higher likelihood of being treated with respect ($OR=1.034$, $CI=1.026-1.042$). For health insurance, every one-unit increase in the number of additional health insurance plans resulted in a lower likelihood of being treated with respect always, usually, or sometimes ($OR=.651$, $CI=.622-.682$). For depression, every one-unit increase in the number of depressive symptoms resulted in a higher likelihood of being treated with respect always, usually, or sometimes ($OR=1.274$, $CI=1.249-1.299$). For anxiety, every one-unit increase in the number of anxiety symptoms led to a lower likelihood of being treated with respect always, usually, or sometimes ($OR=.815$, $CI=.805-.825$). All of the treated with respect odds ratios had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between treated with respect and all the continuous independent variables.

Table 18

Bivariate Association between Treated with Respect and all Continuous Independent Variables

Variable	Range	Odds Ratio	Confidence Interval
Social Network Size	0-5	.000	.000-18.204
Number of Chronic Illnesses	0-8	.409 *	.401-.417
Functional Limitations	0-16	1.034 *	1.026-1.042
Health Insurance	0-3	.651 *	.622-.682
Depression	0-6	1.274*	1.249-1.299
Anxiety	0-6	.815 *	.805-.825

* $p < .05$

Bivariate Results for Decisions without Input and all Categorical Independent Variables

Table 19 shows the bivariate association between having decisions made without input and all categorical independent variables. For the association between age at death and decisions being made without the patient's input, decedents aged 75-79 were more likely to have decisions made without their input (13.1%), followed by those aged 70-74 (8.4%), those aged 80-84 (7.8%), those aged 90 and older (4.0%), those aged 85-89 (3.9%), and then those aged 65-69 (0.00%). Seven point six percent of men had decisions made without their input, compared to 6.4% of women. More Black decedents had decisions made without their input (11.0%) compared to White decedents (6.5%). Black women were the most likely to have decisions made without their input (13.5%), followed by Black men (8.1%), White men (7.5%), and then White women (5.7%). Those with high income were more likely to have decisions made without their input (7.1%), followed by those with low income (6.9%), and those with moderate income (6.7%). Those with only a high school diploma were more likely to have decisions made without their input (9.1%), followed by those with post-secondary education (6.5%), and then those with less than a high school education (4.7%). Those living with others were more likely to have decisions made without their input (7.2%) than those living alone (6.4%). Those living in metropolitan areas were more likely to have decisions made without their input (7.6%) than those living in non-metropolitan areas (4.5%). Those with excellent or good health were more likely to have decisions made without their input (7.9%) than those in fair or poor health (6.2%). Those in round 10 were more likely to have decisions made without their input (13.2%), followed by those in round 3 (10.2%), those in round 7 (9.1%), those in round 8 (7.1%), those in round 9 (7.0%), those in round 4 (5.0%), those in round 6 (4.9%), and those in round 5 (1.9%).

Table 19

Bivariate Association between Decisions without Input and all Categorical Independent Variables

Variable	Value	Percent Who Had Decisions Made Without Their Input	Chi-Square
Age at Death	65-69	0.00%	82029.323 *
	70-74	8.4%	
	75-79	13.1%	
	80-84	7.8%	
	85-89	3.9%	
	90+	4.0%	
Gender	Men	7.6%	2361.839 *
	Women	6.4%	
Race	White	6.5%	10421.128 *

	Black	11.0%	
Race x Gender	White Men	7.5%	19669.939 *
	White Women	5.7%	
	Black Men	8.1%	
	Black Women	13.5%	

* $p < .05$

Table 19 (continued)

Variable	Value	Percent Who Had Decisions Made Without Their Input	Chi-Square
Income	Low Income	6.9%	79.91 *
	Moderate Income	6.7%	
	High Income	7.1%	
Education	Less than High School	4.7%	17501.223 *
	High School	9.1%	
	Post-Secondary	6.5%	
Living Arrangement	Alone	6.4%	1037.285 *
	With Others	7.2%	

Geographic Location	Metropolitan	7.6%	9948.180 *
	Non-Metropolitan	4.5%	

**p*<.05

Table 19 (continued)

Variable	Value		Percent Who Had Decisions Made Without Their Input	Chi-Square
Self-Rated Health	Excellent or Good	7.9%	4701.977 *	
	Fair or Poor	6.2%		
Round	Round 3	10.2%	39185.154 *	
	Round 4	5.0%		
	Round 5	1.9%		
	Round 6	4.9%		
	Round 7	9.1%		
	Round 8	7.1%		

Round 9	7.0%
Round 10	13.2%

* $p < .05$

Bivariate Results for Decisions without Input and all Continuous Independent Variables

Table 20 depicts the bivariate association between treated with respect and all continuous independent variables. For social network size, every one-unit increase in the number of people in a person’s social network led to a lower likelihood of having decisions made without the patient’s input ($OR=.867$, $CI=.864-.870$). For chronic illnesses, every one-unit increase in the number of chronic illnesses resulted in a lower likelihood of having decisions made without the patient’s input ($OR=.838$, $CI=.836-.841$). For functional limitations, every one-unit increase in the number of functional limitations resulted in a lower likelihood of having decisions made without the patient’s input ($OR=.947$, $CI=.946-.948$). For health insurance, every one-unit increase in the number of additional health insurance plans resulted in a higher likelihood of having decisions made without the patient’s input ($OR=1.075$, $CI=1.068-1.083$). For depression, every one-unit increase in the number of depressive symptoms resulted in a higher likelihood of having decisions made without the patient’s input ($OR=1.023$, $CI=1.021-1.026$). For anxiety, every one-unit increase in the number of anxiety symptoms resulted in a higher likelihood of having decisions made without the patient’s input ($OR=1.024$, $CI=1.022-1.026$). All of the decisions without input odds ratios had a small effect size relative to Cohen’s d (Chen et al., 2010), indicating a weak association between having decisions made without input and all the continuous independent variables.

Table 20

Bivariate Association Decisions without Input and all Continuous Independent Variables

Variable	Range	Odds Ratio	Confidence Interval
Social Network Size	0-5	.867 *	.864-.870
Number of Chronic Illnesses	0-8	.838 *	.836-.841
Functional Limitations	0-16	.947 *	.946-.948
Health Insurance	0-3	1.075 *	1.068-1.083
Depression	0-6	1.023 *	1.021-1.026
Anxiety	0-6	1.024 *	1.022-1.026

* $p < .05$

Bivariate Results for Overall Care Rating and all Categorical Independent Variables

Table 21 shows the bivariate association between overall care rating and all categorical independent variables. For the association between age at death and overall care rating,

decedents aged 90 and older were more likely to report having excellent or good care at the end of life (88.0%), followed by those aged 85-89 (86.3%), those aged 80-84 (83.5%), those aged 65-69 (81.9%), those aged 75-79 (78.8%), and those aged 70-74 (70.3%). Men were more likely to have excellent or good care at the end of life (83.6%) than women (81.4%). White decedents were more likely to report having excellent or good care at the end of life (83.9%) compared to Black decedents (79.0%). White men were more likely to have excellent or good care at the end of life (83.9%), followed by White women (81.7%), Black men (80.6%), and then Black women (77.6%). Those with high income were more likely to receive excellent or good care at the end of life (91.9%), followed by those with low income (81.4%), and then those with moderate income (79.5%). Those less than a high school education were more likely to receive excellent or good care at the end of life (84.4%), followed by those with post-secondary education (83.5%), and then those with only a high school diploma (79.4%). Those living with others were more likely to have excellent or good care at the end of life (82.7%) than those living alone (82.0%). Non-metropolitan decedents were more likely to have excellent or good care at the end of life (84.5%) than metropolitan decedents (81.8%). Those with excellent or good health were more likely to have excellent or good care at the end of life (85.1%), than those with fair or poor health (80.2%). Those in Round 5 (86.5%) and Round 9 (86.5%) were the most likely to have excellent or good care at the end of life, followed by those in Round 4 (85.4%), those in Round 3 (83.9%), those in Round 6 (83.3%), those in Round 7 (80.5%), those in Round 8 (76.4%), and those in Round 10 (75.9%).

Table 21*Bivariate Association between Overall Care Rating and all Categorical Independent Variables*

Variable	Value	Percent with Excellent or Good Care	Chi-Square
Age at Death	65-69	81.9%	93915.726 *
	70-74	70.3%	
	75-79	78.8%	
	80-84	83.5%	
	85-89	86.3%	
	90+	88.0%	
Gender	Men	83.6%	3452.196 *
	Women	81.4%	
Race	White	82.7%	3207.639 *

	Black	79.0%	
Race x Gender	White Men	83.9%	6725.590 *
	White Women	81.7%	
	Black Men	80.6%	
	Black Women	77.6%	

* $p < .05$

Table 21 (continued)

Variable	Value	Percent with Excellent or Good Care	Chi-Square
Income	Low Income	81.4%	35762.026 *
	Moderate Income	79.5%	
	High Income	91.9%	
Education	Less than High School	84.4%	12513.247 *
	High School	79.4%	
	Post-Secondary	83.5%	
Living Arrangement	Alone	82.0%	345.703 *

	With Others	82.7%	
Geographic Location	Metropolitan	81.8%	3371.034 *
	Non-Metropolitan	84.5%	
Self-Rated Health	Excellent or Good	85.1%	17234.026 *
	Fair or Poor	80.2%	

* $p < .05$

Table 21 (continued)

Variable	Value	Percent with Excellent or Good Care	Chi-Square
Round	Round 3	83.9%	44025.894 *
	Round 4	85.2%	
	Round 5	86.5%	
	Round 6	83.3%	
	Round 7	80.5%	
	Round 8	76.4%	
	Round 9	86.5%	
	Round 10	75.9%	

* $p < .05$

Bivariate Results for Overall Care Rating and all Continuous Independent Variables

Table 22 depicts the bivariate association between overall care rating and all continuous independent variables. For social network size, every one-unit increase in the number of people in a person’s social network resulted in a higher likelihood of having excellent or good care at the end of life ($OR=1.022$, $CI=1.020-1.024$). For chronic illnesses, every one-unit increase in the number of chronic illnesses resulted in a lower likelihood of having excellent or good care at the end of life ($OR=.951$, $CI=.950-.953$). For functional limitations, every one-unit increase in the number of functional limitations resulted in a lower likelihood of having excellent or good care at the end of life ($OR=.951$, $CI=.950-.953$). For health insurance, every one-unit increase in the number of additional health insurance plans resulted in a higher likelihood of having excellent or good care at the end of life ($OR=1.049$, $CI=1.044-1.053$). For depression, every one-unit increase in the number of depressive symptoms resulted in a lower likelihood of having excellent or good care at the end of life ($OR=.891$, $CI=.890-.893$). For anxiety, every one-unit increase in the number of anxiety symptoms resulted in a lower likelihood of having excellent or good care at the end of life ($OR=.918$, $CI=.917-.919$). All of the overall care rating odds ratios had a small effect size relative to Cohen’s d (Chen et al., 2010), indicating a weak association between overall care rating and all the continuous independent variables.

Table 22

Bivariate Association between Overall Care Rating and all Continuous Independent Variables

Variable	Range	Odds Ratio	Confidence Interval
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Social Network Size	0-5	1.022 *	1.020-1.024
Number of Chronic Illnesses	0-8	.996 *	.995-.997
Functional Limitations	0-16	1.022 *	1.021-1.022
Health Insurance	0-3	1.049 *	1.044-1.053
Depression	0-6	.891 *	.890-.893
Anxiety	0-6	.918 *	.917-.919

* $p < .05$

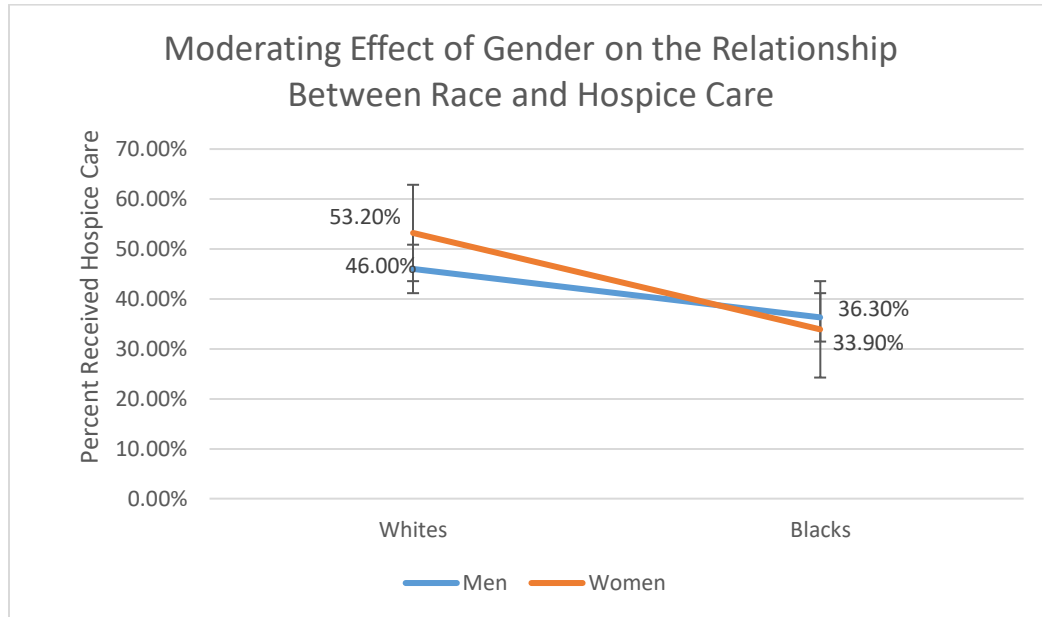
Multivariate

The multivariate analyses included two logistic regression models for each dependent variable. Model 1 (main effect analysis) included all independent variables, without the interaction term. Model 2 (interaction analysis) included the race x gender interaction term to test the moderating effect of gender on the relationship between race and all dependent variables. For all logistic regression models, the assumptions for a logistic regression were met; all of the eight dependent variables were categorical, there were 14 independent variables, and the measures for all variables were not repeated. There was no multicollinearity between the variables, with VIF of less than 10 (Schreiber-Gregory, 2018). There were no logit outliers, and the Box-Tidwell Test revealed no linearity between the independent variables (Sarkar et al., 2011; Schreiber-Gregory, 2018).

Hospice Care

Figure 2

Moderating Effect of Gender on the Relationship between Race and Hospice Care



Note. The differing (non-parallel) slope lines for men and women show that the effect of race on hospice care is dependent on the gender of the decedent.

Table 23

Logistic Regressions for Hospice Care

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Race	White=0	Ref	Ref
	Black=1	.519 (.515-.523) *	.695 (.687-.702) *
Gender	Men=0	Ref	Ref
	Women=1	1.375 (1.369-1.381) *	1.445 (1.438-1.452) *

Race x Gender	-	-	.584 (.576-.593) *
Age at Death	65-69=0	Ref	Ref
	70-74=1	.603 (.596-.611) *	.598 (.590-.605) *
	75-79=2	.614 (.606-.622) *	.616 (.609-.624) *
	80-84=3	.829 (.819-.840) *	.836 (.825-.846) *
	85-89=4	.754 (.745-.764) *	.762 (.753-.772) *
	90+=5	.906 (.895-.917) *	.914 (.902-.925) *

* $p < .05$

Table 23 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Income	Low Income=0	Ref	Ref
	Moderate Income=1	.949 (.944-.955) *	.949 (.943-.954) *
	High Income=2	1.581 (1.570-1.593) *	1.590 (1.579-1.601) *

Education	Less Than High School=0	Ref	Ref
	High School=1	.829 (.824-.833) *	.830 (.825-.834) *
	Post-Secondary=2	.991 (.986-.996) *	.996 (.990-.1.001)
Living Arrangement	Alone=0	Ref	Ref
	With Others=1	1.110 (1.105-1.114) *	1.222 (1.117-1.127) *

* $p < .05$

Table 23 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Geographic Location	Metropolitan=0	Ref	Ref
	Non-Metropolitan=1	1.124 (1.118-1.130) *	1.117 (1.112-1.127) *

Self-Rated Health	Fair or Poor=0	Ref	Ref
	Excellent or Good=1	.641 (.638-.644) *	.639 (.636-.642) *

* $p < .05$

Table 23 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Round	Round 3=0	Ref	Ref
	Round 4=1	1.111 (1.103-1.120) *	1.108 (1.099-1.116) *
	Round 5=2	1.391 (1.379-1.403) *	1.390 (1.378-1.402) *
	Round 6=3	1.169 (1.160-1.179) *	1.158 (1.149-1.168) *
	Round 7=4	1.151 (1.142-1.160) *	1.139 (1.130-1.148) *
	Round 8=5	1.176 (1.167-1.185) *	1.157 (1.148-1.166) *

Round 9=6	1.259 (1.250-1.269) *	1.251 (1.242-1.261) *
Round 10=7	2.287 (2.267-2.307) *	2.283 (2.263-2.303) *

* $p < .05$

Table 23 (continued)

Variable	Value	Main Effect Analysis <i>OR (CI)</i>	Interaction Analysis <i>OR (CI)</i>
Social Network Size	0-5	1.019 (1.017-1.021) *	1.018 (1.016-1.019) *
Number of Chronic Illnesses	0-8	1.007 (1.005-1.008) *	1.1005 (1.004-1.007) *

Functional Limitations	0-16	1.009 (1.008-1.010) *	1.010 (1.009-1.011) *
Health Insurance	0-3	1.042 (1.039-1.046) *	1.040 (1.036-1.043) *
Depression	0-6	1.229 (1.227-1.231) *	1.229 (1.227-1.231) *
Anxiety	0-6	.902 (900-.903) *	.901 (900-.903) *

* $p < .05$

Table 24

Race Effect for the Association between Gender and Hospice Care

Hospice Care – Race Effect		
Comparing Women and Men by Race		
Gender	Race	Likelihood of Receiving Hospice Care
Women	Blacks	Less likely than White women
	Whites	More likely than Black women

Men	Blacks	Less likely than White men
	Whites	More likely than Black men

Table 25

Gender Effect for the Association between Race and Hospice Care

Hospice Care - Gender Effect		
Comparing Blacks and Whites by Gender		
Race	Gender	Likelihood of Receiving Hospice Care
Whites	Men	Less likely than White women
	Women	More likely than White men

Blacks	Men	More likely than Black women
	Women	Less Likely than Black men

Main Effect Analysis. Model 1 of the multivariate logistic regressions included the main effects of all variables, without the race/gender interaction term. Compared to those aged 65-69, decedents aged 70-74 ($OR=.603$, $CI=.596-.611$, $p<.05$), aged 75-79 ($OR=.614$, $CI=.606-.622$, $p < .05$), aged 80-84 ($OR=.829$, $CI=.819-.840$, $p < .05$), aged 85-89 ($OR=.754$, $CI=.745-.764$, $p < .05$), aged 90 and older ($OR=.906$, $CI=.895-.917$, $p < .05$) were all less likely to have received hospice care. Women were more likely to receive hospice care compared to men ($OR=1.375$, $CI=1.369-1.381$, $p < .05$) and Blacks were less likely to receive hospice care compared to Whites ($OR=.519$, $CI=.515-.523$, $p < .05$). Compared to those with low income, those with moderate income were less likely to receive hospice care ($OR=.949$, $CI=.944-.955$, $p < .05$), while those with high income were more likely to receive hospice care ($OR=1.581$, $CI=1.570-1.593$, $p < .05$). Compared to those with less than a high school education, those with only a high school diploma ($OR=.829$, $CI=.824-.833$, $p < .05$) and those with post-secondary education ($OR=.991$, $CI=.986-.996$, $p < .05$) were all less likely to receive hospice care. Those living with others were more likely to receive hospice care compared to those living alone ($OR=1.010$, $CI=1.105-1.114$, $p < .05$), and those living in non-metropolitan areas were more likely to receive hospice care than those living in metropolitan areas ($OR=1.124$, $CI=1.118-1.130$, $p < .05$). Those with excellent or good self-rated health were less likely to receive hospice care than those with fair or poor self-rated health ($OR=.641$, $CI=.638-.644$, $p < .05$). Compared to those in Round 3, decedents in Round 4 ($OR=1.111$, $CI=1.103-1.120$, $p < .05$), Round 5 ($OR=1.391$, $CI=1.379-1.403$, $p < .05$), Round 6 ($OR=1.169$, $CI=1.160-1.179$, $p < .05$), Round 7 ($OR=1.151$, $CI=1.142-1.160$, $p < .05$),

Round 8 ($OR=1.176$, $CI=1.167-1.185$, $p < .05$), Round 9 ($OR=1.259$, $CI=1.250-1.269$, $p < .05$), and Round 10 ($OR=2.287$, $CI=2.267-2.307$, $p < .05$) were all more likely to receive hospice care. Every one-unit increase in social network size was associated with a greater likelihood of receiving hospice care ($OR=1.019$, $CI=1.017-1.021$, $p < .05$), and every one-unit increase in the number of chronic illnesses was also associated with a greater likelihood of receiving hospice care ($OR=1.007$, $CI=1.005-1.008$, $p < .05$). In addition, every one-unit increase in functional limitations was associated with a greater likelihood of receiving hospice care ($OR=1.009$, $CI=1.008-1.010$, $p < .05$). Also, every additional number of health insurance plans increased the likelihood of receiving hospice care ($OR=1.021$, $CI=1.039-1.046$, $p < .05$). Every additional symptom of depression was associated with a greater likelihood of receiving hospice care ($OR=1.229$, $CI=1.227-1.231$, $p < .05$), while every additional symptom of anxiety was associated with a lower likelihood of receiving hospice care ($OR=.902$, $CI=.900-.903$, $p < .05$). All of the hospice care odds ratios in Model 1 had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between the independent variables and hospice care.

Interaction Analysis. Model 2 of the logistic regression included an interaction term for race and gender to determine whether gender moderates the relationship between race and hospice care. The logistic regression results revealed that race and gender interacted with one another to affect the probability of receiving hospice care at the end of life. This suggests that the effect of race on hospice care depends on the gender of the decedent; the effect of gender was dependent on their race, with a $<.05$ p -value for the interaction term. Specifically, among White decedents, women were more likely to receive hospice care compared to men, while among Black decedents, women were less likely to receive hospice care compared to men ($OR=1.445$, $CI=1.438-1.452$, $p <.05$). Regarding race effect, among men, Blacks were less likely than Whites

to receive hospice care; among women, Blacks were also less likely to receive hospice care compared to Whites ($OR=.695$, $CI=.687-.702$, $p < .05$). Compared to those aged 65-69, decedents aged 70-74 ($OR=.598$, $CI=.590-.605$, $p < .05$), those aged 75-79 ($OR=.616$, $CI=.609-.624$, $p < .05$), those aged 80-84 ($OR=.836$, $CI=.825-.846$, $p < .05$), and those aged 90 and older ($OR=.914$, $CI=.902-.925$, $p < .05$) were all less likely to receive hospice care. Compared to those with low income, decedents with moderate income were less likely to receive hospice care ($OR=.949$, $CI=.943-.954$, $p < .05$), while those with high income were more likely to receive hospice care ($OR=1.590$, $CI=1.579-1.601$, $p < .05$). Compared to those with less than a high school education, decedents with only a high school diploma ($OR=.830$, $CI=.825-.834$, $p < .05$) were less likely to receive hospice care, while there was no significant difference between those with less than a high school education and those with post-secondary education. Compared to those living alone, decedents who lived with others were more likely to receive hospice care ($OR=1.22$, $CI=1.117-1.127$, $p < .05$), and decedents living in non-metropolitan areas were more likely to receive hospice care than those in metropolitan areas ($OR=1.117$, $CI=1.112-1.127$, $p < .05$). Decedents with excellent or good self-rated health were less likely to receive hospice care than those with fair or poor health ($OR=.639$, $CI=.636-.642$, $p < .05$). Decedents in Round 4 ($OR=1.108$, $CI=1.099-1.116$, $p < .05$), Round 5 ($OR=1.390$, $CI=1.378-1.402$, $p < .05$), Round 6 ($OR=1.158$, $CI=1.149-1.168$, $p < .05$), Round 7 ($OR=1.139$, $CI=1.130-1.148$, $p < .05$), Round 8 ($OR=1.157$, $CI=1.148-1.166$, $p < .05$), Round 9 ($OR=1.251$, $CI=1.242-1.261$, $p < .05$), and Round 10 ($OR=2.283$, $CI=2.263-2.303$, $p < .05$) were more likely to receive hospice care than decedents in Round 3. Every one-unit increase in social network size resulted in a higher likelihood of receiving hospice care ($OR=1.018$, $CI=1.016-1.019$, $p < .05$), and every additional number of chronic illnesses also increased the likelihood of receiving hospice care ($OR=1.105$,

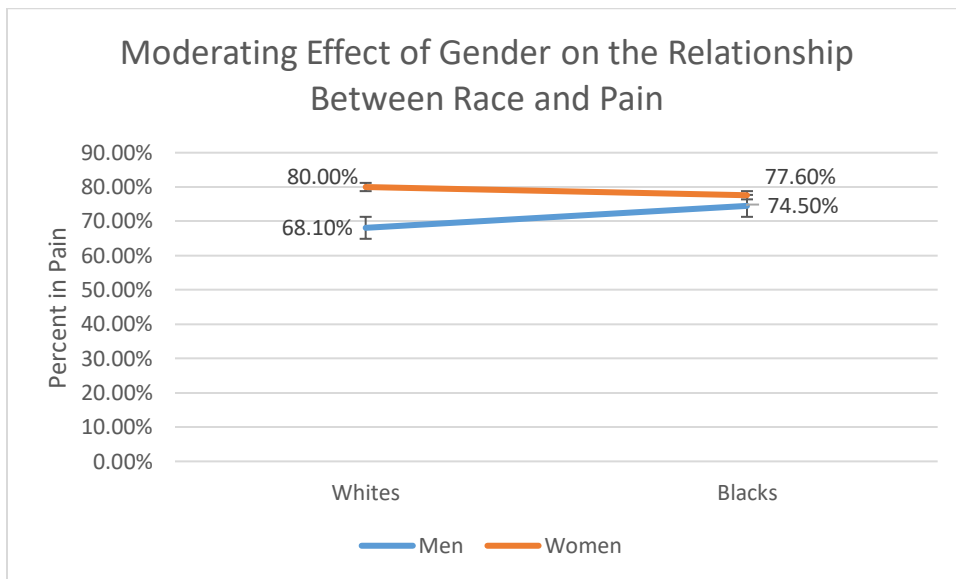
$CI=1.004-1.007, p < .05$). More functional limitations increased the likelihood of receiving hospice care ($OR=1.010, CI=1.009-1.011, p < .05$), and more health insurance plans also increased the likelihood of receiving hospice care ($OR=1.040, CI=1.036-1.043, p < .05$).

More depressive symptoms resulted in a greater likelihood of receiving hospice care ($OR=1.229, CI=1.227-1.231, p < .05$), while more anxiety symptoms decreased the likelihood of receiving hospice care ($OR=.901, CI=900-.903, p < .05$). All of the hospice care odds ratios in Model 2 had a small effect size relative to Cohen's d (Chen et al., 2010), indicating that the association between the independent variables and hospice care is a weak association. Figure 2 shows the moderating effect of gender on the relationship between race and hospice care. Table 23 shows all of the logistic regression results for Model 1 (main effect analysis) and Model 2 (interaction effect analysis) of the hospice care-dependent variable. Table 24 reports the interaction results for race effects, and Table 25 shows the interaction results for gender effects.

Pain

Figure 3

Moderating Effect of Gender on the Relationship between Race and Pain



Note. The differing (non-parallel) slope lines for men and women show that the effect of race on pain depends on the gender of the decedent.

Table 26

Logistic Regressions for Pain

Variable	Value	Main Effect Analysis <i>OR (CI)</i>	Interaction Analysis <i>OR (CI)</i>
Race	White=0	Ref	Ref
	Black=1	.948 (.940-.956) *	1.096 (1.082-1.109) *
Gender	Men=0	Ref	
	Women=1	1.430 (1.422-1.437) *	1.469 (1.461-1.477) *
Race x Gender	-	-	.751 (.738-.763) *

Age at Death	65-69=0	Ref	Ref
	70-74=1	.242 (.235-.250) *	.240 (.232-.247) *
	75-79=2	.101 (.098-.104) *	.101 (.098-.104) *
	80-84=3	.158 (.153-.163) *	.158 (.154-.163) *
	85-89=4	.137 (.133-.142) *	.138 (.134-.142) *
	90+=5	.124 (.121-.128) *	.124 (.121-.128) *

* $p < .05$

Table 26 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Income	Low Income=0	Ref	Ref
	Moderate Income=1	.999 (.992-1.006)	.999 (.992-1.006)
	High Income=2	.721 (.716-.727) *	.723 (.717-.728) *
Education	Less Than High School=0	Ref	Ref
	High School=1	.977 (.971-.984) *	.979 (.973-.986) *

	Post-Secondary=2	.817 (.812-.822) *	.820 (.815-.826) *
Living Arrangement	Alone=0	Ref	Ref
	With Others=1	1.014 (1.009-1.019) *	1.019 (1.013-1.024) *
Geographic Location	Metropolitan=0	Ref	Ref
	Non-Metropolitan=1	1.068 (1.062-1.075) *	1.066 (1.060-1.073) *
Self-Rated Health	Fair or Poor=0	Ref	Ref
	Excellent or Good=1	.882 (.878-.887) *	.881 (.877-.886) *

* $p < .05$

Table 26 (continued)

Variable	Value	Main Effect Analysis		Interaction Analysis	
		<i>OR (CI)</i>		<i>OR (CI)</i>	
Round	Round 3=0		Ref		Ref
	Round 4=1		1.484 (1.472-1.497) *		1.481 (1.468-1.494) *
	Round 5=2		1.264 (1.252-1.276) *		1.260 (1.248-1.272) *
	Round 6=3		1.402 (1.389-1.415) *		1.393 (1.380-1.405) *
	Round 7=4		1.709 (1.693-1.725) *		1.695 (1.680-1.711) *
	Round 8=5		1.097 (1.088-1.107) *		1.085 (1.076-1.095) *

Round 9=6	1.290 (1.279-1.301) *	1.286 (1.275-1.297) *
Round 10=7	2.023 (2.003-2.044) *	2.017 (1.996-2.037) *

* $p < .05$

Table 26 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Social Network Size	0-5	1.149 (1.146- 1.151) *	1.148 (1.145- 1.150) *
Number of Chronic Illnesses	0-8	1.273 (1.271- 1.276) *	1.273 (1.271- 1.276) *

Functional Limitations	0-16	.987 (.986-.988) *	.987 (.986-.988) *
Health Insurance	0-3	.818 (.815-.822) *	.817 (.814-.821) *
Depression	0-6	1.122 (1.120- 1.124) *	1.122 (1.120- 1.124) *
Anxiety	0-6	.970 (968-.971) *	.969 (968-.971) *

* $p < .05$

Table 27

Race Effect for the Association between Gender and Pain

Pain – Race Effect		
Comparing Men and Women by Race		
Gender	Race	Likelihood of Experiencing Pain
Women	Blacks	Less Likely than White women
	Whites	More likely than Black women

Men	Blacks	More likely than White men
	Whites	Less likely than Black men

Table 28

Gender Effect for the Association between Race and Pain

Pain – Gender Effect		
Comparing Whites and Blacks by Gender		
Race	Gender	Likelihood of Experiencing Pain
Whites	Men	Less Likely than White women
	Women	More likely than White men

Blacks	Men	Less likely than Black women
	Women	More likely than Black men

Main Effect Analysis. Model 1 of the multivariate logistic regressions included the main effects of all variables, without the race/gender interaction term. Compared to those aged 65-69, decedents aged 70-74 ($OR=.242$, $CI=.235-.250$, $p < .05$), those aged 75-79 ($OR=.101$, $CI=.098-.104$, $p < .05$), those aged 80-84 ($OR=.158$, $CI=.153-.163$, $p < .05$), those aged 85 to 89 ($OR=.137$, $CI=.133-.142$, $p < .05$), and those aged 90 and older ($OR=.124$, $CI=.121-.128$, $p < .05$) were all less likely to be in pain at the end of life. Women were more likely to be in pain compared to men ($OR=1.430$, $CI=1.422-1.437$, $p < .05$), and Blacks were less likely to be in pain compared to Whites ($OR=.948$, $CI=.940-.956$, $p < .05$). Compared to those with low income, decedents with high income were less likely to be in pain ($OR=.721$, $CI=.716-.727$, $p < .05$), and no significant difference was found in the likelihood of experiencing pain at the end of life for those with low income and those with moderate income. Compared to those with less than a high school education, decedents with only a high school diploma ($OR=.977$, $CI=.971-.984$, $p < .05$) and those with post-secondary education ($OR=.817$, $CI=.812-.822$, $p < .05$) were all less likely to be in pain. Those living with others were more likely to be in pain than those living alone ($OR=1.014$, $CI=1.009-1.019$, $p < .05$), whereas those living in non-metropolitan areas were more likely to be in pain than those living in metropolitan areas ($OR=1.068$, $CI=1.062-1.075$, $p < .05$). Those with excellent or good self-rated health were less likely to be in pain than those with fair or poor health ($OR=.641$, $CI=.638-.644$, $p < .05$), and those in Round 4 ($OR=1.484$, $CI=1.472-1.497$, $p < .05$), Round 5 ($OR=1.264$, $CI=1.252-1.276$, $p < .05$), Round 6 ($OR=1.402$, $CI=1.389-1.415$, $p < .05$), Round 7 ($OR=1.709$, $CI=1.693-1.725$, $p < .05$), Round 8 ($OR=1.097$,

$CI=1.088-1.107$, $p < .05$), Round 9 ($OR=1.290$, $CI=1.279-1.301$, $p < .05$) were all more likely to be in pain than those in round 3. Every one-unit increase in social network size was associated with a greater likelihood of being in pain ($OR=1.149$, $CI=1.146-1.151$, $p < .05$), and every additional number of chronic illnesses was associated with a greater likelihood of being in pain ($OR=1.273$, $CI=1.271-1.276$, $p < .05$). A higher number of functional limitations decreased the likelihood of experiencing pain ($OR=.987$, $CI=.986-.988$, $p < .05$), and additional health insurance plans also decreased the likelihood of experiencing pain ($OR=.818$, $CI=.815-.822$, $p < .05$). More depression symptoms were associated with a greater likelihood of experiencing pain ($OR=1.122$, $CI=1.120-1.124$, $p < .05$), and more anxiety symptoms were associated with a lower likelihood of experiencing pain ($OR=.970$, $CI=.968-.971$, $p < .05$). All of the Model 1 pain odds ratios had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between the independent variables and pain at the end of life.

Interaction Analysis. Model 2 of the logistic regression included an interaction term for race and gender to determine whether gender moderates the relationship between race and pain. The logistic regression results showed that race and gender interacted with one another to affect the probability of experiencing pain at the end of life. This suggests that the effect of race on pain depends on the gender of the decedent; the effect of gender was dependent on their race, with a $<.05$ p -value for the interaction term. Specifically, among White decedents, women were more likely to experience pain compared to men. On the other hand, among Black decedents, women were also more likely to experience pain compared to men ($OR=1.469$, $CI=1.461-1.477$, $p < .05$). Regarding race effect, among men, Blacks were more likely to be in pain compared to Whites, while among women, Blacks were less likely to be in pain compared to Whites ($OR=1.096$, $CI=1.082-1.109$, $p < .05$). Compared to those aged 65-69, decedents aged 70-74

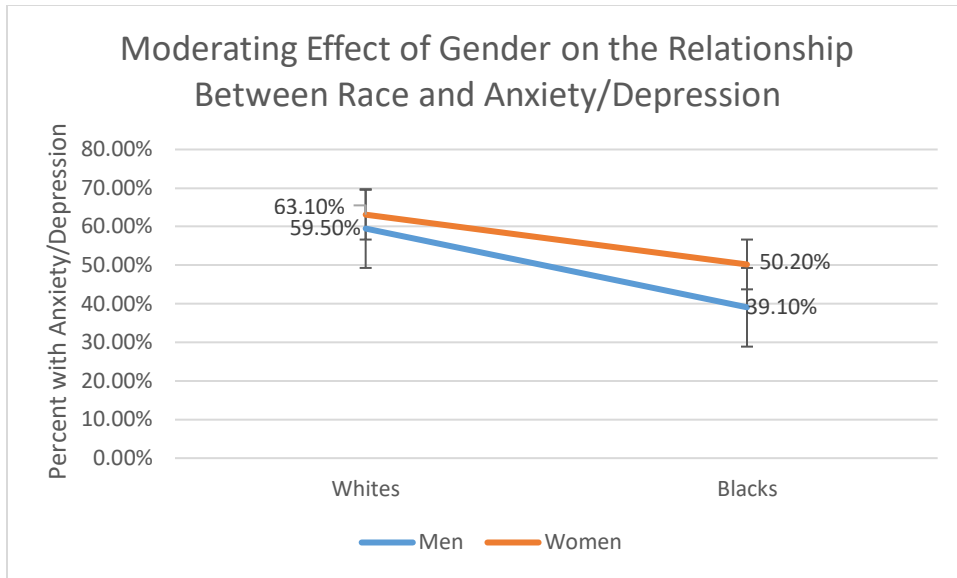
($OR=.240$, $CI=.232-.247$, $p < .05$), those aged 75-79 ($OR=.101$, $CI=.098-.104$, $p < .05$), those aged 80-84 ($OR=.158$, $CI=.154-.163$), and those aged 90 and older ($OR=.124$, $CI=.121-.128$, $p < .05$) were all less likely to be in pain. Compared to those with low income, decedents with high income were less likely to be in pain ($OR=.723$, $CI=.717-.728$, $p < .05$) while there was no difference in pain between those with low income and those with moderate income. Compared to decedents with less than a high school education, those with only a high school diploma ($OR=.979$, $CI=.973-.986$, $p < .05$) and those with post-secondary education ($OR=.820$, $CI=.815-.826$, $p < .05$) were less likely to be in pain at the end of life. Compared to those living alone, decedents who were living with others were more likely to be in pain ($OR=1.019$, $CI=1.013-1.127$, $p < .05$), and those living in non-metropolitan areas were more likely to be in pain than those living in metropolitan areas ($OR=1.066$, $CI=1.060-1.073$, $p < .05$). Decedents with excellent or good self-rated health were less likely to be in pain than those with fair or poor health ($OR=.881$, $CI=.877-.886$, $p < .05$), and decedents in Round 4 ($OR=1.481$, $CI=1.468-1.494$, $p < .05$), Round 5 ($OR=1.260$, $CI=1.248-1.272$, $p < .05$), Round 6 ($OR=1.393$, $CI=1.380-1.405$, $p < .05$), Round 7 ($OR=1.695$, $CI=1.680-1.711$, $p < .05$), Round 8 ($OR=1.085$, $CI=1.076-1.095$, $p < .05$), Round 9 ($OR=1.286$, $CI=1.275-1.297$, $p < .05$), and Round 10 ($OR=2.017$, $CI=1.996-2.037$, $p < .05$) were all more likely to be in pain compared to decedents in Round 3. Every one-unit increase in social network size increased the likelihood of being in pain ($OR=1.148$, $CI=1.145-1.150$, $p < .05$), and every additional number of chronic illnesses also increased the likelihood of being in pain ($OR=1.273$, $CI=1.271-1.276$, $p < .05$). More functional limitations resulted in a lower likelihood of being in pain ($OR=.987$, $CI=.986-.988$, $p < .05$), and additional health insurance plans also resulted in a lower likelihood of being in pain ($OR=.817$, $CI=.814-.821$, $p < .05$). More depressive symptoms resulted in a high likelihood of being in pain

($OR=1.122$, $CI=1.120-1.124$, $p < .05$), while more anxiety symptoms resulted in a lower likelihood of being in pain ($OR=.969$, $CI=.968-.971$, $p < .05$).). All of the pain odds ratios had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between the independent variables and pain at the end of life. Figure 3 depicts the moderating effect of gender on the relationship between race and pain. Table 26 shows all the logistic regression results for Model 1 (main effect analysis) and Model 2 (interaction effect analysis) of the pain-dependent variable. Table 27 shows the interaction results for race effects, and Table 28 reports the interaction results for gender effects.

Anxiety/Depression

Figure 4

Moderating Effect of Gender on the Relationship between Race and Anxiety/Depression



Note. The differing (non-parallel) slope lines for men and women show that the effect of race on anxiety/depression is dependent on the gender of the decedent.

Table 29

Logistic Regressions for Anxiety/Depression

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Race	White=0	Ref	Ref
	Black=1	.570 (.566-.574) *	.480 (.474-.485) *
Gender	Men=0	Ref	
	Women=1	1.100 (1.095-1.105) *	1.065 (1.060-1.070) *
Race x Gender	-	-	1.370 (1.351-1.390) *
Age at Death	65-69=0	Ref	Ref
	70-74=1	.686 (.677-.695) *	.692 (.682-.701) *
	75-79=2	.807 (.797-.818) *	.806 (.796-.817) *
	80-84=3	.891 (.880-.903) *	.889 (.877-.900) *
	85-89=4	.825 (.814-.836) *	.820 (.809-.831) *
	90+=5	.837 (.826-.848) *	.834 (.823-.845) *

* $p < .05$

Table 29 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Income	Low Income=0	Ref	Ref
	Moderate Income=1	1.575 (1.564-1.585) *	1.577 (1.567-1.588) *
	High Income=2	1.202 (1.193-1.211) *	1.198 (1.190-1.207) *
Education	Less Than High School=0	Ref	Ref
	High School=1	1.411 (1.403-1.419) *	1.411 (1.403-1.419) *
	Post-Secondary=2	1.325 (1.318-1.332) *	1.320 (1.313-1.328) *
Living Arrangement	Alone=0	Ref	Ref
	With Others=1	.759 (.756-.763) *	.754 (.750-.757) *
Geographic Location	Metropolitan=0	Ref	Ref
	Non-Metropolitan=1	1.039 (1.034-1.045) *	1.043 (1.037-1.048) *
Self-Rated Health	Fair or Poor=0	Ref	Ref
	Excellent or Good=1	.736 (.732-.739) *	.737 (.734-.740) *

* $p < .05$

Table 29 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Round		Round 3=0	Ref
		Round 4=1	.889 (.882-.896) *
		Round 5=2	1.188 (1.177-1.198) *
		Round 6=3	.725 (.719-.731) *
		Round 7=4	1.017 (1.008-1.025) *
		Round 8=5	.694 (.688-.699) *
		Round 9=6	.830 (.823-.837) *
		Round 10=7	1.151 (1.140-1.161) *
			Ref
			1.153 (1.143-1.163) *

* $p < .05$

Table 29 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Social Network Size	0-5	1.061 (1.059-1.062) *	1.062 (1.060-1.063) *
Number of Chronic Illnesses	0-8	1.092 (1.091-1.094) *	1.093 (1.092-1.095) *
Functional Limitations	0-16	1.017 (1.017-1.018) *	1.017 (1.016-1.017) *
Health Insurance	0-3	1.096 (1.092-1.100) *	1.098 (1.093-1.102) *
Depression	0-6	1.028 (1.026-1.030) *	1.028 (1.027-1.030) *
Anxiety	0-6	1.191 (1.189-1.193) *	1.192 (1.190-1.193) *

**p*<.05

Table 30

Race Effect for the Association between Gender and Anxiety/Depression

Anxiety/Depression – Race Effect		
Comparing Women and Men by Race		
Gender	Race	Likelihood of Experiencing Anxiety/Depression
Women	Blacks	Less likely than White women
	Whites	More likely than Black women
Men	Blacks	Less likely than White men
	Whites	More likely than Black men

Table 31

Gender Effect for the Association between Race and Anxiety/Depression

Anxiety/Depression – Gender Effect		
Comparing Whites and Blacks by Gender		
Race	Gender	Likelihood of Experiencing Anxiety/Depression
Whites	Men	Less likely than White women
	Women	More likely than White men
Blacks	Men	Less likely than Black women
	Women	More likely than Black men

Main Effect Analysis. Model 1 of the multivariate logistic regressions included the main effects of all variables, without the race/gender interaction term. Compared to those aged 65-69, decedents aged 70-74 ($OR=.686$, $CI=.677-.695$, $p < .05$), those aged 75-79 ($OR=.807$, $CI=.797-.818$, $p < .05$), those aged 80-84 ($OR=.891$, $CI=.880-.903$, $p < .05$), those aged 85-89 ($OR=.825$, $CI=.814-.836$, $p < .05$), and those aged 90 and older ($OR=.837$, $CI=.826-.848$, $p < .05$) were all less likely to have anxiety/depression at the end of life. Women were more likely to have anxiety/depression compared to men ($OR=1.100$, $CI=1.095-1.105$, $p < .05$), and Blacks were less likely to have anxiety/depression compared to Whites ($OR=.570$, $CI=.566-.574$, $p < .05$). Compared to those with low income, decedents with moderate ($OR=1.575$, $CI=1.564-1.585$, $p < .05$) and those with high income ($OR=1.202$, $CI=1.193-1.211$, $p < .05$) were all more

likely to have anxiety/depression at the end of life. Compared to those with less than a high school education, decedents with only a high school diploma ($OR=1.411$, $CI=1.403-1.419$, $p < .05$) and those with post-secondary education ($OR=1.325$, $CI=1.318-1.332$, $p < .05$) were more likely to have anxiety/depression at the end of life. Compared to those living alone, decedents who lived with others were less likely to have anxiety/depression at the end of life ($OR=.759$, $CI=.756-.763$, $p < .05$), and those living in non-metropolitan areas were more likely to have anxiety/depression than those in metropolitan areas ($OR=1.039$, $CI=1.034-1.045$, $p < .05$).

Decedents with excellent or good health were less likely to have anxiety/depression at the end of life compared to those in fair or poor health ($OR=.736$, $CI=.732-.739$, $p < .05$), and decedents in Round 4 ($OR=.889$, $CI=.882-.896$, $p < .05$), Round 6 ($OR=.725$, $CI=.719-.731$, $p < .05$), Round 8 ($OR=.694$, $CI=.688-.699$, $p < .05$), and Round 9 ($OR=.830$, $CI=.823-.837$, $p < .05$) were less likely to have anxiety/depression than those in Round 3. Decedents in Round 5 ($OR=1.188$, $CI=1.177-1.198$, $p < .05$), Round 7 ($OR=1.017$, $CI=1.008-1.025$, $p < .05$), and Round 10 ($OR=1.151$, $CI=1.140-1.161$, $p < .05$) were more likely to have anxiety/depression than those in Round 3. Every one-unit increase in social network size increased the likelihood of having anxiety/depression at the end of life ($OR=1.061$, $CI=1.059-1.062$, $p < .05$), and every one-unit increase in a number of chronic illnesses increased the likelihood of having anxiety/depression at the end of life ($OR=1.092$, $CI=1.091-1.094$, $p < .05$). A higher number of functional limitations increased the likelihood of having anxiety/depression at the end of life ($OR=1.017$, $CI=1.017-1.018$, $p < .05$), and additional health insurance plans resulted in a higher likelihood of having anxiety/depression at the end of life ($OR=1.096$, $CI=1.092-1.100$, $p < .05$). A greater number of depressive symptoms resulted in a higher likelihood of having anxiety/depression at the end of life ($OR=1.028$, $CI=1.026-1.030$, $p < .05$), and a greater number of anxiety symptoms also

indicated a higher chance of having anxiety/depression at the end of life ($OR=1.191$, $CI=1.189-1.193$, $p < .05$). All of the Model 1 anxiety/depression odds ratios had a small effect size relative to Cohen's d (Chen et al., 2010), indicating that the association between the independent variables and anxiety/depression is a weak association.

Interaction Analysis. Model 2 of the logistic regression included an interaction term for race and gender to determine whether gender moderates the relationship between race and anxiety/depression. The logistic regression results revealed that race and gender interacted with one another to affect the probability of having anxiety/depression at the end of life. This suggests that the effect of race on anxiety/depression depends on the gender of the decedent; the effect of gender was dependent on their race, with a $<.05$ p -value for the interaction term. Specifically, among White decedents, women were more likely to have anxiety/depression at the end of life compared to men; among Black decedents, women were also more likely to have anxiety/depression compared to men ($OR=1.065$, $CI=1.060-1.070$, $p <.05$). Regarding race effect, among men, Blacks were less likely than Whites to have anxiety/depression at the end of life; among women, Blacks were also less likely to have anxiety/depression compared to Whites ($OR=.480$, $CI=.474-.485$, $p <.05$). Compared to those aged 65-69, decedents aged 70-74 ($OR=.692$, $CI=.682-.701$, $p <.05$), those aged 75-79 ($OR=.806$, $CI=.796-.817$, $p <.05$), those aged 80-84 ($OR=.889$, $CI=.877-.900$, $p <.05$), those aged 85-89 ($OR=.820$, $CI=.809-.831$, $p <.05$), and those aged 90 and older ($OR=.834$, $CI=.823-.845$, $p <.05$) were all less likely to have anxiety/depression at the end of life. Compared to those with low income, decedents with moderate income ($OR=1.577$, $CI=1.567-1.588$) and those with high income ($OR=1.198$, $CI=1.190-1.207$, $p <.05$) were more likely to have anxiety/depression at the end of life. Compared to those with less than a high school education, decedents with only a high school

diploma ($OR=1.411$, $CI=1.403-1.419$, $p < .05$) and those with post-secondary education ($OR=1.320$, $CI=1.313-1.328$, $p < .05$) were more likely to have anxiety/depression at the end of life. Compared to those living alone, decedents who were living with others were less likely to have anxiety/depression at the end of life ($OR=.754$, $CI=.750-.757$, $p < .05$), and decedents living in non-metropolitan areas were more likely to have anxiety/depression at the end of life compared to those living in metropolitan areas ($OR=1.043$, $CI=1.037-1.048$, $p < .05$). Decedents with excellent or good self-rated health were less likely to have anxiety/depression than those with fair or poor health ($OR=.737$, $CI=.734-.740$, $p < .05$), and decedents in Round 4 ($OR=.891$, $CI=.884-.898$, $p < .05$), Round 6 ($OR=.729$, $CI=.723-.735$, $p < .05$), Round 8 ($OR=.700$, $CI=.695-.706$, $p < .05$), and Round 9 ($OR=.834$, $CI=.827-.840$, $p < .05$) were less likely to have anxiety/depression compared to those in Round 3. Decedents in Round 5 ($OR=1.191$, $CI=1.181-1.202$, $p < .05$), Round 7 ($OR=1.024$, $CI=1.016-1.033$, $p < .05$), and Round 10 ($OR=1.153$, $CI=1.143-1.163$, $p < .05$) were more likely to have anxiety/depression than those in Round 3. Every one-unit increase in social network size resulted in a higher likelihood of having anxiety/depression at the end of life ($OR=1.062$, $CI=1.060-1.063$, $p < .05$), and more chronic illnesses resulted in a higher likelihood of having anxiety/depression at the end of life ($OR=1.093$, $CI=1.092-.1.095$, $p < .05$).

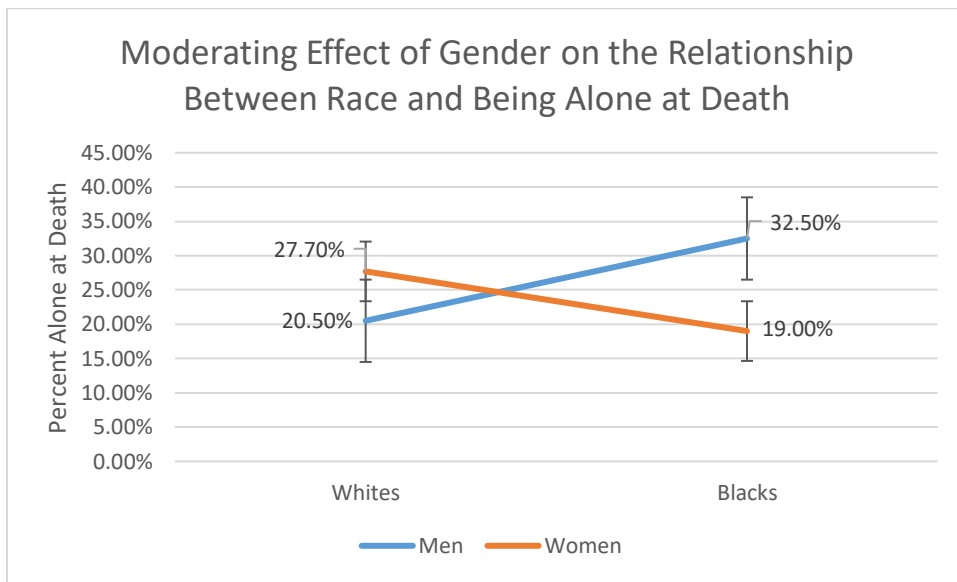
More functional limitations resulted in a higher likelihood of having anxiety/depression at the end of life ($OR=1.017$, $CI=1.016-1.017$, $p < .05$), and more health insurance plans also increased the likelihood of having anxiety/depression at the end of life ($OR=1.098$, $CI=1.093-1.102$, $p < .05$). More depressive symptoms resulted in a higher likelihood of having anxiety/depression at the end of life ($OR=1.028$, $CI=1.027-1.030$, $p < .05$), and more anxiety symptoms also resulted in a higher likelihood of having depression/anxiety at the end of life

($OR=1.192$, $CI=1.190-1.193$, $p < .05$). Each Model 2 anxiety/depression odds ratio had a small effect size relative to Cohen’s d (Chen et al., 2010), thus indicating a weak association between the independent variables and anxiety/depression. Figure 4 depicts the moderating effect of gender on the relationship between race and anxiety /depression. Table 29 shows all the logistic regression results for Model 1 (main effect analysis) and Model 2 (interaction effect analysis) of the anxiety/depression dependent variable. Table 30 reports the interaction results for race effects, and Table 31 shows the interaction results for gender effects.

Alone at Death

Figure 5

Moderating Effect of Gender on the Relationship between Race and Being Alone at Death



Note. The differing (non-parallel) slope lines for men and women show that the effect of race on being alone at death is dependent on the gender of the decedent.

Table 32

Logistic Regressions for Alone at Death

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Race	White=0	Ref	Ref
	Black=1	1.640 (1.623-1.657) *	2.392 (2.360-2.425) *
Gender	Men=0	Ref	Ref
	Women=1	.748 (.744-.753) *	1.486 (1.479-1.494) *
Race x Gender	-	-	.440 (.432-.449) *
Age at Death	65-69=0	Ref	Ref
	70-74=1	2.744 (2.683-2.808) *	2.792 (2.727-2.858) *
	75-79=2	5.879 (5.751-6.010) *	6.118 (5.982-6.258) *
	80-84=3	2.761 (2.701-2.822) *	2.903 (2.838-2.969) *
	85-89=4	3.230- (3.161-3.301) *	3.823 (3.739-3.909) *
	90+=5	3.668 (3.589-3.748) *	3.823 (3.739-3.909) *

* $p < .05$

Table 32 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Income	Low Income=0	Ref	Ref
	Moderate Income=1	.782 (.774-.789) *	.780 (.773-.787) *
	High Income=2	.547 (.541-.554) *	.551 (.544-.558) *
Education	Less Than High School=0	Ref	Ref
	High School=1	1.955 (1.940-1.971) *	1.943 (1.928-1.959) *
	Post-Secondary=2	2.421 (2.402-2.439) *	2.424 (2.405-2.443) *
Living Arrangement	Alone=0	Ref	Ref
	With Others=1	.049 (.048-.049) *	.049 (.049-.049) *
Geographic Location	Metropolitan=0	Ref	Ref
	Non-Metropolitan=1	1.292 (1.282-1.301) *	1.285 (1.276-1.294) *
Self-Rated Health	Fair or Poor=0	Ref	Ref
	Excellent or Good=1	.695 (.690-.699) *	.694 (.689-.698) *

* $p < .05$

Table 32 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Round	Round 3=0	Ref	Ref
	Round 4=1	.971 (.960-.983) *	.958 (.947-.969) *
	Round 5=2	1.891 (1.869-1.914) *	1.882 (1.860-1.905) *
	Round 6=3	2.026 (2.003-2.049) *	1.998 (1.975-2.021) *
	Round 7=4	2.708 (2.679-2.738) *	2.631 (2.602-2.660) *
	Round 8=5	1.662 (1.644-1.681) *	1.615 (1.597-1.632) *
	Round 9=6	1.826 (1.805-1.847) *	1.800 (1.779-1.821) *
	Round 10=7	1.101 (1.086-1.115) *	1.070 (1.056-1.084) *

* $p < .05$

Table 32 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Social Network Size	0-5	1.026 (1.024-1.029) *	1.025 (1.022-1.027) *
Number of Chronic Illnesses	0-8	.825 (.823-.827) *	.824 (.823-.826) *
Functional Limitations	0-16	.916 (.916-.917) *	.918 (.917-.919) *
Health Insurance	0-3	.799 (.795-.803) *	.788 (.784-.793) *
Depression	0-6	.917 (.915-.919) *	.914 (.912-.916) *
Anxiety	0-6	1.052 (1.050-1.054) *	1.056 (1.054-1.058) *

* $p < .05$

Table 33

Race Effect for the Association between Gender and Being Alone at Death

Alone at Death – Race Effect		
Comparing Men and Women by Race		
Gender	Race	Likelihood of Being Alone at Death
Women	Blacks	Less likely than White women
	Whites	More likely than Black women
Men	Blacks	More likely than White men
	Whites	Less Likely than Black men

Table 34*Gender Effect for the Association between Race and Being Alone at Death*

Alone at Death - Gender Effect		
Comparing Blacks and Whites by Gender		
Race	Gender	Likelihood of Being Alone at Death
Whites	Men	Less Likely than White women
	Women	More likely than White men
Blacks	Men	More likely than Black women
	Women	Less Likely than Black men

Main Effect Analysis. Model 1 of the multivariate logistic regressions included the main effects of all variables, without the race/gender interaction term. Compared to those aged 65-69, decedents aged 70-74 ($OR=2.744$, $CI=2.683-2.808$, $p < .05$), those aged 75-79 ($OR=5.879$, $CI=5.751-6.010$, $p < .05$), those aged 80-84 ($OR=2.761$, $CI=2.701-2.822$, $p < .05$), those aged 85-89 ($OR=3.230$, $CI=3.161-3.301$, $p < .05$), and those 90 and older ($OR=3.66$, $CI=3.589-3.748$, $p < .05$) were all more likely to be alone at death. Women were less likely to be alone at death compared to men ($OR=.748$, $CI=.744-.753$, $p < .05$), whereas Blacks were more likely to be alone at death compared to Whites ($OR=1.640$, $CI=1.623-1.657$, $p < .05$). In comparison to those with low income, decedents with moderate income ($OR=.782$, $CI=.774-.789$, $p < .05$) and those

with high income ($OR=.547$, $CI=.541-.554$, $p < .05$) were less likely to be alone at death. In comparison to those with less than a high school education, decedents with only a high school diploma ($OR=1.955$, $CI=1.940-1.971$, $p < .05$) and those with post-secondary education ($OR=2.421$, $CI=2.402-2.439$, $p < .05$) were more likely to be alone at death. Compared to those living alone, decedents living with others were less likely to be alone at death ($OR=.049$, $CI=.048-.049$, $p < .05$), and those living in non-metropolitan areas were more likely to be alone at death than those living in metropolitan areas ($OR=1.292$, $CI=1.282-1.301$, $p < .05$). Those with an excellent or good self-rated health were less likely to be alone at death than those with fair or poor health ($OR=.695$, $CI=.690-.699$, $p < .05$) Decedents in Round 4 ($OR=.971$, $CI=.960-.983$, $p < .05$) were less likely to be alone at death compared to those in Round 3. Decedents in Round 5 ($OR=1.891$, $CI=1.869-1.914$, $p < .05$), Round 6 ($OR=2.026$, $CI=2.003-2.049$, $p < .05$), Round 7 ($OR=2.708$, $CI=2.679-2.738$, $p < .05$), Round 8 ($OR=1.662$, $CI=1.681$, $p < .05$), Round 9 ($OR=1.826$, $CI=1.805-1.849$, $p < .05$), and those in Round 10 ($OR=1.101$, $CI=1.086-1.115$, $p < .05$) were more likely to be alone at death than those in Round 3. Every one-unit increase in social network size led to a higher likelihood of being alone at death ($OR=1.026$, $CI=1.024-1.029$, $p < .05$), and every additional number of chronic illnesses resulted in a lower likelihood of being alone at death ($OR=.825$, $CI=.823-.827$, $p < .05$). More functional limitations led to a lower likelihood of being alone at death ($OR=.916$, $CI=.916-.917$, $p < .05$), and additional health insurance plans also resulted in a lower likelihood of being alone at death ($OR=.799$, $CI=.795-.803$, $p < .05$). Greater depressive symptoms resulted in a lower likelihood of being alone at death ($OR=.917$, $CI=.915-.919$, $p < .05$), while more anxiety symptoms resulted in a higher likelihood of being alone at death ($OR=1.052$, $CI=1.050-1.054$, $p < .05$). Most of the Model 1 alone at death odds ratios had a small effect size relative to Cohen's d (Chen et al.,

2010), indicating a weak association between the independent variables and being alone at death. However, the odds ratios for the association between age at death and being alone at death, as well as the difference between Round 3 and Round 7 decedents had a moderate effect size relative to Cohen's *d* (Chen et al., 2010).

Interaction Analysis. Model 2 of the logistic regression included an interaction term for race and gender to determine whether gender moderates the relationship between race and being alone at death. The logistic regression results showed that race and gender interacted with each other to affect the probability of being alone at death. This suggests that the effect of race on being alone at death depends on the gender of the decedent; the effect of gender was found to depend on their race, with a $<.05$ *p*-value for the interaction term. Specifically, among White decedents, women were more likely to be alone at death compared to men, while women were less likely to be alone at death compared to men among Black decedents ($OR=1.486$, $CI=1.479-1.494$, $p <.05$). Regarding race effect, Blacks were more likely to be alone at death compared to Whites among men, while among women, Blacks were less likely to be alone at death compared to Whites ($OR=2.392$, $CI=2.360-2.425$, $p <.05$). Compared to those aged 65-69, decedents aged 70-74 ($OR=2.792$, $CI=2.727-2.858$, $p <.05$), those aged 75-79 ($OR=6.118$, $CI=5.982-6.258$, $p <.05$), those aged 80-84 ($OR=2.903$, $CI=2.838-2.969$, $p <.05$), those aged 85-89 ($OR=3.823$, $CI=3.739-3.909$, $p <.05$), and those aged 90 and older ($OR=3.823$, $CI=3.739-3.909$, $p <.05$) were more likely to be alone at death. In comparison to those with low income, decedents with moderate income ($OR=.780$, $CI=.773-.787$, $p <.05$) and those with high income ($OR=.551$, $CI=.544-.558$, $p <.05$) were less likely to be alone at death. Compared to those with less than a high school education, decedents with only a high school diploma ($OR=1.943$, $CI=1.928-1.959$, $p <.05$) and those with post-secondary education ($OR=2.424$, $CI=2.405-2.443$, $p <.05$) were

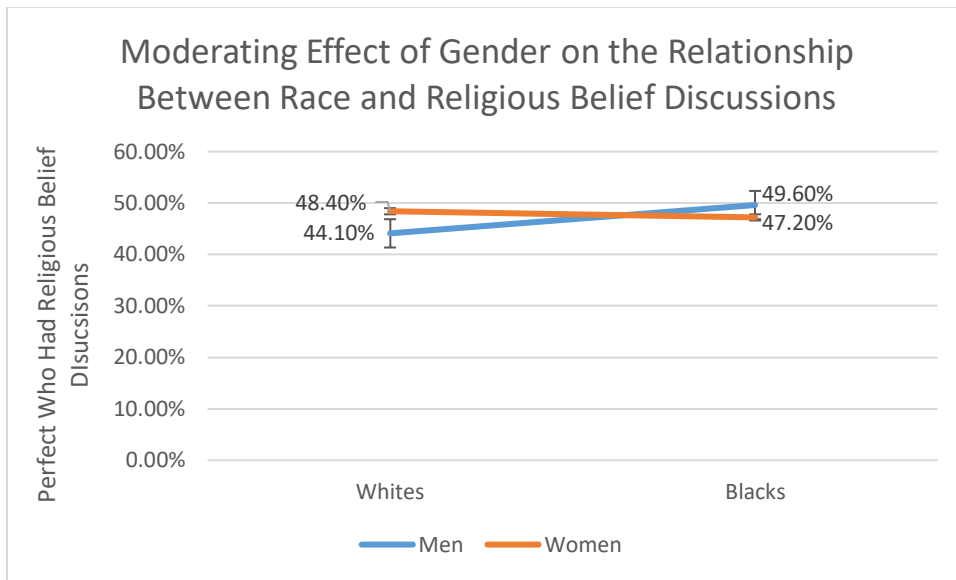
more likely to be alone at death. Compared to those living alone, decedents who were living with others were less likely to be alone at death ($OR=.049$, $CI=.049-.049$, $p < .05$), and those living in non-metropolitan areas were more likely to be alone at death than those living in metropolitan areas ($OR=1.285$, $CI=1.276-1.294$, $p < .05$). Decedents with excellent or good self-rated health were less likely to be alone at death than those in fair or poor health ($OR=.694$, $CI=.689-.698$, $p < .05$). Compared to those in Round 3, decedents in Round 4 were less likely to be alone at death ($OR=.958$, $CI=.947-.969$, $p < .05$), whereas decedents in Round 5 ($OR=1.882$, $CI=1.860-1.905$, $p < .05$), Round 6 ($OR=1.998$, $CI=1.975-2.021$, $p < .05$), Round 7 ($OR=2.631$, $CI=2.602-2.660$, $p < .05$), Round 8 ($OR=1.615$, $CI=1.597-1.632$, $p < .05$), Round 9 ($OR=1.800$, $CI=1.779-1.821$, $p < .05$), and Round 10 ($OR=1.070$, $CI=1.056-1.084$, $p < .05$) were more likely to be alone at death. Every one-unit increase in social network size led to a higher likelihood of being alone at death ($OR=1.025$, $CI=1.022-1.027$, $p < .05$), and every additional number of chronic illnesses lowered the likelihood of being alone at death ($OR=.824$, $CI=.823-.826$, $p < .05$). More functional limitations resulted in a lower likelihood of being alone at death ($OR=.918$, $CI=.917-.919$, $p < .05$), and more health insurance plans also resulted in a lower likelihood of being alone at death ($OR=.788$, $CI=.784-.793$, $p < .05$). More depressive symptoms resulted in a lower likelihood of being alone at death ($OR=.914$, $CI=.912-.916$, $p < .05$), while more anxiety symptoms resulted in a higher likelihood of being alone at death ($OR=1.056$, $CI=1.054-1.058$, $p < .05$). Most of the alone at death odds ratios in the interaction effect analysis (Model 2) had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between the independent variables and being alone at death. However, the odds ratios for the association between age at death and being alone at death as well as the difference between Round 3 and Round 7 decedents had a moderate effect size relative to Cohen's d (Chen et al., 2010). Figure 5

shows the moderating effect of gender on the relationship between race and being alone at death. Table 32 presents all the logistic regression results for the main effect analysis (Model 1) and the interactions effect analysis (Model 2) of the alone at death dependent variable. Table 33 shows the interaction results for race effects while Table 34 depicts the interaction results for gender effects.

Religious Belief Discussion

Figure 6

Moderating Effect of Gender on the Relationship between Race and Religious Belief Discussions



Note. The differing (non-parallel) slope lines for men and women show that the effect of race on religious belief discussions is dependent on the gender of the decedent.

Table 35*Logistic Regressions for Religious Belief Discussions*

Variable	Value	Main Effect Analysis <i>OR (CI)</i>	Interaction Analysis <i>OR (CI)</i>
Race	White=0	Ref	Ref
	Black=1	1.229 (1.220-1.238) *	1.537 (1.521-1.553) *
Gender	Men=0	Ref	Ref
	Women=1	1.100 (1.096-1.105) *	1.147 (1.142-1.152) *
Race x Gender	-	-	.663 (.654-.673) *
Age at Death	65-69=0	Ref	Ref
	70-74=1	1.018 (1.005-1.031) *	1.008 (.995-1.021)
	75-79=2	1.069 (1.055-1.082) *	1.071 (1.058-1.084) *
	80-84=3	1.624 (1.604-1.644) *	1.633 (1.613-1.653) *
	85-89=4	2.176 (2.149-2.203) *	2.196 (2.169-2.224) *
	90+=5	1.628 (1.608-1.648) *	1.638 (1.618-1.658) *

* $p < .05$

Table 35 (continued)

Variable	Value	Main Effect Analysis <i>OR (CI)</i>	Interaction Analysis <i>OR (CI)</i>
Income	Low Income=0	Ref	Ref
	Moderate Income=1	1.201 (1.194-1.209) *	1.201 (1.194-1.208) *
	High Income=2	.758 (.753-.764) *	.761 (.756-.767) *
Education	Less Than High School=0	Ref	Ref
	High School=1	1.025 (1.019-1.031) *	1.027 (1.021-1.033) *
	Post-Secondary=2	1.225 (1.218-1.231) *	1.231 (1.224-1.238) *
Living Arrangement	Alone=0	Ref	Ref
	With Others=1	.926 (.922-.930) *	.934 (.930-.938) *
Geographic Location	Metropolitan=0	Ref	Ref
	Non-Metropolitan=1	1.385 (1.378-1.392) *	1.379 (1.373-1.386) *
Self-Rated Health	Fair or Poor=0	Ref	Ref
	Excellent or Good=1	.577 (.574-.579) *	.575 (.573-.578) *

* $p < .05$

Table 35 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Round	Round 3=0	Ref	Ref
	Round 4=1	.897 (.890-.904) *	.894 (.887-.901) *
	Round 5=2	1.075 (1.066-1.084) *	1.072 (1.063-1.081) *
	Round 6=3	.597 (.592-.602) *	.591 (.587-.596) *
	Round 7=4	1.139 (1.130-1.148) *	1.126 (1.118-1.135) *
	Round 8=5	.761 (.755-.766) *	.750 (.744-.756) *
	Round 9=6	.836 (.830-.843) *	.831 (.824-.837) *
	Round 10=7	1.090 (1.081-1.099) *	1.086 (1.077-1.095) *

* $p < .05$

Table 35 (continued)

Variable	Value	Main Effect	Interaction Analysis	
		Analysis	<i>OR (CI)</i>	
		<i>OR (CI)</i>		
Social Network Size	0-5	1.075 (1.074-1.077) *	1.074 (1.073-1.073-1.076) *	
Number of Chronic Illnesses	0-8	1.044 (1.043-1.046) *	1.043 (1.042-1.045) *	
Functional Limitations	0-16	.994 (.993-.995) *	.995 (.994-.996) *	
Health Insurance	0-3	.827 (.824-.830) *	.825 (.822-.828) *	
Depression	0-6	1.038 (1.036-1.039) *	1.037 (1.035-1.039) *	
Anxiety	0-6	.997 (.995-.998) *	.996 (.995-.998) *	

* $p < .05$

Table 36 Race

Effect for the Association between Gender and Religious Belief Discussions

Religious Belief Discussions – Race Effect		
Comparing Men and Women by Race		
Gender	Race	Likelihood of Having Religious Belief Discussions
Women	Blacks	Less likely than White women
	Whites	More likely than Black women
Men	Blacks	More likely than White men
	Whites	Less Likely than Black men

Table 37*Gender Effect for the Association between Race and Religious Belief Discussions*

Religious Belief Discussions – Gender Effect		
Comparing Blacks and Whites by Gender		
Race	Gender	Likelihood of Having Religious Belief Discussions
Whites	Men	Less likely than White women
	Women	More likely than White men
Blacks	Men	More likely than Black women
	Women	Less Likely than Black men

Main Effect Analysis. Model 1 of the multivariate logistic regressions included the main effects of all variables, without the race/gender interaction term. Compared to those aged 65-69, decedents aged 70-74 ($OR=1.018$, $CI=1.005-1.031$, $p < .05$), those aged 75-79 ($OR=1.069$, $CI=1.055-1.082$, $p < .05$), those aged 80-84 ($OR=1.524$, $CI=1.604-1.644$, $p < .05$), those aged 85-89 ($OR=2.176$, $CI=2.149-2.203$, $p < .05$), and those aged 90 and older ($OR=1.628$, $CI=1.608-1.648$, $p < .05$) were more likely to have religious belief discussions with their providers. Women were more likely to have religious belief discussions compared to men ($OR=1.100$, $CI=1.096-1.105$, $p < .05$), and Blacks were more likely to have religious belief discussions compared to Whites ($OR=1.229$, $CI=1.220-1.238$, $p < .05$). Compared to those with low income, decedents

with moderate income were more likely to have religious belief discussions ($OR=1.201$, $CI=1.194-1.209$, $p < .05$), while decedents with high income were less likely to have religious belief discussions ($OR=.758$, $CI=.753-.764$, $p < .05$). Compared to those with less than a high school education, decedents with only a high school diploma ($OR=1.025$, $CI=1.019-1.031$, $p < .05$), and those with post-secondary education ($OR=1.225$, $CI=1.218-1.231$, $p < .05$) were more likely to have religious belief discussions. Compared to those living alone, decedents living with others were less likely to have religious belief discussions ($OR=.926$, $CI=.922-.930$, $p < .05$), and decedents living in non-metropolitan areas were more likely to have religious belief discussions than those living in metropolitan areas ($OR=1.385$, $CI=1.378-1.392$, $p < .05$). Those with excellent or good self-rated health were less likely to have religious belief discussions than those in fair or poor health ($OR=.577$, $CI=.574-.579$, $p < .05$)., Decedents in Round 4, ($OR=.897$, $CI=.890-.904$, $p < .05$), Round 6 ($OR=.597$, $CI=.592-.602$, $p < .05$), Round 8 ($OR=.761$, $CI=.755-.766$, $p < .05$), and Round 9 ($OR=.836$, $CI=.830-.843$, $p < .05$) were all less likely to have religious belief discussions, whereas decedents in Round 5 ($OR=1.075$, $CI=1.066-1.084$, $p < .05$), Round 7 ($OR=1.139$, $CI=1.130-1.148$, $p < .05$), and Round 10 ($OR=1.090$, $CI=1.081-1.099$, $p < .05$) were more likely to have religious belief discussions. Every one-unit increase in social network size resulted in a greater likelihood of having religious belief discussions ($OR=1.075$, $CI=1.074-1.077$, $p < .05$), and a greater number of chronic illnesses resulted in a greater likelihood of having religious belief discussions ($OR=1.044$, $CI=1.043-1.046$, $p < .05$). More functional limitations resulted in a lower likelihood of having religious belief discussions ($OR=.994$, $CI=.993-.995$, $p < .05$), and more health insurance plans also indicated a lower likelihood of having religious belief discussions ($OR=.827$, $CI=.824-.830$, $p < .05$). More depressive symptoms resulted in a higher likelihood of having religious belief discussions

($OR=1.038$, $CI=1.036-1.039$, $p < .05$), while more anxiety symptoms resulted in a lower likelihood of having religious belief discussions ($OR=.997$, $CI=.995-.998$, $p < .05$). All of the religious belief discussions odds ratios in the main effect analysis (Model 1) had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between the independent variables and religious belief discussions.

Interaction Analysis. Model 2 of the logistic regression included an interaction term for race and gender to determine whether gender moderates the relationship between race and religious belief discussions. The logistic regression results showed that race and gender interacted with each other to affect the probability of having religious belief discussions at the end of life. This suggests that the effect of race on religious belief discussions depends on the gender of the decedent; the effect of gender was dependent on their race, with a $<.05$ p -value for the interaction term. Specifically, women were more likely to have religious belief discussions compared to men among White decedents, while among Black decedents, women were less likely to have religious belief discussions compared to men ($OR=1.147$, $CI=1.142-1.152$, $p <.05$). Regarding race effect, Blacks were more likely to have religious belief discussions compared to Whites among men, while among women, Blacks were less likely to have religious belief discussions compared to Whites ($OR=1.537$, $CI=1.521-1.553$, $p <.05$). No difference was found in the likelihood of having religious belief discussions between decedents aged 65-69 and those aged 70-74. Compared to those aged 65-69, decedents aged 75-79 ($OR=1.071$, $CI=1.058-1.084$, $p <.05$), those aged 80-84 ($OR=1.633$, $CI=1.613-1.653$, $p <.05$), those aged 85-89 ($OR=2.196$, $CI=2.169-2.224$, $p <.05$), and those aged 90 and older ($OR=1.638$, $CI=1.618-1.658$, $p <.05$) were all more likely to have religious belief discussions with their providers. Compared to those with low income, decedents with moderate income ($OR=1.201$, $CI=1.194-1.208$, $p <.05$) were

more likely to have religious belief discussions, while decedents with high income were less likely to have religious belief discussions ($OR=.761$, $CI=.756-767$, $p < .05$). Compared to those with less than a high school education, decedents with only a high school diploma ($OR=1.027$, $CI=1.021-1.033$, $p < .05$) and those with post-secondary education ($OR=1.231$, $CI=1.224-1.238$, $p < .05$) were more likely to have religious belief discussions with their providers. Compared to those living alone, decedents living with others were less likely to have religious belief discussions ($OR=.934$, $CI=.930-.938$, $p < .05$), and decedents living in non-metropolitan areas were more likely to have religious belief discussions than those living in metropolitan areas ($OR=1.379$, $CI=1.373-1.386$, $p < .05$). Decedents with excellent or good self-rated health were less likely to have religious belief discussions compared to those in fair or poor health ($OR=.575$, $CI=.573-.578$, $p < .05$), and decedents in Round 4 ($OR=.894$, $CI=.887-.901$, $p < .05$), Round 6 ($OR=.591$, $CI=.587-.596$, $p < .05$), Round 8 ($OR=.750$, $CI=.744-.756$, $p < .05$), and Round 9 ($OR=.831$, $CI=.824-.837$, $p < .05$) were all less likely to have religious belief discussions compared to those in Round 3. Decedents in Round 5 ($OR=1.072$, $CI=1.063-1.081$, $p < .05$), Round 7 ($OR=1.126$, $CI=1.118-1.135$, $p < .05$), and Round 10 ($OR=1.086$, $CI=1.077-1.095$, $p < .05$) were more likely to have religious belief discussions than those in Round 3. Every one-unit increase in social network size led to a higher likelihood of having religious belief discussions ($OR=1.074$, $CI=1.073-1.076$, $p < .05$), and an additional number of chronic illnesses also resulted in a higher likelihood of having religious belief discussions ($OR=1.043$, $CI=1.042-1.045$, $p < .05$). More functional limitations resulted in a lower likelihood of having religious belief discussions ($OR=.918$, $CI=.917-.919$, $p < .05$), and more health insurance plans also resulted in a lower likelihood of having religious belief discussions ($OR=.825$, $CI=.822-.828$, $p < .05$). More depressive symptoms led to a higher likelihood of having religious belief

discussions ($OR=1.037$, $CI=1.035-1.039$, $p < .05$), while more anxiety symptoms resulted in a lower likelihood of having religious belief discussions ($OR=.996$, $CI=.995-.998$, $p < .05$). All of the religious belief discussions odds ratios in the interaction effect analysis (Model 2) had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between the independent variables and religious belief discussions. Figure 6 depicts the moderating effect of gender on the relationship between race and religious belief discussions. Table 35 shows all the logistic regression results for the main effect analysis (Model 1) and the interaction effect analysis (Model 2) of the religious belief discussions dependent variable. Table 36 shows the interaction results for race effects, and Table 37 depicts the interaction results for gender effects.

Treated With Respect

Table 38

Logistic Regressions for Treated with Respect

Variable	Value	Main Effect Analysis
		OR (CI)
Race	White=0	Ref
	Black=1	30.892 (.000-1.917e+80)
Gender	Men=0	Ref
	Women=1	.000 (.000-6.948E+56)
Race x Gender	-	-
Age at Death	65-69=0	Ref
	70-74=1	.154 (.000-7.731E+133)
	75-79=2	.000 (.000-3.296E+101)
	80-84=3	23.933 (.000-7.884E+118)
	85-89=4	107.269 (3.620E+116)
	90+=5	.013 (.000-6.376E+112)

Table 38 (continued)

Variable	Value	Main Effect Analysis <i>OR (CI)</i>
Income	Low Income=0	Ref
	Moderate Income=1	39.854 (.000-4.475e+73)
	High Income=2	.321 (.000-1.506e+68)
Education	Less Than High School=0	Ref
	High School=1	5.752 (.000-1.506E+68)
	Post-Secondary=2	.005 (.000-1.842E+73)
Living Arrangement	Alone=0	Ref
	With Others=1	.000 (.000-1.051E+42)
Geographic Location	Metropolitan=0	Ref
	Non-Metropolitan=1	.000 (.000-1.484E+37)
Self-Rated Health	Fair or Poor=0	Ref
	Excellent or Good=1	140.337 (.000-8.392E+55)

Table 38 (continued)

Variable	Value	Main Effect Analysis
		<i>OR (CI)</i>
Round	Round 3=0	Ref
	Round 4=1	.648 (.000-2.018E+1-4)
	Round 5=2	.908 (.000-4.321E+85)
	Round 6=3	.287 (.000-2.000E+97)
	Round 7=4	4.190 (.000-4.458E+80)
	Round 8=5	327.071 (.000-1.115E+83)
	Round 9=6	.000 (.000-1.115E+83)
	Round 10=7	11.988 (.000-5.556E+125)

Table 38 (continued)

Variable	Value	Main Effect Analysis <i>OR (CI)</i>
Social Network Size	0-5	.083 (.000-4.911E+10)
Number of Chronic Illnesses	0-8	.072 (.000-1.434E+19)
Functional Limitations	0-16	3.698 (1.654E+11)
Health Insurance	0-3	2.417 (.000-2.747E+48)
Depression	0-6	1.735 (.000-6.607E+17)
Anxiety	0-6	.668 (.000-1.886E+17)

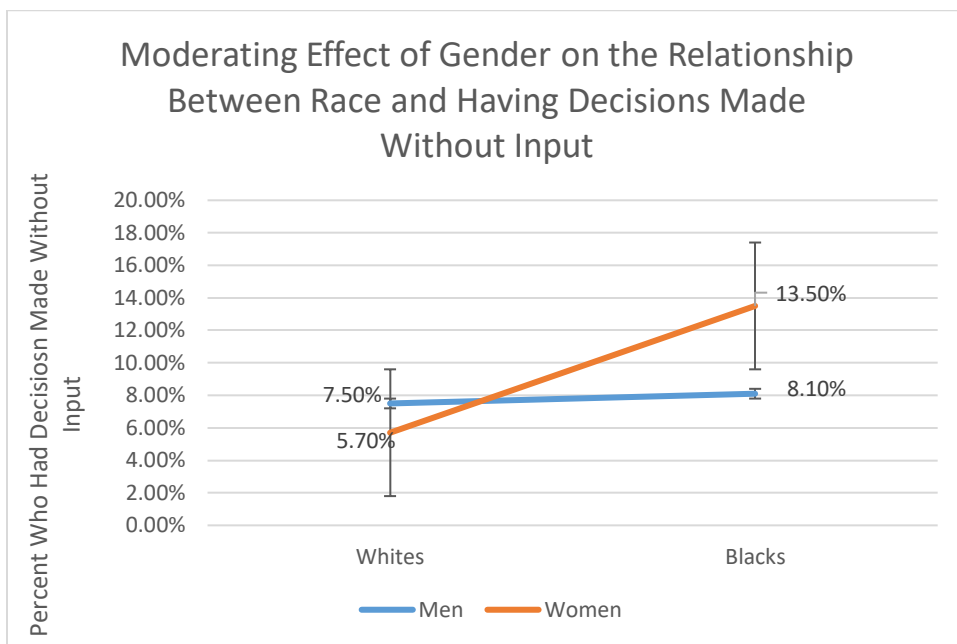
Main Effect Analysis. Model 1 of the multivariate logistic regressions included the main effects of all variables, without the race/gender interaction term. There were no significant differences in the likelihood of being treated with respect based on age at death, gender, race, income, education, living arrangement, geographic location, the round of interview, social network size, number of chronic illnesses, functional limitations, health insurance, depression, or anxiety. Table 38 shows the results for Model 1 of the treated with respect variable. Because the

interaction term was insignificant, only the main effect is reported for the treated with respect variable.

Decisions Made Without Input

Figure 7

Moderating Effect of Gender on the Relationship between Race and Having Decisions Made Without Input



Note. The differing (non-parallel) slope lines for men and women show that the effect of race on decisions without input is dependent on the gender of the decedent.

Table 39*Logistic Regressions for Decisions without Input*

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Race	White=0	Ref	Ref
	Black=1	1.700 (1.679-1.721) *	.1.082 (1.063-1.102) *
Gender	Men=0	Ref	Ref
	Women=1	.841 (.833-.848) *	.708 (.702-.715) *
Race x Gender	-	-	3.367 (3.285-3.450) *
Age at Death	65-69=0	Ref	Ref
	70-74=1	133948635.1 (.000-3.211E+98)	150111124.3 (.000-2.709E+97)
	75-79=2	212685888.8 (.000-5.098E+98)	224374858.1 (.000-4.049E+97)
	80-84=3	139122084.2 (.000-1.376E+98)	140546821.9 (.000-2.537E+97)
	85-89=4	57410272.85 (.000-1.376E+98)	57139916.77 (.000-1.031E+97)
	90+=5	59014988.92 (.000-1.415E+98)	60527644.76 (.000-1.092E+97)

**p*<.05

Table 39 (continued)

Variable	Value	Main Effect Analysis <i>OR (CI)</i>	Interaction Analysis <i>OR (CI)</i>
Income	Low Income=0	Ref	Ref
	Moderate Income=1	.758 (.749-.767) *	.771 (.762-.780) *
	High Income=2	.891 (.879-.903) *	.885 (.873-.897) *
Education	Less Than High School=0	Ref	Ref
	High School=1	2.186 (2.160-2.212) *	2.225 (2.198-2.251) *
	Post-Secondary=2	1.445 (1.427-1.463) *	1.442 (1.425-1.460) *
Living Arrangement	Alone=0	Ref	Ref
	With Others=1	.974 (.966-.983) *	.945 (.937-.954) *
Geographic Location	Metropolitan=0	Ref	Ref
	Non-Metropolitan=1	.643 (.635-.650) *	.644 (.637-.651) *
Self-Rated Health	Fair or Poor=0	Ref	Ref
	Excellent or Good=1	1.321 (1.310-1.333) *	1.362 (1.350-1.374) *

* $p < .05$

Table 39 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Round	Round 3=0	Ref	Ref
	Round 4=1	.486 (.478-.493) *	.485 (.478-.493) *
	Round 5=2	.217 (.211-.222) *	.223 (.218-.229) *
	Round 6=3	.460 (.453-.468) *	.480 (.472-.487) *
	Round 7=4	1.094 (1.080-1.109) *	1.180 (1.164-1.196) *
	Round 8=5	.854 (.842-.866) *	.908 (.895-.920) *
	Round 9=6	.767 (.756-.777) *	.778 (.767-.789) *
	Round 10=7	1.170 (1.153-1.187) *	1.205 (1.188-1.223) *

* $p < .05$

Table 39 (continued)

Variable	Value	Main Effect Analysis OR (CI)	Interaction Analysis OR (CI)
Social Network Size	0-5	.875 (.872-.878) *	.879 (.875-.882) *
Number of Chronic Illnesses	0-8	.856 (.853-.859) *	.857 (.854-.860) *
Functional Limitations	0-16	.962 (.960-.963) *	.960 (.958-.961) *
Health Insurance	0-3	.982 (.975-.989) *	.993 (.985-1.000)
Depression	0-6	1.037 (1.034- 1.041) *	1.036 (1.033- 1.040) *
Anxiety	0-6	1.070 (1.066- 1.073) *	1.073 (1.069- 1.076) *

* $p < .05$

Table 40

Race Effect for the Association between Gender and Decisions without Input

Decisions Without Input – Race Effect		
Comparing Men and Women by Race		
Gender	Race	Likelihood of Having Decisions Made Without Input
Women	Blacks	More likely than White women
	Whites	Less likely than Black women
Men	Blacks	More likely than White men
	Whites	Less Likely than Black men

Table 41*Gender Effect for the Association between Race and Decisions without Input*

Decisions Without Input- Gender Effect		
Comparing Blacks and Whites by Gender		
Race	Gender	Likelihood of Having Decisions Made Without Input
Whites	Men	More likely than White women
	Women	Less likely than White men
Blacks	Men	Less likely than Black women
	Women	More likely than Black men

Main Effect Analysis. Model 1 of the multivariate logistic regressions included the main effects of all variables, without the race/gender interaction term. There were no significant differences in the likelihood of having decisions made without the patient's input based on age at death. Women were less likely to have decisions made without their input compared to men ($OR=.841$, $CI=.833-.848$, $p < .05$), and Blacks were more likely to have decisions made without their input compared to Whites ($OR=1.700$, $CI=1.679-1.721$, $p < .05$). Compared to those with low income, decedents with moderate income ($OR=.758$, $CI=.749-.767$, $p < .05$) and those with high income ($OR=.891$, $CI=.879-.903$, $p < .05$) were less likely to have decisions made without their input. Compared to those with less than a high school education, decedents with only a high

school diploma ($OR=2.186$, $CI=2.160-2.212$, $p < .05$) and those with post-secondary education ($OR=1.445$, $CI=1.427-1.463$, $p < .05$) were more likely to have decisions made without their input. Those living with others were less likely to have decisions made without their input compared to those living alone ($OR=.974$, $CI=.966-.983$, $p < .05$), and those living in non-metropolitan areas were less likely to have decisions made without their input compared to those living in metropolitan areas ($OR=.643$, $CI=.635-.650$, $p < .05$). Decedents with excellent or good self-rated health were more likely to have decisions made without their input compared to those with fair or poor health ($OR=1.321$, $CI=1.310-1.333$, $p < .05$). Decedents in Round 4 ($OR=.486$, $CI=.478-.493$, $p < .05$), Round 5 ($OR=.217$, $CI=.211-.222$, $p < .05$), Round 6 ($OR=.460$, $CI=.453-.468$, $p < .05$), Round 8 ($OR=.854$, $CI=.842-.866$, $p < .05$), and Round 9 ($OR=.767$, $CI=.756-.777$, $p < .05$) were less likely to have decisions made without their input compared to decedents in Round 3, while Decedents in Round 7 ($OR=1.094$, $CI=1.080-1.109$, $p < .05$) and in Round 10 ($OR=1.170$, $CI=1.153-1.187$, $p < .05$) were more likely to have decisions made without their input compared to decedents in Round 3. Every one-unit increase in social network size resulted in a lower likelihood of having decisions made without the patient's input ($OR=.875$, $CI=.872-.878$, $p < .05$), and every additional number of chronic illnesses also decreased the likelihood of having decisions made without the patient's input ($OR=.856$, $CI=.853-.859$, $p < .05$). More functional limitations resulted in a lower likelihood of having decisions made without the patient's input ($OR=.962$, $CI=.960-.963$, $p < .05$), and additional health insurance plans also reduced the likelihood of having decisions made without the patient's input ($OR=.982$, $CI=.975-.989$, $p < .05$). More depressive symptoms resulted in a higher likelihood of having decisions made without the patient's input ($OR=1.037$, $CI=1.034-1.041$, $p < .05$), and more anxiety symptoms also resulted in a higher likelihood of having decisions made

without the patient's input ($OR=1.070$, $CI=1.066-1.073$, $p < .05$). All of the decisions made without input odds ratios in the main effect analysis had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between the independent variables and having decisions made without input at the end of life.

Interaction Analysis. Model 2 of the logistic regression included an interaction term for race and gender to determine whether gender moderates the relationship between race and decisions made without input. The logistic regression results showed that race and gender interacted with each other to affect the probability of having decisions made without input at the end of life. This suggests that the effect of race on decisions being made without input depends on the gender of the decedent; the effects of gender were dependent on their race, with a $<.05$ p -value for the interaction term. Specifically, women were less likely to have decisions made without their input compared to men among White decedents, while among Black decedents, women were more likely to have decisions made without their input compared to men ($OR=.708$, $CI=.702-.715$, $p <.05$). Regarding race effect, Blacks were more likely to have decisions made without their input compared to Whites among men. Meanwhile, among women, Blacks were also more likely to have decisions made without their input compared to Whites ($OR=1.082$, $CI=1.063-1.102$, $p <.05$). No significant difference was found in the likelihood of decisions being made without the patient's input based on age at death. Compared to those with low income, decedents with moderate income ($OR=.771$, $CI=.762-.780$, $p <.05$) and those with high income ($OR=.885$, $CI=.873-.897$, $p <.05$) were less likely to have decisions made without their input. In comparison to those with less than a high school education, decedents with only a high school diploma ($OR=2.225$, $CI=2.198-2.251$, $p <.05$) and those with post-secondary education ($OR=1.442$, $CI=1.425-1.460$, $p <.05$) were more likely to have decisions made without their

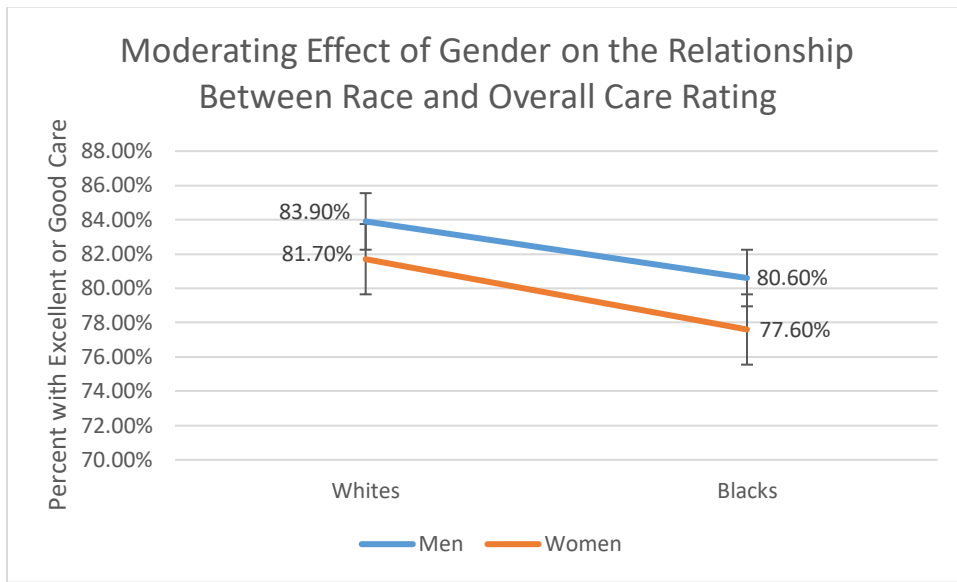
input. Those living with others were less likely to have decisions made without their input compared to those living alone ($OR=.945$, $CI=.937-.954$, $p < .05$), and those living in non-metropolitan areas were less likely to have decisions made without their input compared to those living in metropolitan areas ($OR=.644$, $CI=.637-.651$, $p < .05$). Decedents with excellent or good self-rated health were more likely to have decisions made without their input compared to those with fair or poor health ($OR=1.362$, $CI=1.360-1.374$, $p < .05$). Compared to those in Round 3, decedents in Round 4 ($OR=.485$, $CI=.478-.493$, $p < .05$), Round 5 ($OR=.223$, $CI=.218-.229$, $p < .05$), Round 6 ($OR=.480$, $CI=.472-.487$, $p < .05$), Round 8 ($OR=.908$, $CI=.895-.920$, $p < .05$), and Round 9 ($OR=.778$, $CI=.767-.789$, $p < .05$) were less likely to have decisions made without their input; however, decedents in Round 7 ($OR=1.180$, $CI=1.164-1.196$, $p < .05$) and those in Round 10 ($OR=1.205$, $CI=1.188-1.223$, $p < .05$) were more likely to have decisions made without their input compared to those in Round 3. Every one-unit increase in social network size led to a lower likelihood of having decisions made without the patient's input ($OR=.879$, $CI=.875-.882$, $p < .05$), and every additional chronic illness also decreased the likelihood of having decisions made without the patient's input ($OR=.857$, $CI=.854-.860$, $p < .05$). More functional limitations resulted in a lower likelihood of having decisions made without the patient's input ($OR=.960$, $CI=.958-.961$, $p < .05$), and more health insurance did not predict the likelihood of having decisions made without the patient's input. More depressive symptoms resulted in a higher likelihood of having decisions made without the patient's input ($OR=1.036$, $CI=1.033-1.040$, $p < .05$), whereas more anxiety symptoms also resulted in a higher likelihood of having decisions made without the patient's input ($OR=1.073$, $CI=1.069-1.076$, $p < .05$). All of the decisions made without input odds ratios in the interaction effect analysis (Model 2) had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between

the independent variables and having decisions made without input at the end of life. Figure 7 shows the moderating effect of gender on the relationship between race and decisions without input. Table 39 depicts all the logistic regression results for the main effect analysis (Model 1) and the interaction effect analysis (Model 2) of the decisions made without an input dependent variable. Table 40 reports the interaction results for race effects, and Table 41 shows the interaction results for gender effects.

Overall Care Rating

Figure 8

Moderating Effect of Gender on the Relationship between Race and Overall Care Rating



Note. The differing (non-parallel) slope lines for men and women show that the effect of race on overall care rating is dependent on the gender of the decedent.

Table 42*Logistic Regressions for Overall Care Rating*

Variable	Value	Main Effect Analysis <i>OR (CI)</i>	Interaction Analysis <i>OR (CI)</i>
Race	White=0	Ref	Ref
	Black=1	.951 (.943-.960) *	801 (.791-.811) *
Gender	Men=0	Ref	Ref
	Women=1	.966 (.961-.972) *	862 (.857-.866) *
Race x Gender	-	-	.668 (.656-.679) *
Age at Death	65-69=0	Ref	Ref
	70-74=1	.366 (.361-.372) *	.361 (.355-.357) *
	75-79=2	.695 (.684-.705) *	.695 (.684-.706) *
	80-84=3	.914 (.900-.929) *	.919 (.904-.934) *
	85-89=4	1.198 (1.179-1.218) *	1.207 (1.187-1.226) *
	90+=5	1.532 (1.508-1.557) *	1.536 (1.511-1.561) *

* $p < .05$

Table 42 (continued)

Variable	Value	Main Effect Analysis <i>OR (CI)</i>	Interaction Analysis <i>OR (CI)</i>
Income	Low Income=0	Ref	Ref
	Moderate Income=1	.915 (.908-.922) *	.913 (.906-.920) *
	High Income=2	2.736 (2.704-2.768) *	2.746 (2.714-2.778) *
Education	Less Than High School=0	Ref	Ref
	High School=1	.620 (.615-.624) *	.619 (.615-.624) *
	Post-Secondary=2	.772 (.767-.778) *	2.726 (2.714-2.778) *
Living Arrangement	Alone=0	Ref	Ref
	With Others=1	1.232 (1.225-1.240) *	1.244 (1.237-1.252) *
Geographic Location	Metropolitan=0	Ref	Ref
	Non-Metropolitan=1	1.270 (1.262-1.279) *	1.264 (1.255-1.273) *
Self-Rated Health	Fair or Poor=0	Ref	Ref
	Excellent or Good=1	1.105 (1.098-1.111) *	1.100 (1.093-1.106) *

* $p < .05$

Table 42 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Round	Round 3=0	Ref	Ref
	Round 4=1	.956 (.946-.966) *	.955 (.945-.965) *
	Round 5=2	1.026 (1.014-1.039)	1.025 (1.013-1.038) *
	Round 6=3	.815 (.806-.824) *	.807 (.799-.816) *
	Round 7=4	.652 (.645-.659) *	.643 (.637-.650) *
	Round 8=5	.513 (.508-.519) *	.506 (.501-.511) *
	Round 9=6	1.031 (1.020-1.043) *	1.024 (1.013-1.035) *
	Round 10=7	.504 (.499-.509) *	.502 (.496-.507) *

* $p < .05$

Table 42 (continued)

Variable	Value	Main Effect Analysis	Interaction Analysis
		<i>OR (CI)</i>	<i>OR (CI)</i>
Social Network Size	0-5	.985 (.983-.988) *	.985 (.983-.987) *
Number of Chronic Illnesses	0-8	1.035 (1.033-1.037) *	1.034 (1.032-1.036) *
Functional Limitations	0-16	.969 (.968-.970) *	.970 (.969-.971) *
Health Insurance	0-3	1.175 (1.169-1.181) *	1.171 (1.165-1.177) *
Depression	0-6	.966 (.964-.968) *	.965 (.963-.967) *
Anxiety	0-6	.956 (.946-.966) *	.963 (.962-.965) *

* $p < .05$

Table 43

Race Effect for the Association between Gender and Overall Care Rating

Overall Care Rating – Race Effect		
Comparing Men and Women by Race		
Gender	Race	Likelihood of Having Excellent or Good Care
Women	Blacks	Less likely than White women
	Whites	More likely than Black women
Men	Blacks	Less likely than White men
	Whites	More likely than Black men

Table 44*Gender Effect for the Association between Race and Overall Care Rating*

Overall Care Rating - Gender Effect		
Comparing Blacks and Whites by Gender		
Race	Gender	Likelihood of Having Excellent or Good Care
Whites	Men	More likely than White women
	Women	Less likely than White men
Blacks	Men	More likely than Black women
	Women	Less Likely than Black men

Main Effect Analysis. Model 1 of the multivariate logistic regressions included the main effects of all variables, without the race/gender interaction term. Compared to those aged 65-69, decedents aged 70-74 ($OR=.366$, $CI=.361-.372$, $p < .05$), those aged 75-59 ($OR=.695$, $CI=.684-.705$, $p < .05$) and those aged 80-84 ($OR=.914$, $CI=.900-.929$, $p < .05$) were less likely to have excellent or good care at the end of life. However, those aged 85-89 ($OR=1.198$, $CI=1.179-1.218$, $p < .05$) and those aged 90 and older ($OR=1.532$, $CI=1.508-1.557$, $p < .05$) were more likely to have excellent or good care compared to those aged 65-69. Women were less likely to have excellent or good care compared to men ($OR=.966$, $CI=.961-.972$, $p < .05$), and Blacks were less likely to have excellent or good care compared to Whites ($OR=.951$,

$CI=.943-.960, p < .05$). In comparison to those with low income, decedents with moderate income ($OR=.915, CI=.908-.922, p < .05$) were less likely to have excellent or good care at the end of life, while those with high income ($OR=2.736, CI=2.704-2.768, p < .05$) were more likely to have excellent or good care at the end of life. Compared to those with less than a high school education, those with only a high school diploma ($OR=.620, CI=.615-.624, p < .05$) and those with post-secondary education ($OR=.772, CI=.767-.778, p < .05$) were less likely to have excellent or good care at the end of life. Decedents living with others were more likely to have excellent or good care at the end of life compared to those living alone ($OR=1.232, CI=1.225-1.240, p < .05$), and those living in non-metropolitan areas were more likely to have excellent or good care compared to those living in metropolitan areas ($OR=1.035, CI=1.033-1.037, p < .05$). Decedents with excellent or good self-rated health were more likely to have excellent or good care at the end of life compared to those with fair or poor health ($OR=1.105, CI=1.098-1.111, p < .05$). Compared to those in Round 3, decedents in Round 4 ($OR=.956, CI=.946-.966, p < .05$), Round 6 ($OR=.815, CI=.806-.824, p < .05$), Round 7 ($OR=.652, CI=.645-.659, p < .05$), Round 8 ($OR=.513, CI=.508-.519, p < .05$), and Round 10 ($OR=.504, CI=.499-.509, p < .05$) were less likely to have excellent or good care, whereas decedents in Round 5 ($OR=1.026, CI=1.014-1.039, p < .05$) and Round 9 ($OR=1.031, CI=1.020-1.043, p < .05$) were more likely to have excellent or good care. Every one-unit increase in social network size resulted in a lower likelihood of having excellent or good care at the end of life ($OR=.985, CI=.983-.988, p < .05$), and additional number of chronic illnesses resulted in a greater likelihood of having excellent or good care ($OR=1.035, CI=1.033-1.037, p < .05$). More functional limitations resulted in a lower likelihood of having excellent or good care ($OR=.969, CI=.968-.970, p < .05$), and more health insurance plans led to a higher likelihood of having excellent or good care ($OR=1.175,$

$CI=1.169-1.181, p < .05$). More depressive symptoms resulted in a lower likelihood of having excellent or good care ($OR=.966, CI=.964-.968, p < .05$), and more anxiety symptoms also resulted in a lower likelihood of having excellent or good care ($OR=.956, CI=.946-.966, p < .05$). Most of the overall care rating odds ratios in the main effect analysis (Model 1) had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between the independent variables and overall care rating at the end of life. However, the odds ratio for the difference in overall care rating for low-income and high-income decedents had a moderate effect size relative to Cohen's d (Chen et al., 2010).

Interaction Analysis. Model 2 of the logistic regression included an interaction term for race and gender to determine whether gender moderates the relationship between race and overall care rating. The logistic regression results showed that race and gender interacted with each other to affect the probability of having excellent or good care at the end of life. This suggests that the effect of race on overall care rating depends on the gender of the decedent; the effect of gender was dependent on their race, with a $<.05$ p -value for the interaction term. Specifically, women were less likely to have excellent or good care at the end of life compared to men among White decedents; meanwhile, decedents women were also less likely to have excellent or good care compared to men Black decedents ($OR=.862, CI=.857-.866, p < .05$). Regarding race effect, among men, Blacks were less likely than Whites to have excellent or good care at the end of life; among women, Blacks were also less likely to have excellent or good care compared to Whites ($OR=.801, CI=.791-.811, p < .05$). Compared to those aged 65-69, decedents aged 70-74 ($OR=.361, CI=.355-.367, p < .05$), those aged 75-79 ($OR=.695, CI=.684-.706, p < .05$), those aged 80-84 ($OR=.919, CI=.904-.934, p < .05$) were less likely to have excellent or good care at the end of life, while those aged 85-89 ($OR=1.207, CI=1.187-$

1.226 $p < .05$) and those aged 90 and older ($OR=1.536$, $CI=1.511-1.561$, $p < .05$) were more likely to have excellent or good care. In comparison to those with low income, decedents with moderate income were less likely to have excellent or good care at the end of life ($OR=.913$, $CI=.906-.920$, $p < .05$), while those with high income were more likely to have excellent or good care at the end of life ($OR=2.746$, $CI=2.714-2.778$, $p < .05$). Compared to those with less than a high school education, decedents with only a high school diploma were less likely to have excellent or good care at the end of life ($OR=.619$, $CI=.615-.624$, $p < .05$), while those with post-secondary education were more likely to have excellent or good care at the end of life ($OR=2.726$, $CI=2.714-2.778$, $p < .05$). Compared to those living alone, decedents who were living with others were more likely to have excellent or good care at the end of life ($OR=1.244$, $CI=1.237-1.252$, $p < .05$), and decedents living in non-metropolitan areas were more likely to have excellent or good care compared to those living in metropolitan areas ($OR=1.264$, $CI=1.255-1.273$, $p < .05$). Decedents with excellent or good self-rated health were more likely to have excellent or good care at the end of life compared to those with fair or poor health ($OR=1.100$, $CI=1.093-1.106$, $p < .05$). Compared to those in Round 3, decedents in Round 4 ($OR=.955$, $CI=.945-.965$, $p < .05$), Round 6 ($OR=.807$, $CI=.799-.816$, $p < .05$), Round 7 ($OR=.643$, $CI=.637-.650$, $p < .05$), Round 8 ($OR=.506$, $CI=.501-.511$, $p < .05$), and those in Round 10 ($OR=.502$, $CI=.496-.507$, $p < .05$) were less likely to have excellent or good care, while decedents in Round 5 ($OR=1.025$, $CI=1.013-1.038$, $p < .05$) and those in Round 9 ($OR=1.024$, $CI=1.013-1.035$, $p < .05$) were more likely to have excellent or good care at the end of life. Every one-unit increase in social network size resulted in a lower likelihood of having excellent or good care ($OR=.985$, $CI=.983-.987$, $p < .05$), and additional chronic illnesses also resulted in a lower likelihood of having excellent or good care ($OR=.857$, $CI=.854-.860$, $p < .05$).

More functional limitations resulted in a lower likelihood of having excellent or good care ($OR=.970$, $CI=.969-.971$, $p < .05$), and more health insurance plans resulted in a higher likelihood of having excellent or good care at the end of life ($OR=1.171$, $CI=1.165-1.177$, $p < .05$). More depressive symptoms resulted in a lower likelihood of having excellent or good care ($OR=.965$, $CI=.963-.967$, $p < .05$), and more anxiety symptoms also resulted in a lower likelihood of having excellent or good care ($OR=.963$, $CI=.962-.965$, $p < .05$). All of the overall care rating odds ratios in the interaction effect analysis had a small effect size relative to Cohen's d (Chen et al., 2010), indicating a weak association between the independent variables and overall care rating at the end of life. Figure 8 depicts the moderating effect of gender on the relationship between race and overall care rating. Table 42 presents all the logistic regression results for the main effect analysis (Model 1) and the interaction effect analysis (Model 2) of the overall care rating dependent variable. Table 43 reports the interaction results for race effects, and Table 44 presents the interaction results for gender effects. Table 45 provides an overall summary of the race effects of all eight variables within the study, whereas Table 46 provides an overall summary of the gender effects for all eight variables.

Table 45*Overall Summary for Gender Effects (Among Whites and Among Blacks) Across All Eight**Dependent Variables*

	White Men	White Women	Black Men	Black Women
Hospice Care (No)			x	x
Pain (Yes)		x	x	
Anxiety/Depression (Yes)	x	x		
Alone at Death (Yes)		x	x	
Religious Belief Discussions (No)	x			x
Treated With Respect (No)	-	-	-	-
Decisions Without Input (Yes)			x	x
Overall Care Rating (Fair/Poor)			x	x
Total	2	3	5	4

Note. The “x” delineates the group that experienced the worse outcomes for each variable based on gender effects. The brackets indicate which option was considered “worse.”

Table 46

Overall Summary for Race Effects (Among Men and Among Women) Across All Eight Dependent Variables

	White Men	White Women	Black Men	Black Women
Hospice Care (No)			x	x
Pain (Yes)		x	x	
Anxiety/Depression (Yes)	x	x		
Alone at Death (Yes)		x	x	
Religious Belief Discussions (No)	x			x
Treated With Respect (No)	-	-	-	-
Decisions Without Input (Yes)			x	x
Overall Care Rating (Fair/Poor)			x	x
Total	2	3	5	4

Note. The “x” delineates the group that experienced the worse outcomes for each variable based on race effects. The brackets indicate which option was considered “worse.”

DISCUSSION

This study aimed to explore the intersectional impact of race and gender on quality of life at the end of life, using the National Health and Aging Trends Study (NHATS). It provides an overview of end-of-life outcomes for decedents representing the general population in the US. Overall, the majority of decedents did not have hospice care at the end of life, which mirrors prior studies often reporting that older adults do not use hospice services at the end of life (Haines et al., 2018; Shega et al., 2008). A large majority of the decedents experienced pain at the end of life, which may reflect the high rates of chronic illness among individuals aged 65 and older, which are often associated with chronic pain (Hendriks et al., 2015; National Council on Aging, 2018; Van den Beuken-van Everdingen et al., 2007). In prior studies about mental health outcomes at the end of life, researchers often found a low prevalence of anxiety and depression, but the results of this study indicate that most decedents experienced some level of anxiety and/or depression at the end of life (Rosenstein, 2011; Spencer et al., 2010). For the variable “alone at death,” a vast majority of the decedents did not die alone, and this matches results from prior studies showing that most individuals have a preference for being surrounded by other individuals at death (Frommer, 2016; Larsson et al., 2017).

Although the role of religiosity and spirituality has been heavily studied in prior end-of-life research (Bülow et al., 2012; Karches et al., 2012), religious belief discussions have not elicited as much attention in the field of end-of-life as other variables used in this study. However, the results indicate that most of the decedents did not engage in religious belief discussions with their providers. This may reflect the novel state of religious/spiritual-cultural

competence within the healthcare system, as providers have just recently begun to incorporate religious preferences into practice (Gijsberts et al., 2019). Treatment with respect has also not been well-studied in the literature, and the study findings indicate that most decedents were treated with respect always, sometimes, or usually. In fact, only one decedent was never treated with respect by providers. Regarding autonomy in decision-making at the end of life, most of the decedents did not have decisions made without their input, which may indicate the impact that the Patient Self Determination Act has had on provider treatment of patients (Cerminara & Meisel, 2015; Library of Congress, 1990). Finally, most decedents within the study had excellent or good care at the end of life, which is also consistent with the findings of prior studies related to the general population (Watchterman et al., 2016; Wright et al., 2016). The next few paragraphs will discuss findings on the main effect of race and gender separately, followed by the results from the analysis using the interaction of the two variables in accordance with the theory of intersectionality.

Hospice Care

In Model 1 of the logistic regressions (the main effect analysis), results showed that Black decedents were less likely to receive hospice care at the end of life compared to their White counterparts, thus supporting Hypothesis 1.1. In prior studies, researchers often found significant racial disparities in the receipt of hospice care between Blacks and Whites (Hardy et al., 2014; Ornstein et al., 2020). In further analyses, prior studies also found that Blacks were less likely to receive hospice referrals from providers, and even when they did, it was often delayed when compared to their White counterparts (Karanth et al., 2018; Wasp et al., 2020). Researchers have also identified that Black individuals who do use hospice services are more likely to end hospice care before death and are more likely to have multiple hospice facility

transitions (Laguna, 2014; Wang et al., 2019). This indicates both a systemic barrier and an individual-level barrier to care, consistent with the tenets of the critical race theory (Delgado & Stefancic, 2017). Medical providers often disfavor Black patients by providing limited or delayed knowledge about services, and sometimes simply refusing to provide patient education (Hall et al., 2015). There is also an inherent distrust in the medical care system among Black individuals, which may lead to an inability to adhere to a medical provider's advice (Penner et al., 2009). Black individuals are also less likely to have post-secondary education compared to Whites, which, in turn, may affect their knowledge, awareness, and attitude towards hospice care (Ryan & Bauman, 2015; Taber et al., 2019). Another consideration is the role of cultural/religious factors in the Black community, since the pursuit of comfort/non-aggressive care may often be viewed as a sign of giving up or a deviation from religious values that often favor the preservation of life (Bazargan & Bazargan-Hejazi, 2021; Bullock, 2011).

For the main effect of gender, results indicated that women were more likely to use hospice services compared to men. Although prior studies have found that men were more likely to have access to medical services, researchers have also discovered that women tend to have a more positive view of non-aggressive care when compared to men (Saeed et al., 2018). While men may have the resources to be able to access hospice care; they are more likely to prefer pursuing all treatment possible at the end of life (Cameron et al., 2010; Sharma et al., 2015). The difference in stressors or hardships experienced at the end of life is another potential explanation. Women have been found to have a biologically lower threshold for pain than men and are also more likely to experience mental health issues such as depression and anxiety (Altemus et al., 2014; Bartley & Fillingim, 2013). Hospice care includes symptom management, spiritual care, and mental health care, for which women may be more in need (Wittenberg-Lyles et al., 2010).

Even when men do experience pain and emotional distress, they are less likely to report it. Thus, they may be less likely to be referred for hospice services (Altemus et al., 2014; Bartley & Fillingim, 2013).

In Model 2 of the logistic regressions (the interaction effect analysis), an interaction term for race and gender was added. This revealed that race and gender do interact to affect the receipt of hospice care at the end of life, thus supporting Hypothesis 2.1. White women were the most likely to receive hospice care, followed by White men, Black men, and Black women, who were the least likely to have hospice care at the end of life. While the main effect of gender suggests that women are more likely to receive hospice care, the consideration of race clearly shows that Black women do not have the same access to hospice services as White women do, likely due to their intersectional identities (Crenshaw, 1989). Although women tend to have a higher preference for non-aggressive care than men, the results of this study show that systemic barriers related to race may contribute to a lower likelihood of access to hospice care among Black women (Johnson, 2013; Saeed et al., 2018). Black women are generally less likely to have post-secondary education compared to Black men, White women, and White men and are also less likely to have health insurance compared to Black men, White women, and White men (American Association of University Women, 2022; Hinze et al., 2018; National Partnership for Women and Families, 2019). As such, the effect of gender on the receipt of hospice care is trumped by the systemic barriers that Black women may face in their access to hospice services at the end of life.

Pain

In Model 1 of the logistic regressions, the results indicated that Black decedents were less likely to experience pain at the end of life compared to Whites, which does not support

Hypothesis 1.2. Prior studies on racial disparities in the prevalence of pain suggest that Black individuals may be more likely to experience pain compared to Whites due to historical and systemic barriers identified by the critical race theory and the social determinants of health (Campbell & Edwards, 2013; Delgado & Stefancic, 2017; Healthy People, 2020; Wyatt, 2013). Additionally, prior research found that Black individuals were less likely to be accurately assessed for pain and were also less likely to receive appropriate pain management (Booker et al., 2020). This may partly be due to the pharmacogenetic differences in how different groups react to certain medications, especially because minority groups are often excluded from clinical trials (Boyle, 2021; Kaye et al., 2019). Black persons are also less likely to adhere to pain medication and may express hesitancy in receiving medical advice from professionals (Hoffman et al., 2016; Yeager et al., 2019). Prior research attributes this hesitancy to the mistrust in providers among Blacks, which may prevent them from reporting pain symptoms (Campbell & Edwards, 2013). Combined with research showing that Black persons are less likely to be accurately assessed for pain, the results of this study may point to a systemic discrepancy rather than an accurate account of pain experienced by the Black decedents (Booker et al., 2020). Among these discrepancies are the ways in which pain is measured within the medical system, which often includes the visual analogue scale (VAS) and the numeric rating scale (NRS), which have reliability and validity, but may have operationalization flaws that distort findings (Bendinger & Plunkett, 2016).

For the main effect of gender, Women were more likely to experience pain at the end of life compared to Men. This result mirrors findings from other studies generally suggesting that women may experience more pain than men based on a review of clinical studies focused on physiological/biological differences in pain between the sexes (Barkley & Filligim, 2013; Mogil,

2012). However, pain is often subjective, and studies also suggest that women may simply have a lower threshold for pain than men (Barkley & Filligim, 2013; Pieretti et al., 2016). Another important consideration is the existence of common chronic pain syndromes that occur only in women, including endometriosis, vulvodynia, and menstrual pain (Mogil, 2012). Women are also overrepresented in the profile of patients with common chronic pain syndromes that occur in both genders, including fibromyalgia, chronic fatigue, migraines, neck pain, and knee pain (Mogil, 2012). Masculine culture may also play a role in the experience of pain for men, as pain is often viewed as a sign of weakness (Barkley & Filligim, 2013). This may result in a lower likelihood of reporting pain among men, while women may be more open to expressing that they are in pain and may also be more open to receiving pain treatment as a result.

In Model 2 of the logistic regressions, the race/gender interaction term revealed that race and gender do interact to affect the experience of pain at the end of life, which supports Hypothesis 2.2. White women were most likely to experience pain, followed by Black women, Black men, and then White men, who were the least likely to experience pain. While prior studies suggest that women may be more likely to experience pain than men, adding the race/gender interaction term provided more insight into the disparity between Black men and White men (Barkley & Filligim, 2013; Mogil, 2012). Black men may experience more pain at the end of life as a result of the aforementioned underdiagnoses and undertreatment of pain among Black patients (Barkley & Filligim, 2013; Travers, 2019). Another possible explanation is the nature of the illness trajectory for Black men, who are generally more likely to be diagnosed at later stages of a disease, which, in turn, may increase the level of pain that they experience at the end of life (Virnig et al., 2009). On the other hand, White men may have more access to pain management earlier in the disease trajectory, leading to a lesser level of pain at the end of life

(Virnig et al., 2009). Similar to Black men, Black women are also less likely to be diagnosed at early stages and may also lack the resources to engage in early intervention (George et al., 2015). One study specifically found that the majority of sampled White medical students believed that there was a biological difference in the pain threshold of Black persons compared to their White counterparts and that those who held such beliefs were more likely to report lower ratings of pain for Blacks (Hoffman et al., 2016). This is an example of why the critical race theory is important in understanding racial disparities, as race is often viewed as a biological difference, while the critical race theory stands on the tenet that race is a social construct (Delgado & Stefancic, 2017). These false beliefs likely contribute to the underestimation of pain among Black individuals when compared to Whites, which leads to under/untreated and more severe pain symptoms (Hoffman et al., 2016).

Anxiety/Depression

In Model 1 of the logistic regressions, the results showed that Black decedents were less likely to have anxiety/depression at the end of life compared to White decedents, which does not support Hypothesis 1.3. Prior research on the prevalence of mental illness among Blacks generally suggests that they are less likely to experience anxiety or depression across the lifespan, likely due to the stigma associated with mental illness in the Black community (Asnaani et al., 2010; Bailey et al., 2019). However, other studies indicate that the presence of anxiety and/or depression may be particularly evident among Black individuals with chronic illnesses, who are more likely to experience the negative mental health effects of chronic illnesses (Alcalá, 2014; Calhoun et al., 2015). This may be attributable to the intersectional stressors of race and other social identities across the lifespan, which may take a toll on a person with a terminal illness (Crenshaw, 1989; Delgado & Stefancic, 2017). Mental health within the Black

community is also often stigmatized, which discourages help-seeking behavior and may also prevent reporting of mental health concerns (Conner et al., 2010). As such, while Black decedents within this study were less likely to have anxiety/depression at the end of life, which could be attributable to the mental health disclosure among Black individuals. Another consideration is the role of protective factors within the Black community, including social bonds through congregations, extended family networks, and other social networks that have been found to act as buffers for experiencing mental illness (Grill et al., 2021; Nguyen et al., 2017).

For the effect of gender on anxiety/depression at the end of life, the results showed that women were more likely to have anxiety/depression at the end of life when compared to men. Previous studies on the prevalence of mental illness often show that women were generally more likely to have anxiety and depression when compared to men (Altemus et al., 2014; McLean et al., 2011). While this may be objectively true, it is also important to consider the role of gender norms pertaining to mental illness (Altemus et al., 2014). In particular, men are often conditioned to be less expressive about emotions and feelings, while coping methods such as substance use are more acceptable or more expected (Altemus et al., 2014). While women may present more symptoms of depression and anxiety, men are simply less likely to admit to experiencing similar symptoms or may even suppress those symptoms.

In Model 2 of the logistic regressions, the results showed that race and gender do interact to affect the experience of anxiety/depression at the end of life, which supports hypothesis 2.3. White women were the most likely to experience anxiety/depression at the end of life, followed by White men, Black women, and then Black men. Although women have been found to have a higher prevalence of depression and anxiety when compared to men, the race/gender interaction

effect shows the impact of race on mental illness, with Black women being less likely to have anxiety/depression compared to White men (Altemus et al., 2014). The mental health stigma within the Black community is likely contributing to this result, given that Black women may suppress symptoms of anxiety or depression and may also be less likely to report those symptoms (Conner et al., 2010).

Alone at Death

In Model 1, the results showed that Black individuals were more likely to be alone at death when compared to White decedents, supporting Hypothesis 1.4. Previously, researchers have identified the importance of social bonds among Black individuals, who are more likely to prioritize family and friends, comfort from the church, and the presence of other individuals at the end of life (Grill et al., 2021). However, other studies suggest that while Black individuals may have more social bonds earlier in life, Black individuals at the end of life may be more likely to live and die alone compared to Whites (Bernato et al., 2009; Fabius & Robison, 2019; Thorpe et al., 2012). Extended family living arrangements are very common in the Black community, and Black persons are more likely to have strong social support networks than Whites (Taylor et al., 2013). However, the location of death may point to the discrepancy observed in this study. Black individuals are more likely to die in a hospital compared to their White counterparts, and often more likely to spend time in the emergency room or in the intensive care unit, indicating a more severe illness trajectory that likely stem from systemic barriers highlighted by the critical race theory (Delgado & Stefancic, 2017; Kirtane et al., 2018; Orlovic et al., 2019). While Black individuals may have a preference for family bonds, the suddenness of death in a hospital may inhibit family members from being present at the time of death. Particularly during times like the COVID-19 pandemic, family members were often

unable to be with their loved ones in the final moments of life, even when they had a desire to be able to do so (Anderson-Shaw & Zar, 2020).

For the main effect of gender, the findings of this study indicated that women were significantly less likely to be alone at death compared to men. In studies across the lifespan, researchers have consistently found that women were more likely to have stronger social bonds and stronger social networks when compared to men (Psylla et al., 2017; Szell & Thurner, 2013). Particularly among older adults, studies suggest that older women are more likely to value friendship bonds and also more likely to place emphasis on intimacy later in life (Felmlee & Muraco, 2009). Women in older adulthood are also more likely to remain connected with their family members, sometimes even playing integrate roles as a caregiver to their grandchild (Thomas et al., 2017). Women are also more likely to live with other family members, while men are more likely to be objectively socially isolated (Henning-Smith et al., 2018). Considering the close association between living arrangements and dying alone, women are more positioned to be surrounded by other individuals at death than men. Additionally, the results of this study and that of others show that women are more likely to use hospice than men and the majority of hospice services are provided in a location that the individual considers “home” (NHPCO, 2020; Saeed et al., 2018; Sharma et al., 2015). As such, women are more likely to die in home-like settings due to the higher likelihood of using home-based services such as hospice and palliative care, leading to a greater chance of being surrounded by other individuals at death (Cohen et al., 2011).

In Model 2, the results showed that race and gender do interact with one another to influence the likelihood of being alone at death, thus supporting Hypothesis 2.4. Black men were the most likely to be alone at death, followed by White women, White men, and then Black

women, who were the least likely to be alone at death. The result of the race/gender interaction term explains the discrepancy between prior findings and the results in Model 1 of the alone at death dependent variable. Research suggests that Black individuals have more social bonds than Whites, yet that Black older adults are more likely to die alone (Taylor et al., 2013). The inclusion of the interaction term shows that this is only applicable to Black men, as Black women are actually less likely to die alone than White men and White women. Black women in particular may be benefitting from the combined higher likelihood of social bonds found among women and Black individuals in general (Psylla et al., 2017; Szell & Thurner, 2013; Taylor et al., 2013). Black men, on the other hand, may be experiencing the impact of gender differences in closeness with family at the end of life, highlighting the role of intersectional identities (Crenshaw, 1989; Thomas et al., 2017). Additionally, Black men are more likely to be incarcerated, are more likely to have substance use dependencies, and are more likely to experience financial difficulties, which may all contribute to their alienation from family members, leading to a higher likelihood of dying alone (Chetty et al., 2020; Mukku et al., 2012; Rowell-Cunsolo et al., 2016).

Religious Belief Discussions

In Model 1 of the logistic regressions, the results showed that Black decedents were more likely to have religious belief discussions at the end of life compared to White decedents, which does not support Hypothesis 1.5. A major limitation to this variable is the inability to discern whether the religious belief discussion was engaged by the patient themselves, or by the provider. However, prior studies have shown that Black individuals are more likely to hold strong religious beliefs compared to their White counterparts and that these religious beliefs often dictate decisions made at the end of life (Balboni et al., 2013; Brown, 2014; Givler et al.,

2020; Koffman et al., 2008; Sanders et al., 2016; Witcher & Meeker, 2012). Considering the importance of religion for Black persons, the patient and/or the family are more likely to initiate those conversations with their providers. While religious beliefs are also important to some White persons, a higher proportion of Black individuals prioritize religious beliefs at the end of life (Scherer et al., 2021). This is another example of the importance of the critical race theory in examining current outcomes, as religion was often a safe haven for enslaved Blacks in the antebellum era and remains a critical consideration to date, impacting factors such as end-of-life needs (Delgado & Stefancic, 2017; Scherer et al., 2021).

For the main effect of gender, the results showed that women were more likely to engage in religious belief discussions compared to men. A demographic study from the Pew Research Center (2016) focused on gender differences in faith around the world and found that women were more likely to be religious compared to men, especially among Christians. The study also found that women were more likely to say that religion was very important to them; they were more likely to attend religious services and were more likely to report that they pray daily (Pew Research Center, 2016). Particularly at the end of life, women have also been found to be more likely to hold strong religious beliefs, and more likely to report that their religious beliefs were important (Scherer et al., 2021).

In Model 2, the results showed that race and gender do interact to affect religious belief discussions at the end of life, which supports Hypothesis 2.5. Black men were the most likely to have religious belief discussions, followed by White women, Black women, and then White men, who were the least likely to have religious belief discussions. In general, there is a higher focus on faith and religious belief among Black individuals, and among women (Scherer et al., 2021). Men have generally been found to be less likely to attend religious services, less likely to

pray often, and less likely to report that their religious beliefs are important (Pew Research Center, 2016). Similarly, Blacks have been found to value religious beliefs more than Whites, and religion and faith were often used as a coping mechanism for enslaved Blacks in the antebellum era (Basu-Zharku, 2011; Sanders et al., 2016; Witcher & Meeker, 2012). As members of two groups that are less likely to have strong religious beliefs, White men may not value religious belief discussions with their providers and are unlikely to initiate those discussions as a result. The difference between Black women and White women may point to a racial advantage for White women, who may be more trusting of their medical providers (Campbell & Edwards, 2013; Penner et al., 2009). Similarly, the difference between Black men and Black women may also point to a gender advantage for Black men, as providers have been found to favor men over women in the healthcare system, thereby emphasizing the impact of intersectional identities (Crenshaw, 1989; Paulsen, 2020; Samulowitz et al., 2018).

Treated with Respect

For both the main effects and the race/gender interaction term, no significant differences were found in the probability of being treated with respect always, usually, or sometimes, which does not support Hypothesis 1.6 and 2.6. While respect at the end of life has not been well-studied in the past, prior research does suggest that women and Black individuals may be less likely to be treated respectfully by medical providers than men and Whites (Duffy et al., 2006; Gardner et al., 2018; Gott et al., 2020; Johnson, 2013; Koss & Baker, 2017). This is also suggested by scholars in the critical race theory movement, who have observed a history of both systemic and interpersonal racism toward Black persons (Delgado & Stefancic, 2017). Researchers have found that Black individuals often experience poor communication and discrimination from providers compared to Whites, while women have experienced a long

history of having their pain and other uncomfortable symptoms dismissed by providers compared to men (Johnson, 2013; Gott et al., 2020). The insignificant results from this study may be due to a flaw in the operationalization of the variable “treated with respect,” which aimed to distinguish between those being treated with respect always, usually, or sometimes, compared to those who were never treated with respect. The combination of three categories into one resulted in an imbalance of participants, and only one individual within the entire study indicated that they were never treated with respect. Recoding the variable in a different matter may provide more insights into the true nature of provider treatment at the end of life. However, quality assessment tools in the health care system such as the Hospital Consumer Assessment of Healthcare Providers and Systems survey often use a similar coding structure to determine the quality of services provided to patients, where any response other than “always” would be considered negative (Centers for Medicare & Medicaid Services, 2021).

Decisions Made Without Input

In Model 1, the results showed that Black decedents were more likely to have decisions made without their input when compared to White decedents, thus supporting Hypothesis 1.7. Previous studies have found a disparity in the treatment of Black individuals within the healthcare system (Cain et al., 2018; Loggers et al., 2009). Some studies suggest that Black individuals are less likely to have their wishes honored, less likely to have input in their care, and are perceived to be less likely to have the adequate medical knowledge to make decisions, which supports ideas stemming from the critical race theory (Delgado & Stefancic, 2017; Haley, 2005; Loggers et al., 2009). One study even found that, when Black individuals did have the knowledge and opportunity to express their wishes for care, those wishes were less likely to be honored by providers (Loggers et al., 2009). Combined with the history of medical racism, there

is an inherent mistrust in the healthcare system as a consequence of poor treatment from providers, which has led to adverse health behaviors such as avoidance of medical facilities, lack of engagement in preventative care, and a distrust of medical advice from providers (Armstrong et al., 2007). The results of this study show that despite the enactment of policies such as the Patient Self Determination Act, Black individuals are still not provided with autonomy in decision-making at the end of life, (Library of Congress, 1990).

For the main effect of gender, the results showed that women were less likely to have decisions made without their input when compared to men. Most prior studies suggest that women experience discrimination within the healthcare system and that providers are less likely to view women as capable of making medical decisions for themselves (Paulsen, 2020; Samulowitz et al., 2018)). Providers are also more likely to dismiss or ignore symptoms that women say they are experiencing, are less likely to provide evidence-based care to women, and women are less likely to be included in clinical trials (Gott et al., 2020; Paulsen, 2020; Samulowitz et al., 2018). Therefore, these studies suggest that women may be less likely to have input in decisions made about their medical care; however, this study's findings indicate that women are actually less likely to have decisions made without their input. This may be a result of increased efforts to mitigate gender disparities in the healthcare system, which have included interventions such as provider training, increasing the number of female physicians, and including women in clinical trials (Paulsen, 2020). Another consideration is the gender difference in the willingness to engage in end-of-life discussions, as research shows that women may be more likely to discuss their wishes for care at the end of life compared to men (Seifart et al., 2020). As such, the results of this study may reflect women's willingness to discuss their wishes for care, leading to a lower likelihood of having decisions made without their input.

Research efforts are needed to further examine the gender effect (or gender difference) in the decision-making experience at the end of life.

While there have been increasing efforts to address gender disparities in the healthcare system, the result of the race-gender interaction model suggests that similar efforts around race may not be as successful (Paulsen, 2020). In particular, Black women were the most likely to have decisions made without their input, which shows the intersectional impact of discrimination based on both their race and their gender (Crenshaw, 1989). Several stereotypes are often assumed about Black women in healthcare settings, including that they are not competent or knowledgeable enough to make decisions about their bodies, that they don't have health insurance, and that they are difficult to deal with, among others (Rao, 2020). The gender and racial bias that providers often hold, therefore, contributes to reinforcing the infantilization of Black women in medical settings, thus leading to poor outcomes such as late prognosis, higher mortality, and more pain at the end of life (Armstrong et al., 2007; Chinn et al., 2021; Samulowitz et al., 2018).

Overall Care Rating

In Model 1, the results showed that Black individuals were less likely to have excellent or good care at the end of life, compared to White decedents, thus supporting Hypothesis 1.8. This supports results from prior studies, where researchers have consistently found that Black individuals are less likely to have good overall care at the end of life (Kutney-Lee et al., 2019; Lee et al., 2016). Meanwhile, the other seven dependent variables in this study showed mixed results for Black decedents, the overall care rating variable provides a more comprehensive assessment of the quality of care provided at the end of life. Provider bias and discrimination likely contribute to this result, as studies have found a high prevalence of both conscious and

unconscious racism toward Black individuals in medical settings and across other avenues such as the legal system that inspired the critical race theory (Bridges, 2018; Delgado & Stefancic, 2017). The geographic placement of medical facilities is another consideration, with research showing fewer medical facilities in Black-populated areas, coupled with lower quality of services within those facilities (Jha et al., 2007). Thus, the lower quality of care received by Black individuals at the end of life may reflect the lower quality of the facilities that they may have access to. While individual variables of end-of-life outcome may suggest some equity in the treatment of older adults at the end of life, the result from Model 1 clearly shows that a significant disparity still exists in the quality of care provided at the end of life.

For the main effect of gender, women were less likely to have excellent or good care at the end of life compared to men. Similar to the result from the main effect of race, the overall care rating variable provides the most comprehensive and conclusive assessment of care quality at the end of life. Across several variables, women appeared to have positive outcomes when compared to men, but this result suggests that the overall quality of care for women remains lower than that of men. Most of the physicians in the healthcare system are still male, and male physicians have been found to be more likely to have a bias toward female patients (Berger, 2008). This likely contributes to the lower quality of care that women receive, which is due to years of gender-based exclusion in the medical field (Paulsen, 2020).

In Model 2, the results showed that gender and race do interact to influence overall care rating at the end of life, which supports Hypothesis 2.8. White men were the most likely to have excellent or good care at the end of life, followed by White women, Black men, and then Black women, who were the least likely to have excellent or good care at the end of life. Observing results from the main effects alone, it could be assumed that White women, Black men, and

Black women would have a lower quality of care compared to White men, but the race-gender interaction term provides greater insights into the specific group that experiences the lowest quality of care. Black women were the least likely to have excellent or good care at the end of life, thereby underscoring the importance of incorporating the theory of intersectionality into research on end-of-life outcomes (Chinn et al., 2021; Crenshaw, 1989). This result suggests that Black women are the group most in need of quality care, as the combined effects of gender and racial discrimination are likely to contribute to unfair treatment in medical settings (Armstrong et al., 2007; Chinn et al., 2021; Samulowitz et al., 2018).

Implications

Practice

Across all variables examined within this study, Black women had the highest number of negative outcomes, compared to all other groups. This included the overall care rating variable, which provides the most comprehensive assessment of quality care at the end of life. Additionally, the other variables (hospice care, pain, and decisions made without input) are also indicative of provider treatment at the end of life, as these are outcomes that are influenced by the actions of providers within medical settings. Specifically compared to Black men, Black women also experienced more anxiety/depression at the end of life and were less likely to have religious belief discussions with their providers, despite the importance of religiosity among Black individuals and among women. Starting with hospice care, it is important to consider the role of patient education and provider referral in one's ability to access hospice care, especially because the critical race theory shows that current outcomes are often influenced by generational access to socio-economic resources, which Black individuals often lack (Delgado & Stefancic, 2017; Weckmann, 2008). Research shows that most people either do not know what hospice is or

have misconceptions about the role of hospice in end-of-life care (Shalev et al., 2018). As such, it is important for providers in medical settings to educate patients about their end-of-life options, including the potential benefits of hospice and palliative care (Kozlov et al., 2018). This education can be provided by physicians or nurses but should also be provided by social workers in medical settings, as social workers are well-suited for health education for the vulnerable population as their professional training emphasizes cultural sensitivity and competency (Feize & Gonzalez, 2018; Hebert et al., 2008). Provider education should also include culturally-tailored information that considers the historical, cultural, and religious factors encouraged by the critical race theory, which may serve as both protective factors and barriers to end-of-life care for Black individuals (Bullock, 2011; Delgado & Stefancic, 2017; LaPresti et al., 2016; Rhodes et al., 2015; Rhodes et al., 2017). In addition to educating patients about hospice care, providers should also ensure that they are making timely referrals to hospice care, as research shows that providers are less likely to provide timely referrals for Black individuals (Wasp et al., 2019). In conjunction with patient education, providers should be made aware of their potential biases through the provision of ongoing cultural humility training (Stubbe, 2020).

For the experience of pain at the end of life, providers should consider adjusting the assessment tools that are used to identify pain, ensuring that those tools have been tested among diverse populations (Givler, 2020). Providers should also ensure that pain management is offered in a timely manner, especially for Black women who may be less likely to engage in early intervention (Rao, 2020). This lack of desire to engage in preventative care is also a result of years of gender and racial maltreatment within the medical system, which providers can address by treating Black women with respect and ensuring positive encounters (Armstrong et al., 2007; Rao, 2020; Samulowitz et al., 2018). One critical finding within this study was the fact that

Black women were more likely to have decisions made without their input, and this was despite the legal mandate of the Patient Self Determination Act (Library of Congress, 1990). The disparity is likely due to the assumption that Black women are not educated enough to make sound medical decisions for themselves, which is a direct result of provider bias (Rao, 2020). The first and most important step to addressing bias is to recognize the existence of that bias, which is best accomplished through cultural humility training that includes understanding core concepts of the critical race theory such as race as a social construct and the importance of intersectionality, as along with ongoing self-reflection (Crenshaw, 1989; Delgado & Stefancic, 2017; Stubbe, 2020). Providers need to recognize the prejudices that they hold toward Black women and should make an active effort to dispel or mitigate these prejudices in their day-to-day interactions with them. To facilitate cultural humility training, there is a great need for a curriculum and guides on facilitating cultural humility and sensitivity training programs within the healthcare field (Hughes et al., 2019). Such a manual would help ensure consistency of patient treatment across medical facilities, which would increase the quality of care received by Black patients regardless of location.

Finally, the overall quality of care provided at the end of life was lowest among Black women, who according to the theory of intersectionality are less likely to have positive outcomes due to their membership in two vulnerable groups (Crenshaw, 1989). Black women experience the negative impact of being a member of their racial group but are also being affected by the years of gender disparities that exist in the medical system (Armstrong et al., 2007; Rao, 2020; Samulowitz et al., 2018). While it may be difficult to cure these inequities on a systemic level, some interventions may serve as small steps in addressing health disparities for Black women. One potential consideration is the importance of making a cultural match between patient and

provider, and prior studies show that Black individuals particularly desire providers of the same race and/or those that understand their cultural backgrounds (Hansen et al., 2016; Meghani et al., 2009). Research also shows that Black individuals may indeed experience more positive outcomes when paired with a provider from a similar cultural background (Meghani et al., 2009). This may also be accomplished by making active efforts to recruit diverse providers, and also reducing the economic barriers that often prevent diverse individuals from pursuing medical careers (Associated Medical Schools of New York, 2020).

Policy

On a policy level, there are several factors to consider, especially about the negative outcomes that Black women may experience. The critical theory often examines how policies and eligibility requirements have impacted the lives of Black individuals within the United States (Delgado & Stefancic, 2017). Cost and health insurance, for example, are major barriers to accessing hospice and other medical services (McAteer & Wellbery, 2013). Research shows that Black individuals are less likely to have access to health insurance and that, while there are no significant disparities in health insurance by gender, women do experience greater delays in care and are more likely to rely on public health insurance (Becker & Babey, 2019; Tolbert & Orgera, 2020). Expanding the eligibility criteria for public insurance programs for lower-income individuals such as Medicaid would allow more individuals to have access to hospice care (Garfield & Orgera, 2021). In some states, the eligibility criteria for Medicaid are so limited that many individuals fall short of qualifying for public health insurance but are also unable to afford health insurance on their own (Garfield & Orgera, 2021). While a universal health insurance option has been a major debate in the US for the past few decades, other countries have been able to implement successful universal health insurance programs that provide equitable options

for all citizens (Schneider, 2017). A universal option would not only increase access to hospice services for Americans but also equalize the quality of hospice programs, which is currently determined by the quality of health insurance that an individual has (Schneider, 2017). In considering policy-level interventions to increase hospice usage among Blacks, it is also important to consider the cultural incongruence between the finality of hospice services and the life-preservation values that are often held within Black communities (Bazargan & Bazargan-Hejazi, 2021; Bullock, 2011). One strategy to bridge this cultural gap is the open-access hospice model, which allows individuals to start hospice services while still receiving treatment (Accent Care, 2022; *The Debate in Hospice Care*, 2008). Embracing the open-access model may be a pathway to increasing hospice use by Black individuals, who may be deterred by the existing eligibility requirements for most hospice services (Aldridge et al., 2013; Furman et al., 2010). The critical race theory also notes that systems are often designed to benefit the oppressor, and actively making efforts to reduce barriers for Black individuals would contribute to mitigating existing inequities (Delgado & Stefancic, 2017).

For the disparity in the level of pain experienced at the end of life, health insurance is once again a very important consideration. Pain at the end of life is often dictated by the type of chronic illness that an individual has, but also by the illness trajectory (Morrissey et al., 2014). Black individuals are less likely to engage in preventative care due to their mistrust in the medical system and are, therefore, more likely to be diagnosed at later disease stages, where the ability to manage pain may be limited (Armstrong et al., 2007; George et al., 2015; Virnig et al., 2009). By addressing the mistrust in the medical system and increasing access to primary care services, Black individuals may be more able to engage in earlier interventions, thus leading to lower levels of pain at the end of life. Black women in particular tend to have lower income and

lower education than all other groups within this study and access to health care is often aided by socioeconomic status (Braveman & Gottlieb, 2014; Ortiz-Ospina & Roser, 2018). By having work-based health insurance plans instead of a universal option that is accessible to all, Black women are excluded from having the same level of care as others and, therefore, more susceptible to severe chronic illness and worse symptoms at the end of life. This demonstrates the impact of policies highlighted by the critical race theory, as laws and systems are often designed to exclude the most disadvantaged groups, such as Black women, from basic rights such as health care (Delgado & Stefancic, 2017).

The Patient Self Determination Act was implemented to increase patient autonomy in medical settings, but the results of this study suggest that Black women are not provided with the same treatment as others (Library of Congress, 1990). While the policy exists on a federal level, provider bias is often not visible in the medical system, which allows providers to discriminate against Black women without any consequences (Bridges, 2021). One potential policy-level intervention would be to increase the level of scrutiny towards providers, which may be accomplished by requiring documentation of the decision-making process (Karnik, & Kanekar, 2016). Most medical systems have occasional audits that aim to assess the quality of care being provided, but there are vast differences in the procedure and frequency of quality assessments (Donabedian, 2005). By adding an addendum that requires documentation of the decision-making process, providers may be incentivized to honor autonomy for all patients, regardless of race or gender. Additionally, quality assessment can be ensured by requiring a second provider to be present during discussions about medical care, to make sure that the patient and/or family are fully involved in the decision-making process.

The overall care rating for Black women was also lower than for other groups, which can also be addressed by increasing access to quality health insurance and requiring documentation of fidelity among providers. To ensure the mitigation of bias, hospitals can also address racial and gender disparities by requiring frequent cultural humility trainings for all staff and also include quality assessments to make sure that the trainings are effective (Beim, 2020). The results of this study also showed that Black men were more likely to die alone, which may be attributable to systemic racism such as mass incarceration. Black men are disproportionately represented in the criminal justice system, and research shows that Black men are more likely to be incarcerated at the end of life, compared to other race/gender intersectional groups (Martinez, 2016). Addressing mass incarceration would indirectly ensure that Black men are surrounded by loved ones at death and would also increase end-of-life quality for Black men, who may have access to poor end-of-life care behind bars.

Research

This study aimed to identify the intersectional impact of race and gender on quality of life at the end of life, but many additional areas of research must be addressed. This study was quantitative in nature, which resulted in many gaps in the interpretation of the results that were found. For example, Black women were found to be the least likely to have excellent or good care at the end of life, but the explanation for that result needs further refinement and expansion through in-depth investigations. Future research should aim to conduct qualitative studies with family members to provide further insights into the areas where quality care was lacking for Black women. This also applies to other variables within the study, where the rationale behind the results was not evident. Replicating this study using qualitative research would provide further insights and, therefore, help provide more targeted strategies to reduce the disparity.

Furthermore, intervention research would provide clarity on the specific actions that can be taken to mitigate the identified disparities.

Policy-level efforts should be made to ensure and promote the inclusion of Black women in end-of-life research studies. Historically, women have often been excluded from clinical trials, because researchers were unable to control hormonal changes and the overall impact of the female cycle on study results (Paulsen, 2020). Similarly, Black individuals were often excluded from research studies and were only included in studies where they were exploited or misled by the researchers (Scharff et al., 2010). One prominent example is the Tuskegee Study of Untreated Syphilis in the Negro Male. Guided by the United States Public Health Service, researchers identified about 400 Black men to observe the natural progression of syphilis in Black populations (CDC, 2021). The researchers did not collect informed consent from the men and deceived the participants by informing them that they would be treated for “bad blood” (CDC, 2021). Along the trajectory of the study, a treatment for syphilis became widely available, but the participants were not offered or informed of the treatment (CDC, 2021). This study has had significant implications for the Black community and contributes to the hesitancy to participate in research studies from Black individuals in the present day (Scharff et al., 2010).

Other examples of medical exploitation include the use of enslaved Blacks for medical experiments in the Antebellum area and the use of psychiatric diagnoses to depict Black activists as paranoid, hostile, and delusional during the civil rights era (Savitt, 1982; Metz, 2010). One example of the race-gender intersection is the use of Henrietta Lack’s cells to conduct several experiments. Henrietta Lacks, a Black woman, was exploited by researchers who removed two samples of her cervix during surgery without her consent (Skloot, 2017). For years after her death, her cells were used to conduct several research studies, which researchers published

without her family's consent or knowledge (Skloot, 2017). As a combination of all these events, Black individuals are often not represented in research studies, therefore, receiving treatments and interventions that may not have been tested specifically for them (Scharff et al., 2010). Active efforts should be made to identify the needs of Black women at the end of life, and provider training should include a comprehensive history of racism in medical practice and research that has long contributed to Blacks' mistrust in the healthcare system (Beim, 2020). Future studies should also explore how to increase overall healthcare, not limited to end-of-life care, among Black women, which may include providing digital devices for healthcare education and services, provider cultural matching, and gas vouchers to decrease transportation barriers (Fehily et al., 2020).

Limitations

This study has several limitations that must be considered. First, the study is cross-sectional in nature, as the data was only collected after the individuals died. To provide a more accurate assessment of the quality of life at the end of life, future research should consider following the patient and families along the disease trajectory, from diagnosis to the end of life. Second, the respondents within this study were not the actual participants themselves, but proxies who may or may not have accurate accounts of the decedents' last month of life. While most of the proxies were family members, some proxies were staff or providers at facilities, who may not have as much insight about the decedent as the family does. This resulted in a high rate of missingness among many variables, as there were several responses of "don't know" or "refused" from the proxies. Furthermore, staff or providers who responded to the interviews might have been biased in answering some of the questions, especially those specifically related to providing treatment at the end of life. Even among family respondents, it is unlikely that they

were able to be with the decedent at all times during the last month of life, and some of the information provided within the study may have been inaccurate. Third, this study was limited by the nature of secondary data, as several important variables were not able to be included in the study. One such variable is health literacy, which is a critical social determinant of health that may affect outcomes such as knowledge about hospice care. Another important limitation was specifically related to the gender variable, which was binary in nature and did not allow for the inclusion of gender-diverse individuals. As such, most of the discussion within this study featured inaccurate views of gender that do not reflect the author's values and beliefs. Overall, the results of this study may not necessarily be due to the independent variables, as there may be additional moderating and/or mediating factors that were not included in the models. Furthermore, although most of the results within this study were significant, the majority of the effect sizes for the odds ratios were small relative to Cohen's *d*, indicating a weak association between the independent variables and the eight indicators of quality of life at the of life (Chen et al., 2010).

Another limitation was the types of dependent variables available within the study, which were not always in accurate alignment with the NCP guidelines that were used to select dependent variables. One of the NCP guidelines was the structure and processes of care, which speaks to the role of the interdisciplinary team in providing care at the end of life. There was no evident variable that spoke to whether the care team at the end of life was interdisciplinary or not, and the hospice care variable was simply the closest available variable. Another limited variable was related to the importance of religious/spiritual care at the end of life. The variable that would have provided the best insight into the provision of religious/spiritual care (religious belief contact) had to be substituted with a less-accurate variable because of having too much

missingness. The substituted variable (religious belief discussions) was also unclear, in terms of the direction of the conversation. The variable simply asks whether the patient had religious belief discussions with one's provider but does not ask who initiated the conversation. As such, it is not clear whether the patient's religious beliefs were strong enough to prompt the initiation of such discussions with the provider, or if the provider was culturally competent enough to initiate such conversations with the patient. Future research should, therefore, consider collecting primary data that would allow for more accurate connections between the NCP guidelines and the variables measured. Additionally, qualitative data should be collected to provide further insight into the quantitative data.

Conclusion

This dissertation aimed to assess the intersectional impact of race and gender on quality of life at the end of life, using data from the National Health and Aging Trends Study. Model 1 of the analysis showed several gender and racial disparities across multiple outcomes. In Model 2, the race-gender interaction term revealed that Black women had the worst outcomes across several variables, including hospice care, pain, decisions made without the patient's input, and overall care rating. Providers should address these disparities by engaging in continuous self-reflection, cultural humility training, and considering cultural matches between patients and providers. On a policy level, it is important to consider the role of health insurance in access to end-of-life care services as well as in the ability to engage in overall healthcare services including preventative care. Future research should consider primary data collection and should also include qualitative accounts to provide further insight into the needs of Black women and to inform interventions.

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