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END OF LIFE HEALTH DISPARITIES: EXAMINING COUNTY-LEVEL AND INDIVIDUAL-LEVEL CORRELATES OF HOSPICE CARE AND AVAILABILITY

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Nursing

by

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ABSTRACT

Hospice care is a specialized form of healthcare for individuals approaching the end of life. Hospice care is increasingly recognized as a means to improve quality of life in the days, weeks, and months prior to death. As a result, use of hospice care prior to death, especially for older adults, has increased dramatically over the last two decades. Concerns about hospice quality emerged as the hospice industry changed to meet increased demand among the growing older adult population. Following this development, the Centers for Medicare and Medicaid (CMS) created the Hospice Quality Reporting Program (HQRP).

This relatively new hospice quality oversight program provides the opportunity to examine hospice care quality disparities using measures of both care processes and patient outcomes (measured as patient experience and satisfaction). The purpose of this study is to combine data from the HQRP with county-level sociodemographic data to explore potential spatial and social disparities in access to hospice care (e.g., availability of hospice care) and quality of available hospice. The first aim of this study is to explore county-level sociodemographic correlates of hospice availability and quality, while the second aim of the study is to stratify counties by rural or urban status to draw comparisons between rural and urban county correlates of hospice care availability and quality. The final aim of this study is to explore the relationship between individual-level sociodemographic characteristics and the quality score of the hospice from which care was received.

This secondary, population-level analysis combines data from the HQRP with United States Census Bureau data and estimates a series of linear regression models to explore the relationships between county-level and individual-level correlates of hospice care quality. The study's results showed statistically significant relationships between county-level sociodemographic characteristics – including age, educational attainment, racial/ethnic composition, and poverty rate – and hospice availability. These relationships were largely similar across both rural and urban counties. This study also found statistically significant relationships between these county-level sociodemographic characteristics and the quality of availability; however, these relationships varied across the different measures of quality.

The findings of this study suggest that using traditional county-level sociodemographic characteristics to examine disparities in hospice care availability and quality may not be sensitive to the specific characteristics of the unique subpopulation of older adults using hospice care. As a result, this study provides valuable insight into the science of end-of-life healthcare disparities that can inform future research and ultimately impact policy and practice.

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List of Abbreviations

- ACS- American Community Survey
- AHRQ- Agency for Healthcare Research and Quality
- CAHPS- Consumer Assessment of Healthcare and Provider Services
- CMS- Centers for Medicare and Medicaid Services
- HIS- Hospice Item Set
- HQRP- Hospice Quality Reporting Program
- IHI- Institute for Healthcare Improvement
- NCHS- National Center for Health Statistics
- USCB- United States Census Bureau

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Chapter 1: Introduction to the Study

Introduction

Since Dame Cecily Saunders introduced the hospice movement to the United States in the 1960s, hospice has been widely adopted by millions of older adults seeking relief from the physical and psychosocial suffering that can accompany death. Hospice care focuses on addressing the unique physical and psychosocial needs of dying patients and their families. What started as a grassroots movement in the 1960s to meet the needs of terminal cancer patients has since evolved into a specialized form of healthcare for any individual who chooses to forego curative or life-prolonging treatments, and has a life expectancy of six months or less.

Older adults make up approximately 88% of hospice patients, making the Centers for Medicare and Medicaid (CMS) – the provider of health insurance for over 90% of older adults in the United States – the largest payer for hospice patients in the US (Medicare Payment Advisory Committee [MedPAC], 2014; NHPCO, 2015). As such, CMS hospice program eligibility requirements and service coverage have driven the model of hospice care in the US. CMS created its hospice program in 1982 with the passage of the Tax Equity and Fiscal Responsibility Act (MedPAC, 2014). The provisions within TERFA would allow CMS beneficiaries with a terminal diagnosis and a life expectancy of six months or less to access hospice care with full coverage. Over subsequent decades, CMS's hospice program has grown, adopting reimbursement and regulatory reforms that continue to expand hospice care access for beneficiaries. This has, in turn, increased the supply of hospices by promoting growth within the industry (MedPAC, 2014).

CMS's decision to increase access to palliative care programs, such as hospice care, was driven in part by increased attention to changing end-of-life experiences. For instance, in 1997,

the Institute of Medicine (IOM) published *Approaching Death: Improving Care at the End of Life* – a landmark report that detailed multiple failings of the current health care system in supporting individuals and families at the end of life. Beginning in 2000 – just three years after the IOM's report – the hospice industry began a decade of growth that saw a 65% increase in the number of hospice providers and a \$12.2 billion increase in Medicare spending on hospice (MedPAC, 2015).

Changing end-of-life experiences are related to advances in health promotion and disease management that have given way to a uniquely modern life course stage, referred to hereafter as the end of life, that precedes most deaths from chronic disease and/or old age (Carr & Luth, 2019). This end-of-life period is characterized by serious illness and increasing functional impairment. Additionally, the medicalization of the dying experience itself was characterized by pain, suffering, and invasive (even futile and unwanted) medical care (IOM, 1997). While the hospice movement shed light on the difficult experience of cancer patients and families at the end of life, the IOM's 1997 report, as well as its 2015 landmark report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* drew attention to the universality of death and the death-related issues affecting the millions of people who die each year. The IOM reports called for broad changes in how individuals are cared for at the end of life, recommending expanded access to palliative care and hospice (both of which promote quality of life at the end of life) (IOM, 1997, 2015).

Over the past several decades, there has been ample research into the effects of hospice on individuals, their caregivers/families, and the healthcare system. This research consistently finds substantial benefits in quality of life for individuals and their caregivers/families, as well as reductions in unnecessary, high-cost end-of-life medical care. As a result, hospice use prior to death is often considered a standard of care and/or an indicator of the quality of the end-of-life experience for individuals and their caregivers/families.

Despite hospice care being the standard of care for most older adults with an estimated life expectancy of six months or less and the near-universal coverage of hospice care by CMS, disparities in the use of hospice care have persisted. These disparities are characterized by a clear and consistent pattern of more hospice use among "advantaged" older adults, such as those who are more educated, socioeconomically resourced, or live in areas with more health care infrastructure (Hardy et al., 2011; Hughes & Vernon, 2019; Johnson, 2013; Silveira et al., 2011). Medicare's reforms led to a proliferation of new hospice agencies and increased hospice use among beneficiaries, particularly for those with non-cancer conditions such as dementia or end-stage heart disease (MedPAC, 2014).

However, the proliferation of new hospice facilities raised concerns that care quality had decreased in order to maximize profitability. Unusually long stays, fewer visits from the care team, and disenrollment from hospice prior to death all seemed to suggest this conclusion (Carlson et al., 2009; Lorenz et al., 2002). In response to these concerns, Medicare developed the Hospice Quality Reporting Program (HQRP) to ensure adequate care quality for its beneficiaries (Anhang Price et al., 2018). This mandated reporting program requires that providers meet certain quality thresholds in order to receive certification and reimbursement from CMS.

There are many ways to measure quality of hospice care (National Quality Forum [NQF], 2016). At the individual level, measures of pain or psychosocial distress can inform how effective hospice is for patients, particularly when compared to non-hospice users. Additionally, caregiver/family reports of care satisfaction and perception of care quality can help to indicate hospice quality. Length of hospice enrollment (i.e., length of stay) and number of visits or

services provided to patients while enrolled are also useful measures of hospice quality (Anhang Price et al., 2020; Anhang Price et al., 2018; NQF, 2016).

Statement of the Problem

As the Institute of Medicine's 2001 report *Crossing the Quality Chasm* states, "healthcare routinely fails to deliver its potential benefits" (Institute of Medicine, 2001, pg. 1). In the case of hospice, individuals receiving poor quality hospice are at risk of experiencing poor quality of life at the end of life, including uncontrolled pain, high symptom burden, inadequate spiritual support, and poor bereavement care for family members. Quality measures are an important step in beginning to understand how end-of-life health disparities may exist among the increasing share of beneficiaries using hospice. Individual sociodemographic characteristics and geographic availability of care strongly influence the quality of care that individuals may receive. Little is known about how the quality of available hospice influences disparities in the quality of hospice care received by different sociodemographic groups. This investigation will expand our understanding of disparities in hospice quality, which can, in turn, inform future research and policy aimed at promoting greater equity in health care quality.

Purpose

The overall purpose of this project is to examine end-of-life healthcare disparities among older adults using hospice by examining (1) sociodemographic factors associated with hospice quality; (2) quality of hospice available in rural counties; and (3) the relationship between availability of quality hospice and the quality of hospice received by sociodemographic groups.

Research Questions, Aims, & Hypotheses

The research questions, aims, and hypotheses examined in this study are listed in Table 1.

Table 1

Questions	Aims	Hypotheses
What sociodemographic factors are associated with availability and quality of hospice in US counties?	1: Examine geographic (county- level) sociodemographic correlates of hospice quality	h1.1: Population socioeconomic indicators (poverty rate, educational attainment) are correlated with quality of available hospice. h1.2: Population age structure and racial/ethnic composition are correlated with quality of available hospice.
What sociodemographic factors are associated with availability and quality of hospice in rural counties?	2: Examine geographic correlates of hospice quality and compare patterns to urban (i.e., non-rural) US counties.	h2: Geographic correlates of hospice availability and quality of available hospice will differ between rural and urban counties.
Are individual-level sociodemographic characteristics correlated with the quality of the hospice from which care was received?	3: Examine sociodemographic correlates of the care quality of the hospice from which care was received.	h3: Individual-level sociodemographic characteristics – specifically, race and rural/urban status – are correlated with quality of hospice from which care was received.

Research Questions, Aims, & Hypotheses for the Study

Theoretical and Conceptual Frameworks for the Study

Multiple theoretical and conceptual frameworks inform this research. First, the Epidemiologic Transition Model (ETM) – originally proposed in 1971 and refined over subsequent decades as new population-level trends in health and disease emerged – is a theoretical framework for population health that informs the approach of the study (Omran, 1998; Omran, 1971). More specifically, the ETM explicates the broader social, technological, and health transitions that have led to current population demographics, particularly as they relate to morbidity and mortality among the growing population of older adults with increasingly complex health needs. The ETM emphasizes the need to focus on issues related to quality of life among older adults, especially as their health and functional status worsen and quality of life becomes compromised (see Figure 1). The current study fits into this framework by examining issues related to a quality-of-life-enhancing intervention (hospice) for the older adult population.

Figure 1

Epidemiologic Transition Model



Note: CVD = cardiovascular death. Original source of model is Omran, A. R. (1998). The epidemiologic transition theory revisited thirty years later. *World Health Statistics Quarterly, 53*(2, 3, 4), 99-119.

The National Institute for Minority Health's (NIMHD) Health Disparities Framework combines elements of the sociodemographic model with a health disparities framework and guides this study.

Figure 2

Health Disparity Populations: Race/Ethnicity, Low SES, Rural, Sexual/Gender Minority Other Fundamental Characteristics: Sex/Gender, Disability, Geographic Region Levels of Influence **Domains of** Influence Community Individual Interpersonal Societal Caregiver-Child Community Illness Sanitation **Biological Vulnerability** Interaction Exposure Biological Immunization and Mechanisms Pathogen exposure **Family Microbiome** Herd Immunity Family Functioning **Health Behaviors** Community **Behavioral** Policies and Laws School/Work **Coping Strategies** Functioning Functioning Household Community Physical/Built Environment Environment Environment Life Course **Personal Environment** Societal Structure School/Work Community Environment Resources Sociodemographics Sociocultural Social Networks Limited English **Community Norms** Societal Norms Environment Family/Peer Norms **Cultural Identity** Local Structural Societal Structural Interpersonal Discrimination Discrimination **Response to** Discrimination Discrimination Patient-Clinician **Health Care** Availability of Insurance Coverage Relationship Quality of Care System **Health Services** Health Literacy **Health Care Policies** Medical Decision-**Treatment Preferences** Safety Net Services Making Health Family/ Community Population Outcomes **Individual Health** Organizational Health Health Health

NIMHD Health Disparity Framework

Note. Source is Alvidrez, J., Castille, D., Laude-Sharp, M., Rosario, A., & Tabor, D. (2019), The National Institute on Minority Health and Health Disparities Research Framework, *American Journal of Public Health*, *109*(S1), S16-S20.

As Figure 2 illustrates, the sociodemographic model's levels of influence (top, x-axis) are combined with a health disparities domains of influence framework (i.e., determinants of health; y-axis). In doing so, individual, interpersonal, community, and societal levels exist for each domain of influence: biological, behavioral, physical/built environment, sociocultural environment, and healthcare system. Within each cell are examples of factors that influence health, situated within their respective levels. Availability of health services and quality of care are included in the healthcare system domains of influence at the community and societal levels. Quality is a central concept of this study and is defined according to the IOM's definition. The IOM defines quality as "the degree to which healthcare services for individuals and populations increase the likelihood of desired outcomes and are consistent with current professional knowledge" (IOM, 1990, p. 4). Additionally, the IOM's landmark report on quality, "Crossing the Quality Chasm," identified six key dimensions of healthcare quality to guide future efforts aimed at understanding and improving healthcare quality: safety, efficacy, patientcenteredness, timeliness, efficiency, and equity (IOM, 2001). To measure quality, the study uses the Donabedian (1985) Quality Framework. The measures of quality included in the Hospice Quality Reporting Program (HQRP) assess aspects of quality within all three components of the Donabedian framework (Zheng et al., 2018).

The definition of quality put forth by the IOM is used in this study for several reasons. First, it includes individuals as well as populations, acknowledging that both are important for understanding healthcare quality. Second, "desired outcomes" are patient-centered: that is, they are determined based on patient desires and preferences and include health outcomes consistent with hospice. Such outcomes include health-related quality of life, management of physical and psychological symptoms, and interpersonal aspects of care, (patients' concerns and expectations, sense of dignity, participation in decision-making, spiritual well-being, and reduced burden on family and caregivers) (IOM, 1990). Third, the IOM's definition emphasizes the importance of considering research and evidence with its inclusion of the phrase "consistent with professional knowledge" (IOM, 1990).

Definitions of Key Terms

Centers for Medicare and Medicaid Services (CMS): government agency within the federal Department of Health and Human Services (DHHS) that administers national health insurance programs (Medicare and Medicaid), certifies hospices for reimbursement, and administers the Hospice Quality Reporting Program (HQRP) used in this study.

CMS or Medicare Beneficiary: an individual with health insurance through the Medicare program.

CMS or Medicare Decedent: an individual with Medicare insurance who dies.

Healthcare Disparities: defined according to the AHRQ as "differences in access to or availability of medical facilities and services and variation in rates of disease occurrence and disabilities between population groups defined by socioeconomic characteristics such as age, ethnicity, economic resources, or gender and populations identified geographically" (AHRQ, 2020a).

Health Disparities: health disparities are defined by Healthy People 2020 as "a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion" (United States Department of Health and Human Services, 2010, p. 28).

Hospice: a comprehensive, specialized healthcare service for individuals with a life-limiting illness and resultant life expectancy of six months or less who choose to forego curative medical care.

Hospice Availability: a component of healthcare access, which is necessary for obtaining healthcare and refers to an individual's ability to enter the healthcare system. Healthcare access is often measured as having (adequate) health insurance, having a source of available care, encountering difficulties when seeking care, and obtaining care as soon as desired (AHRQ Report, 2018). Availability alone is a necessary, but not sufficient component of access. Other conditions such as lack of insurance can affect access even in the context of availability.

Quality (healthcare): defined according to the IOM as "the degree to which health care services for individuals and populations increase the likelihood of desired outcomes and are consistent with current professional knowledge" (IOM, 1990, pg. 4)

Hospice Decedent: a decedent (an individual who has died) who has received hospice care.

Rural: rurality is defined according to the National Center for Health Statistics' 2013 Urban-Rural Classification Scheme for Counties (used by the CDC and AHRQ disparities report). The scheme includes a continuum of six urbanization levels ranging from most urban to most rural. These levels include four metropolitan and two rural categories: micropolitan and noncore. Metropolitan refers to the presence of large, principal cities (i.e., nucleus) and their surrounding counties that are socially and economically tied to the county of the principal city. By contrast, micropolitan counties are considered less urbanized and more rural, having a smaller nucleus than metropolitan counties. The most rural counties are those that do not qualify as micropolitan; they are not connected to micro- or metropolitan statistical areas (MSAs) developed by the Office of Management and Budget that were based on 2010 decennial census data. Large, central metropolitan counties – the most urbanized category – are counties in MSAs with a population of 1 million or more in which the entire population of the principal city of the MSA resides or the entire county population resides in the principal MSA city, or at least 250,000 county inhabitants reside in the principal MSA city. Rural counties are within micropolitan statistical areas (i.e., micropolitan counties) or counties that do not qualify as micropolitan (i.e., noncore counties). The classification system ranges from one (largest metropolitan counties) to six (smallest, noncore counties). For this study, metropolitan counties are those with a classification of one to four, while rural counties have a classification of five or six.

Assumptions

The following assumptions inform this study:

- 1. Availability of hospice care affects access to hospice care.
- Higher quality of hospice care increases the quality of the death experience for decedents using hospice care.
- 3. Quality is a multidimensional construct.
- Medicare administrative claims databases represent hospice use and enrollment/demographic information for the population of older adults in the United States.

Significance

More than 2 million deaths occur each year in the United States, the majority of which occur among older adults (US Census Bureau, 2017). Hospice has significant individual, family, and societal benefits. First, hospice improves dying individuals' quality of life as well as that of their family. Additionally, hospice reduces unnecessary and unwanted care at the end of life, thereby substantially benefitting the healthcare system.

Chapter Summary

As the use of hospice care increases alongside a growing population of older adults approaching the end of life, the need to understand spatial and social disparities in hospice availability and quality also increases. The objective of this study is to provide a critical first step in identifying end-of-life health disparities upon which future studies can build. To do so, this study explores: 1) the relationship between spatial (county-level) sociodemographic characteristics and hospice care availability and quality; 2) these same relationships, stratified by rural and urban counties, in order to compare across rural and urban counties; and 3) the relationship between individual-level characteristics and the quality of the hospice from which care was received. This work will advance the science of end-of-life health disparities by focusing on potential disparities in healthcare access (availability) and quality.

Chapter 2: Review of Literature

Introduction

This chapter provides a critical review of the literature relevant to the study aims, assessing the state of the science while also discussing specific gaps in knowledge related to the current study. This literature review begins with an overview of the CMS hospice care program and evidence supporting the use of hospice care prior to death. This section is then followed by an overview of the population-level demographic and healthcare trends that have led to the need for specialized, end-of-life care such as hospice. The review then details current knowledge regarding differential use of hospice care and disparities in hospice care quality, situating them within the context of broader health and healthcare disparities experienced by sociodemographic groups. The literature review concludes with a thorough exploration of the theoretical frameworks that inform the study.

Hospice Care

History of Hospice Care

In the 1960s, the plight of the dying garnered increased public attention. Two leading figures in this watershed moment were Dame Cicely Saunders, a nurse, and Elizabeth Kubler-Ross, a psychiatrist., Saunders first introduced the idea of providing specialized healthcare to dying individuals; in 1967, she established the first hospice in the United Kingdom. Two years later, Kubler-Ross published *On Death and Dying*, a landmark study outlining five stages of terminal illness progression. These two events mark the beginning of what would become the hospice movement in the United States. Over the course of the next decade and a half, multiple developments in this field culminated in the passage of a permanent Medicare hospice benefit in 1985. These developments included the formation of a national hospice organization, a series of

expert = Congressional testimonies promoting legislation on dignified death, and demonstration programs that helped to determine what a federal hospice program should encompass (NHPCO, 2020b).

Historically, the majority of hospice care recipients were those with terminal cancer. More recently, however, there has been a substantial shift as more individuals with non-cancer terminal illnesses enroll in hospice. In 2018, for instance, less than one third of hospice decedents (i.e., those who died while enrolled in hospice) had a primary diagnosis of cancer, while cardiovascular disease (17.6%), dementia (15.6%), "other" (13.9%), respiratory (11.0%), and chronic kidney disease (2.3%) made up the bulk of hospice patients' primary diagnoses (NHPCO, 2020a).

This change in the composition of hospice decedents is due, in part, to efforts made to increase access to care that would improve the death experience. Such efforts followed the publication of *Approaching Death: Improving Care at the End of Life* – a landmark report published by the Institute of Medicine (IOM) that detailed multiple failings of the current healthcare system in supporting individuals and families at the end of life. Beginning in 2000 – just three years after the IOM's report – the hospice industry began a decade of growth that saw a 65% increase in the number of hospice providers and a \$12.2 billion increase in Medicare spending on hospice (MedPAC, 2015).

Medicare Hospice Benefit

As the payer for the vast majority of adult hospice care, CMS has largely driven the model of hospice care in the United States after it began offering the hospice benefit in the 1980s. As a result, hospice care in its current form is a comprehensive, specialized healthcare service for individuals with a life-limiting illness and resultant life expectancy of six months or

less who choose to forego curative medical care for the specific, life-limiting condition that initiated the hospice enrollment. The Medicare hospice benefit encompasses a broad set of services, including nursing care, physician services, counseling and social worker services, hospice or home health aide and homemaker services, short-term inpatient hospice care (including respite care), medications and home medical equipment for comfort and symptom management, therapies (occupational, physical, and speech), bereavement services for family members, and other, related palliative care services (MedPAC, 2019).

Epidemiologic Transition Model

The substantial growth in hospice use was, in part, fueled by CMS's implementation of several reforms and policies aimed at increasing access to hospice care. These reforms included provisions for reimbursement reform and the entry of new hospices with different ownership types (e.g., for-profit) into the hospice market. However, several other factors have also led to an increased interest in how to best care for an aging, chronically ill population. These factors include the increasing share of the population approaching old age (e.g., the "Baby Boomer" cohort), healthcare advances that allow older individuals to live longer, and increasingly complex health needs.

The Epidemiologic Transition Model (ETM) provides a useful framework from which to explore the population-level changes in health and disease patterns that have occurred over time, their respective determinants, and their consequences for end-of-life care (Omran, 1998; Omran, 1971). According to the ETM, changes in the determinants of disease and mortality alongside lifestyle, education, and healthcare changes have resulted in changing patterns of health, survival, disease and mortality that ultimately affect population dynamics (see Figure 3).

Figure 3



The Epidemiologic Transition Model

Note: CVD = cardiovascular death. Original source of model is Omran, A. R. (1998), The epidemiologic transition theory revisited thirty years later, *World Health Statistics Quarterly*, *53*(2, 3, 4), 99-119.

As individuals live longer, it follows that experiences of death have changed. As a result of these epidemiologic transitions, most deaths among older adults now occur after a prolonged period of decline, with progressive chronic conditions and medical care playing an increasingly large role as an individual approaches death. In other words, death is now often expected, anticipated, and prepared for, such that quality of life and the dying experience can become a primary concern of healthcare interventions.

Health Disparities at the End of Life

A major focus of population health is identifying health disparities within a population and the mechanisms that underly them. Health disparities are defined by Healthy People 2020 as "a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion" (United States Department of Health and Human Services, 2010, p. 28).

Healthcare services, including access to healthcare and quality of healthcare received, represent one mechanism that can mitigate or exacerbate health disparities. However, unlike many other types of health disparities for which healthcare plays a minor role when compared to socioeconomic and psychosocial resources (among others), healthcare services play a large role in maintaining well-being at the end of life (Carr & Luth, 2019). Healthcare services play a larger role at the end of life due to the high physical, psychological, and emotional symptom burden that accompanies advanced disease and dying.

The influence of healthcare interventions on the death experience is illustrated in the Good Death Framework (Emanuel & Emanuel, 1998; Figure 4). According to this framework, healthcare interventions aimed at modifiable dimensions of the patient's end-of-life experience (such as physical, psychological, and cognitive symptoms; social relationships and support; caregiving needs; and spiritual and emotional support) can positively affect the overall dying experience.

Figure 4

Good Death Framework



Note. Source: Emanuel, E. J., & Emanuel, L. L. (1998). The promise of a good death. *The Lancet*, *351*, SII21-SII29. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(98)90329-4/fulltext

Hospice Care Disparities

Hospice care provides many of the supportive healthcare interventions to dying individuals and their loved ones that are deemed important in the Good Death Framework. For example, hospice care provides interventions from healthcare providers such as nurses, physicians, and occupational, physical, and speech therapists with specialized training in end-oflife care and symptom management; social interventions such as access to social worker services and counseling; and family interventions such as bereavement counseling.

However, hospice care's ability to positively affect the well-being of dying individuals and their families is dependent on the quality of the hospice care being provided. Moreover, poor quality hospice care has the potential to negatively affect the well-being of dying individuals and their families, for example if symptoms are poorly controlled and cause the patient to disenroll from hospice.

Systematic failure of hospice care to provide critical interventions for certain sociodemographic groups can create disparities in end-of-life well-being. This section first reviews individual and family outcomes associated with hospice use. It then examines known disparities in hospice care use/patterns that ultimately led to the creation and implementation of the Hospice Quality Reporting Program. This section then reviews research examining outcomes from the Hospice Quality Reporting Program, discusses gaps in knowledge related to disparities in hospice quality, and concludes with a thorough discussion of the concept of quality and quality assessment.

Impact of Hospice Care on Individuals, Families, and the Healthcare System

Multiple studies have demonstrated that individuals receiving hospice care experience less pain and fewer burdensome care transitions (e.g., emergency room visits, hospital or skilled nursing facility admissions in the three days prior to death) at the end of life (Teno et al., 2013, 2018). Further, individuals receiving hospice care are more likely to receive care that is concordant with their stated wishes, which in turn improves patient and caregiver satisfaction (Khandelwal et al., 2017; Makaroun et al., 2018; Schockett et al., 2005). Additionally, caregivers and families of individuals receiving hospice care receive support in managing symptoms when caring for their loved ones, and perceive the death of their loved ones as less painful and more peaceful (Teno et al., 2011). Additionally, hospice decreases negative outcomes for caregivers, such as depressive symptoms that persist beyond a grieving period (Ornstein et al., 2017, 2015). As a result, receiving hospice care prior to death is considered an indicator of quality of life at the end of life by many researchers and policymakers (Carr & Luth, 2019).

Many proponents of hospice point to the potential impact of increased hospice use on reducing healthcare expenditures at the end of life in the United States. CMS is the largest insurer in the United States, providing insurance for 44 million older Americans, including approximately 95% of adults age 65 and older (American Association of Retired Persons, 2009). CMS spent \$750 billion on medical care in 2018 and accounted for 21% of national healthcare expenditures. Concerns about cost reduction stem from concerns about the U.S. healthcare system's overall annual healthcare expenditures, estimated at \$3.6 trillion in 2018. National healthcare expenditures account for approximately 18% of the United States' annual gross domestic product (National Health Expenditure Data, 2020; Papanicolas, 2018) – a proportion that has increased markedly over the past several decades and continues to take up a significant share of the U.S. economy.

The distribution of these healthcare expenditures is highly uneven, with older and chronically ill individuals incurring higher healthcare expenditures than younger, healthier individuals. Within CMS, there is substantial concentration of spending: 10% of Medicare beneficiaries (hereafter referred to as beneficiaries) account for 52% of CMS's medical spending each year (De Nardi et al., 2015). Among the Medicare population, healthcare expenditures more than double between the ages of 70 and 90 years, which is the time most individuals are nearing the end of life (De Nardi et al., 2015).

Analyses of costs and quality of care associated with hospice use demonstrate its high value and assert that more effort should be made to increase hospice use among those with serious illness prior to death (Teno & Higginson, 2018; Kelley et al., 2013). More specifically, hospice substantially increases the quality of care and quality of life an individual experiences at the end of life while also reducing the cost of care (Kelley et al, 2013). Hospice's estimated cost reduction depends on length of enrollment but is estimated to generate a per beneficiary reduction of \$2,650, \$5,040, and \$6,430 for lengths of enrollment of 1-7 days, 8-14 days, and 15-30 days, respectively (Kelley et al., 2013).

Disparities in Hospice Care Use and Hospice Care Patterns

Disparities in hospice use may be related to access to hospice care, while disparities in hospice care patterns may be related to the quality of hospice care. Both are relevant to the study, which seeks to examine the effect of both hospice availability (one of several measures of access) and quality of available hospice on sociodemographic groups. This section therefore explores individual-level and ecological-level sociodemographic factors associated with differences in hospice use.

Individual-Level Factors Associated with Hospice Use

First, the literature consistently demonstrates that racial and ethnic minority groups use hospice at lower rates than whites. Additionally, socioeconomic status, age, sex, and marital status are associated with hospice use disparities. The following sections present relevant literature demonstrating these assertions.

Race and Ethnicity

Racial and ethnic minority groups' lower use of hospice care is well-documented (Johnson, 2013), and there are a variety of possible explanations for this phenomenon. These

explanations include: (1) less exposure to information about hospice care, resulting in less knowledge about hospice care and less favorable attitudes toward hospice care; (2) lower rates of advance care planning; (3) different hospice referral patterns by providers; (4) preferences related to treatment intensity and cultural/spiritual beliefs about the healthcare system, end-oflife treatments, and death (Johnson, 2013).

The first possible explanation for lower hospice use among racial and ethnic minorities relates to knowledge of hospice. More specifically, an individual's knowledge and understanding of hospice influences their attitude toward it (Johnson, Kuchibhatla, & Tulsky, 2009). Johnson and colleagues (2009) demonstrated that less knowledge and understanding of hospice leads to disproportionately negative attitudes toward hospice, which ultimately impacts decisions related to hospice use (Johnson et al., 2009). As a result, varying exposure to information about hospice is a potential explanation for less hospice use. For example, prior research has found that 19% of Black individuals had never heard of hospice, compared to only 4% of white individuals (Johnson, 2009). Moreover, Johnson and colleagues (2009) found that the most powerful correlate of a positive attitude toward hospice was having a personal experience with hospice via a relative or friend. It is plausible to assume that when fewer individuals within racial and ethnic minority groups are receiving hospice at baseline, this also results in fewer opportunities for other individuals in their social networks to have direct experience with hospice. That is, rates of hospice use may be perpetuated if Black individuals have less exposure to hospice care via a relative or friend that leads to more positive attitudes toward it.

Relatedly, communication from providers about the end of life is inconsistent and of lower quality for Black individuals. Further, less communication related to end-of-life issues has ramifications beyond individual understanding of hospice (Johnson, 2013). For instance, research has demonstrated that activities related to communication with providers about end-oflife, such as advance care planning (e.g., advance directives completion, goals of care discussions), is lower for racial and ethnic minorities (Carr, 2012, 2016). Engagement in such activities is associated with greater use of end-of-life care services such as hospice. As a result, lower engagement in end-of-life care planning activities is likely another mechanism by which racial and ethnic disparities arise in hospice use.

The relationship between racial and ethnic minority status and advance care planning is partially explained by socioeconomic status, greater distrust of the healthcare system, less comfort discussing death, a greater likelihood of preferring life-prolonging therapies, and a greater likelihood of agreeing with the sentiment that advance directives are not needed if one believes in God among Black individuals (Carr, 2012, 2016; Johnson, Kuchibhatla, & Tulsky, 2008). Racial and ethnic disparities in socioeconomic status, particularly measures of wealth such as homeownership, also account for racial differences in formal advance care planning activities (e.g., completing an advance directive and designating a durable power of attorney for healthcare) that could subsequently affect the use of hospice (Carr, 2012, 2016).

Additionally, differences in end-of-life care preferences (including treatment intensity and place of death) may also contribute to differences in hospice care use as it relates to live discharges. Rates of live discharge, or disenrolling from hospice care prior to death, are markedly higher for Black individuals and not fully explained by differential preferences for inhospital death, life-prolonging drugs that may reduce quality of life, and extended periods of mechanical ventilation. Instead, higher rates of live discharge are associated with hospice organization characteristics such as profit status, size, and region (Dolin et al., 2017). Live discharges' association with profit margins and profit status of hospices is another indication that the way that hospice-level characteristics impact older adults' quality of life at the end of life. Moreover, Dolin et al. (2017) find regional and sociodemographic differences in live discharge rates, further indicating the need to assess how hospice-level characteristics may differentially place sociodemographic groups at risk of receiving lower quality hospice care.

Research has also demonstrated differences in for-profit hospice use by race/ethnicity. Black individuals have higher rates of for-profit hospice care use (Hughes & Vernon, 2019). As Hughes & Vernon (2019) note, the presence of for-profit hospices increases the use of hospice among racial/ethnic groups due to community outreach that targets racial/ethnic minorities. However, little is known about whether the quality of hospice care received may be lower among these types of hospices. Anhang Price et al (2020) find some evidence suggesting that hospices' organizational characteristics are associated with quality measures. A subsequent study, also conducted by Anhang Price and colleagues (2017), provides evidence that racial/ethnic minorities are receiving lower quality care as a result of their higher likelihood of receiving care from for-profit hospices with higher rates of live discharges. Further studies examining disparities in hospice care quality, and – in particular – whether such disparities vary within sociodemographic groups, are critically needed (Johnson, 2013).

Socioeconomic Status

The majority of studies examining the relationship between socioeconomic status (SES) and hospice use demonstrate a negative association with use of hospice care. This is true despite the wide variety of indicators used to determine SES when examining its association with hospice use, which include household income, residence in a low-income area, educational attainment, health literacy, etc. Despite the use of different measures, low SES is consistently associated with lower use of hospice (Hardy et al., 2011; Lackan, 2005; Parajuli et al., 2020).

Sex, Caregiver Relationships, Marital Status, Age

Higher rates of hospice use are consistently seen among women. However, some heterogeneity exists among women, namely that married or ever married (i.e., divorced or widowed) women use hospice at higher rates than never married women (Lackan, 2005). Similarly, while men consistently use hospice at lower rates than women, ever married men use hospice at higher rates than never married men. When attempting to understand the mechanisms underlying these observed differences in hospice use by marital status, it is important to note that there is often a requirement for hospice eligibility that the patient have a caregiver. As the majority (>95%) of hospice care is delivered in the patient's home (NHPCO, 2018), a requirement of hospice is having someone to care for the dying when hospice staff are not present. Spouses and adult children are most likely to fill this caregiver role; the absence of a spouse or an adult child is likely preventing some patients from receiving home-based hospice care. Finally, hospice use is highest among older age groups (e.g., 75 years and over) within the older adult population.

Ecological Factors Associated with Hospice Availability

Prior research has demonstrated lower rates of hospice availability among rural populations and among populations with lower median household income, lower educational attainment, and lower population density (Silveira et al., 2011; Virnig et al., 2000; Virnig et al., 2004). Few studies examining hospice availability as it relates to area-based (i.e., ecological) socioeconomic status exist; those that do exist do not assess the quality of available hospice. For instance, a study by Silveira and colleagues (2011) found that an area's median household income, level of education, racial/ethnic composition, and population density predicted community supply of hospice.
Hospice Quality Reporting Program

Systematic differences in hospice care patterns, including higher rates of hospice disenrollment, higher rates of unusually long stays within for-profit hospices, and their potential relationship with for-profit hospices' profit margins (Aldridge et al., 2014; Dolin et al., 2017) generated concerns about the quality of hospice care being provided by different types of hospices (Broyles et al., 2016). As a result, CMS developed the Hospice Quality Reporting Program (HQRP). HQRP consists of two separate assessments of quality: the Hospice Item Set (HIS) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey. HIS was implemented in 2014 and the CAHPS Hospice Survey was implemented in 2015. These measures of hospice quality underwent validity and reliability testing during their development, prior to implementation by CMS (Anhang Price et al., 2018). Table 2 displays the individual items within the HIS. The HIS includes seven individual items as well as two more global measures of quality (not listed in the table): percentage of patients getting at least one visit from a registered nurse, a physician, a nurse practitioner, or a physician assistant in the last three days of life and percentage of patients who got an assessment of all seven HIS quality measures at the beginning of hospice care to meet the HIS Comprehensive Assessment Measure Requirements.

Table 2

Hospice Item Set Quality Indicators

Percentage of patients or caregivers who were asked about treatment preferences like hospitalization and resuscitat at the beginning of hospice care. Having discussions with hospice staff about the treatments that patients want or don't want helps ensure the patients get the care they want at the end of life.
Percentage of patients or caregivers who were asked about their beliefs and values at the beginning of hospice care Patients and caregivers should have the opportunity to discuss their spiritual and religious needs, beliefs a values to help ensure these care needs are met.
Percentage of patients who were checked for pain at the beginning of hospice care Pain is common and often undertreated for hospice patients. It can interfere with patients' daily activities and can be very distressing for patients and families.
Percentage of patients who got a timely and thorough pain assessment when pain was identified as a problem <i>Within a day of finding that pain is a problem, hospice staff should collect information about the pain, like location, how long it lasts, and its severity.</i>
Percentage of patients who were checked for shortness of breath at the beginning of hospice care Shortness of breath is common and often undertreated in hospice patients. It can interfere with patients' routine and can be upsetting for patients and families.
Percentage of patients who got timely treatment for shortness of breath Within a day of finding that shortness of breath is a problem, hospice staff should start treatment. Treatme can be medication, relaxation or breathing exercises.
Percentage of patients taking opioid medication who were offered care for constipation Constipation is a side effect of opioid use. Staff can recommend treatment options, like laxatives or fiber, to prevent and treat opioid-related constipation.

Note. Quality indicators from the Hospice Quality Reporting Program administered by CMS. Source: CMS (2018). Getting Started with Hospice CASPER Quality Measure Reports. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Downloads/Fact-Sheet_CASPER-QM-Reports_February-2018.pdf

Table 3 shows the items included in the CAHPS Hospice Survey, which focuses on the

experience of the patient receiving hospice and is completed after their death by their caretaker.

Table 3

Consumer Assessment of Healthcare Providers and Systems (CAHPS) Quality Indicators

Consumer Assessment of Healthcare Providers and Systems (CAHPS) Quality Indicators Communication with family Percentage of caregivers reporting the hospice team always communicated well. Getting timely help Percentage of caregivers reporting the hospice team always gave patients and families help when they needed it. Treating patients with respect Percentage of caregivers reporting the hospice team always treated the patient with dignity and respect. Emotional and Spiritual Support Percentage of caregivers reporting the hospice team provided the right amount of emotional and spiritual support. Help for pain and symptoms Percentage of caregivers reporting the hospice team always gave the patient as much help as needed for pain and other symptoms.

Training family to care for patient

Percentage of caregivers reporting the hospice team always gave family members the training and information they needed to care for the patient.

Rating of this hospice

Percentage of caregivers who gave the agency a total rating of 9 or 10 (where 10 is the best).

Willingness to recommend this hospice

Percentage of caregivers who would definitely recommend this hospice agency to friends and family.

Note. Quality indicators from Hospice Care Compare, CMS (2020). *Care Compare*, https://www.medicare.gov/care-compare/

Due to the relatively recent implementation of the Hospice Quality Reporting Program,

there is little research examining how hospice quality as measured by the HIS and CAHPS

Hospice Survey differs by sociodemographic group. One study, examining only the CAHPS

Hospice Survey, found that racial/ethnic minorities were more likely to receive poorer quality

hospice than their white counterparts (Anhang Price et al., 2017). Another study examined

hospice characteristics that predicted high-quality ratings on both the HIS and CAHPS (Anhang Price et al., 2021).

Quality

Quality is a central concept of the study. The Institute of Medicine (IOM) defines quality as "the degree to which healthcare services for individuals and populations increase the likelihood of desired outcomes and are consistent with current professional knowledge" (IOM, 1990). Additionally, quality is a multidimensional concept. The IOM's landmark report on quality, "Crossing the Quality Chasm," identified six key dimensions of healthcare quality to guide future efforts aimed at understanding and improving healthcare quality: safety, efficacy, patient-centeredness, timeliness, efficiency, and equity.

The definition of quality put forth by the IOM was used in this study, and was selected for several reasons. First, it includes individuals and populations, acknowledging that both are important for understanding healthcare quality. Second, "desired outcomes" can be determined based on patient desires and preferences (i.e., patient-centered) and include health outcomes consistent with hospice, such as health-related quality of life, management of physical and psychological symptoms, and interpersonal aspects of care such as patients' concerns and expectations, sense of dignity, participation in decision-making, spiritual well-being, and reduced burden on family and caregivers (IOM, 1990). Third, the definition emphasizes the importance of considering research and evidence with its inclusion of the phrase "consistent with professional knowledge" (IOM, 1990).

Additionally, as alluded to in the prior section describing the measures included in the HQRP, the Donabedian Quality Framework (1985) for assessing care quality also informs this

study's conceptualization of care quality. The Donabedian framework was further expanded upon in a subsequent section describing relevant frameworks for the study.

Theoretical Frameworks

The theory providing the motivation for examining population-level end-of-life health disparities in this study is the Epidemiologic Transition Model (ETM), while the framework that guides this study's hypothesized relationships is based on the National Institute of Minority Health and Health Disparities (NIMHD) health disparity research framework (Alvidrez, et al., 2019; Olshansky & Ault, 1986; Omran, 1971; Omran, 1998). This section first provides an overview of the ETM, its use in other research contexts, and its relevance to the study. This section will then describe in detail the NIMHD's health disparity research framework, including its rationale for combining two existing frameworks, as well as how these frameworks have been used in other research contexts and the overall model's relevance to the study.

The Epidemiologic Transition Model

The objective of the study is to better understand health disparities that arise at the end of life. This objective stems, in part, from the understanding that when and how individuals die has changed, and that the number of individuals nearing or at the end of life is increasing (U.S. Census Bureau, 2017; U.S. Census Bureau, 2020; Prof, Beard, & Bloom, 2015). Due to these changes, there should be increased focus on the quality of life for this unique (and growing) population. Hospice is a specific type of care that can positively impact an individual's quality of life at the end of life (Kumar et al., 2016; Meier, 2011). The ETM, which is displayed in Table 3, provides the theoretical basis for these broader, population-level phenomena that motivate the study.

The ETM posits that socioeconomic development and/or industrialization transition populations through five stages by affecting both determinants of population decline and population growth (Hazra & Gulliford, 2017; Olshansky & Ault, 1986; Omran, 1998; Omran, 1971). The determinants of population decline and growth that ultimately shift a population's demographic makeup are influenced by multiple factors. These include lifestyle and education, advances in healthcare and technology, and environmental factors. As populations progress through stages, they experience declines in certain types of death (the example used in the model, for instance, is cardiovascular death) and increases in chronic disease burden ("chronicity") and aging-related mortality. According to the theory, this end result – an increased proportion of older adults and increased chronic disease burden among older adults – necessitates a focus on improving later-life quality of life (Hazra & Gulliford, 2017; Omran, 1998).

The prevailing context in which the ETM has been used in empirical research is in examining population-level trends in aging, fertility, morbidity, and mortality. For instance, a recent empirical study used the ETM as its guiding theory by hypothesizing that, given socioeconomic development/industrialization circumstances, there would be mortality-related changes as well as an overall increase in age-related impairments, particularly among the "oldest old" (those aged 80 years and above) from 1995-2014 in the U.K. (Hazra & Gulliford, 2017). Their findings largely align with expected outcomes guided by the ETM – for instance, they found that the oldest old population is experiencing rapid growth as well as changing incidence patterns of chronic diseases such as cardiovascular and respiratory diseases, cancer, diabetes, and dementia (Hazra & Gulliford, 2017).

Socioecological Model

While the ETM provides a theoretical basis for conducting population-level studies of end-of-life health outcomes, the socioecological model provides the theoretical framework needed to examine factors that affect the individuals comprising populations. That is, populationlevel outcomes reflect the dynamic relationship that exists between an individual and their broader socioecological context, and a framework is needed for examining the interaction between individual-level characteristics and broader ecological context.

The socioecological model has a long history of use in empirical research. First proposed by Bronfenbrenner (1977) and then adapted for use in public health promotion by McLeroy et al. (1988), the socioecological model posits that health is influenced by multiple factors that exist at various levels (Bronfenbrenner,1977; McLeroy et al., 1988). These levels are nested, progressing from intrapersonal (individual) to interpersonal to community to societal, with factors within each level that influence health in complex ways. The socioecological model is frequently used in public health and health-promotion research (Golden & Earp, 2012; McLeroy et al., 1988).

The socioecological model has also been used to examine disparities in health services utilization. For instance, a recent study evaluated the reasons that disparities in cervical cancer screening may arise, particularly as they relate to accessibility of services (Johnson, et al., 2020). Additionally, the conceptual framework for a study of hospice disenrollment (i.e., live discharges) incorporated the socioecological levels that influence the decision to disenroll from hospice prior to death (Dolin, Hanson, et al., 2017).

The social determinants of health framework is also frequently used in research examining health disparities. This framework posits that biological, behavioral, socioeconomic, environmental, and healthcare system domains influence health outcomes (Hill et al., 2015). However, the traditional social determinants model lacks the multi-level influence component that is a particular strength of the socioecological model (Alvidrez et al., 2019; Zavala et al., 2021). As a result, frameworks that integrate the health disparities domains with the ecological levels of influence have been developed. An example of a context in which this type of integrated model has been used is in cancer epidemiology. A 2013 study examined the relationship between biological susceptibility to poor prostate cancer outcomes and community-level correlates (neighborhood disadvantage), finding that time to prostate cancer care influenced the extent to which biology was responsible for the observed relationships between cancer type and health outcomes (Lynch & Rebbeck, 2013).

The domains within a social determinants of health framework can exist within each level of the socioecological model. For instance, individual-level as well as community-level socioeconomic factors influence access to care. Therefore, the study uses a framework that is a hybrid of both a socioecological framework and a health disparities framework. This hybrid framework was recently developed by the National Institute of Minority Health and Health Disparities (NIMHD; Alvidrez et al., 2019).

The NIMHD Framework (Figure 5) was selected for the study because it combines the socioecological model's levels of influence (individual/intrapersonal, interpersonal, community, public policy/society) with a health disparities research framework (Alvidrez et al., 2019).

Figure 5

NIMHD Health Disparities Framework

Other Fundamental Characteristics: Sex/Gender, Disability, Geographic Region						
Domains of Influence		Levels of Influence				
		Individual Interpersonal Com		Community	Societal	
Biological			Biological Vulnerability and Mechanisms	Caregiver–Child Interaction Family Microbiome	Community Illness Exposure Herd Immunity	Sanitation Immunization Pathogen exposure
Behavioral			Health Behaviors Coping Strategies	Family Functioning School/Work Functioning	Community Functioning	Policies and Laws
Physical/Built Environment	ical/Built ronment Docultural ronment th Care em		Personal Environment	Household Environment School/Work Environment	Community Environment Community Resources	Societal Structure
Sociocultural Environment			Sociodemographics Limited English Cultural Identity Response to Discrimination	Social Networks Family/Peer Norms Interpersonal Discrimination	Community Norms Local Structural Discrimination	Societal Norms Societal Structural Discrimination
Health Care System			Insurance Coverage Health Literacy Treatment Preferences	Patient-Clinician Relationship Medical Decision- Making	Availability of Health Services Safety Net Services	Quality of Care Health Care Policies
Health Outcomes			Individual Health	Family/ Organizational Health	Community Health	Population Health

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As Figure 5 illustrates, the socioecological model's levels of influence (top, x-axis) are combined with a health disparities domains of influence framework (i.e., determinants of health; y-axis). In doing so, individual, interpersonal, community, and societal levels exist for each domain of influence – biological, behavioral, physical/built environment, sociocultural environment, and healthcare system. Within each cell are examples of factors that influence health, situated within their respective levels.

Strengths and Limitations of NIMHD Framework

The health disparities research framework does have areas where there is some conceptual overlap. For instance, creating a separate healthcare system domain places "availability of health services" and "safety net services" at the community level of the healthcare system domain but there is also some potential conceptual overlap with community resources within the physical/built environment (Alvidrez et al., 2019). Though this is a weakness of the framework, it does not diminish the utility of the framework for the study, particularly given the strengths that the framework's hybrid nature adds to existing socioecological frameworks. An additional weakness is that, given its relatively recent development, the framework has not been used extensively in empirical studies (Bartels et al., 2020; Campbell & Egede, 2020).

Despite these weaknesses, the NIMHD framework was selected for its utility in examining issues related to care utilization, which is a focus of the study. For instance, the NIMHD framework has been used in research examining individual-, community-, and health system-level barriers to optimal diabetes care as well as factors associated with retention in lupus care (Bartels et al., 2020; Campbell & Egede, 2020). A strength of the NIMHD framework is that it incorporates two complementary frameworks that allow for a multilevel approach to examining health disparities, including those that arise as a result of healthcare disparities (Alvidrez et al., 2019).

Study Conceptual Framework and Model

The study's conceptual framework is adapted from the NIMHD's health disparity research framework. Figure 5 displays the NIMHD framework in its original form, while Figure 6 reconfigures the NIMHD health disparity framework into the familiar visual representation of the socioecological model's nested levels of influence, in order to better display the specific levels of influence that were examined within each of the study's three aims.

Figure 6.

Adapted Socioecological Conceptual Framework



Figure 6 is a reconfiguration of the NIMHD health disparities research framework that includes all levels of the socioecological model in a nested format to show which levels the study's aims will examine. On the left side of the framework, the arrow extending from Aims 1 and 2 emphasizes that these aims focus solely on the community level. Aims 1 and 2 seek to answer the following questions: to what degree is high-quality hospice available among all US counties (Aim 1) and among rural US counties (Aim 2); what are the community-level characteristics associated with quality of available hospice for all US counties (Aim 1) and for all rural US counties (Aim 2)? – Aims 1 and 2 are interested in the relationship between community-level characteristics, hypothesizing that community-level characteristics relate to hospice availability, which is itself a community-level characteristic that influences hospice use.

The arrow extending from the right of the framework emphasizes that Aim 3 focuses on the relationship between community-level characteristics and individual-level characteristics.

The purpose of depicting the study's theoretical socioecological framework in this way is to emphasize the multilevel nature of the health disparities research framework that provides the theoretical basis for the conceptual model. This framework includes many factors that cannot be examined within the scope of the study. Therefore, the conceptual model (Figure 7) focuses only on the levels and factors that are the primary focus of the study. Figure 7 is a conceptual model for the study that includes the relationships that were tested, showing only those levels and variables that are to be included in the study.

Figure 7

Study Conceptual Model



Community (County) Sociodemographic Characteristics

The conceptual model (Figure 7) focuses only on the two ecological levels of influence that were tested in the research study. The squares represent the ecological levels, while circles

represent the specific factors within each level whose relationships were tested. Specific variables are listed with their respective factors. The conceptual model proposes that county-level socioeconomic and demographic composition predict the community's supply of high-quality hospice care, which in turn predicts the quality of care received by residents of the community.

Prior research has demonstrated a relationship between county-level socioeconomic indicators and a community's supply of hospice, but no previous studies have examined the relationship between these county-level factors and the quality of the hospice supply. The conceptual model also proposes that there is a moderating effect of rural/urban status such that the county-level factors influencing supply differ between rural and non-rural counties. The empirical basis for the proposed relationship stems from research examining hospital and nursing home quality indicators, which suggest that those in rural areas are on average of lower quality than those in nonrural areas (Lutfiyya et al., 2007; Lutfiyya et al., 2013).

Specific county-level indicators of interest will include age, educational attainment, poverty rate, racial/ethnic composition and nativity (i.e., foreign-born). Nativity is included in the model because it captures differences in English language and legal status, among other factors, that are correlated with healthcare use. This also helps to further isolate the effect of race/ethnicity; for example, places with large Hispanic populations might also have large foreign-born populations (Lebrun, 2012; Riosmena et al., 2017; Stimpson et al., 2010; Ye et al., 2012).

The model also proposes that individual-level sociodemographic characteristics will predict the quality of the hospice from which an individual receives care, and that this relationship is moderated by the community's supply of hospice. A recent study demonstrating a greater tendency for Black and Hispanic patients to receive care from hospices with lower quality ratings (without examining the role of supply), as well as several others suggesting that Black beneficiaries receive care from more for-profit hospices with higher discharge rates, provide the empirical basis for this aspect of the conceptual model (Anhang Price et al., 2017; Anhang Price et al., 2020; Dolin et al., 2017; Teno et al., 2014)

Donabedian Quality Framework

Quality is a multidimensional concept and a focus of this study. The Hospice Quality Reporting Program provides two distinct measures of quality: the Hospice Item Set measures care processes, and the CAHPS Hospice Survey measures patient experience (Zheng et al., 2018).

The framework for assessing healthcare quality described by Donabedian (1985) describes the existence of structures of care, processes of care, and outcomes of care as core components of quality. The measures of quality included in the Hospice Quality Reporting Program (HQRP) represent care processes (as measured by the HIS) and outcomes (as measured by the CAHPS Hospice Survey and hospice disenrollment).

Figure 8.

Donabedian Framework



Chapter Summary

Hospice care developed as a response to the unmet needs of dying individuals. Since its emergence as a specialized form of care for individuals dying of cancer, it has evolved into a specialized end-of-life healthcare service that can be used by any dying individual regardless of diagnoses. As such, it is increasingly used by older adults as they approach the end of life. As the government (CMS) has become the primary payor for hospice services, it has also provided regulatory oversight. This oversight, along with empirical research, has found differences in hospice care use patterns that resulted in the development of the HQRP. The HQRP, developed after a robust process of identifying fundamental care processes and patient experience measures, presents unique opportunities to identify social and spatial disparities in hospice availability and quality. Guided by elements of the ETM, the socioecological health framework, the Good Death Framework, and the Donabedian Quality Framework, this study seeks to better understand hospice care disparities that may contribute to end-of-life health disparities among older adults.

Chapter 3: Research Design and Methods

Introduction

The study was conducted using secondary analyses of existing, administrative data

obtained from the Centers for Medicare and Medicaid (CMS), the United States Census Bureau

(USCB), and the National Center for Health Statistics (NCHS). The purpose of this chapter is to

provide a detailed description of the research design and methods used to investigate the study's

three aims listed in Table 4.

Table 4

Research Questions, Aims, and Hypotheses

Questions	Aims	Hypotheses
What sociodemographic factors are associated with availability and quality of hospice in U.S. counties?	1: Examine geographic (county- level) sociodemographic correlates of hospice quality	h1.1: Population socioeconomic indicators (poverty rate, educational attainment) are correlated with quality of available hospice. h1.2: Population age structure and racial/ethnic composition are correlated with quality of available hospice.
What sociodemographic factors are associated with availability and quality of hospice in rural counties?	2: Examine geographic correlates of hospice quality and compare patterns to urban (i.e., non-rural) US counties.	h2: Geographic correlates of hospice availability and quality of available hospice will differ between rural and urban counties.
Are individual-level sociodemographic characteristics correlated with the quality of the hospice from which care was received?	3: Examine sociodemographic correlates of the care quality of the hospice from which care was received.	h3: Individual-level sociodemographic characteristics – specifically, race and rural/urban status – are correlated with quality of hospice from which care was received.

This chapter first describes the research design, including the rationale, strengths, and

weaknesses of such a design. Next, a detailed description of each data source and the contents of

the datasets will provide information relevant to the sample and setting of the research. A detailed plan for data preparation, including the process for merging multiple datasets and generating specific variables to be used in the study will also be included in the description of the sample and setting. Finally, measures and analytic techniques are described.

Study Design

Aims 1 and 2

Aims 1 and 2 of the research were conducted using a cross-sectional, retrospective, observational, ecological study design to examine geographic correlates of quality of available hospice, with the first aim examining all U.S. counties and the second aim focusing specifically on rural U.S. counties. The third aim will use a cross-sectional, retrospective, observational, population-based design to examine the relationship between individual-level sociodemographic characteristics, the quality of hospice available, and the quality of hospice received. The purpose of this section is to describe the research design and its strengths and limitations.

Ecological Study Design

The research examining hospice availability will use an ecological (geographical) design in which specific geographies (counties) are the units of observation for which data is collected; analyses and interpretations of findings occur at the county-level and as a result do not include data on individuals. More specifically, the data being used are the aggregates of data collected from individuals residing in a given county and aggregated to the county level (e.g., county's median household income reflects the aggregation of individual household incomes).

The rationale for an ecological study design is that such studies can provide insight into the effects of ecological context on healthcare factors that ultimately affect individual and population health outcomes. Ecological research designs are useful for monitoring population health outcomes and identifying disparities that can in turn be used to inform priorities/strategies for future research, intervention, and policy. Additionally, ecological designs are useful for comparing across populations that likely have similar exposure (in this case, available hospices). The rationale for using an ecological design is supported theoretically by the socioecological model (SEM). Further, the relationships between ecological factors, healthcare, and health have been demonstrated empirically in numerous studies, as described in the previous chapter.

Limitations of Ecological Studies

Ecological designs can provide insight into how general community context may affect individual health (BMJ, 2020; Slusser, 1994). A major assumption underlying the research, as well as all ecological study designs, is that the outcome of interest is constant across the entire geographic area of interest. This assumption represents one of the major limitations of ecological studies and the use of population-level data, which is the inability to draw conclusions about individuals based on observations made with aggregated data. That is, because data are aggregated, the outcomes that are observed at the ecological (geographical) level cannot be assumed to exist at the individual level. Falsely inferring that what is observed with aggregated data is true for individuals is considered ecological fallacy (Slusser, 1994). Moreover, there are confounders that exist at the individual level that are not measurable at the ecological-level and risk biasing results (Slusser, 1994).

Aim 3

To overcome some of the limitations in Aims 1 and 2, the third aim of the study examines the relationship between individuals' sociodemographic characteristics and quality of hospice from which care was received, using a cross-sectional, population-based, observational design. A strength of using a population-level approach is that it can provide important insight into patterns of disparities that may be occurring within subgroups of the population. Additionally, population-based study designs can provide information about an entire population, as opposed to examining only a sample of the population, therefore avoiding potential issues related to generalizability of findings due to representativeness of samples in non-population-based studies.

Sample & Setting

Aims 1 and 2

Ecological Study Design Inclusion and Exclusion Criteria

The first two aims of the research will use an ecological design to examine county-level hospice availability, with the first aim examining U.S. counties and the second aim focusing specifically on rural U.S. counties. U.S. counties therefore represent the unit of observation and make up the sample for each of the ecological studies. The rationale for including U.S. counties as the unit of observation for the research is that counties allow for more granularity than, for instance, state-level analyses, but not as much granularity as, for instance, ZIP code or neighborhood tract. As a result, county units more accurately reflect the broad settings/community context in which individuals receive care. An assumption underlying the use of counties is that (1) hospices often define their service areas at the county-level; and (2) people likely often receive healthcare services outside of their immediate neighborhoods, making counties a reasonable level from which to examine availability of healthcare services (Silveira et al., 2011).

County Inclusion and Exclusion Criteria

Counties were included in the sample if they meet the U.S. Census Bureau (USCB) definition of a county or county equivalent, are located within the 50 U.S. states and the District of Columbia, and have all relevant data available from the 2016 American Community Survey

(ACS). Puerto Rico and other U.S. territories were excluded from the sample. The rationale for excluding Puerto Rico and other U.S. territories is that there are likely some confounding effects related to their classification as non-states that would be difficult to account for and complicate interpreting the results for those areas (US Census Bureau, 2016). The rationale for using the USCB's inclusion criteria for the sample of counties is that (1) the USCB administers the surveys used to provide the county-level sociodemographic and economic data to be included in the study and reports them according to their county definition; (2) the USCB definition of counties underlies the Social Security Administration (SSA) county codes that are used to report beneficiary residence in CMS's restricted datasets. Therefore, using all counties defined as such by the USCB not only ensures that nearly all areas of the U.S. are included in the study but also ensures that the county variable is harmonized across each of the study's datasets.

The USCB defines counties as "the primary legal divisions of most states" and designates "county equivalents" in a few instances (U.S. Census Bureau, 2016). Louisiana, whose primary legal divisions are known as parishes but are considered county equivalents by the USCB, was included in the study sample. Additionally, the USCB's county equivalents for Alaska – which includes an organization of boroughs, municipalities, and "census areas" – were included as counties in the sample. Finally, four states have one or more cities that are considered "independent" from counties but treated by the USCB as county equivalents and will therefore be included in the sample as counties.

Hospices

All CMS-certified hospices were included in the sample, regardless of whether hospice quality scores were available. CMS is the primary payor for the majority of hospice care, as older adults make up most of the population of hospice users. CMS certification is required for hospices to receive reimbursements from CMS for hospice care provided. As such, it is assumed that, with likely very few exceptions, nearly all hospices have CMS certification. Therefore, it is assumed that the "sample" of hospices used in this study is nearly equal to the entire population of hospices servicing CMS beneficiaries.

Many aspects of the sample and setting are similar between Aim 1 and Aim 2. For instance, the definition of counties and hospices that provide the basis for inclusion and exclusion criteria are identical with one major exception: the counties that make up the sample for Aim 2 are only those that meet criteria for being considered "rural."

Multiple definitions of rurality exist, as do rural classification schemes. The definition and classification scheme used to obtain the sample of counties for Aim 2, which examines the effect of rurality on the relationship between county-level sociodemographic factors and availability of quality hospice, will likely influence the findings. This section first describes the definition and classification scheme used for identifying rural counties.

The second aim of the study uses the National Center for Health Statistics (NCHS) 2013 Urban-Rural Classification Scheme for Counties (National Center for Health Statistics, 2013). Counties are considered rural if they meet the inclusion criteria for one of the two rural county categories (micropolitan and noncore). More specifically, micropolitan refers to counties that have a small "nucleus" of development/urbanization but are less urbanized and more rural than metropolitan counties which, in contrast, have large, principal cities (referred to as a nucleus). Noncore counties are the most rural counties and are not connected to a nucleus/core.

While multiple definitions of rurality exist, the NCHS classification scheme was selected based on its intended use in health research, its prior use in research conducted by agencies such as the Centers for Disease Control and Prevention and the Agency for Healthcare Quality Research, and its inclusion of different levels of rurality and urbanicity. More specifically, the classification scheme includes subcategories for both rural and metropolitan (i.e., nonrural) that could allow for some additional subgroup analyses (i.e., sensitivity analyses) within rural and nonrural counties (i.e., comparing most rural to less rural).

Aim 3

Aim 3 examines whether individual-level sociodemographic characteristics are associated with the quality of hospice from which an individual receives hospice care, and whether disparities in the quality of hospice available to and received by individuals exist at the population level.

Population-Based Study Inclusion and Exclusion Criteria

The population-based study design focuses on hospice recipient (i.e., individual-level) data that is intended to represent the entirety of the U.S. older adult population. A critical step in conducting population-based studies is defining the population to be studied. The population of interest to the study is older adults using hospice care. To ensure that the population included in the analyses is, indeed, comprised of older adults, age is an important inclusion criterion. Age is an important delimiter to be used in the study because individuals can qualify for Medicare benefits for reasons other than age (for instance, disability and end stage renal disease also entitle individuals to Medicare benefits). Limiting the beneficiaries to only those age 65 years and above will reduce any confounding effects that could occur due to including younger and/or disabled beneficiaries. Additionally, only beneficiaries using hospice (i.e., those in the Hospice LDS) were included in the population-based study. Exclusion criteria to be used for determining the population of beneficiaries included in the analysis will mirror those used for counties in the ecological study. More specifically, only beneficiaries residing in the 50 U.S. states and the

District of Columbia were included in the study sample to avoid any potential confounding effects from non-state residency, and to facilitate the examination of rural residents.

Data Sources

The study draws upon several public and restricted datasets from three main sources: the Centers for Medicare and Medicaid (CMS), the United States Census Bureau (USCB), and the National Center for Health Statistics. This section provides a detailed description of each of the data sources that were used in the study. Table 5 outlines which sources were used for each of the three aims of the study.

Table 5

Study Aims and Data Sources

Aim	Data Sets	Data Source
Examine geographic	CAHPS	HQRP (CMS)
(county-level)	Hospice	
sociodemographic	Survey	
correlates of hospice	Hospice Item	HQRP (CMS)
quality	Set	
	American	USCB
	Community	
	Survey	
	(ACS)	
	Hospice	CMS
	Public Use	
	File	
Aim 2	CAHPS	HQRP (CMS)
	Hospice	
	Survey	
	Hospice Item	HQRP (CMS)
	Set	
	American	USCB
	Community	
	Survey	
	(ACS)	
	Hospice	CMS
	Public Use	
	File	

	2013 Urban-	NCHS		
	Rural County			
	Classification			
	Scheme			
Aim 3	Hospice	CMS		
	Limited Data			
	Set*			
	Master	CMS		
	Beneficiary			
	Summary			
	File*			
	CAHPS	HQRP (CMS)		
	Hospice			
	Survey			
	Hospice Item	HQRP (CMS)		
	Set			
	Hospice	CMS		
	Public Use			
	File			
	2013 Urban-	NCHS		
	Rural County			
	Classification			
	Scheme			
CMS = Centers for Medicare and Medicaid; NCHS = National Center for Health Statistics;				
USCB = United States Census Bureau; HQRP = Hospice Quality Reporting Program				
*Individual-level, restricted access datasets				

Public Use CMS Datasets

The study will draw upon three publicly available CMS datasets: the Hospice Item Set,

the CAHPS Hospice Survey, and the Hospice Public Use File. These datasets are described in

detail below.

Hospice Compare (including Hospice Item Set and CAHPS Hospice Survey)

Two of the publicly available CMS datasets that were used in the research are obtained

from Hospice Compare, a resource provided by CMS as part of its Hospice Quality Reporting

Program (CMS, 2021).

Hospice Item Set

The Hospice Item Set assesses the extent to which hospices provide care in accordance with established standards. More specifically, the Hospice Item Set consists of specific process measures relevant to hospice care. A total of nine items are contained within the Hospice Item Set, with the first two being more global/general measures while the remaining seven items are specific to treatment preferences and symptom management. The two more global/general measures are (1) the percentage of patients in a given hospice who received visits from a nurse, physician, or other advance practice provider in the last three days of life; and (2) the percentage of patients in a given hospice who received a comprehensive assessment (i.e., *all* seven of the individual items were completed) upon admission to hospice. The seven items focus on treatment preferences and symptom management and include the percentage of patients who received: (1) an assessment of treatment preferences such as hospitalization and resuscitation upon admission; (2) an assessment of their beliefs and values upon admission; (3) a pain assessment upon admission; (4) a more thorough pain assessment and treatment when pain was identified as a problem; (5) an assessment of dyspnea upon admission to hospice care; (6) treatment for dyspnea when it was identified as a problem in the admission assessment; and (7) prophylactic constipation regimen when taking an opioid medication (CMS, 2021).

CAHPS Hospice Survey

In contrast to the Hospice Item Set's focus on whether care processes were followed, the CAHPS Hospice Survey focuses on the patient and caregiver experience when receiving hospice care. The CAHPS Hospice Survey results, which are reported through CMS's Hospice Compare alongside the Hospice Item Set results, report the percentage of patients who gave the "top-box" score (i.e., the highest possible scores) in each of the following six domains: communication, getting timely help, treating patients with respect, emotional and spiritual support, help for pain and symptoms, and training to help family care for the patient. The CAHPS Hospice Survey also includes two additional, global measures: the percentage of patients' caregivers who rated the hospice a nine or ten out of ten as well as their rating of their willingness to recommend this hospice, reported as the percentage who responded they would definitely recommend this hospice to friends and family (CMS, 2021).

The Hospice Compare datasets – which include both the Hospice Item Set and the CAHPS Hospice Survey results – are aggregated to the hospice level such that each individual hospice's scores are readily available. In addition to the survey results, Hospice Compare also reports the provider number (NPI number) for each hospice alongside the hospice's geographic location (i.e., physical address). The inclusion of the NPI will allow for linkage between the Hospice Limited Data Set (LDS) and the quality measures to determine the quality of the hospice from which individual beneficiaries received care.

Hospice Public Use File

The Hospice Public Use File is an annual file produced by CMS that reports hospicelevel information, including the hospice name, NPI number, address, the number of beneficiaries serviced, the demographic composition of beneficiaries serviced, their rate of disenrollment prior to death, the average length of stay for beneficiaries, the percentage of beneficiaries with very short (<3 days), short (<7 days), and long (>180 days) stays, the percentage of hospice disenrollment, and the percentage of patients with primary diagnoses in each of the following categories: cardiovascular, respiratory, cancer, dementia, stroke, and other (CMS, 2020b).

Ecological Data

County-level ecological data were obtained from the United States Census Bureau's American Community Survey (ACS; U.S. Census Bureau, 2020). The ACS is a nationwide survey conducted on an annual basis by the United States Census Bureau and collects social, demographic, and economic information. Unlike the decennial census, which attempts to collect information on every person living in the U.S., the ACS is an annual sample of approximately 3.5 million individuals that is used to produce annual estimates during non-decennial census years. In addition to annual estimates, the ACS provides three- and five-year pooled estimates of these social, demographic, and economic characteristics. ACS's 2016 five-year pooled estimates were used for the research, as these are most appropriate for areas with total populations of less than 65,000 (U.S. Census Bureau, 2020). The county-level variables from the ACS that were included in the research include social characteristics (educational attainment), economic characteristics (income, unemployment), and demographic characteristics (age, sex, race, Hispanic origin).

Restricted Datasets

The study will use two restricted-access datasets produced by the Centers for Medicare and Medicaid (CMS): the Hospice Limited Data Set and the Master Beneficiary Summary File (CMS, 2019; CMS, 2020a.). Each includes a combination of beneficiary-level sociodemographic, administrative (i.e., enrollment), and claims information.

The Hospice Limited Data Set and Master Beneficiary Summary File are restricted access datasets produced by CMS for use in research. There are three levels of access for CMS datasets: public use, limited datasets, and research identifiable files (ResDAC, 2021). The Hospice Limited Data Set and Master Beneficiary Summary File are in the limited dataset category, meaning that they are restricted access (i.e., require data user agreement) but certain variables have been altered to avoid potential beneficiary identification. Examples of these types of data alterations include altering the date of death by a few days to protect privacy, providing only the beneficiary's age (but not their date of birth), and including a window of service dates for claims (instead of specific days) within a corresponding annual quarter. Additionally, only the beneficiary's county of residence – but not their full address or ZIP code – is provided. A description of each restricted dataset follows (ResDAC, 2021).

Hospice Limited Dataset (LDS)

The Hospice LDS is an annual dataset that includes all hospice service claims for all beneficiaries during the one-year period (CMS, 2020). This dataset can be linked to the Master Beneficiary Summary File to obtain additional enrollment and demographic information for each beneficiary using a beneficiary identification number (CMS, 2020).

Master Beneficiary Summary File (MBSF)

Unlike the Hospice LDS, the MBSF includes all Medicare beneficiaries enrolled during the one-year period, not just those that used a specific service such as hospice. The MBSF includes demographic information for each beneficiary, including age, race/ethnicity, county and state of residence, as well as enrollment and entitlement information (CMS, 2020). Specific enrollment information is available for each month within the annual file (e.g., enrolled, terminated, reason for termination) as well as original and current reasons for benefit.

Measures

The operational measures used in the research include county-level sociodemographic characteristics extracted from the USCB (Aims 1 and 2), hospice quality assessments extracted from CMS's Hospice Quality Reporting Program (Aims 1, 2, and 3), and individual-level sociodemographic characteristics extracted from the Hospice LDS and MBSF. Detailed operational definitions and the processes for measuring relevant outcomes are discussed in detail by aim as follows.

Aim 1

Aim 1 examines the relationships between county-level sociodemographic characteristics and the quality of available hospice. Toward that end, several standard demographic measures produced by the United States Census Bureau (USCB) American Community Survey (ACS) were used in the study.

Sociodemographic Factors

The sociodemographic factors of interest for the study can be broadly categorized as socioeconomic, demographic, and spatial. Socioeconomic factors are of interest to the study given their relationship with population health and healthcare-related outcomes. For the study, county-level socioeconomic characteristics were measured using median household income, educational attainment (defined as less than high school, high school and some college, and college degree), percentage of population with income below the federal poverty level, and unemployment rate. County-level demographic characteristics were measured by examining age (mean age, percentage of adults 65 years and older) and racial/ethnic composition. A spatial variable included in the study was the county's rural or urban status.

Quality of Available Hospice

For this study, quality of available hospice was measured at the county level and its operationalization for use in the research study encompasses both patient-reported experiences and care processes.

Patient-Reported Experience

Quality, measured as patient-reported experiences, were measured with the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey. CMS contracted the RAND Corporation to develop and test the CAHPS Hospice Survey in 2012. CMS' development of the CAHPS Hospice Survey allows CMS to provide a publicly available source of information for beneficiaries to review when choosing a hospice from which to receive care, aid hospices in internal review and external benchmarking of their care quality, and provide data from which to monitor the quality of care for which CMS was reimbursing hospices.

A robust process was undertaken to develop the CAHPS Hospice Survey that included a call for topic areas (i.e., inviting stakeholder groups to submit requests/recommendations for survey content areas) published in the Federal Register, a review of the existing literature and tools for measuring end-of-life care experiences, qualitative interviews and focus groups with caregivers of hospice patients to inform initial survey items and concepts, expert panel review of initial survey items and concepts, subsequent field testing to examine issues related to item nonresponse, floor and ceiling effects and psychometric properties of single items and multi-composites for specific concepts of interest.

The multi-item concepts measured in the survey include communication, getting timely care, family member treated with respect, providing emotional support, getting help for symptoms, and training (home setting only). The single-item concept measured in the survey relates to providing religious/spiritual support. Additionally, the CAHPS Hospice Survey includes global measures of overall satisfaction which are a caregiver's willingness to recommend hospice and their overall rating of hospice from 0-100. Crohnbach's alpha, a measure of internal consistency that assesses the extent to which items in a given instrument measure the same construct/concept, was calculated for each of the multi-item constructs/concepts in the CAHPS Hospice Survey. Each of the items scored within the acceptable ranges of .70 to .95 with the exception of "providing emotional support" which had a Cronbach's alpha of .68.

The scores published for each hospice in CMS's Hospice Compare dataset are calculated using a "top-box" approach. More specifically, the "scores" for each construct/concept captured in the HIS or the CAHPS survey items are the percentage of respondents that selected the highest possible score for each item used to measure the concept. For example, the score provided for the concept of "training family to care for patient" is the percentage of responses that were the highest possible response to each item included in the concept. The full survey administered to participants (decedent's primary caregivers) as well as a detailed explanation of the scoring methodology is included in Appendix A.

Care Processes

Quality, measured as whether specific care processes considered to be the standard of care for hospices, were measured with the Hospice Item Set (HIS). A robust process of developing the standard care processes that are measured by the HIS was undertaken by CMS - care processes included in the HIS are based on recommendations made by the National Quality Forum. The measure consists of seven items that represent care processes considered fundamental to hospice care and include care processes such as whether pain was evaluated and treated and whether care preferences were discussed and documented. These items are measured as binary outcomes (yes, this care process was carried out or no, it was not) and the percentage of the time that the care process was carried out for all hospice recipients within a hospice is how this measure is reported.

Hospice Disenrollment

Hospice disenrollment is an outcome of interest to this study as it may relate to the quality of hospice care being provided (Wu & Volker, 2019; Dolin et al., 2017).

Aim 2

Rural

Multiple definitions of rural/urban exist. Some are based solely on population density, while others account for population size, commuting patterns, and distance to large metropolitan areas. These latter definitions consider rurality (urbanicity) to exist on a continuum with multiple levels within the category of urban as well as within the category of rural. The second aim of the study – which examines only rural counties and compares them to nonrural counties – uses the National Center for Health Statistics' (NCHS) 2013 Urban-Rural Classification Scheme for Counties. The NCHS classification scheme is based largely on the well-established and widely used metropolitan statistical areas (MSAs) delineated and defined by the Office of Management and Budget (OMB). This classification scheme allows for examining the effect of rurality on a continuum, as there are six levels (large metro, large fringe metro, medium metro, small metro, micro, non-core) across the urban-rural continuum. As such, this aim can examine the effect of rurality in terms of the broad conceptualization of a binary rural/urban as well as examine differences within various types of rural counties (e.g., micro versus non-core).

More specifically, counties are considered rural if they meet the inclusion criteria for one of the two rural county categories: micropolitan and noncore. Micropolitan refers to counties that have a small "nucleus" of development/urbanization but are less urbanized and more rural than metropolitan counties which, in contrast, have large, principal cities (referred to as a nucleus). Noncore counties are the most rural counties and are not connected to a nucleus/core. Counties are classified as urban if they are within any of the three urban categories as defined by the NCHS. While multiple definitions of rurality exist, the NCHS classification scheme was selected based on its intended use in health research and its prior use in research conducted by agencies such as the Centers for Disease Control and Prevention and the Agency for Healthcare Quality Research. Additionally, the classification scheme includes subcategories for both rural and metropolitan (i.e., nonrural) that could allow for some additional subgroup analyses within rural and nonrural counties (i.e., comparing most rural to least rural; most metropolitan to least metropolitan; CDC, 2017).

Data for the NCHS county coding scheme was obtained from the CDC as an Excel file that was converted into a Stata-compatible dataset and merged to the existing dataset using the county identifier code (i.e., FIPS code). Counties classified as micropolitan and non-core counties in the NCHS classification dataset were coded as rural using a one and zero if they were coded as any of the four metropolitan designations.

Aim 3

The third aim of the study used beneficiary-level data to examine whether an individual's sociodemographic characteristics relate to the quality of the hospice from which they received care.

Demographics

Individuals' demographic characteristics were extracted from the Hospice Limited Data Set (Hospice LDS) and MBSF. These characteristics include age, sex, and race/ethnicity.

Socioeconomic status

Socioeconomic status was operationalized and measured as a beneficiary's dualeligibility status. Dual eligibility refers to being eligible for both Medicare and Medicaid, and has been used in prior research as a proxy for socioeconomic status. The Hospice LDS does not include dual eligibility; dual eligibility variables are included in the Master Beneficiary Summary File (MBSF). A variable to link beneficiaries across the Hospice LDS and MBSF exists that will allow for inclusion of this variable in the analyses.

Residency

Beneficiaries' county of residence is included in the Hospice LDS as a unique county code. County of residence was used when measuring the quality of the hospice from which an individual received hospice care. County of residence will also be used to generate a rural-urban indicator for the beneficiary to include in the analyses.

Data Collection & Management

The study was a secondary analysis of data collected by CMS. Data were downloaded from multiple sources across several CMS data reporting programs, including Care Compare (formerly Hospice Compare), Hospice Public Use File, Hospice Limited Data Set (LDS), and the Master Beneficiary Summary File (MBSF). Additionally, county-level sociodemographic data were obtained from the United States Census Bureau's American Community Survey (ACS) for use in the study. Data were stored on a secured server in accordance with both CMS and Penn State procedures for securing sensitive health data. A copy of the IRB Approval is included in Appendix B. A detailed description of the data management plan is included first for Aims 1 and 2 and then separately for Aim 3 in this section.

Aims 1 and 2

Aims 1 and 2 required merging several datasets to generate the variables necessary for the analyses. Table 6 displays the datasets to be combined to accomplish Aims 1 and 2 as well as the variables that were used to merge across datasets.

Aim 3

Aggregate variables generated for hospice quality and availability in Aims 1 and 2 were used to examine the relationship between individual-level sociodemographic characteristics and hospice quality.

Table 6

Data Sources with Selected Variables of Interest

Aim	Dataset	Data Source	Variables of interest	Merge Variable
Aim 1	CAHPS Hospice Survey	CMS	Hospice patient experience scores	Hospice Identification Number
	Hospice Item Set	CMS	Hospice care process scores	Hospice Identification Number
	American Community Survey	USCB	County sociodemographic factors	County FIPS Code
	Hospice Public Use File	CMS	Hospice disenrollment rates	Hospice Identification Number
Aim 2	CAHPS Hospice Survey	CMS	Hospice patient experience scores	Hospice Identification Number
	Hospice Item Set	CMS	Hospice care process scores	Hospice Identification Number
	American Community Survey	USCB	County sociodemographic factors	County FIPS Code
	Hospice Public Use File	CMS	Hospice disenrollment rates	Hospice Identification Number

	2013 Urban-Rural County Classification Scheme	NCHS	Rural-urban classification code	County FIPS Code	
CMS = Centers for Medicare and Medicaid; NCHS = National Center for Health Statistics; USCB = United States Census Bureau					

Table 7 displays the variables of interest to this study that are available in the Hospice

LDS file and the Master Beneficiary Summary File, as well as how they can be used to merge

across datasets to construct the study's dataset and specific variables for analyses.

Table 7

	Hospice LDS	and MBSF	Variable	Descriptions	and U	tilitv
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Variable	Numeric/	Definition and Utility for the Study
(source)	Categorical/Range	
Beneficiary ID	String	A key to link data for each beneficiary between
(HLDS and		Hospice LDS file and Master Beneficiary Summary
MBSF)		File
Claim Number	Numeric	Together with beneficiary ID, identifies unique
(HLDS)		hospice claims for a beneficiary
Patient	Categorical	Discharged
Discharge Status		Died
(HLDS)		Still Patient
NPI Number	Numeric	Identifies provider from which patient received
(HLDS)		hospice; can be used to link with hospice quality
		datasets to obtain hospice's quality scores
Age (HLDS and	Numeric (years)	Age of beneficiary at end of prior year
MBSF)		
Sex (HLDS and	Categorical	Male
MBSF)		Female
Race/Ethnicity	Categorical	White
(HLDS and		Black
MBSF)		Other
		Asian
		Hispanic
		North American Native
County Code	Numeric (SSA	Together with state code, identifies county in which
(HLDS and	Code)	beneficiary resides
MBSF)		
State Code	Numeric (SSA	Together with county code, identifies county in
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(HLDS and	Code)	which beneficiary resides
MBSF)		
Reason for	Categorical	Old Age and Survivors Insurance
entitlement		Disability
(MBSF)		ESRD
		Both Disability and ESRD

HLDS = Hospice Limited Data Set

MBSF = Master Beneficiary Summary File

Protections Against Risk

The ecological study design to be used in Aims 1 and 2 does not involve the use of human subjects. Instead, the units of observation are counties and the quality of available hospice is aggregated to the hospice level by CMS. As such, there is no human subject involvement. Aim 3, however, includes the use of individual-level personal health information (PHI). CMS takes several steps to de-identify and/or remove personal identifiers within the LDS files that include providing a "date of death" switch (i.e., adjusting actual dates of death by a few days in order to obscure actual date of death) for decedents in the dataset, providing the number of days within a quarter that a beneficiary received hospice instead of specific service dates, removing ZIP code and street address and only providing county of residence, and providing a beneficiary identification number that is only relevant to the LDS and cannot be used to identify beneficiaries in any other claims or databases. Despite these precautions taken by CMS to prevent the identification of individuals in the Hospice LDS and MBSF, the use of individuallevel PHI did require both Institutional Review Board (IRB) approval as well as a Data Use Agreement (DUA) with a plan for data security. The use of this data was approved by the Pennsylvania State University Institutional Review Board (see Appendix B).

Data Analysis

All statistical analyses were performed in Stata. Linear regression was used to examine each of the three aims as detailed below by study aim. For each aim, descriptive statistics of all independent and dependent variables were described and discussed in detail.

Sample Size Considerations

Missing Data

Missing data can introduce bias and undermine the ability to make valid inferences (Mack et al., 2018). Determining the most appropriate analytic strategy for handling missing data should be guided by a thorough understanding of the types and reasons for missing data (Mack et al., 2018). Steps were taken in the analyses to avoid or minimize the amount of missing data in the research prior to conducting analyses. Additionally, the amount of missing data and the strategies used to manage missing data were reported prior to interpreting results. Results interpretation will consider the impact of the missing data; sensitivity analyses may also be warranted.

The research study used data from administrative datasets as well as patient- and provider-reported quality surveys. Due to differences in the type of data included in each dataset, the types and amount of missing data may vary. "Left truncation" refers to a type of selection bias in which the "event of interest" (in this case, hospice enrollment) occurs before the time period captured in the administrative dataset (Mack et al., 2018). Truncation can result in a less accurate reflection of the true population of interest (in this case, hospice users). Relatedly, those who are already enrolled in hospice at the start of the administrative dataset's captured time period may have a different baseline. Differences in baseline may be more of a threat in studies in which timing of diagnosis and services received/healthcare utilization patterns are of key importance (Mack et al., 2018). However, in this case, differences in availability of hospice may occur for individuals with a different baseline but are likely marginal differences. Focusing on individuals that enroll in hospice during the stated period can minimize threats from left truncation and differences in baseline hospice availability.

After careful consideration of the issues above, the study's adopted the following general approach for managing missing data. The amount of missing data was examined, as well as whether any patterns could be discerned from the missing data, particularly as pertaining to differences between observations with and without missing data.

Validity and Reliability

Despite the strengths of the study, such as its population-based design and inclusion of validated quality measures, threats to validity and reliability remain. This section describes limitations of the datasets and explains steps that can be taken to minimize threats to validity.

Dataset limitations

Many dataset limitations were noted when discussing desired additional variables that would enhance the study. Such limitations include that the restricted access datasets are crosssectional (2016), and may contain individuals that remain alive and enrolled in hospice beyond 2016. This makes it impossible to know these individuals' discharge disposition. Excluding these beneficiaries from the sample when specifically examining disenrollment prior to death will minimize any issues that would arise due to spanning multiple years and can be accomplished by excluding anyone with a final claim status of still enrolled. Additionally, death after disenrollment from hospice can be validated using the MBSF termination and date of death variables alongside the hospice discharge disposition. The years for which data are available may introduce some threats to validity. More specifically, the Hospice Quality Reporting Program is relatively new, and the first year for which both the CAHPS Hospice Survey and Hospice Item Set are available is 2017. As a result, the beneficiaries included in the 2016 restricted access files did not contribute to those quality reports. The plan for minimizing this threat to validity is to use the dataset that is closest to 2016, assuming that there were no major changes that occurred in the short timeframe between reporting years. Additionally, there is an option to use quarterly Hospice Compare datasets within 2017; furthermore, including scores from the first quarter or half of 2017 may be a more valid reflection of 2016 quality. However, this reduces the sample that makes up the scores. One potential plan would be to examine both, to see if there are marked differences between scores at the beginning of 2017 versus across the entire year, and to then discuss this transparently in the study's limitations.

Another threat to validity posed by the datasets relates to availability. It is not possible to determine the actual availability of certain hospices to individuals – e.g., there may be some type of hospice enrollment eligibility criteria that limits their access to a hospice that cannot be determined with the data, such as distance hospice recipients are willing to travel. Focusing on Medicare beneficiaries – all of whom receive the hospice benefit – and only CMS-certified hospices (those participating in the Hospice Quality Reporting Program and for which data is available through Hospice Compare) reduces some of this risk to validity.

Other issues may arise related to aggregating availability to the county-level. For instance, a hospice may only service part of a county and therefore be unavailable to beneficiaries residing in other parts of the county. While county-level (as opposed to state-level) availability provides more granularity, it nevertheless has its own limitations in terms of accurately indicating hospices available to an individual. Given the datasets' limitations, this is unavoidable but can be discussed transparently as a limitation and taken into consideration when interpreting results.

Finally, a major exemption criterion for participating in the Hospice Quality Reporting Program is having fewer than 50 survey-eligible decedents in a one-year period (Ahnang Price et al., 2017). This exemption likely disproportionately affects rural hospices, given their smaller populations. In addition to examining characteristics of the hospices that do not have scores reported in Hospice Compare, the study examines the characteristics of beneficiaries that receive care from hospices that do not participate in Hospice Compare. This was possible because of the inclusion of the hospice from which a beneficiary received care in the restricted access files, which could represent a sub-group analysis within the study. Additionally, a potential way to minimize this threat to validity is to include the following as additional indicators of hospice quality for the sub-group analysis: 1) disenrollment rates; 2) percentage of unusually short (long) lengths of stay; and 3) profit status. These can be obtained for most hospices in the Hospice Public Use File.

Chapter Summary

The methods of analysis used in this study examine relationships between county-level and individual-level sociodemographic factors and hospice availability and quality of available hospice care. The overall purpose of the study is to gain further insight into hospice availability and quality, as well as potential hospice care disparities.

Chapter 4

Introduction

Study results are presented in this chapter by aim. Each aim is listed below in Table 8.

Within each aim, results are also stratified by urbanicity (i.e., rural or urban).

Table 8

Questions	Aims	Hypotheses
What sociodemographic factors are associated with availability and quality of hospice within U.S. counties?	1. Examine geographic (county-level) sociodemographic correlates of hospice quality	 h1.1: Population socioeconomic indicators (poverty rate, educational attainment) are correlated with quality of available hospice. h1.2: Population age structure and racial/ethnic composition are correlated with quality of available hospice.
What sociodemographic factors are associated with availability and quality of hospice in rural counties?	2. Examine geographic correlates of hospice quality and compare patterns to urban (i.e., non- rural) US counties.	h2: Geographic correlates of hospice availability and quality of available hospice will differ between rural and urban counties
Are individual-level sociodemographic characteristics correlated with the quality of the hospice from which care was received?	3. Examine sociodemographic correlates of the care quality of the hospice from which care was received.	h3.: Individual-level sociodemographic characteristics – specifically, race and rural/ urban status – are correlated with quality of hospice from which care was received.

Study Questions, Aims, and Hypotheses

Sample Description

Descriptive statistics for each of the samples and measures used in Aims 1-3 are

presented in this section. For both Aims 1 and 2, the unit of observation is a U.S. county. Table 9

displays the descriptive statistics for the sample/population of U.S. counties included in the

analysis. This data was obtained from the American Community Survey (ACS) of the United States Census Bureau (USCB).

County Descriptive Statistics

The first set of descriptive characteristics for U.S. counties in this analysis focus on county-level age structure and are shown in Table 9. On average, the majority of a county's age structure is working age (i.e., age 16 to 64 years), which is approximately 63.80% with a standard deviation of 3.72. The remainder of the county's age composition is similarly split between those who are 15 years old and younger and those who are age 65 years and over. On average, 18.64% of a county's population is age 15 years or younger while 17.56% of its population is age 65 years and over.

The next variables focus on educational attainment. On average, 14.16% of a U.S. county's adult population has less than a high school degree, 65.01% has a high school degree and/or some college, and 20.80% has a college degree.

The next set of variables included in the study focus on county racial and ethnic composition. Among U.S. counties, the average share of the population that is non-Hispanic white is 77.06%, followed by 8.95% Hispanic, 8.89% non-Hispanic Black, 3.82% Other racial/ethnic minorities, and 1.28% Asian. The percentage of foreign-born residents in a county is, on average, 4.65%, and the average poverty rate among U.S. counties is 16.41%. Finally, 63.94% of U.S. counties are rural, while 37.06% of U.S. counties are urban.

Table 9

Sociodemographic Descriptive Information for All United States Counties

Variable	n = 3,142 counties
Age category % (SD)	
15 years old or younger	18.6 (3.1)
Working age (16 years-64 years)	63.8 (3.7)
65 years and over	17.6 (4.5)

Education, % (SD)	
Less than high school	14.2 (6.5)
High school degree - some college	65.0 (7.4)
College degree	20.8 (9.1)
Race/Ethnicity, % (SD)	
Non-Hispanic White	77.1 (20.0)
Non-Hispanic Black	8.9 (14.5)
Hispanic	9.0 (13.6)
Asian	1.3 (2.7)
Other	3.8 (8.2)
Foreign-Born, % (SD)	4.7 (5.7)
Poverty Rate, % (SD)	16.4 (6.6)
Urbanicity, %	
Rural	63.9
Urban	37.1

County Descriptive Statistics by Rurality

Descriptive statistics for county-level hospice availability and quality are shown in Tables 10 and 11. On average, rural counties have lower shares of the population that are working age and higher shares of the population that are 65 years and over. Additionally, rural counties have, on average, less educational attainment, are less racially/ethnically diverse, and have higher rates of poverty.

Table 10

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Sociodemographic Descriptive Information for United States Counties, Urban versus Rural

Urban (n = 1,166)	Rural (n = 1,976)
18.9 (2.8)	18.5 (3.2)
65.5 (3.2)	62.8 (3.7)
15.6 (3.9)	18.8 (4.4)
12.6 (5.5)	15.2 (6.9)
61.9 (8.4)	66.8 (6.1)
25.5 (10.6)	18.0 (6.8)
74.3 (18.8)	78.7 (20.6)
10.8 (13.5)	7.8 (14.9)
9.6 (12.5)	8.6 (14.2)
2.3 (3.6)	0.7 (1.6)
3.0 (3.9)	4.3 (9.8)
	Urban (n = 1,166) 18.9 (2.8) 65.5 (3.2) 15.6 (3.9) 12.6 (5.5) 61.9 (8.4) 25.5 (10.6) 74.3 (18.8) 10.8 (13.5) 9.6 (12.5) 2.3 (3.6) 3.0 (3.9)

Foreign-Born, % (SD)	6.4 (6.8)	3.6 (4.6)
Poverty Rate, % (SD)	14.7 (5.6)	17.4 (6.9)

Table 11

County-Level Hospice Availability and Quality

Variable		
Hospice Availability		
Count of Providers, mean (SD)	19.05 (25.01)	
Hospice Quality		
Patient Experience/Satisfaction (CAHPS; N=3118)*	82.08 (1.90)	
Process Measures (HIS; N=3,122)*	95.69 (1.58)	
Hospice Facility Type (N=4,084)		
In-patient (hospital, SNF), n (%)	373 (9.13)	
Home Health Agency	426 (10.43)	
Freestanding Hospice	3,285 (80.44)	
Hospice Profit Status (N=4,084)		
Non-Profit, n (%)	1,021 (25.00)	
For-Profit, n (%)	2,497 (61.15)	
Government, n(%)	110 (3.34)	
Other	436 (10.43)	
*County-level average CAHPS score among all hospices in county		
SNF = Skilled Nursing Facility		
CAHPS = Consumer Assessment of Healthcare Providers and Systems		
Hospice Survey (includes patient reports of hospice quality)		
HIS = Hospice Item Set (includes hospice reports of hospice care		
provided)		

Hospice Quality Descriptive Statistics

Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey

Descriptive statistics for the Consumer Assessment of Healthcare Providers and Systems

(CAHPS) Hospice Survey are shown in Table 12. This survey is designed to capture and

evaluate the experiences of hospice beneficiaries and is comprised of eight domains:

communication, timely care, respect, emotional/relationship support, symptom management,

caregiver training, overall rating, and willingness to recommend. The responses are reported as

the percentage of respondents selecting the "top box value" or highest rating for a given item.

The mean hospice score for the first item, communication ("The hospice team always communicated well"), was 80.54%, with a standard deviation of 5.25%, a minimum of 54% and a maximum of 97%. For the next item of interest, timely care ("The hospice team always gave patients and families help when they needed it"), the mean hospice score was 78.01% with a standard deviation of 6.87, minimum score of 47% and maximum score of 96%. Hospices' mean score for the item examining respect ("the hospice team always treated the patient with dignity and respect) had a mean score of 90.62%, standard deviation of 3.84%, minimum of 71% and maximum of 100%.

The average hospice score for the next item, which examines emotional and spiritual support ("the hospice team provided the right amount of emotional and spiritual support"), was 89.81% with a standard deviation of 3.55%, a minimum of 67% and a maximum of 100%. The following two items focused on symptom management and caregiver training. The average hospice score for symptom management ("the hospice team always gave the patient as much help as needed for pain and other symptoms") was 75.19%, with a standard deviation of 6.07, minimum of 42%, and maximum of 94%. The average hospice score for caregiver training ("the hospice team always gave family members the training and information they needed to care for the patient") was 75.37% with a standard deviation of 6.96%, a minimum of 45% and a maximum of 97%.

The final two items are more global measures of overall patient satisfaction. First, respondents were asked to provide their overall rating of a hospice where 10 is the best. The average percentage of respondents giving a 9 or a 10/10 for hospice's overall rating was 80.68%, with a standard deviation of 6.38%, a minimum of 52%, and a maximum of 99%. The second global measure of overall patient satisfaction/experience was their willingness to recommend the

hospice to others. The average percentage of respondents who stated they would "definitely"

recommend the hospice to friends and family for a hospice was 84.47%, with a standard

deviation of 6.79%, a minimum of 51% and a maximum of 100%.

Table 12

CAHPS Hospice Survey

Item	Ν	Mean	SD	Min	Max
Communication	2878	80.54	5.25	54	97
The hospice team always communicated well.					
Timely Care	2878	78.01	6.87	47	96
The hospice team always gave patients and families help					
when they needed it.					
Respect	2878	90.62	3.84	71	100
The hospice team always treated the patient with dignity					
and respect.					
Emotional and Spiritual Support	2878	89.81	3.55	67	100
The hospice team provided the right amount of emotional					
and spiritual support.					
Symptom Management	2878	75.19	6.07	42	94
The hospice team always gave the patient as much help as					
needed for pain and other symptoms.					
Caregiver Training	2862	75.37	6.96	45	97
The hospice team always gave family members the					
training and information they needed to care for the					
patient.					
Overall Rating	2878	80.68	6.38	52	99
Family caregivers who gave the agency a total rating of 9					
or 10 (where 10 is the best).					
Willingness to Recommend	2878	84.47	6.79	51	100
Family caregivers who would definitely recommend this					
hospice agency to friends and family.					

Note. These are the percentages of respondents giving the "top box value" response to each item.

Hospice Item Set

The second measure of hospice quality examined in this study is the Hospice Item Set (HIS). The HIS examines the care patterns (i.e., care processes) of a hospice in order to evaluate the extent to which a hospice is providing fundamental care to patients and families. These processes are reported by the hospice to CMS. Items included in the HIS include asking about

patient treatment preferences, elucidating beliefs and values, screening for pain, assessing for pain among patients screening positive for pain, screening for dyspnea (i.e., shortness of breath), treatment of dyspnea among patients reporting it, and care for constipation among patients taking opioid medications for pain.

The mean hospice score for treatment preferences (i.e., the percentage of patients or caregivers who were asked about treatment preferences such as hospitalization or resuscitation) was 98.89%, with a standard deviation of 4.06%, minimum of 6% and maximum of 100%. Beliefs and values were asked about by a hospice, on average, about 95.50% of the time with a standard deviation of 9.13%, a minimum of 4.4% and a maximum of 100%. The average hospice score for pain screening (i.e., the percentage of patients within a hospice who were screened for pain), was 95.93% with a standard deviation of 6.29%, a minimum of 17% and a maximum of 100%. Among patients who screened positive for pain, hospice-level scores for giving timely and thorough pain assessments were, on average, 86.13%, with a standard deviation of 14.35%, a minimum of 0% and a maximum of 100%.

The next two items of the HIS focus on dyspnea screening and treatment. On average, hospices screened patients for dyspnea 98.09% of the time, and provided treatment for those screening positive for dyspnea 96.13% of the time. The final item in the HIS – whether individuals receiving opioid treatment were provided a bowel regimen – shows that, on average, hospices provide this specific care process 95.96% of the time (see Table 13).

Table 13

Hospice Quality Descriptive Statistics (question-level HIS)

Item	N	Mean	SD	Min	Max
Treatment Preferences	3734	98.89	4.06	6	100

Patients or caregivers who were asked about treatment					
preferences like hospitalization and resuscitation at the					
beginning of hospice care.					
Beliefs and Values	3734	95.50	9.13	4.4	100
Patients or caregivers who were asked about their beliefs					
and values at the beginning of hospice care.					
Pain Screening	3734	95.93	6.29	17	100
Patients who were checked for pain at the beginning of					
hospice care.					
Pain Assessment (among + screen)	3302	86.13	14.35	0	100
Patients who got a timely and thorough pain assessment					
when pain was identified as a problem.					
Dyspnea Screening	3734	98.09	4.19	19	100
Patients who were checked for shortness of breath at the					
beginning of hospice care.					
Dyspnea Treatment (among + screen)	3352	96.13	6.00	5.7	100
Patients who got timely treatment for shortness of breath.					
Bowel Regimen (among + opioids)	2831	95.96	6.79	34.1	100
Patients taking opioid medication who were offered care					
for constipation.					

Aim 1

Aim 1 examined whether and how county-level sociodemographic characteristics were associated with the availability of hospice and the quality of available hospice providers.

Sociodemographic Correlates of County-Level Hospice Availability

A linear regression model examining the relationship between the availability of hospice providers (i.e., the number of hospice providers per 10,000 residents within a county) shows the overall association between county characteristics and hospice availability. The first set of correlates of interest focuses on age structure. The results show that counties with older populations (i.e. those with a higher proportion of individuals over 65 years old) had significantly more hospice availability (b = 0.752, SE = 0.095, p < .001). Each percentage point increase in the share of the population aged 65 or older was associated with an approximately 0.752-provider increase in per-capita hospice availability. The share of working-age population in each county is not significantly associated with hospice availability (b = -0.169, SE = 0.114, p = 0.139).

The next variables of interest capture county educational attainment. Counties with lower levels of educational attainment (greater proportion of the population with less than high school) had significantly more hospice providers than those with a high school degree and/or some college (b = 0.391, SE = 0.078, p < .001). Each percentage point increase in the share of adults with such low education was associated with a 0.391 increase in the number of per capita hospice providers. In contrast, higher educational attainment (college degree or higher) was not a significant correlate of hospice availability (b = 0.094, SE = 0.094, p = 0.054).

The relationship between county-level racial, ethnic, and nativity (i.e., foreign-born) composition was also examined in the linear regression model shown in Table 14. Higher proportions of non-Hispanic Black residents were associated with a higher rate of per capita hospice providers (b = 0.132, SE = 0.022, p < .001). Each percentage point unit in the Black population share was associated with a 0.132-provider increase in hospice availability. Similarly, higher proportions of Hispanic residents and Other racial groups (i.e., other racialized minority groups not included in the other variables) were significantly associated with higher per capita rates of hospice providers (b = 0.227, SE = 0.031, p < .001 and b = 0.086, SE = 0.036, p = 0.016, respectively). A one percentage point increase in the Hispanic population was associated with a 0.227-provider increase in hospice availability per capita, while similar increases in the Other population share were associated with a 0.086-provider increase per capita. The proportion of residents within a county that were not born in the United States (i.e., foreign-born), had a negative association with the number of hospice providers (b = -0.376, SE = 0.093, p < .001).

Finally, the model also measures the association between both poverty and urbanicity and hospice availability. Poverty rate was significantly, negatively associated with the per capita hospice provider rate (b = -0.359, SE = 0.060, p < .001). A one-percentage point increase in the poverty rate was associated with a 0.359-provider decrease in hospice availability per capita. Level of urbanicity was strongly associated with lower rates of per-capita hospice providers (b = -3.743, SE = 0.060, p < .001). On average, urban counties had 3.7 fewer hospice providers per 10,000 residents than rural counties.

Table 14

Per Capita Providers	B (SE)	р
Age (reference age 15 years and under)		
Working age	-0.169 (0.114)	0.139
Age 65 years and over	0.752 (0.095)	< 0.001
Education (reference HS, some college)		
Less than high school	0.391 (0.078)	< 0.001
College	0.094 (0.047)	0.054
Race		
Non-Hispanic Black	0.132 (0.022)	< 0.001
Hispanic	0.227 (0.031)	< 0.001
Asian	-0.141 (0.014)	0.320
Other	0.086 (0.036)	0.016
Foreign-born	-0.376 (0.093)	< 0.001
Poverty Rate	-0.359 (0.060)	< 0.001
Urban	-3.743 (0.609)	< 0.001
N = 3142		

Aim 1: County Sociodemographic Correlates of Hospice Availability

Sociodemographic Correlates with County-Level Hospice Quality

Next, linear regression models examining the relationship between county-level sociodemographic characteristics and hospice quality were estimated. Two separate models were estimated – one for each outcome measure of quality. The first measure of quality examined was mean CAHPS score of available hospices in the county, which captures quality as patient experience and overall satisfaction. The second measure of quality examined was mean HIS score of available hospices in the county, which captures specific hospice processes.

Patient Experience/Satisfaction Scores

A linear regression model shows the overall association between county sociodemographic characteristics and the average quality of available hospice as measured by CAHPS (patient experience/satisfaction; Table 15). These models take the true average of the hospice scores within each county irrespective of the size of each hospice. The first set of correlates of interest focus on county age structure. The results show that counties with older populations (those with a higher proportion of individuals age 65 years and over) had significantly lower patient experience/satisfaction scores (b = -0.071, SE = 0.011, p < 0.001). Each percentage point increase in the share of the population aged 65 years and over was associated with an approximately 0.071 decrease in the mean CAHPS score. Similarly, counties with higher shares of working-age individuals also had a significant, negative relationship with mean CAHPS score (b = -0.045, SE = 0.014, p = 0.001). For each percentage point increase in the share of working-age population (i.e., population ages 15-64 years), there was a -0.045 decrease in the mean CAHPS score.

The next set of variables of interest focus on educational attainment and its relationship to county-level hospice quality as measured by patient experience/satisfaction. Lower rate of educational attainment (i.e., less than high school degree) is significantly associated with higher patient experience/satisfaction scores (b = 0.086, SE = 0.009, p < 0.001). That is, for each percentage point increase in the share of adults with less than a high school degree, there is an increase of 0.086 in the mean CAHPS score. Similarly, higher educational attainment was also significantly associated with higher patient experience/satisfaction scores (b = 0.009, p < 0.001). For each percentage point increase in the proportion of county residents with a college degree, there is a 0.019 increase in patient experience/satisfaction scores.

The relationship between county-level racial, ethnic, and nativity composition and quality of available hospice was also examined in the linear regression model shown in Table 15. High proportions of non-Hispanic Black, Hispanic, and Other (i.e., other racialized minority groups not included in the other variables) were significantly associated with lower patient experience/satisfaction scores (b = -0.016, SE = 0.002, p < 0.001; b = -0.043, SE = 0.004, p < 0.001; and b = -0.040, SE = 0.004, p < 0.001, respectively). A one percentage point increase in the non-Hispanic Black population was associated with a 0.016 decrease in the mean CAHPS score, while a one percentage point increase in the Hispanic population was associated with a 0.043 decrease in the mean CAHPS score. Similarly, a one percentage point increase in the proportion of the population that identifies as Other racialized minority and ethnic groups was associated with a 0.040 decrease in the mean CAHPS score.

The proportion of residents within a county that were not born in the United States (i.e., foreign-born), had a negative association with mean patient experience/satisfaction scores. (b = -0.083, SE = 0.011, p < 0.001). For each percentage point increase in the share of the population born outside of the United States, there was a 0.083 decrease in the mean CAHPS score. The final two correlates of interest, poverty rate and urbanicity (i.e., urban or rural) were significantly associated with mean CAHPS score. First, higher county-level poverty rates were positively associated with patient experience/satisfaction scores (b = 0.049, SE = 0.007, p < 0.001). That is, the mean CAHPS score increased by 0.049 for each percentage point increase in the county-level poverty rate. In contrast, urbanicity was negatively associated with patient experience/satisfaction scores (b = -0.251, SE = 0.072, p = 0.001). On average, urban counties had 0.251-point lower CAHPS scores than rural counties.

Table 15

	Unwei	ghted	И	Veighted
Patient Experience/Satisfaction (CAHPS)	B (SE)	р	B (SE)	р
Age				
Working age	-0.045 (0.014)	0.001	-0.063	< 0.001
Age 65 years and over	-0.071 (0.011)	< 0.001	-0.094	< 0.001
Education				
Less than high school	0.086 (0.009)	< 0.001	0.087	< 0.001
College	0.019 (0.006)	0.001	0.023	< 0.001
Race				
Non-Hispanic Black	-0.016 (0.002)	< 0.001	-0.011	< 0.001
Hispanic	-0.043 (0.004)	< 0.001	-0.033	< 0.001
Asian	0.008 (0.017)	0.637	0.013	0.445
Other	-0.040 (0.004)	< 0.001	-0.028	< 0.001
Foreign-born	-0.083 (0.011)	< 0.001	-0.111	< 0.001
Poverty Rate	0.049 (0.007)	< 0.001	0.037	< 0.001
Urban	-0.251 (0.072)	0.001	-0.227	0.002
N = 3,114				

Aim 1: County Sociodemographic Correlates of Hospice Quality (CAHPS)

The previous results did not consider size of different hospices within each county. As a result, there may have been undue weight given to small hospices or to the experiences of patients in small hospices. To account for these issues, a supplemental analysis using hospice quality scores that are weighted by the size of each hospice was performed. In other words, these scores give greater weight to scores of larger hospices than smaller hospices in a county (Table 15). The magnitude of the point estimates changed slightly; however, the direction and significance of the coefficients did not change between the weighted and unweighted results. The implication of this finding is that weighting quality scores by hospice size does not change substantive conclusions.

Hospice Process Measures

A linear regression model was also estimated to examine the relationship between county-level sociodemographic variables and hospice process measures, the second measure used in this analysis to examine available hospice quality and its relationship to county-level sociodemographic information. The results of these models are shown in Table 16. These models take the true average of the hospice scores within each county irrespective of the size of each hospice. The first set of correlates of interest focus on county age structure. Working age and age 65 years and over were both significantly and positively associated with HIS scores (b = 0.057, SE = 0.013, p < 0.001; b = 0.044, SE = 0.010, p < 0.001, respectively). For each percentage point increase in the proportion of the population that is working age (i.e., age 15 to 64 years), there is a corresponding 0.057 increase in the mean HIS score for available hospices. There is a 0.044-point increase in the mean HIS score for available hospices for each percentage point increase in the share of the population that is age 65 years and over.

The next set of correlates examined county-level educational attainment and its relationship to mean HIS score. Educational attainment was not a significant correlate of HIS scores (less than high school: b = 0.015, SE = 0.008, p = 0.078; college degree: b = -0.002, SE = 0.005, p = 0.697).

The relationship between county-level racial, ethnic, and nativity composition and quality of available hospice was also examined in the linear regression model shown in Table 16. Both non-Hispanic Black and Hispanic were significantly, negatively associated with HIS scores (b = -0.012, SE = 0.002, p < 0.001; b = -0.029, SE = 0.003, p < 0.001, respectively). For a onepercentage point increase in the non-Hispanic Black population, there was a 0.012 decrease in the mean HIS score. Similarly, for each percentage point increase in the Hispanic population, there was a 0.029 decrease in the mean HIS score. Asian and Other race(s), and foreign-born composition, are not significantly associated with HIS scores (b = 0.019, SE = 0.016, p = 0.226; b = 0.004, SE = 0.004, p = 0.293; b = 0.001, SE = 0.010, p = 0.091, respectively). Similarly, poverty rate does not have a significant relationship with mean HIS score (b = 0.005, SE = 0.007, p = 0.484), nor does urbanicity (b = 0.037, SE = 0.066, p = 0.581).

Table 16

	Unweigh	ted		Weighted
Hospice Process Measures	B (SE)	р	B (SE)	р
(HIS)				
Age				
Working age	0.057 (0.013)	< 0.001	0.060 (0.014)	< 0.001
Age 65 years and over	0.044 (0.010)	< 0.001	0.027 (0.012)	0.019
Education				
Less than high school	0.015 (0.008)	0.078	-0.021 (0.009)	0.022
College	-0.002 (0.005)	0.697	-0.009 (0.005)	0.136
Race				
Non-Hispanic Black	-0.012 (0.002)	< 0.001	-0.021 (0.032)	< 0.001
Hispanic	-0.029 (0.003)	< 0.001	-0.016 (0.004)	< 0.001
Asian	0.019 (0.016)	0.226	0.035 (0.018)	< 0.001
Other	0.004 (0.004)	0.293	-0.002 (0.004)	0.659
Foreign-born	0.001 (0.010)	0.091	-0.015 (0.011)	0.183
Poverty Rate	0.005 (0.007)	0.484	0.031 (0.007)	< 0.001
Urban	0.037 (0.066)	0.581	-0.004 (0.074)	0.953
N = 3,119	· /		. ,	

Aim 1: County Sociodemographic Correlates of Hospice Quality

To account for differences in hospice size, the analysis again fits a separate regression model in which the outcome is a weighted average of hospice quality within each county that accounts for the size of the hospice. The underlying reason for conducting a separate, weighted analysis was due to concern that some populations may be disproportionately likely to live in counties where there are large hospices with lower scores and a number of small hospices with higher scores. Not accounting for those differences in hospice size may lead one to conclude that hospice quality is better than actually experienced by the average hospice patient (i.e., upwardly biased).

The estimates for rural and urban counties largely resemble the overall model results. Three differences are observed. First, the relationship between county composition of residents with less than a high school degree is significantly, negatively associated with hospice quality in the weighted model, and nonsignificant in the unweighted model. Next, the county share of Asian residents is significantly, positively associated with hospice quality in the weighted model but is non-significant in the unweighted model. Finally, county-level poverty rate is significantly associated with hospice quality in the weighted model but nonsignificant in the unweighted model. That these differences are not major suggests that the size of the hospice does not significantly impact the results.

Hospice Disenrollment (Live Discharge) Rates

The next set of analyses examine county-level correlates of hospice disenrollment (i.e., live discharges). The first set of variables of interest again focus on county-level age structure. Working age and age 65 years and over were both significantly and negatively associated with county-level hospice disenrollment rates (b = -0.001, SE = 0.0002, p < 0.001; b = -0.0005, SE = 0.0001, p < 0.001, respectively). For each percentage point increase in the proportion of the population that is working age, there is a corresponding 0.001-point decrease in the county-level hospice disenrollment rate. For each percentage point increase in the share of the population that is age 65 years and over, there is a 0.0005-point decrease in the county-level mean hospice disenrollment rate.

The next set of county-level variables examined in the regression model focus on countylevel educational attainment and its relationship to hospice disenrollment rate. Educational attainment was significantly and positively correlated with hospice disenrollment rates at the county-level (less than high school: b = 0.0004, SE = 0.0001, p = 0.001; college degree: b = 0.0002, SE = 0.00007, p = 0.017).

The relationships between county-level racial, ethnic, and nativity composition and county-level mean hospice disenrollment rates were also examined in the linear regression model shown in Table 17. Both non-Hispanic Black and Hispanic county-level composition were significantly, positively associated with hospice disenrollment rates at the county-level (b =

0.0008, SE = 0.00003, p < 0.001; b = 0.0003, SE = 0.0002, p < 0.001, respectively). For a onepercentage point increase in the non-Hispanic Black population, there was a 0.0008 increase in the mean county-level hospice disenrollment rate. Similarly, for each percentage point increase in the Hispanic population, there was a 0.0003 increase in the mean county-level hospice disenrollment rate.

Asian race was not significantly associated with hospice disenrollment rates (b = 0.0004, SE = 0.0002, p = 0.061). Other race was significantly, positively associated with hospice disenrollment rates (b = 0.0002, SE = 0.00005, p = 0.001). In contrast, foreign-born composition is significantly, negatively associated with county-level hospice disenrollment rates (b = -0.0003, SE = 0.0001, p = 0.039). For each percentage point increase in the share of the county population that is foreign-born, there is a 0.0003-point decrease in the hospice disenrollment rate. Similarly, poverty rate also has a significant, negative relationship with mean county-level hospice disenrollment rate (b = -0.0002, SE = 0.00008, p = 0.007). In contrast, urban county status has a significant, positive relationship with county-level mean hospice disenrollment rates (b = 0.0029, SE = 0.0008, p = 0.001). This data is shown in Table 17.

Table 17

	B (SE)	р
Age		
Working age	-0.001 (0.001)	< 0.001
Age 65 years and over	-0.001 (0.001)	< 0.001
Education		
Less than high school	0.0003 (0.008)	0.001
College	0.0002 (0.0001)	0.017
Race		
Non-Hispanic Black	-0.012 (0.002)	< 0.001
Hispanic	-0.029 (0.003)	< 0.001
Asian	0.019 (0.016)	0.226

Aim 1: County Sociodemographic Correlates of Hospice Disenrollment (Live Discharge)

Other	0.004 (0.004)	0.293
Foreign-born	0.001 (0.010)	0.091
Poverty Rate	0.005 (0.007)	0.484
Urban	0.037 (0.066)	0.581
N = 3,100		

Aim 2

Aim 2 examined whether and how county-level sociodemographic characteristics predicted availability and quality of available hospice among rural counties in order to draw comparisons between these relationships in both urban and rural counties. Data were stratified by rural/urban, and separate models were fit for rural counties and urban counties.

Rural Sociodemographic Correlates of County-Level Hospice Availability

A linear regression model examining the relationship between the availability of hospice providers (i.e., the number of providers per capita) shows the overall association between county characteristics and hospice availability when stratified by rural/urban status. The first set of correlates of interest focus on age structure.

The results of both the regression analysis examining only urban counties and the regression analysis examining only rural counties shows that a higher proportion of residents age 65 years and over was significantly, positively associated with the number of per capita hospice providers for both urban and rural counties (b = 0.264, SE = 0.072, p < .001; and b = 1.011, SE = 0.142, p < .001). Among rural counties, there was a 0.142 increase in the number of per capita hospice providers for each percentage point increase in the share of the population age 65 years and over. Among urban counties, each percentage point increase in the proportion of the population age 65 years and over was associated with a 0.264 increase in the number of hospice providers per capita. Higher proportions of working age residents were not significantly associated with the number of per capita hospice provider for both urban and rural counties (urban: b = 0.041, SE = 0.095, p = 0.666; and rural: b = -0.197, SE = 0.165, p = .232, respectively).

The next set of correlates of interest capture educational attainment. Lower educational attainment (less than high school degree) was significantly, positively associated with the number of per capita hospice providers for both urban and rural counties (urban: b = 0.331, SE =0.067, p < 0.001; and rural: b = 0.398, SE = 0.113, p < 0.001, respectively). Among rural counties, for each percentage point increase in the share of the population with less than a high school degree, there was a 0.398 increase in the number of hospice providers per capita. Similarly, in urban counties there was a 0.331 increase in the number of hospice providers per capita for each percentage point increase in the share of the population with less than a high school degree. By contrast, higher educational attainment (i.e., college degree) was marginally, significantly associated with *lower* per capita hospice provider rates among urban counties (b = -0.061, SE = 0.033, p = 0.065) and significantly associated with higher number of per capita hospice providers among rural counties (b = 0.158, SE = 0.081, p = 0.050). Among rural counties, for each percentage point increase in the share of residents with a college degree, there was a 0.158 increase in the number of hospice providers per capita. Among urban counties, there was a 0.033 decrease in the number of hospice providers per capita for each percentage point increase in the proportion of residents with a college degree, and this relationship was only marginally significant.

The next set of correlates of interest capture county-level racial, ethnic, and nativity (i.e., foreign-born) composition. A county's racial composition – specifically non-Hispanic Black – was significantly, positively associated with per capita hospice provider rate for both urban and rural counties (urban: b = 0.055, SE = 0.016, p = 0.001; and rural: b = 0.165, SE = 0.034, p < 0.001, respectively). Among rural counties, a one percentage point increase in the share of the non-Hispanic Black population was associated with a 0.165 increase in the number of hospice

providers per capita. The number increase in hospice providers per capita in urban counties is 0.055 for each percentage point increase in the proportion of the population that is non-Hispanic Black.

Similarly, Hispanic composition was significantly, positively associated with the number of hospice providers per capita for both urban and rural counties (urban: b = 0.081, SE = 0.027, p < 0.001; and rural: b = 0.241, SE = 0.044, p < 0.001, respectively). The results show a 0.081 increase in the number of hospice providers per capita for each percentage point increase in the Hispanic population among urban counties and a 0.241 increase among rural counties.

Among both urban counties, Asian racial composition was not significantly associated with per capita hospice provider rate (b = 0.057, SE = 0.086, p = 0.511); however, this relationship was marginally significant and negative among rural counties (b = -0.504, SE =0.279, p = 0.072). Among rural counties, for each percentage point increase in the proportion of Asian residents, there was a 0.505 decrease in the number of hospice providers per capita, though this association was only marginally significant. Higher composition of Other race(s) was significantly, positively associated with per capita hospice provider rate among rural counties (b = 0.128, SE = 0.047, p = 0.006) but non-significant among urban counties (b = 0.041, SE =0.050, p = 0.411). That is, for rural counties a one percentage point increase in Other race(s) was associated with a 0.128 increase in the number of hospice providers per capita whereas there was no significant relationship between Other racial composition and hospice availability.

Finally, nativity (i.e., foreign-born) composition was significantly, negatively associated with per capita hospice provider rate for urban counties (b = -0.334, SE = 0.064, p < 0.001) and non-significant in rural counties (b = -0.173, SE = 0.153, p = 0.258). Among only urban counties,

a one percentage point increase in the proportion of residents born outside of the United States was associated with a 0.334 decrease in the number of hospice providers per capita.

The final correlates of interest examined in the linear regressions focused on the relationship between county-level sociodemographic variables and hospice availability (stratified by rural-urban status) was county-level poverty rate. The overall county poverty rate was significantly, negatively associated with the number of hospice providers per county for both urban and rural counties (urban: b = -0.277, SE = 0.049, p < 0.001; and rural: b = -0.355, SE = 0.089, p < 0.001, respectively). Among rural counties, for each percentage point increase in the poverty rate there was a 0.355 decrease in the number of available hospice providers per capita. Among urban counties, there was a 0.277 decrease in the number of hospice providers per capita for each percentage point increase in the poverty rate (Table 18).

Table 18

	Urban (n=)		Rural (n=)	
Per Capita Provider	B (SE)	р	B (SE)	р
Working age	0.041 (0.095)	0.666	-0.197 (0.165)	0.232
Age 65 years and over	0.264 (0.072)	< 0.001	1.011 (0.142)	< 0.001
Education (reference HS, some college)				
Less than high school	0.331 (0.067)	< 0.001	0.398 (0.113)	< 0.001
College	-0.061 (0.033)	0.065	0.158 (0.081)	0.050
Race				
Non-Hispanic Black	0.055 (0.016)	0.001	0.165 (0.034)	< 0.001
Hispanic	0.081 (0.027)	< 0.001	0.241 (0.044)	< 0.001
Asian	0.057 (0.086)	0.511	-0.504 (0.279)	0.072
Other	0.041 (0.050)	0.411	0.128 (0.047)	0.006
Foreign-born	-0.334 (0.064)	< 0.001	-0.173 (0.153)	0.258
Poverty Rate	-0.277 (0.049)	< 0.001	-0.355 (0.089)	< 0.001

Aim 2: County Sociodemographic Correlates of Hospice Availability, Urban versus Rural

Rural Sociodemographic Correlates of County-Level Hospice Quality

Next, stratified linear regression models examining the relationship between county-level sociodemographic characteristics and hospice quality were fit for rural counties and urban counties (i.e., the data were stratified by rural and urban, and separate models were fit).

Patient Experience/Satisfaction Scores

A linear regression model shows the overall association between county-level sociodemographic characteristics and the quality of available hospice as measured by CAHPS (patient experience/satisfaction; Table 19) for urban counties and, separately, for rural counties. Most of the results are very similar in both the rural and urban models, both in their direction and, in many cases, their magnitude. County age structure is the first set of correlates of interest in these models. These models take the true average of the hospice scores within each county irrespective of the size of each hospice. Working age was significantly and negatively associated with CAHPS scores among both urban and rural counties (urban: b = -0.453, SE = 0.014, p = 0.001; rural: b = -0.044, SE = 0.017, p = 0.008, respectively). Among rural counties, there was a 0.044 decrease in the mean CAHPS score for each percentage point increase in the share of the population that is working age (i.e., ages 15-64 years). Among rural counties, there was an associated 0.453 decrease in the average CAHPS score for each percentage point increase in share of working-age residents.

Similarly, higher county composition of residents age 65 years and over was negatively associated with mean CAHPS scores for both urban and rural counties (urban: b = -0.071, SE = 0.011, p < 0.001; rural: b = -0.058, SE = 0.014, p < 0.001, respectively). Specifically, among rural counties there was a 0.058 decrease in the mean CAHPS score for each percentage point increase in the share of residents age 65 years or over. Among urban counties, there was an

associated 0.071 decrease in patient experience/satisfaction scores for each percentage point increase in the share of residents age 65 years and over.

The next set of variables of interest pertain to educational attainment and seek to understand the relationship between county-level educational attainment and its relationship with hospice quality as measured by patient experience/satisfaction (i.e., CAHPS score). Lower educational attainment (i.e., less than high school education) is significantly, positively associated with mean CAHPS scores (urban: b = 0.086, SE = 0.009, p < 0.001; and rural: b =0.086, SE = 0.011, p < 0.001, respectively). Among rural counties, the average CAHPS score increases by 0.086 for each percentage point increase in the proportion of residents with less than a high school education. For each percentage point increase in the share of the county population with a college degree, there is a 0.086 increase in the mean CAHPS score among urban counties as well. Higher educational attainment (i.e., college degree) is also significantly and positively associated with CAHPS scores among both urban and rural (urban: b = 0.019, SE = 0.005, p =0.001; and rural: b = 0.021, SE = 0.008, p = 0.011, respectively). Specifically, among rural counties there is a 0.021 increase in the mean CAHPS score for each percentage point increase in the share of the population with a college degree; similarly, there is a 0.019 increase among urban counties.

Next, the regression analyses focused on variables related to racial, ethnic, and nativity composition and their relationship to county-level hospice quality as measured by mean CAHPS scores. County racial composition is significantly associated with patient experience (satisfaction). For both urban and rural counties, a higher composition of non-Hispanic Black, Hispanic, and Other racial category is associated with lower patient experience/satisfaction (CAHPS) scores (non-Hispanic Black, urban counties: b = -0.015, SE = 0.003, p < 0.001; non-

Hispanic Black, rural counties: b = -0.134, SE = 0.003, p < 0.001; Hispanic, urban counties: b = -0.043, SE = 0.004, p < 0.001; Hispanic, rural counties: b = -0.045, SE = 0.004, p < 0.001; Other race(s), urban counties: b = -0.040, SE = 0.005, p < 0.001; Other race(s), rural counties: b = -0.038, SE = 0.005, p < 0.001).

Among rural counties, a one-percentage point increase in the share of the non-Hispanic Black population is associated with a 0.134 decrease in mean CAHPS score; in urban counties there is a 0.015 decrease in mean CAHPS score. For each percentage point increase in the share of Hispanic residents, there is a 0.045 decrease in the mean CAHPS score in rural counties. In urban counties, there is an associated 0.043 decrease in mean CAHPS scores per percentage point increase in Hispanic population. A one percentage point increase in the Other race(s) population of a rural county is associated with a 0.038 decrease in the mean CAHPS score for a percentage point increase in Other race(s) composition.

The relationship between Asian racial composition and CAHPS scores was nonsignificant in urban counties (b = 0.008, SE = 0.017, p = 0.637) and marginally significantly positive in rural counties (b = 0.048, SE = 0.031, p = 0.116). Nativity, measured as county foreign-born population composition, was significantly, negatively associated with patient experience/satisfaction (CAHPS) scores in both urban and rural county scores (urban: b = -0.083, SE = 0.011, p < 0.001; and rural: b = -0.046, SE = 0.015, p = 0.003, respectively). Among urban counties, there was a 0.083 decrease in mean CAHPS score for each percentage point increase in the share of foreign-born residents; in rural counties, there was a 0.046 decrease in mean CAHPS score. Poverty rate was significantly, positively associated with patient experience/satisfaction (CAHPS) scores among both urban and rural counties (urban: b = 0.049, SE = 0.007, p < 0.001; and rural: b = 0.037, SE = 0.009, p < 0.001, respectively). Mean patient experience/satisfaction scores increased, on average, about 0.037 for each percentage point increase in the poverty rate for rural counties; for urban counties, this increase was approximately 0.049.

Table 19

Aim 2: County Sociodemographic Correlates of Hospice Quality (patient experience), Urban versus Rural

	Urban		Rural	
Patient Experience/Satisfaction (CAHPS)	B (SE)	р	B (SE)	р
Age				
Working age	-0.453 (0.014)	0.001	-0.044 (0.017)	0.008
Age 65 years and over	-0.071 (0.011)	< 0.001	-0.058 (0.014)	< 0.001
Education (reference HS, some college)				
Less than high school	0.086 (0.009)	< 0.001	0.086 (0.011)	< 0.001
College	0.019 (0.005)	0.001	0.021 (0.008)	0.011
Race				
Non-Hispanic Black	-0.015 (0.003)	< 0.001	-0.134 (0.003)	< 0.001
Hispanic	-0.043 (0.004)	< 0.001	-0.045 (0.004)	< 0.001
Asian	0.008 (0.017)	0.637	0.048 (0.031)	0.116
Other	-0.040 (0.005)	< 0.001	-0.038 (0.005)	< 0.001
Foreign-born	-0.083 (0.011)	< 0.001	-0.046 (0.015)	0.003
Poverty Rate	0.049 (0.007)	< 0.001	0.037 (0.009)	< 0.001

The analysis again attempts to account for differences in hospice sizes by fitting another regression model in which the outcome is a weighted average of hospice quality within each county. Consistent with the overall results, the estimates for rural and urban counties are largely similar between the models using the weighted and unweighted outcome. Only two minor differences are observed. The relationship between county composition of non-Hispanic Black residents and hospice quality is non-significant in the weighted model for rural counties but significant in the unweighted model. Similarly, the share of other races in a county's population is not significantly associated with the weighted hospice quality score in urban counties but is negatively associated in the model of unweighted scores.

Hospice Process Measures (HIS)

A linear regression model shows the overall association between county-level sociodemographic characteristics and the quality of available hospice as captured by hospice process measures reported in the Hospice Item Set (HIS) for urban counties and, separately, for rural counties. The results are similar across both rural and urban counties, with some exceptions noted below. These models take the true average of the hospice scores within each county irrespective of the size of each hospice.

County age structure is the first set of correlates of interest in these models. County age structure is positively associated with hospice process measures (i.e., mean HIS scores) for both urban and rural counties (working age, urban: b = 0.065, SE = 0.022, p = 0.002; working age, rural: b = 0.049, SE = 0.016, p = 0.002; age 65 years and over, urban: b = 0.054, SE = 0.016, p = 0.001; and age 65 years and over, rural: b = 0.032, SE = 0.014, p = 0.020). For each one percentage point increase in the working age population of a county, the average HIS score increases by 0.065 (urban) and 0.049 (rural). For each one unit increase in the share of the population over 65 years old, the average HIS score increases by 0.054 (urban) and 0.032 (rural).

The next variables of interest pertain to education. Lower educational attainment is not significantly associated with mean HIS scores for both rural and urban counties (less than high school among urban counties: b = 0.019, SE = 0.015, p = 0.201; less than high school among rural counties: b = 0.016, SE = 0.011, p = 0.136, respectively). Similarly, higher educational attainment is not significantly associated with mean HIS scores (college degree among urban counties: b = 0.003, SE = 0.007, p = 0.668; college degree among rural: b = -0.005, SE = 0.008, p = 0.496, respectively).

Race and ethnicity are the next variables of interest explored in the regression models shown in Table 20. County racial composition is significantly associated with patient experience (satisfaction). For both urban and rural counties, higher composition of non-Hispanic Black and Hispanic is associated with lower mean HIS scores (non-Hispanic Black, urban counties: b = -0.020, SE = 0.014, p < 0.001; non-Hispanic Black, rural counties: b = -0.008, SE = 0.003, p = 0.014; Hispanic, urban counties: b = -0.037, SE = 0.006, p < 0.001; Hispanic, rural counties: b = -0.024, SE = 0.003, p < 0.001). The relationship between other racial composition and mean HIS score was marginally negatively significant among urban counties and marginally positively significant among rural counties (urban: b = -0.013, SE = 0.001, p = 0.245; rural: b = 0.007, SE = 0.005, p = 0.141). The relationship between Asian racial composition and mean HIS scores was non-significant in both urban and rural counties (urban: b = -0.001, SE = 0.019, p = 0.953; rural: b = 0.028, SE = 0.030, p = 0.342). Foreign born composition was marginally, significantly associated with higher mean HIS scores in rural counties (urban: b = 0.024, SE = 0.014, p = 0.024, SE = 0.014, p = 0.023, SE = 0.015, p = 0.120).

Poverty rate was marginally, significantly associated with higher mean HIS scores in urban counties (b = 0.026, SE = 0.011, p = 0.011). In rural counties, the relationship between poverty rate and mean HIS score was non-significant (b = -0.008, SE = 0.009, p = 0.334).

Table 20

	Urban (N= 1,165)		Rural (N= 1,954)	
Hospice Process Measures (HIS)	B (SE)	р	B (SE)	р
Age				
Working age	0.065 (0.022)	0.002	0.049 (0.016)	0.002
Age 65 years and over	0.054 (0.016)	0.001	0.032 (0.014)	0.020
Education (reference HS, some college)				
Less than high school	0.019 (0.015)	0.201	0.016 (0.011)	0.136
College	0.003 (0.007)	0.668	-0.005 (0.008)	0.496
Race				
Non-Hispanic Black	-0.020 (0.014)	< 0.001	-0.008 (0.003)	0.014

Aim 2: County Sociodemographic Correlates of Hospice Quality (hospice process measures), Urban versus Rural

	Urban (N= 1,165)		Rural (N= 1,954)	
Hospice Process Measures (HIS)	B (SE)	р	B (SE)	р
Age				
Hispanic	-0.037 (0.006)	< 0.001	-0.024 (0.003)	< 0.001
Asian	-0.001 (0.019)	0.953	0.028 (0.030)	0.342
Other	-0.013 (0.011)	0.245	0.007 (0.005)	0.141
Foreign-born	0.024 (0.014)	0.092	-0.023 (0.015)	0.120
Poverty Rate	0.026 (0.011)	0.018	-0.008 (0.009)	0.334

To avoid giving undue weight to smaller hospices, the analysis again attempts to account for differences in hospice sizes by fitting another regression model in which the outcome is a weighted average of hospice quality within each county. Much like the overall results, the estimates for rural and urban counties are largely similar between the models using the weighted and unweighted outcome. Three minor differences are observed. First, the relationship between county composition of residents aged 65 years and over and hospice quality is non-significant in the weighted model for rural counties, but significant in the unweighted model. Second, the share of foreign-born residents in a county's population is significantly, negatively associated with the weighted hospice quality score in rural counties, but this relationship is nonsignificant in the model of unweighted scores. Third, both age variables (working age and age 65 years and over) are nonsignificant in the weighted model for urban counties, but significant in the unweighted model.

Aim 3

Aim 3 examined whether and how individual-level sociodemographic characteristics were associated with the quality of hospice an individual received. First, an overall regression model was fit for all beneficiaries receiving hospice. Next, the data were stratified by rural/urban, and separate models were fit for individuals residing in rural/urban counties for comparison of similarities and differences in relationships.

Beneficiary Sociodemographic Correlates of Quality of Hospice Received (Patient Experience-CAHPS)

A linear regression model examining the relationship between the quality of the hospice from which an individual received care and individual-level sociodemographic characteristics shows the overall association between individual sociodemographic characteristics and quality of hospice received (Table 21). The first correlates of interest are age. The results show that older beneficiary age was associated with receiving hospice care from a hospice with significantly poorer patient experience/satisfaction scores (b = -0.017, SE = 0.0004, p < .001). Each one unit increase in the age of a hospice beneficiary was associated with an approximately 0.017 decrease in the patient experience/satisfaction score. The next variable of interest is sex. The results show that female sex is associated with a lower patient experience/satisfaction score (b = -0.041, SE =0.008, p < .001). More specifically, female sex of beneficiaries is associated with receiving care from a hospice with a 0.041-point lower CAHPS score than male sex of beneficiaries.

The next variables of interest focus on the effect of racial and ethnic background on patient experience/satisfaction CAHPS scores. The results show that beneficiaries of racial or ethnic minority groups received care from hospices with lower patient experience/satisfaction scores relative to white beneficiaries (non-Hispanic Black: b = -0.933, SE = 0.014, p < 0.001; Hispanic: b = -3.176, SE = 0.028, p < 0.001; Asian: b = -2.387, SE = 0.035, p < 0.001; North American Native: b = -0.181, SE = 0.065, p = 0.005; Other: b = -1.848, SE = 0.037, p < 0.001). On average, non-Hispanic Black beneficiaries received care from a hospice with 0.933 point lower patient satisfaction/experience scores relative to non-Hispanic white beneficiaries.

Similarly, Hispanic beneficiaries on average received care from a hospice with a 3.716point lower patient experience/satisfaction CAHPS score than white beneficiaries. For Asian beneficiaries, the average patient satisfaction/experience score was 2.387 points lower than white beneficiaries, while for Other racial/ethnic groups the average CAHPS score was approximately 1.848 points lower than for white beneficiaries. North American Native beneficiaries on average received care from hospices with a 0.181-point lower patient experience/satisfaction score than white beneficiaries. The next variable of interest included in the overall model was urban/rural status. Hospice beneficiary residence in an urban county was associated with receiving care from a hospice with a lower patient experience/satisfaction CAHPS score, on average (b = -2.521, SE = 0.001, p < 0.001).

Table 21

Aim 3: Beneficiary Demographic Correlates of CAHPS Scores, All Counties

CAHPS scores	B (SE)	р
Age	-0.017 (0.0004)	< 0.001
Sex	-0.041	< 0.001
Race		
Non-Hispanic Black	-0.933 (0.014)	< 0.001
Hispanic	-3.176 (0.028)	< 0.001
Asian	-2.387 (0.035)	< 0.001
North American Native	-0.181 (0.065)	0.005
Other	-1.848 (0.037)	< 0.001
Urban	-2.521 (0.010)	< 0.001
N = 1,264,344	- -	

Correlates of patient experience/satisfaction CAHPS scores were also examined by beneficiary rural/urban status. Among rural beneficiaries, non-Hispanic Black race was *positively* associated with patient experience/satisfaction CAHPS score (b = 0.400, SE = 0.037, p < 0.001). Interestingly, this relationship was *negative* among urban populations (b = -1.113, SE = 0.068, p < 0.001). That is, the average CAHPS score of the hospice from which *rural* non-Hispanic Black hospice beneficiaries received care was 0.400 points *higher* relative to white hospice beneficiaries. In *urban* counties, the average CAHPS score of the hospice from which *urban* non-Hispanic Black hospice beneficiaries received care was 1.113 points *lower* relative to white hospice beneficiaries.

The direction of the relationship between Hispanic, Asian, North American Native, and Other racial/ethnic minority groups was not different between rural and urban hospice
beneficiaries. However, there was no significant relationship between urban North American

Native race and average score of the hospice, and between rural Asian race and average score of

the hospice (Table 22).

Table 22

	Urban (N = 1,051,717)		Rural (N = 212,627)	
CAHPS	B (SE)	р	B (SE)	р
Age	-0.019	< 0.001	-0.012 (0.001)	< 0.001
	(0.0004)			
Sex	-0.038 (0.008)	< 0.001	-0.057 (0.017)	0.001
Race				
Non-Hispanic Black	-1.113 (0.068)	< 0.001	0.400 (0.037)	< 0.001
Hispanic	-3.260 (0.029)	< 0.001	-1.837 (0.113)	< 0.001
Asian	-2.490 (0.036)	< 0.001	-0.043 (0.166)	0.795
North American Native	0.104 (0.086)	0.225	-0.520 (0.093)	< 0.001
Other	-1.991 (0.039)	< 0.001	-0.255 (0.038)	0.038

Aim 3: Beneficiary Demographic Correlates of CAHPS Scores, Urban versus Rural Counties

Hospice Process Measures (HIS)

The next set of models examines the relationship between beneficiary sociodemographic characteristics and the average hospice quality score from which they received hospice as measured by the Hospice Item Set (HIS). The HIS measures the frequency by which hospices perform essential processes necessary for quality hospice care, such as assessing and treating pain, breathing difficulties, and other end-of-life needs.

The results of the first regression model, which examines all hospice beneficiaries, show that age, sex, race, and urban residency are significantly associated with the average HIS score of the hospice from which the beneficiary received care. More specifically, a one-year increase in a hospice beneficiary's age is associated with a 0.003 decrease in the average HIS score of the hospice from which the beneficiary received care (b = -0.003, SE = 0.0004, p < 0.001). Female sex of the hospice beneficiary was associated with a -0.041-point lower HIS score (b = -0.041; SE = 0.007, p < 0.001). The next set of sociodemographic characteristics in Table 23 focus on racial and ethnic characteristics and their relationship to the quality of hospice from which a beneficiary receives care. Non-Hispanic Black race of the hospice beneficiary was associated with receiving care from a hospice with a 0.330-point lower HIS score (b = -0.330, SE = 0.014, p < 0.001), while Hispanic ethnicity was associated with receiving care from a hospice with a 0.685-point lower HIS score (b = -0.685, SE = 0.025, p < 0.001). Asian race was marginally, negatively associated with the average HIS score of the hospice from which care was received (b = -0.056, SE = 0.030, p = 0.071), while Other race/ethnicity was not significantly associated with the HIS score of the hospice from which care was received (b = -0.288). North American Native race was associated with a 0.429-point lower HIS score of the hospice from which care was received (b = -0.429 SE = 0.059, p < 0.001).

Finally, urban residency had a significant, negative relationship with the average HIS score from which a hospice beneficiary received care (b = -0.190, SE = 0.009, p < 0.001). That is, on average, hospice beneficiaries residing in urban counties received care from a hospice with a 0.190-point lower HIS score.

Table 23

Per Capita Providers	B (SE)	р	
Age	-0.003 (0.0004)	< 0.001	
Sex	-0.041 (0.007)	< 0.001	
Race			
Non-Hispanic Black	-0.330 (0.013)	< 0.001	
Hispanic	-0.685 (0.025)	< 0.001	
Asian	-0.056 (0.030)	0.071	
North American Native	-0.429 (0.059)	< 0.001	
Other	0.040 (0.033)	0.228	
Urban	-0.190 (0.009)	< 0.001	
N 1 211 000			

Aim 3: Beneficiary Demographic Correlates of HIS Scores, All Counties

N = 1,311,800

Next, separate regression models were fit for urban hospice beneficiaries and rural

hospice beneficiaries to compare and examine potential differences in relationships between

sociodemographic characteristics and quality of hospice received. The results, displayed in Table 24, show that age is a significant correlate of average HIS score from which the beneficiary received care (urban: b = -0.190, SE = 0.009, p < 0.001; rural: b = -0.003, SE = 0.0004, p < 0.001). Among urban hospice beneficiaries, for each one-year increase in age of the hospice beneficiary, there is an associated 0.019 decrease in the HIS score of the hospice from which care was received. Among rural hospice beneficiaries, there is a 0.003-point decrease in the HIS score for each 1-year increase in age.

Sex is a significant correlate of a hospice's average HIS score from which care was received for urban hospice beneficiaries. However, this relationship was not significant for rural hospice beneficiaries (urban: b = -0.044, SE = 0.008, p < 0.001; rural: b = -0.024, SE = 0.016, p = 0.144). The results suggest that for urban hospice beneficiaries, female sex is associated with a 0.044 decrease in the average HIS score of the hospice from which care was received.

The next set of variables focus on the relationship between race and ethnicity on hospice HIS score, stratified by rural and urban status. Non-Hispanic black hospice beneficiaries residing in urban counties received, on average, care from a hospice with a 0.394-point lower HIS score relative to white hospice beneficiaries residing in urban counties (b = -0.394, SE = 0.014, p < 0.001). Meanwhile, non-Hispanic Black hospice beneficiaries residing in rural counties received care from hospices with an average HIS score that was 0.145 points *higher* than white hospice beneficiaries residing in rural counties (b = 0.145, SE = 0.035, p < 0.001).

The relationship between Hispanic ethnicity and average HIS score of the hospice from which care was received was significant and negative for both urban and rural hospice beneficiaries (urban: b = -0.651, SE = 0.026, p < 0.001; rural: b = -1.357, SE = 0.103, p < 0.001). More specifically, Hispanic ethnicity of a hospice beneficiary was associated with an average

HIS score that was 0.651 points lower for urban Hispanic residents and 1.357 points lower for rural Hispanic residents.

The relationship between Asian race and average HIS score was significant for Asian hospice beneficiaries residing in rural counties, but not urban (rural: b = -0.702, SE = 0.159, p < 0.001; urban: b = -0.036, SE = 0.031, p = 0.251). Thus, among Asian hospice beneficiaries residing in rural counties, Asian race is associated with receiving hospice care from a hospice with a 0.702-point lower HIS score, but this association is non-significant for Asian hospice beneficiaries residing in urban counties. North American Native race was associated with lower HIS scores for both rural and urban hospice 101beneficiaries (rural: b = -0.500, SE = 0.103, p < 0.001; urban: b = -0.375, SE = 0.078, p < 0.001). Other race/ethnicity was also associated with lower HIS scores for rural hospice beneficiaries; however, this relationship was non-significant among urban hospice beneficiaries (rural: b = -0.548, SE = 0.118, p < 0.001; urban: b = 0.084, SE = 0.035, p = 0.016).

Table 24

Aim 3	: Beneficiary	Demographic	Correlates	of HIS Scores,	Urban versus	Rural Counties

	Urban (N = 1,090,924)		Rural (N = 221,506)	
HIS	B (SE)	р	B (SE)	р
Age	-0.019	< 0.001	-0.003 (0.0004)	< 0.001
	(0.0004)			
Sex	-0.044 (0.008)	< 0.001	-0.024 (0.016)	0.144
Race				
Non-Hispanic Black	-0.394 (0.014)	< 0.001	0.145 (0.035)	< 0.001
Hispanic	-0.651 (0.026)	< 0.001	-1.357 (0.103)	< 0.001
Asian	-0.036 (0.031)	0.251	-0.702 (0.159)	< 0.001
North American Native	-0.375 (0.078)	< 0.001	-0.500 (0.103)	< 0.001
Other	0.084 (0.035)	0.016	-0.548 (0.118)	< 0.001

Chapter 5: Discussion of Study Findings and Implications

Introduction

This study examined county-level and individual-level correlates of hospice care availability and quality to better understand end-of-life health disparities among older adults. The study used data from the HQRP, which included measures of service quality and geographic information for hospice service areas. It then combined these data from HQRP with county-level data from the USCB. Linking these various geo-identified datasets allowed for an analysis of the geographic distribution of hospice quality and the identification of county-level correlates of hospice availability and the quality of available hospice. Combining hospice quality data with individual-level beneficiary data allowed for an additional analysis that examined individuallevel sociodemographic correlates of the quality of the hospice from which an individual received care.

The HQRP consists of two validated, comprehensive measures of hospice quality: the Consumer Assessment of Healthcare Providers and Systems Hospice Survey (CAHPS) and the Hospice Item Set (HIS; Zheng et al., 2018). The HQRP, like other CMS quality monitoring and reporting programs (e.g., CMS's hospital and nursing home quality oversight programs), serves as a means for identifying deficiencies in hospice quality that would affect CMS reimbursement (MedPAC, 2019). As such, the HQRP provided a unique opportunity for examining geographic (county-level) disparities in hospice availability and quality. Studying these disparities is important since there has been little empirical research in this area to date.

Both CAHPS and HIS were used in this study to examine geographic and sociodemographic differences in the quality of hospice care available to older adults among all U.S. counties (Aim 1) and among rural U.S. counties, with comparisons to urban counties (Aim 2). Additionally, both measures were then used to examine whether the quality of the hospice care received is related to the individual's sociodemographic characteristics (Aim 3). Together, addressing these aims provided new information about spatial and social disparities in hospice availability and quality.

A series of linear regression models were used to identify relationships between countylevel and individual-level sociodemographic characteristics and availability and quality of hospice care for each of the three aims. This chapter first discusses the results of the study by each study aim, and then highlights associated limitations. The chapter concludes by discussing potential clinical implications and areas of future research.

Results by Aim

Aim 1: Sociodemographic Correlates of Hospice Availability

Aim 1 used linear regression to first explore relationships between county-level sociodemographic characteristics (e.g., the county-level age structure, racial/ethnic composition, poverty rate) and county-level hospice availability. Statistically significant relationships between many of these characteristics and hospice level availability and the quality of available hospice were found. Counties with older age structures, lower educational attainment, and increased racial/ethnic diversity (i.e., higher proportions of non-Hispanic Black and Hispanic residents) had higher levels of hospice availability per capita than other counties, all else being equal. In contrast, counties with a greater share of foreign-born residents, higher poverty rates, and those classified as urban had lower average levels of hospice availability. Counties with higher shares of foreign-born residents having less hospice may reflect differences in Medicare enrollment from the U.S.-born older adult population.

While these statistically significant associations were found between county-level characteristics and hospice availability, the findings do not lend themselves to straightforward interpretation, as some of the results appear potentially contradictory. Because hospice is a specialized healthcare model that serves a unique and small share of the overall population, there are likely unique sub-population-level indicators that drive hospices' location and target population. Many of these factors may be masked by the county-level population characteristics used in the analyses. For instance, this study found that a higher proportion of older adults within a county is associated with a higher per capita hospice provider count relative to those counties with higher proportions of residents ages 15 years and younger. However, a higher share of working-age adults is associated with a lower hospice provider count relative to counties with a higher share of residents ages 15 years and younger. This observed pattern makes it difficult to simply state that older populations have more hospice availability, and instead suggests that counties with very young, moderate, and older populations face different circumstances in terms of hospice availability.

Continuing with this example, one potential reason for this conflicting finding is that these broad age structure categories may mask more nuanced aspects of county age composition that would influence a hospice's decision to locate itself within a given area. For instance, a given set of counties may have a large percentage of residents that are age 65 years and above, but there can be a high degree of variability in the actual age structures. Some of those counties may have a higher share of the oldest-old (ages 80 years and above) while others may have a higher share of adults closer to age 65 years.

The same dynamic may influence the interpretation of the association between the percentage of the population in working ages and hospice availability, and perhaps even more so

since the range of this age group is so large (25-64 years). These measurement issues may be masking a straightforward relationship between county age composition and hospice availability. Of course, these estimates may also be influenced by confounding variables that are not included in the models. For example, there are geographic differences in enrollment in Medicare Advantage (MA) participation versus traditional Medicare participation (referred to as MA penetration at the county level). Enrollment in MA versus traditional Medicare appears to significantly impact the health service use of older adults (Ankuda et al., 2023; Meyers & Johnston, 2021; Meyers et al., 2018; Park et al., 2022).

County-level educational attainment was also related to hospice provider availability in an unexpected way. More specifically, the counties with a higher share of residents with less than a high school education and those with a higher proportion of residents with a college degree or higher had more hospice availability relative to counties with average educational attainment (i.e., high school degree and/or some college). Typically, lower educational attainment is associated with less healthcare access and higher educational attainment associated with more healthcare access, making this finding difficult to interpret (Litaker et al., 2005). There may be some aspect of uncaptured age structure complicating or confounding these results. For example, the oldest old (those age 80 years and above) are more likely to have lower levels of education (Voss et al., 2022), and so the educational coefficient may be capturing some uncontrolled-for aspects of age structure (as suggested in the example above). Perhaps even more importantly, these findings may reflect geographic differences in educational attainment and hospice care, such as if there are many hospices in regions with low educational attainment. If the placement of hospices in these areas is driven by policy or other factors not associated with education, the observed relationship may be spurious.

These cases exemplify the challenges of using county-level sociodemographic characteristics to examine a specialty healthcare service such as hospice care. In addition to the general challenges associated with ecological analyses, models with county-level population characteristics may not be sensitive enough to the specific population that hospices cater to, which are often fairly narrow sub-populations within a location (e.g., a county's older-age and high-morbidity populations).

The findings of this study support the relationships posited in both the sociodemographic model and the NIMDH health disparities framework in that the relationships between individuals, their environment, and their patterns of healthcare use are all relevant for identifying and understanding health and healthcare disparities. At the same time, these models provide a broad/non-specific list of the structural, environmental, and individual/family factors that can influence disparities and healthcare use. The findings of this study suggest that these models fall short when examining specific healthcare disparities within a unique subpopulation of older adults using a specialty healthcare service such as hospice.

This study also raises questions about the unexpected finding of more hospice availability in counties with higher racial and ethnic diversity alongside less hospice availability in urban counties. This finding is potentially surprising because urban counties tend to be more racially and ethnically diverse than rural counties (there is evidence that this trend in rural county racial diversity is changing; Lichter, 2012). The implication is that other aspects of urbanicity (net of racial and ethnic composition) are associated with lower hospice availability per capita.

Less hospice availability was also observed among counties with a higher share of foreign-born residents. This finding is consistent with evidence that the foreign-born population suffers from multiple barriers to healthcare access, and hospice availability may be yet another example of this. For example, if healthcare insurance and utilization is lower among the foreign born, hospices may be less likely to establish themselves in areas with large concentrations of this population. On the other hand, this finding could also relate to aspects of the age composition of a county that are unaccounted for in the broad age groups used in the model, as counties with higher proportions of foreign-born residents may skew toward being younger or older (Lichter, 2012).

While these findings are not all straightforward to interpret, they do underscore the notion that hospice represents a unique healthcare market that is increasingly made up of for-profit institutions that may operate differently than other types of healthcare markets (Aldridge et al., 2021). For example, Aldridge and colleagues (2021) found a broad and rapid shift in the hospice industry in which the entire hospice sector shifted from a majority nonprofit sector to a sector in which nearly two-thirds of all hospice agencies are for-profit, publicly-traded companies over a 30-year period. As such, decisions about where to locate and provide hospice care may be made differently than in other types of healthcare industries, potentially to the disadvantage of marginalized populations.

Other potential confounders may be related to variation in health status of county sociodemographic groups. For example, lower educational attainment is often associated with poorer health and the extent to which health is correlated with hospice availability is unknown. While poorer health may lead to differences in hospice use (e.g., enrolling earlier and/or for longer periods of time) and availability, other indicators that would traditionally also be associated with poorer health showed different relationships with hospice availability. One such indicator is poverty status, which was found to have a negative association with hospice availability markets

in southern, rural, majority-Black areas (Dolin et al., 2017). There may, therefore, be some regional effects unaccounted for in the present study. Understanding the factors that drive decisions about which populations to serve within the unique hospice care industry may help with subsequent examinations of disparities in hospice care availability and utilization. As the present study has demonstrated, the traditional county-level sociodemographic indicators used in geographic analyses of health disparities may be inadequate for identifying groups with less hospice care access.

Aim 1: Sociodemographic Correlates of Hospice Quality

Aim 1 then used linear regression to examine the relationship between county-level sociodemographic characteristics and quality of available hospice, with the underlying hypothesis being that lower socioeconomic status indicators at the county level would be associated with the quality of hospice care available within the county. The findings about the association between county-level age structure and hospice quality demonstrated lower CAHPS (patient experience) scores for counties with both higher shares of older residents and working age residents relative to younger residents. However, the opposite was true when hospice quality was measured using the HIS score. In this case, quality scores were actually higher in counties with greater proportions of older and working age populations when quality was measured using HIS (process measure scores).

Different relationships were also observed between the two measures with respect to county-level urban/rural status. Urban county status was associated with lower CAHPS scores but there was no significant relationship between urban status and HIS scores. This finding may relate to hospice-level differences that affect quality scores and are not accounted for in the present study's analysis. For example, a recent study by Anhang Price and colleagues (2021)

found that there are differences in the types of hospices that score in the top quantile for CAHPS versus HIS. More specifically, this study found that smaller hospices and those serving rural areas tended to receive higher CAHPS scores but not higher HIS scores (Anhang Price et al., 2021). Additionally, the setting in which hospice care is received (e.g., at home, in a nursing home, in an assisted living facility, etc.) is associated with the quality of care measured using the CAHPS Hospice Survey (Parast et al., 2021). The types of hospices available differ between rural and urban counties, which may therefore help explain the results of this analysis. Importantly, this study was not able to measure the setting in which hospice was received (at the county level), highlighting the need to measure available hospice type in subsequent research.

The findings of Anhang Price and colleagues (2021) about different types of hospices scoring better on CAHPS versus HIS quality scores, along with the differences noted between the two measures in this study, may also raise the question of whether the HQRP is measuring what is actually important to patients and families. That is, a disconnect between quality measures when measured as care processes, patient satisfaction, and observed differences by setting may suggest that care processes are not perceived as important by the family when they report their care satisfaction. This may also suggest that the structure and ways in which care processes are carried out influence patient satisfaction in ways that are not fully captured by the current measures.

Indeed, there are likely hospice-level characteristics that are not fully captured in the current study and make the interpretation of the resulting relationship between county-level characteristics and quality of available hospice difficult to interpret. Interestingly, however, the relationship between county-level racial and ethnic diversity was consistent across both the CAHPS and HIS measures of quality. That is, counties with higher racial and ethnic diversity are

associated with lower average hospice quality scores when quality is measured using both CAHPS and HIS. There is evidence of lower quality hospice care being provided to Black and Hispanic patients in prior research as well. More specifically, prior research has found that Black and Hispanic patients were less likely to be visited by hospice staff in the last two days of life (Teno et al., 2016) and had higher rates of being discharged prior to death (Canavan et al., 2013; Cherlin et al., 2010; Gandhi, 2012; Prsic et al., 2016; Russell et al., 2017; Stevenson et al., 2016; Teno et al., 2014; Teno et al., 2016). Additionally, a higher share of Black hospice recipients receive care from for-profit hospices (Stevenson et al., 2016), which on average have fewer clinical services available and fewer skilled staff providing care.

Differences in when and how patients are referred to hospice may also impact the quality of hospice care received, particularly when measured by patient experience (CAHPS). Evidence suggests that the setting from which a patient is referred to hospice affects where they receive hospice care and subsequently the quality of the hospice they receive (Parast et al., 2021). Older patients are more often referred to hospice from a nursing home or assisted living facility and subsequently more likely to receive hospice care in these settings. Hospice quality scores (measured by CAHPS) are on average lower in nursing home and assisted living facility settings (Parast et al., 2021).

Aim 2: Sociodemographic Correlates of Hospice Availability Among Rural Counties

Using the NIMHD's health disparities framework, this study hypothesized that sociodemographic characteristics at the geographic (county) level would be correlated to the overall availability of hospice as well as the quality of available hospice, and that, given differences in rural healthcare services and rural population demographics, these relationships would look different for rural counties. In contrast to these expectations, many of the countylevel sociodemographic correlates of hospice availability were very similar across both rural and urban counties. Higher proportions of residents aged 65 years and older correlated with increased hospice availability for both rural and urban counties, and having a higher share of residents with less than a high school degree was also correlated with higher hospice availability for both rural and urban counties. Additionally, higher racial and ethnic diversity is associated with more hospice availability and poverty rate is associated with less hospice availability for both rural and urban counties. Some of these unexpected findings raise similar questions about the influence of confounding variables in the models as in Aim 1 (e.g., is the positive relationship between low education and hospice availability observed in the present study due to some unaccounted-for effect of age composition, regional differences in demographics and hospice, or other such factors?). While results that are contrary to expectations and prior evidence are not necessarily incorrect, they raise important questions for future research. It may be that there are differences in rural and urban county hospice availability, but the relative contributions of county-level sociodemographic characteristics to hospice availability is similar in both rural and urban counties.

County-Level Correlates of Hospice Quality in Rural versus Urban Counties

As in Aim 1, Aim 2 of this study used linear regression models to examine the countylevel correlates of available hospice quality using two different measures of quality. However, Aim 2 stratified counties by rural and urban status for comparisons of similarities and differences of observed relationships. Again, similar patterns were observed across rural and urban counties, with lower CAHPS (patient experience) quality scores for counties with higher shares of older residents and, in contrast, higher HIS quality scores. Stated another way, the average quality of available hospice was lower among counties with a larger share of residents aged 65 years and over when measured by the CAHPS Hospice Survey, whereas the average quality score of available hospice was higher among counties with more older adults when measured using the HIS. Further, this pattern was consistent across both rural and urban counties.

As discussed earlier, this may reflect known differences in hospice characteristics that are correlated with better hospice performance on the HIS versus CAHPS (Anhang Price et al., 2020). Such studies do not aggregate available hospices to a county-level to look for geographic disparities in the quality of available hospice, but rather, focus on hospice-level characteristics and their correlation with performance on the CAHPS and HIS quality reports. The findings of lower average hospice quality for older adults when measured by the CAHPS hospice survey – but not the HIS – warrant further investigation, particularly given that the findings by Anhang Price and colleagues (2020) show that higher performance on the HIS is correlated with hospices that are for-profit, part of a chain, and have a lower proportion of nursing home residents. Rural counties and counties with higher proportions of non-Hispanic, Black residents are more likely to be serviced by such hospices (Stevenson et al., 2016), which may disproportionately impact specific sociodemographic groups such as older adults. The present study also found little variation in the HIS scores relative to the CAHPS scores. A potential implication of this is that CAHPS may be more sensitive to actual variation in hospice quality, given that the majority of hospices score nearly perfectly on the self-reported HIS measures (Anhang Price et al., 2020; Zheng et al., 2018). This may also warrant future research into hospice care processes oversight.

Aim 3: Individual-Level Correlates of Hospice Quality

Finally, this study explored the relationship between an individual's sociodemographic characteristics (e.g., sex, age, race/ethnicity, rural/urban residency) and the quality score of the hospice from which they received care. Using the NIMHD's health disparities framework, this

study hypothesized that sociodemographic characteristics at both the geographic (county) level and the individual level would be related to the quality of available hospice and the quality of hospice care received. By linking the hospice's quality scores to individual-level CMS hospice beneficiary information, this study was able to examine how individual-level sociodemographic characteristics may be related to the quality of the hospice from which the individual received care.

First, sex is associated with hospice quality. Though the coefficient size is small, there was a significant, negative relationship between female sex and quality of the hospice from which care was received. Prior studies have shown that women are more likely to be widowed and be in a nursing home or assisted living setting prior to death (Furuno et al., 2020). These differences in caregiver types and setting of hospice care may potentially result in sex-based disparities in hospice care quality and warrant further investigation. These potential sex-based disparities are important to investigate because they may indicate that older, widowed adults have higher care needs at the end of life that are not being met by hospice.

Second, increased age was associated with receiving care from a hospice with a lower quality score. Like the observed relationship between sex and hospice quality, this finding may again be related to the setting in which care is received. Older patients may be more likely to be in a nursing home or assisted living setting, which may in turn be correlated with receipt of lower-quality hospice care (Zheng et al., 2018). However, there may also be a higher degree of symptom burden for older adults. Such burdens can make it more difficult to control or manage end-of-life symptoms. This finding, in particular, supports the Donabedian framework, which posits that the setting in which care is received is also an important construct within the quality concept. The results also show racial and ethnic disparities in individuals' hospice quality.

Cultural differences in dying and end of life are well-documented in the literature (Johnson et al., 2008; Bullock, 2011). The racial and ethnic differences found in the average hospice quality score of the hospice from which an individual received care may reflect some of these differences. That is, the hospice care model may not align with specific cultural aspects for some racial and ethnic minority groups. Additionally, there may be within-group differences in which individuals within a racial/ethnic minority group elect to use hospice. Stated another way, if the broader cultural trend for a racial/ethnic minority group is to not use hospice care, there may be uncaptured differences among those within the group that do elect to use hospice.

Study Strengths

This study has several notable strengths. First, its population-level approach is a unique strength made possible by the near-universal enrollment in Medicare among the U.S. older adult population. More specifically, this population-level approach increases the likelihood that the "sample" included in the analyses of individual-level data are representative of the U.S. older adult population. This is particularly important given an aging population and declining health across the U.S. Further, many of these patterns of health decline are socially uneven and any insight into the potential drivers of these uneven health patterns can help to identify causes that may be potentially rectified by future policy.

Similarly, the spatial (county) analyses allowed for a more granular approach to understanding spatial and sociodemographic correlates of hospice care availability and quality than would be possible in a regional- or state-level analysis. Drawing attention to social and spatial disparities in hospice availability and quality is unique to this study and helps to fill a gap in the current literature examining hospice care disparities. The combination of both county- and individual-level data is another unique strength of this study.

The multidimensional exploration of quality using different quality indicators as outcome measures is another unique strength of this study. The HIS and CAHPS hospice survey went through a rigorous development process and underwent validity and reliability testing prior to launching. An additional strength of this study is exploring hospice disenrollment rates as an outcome of interest that may relate to individual- and county-level characteristics. As prior research has suggested, hospice disenrollment rates are a hospice-level outcome that reflects complex individual-, hospice-, and regional-level variation (Dolin et al., 2017) but nevertheless can add further insight into our overall understanding of end-of-life healthcare disparities.

Study Limitations

While this study has contributed new knowledge to the field of end-of-life health disparities, it has several limitations. The overall goals of this dissertation are descriptive: to document geographic and social disparities in hospice availability and quality. The analyses achieve this goal, but they should not be used to make stronger claims about factors that have a causal effect on hospice availability and use.

Additionally, the geographic data used to generate the measures of mean hospice care availability and hospice quality used in the analyses are themselves imperfect. For example, the data reported by hospices on the location of care are reported as any and all ZIP code(s) serviced by a hospice in a given year. ZIP codes were developed for the purpose of postal delivery services (e.g., to develop efficient delivery routes). In addition to physical location, these codes can include P.O. boxes, large volume mail customers, and similar entities. To be used for spatial/geographic analyses, ZIP codes must be converted to a similar, spatial unit known as a ZIP code tabulation area (ZCTA). ZIP codes and ZCTAs do not always align perfectly, which introduces some measurement error (USCB, 2022).

Additionally, both ZIP codes and ZCTAs can cross county borders (i.e., the same ZIP code can be in two different counties), which complicates the conversion from a ZCTA- to a county-level dataset. In this study, a hospice provider was counted as servicing a county if any part of the ZCTA fell within the county boundary. It is important to note that there is the potential for a hospice provider to only provide services to a portion of a ZCTA or a county. In summary, the measures of hospice availability and quality are limited by how the Hospice Quality Reporting Program produces data on hospice service areas and by the challenges of using ZIP-code-level data for county-level analyses. A third limitation of this study is that Aim 1 and Aim 2 are addressed using cross-sectional, county-level data which are used to fit a series of linear regression models. These regression models include the variables of interest but are not without limitations. For instance, the limitations of ecological studies must be considered when interpreting results because data for Aim 1 and Aim 2 are aggregated to the county-level. That is, these results represent county-level averages. Further, some variables, such as county age composition, could be measured with more precision. Finally, some control variables, including geographic region and state-level policy variation, were not included. Aim 3 also has several important limitations in addition to several of the limitations noted for Aims 1 and 2 (e.g., county-level analyses are not representative of the hospice patient population). First, while this aim uses individual-level data, the linked hospice quality score is at the hospice-level and is not the quality of care being reported by the individual. This again represents an ecological issue, where the average hospice care quality score for the entire hospice may not be representative of the actual care quality for that individual beneficiary.

Nevertheless, the findings can provide preliminary, valuable insight into systematic care quality disparity patterns that can be more comprehensively addressed in subsequent studies. Additionally, not all relevant variables were able to be observed. The socioeconomic status variable of interest – dual Medicaid and Medicare eligibility status – was not available in the beneficiary-level data as expected. Further, factors that are known to influence hospice care quality such as the care setting in which the beneficiary received care, or the type of caregiver involved in the hospice care, were not available. Making claims about socioeconomic disparities is always difficult, especially from cross-sectional data. For example, it may be difficult to prove that racial disparities actually reflect racial discrimination, and this limitation is compounded by the use of hospice-level average quality scores linked to beneficiary-level data. As stated earlier, these results are descriptive, exploratory, and provide a baseline for future studies to build from.

Clinical Significance and Research Implications

This study, while exploratory in nature, does have clinical, research, and policy implications. From a clinical perspective, the findings suggest a need for ongoing review and scrutiny of care process measures. That is, at the hospice or organizational level there is a need to review not just whether care processes were carried out, but *how* they were carried out. This is especially helpful when there are discordant quality indicators on the patient experience side. Stated differently, if all care process quality indicators suggest that the quality of hospice care is high, but patient experience quality indicators are poor, then a review of how the care processes are being carried out may help to explain the discordance. This will involve including clinical staff (particularly nurses) in the quality improvement process. Nurses' practical experience and knowledge can inform understanding of healthcare service delivery barriers (McFarland & MacDonald, 2019) and inform future research and policy regarding how best to measure care processes. This is particularly important if discrepancies between the care process and patient experience quality measures exist, as clinical staff such as nurses are the ones carrying out these processes and delivering the care experienced by the patient and family.

Further, the potential discrepancies between care process quality indicators and outcome quality indicators (e.g., patient experience or hospice disenrollment) have both practical and clinical significance in that the care processes and/or experience measures may not be measuring what is actually important to patients or families. While the process for developing the measures that make up the HQRP was robust, these measures should be continually and critically evaluated, particularly as these discrepancies are found in empirical research. Future qualitative analysis of care processes measurement and how this may affect or limit utility of HIS scores would be informative.

Additionally, this study noted that there is substantial heterogeneity within hospice care itself (e.g., with regards to the setting and array of services provided). This heterogeneity should be a focus of future research examining geographic disparities in hospice care quality and availability, as it was unable to be fully captured in the current study, and yet – as the third element of Donabedian's quality framework – it likely has a significant impact on overall hospice quality measures. For example, are a larger share of older adults in a given area unable to access hospice outside of a nursing home? Does this represent a type of healthcare quality disparity as hospice care provided by a nursing home is associated with lower care quality measures? Similarly, marital status and caregiver relationship may have a meaningful impact on end-of-life care quality as it can affect the setting in which an individual receives care. These individual-level factors should be considered in future investigation, particularly given the present study's findings regarding potential disparities for women. Qualitative research may help

to inform how hospice can better support more diverse caregiver types to help reduce these disparities.

Future research should consider different approaches to modeling that can account for the multiple levels of sociodemographic influence that likely complicated the results of the present study. For instance, multilevel modeling that can nest individuals within hospices and within counties would build upon the results of this exploratory study. Future research could also investigate how hospices make their location and placement decisions: are there specific indicators within a given population that drive these decisions? Is there an effect of workforce availability that was unaccounted for in the present study?

The present study also found potential racial and ethnic disparities in access to hospice quality. Future research should examine whether this relationship holds up to more rigorous statistical analyses and whether this reflects discrimination, socioeconomic disparities, or what other forces may be contributing to this disparity.

Some of the findings of this study are consistent with the notion that older adults may have increased care needs at the end of life, or possibly that the amount of time in which they receive hospice (very short or very long hospice stays) may affect the overall patient experience. The types of caregivers for the oldest old may vary relative to those closer to age 65 (e.g., the oldest old may be cared for by an adult child instead of a spouse). Future research examining sociodemographic correlates of hospice quality should seek to understand how the circumstances in which an individual enrolls in hospice (i.e., pathway to hospice) and caregiver/family-level dynamics affect hospice care quality. Finally, future research could place more attention on the effects of policy in shaping hospice availability and quality, and disparities therein. For example, studies should identify relevant policy changes and evaluate whether they have influenced hospice availability/quality.

Significance to Nursing Science

Since its inception as a profession and, later, as an academic discipline, nursing has emphasized identifying and eradicating social and environmental contributors to health disparities through scientific research and advocacy (Disch, 2020). Prominent nurse scholars have argued that health equity, which involves identifying and eradicating health disparities, should be an area of focus for nurses that includes "both the conditions that shape access to health services and the structural conditions that influence health and produce health inequities" (Pauly et al., 2009, p. 118; Disch, 2020). Others have argued that nursing has a "clear mandate to ensure access to health and healthcare by providing sensitive empowering care to those experiencing inequities and working to change underlying social conditions that result in and perpetuate health inequities" (Reutter & Kushner, 2010, p. 269, Disch, 2020, p. 10).

This study examined elements of access as well as potential structural and social conditions that may influence end-of-life care quality disparities. As such, this study advances the science of nursing – particularly the areas within nursing science which seek to identify and understand drivers of health inequity and disparities. From a research perspective, this study highlights unique challenges to identifying ecological and person-level correlates of hospice care availability and quality and provides insight into how to conduct future research. Future research should account for sociodemographic characteristics specifically within the older adult population – e.g., poverty rate, and/or educational attainment, among those over age 65.

Researchers should also account for differences in overall health status and the pathway of referral to hospice.

Conclusion

The increased use of hospice care at the end of life presents an important step forward in improving the quality of life for the affected. As the hospice industry has changed to meet demand among a growing population of older adults with non-cancer, terminal health conditions, the need to monitor hospice care quality has increased. The HQRP exists to provide this quality oversight. This study leverages data collected from the HQRP to provide an initial understanding of disparities in end-of-life healthcare by examining correlates of both hospice availability and quality. It places particular emphasis on differences among social and demographic groups and between rural and urban areas, which are common axes of inequality in the United States.

In doing so, the study begins to address an important gap in our understanding of end-oflife healthcare disparities. This is an important issue in general, but especially in the contemporary United States where social and spatial inequalities are large and where there are many challenges to population health. This study also has the potential to inform current practice and future research. For example, the analyses highlight the need for multidimensional care quality measures to meaningfully capture the effects of heterogeneity of hospice care structures (e.g., the setting in which hospice is being provided), hospice care processes (e.g., the difference between documenting and truly implementing end-of-life care preferences into care plans), and hospice care outcomes.

This study and its findings underscore the need to continue monitoring, documenting, and disseminating evidence about disparities in hospice availability and quality. It also highlights the need to collect and share new or improved data on the hospice sector. Perhaps most importantly,

the findings suggest the need for practitioners and policymakers to modify practices and develop interventions that can ultimately reduce these disparities. As the United States population ages, such efforts are needed to ensure that growing demand for hospice care can be met in an equitable and effective manner.

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Appendix A Scoring Methodology



Hospice Quality Reporting Program (HQRP) Current Measures

This document contains the details for the measures that can be calculated using the Hospice Item Set (HIS) and Hospice CAHPS[®].

Quality Measures Calculated using the HIS

NQF #1617 Patients Treated with an Opioid who are Given a Bowel Regimen		
Measure Description	Percentage of patient stays treated with an opioid that are offered/prescribed a bowel regimen or documentation of why this was not needed.	
Numerator Statement:	Patients from the denominator that are given a bowel regimen or there is documentation as to why this was not needed.	
Denominator Statement:	Patient stays, except for those with an exclusion, where a scheduled opioid that is initiated or continued.	
Denominator Exclusions:	Patients are excluded from the denominator if they are under 18 years of age.	

Measure Type: Process.

NQF #1634 Pain Screening

Measure Description	Percentage of patient stays during which the patient was screened for pain during the initial nursing assessment.
Numerator Statement:	Patient stays from the denominator who are screened for the presence or absence of pain and, if present, rating of its severity using a standardized tool within 2 days of admission to hospice.
Denominator Statement:	All patient stays except for those with exclusions.

Denominator Exclusions: Patients are excluded from the denominator if they are under 18 years of age.

Measure Type: Process.

NQF #1637 Pain Assessment

Measure Description	Percentage of patient stays during which the patient screened positive for pain and received a comprehensive assessment of pain within 1 day of the screening.
Numerator Statement:	Patient stays from the denominator who received a comprehensive pain assessment within 1 day of the pain screening and the pain assessment included at least 5 of the following characteristics: location, severity, character, duration, frequency, what relieves or worsens that pain, and the effect on function or quality of life.
Denominator Statement:	Patients stays, except for those with exclusions, where the patient's pain severity at the pain screening was rated mild, moderate, or severe.
Denominator Exclusions:	Patient stays are excluded from the denominator if they are under 18 years of age.
Measure Type:	Process.

NQF #1639 Dyspnea Screening

Measure Description	Percentage of patient stays during which the patient was screened for dyspnea during the initial nursing assessment.
Numerator Statement:	Percentage of patient stays during which the patient was screened for dyspnea during the initial nursing assessment.
Denominator Statement:	All Patient stays, except for those with exclusions.
Denominator Exclusions:	Patient stays are excluded from the denominator if they are under 18 years of age.
Measure Type:	Process.

NQF #1638 Dyspnea Treatment

Measure Description	Percentage of patient stays during which the patient screened positive for dyspnea and received treatment within 1 day of the screening.
Numerator Statement:	Patient stays from the denominator who received treatment within 1 day of screening positive for dyspnea.
Denominator Statement:	Patient stays, except those with exclusions, where the patient screened positive for dyspnea at the initial screening encounter.
Denominator Exclusions:	Patient stays are excluded from the denominator if they are under 18 years of age
Measure Type:	Process.

NQF #1641 Treatment Preferences

Measure Description	Percentage of patient stays with chart documentation that the hospice discussed (or attempted to discuss) preferences for life sustaining treatments.
Numerator Statement:	Patient stays from the denominator where the patient/responsible party was asked about preference regarding use of cardiopulmonary resuscitation, or hospitalization, or other life- sustaining treatments no more than 7 days prior to admission or within 5 days of the admission date
Denominator Statement:	All patient stays, except those with exclusions.
Denominator Exclusions:	Patients are excluded from the denominator if they are under 18 years of age.
Measure Type:	Process.

NQF #1647 Beliefs/Values Addressed (if desired by the patient)

Measure Description	Percentage of patient stays with documentation of a discussion of spiritual/religious concerns or documentation that the patient and/or caregiver did not want to discuss spiritual/religious concerns.
Numerator Statement:	Number of patient stays from the denominator where the patient and/or caregiver was asked about spiritual/existential concerns no more than 7 days prior to admission or within 5 days of the admission date.
Denominator Statement:	All patient stays, except for those with exclusions.
Denominator Exclusions:	Patient stays are excluded from the denominator if they are under 18 years of age
Measure Type:	Process.

Hospice Visits w	Iospice Visits when Death is Imminent This measure is a measure pair assessing hospice staff visits to patients at the end of life.	
Measure Description	Measure 1: Percentage of patients receiving at least one visit from registered nurses, physicians, nurse practitioners, or physician assistants in the last 3 days of life.	
	Measure 2: Percentage of patients receiving at least two visits from medical social workers, chaplains or spiritual counselors, licensed practical nurses or hospice aides in the last 7 days of life.	
Numerator Statement:	Measure 1: Number of patients from the denominator receiving at least one visit from registered nurses, physicians, nurse practitioners or physician assistants in the last 3 days of life.	
	Measure 2: Number of patients from the denominator receiving at least two visits from medical social workers, chaplains or spiritual counselors, licensed practical nurses or hospice aides in the last 7 days of life.	
Denominator	Measure 1: All patients, except for those with	
Statement:	exclusions. Measure 2: All patients, except for those	
	with exclusions.	
Denominator Exclusions:	Measure 1: Patients are excluded from the denominator if the patient did not expire in hospice care or the patient received any continuous home care, respite care, or general inpatient care in the last 3 days of life.	
	Measure 2: Patients are excluded from the denominator if the patient did not expire in hospice care or the patient received any continuous home care, respite care, or general inpatient care in the last 7 days of life, or had a length of stay of one day.	
Measure Type:	Process.	

NQF #3235 Hospice and Palliative Care Composite Process Measure – Comprehensive Assessment at Admission

Measure Description	Percentage of patient stays during which the patient received all care processes captured by quality measures NQF #1617, NQF #1634, NQF #1637, NQF #1638, NQF #1639, NQF #1647, NQF #1641, as applicable.
Numerator Statement:	All patient stays from the denominator who meet the numerator criteria for the individual component QMs applicable to the patient.
Denominator Statement:	All patient stays, except for those with exclusions.
Denominator Exclusions:	Patient stays are excluded from the denominator if they are under 18 years of age.

Measure Type: Process.

Measures calculated from the CAHPS® Hospice Survey

The CAHPS® Hospice Survey was considered as a single measure by NQF and endorsed as NQF #2651.

Communication with family

Measure Description	Multi-item measure. "While your family member was in hospice care" P1: "How often did the hospice team keep you informed about when they would arrive to care for your family member?" P2: "How often did the hospice team explain things in a way that was easy to understand?" P3: "How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?" P4: "How often did the hospice team keep you informed about your family member's condition?" P5: "How often did the hospice team listen carefully to you? P6: "How often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?"
Numerator Statement:	CAHPS Hospice Survey measures are calculated using top-box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response. For questions P1 through P5 in this measure, the top box numerator is the number of respondents who answer "Always." For question P6, the top box numerator is the number of respondents who answer "Never." Top box scores for each survey question within the measure are adjusted for mode of survey administration (at the individual respondent level) and case mix (at the hospice level), and then averaged to calculate the overall hospice-level measure score.
Denominator Statement:	The top box denominator is the number of respondents who answer at least one question in the multi-item measure (i.e., one of P1 through P6).
Exclusions:	The hospice patient is still alive -The decedent's age at death was less than 18 -The decedent died within 48 hours of his/her last admission to hospice care -The decedent had no caregiver of record -The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address -The decedent had no caregiver other than a nonfamilial legal guardian -The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted) -The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased -The caregiver reports on the survey that he or she "never" oversaw or took part in decedent's hospice care

Measure Type: Outcome

Getting timely help

Measure Description	Multi-item measure P1: "While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?" P2: "How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?"
Numerator Statement:	CAHPS Hospice Survey measures are calculated using top-box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response. The top box numerator is the number of respondents who answer "Always." Top box scores for each survey question within the measure are adjusted for mode of survey administration (at the individual respondent level) and case mix (at the hospice level), and then averaged to calculate the overall hospice-level measure score.
Denominator Statement:	The top box denominator is the number of respondents who answer at least one question in the multi-item measure (i.e., one of P1 or P2).
Exclusions:	Exclusions from the Denominator Statement: -The hospice patient is still alive -The decedent's age at death was less than 18 -The decedent died within 48 hours of his/her last admission to hospice care -The decedent had no caregiver of record -The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address - The decedent had no caregiver other than a nonfamilial legal guardian -The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted) -The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased -The caregiver reports on the survey that he or she
Measure Type:	"never" oversaw or took part in decedent's hospice care Outcome

Treating patient with respect

Measure Description	Multi-item measure P1: "While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?" P2: "While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?
Numerator Statement:	CAHPS Hospice Survey measures are calculated using top-box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response. For both questions in this measure, the top box numerator is the number of respondents who answer "Always." Top box scores for each survey question within the measure are adjusted for mode of survey administration (at the individual respondent level) and case mix (at the hospice level), and then averaged to calculate the overall hospice-level measure score.
Denominator Statement:	The top box denominator is the number of respondents who answer at least one question in the multi-item measure (i.e., one of P1 or P2).

Exclusions:	The hospice patient is still alive -The decedent's age at death was less than 18 -The decedent died within 48 hours of his/her last admission to hospice care -The decedent had no caregiver of record -The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address -The decedent had no caregiver other than a nonfamilial legal guardian -The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted) -The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased -The caregiver reports on the survey that he or she "never" oversaw or took part in decedent's hospice care
Measure Type:	Outcome

Emotional and spiritual support

Measure Description:	Multi-item measure P1: "While your family member was in hospice care, how much emotional support did you get from the hospice team?" P2: "In the weeks after your family member died, how much emotional support did you get from the hospice team?" P3: "Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?"
Numerator Statement:	CAHPS Hospice Survey measures are calculated using top-box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response. For all questions in this measure, the top box numerator is the number of respondents who answer "Right amount." Top box scores for each survey question within the measure are adjusted for mode of survey administration (at the individual respondent level) and case mix (at the hospice level), and then averaged to calculate the overall hospice-level measure score.
Denominator Statement:	The top box denominator is the number of respondents who answer at least one question in the multi-item measure (i.e., one of P1 through P3).
Exclusions:	The hospice patient is still alive -The decedent's age at death was less than 18 -The decedent died within 48 hours of his/her last admission to hospice care -The decedent had no caregiver of record -The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address -The decedent had no caregiver other than a nonfamilial legal guardian -The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted) -The caregiver is institutionalized, has mental/physical
Measure Type:	incapacity, has a language barrier, or is deceased -The caregiver reports on the survey that he or she "never" oversaw or took part in decedent's hospice care Patient Reported Outcome

Help for pain and symptoms

Measure Description:	Multi-item measure P1: "Did your family member get as much help with pain as he or she needed?" P2: "How often did your family member get the help he or she needed for trouble breathing?" P3: "How often did your family member get the help he or she needed for trouble with constipation?" P4: "How often did your family member receive the help he or she needed from the hospice team for feelings of anxiety or sadness?"
Numerator Statement: Denominator	CAHPS Hospice Survey measures are calculated using top-box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response. For question P1, the top box numerator is the number of respondents who answer "Yes, definitely." For questions P2, P3 and P4, the top box numerator is the number of respondents who answer "Always." Top box scores for each survey question within the measure are adjusted for mode of survey administration (at the individual respondent level) and case mix (at the hospice level), and then averaged to calculate the overall hospice- level measure score. The top box denominator is the number of respondents who answer at least one question
Statement:	in the multi-item measure (i.e., one of P1 through P4).

Exclusions: The hospice patient is still alive -The decedent's age at death was less than 18 -The decedent died within 48 hours of his/her last admission to hospice care -The decedent had no caregiver of record -The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address -The decedent had no caregiver other than a nonfamilial legal guardian -The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted) -The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased -The caregiver reports on the survey that he or she "never" oversaw or took part in decedent's hospice care

Measure Type: Patient Reported Outcome

Training family to care for patient

Measure	Multi-item measure P1: Did the hospice team give you the training you needed				
2 000 ipuon.	team give you the training you needed about if and when to give more pain medicine to your family member? P3: Did the hospice team give you the training				
	you needed about how to help your family member if he or she had trouble breathing? P4: Did the bospice team give you the training you needed about what				
	to do if your family member became restless or agitated? P5: Side effects of pain medicine include things like sleepiness. Did any member of the hospice team				
	discuss side effects of pain medicine with your or your family member?				
Numerator Statement:	CAHPS Hospice Survey measures are calculated using top-box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response. For all questions in this measure, the top box numerator is the number of respondents who answer "Yes, definitely." Top box scores for each survey question within the measure are adjusted for mode of survey administration (at the individual respondent level) and case mix (at the hospice level), and then averaged to calculate the overall hospice-level measure score.				
Denominator Statement:	The top box denominator is the number of respondents who answer at least one question in the multi-item measure (i.e., one of P1 through P5).				
Exclusions:	The hospice patient is still alive -The decedent's age at death was less than 18 -The decedent died within 48 hours of his/her last admission to hospice care -The decedent had no caregiver of record -The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address -The decedent had no caregiver other than a nonfamilial legal guardian -The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted) -The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased -The caregiver reports on the survey that he or she "never" oversaw or took part in decedent's hospice care				
Measure Type:	Patient Reported Outcome				

Rating of this hospice

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Measure Description:	Individual survey item asking respondents: "Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?" 0-10 rating scale with 0=Worst hospice care possible and 10=Best hospice care possible			
Numerator Statement:	The top box numerator is the number of respondents in the hospice who answer "9" or "10." Top box scores for the measure are adjusted for mode of survey administration (at the individual respondent level) and case mix (at the hospice level) to calculate the overall hospice-level measure score.			
DenominatorThe top box denominator is the total number of respondents in the hoseStatement:who answered the item.				
Exclusions:	The hospice patient is still alive -The decedent's age at death was less than 18 -The decedent died within 48 hours of his/her last admission to hospice care -The decedent had no caregiver of record -The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address -The decedent had no caregiver other than a nonfamilial legal guardian -The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted) -The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased -The caregiver reports on the survey that he or she "never" oversaw or took part in decedent's hospice care			
Measure Type:	Patient Reported Outcome			

Willing to recommend	l this	hospice

Measure Description	Individual survey item asking respondents: "Would you recommend this hospice to your friends and family?"		
Numerator Statement:	The top box numerator is the number of respondents in a hospice program who responded "Definitely yes." Top box scores for the measure are adjusted for mode of survey administration (at the individual respondent level) and case mix (at the hospice level) to calculate the overall hospice-level measure score.		
Denominator Statement:	The top box denominator is the total number of respondents in the hospice that answered the item.		

Exclusions:	The hospice patient is still alive -The decedent's age at death was less than 18 -The decedent diad within 48 hours of his/har last admission to hospice care. The
	decedent died within 48 hours of his/her last admission to hospice care - The
	decedent had no caregiver of record -The decedent had a caregiver of record, but
	the caregiver does not have a U.S. or U.S. Territory home address -The decedent
	had no caregiver other than a nonfamilial legal guardian - The decedent or
	caregiver requested that they not be contacted (i.e., by signing a no publicity
	request while under the care of hospice or otherwise directly requesting not to be
	contacted) -The caregiver is institutionalized, has mental/physical incapacity, has a
	language barrier, or is deceased -The caregiver reports on the survey that he or she
	"never" oversaw or took part in decedent's hospice care

Measure Type: Patient Reported Outcome

Appendix B IRB Approval



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APPROVAL OF SUBMISSION

Date: January 18, 2019

From: Philip Frum, IRB

Analyst

Type of Submission:	Initial Study
To: Lisa Kitko	

Title of Study:	Availability of Hospice and Palliative Care in Rural Pennsylvania
Principal Investigator:	Lisa Kitko
Study ID:	STUDY00011089
Submission ID:	STUDY00011089
Funding:	Center for Rural Pennsylvania
IND, IDE, or HDE:	Not Applicable

Documents Approved:	 Appendix A for CMS Data Use Agreement (0.01), Category: Other CRP 2019 Mini Grant Proposal_vFinal.docx (0.01), Category: Sponsor Attachment Data Security Flow Plan (0.01), Category: Other Data Security Flow Plan (0.01), Category: Other Data use Agreement ProposalNot signed (0.01), Category: Other Document 1001 Recruitment Emails.docx (0.01), Category: Recruitment Materials Document 1002 Interview Guide.docx (0.01), Category: Data Collection Instrument Document 1003_Demographic Form.docx (0.01), Category: Data Collection Instrument Document 1004 - Consent Form_CRP.pdf (0.02), Category: Consent Form HRP-591 - Protocol for Human Subject Research_Hospice Utilization in Rural PA (1).pdf (0.03), Category: IRB Protocol
	Utilization in Rural PA (1).pdf (0.03), Category: IRB Protocol
Review Level:	Expedited

On 1/18/2019, the IRB approved the above-referenced Initial Study. This approval is effective through 1/17/2020 inclusive. You must submit a continuing review form with all required explanations for this study at least 45 days before thestudy's approval end date. You can submit a continuing review by navigating to the active study and clicking 'Create Modification / CR'.

If continuing review approval is not granted before 1/17/2020, approval of this study expires on that date.

Attached are stamped approved consent documents. Use copies of these documents to document consent.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (<u>HRP-103</u>), which can be found by navigating to the IRB Library within CATS IRB (<u>http://irb.psu.edu</u>). These requirements include, but are not limited to:

- Documenting consent
- Requesting modification(s)
- Requesting continuing review
- Closing a study
- Reporting new information about a study
- Registering an applicable clinical trial
- Maintaining research records

This correspondence should be maintained with your records.

VITA

Elizabeth Thiede

EDUCA	ΓΙΟΝ			
2023	Ph.D.	Nursing	The Pennsylvania State University	University Park, PA
2021	M.S.N.	Nursing	The Pennsylvania State University	University Park, PA
2014	B.S.N.	Nursing	Georgetown University	Washington, DC
SELECT	SELECTED PUBLICATIONS			

- 1. **Thiede, E.,** & Miyamoto, S. (2021). Rural availability of sexual assault nurse examiners (SANEs). The Journal of Rural Health, 37(1), 81-91.
- Thiede, E., Levi, B. H., Lipnick, D., Johnson, R., Seo La, I., Lehman, E. B., ... & Van Scoy, L. J. (2021). Effect of advance care planning on surrogate decision makers' preparedness for decision making: results of a mixed-methods randomized controlled trial. Journal of palliative medicine, 24(7), 982-993.
- Lipnick, D., Green, M., Thiede, E., Smith, T. J., Lehman, E. B., Johnson, R., ... & Van Scoy, L. J. (2020). Surrogate decision maker stress in advance care planning conversations: a mixed-methods analysis from a randomized controlled trial. Journal of pain and symptom management, 60(6), 1117-1126.
- 4. Van Scoy, L. J., Green, M. J., Creswell, J., **Thiede, E.,** Wiegand, D., La, I. S., ... & Levi, B. H. (2021). Generating a new outcome variable using mixed methods in a randomized controlled trial: The Caregiver Study—An Advance Care Planning investigation. Journal of Mixed Methods Research, 15(4), 567-586.
- Miyamoto, S., Thiede, E., Dorn, L., Perkins, D. F., Bittner, C., & Scanlon, D. (2021). The sexual assault forensic examination telehealth (SAFE-T) Center: A comprehensive, nurse-led telehealth model to address disparities in sexual assault care. The Journal of Rural Health, 37(1), 92-102.

AWARD

2017-2018 University Graduate Fellowship, Pennsylvania State University