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Understanding Health Inequities in Chronic Illness:
An Examination of End-of-Life Care in Heart Failure
and Caregiver Perspectives in Dementia

A dissertation submitted in partial satisfaction of the
requirements for the degree of Doctor of Philosophy
in Health Policy and Management

by

Sara Gentry McCleskey

2021

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ABSTRACT OF THE DISSERTATION

Understanding Health Inequities in Chronic Illness:
An Examination of End-of-Life Care in Heart Failure
and Caregiver Perspectives in Dementia

by

Sara Gentry McCleskey

Doctor of Philosophy in Health Policy and Management

University of California, Los Angeles, 2021

Professor Emmeline Chuang, Co-Chair

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This dissertation consists of three papers examining differences between racial and ethnic groups in quality and experiences of care for older adults with heart failure (HF), as well as caregivers of patients with Alzheimer's and related dementias (ADRD). In the first paper, I used data from a nationally representative sample of older adults to examine differences in the intensity of medical intervention received at the end of life by patients with HF. Specifically, I analyzed whether non-Hispanic Black patients with HF were more likely to have a higher number of hospital admissions, more likely to be admitted to the intensive care unit and utilize life support, and more likely to die in a hospital than non-Hispanic White patients. I found that Black HF patients were more likely than White HF patients to experience high levels of

treatment intensity at the end of life. Black patients with HF were more likely to die in a hospital and more likely to spend time on life support in the last two years of life than White patients. Additionally, I found that Black patients were less likely to have an advance directive in place at the end of life relative to White patients. In the second paper, I used the same nationally representative sample of older adults to examine factors associated with symptom burden in HF at the end of life. Specifically, I analyzed whether non-Hispanic Black patients were more likely to experience the most common symptoms associated with HF in the last months of life, including fatigue, shortness of breath, pain, and depression relative to non-Hispanic White patients. I found that contrary to expectation, Black patients were not more likely than White patients to experience fatigue, shortness of breath, pain, or depression in the last months of life. In fact, Black patients were less likely to report feeling fatigue, less likely to experience depression, and less likely to report a higher symptom count overall. A range of other factors, including health status, socioeconomic status, health care access, and religiosity, were associated with unmet need for symptom management. The third paper in this dissertation used a qualitative study design and a directed content analysis approach to examine Hispanic/Latinx ADRD caregivers' perspectives on interactions with the health care system, use of formal and informal supports, and experiences with racism and discrimination in medical contexts. Findings revealed several important barriers to high quality care, including language barriers, feelings of marginalization in medical contexts, a desire for racial and ethnic concordance with providers, medical mistrust, and a need for health care providers to better understand the cultural background of their patients. Findings from this dissertation contribute to the growing evidence base documenting health inequities in quality and experiences of care in chronic illness.

The dissertation of Sara Gentry McCleskey is approved.

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For Eden

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CHAPTER 1: INTRODUCTION

Population Aging in the United States

The United States (U.S.) population is aging rapidly. In 2019, people age 65 and older represented 16% of the population, but this group is expected to grow to 21.6% of the population by 2040.¹ Moreover, the number of older adults from racial and ethnic minority groups is growing at a faster pace than the number of non-Hispanic White older adults. Between 2019 and 2040, the Hispanic/Latinx population age 65 and older is expected to increase 161% and the non-Hispanic Black population is expected to grow 80%, compared to a 29% projected increase for the non-Hispanic White population.¹

Growing Disease Burden

The aging of the U.S. population has major implications for the health of older adults. Longer lifespans increase the likelihood of chronic disease and functional impairment that may adversely affect overall quality of life.² A chronic illness is defined as a physical or mental health condition that lasts more than one year and causes functional restrictions or requires ongoing monitoring or treatment.³ The clinical and economic burden of chronic illness is substantial. Older adults with one or more chronic illnesses experience higher rates of disability, increased mortality, and more frequent use of health care services.⁴ In 2016, the cost of direct care for chronic conditions in the U.S. was \$1.1 trillion, equivalent to nearly six percent of the nation's GDP.⁵

Two of the most common chronic illnesses among older adults include heart failure (HF) and Alzheimer's disease and related dementias (ADRD). The Centers for Medicare and Medicaid Services place both HF and ADRD in the top ten most common chronic conditions for

adults 65 and older, with a prevalence of 14% and 11% in the older adult population respectively.⁶

Heart Failure

Definition and Disparities

HF is a chronic progressive clinical syndrome with great physical and psychological burden, as well as high morbidity, mortality, and health care utilization.^{7,8} HF is defined as the inability of the heart to fill with or eject blood sufficient to meet metabolic demands, and often requires complex medication protocols, implantable cardioverter defibrillators, and diet and lifestyle changes to manage.^{8,9} Older adults of color are disproportionately impacted by HF, particularly Black populations. Black Americans experience the highest incidence and prevalence of HF, and worst clinical outcomes, of any racial or ethnic group.^{7,10-14}

End-of-Life Issues in Heart Failure

While a large body of evidence exists to inform the management of HF at earlier stages of the disease, care at the end of life is less defined.¹⁵ HF follows an unpredictable disease trajectory, with patients experiencing acute episodes of illness followed by symptom improvement, with prolonged functional impairment, gradual deterioration, and often sudden cardiac arrest.^{8,16,17} This creates a unique set of issues for health care delivery at the end of life. Due to the unpredictability of HF, it is often difficult to identify exactly when a patient is in the terminal stages of the disease or establish a realistic prognosis. Thus, HF patients frequently experience subpar care at the end of life.

Palliative care, an important model in high quality end-of-life care, is a type of specialized medical care aimed at managing symptom burden and providing psychosocial and

spiritual support to patients with serious illness and their families.¹⁸ Palliative care can improve the quality of life of patients and their families, reduce symptom burden, and potentially help patients live longer, due to improved quality of life and appropriate administration of disease-directed treatments.¹⁹ Despite these benefits, palliative care utilization for patients with HF lags far behind that of diseases such as cancer.^{17,20} HF patients are referred to palliative care at much lower rates, undergo more aggressive medical intervention, and endure greater symptom burden than patients in other disease categories.²¹⁻²³

These end-of-life issues are exacerbated among HF patients of color, particularly Black older adults. Not only do Black older adults have a higher prevalence of HF and worse outcomes across the disease trajectory when compared with White older adults, they also experience lower quality of care at the end of life. A small body of literature indicates that Black HF patients have even lower odds of inpatient palliative care encounters and are admitted to hospice, a care model offering palliative services at the terminal stage of disease, at even lower rates than White HF patients.²⁴⁻³³ Research from other illness populations, such as cancer and chronic obstructive pulmonary disease, indicates inequities across a variety of other end-of-life outcomes, such as treatment intensity and symptom burden. In general, non-Hispanic Black patients at the end of life receive more aggressive medical interventions, have greater unmet symptom management needs, and are more likely to die in a hospital than White patients,³⁴⁻³⁷ but less is known about these end-of-life outcomes in HF specifically.

Alzheimer's Disease and Related Dementias

Definition and Disparities

ADRD is a complex medical and psychosocial disease, leading to cognitive deterioration, behavioral changes, and often severe functional limitations necessitating caregiver support.³⁸

ADRD is a significant and growing issue in the Hispanic/Latinx population in the U.S.

Currently, Hispanic/Latinx older adults are one and a half times more likely to have ADRD than White older adults, and estimates show that the Hispanic/Latinx population in the U.S. will face the largest increase in ADRD of any racial or ethnic group by 2060.^{39,40} Additionally, substantial differences exist in quality and access to care. When compared with White older adults, Hispanic/Latinx older adults are more likely to receive a delayed diagnosis of ADRD, less likely to receive referrals to dementia specialist care, and less likely to be prescribed anti-dementia medications.⁴¹

Caregiving Issues in Alzheimer's Disease and Related Dementias

Long-term services and supports serving older adults with ADRD in the U.S. are often fragmented, expensive, and low quality.⁴² Informal, unpaid care delivered by family members or friends frequently fills this gap, with more than 11 million Americans providing unpaid care for a person with ADRD.⁴⁰ The burden of caring for a person with ADRD is high, involving a significant expenditure of time, energy, and money providing personal care and navigating the health care system.⁴³ ADRD caregivers typically endure higher levels of stress and depression and poorer physical health than the general population.⁴⁴

Substantial racial and ethnic inequities exist in ADRD caregiving. While the responsibilities and activities of caregiving are similar across racial and ethnic groups, when

compared with White ADRD caregivers, Hispanic/Latinx caregivers indicate greater care demands, lower utilization of formal supportive services, lower levels of physical well-being, and higher rates of depression.⁴⁵⁻⁴⁸ Data from a recent nationally representative survey of unpaid caregivers by the Alzheimer's Association revealed that discrimination is a barrier to ADRD care, with one-third of Hispanic/Latinx caregivers reporting experiencing discrimination when seeking health care for themselves or their care recipient.⁴⁹

Despite documented inequities in the caregiving experiences of Hispanic/Latinx caregivers, and evidence that discrimination plays a role in caregiver burden in communities of color, there has been little direct exploration of discrimination in the ADRD caregiving literature.

Understanding Health Inequities in Chronic Illness

Given the rapidly aging population and the disproportionate impact of diseases like HF and ADRD on older adults of color, efforts are needed to better characterize the experiences of minority populations with chronic illness. This three-paper dissertation aims to examine differences between racial and ethnic groups in quality and experiences of care for older adults with HF, as well as ADRD patients and their caregivers.

In the first paper, I draw on data from a nationally representative sample of older adults to examine differences in the intensity of medical intervention received at the end of life by patients with HF. Specifically, I analyze whether non-Hispanic Black patients with HF are more likely to have a higher number of hospital admissions at the end of life, more likely to be admitted to the intensive care unit and utilize life support, and more likely to die in a hospital than non-Hispanic White patients.

In the second paper, I use the same nationally representative sample of older adults to examine factors associated with symptom burden in HF at the end of life. Specifically, I analyze whether non-Hispanic Black patients are more likely to experience the most common symptoms associated with HF in the last months of life, including fatigue, shortness of breath, pain, and depression.

The third paper uses a qualitative study design and a directed content analysis approach to examine Hispanic/Latinx ADRD caregivers' perspectives on interactions with the health care system, use of formal and informal supports, and experiences with racism and discrimination in medical contexts.

CHAPTER 2: Factors Associated with Treatment Intensity at the End of Life Among Older Adults with Heart Failure: Evidence from the Health & Retirement Study

INTRODUCTION

Heart failure (HF) is a chronic progressive clinical syndrome with great physical and psychological burden, as well as high morbidity, mortality, and health care utilization.^{7,8} HF is defined as the inability of the heart to fill with or eject blood sufficient to meet metabolic demands.⁸ This can be the result of either a structural or functional disorder, and often requires complex medication protocols, implantable cardioverter defibrillators, and diet and lifestyle changes to manage.⁹ Currently, an estimated 6.2 million adults have a HF diagnosis in the United States (U.S.), and this number is expected to increase to 8 million by 2030.⁷ HF is most prevalent among older adults, with people 65-years and older constituting over 80% of HF patients.⁷ Racial and ethnic minority groups are disproportionately affected by HF, with Black Americans experiencing the highest incidence and prevalence, and worst clinical outcomes, of any racial or ethnic group.^{7,10-14} Age-adjusted HF-related death rates have increased more rapidly since 2017 for both Black men and women compared with White men and women,⁵⁰ and Black HF patients experience higher rates of hospital readmissions^{51,52} and lower health status⁵³ relative to White HF patients. Despite advancement in available HF treatments and gains in overall HF survival in the last two decades, racial and ethnic inequities in HF burden and mortality persist.⁵⁴

For adults with HF, the last six months of life are characterized by increasing illness severity, new and worsening symptoms, greater disability, and emotional distress.^{55,56} Though the physical and psychological burden of end stage HF is large, end-of-life care is frequently suboptimal due to the unique challenges of the disease. High quality care at the end of life can be broadly defined as care focused on alleviating symptoms and respecting patient preferences for

level of medical intervention and place of death.¹⁸ Palliative care, a type of specialized medical care aimed at managing symptom burden and enhancing quality of life for patients with serious illness, represents an important model of high quality end-of-life care.¹⁸ A palliative care team, including specialist doctors and nurses, social workers, nutritionists, and chaplains, provides medical, social, emotional, and practical support to patients with serious illness across a variety of health care settings.¹⁸ Palliative care can improve the quality of life of patients and their families, reduce symptom burden, and potentially help patients live longer, due to improved quality of life, appropriate administration of disease-directed treatments, and early referral to hospice, a care model offering palliative services at the terminal stage of disease.¹⁹

While the involvement of a palliative care team is recommended in HF treatment guidelines from the American College of Cardiology,²⁰ palliative care utilization for patients with HF lags far behind that of diseases such as cancer.¹⁷ Roadblocks to palliative care in HF include a lack of consensus regarding referral criteria, an unpredictable disease trajectory, limited patient and provider knowledge about palliative care, and variable access to specialty palliative care.^{17,57,58} Additionally, advance care planning and goals of care discussions between HF patients and providers are often limited and initiated late in the course of the disease.⁵⁹⁻⁶¹ As a result, burdensome, non-beneficial medical intervention persists despite research suggesting that HF patients largely prefer symptom relief over longer survival time, and prefer dying at home over dying in a hospital.^{55,62,63} HF patients in the terminal stages of disease experience numerous hospital admissions, admission to the intensive care unit (ICU), invasive procedures such as the insertion of implantable cardioverter defibrillators and mechanical ventilation with little hope of survival, and dying in a hospital.^{64,65}

These end-of-life issues are exacerbated among racial and ethnic minority groups, with well documented inequities in end-of-life care in general.^{66,67} While Black Americans have lower rates of health care utilization throughout the life course, at the end of life, Black patients experience more intensive medical intervention and worse outcomes when compared with White patients.^{34,36,68-75} For example, Black patients across disease categories are less likely to utilize palliative care near the end of life, more likely to have repeated hospital admissions and emergency department visits, and more likely to die in a hospital than White patients.^{68,76-78}

Most of the work on racial inequities in end-of-life care has focused primarily on cancer, general cardiovascular disease, or was not disease-specific. As a result, little is known about racial inequities in end-of-life care in HF specifically, a disease with significantly higher rates among racial and ethnic minority groups.⁶⁷ A small body of literature suggests that in the terminal stage of the disease, Black HF patients are admitted to hospice at even lower rates than White HF patients^{24-27,29,30} and have lower odds of inpatient palliative care encounters.^{31,32,79} However, limited research has examined racial differences in receipt of burdensome, non-beneficial medical intervention among HF patients at the end of life.

Given the growing number of older adults with HF and the increased burden and mortality experienced by HF patients of color, more research is needed on inequities across a broad range of end-of-life outcomes. This study seeks to examine the intensity of medical intervention received at the end of life by non-Hispanic Black HF patients compared with non-Hispanic White HF patients, including hospital admissions, ICU admissions, life support utilization, and place of death. In this study, we hypothesize that Black HF patients experience a greater number of hospital admissions in the last months of life when compared with White HF patients. Of those admitted to the hospital in the last months of life, we hypothesize that Black

HF patients are more likely to be admitted to the ICU, more likely to utilize life support, and more likely to die in a hospital than White HF patients.

METHODS

Data Source

This study used data from the Health and Retirement Study (HRS), a nationally representative multi-stage area probability survey of non-institutionalized, community-dwelling Americans ages 51-years and older.^{80,81} The HRS is sponsored by the National Institute on Aging (grant number NIA U01AG009740) and is conducted by the University of Michigan. The survey is intended to provide insight into changing health and economic circumstances associated with aging at both the individual and population levels.⁸⁰ Sampled individuals have been re-interviewed biannually since 1992, with new cohorts added over time to maintain the nationally representative nature of the survey. Spouses are also interviewed, regardless of age, to obtain data at the household level.⁸² When an HRS respondent has died, an exit interview is conducted with a knowledgeable proxy reporter, typically a surviving spouse or adult child, to obtain information about the respondent, including end of life experiences and circumstances of death.^{83,84} More detailed information about the survey is available elsewhere.^{81,82,85}

Sample

Our analytic sample included patients 65-years and older with HF whose proxy informant participated in an exit interview between 2002 and 2016 (n=2,333). Our analysis did not include data prior to 2002 because proxy respondents were not asked about advance directives at the end of life until that time period. Presence of HF was identified based on a positive proxy response to the question, “Did a doctor ever tell [the respondent] that he/she had congestive heart failure?”

We excluded an additional 182 patients who did not identify as either non-Hispanic White or non-Hispanic Black. Small sample sizes in the HRS Exit Interview data precluded meaningful analyses of additional racial and ethnic groups, and current best practices on the reporting of race and ethnicity advise against aggregating groups into one “Other” category.^{86,87} Additionally, we excluded 7 patients who were uninsured as this category was also too small for meaningful analysis.

Finally, we excluded 537 cases with missing data after multiple imputation revealed no significant differences between regression estimates run on imputed data and those from complete case analysis (not shown but available upon request).⁸⁸⁻⁹⁰ Multiple imputation was performed using Multiple Imputation by Chained Equations (MICE), as our dataset included binary and categorical variables which cannot be modeled with Multivariate Normal imputation (MVN).^{88,89} Twenty imputed datasets were created and compared with complete case analysis.⁹¹ Our final analytic sample included 1,607 older adults.

Outcomes of Interest

Four outcome variables were examined in separate regression models: (1) the number of hospital admissions in the last two years of life,⁹²⁻⁹⁴ (2) if the patient was admitted to the intensive care unit (ICU) in the last two years of life,⁹²⁻⁹⁶ (3) if the patient spent time on life support in the last two years of life,^{94,96,97} and (4) the patient’s site of death.^{92-94,98}

A high number of hospital admissions near the end of life represents an important indicator of potential treatment intensity,⁹²⁻⁹⁴ particularly in HF where over one in five patients is readmitted to the hospital within 30 days^{99,100} and two or more hospitalizations within one year increases mortality risk by almost 30%.^{54,101} In this analysis, the number of hospital admissions

was identified based on proxy response to the question, “Including the final hospitalization, how many different times was [the respondent] a patient in a hospital overnight since the previous wave/in the last two years?” The number of hospital admissions was constructed as a count variable.

ICU admission at the end of life may also indicate aggressive, non-beneficial medical intervention for patients with advanced incurable disease.^{92,93,95,96} ICU admission was identified in this study based on proxy report of whether the patient spent any time in the ICU during any hospitalization since the previous wave or in the last two years of life. ICU admission was dichotomized in this analysis as “yes” or “no.”

The provision of life support, which can encompass a variety of medical interventions without which the patient is expected to die from their underlying illness,¹⁰² represents a particularly burdensome intervention in end-of-life care, especially among older adults.^{94,96,97} The HRS asks if the respondent used “life support equipment, such as a respirator” during any hospital stay since the previous interview wave or in the last two years of life.¹⁰³ Life support utilization is dichotomized in this analysis as “yes” or “no.”

Finally, place of death is a potential indicator of care quality at the end of life.^{92-94,98} Older adults frequently express a preference against dying in a hospital,^{92,104-106} and dying in a hospital may indicate failure to accommodate patient preferences for care at the end of life or the decision to provide unnecessary interventions despite little hope of recovery.^{92-94,98,107} In this study, we operationalized place of death as a dichotomous variable set =1 if the patient died in a hospital, and set =0 if the patient passed away elsewhere (e.g., at home, in a nursing home, in a hospice, or in an assisted living facility).

Race and Ethnicity

Racial identity was our primary predictor of interest. Race and ethnicity were identified based on proxy responses to the following exit interview questions: “Did [the respondent] consider himself/herself Hispanic or Latino?” and “What race did [the respondent] consider himself/herself to be: White, Black or African American, American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander, or something else?” In this analysis, race and ethnicity was constructed as a dichotomous variable set =1 if the patient identified as non-Hispanic Black and set =0 if non-Hispanic White (reference category).

Other Covariates

We controlled for eight additional demographic, social, and health characteristics hypothesized to be associated with treatment intensity at the end of life.

Insurance status, a proxy for health care access and socioeconomic status,¹⁰⁸ was constructed as: Medicare and private insurance (reference category); Medicare and Medicaid (dual-enrolled); and Medicare-only. Broadly speaking, Medicare is available for people 65-years or older and covers hospital and medical services, but not long-term care. Medicaid eligibility requirements vary from state to state and depend on factors such as household income. Medicaid covers hospital, medical, and nursing facility services.¹⁰⁹ Patients with Medicare and private insurance likely have higher socioeconomic status and access to higher quality care than those with Medicare and Medicaid, while patients with Medicare-only may be particularly vulnerable if they fall into a coverage gap in which their income is above their state’s eligibility for Medicaid but below the poverty line.¹¹⁰

The presence of an advance directive, defined as written instructions about the treatment the patient wished to receive during the final days of life, was dichotomized as “yes” (reference category) or “no.” Research suggests that advance directives are associated with a reduction in burdensome medical intervention at the end of life, an increase in palliative care provision, and can serve as a proxy indicator that goals of care have been discussed with medical providers.¹¹¹

Religiosity represents a potential factor in end-of-life decision-making, with studies suggesting that more religious individuals are less likely to engage in advance care planning and more likely to desire aggressive medical intervention at the end of life.¹¹²⁻¹¹⁵ In this study, religiosity was constructed as a dichotomous variable including: religious (attended religious services during the last year of life [reference category]); and not religious (did not attend religious services in the last year of life).

Total number of comorbidities was included in this study as a potential measure of health status. Comorbidity prevalence often increases over time in HF and can complicate treatment and reduce quality of life in HF patients.¹¹⁶⁻¹¹⁸ In this study, the presence of comorbidities was constructed as a count variable (0-8) limited to the diseases present in HRS Exit Interviews, including cancer, lung disease, stroke, hypertension, diabetes, arthritis, psychiatric issues, and dementia.

Educational attainment included: less than high school (reference category); high school graduate; and college and above. Marital status at time of death, a potential indicator of social support,¹¹⁹ was categorized as married and unmarried, which included divorced, widowed, and never married (reference category). Age at death was a continuous variable (65-111) and patient sex was categorized as female (reference category) and male.

Analyses

Descriptive statistics were used to characterize our study sample. We reported separately on the full analytic sample of patients with HF (n=1,607), and a subsample of those admitted to a hospital in the last two years of life (n=1,242). This subsample was created to ensure a more homogenous population for analysis of hospital-based care, including ICU admission, life support utilization, and dying in a hospital. Due to over-dispersion issues in the hospital admissions count variable, negative binomial regression was used to identify factors associated with number of hospital admissions in the last months of life.¹²⁰ In the subsample of HF patients admitted to the hospital in the last months of life, logistic regression models examined factors associated with ICU admissions, utilization of life support, and place of death.

Sampling weights within the HRS account for differential selection probabilities as well as potential bias resulting from survey non-response, and thus yield estimates that are nationally representative of non-institutionalized, community-dwelling adults age 51-years and older in the U.S.^{81,83,121} Weights use respondent gender, race, ethnicity, and birth cohort as the basis for post-stratification, adjusting for sample attrition and mortality, and yielding weight sums corresponding to the number of people in the U.S. population as measured by the March U.S. Current Population Survey (CPS) for the year of data collection.¹²¹ As all respondents in the HRS Exit Interviews are deceased, the respondent-level weight in the survey wave prior to death was used to ensure that results were representative of the U.S. population.¹²¹

Analyses were performed using Stata version 17. This study was approved by the Institutional Review Board (IRB) at the University of California, Los Angeles.

RESULTS

Descriptive Statistics

The majority of the analytic sample identified as White (86%) and female (56%) (Table 1). On average, patients were 83-years old at time of death ($SD=8.32$) and were unmarried, including divorced, widowed, or never married (65%). Approximately 64% had earned a high school diploma or higher. About half had both Medicare and private insurance (52%), about one quarter were dual-eligible recipients of Medicare and Medicaid (26%), and 23% had Medicare only. On average, patients had three comorbidities in addition to HF ($SD=1.45$). More than half of patients were religious (56%) and had an advance directive in place at time of death (56%). On average, patients had five hospital admissions in the last two years of life ($SD=13.53$). Among those who were admitted to a hospital in the last two years of life, 53% were admitted to the ICU but most did not use life support (72%) or die in a hospital (67%).

Factors Associated with Number of Hospital Admissions

Negative binomial regression results found that racial identity was not significantly associated with the number of hospital admissions in the last two years of life (Table 2). Factors that did emerge as significantly associated with the number of hospital admissions included number of comorbidities ($IRR=1.15$, $CI=1.05$ to 1.25 , $p=0.00$), being married ($IRR=1.41$, $CI=1.10$ to 1.82 , $p=0.01$), and age ($IRR=0.98$, $CI=0.97$ to 1.00 , $p=0.02$), holding other variables constant.

Factors Associated with ICU Admission

Separate logistic regression models examined the association of demographic, social, and health characteristics on ICU admission, use of life support, and place of death in a subsample of

patients with HF who were admitted to a hospital in the last two years of life (n=1,242) (Table 3). Racial identity was not significantly associated with admission to the ICU, however insurance status and age were both statistically significant and negatively associated with ICU admission. Holding other variables constant, patients with dual enrollment in Medicare and Medicaid were less likely to be admitted to the ICU (OR=0.63, CI=0.47 to 0.86, $p=0.00$) when compared with patients with Medicare and private insurance, and patients of older age were less likely than younger patients (OR=0.95, CI=0.93 to 0.97, $p=0.00$).

Factors Associated with Life Support Utilization and Death in a Hospital

Black patients were more likely to spend time on life support (OR=2.16, CI=1.35 to 3.44, $p=0.00$) and more likely to die in a hospital (OR=1.53, CI=1.03 to 2.28, $p=0.04$) than White patients. Those with a college degree or higher were more likely to spend time on life support (OR=1.57, CI=1.11 to 2.23, $p=0.01$) while those of older age were less likely to utilize life support (OR=0.96, CI=0.94 to 0.97, $p=0.00$) and less likely to die in a hospital (OR=0.97, CI=0.95 to 0.99, $p=0.00$), holding other variables constant.

Post Hoc Sensitivity Analyses

Sensitivity analyses examined if racial identity was associated with the highest number of hospital admissions as well as the presence of an advance directive. Although racial identity was not significantly associated with number of hospital admissions, we were curious if this held true for the subset of those with the highest number of admissions. We constructed a dichotomous variable set =1 if the patient was in the top quartile of number of hospital admissions, and set =0 if the patient was in the bottom three quartiles. A logistic regression model controlling for patient characteristics was used to examine racial differences in the highest number of hospital

admissions in the full sample (n=1,607). While there was a tendency for Black HF patients to be in the top quartile of hospital admissions (OR=1.25, CI=0.88 to 1.79, $p=0.20$), this result was not significant (Appendix Table A).

Additionally, we were interested in whether differences in the presence of an advance directive might account for the higher likelihood of utilizing life support and dying in a hospital experienced by Black patients. Evidence suggests that advance directives are related to a decrease in life-sustaining treatments, a decrease of in-hospital deaths, and more frequent receipt of palliative care, and that Black older adults have lower rates of advance directive completion than White older adults.^{111,122} In this analysis, we hypothesized that Black HF patients would be less likely to have an advance directive in place than White HF patients. We constructed a dichotomous variable set =1 if the patient had an advance directive in place at the end of life, and set =0 if the patient did not. Logistic regression controlling for patient characteristics was used to examine racial differences in the presence of an advance directive in the sample of patients admitted to a hospital (n=1,242). We found that Black HF patients were less likely to have an advance directive in place at the end of life (OR=0.29, CI=0.21 to 0.41, $p=0.00$) when compared with White HF patients, holding other variables constant (Appendix Table B).

DISCUSSION

In this study of patients with heart failure from a nationally representative sample of Americans over the age of 65, we found that Black patients were more likely than White patients to experience high levels of treatment intensity at the end of life. Black patients with HF were more likely to die in a hospital and more likely to spend time on life support in the last two years of life than White patients. Additionally, while there was a tendency for Black patients to have a greater number of hospital admissions and to spend time in the ICU at the end of life, these

associations were not statistically significant. Our findings highlight important differences in the end-of-life experiences of Black HF patients when compared with White HF patients and have implications for better supporting HF patients of color across the disease trajectory.

Our findings are consistent with recent work demonstrating racial differences in treatment intensity at the end of life. An analysis also using data from the Health and Retirement Study found that Black and Hispanic/Latinx people with any diagnosis are more likely than White people to use life support and kidney dialysis before death.³⁶ Similarly, Black patients in a large health care system were more likely than White patients to receive cardiopulmonary respiration, mechanical ventilation, and ICU care in the last 30 days of life.⁷² Our study supports these findings while being among the first to examine racial differences in end-of-life treatment intensity in the context of HF specifically. This is a crucial area of study as Black patients have the highest incidence and prevalence of HF as well as the worst clinical outcomes compared to other racial and ethnic groups.^{7,11,50}

Several factors may explain the higher levels of treatment intensity received by Black HF patients in our study. One possibility is the link between advance directives and lower intensity care at the end of life. Evidence suggests that advance directives are associated with less intensive medical intervention, a lower rate of death in a hospital, and more frequent receipt of palliative care.¹¹¹ In HF specifically, evidence indicates that advance care planning improves quality of life, patient satisfaction with end-of-life care, and the quality of end-of-life communication.⁵⁹ Despite the benefits of advance directives, advance care planning and goals of care discussions between HF patients and providers are often limited and initiated late in the course of the disease.^{59,60} The results of our analyses indicated that those without an advance directive were more likely to be admitted to the ICU, spend time on life support, and die in a

hospital, though these results were not significant. A sensitivity analysis showed that Black HF patients were less likely to have an advance directive in place at the end of life when compared with White HF patients ($p=0.00$), which may partially explain the higher odds of utilizing life support and dying in a hospital observed in our study. These findings are consistent with the literature, which suggests that Black older adults have lower rates of advance directive completion than White older adults.¹²²⁻¹²⁴

Additionally, it is possible that the higher intensity care experienced by Black patients in our study might reflect actual patient preferences. While many older adults express a preference against burdensome medical care at the end of life^{125,126} and against dying in a hospital,^{104,105} Black patients frequently express a preference for life-sustaining interventions over palliative care.^{115,127,128} A complex history of medical racism, inequities in access to health care, and negative personal experiences with the health care system present several explanations for medical mistrust among Black patients that can impact decision-making at the end of life.^{13,128-130} Patient-level factors such as religious beliefs, cultural and familial influences, and health literacy,^{115,124,127,131,132} provider-level factors such as communication skills, knowledge of palliative care, and implicit bias,^{11,57,131-134} and structural factors like under-resourced health care facilities, lack of access to high quality health insurance, and disjointed coordination of care^{13,128,135} all pose significant barriers to equitable care at the end of life.

Implications

Our findings underscore the importance of advance care planning in the context of HF and the need for creative interventions to reach underserved populations in end-of-life care.

First, goals of care conversations must be routinized in the treatment of HF. Providers should speak with HF patients about their end-of-life care options early in the course of the disease and revisit the topic of advance care planning throughout the disease trajectory. Clear guidelines for advance care planning initiation in HF and efforts to integrate these guidelines more fully into clinical practice are necessary. For example, a HF patient's unscheduled hospital visit, a deterioration in health status, or a significant change in treatment could serve as a trigger to initiate an advance care planning conversation.^{59,136} Additionally, prior research suggests that successful advance care planning discussions focus more on goals of care than specific treatments, involve providers being responsive to the emotional content of the discussion, and should ideally take place over a number of meetings.^{59,136} Organizations should focus on providing focused and relevant educational opportunities to enhance provider communication skills. Finally, efforts must be made to find new and innovative ways to engage with underserved patient populations regarding advance care planning. Several recent interventions have shown promise, such as the Hello Project, a low-cost, community-based end-of-life conversation game hosted by religious and community organizations to promote advance directive completion in underserved communities,¹³⁷ and the Thinking Ahead Project, a multicomponent program integrating motivational interviewing, an evidence-based advance care planning facilitation program, and a revised advance directive form designed to meet the health literacy level of most adults in the United States.¹³⁸ Policies and funding to support community-based programs such as these are essential to educating and supporting underserved communities in end-of-life decision-making.

Limitations

This study has several limitations. Due to small sample sizes in the HRS Exit Interview data, we were unable to examine additional racial and ethnic groups beyond non-Hispanic White and non-Hispanic Black. Hispanic/Latinx and Chinese American populations in particular are at high risk of developing HF and experience persistent inequities in health care access and quality throughout the life course.^{7,10,139,140} The ongoing issue of study recruitment for minority groups requires urgent attention as inequities grow in HF epidemiology, clinical severity, and access to care at the end of life. Additionally, while the HRS Exit Interviews attempt to capture the end-of-life experience of patients, the survey questions cover a broad timeframe. Proxy respondents are asked to consider the last two years of life of the respondent, which may not serve as a precise measurement of the end of life. Despite the wide timeframe, however, we still detected racial differences in treatment intensity and these findings are likely to be magnified closer to the time of death. Additionally, although we control for a wide range of factors associated with treatment intensity at the end of life, other important determinants of end-of-life care may be absent from this analysis. For example, we did not have detailed information on patient or family preferences for care at the end of life or whether the treatment received was concordant with preferences. These are important factors in evaluating quality of care at the end of life that were unavailable in the data set. Finally, this analysis relies on proxy-reported data, which may lead to missing or inaccurate information. Proxy interviews in end-of-life research have been validated, particularly across constructs such as service provision and observable symptoms, but missing or inaccurate information may impact analysis.¹⁴¹

In conclusion, this study found that Black patients with HF experience higher levels of treatment intensity at the end of life relative to White HF patients. More comprehensive and

sustained efforts to address issues of health equity must be made in order to guarantee better care for all at the end of life.

CHAPTER 2: Tables

Table 1. Characteristics of Patients with HF Diagnosis Age 65-Years and Older, Health & Retirement Study Exit Interviews 2002-2016

	Non-Hispanic White N (%)	Non-Hispanic Black N (%)	Total N (%)
Race and ethnicity	1,374 (85.50)	233 (14.50)	1,607 (100.00)
Age			
Mean (SD)	83.78 (8.08)	80.64 (9.23)	83.32 (8.32)
Sex			
Female	760 (84.63)	138 (15.37)	898 (55.88)
Male	614 (86.60)	95 (13.40)	709 (44.12)
Education			
Less than HS	433 (75.04)	144 (24.96)	577 (35.91)
HS graduate	542 (91.09)	53 (8.91)	595 (37.03)
College & above	399 (91.72)	36 (8.28)	435 (27.07)
Marital status			
Married	490 (86.27)	78 (13.73)	568 (35.35)
Unmarried	884 (85.08)	155 (14.92)	1,039 (64.65)
Insurance status			
Medicare & Private	778 (93.62)	53 (6.38)	831 (51.71)
Medicare & Medicaid	291 (70.46)	122 (29.54)	413 (25.70)
Medicare only	305 (84.02)	58 (15.98)	363 (22.59)
Number of comorbidities			
Mean (SD)	3.25 (1.46)	3.49 (1.38)	3.29 (1.45)
Religiosity			
Religious	739 (81.57)	167 (18.43)	906 (56.38)
Not religious	635 (90.58)	66 (9.42)	701 (43.62)
Advance directive			
Yes	829 (92.94)	63 (7.06)	892 (55.51)
No	545 (76.22)	170 (23.78)	715 (44.49)
Number of hospital admissions			
Mean (SD)	4.73 (12.79)	6.99 (17.20)	5.05 (13.53)
Subpopulation: Patients with HF diagnosis who were admitted to hospital			1,242 (100.00)
Admitted to ICU			
Yes	545 (83.59)	107 (16.41)	652 (52.50)
No	519 (48.78)	71 (12.03)	590 (47.50)
Spent time on life support			
Yes	272 (77.71)	78 (22.29)	350 (28.18)
No	792 (88.79)	100 (11.21)	892 (71.82)
Place of death			
Hospital	325 (80.45)	79 (19.55)	404 (32.53)
Not hospital	739 (88.19)	99 (11.81)	838 (67.47)

Table 2. Association of Patient Characteristics with Number of Hospital Admissions in the Last Two Years of Life for Patients with HF Diagnosis

Independent variable	Number of hospital admissions Negative binomial regression results (n=1,607)	
	Incidence rate ratio (95% CI)	p-value
Race and ethnicity		
<i>Non-Hispanic Black</i>	1.41 (0.84-2.35)	0.19
Insurance status		
<i>Medicare & Medicaid</i>	1.37 (0.99-1.90)	0.06
<i>Medicare only</i>	1.16 (0.93-1.46)	0.19
Advance directive		
<i>No</i>	0.89 (0.72-1.10)	0.28
Religiosity		
<i>Not religious</i>	1.29 (0.95-1.75)	0.10
Number of comorbidities	1.15* (1.05-1.25)	0.00
Education		
<i>HS graduate</i>	1.10 (0.83-1.45)	0.50
<i>College & above</i>	0.83 (0.64-1.09)	0.18
Marital status		
<i>Married</i>	1.41* (1.10-1.82)	0.01
Age	0.98* (0.97-1.00)	0.02
Sex		
<i>Male</i>	1.01 (0.80-1.28)	0.95

*p<0.05

Table 3. Association of Patient Characteristics with ICU Admission, Use of Life Support, and Death in a Hospital for Subpopulation: Patients with HF Diagnosis Admitted to a Hospital in the Last Two Years of Life

Independent variable	Admitted to ICU (n=1,242)		Spent time on life support (n=1,242)		Died in hospital (n=1,242)	
	Odds ratio (95% CI)	p-value	Odds ratio (95% CI)	p-value	Odds ratio (95% CI)	p-value
Race and ethnicity						
<i>Non-Hispanic Black</i>	1.48 (0.96-2.30)	0.08	2.16* (1.35-3.44)	0.00	1.53* (1.03-2.28)	0.04
Insurance status						
<i>Medicare & Medicaid</i>	0.63* (0.47-0.86)	0.00	0.97 (0.71-1.33)	0.86	0.77 (0.52-1.13)	0.17
<i>Medicare only</i>	1.17 (0.81-1.67)	0.39	1.28 (0.93-1.76)	0.13	0.77 (0.58-1.03)	0.08
Advance directive						
<i>No</i>	1.04 (0.80-1.36)	0.75	1.21 (0.95-1.53)	0.12	1.25 (1.00-1.57)	0.05
Religiosity						
<i>Not religious</i>	1.07 (0.87-1.31)	0.54	1.00 (0.77-1.31)	0.97	0.86 (0.66-1.12)	0.26
Number of comorbidities	1.01 (0.93-1.11)	0.77	1.07 (0.98-1.16)	0.15	1.06 (0.96-1.16)	0.27
Education						
<i>HS graduate</i>	0.99 (0.72-1.38)	0.97	1.33 (1.00-1.79)	0.05	0.79 (0.61-1.03)	0.09
<i>College & above</i>	1.16 (0.83-1.62)	0.38	1.57* (1.11-2.23)	0.01	0.89 (0.62-1.28)	0.51
Marital status						
<i>Married</i>	0.95 (0.70-1.29)	0.73	1.13 (0.84-1.51)	0.41	1.13 (0.86-1.49)	0.38
Age	0.95* (0.93-0.97)	0.00	0.96* (0.94-0.97)	0.00	0.97* (0.95-0.99)	0.00
Sex						
<i>Male</i>	0.94 (0.70-1.26)	0.68	0.91 (0.68-1.22)	0.53	0.98 (0.74-1.30)	0.90

*p<0.05

CHAPTER 2: Appendix

Appendix Table A: Sensitivity Analysis of Highest Number of Hospital Admissions Among Patients with HF Diagnosis

Independent variable	Upper quartile of hospital admissions (n=1,607)	
	Odds ratio (95% CI)	p-value
Hospital admissions: 0=bottom 3 quartiles; 1=upper quartile		
Race and ethnicity		
<i>Non-Hispanic Black</i>	1.25 (0.88-1.79)	0.20
Insurance status		
<i>Medicare & Medicaid</i>	1.02 (0.72-1.44)	0.91
<i>Medicare only</i>	0.82 (0.59-1.13)	0.22
Religiosity		
<i>Not religious</i>	1.04 (0.78-1.38)	0.79
Number of comorbidities	1.09 (1.00-1.19)	0.06
Education		
<i>HS graduate</i>	0.85 (0.65-1.12)	0.25
<i>College & above</i>	0.71 (0.49-1.01)	0.06
Marital status		
<i>Married</i>	0.93 (0.64-1.36)	0.72
Age	0.97* (0.96-0.98)	0.00
Sex		
<i>Male</i>	1.25 (0.92-1.70)	0.15

*p<0.05

Appendix Table B: Sensitivity Analysis of Presence of Advance Directive for Subpopulation: Patients with HF Diagnosis Admitted to a Hospital in the Last Two Years of Life

Independent variable	Presence of advance directive (n=1,242)	
	Odds ratio (95% CI)	p-value
Advance directive: 0=no; 1=yes		
Race and ethnicity		
<i>Non-Hispanic Black</i>	0.29* (0.21-0.41)	0.00
Insurance status		
<i>Medicare & Medicaid</i>	0.62* (0.47-0.80)	0.00
<i>Medicare only</i>	0.74 (0.50-1.10)	0.14
Religiosity		
<i>Not religious</i>	0.81 (0.62-1.04)	0.10
Number of comorbidities	1.05 (0.95-1.16)	0.32
Education		
<i>HS graduate</i>	1.38 (0.94-2.02)	0.10
<i>College & above</i>	1.51 (0.93-2.43)	0.09
Marital status		
<i>Married</i>	0.84 (0.65-1.08)	0.17
Age	1.04* (1.02-1.05)	0.00
Sex		
<i>Male</i>	1.13 (0.87-1.47)	0.36

*p<0.05

CHAPTER 3: Factors Associated with Symptom Burden at the End of Life Among Older Adults with Heart Failure: Evidence from the Health & Retirement Study

INTRODUCTION

Heart failure (HF) is a chronic clinical syndrome associated with great physical and psychological burden, high rates of health care utilization, and mortality.^{7,8} Currently, an estimated 6.2 million adults have HF in the United States, and this number is expected to increase to 8 million by 2030.⁷ HF is most prevalent among older adults, with people 65-years and older constituting over 80% of HF patients.⁷ Racial and ethnic minority groups are disproportionately affected by HF, with Black Americans having the highest incidence and prevalence, and experiencing the worst clinical outcomes, of any racial or ethnic group.^{7,10-13} Relative to White HF patients, Black HF patients experience higher rates of hospital readmissions,^{51,52} lower health status,⁵³ and have higher age-adjusted HF-related death rates.⁵⁰

Advances in available medications and implantable devices to treat HF have led to significant gains in overall survival in the last two decades.^{7,8} With increased longevity, however, many HF patients endure extended chronic illness. HF occurs in four stages as defined by the American College of Cardiology and the American Heart Association: (1) stage A includes individuals with risk factors for HF but without structural heart disease; (2) stage B comprises patients with structural heart disease but no HF symptoms; (3) stage C includes symptomatic HF; and (4) stage D represents HF symptoms resistant to medical therapy.²⁰ HF follows an unpredictable disease trajectory, with patients moving back and forth between stages based on symptoms.⁸ Management of HF often requires complex medication protocols, implantable cardioverter defibrillators, and intensive diet and lifestyle changes.⁹ Symptom management is cited as a top priority for HF patients, particularly at the end of life, yet HF patients experience

high rates of symptom burden, including pain, fatigue, shortness of breath, psychological distress, and reduced quality of life at the end of life.^{23,142-146}

Palliative care, a type of specialized medical care aimed at managing symptom burden and enhancing quality of life for patients with serious illness, represents an important model of high quality end-of-life care.¹⁸ A palliative care team, including specialist doctors and nurses, social workers, nutritionists, and chaplains, provide medical, social, emotional, and practical support to patients with serious illness across a variety of health care settings.¹⁸ Palliative care can improve the quality of life of patients and their families, reduce symptom burden, and potentially help patients live longer, due to improved quality of life, appropriate administration of disease-directed treatments, and early referral to hospice, a care model offering palliative services at the terminal stage of disease.¹⁹

While the involvement of a palliative care team is recommended in HF treatment guidelines from the American College of Cardiology,²⁰ palliative care utilization for patients with HF lags far behind that of diseases such as cancer.¹⁷ Roadblocks to palliative care in HF include a lack of consensus regarding referral criteria, an unpredictable disease trajectory, limited patient and provider knowledge about palliative care, and variable access to specialty palliative care.^{17,57,58} Additionally, advance care planning and goals of care discussions between HF patients and providers are often limited and initiated late in the course of the disease.⁵⁹⁻⁶¹ As a result, the terminal stage of HF is frequently characterized by severe pain, shortness of breath, depressive symptoms, and functional impairment.⁵⁵

These end-of-life issues are exacerbated for HF patients of color, with health inequities throughout the course of the disease culminating in widely disparate outcomes at the end of life. Black HF patients experience longer duration of illness, with a higher likelihood of acquiring the

disease before the age of 50 when compared with White HF patients, and experience a greater number of hospitalizations and readmissions, and lower utilization of guideline-directed medical therapy.⁵⁴ In the terminal stages of the disease, Black HF patients are admitted to hospice at even lower rates than White HF patients²⁴⁻³⁰ and have lower odds of inpatient palliative care encounters.^{31,32,79} This suggests access issues to high quality end-of-life care and the potential for unmet symptom management needs among Black HF patients. However, evidence is limited regarding racial differences in symptom burden among HF patients at the end of life.

Given the growing number of older adults with HF and the increased burden and mortality experienced by HF patients of color, more research is needed on inequities across a broad range of end-of-life outcomes. This study aims to examine symptom burden at the end of life experienced by non-Hispanic Black HF patients compared with non-Hispanic White HF patients, including fatigue, shortness of breath, pain, and depression. In this study, we hypothesize that Black HF patients will be more likely to experience fatigue, shortness of breath, pain, and depression and that they will experience a higher number of total symptoms in the last months of life than White HF patients.

METHODS

Data Source

This study used data from the Health and Retirement Study (HRS), a nationally representative multi-stage area probability survey of non-institutionalized, community-dwelling Americans ages 51-years and older.^{80,81} The HRS is sponsored by the National Institute on Aging (grant number NIA U01AG009740) and is conducted by the University of Michigan. The survey is intended to provide insight into changing health and economic circumstances associated with

aging at both the individual and population levels.⁸⁰ Sampled individuals have been re-interviewed biannually since 1992, with new cohorts added over time to maintain the nationally representative nature of the survey. Spouses are also interviewed, regardless of age, to obtain data at the household level.⁸² When an HRS respondent has died, an exit interview is conducted with a knowledgeable proxy reporter, typically a surviving spouse or adult child, to obtain information about the respondent, including end of life experiences and circumstances of death.^{83,84} More detailed information about the survey is available elsewhere.^{81,82,85}

Sample

Our analytic sample included patients 65-years and older with HF whose proxy informant participated in an exit interview between 2002 and 2016 (n=2,333). Our analysis did not include data prior to 2002 because proxy respondents were not asked about advance directives at the end of life until that time period. Presence of HF was identified based on a positive proxy response to the question, “Did a doctor ever tell [the respondent] that he/she had congestive heart failure?”

We excluded an additional 182 patients who did not identify as either non-Hispanic White or non-Hispanic Black. Small sample sizes in the HRS Exit Interview data precluded meaningful analyses of additional racial and ethnic groups, and current best practices on the reporting of race and ethnicity advise against aggregating groups into a single “Other” category.^{86,87} Additionally, we excluded 7 patients who were uninsured as this category was also too small for meaningful analysis.

Finally, we excluded 537 cases with missing data after multiple imputation revealed no significant differences between regression estimates run on imputed data and those from complete case analysis (not shown but available upon request).⁸⁸⁻⁹⁰ Multiple imputation was

performed using Multiple Imputation by Chained Equations (MICE), as our dataset included binary and categorical variables which cannot be modeled with Multivariate Normal imputation (MVN).^{88,89} Twenty imputed datasets were created and compared with complete case analysis.⁹¹ Our final analytic sample included 1,607 older adults.

Outcomes of interest

Four outcome variables were examined in separate regression models: the presence of (1) fatigue,¹⁴⁷⁻¹⁵⁰ (2) shortness of breath,¹⁴⁷⁻¹⁵⁰ (3) pain,^{147,148,150} and (4) depression.^{147,148} Symptoms were identified based on proxy response to the questions, “Was there a period of at least one month during the last year of [the respondent’s] life when [he/she] had *severe fatigue or exhaustion; difficulty breathing; depression?*” and “Was [he/she] often troubled with pain in the last year of life?”

Lack of energy is among the most frequently reported symptoms of HF, impacting up to 96% of HF patients.^{147,151-153} Fatigue is correlated with low quality of life, poor physical health, and patient distress.^{151,154} Fatigue in the last year of life is dichotomized in this study as “yes” or “no.”

Shortness of breath is also characteristic of HF, and is cited as one of the most common reasons for hospitalization among older adults with HF.^{147,148,155,156} Shortness of breath in the last year of life is dichotomized in this study as “yes” or “no.”

Pain, whether characterized as chest pain or pain elsewhere in the body, is also a common symptom among older adults with HF.^{147,148,150,157} Pain reported by HF patients may arise through different mechanisms such as ischemia, inflammation, or neuropathy.¹⁵⁷ Studies show that pain in HF can exacerbate other issues and contribute to hospitalizations, but may be

underrecognized and undertreated.^{158,159} Pain in the last year of life is dichotomized in this study as “yes” or “no.”

All of these symptoms are strongly associated with psychological distress in HF patients.^{142,147,148,155,160} Up to 30% of HF patients suffer from diagnosed depression and even more have depressive symptoms.¹⁶¹ Depression in HF is associated with lower quality of life, decreased ability to engage in self-care, increased rates of mortality, and an increase in reported symptom burden.¹⁶²⁻¹⁶⁵ Depression is dichotomized in this analysis as “yes” or “no.”

A fifth outcome variable comprised a count of all four symptoms (the presence of fatigue, shortness of breath, pain, and depression). Symptoms rarely occur in isolation, often presenting in pairs, groups, or clusters that interact with and amplify one another.^{153,166} Previous work has shown that depression in particular is associated with a greater number of symptoms in HF, which is associated with lower quality of life.¹⁶⁷

Race and Ethnicity

Racial identity was our primary predictor of interest. Race and ethnicity were identified based on proxy responses to the following exit interview questions: “Did [the respondent] consider himself/herself Hispanic or Latino?” and “What race did [the respondent] consider himself/herself to be: White, Black or African American, American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander, or something else?” In this analysis, race and ethnicity was constructed as a dichotomous variable set =1 if the patient identified as non-Hispanic Black and set =0 if non-Hispanic White (reference category).

Other Covariates

We controlled for eight additional demographic, social, and health characteristics hypothesized to be associated with symptom burden at the end of life.

Insurance status, a proxy for health care access and socioeconomic status,¹⁰⁸ was constructed as: Medicare and private insurance (reference category); Medicare and Medicaid (dual-enrolled); and Medicare-only. Broadly speaking, Medicare is available for people 65-years or older and covers hospital and medical services, but not long-term care. Medicaid eligibility requirements vary from state to state and depend on factors such as household income, covering hospital, medical, and nursing facility services.¹⁰⁹ Patients with Medicare and private insurance likely have higher socioeconomic status and access to higher quality care than those with Medicare and Medicaid, while patients with Medicare-only may be particularly vulnerable if they fall into a coverage gap in which their income is above their state's eligibility for Medicaid but below the poverty line.¹¹⁰

The presence of an advance directive, defined as written instructions about the treatment the patient wished to receive during the final days of life, was dichotomized as “yes” (reference category) or “no.” Research suggests that advance directives are associated with a reduction in aggressive measures at the end of life, an increase in palliative care provision, and can serve as a proxy indicator that goals of care have been discussed with medical providers.¹¹¹

Religiosity represents a potential factor in end-of-life decision-making, with studies suggesting that more religious individuals are less likely to engage in advance care planning and more likely to desire intensive medical intervention at the end of life.¹¹²⁻¹¹⁵ In this study, religiosity was constructed as a categorical variable including: religious (attended religious

services during the last year of life [reference category]); and not religious (did not attend religious services in the last year of life).

The total number of comorbidities was included in this study as a potential measure of health status. Increased comorbidities can complicate HF treatment and reduce quality of life in HF patients.^{116,117} In this study, the presence of comorbidities was constructed as a count variable (0-8) limited to the diseases present in HRS Exit Interviews, including cancer, lung disease, stroke, hypertension, diabetes, arthritis, psychiatric issues, and dementia.

Educational attainment included: less than high school (reference category); high school graduate; and college and above. Marital status at time of death, a potential indicator of social support,¹¹⁹ was categorized as married and unmarried, which included divorced, widowed, and never married (reference category). Age at death was a continuous variable (65-111) and patient sex was categorized as female (reference category) and male.

Analyses

Logistic and negative binomial regression models were used to examine the association of racial and ethnic background and patient characteristics on symptom burden among HF patients.¹²⁰ Separate logistic regression models were used to model fatigue, shortness of breath, pain, and depression (n=1,607). Due to over-dispersion issues in the symptom count variable, negative binomial regression was used to identify factors associated with the number of symptoms in the last months of life (n=1,607).¹²⁰

Sampling weights within the HRS account for differential selection probabilities as well as potential bias resulting from survey non-response, and thus yield estimates that are nationally representative of non-institutionalized, community-dwelling adults age 51-years and older in the

U.S.^{81,83,121} Weights use respondent gender, race, ethnicity, and birth cohort as the basis for post-stratification, adjusting for sample attrition and mortality, and yielding weight sums corresponding to the number of people in the U.S. population as measured by the March U.S. Current Population Survey (CPS) for the year of data collection.¹²¹ As all respondents in the HRS Exit Interviews are deceased, the respondent-level weight in the survey wave prior to death was used to ensure that results were representative of the U.S. population.¹²¹

Analyses were performed using Stata version 17. This study was approved by the Institutional Review Board (IRB) at the University of California, Los Angeles.

RESULTS

Descriptive Statistics

The majority of the analytic sample identified as White (86%) and female (56%) (Table 4). On average, patients were 83-years old at time of death (SD=8.32) and were unmarried, including divorced, widowed, or never married (65%). Approximately 64% had earned a high school diploma or higher. About half had both Medicare and private insurance (52%), about one quarter were dual-eligible recipients of Medicare and Medicaid (26%), and 23% had Medicare only. On average, patients had three comorbidities in addition to HF (SD=1.45). More than half of patients were religious (56%) and had an advance directive in place at time of death (56%). The majority reported feeling fatigue (69%), shortness of breath (75%), pain (65%), and depression (54%) in the last months of life.

Association of Racial Identity with Symptom Burden

Logistic regression results revealed that racial identity was a significant predictor of fatigue and depression at the end of life, but not shortness of breath or pain (Table 5). Holding

other variables constant, Black patients were less likely to report feeling fatigue in the last months of life (OR=0.51, CI=0.35 to 0.72, $p=0.00$) when compared with White patients, and less likely to experience depression (OR=0.38, CI=0.26 to 0.55, $p=0.00$). Black patients were similarly less likely to experience shortness of breath (OR=0.86, CI=0.54 to 1.39, $p=0.54$) than White patients, but this result was not significant. Racial identity had no effect on experiencing pain (OR=1.00, CI=0.68 to 1.48, $p=1.00$).

Factors Associated with Fatigue

Factors associated with fatigue included age, religiosity, and presence of an advance directive. Holding other variables constant, older age (OR=0.96, CI=0.94 to 0.98, $p=0.00$) and not having an advance directive (OR=0.76, CI=0.60 to 0.97, $p=0.03$) were negatively associated with fatigue. Those who were not religious were more likely to experience fatigue in the last months of life (OR=1.37, CI=1.07 to 1.75, $p=0.01$) than those who were religious, holding other variables constant.

Factors Associated with Shortness of Breath

Significant predictors of shortness of breath included number of comorbidities and age. For each additional comorbidity, a patient was more likely to experience shortness of breath (OR=1.23, CI=1.10 to 1.38, $p=0.00$), while each additional year of age made a patient less likely to have shortness of breath (OR=0.96, CI=0.94 to 0.98, $p=0.00$), holding other variables constant.

Factors Associated with Pain

Pain was associated with age, religiosity, and number of comorbidities. Patients of older age were less likely to experience pain (OR=0.95, CI=0.94 to 0.96, $p=0.00$) than those of

younger age, holding other variables constant. Not being religious (OR=1.34, CI=1.09 to 1.65, $p=0.01$) and having a higher number of comorbidities (OR=1.26, CI=1.14 to 1.38, $p=0.00$) were both predictors of increased likelihood of experiencing pain, holding other variables constant.

Factors Associated with Depression

Several factors were predictive of depression, including insurance status, presence of an advance directive, religiosity, number of comorbidities, and age. Factors that increased the likelihood of experiencing depression included being a dual-eligible recipient of Medicare and Medicaid (OR=1.60, CI=1.13 to 2.26, $p=0.01$), not being religious (OR=1.45, CI=1.10 to 1.91, $p=0.01$), and having a higher number of comorbidities (OR=1.19, CI=1.07 to 1.32, $p=0.00$), holding other variables constant. Each additional year of age made a patient less likely to report feeling depressed (OR=0.97, CI=0.95 to 0.98, $p=0.00$) than younger patients, holding other variables constant.

Factors Associated with Total Symptom Count

A negative binomial regression model examined the association of patient characteristics and total symptom count, including fatigue, shortness of breath, pain, and depression (Table 6). Results showed that the expected number of symptoms decreased for Black patients (IRR=0.87, CI=0.81 to 0.98, $p=0.01$) when compared with White patients, holding other variables constant. Not having an advance directive (IRR=0.93, CI=0.88 to 0.99, $p=0.03$) and being of older age (IRR=0.99, CI=0.98 to 0.99, $p=0.00$) were also associated with a decrease in expected number of symptoms. Being a recipient of Medicare and Medicaid (IRR=1.09, CI=1.01 to 1.18, $p=0.03$), not being religious (IRR=1.09, CI=1.03 to 1.16, $p=0.01$), and having a higher number of

comorbidities (IRR=1.06, CI=1.04 to 1.08, $p=0.00$) were associated with an increase in expected number of symptoms, holding other variables constant.

DISCUSSION

This study of patients with heart failure from a nationally representative sample of Americans over the age of 65 revealed differences between Black and White patients in symptom burden in the last year of life. Contrary to expectation, Black HF patients were not more likely than White HF patients to experience fatigue, shortness of breath, pain, or depression. In fact, Black patients were less likely to report feeling fatigue, less likely to experience depression, and less likely to report a higher symptom count overall. No significant associations were observed between racial identity and shortness of breath or pain. Our findings reveal that a range of other factors, including health status, socioeconomic status, health care access, and religiosity, were associated with unmet need for symptom management.

Our finding that Black HF patients were less likely to experience depression than White HF patients is supported by prior research indicating a similar dynamic. Several studies have demonstrated significantly lower lifetime prevalence of depression in both Black men and women when compared with White men and women.¹⁶⁸⁻¹⁷² This is qualified, however, by underdiagnosis and undertreatment of depression among Black Americans,^{173,174} as well as higher rates of chronic depression, more severe symptoms, and greater functional impairment among Black patients who are diagnosed with depression.^{168,169} Several factors may account for these differences. Cultural stigma against mental illness, limited availability of mental health resources, experiences with discrimination in the health care system, bias in the presentation and diagnosis of psychiatric symptoms among patients of color, and the unaffordability of care may all play a role in the mental health service use patterns of Black Americans.¹⁷⁴

Underreporting of symptoms among minority populations may partially account for our findings that Black HF patients are less likely to report fatigue and more likely to report a lower total symptom count overall than White HF patients. Racial and ethnic inequities in pain diagnosis and management are particularly relevant. Prior research indicates that people from minority groups receive lower quality pain care than non-Hispanic White people.¹⁷⁵⁻¹⁷⁷ Many factors account for this, including provider bias and access issues to high quality health care in general, but patient-level factors such as the underreporting of pain may also play a role.^{175,178} Studies have shown that patients from minority groups are less likely than non-Hispanic White patients to report pain.^{175,178,179} However, among those with pain, patients from minority groups report higher pain severity relative to White patients.^{180,181} This tendency to underreport may extend to other medical issues beyond pain. Our findings that Black HF patients experience less fatigue and a lower symptom count overall may be more representative of symptom underreporting than actual differences, but more work is needed in this area.

Patients with an increased number of comorbidities were more likely to report shortness of breath, pain, and depression. While it makes intuitive sense that sicker individuals would experience higher symptom burden, there are also important factors to consider in the context of end-of-life care in HF specifically. Cancer remains the primary diagnosis for receipt of both hospice and palliative care,^{182,183} but illnesses like HF can produce symptoms as severe as those of cancer.^{7,17} Our findings support the possibility that patients with HF are less likely to receive key elements of high quality end-of-life care that may account for higher symptom burden at the end of life.¹⁸⁴

Additionally, we found that those who did not identify as religious were 45% more likely to experience depression than those who were religious. They were also more likely to

experience fatigue and pain. This is in line with previous research indicating that spiritual wellbeing is associated with lower levels of depression in HF, which may moderate overall symptom burden.¹⁸⁵⁻¹⁸⁹

Patients of older age were slightly less likely to experience fatigue, shortness of breath, pain, or depression than younger patients. This finding is contrary to previous work demonstrating high symptom burden in HF patients of advanced age,^{142,190} but aligned with studies suggesting that younger age is a predictor of lower quality of life in HF patients.^{148,191}

Additionally, our results showed that those who did not have an advance directive in place at the end of life were less likely to experience fatigue or depression. This was also true for shortness of breath and pain, but these results were not significant. One possible explanation is that goals of care conversations between HF patients and providers are often limited and initiated late in the course of the disease.^{59,60} Those with less severe symptoms may be less likely to initiate advance care planning for themselves or have a provider initiate a goals of care conversation. HRS data do not contain information regarding HF stage or severity of HF symptoms so we were unable to test this empirically.

Implications

Our findings suggest the need for improved patient-provider communication regarding symptom management in HF at the end of life. Greater effort should be made to elicit and understand patient experience, particularly with more subjective symptoms such as fatigue, pain, and depression. An overreliance on pain and depression scales has the potential to miss more nuanced aspects of the patient experience, leading to underreporting and undertreatment. Symptoms should be explored in a multifaceted way when possible, including how a patient

perceives their symptom burden and how it impacts their social and physical functioning and quality of life.

Additionally, our findings underscore the importance of advance care planning in the context of HF. Waiting until a patient is highly symptomatic to initiate a goals of care conversation is likely to hinder the delivery of high quality end-of-life care and potentially lead to preventable suffering. Providers must speak with HF patients about their end-of-life care options early in the course of the disease and revisit the topic of advance care planning throughout the disease trajectory.

Limitations

Our study has several limitations. Although data from the HRS Exit Interviews provides insight into a wide range of content areas at the end of life, the depth available on any single measure is limited. We were unable to examine details of patients' HF diagnosis or explore degrees of symptom severity. Future research into inequities at the end of life would be stronger by linking HRS data to administrative data to acquire a more nuanced picture. Additionally, due to small sample sizes in the HRS Exit Interview data, we were unable to examine additional racial and ethnic groups beyond non-Hispanic White and non-Hispanic Black. Hispanic/Latinx and Chinese American populations in particular are at high risk of developing HF and experience persistent inequities in health care access and quality throughout the life course.^{7,10} The ongoing issue of study recruitment for minority groups requires urgent attention as inequities grow in HF epidemiology, clinical severity, and access to care at the end of life. Finally, while we were able to control for multiple factors associated with quality of care at the end of life, it is possible that important predictors of inequity in care remain unmeasured.

This study found that a range of factors, including health status, socioeconomic status, health care access, and religiosity, are associated with unmet need for symptom management at the end of life among patients with HF. Our work supports the need for better detection of symptom burden in HF patients and the importance of initiating goals of care conversations early and often.

CHAPTER 3: Tables

Table 4. Characteristics of Patients with HF Diagnosis Age 65-Years and Older, Health & Retirement Study Exit Interviews 2002-2016

	Non-Hispanic White N (%)	Non-Hispanic Black N (%)	Total N (%)
Race and ethnicity	1,374 (85.50)	233 (14.50)	1,607 (100.00)
Age			
Mean (SD)	83.78 (8.08)	80.64 (9.23)	83.32 (8.32)
Sex			
Female	760 (84.63)	138 (15.37)	898 (55.88)
Male	614 (86.60)	95 (13.40)	709 (44.12)
Education			
Less than HS	433 (75.04)	144 (24.96)	577 (35.91)
HS graduate	542 (91.09)	53 (8.91)	595 (37.03)
College & above	399 (91.72)	36 (8.28)	435 (27.07)
Marital status			
Married	490 (86.27)	78 (13.73)	568 (35.35)
Unmarried	884 (85.08)	155 (14.92)	1,039 (64.65)
Insurance status			
Medicare & Private	778 (93.62)	53 (6.38)	831 (51.71)
Medicare & Medicaid	291 (70.46)	122 (29.54)	413 (25.70)
Medicare only	305 (84.02)	58 (15.98)	363 (22.59)
Number of comorbidities			
Mean (SD)	3.25 (1.46)	3.49 (1.38)	3.29 (1.45)
Religiosity			
Religious	739 (81.57)	167 (18.43)	906 (56.38)
Not religious	635 (90.58)	66 (9.42)	701 (43.62)
Advance directive			
Yes	829 (92.94)	63 (7.06)	892 (55.51)
No	545 (76.22)	170 (23.78)	715 (44.49)
Fatigue			
Yes	971 (87.64)	137 (12.36)	1,108 (68.95)
No	403 (80.76)	96 (19.24)	499 (31.05)
Shortness of breath			
Yes	1,019 (85.06)	179 (14.94)	1,198 (74.55)
No	355 (86.80)	54 (13.20)	409 (25.45)
Pain			
Yes	883 (84.58)	161 (15.42)	1,044 (64.97)
No	491 (87.21)	72 (12.79)	563 (35.03)
Depression			
Yes	775 (89.18)	94 (10.82)	869 (54.08)
No	599 (81.17)	139 (18.83)	738 (45.92)
Number of symptoms			
Mean (SD)	2.64 (1.22)	2.44 (1.20)	2.61 (1.22)

Table 5. Association of Patient Characteristics with Fatigue, Shortness of Breath, Pain, and Depression for Patients with HF Diagnosis

Independent variable	Fatigue (n=1,607)		Shortness of breath (n=1,607)		Pain (n=1,607)		Depression (n=1,607)	
	Odds ratio (95% CI)	p-value	Odds ratio (95% CI)	p-value	Odds ratio (95% CI)	p-value	Odds ratio (95% CI)	p-value
Race and ethnicity								
<i>Non-Hispanic Black</i>	0.51* (0.35-0.72)	0.00	0.86 (0.54-1.39)	0.54	1.00 (0.68-1.48)	1.00	0.38* (0.26-0.55)	0.00
Insurance status								
<i>Medicare & Medicaid</i>	1.23 (0.85-1.74)	0.28	1.56 (0.95-2.57)	0.08	1.26 (0.84-1.88)	0.26	1.60* (1.13-2.26)	0.01
<i>Medicare only</i>	0.97 (0.68-1.37)	0.84	1.89 (0.89-1.58)	0.23	1.08 (0.80-1.45)	0.61	1.12 (0.80-1.57)	0.51
Advance directive								
<i>No</i>	0.76* (0.60-0.97)	0.03	0.85 (0.65-1.11)	0.24	0.92 (0.72-1.18)	0.51	0.75* (0.58-0.98)	0.03
Religiosity								
<i>Not religious</i>	1.37* (1.07-1.75)	0.01	1.24 (0.93-1.65)	0.14	1.34* (1.09-1.65)	0.01	1.45* (1.10-1.91)	0.01
Number of comorbidities	1.10 (0.99-1.22)	0.09	1.23* (1.10-1.38)	0.00	1.26* (1.14-1.38)	0.00	1.19* (1.07-1.32)	0.00
Education								
<i>HS graduate</i>	0.87 (0.68-1.11)	0.26	0.86 (0.62-1.18)	0.34	0.91 (0.66-1.23)	0.53	1.08 (0.82-1.41)	0.59
<i>College & above</i>	0.98 (0.72-1.33)	0.89	1.03 (0.81-1.30)	0.82	0.89 (0.67-1.18)	0.41	0.82 (0.57-1.18)	0.27
Marital status								
<i>Married</i>	1.23 (0.96-1.58)	0.10	0.97 (0.66-1.44)	0.88	0.98 (0.76-1.28)	0.90	1.06 (0.79-1.41)	0.71
Age	0.96* (0.94-0.98)	0.00	0.96* (0.94-0.98)	0.00	0.95* (0.94-0.96)	0.00	0.97* (0.95-0.98)	0.00
Sex								
<i>Male</i>	0.85 (0.65-1.11)	0.23	0.89 (0.67-1.19)	0.43	0.83 (0.64-1.07)	0.14	0.93 (0.72-1.19)	0.55

*p<0.05

Table 6. Association of Patient Characteristics with Total Symptom Count for Patients with HF Diagnosis

Independent variable	Total symptom count Negative binomial regression results (n=1,607)	
	Incidence rate ratio (95% CI)	p-value
Race and ethnicity		
<i>Non-Hispanic Black</i>	0.87* (0.81-0.98)	0.01
Insurance status		
<i>Medicare & Medicaid</i>	1.09* (1.01-1.18)	0.03
<i>Medicare only</i>	1.00 (0.92-1.08)	0.94
Advance directive		
<i>No</i>	0.93* (0.88-0.99)	0.03
Religiosity		
<i>Not religious</i>	1.09* (1.03-1.16)	0.01
Number of comorbidities	1.06* (1.04-1.08)	0.00
Education		
<i>HS graduate</i>	1.00 (0.93-1.07)	0.91
<i>College & above</i>	0.99 (0.91-1.07)	0.76
Marital status		
<i>Married</i>	1.02 (0.94-1.09)	0.66
Age	0.99* (0.98-0.99)	0.00
Sex		
<i>Male</i>	0.97 (0.91-1.04)	0.42

*p<0.05

CHAPTER 4: Sociocultural Barriers in Dementia Care: Hispanic/Latinx Caregivers' Perspectives on Interactions with the Health Care System in the United States

INTRODUCTION

There are an estimated five million adults age 65 and older living with Alzheimer's disease and related dementias (ADRD) in the United States (U.S.), a number projected to increase to nearly 14 million by 2060.¹⁹² Racial and ethnic minority groups have an increased risk of ADRD, with older Hispanic/Latinx Americans disproportionately more likely to have ADRD than older White Americans.^{39,49,193} The Centers for Disease Control and Prevention reports that the number of Hispanic/Latinx adults age 65 and older will nearly quadruple by 2060, and Hispanic/Latinx older adults will face the largest increase in ADRD of any racial or ethnic group in the United States.³⁹

ADRD is a complex medical and psychosocial disease, leading to cognitive deterioration, behavioral changes, and often severe functional limitations.³⁸ The health care system tends to focus primarily on the medical component of care, but many older adults with ADRD also require significant custodial care. Long-term services and supports in the United States encompass a variety of health, health-related, and social services that assist individuals with functional limitations, but are often fragmented, expensive, and low quality.^{42,194} As a result, informal, unpaid care, often by family members, is the primary source of custodial care, with more than 11 million Americans providing unpaid care for people with ADRD.⁴⁰ The burden of caring for a person with ADRD is high, involving a significant expenditure of time, energy, and money providing personal care and navigating the health care system.⁴³ Twice as many ADRD caregivers report emotional, financial, and physical challenges when compared with caregivers of people in other illness populations.⁴⁴

While similarities in the responsibilities and activities of caregiving exist across racial and ethnic groups,⁴⁵ only recently have population-based studies examined racial inequities in caregiving for older adults.^{46,47} When compared with White ADRD caregivers, for example, Hispanic/Latinx caregivers indicate greater care demands, lower utilization of formal supportive services, lower levels of physical well-being, and higher rates of depression.⁴⁵⁻⁴⁸ Racism and discrimination in the health care system may account for some of the inequities observed in caregiving. Discrimination is characterized as differential treatment of groups based on race, and can occur at the structural, organizational, and clinical levels.^{129,195,196} This can manifest as differences in environmental exposures and opportunities, differential access to health care, and differential care within the health care system.¹⁹⁶ Experiencing discrimination at any level can lead to adverse health outcomes, including delayed care and lack of treatment adherence.^{129,197-201} A recent nationally representative survey found that 20 percent of Hispanic/Latinx adults reported experiencing discrimination in clinical encounters, and 17 percent said that anticipated discrimination led them to avoid seeking health care for themselves or a family member.²⁰² Echoing this, a recent survey conducted by the Alzheimer's Association found that discrimination posed a barrier to ADRD care, with approximately one third of Hispanic/Latinx Americans reporting experiencing discrimination when seeking health care for themselves or a relative.⁴⁹

Despite growing evidence that racism and discrimination pose a critical barrier to high quality ADRD care, there has been little direct exploration of discrimination in the ADRD caregiving literature. This study aims to examine Hispanic/Latinx ADRD caregivers' perspectives on interactions with the health care system, use of formal and informal supports, and experiences with racism and discrimination in medical contexts.

METHODS

This study involved in-depth interviews with community-based informal caregivers of Hispanic/Latinx patients with ADRD in the greater Southern California area.

Participant Recruitment

We targeted caregiver recruitment using a purposive sampling strategy, a technique of deliberately selecting participants who can provide the most relevant information based on the study's research questions and goals.²⁰³ Inclusion criteria for this study included individuals who (1) were over 18 years of age, (2) identified as Hispanic/Latinx, and (3) served as an unpaid/informal caregiver for a friend or family member with ADRD who also identified as Hispanic/Latinx. Participants were recruited in a variety of ways. We sent information about the study to community-based and religious organizations offering support services for caregivers, and participants followed up via email or telephone if interested in participating. We also published a study description in the newsletter of a large academic medical center in Los Angeles, CA and partnered with a geriatrician to obtain direct referrals. Snowball sampling was also used, wherein interview participants are asked to refer others to the study.²⁰⁴ The research team conducted short participant screenings via email or telephone to determine study eligibility and to gather demographic information.

Data Collection

Interviews were conducted via telephone by two members of the research team at a time convenient to participants and lasted between 30 and 90 minutes each. Participants received a \$60 gift card to a local retailer as compensation for their time. English or Spanish was spoken according to participant preference. All research activities were approved by the University of

California, Los Angeles and Cedars-Sinai Medical Center Institutional Review Boards, and interview participants provided informed consent prior to the interviews.

A multidisciplinary team of advisors from geriatrics, health equities research, and qualitative methods helped develop a semi-structured interview guide based on subject matter expertise, qualitative experience, and review of the literature. The interview protocol is available in Appendix Table C. Participants were asked about interactions with the health care system, utilization of formal and informal supports, and experiences with racism and discrimination in the health care system. A pilot interview was performed leading to minor revisions of the interview guide.

Data Analysis

All interviews were recorded with permission from participants and transcribed verbatim. Interviews in Spanish (1) were translated to English for analysis. We used a directed content analysis approach,²⁰⁵ creating an initial coding framework guided by our research questions using extant literature on ADRD caregiving and health equity research. One member of the research team coded all transcripts using NVivo (released in March 2020). The coding process involved reviewing transcripts to identify meaningful segments of text, categorizing these segments using the coding framework, and collapsing these categories into themes.^{203,205} Themes were then reviewed by a second member of the research team and discussed between researchers. Coding disagreement was reconciled via consensus and transcript review if needed. The initial coding framework was revised throughout the coding process and expanded inductively to include subthemes.

RESULTS

A total of eight caregivers participated in interviews (Table 7). The majority of caregivers were female (n=6) and ranged in age from 30- to 95-years old. Caregivers identified as Mexican, Chicano, Venezuelan, Peruvian, and Salvadoran. All caregivers were family members of the person with ADRD (daughter=3; wife=2; son=1; granddaughter=1; grandson=1). Most caregivers were college graduates or had attended some college (n=7), and most were first-generation American citizens (n=5). Half of the ADRD patients for whom they cared were female and half were male, ranging in age from 76- to 98-years old. Caregivers identified their relatives as Mexican, Mexican-American, Venezuelan, Salvadoran, and multiethnic. All persons with ADRD had a high school education or less and were immigrants to the United States.

Two major themes emerged from interview conversations: (1) the existence of *sociocultural barriers to care* within the health care system; and (2) the importance of *community-based support services*. Table 8 includes interview themes and subthemes.

Sociocultural Barriers to Care

Caregivers described facing numerous sociocultural barriers to care when navigating the health care system on behalf of their relatives with ADRD. Sociocultural barriers include the overlap and integration of social factors like socioeconomic status and cultural factors such as health beliefs and behaviors, and can occur at the structural, organizational, and clinical levels of the health care system.¹⁹⁵

Structural barriers to care included language barriers and feelings of marginalization in medical contexts. While most of the caregivers spoke English, their relatives with ADRD were native Spanish speakers. Caregivers reported being offered a translator for medical appointments, but some felt like this was viewed by medical personnel as an inconvenience. “It's

like, “oh she needs a translator.” It just seems like a burden,” explained one caregiver.

Additionally, simply translating medical information was not seen as sufficient. Caregivers expressed a desire for greater understanding of cultural nuances when communicating with health care professionals. Said one caregiver:

Translating what the dietician is saying word for word is much different than someone who understands the cultural background. I mean that person doesn't have to be Latino, but that person can know a little bit more about Latino culture or a little bit more about the different foods or a little bit more about [...] that kind of cultural background.

While no one reported overt acts of racism, there was an underlying feeling of marginalization when navigating the health care system. As one caregiver explained: “Speaking Spanish or coming from a different cultural background is seen as an obstacle, seen as a difficulty. [...] English and American are the center of every way that everything is taught and explained.” Overall, caregivers experienced marginalization as a subtle, insidious force rather than a specific encounter with a particular medical professional. “It's definitely difficult. It's systemic, it happens at multiple levels. It's not bad, it's just kind of [like] neglect,” explained one caregiver.

Caregivers also described organizational and clinical barriers to care, including a lack of trust in the health care system, a desire for racial and ethnic concordance with providers, and the need for providers to better understand the cultural background of patients. A feeling of mistrust in the health care system came up across interviews. While caregivers reported many positive interactions with individual health care providers, there were also instances where they felt they did not receive optimal care. It was difficult for the caregiver to judge if this was because of prejudice on the part of the provider or some other factor. When asked if she had experienced prejudice or racism in a health care setting, one caregiver questioned a particular interaction she had with her husband's physician:

They ran all sorts of tests and they did find a small problem. [...] And he said, “There’s nothing left to do anymore.” And I said, “How can it be possible? Some people have the surgery and it improves that situation.” And he said, “No.” Well, I didn’t feel satisfied with his answer and I asked the primary care physician to refer me to another specialist for a second opinion.

Other caregivers described feeling more comfortable interacting with doctors with a White family member in the room. They believed this provided a barrier against discrimination and made it easier to communicate. Said one caregiver, “We haven't really experienced racism, [...] I think we've been very fortunate. [...] Maybe because my husband is White.”

One way caregivers dealt with feelings of mistrust was by seeking out providers of the same race or ethnicity. Some caregivers felt more comfortable expressing themselves and more easily understood by providers with a shared cultural background. “There was a Spanish speaking provider so that sealed the deal. The Spanish speaking provider [...] that I knew, that I trusted, was good,” said one caregiver. Another caregiver described her father’s experience at an adult day center: “Most of the caregivers were Latin American women, so this obviously facilitated my father's state of mind because he just felt that he was back home.” Seeking care from a provider of the same race or ethnicity was not always a positive thing, however. In the case of one caregiver, the instinct to seek care from a provider of similar background led to suboptimal care for her grandmother:

Instead of getting her a good doctor, [...] she ended up choosing this doctor that was from [...] El Salvador. [...] She was even going to another place where it was all Latinos, but it was very, very badly maintained. [...] It's like a fear of being discriminated [against] that keeps us in this mentality of "I guess this is the only option we have."

Seeking Support Outside the Medical System

Caregivers spoke about the importance of community-based support services as a means of filling in the gaps they experienced in the health care system. Many caregivers expressed positive interactions with different organizations. One caregiver explained that she often had

trouble reaching her grandmother's doctors but felt very supported by her local senior center. She said: "[They] do a really good job of sending out emails and letters in case someone needs support. I feel like [...] I could always talk to them, and the best part is that they've given me their cell phone numbers. So I can call them [anytime]." Another caregiver said of her father: "It became very clear to us that [the adult day center] was the most important thing in his life. That's the thing that I really need you to understand. It was the most important thing in his life. [...] It was just really amazing."

While caregivers spoke about the benefits of different community-based support services, issues with accessing these resources were mentioned across interviews. Caregivers either did not know about existing support services or when they did know, were unsure of how to or unable to access them. Many caregivers described having to advocate for their relatives with ADRD by searching for support services themselves. "There is help out there, we do the research and try to find the help," said one caregiver. Another wished that medical institutions had better systems for sharing information: "I think there should have been maybe some more sharing across the institutions. [...] At least the dementia programs. [All the big hospitals] have a geriatric dementia program. [...] More communication among those and pooling of resources would be good."

The COVID-19 pandemic created a major challenge in accessing resources after much of Southern California went under lockdown orders. "There's a lot of different aid, but there's a pandemic right now that kind of shut stuff down. [...] When that center was open, I was able to take her two or three days out of the week where I can get some time to myself," said one caregiver. Another caregiver explained that her husband had lost his job because of the pandemic and the burden of financially supporting the family now fell on her. This made it difficult to

utilize support services for herself and her relative with ADRD. “[The senior center] offers a support group I think twice a month. It's Tuesday afternoons. And that's when I'm working,” she said.

DISCUSSION

This qualitative study used in-depth interviews with caregivers of Hispanic/Latinx ADRD patients to examine perspectives on interactions with the health care system, use of formal and informal supports, and experiences with racism and discrimination in medical contexts. Two major themes shed light on the subtle ways racism can manifest in medical interactions and how Hispanic/Latinx caregivers navigate these challenges. Key findings include discrimination as an important barrier to high quality care and the continued challenge of acquiring both formal and informal support.

Caregivers noted underlying feelings of marginalization while navigating the health care system. This presented primarily through language barriers and a lack of cultural understanding on the part of medical providers. Many previous qualitative studies with ethnically diverse ADRD caregivers support our findings that Spanish-speaking patients face major obstacles in accessing high quality care.^{45,47,206,207} Interestingly, we found that these feelings persist even when translators are present. Simply addressing the language barrier alone is not sufficient in addressing caregivers’ concerns. Additionally, caregivers reported that many providers seemed well intentioned but lacked the cultural knowledge to address their concerns. A recent survey by the Alzheimer’s Association found that an overwhelming majority of non-White Americans say it is important for ADRD care providers to understand their unique experiences and backgrounds, but do not feel confident that they will be able to access culturally competent providers.⁴⁹ Similarly, a recent study assessing the LGBT cultural competency of ADRD care

providers found that providers reported very high affirming attitudes about working with the LGBT population but only moderate knowledge about specific issues important to LGBT health care.²⁰⁸ Our findings support the possibility that a similar dynamic is present across other minority groups, including Hispanic/Latinx ADRD caregivers.

Feelings of cultural marginalization among caregivers fostered mistrust in the health care system. Medical mistrust was defined in a recent systematic review as a “tendency to distrust medical systems and personnel believed to represent the dominant culture in a given society.”²⁰⁰ Everyday experiences of discrimination as well as prior negative experiences in the health care system are associated with medical mistrust, and those who experience racism are more likely to report lack of trust in the health care system, lower satisfaction with health services, and poor quality communication with health care providers.^{197,200,209,210} The caregivers in this study took several steps to combat mistrust, including seeking out providers of the same race or ethnicity and seeking support outside the medical system. While many studies have found that patients express a preference for racially and ethnically concordant health care providers, there is limited research on the reasons underlying these preferences.^{133,211-214} Our findings suggest that language barriers and fear of discrimination are important factors in the care-seeking behavior of Hispanic/Latinx ADRD caregivers.

Additionally, seeking support outside the medical system was common amongst caregivers in our study, but often this did not entirely address their needs. Information about available community-based support services was difficult to find, and even when caregivers knew about resources, it was often challenging to access them. This finding is confirmed by recent research about barriers to service use among ADRD family caregivers, which found that

the inability to find information about relevant supports and the inflexibility of services were among the largest barriers to access.²¹⁵

Limitations

This qualitative study employed a small sample size in a coastal urban area, and thus findings are not intended to be representative. We recruited participants from the Southern California area using community-based organizations, physician referrals, and promotion in an online newsletter. This likely produced a sample that is more urban, more involved in the community, more likely to see a doctor, and more technologically savvy than average. Furthermore, Hispanic/Latinx people represent a heterogeneous group of different nationalities, ethnicities, races, generational statuses, and levels of acculturation that is reflected in our sample, and results should not be interpreted as representative of all Hispanic/Latinx individuals.²¹⁶

Additionally, recruitment issues due to COVID-19 pandemic restrictions made it difficult to assess if thematic saturation was achieved.^{217,218} We were unable to visit community-based and religious organizations in person to promote the study and obtained only a small number of physician referrals due to reduced patient volume in specialty care. While past research demonstrates that 10 or fewer interviews often produce the majority of salient themes in interview and focus group analyses,²¹⁹⁻²²² it is likely that additional interviews would have revealed meaningful insight.

Finally, we did not examine experiences of discrimination due to caregivers' other social identities, such as gender or sexual orientation, which may create compounding experiences of discrimination.²²³ We were also unable to analyze responses by level of acculturation, or the degree to which an individual has adopted the values of the dominant culture of the country they

have immigrated to, an important factor in cognitive health and health care access.^{224,225} Future studies of discrimination in ADRD care should explore other forms of discrimination and levels of acculturation among first- and second-generation citizens to obtain a more complete picture across a variety of minority groups.

Despite these limitations, our study highlights the importance of examining interactions with the health care system across different racial and ethnic minority groups and hearing directly from caregivers about how racism and discrimination impacts their lives.

Implications

Several recommendations for practice arise from our research. At the structural level, there is a real need for proactive interventions addressing language barriers for non-English speaking patients and caregivers. Culturally and linguistically appropriate health education materials about ADRD, caregiving, and available eldercare resources are urgently needed. Many caregivers either did not know about existing support services or when they did know, were unsure of how to or unable to access them. Better coordination between health care systems and community-based organizations is necessary to connect patients and caregivers with resources to support custodial care. At the organizational level, our findings highlight the necessity of recruiting, hiring, and supporting a diverse health care workforce that better reflects the populations served. At the clinical level, ongoing cultural competence and cultural humility training for providers is necessary to equip providers with knowledge and skills to address sociocultural issues. Finally, at every level there is a need for direct collaboration with caregivers from racial and ethnic minority groups to develop effective and relevant interventions and supportive resources.

CHAPTER 4: Tables

Table 7: Demographics of Interview Participants

Caregiver gender	Caregiver age	Caregiver identity	Caregiver education	Caregiver generational status	Caregiver relationship to PWD*	PWD gender	PWD age	PWD identity	PWD education	PWD generational status
Female	52	Peruvian	College graduate	Immigrant	Daughter	Female	98	Multiethnic, unspecified	<HS	Immigrant
Female	34	Salvadoran	Some college	First generation American citizen	Granddaughter	Female	88	Salvadoran	<HS	Immigrant
Male	30	Chicano	College graduate	First generation American citizen	Son	Female	78	Mexican-American	<HS	Immigrant
Male	41	Salvadoran	Some college	First generation American citizen	Grandson	Female	88	Salvadoran	<HS	Immigrant
Female	34	Mexican	Some college	First generation American citizen	Daughter	Male	76	Mexican	<HS	Immigrant
Female	57	Mexican	<HS	Immigrant	Wife	Male	76	Mexican	<HS	Immigrant
Female	65	Venezuelan	Doctoral degree	First generation American citizen	Daughter	Male	95	Venezuelan	HS graduate	Immigrant
Female	95	Venezuelan	Master's degree	Immigrant	Wife	Male	95	Venezuelan	HS graduate	Immigrant

*Person with dementia

Table 8: Themes & Subthemes

Theme	Definition	Example
Sociocultural Barriers to Care		
<i>Structural</i>		
Language barriers	Difficulty communicating with health care providers due to language differences and lack of culturally and linguistically appropriate health education materials	<i>“[It’s been hard to get a referral for the neurologist.] Right now, since it’s my mom being his primary caregiver, I don’t know if it’s a language barrier thing.”</i>
Marginalization	A feeling of insignificance in the health care system	<i>“It’s not that we were treated poorly. It’s not that the care wasn’t at a good level, it’s that [...] it’s not culture first. It’s not really person-centered. [...] It was, like, American-person-centered.”</i>
<i>Organizational</i>		
Racial and ethnic concordance	Desire for health care providers to match the race and/or ethnicity of the patient	<i>“She was familiar with my mom. I’m familiar with her. And we’ve talked many times at the hospital, so I decided to choose her. So now she is my mom’s main doctor.”</i>
<i>Clinical</i>		
Medical mistrust	Distrust of health care providers and the health care system	<i>“It might not be direct racism, but I do believe that it has something to do with the fact that people in general feel scared to be discriminated against.”</i>
Cultural competency/cultural humility	Desire for health care providers to better understand the cultural background of their patients	<i>“My mother’s been living in the United States for a really long time. She’s an American. But it doesn’t take into account the cultural aspects of care. And if you’re treating that person holistically, it has to be part of it.”</i>

Table 8, continued.

Seeking Support Outside the Medical System		
Community-based support services	The importance of community-based support services as a means of filling in gaps experienced in the health care system	<i>“She used to go [to the senior center] at least four times a week, if not the five. And she loved to sit there. And she got to exercise and play with kids. And she was extremely happy.”</i>
Access issues	Difficulties locating and accessing available resources	<i>“I would like to be able to be in a support group where I can hear what other people are going through and where they might have some speakers to talk about strategies on how to handle certain things. [...] I wish I could talk to more people that are going through the same things.”</i>

CHAPTER 4: Appendix

Appendix Table C: Interview Guide

<i>Question</i>
1. Tell us about the doctors or other providers you have met with and talked to about your loved one. <i>Probe: What was the last visit like? What did you talk about?</i>
2. Do you feel that you are getting the support you need as a caregiver? <i>Probe: What has been most helpful to you? What do you feel is missing or lacking?</i>
3. If you could have anything you wanted to help improve your loved one's quality of life, what would it be?
4. Have you ever experienced feeling/thinking like you were not offered optimal care because of racism or prejudice? <i>Probe: What was that like for you and your loved one?</i>

CHAPTER 5: CONCLUSION

The three papers in this dissertation aimed to examine differences between racial and ethnic groups in the quality and experiences of care for older adults with chronic illness. In Chapters 2 and 3, I examined outcomes at the end of life, including treatment intensity and symptom burden, among non-Hispanic Black and non-Hispanic White older adults with heart failure (HF). In Chapter 4, I examined the perspectives of Hispanic/Latinx caregivers of persons with Alzheimer's disease and related dementias (ADRD) on interactions with the health care system, use of formal and informal supports, and experiences with racism and discrimination in medical contexts.

Key Findings

Racial Identity is a Significant Predictor of Treatment Intensity at the End of Life

The results from Chapter 2 suggest that Black patients with HF undergo more aggressive medical intervention at the end of life and are more likely to die in a hospital than White patients. Analysis of a nationally representative sample of Americans 65-years and older revealed that Black patients with HF were more likely to die in a hospital and more likely to spend time on life support in the last months of life relative to White HF patients.

Racial differences in end-of-life treatment intensity among HF patients have not been described previously but are consistent with findings from other illness groups. Differences between Black and White Americans in hospital admissions, intensive care unit (ICU) admissions, life support utilization, and place of death have been observed in cancer and non-disease specific populations.^{36,68,69,72} Additionally, prior work suggests that advance directives are related to less burdensome medical intervention, lower likelihood of dying in a hospital, and

more frequent receipt of palliative care, and that Black older adults have lower rates of advance directive completion than White older adults.^{111,122} I found in Chapter 2 that Black HF patients were less likely to have an advance directive in place when compared with White HF patients, which may partially explain the higher odds of utilizing life support and dying in a hospital.

A Range of Factors, Including Health Status, Socioeconomic Status, and Religiosity, Are Associated with Symptom Burden at the End of Life

Findings from Chapter 3 indicate that HF patients with a higher number of comorbidities, those who were not religious, and those who were dual-eligible recipients of Medicare and Medicaid were more likely to experience unmet need for symptom management at the end of life. Contrary to expectation, Black HF patients were not more likely than White HF patients to experience fatigue, shortness of breath, pain, or depression in the last months of life. In fact, Black patients were less likely to report feeling fatigue, less likely to experience depression, and less likely to report a higher symptom count overall.

Barriers to High Quality Dementia Care Occur at Multiple Levels of the Health Care System

The results of Chapter 4 highlight structural, organizational, and clinical barriers to care reported by Hispanic/Latinx caregivers of ADRD patients. At the structural level, language barriers and feelings of marginalization in medical contexts were noted across interviews. Caregivers described communication difficulties due to language differences and an absence of linguistically appropriate health education materials. They also spoke of a feeling of insignificance in medical interactions and a feeling that the medical system was oriented toward the dominant White American culture. At the organizational level, caregivers expressed a desire for racial and ethnic concordance with their providers. Several described seeking out providers of

the same racial or ethnic background as this created a feeling of trust and minimized opportunities for discrimination. Barriers at the clinical level included medical mistrust and the need for increased cultural competency and humility among providers. Caregivers said that while most providers seemed well intentioned, they observed that providers frequently lacked the cultural knowledge to fully address their concerns.

Additionally, seeking support outside the medical system was common amongst caregivers, but often this did not entirely address their needs. Information about available community-based support services was difficult to find and even when caregivers knew about resources, it was often challenging to access them.

Synthesizing the Findings

Taken together, the results of this dissertation contribute to the growing evidence base documenting health inequities in quality and experiences of care in chronic illness.

Discrimination emerged directly and indirectly across the three papers as a barrier to high quality care among older adults with chronic illness. Discrimination was directly discussed in my qualitative analysis in Chapter 4. Hispanic/Latinx caregivers described feeling that they sometimes received suboptimal care due to their race or ethnicity, or the race or ethnicity of their relative with ADRD. As a result of past experiences with discrimination in medical contexts, a general feeling of distrust in the health care system developed. Medical mistrust led caregivers to seek out providers of the same race or ethnicity, have a White family member attend medical appointments with them, or seek out community-based support services where they felt more comfortable.

In my quantitative analyses in Chapters 2 and 3, discrimination was not directly measured. However, racial differences in outcomes among older adults with HF persisted after controlling for a wide range of patient characteristics. In particular, the effects of racial identity on treatment intensity at the end of life were only partially mediated by other social determinants of health. This suggests the possibility of unobserved heterogeneity, which could include factors similar to the issues discussed among ADRD caregivers in Chapter 4, such as racism and discrimination in the health care system and medical mistrust.

Implications

The results of this dissertation have important implications for policy and practice. First, I would like to highlight the importance of advance care planning among racial and ethnic minority groups, in HF specifically and chronic illness generally. Advance care planning is associated with increased palliative care utilization and the provision of goal-concordant care, yet advance directives are an underutilized tool in chronic disease management, particularly among patients of color. Since the onset of the COVID-19 pandemic, policies have been enacted at the federal and state levels with implications for advance care planning, particularly around telehealth. In 2020, the Centers for Medicare and Medicaid Services released waivers allowing payment for advance care planning conversations between Medicare beneficiaries and their providers over the telephone²²⁶ and several states have issued executive orders allowing remote notarization of certain legal documents, including advance directives.²²⁷ These policies were intended to expand access to advance care planning, but more work needs to be done in this area. Goals of care conversations must be initiated early and often in the course of chronic illness, and it is crucial to equip providers with the necessary skills to do so. Supplementary training and support for advance care planning should be made available to a wide range of providers.

Additionally, it is essential to expand the types of providers who can have advance care planning conversations with patients. Currently, only physicians, nurse practitioners, and physician assistants can bill Medicare for advance care planning reimbursement. Empowering and paying social workers and other credentialed nurses to initiate these conversations would expand access to this vital service.

Additionally, there is a real need for proactive care coordination between health care systems and community-based organizations offering supportive services to patients with chronic illness. One successful program, the Care Ecosystem model, offers personalized, cost-efficient care coordination to ADRD patients and their caregivers.²²⁸ In this telephone and web-based intervention, a care team navigator is the main point of contact for patients and caregivers. Navigators are unlicensed but trained to screen for ADRD-related needs and provide support, information, and guidance. They follow established care protocols and are supervised by a nurse or social worker. A randomized clinical trial of over 1,500 participants in rural and urban regions across three states found that the Care Ecosystem improved quality of life for ADRD patients, decreased admissions to the emergency department, and decreased caregiver burden.²²⁹ Our work supports the importance of this type of care model in ADRD and highlights the need for personalized care coordination in other chronic diseases such as HF.

Future Research

Foundational Causes of Racial and Ethnic Health Inequities

There is a urgent need to confront the issue of structural racism as a foundational cause of health inequities. Much of the work in public health and medicine regarding racial and ethnic health disparities has focused on describing differences in outcomes between populations and on

interpersonal racism as a psychosocial stressor. Structural factors in particular remain understudied. Structural racism is defined as “the totality of ways in which societies foster racial discrimination, through mutually reinforcing inequitable systems (in housing, education, employment, earnings, benefits, credit, media, health care, criminal justice, and so on) that in turn reinforce discriminatory beliefs, values, and distribution of resources, which together affect the risk of adverse health outcomes.”²³⁰ Multiple pathways exist between racism and health, including poor access to health care, environmental inequities such as poor housing conditions, underfunded schools, increased incarceration, and poor access to capital.^{13,129} Research investigating these pathways between racism and health must be prioritized going forward.

Medical Mistrust

Despite a large body of literature documenting the concept of medical mistrust, there exists a lack of clear consensus on exactly what it is, how it operates, and the foundational mechanisms underpinning it. A recent systematic review found associations between medical mistrust and demographic variables, such as race and ethnicity, income, and education level, but concluded that existing research lacks clear measurement tools, complex modeling and analyses, and inclusion of diverse patient populations.²⁰⁰ There is a real opportunity for intentional qualitative exploration of the concept of medical mistrust across patient populations of different races, ethnicities, and socioeconomic backgrounds with the goal of deepening our conceptual understanding of medical mistrust, examining the behavioral and health effects of medical mistrust, and identifying areas for intervention.

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