Achieving Goal-Concordant End-of-Life Care: The Roles of Race/Ethnicity and Advance Care Planning

by

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Dedication

This dissertation is dedicated to my husband, Matt, whose sense of humor, patient tech support, and steady love carried me through the toughest parts of the graduate school journey and played a crucial role in the successful completion of this dissertation; and to the son we never got to meet, who taught us so much about deep grief and enduring love.
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Finally, I am grateful to the central Pennsylvanian older adults who allowed me to care for them in their last days of life and to the small but mighty palliative care team at Mount Nittany Medical Center in State College, PA who so expertly educate their colleagues, patients, and patients’ loved ones on the benefits of palliative care at all stages of wellness and illness. Caring for older adults in their last phase of life can be hard work, but it is good, important work, and I am grateful for and proud of all who do so with grace, kindness, and respect.
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Abstract

Goal-concordant care, care that aligns with patients’ preferences, values, and goals, is an important component of quality healthcare, particularly for seriously ill older adults approaching the end of life who commonly face a period of increased contact with the healthcare system. Advance care planning (ACP) provides space for patients to identify their preferences, values, and goals regarding future healthcare treatment via advance directives (i.e., formal ACP) or goals-of-care conversations with loved ones and providers (i.e., informal ACP). ACP has been promoted as a means to achieve goal-concordant care, reduce overly intensive end-of-life care, and improve both patient and family member outcomes. Unfortunately, substantial research suggests inadequate completion of advance directives, particularly among racially and ethnically minoritized groups. Further, little is known about racial/ethnic differences in the prevalence of informal ACP among older adults and few studies have explored the relationship between either ACP type and goal-concordant end-of-life care among a racially and ethnically diverse sample of older adults. Finally, no studies known to this author have examined how either ACP type impacts the health-related bereavement outcomes of recently bereaved loved ones.

The purpose of this dissertation was to examine the use of formal and informal ACP among a racially and ethnically diverse sample of older adults and to identify relationships between both ACP types, goal-concordant end-of-life care, and the health-related bereavement outcomes of recently bereaved partners. This dissertation includes three manuscripts that summarize findings from studies using data from the 2012-2018 waves of the nationally representative, longitudinal Health and Retirement Study. The first manuscript summarizes...
findings from sequential, multinomial logistic regression modeling used to assess relationships between race/ethnicity and ACP type (i.e., no ACP, informal ACP only, formal ACP only, or both ACP types). Non-Hispanic Black and Hispanic respondents were more likely to report no ACP and less likely to report both ACP types compared to non-Hispanic White respondents. The second manuscript describes a study examining the relationship between the two ACP types and goal-concordant end-of-life care and examining whether the relationship between ACP types and goal-concordant care differed by race/ethnicity. Multivariable logistic regression models showed that informal ACP was associated with significantly higher odds of goal-concordant care, and formal ACP increased the predicted probability of goal-concordant care for Black respondents.

The third manuscript describes the final study, which used multivariable ordinal and negative binomial regression to examine the association between decedents’ ACP and their bereaved partners’ self-rated health and depressive symptoms, respectively. Neither formal ACP nor informal ACP were significantly associated with bereaved partners’ self-rated health or depressive symptoms.

In summary, this dissertation supports important relationships between ACP, race/ethnicity, and end-of-life outcomes. Specifically, our findings indicate that informal ACP contributes to goal-concordant care, but racial/ethnic differences remain in ACP use and disparities may be present in receipt of goal-concordant care at the end of life. Future work must identify mechanisms for engraining appropriate ACP into routine healthcare for older adults, adapting existing ACP interventions to the needs and preferences of a racially and ethnically diverse older adult population, and addressing ongoing racial and ethnic disparities in end-of-life planning and care.
Chapter 1 Introduction

Goal-concordant care, care that aligns with patients’ preferences, values, and goals, is an important component of quality healthcare, particularly for seriously ill older adults approaching the end of life. Older adults in the United States commonly face a period of increased contact with the healthcare system and intensive, life-sustaining treatments in their final months and weeks (Cardona-Morrell et al., 2016; Duncan et al., 2019). Such care may contribute to decreased quality of life for both dying older adults and their family members and occurs despite widespread preferences for a peaceful, comfortable death (Kinoshita et al., 2015; Miccinesi et al., 2012; Ornstein et al., 2017, 2018; Sandsdalen et al., 2015; Wennberg et al., 2009; Zhang et al., 2012). Further pursuit of a “good death”, albeit a highly individualistic and subjective phenomenon, is important to improve end-of-life care outcomes for all older adults and their families. The IOM’s 2015 report, “Dying in America,” acknowledged progress in this area but reasserted the need for improved quality in end-of-life care, including a greater focus on patient end-of-life care preferences.

Since the passage of the Patient Self-Determination Act in 1990, advance care planning (ACP) has been promoted as a means for reducing overly intensive end-of-life care, improving patient and family member outcomes, and aligning older adults’ treatment goals and preferences with actual care received (Institute of Medicine, 2015; Jimenez et al., 2018; La Puma et al., 1991). ACP supports patients in identifying their values, goals, and preferences regarding future healthcare. Unfortunately, substantial research indicates inadequate completion of advance
directives across the United States, and there is little evidence to support associations between either advance directives or goals-of-care conversations and the receipt of goal-concordant care (Brinkman-Stoppelenburg et al., 2014; Jimenez et al., 2018; Morrison, 2020). The dearth of evidence regarding an association between ACP and higher rates of goal-concordant care may be explained by a primary focus on legally documented advance directives (i.e., formal ACP) at the exclusion of goals-of-care conversations (i.e., informal ACP) that adults may have with their providers and loved ones (Brinkman-Stoppelenburg et al., 2014; Weathers et al., 2016).

Racially and ethnically minoritized individuals in the United States are at increased risk of poor end-of-life outcomes due, in part, to disproportionately high rates of intensive end-of-life care (Barnato et al., 2018; Orlovic et al., 2019; Ornstein et al., 2020). Several of these groups have been consistently found to have lower rates of advance directive completion than non-Hispanic White individuals (Huang et al., 2016; Portanova et al., 2017; Rahemi & Williams, 2016). This may be explained by reduced access to ACP resources, mistrust in healthcare systems that demonstrate ongoing bias and treatment disparities or, perhaps, preferences for ongoing, family-oriented decision-making processes that are routinely ignored by the more autonomy-centered, formal advance directives (Collins et al., 2018; Hansen et al., 2016; Kataoka-Yahiro et al., 2011; Lee et al., 2014). Thus, heightened attention to advance directives over the last three decades may have exacerbated existing racial/ethnic disparities in end-of-life care.

Planning for end-of-life and receiving goal-concordant care may be equally important for patients’ family members as it is for the patients themselves. Preliminary evidence suggests that goals-of-care discussions with family members may improve concordance between healthcare proxy decisions and patient preferences and reduce family member distress after the death of a
loved one (Haines et al., 2019; Houben et al., 2014; Weathers et al., 2016). Several studies also suggest that higher intensity end-of-life care contributes to poorer health outcomes among bereaved loved ones, particularly spouses (Harrop et al., 2016; Ornstein et al., 2017). Identifying effective mechanisms for improving end-of-life care decisions and outcomes may therefore improve outcomes among bereaved persons as well.

This dissertation examines the use of formal and informal ACP among a large, racially and ethnically diverse sample of older adults in the United States and the impact of formal and informal ACP on decedents and their bereaved partners. Following a thorough literature review, the first manuscript examines racial and ethnic differences in formal and informal ACP among a living sample of primarily community-dwelling older adults in the United States. The second examines the impact of these different ACP types on goal-concordant end-of-life care for older adults and racial/ethnic disparities within this relationship. Finally, the third manuscript examines the relationship between decedents’ ACP and end-of-life care and the bereavement outcomes of their older adult partners.

**Gaps in Knowledge and Manuscript Aims**

**Manuscript 1**

Published work examining racial/ethnic differences in advance directive completion has identified significantly lower prevalence among several racially and ethnically minoritized older adult groups compared to non-Hispanic White groups in the United States (Portanova et al., 2017; Sullivan & Klingman, 2019). Despite potential preferences for informal ACP among some racial/ethnic groups (Collins et al., 2018; McCleskey & Cain, 2019), no study, to date, has examined racial/ethnic differences in both advance directive completion and goals-of-care conversations among a national sample of living older adults. The purpose of this study was to
examine trends in informal and formal ACP among a national sample of living older adults as well as to explore potential mechanisms behind those trends. Findings from this study fill an important gap in the ACP literature in their examination of ACP engagement across a racially and ethnically diverse sample of older adults in the United States.

**Manuscript 2**

Goal-concordant care is widely considered to be a key indicator of quality care for older adults approaching the end-of-life (Halpern, 2019). Though the purpose of ACP is to promote patient care that aligns with their values, goals, and preferences (Sudore et al., 2017), few studies have examined the impact of current ACP types on goal-concordant care. The purpose of this study was to evaluate the relationship between informal and formal ACP and goal-concordant end-of-life care across a racially and ethnically diverse sample of older adults. A better understanding of the relationships between formal and informal ACP and goal-concordant care has the potential to guide strategies to equitably improve end-of-life care for all older adults.

**Manuscript 3**

Many individuals experience poor mental and physical health outcomes following the loss of a loved one (Stroebe et al., 2007). Spousal or partner loss is a particularly stressful event among older adults that is commonly associated with an increased risk for several chronic illnesses and mortality (Blanner et al., 2020; Ennis & Majid, 2019; Luhmann et al., 2012). Poor end-of-life communication and higher intensity end-of-life care have previously been associated with poorer outcomes among widowed persons (Harrop et al., 2016; Ornstein et al., 2017). ACP may improve bereaved loved ones’ mental and physical well-being by preparing both patients and their loved ones for end-of-life communication and decision-making. The purpose of this
study was to examine the impact of current ACP types and goal-concordant care on the overall health and emotional health of recently bereaved older adults. Results may inform end-of-life care practices for older adults that dually support dying patients and their loved ones.

**Review of the Literature**

This section begins with an overview of current end-of-life care trends among older adults in the United States and how those trends relate to prominent preferences within this group. This is followed by a brief description of ACP in the United States, as well as factors associated with advance directive completion and known racial/ethnic differences in ACP engagement. Bereavement outcomes among widowed spouses/partners are then described as well as end-of-life care and communication factors associated with those outcomes. The chapter concludes with the theoretical framework that guided this dissertation.

**Older Adults’ Preferences for End of Life**

End-of-life priorities among older adults include meaningful experiences in which individuals can connect with and say goodbye to their loved ones (Miccinesi et al., 2012; Sandsdalen et al., 2015). Across studies, patients nearing the end of life have indicated a desire to improve quality-of-life, maximize comfort, and minimize physical suffering (Heyland et al., 2017; Higginson et al., 2017; Knops et al., 2005). Indeed, one large study examining the end-of-life treatment preferences of older adults found widespread rejection of life-sustaining treatments in two hypothetical cases of terminal illness (Carr & Moorman, 2009). Meier et al. (2016) reviewed extant literature to identify common themes associated with a “good death”. Their review found “pain-free status” to be the second most-frequent theme of a good death following only “preferences for the dying process”.

5
Older adults’ healthcare treatment preferences may increasingly shift towards optimizing quality of life and reducing treatment intensity as they near the end of life. Street et al. (2012) notes that patients’ healthcare preferences are more likely to shift towards less intensive care with a change in health status or when facing a serious condition. Experiencing a change in health increased the odds that Dutch older adults reviewed their advance directive with a family member or physician (van Wijmen et al., 2018). In a study of seriously ill veterans presenting to the emergency room across the United States, those with higher risk of hospitalization or death had more requests to limit life-sustaining treatments including cardiopulmonary resuscitation (Foglia et al., 2020). In their systematic review examining preference stability, Auriemma et al. (2014) found that while more than 70% of patients’ end-of-life preferences remained stable over time, patients’ preferences to forgo therapies were generally more stable than those involving receipt of therapies. These findings suggest that older adults’ preferences shift towards less intensive care as they experience deteriorating health and are then unlikely to shift back towards intensive care.

**End-of-Life Care in the United States**

Since the early 1990’s, a growing body of research among geriatric populations has attempted to maximize quality-of-life among those with chronic illness and improve their end-of-life care and outcomes (Aziz et al., 2012). Approximately two million adults aged 65 and older die in the United States each year, a number that is expected to increase dramatically as the population ages and the older adult population grows (Kochanek et al., 2019; Vespa et al., 2020). Most older adults die of chronic illness-related causes. In 2019, the top three causes of death among adults aged 65 and older were heart disease (25.1%), cancer (20.6%), and chronic lower respiratory disease (6.3%) (Heron, 2021). Individuals with one or several of these diseases
commonly experience pain, dyspnea, depression, and anxiety, symptoms that reduce quality of life near the end of life and that may complicate the dying process (Hermann & Looney, 2011; McMillan et al., 2007; Moens et al., 2014).

Unfortunately, the continued prevalence of high-intensity end-of-life care among older adults in the United States contradicts many of the preferences described above. Intensive healthcare treatments diminish quality-of-life at the end of life and reduce the likelihood of a peaceful death in a comfortable environment. Indeed, intensive care unit stays, hospital deaths, patient worry, feeding tube use, and chemotherapy during the final week of life were all found to significantly reduce patient quality-of-life in the final week before death (Zhang et al., 2012). Researchers in Japan found that, compared to the hospital setting, the quality of death and dying was significantly higher at home where low-intervention deaths are more likely (Kinoshita et al., 2015). Substantial evidence from bereaved family members in the United States suggests that intensive care is associated with lower ratings of end-of-life care (Ersek et al., 2017; Richards et al., 2019; Wright et al., 2016).

Though older Americans are now more likely than in recent decades to receive hospice and other end-of-life care that reflects widespread preferences to forgo intensive treatment at the end of life, a significant proportion still receives overly intense end-of-life care in their final months of life (Aldridge et al., 2015). Among a random sample of Medicare fee-for-service decedents in 2015, only 40% died in a home or community setting (i.e., assisted living facility) whereas nearly 20% of decedents died in an acute care hospital and 25% in a nursing home (Teno et al., 2018). The same study identified an overall increase in the use of intensive care units in the last 30 days of life from 24% in 2000 to 29% in 2015. Others have identified similarly high rates of end-of-life intensive care unit usage in both cancer and non-cancer
populations (Iyer et al., 2020; Kim et al., 2019; Teno et al., 2018; Van Spall et al., 2021). In another recent study, 61% of Medicare sepsis survivors who died within a year of hospital discharge were admitted to an intensive or cardiac care unit in the last 30 days of life and 27% died in an acute care hospital (Courtright et al., 2020). Other recent data describe high overall rates of high intensity end-of-life care but found that rates were influenced by geographic region and whether an individual resides in a metropolitan area (Heller et al., 2019; Nicholas et al., 2011; Wang et al., 2016).

Several studies have demonstrated higher rates of intensive end-of-life care among racially and ethnically minoritized populations that have experienced long histories of discrimination and marginalization. These differences in end-of-life care may contribute to poorer quality-of-life among patients and their family members, furthering existing health disparities. Black, Hispanic, and other racially or ethnically minoritized Americans with lung cancer have been shown to have higher odds of experiencing four potentially preventable medical encounters in the last month of life, including multiple emergency department visits, multiple hospital stays, a stay in the intensive care unit, and death in an acute care setting (Karanth et al., 2018). The rate of high-intensity, intensive end-of-life care is higher in Black men with prostate cancer than White men, and racial differences in end-of-life treatment intensity may be even more pronounced in those with non-cancer diagnoses (Abdollah et al., 2015; Ornstein et al., 2020). Though disparities in hospice care have decreased in recent decades, older adults of racial/ethnic minority in the United States are still less likely to receive hospice care and more likely to have shorter hospice stays prior to death compared to non-Hispanic White older adults (Cohen, 2008; Ornstein et al., 2020; Wang et al., 2019). Though differences in end-of-life care between racial/ethnic groups may partially reflect differing preferences or
healthcare treatment goals, there remains a need for effective strategies to equitably improve quality-of-death and dying across the older adult population in the United States.

**Advance Care Planning in the United States**

Advance care planning (ACP) allows patients to identify their healthcare treatment preferences in the event that they will no longer be able to do so in the future (Institute of Medicine, 2015; Singer et al., 1998). A recently convened, multidisciplinary Delphi panel defined ACP as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care” (Sudore et al., 2017, p. 826). The panelists concurred that: 1) The goal of ACP remains to ensure that people – particularly those navigating a serious or chronic illness – receive healthcare that aligns with their values, goals, and preferences, and 2) The ACP “process” often involves choosing another person (or persons) to make medical decisions for an individual in the event that the individual can no longer make such decisions for themselves. Thus, ACP is of particular relevance to older adults who are at higher risk for many chronic illnesses and may require more assistance in decision-making than other adult populations.

ACP emerged in the final quarter of the 20th century as a proposed means for improving end-of-life care concordance with patients’ treatment goals and reducing rates of intensive and expensive healthcare at the end of life (Sabatino, 2010). In 1990, the United States Congress passed the Patient Self-Determination Act (PSDA), requiring all Medicare and Medicaid provider organizations to provide information about and access to advance directives to all patients (La Puma et al., 1991; Sabatino, 2010). Advance directives (i.e., formal ACP) are legal documents in which a patient either designates a healthcare proxy or outlines their preferences for healthcare in the event that they are unable to do so in the future. Since the passage of the
PSDA, all 50 states and the District of Columbia have passed legislation creating state-specific advance directive documents and healthcare institutions around the country have introduced their own ACP programs (Gunter-Hunt et al., 2002; Sadeghi et al., 2016).

Today, ACP typically manifests in one of two ways: 1) an advance directive, or 2) one or several goals-of-care conversations (i.e., informal ACP) in which a patient discusses their values, goals, and healthcare treatment preferences with their loved ones and/or healthcare providers. Repeated goals-of-care discussions with family members and providers allow individuals to express and update their current preferences. Individual patients may engage in one, both, or neither type of ACP. ACP may occur simultaneously with the implementation of provider orders regarding specific healthcare and treatment. A summary of the types of ACP and their definitions is found in Table 1.1.

Table 1.1 - Types of Advance Care Planning

<table>
<thead>
<tr>
<th>Type</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal ACPa</td>
<td>Conversation(s) between an individual, their loved ones, and/or their healthcare provider(s) regarding their values and goals for healthcare, particularly regarding end of life</td>
</tr>
<tr>
<td>Goals-of-care conversations</td>
<td></td>
</tr>
<tr>
<td>Formal ACP (i.e., Advance directivesb)</td>
<td>A formal, legal document designating a healthcare surrogate/proxy who will make decisions for a person in the event that they become unable to do so</td>
</tr>
<tr>
<td>Durable healthcare power of attorney (DPOA)</td>
<td></td>
</tr>
<tr>
<td>Living will</td>
<td>A legal, written statement describing a person’s preferences for life-sustaining and other medical treatment in the event of incapacity</td>
</tr>
</tbody>
</table>

a (Singer et al., 1998)  
b (Gunter-Hunt et al., 2002)

**Older Adults’ Advance Care Planning Engagement**

Advance directives (i.e., living wills or durable healthcare powers of attorney) are the most studied types of ACP (Jimenez et al., 2018). Since the early 1990’s, advance directives
have been widely promoted by both researchers and policy makers as important measures for assuring and enhancing patient autonomy in terminal illness or near the end of life (La Puma et al., 1991). However, despite over $300 million in federal research funding dedicated to the study of ACP and to various initiatives aiming to increase rates of advance directive completion across federal, state, and institutional levels, their use remains low in the United States (Morrison, 2020). A recent systematic review found that only one third of all American adults have an advance directive of either type, with 33% having a durable power of attorney and 29% a living will (Yadav et al., 2017). While older age has been consistently associated with an increased likelihood of advance directive completion, current evidence regarding advance directive prevalence among living adults aged 65 and older is limited (Choi et al., 2020; Detering et al., 2019; Huang et al., 2016; Rao et al., 2014). The latest study examining advance directive prevalence among a national sample of decedents aged 60 and older found that 72% had an advance directive of any kind at the time of death (Silveira et al., 2014).

Though older age is associated with higher rates of advance directive completion, completion rates vary significantly by health status. Deteriorating health status (i.e., having multiple diagnosed chronic conditions, increased contact with the healthcare system, or approaching the final weeks of life) has been associated with increased likelihood of advance directive completion (Choi et al., 2020; Enguidanos & Ailshire, 2017). Further, individuals with a cancer diagnosis (compared to those with non-cancer chronic illness diagnoses) are more likely to complete an advance directive, as are those with poorer functional status (Detering et al., 2019; Park et al., 2015).

Various sociodemographic factors are also associated with increased rates of advance directive completion. Individuals who are retired or disabled are more likely than their employed
peers to have an advance directive (Choi et al., 2020; Huang et al., 2016). Higher income, greater educational attainment, and internet access are also associated with increased advance directive usage (Choi et al., 2020; Huang et al., 2016; Khosla et al., 2016; Rao et al., 2014). Similarly, increased attendance at religious services has been associated with higher rates of advance directive completion (Koss, 2018).

Despite public engagement initiatives like “The Conversation Project” and “Death Over Dinner”, which encourage individuals to discuss their end-of-life care goals and wishes with their family members, less is known about informal ACP engagement in the United States. In a study of Massachusetts residents aged 18 years or older, fewer than one in five respondents reported discussing their end-of-life care preferences with a healthcare provider despite over half of respondents discussing those preferences with someone other than a healthcare provider (Clark et al., 2018). Though goals-of-care conversations may be relatively common among those with terminal illness (Brazee et al., 2021), less is known about their prevalence across the general older adult population.

**Racial/Ethnic Differences in Advance Care Planning**

Recent evidence also indicates an association between race/ethnicity and advance care planning even when controlling for known associated covariates. Non-Hispanic White Americans complete advance directives at rates up to three times higher than that of Americans of other racial/ethnic identities (Portanova et al., 2017; Sullivan & Klingman, 2019). In a nationally representative sample of adults aged 50 and older, 44% of White participants had completed an advance directive compared to only 24% of Black participants and 29% of Hispanic participants (Huang et al., 2016). In two samples of Asian Americans in the southwestern United States, only one in ten had completed an advance directive (Gao et al.,
Less is known about advance directive completion among Native American/Indigenous peoples, Pacific Islanders, or other racially or ethnically minoritized groups, but preliminary evidence suggests reduced interest in formal ACP (Gebauer et al., 2016).

Though less is known overall about informal ACP engagement compared to formal ACP, preliminary evidence suggests that racial and ethnic differences in advance directive completion may extend to goals-of-care conversations. Data from partnered young-/middle-aged adults, chronically ill adults, and nursing home residents collected more than a decade ago found that Black, Hispanic, and Asian respondents were less likely to report discussing their healthcare preferences with others compared to White respondents (Carr, 2011, 2012; Rich et al., 2009). Whether racial/ethnic differences in informal ACP persist across the broader older adult population is less well known.

Racial/ethnic differences in advance care planning may be partially explained by the health-related and sociodemographic factors described above. However, there are several additional factors likely contributing to lower advance directive rates among racially or ethnically minoritized individuals in the United States. For instance, it has been acknowledged that advance directives were designed to address European American values such as patient autonomy, informed decision-making, truth-telling, and open discussions related to the dying process (Zager & Yancy, 2011). Thus, advance directive documents and other ACP processes often fail to address important cultural values of the other highly diverse cultural groups in the United States. As social constructs with historical roots, race and ethnicity labels may indicate affiliation with a cultural group. Several studies suggest preferences for a collective, family-centered decision-making process among Black, Asian, and Pacific Islander Americans which
may be inadequately addressed with the more autonomy-centered advance directives (Collins et al., 2018; Kataoka-Yahiro et al., 2011; Lee et al., 2014).

Additionally, lingering mistrust of providers and healthcare systems may present a barrier to ACP following the long history of exploitative biomedical research, medical malpractice, and disparities in healthcare experienced by racially and ethnically minoritized communities in the United States (Braveman et al., 2011; Collins et al., 2018; McCleskey & Cain, 2019; Washington, 2008). Such mistrust and ongoing healthcare disparities may, in part, explain why Black Americans are more likely than individuals of other racial/ethnic identities to choose higher-intensity, potentially life-prolonging treatments at the end of life (Collins et al., 2018; Portanova et al., 2017). Because such treatment is the medical “default,” ACP may seem unnecessary.

**The Impact of Advance Care Planning on End-of-Life Care**

Though ACP is intended to align patients’ treatment goals and preferences with actual care received (i.e., goal-concordant care), there is limited evidence that formal or informal ACP does so. Advance directives are limited by the inability to address or anticipate all future health care decisions and, thus, may reflect out-of-date or inappropriate preferences (Morrison, 2020). ACP interventions that include a communication element may increase the likelihood of goal-concordant end-of-life care, but the few studies supporting this finding examined only small, homogenous samples (Houben et al., 2014; Weathers et al., 2016).

Further, studies examining the effects of ACP on end-of-life care have primarily focused on specific treatments and location of care. Fewer studies have examined the effect of ACP on the alignment of care received with patients’ end-of-life wishes (Brinkman-Stoppelenburg et al., 2014; Jimenez et al., 2018). Though Haines et al. (2019) identified an association between ACP
and goal-concordant care in their multivariable analyses, their study did not distinguish between formal and informal ACP. Studies, to date, have not examined the relationship between different types of ACP and goal-concordant care using a nationally representative sample of individuals with a variety of health conditions. Thus, goal-concordant care for the broad population of older Americans remains an elusive phenomenon and a priority of the National Academy of Medicine (Dzau et al., 2017).

**Advance Care Planning and Partner Bereavement**

Goal-concordant end-of-life care may also be important for older adults’ loved ones, particularly their bereaved partners (i.e., spouse or other co-habitating partner, hereafter referred to collectively as “partners”). Though grief and some depressive symptoms are common while mourning loss, losing one’s life partner may be particularly stressful and is associated with poor health outcomes (Carr & Jeffreys, 2011; Luhmann et al., 2012). Widowed persons report poorer health than the general population and are at increased risk for cancer, cardiovascular disease, and chronic pain (Ennis & Majid, 2019). Approximately half of individuals report poor sleep quality or insomnia one month after the loss of their partner (Carlsson & Nilsson, 2007; Lerdal et al., 2016). Widowhood is also associated with an increased risk for mortality among older adults, particularly among men (Blanner et al., 2020; Ennis & Majid, 2019; Stroebe et al., 2001). Approximately one in four grieving older adults have been found to experience complicated grief, which is characterized by a prolonged grief experience and more severe psychological distress (Newson et al., 2011).

Recent evidence suggests that end-of-life communication and care may impact partners’ bereavement outcomes. Bereaved caregivers of patients with cancer experience greater depressive and grief symptoms when their loved one dies in an acute care setting than when they
die in hospice, at home, or in a palliative care unit (Hatano et al., 2017). Studies from Taiwan and the United States have found an association between the use of life-sustaining procedures (e.g., cardiopulmonary resuscitation) in the last month of life and increased depressive symptoms among partners/family members in bereavement (Ornstein et al., 2017; Tang et al., 2021). A recent qualitative study suggested associations between “traumatic” deaths (e.g., deaths involving significant physical suffering) and feelings of guilt and regret in surviving family members, which may contribute to maladaptive health outcomes (Harrop et al., 2016; Li et al., 2014). Another study identified an association between in-hospital death and higher Medicare spending among partners in the year following death, suggesting an increase in physical health complaints. In contrast, older adults whose partners received hospice care had reduced depressive symptoms compared to those whose partners did not (Ornstein et al., 2018). Finally, better quality of death as reported by surviving caregivers has been associated with improved caregiver health-related quality-of-life (Garrido & Prigerson, 2014; Ornstein et al., 2015).

Given widespread preferences for lower intensity care at the end of life, improving goal-concordant care for the dying may lessen distress and poor health outcomes among bereaved family members. Family participation in goals-of-care conversations may; 1) improve concordance between patients’ preferences and proxy decisions, and 2) assure family members that their loved one received their preferred care at end of life. Several international studies have identified associations between poor end-of-life communication and increased emotional distress among grieving family members, a phenomenon that was exacerbated by the COVID-19 pandemic (Feder et al., 2020; Harrop et al., 2016, 2020). In contrast, family caregivers of patients with terminally ill cancer experienced reduced psychological distress in bereavement when they had engaged in discussions about illness and impending death with their dying loved one.
Interviews with recently bereaved Black family members revealed that those who experienced higher quality communication during the final weeks prior to death had lower decisional conflict afterward (Smith-Howell et al., 2016). Therefore, increased use of informal ACP in which family members have improved, up-to-date communication about preferences, plus resultant goal-concordant care at the end of life, may contribute to better emotional and other health outcomes for surviving partners.

Gaps

In summary, there are several ongoing gaps in our understanding of ACP and end-of-life care among older adults. First, little is known about national patterns in informal ACP engagement and whether racial/ethnic differences in advance directive completion extend to informal ACP. Second, the relationships between formal and informal ACP and family perceptions of goal-concordant end-of-life care, as well as racial/ethnic disparities within this relationship, are not well understood. Finally, few authors have explored the impact of ACP engagement and goal-concordant care on bereaved partners’ health outcomes in the period immediately following death. My research addresses these gaps and is summarized in the three manuscripts that follow this chapter.

Theoretical Approach

The conceptual model guiding this dissertation was adapted from that put forth by Sanders et al. (2018) which identified the key processes that contribute to goal-concordant end-of-life care. Their model focuses centrally on the role of communication in achieving goal-concordant care. They suggest that the various components of high-quality communication (i.e., information gathering, information sharing, responding to emotion, and fostering relationship)
improve patients’ overall well-being, enhance patient trust, and improve therapeutic alliance between patients and their healthcare providers. Based on this model, ACP must include these components of communication to be most effective toward goal-concordance. Sanders and colleagues assert that goal-concordant care influences bereaved caregivers’ outcomes, citing supporting associations between bereaved caregivers’ perceptions of alignment between their loved one’s end-of-life care and values and better caregiver mental health and well-being (Wright et al., 2016).

Though Sanders’ model is novel in its inclusion of goal-concordant care and the bereaved caregiver experience, its narrow focus on communication does not address important factors that likely preclude patient-provider communication and indirectly impact goal-concordant care. Kelley and colleagues (2010) describe such factors in their conceptual framework of determinants of treatment intensity for individuals with serious illness. They note that geographic location is highly correlated with healthcare treatment, likely due to regional supply of medical resources (e.g., hospital beds, hospice availability, etc.) and local and individual physician practice patterns. While geographic location may determine what kind of care is available, Kelley et al., acknowledge that patient and family characteristics influence engagement with the large and complex healthcare system. These characteristics include financial access to care, the likelihood of patient benefit from treatment or healthcare status, and patient and family healthcare preferences.

To inform and address the aims of this dissertation, I have synthesized and expanded on these models to better depict the comprehensive process of ACP and potential outcomes. The synthesized model focuses centrally on the role of ACP in achieving goal-concordant care and, subsequently, the outcomes of bereaved partners. In addition to the important factors highlighted
by Sanders and Kelly, my conceptual model includes the sociodemographic and health-related concepts (e.g., socioeconomic status, health status, and religiosity) that have previously been associated with ACP engagement or end-of-life care preferences (Auriemma et al., 2014; Carr & Moorman, 2009; Enguidanos & Ailshire, 2017). Importantly, the proposed model emphasizes the sweeping impact of healthcare disparities on preferences, engagement in ACP, actual care received, and bereaved partners’ experiences. Figure 1.1 depicts the synthesized and expanded model with concepts from Sanders’ model shown in blue and from Kelley’s model in yellow. Concepts shown in solid frames will be measured directly or indirectly in this study.

Figure 1.1 - Conceptual Model of Advance Care Planning and Goal-Concordant Care
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Chapter 2 Racial and Ethnic Differences in Informal and Formal Advance Care Planning Among U.S. Older Adults

Abstract

Objective: To examine advance care planning (ACP) trends among an increasingly diverse aging population, we compared informal and formal ACP use by race/ethnicity among U.S. older adults (≤ 65 years).

Methods: We used Health and Retirement Study data (2012-2018) to assess relationships between race/ethnicity and ACP type (i.e., no ACP, informal ACP only, formal ACP only, or both ACP types). We reported adjusted risk ratios with 95% confidence intervals.

Results: Non-Hispanic Black and Hispanic respondents were 1.77 (1.60, 1.96) and 1.76 (1.55, 1.99) times as likely, respectively, to report no ACP compared to non-Hispanic White respondents. Non-Hispanic Black and Hispanic respondents were 0.74 (0.71, 0.78) and 0.74 (0.69, 0.80) times as likely, respectively, to report using both ACP types as non-Hispanic White respondents.

Discussion: Racial/ethnic differences in ACP persist after controlling for a variety of barriers to and facilitators of ACP which may contribute to disparities in end-of-life care.

1 This paper was published in Journal of Aging and Health (2022)
Introduction

Extensive advance care planning (ACP) programs, in which individuals are supported in identifying and describing their healthcare treatment values, goals, and preferences, have been shown to increase patients’ satisfaction with care, lessen decisional conflict among patient surrogates, and reduce healthcare treatment intensity at the end-of-life (Brinkman-Stoppelenburg et al., 2014; Jimenez et al., 2018; Smith-Howell et al., 2016; Sudore et al., 2017). ACP that incorporates goals-of-care conversations between patients, their family members, and providers (i.e., informal ACP) may be especially effective at maximizing important end-of-life outcomes when compared to written documents alone (Baidoobonso, 2014; Jimenez et al., 2018).

However, less is known about national trends and practices in informal ACP compared to formal ACP (i.e., advance directives) since most research efforts have concentrated on the legal documentation of patients’ preferences.

The focus on advance directives has limited our understanding of the breadth of ACP types used across an increasingly racially and ethnically diverse U.S. older adult population (Administration on Aging, 2021). Several racially and ethnically minoritized older adult groups are less likely to complete advance directives than their non-Hispanic White peers (Portanova et al., 2017; Sullivan & Klingman, 2019). The decision-making practices of these groups regarding end-of-life care may be less adequately addressed by traditional, autonomy-centered advance directives than by informal ACP (Zager & Yancy, 2011). Indeed, Black Americans are more likely to rely on trusted family members or clergy to communicate their end-of-life preferences than to express those preferences in advance directives (Collins et al., 2018; Sanders et al., 2016). Similarly, Hispanic patients’ preference to include family members in healthcare
decision-making and strong religious beliefs are not adequately accommodated by formal ACP (Cervantes et al., 2017; Shen et al., 2020).

Though evidence suggests some racially and ethnically minoritized older adult groups have identified preferences for informal ACP over formal ACP, a few studies exploring trends among older adults with chronic illness or living in a nursing home suggest that racial/ethnic differences in formal ACP extend into informal ACP (Carr, 2011; Rich et al., 2009). However, while racial/ethnic differences in formal ACP have consistently been associated with sociodemographic factors like estate planning, religious preferences, and acculturation as well as health factors (Koss & Baker, 2018; Sanders et al., 2016; Yi, 2019), less is known about the factors contributing to racial/ethnic differences in older adults’ informal ACP. In addition, we were unable to identify a study that examined racial/ethnic differences in both formal and informal ACP among a national, primarily community-dwelling sample of U.S. older adults.

Prior work has consistently identified racial/ethnic differences in formal ACP across the U.S. older adult population with recent work additionally indicating differences in informal ACP among specific population groups. We build on this work by examining racial/ethnic differences and trends in formal and informal ACP using data from a nationally representative survey of older adults in the U.S and identifying potential mechanisms behind these differences. Specifically, we aimed to 1) assess the relationship between race/ethnicity and ACP among U.S. adults aged 65 and older and 2) explore sociodemographic characteristics, potential barriers to and facilitators of ACP, and health factors that may explain this relationship. Our findings offer insight into the decision-making preferences and patterns of various racial/ethnic groups, and potential explanations for racial/ethnic differences in the use of ACP, with important implications for future ACP practice.
Methods

Data and Study Participants

We conducted a retrospective, cross-sectional study using data from the Health and Retirement Study (HRS), a large, nationally representative longitudinal survey consisting of multiple birth cohorts of adults aged 51 and older (Sonnega et al., 2014). HRS data was chosen for this study because of the survey’s oversampling of key racial/ethnic groups, specifically Black and Hispanic households, and its inclusion of self-reported ACP. Respondents and their spouses/partners are interviewed approximately every two years on various topics related to aging. HRS is sponsored by the National Institute on Aging (grant number NIA U01AG009740) and conducted by the University of Michigan. Because of its use of publicly available, deidentified data, this study was deemed “not regulated” by the Health Sciences and Behavioral Sciences Institutional Review Board at the University of Michigan (HUM00196992).

We used pooled 2012 to 2018 data from HRS respondents for whom complete data was available. This range was selected because 2012 was the first year in which HRS investigators asked respondents about their ACP. We captured data from respondents’ last available interview during the study period, which was either of a) the last interview in which living respondents participated (through 2018), or b) the interview immediately preceding death for decedents. Because we were specifically interested in the ACP of older adults, we included only respondents aged 65 and older at the time of the interview.

Measures

Outcome

Our primary outcome was ACP type, a nominal variable with four distinct, mutually exclusive categories: 1) No ACP, 2) Informal ACP only, 3) Formal ACP only, and 4) Both
informal and formal ACP. We constructed this variable based on responses to the following three HRS questions:

1. “Have you discussed with anyone the care or medical treatment you would want to receive if you were to become seriously ill (i.e., goals-of-care conversations)?”

2. “Have you written instructions about the care or medical treatment that you would want to receive if you cannot make those decisions yourself (i.e., living will)?”

3. “Have you completed a legal arrangement for a specific person(s) to make decisions about your care or medical treatment if you cannot make those decisions yourself (i.e., durable power of attorney)?”

Respondents who reported no goals-of-care conversations nor possession of either advance directive (i.e., living will or durable power of attorney) were categorized as “No ACP”. Respondents who reported having a goals-of-care conversation but no advance directive were categorized as “Informal ACP only”. Respondents who did not report having a goals-of-care conversation but did report completion of at least one advance directive were categorized as “Formal ACP only”. Respondents who reported having a goals-of-care conversation and at least one advance directive were categorized as “Both ACP Types”.

**Predictor of Interest**

To compare the use of ACP types by race/ethnicity, we identified respondents’ self-reported race/ethnicity, categorized into three groups: non-Hispanic White (i.e., White), non-Hispanic Black (i.e., Black), and Hispanic. Due to the small size (equal to less than 2.5% of the total sample) and racial/ethnic heterogeneity of the remaining sample, respondents who self-identified as American Indian, Alaskan Native, Asian, Native Hawaiian, Pacific Islander, or any other race/ethnicity were excluded from our analyses.
Covariates

Models controlled for sociodemographic characteristics that have previously demonstrated an association with ACP or at least partially explained racial or ethnic differences in advance directive completion (Khosla et al., 2016; Rao et al., 2014). Sociodemographic characteristics included age (at interview), gender (i.e., female versus male), marital status, educational level, Medicaid eligibility, rural residence, country of birth (i.e., U.S. born versus elsewhere), attendance at religious services, net worth (in quartiles), and nursing home residence. Recent work indicates that older adults dually eligible for Medicare and Medicaid are less likely to have an outpatient ACP claim than those with Medicare eligibility alone (Palmer et al., 2021). We controlled for rural residence using the 2013 Beale Rural-Urban Continuum codes (i.e., rural versus urban/suburban) because end-of-life care practices may vary by geographic region, potentially impacting patient decision-making (Nicholas et al., 2011), and because older adults in rural areas may have fewer resources for engaging in ACP (Christensen et al., 2019). We included country of birth as a proxy measure for acculturation, given several studies’ findings that greater acculturation is associated with advance directive completion (Kelley et al., 2010; Yi, 2019). We also included attendance at religious services because prior work has demonstrated a positive association between religious service attendance (independent of religious affiliation) and advance directive completion (Hoe & Enguidanos, 2020; Koss, 2018). Several studies have also documented positive associations between advance directive completion and both greater financial resources (Kelly et al., 2013) and nursing home residence (Jones et al., 2011). These characteristics were divided into three categories according to their association with ACP: 1) baseline demographics (i.e., age, gender, marital status, and education), 2) potential barriers to ACP (i.e., Medicaid eligibility, rural residence, and birth outside the
U.S.), and 3) facilitators of ACP (i.e., religious service attendance, net worth, and nursing home residence).

We also controlled for health characteristics that may increase the perceived need for ACP or access to ACP within the healthcare system. These included self-rated health, diagnosis of several chronic conditions, and functional status. We included a binary measure of self-rated health (i.e., good, very good, or excellent versus poor or fair) as a proxy for overall health given its strong associations with a number of important health outcomes (Giltay et al., 2012; Lee, 2000; van der Linde et al., 2013). We also included an index of seven common chronic conditions (i.e., Alzheimer’s disease and related dementias, arthritis, diabetes, heart disease, lung disease, psychiatric illness, stroke history). We separately controlled for a history of any cancer (excluding skin cancer) because individuals with a cancer diagnosis are more likely to complete an advance directive than those without (Park et al., 2015). Finally, we controlled for difficulties with Activities of Daily Living (e.g., bathing or dressing; range 0-5) or Instrumental Activities of Daily Living (e.g., handling money or taking medication; range 0-5) because individuals with poorer functional status have previously been more likely to complete ACP (Hansen et al., 2019; Kim et al., 2021).

**Statistical Analyses**

First, we reported descriptive statistics overall and by racial/ethnic group using counts and percentages for categorical variables and means with standard deviations for continuous variables. We examined differences in respondent characteristics across racial/ethnic groups using ANOVA, chi-square, and Kruskal Wallis tests and we computed a correlation matrix between all continuous and ordinal covariates (Table 2.2). We then estimated a series of five, sequential multinomial logistic regression models to explore factors that may help to explain the
relationship between race/ethnicity and ACP type. In the first model, we regressed the nominal outcome, ACP type, on race/ethnicity indicators (i.e., Black and Hispanic with White as the omitted reference category). Subsequent models added the groups of covariates described above, beginning with the baseline demographics, then adding factors we characterize as potential barriers to ACP, then facilitators of ACP, and finally, health factors that may increase the perceived need for ACP. We employed this sequential modeling strategy to identify the extent to which any associations between race/ethnicity and ACP type could be independently explained by known or potential drivers, including barriers to or facilitators of ACP, that may differ between racial/ethnic groups. To account for potential correlation between spouses’/partners’ ACP (Koss, 2017), we clustered standard errors by household, allowing for intragroup correlation.

Multinomial logistic regression models were estimated for each of the five models to account for the nominal outcome (i.e., ACP type). These models produce a set of coefficients for all model covariates for each level of the nominal outcome except the baseline (i.e., reference) category. The model coefficients associated with each outcome (i.e., informal ACP only, formal ACP only, or both ACP types) represent the relative risk ratios (RRR) (and their 95% confidence intervals) of reporting a specific ACP type (e.g., formal ACP only) compared to no ACP for respondents of a specific race/ethnicity (e.g., Hispanic) compared to respondents of the reference race/ethnicity (e.g., White).

Because the model coefficients’ magnitudes are difficult to interpret, we additionally obtained adjusted risk ratios (aRRs) and 95% confidence intervals for each of the nominal outcomes using Stata’s adjrr post-estimation command. Unlike RRRs, aRRs represent relative likelihoods of a specific outcome (e.g., formal ACP only) for individuals of one racial/ethnic
group compared to the specified reference group (whereas RRRs are relative likelihoods of a specific outcome compared to the baseline outcome [i.e., no ACP use] for each race/ethnicity compared to White). ARRs are conditional on the outcome; for instance, if most individuals in one racial/ethnic group use both ACP types, then the remaining individuals of that group may be less likely to have just one type of ACP. For this reason, a group could have an RRR<1, but an aRR>1. aRRs do not depend on the reference category in the original model, allowing us to make comparisons between any two racial/ethnic groups.

Results

Unadjusted Results

Our final analytic sample included 13,117 unique older adults. Of these, 72% self-identified as White, 17% as Black, and 11% as Hispanic. The mean age of the White respondents was three years higher than that of the Black and Hispanic respondents. Fewer than 50% of the Hispanic respondents were born in the United States compared to over 90% of White and Black respondents. Additionally, a higher proportion of those in the Black and Hispanic groups rated their own health as poor or fair compared to the White group (Table 2.1).

Figure 2.1 shows the unadjusted distribution of ACP use across racial/ethnic groups. Overall, 82% of all respondents reported at least one ACP type and 59% reported using both formal and informal ACP. By group, 81% of White, 59% of Black, and 53% of Hispanic respondents reported using informal ACP, while 74% of White, 51% of Black, and 37% of Hispanic respondents reported using formal ACP. “Both ACP Types” was the most common outcome among White and Black respondents, while “No ACP” was the most common outcome among Hispanic respondents. Additionally, the respective unadjusted proportions of Black and
Hispanic respondents reporting no ACP were approximately three and four times greater than those of the White group.

**Adjusted Results**

In adjusted results, across all five models, Black respondents were significantly less likely to use informal ACP only (Model 5 [M5] RRR 0.57 [95% CI 0.48, 0.68]) or both ACP types (M5 RRR 0.36 [95% CI 0.31, 0.42]) relative to no ACP compared to White respondents (Table 2.3). However, while Black respondents were significantly less likely to use formal ACP relative to no ACP compared to White respondents in the first three models, this difference was no longer statistically significant with the addition of the facilitators of ACP (i.e., religious service attendance, net worth, and nursing home residence) in the fourth model (RRR 0.81 [95% CI 0.66, 1.00]). Across all models, Hispanic respondents were significantly less likely to use each ACP type relative to no ACP compared to White respondents (M5 RRR’s informal ACP only 0.78 [95% CI 0.63, 0.97], formal ACP only 0.42 [0.31, 0.57], both ACP types 0.35 [0.29, 0.43]).

Figure 2.2 depicts the adjusted relative risks derived from the final model (including all covariates) with White respondents as the reference group (aRRs for each of the five models are available in Table 2.4). As shown, Black respondents were 77% more likely and Hispanic respondents 76% more likely to report no ACP compared to White respondents. Hispanic respondents were also 45% more likely to report informal ACP only and Black respondents were 58% more likely to report formal ACP only compared to White respondents. Black and Hispanic respondents were both 26% less likely to report using both ACP types than White respondents. Additionally, Black respondents were 89% more likely to report formal ACP only than Hispanic
respondents and Hispanic respondents were 35% more likely to report informal ACP only compared to Black respondents.

Discussion

ACP types varied significantly by race and ethnicity in this study of U.S. older adults. Goals-of-care conversations (i.e., informal ACP) were common. However, Black and Hispanic individuals were more likely to report no ACP and less likely to report both informal and formal ACP compared to White respondents, even after accounting for various barriers and facilitators previously associated with ACP. Collectively, these findings illustrate substantial gaps in national use of both informal and formal ACP among older adults, suggesting that current ACP practices may be inadequate for the needs of an increasingly racially and ethnically diverse U.S. older adult population.

We observed a higher overall prevalence of ACP compared to previous estimates, perhaps due to our incorporation of goals-of-care conversations in assessments of ACP use. Previous work shows that, despite recent growth, there is low uptake of formal ACP in both the older adult and general population (Silveira et al., 2014; Yadav et al., 2017). In a recent systematic review, only 46% of older adults had completed an advance directive (Yadav et al., 2017). In comparison, four out of five respondents in our study reported at least one ACP type and three out of five reported both. Including informal ACP with more traditionally assessed formal ACP methods increased observed prevalence of ACP, suggesting that informal ACP complements or, in some cases, is used in place of formal ACP among many older Americans.

We built on less representative prior work that separately examined formal or informal ACP by simultaneously identifying racial/ethnic differences in both ACP types among older adults. Prior studies consistently demonstrated lower rates of advance directive completion
among racially and ethnically minoritized samples compared to White samples (Huang et al., 2016; Jimenez et al., 2018; Portanova et al., 2017), with some additional evidence indicating that these differences extend into informal ACP (Carr, 2012; Clark et al., 2018). We found that, while more than half of respondents reported informal ACP, there were substantial racial/ethnic differences in informal ACP, and these differences persisted after adjustment for factors that typically explain ACP use. These gaps were similar in nature to those related to formal ACP use. Together, these findings suggest substantial variation by race in perceptions of or access to ACP, whether informal or formal, meaning efforts to broaden access and use of ACP will require more tailored efforts.

Though we found that, compared to White respondents, Black respondents were more likely to use formal ACP only and Hispanic respondents were more likely to use informal ACP only, this potential discrepancy (less likelihood of any ACP use compared to no ACP, but greater likelihood of specific ACP use) is explained by the distribution of individuals by race/ethnicity in each outcome category. Because more White respondents than other individuals used both types of ACP, more Black and Hispanic respondents were in the other ACP outcome categories. Smaller proportions of Black and Hispanic respondents used either ACP type compared to White respondents, and adjusted results indicated that Black and Hispanic respondents were significantly more likely to report no ACP compared to White respondents. In all, these findings suggest that, even when accounting for goals-of-care conversations, Black and Hispanic older Americans are substantially less likely to complete any ACP compared to White older Americans.

There are several potential explanations for these persistent gaps in ACP across racial/ethnic groups. In our sequential models, modest attenuation in the relationship between
race/ethnicity and ACP type was primarily explained by sociodemographic characteristics (e.g., age and education) and not by factors representing potential barriers to or facilitators of ACP. However, country of birth, nursing home residence, number of noncancer chronic conditions, and history of cancer were all significantly associated with each ACP type in the final model. In the case of Black respondents using formal ACP only relative to no ACP, the addition of potential facilitators of ACP muted observed differences in the relative odds of ACP versus no ACP use by race/ethnicity. These findings corroborate a large body of prior work which suggests that greater social and economic resources enhance the use of advance directives and more recent work suggesting that socioeconomic disadvantage reduces the odds of having end-of-life conversations (Boerner et al., 2021; Hong & Kim, 2020; Khosla et al., 2016).

Fewer social and economic resources among racially and ethnically minoritized older adults due to structural racism may impact ACP (Bailey et al., 2017). For example, our study and others identified an association between nursing home residence and completion of ACP (Jones et al., 2011). However, racial segregation persists in nursing home settings across the United States with Black residents often receiving poorer quality care (Estrada et al., 2021; Mack et al., 2020). Similarly, though greater educational attainment is also consistently associated with ACP (Huang et al., 2016; Rao et al., 2014), Black and Hispanic respondents in our study reported lower overall educational attainment than White respondents, potentially reflecting reduced access to ACP resources.

However, large differences in ACP by race/ethnicity remained even after accounting for known barriers and facilitators to ACP, implying a need for alternative explanations for such gaps. Though we controlled for several factors previously associated with healthcare treatment preferences, including socioeconomic status, chronic illness diagnoses, and functional status
(Chang et al., 2014; Higginson et al., 2017), we were unable to measure respondents’ specific healthcare treatment preferences. In several prior studies, Black Americans were more likely to prefer life-sustaining treatments at the end-of-life than their peers of other racial/ethnic groups, reducing the perceived need for ACP (Barnato et al., 2009; Johnson et al., 2008; Rahemi & Williams, 2016). Recent work has suggested an effect of subjective life expectancy on informal ACP use and identified more optimistic life expectancy estimates among Black older adults and more pessimistic estimates among Hispanic older adults compared to White older adults. However, racial/ethnic differences in ACP persisted after controlling for subjective life expectancy, suggesting that other factors may play a larger role (Lou & Carr, 2022).

Another alternative explanation involves unmeasured patient-provider factors. Clinicians are less likely to initiate ACP conversations with individuals with whom there are perceived or real barriers to communication (e.g., language barriers, differences in communication style, etc.) or if they have preconceived views about their patients’ preferences (Ashana et al., 2022; Bazargan et al., 2021; Ladin et al., 2021). Implicit bias may therefore perniciously influence how informal and formal ACP is offered. Clinicians’ lack of awareness about racial/ethnic differences in subjective life expectancy and other culturally varying factors might inhibit efforts to offer nuanced and beneficial support to patients and family members. Healthcare system factors, including limited access to high-quality care, may also contribute to lack of awareness of healthcare treatment options, which has been observed among Hispanic older adults (Carr, 2012; Maldonado et al., 2019; Shen et al., 2020).

More broadly, ACP centers around traditionally western values (i.e., patient autonomy, informed decision-making, truth-telling, and discussing the dying process), excluding groups with different values who must adapt in order to complete traditional ACP (Blackhall et al.,
Lower ACP rates among racially and ethnically minoritized groups may also be a consequence of a healthcare system that has historically failed to invest in culturally competent care models (Braveman et al., 2011; McCleskey & Cain, 2019; Washington, 2008). In our study, the relative risks of using each ACP type relative to no ACP were significantly higher for respondents born in the United States compared to those born elsewhere. It has been proposed that, in addition to improving overall access to healthcare, policymakers and funding organizations should direct resources towards developing and improving access to culturally responsive palliative care interventions that support patients as they encounter significant health changes, rather than focusing on planning for unknown future crises in advance (Morrison, 2020; Rutz Voumard et al., 2021). Indeed, ACP may occur more frequently and function more effectively within the context of clinically relevant palliative care.

Our findings must be considered within the context of two important limitations. First, the lack of differentiation between other racial/ethnic groups in the larger HRS dataset (e.g., Asian Americans, Native Americans, and Pacific Islanders) precluded our ability to identify patterns among them, an important limitation given known differences in end-of-life care planning and preferences among these groups (McDermott & Selman, 2018; Zager & Yancy, 2011). Second, our measures of ACP were dependent on respondents’ or their proxies’ self-report, which were subject to recall and other self-report biases. Future, prospective research may better elicit the persons (i.e., family members, healthcare providers, etc.) with whom the respondents’ completed ACP, particularly during goals-of-care conversations. Despite these limitations, this project fills an important gap in the ACP research literature. The use of HRS, a large, nationally representative longitudinal survey that oversamples several key demographic groups, strengthened our ability to examine ACP trends among populations (e.g., older adult,
Black, and Hispanic households) which have been particularly vulnerable to poor health outcomes during the ongoing pandemic. Additionally, our inclusion of informal ACP revealed sizable differences in ACP utilization between racial/ethnic groups in a national sample of older adults, which may reflect important deficiencies in current ACP structures in U.S. healthcare.

Our study revealed important differences in ACP among older adults of different racial/ethnic groups in the United States. Racially and ethnically minoritized older individuals were less likely to use a combination of informal and formal ACP and more likely to be without any ACP. Though these differences may be explained, in part, by racial/ethnic differences in sociodemographic characteristics, barriers to ACP, facilitators of ACP, or health factors commonly associated with ACP, further work is needed to identify patient preferences or healthcare system factors that may impact older adults’ ability to complete advance directives or willingness to discuss their healthcare treatment goals. Our study identified racial and ethnic differences in both formal and informal ACP as well as potential mechanisms behind those differences using a national sample of older adults. Future work must identify additional strategies to equitably improve end-of-life care for older adults in the United States.
References


https://doi.org/10.1634/theoncologist.2014-0152


https://doi.org/10.1089/jpm.2017.0374


https://doi.org/10.1016/j.jpainsymman.2019.02.018


Table 2.1 - Characteristics of Respondents (n=13,117)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total</th>
<th>NH White (n=9,489)</th>
<th>NH Black (n=2,168)</th>
<th>Hispanic (n=1,460)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong>*, mean ± SD, years</td>
<td>77.2 ± 8.2</td>
<td>78.1 ± 8.2</td>
<td>75.1 ± 7.9</td>
<td>74.8 ± 8.0</td>
</tr>
<tr>
<td><strong>Female gender</strong>*</td>
<td>7,609 (58.0)</td>
<td>5,425 (57.2)</td>
<td>1,349 (62.2)</td>
<td>835 (57.2)</td>
</tr>
<tr>
<td><strong>Marital status</strong>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/partnered</td>
<td>6,971 (53.1)</td>
<td>5,302 (55.9)</td>
<td>853 (39.4)</td>
<td>816 (55.9)</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>1,564 (11.9)</td>
<td>908 (9.6)</td>
<td>461 (21.3)</td>
<td>195 (13.4)</td>
</tr>
<tr>
<td>Widowed</td>
<td>4,137 (31.5)</td>
<td>3,043 (32.1)</td>
<td>708 (32.7)</td>
<td>386 (26.4)</td>
</tr>
<tr>
<td>Never married</td>
<td>445 (3.4)</td>
<td>236 (2.5)</td>
<td>146 (6.7)</td>
<td>63 (4.3)</td>
</tr>
<tr>
<td><strong>Education</strong>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>2,638 (20.1)</td>
<td>1,187 (12.5)</td>
<td>659 (30.4)</td>
<td>792 (54.3)</td>
</tr>
<tr>
<td>High school graduate/GED</td>
<td>4,606 (35.1)</td>
<td>3,578 (37.7)</td>
<td>687 (31.7)</td>
<td>341 (23.4)</td>
</tr>
<tr>
<td>Some college</td>
<td>3,021 (23.0)</td>
<td>2,270 (23.9)</td>
<td>518 (23.9)</td>
<td>233 (16.0)</td>
</tr>
<tr>
<td>College graduate</td>
<td>2,852 (21.7)</td>
<td>2,454 (25.9)</td>
<td>304 (14.0)</td>
<td>94 (6.4)</td>
</tr>
<tr>
<td>Medicaid beneficiary***</td>
<td>1,560 (11.9)</td>
<td>642 (6.8)</td>
<td>481 (22.2)</td>
<td>437 (29.9)</td>
</tr>
<tr>
<td>Rural residence***</td>
<td>3,650 (27.8)</td>
<td>3,106 (32.7)</td>
<td>362 (16.7)</td>
<td>182 (12.5)</td>
</tr>
<tr>
<td>Born in the US***</td>
<td>11,711 (89.3)</td>
<td>9,070 (95.6)</td>
<td>2,025 (93.4)</td>
<td>616 (42.2)</td>
</tr>
<tr>
<td>Attends religious services***</td>
<td>9,064 (69.1)</td>
<td>6,260 (66.0)</td>
<td>1,732 (79.9)</td>
<td>1,072 (73.4)</td>
</tr>
<tr>
<td><strong>Net worth</strong>*, quartile</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 (Low)</td>
<td>2,547 (19.4)</td>
<td>1,211 (12.8)</td>
<td>800 (36.9)</td>
<td>536 (36.7)</td>
</tr>
<tr>
<td>2</td>
<td>3,095 (23.6)</td>
<td>1,926 (20.3)</td>
<td>742 (34.2)</td>
<td>427 (29.3)</td>
</tr>
<tr>
<td>3</td>
<td>3,493 (26.6)</td>
<td>2,730 (28.8)</td>
<td>433 (20.0)</td>
<td>330 (22.6)</td>
</tr>
<tr>
<td>4 (High)</td>
<td>3,982 (30.4)</td>
<td>3,622 (38.2)</td>
<td>193 (8.9)</td>
<td>167 (11.4)</td>
</tr>
<tr>
<td>Nursing home resident***</td>
<td>859 (6.6)</td>
<td>726 (7.7)</td>
<td>90 (4.2)</td>
<td>43 (3.0)</td>
</tr>
<tr>
<td>Self-reported health poor/fair***</td>
<td>4,819 (36.7)</td>
<td>3,145 (33.1)</td>
<td>927 (42.8)</td>
<td>747 (51.2)</td>
</tr>
<tr>
<td>Noncancer chronic illnesses, mean ± SD</td>
<td>1.9 ± 1.3</td>
<td>1.9 ± 1.3</td>
<td>2.0 ± 1.4</td>
<td>1.9 ± 1.3</td>
</tr>
<tr>
<td>Cancer history***</td>
<td>2,998 (22.9)</td>
<td>2,388 (25.2)</td>
<td>395 (18.2)</td>
<td>215 (14.7)</td>
</tr>
<tr>
<td><strong>Functional status</strong>*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of ADL difficulties***, median (IQR)</td>
<td>0 (1)</td>
<td>0 (1)</td>
<td>0 (1)</td>
<td>0 (1)</td>
</tr>
<tr>
<td>No. of IADL difficulties***, median (IQR)</td>
<td>0 (1)</td>
<td>0 (1)</td>
<td>0 (1)</td>
<td>0 (1)</td>
</tr>
</tbody>
</table>
Note. Not all categories total 100% due to rounding. Data represents respondents with complete data for final analytical model. Net worth quartiles defined as follows: 25%=$13,000; 50%=$130,000; 75%=$431,000. Counted chronic illnesses include Alzheimer’s disease and related dementias, arthritis, diabetes, heart disease, lung disease, psychiatric illness, and history of stroke (range 0-7). Rural-Urban status derived from the 2013 Beale Rural-Urban Continuum Codes. ACP indicates advance care planning; ADL, activities of daily living; GED, General Educational Diploma; IADL, instrumental activities of daily living; IQR, interquartile range; NH, non-Hispanic; SD, standard deviation; US, United States. ***p<.001
Figure 2.1 - Distribution of Advance Care Planning Types within Racial and Ethnic Groups

Note. $\chi^2$ test $p<.001$.
ACP indicates advance care planning; NH, non-Hispanic.
Figure 2.2 - Adjusted Relative Risks from Multinomial Logit Model of Advance Care Planning Type by Race/Ethnicity

<table>
<thead>
<tr>
<th>Advance Care Planning Type and Race/Ethnicity</th>
<th>Relative Risk (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>No ACP</strong></td>
<td></td>
</tr>
<tr>
<td>NH Black</td>
<td>1.77 (1.60, 1.96)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.76 (1.55, 1.99)</td>
</tr>
<tr>
<td><strong>Informal ACP Only</strong></td>
<td></td>
</tr>
<tr>
<td>NH Black</td>
<td>1.07 (0.95, 1.21)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.45 (1.25, 1.67)</td>
</tr>
<tr>
<td><strong>Formal ACP Only</strong></td>
<td></td>
</tr>
<tr>
<td>NH Black</td>
<td>1.58 (1.34, 1.86)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.84 (0.65, 1.08)</td>
</tr>
<tr>
<td><strong>Both ACP Types</strong></td>
<td></td>
</tr>
<tr>
<td>NH Black</td>
<td>0.74 (0.71, 0.78)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.74 (0.69, 0.80)</td>
</tr>
</tbody>
</table>

Note. Model specification uses complete-case analysis (n=13,117). The reference category is “non-Hispanic White.” Adjusted relative risks were calculated using Stata’s adjrr post-estimation command after running the multinomial logit model. Diamonds indicate point estimates and lines indicate 95% CIs. ACP indicates advance care planning; CI, confidence interval; NH, non-Hispanic.
Table 2.2 - Correlation Matrix of Ordinal/Continuous Covariates

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Education (per rising level)</td>
<td>-0.07</td>
<td>0.73</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Attends religious services</td>
<td>-0.02</td>
<td>0.03</td>
<td>0.43</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Net worth (quartile)</td>
<td>0.00</td>
<td>0.25</td>
<td>0.03</td>
<td>0.74</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Self-rated health</td>
<td>0.06</td>
<td>-0.12</td>
<td>-0.05</td>
<td>-0.13</td>
<td>0.46</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. No. non-cancer chronic illnesses</td>
<td>0.17</td>
<td>-0.09</td>
<td>-0.04</td>
<td>-0.13</td>
<td>0.19</td>
<td>0.78</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. No. ADL difficulties</td>
<td>0.29</td>
<td>-0.09</td>
<td>-0.05</td>
<td>-0.12</td>
<td>0.18</td>
<td>0.18</td>
<td>0.47</td>
<td></td>
</tr>
<tr>
<td>8. No. IADL difficulties</td>
<td>0.33</td>
<td>-0.09</td>
<td>-0.05</td>
<td>-0.11</td>
<td>0.17</td>
<td>0.18</td>
<td>0.29</td>
<td>0.46</td>
</tr>
</tbody>
</table>

Note. Kendall’s coefficient of rank correlation tau-sub-b, τb, was computed to measure the strength of association between continuous variables and ordinal variables with fewer than five categories as well as between two ordinal variables. Spearman’s rank correlation was computed to measure the strength of the association between continuous variables and ordinal variables with five or more levels.

ADL indicates activities of daily living; IADL, instrumental activities of daily living.
<table>
<thead>
<tr>
<th>Characteristic (Reference)</th>
<th>Informal ACP RRR [95% CI]</th>
<th>Formal ACP RRR [95% CI]</th>
<th>Both ACP Types RRR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M1</td>
<td>M2</td>
<td>M3 M4 M5</td>
</tr>
<tr>
<td>Race/ethnicity (NH White)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NH Black</td>
<td>0.52***</td>
<td>[0.49, 0.60]</td>
<td>[0.48, 0.67]</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.48***</td>
<td>[0.41, 0.57]</td>
<td>[0.42, 0.53]</td>
</tr>
<tr>
<td>Age, years</td>
<td>1.01**</td>
<td>[1.01, 1.02]</td>
<td>[1.01, 1.03]</td>
</tr>
<tr>
<td>Female gender (Male)</td>
<td>1.61***</td>
<td>[1.42, 1.82]</td>
<td>[1.43, 1.83]</td>
</tr>
<tr>
<td>Marital status (Married/partnered)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>1.04</td>
<td>[0.86, 1.24]</td>
<td>[0.87, 1.25]</td>
</tr>
<tr>
<td>Widowed</td>
<td>0.97</td>
<td>[0.82, 1.14]</td>
<td>[0.82, 1.13]</td>
</tr>
<tr>
<td>Never married</td>
<td>0.59**</td>
<td>[0.43, 0.81]</td>
<td>[0.43, 0.81]</td>
</tr>
<tr>
<td>Education (Less than high school)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school diploma/GED</td>
<td>1.40***</td>
<td>[1.18, 1.65]</td>
<td>[1.13, 1.59]</td>
</tr>
<tr>
<td>Some college</td>
<td>1.87***</td>
<td>[1.55, 2.25]</td>
<td>[1.46, 2.13]</td>
</tr>
<tr>
<td>College graduate</td>
<td>2.27***</td>
<td>[1.84, 2.81]</td>
<td>[1.76, 2.71]</td>
</tr>
<tr>
<td>Medical beneficiary</td>
<td>0.94</td>
<td>[0.79, 1.13]</td>
<td>[0.95, 1.15]</td>
</tr>
<tr>
<td>Rural residence</td>
<td>0.91</td>
<td>[0.79, 1.05]</td>
<td>[0.91, 1.05]</td>
</tr>
<tr>
<td></td>
<td>1.56*** [1.27, 1.91]</td>
<td>1.57*** [1.27, 1.93]</td>
<td>1.49*** [1.21, 1.84]</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-----------------------</td>
<td>-----------------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>Born in the US</td>
<td>1.02 [0.89, 1.17]</td>
<td>1.04 [0.91, 1.19]</td>
<td>1.13 [0.95, 1.34]</td>
</tr>
<tr>
<td>Attends religious services</td>
<td>1.02 [0.89, 1.17]</td>
<td>1.04 [0.91, 1.19]</td>
<td>1.13 [0.95, 1.34]</td>
</tr>
<tr>
<td>Net worth, quartile</td>
<td>0.98 [0.91, 1.05]</td>
<td>1.01 [0.94, 1.08]</td>
<td>1.18*** [1.08, 1.29]</td>
</tr>
<tr>
<td>Nursing home resident</td>
<td>0.70 [0.46, 1.07]</td>
<td>0.63* [0.41, 0.98]</td>
<td>2.08*** [1.43, 3.02]</td>
</tr>
<tr>
<td>Self-reported health poor/fair (Good, very good, or excellent)</td>
<td>0.90 [0.78, 1.04]</td>
<td></td>
<td>0.98 [0.82, 1.18]</td>
</tr>
<tr>
<td>No. of chronic illnesses</td>
<td>1.19*** [1.13, 1.25]</td>
<td></td>
<td>1.27* [1.04, 1.54]</td>
</tr>
<tr>
<td>Cancer history</td>
<td>1.25** [1.06, 1.47]</td>
<td></td>
<td>1.27* [1.04, 1.54]</td>
</tr>
<tr>
<td>Functional status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of ADL difficulties</td>
<td>0.98 [0.91, 1.06]</td>
<td></td>
<td>0.99 [0.91, 1.08]</td>
</tr>
<tr>
<td>No. of IADL difficulties</td>
<td>1.02 [0.95, 1.10]</td>
<td></td>
<td>1.12* [1.02, 1.22]</td>
</tr>
</tbody>
</table>

*Note.* Model specification uses complete-case analysis (n=13,117). The reference category in the multinomial logit model is “No ACP.” RRRs indicate the odds of utilizing that ACP type relative to no ACP (i.e., the reference category) for that value of the variable in question, holding all other variables constant. M1 is unadjusted. M2 adds sociodemographic characteristics. M3 adds barriers to ACP. M4 adds facilitators of ACP. M5 adds health characteristics. Net worth quartiles defined as follows: 25%=$13,000; 50%=$130,000; 75%=$431,000. Rural-Urban status derived from the 2013 Beale Rural-Urban Continuum Codes. ACP indicates advance care planning; ADL, activities of daily living; CI, confidence interval; GED, General Educational Diploma; IADL, instrumental activities of daily living; M1, Model 1; M2, Model 2; M3, Model 3; M4, Model 4; M5, Model 5; NH, non-Hispanic; RRR, relative risk ratio; SD, standard deviation; US, United States. *p<.05 **p<.01 ***p<.001
Table 2.4 - Relative Risks from Sequential Multinomial Logit Models of Advance Care Planning Type by Race/Ethnicity

<table>
<thead>
<tr>
<th></th>
<th>No ACP (n=2,383)</th>
<th>Informal ACP Only (n=2,083)</th>
<th>Formal ACP Only (n=956)</th>
<th>Both ACP Types (n=7,740)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M1</td>
<td>M2</td>
<td>M3</td>
<td>M4</td>
</tr>
<tr>
<td>NH</td>
<td>2.61</td>
<td>1.95</td>
<td>1.96</td>
<td>1.82</td>
</tr>
<tr>
<td></td>
<td>[2.39, 2.85]</td>
<td>[1.78, 2.15]</td>
<td>[1.65, 2.01]</td>
<td>[1.60, 1.96]</td>
</tr>
<tr>
<td>Black</td>
<td>3.44</td>
<td>2.32</td>
<td>1.94</td>
<td>1.82</td>
</tr>
<tr>
<td></td>
<td>[3.15, 3.76]</td>
<td>[2.10, 2.56]</td>
<td>[1.61, 2.19]</td>
<td>[1.55, 2.06]</td>
</tr>
</tbody>
</table>

Note. Model specification uses complete-case analysis (n=13,117). The reference category is “non-Hispanic White.” Adjusted relative risks were calculated using Stata’s adjrr post-estimation command after running each multinomial logit model. M1 is unadjusted. M2 adds sociodemographic characteristics. M3 adds barriers to ACP. M4 adds facilitators of ACP. M5 adds health characteristics. ACP indicates advance care planning; CI, confidence interval; M1, Model 1; M2, Model 2; M3, Model 3; M4, Model 4; M5, Model 5; NH, non-Hispanic; RR, relative risk.
Chapter 3 Achieving Goal-Concordant End-of-Life Care: The Impact of Formal and Informal ACP for White, Black, and Hispanic Older Adults

Abstract

**Background:** The purpose of advance care planning (ACP) is to help ensure that patients receive goal-concordant care, which is especially important for racially or ethnically minoritized populations who are at higher risk of poor end-of-life outcomes. However, few studies have evaluated the impact of advance directives (i.e., formal ACP) or goals-of-care conversations (i.e., informal ACP) on goal-concordant end-of-life care among a racially or ethnically diverse sample of older adults.

**Objective:** To examine the relationship between formal and informal ACP and goal-concordant end-of-life care among U.S. adults aged 65 and older and to determine whether the impact of formal and informal ACP on goal-concordant care differs between individuals who identify as White, Black, or Hispanic.

**Methods:** We conducted a retrospective cohort study using 2012-2018 data from the biennial Health and Retirement Study. We examined the relationship between goal-concordant end-of-life care and formal and informal ACP using two, separate multivariable logistic regression models. Model 1 regressed a proxy report of goal-concordant care on the two types of ACP and sociodemographic and health-related covariates. Model 2 added interaction terms between race/ethnicity and the types of ACP.
Results: Our sample included 2,047 older adults. Bivariate analyses indicated a significant
difference in the proportions of White, Black, and Hispanic respondents who received goal-
cordant care (83.2%, 75.1%, and 71.1%, respectively; p<.001). In multivariable analyses, informal ACP was associated with significantly higher odds of goal-concordant care (adjusted Odds Ratio [aOR]=1.37 [95% CI 1.04, 1.80]). In Model 2, the use of formal ACP increased the predicted probability of goal-concordant care by an average of 11 (95% CI 1, 22) percentage points for Black respondents and the use of informal ACP increased the predicted probability of goal-concordant care by an average of 5 (95% CI 0, 11) percentage points for White respondents. White respondents had higher predicted probabilities of receiving goal-concordant care than Black or Hispanic respondents whether they had no ACP, informal ACP only, or both types of ACP, but these differences were not statistically significant.

Discussion: Our results build on previous work by indicating the importance of incorporating goals-of-care conversations into routine healthcare for older adults and addressing racial/ethnic disparities in end-of-life care.

Introduction

Patients, their family members, and prominent healthcare organizations alike recognize goal-concordance (i.e., alignment with patients’ stated preferences, values and goals) as an important component of high-quality healthcare (Dzau et al., 2017; Ernecoff et al., 2018; Heyland et al., 2006). Goal-concordant care is particularly important when individuals are navigating serious illness or nearing their end of life and are at increased risk of unwanted healthcare treatment (Berlin, 2017). Older adults who desire comfort-focused treatment over costly life-sustaining treatment or who identify with a racially or ethnically minoritized group are at especially high risk for receiving care that does not align with their goals (Bazargan, Cobb,
Though older adults are more likely to receive hospice care at the end of life and less likely to die in an acute care setting than in previous decades, a significant proportion of this group and their family members continue to report healthcare treatment that doesn’t match their preferences (Khandelwal et al., 2017; Teno et al., 2018).

The purpose of advance care planning (ACP) is to help ensure that patients receive healthcare treatment that aligns with their preferences, values, and goals (Sudore et al., 2017). ACP provides space for patients to identify their healthcare treatment preferences in advance of an unexpected health event and prepares patients and their surrogates for future healthcare decision-making (Inoue & Moorman, 2015; Song et al., 2017). However, few studies have evaluated the impact of the various types of ACP (i.e., living wills, durable powers of attorney, and/or goals-of-care conversations) on goal-concordant care, particularly for racially and ethnically minoritized populations who may be at higher risk of poor end-of-life care (Estrada et al., 2021; Karanth et al., 2018). Though two systematic reviews suggested that ACP interventions that included a communication element increased the likelihood of goal-concordant end-of-life care, the few studies supporting this finding examined only small, homogenous samples (Houben et al., 2014; Weathers et al., 2016).

Identifying the most effective mechanisms for obtaining goal-concordant care for the large and increasingly diverse older adult population in the United States remains an important endeavor. In this study, we examine the impact of advance directives and goals-of-care conversations on goal-concordant end-of-life care among different racial/ethnic groups. Specifically, the aims of this study were: 1) to examine the relationship between formal (i.e., living wills or durable powers of attorney) and informal (i.e., goals-of-care conversations) ACP and goal-concordant end-of-life care among U.S. adults aged 65 and older; and 2) to determine
whether the impact of formal and informal ACP on goal-concordant care differs between individuals who identify as White, Black, or Hispanic.

Methods

Data and Study Participants

We conducted a retrospective cohort study using data from the Health and Retirement Study (HRS). HRS is a large, nationally representative longitudinal survey consisting of multiple birth cohorts of adults aged 51 and older (Sonnega et al., 2014). HRS respondents and their spouses/partners complete core interviews approximately every two years covering various topics related to aging. When a respondent dies, an exit interview is conducted with a proxy respondent (usually the bereaved partner or another close family member) to gather information regarding the decedent’s health, family, and financial situation during the final stage of life. HRS is sponsored by the National Institute on Aging (grant number NIA U01AG009740) and conducted by the University of Michigan (Health and Retirement Study, 2021). Because of its use of publicly available, deidentified data, this study was deemed “not regulated” by the Health Sciences and Behavioral Sciences Institutional Review Board at the University of Michigan (HUM00196992).

For this study, we used pooled data from HRS respondents who died between the 2012 and 2018 survey waves, whose final core interview occurred in 2012 or later and within two years of their death, and for whom an exit interview was completed. This range was selected because 2012 was the first year in which the HRS core interview included questions regarding respondents’ ACP. Because we were specifically interested in the ACP of older adults, we included only decedents aged 65 and older at the time of their last core interview.

Measures
**Outcome**

Our primary outcome of interest was goal-concordant care, which we measured using a binary indicator based on proxy responses to the HRS exit interview question, “Thinking about [the respondent’s] experiences with the health care system over the past year, how often were [the respondent’s] preferences for care taken into account: never, sometimes, usually, or always?” As in previous studies, proxy responses of “Usually” or “Always” were categorized as the decedent having received goal-concordant end-of-life care while proxy responses of “Sometimes” or “Never” were categorized as the decedent not having received goal-concordant end-of-life care (Haines et al., 2019). Family members’ shared experiences with persons at end of life have been shown to reliably measure patients’ own perceptions of goal-concordant end-of-life care (McPherson & Addington-Hall, 2003; Sanders et al., 2018). Therefore, the use of proxy reports to measure goal-concordant care were expected to provide reasonable approximations of decedents’ actual end-of-life care experiences and perceptions.

**Variables of Interest**

**Advance Care Planning.** Our primary factors of interest were the ACP types, formal and informal.

**Formal Advance Care Planning.** We constructed a binary variable indicating whether decedents had completed formal ACP (i.e., an advance directive) based on their responses to the following two HRS questions in their last core interview: 1) “Have you written instructions about the care or medical treatment that you would want to receive if you cannot make those decisions yourself (i.e., living will)?” and 2) “Have you completed a legal arrangement for a specific person(s) to make decisions about your care or medical treatment if you cannot make those decisions yourself (i.e., durable power of attorney)”? Decedents who completed at least one
advance directive (i.e., living will or durable power of attorney) were categorized as having formal ACP. Decedents who had not completed either advance directive were categorized as having no formal ACP.

*Informal Advance Care Planning.* Similarly, we constructed a binary variable indicating whether decedents had completed any informal ACP based on their response to the following question in their last core interview: “Have you discussed with anyone the care or medical treatment you would want to receive if you were to become seriously ill (i.e., goals-of-care conversations)?” Decedents who reported a goals-of-care conversation were categorized as having informal ACP. Decedents who did not report a goals-of-care conversation were categorized as having no informal ACP.

*Race/ethnicity.* To examine potential racial/ethnic disparities in care between three of the largest racial/ethnic groups in the U.S., we identified decedents' self-reported race/ethnicity, categorized into three categories: non-Hispanic White (i.e., White), non-Hispanic Black (i.e., Black), and Hispanic. Due to small sample sizes, decedents who self-identified as American Indian, Alaskan Native, Asian, Native Hawaiian, Pacific Islander, or any other race/ethnicity were excluded from these analyses.

*Covariates*

All models controlled for sociodemographic and clinical characteristics that have previously demonstrated an association with ACP or end-of-life care (Choi et al., 2020; Enguidanos & Ailshire, 2017; Khosla et al., 2016; Rao et al., 2014). We extracted all covariate measures from decedents’ last core interview excepting marital status, which was measured in the exit interview (i.e., marital status at the time of death). Covariates included age, gender (i.e., male, female), educational level (i.e., high school graduate vs. less than high school), marital
status (i.e., married/partnered vs. single/divorced), supplemental health insurance coverage (i.e., Medicaid vs. no Medicaid and some private insurance vs. none), and nursing home residence. We controlled for country of birth (i.e., U.S. born versus elsewhere) as a proxy measure for acculturation given known differences in ACP practices among racially and ethnically minoritized older immigrants and more frequent challenges in communicating end-of-life preferences and navigating the healthcare system among older immigrants in general (Yarnell et al., 2017; Yi, 2019). We also controlled for attendance at religious services as prior work has demonstrated an association between belief in a higher power and healthcare treatment preferences at the end of life (Hoe & Enguidanos, 2020; Koss, 2018). Because end-of-life care practices vary by geographic region (Heller et al., 2019; Nicholas et al., 2011; Wang et al., 2016), we also included an indicator of rural status (i.e., metropolitan area based on the 2013 Beale Rural-Urban Continuum codes).

Clinical covariates included a summary index of up to seven self-reported chronic diseases (i.e., Alzheimer’s disease and related dementias, arthritis, diabetes, heart disease, lung disease, psychiatric illness, stroke history). We separately controlled for a history of any cancer (excluding skin cancer) because individuals with a cancer diagnosis have previously been more likely to complete an advance directive than those without and because of the more predictable decline of patients with a cancer diagnosis compared to those with noncancer chronic illness (Lunney et al., 2003; Stolz et al., 2021). We also included a binary measure of self-rated health (i.e., good, very good, or excellent vs. poor or fair) and difficulties with Activities of Daily Living (e.g., bathing or dressing; range 0-5). These measures were used as proxies for overall health given their strong associations with a number of important health outcomes (Giltay et al., 2012; Lee, 2000; van der Linde et al., 2013). Finally, we controlled for whether the decedents’
passing was expected, as this may have impacted the timeline of death and care received (Barclay et al., 2014).

**Statistical Analyses**

First, we calculated the frequencies and percentages of categorical variables and means with standard deviation of continuous variables. We then used chi-square and Wilcoxon rank-sum tests to test for differences between those who received goal-concordant end-of-life care and those who did not. To examine the relationship between goal-concordant care and ACP type, we then estimated two, separate multivariable logistic regression models. Model 1 regressed the primary outcome on the two ACP variables, formal and informal ACP. Model 2 explored whether the relationship between formal and informal ACP and goal-concordant care differed by race/ethnicity by adding interaction terms. For ease of interpreting these interactions, we computed the average marginal effects (i.e., the percentage point difference in the predicted probability of receiving goal-concordant care) of each ACP type compared to not having that ACP for each racial/ethnic group. We also computed the predicted probabilities of receiving goal-concordant care for each racial/ethnic group using no ACP, each type of ACP on its own, or both types of ACP. Both models controlled for the robust set of sociodemographic and clinical characteristics listed above.

**Results**

Our final analytic sample included 2,047 unique older adults who died between June of 2012 and December of 2018 (Table 3.1). In bivariate analyses, both formal and informal ACP were significantly associated with receiving goal-concordant end-of-life care (p<.01). Though a majority of individuals in each racial/ethnic group received goal-concordant end-of-life care, a
greater proportion of White compared to Black and Hispanic respondents received such care (83.2% vs. 75.1% and 71.1%, respectively; \( \chi^2 \) p<.001).

In Model 1, the adjusted odds of receiving goal-concordant care for those using informal ACP was 1.37 (95% CI 1.04, 1.80) times that of those with no informal ACP (Table 3.2). In post hoc analyses, this translated to a 5 (95% CI 1, 10) percentage point average increase in the probability of goal-concordant care for those with informal ACP compared to those with no informal ACP. The adjusted odds of receiving goal-concordant care for those with formal ACP compared to those with no formal ACP were not statistically significantly different. Similarly, although the adjusted odds of receiving goal-concordant care were lower for Black and Hispanic respondents compared to White respondents, the differences were not statistically significant.

In Model 2, the use of formal ACP increased the predicted probability of goal-concordant care by an average of 11 (95% CI 1, 22) percentage points for Black respondents. Additionally, the use of informal ACP increased the predicted probability of goal-concordant care by an average of 5 (95% CI 0, 11) percentage points for White respondents (Figure 3.1). There were no significant differences in the predicted probability of receiving goal-concordant care for Hispanic individuals using either type of ACP.

Table 3.3 depicts the predicted probabilities of receiving goal-concordant care from Model 2 for each racial/ethnic group using no ACP, each type of ACP on its own, or both types of ACP. As shown, White respondents had the highest predicted probabilities of receiving goal-concordant care compared to Black or Hispanic respondents whether they had no ACP, informal ACP only, or both types of ACP, but these differences were not statistically significant. Across all three racial/ethnic groups, the predicted probability of receiving goal-concordant care was
higher for those who engaged in one or both types of ACP than those with no ACP, but, again, these differences were not statistically significant.

**Discussion**

In this study of older adults who died between 2012 and 2018, over 70% of White, Black, and Hispanic decedents were reported to have received goal-concordant care at the end-of-life. Decedents who had discussed the care or medical treatment they would want in the event of serious illness were more likely to receive goal-concordant end-of-life care than those who did not. In addition, formal ACP was associated with statistically significantly greater benefit for Black older adults but not White or Hispanic older adults. Although Black and Hispanic decedents were less likely to receive goal-concordant care compared to White respondents regardless of ACP use in our second model, the differences were not statistically significant. Our findings emphasize the importance of discussing healthcare treatment preferences for achieving goal-concordant end-of-life care but caution against a “one-size-fits-all” approach among racially and ethnically diverse older adult populations.

Previous investigators have demonstrated an association between complex ACP programs and several improved end-of-life outcomes, including reduced rates of hospitalization at the end-of-life and improved congruence between patients and surrogates or clinicians (Brinkman-Stoppelenburg et al., 2014; McMahan et al., 2021). In contrast, our findings specifically emphasize the importance of informal ACP in achieving goal-concordant care. In goals-of-care conversations, patients and their family members discuss their healthcare treatment preferences and prepare for later, in-the-moment decision-making, a key component of quality ACP (Fleuren et al., 2020; Sudore et al., 2017). Identifying patients’ values and healthcare treatment preferences ahead of time may reduce decisional conflict among patient surrogates and
thus increase the likelihood of goal-concordant care when individuals are no longer able to make
decisions for themselves (Brinkman-Stoppelenburg et al., 2014; Jeon et al., 2018). This may be
especially important for patients prioritizing comfort at the end-of-life as they have been found
less likely to receive goal-concordant care than those preferring life-sustaining treatments
(Bandini et al., 2021; Modes et al., 2020; Rutz Voumard et al., 2021).

Our findings also suggest that formal ACP, legal documents in which individuals
document their healthcare treatment preferences or designate a proxy decision-maker, may
contribute to goal-concordant care among Black older adults. Black older adults frequently
report a sense of marginalization within the healthcare system and an increased need to advocate
for themselves or their family members (Bazargan, Cobb, & Assari, 2021; McCleskey & Cain,
2019). They have also been less likely to receive hospice care at the end of life and more likely
to report poor pain and symptom management in this period compared to their White peers
(Estrada et al., 2021; Ornstein et al., 2020). Black older adults may choose to document their
healthcare treatment preferences in an advance directive rather than discuss those preferences
with a healthcare provider with whom they have not yet established trust. Formal ACP may also
be a particularly effective tool for promoting goal-concordant care among the Black older adult
population if clinicians regard legal documents more highly than informally stated preferences.

Although we did not observe significant racial/ethnic differences in the receipt of goal
concordant care in the HRS data in Model 2, previous data have identified racial/ethnic
disparities in preventable medical encounters, overall treatment intensity, and symptom
management at end-of-life (Estrada et al., 2021; Karanth et al., 2018; Orlovic et al., 2019). It has
been suggested that these disparities may be due, in part, to greater preferences for life-sustaining
treatment among both Black older adults (Benton et al., 2015; Rahemi & Williams, 2016) and
individuals facing serious illness at younger ages (Rietjens et al., 2012). In our study, Black and Hispanic decedents were on average, three and two years younger, respectively, than White decedents, with the lowest average age occurring among Black and Hispanic men (see Table 3.4). It is possible that this age difference impacted both ACP and goal-concordant care for minoritized groups, however, the nature of the HRS data precluded our ability to fully examine this. Future work must disentangle the effects of patient preferences and racial/ethnic disparities in healthcare on goal-concordant end-of-life care.

Our study had several important limitations. First, our measure of goal-concordance was dependent on proxy reports which may have been subject to recall bias or, perhaps, inaccurately represented decedents’ own assessments of events. However, previous evidence suggests that family members’ reports may be more closely aligned with decedents’ actual assessments of end-of-life care than other measures, particularly given that preferences may change rapidly at the end of life (McPherson & Addington-Hall, 2003; Sanders et al., 2018). Additionally, smaller sample sizes among the Black and Hispanic groups relative to the White group likely limited our ability to demonstrate statistical significance in the marginal effects of different types of ACP among these racially and ethnically minoritized groups. We were also unable to describe ACP and goal-concordant care patterns among other, smaller racial/ethnic groups in the United States due to small sample sizes and lack of differentiation in HRS. Finally, given the limitations of the HRS surveys, we were unable to examine the treatment preferences of the older adults in our study. Thus, our analyses could not determine the impact of patient preferences (i.e., life-sustaining treatments versus comfort-focused care) on receiving goal-concordant care.

In this study, informal ACP was associated with an increased odds of receiving goal-concordant end-of-life care for U.S. older adults, and formal ACP was especially beneficial for
Black older adults. Our results build on previous work by indicating the importance of incorporating goals-of-care conversations into routine healthcare for older adults and addressing racial/ethnic disparities in end-of-life care.
References


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Table 3.1 - Characteristics of Decedents Overall and By Receipt of Goal-Concordant End-of-Life Care (n=2,047)

<table>
<thead>
<tr>
<th></th>
<th>No. (%) / mean ± SD</th>
<th>Goal-Discordant Care (n=386 [18.9%])</th>
<th>Goal-Concordant Care (n=1,661 [81.1%])</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race/Ethnicity*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NH White</td>
<td>1,601 (78.2)</td>
<td>270 (70.0)</td>
<td>1,331 (80.1)</td>
</tr>
<tr>
<td>NH Black</td>
<td>303 (14.8)</td>
<td>75 (19.4)</td>
<td>228 (13.7)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>143 (7.0)</td>
<td>41 (10.6)</td>
<td>102 (6.1)</td>
</tr>
<tr>
<td>Age, years</td>
<td>82.2 ± 8.3</td>
<td>81.6 ± 8.2</td>
<td>82.4 ± 8.3</td>
</tr>
<tr>
<td>Female gender</td>
<td>1,074 (52.5)</td>
<td>189 (49.0)</td>
<td>885 (53.3)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>578 (28.2)</td>
<td>124 (32.1)</td>
<td>454 (27.3)</td>
</tr>
<tr>
<td>High school graduate/GED</td>
<td>743 (36.3)</td>
<td>150 (38.9)</td>
<td>593 (35.7)</td>
</tr>
<tr>
<td>Some college</td>
<td>406 (19.8)</td>
<td>64 (16.6)</td>
<td>342 (20.6)</td>
</tr>
<tr>
<td>College graduate</td>
<td>320 (15.6)</td>
<td>48 (12.4)</td>
<td>272 (16.4)</td>
</tr>
<tr>
<td>Marital status at death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/partnered</td>
<td>851 (41.6)</td>
<td>172 (44.6)</td>
<td>679 (40.9)</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>218 (10.7)</td>
<td>45 (11.7)</td>
<td>173 (10.4)</td>
</tr>
<tr>
<td>Widowed</td>
<td>913 (44.6)</td>
<td>155 (40.2)</td>
<td>758 (45.6)</td>
</tr>
<tr>
<td>Never married</td>
<td>65 (3.2)</td>
<td>14 (3.6)</td>
<td>51 (3.1)</td>
</tr>
<tr>
<td>Attends religious services</td>
<td>1,230 (60.1)</td>
<td>226 (58.6)</td>
<td>1,004 (60.5)</td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>372 (18.2)</td>
<td>85 (22.0)</td>
<td>287 (17.3)</td>
</tr>
<tr>
<td>Private insurance*</td>
<td>788 (38.5)</td>
<td>120 (31.1)</td>
<td>668 (40.2)</td>
</tr>
<tr>
<td>Nursing home resident</td>
<td>398 (19.4)</td>
<td>90 (23.3)</td>
<td>308 (18.5)</td>
</tr>
<tr>
<td>Born in the US</td>
<td>1,889 (92.3)</td>
<td>344 (89.1)</td>
<td>1,545 (93.0)</td>
</tr>
<tr>
<td>Rural residence</td>
<td>613 (30.0)</td>
<td>116 (30.1)</td>
<td>497 (29.9)</td>
</tr>
<tr>
<td>Death expected</td>
<td>1,296 (63.3)</td>
<td>230 (59.6)</td>
<td>1,066 (64.2)</td>
</tr>
<tr>
<td>Self-reported health poor/fair</td>
<td>1,223 (59.8)</td>
<td>236 (61.1)</td>
<td>987 (59.4)</td>
</tr>
<tr>
<td>Non-cancer chronic illnesses</td>
<td>2.5 ± 1.4</td>
<td>2.4 ± 1.4</td>
<td>2.5 ± 1.4</td>
</tr>
<tr>
<td>History of cancer</td>
<td>657 (32.1)</td>
<td>112 (29.0)</td>
<td>545 (32.8)</td>
</tr>
<tr>
<td>ADL difficulties</td>
<td>1.7 ± 1.9</td>
<td>1.9 ± 1.9</td>
<td>1.7 ± 1.9</td>
</tr>
<tr>
<td>ACP</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Formal ACP*</td>
<td>1,545 (75.5)</td>
<td>258 (16.7)</td>
<td>1,287 (83.3)</td>
</tr>
<tr>
<td>Informal ACP*</td>
<td>1,481 (72.4)</td>
<td>242 (16.3)</td>
<td>1,239 (83.7)</td>
</tr>
</tbody>
</table>

Note. Not all categories total 100% due to rounding. Data represents decedents with complete data for final analytical model. Rural-Urban status derived from the 2013 Beale Rural-Urban Continuum Codes. Counted chronic illnesses include Alzheimer’s disease and related dementias, arthritis, diabetes, heart disease, lung disease, psychiatric illness, and history of stroke. ACP indicates advance care planning; ADL, activities of daily living; NH, Non-Hispanic; SD, standard deviation; US, United States.

*p<.01
Table 3.2 - Effect of Type of Advance Care Planning and Race/Ethnicity on Receipt of Goal-Concordant Care at the End of Life

<table>
<thead>
<tr>
<th>Characteristic (Reference)</th>
<th>Odds Ratio [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACP type</td>
<td></td>
</tr>
<tr>
<td>Formal ACP</td>
<td>1.30 [0.97, 1.73]</td>
</tr>
<tr>
<td>Informal ACP*</td>
<td>1.37 [1.04, 1.80]</td>
</tr>
<tr>
<td>Race/Ethnicity (NH White)</td>
<td></td>
</tr>
<tr>
<td>NH Black</td>
<td>0.74 [0.53, 1.04]</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.74 [0.45, 1.21]</td>
</tr>
<tr>
<td>Age, mean (SD), years</td>
<td>1.01 [0.99, 1.02]</td>
</tr>
<tr>
<td>Female gender (Male)</td>
<td>1.19 [0.93, 1.52]</td>
</tr>
<tr>
<td>High school graduate</td>
<td>0.98 [0.75, 1.29]</td>
</tr>
<tr>
<td>Married/partnered at death</td>
<td>0.87 [0.67, 1.13]</td>
</tr>
<tr>
<td>Attends religious services</td>
<td>1.08 [0.86, 1.37]</td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>1.06 [0.77, 1.47]</td>
</tr>
<tr>
<td>Private insurance*</td>
<td>1.29 [1.00, 1.66]</td>
</tr>
<tr>
<td>Nursing home resident*</td>
<td>0.62 [0.45, 0.87]</td>
</tr>
<tr>
<td>Born in the US</td>
<td>1.30 [0.83, 2.04]</td>
</tr>
<tr>
<td>Rural residence</td>
<td>0.93 [0.72, 1.20]</td>
</tr>
<tr>
<td>Self-reported health poor/fair (Good/very good/excellent)</td>
<td>1.01 [0.78, 1.30]</td>
</tr>
<tr>
<td>Non-cancer chronic illnesses</td>
<td>1.05 [0.96, 1.14]</td>
</tr>
<tr>
<td>History of cancer</td>
<td>1.09 [0.84, 1.40]</td>
</tr>
<tr>
<td>ADL difficulties</td>
<td>0.96 [0.89, 1.04]</td>
</tr>
<tr>
<td>Death expected</td>
<td>1.16 [0.91, 1.48]</td>
</tr>
</tbody>
</table>

Notes. Results are from Model 1, which regressed the primary outcome, receipt of goal-concordant care, on the two types of ACP: formal ACP and informal ACP. ACP indicates advance care planning; ADL, activities of daily living; IADL, instrumental activities of daily living; NH, Non-Hispanic; SD, standard deviation; US, United States. *p<.05
Figure 3.1 - Average Marginal Effects of Advance Care Planning Type on Goal-Concordant Care by Race/Ethnicity

Notes. Results are from Model 2, which regressed the primary outcome, receipt of goal-concordant care, on formal ACP and informal ACP and introduced interaction terms between these ACP types and racial/ethnic identities. Average marginal effects represent the percentage point difference in the predicted probability of receiving goal-concordant care when using the indicated ACP type (e.g., formal ACP) compared to not using it for individuals of the indicated racial/ethnic group. These graphs display 95% confidence intervals.
Table 3.3 - Predicted Probabilities of Receiving Goal-Concordant Care by Type of Advance Care Planning and Race/Ethnicity

<table>
<thead>
<tr>
<th>ACP Type</th>
<th>% [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>No ACP</td>
<td></td>
</tr>
<tr>
<td>NH White</td>
<td>77.3 [71.6, 83.0]</td>
</tr>
<tr>
<td>NH Black</td>
<td>67.8 [58.7, 77.0]</td>
</tr>
<tr>
<td>Hispanic</td>
<td>68.1 [55.3, 80.8]</td>
</tr>
<tr>
<td>Formal ACP Only</td>
<td></td>
</tr>
<tr>
<td>NH White</td>
<td>78.9 [73.7, 84.1]</td>
</tr>
<tr>
<td>NH Black</td>
<td>79.6 [71.1, 88.1]</td>
</tr>
<tr>
<td>Hispanic</td>
<td>74.6 [58.0, 91.2]</td>
</tr>
<tr>
<td>Informal ACP Only</td>
<td></td>
</tr>
<tr>
<td>NH White</td>
<td>83.0 [78.0, 88.0]</td>
</tr>
<tr>
<td>NH Black</td>
<td>70.5 [59.0, 82.1]</td>
</tr>
<tr>
<td>Hispanic</td>
<td>76.8 [62.3, 91.2]</td>
</tr>
<tr>
<td>Both ACP Types</td>
<td></td>
</tr>
<tr>
<td>NH White</td>
<td>84.3 [82.1, 86.5]</td>
</tr>
<tr>
<td>NH Black</td>
<td>81.6 [74.9, 88.3]</td>
</tr>
<tr>
<td>Hispanic</td>
<td>82.0 [71.7, 92.2]</td>
</tr>
</tbody>
</table>

Notes. Results are from Model 2, which regressed the primary outcome, receipt of goal-concordant care, on formal ACP and informal ACP and introduced interaction terms between these ACP types and racial/ethnic identities.

ACP indicates advance care planning; CI, confidence interval; NH, Non-Hispanic.
Table 3.4 - Characteristics of Decedents Overall and By Race/Ethnicity (n=2,047)

<table>
<thead>
<tr>
<th></th>
<th>No. (%) / mean ± SD</th>
<th>Total (n=2,047)</th>
<th>NH White (n=1,601 [78.2%])</th>
<th>NH Black (n=303 [14.8%])</th>
<th>Hispanic (n=143 [7.0%])</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age*, years</td>
<td>82.2 ± 8.3</td>
<td>82.9 ± 8.1</td>
<td>79.6 ± 8.8</td>
<td>80.5 ± 8.3</td>
<td></td>
</tr>
<tr>
<td>Female gender</td>
<td>1,074 (52.5)</td>
<td>825 (51.5)</td>
<td>167 (55.1)</td>
<td>82 (57.3)</td>
<td></td>
</tr>
<tr>
<td>Education*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>578 (28.2)</td>
<td>336 (21.0)</td>
<td>142 (46.9)</td>
<td>100 (69.9)</td>
<td></td>
</tr>
<tr>
<td>High school graduate/GED</td>
<td>743 (36.3)</td>
<td>626 (39.1)</td>
<td>91 (30.0)</td>
<td>26 (18.2)</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>406 (19.8)</td>
<td>348 (21.7)</td>
<td>46 (15.2)</td>
<td>12 (8.4)</td>
<td></td>
</tr>
<tr>
<td>College graduate</td>
<td>320 (15.6)</td>
<td>291 (18.2)</td>
<td>24 (7.9)</td>
<td>5 (3.5)</td>
<td></td>
</tr>
<tr>
<td>Marital status at death*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/partnered</td>
<td>851 (41.6)</td>
<td>688 (43.0)</td>
<td>106 (35.0)</td>
<td>57 (39.9)</td>
<td></td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>218 (10.7)</td>
<td>141 (8.8)</td>
<td>58 (19.1)</td>
<td>19 (13.3)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>913 (44.6)</td>
<td>733 (45.8)</td>
<td>121 (39.9)</td>
<td>59 (41.3)</td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>65 (3.2)</td>
<td>39 (2.4)</td>
<td>18 (5.9)</td>
<td>8 (5.6)</td>
<td></td>
</tr>
<tr>
<td>Attends religious services*</td>
<td>1,230 (60.1)</td>
<td>934 (58.3)</td>
<td>211 (69.6)</td>
<td>85 (59.4)</td>
<td></td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid*</td>
<td>372 (18.2)</td>
<td>197 (12.3)</td>
<td>107 (35.3)</td>
<td>68 (47.6)</td>
<td></td>
</tr>
<tr>
<td>Private insurance*</td>
<td>788 (38.5)</td>
<td>708 (44.2)</td>
<td>60 (19.8)</td>
<td>20 (14.0)</td>
<td></td>
</tr>
<tr>
<td>Nursing home resident*</td>
<td>398 (19.4)</td>
<td>341 (21.3)</td>
<td>38 (12.5)</td>
<td>19 (13.3)</td>
<td></td>
</tr>
<tr>
<td>Born in the US*</td>
<td>1,889 (92.3)</td>
<td>1,535 (95.9)</td>
<td>289 (95.4)</td>
<td>65 (45.5)</td>
<td></td>
</tr>
<tr>
<td>Rural residence*</td>
<td>613 (30.0)</td>
<td>536 (33.5)</td>
<td>57 (18.8)</td>
<td>20 (14.0)</td>
<td></td>
</tr>
<tr>
<td>Death expected*</td>
<td>1,296 (63.3)</td>
<td>1,056 (66.0)</td>
<td>159 (52.5)</td>
<td>81 (56.6)</td>
<td></td>
</tr>
<tr>
<td>Self-reported health poor/fair*</td>
<td>1,223 (59.8)</td>
<td>924 (57.7)</td>
<td>199 (65.7)</td>
<td>100 (69.9)</td>
<td></td>
</tr>
<tr>
<td>Non-cancer chronic illnesses</td>
<td>2.5 ± 1.4</td>
<td>2.5 ± 1.3</td>
<td>2.5 ± 1.5</td>
<td>2.4 ± 1.5</td>
<td></td>
</tr>
<tr>
<td>History of cancer*</td>
<td>657 (32.1)</td>
<td>555 (34.7)</td>
<td>77 (25.4)</td>
<td>25 (17.5)</td>
<td></td>
</tr>
<tr>
<td>ADL difficulties*</td>
<td>1.7 ± 1.9</td>
<td>1.6 ± 1.9</td>
<td>2.0 ± 2.0</td>
<td>2.3 ± 2.0</td>
<td></td>
</tr>
<tr>
<td>ACP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Formal ACP*</td>
<td>1,545 (75.5)</td>
<td>1,314 (82.1)</td>
<td>171 (56.4)</td>
<td>60 (42.0)</td>
<td></td>
</tr>
<tr>
<td>Informal ACP*</td>
<td>1,481 (72.4)</td>
<td>1,265 (79.0)</td>
<td>148 (48.8)</td>
<td>68 (47.6)</td>
<td></td>
</tr>
</tbody>
</table>
Note. Not all categories total 100% due to rounding. Data represents decedents with complete data for final analytical model. Rural-Urban status derived from the 2013 Beale Rural-Urban Continuum Codes. Counted chronic illnesses include Alzheimer’s disease and related dementias, arthritis, diabetes, heart disease, lung disease, psychiatric illness, and history of stroke. ACP indicates advance care planning; ADL, activities of daily living; NH, Non-Hispanic; SD, standard deviation; US, United States. *p<.01
Chapter 4 The Association Between Decedents’ Advance Care Planning and Bereaved Partners’ Self-Rated Health and Depressive Symptoms

Abstract

Background: Poorer quality end-of-life care and communication may contribute to poorer health outcomes among recently widowed spouses/partners. Advance care planning (ACP) provides space for patients and their surrogates to practice difficult communication and make healthcare decisions prior to the end-of-life period. ACP may, thus, improve poor health outcomes among bereaved partners by improving communication and increasing the occurrence of goal-concordant end-of-life care.

Objective: To examine the association between decedents’ formal (i.e., advance directives) and informal (i.e., goals-of-care conversations) ACP and their bereaved partners’ self-rated health and depressive symptoms.

Methods: We used 2012-2018 Health and Retirement Study (HRS) data to construct a dyadic dataset pairing decedents’ ACP and end-of-life care outcomes with their bereaved partners’ (aged 65 years and older) health outcomes (n=646). We then examined the associations between decedents’ formal and informal ACP and each of bereaved partners’ self-rated health and depressive symptoms using ordinal logistic and negative binomial regression models, respectively. We also explored whether decedent receipt of goal-concordant end-of-life care was associated with bereaved partners’ health outcomes by repeating the models with a measure of
goal-concordant care in place of the two ACP variables. All models controlled for a number of
sociodemographic and clinical characteristics.

Results: There was no association between decedents’ use of formal (OR=1.14 [95% CI 0.80,
1.64]) or informal (OR=0.80 [0.56, 1.14]) ACP and bereaved partners’ post-loss self-rated
health. There was also no association between decedents’ use of formal (IRR=0.94 [0.79, 1.12])
or informal (IRR=0.88 [0.74, 1.04]) ACP and bereaved partners’ depressive symptoms. Decedent
receipt of goal-concordant care was also not significantly associated with either of bereaved
partners’ self-rated health or depressive symptoms.

Discussion: Though previous data suggested a relationship between end-of-life care and
communication and bereavement outcomes, our study using HRS data did not find significant
relationships between either decedent ACP type and bereaved partners’ health outcomes. Future
research must further examine communication strategies and timing near the end-of-life to
ascertain the optimal approach for supporting older adults and their spouses/partners at the end of
life.

Introduction

Spousal or partner loss in older adulthood, though common, is considered one of life’s
most stressful events and is consistently associated with poor physical and mental health
outcomes (Carr & Jeffreys, 2011; Holmes & Rahe, 1967; Luhmann et al., 2012). Widowed
persons report poorer overall health than the general population and are at increased risk for
cardiovascular disease, cognitive decline, and chronic pain (Ennis & Majid, 2019; Singham et
al., 2021). Approximately one in four grieving older adults experience complicated grief,
characterized by a prolonged grief experience and more severe psychological distress than is
typically experienced within a normal grieving process (Newson et al., 2011).
Prior work suggests that poor end-of-life communication and low-quality end-of-life care may exacerbate poor health outcomes among widowed partners. Poor end-of-life communication is associated with increased emotional distress among grieving family members, a phenomenon that has been exacerbated by the ongoing COVID-19 pandemic (Feder et al., 2020; Harrop et al., 2016, 2020). In contrast, family members engaged in higher quality communication with their loved one during the final weeks prior to that loved one’s death have been found to experience reduced psychological distress and lower decisional conflict following the loss (Bachner et al., 2009; Smith-Howell et al., 2016). Similarly, widowed persons whose partners experience higher overall quality of death or hospice care experience higher health-related quality-of-life and fewer depressive symptoms following their partners’ death (Garrido & Prigerson, 2014; Ornstein et al., 2015, 2018).

Advance care planning (ACP) provides space for patients to communicate their healthcare treatment preferences, values, and goals regarding future medical care to their loved ones and providers (Sudore et al., 2017). This occurs via legally documented preferences in the form of advance directives (i.e., formal ACP) or goals-of-care conversations with family members and/or providers (i.e., informal ACP). The purpose of ACP is to improve healthcare concordance with the patients’ stated preferences, values, and goals (i.e., goal-concordant care). Ideally, ACP not only provides space for patients to communicate their preferences, but also allows patients and their partners or surrogates to practice difficult communication and prepares surrogates for future decision-making (Institute of Medicine, 2015; Sudore & Fried, 2010). It has been proposed that ACP may thereby mitigate bereaved surrogates’ post-loss decisional regret and associated poor bereavement outcomes (Jeon et al., 2018; Sudore et al., 2018).
ACP may improve bereaved partners’ mental and physical well-being because of the way it prepares both patients and their loved ones for the end-of-life period. In this study, we examine the association between decedents’ formal and informal ACP and the physical and emotional health outcomes of their bereaved partners (i.e., spouses or cohabitating partners, hereafter referred to collectively as “partners”). We hypothesized that both ACP types would be associated with improved health outcomes among bereaved partners.

**Methods**

**Data and Study Participants**

We conducted a retrospective cohort study using data from decedents and their bereaved partners in the Health and Retirement Study (HRS). HRS is a large, nationally representative longitudinal survey of adults aged 51 years and older and their partners that is conducted by the University of Michigan and sponsored by the National Institute on Aging (grant number NIA U01AG009740) (Health and Retirement Study, 2021). HRS respondents participate in biennial core interviews covering a broad range of topics related to aging, including ACP. When a respondent dies, an exit interview is conducted with a proxy respondent (usually the bereaved partner or another close family member) to gather information regarding the decedent’s health, family, and financial situation during the final stage of life.

For this study, we used pooled data from HRS respondents aged 65 years and older whose partner recently died. We included data from bereaved partners who completed HRS core interviews at times preceding and following their partner’s death and whose deceased partners completed a core interview within two years of their death and for whom an exit interview was conducted. This allowed for construction of a dyadic dataset with paired information from both the bereaved partner and the decedent. We only included data from the 2012-2018 HRS survey
waves as 2012 was the first year that HRS core interviews included survey questions regarding ACP. This project was deemed “not regulated” by the IRB-HSBS at the University of Michigan given its use of publicly available, deidentified data (HUM00196992).

**Measures**

**Outcomes**

This study had two outcomes of interest, bereaved partners’ overall health and depressive symptoms. Both outcomes were measured in the bereaved partners’ HRS core interviews that directly followed the deaths of the decedents.

**Poorer self-rated health.** We measured overall health using bereaved partners’ self-rated health in response to the HRS core interview question, “Would you say your health is excellent, very good, good, fair, or poor?” This item created a five-level ordinal measure (i.e., 1=excellent to 5=poor) where smaller values indicated better health and larger values indicated poorer health. There is strong evidence that self-rated health is a valid measure of overall health, as it is strongly associated with a number of important health outcomes, including functional status, chronic illness morbidity, and mortality (Giltay et al., 2012; Lee, 2000; van der Linde et al., 2013).

**Depressive symptoms.** We used the short-form version of the Center for Epidemiologic Studies Depression Scale (CES-D) to measure depressive symptoms among bereaved partners. The original CES-D is a 20-item self-report scale used to measure depressive symptomatology in the general population (Radloff, 1977). The short-form version includes 8 depressive symptoms (e.g., feeling depressed, lonely, unmotivated, etc.) where participants indicate “yes” to each item that was “true for you much of the time this past week”. Total scores range from 0 to 8, and the
scale has previously demonstrated good internal consistency (Cronbach’s $\alpha \geq .78$) and construct validity among groups of older adults (Karim et al., 2015; Turvey et al., 1999).

**Variables of Interest**

**Advance Care Planning.** Our primary variables of interest were decedents’ use of formal and informal ACP prior to death.

**Formal Advance Care Planning.** We constructed a binary variable indicating whether decedents had completed formal ACP (i.e., an advance directive) based on their responses to the following two HRS questions in their final core interview: 1) “*Have you written instructions about the care or medical treatment that you would want to receive if you cannot make those decisions yourself (i.e., living will)?*” and 2) “*Have you completed a legal arrangement for a specific person(s) to make decisions about your care or medical treatment if you cannot make those decisions yourself (i.e., durable power of attorney)?*” Decedents who completed at least one advance directive (i.e., living will or durable power of attorney) were categorized as having formal ACP while those who indicated neither were categorized as having no formal ACP.

**Informal Advance Care Planning.** Similarly, we constructed a binary variable indicating whether decedents had completed any informal ACP based on their response to the following question in their final core interview: “*Have you discussed with anyone the care or medical treatment you would want to receive if you were to become seriously ill (i.e., goals-of-care conversations)?*”

**Goal-Concordant Care.** To explore whether ACP might impact the health outcomes of interest by contributing to goal-concordant end-of-life care, a key component of high-quality healthcare at the end-of-life (Dzau et al., 2017; Sudore et al., 2018), we constructed a binary variable indicating decedent receipt of goal-concordant care (i.e., exit interview responses to the
question, “Thinking about [the decedent’s] experiences with the health care system over the past year, how often were [the decedent’s] preferences for care taken into account: never, sometimes, usually, or always?” with “Usually” or “Always” indicating goal-concordant care) (Haines et al., 2019).

*Covariates*

All models controlled for sociodemographic and clinical characteristics that have previously demonstrated an impact on bereaved partners’ overall health or depressive symptoms. We extracted all covariates from bereaved partners’ core interviews immediately preceding the decedents’ passing as covariates measured following the decedents’ passing may have been impacted by the loss. Covariates included age, gender (i.e., male, female), educational level (i.e., high school graduate vs. less than high school), and net worth (in quartiles, treated as continuous). We also included self-reported race/ethnicity to account for the differing trajectories of depressive symptoms between non-Hispanic White, non-Hispanic Black, and Hispanic older adult populations (Assari et al., 2016; Liang et al., 2011). We included measures of health insurance other than Medicare (i.e., Medicaid vs. no Medicaid and some private insurance vs. none) as the prevalence of psychiatric conditions has previously shown to vary by insurance coverage and these insurance plans may cover additional health services potentially impacting both overall health and depressive symptoms (Choi et al., 2016; Stahl et al., 2017). Attendance at religious services was also included since prior work suggests an association between religiosity and reduced severity of bereavement outcomes (Hawes et al., 2022).

Bereaved partners’ clinical characteristics included a count of their chronic diseases because of the known impact of physical health on mental health outcomes (Luo et al., 2020). These included Alzheimer’s disease and related dementias, arthritis, diabetes, history of cancer.
(excluding skin cancer), heart disease, lung disease, psychiatric illness, and history of stroke (summary score 0-8). Measures of difficulties with activities of daily living (e.g., bathing and dressing; range 0-5) and regular exercise (i.e., moderate or vigorous exercise at least three times a week) were included due to their potential impact on depressive symptomology (Belvederi Murri et al., 2015; Parajuli et al., 2021). We also controlled for partners’ self-rated health or depressive symptoms in the core interview immediately prior to the decedent’s passing (i.e., baseline, or pre-bereavement, self-rated health/depressive symptoms), as this allowed us to explore the change in the outcome that was related to the primary variables of interest rather than partners’ baseline health condition.

To account for the potentially diminished impact of bereavement over time on partners’ outcomes, we included the number of months elapsed between the decedent’s passing and the date of the partner’s subsequent core interview. Finally, we controlled for whether the decedents’ passing was expected, as this may have impacted the timeline of death, communication near the end-of-life, and end-of-life care received, and has previously shown to impact family members’ ability to prepare for and adapt to loss (Barclay et al., 2014; Keyes et al., 2014).

**Statistical Analyses**

All analyses were conducted in Stata SE (version 17.0). We first described the characteristics of the bereaved partners, overall and among subsamples whose deceased partners had completed formal and informal ACP. We calculated the frequencies and percentages of categorical variables and means with standard deviations of continuous variables. We then compared bereaved partners’ post-loss self-rated health and depressive symptoms to their pre-loss self-rated health and depressive symptoms, respectively, to determine what proportion of the sample was experiencing worse, better, or the same level of health. We used Wilcoxon signed
rank sum tests to compare each of self-rated health and depressive symptoms before compared to after partner loss.

**Self-Rated Health.** We examined the association between decedents’ formal and informal ACP and their bereaved partners’ self-rated health with ordinal logistic regression, adjusting for all covariates. The odds ratios presented in these models represent the odds of being above or below any one of the cut points (e.g., reporting poor or fair health compared to reporting good, very good, or excellent health). We then computed the adjusted relative risks of reporting each specific health category outcome (e.g., good) according to decedent ACP type using Stata’s adjrr command. To explore whether ACP might impact bereaved partners’ self-rated health by improving goal-concordant care, we re-estimated the model with the binary measure of goal-concordant end-of-life care in place of the two decedent ACP indicators.

**Depressive Symptoms.** We examined the association between decedents’ ACP and their bereaved partners’ depressive symptoms using a negative binomial regression model, adjusting for all covariates. Negative binomial regression was used because the CES-D is a count of eight different depressive symptoms and because of the overdispersion in the distribution of this outcome variable (i.e., the variance more than doubled the mean). Use of an ordinary least squares regression with a count dependent variable can result in inefficient, inconsistent, and biased estimates (Hidayat & Pokhrel, 2010). We then computed the average difference in the number of depressive symptoms between the bereaved whose deceased partners had formal or informal ACP versus no formal or informal ACP (i.e., average marginal effects). To explore whether ACP might impact bereaved partners’ depressive symptoms by improving goal-concordant care, we re-estimated the model with the binary measure of goal-concordant end-of-life care in place of the two decedent ACP indicators.
Results

Our final analytic sample included data from 646 bereaved partner-decedent dyads. The characteristics of the bereaved partners are described in Table 4.1. A majority of the decedents had reported use of formal ACP (69.4%) and informal ACP (69.5%). Over half (52.5%) of bereaved partners rated their overall health at the same level after their loss compared to before, 19.5% rated it better, and 28.0% rated it worse. There was a statistically significant difference between pre-loss and post-loss self-rated health (p=.002). Only 30.5% of bereaved partners reported the same number of depressive symptoms after their loss compared to before, 52.0% reported a greater number, and 17.5% reported fewer. The median (IQR) number of depressive symptoms in the post-loss interviews was 2 (0-4), which was significantly higher than the median number of depressive symptoms in the pre-loss interviews (0.5 [0-2], p<.001).

There was no statistically significant association between decedents’ use of formal or informal ACP and the bereaved partners’ post-loss self-rated health (ORs=1.14 [95% CI 0.80, 1.64] and 0.80 [0.56, 1.14], respectively; see Table 4.2). Instead, a greater number of chronic illnesses and poorer self-rated health prior to loss were significantly associated with increased odds of poorer self-rated health following bereavement (Table 4.2). Decedent use of formal ACP or informal ACP was not significantly associated with bereaved partners’ likelihood of reporting any of the five self-rated health categories (Table 4.6). Decedent receipt of goal-concordant care was also not significantly associated with bereaved partners’ self-rated health (OR=1.05 [0.72, 1.53]; see Table 4.3).

Figure 1 depicts bereaved partners’ depressive symptoms over the first 24 months following loss. There was no statistically significant association between decedents’ use of formal or informal ACP and bereaved partners’ depressive symptoms (IRRs=0.88 [0.74, 1.04]).
and 0.94 [0.79, 1.12], respectively; see Table 4.4). Higher education and greater time between loss and interview were associated with decreased odds of greater depressive symptoms. Decedent receipt of goal-concordant care was not significantly associated with bereaved partners’ depressive symptoms (IRR=1.04 [0.86, 1.25]); see Table 4.5).

**Discussion**

In this sample of bereaved older adults, respondents rated their own overall health worse and reported a greater number of depressive symptoms after compared to before losing their partner. Bereaved partners’ self-rated health and depressive symptoms following their loss were not significantly associated with their deceased partners’ use of formal or informal ACP. Collectively, findings from this sample suggest that decedents’ ACP may have a limited impact on bereaved older partners’ health outcomes in the years immediately following loss.

Our findings of poorer overall health and worsening depressive symptoms among older adults following the loss of their partner is unsurprising given the substantial body of literature that has documented the negative impact of partner loss on older adults’ physical and emotional health outcomes (Stroebe et al., 2007; van den Berg et al., 2011). Widowed older adults report poorer health and a greater number of symptoms than the general population (Ennis & Majid, 2019), and partner loss has been associated with increased healthcare spending among female older adults up to two years following spousal loss (Ornstein et al., 2019). Depressive symptoms are known to increase sharply in the first month following spousal loss (Kristiansen et al., 2019). Though they typically decrease in the years following bereavement, they remain higher among bereaved persons compared to the general population and have shown to contribute to worsening physical health outcomes up to five years after widowhood (Domingue et al., 2020; Kristiansen et al., 2019).
Our findings suggest that decedents’ ACP may have limited impact on bereaved partners’ overall health in the first few years following loss. Prior work demonstrated an association between decedents’ end-of-life treatment intensity and bereaved partners’ healthcare utilization (Ornstein et al., 2015, 2018). We have previously demonstrated that informal ACP may improve goal-concordant care at the end-of-life (Manuscript 2) and others have identified an association between ACP and reduced end-of-life treatment intensity (Brinkman-Stoppelenburg et al., 2014; Weissman et al., 2021). However, our findings suggest that the impact of ACP on such end-of-life outcomes may be insufficient to meaningfully affect bereaved partners’ health in the years immediately following their loss, whether independently or via its contributions to goal-concordant end-of-life care. Decedent receipt of goal-concordant end-of-life care, though an important outcome of successful ACP and indicator of high-quality end-of-life care, is likely insufficient to ameliorate the effects of significant loss on health outcomes in bereavement.

Similarly, decedents’ use of formal or informal ACP prior to death was not significantly associated with bereaved partners’ depressive symptoms afterward. This finding is somewhat perplexing given previous studies suggesting an association between high-quality communication in the final weeks of life and reduced psychological distress among bereaved loved ones in the first few months following their loss (Bachner et al., 2021; Feder et al., 2020). Our results suggest that any potential impact of ACP on bereaved partners’ emotional health, whether independently or via its contributions to goal-concordant end-of-life care, may not extend to the longer period of bereavement experienced by partners in this study. The nature of the HRS dataset also made it impossible for us to assess the content or quality of decedents’ ACP. Rather, decedents merely indicated whether they had completed either ACP type. Further,
though decedents indicated their ACP, it is unclear whether or how bereaved partners were involved in that ACP.

Our results did demonstrate interesting associations between bereaved partners’ own higher education, greater time from loss, and fewer depressive symptoms. Prior work has revealed similar relationships between bereaved partners’ educational attainment and depressive symptoms, suggesting that educational attainment and related socioeconomic advantage may lessen susceptibility to depression throughout later life (Fiske et al., 2009; Khalaila, 2016). A recent systematic review and meta-analysis examining depression in widowhood over time suggested that the prevalence of depression among bereaved spouses is highest within the first month of widowhood and lowest after two to five years (Kristiansen et al., 2019). Together, these findings suggest that less educated older adults who have very recently lost their partner may be at particularly high risk of depressive symptoms compared to the general older adult population. Additionally, because depressive symptoms are highest in the first month following loss and typically decrease thereafter, measuring our outcomes of interest for several years following partner loss may have diminished the potential effects of decedents’ ACP.

Our study had several notable limitations. First, our measures of ACP were dependent on self-report, which may have been subject to recall bias. We were also unable to assess the content, quality, or timing of either ACP type, which may have impacted the outcomes of interest as ACP occurring closer to the end-of-life and higher-quality ACP that includes both providers and loved ones may have greater impact on poor health outcomes in bereavement. Importantly, the HRS dataset may not be representative of the population at large, as participation may reflect a selection bias. Additionally, small sample sizes limited our statistical power and precluded us from examining racial/ethnic differences in the relationships between decedents’ ACP and their
partners’ health outcomes. Finally, we were unable to examine bereavement outcomes among non-partner family members due to the constraints of the dataset. However, prior work indicates that partners are more likely than other loved ones to experience difficulty coping after loss, suggesting that this was an ideal sample for examining the relationships of interest (McNamara & Rosenwax, 2010).

Though previous literature has suggested a relationship between end-of-life communication and bereavement outcomes, our study did not demonstrate differences in bereaved partners’ self-rated health or depressive symptoms according to decedent use of formal or informal ACP. Future research must further examine communication strategies and timing near the end-of-life in order to ascertain the optimal approach for supporting older adults and their partners at the end of life.
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https://doi.org/10.1177/00302228211051509

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https://doi.org/10.3390/ijerph7010009


https://doi.org/10.1176/appi.ajp.2014.13081132


https://doi.org/10.1007/s10433-016-0384-1


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McNamara, B., & Rosenwax, L. (2010). Which carers of family members at the end of life need more support from health services and why? *Social Science and Medicine, 70*(7), 1035–1041. https://doi.org/10.1016/j.socscimed.2009.11.029


https://doi.org/10.1017/s1041610299005694


Table 4.1 - Characteristics of Older Adult Bereaved Partners, Overall and by Decedents’ Advance Care Planning Type

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Full Sample (n=646)</th>
<th>Formal ACP (n=448)</th>
<th>Informal ACP (n=449)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years</td>
<td>76.8 ± 6.6</td>
<td>77.5 ± 6.6</td>
<td>77.0 ± 6.7</td>
</tr>
<tr>
<td>Female gender</td>
<td>462 (71.5)</td>
<td>327 (73.0)</td>
<td>326 (72.6)</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NH White</td>
<td>539 (83.4)</td>
<td>402 (89.7)</td>
<td>398 (88.6)</td>
</tr>
<tr>
<td>NH Black</td>
<td>62 (9.6)</td>
<td>31 (6.9)</td>
<td>34 (7.6)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>45 (7.0)</td>
<td>15 (3.4)</td>
<td>17 (3.8)</td>
</tr>
<tr>
<td>High school graduate/GED</td>
<td>543 (84.1)</td>
<td>390 (87.1)</td>
<td>389 (86.6)</td>
</tr>
<tr>
<td>Net worth, quartiles</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 (Low)</td>
<td>62 (9.6)</td>
<td>33 (7.4)</td>
<td>34 (7.6)</td>
</tr>
<tr>
<td>2</td>
<td>152 (23.5)</td>
<td>102 (22.8)</td>
<td>100 (22.3)</td>
</tr>
<tr>
<td>3</td>
<td>218 (33.8)</td>
<td>132 (29.5)</td>
<td>141 (31.4)</td>
</tr>
<tr>
<td>4 (High)</td>
<td>214 (33.1)</td>
<td>181 (40.4)</td>
<td>174 (38.8)</td>
</tr>
<tr>
<td>Attends religious services</td>
<td>471 (72.9)</td>
<td>326 (72.8)</td>
<td>324 (72.2)</td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>38 (5.9)</td>
<td>21 (4.7)</td>
<td>19 (4.2)</td>
</tr>
<tr>
<td>Private insurance</td>
<td>296 (45.8)</td>
<td>210 (46.9)</td>
<td>206 (45.9)</td>
</tr>
<tr>
<td>Chronic illnesses</td>
<td>1.9 ± 1.2</td>
<td>1.9 ± 1.2</td>
<td>1.9 ± 1.2</td>
</tr>
<tr>
<td>ADL difficulties</td>
<td>0.2 ± 0.6</td>
<td>0.2 ± 0.6</td>
<td>0.2 ± 0.6</td>
</tr>
<tr>
<td>Regular exercise</td>
<td>121 (18.7)</td>
<td>89 (19.9)</td>
<td>85 (18.9)</td>
</tr>
<tr>
<td>Months since bereavement</td>
<td>11.8 ± 6.9</td>
<td>12.1 ± 6.9</td>
<td>12.0 ± 6.9</td>
</tr>
<tr>
<td>Decedent death expected</td>
<td>405 (62.7)</td>
<td>297 (66.3)</td>
<td>296 (65.9)</td>
</tr>
</tbody>
</table>

Note. Not all categories total 100% due to rounding. Data represent respondents with complete data for final analytical models. Net worth quartiles defined as follows: 25%=$15,200; 50%=$132,000; 75%=$430,000. Rural-Urban status derived from the 2013 Beale Rural-Urban Continuum Codes. Counted chronic illnesses include Alzheimer’s disease and related dementias, arthritis, diabetes, history of cancer (excluding skin cancer), heart disease, lung disease, psychiatric illness, and history of stroke.
ADL indicates activities of daily living; GED, general educational development; NH, non-Hispanic; SD, standard deviation.
Table 4.2 - Association Between Decedents’ Advance Care Planning and Bereaved Partners’ Poorer Self-Rated Health

<table>
<thead>
<tr>
<th>Characteristic (Reference)</th>
<th>OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decedent ACP</td>
<td></td>
</tr>
<tr>
<td>Formal</td>
<td>1.14 [0.80, 1.64]</td>
</tr>
<tr>
<td>Informal</td>
<td>0.80 [0.56, 1.14]</td>
</tr>
<tr>
<td>Decedent death expected</td>
<td>0.92 [0.67, 1.26]</td>
</tr>
<tr>
<td>Race/ethnicity (NH White)</td>
<td></td>
</tr>
<tr>
<td>NH Black</td>
<td>0.97 [0.58, 1.61]</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.29 [0.68, 2.45]</td>
</tr>
<tr>
<td>Age</td>
<td>1.01 [0.99, 1.04]</td>
</tr>
<tr>
<td>Female gender</td>
<td>0.96 [0.69, 1.34]</td>
</tr>
<tr>
<td>High school graduate/GED</td>
<td>1.25 [0.79, 1.96]</td>
</tr>
<tr>
<td>Net worth, quartile</td>
<td>0.87 [0.73, 1.03]</td>
</tr>
<tr>
<td>Attends religious services</td>
<td>1.04 [0.73, 1.47]</td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>1.56 [0.80, 3.05]</td>
</tr>
<tr>
<td>Private insurance</td>
<td>0.98 [0.72, 1.32]</td>
</tr>
<tr>
<td>Chronic illnesses</td>
<td>1.37* [1.20, 1.57]</td>
</tr>
<tr>
<td>ADL difficulties</td>
<td>1.21 [0.92, 1.59]</td>
</tr>
<tr>
<td>Regular exercise</td>
<td>0.87 [0.58, 1.29]</td>
</tr>
<tr>
<td>Months since bereavement</td>
<td>0.98 [0.96, 1.01]</td>
</tr>
<tr>
<td>Baseline self-rated health</td>
<td>4.16* [3.37, 5.13]</td>
</tr>
</tbody>
</table>

*Note. HRS’s five-level ordinal measure for self-rated health is coded from 1=excellent to 5=poor (i.e., larger values indicate poorer health). The table displaces the adjusted odds ratios from the ordinal logistic regression examining the association between decedents’ ACP type and their bereaved partners’ self-rated health. ACP indicates advance care planning; ADL, activities of daily living; CI, confidence interval; GED, general educational development; NH, non-Hispanic; OR, odds ratio.
*p<.05
Table 4.3 - Association Between Decedent Receipt of Goal-Concordant Care and Bereaved Partners’ Poorer Self-Rated Health

<table>
<thead>
<tr>
<th>Characteristic (Reference)</th>
<th>OR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decedent Received Goal-Concordant Care</td>
<td>1.05 [0.72, 1.53]</td>
</tr>
<tr>
<td>Decedent death expected</td>
<td>0.89 [0.65, 1.22]</td>
</tr>
<tr>
<td>Race/ethnicity (NH White)</td>
<td></td>
</tr>
<tr>
<td>NH Black</td>
<td>0.97 [0.58, 1.60]</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.36 [0.72, 2.58]</td>
</tr>
<tr>
<td>Age</td>
<td>1.01 [0.99, 1.04]</td>
</tr>
<tr>
<td>Female gender</td>
<td>0.95 [0.68, 1.34]</td>
</tr>
<tr>
<td>High school graduate/GED</td>
<td>1.24 [0.78, 1.96]</td>
</tr>
<tr>
<td>Net worth, quartile</td>
<td>0.85 [0.71, 1.01]</td>
</tr>
<tr>
<td>Attends religious services</td>
<td>1.02 [0.71, 1.45]</td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>1.50 [0.77, 2.93]</td>
</tr>
<tr>
<td>Private insurance</td>
<td>1.06 [0.78, 1.45]</td>
</tr>
<tr>
<td>Chronic illnesses</td>
<td>1.35* [1.18, 1.55]</td>
</tr>
<tr>
<td>ADL difficulties</td>
<td>1.19 [0.90, 1.57]</td>
</tr>
<tr>
<td>Regular exercise</td>
<td>0.95 [0.64, 1.43]</td>
</tr>
<tr>
<td>Months since bereavement</td>
<td>0.99 [0.97, 1.01]</td>
</tr>
<tr>
<td>Baseline self-rated health</td>
<td>4.31* [3.47, 5.34]</td>
</tr>
</tbody>
</table>

Note. HRS’s five-level ordinal measure for self-rated health is coded from 1=excellent to 5=poor (i.e., larger values indicate poorer health). The table displaces the adjusted odds ratios from the ordinal logistic regression examining the association between decedent receipt of goal-concordant care and bereaved partners’ self-rated health.
ACP indicates advance care planning; ADL, activities of daily living; CI, confidence interval; GED, general educational development; NH, non-Hispanic; OR, odds ratio.
*p<.05
Table 4.4 - Association Between Decedents’ Advance Care Planning and Bereaved Partners’ Depressive Symptoms

<table>
<thead>
<tr>
<th>Characteristic (Reference)</th>
<th>IRR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decedent ACP</td>
<td></td>
</tr>
<tr>
<td>Formal</td>
<td>0.94 [0.79, 1.12]</td>
</tr>
<tr>
<td>Informal</td>
<td>0.88 [0.74, 1.04]</td>
</tr>
<tr>
<td>Decedent death expected</td>
<td>0.89 [0.76, 1.03]</td>
</tr>
<tr>
<td>Race/ethnicity (NH White)</td>
<td></td>
</tr>
<tr>
<td>NH Black</td>
<td>0.82 [0.63, 1.07]</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.97 [0.71, 1.31]</td>
</tr>
<tr>
<td>Age, mean (SD), years</td>
<td>0.99* [0.98, 1.00]</td>
</tr>
<tr>
<td>Female gender</td>
<td>0.98 [0.83, 1.16]</td>
</tr>
<tr>
<td>High school graduate/GED</td>
<td>0.72* [0.59, 0.89]</td>
</tr>
<tr>
<td>Net worth, quartile</td>
<td>1.02 [0.94, 1.11]</td>
</tr>
<tr>
<td>Attends religious services</td>
<td>0.96 [0.81, 1.14]</td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>1.25 [0.91, 1.72]</td>
</tr>
<tr>
<td>Private insurance</td>
<td>0.99 [0.85, 1.15]</td>
</tr>
<tr>
<td>Chronic illnesses</td>
<td>1.16* [1.09, 1.23]</td>
</tr>
<tr>
<td>ADL difficulties</td>
<td>1.00 [0.89, 1.13]</td>
</tr>
<tr>
<td>Regular exercise</td>
<td>0.87 [0.71, 1.06]</td>
</tr>
<tr>
<td>Months since bereavement</td>
<td>0.98* [0.97, 0.99]</td>
</tr>
<tr>
<td>Baseline depressive symptoms</td>
<td>1.18* [1.13, 1.23]</td>
</tr>
</tbody>
</table>

Note. The table displays the adjusted incidence rate ratios from the negative binomial regression examining the association between decedents’ ACP type and their bereaved partners’ depressive symptoms.

ACP indicates advance care planning; ADL, activities of daily living; CI, confidence interval; GED, general educational development; NH, non-Hispanic; IRR, incidence rate ratio.

*p<.05
Table 4.5 - Association Between Decedent Receipt of Goal-Concordant Care and Bereaved Partners’ Depressive Symptoms

<table>
<thead>
<tr>
<th>Characteristic (Reference)</th>
<th>IRR [95% CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decedent Received Goal-Concordant Care</td>
<td>1.04 [0.86, 1.25]</td>
</tr>
<tr>
<td>Decedent death expected</td>
<td>0.87 [0.74, 1.01]</td>
</tr>
<tr>
<td>Race/ethnicity (NH White)</td>
<td></td>
</tr>
<tr>
<td>NH Black</td>
<td>0.84 [0.64, 1.10]</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.01 [0.74, 1.37]</td>
</tr>
<tr>
<td>Age, mean (SD), years</td>
<td>0.99* [0.98, 1.00]</td>
</tr>
<tr>
<td>Female gender</td>
<td>0.99 [0.83, 1.17]</td>
</tr>
<tr>
<td>High school graduate/GED</td>
<td>0.73* [0.59, 0.91]</td>
</tr>
<tr>
<td>Net worth, quartile</td>
<td>1.00 [0.91, 1.09]</td>
</tr>
<tr>
<td>Attends religious services</td>
<td>0.97 [0.81, 1.15]</td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>1.23 [0.89, 1.69]</td>
</tr>
<tr>
<td>Private insurance</td>
<td>0.98 [0.83, 1.14]</td>
</tr>
<tr>
<td>Chronic illnesses</td>
<td>1.16* [1.09, 1.24]</td>
</tr>
<tr>
<td>ADL difficulties</td>
<td>1.00 [0.88, 1.13]</td>
</tr>
<tr>
<td>Regular exercise</td>
<td>0.87 [0.71, 1.07]</td>
</tr>
<tr>
<td>Months since bereavement</td>
<td>0.98* [0.97, 0.99]</td>
</tr>
<tr>
<td>Baseline depressive symptoms</td>
<td>1.18* [1.12, 1.23]</td>
</tr>
</tbody>
</table>

*Note. The table displaces the adjusted incidence rate ratios from the negative binomial regression examining the association between decedent receipt of goal-concordant care and their bereaved partners’ depressive symptoms. ACP indicates advance care planning; ADL, activities of daily living; CI, confidence interval; GED, general educational development; NH, non-Hispanic; IRR, incidence rate ratio. *p<.05
Table 4.6 - Adjusted Relative Risks from Ordinal Logistic Regression of Bereaved Partners’ Self-Rated Health by Decedents’ Advance Care Planning Type

<table>
<thead>
<tr>
<th>Self-Rated Health Category</th>
<th>Adjusted Risk Ratios [95% CI]</th>
<th>Formal ACP</th>
<th>Informal ACP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>0.90 [0.67, 1.20]</td>
<td>1.21 [0.90, 1.62]</td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td>0.95 [0.84, 1.08]</td>
<td>1.09 [0.95, 1.25]</td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>1.01 [0.98, 1.03]</td>
<td>0.99 [0.97, 1.01]</td>
<td></td>
</tr>
<tr>
<td>Fair</td>
<td>1.05 [0.92, 1.21]</td>
<td>0.92 [0.80, 1.05]</td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>1.11 [0.84, 1.45]</td>
<td>0.84 [0.65, 1.10]</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* The adjusted relative risks were derived from the models that included all covariates. In the full sample, 6.4% of bereaved partners reported excellent health, 28.2% reported very good, 37.2% reported good, 21.5% reported fair, and 6.8% reported poor health. ACP indicates advance care planning; CI, confidence interval.
Figure 4.1 - Average Marginal Effects of Decedents’ Formal and Informal Advance Care Planning on Bereaved Partners’ Depressive Symptoms

Note. The graph depicts the average marginal effects (with 95% confidence intervals) of decedents’ formal and informal ACP on their bereaved partners’ number of depressive symptoms. Results are from the fully adjusted Poisson model including all bereaved partners. Only the first 24 months are displayed, representing over 96% of the sample. ACP indicates advance care planning.
Chapter 5 Synthesis and Conclusions

Summary of Main Research Findings

The purpose of this dissertation research was to examine the relationships between ACP and end-of-life outcomes among older adults (i.e., adults aged 65 or more years) of diverse racial/ethnic identities and their loved ones. This work addressed important gaps in the literature by examining: 1) the use of informal ACP in addition to the more traditionally assessed formal ACP, 2) the association between both ACP types and goal-concordant end-of-life care, 3) the association between decedents’ ACP and bereaved partners’ physical and emotional health outcomes, and 4) racial/ethnic differences within each of these relationships. The following paragraphs summarize the primary findings from each of the three manuscripts.

Though we observed a higher overall prevalence of ACP among living older adults compared to previous estimates, there remained statistically significant differences in ACP between White, Black, and Hispanic older adults (Manuscript 1). Black and Hispanic respondents were 77% and 76% more likely, respectively, to report no use of ACP compared to White respondents in our final analysis, which adjusted for sociodemographic characteristics, barriers to and facilitators of ACP, and clinical characteristics (n=13,117). Black and Hispanic respondents were also both 26% less likely to report using both ACP types compared to White respondents. Residual racial/ethnic differences in ACP that remained significant after controlling for a number of potentially confounding factors suggests a need to examine underlying
explanations. There may be differences in unmeasured healthcare treatment preferences or healthcare system factors that perpetuate racial/ethnic disparities in healthcare for older adults.

Next, we found that informal ACP was associated with higher odds of goal-concordant end-of-life care for older adults in general, but formal ACP was associated with significant benefit for only Black older adults (Manuscript 2). In our sample (n=2,047), a greater proportion of White compared to Black and Hispanic decedents reported goal-concordant care (83.2% vs. 75.1% and 71.1%, respectively; $\chi^2 p<.001$). In adjusted results, the odds of receiving goal-concordant care for decedents who used informal ACP was 1.37 times that of those with no informal ACP. Further, when examining interactions between race/ethnicity and ACP type, we found that formal ACP increased the predicted probability of goal-concordant care by 11 percentage points for Black decedents. In these additional subset analyses, though White decedents had the highest predicted probabilities of receiving goal-concordant end-of-life care regardless of ACP use, these proportions were not significantly higher compared to those of Black and Hispanic decedents in this sample. These results suggest that clinicians and policymakers should consider emphasizing informal ACP to achieve goal-concordant care for the general older adult population but should also support formal ACP for some racially and ethnically minoritized populations who may be less comfortable discussing their preferences, values, and goals within traditional healthcare settings.

Finally, we found that neither formal nor informal ACP among decedents were significantly associated with improved physical or emotional health outcomes among their bereaved partners in their first few years of widowhood (Manuscript 3). On average, and consistent with prior work, our smaller sample of bereaved partners (n=646) rated their own health poorer and reported a greater number of depressive symptoms after compared to prior to
their loss. However, bereaved partners’ self-rated health and depressive symptoms were not associated with the paired decedents’ use of ACP. Additionally, decedent receipt of goal-concordant care was not associated with bereaved partners’ self-rated health or depressive symptoms. The absence of observed effects of decedents’ ACP or goal-concordant care on bereaved partners’ health may be, in part, related to our inability to examine the quality, timing, content, or bereaved partner involvement in ACP due to constraints of the HRS dataset. Our results suggest that the potential impact of ACP on bereaved partners’ health outcomes, whether independently or via its contributions to decedents’ goal-concordant end-of-life care, may not extend to participants surveyed up to two years following their loss.

**Significance**

Overall, this dissertation highlights the previously underacknowledged importance of goals-of-care conversations (i.e., informal ACP) for improving goal-concordant end-of-life care. However, our findings also caution against a “one-size-fits-all” ACP approach that may be inappropriate for optimizing end-of-life healthcare among a racially and ethnically diverse older adult population. Findings highlighted racial/ethnic differences in ACP use and suggested that ACP may not substantially benefit bereaved partners in the first few years following bereavement.

My research affirms the need to reevaluate the potential benefit and application of advance directives for achieving goal-concordant care and emphasizes the continued importance of goals-of-care conversations. Findings also suggest that a more individualized ACP approach may better support older adults and their loved ones near the end-of-life. Recent conceptualizations of ACP as a “process” in which adults share their values, goals, and preferences in advance of future healthcare treatment decisions suggest a paradigm shift away
from advance directives toward ongoing goals-of-care discussions to better elicit patients’ healthcare treatment preferences (Sudore et al., 2017). A small, but vocal number of palliative care scholars have somewhat radically suggested that ACP has failed to improve the quality of end-of-life care and related outcomes. Instead, they suggest that healthcare initiatives should focus on appointing surrogate decision-makers and improving in-the-moment shared decision-making between patients, proxies, and clinicians (Morrison et al., 2021). In contrast, my research suggests that goals-of-care conversations remain valuable before the end-of-life period. Such conversations may support optimal end-of-life care by making patients’ current preferences and goals clearer to providers, preparing surrogates to make future decisions that are better aligned with patients’ preferences, and allowing both patients and surrogates to practice difficult conversations in preparation for later, in-the-moment decision-making (Inoue & Moorman, 2015; Song et al., 2017; Sudore & Fried, 2010).

While this dissertation specifically highlights the importance of informal ACP for improving goal-concordant care, we found support for both ACP types (i.e., formal and/or informal) for improving end-of-life care within specific subpopulations of older adults. Thus, though we identified significant racial/ethnic differences in formal and informal ACP use among participants in the Health and Retirement Study (HRS), of greater concern are the high proportions of respondents with no ACP, particularly among Hispanic older adults.

Lower ACP use among Black and Hispanic older adults may be due to limited knowledge of treatment options, real or perceived discrimination from providers, or mistrust in providers or a healthcare system that has historically failed to provide the same quality of care to racially or ethnically minoritized older adults as to White older adults (Center to Advance Palliative Care, n.d.; Washington, 2008). Though several studies indicate that Hispanic older adults are receptive
to ACP, they also frequently report a lack of awareness regarding treatment options or the need to choose from among them (Maldonado et al., 2019; Shen et al., 2020). Providers have also identified communication difficulties as a primary barrier to ACP with racially and ethnically minoritized persons (Ashana et al., 2021; Ladin et al., 2021). Fewer than half of the Hispanic respondents in the HRS sample were born in the United States, suggesting that communication and cultural differences may be a key barrier to ACP knowledge and engagement within this population. Future work attempting to increase informal ACP among this population must acknowledge and identify strategies to address such barriers.

Black older adults emphasize the importance of establishing trust prior to engaging in serious illness conversations (Collins et al., 2018; Hansen et al., 2016) and may choose to complete advance directives rather than discussing healthcare treatment preferences with providers. Though Black older adults should not be expected to identify and utilize alternate pathways to receive the same quality end-of-life care as their peers of other racial/ethnic identities, they should be supported in identifying their healthcare treatment preferences via their preferred mechanism to receive optimal end-of-life care. Formal ACP may be a promising and appropriate intervention for improving end-of-life outcomes among Black older adults while clinicians, researchers, and policymakers work to address ongoing healthcare disparities and build trust within underserviced communities.

Finally, while my research identified significant relationships between ACP and goal-concordant care among older adults, the benefits of ACP did not extend to bereaved partners in the time period covered by this study. Since previous data suggests that high-quality end-of-life communication may improve bereaved partners’ emotional health outcomes in the first months following loss (Bachner et al., 2021; Feder et al., 2020), future work might use more detailed
measures and longitudinal analyses statistically powered to examine the early bereavement period to explore the optimal communication timing, preferences, and content to better individualize care and support both patients and loved ones facing bereavement.

**Implications for Nursing Practice**

Findings described within this dissertation have several important implications for nursing practice. Nursing roles are increasingly expanding in primary care settings across the globe and hospitalized patients spend a greater amount of time with nurses than with any other provider (Butler et al., 2018; Maier & Aiken, 2016). Nurses, therefore, have greater opportunities to develop rapport with patients and to elicit patients’ preferences. Thus, nurses have a responsibility to advocate for their patients’ needs and preferences and document those needs and preferences in the health record (Fliedner et al., 2021). Such documentation may facilitate ACP discussions between patients, their family members, and their healthcare team.

Nurses, particularly advanced practice registered nurses who may sign orders aligning patients’ care with their preferences, also have a responsibility to initiate and continue ACP discussions with their patients (Fliedner et al., 2021; Hayes et al., 2017). To prepare nurses to do so effectively, nursing curricula must include training on ACP at the undergraduate and graduate levels. Nurses who care for seriously ill populations should pursue continuing education from organizations like Five Wishes (fivewishes.org), Respecting Choices (respectingchoices.org), or the Center to Advance Palliative Care ACP (capc.org).

Finally, though Americans consistently rate the honesty and ethics of nurses higher than any other profession, this trust in the nursing profession is not universal across racially and ethnically minoritized populations (Reinhart, 2020). As part of a greater effort towards health equity, nurses have a responsibility to provide clinically excellent and culturally competent care.
within underserviced communities in order to develop greater trust and build a foundation for ACP discussions between patients, family members, and clinicians. Nursing curricula across all levels of training must also include content emphasizing equitable, culturally competent care to individuals of all sexes, races, and ethnicities.

**Future Directions for Research and Policy**

Findings described within this dissertation also have broader implications for clinicians, researchers, and policymakers alike. In 2016, fee-for-service Medicare began reimbursing providers for ACP, including goals-of-care conversations, during outpatient visits. However, recent work indicates that fewer than 7.5% of fee-for-service Medicare beneficiaries have an ACP claim annually (Palmer et al., 2021). Limited time for potentially lengthy ACP conversations and lack of training have been cited as common barriers for clinicians to engage in ACP (Fulmer et al., 2018). Though there are several lay person initiatives (including “The Conversation Project” and “Death Over Dinner”) that encourage families to discuss end-of-life treatment preferences, there are fewer established interventions for improving the frequency and content of goals-of-care conversations within and beyond clinical settings with diverse populations. Additional funding resources are needed to encourage and support clinicians in engaging in existing ACP training opportunities and supporting patients in completing ACP. Research priorities include identifying strategies for increasing appropriate ACP among populations with high proportions of individuals without ACP, identifying the optimal timing and content of ACP in order to support both patients and their loved ones, and validating this dissertation’s findings with other racially or ethnically minoritized populations and those at greater risk of poor end-of-life outcomes.
Identify strategies for increasing individualized ACP among populations with high proportions of individuals without ACP. Our findings suggested that a more individualized ACP approach may better support older adults and their loved ones near the end-of-life. Specifically, though goals-of-care conversations are positively associated with goal-concordant end-of-life care for older adults in general, formal ACP was associated with significant benefit for Black older adults and may additionally benefit other populations that were not included in our sample. Existing interventions meant to increase the rates of specific ACP types must be tailored to meet the preferences and needs of the older adults who may benefit most. Commonly cited barriers to goals-of-care conversations within the clinical setting include lack of time or clinician training (van der Steen et al., 2014). Existing ACP training programs should be implemented within and beyond healthcare systems to reduce the barriers of clinician time and training in achieving greater ACP rates. Tailoring ACP methods to the preferences and needs of diverse population groups is a critical need in order to better facilitate goal-concordant care at the end-of-life.

Identify the optimal timing and content of ACP in order to support both patients and their loved ones. A limitation of my research was the inability to identify when ACP occurred, how often it occurred, the content or quality of the ACP, and whether bereaved partners or other family members were engaged in the ACP. Further, it is unclear whether the ACP involved an attorney, a primary care provider, or a specialty provider. Other authors suggest that optimal communication in the final weeks of life supports both patients and their loved ones before and after death (Bachner et al., 2009; Smith-Howell et al., 2016), but our findings suggest that conversations occurring before the end-of-life period may also improve patients’ end-of-life outcomes. Previous authors have suggested that goals-of-care conversations
should occur alongside changes in health status and should include discussions regarding patients’ life goals and values, specific medical treatments, and the designation of a proxy decision-maker (Sudore et al., 2017). Most older adults desire such conversations sooner rather than later (Sharp et al., 2013), but more research is needed to identify the optimal timing and content of such conversations in order to support both patients and their loved ones.

**Validate findings with other racially or ethnically minoritized populations and those at greater risk of poor end-of-life outcomes.** My use of HRS data precluded the ability to examine trends among smaller racially and ethnically minoritized groups in the United States. Prior work indicates that some racially and ethnically minoritized groups not studied in this dissertation may be highly amenable to informal ACP but may experience similar barriers to ACP as those reported by Black and Hispanic older adults (Dennis & Washington, 2018; Radhakrishnan et al., 2017). Future work must identify which ACP strategies are most effective for improving end-of-life outcomes among other racially or ethnically minoritized groups as well as subpopulations of older adults at higher risk for poor end-of-life outcomes.

**Strengths and Limitations**

The work embodied in this dissertation has several strengths. First, I conducted a thorough review of the literature to identify several gaps in past research regarding ACP practice among older adults in the United States. Next, I synthesized a conceptual framework that guided three studies to fill the identified gaps. Findings from my sequential studies filled several gaps in past research regarding national patterns in informal ACP engagement, the relationships between both formal and informal ACP and goal-concordant end-of-life care, and the impact of ACP on bereaved partners. My research also revealed important racial/ethnic differences in ACP use and potential racial/ethnic disparities in goal-concordant end-of-life care. A better understanding of
these phenomena is particularly germane given the devastating impact of the COVID-19 pandemic that has disproportionately affected the mortality of both the older adult and Black, Hispanic, and other racially or ethnically minoritized populations in the United States.

The use of HRS, a large, nationally representative longitudinal survey that oversamples several key demographic groups (e.g., Black and Hispanic Americans), strengthened my ability to examine the concepts of interest among populations at increased risk of poor health outcomes during the ongoing pandemic. My use of this large dataset allowed for an examination of outcomes using relatively large sample sizes. Additionally, the inclusion of partner data in the HRS dataset provided a unique opportunity to examine dyadic outcomes important to older adult health and well-being.

My overall research also had several limitations. The lack of differentiation between other racial/ethnic groups in the HRS dataset (e.g., Asian Americans, Native Americans, and Pacific Islanders) limited my ability to identify patterns among them, an important limitation given the known differences in end-of-life care planning and preferences among these groups (Heeringa & Connor, 1995). Additionally, the measure of goal-concordance was dependent on proxy reports which may have inaccurately represented the decedent’s own assessment of events or been subject to recall bias. Bereaved partners who completed the decedent’s exit interview may have introduced their own personal bias which could have inflated or marginalized findings in our studies. However, previous evidence suggests that family members’ reports may be more closely aligned with decedents’ actual assessments of end-of-life care than other measures, thus serving as a reasonable measure of this construct (McPherson & Addington-Hall, 2003; Sanders et al., 2018). Finally, we were unable to examine the post-death health outcomes of non-partner family members of decedents, as HRS includes partner but no other family data, precluding our
ability to generalize the results to extended family members and friends. This limitation is less important given evidence suggesting that partners are more likely to experience difficulties coping after loss than others (McNamara & Rosenwax, 2010). Despite these limitations, this dissertation filled important gaps in the research literature and has the potential to substantially benefit the diverse group of older adults approaching end of life in the United States.

Conclusions

In summary, this dissertation supports important relationships between ACP, race/ethnicity, and end-of-life outcomes. Specifically, our findings indicate that informal ACP contributes to goal-concordant care, but racial/ethnic differences remain in ACP use and disparities may be present in receipt of goal-concordant care at the end of life. Future work must identify mechanisms for engraining appropriate ACP into routine healthcare for older adults, adapting existing ACP interventions to the needs and preferences of a racially and ethnically diverse older adult populations, and addressing ongoing racial and ethnic disparities in end-of-life planning and care.
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