

End-of-Life Care Discussions with Doctors: Evidence from the United States and China

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Abstract

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Chapter 1 presents the backgrounds and research questions of the dissertation project. Although everyone hopes to die with dignity, a “good death” is often privileged. Inequality in end-of-life care in the United States is striking; older minorities are 3 times more likely to receive intrusive care and experience hospital readmission and less likely to use hospice care and die at home. With the hope to address disparities in end-of-life outcomes, as part of the Affordable Care Act, Medicare expanded its benefit and started to reimburse end-of-life care planning services from 2016. This dissertation examines the roles of health insurance policy and its advocated intervention in ensuring person-centered dying experiences in the United States and the public readiness for establishing a similar end-of-life care policy in China.

The second chapter examines whether physician–patient advance care planning (ACP) discussions, the “intervention” embedded in the policy, is effective at prompting end-of-life care planning behaviors and improving end-of-life experiences. I also studied the heterogenous effects by race and ethnicity. I used exit data about 7,282 deceased Medicare-eligible respondents from the Health and Retirement Study (HRS) from 2012 to 2020, a nationally representative biennial survey of U.S. older adults. I conducted latent class analysis to identify

different end-of-life experiences and used multinomial logistic regression models to study the relationship between having ACP discussions with doctors and different end-of-life experiences in full and stratified samples by race and ethnicity. Then I used path analyses to test whether completing legal documentation initiated by ACP services explains the effectiveness of the intervention. The results show three types of end-of-life experiences among White, Black, and Hispanic older adults; significant effects of end-of-life care discussions with doctors on uncomfortable dying experiences and extensive use of invasive treatments in the older White population; and the partial mediating role of completion of legal health care documents on the relationship between ACP discussions and end-of-life outcomes. This study identified the limited effectiveness of physician–patient ACP discussions among minority older adults and emphasizes the importance of quality, content (e.g., to cover legal documentation during the conversation), and cultural appropriateness of ACP consultations led by doctors.

The third chapter examines the heterogeneous intent-to-treat effect of the Medicare policy on older adults' motivation to plan for care by exploiting policy intervention as a natural experiment. Taking advantage of the longitudinal nature of the HRS, I used core data with 47,982 observations nested in 15,647 individuals across 9 years (2012–2020). I used two quasi-experimental models—interrupted time series analysis and difference-in-difference—to study the care-planning outcomes before and after the policy implementation between older adults eligible or not eligible for Medicare. I studied the heterogeneous effects in stratified samples by race and ethnicity, immigration background, and socioeconomic status proxied by education and wealth. I used coarsened exact matching to address the potential bias of the comparison group not being the ideal counterfactual control unit. I found that in the total population, the Medicare policy was associated with a significant increase in the proportion of older adults who completed a living

will and designated a durable power of attorney for health care, but not having an ACP conversation. Furthermore, although there were immediate positive policy effects, the increases in ACP outcomes driven by the ACA Medicare benefit expansion were not sustained. Finally, I found no evidence that the ACA Medicare benefit expansion was effective in improving the rates of ACP among Black, Hispanic, Asian, Native American, or non-U.S.-born older adults. I also identified heterogeneous policy effects by socioeconomic status. I discuss promising recommendations for health care policy and practice to improve the participation rate of end-of-life care planning.

Chapter 4 explores the feasibility of encouraging physicians to discuss end-of-life care wishes with older patients in China. Knowledge of a medical diagnosis is critical for end-of-life decision making. However, a patient's right to know their diagnosis is neither guaranteed nor protected by law in China. Doctors typically inform family members of the patient's illness diagnosis and prognosis and let them decide whether to disclose this information to the patient. This study examined middle-aged and older Chinese adults' preferences for disclosing their and significant others' diagnoses and whether sociodemographic, economic, and cultural factors were associated with these preferences. The research team surveyed 571 adults aged 50 or older in Shanghai from 2021 to 2022. The outcome measures are preferences for diagnosis disclosures, including whether and to whom diagnoses should be disclosed. I characterized preference types using latent class analysis and estimated multinomial logistic regression to identify the covariates associated with each preference type. Three latent classes were identified. The transparent group (34%) believed patients, whether self or a significant other, should be informed of their diagnoses. The contradictory group (50%) held conflicting attitudes; they preferred to know their diagnosis but preferred that significant others not be informed of their diagnoses. The avoidant

group (16%) preferred not to know their diagnosis or to disclose significant others' diagnoses to them. Familism attitudes were positively associated with holding contradictory views. Experiences with hospitalization and medical decision-making for family members were associated with holding transparent views. I discuss the importance of illness disclosure for honoring patients' autonomous decision-making.

Table of Contents

List of Tables	iii
Acknowledgments.....	vi
Dedication.....	viii
Chapter 1: Introduction and Research Questions.....	1
Chapter 2: Do Advance Care Planning Discussions between Older Adults and Physicians Improve End-of-Life Care?.....	7
Introduction.....	7
Literature Review.....	8
Method	17
Results.....	23
Discussion.....	33
Chapter 3: Advance Care Planning from 2012 to 2021: The Effectiveness of Medicare Reimbursement for Physician–Patient Discussions.....	41
Introduction.....	41
Literature Review.....	42
Method	48
Results.....	55
Discussion.....	67
Chapter 4: To Tell or Not: Chinese Older Chinese Adults’ Preferences for Disclosing or Concealing Serious Illness Diagnoses	75

Introduction.....	75
Literature Review.....	77
Method.....	83
Results.....	88
Discussions.....	97
Chapter 5: Conclusions.....	105
References.....	109
Appendix A.....	136
Appendix B.....	137
Appendix C.....	140

List of Tables

Table 2.1: List of Key Measures and Questions Used in HRS Exit Data.....	21
Table 2.2: Statistics of 9,282 Medicare-Eligible Older Decedents from 2002 to 2018, HRS.....	24
Table 2.3: End-of-Life Outcomes and Mediator of 9,282 Decedents from 2002 to 2018, HRS.....	27
Table 2.4: Comparison of Latent Class Analysis Models with Two to Six Classes.....	28
Table 2.5: Prevalence of Latent Class and Item-Response Probabilities from Three-Class Model	29
Table 2.6: Results from Multinomial Regression Model on Type of End-of-Life Care Experience.....	31
Table 2.7: Results from Multinomial Regression Model on Type of End-of-Life Care Experience in Stratified Samples, RRR (CI)	32
Table 2.8: Mediating Results of Path Analysis.....	33
Table 3.1: Demographic Information by Medicare status, HRS Wave 2012 to 2020 ($N =$ 47,982)	56
Table 3.2: Changes in Advance Care Planning Outcomes Associated with ACA Medicare Benefit Expansion on End-of-Life Care Planning	60
Table 3.3: Changes in Advance Care Planning Outcomes Associated with ACA Medicare benefit Expansion on End-of-Life Care Planning (DID Estimates) Stratified by Race and Immigration Background	62

Table 3.4: Changes in Advance Care Planning Outcomes Associated with ACA Medicare benefit Expansion on End-of-Life Care Planning (DID Estimates) Stratified by Educational Attainment and Wealth Quartile	63
Table 3.5: Results of Simple ITS with Time-Variant Controls ($N = 47,982$).....	65
Table 4.1: Means (and Standard Deviations) or Proportions, All Measures Used in Analysis ($N=571$).....	88
Table 4.2: Comparison of latent class analysis models with two to six classes ($N = 571$)	90
Table 4.3: Three-class Model of Preferences for Disclosure of Critical Illness Among Older Adults in China ($N=571$)	93
Table 4.4: Means (and Standard Deviations) and Proportions, by Latent Class Group ($N = 571$)	96
Table 4.5: Multinomial Logistic Regression Predicting Disclosure Preference Class	97
Table A.1: Prevalence of Latent Class and Item-Response Probabilities from 4-Class Model	136
Table B.1: Changes in Advance Care Planning Outcomes associated with ACA Medicare Benefit Expansions on End-of-life Care Planning ($n = 47,982$).....	137
Table B.2: Results of Comparative ITS with Time-varying Controls ($n = 47,982$).....	139

List of Figures

Figure 3.1: Percentage of Older Adults in the HRS Who Had Informal ACP Discussions, Living Will, and DPAHC, 2012–2018 ($N = 47,982$).....	58
Figure 3.2: Predicted Segmented Regression Lines from ITS with Comparison Group ($N = 47,982$).....	66
Figure 4.1: Item Response Probabilities of Three-class Model of Preferences on Diagnosis Disclosure of Critical Illness Among Older Adults in China	94
Figure C.1: Reasons Respondents Would Prefer to Not to Disclose Significant Others' Diagnoses.....	140

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Dedication

To my dearest great-grandparents who raised me, in loving memory.

献给将我养育长大的太公余金海和太太朱翠云。

Chapter 1: Introduction and Research Questions

Death and dying happen to everyone. Due to the ever-growing number of medical interventions, the interval between the time of “crisis knowledge of death” and actual death has been lengthened significantly and is now usually measured in years (Bern-Klug, 2009; Lynn, 2005). End-of-life care describes all support and medical care given during the time surrounding death (Hayes, 2012). Older adults living with one or more chronic diseases, who account for 80% of the 703 million people aged 65 or older globally in 2019 (United-Nations, 2019), will benefit from quality end-of-life care during the weeks, months, or even years before death. However, each story is different at the end of life and every person has their own understanding of a “good death” (Meier et al., 2016). A person-centered approach has thus been adopted to deliver end-of-life care, and the most critical quality measure suggested by the Institute of Medicine (2015) is whether individuals receive care that is aligned with their values, preferences, and goals.

However, the current person-centered model on the ground assumes that older adults can act independently and engage families in end-of-life caregiving and decision making without additional support. As much as people may want and expect to be in control of decisions about their end-of-life care, more than 70% of older adults are cognitively or physically unable to make decisions when the time comes (Sudore & Fried, 2010). It is impossible to deliver goal-concordant end-of-life care without knowing the patient’s wishes. Therefore, advance care planning (ACP), a preparation process of discussing and recording wishes for end-of-life care with loved ones and physicians in advance of any medical crisis (Sudore et al., 2017), is particularly important because it is increasingly difficult to recognize when the death is approaching. The COVID-19 pandemic further highlighted the need for ACP among older adults

with preconditions, because the duration between illness onset and death is more compressed than for chronic diseases that are leading causes of death for older adults, like heart disease or cancer (Moorman et al., 2020).

In the United States, ACP was formally recognized in 1991 through the Patient Self-Determination Act (Larson & Eaton, 1997). Despite years of advocacy, only 46% of U.S. older adults have completed an advance directive (AD) to make formal plans for end-of-life care (Yadav et al., 2017) and 17% of adult patients have had discussions with their physicians about their end-of-life treatment choices, according to a national poll (DiJulio et al., 2015). Although the effectiveness of legal forms on improving quality of end-of-life care and decreasing family members' bereavement is well documented (see Brinkman-Stoppelenburg et al., 2014 for a review), we know relatively little about whether and how ACP conversations, particularly those between physicians and patients, are effective among older adults with different backgrounds.

Though death is inevitable, the dying process may vary by social context, including culture, health care system, and public knowledge and perception. Patient autonomy and informed consent are not legally protected in most Asian countries (Jimenez et al., 2018). ACP, as a Western concept, needs to be contextualized and adapted to local cultures and environments. Although studies on perceptions of ACP are mounting in Asian countries, empirical evidence on the topic of ACP among older adults in China is extremely limited. In China, where the world's largest aging population resides (Shen, 2021), the concepts of ACP and policies related to palliative and hospice care are still emerging. Thus, families of patients with terminal illnesses in China often face significant caregiving, financial, and treatment decision-making challenges, compared to the developed countries (Yan et al., 2020). Despite mounting studies regarding end-of-life care and planning in the U.S., it remains unclear whether legislating ACP and facilitating

ACP conversations between older adults and doctors is a feasible plan to improve the quality of end-of-life care in China, given China's unique social policy and cultural contexts.

Thus, this dissertation fills the gap by focusing on whether physician-patient conversations on end-of-life care work for older adults with diverse backgrounds in the United States and China. Specifically, it studies the effects of ACA Medicare benefit expansion on end-of-life care planning under the Affordable Care Act (ACA) on U.S. older adults' end-of-life health, mental health, and service utilization and the feasibility of establishing such a health insurance policy in China. It also investigates current policy as an underlying driver that reproduces disparities in end-of-life outcomes and informs future improvements, which is timely because COVID-19 has further exacerbated inequalities in dying experiences. This dissertation provides promising practice and policy suggestions on supporting "good death" among older adults with disadvantaged backgrounds nationally and globally.

The studies in Chapter 2 and 3 were motivated by fundamental cause theory (FCT), which considers societal factors, such as socioeconomic status (SES), gender, and race and ethnicity, as the fundamental causes of health outcomes and disparities. FCT argues that those factors affect the ability to access and use resources (e.g., power, knowledge, money, social connections, etc.) for risk-reducing health behaviors to improve health. According to FCT, if a health intervention or policy fails to reduce the degree of resource inequality related to certain health behaviors, the policy intervention will likely further reproduce the social gradient of health (Phelan & Link, 2013). Based on FCT, older adults may not have equal access to ACP services even if Medicare tries to provide them to every beneficiary. For older adults who had discussions with doctors, whether the conversations translate to actual ACP behaviors (e.g., completion of legal documents and communicating wishes with loved ones) and better end-of-

life outcomes (e.g., being comfortable) vary by individual socioeconomic backgrounds, because extra resources are needed like a usual source of care, advanced level of health literacy to interpret medical information, and trust in doctors and the health care system.

The first paper (Chapter 2) explores whether and how ACP conversation with physicians, the “intervention” embedded in the policy, is effective at prompting end-of-life care planning behaviors and improving end-of-life dying experiences. Previous studies documented mixed results regarding the impact of physician intervention in ACP on end-of-life care outcomes measured by individual indicators (McMahan et al., 2021), and the evidence is mostly limited to White older adults with certain diseases (e.g., cancer) or in specific settings (e.g., inpatient center or intensive care unit [ICU]). We know very little about the impact of physician–patient ACP conversations on end-of-life experience as a multidimensional concept among older minorities and those with different health statuses. Using data on 7,282 deceased respondents from nationally representative data on older adults, the Health and Retirement Study (HRS) Waves 2002 to 2018, I first categorized types of end-of-life experiences among older adults based on their health service utilization, health and mental health, and quality of care during their last periods of lives, using latent class analysis (LCA). Then, I conducted multinomial logistic regressions with the full and stratified sample to study whether and to what extent having end-of-life care planning discussions with doctors was associated with different end-of-life experiences and whether the relationships varied by race and ethnicity. Last, I used structural equation modeling to test whether having care-planning behavior initiated by Medicare mediated the impact of ACP discussions with doctors on end-of-life outcomes. The study shed light on the importance of ensuring documentation after discussing the end-of-life care wishes and providing culturally appropriate ACP services to older Blacks, Hispanics, Asians, and Native Americans. I

also discuss potential organization-level efforts that can help physicians provide more high-quality and effective ACP services.

The second paper (Chapter 3) focuses on whether insurance coverage for patients under the ACA is an effective mechanism to improve older adults' ACP rate and health encounters. ACP service was enacted as an itemized benefit for physicians to bill through Medicare in 2016 (van Zyl & Gross, 2018); however, the policy effect has not been rigorously studied. By exploiting policy intervention as a natural experiment, this paper examines the heterogeneous intent-to-treat effect of the Medicare policy on older adults' motivation to plan for care. Based on FCT, this Medicare policy may not have long-term effectiveness or be beneficial to older adults with disadvantaged backgrounds, including older minorities, immigrants, and adults with low SES, because it doesn't address the fundamental cause—the resource inequality of accessing and using ACP services (e.g., usual source of care). Taking advantage of the longitudinal nature of the HRS, I used core data on 15,647 individuals from the HRS Waves 2012 to 2020. I conducted two quasi-experimental models—an interrupted time series (ITS) analysis and difference-in-difference (DID) model—to compare care-planning outcomes before and after the policy implementation between older adults eligible or not eligible for Medicare. I also studied whether the policy had immediate and sustained effects by observing the level and slope changes of the ITS model. I then studied the heterogeneous effects in stratified samples by race and ethnicity, immigration background, and SES. The study provides evidence of the role of Medicare in providing equal access to ACP benefits and suggestions for future policy improvements to address the fundamental cause of inequality in end-of-life care and planning.

However, death and dying are significantly affected by social contexts. According to social constructivism, change in public attitudes and societal acceptance are key conditions to

legitimize social problems and form new policies (Stone, 1989). The third paper (Chapter 4) thus explores the feasibility of having a similar policy to promote physician–patient ACP discussions in China by investigating whether discussing diagnosis, prognosis, and end-of-life wishes with physicians is culturally appropriate and acceptable for older adults in China. Open communication on diagnosis and prognosis is the foundation of physician-led ACP consultation; however, the patient’s right to know their diagnosis is neither guaranteed nor protected by law in China (Jimenez et al., 2018). Doctors typically inform family members of the patient’s diagnosis of a serious illness (e.g., cancer) and prognosis and let them decide whether to disclose this information to the patient. Therefore, I examined middle-aged and older Chinese adults’ preferences for disclosure of their and significant others’ diagnoses of serious illness by collecting survey data from 570 community-dwelling older adults in Shanghai. I used LCA and multinomial logistic regression to characterize older Chinese adults’ preferences for diagnosis disclosure and the sociodemographic, economic, and cultural factors associated with these preferences. The study is first of its kind, and the results shed light on public perceptions of patient autonomy regarding serious illness and public readiness for having doctor–patient end-of-life care discussions.

Chapter 2: Do Advance Care Planning Discussions between Older Adults and Physicians Improve End-of-Life Care?

INTRODUCTION

People nearing the end of life are often unable to make decisions for their care and treatments. ACP is a preparation process to ensure older adults receive the treatments they want (see Sudore et al., 2018 for a review). Comprehensive ACP is a two-pronged approach involving conversations with loved ones and health care professionals and completion of ADs regarding their end-of-life care wishes in advance of a medical crisis (Sudore et al., 2017). ADs are legal documents with two main instruments: a living will in which individuals specify their personal preferences for future end-of-life medical care (e.g., whether to forgo life-sustaining treatments or not), and a durable power of attorney for health care (DPAHC) designation regarding who makes decisions when patients are unconscious or otherwise unable to communicate (Silveira et al., 2014). ACP is most effective to ensure older adults receive care aligned with their wishes when adopting the two-pronged approach before a medical crisis (Bomba, 2017).

Despite the importance of ACP, more than 70% of all older patients in the United States are not involved in their end-of-life care decisions, with well-documented racial disparities (Yadav et al., 2017), such that Black and Hispanic older adults (18%) are far less likely than Whites (34%) to have any type of AD (Carr, 2012a; Peterson et al., 2019). Most older adults who completed ADs had discussions with their family members (Carr et al., 2013), but very few of them discussed end-of-life preferences with their doctors in routine care, ranging from 1% to 5% among Medicare beneficiaries across studies (Grant, 2017; Keary & Moorman, 2015). Older adults who do not have end-of-life discussions with physicians are less likely to complete ADs or

be referred to hospice or palliative care in time and more likely to receive unwanted care, even if they filed ADs (Jimenez et al., 2018).

To improve ACP participation and end-of-life quality of life, the Centers for Medicare & Medicaid Services (CMS; 2015) launched a Medicare policy for adults aged 65 or older in which clinicians can bill for ACP face-to-face discussions with patients and surrogates, effective on January 1, 2016 (Mehta & Kelley, 2019). The core assumption behind the policy is that physician-led ACP consultations, as a treatment, can improve individuals' knowledge of end-of-life care issues, motivate older adults to conduct formal ACP, and ultimately increase the likelihood of receiving person-centered health care (He et al., 2020). However, rigorous evidence on the impact of physician–patient ACP conversation on patients' end-of-life outcomes is limited to regional data with White older adults with certain advanced illnesses. To fill the research gaps and provide policy-relevant suggestions, this paper explore whether, to what extent, and through which path (e.g., completion of ADs) ACP discussions with doctors improve end-of-life care outcomes among older adults of different races and ethnicities using a nationally representative survey data from U.S. older adults.

LITERATURE REVIEW

Physician–Patient End-of-Life Care Discussions

Health care providers, such as physicians, are integral to ACP and the end-of-life decision-making process. Studies have underscored the role of physicians in initiating end-of-life care conversations (Lockett et al., 2014). Patients rely on information obtained from interactions with physicians, including the likely trajectory of their current and potential future health conditions and the efficacy of the treatments they might consider, to make informed end-of-life care decisions (Carpenter & McDarby, 2018). Moreover, a lack of physician–patient

conversations undermines the effectiveness of formal documentation (Boerner et al., 2020). Most older adults who filed a living will didn't inform their doctors (Harrison et al., 2016). Without understanding patients' wishes clearly, physicians are more likely to deliver default intrusive care to the patients, regardless of their wishes to limit treatments as expressed in these documents (Chen et al., 2015).

However, physician–patient conversations are often overlooked in clinical settings. Only 12% of older adults who engaged in formal planning reported that they had discussed their preferences and choices with doctors (Hemsley et al., 2019). Even so, most of those conversations happened too late to be useful (America, 2014; Makaroun et al., 2018). For example, in several multisite studies with cancer patients who had end-of-life discussions, half of them died less than 30 days after their initial conversation with their doctors at hospital admission for acute symptoms (Lopez-Acevedo et al., 2013; Mack, Cronin, Taback, et al., 2012).

Medicare Reimbursement for ACP Discussions

To encourage physicians to be involved in patients' decision making before any crisis, the ACA included discussions on end-of-life care wishes as a routine benefit for adults aged 65 or older (Mehta & Kelley, 2019). Medicare pays a physician \$80 for an inpatient visit or \$86 in an outpatient setting to have an initial 30-minute conversation on end-of-life care planning with patients and their surrogates. Starting in 2017, the ACP benefit can be billed under telehealth in addition to traditional face-to-face consultation (CMS, 2018). If patients desire, additional 30-minute sessions can be scheduled. Each additional session is paid at a rate of \$75 (CMS, 2015). There is no limit on the number of times or how frequently the ACP service can be billed for one person. However, supporting documents are expected, such as changes in health status or wishes, if multiple sessions are billed to one person in a given period of time (CMS, 2016).

Completion of ADs, although not required, is highly encouraged by the policy due to the nature of services that would be payable under the current billing code. CMS (2015) defines billable ACP discussions as “services including the explanation and discussion of ADs such as standard forms (with completion of such forms, when performed)” in the payment guidance rule. Formal documentation is viewed as a process outcome of this policy that in turn, would produce less aggressive care and increase patients’ end-of-life care quality (van Zyl & Gross, 2018).

There is an ongoing debate, documented in the CMS final rule with comment periods, on whether to require documentation and transmission of the results of ACP among physicians in the reimbursement policy (CMS, 2015). Although the efficacy of ADs on end-of-life care is well documented (Brinkman-Stoppelenburg et al., 2014; Klingler et al., 2016), it remains a question whether the discussion alone or the completion of a legal form motivated by the discussion effectively ensures that older adults receive the care they want. Although the field has reached a consensus that greater emphasis should be placed on the process, not the forms, it is too early to move away from the legal transactional mode of ACP to a communication-only model, as suggested by some scholars (Mehta & Kelley, 2019; Sabatino, 2010). Therefore, one aim of this study was to investigate whether AD completion may partially account for the effects of ACP conversations on end-of-life care, as intended with the policy.

Effectiveness of ACP Conversations with Doctors

There is mounting empirical evidence on the effects of doctor–patient end-of-life discussions, but with mixed findings. Most retrospective observational studies found that ACP discussions between doctors and patients led to positive behavior, health care utilization, and end-of-life quality outcomes. Specifically, cohort studies consistently found that doctor–patient end-of-life discussions were significantly associated with a higher completion rate of ADs and

greater use of hospice care (Mack, Cronin, Keating, et al., 2012; Pedraza et al., 2017). Some studies also linked ACP discussion with a lower likelihood of receiving intensive or acute care (Ahluwalia et al., 2015; Zaros et al., 2013), lower health care costs (Garrido et al., 2015; Garrido et al., 2016), and lower use of emergency rooms and hospitalization in the last 30 to 90 days of life (Lopez-Acevedo et al., 2013; Starr et al., 2019). However, some multisite observation studies and research using nationally representative data such as the HRS found no significant relationships between ACP behaviors, including having end-of-life discussions, and use of various intensive treatments during the end-of-life period (Bischoff et al., 2013; Jimenez et al., 2018; Loggers et al., 2013). Finally, end-of-life discussions with doctors also increased the likelihood of dying at home (see Martin et al., 2016 for a review), a death location preferred by most U.S. older adults (Gomes et al., 2013).

On the other hand, most randomized controlled trials (RCTs) in the United States have failed to prove the significant effects of ACP discussions provided by health care professionals, including doctors and nurses, on patients' quality of life. Perhaps the most famous one is the Study to Understand Prognoses and Preferences for Outcome and Risks of Treatments, a multisite intervention study with 4,894 hospitalized patients (Murphy et al., 2000). The intervention was ACP discussions led by physicians and specifically trained nurses. The study found it was not effective in five targeted outcomes: incidence or timing of completing an AD, length of stay in the ICU, mechanical ventilation, comatose before death, and level of pain (Connors et al., 1995). McMahan et al. (2021) conducted a scoping review of 69 high-quality RCTs from 2010 to 2020, in which 42% of interventions were facilitated discussions. Among those discussion-oriented interventions, 67% of them demonstrated significant effects. However, only positive impacts on process (e.g., readiness or AD completion) and action outcomes (e.g.

satisfaction of communication) were detected, with no effect on goal concordance, health service utilization, and quality-of-life outcome (McMahan et al., 2021). A review of RCTs before 2010 also generated similar conclusions that end-of-life care discussions led by doctors don't or only mildly improve goal-concordant end-of-life care (Jimenez et al., 2018).

Multilevel barriers and challenges have been identified to help explain why some but not all ACP discussions with doctors were effective. First, timing of the discussions is critical because conversations in a late stage of illness may prevent patients from receiving comforting care in time (Enguidanos & Ailshire, 2017; Makaroun et al., 2018). Although studies have underscored the role of physicians in initiating end-of-life conversations (Luckett et al., 2014; Song, 2004), doctors frequently reference discomfort talking about death, uncertainty of prognosis, and waiting for patients to initiate conversations as reasons for not discussing end-of-life care preferences with their patients (Coleman, 2013; He et al., 2020). Second, the conversation quality also significantly affects its effectiveness. End-of-life care is a difficult topic to discuss and requires specific communication skills (De Vleminck et al., 2013), sufficient knowledge of the patients and their end-of-life care options (Johnson et al., 2016), and unbiased attitudes to convey the right information to support patients' decision making (Luckett et al., 2014). However, doctors don't receive specialized training on necessary skills for ACP discussions (Gilissen et al., 2017). For example, some clinicians reported that they only learn how to "save people" in medical school and know very little about the process of death and dying and the efficacy of different treatment options (Malhotra et al., 2022; Moore et al., 2019).

Besides inconclusive results, the current evidence on the effectiveness of doctor-patient end-of-life discussions has limitations. First, both cohort and RCT studies have mostly sampled White older adults (Ashana et al., 2019; Connors et al., 1996; Keary & Moorman, 2015). We

know relatively little about whether ACP discussions work for older adults with minority racial and ethnic identities in a national representative sample. ACP discussions with physicians may not significantly affect patients' end-of-life care unless the conversations are ongoing, with trusted clinicians, or conducted in a careful and culturally appropriate manner (Detering et al., 2014). Moreover, minority older adults are less likely to have quality conversations with health professionals due to their SES, health literacy, or language barriers (Hong et al., 2018). Therefore, even if they discuss this issue with a doctor, the effectiveness of the conversation is not guaranteed.

Relatedly, most research has relied on older adults who are terminally ill (Ashana et al., 2019; Jimenez et al., 2018), with certain diseases (e.g., cancer; (Dixon et al., 2018; Starr et al., 2019), or in specific settings (e.g., ICU, emergency room) using regional data (Flannery et al., 2016; Lobo et al., 2017). As such, the results have limited generalizability to older adults who had ACP with doctors in routine or preventive care before they were seriously ill and do not inform population-level estimates given the significant regional variations in the rate of ACP discussions among Medicare beneficiaries (Belanger et al., 2019). Moreover, many observational studies didn't treat discussions with doctors as a standalone variable (McMahan et al., 2021). Instead, they measured discussions with any person as the key independent variable; as such, the effectiveness of discussion with doctors specifically remains unknown. To fill these gaps, this study used a nationally representative sample of older decedents to study the heterogeneous effects of end-of-life discussions with doctors on end-of-life outcomes among older Whites, Blacks, and Hispanics.

Multidimensional End-of-Life Care Outcomes

End-of-life care quality is a multidimensional concept including service utilization, symptom management, and quality of care. However, most existing studies measured end-of-life experience with an individual indicator or discrete measures (e.g. Bischoff et al., 2013; Makaroun et al., 2018; Teno et al., 2007), overlooking the co-occurrence of various aspects of end-of-life care experiences. Very few studies have attempted to capture the complexity of end-of-life care by exploring how multiple dimensions of experiences coexist among older adults. Luth (2017) was among the first to understand how different subsets of end-of-life care represent different dying experiences by classifying nine subjective proxy-reported assessments of end-of-life symptoms, encounters with health care providers, and respect and dignity in a nationally representative sample from the National Health and Aging Trends study. Building on Luth's work, another study used the same dataset to classify end-of-life patterns with a more comprehensive set of variables (Bhagianadh & Arora, 2022). Specifically, besides subjective quality of care and symptom measures, Bhagianadh and Arora also included care process (e.g., late transition and use of hospice) and site of death indicators to simultaneously understand interpersonal and technical aspects of end-of-life care such as care coordination and care setting.

Although both studies added significantly to the literature on how symptom management and care experiences co-occur in end-of-life care, a potentially important yet underexplored dimension of end-of-life care is service utilization that may impel or impede a "good death." First, what kinds of medical services a person used during the end-of-life stage may lead to very different dying experiences (Lynn, 2005). With ever-advancing technologies, older adults, particularly those with comorbidities, often face multiple treatment options with different advantages (e.g., potential of extending life) and tradeoffs (e.g., side effects). Choice of treatment type is likely to affect a person's quality of life. For example, older adults who receive

chemotherapy at the late stage of cancer or go to emergency rooms as a usual place of care may be more likely to suffer from pain and depression than those who choose hospice or palliative care (Aldridge, Epstein, et al., 2016; Hui et al., 2014; Lorenz et al., 2008).

Moreover, the amount of health services used by an older adult may also significantly impact their end-of-life quality. Older adults who use multiple services at the same time need extra time and effort on tasks like care coordination (McIlfatrick, 2007), commuting (Epiphaniou et al., 2014), recovery from side effects of each treatment, and even therapeutic competition of multiple co-occurring treatments (Yabroff et al., 2004). Therefore, they may experience higher levels of physical burden and mental exhaustion due to the labor- and time-consuming process of navigating the fragmented health care system (Aldridge, Hasselaar, et al., 2016). On the other hand, some older adults used various types of end-of-life care asynchronously because they changed their treatment plans (Attema et al., 2013). For those older adults, change of treatment plan may increase mental stress, anxiety, and depression because it usually involves difficult health care decision-making processes (Bern-Klug, 2017). Therefore, how many services a person used during the last period of life, either simultaneously or not, may greatly affect their end-of-life journey.

To address the identified gaps in evaluating end-of-life care outcomes, this study built on previous work on composite end-of-life care categories to examine the impact of physician–patient ACP discussion on a multidimensional end-of-life care outcome, constructed through LCA with both subjective proxy-rated quality of care and symptom management indicators and objective measures such as health care utilization and location of death.

Factors That May Influence End-of-Life Discussion and Outcomes

Informed by socio-environmental theory that provides a framework of personal and environmental influencers on health behaviors and related outcomes (Gubrium, 1972), the analyses were adjusted for demographics, SES, physical health, and health communication factors that may confound the relationships among ACP discussions, AD completion, and end-of-life outcome (see Sanders et al., 2016 for a review). Older adults (Moorman et al., 2013), women (Carr & Khodyakov, 2007), married people (Moorman et al., 2013), and parents (Boerner et al., 2013) are more likely than younger, unmarried, and childless people to do any kind of ACP and receive less aggressive treatments. Socioeconomic characteristics, most notably higher education, also are documented predictors of ACP behaviors (Carr, 2012b; Lou & Liu, 2021), receiving care that aligned with wishes, and having a “good death.”

Type of diagnosed diseases, functional limitations, and health communication may also influence the effect of ACP on end-of-life experience. Certain diseases have more impact on ACP and end-of-life quality. For example, diseases with more acute onsets, such as cancer, heart attack, lung disease, and stroke, have shorter courses and require more intrusive treatments than nonacute diseases like hypertension, diabetes, and arthritis. As such, older adults with acute diseases are more likely to experience stressful dying experiences and may be more motivated to do ACP (Lou & Liu, 2021; Sullivan et al., 2017). Similarly, functional limitations significantly affect individuals’ quality of life and thus, may also influence end-of-life outcomes and perceptions of whether aggressive treatment (e.g., surgery or chemotherapy) is worthwhile (Lovell & Yates, 2014). Last, having end-of-life care communication with family members is a strong predictor of ACP involvement and better end-of-life outcomes. Because the treatment choices made by older adults in a living will only apply to certain situations, in clinical settings, physicians often need to follow the decisions of family surrogates, whose decision-making

power is legally protected (Sabatino, 2010). Lack of communication between family members and older adults may have significant negative impacts on the effectiveness of physician–patient discussions on end-of-life goal-concordant care.

Present Study

The goal of this study was to understand the impact of physician-led ACP conversations on end-of-life care outcomes among U.S. older adults. Although studies have explored whether discussions improve end-of-life care, they focused on analyzing end-of-life care as an individual measure, neglecting the complexity of dying experiences. Moreover, there is a dearth of knowledge on the effect of end-of-life care discussions among minority older adults and those who had conversations before an advanced stage of illness. Last, little is known about through which paths discussions may change end-of-life experiences. Therefore, this study extended the current literature to examine the following research questions: (Q1) Are physician–patient ACP conversations associated with different types of end-of-life experiences?; (Q2) Does the relationship between discussions and end-of-life care types vary by race and ethnicity?; and (Q3) Does AD completion mediate the relationship between discussions and end-of-life care typologies?

METHOD

Data and Sample

This study relied on the HRS, conducted by the Institute for Social Research at the University of Michigan. The HRS is a nationally representative biennial survey of U.S. adults aged 50 or older on their health, marital, economic, family status, and public and private support system. The HRS collects survey data through face-to-face or telephone interviews. Starting in 2018, the HRS added the internet as an alternate data collection method (Bugliari et al., 2019). If

a respondent's spouse or partner is available, the HRS interviews both dyad members (HRS, 2019). The HRS follows the respondents once recruited and replenishes the sample every 6 years with a younger cohort (Sonnegg et al., 2014). The survey data are available to the public through the HRS website: <https://hrsonline.isr.umich.edu/>. The HRS oversampled Black and Hispanic individuals.

The HRS has two portions of data: core data with live respondents and exit data. For older adults who died between waves, the HRS conducts exit interviews with proxies or family members on the respondents' end-of-life experiences, including health care utilization, quality of life, and wealth transfer.

This study used HRS exit data from 2002 to 2018, including older adults who died between April 2002 to April 2019. I dropped 128 respondents who were non-Hispanic Asian, American Indian, Alaska Native, Native Hawaiian, or Pacific Islander because the sample sizes of these racial and ethnic groups were too small for powered comparison analysis. The final sample of this study featured 9,282 adults who (a) died at age 65 or older between April 2002 and April 2019, (b) were Medicare eligible, and (c) had valid responses on end-of-life care indicators and the key independent variable, ACP discussion with doctors.

Measures

A list of key measures is presented in Table 2.1. The independent variable was whether participants had discussions on their end-of-life care wishes with physicians. The measure was generated from questions asking "With whom did the respondent discuss end-of-life treatment? That is, what was their relationship to the respondent?" A maximum of five people could be identified. Following previous studies (Keary & Moorman, 2015), older adults who had

discussions with physicians or other health care professionals (e.g., registered nurse) as one of the five people they talked to were identified as having an ACP discussion with doctors.

Thirteen end-of-life care outcome indicators were used in the identification of the latent classes. They were classified in three major categories: end-of-life service utilization, symptom management, and quality of care. End-of-life service utilization indicators included use of aggressive and supportive care in the last 2 years of lives. Aggressive care includes hospitalization, time in the ICU, life support equipment such as a respirator, kidney dialysis, or any type of major surgery. Supportive care includes use of hospice or palliative care and specialized services that involve adult care centers, social work services, outpatient rehabilitation programs, physical therapy, or transportation services for older adults or people with disabilities. The three symptom management indicators were proxy-reported pain, breathing difficulty, and depression in the last year of life. Proxies were asked: “Was the respondents often troubled with pain?”; “Was there a period of at least one month during the last year of his/her life when he/she had difficulty breathing?”; and “Was there a period of at least one month during the last year of his/her life when he/she had depression?” Quality of care indicators included one objective measure—location of death (home, hospital, or specialized facilities including hospice center, assisted-living facility, retirement home, or senior care home)—and two subjective measures: satisfaction of care (1 = *satisfied or somewhat satisfied*, 0 = *neutral, somewhat dissatisfied, or very dissatisfied*) and whether respondents’ preferences for care were considered in the last year of health care experiences (1 = *always, usually, or sometimes*, 0 = *never*).

The mediator was the completion of an AD, and I focused on one type of AD: the living will, which documents individual medical preferences under specific situations (e.g., no longer able to communicate). A living will provides specific guidance to doctors on patients’ end-of-life

care wishes and values. Respondents were first asked: “Has the respondent provided written instructions about the care or medical treatment that he/she wanted to receive if he/she could not make those decisions himself/herself? This is sometimes called a living will or physician orders for life-sustaining treatment.” For older adults who reported having a living will, the following question was: “Did these instructions express a desire to receive all care possible under any circumstances in order to prolong life?” Given that different preferences may lead to different treatment plans, I categorized this variable as 1 (*didn't have a living will*), 2 (*had a living will with no intention to prolong life*), and 3 (*had a living will with intention to prolong life*).

The moderator was race and ethnicity. Respondents were asked to report their race and Hispanic ethnicity in separate questions. I categorized the race and ethnicity variable as non-Hispanic White, non-Hispanic Black, and Hispanic.

Table 2.1: List of Key Measures and Questions Used in HRS Exit Data

Independent variable	1. Did R ever discuss with you or anyone else the treatment or care [he/she] wanted to receive in the final days of [his/her] life?
End-of-life discussion	2. With whom did [he/she] discuss it? (that is, what was their relationship to R?) [Select from: non-spouse proxy respondent, spouse/partner, child/child-in-law/grandchild, other relative, friend, physician/healthcare professional, minister/rabbi/priest/religious advisor, attorney, social worker]*
Mediator	
Whether had living will with prolong life preferences	1. Did R provide written instructions about the care or medical treatment that [he/she] wanted to receive if [he/she] cannot make those decisions? This is sometimes called a “living will.” 2. Did these instructions express a desire to receive all care possible under any circumstances in order to prolong life?
End-of-life care outcome	
<i>Health care utilization indicators</i>	
Hospitalization	1. Including [his/her] final hospitalization, how many different times was [he/she] a patient in a hospital overnight in the last two years? 2. Altogether how many nights were [he/she] a patient in a hospital in the last two years?
ICU	During any of those hospital stays, did [R] spend any time in an intensive care unit?
Kidney dialysis	During any of those hospital stays, did [he/she] use kidney dialysis services?
Life support machine	During any of those hospital stays, did [he/she] use life support equipment, such as a respirator?
Surgery	1. In the last two years, had [he/she] had outpatient surgery? 2. Since [R’s previous wave], what sort of treatments had [he/she] received for cancer? (choice: surgery)* 3. In the last two years, before [his/her] death] did [he/she] have surgery on [his/her] heart?
Hospice or palliative care	1. In the last two years, had [he/she] received any hospice services? 2. [Aside from hospice,] Did [R] receive palliative care in the months or years prior to death?
<i>Quality of care indicators</i>	
Satisfaction with health care	Thinking about the quality, cost, and convenience of [his/her] health care, how satisfied was [he/she] overall? (very satisfied, somewhat satisfied, neutral, somewhat dissatisfied, or very dissatisfied)
Whether wishes were respected in health care	Thinking about [his/her] experiences with the health care system over the past year, how often were [his/her] preferences for care taken into account? (never, sometimes, usually, or always)
Location of death	At the time of death, was [he/she] in a hospital, in a nursing home, at home, in a hospice, or what? Note: If R was receiving hospice care at home at the time of death select “At home.”
<i>Symptom management indicators</i>	
Level of pain	Was [he/she] often troubled with pain?
Difficulty breathing	Was there a period of at least one month during the last year of [his/her] life when [he/she] had difficulty breathing?
Depression	Was there a period of at least one month during the last year of [his/her] life when [he/she] had depression?

Note: R = respondent’s name. Questions that were the same in core and exit interviews only changed pronouns.

*Same questions repeated several times.

Control variables included demographics, SES, and medical history and health communication factors. Demographic factors include age at death as a continuous variable; gender (1 = *female*); marital status (currently married [reference category]; widowed; or divorced, separated, or never married), and religious denomination (Protestant [reference category], Catholic, or other or none). SES encompassed the highest degree of schooling completed (less than high school, high school graduate [reference group], some college, or college degree or beyond) and whether the respondent received Medicaid in the past year as a proxy for wealth. Medical history covariates included variables for disease diagnoses and functional limitations. Disease diagnoses were proxied by dichotomous variables (1 = *yes*) that indicated whether the respondent ever had cancer, lung disease, heart attack, stroke, or a diagnosed memory problem. Function limitations was measured by a dichotomous variable indicating whether the respondent had a fall in the last 2 years of their lives (1 = *yes*) and a categorical variable on the number of days being bed bound in the last 3 months of life (1 = *0 days* [reference group], 2 = *1–89 days*, 3 = *all the time or 90 days or more*). End-of-life health communication was proxied by whether the respondent had an end-of-life conversation with any family member (1 = *yes*), including their spouse or partner, child, child-in-law, grandchild, or other relatives.

Analytic Strategy

I first conducted bivariate analyses to explore any significant differences in end-of-life care outcomes, demographics, SES, physical health, and health communication between older adults who did or did not have end-of-life discussions with doctors. To answer the first research question, I carried out LCA to identify the patterns of end-of-life care experiences based on all 13 indicators. I fitted LCA models with two to five classes and decided the optimal number of

classes based on the interpretability of each class and model fit statistics, including Akaike's information criterion (AIC), Bayesian information criterion (BIC), and entropy. Larger decreases in AIC and BIC between the two models indicate improvements in model fit (Nylund et al., 2007). A higher entropy reflects better quality of classification in the current model (Anderson & Burnham, 2004). I then ran multinomial logistic regression to estimate the effects of end-of-life care discussions with doctors on the predicted membership by end-of-life care types in the LCA, net of all control variables.

To explore any heterogeneous effects regarding the second research question, I reran the multinomial logistic regression model in stratified samples by race and ethnicity. Last, I carried out path analysis to investigate the mediating effect of completing an AD on the effects of physician-patient end-of-life discussions and care patterns. A small amount (6%) of missing values across predictors were listwise deleted. Data cleaning, bivariate analysis, and regression and path analysis (*gsem* package) were conducted in Stata 17.0 and LCA was done in MPlus 8.7.

RESULTS

Descriptive Results

Table 2.2: Statistics of 9,282 Medicare-Eligible Older Decedents from 2002 to 2018, HRS

Variables	Total	Didn't discuss EoL care wishes with doctor	Discussed EoL wishes with doctor	<i>p</i>
<i>N</i>	9,282	8,924	358	
Demographics				
Age at death	82.44 (8.70)	81.78 (8.56)	82.46 (8.70)	.146
Female (%)	54.12	54.14	53.63	.848
Race (%)				.001
White	76.4	76.05	85.2	
Black	14.76	14.95	10.06	
Hispanic	7.12	7.26	3.63	
Other	1.72	1.74	1.12	
Marital status (%)				.393
Married	39.92	39.88	41.06	
Divorced, separated, or never married	11.85	11.78	13.69	
Widowed	48.23	48.35	45.25	
Religion (%)				.191
Protestant	65.46	65.33	68.72	
Catholic	25.59	25.75	21.51	
Other or none	8.95	8.92	9.78	
Number of children	2.98 (2.17)	2.63 (2.10)	2.99 (2.17)	.002
Socioeconomic status				
Education (%)				.002
Lower than high school (< 12 years)	36.00	36.39	26.54	
High school graduate (12 years)	33.88	33.71	37.99	
Some college (13–15 years)	16.83	16.66	20.95	
College graduate (16+ years)	13.29	13.24	14.53	

Table 2.2 (Continued): Statistics of 9,282 Medicare-Eligible Older Decedents from 2002 to 2018, HRS

Variables	Total	Didn't discuss EoL care wishes with doctor	Discussed EoL wishes with doctor	<i>p</i>
Medicaid (%)	25.32	25.52	20.63	.040
Physical health and communication				
Cancer (%)	36.26	35.76	48.60	.000
Lung disease (%)	25.72	25.26	37.08	.000
Heart attack (%)	9.21	9.20	9.32	.939
Stroke (%)	28.50	28.44	29.97	.529
Diagnosed memory issue (%)	23.75	23.87	20.79	.180
Had fall in last 2 years (%)	52.68	52.36	60.56	.002
Bed-bound days in last 3 month of life				.001
0 days	28.48	28.85	19.48	
1–89 days	42.93	42.71	48.26	
All the time (90 days or more)	28.59	28.44	32.27	
Had discussion with family members (%)	53.86	52.73	81.84	< .001

Note. EoL = end-of-life.

Table 2.2 presents the descriptive and comparative analysis results of background statistics of older adults by whether they had end-of-life care discussions with their doctors. In the study sample, 3.9% ($n = 358$) of older adults had end-of-life care discussions with their doctors. Older adults who discussed with doctors were more likely to be White, had more children, had better SES, had cancer or lung disease, and had a fall in the last 2 years. They were also more likely to have had end-of-life care discussions with family members. There were no significant differences in age at death, gender, marital status, and religious denomination between older adults who did or did not have end-of-life discussions with doctors. The two groups also had no statistical differences in the percentage of having a stroke and a diagnosed memory issue in the last 2 years.

Table 2.3 reports the descriptive and bivariate analysis results of outcome indicators and the mediator between the two groups of older adults. Among 9,282 older adults in the sample, nearly half of them (53%) didn't have a living will, 45% of them had a living will that indicated their preference to not use medical intervention to prolong their life, and the remaining 3% documented their wish to extend their life through any possible treatment in their living will. Approximately 70% of the sample had been hospitalized, 36% had stayed in the ICU, and 22% received life support during the last 2 years of life. In this sample, 26% of respondents used specialized services provided by social workers and other professionals and 23% received hospice or palliative care. Most (78%) proxies reported that they were satisfied with the end-of-life care received by the respondents and more than half of them observed that respondents' wishes were respected in their care. Around half of the respondents had managed their end-of-life symptoms relatively well, such that they weren't troubled with pain and didn't have difficulty with breathing or depression in the last year of life. In general, older adults who had

end-of-life discussions with doctors were more likely to complete a living will, die at home, and use health care services including hospice or palliative care, specialized services, and some types of aggressive care like hospitalization and ICU stays. However, surprisingly, they also had significantly worse symptoms, with higher rates of difficult breathing, depression, and being troubled by pain.

Table 2.3: End-of-Life Outcomes and Mediator of 9,282 Decedents from 2002 to 2018, HRS

	Total	Didn't discuss EoL care wishes with doctor (n = 8,924)	Discussed EoL wishes with doctor (n = 358)	p
EoL care service utilization				
Hospitalization	67.14	66.64	79.55	< .001
ICU	35.99	35.59	46.22	< .001
Life support	22.31	22.24	23.92	.463
Kidney dialysis	5.99	5.89	8.41	.054
Surgery	15.88	15.81	17.72	.350
Specialized service	26.04	25.60	36.86	< .001
Hospice or palliative care	22.69	22.39	30.34	< .001
Quality of EoL care				
Satisfied with EoL care	78.27	78.07	82.58	.183
Wishes respected in EoL care	53.77	53.54	59.43	.233
Location of death				.009
Home	28.83	28.54	36.03	
Hospital	34.01	34.14	30.73	
Specialized facilities	37.16	37.32	33.24	
Symptom management				
Troubled with pain	57.13	56.86	63.66	.011
Difficulty breathing in last year of life	51.42	50.94	63.08	< .001
Depression in the last year of life	49.53	49.17	58.11	.001
Mediator				
Advance directive				< .001
Didn't have AD	52.71	53.55	32.08	
Had AD with no intention to prolong life	44.62	43.83	64.15	
Had AD with intention to prolong life	2.67	2.62	3.77	

Note. EoL = end-of-life.

Latent Class Analysis

Table 2.4 shows the model fit statistics of the LCA with two to five classes. Larger decreases in either AIC or BIC between two models indicate improved model fit, and higher entropy reflects better classification quality (Anderson & Burnham, 2004). The three-class model was optimal, because the decrease in AIC and BIC from the three-class to two-class models ($\Delta\text{AIC} = 2,513.322$, $\Delta\text{BIC} = 2,405.574$) was more substantial than the decrease from the four-class to three-class ($\Delta\text{AIC} = 477.254$, $\Delta\text{BIC} = 369.507$) or five-class to four-class ($\Delta\text{AIC} = 477.696$, $\Delta\text{BIC} = 369.948$) models. The three-class model also had the best separation of classes and classification quality, indicated by its highest entropy.

Table 2.4: Comparison of Latent Class Analysis Models with Two to Six Classes

Classes	<i>df</i>	AIC	BIC	Entropy
2	11,993	128,944.395	129,152.707	.712
3	12,003	126,431.073	126,747.133	.761
4	11,979	125,953.819	126,377.626	.691
5	11,978	125,476.123	126,007.678	.671

Note. Bold indicates the selected latent class model.

I selected the three-class model also due to its interpretability according to the item-response probabilities of each class, shown in Table 2.5. I also reported the item-response probabilities of the four-class model in the Appendix (Table A.1) for comparison.

The first class, labeled “minimum service user with good death,” was the most common type and accounted for 44% of the sample. People in this category were least likely to use any type of medical care, either aggressive or comforting, and were more likely to have a “good death,” defined by the best end-of-life symptom management and quality of received care. Specifically, this group had the lowest probability of being hospitalized (46%) across the three categories, and its members didn’t receive any life support or ICU services during the last period of life. They also didn’t use much treatment to extend their lives, such as kidney analysis (0% of

likelihood) and surgery (8% of probability). At the same time, they also had low probabilities of using supportive care like specialized services (18%) and hospice or palliative care (20%). Many older adults in this group died in a non-hospital setting and had high-quality dying experience, such that they had relatively low probabilities of being troubled with pain (46%), difficulty breathing (37%), and depression and were most likely to receive end-of-life care that aligned with their wishes.

Table 2.5: Prevalence of Latent Class and Item-Response Probabilities from Three-Class Model

	C1: Minimum service user with good death	C2: Intensive care user	C3: Extensive service user with uncomfortable death
Latent class prevalence (%)	44.42	22.22	33.36
Item-response probabilities			
<i>End-of-life service utilization</i>			
Hospitalization	.46	.59	1.00
ICU	.00	.78	.56
Life support	.00	.58	.29
Kidney dialysis	.00	.15	.07
Surgery	.08	.30	.17
Specialized service	.18	.25	.38
Hospice or palliative care	.20	.04	.39
<i>End-of-life health status</i>			
Troubled with pain	.46	.60	.69
Difficulty breathing in last year of life	.37	.57	.66
Depression in last year of life	.41	.47	.62
<i>Quality of care</i>			
Satisfied with end-of-life care	.80	.77	.77
Wishes respected in end-of-life care	.56	.50	.53
Location of death			
Home	.37	.00	.37
Hospital	.21	1.00	.07
Specialized facilities	.42	.00	.56

I labeled the second group “intensive care user,” accounting for 22% of the sample. The older adults in this group were characterized by very high use of aggressive treatments (ranging from 15% receiving kidney dialysis to 78% staying in the ICU) and the lowest probabilities of using specialized services and hospice or palliative care (25% and 4%, respectively). More than half of the people in this group struggled with physical pain, breathing, or psychological problems and had been hospitalized during the last 2 years of their life. All of them died in a hospital setting.

The third group accounted for 33% of the sample and was labeled “extensive service user with uncomfortable death.” All people in this group had been hospitalized during the last 2 years of their life, almost twice the probability of hospitalization relative to the other two groups. They were likely to receive aggressive care such as ICU stays (56%) and life support (29%); however, these probabilities are lower than those in the second latent class, the intensive care users. Although this group of older adults had the highest probabilities of using hospice or palliative care and specialized supportive care, they also had the worst end-of-life symptom management (69%, 66%, and 62% had pain, breathing difficulty, and depression, respectively). More than half of the people in this group died in specialized facilities.

Multinomial Logistic Regression in Full and Stratified Sample

Table 2.6 reports relative risk ratios (RRRs) from multinomial logistic regression. Model 1 (M1) is the full model with the focal independent variable, end-of-life discussion with doctors, and demographic, SES, health status, and communication covariates. I found significant effects of end-of-life discussions on the predicted class membership in the LCA after controlling for all covariates. Specifically, older adults who discussed their end-of-life wishes with their doctors

were 53% more likely to be an extensive service user with uncomfortable death rather than a minimum service user with good death ($p < .01$).

Table 2.6: Results from Multinomial Regression Model on Type of End-of-Life Care Experience

	C2: Intensive care user ($n = 2062$)		C3: Extensive service user with uncomfortable death ($n = 3097$)	
	RRR	CI	RRR	CI
Discussed with doctor	1.35+	0.99, 1.85	1.53**	1.17, 2.00
Covariates				
Demographics				
Age at death	0.96***	0.95, 0.96	0.97***	0.97, 0.98
Female	0.99	0.87, 1.13	0.91	0.81, 1.03
Race (ref: White)				
Black	1.62***	1.35, 1.95	1.02	0.85, 1.21
Hispanics	1.62***	1.23, 2.13	1.26+	0.97, 1.64
Marital status (ref: Married)				
Divorced, separated, or never married	0.97	0.79, 1.20	1.06	0.87, 1.29
Widowed	0.93	0.80, 1.08	1.15+	1.00, 1.31
Religion (ref: Protestant)				
Catholic	1.13	0.97, 1.31	1.16*	1.02, 1.33
Other or none	1.19	0.95, 1.48	1.12	0.92, 1.36
Number of children	1.02	1.00, 1.05	1.03*	1.01, 1.06
Socioeconomic status				
Education (ref: < 12 years)				
High school graduate 12 years	1.07	0.92, 1.24	1.06	0.92, 1.21
Some college 13–15 years	0.92	0.76, 1.11	1.09	0.92, 1.28
College graduate 16+ years	1.06	0.86, 1.29	0.90	0.75, 1.08
Medicaid	0.95	0.81, 1.11	1.13+	0.98, 1.29
Born in United States	0.86	0.68, 1.09	1.10	0.88, 1.38
Health status and communication				
Cancer	0.66***	0.58, 0.75	1.13*	1.01, 1.27
Lung disease	1.74***	1.52, 2.00	1.83***	1.61, 2.07
Heart attack	2.38***	1.95, 2.92	1.86***	1.52, 2.27
Stroke	1.37***	1.19, 1.56	1.27***	1.12, 1.43
Had diagnosed memory issue	0.52***	0.44, 0.61	0.83**	0.73, 0.94
Had fall in last 2 years	1.24***	1.09, 1.40	1.71***	1.53, 1.91
Bed-bound days in last 3 months of life (ref: 0 days)				
1–89 days	1.11	0.96, 1.28	2.16***	1.87, 2.49
All the time	0.86+	0.73, 1.01	2.71***	2.32, 3.16
Discussed with family	1.37***	1.21, 1.56	1.46***	1.30, 1.63

Note: Reference class was Class 1: good death with minimum service user.

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 2.7 reports the results of moderation analysis in stratified samples by race and ethnicity. The significant effects of end-of-life care discussion and AD completion only remained in the non-Hispanic White sample. Specifically, among White older adults, having discussions with doctors on end-of-life preferences significantly increased the likelihood of being an extensive service user who might experience uncomfortable dying experiences by 63% ($p < .01$). I found no significant effects of patient–physician ACP discussions among non-Hispanic Black and Hispanic older adults. Post-hoc analyses using interaction terms confirmed the significant differences in the White-Black gap, but not for the White-Hispanic gap, potentially due to the relatively low small sample of Hispanic older adults.

Table 2.7: Results from Multinomial Regression Model on Type of End-of-Life Care Experience in Stratified Samples, RRR (CI)

	White (n = 7,466)		Black (n = 1,420)		Hispanic (n = 671)	
	C2	C3	C2	C3	C2	C3
Discussed with doctor	1.33 (0.93, 1.90)	1.62** (1.21, 2.16)	1.48 (0.61, 3.60)	1.00 (0.39, 2.55)	0.56 (0.09, 3.54)	1.57 (0.39, 6.26)

Note. C1 = minimum service user with good death (reference category), C2 = intensive care user, C3 = extensive service user with uncomfortable death.

* $p < .05$. ** $p < .01$. *** $p < .001$.

Mediation Analysis

Figure 2.1 presents the results of path analysis in the full sample. First, I found that completion of an AD has significant effects on types of end-of-life experiences when controlling for end-of-life discussion and other covariates. Having a completed AD, regardless of the preferences, increased the likelihood of being an extensive service user with an uncomfortable death (Class 3) significantly (AD with no intention to prolong life: $RRR = 1.37, p < .001$; AD with intention to prolong life: $RRR = 1.96, p < .001$). Having an AD asking for invasive care also increased the probability of being an intensive care user ($RRR = 2.09, p < .001$).

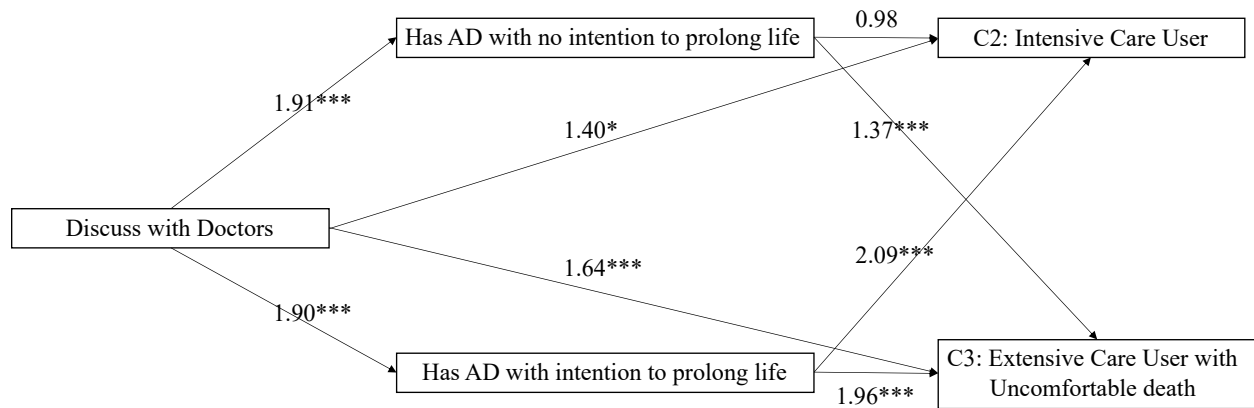


Figure 2.1: Path Analysis between Discussion with Doctors, Completion of Advance Directives, and Type of End-of-Life Care Experiences

The results of the mediation analysis are shown in Table 2.8. AD completion partially mediated the relationship between doctor–patient end-of-life care discussions and types of end-of-life experiences. Specifically, the positive effects of discussions on being in the second class (total effect = 2.22, $p < 0.01$), the intensive care users, was accounted for by AD completion by 71.6%. The increasing likelihood (total effect = 3.07, $p < .001$) of being in the third class brought by end-of-life discussions with doctors was mediated by AD completion by 61.2%.

Table 2.8: Mediating Results of Path Analysis

Path	Total effect	Indirect effect	Total effect mediated (%)
Discussion → AD completion → C2	2.22*	1.59**	71.6
Discussion → AD completion → C3	3.07**	1.88**	61.2

Note. C2 = intensive care user, C3 = extensive service user with uncomfortable death.

* $p < .01$. ** $p < .001$.

DISCUSSION

The study appears to be the first to explore whether, to what extent, and through which paths physician–patient end-of-life discussions are associated with different end-of-life experiences based on nationally representative data. Specifically, I (a) identified three types of

end-of-life experiences among White, Black, and Hispanic older adults; (b) found significant effects of end-of-life care discussions with doctors on uncomfortable dying experiences and extensive use of invasive treatments in the older White population; and (c) confirmed the partial mediating role of AD completion between end-of-life discussions and outcomes. The results of this study have significant policy, practice, and research implications for engaging older adults in the ACP process and ensuring goal-concordant care.

First, I observed three statistically and conceptually distinct clusters of end-of-life care experiences among U.S. older adults based on their service utilization, symptom management, and quality of received care during their last 2 years of life. Best to worst end-of-life experiences were based on the probabilities of receiving satisfied and respected care and not being troubled by pain, depression, and breathing problems in each class. Specifically, the largest group (44% of the sample) seemed to have the best dying experience because they had the highest likelihood of being symptom-free during their last period of life and being satisfied with their goal-concordant care, compared to the other two groups. Older adults in the third class of uncomfortable death (33% of the sample), however, had an opposite end-of-life experience from people in the first class. Moreover, based on the results in Table 2.6, White older adults were more likely to be in the class of minimum service users with a good death compared to older minorities. This is consistent with the previous finding that older Blacks and Hispanics have higher probabilities of receiving unwanted intensive care, dying in the hospital, and not receiving quality end-of-life care (Laguna et al., 2012; Ornstein et al., 2020).

The LCA confirmed that end-of-life care is a multidimensional experience in which certain aspects of experiences always co-occur, based on the item-response probabilities in each class. Service utilization patterns corresponded to different symptom management and quality of

care during the end-of-life stage and the location of death. Higher likelihoods of using various types of aggressive treatments (e.g., ICU, life support) coexisted with higher probabilities of having worse symptom management and quality of care. However, use of specialized supportive care and hospice or palliative care didn't necessarily co-occur with better satisfaction with care and symptom management. Based on the results, it is likely the amount of services older adults used, rather than what kind of services they used, had a greater effect on individual end-of-life experiences. As previous literature documented, navigating the complicated health care system to access various kinds of medical services may increase older adults' fatigue and emotional burden (Aldridge, Epstein, et al., 2016; Bailey et al., 2020). Indeed, the people with the best dying experience were those who used minimal care, including hospice, whereas those who had the worst quality of dying used all types of possible care, including both aggressive and comforting care.

Counter to what policy makers seemingly intended with Medicare ACP benefits, I found that having end-of-life care discussions with doctors significantly increased the likelihood of using all types of invasive treatments and having an uncomfortable dying experience by 53%. This is not aligned with the null findings in most previous RCTs and observational studies (McMahan et al., 2021). One potential reason for this result may be that the sample used in this population study included 32% of older adults who had no chronic illness with acute symptoms (e.g., cancer or heart disease) or died because of sudden events (e.g., car accident) and would not have been included in previous studies, which mostly used hospital data from older adults with certain diseases. For these people, who likely had less time to consider their death, choosing to limit care for quality of life may not have been their preference, even after having an ACP discussion with their doctor.

Another potential explanation for the significant relationship between ACP discussion and worse end-of-life outcomes is the content and quality of the conversations guided by doctors. ACP may be a frightening and uncomfortable process for some older adults because it requires them to think about death and dying (Bollig et al., 2016). As such, an end-of-life conversation without high quality may not translate into actual ACP behavior. For example, physicians who lack professional value-oriented conversation skills, such as active listening, reflecting or asking for clarification, and culturally appropriate responses, may fail to build rapport with patients and provide a quality consultation on this uncomfortable life topic. Further, the content covered in the discussion also matters because physicians may bring implicit bias into these conversations (Schickedanz et al., 2009). Without systematic training in palliative care, a doctor may be more comfortable explaining and following a traditional care plan, underestimating the side effects of the possible treatment options and unconsciously delivering that information to patients (Hemsley et al., 2019).

Third, aligned with the hypothesis, I found that the discussions only had significant effects on White older adults, not Black and Hispanic older adults. To be effective in improving end-of-life outcomes, a physician-led discussion should be initiated and provided in a culturally sensitive manner that is aligned with the older adults' values (Hemsley et al., 2019), and the wishes clarified during the meetings should be documented and communicated with family members thoroughly and firmly followed by proxies and doctors (Brinkman-Stoppelenburg et al., 2014). However, racial and ethnic minority older adults face extra challenges in every step of the process, from discussion to documentation and implementation, including lack of culturally appropriate services, language barriers, and disadvantaged ability to advocate for their or their loved one's treatment preferences (Hemsley et al., 2019; Hong et al., 2018). Therefore, even

though some older Blacks and Hispanics were able to have ACP conversations with their doctors, the effectiveness of those discussions on their ultimate end-of-life care outcomes may be undermined by the barriers they experience in the health care system.

Last, path analyses suggested that the effects of physician–patient discussions on end-of-life outcomes were partially mediated by the completion of ADs, regardless of the type of preferences (limiting intrusive care or not). This is aligned with prior research indicating that the increasing rate of ADs is a direct outcome of physician–patient discussions. Previous qualitative studies shed light on older adults’ various concerns about completing an AD, including uncertainty about available future treatment plans, worries of not being able to change their decisions, and lack of motivation due to stable health status (Jabbarian et al., 2018; Ke et al., 2017). ACP discussions with doctors, in which doctors explain the benefits and function of an AD and advantages and disadvantages of various end-of-life care plans, can address older adults’ concerns about ACP and further motivate them to complete an AD. Further, previous studies observed more consistent findings of the effectiveness of ADs on end-of-life care than physician-involved discussions, and this may explain the significant role of completing an AD in the relationship between discussions and end-of-life care outcomes.

Limitations

These analyses had certain limitations. First, the indicator of the key independent variable, end-of-life care discussion with a physician, was not ideal. The variable was extracted from a question asking proxies about with whom the respondents had end-of-life conversations, and a physician was one option. Older adults who had conversations with doctors might not have inform their loved ones and thus, these discussions are likely underestimated. Similarly, end-of-life care indicators in this study, including the objective health service utilization measures, were

all reported by proxies. There is a possibility that proxy-reported use of care was not very precise, leading to potential over- or underestimation. Future research can consider using claim data, if available, to retrieve more accurate medical information. Moreover, the timing of having discussions with doctors was not available in the data; it could have taken place after respondents completed an AD, influencing the impact of the conversation on end-of-life outcomes. Last, due to availability, some potential confounders were not included in the study that could be addressed in future studies. For example, older adults' family support and relationship may affect both end-of-life decision-making and dying experiences. Physician's characteristics may also significantly confound the relationship between conversations and end-of-life experiences. For instance, if a physician comes from same racial/ethnic background as the patient, the doctor may be more likely to provide high-quality culturally-appropriate consultation that leads to better end-of-life outcomes.

Policy, Practice, and Research Implications

Despite these limitations, the study has strong policy and practice implications for improving the provision of ACP services. First, because it is concerning that patient–physician ACP discussion led to increased use of all types of invasive treatments and uncomfortable dying experiences, hospitals should provide more organizational supports and resources to help physicians improve the quality and effectiveness of these conversations. For example, hospitals can develop practical guidelines to standardize the content that needs to be covered in these conversations. Moreover, organizations can provide training on health communication and palliative and hospice care to improve doctors' end-of-life care knowledge and skills to lead difficult life discussions. Nevertheless, future research can more systematically investigate

organizational obstacles to inform innovative interventions on hospital policies or administration (e.g., performance reward system).

Alternatively, hospitals can consider organizing an interdisciplinary team that includes doctors, nurses, social workers, and chaplains to participate in ACP services, rather than relying only on doctors. End-of-life care planning is a complex process that involves intensive emotion processing, health information exchanging, value reflection, and family discussions. As such, only an interdisciplinary team of professionals trained to address medical, psychosocial, and spiritual needs of older adults and their family members can provide comprehensive, person-centered, and quality end-of-life care planning services (Dyess et al., 2014). For example, a social worker can provide individual psychological service or family therapy if necessary and work as a care coordinator to make sure patients' preferences are known by the whole care team, including specialists or emergency department physicians. Meanwhile, physicians and nurses have the irreplaceable responsibility to provide medical information and evaluation of illness trajectory, prognosis, treatment options, and potential outcomes, whereas chaplains can help with religious or spiritual needs. Moreover, the interdisciplinary approach is also payable under the current Medicare reimbursement mechanism, which allows billing these services directly to a team or the responsible physician.

Moreover, more efforts are needed to improve the availability of culturally sensitive ACP services for older minorities. Because ACP is a value- and culture-based activity, lack of cultural sensitivity while providing these services may significantly affect the effectiveness of the services. Policies and hospitals can provide extra support to physicians and other health care professionals of color who are willing to serve their communities. For example, grants and funding can be provided to compensate for their time in building trusting relationships with local

communities. Also, more within-group and community-based participatory research is needed to understand older minorities' unique health care decision-making experiences, needs, and challenges to inform frontline culturally sensitive practice.

Last, the results highlight the important role of completing ADs in the process of making end-of-life care decisions. Putting end-of-life care wishes in written documents after thorough conversations with loved ones and health professionals may be more effective in ensuring goal-concordant end-of-life care than having discussions alone. While having conversations, physicians are advised to encourage patients to complete ADs and help with the documentation if desired. Moreover, physicians and other health care professionals can provide more education on how to properly store, update, or change preferences when needed and execute written ADs to make sure they are not "lost in the shuffle."

Chapter 3: Advance Care Planning from 2012 to 2021: The Effectiveness of Medicare Reimbursement for Physician–Patient Discussions

INTRODUCTION

By 2030, 1 in 5 Americans is projected to be 65 years old or older (Colby & Ortman, 2015), of which 90% will have one or more chronic conditions and 14% will have six or more chronic diseases (CMS, 2020). The high prevalence of age-related diseases in society highlights the importance of end-of-life planning, because comorbidities often lead to challenging decisions in prioritizing competing treatment options for extending life expectancy or improving quality of life (Pelland et al., 2019). ACP is a preparation process taken to convey preferences for end-of-life care prior to cognitive unconsciousness, including legal documentation such as a living will and DPAHC and informal conversations with loved ones and health care providers (Sudore et al., 2018). Without specifying care preferences in advance, older adults are more likely to experience burdensome transitions between care places, suffer from side effects caused by invasive treatments like chemotherapy and cardiopulmonary resuscitation (Thelen, 2005), and receive care that is not aligned with their wishes (Teno et al., 2007).

Despite the importance of ACP, more than 70% of all older patients in the United States were not involved in their end-of-life care decisions, with well-documented racial and ethnic disparities such that Black and Latinx persons (18%) are far less likely than Whites (34%) to have a living will and DPAHC (Moorman et al., 2020; Yadav et al., 2017). The disparity of ACP engagement further exacerbates the health inequality during end-of-life—non-White older patients are more likely to receive “default care” due to the lack of ACP, including intensive

treatment and hospitalization in the last 6 months of life, and are less likely to use hospice care (Ornstein et al., 2020).

With the hope of improving end-of-life quality of life of U.S. older adults, ACA Medicare benefit expansion under the ACA included ACP as a reimbursed service. As of January 1, 2016, physicians can bill for ACP discussions with patients (Mehta & Kelley, 2019). After 6 years of implementation, the field lacks rigorous evidence on whether this mechanism is effective, especially among non-White older adults. FCT argues that if a health policy fails to reduce the degree of resource inequality related to certain health behavior, the policy intervention will likely further reproduce the social gradient of health (Phelan & Link, 2013). Although Medicare makes the option of physician–patient ACP discussion available to everyone, minority older adults may face extra barriers to ACP with providers. Thus, motivated by FCT, this study explored whether the policy effectively instituted ACP as a health behavior that can be initiated irrespective of individuals’ race and related SES factors. The results can guide future improvements of the health policy intervention on ACP to address the inequality in end-of-life care.

LITERATURE REVIEW

History of ACP Laws and Policies in the United States

In the 1970s, legal and ethical problems regarding who should make end-of-life decisions were brought to the attention of the American public, when family members of patients in a comatose state for years requested to withdraw life-sustaining treatments like ventilators, cardiopulmonary resuscitation, and intravenous care (Flory & Emanuel, 2005). In 1974, ACP was introduced to the United States along with the concept of hospice care to honor people’s desire for comfort, dignity, and a “good death.” In 1990, the U.S. Supreme Court decision in *Cruzan v. Director, Missouri Health Department* supported the individual constitutional right to

refuse life-sustaining treatment and held state governments responsible for providing clear and convincing evidence for individual requests, such as a living will or DPAHC (Larson & Eaton, 1997). Soon after, ACP and related legal documents were formally recognized in 1991 through the Patient Self-Determination Act passed by Congress (Sabatino, 2010). The act requires that all federally funded health centers and hospitals ask patients whether they have an AD (an umbrella term for end-of-life care-related directives such as a living will and DPAHC) and must provide them with educational materials and an opportunity to execute one, should they desire (Larson & Eaton, 1997).

Although the goal of the legislation is to empower patients to gain more control over their end-of-life care through legal documents, the rate of ACP on the frontlines remains low despite 30 years of advocacy. The limited success of the act can be attributed to exclusive attention to the “meaningless formality” of the legal documents and neglect of the importance of conversations (Boerner et al., 2020; Larson & Eaton, 1997). Notably, the discussion may be more important than the forms (Silveira et al., 2014), because conversations can ensure older adults’ wishes are clearly enacted and correctly interpreted by family members and doctors (Boerner et al., 2020). Additionally, end-of-life decision making requires a certain level of health literacy to understand documents, treatment options, and potential outcomes (Hong et al., 2018); as such, conversations with doctors and loved ones are particularly important for older adults to evaluate the situation comprehensively and make an informed decision. However, even among older adults with legal documents, only 12% had informed their physicians (Hemsley et al., 2019).

Recognizing the importance of conversations, the field has pushed for a move from a legal transaction model to a communication-oriented approach (Sabatino, 2010). Yet end-of-life

conversations are hard and require skills to initiate. Doctors often reference “uncomfortable death talks” and lack of training that often lead to delaying these conversations until a medical crisis calls for immediate decisions, when older adults, in most cases, cannot participate in informed consent (Frankford, 2015; Hemsley et al., 2019; Romo et al., 2016). With the intention to encourage doctors to have timely ACP discussions with patients, the ACA provision for physician–patient discussions was approved in 2015 after years of discussion (Frankford, 2015).

Medicare Policy on ACP and Current Evidence of Policy Outcomes

To improve ACP participation and health encounters through personal communication between patients and physicians, CMS launched a Medicare policy for older adults aged 65 or older, in which clinicians can bill for ACP face-to-face discussions with patients or surrogates, effective on January 1, 2016 (Mehta & Kelley, 2019). Each ACP session can last for 30 minutes, but there is no limit on the number of sessions a physician can bill, as long as the patients feel they are necessary (Center for Medicare and Medicaid Services, 2015). Additionally, the services can be provided in both inpatient and outpatient settings and any time after Medicare eligibility (van Zyl & Gross, 2018).

By assigning a Current Procedural Terminology code, the policy implies that ACP conversations, like other medical procedures, are “indeed procedures with indications, contraindications, and complications” that require certain training, instructions, and practice of decision-making and communicational skills (van Zyl & Gross, 2018). Before 2016, an ACP conversation was not a standalone item covered by Medicare and was considered a topic that can be discussed during the once per lifetime “Welcome to Medicare” preventive visit (He et al., 2020).

Descriptive studies have increased on the pattern of code use in the first few years of policy implementation. Preliminary results on the direct outcomes of the policy show the room and necessity for further intervention. According to Medicare data, in the first year of policy implementation, approximately 570,000 (1.9%) beneficiaries had ACP conversations with 22,000 physicians, of which 99% billed only one session (Grant, 2017). The use of service significantly varied by location, ranging from 1% to 10.9% across states (Belanger et al., 2019). Most billed ACP visits were office visits, and 40% of them happened during annual wellness visits—an encouraging pattern indicating that ACP conversations were included in usual preventive care management (Pelland et al., 2019).

However, the overall uptake rate remains low and significantly varies by older adults' SES. The rate of ACP service utilization (less than 2%) is lower than expected because 89% of older patients said that discussing end-of-life treatment choices with their physicians is important, according to a national poll in 2015 (DiJulio et al., 2015). The majority (84%) of older adults who used the services were White (He et al., 2020), whereas older Spanish-speaking Latinos and Asians had the lowest percentages (Pelland et al., 2019). Beneficiaries who used the codes were more likely to be non-Hispanic White, female, with a college degree, without dual eligibility of Medicare and Medicaid, and with a median income exceeding \$71,000 (Harrison et al., 2016; Mehta & Kelley, 2019), a population that likely would have initiated ACP even without using the services from the reimbursement policy.

The policy effectiveness has not yet been rigorously addressed, and current observational studies considering the use of codes as the policy outcome may underestimate the actual impact of the policy on older adults' ACP engagements. First, ACP billing may not be a good proxy for actual ACP practice. According to a study by Belanger and his colleagues (2019), two thirds of

physicians working in hospice and palliative departments didn't file an ACP bill after 2016, though it is unlikely that they would have had no ACP conversations with patients and their loved ones (Scheunemann et al., 2015). It is possible that physicians discussed end-of-life care wishes with their patients without billing, due to lack of awareness and uncertainty about the appropriate code (Mehta & Kelley, 2019) and inability to incorporate this extra billing into their regular workflow, according to qualitative interviews with doctors (He et al., 2020).

Second, the policy may increase the willingness to participate in ACP among older adults not only through using reimbursed service, but also through messages delivered from the policy to the public that ACP is an important step to make dying more humane (CMS, 2016). ACP discussion as an ACA component was derailed and dropped in 2009 by the political misnomer “death panels”; it described government involvement in and purchasing of ACP discussions as threatening to “pull the plug on Grandma” and something that “necessitates accountability and cost control” (Frankford, 2015). When the policy was quietly reintroduced 10 years later in 2016, however, the public was more likely to accept the policy and perceived it as a signal that their voices and preferences should be valued and heard (van Zyl & Gross, 2018). Therefore, instead of using billing code use as the proxy for policy intervention, we also need to estimate the intent-to-treat effects on actual ACP participation to understand the policy-relevant effectiveness, which was the analytic goal of this study.

Theoretical Foundation

Potential heterogeneous effects of the policy across people with different racial and ethnic and SES backgrounds are also overlooked in the current literature. FCT, developed by Phelan and Link (1995), links social status to health-protecting behaviors and health disparities. It argues that social factors, such as race and SES, are “persistent and fundamental causes of

disease” (Link & Phelan, 1995). According to the theory, social factors affect access to and use of basic resources, including knowledge, skills, power, wealth, and social connections, and ultimately influence the ability to exert positive health behaviors to avoid certain diseases or negative health consequences (Masters et al., 2015). For example, being a member of a racial and ethnic majority or having a higher SES provides individuals with greater and more timely access to risk-reducing resources, such as nondiscriminatory quality care. As such, they are more likely to afford health-enhancing behaviors (e.g., ACP) that enhance their likelihood of having better end-of-life health and mental health (Luth, 2017).

FCT provides a strong rationale for studying health policies that may remedy or reproduce health inequalities. Based on FCT, if a social policy addresses resource inequality (e.g., money to pay for care) associated with fundamental causes (e.g., race and ethnicity or SES) of health, the policy intervention can successfully disrupt the social construction of the health inequality (Riley, 2020). For example, policies that ensure universal access to resources regardless of social status, such as unemployment insurance, have proven to reduce health disparities effectively (Cylus et al., 2015). On the other hand, if the health policy fails to eliminate the effect of a fundamental condition by only focusing on intervening variables, the policy intervention will likely further reproduce the social gradient of health, even if it is “effective” in the short run (Phelan & Link, 2013). In other words, a policy will likely exacerbate disparities if the benefit is only available or accessible to certain groups of people with requisite resources (Clouston & Link, 2021). For example, telehealth may limit opportunities for people who don’t have adequate access to the internet and technology skills.

Although Medicare makes the option of physician–patient ACP discussion available to everyone, older adults from disadvantaged backgrounds may be less likely to benefit from the

policy. Making end-of-life care decisions is deeply affected by structural inequality (Huang et al., 2016). ACP requires older adults to have adequate health literacy, knowledge of medical treatment, and the capacity to analyze the risks and benefits of those decisions (Hemsley et al., 2019); maintain more stable and trusting relationships with a primary doctor (Hong et al., 2018); and believe that their preferences will be respected (Ornstein et al., 2020; Wicher & Meeker, 2012). However, those degrees of resource and knowledge inequalities related to ACP are not addressed by the current Medicare policy.

Therefore, based on FCT, it is reasonable to surmise that the Medicare ACP benefit, which is universal to all older beneficiaries, may have a short-term effect on health behavior, but no long-term effectiveness in terms of promoting end-of-life equity. Specifically, it is possible that the policy is effective for White older adults with higher SES, who have the resources to meet with trusted providers and have comprehensive ACP conversations, but doesn't work for older minorities, especially those with low SES. Thus, this study investigated if the policy is equally effective for all subpopulations; if not, end-of-life health disparities will likely persist (Phelan & Link, 2013).

Present Study

Guided by FCT, this study relied on the population-based longitudinal HRS to fill the identified research gaps. Specifically, the present study examined three questions: (Q1) Did Medicare coverage of ACP conversations improve the ACP participation rate? and (Q2) Do the associations tested in Q1 vary by SES, as indicated by education, wealth, race and ethnicity, and immigration background?

METHOD

Data and Sample

This study relied on the HRS, conducted by the Institute for Social Research at the University of Michigan. The HRS is a nationally representative biennial survey of U.S. adults aged 50 or older regarding their demographics, health and health insurance, marital status, employment and retirement status, finances, and public and private support systems. The HRS follows respondents over time once recruited and replenishes the sample every 6 years with a younger cohort (Sonnegg et al., 2014). The HRS is a household survey; respondents' spouses are also approached and interviewed if they consent (HRS, 2019). The HRS oversamples Black and Hispanic individuals. Individual-level sampling weights are applied to achieve population-based estimations.

This paper used HRS core data with living respondents from Wave 2012 to Wave 2020, covering interviews conducted between April 2012 and June 2021. From Wave 2012, the HRS core started to collect information on end-of-life care planning in a core module, Wills and Life Insurance, and tracked any changes in ACP every 2 years. I limited my sample to adults aged 65 or older at the interview date and who had valid answers to all ACP questions. The final sample was 47,982 observations nested in 15,647 individuals across 9 years. Among them, 28% ($n = 4,426$) had valid interview information for all five waves and 3,187 individuals had been interviewed one time.

Measures

Three dependent variables were used to indicate the outcomes of ACP at the date of the interview: DPAHC appointment, living will, and informal discussions about treatment preferences with others. The behaviors were assessed by three questions: (1) "Have you made any legal arrangements for a specific person or persons to make decisions about your care or medical treatment if you cannot make those decisions yourself? This is sometimes called a

DPAHC”; (2) “Have you provided written instructions about the care or medical treatment that you want to receive if you cannot make those decisions yourself? This is sometimes called a living will”; and (3) “Have you ever discussed with anyone the care or medical treatment you would want to receive if you were to become seriously ill in the future?” Based on the responses to these questions, I coded them into dichotomous variables (1 = *yes*, 0 = *no*).

The key intervention variable in the analysis was whether the ACA Medicare benefit expansion on ACP services was implemented at the date of the interview. The interview date was used to construct the pre–post trend indicator (1 = on or after *1/1/2016*, 0 = *before 1/1/2016*). The variable to differentiate the treatment and comparison groups was whether the older adult was covered by Medicare at the time of the interview (1 = *covered* [treatment group], 0 = *not covered* [comparison group]). Medicare coverage was self-reported by the respondents.

Moderators were four variables indicating SES: highest educational degree obtained (1 = *less than high school* [reference group], 2 = *high school graduate or GED*, 3 = *some college*, 4 = *college or higher*); household wealth quartile for the year of the interview (1 = *< 0 or in debt* [reference group], 2 = *0 to 25th percentile*, 3 = *25th to 50th percentile*, 4 = *50th to 75th percentile*, 5 = *75th to 100th percentile*); race and ethnicity (1 = *non-Hispanic White* [reference group], 2 = *non-Hispanic Black*, 3 = *Latino*, 4 = *Others including Asian, American Indian, Alaska Native, Native Hawaiian, or Pacific Islander*); and immigration background (1 = *born in the United States*, 0 = *not born in the United States*). A wealth variable was obtained from RAND that imputed wealth data regarding the dollar value of the respondents’ total assets. The imputation was done by adding older adults’ owned houses, real estate, vehicles, business, stocks and mutual funds, savings, bonds, and all other savings and subtracting all debt, including mortgages, other home loans, and any other debts like credit card balances, medical debts, and

life insurance policy loans. I categorized individual wealth quartiles based on the RAND imputed monetary value. In the preliminary analyses, I also included the eligibility for Medicaid as a proxy for older adults' income and wealth status. I dropped the Medicaid variable because it is highly correlated with wealth quartile. Education, race and ethnicity, and immigration background variables were time-invariant measures, and wealth was a time-variant variable.

Based on the literature review on end-of-life care planning and multi-level impact factors on health by socioenvironmental theory (Hemsley et al., 2019; Gubrium, 1972), I adjusted for sociodemographic, SES, medical history factors that may affect ACP behaviors. Demographic variables included age in years, gender (1 = *female*, 0 = *male*), marital status (1 = *married*, 0 = *divorced, widowed, or never married*), and religion (1 = *none* [reference group], 2 = *Protestant or Catholic*, 3 = *other*). Medical history included physical and mental health factors. Physical health history variables include self-reported health (1 = *good, very good, or excellent*, 0 = *poor or very poor*) and number of diagnosed diseases, including hypertension, diabetes, cancer, stroke, lung problems, heart problems, and arthritis. Mental health was proxied by depressive symptoms, which was assessed with the 8-item version of the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). Symptoms included feeling alone and restless sleep; responses were averaged, and scores ranged from 0 to 8. Higher scores indicated high levels of depressive symptoms ($\alpha = .79$). Health and mental health indicators were controlled as time-variant covariates in the models.

Analytic Strategy

Using microlevel data in the HRS core from 2012 to 2020, I used two quasi-experimental models: DID and ITS. The two quasi-experimental designs compensated for each other. ITS incorporates time in the model, such that segmented linear regression models are used; as such, it

is a powerful model to understand the level and trends (or slope) before and after an intervention (Turner et al., 2021). DID, on the other hand, only measures outcomes at a single pre–post point and thus, doesn't consider time. However, DID can be used with more flexible synthetic controlling methods and moderation analyses when individual-level data are available (Lopez Bernal et al., 2019).

One important prerequisite of DID to obtain internal validity is the parallel assumption, which requires that the differences between the treatment and control groups are constant over time in the absence of treatment. I first plotted the trends and adopted the traditional visual inspection approach to examine whether the data met the parallel assumption. Additionally, ITS as an event study model also helped me check the assumption. Although there is no formal statistical test for this assumption, ITS can provide useful information on whether significant differences exist between two groups along a trend.

Difference-in-Difference Model

I first checked whether the parallel assumption was met through visual inspection of the trends of dependent variables. I used the ITS model, described in the next section, to confirm the results of my visual check. With the assumption met, I proceeded with the DID design to compare older adults with and without Medicare before and after the ACA Medicare benefit expansion on ACP. Advance care planning is covered under Medicare Part B and older adults with only Medicaid will not be able to receive coverage for ACP services (CMS, 2016). I estimated linear probability models for each outcome of ACP with an interaction term between an indicator for older adults with Medicare ($1 = \text{yes}$, $0 = \text{no}$) and an indicator for whether the interview occurred before or after the policy implementation, as well as year-based fixed effects. The coefficient of the interaction term is the DID estimate of the difference in change before and

after the policy between the treatment and control groups. I also controlled for both time-variant and time-invariant demographic, SES, health, and mental health covariates. Clustering standard errors were set for the correlation of the error terms by each individual in the panel data. Multiple imputation was used to address missing covariates.

Interrupted Time Series Analysis

I started with a simple ITS with no comparison groups. I investigated the yearly trends (based on interview dates) of ACP outcomes using segmented regression models (1). Relatively stable outcomes over time provided me with a stronger rationale to conduct ITS.

$$(1) Y_t = \beta_0 + \beta_1 TIME + \beta_2 POST + \beta_3 (TIME * POST)_{it} + \beta_4 X_{it} + \varepsilon_{it}$$

In this equation, Y is engagement in ACP and health care encounter outcomes at time t. TIME is the years elapsed since January 2012. Implementation of Medicare ACP reimbursement is considered an intervention in the analysis. POST is a dummy variable indicating the postintervention period. B_0 represents the baseline level at TIME = 0. B_1 reports the change in the outcome associated with a time-unit increase. B_2 indicates the level changes following the intervention (immediate effects). B_3 is interpreted as the slope change following the event (sustained effects). One advantage of ITS is that the estimation is generally unaffected by time-invariant confounders (Bernal et al., 2020); however, it may be biased by time-variant factors (such as seasonality). Therefore, I adjusted for X_{it} , the time-variant variables previously listed.

I then strengthened the ITS approach by including a comparative control series. The comparative ITS models compared the outcome of the treatment group (older adults with Medicare coverage) and control group (older adults without Medicare coverage) before and after the intervention. With the comparison group, I also investigated whether the level and slope

changes of the treatment series were significantly different from the control series (Bernal et al., 2020). The regression model was expanded to (2):

$$(2) Y_t = \beta_0 + \beta_1 TIME + \beta_2 TREATMENT + \beta_3 POST + \beta_4 (TIME * TREATMENT)_{it} + \beta_5 (TIME * POST)_{it} + \beta_6 (TREATMENT * POST)_{it} + \beta_7 (TIME * TREATMENT * POST)_{it} + \beta_8 X_{it} + \varepsilon_{it}$$

In this equation, Treatment represents whether the older adult had Medicare coverage. $TIME * TREATMENT * POST$ indicated if the observation occurred after the intervention for the treatment group (older adults with Medicare). Similar to Equation (1), I controlled for time-variant factors.

The analyses were conducted in Stata using the package *xtitsa*. The command was developed by Linden (2021) to perform ITS with individual-level panel data. Compared to the classic ITS package that requires researchers to collapse individuals into a single aggregate unit, the *xtitsa* command releases this requirement and accounts for within-group variability during estimation. I used the *figure* option in the package to draw line plots of the fitted outcome values over time after running the ITS regressions. Multiple imputation was used to address missing covariates.

Moderation Analyses

To answer the second research question, I conducted the analyses in subsamples categorized by race and ethnicity, nativity, education, and income quartile to explore potential heterogeneous effects.

Sensitivity Analysis

In the U.S., around 10-percent of older adults aged 65 and older are not eligible or using Medicare with potential reasons including citizenship, employment history in the United States, marriage history, history of being homeless, etc. (Cohen et al., 2021). A major concern of using

comparisons in ITS and DID designs is that older adults with and without Medicare may be statistically different in their characteristics in such a way that confounds their exposure to the policy (e.g., age, length of stay in the United States, SES, etc.). To address the potential bias of the comparison group not being the ideal counterfactual control unit, I conducted a robustness test with a matched comparison sample using coarsened exact matching to select a smaller “treated” sample whose characteristics were similar to the comparison group (Page et al., 2019).

Another concern is that analyzing and plotting trends by interview date may cause an overestimation of the policy effect. For example, although the question is asked every 2 years, older adults who reported engaging in ACP after January 2016 may have had ACP discussions before 2016. HRS provided three interview dates: survey begin, midpoint, and survey end. As indicated, the survey end was my primary measure of the time, and I conducted sensitivity analyses with beginning and midpoint dates and 1-year policy lag effects.

RESULTS

Descriptive Results

Table 3.1: Demographic Information by Medicare status, HRS Wave 2012 to 2020 (N = 47,982)

	Total	With Medicare (n = 45,685)		Without Medicare (n=2,297)		Sig. ^a
		Pre-policy (n = 19,888)	Post-policy (n = 25,797)	Pre-policy (n = 811)	Post-policy (n = 1,486)	
Demographics						
Age (65–103)	75.91 (7.64)	76.29 (7.43)	76.03 (7.70)	71.88 (7.54)	72.02 (7.17)	abcd
Female (%)	58.95	58.86	59.56	52.23	53.40	ab
Married (%)	56.01	57.24	54.52	62.29	62.12	abc
Race and ethnicity (%)						abcd
Non-Hispanic White	70.65	74.93	68.93	61.13	48.26	
Non-Hispanic Black	15.75	13.93	16.86	16.85	20.16	
Hispanic	11.10	8.96	11.61	18.17	26.97	
Asian, Pacific Islander, or Indigenous	2.51	2.18	2.61	3.85	4.61	
Religion (%)						abd
None	2.01	2.03	1.96	2.30	2.52	
Protestant or Catholic	89.79	91.25	89.06	86.42	84.63	
Other	8.20	6.72	8.97	11.27	12.86	
SES						
Educational attainment (%)						abc
Less than high school	19.31	21.07	17.65	24.82	21.62	
GED	34.81	36.67	33.88	30.36	28.58	
Some college	22.94	21.52	24.07	20.00	23.87	
College degree or beyond	22.94	20.74	24.40	24.82	25.93	
Wealth (%)						
< 0 (in debt)	9.30	8.53	9.63	14.68	14.83	abc
0–25 percentile	24.00	24.91	22.77	28.52	24.07	
25–50 percentile	22.48	22.48	22.65	20.7	20.85	
50–75 percentile	22.46	22.75	22.38	19.13	20.75	
75–100 percentile	21.76	21.33	22.57	16.97	19.5	
Born in United States (%)	87.82	89.78	87.80	75.27	68.98	abcd
Health and mental health						
Self-reported good health (%)	69.12	68.66	69.59	65.86	68.72	c
Number of diseases (0–7)	2.71 (1.49)	2.66 (1.46)	2.79 (1.49)	2.32 (1.50)	2.26 (1.56)	abc
CES-D depression score (0–8)	1.64 (1.88)	1.38 (1.89)	1.82 (1.85)	1.51 (2.08)	1.87 (1.90)	cd

Note: Table reports percentage or mean (standard deviation in parentheses). The pre-policy columns represent the average characteristics of 2012–2015 prior to ACA Medicare benefit expansion. The post-policy columns represent the average characteristics of 2016–2021 after ACA Medicare benefit expansion.

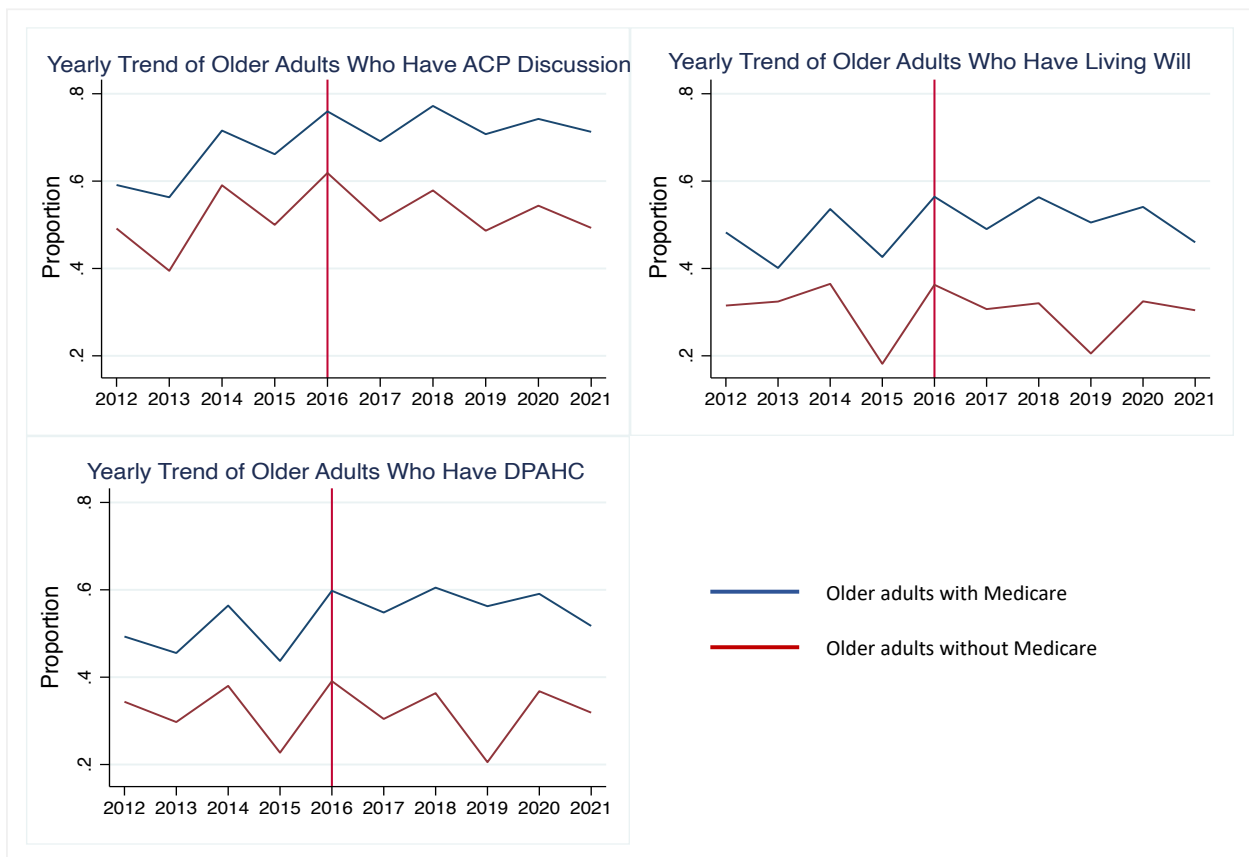
^a Statistically significant difference ($p < .05$) between subgroups: a = older adults with vs. without Medicare during pre-implementation period; b = older adults with vs. without during postimplementation period; c = older adults during pre- vs. postimplementation periods among older adults with Medicare; d = older adults during pre- vs. postimplementation period among older adults without Medicare.

Table 3.1 reports the descriptive information of the 47,982 older adults in the final sample by Medicare coverage status for the pre-policy and post-policy periods. Overall, respondents had an average age of 76 years and approximately 60% of them were female and married. Most individuals were non-Hispanic White (70.65%), Protestant or Catholic (89.79%), and born in the United States (87.82%). Only 2.51% of the respondents self-reported as Asian, Pacific Islander, or Indigenous; however, due to the large size of the overall sample, I still had decent statistical power for analyses in this category. Approximately half of the sample had a college degree or beyond, and nearly 10% of the sample was in debt. On average, the respondents had 2.71 types of chronic conditions and a score of 1.64 on the CES-D scale; 70% of the respondents reported having good health in the last 2 years.

Table 3.1 also reports the results of bivariate analyses on personal characteristics between older adults with or without Medicare and between pre-policy and post-policy periods. Older adults with Medicare were more likely to be older, female, married, White, and Christian; had higher income on average; and were less likely to have less than a high school degree during both pre- and post-policy periods. There was no significant difference in self-reported health and depressive symptoms between older adults with or without Medicare. Among older adults with Medicare, a higher percentage had higher income and educational attainment after the policy implementation. The percentage of Hispanic older adults was significantly higher after the policy implementation. The proportion of U.S.-born older adults was significantly lower during the post-policy period.

Figure 3.1 visualizes the descriptive information of the three outcome variables. Specifically, it shows the percentage of older adults in the final sample who had informal ACP discussions, a living will, and DPAHC from 2012 to 2018. Overall, the percentage with either legal documentation (living will or DPAHC) ranged from approximately 20% to 60%, and the range of older adults who had discussed their end-of-life care wishes with loved ones was around 40% to 75%. Upon visual inspection, the trends of ACP outcomes among older adults with and without Medicare were parallel prior to the policy implementation.

Figure 3.1: Percentage of Older Adults in the HRS Who Had Informal ACP Discussions, Living Will, and DPAHC, 2012–2018 (N = 47,982)



Note. Percentages were based on the unweighted total sample.

DID Results

Table 3.2 presents the percentages and range of percentages of the three ACP outcomes in the treatment and comparison groups before and after the policy implementation. Table 2 also summarizes the DID estimates for changes in the three ACP outcomes associated with the ACA Medicare coverage expansions from M1 to M3. M1 is the unadjusted model without any controlling variables. M2 is the full model adjusting for demographic, SES, and health and mental health variables in the total sample. I reran the M2 in a matched sample using coarsened exact matching as a sensitivity test; the results are shown in M3. That is, ACA Medicare coverage expansion on end-of-life care planning benefits was associated with a 0.05 percentage point increase in completing a living will or DPAHC, and the expansion was not significantly associated with a change in ACP discussions with loved ones at a .05 level. The results were consistent in magnitude and significance in the matched sample, showing that the new policy was driven by a 0.05 (95% CI [0.00, 0.11]) percentage point increase in the proportion of respondents who completed a living will, a 0.03 (95% CI [0.00, 0.09]) percentage point increase in appointing a DPAHC, and a marginally significant increase (0.03 percentage points, 95% CI [-0.02, 0.08]) in having family conversations on end-of-life wishes. Moreover, similar results were observed in the sensitivity analyses, where I tested one-year lagged effects or used the beginning and midpoint interview dates to construct treatment variables. The full regression results from the adjusted DID models (M2) are reported in the Appendix (Table B.1).

Table 3.2: Changes in Advance Care Planning Outcomes Associated with ACA Medicare Benefit Expansion on End-of-Life Care Planning

	With Medicare (<i>n</i> = 45,685)		Without Medicare (<i>n</i> =2,297)		M1: Unadjusted DID	M2: Adjusted DID	M3: DID in Matched Sample
	Pre-policy (<i>n</i> = 19,888)	Post-policy (<i>n</i> = 25,797)	Pre-policy (<i>n</i> = 811)	Post-policy (<i>n</i> = 1,486)	Difference-in-difference Estimate (95% CI)		
Outcome	% (Range)						
LW	50.43 (40.12–53.60)	55.79 (45.99–57.28)	33.67 (18.18–36.57)	33.02 (20.55–36.26)	0.06** (0.02, 0.10)	0.05* (0.00, 0.09)	0.05* (-0.00, 0.11)
DPAHC	52.45 (45.54–56.40)	59.90 (51.73–61.48)	35.66 (22.73, 38.11)	36.26 (20.55–39.09)	0.07** (0.03, 0.12)	0.05* (-0.00, 0.09)	0.03* (0.00, 0.09)
Discussion	65.06 (56.31–71.57)	75.34 (69.14–75.97)	53.64 (39.47, 59.19)	56.33 (48.65–61.86)	0.08*** (0.04, 0.,12)	0.04+ (-0.00, 0.08)	0.03+ (-0.02, 0.08)

Note. Data were weighted using HRS individual-level survey weights. Sample sizes presented are the unweighted totals of HRS respondents. The DID model was adjusted for age, gender, marital status, race and ethnicity, religion, educational attainment, wealth quartile, born in the United States, self-reported good health, number of diseases, CES-D depression scores, and year-based fixed effects. Multiple imputation was used for missing values. Standard errors were clustered by state. Estimates are presented as percentage points. CI is the confidence interval.

+*p* < .10. **p* < .05. ***p* < .01. ****p* < .001.

Table 3 reports the DID estimates in stratified samples by race and ethnicity and immigration background. I found no evidence of changes in any ACP outcomes driven by the ACA Medicare benefit expansion among Black, Hispanic, Asian, and Native American older adults. The policy implementation was associated with a 0.05 percentage point increase (95% CI [-0.01, 0.11]) in living will and a 0.06 percentage point increase (95% CI [-0.01, 0.12]) in DPAHC in the older White population. Among U.S.-born older adults, the policy was associated with a 0.07 percentage point (95% CI [0.01, 0.12]) and 0.05 percentage point (95% CI: [-0.01, 0.10]) increase in living will and DPAHC, respectively. No significant policy effects were found among older immigrants.

Table 4 presents the DID estimates in stratified samples by SES indicators of education and wealth. I found no evidence of changes in any ACP outcomes among older adults with lower than a high school degree, those with college or higher than a college degree, or those whose wealth quartile was in the 0 to 75th percentile range. Among older adults with GED education, the ACA Medicare benefit expansion was significantly associated with a 0.09 percentage increase (95% CI [0.01, 0.16]) in living will, a 0.11 percentage point increase (95% CI [0.03, 0.19]) in DPAHC, and a 0.09 percentage increase (95% CI [0.01, 0.17]) in having ACP conversations. Among older adults with a college degree, the policy was associated with a 0.11 percentage point increase (95% CI: [0.02, 0.21]) in completing a living will, but no associations were found with changes in the other two ACP outcomes. ACA Medicare benefit expansion was also associated with a 0.14 percentage point increase (95% CI [0.03, 0.26]) in having DPAHC among older adults who were in debt and a 0.11 percentage point increase (95% CI [0.01, 0.20]) in having ACP discussions among the wealthiest older adults.

Table 3.3: Changes in Advance Care Planning Outcomes Associated with ACA Medicare benefit Expansion on End-of-Life Care Planning (DID Estimates) Stratified by Race and Immigration Background

	Race				Immigration Background	
	Non-Hispanic White (n = 36,858)	Non-Hispanic Black (n = 5,767)	Hispanic (n = 4,025)	Other (n = 890)	U.S.-Born (n = 32,483)	Non-U.S.-Born (n = 4,407)
LW	0.05* (-0.01, 0.11)	0.05 (-0.06, 0.15)	0.07 (-0.02, 0.16)	0.07 (-0.17, 0.30)	0.07** (0.01, 0.12)	0.01 (-0.08, 0.09)
DPAHC	0.06* (-0.01, 0.12)	-0.02 (-0.13, 0.09)	0.06+ (-0.04, 0.16)	0.22+ (-0.03, 0.44)	0.05* (-0.01, 0.10)	0.04 (-0.05, 0.12)
Discussion	0.04 (-0.01, 0.10)	-0.01 (-0.12, .11)	0.05 (-0.05, 0.16)	0.02 (-0.22, 0.26)	0.04 (-0.01, 0.09)	0.01 (-0.08, 0.10)

Note. Data were weighted using HRS individual-level survey weights. Sample sizes presented are the unweighted totals of HRS respondents. DID model was adjusted for age, gender, marital status, race and ethnicity, religion, educational attainment, wealth quartile, born in the United States, self-reported good health, number of diseases, CES-D depression score, and year-based fixed effects. Multiple imputation was used for missing values. Standard errors were clustered by state. Estimates are presented as percentage points; CI is the confidence interval, shown in parentheses. + $p < .10$. * $p < .05$.

Table 3.4: Changes in Advance Care Planning Outcomes Associated with ACA Medicare benefit Expansion on End-of-Life Care Planning (DID Estimates) Stratified by Educational Attainment and Wealth Quartile

	Educational Attainment				Wealth				
	< High School (<i>n</i> = 6,814)	GED (<i>n</i> = 12,955)	Some college (<i>n</i> = 8,401)	College or beyond (<i>n</i> = 8,367)	In debt (<i>n</i> = 3,167)	0–25 (<i>n</i> = 8,571)	25–50 (<i>n</i> = 8,318)	50–75 (<i>n</i> = 8,339)	75–100 (<i>n</i> = 8,142)
LW	0.04 (-0.03, 0.12)	0.09* (0.01, 0.16)	0.11* (0.02, 0.21)	-0.03 (-0.11, 0.06)	0.15 (0.05, 0.25)	0.07+ (-0.01, 0.15)	0.00 (-0.10, 0.10)	-0.01 (-0.11, 0.10)	0.10+ (-0.01, 0.20)
DPAHC	0.07 (-0.02, 0.15)	0.11** (0.03, 0.19)	0.09 (-0.01, 0.19)	-0.05 (-0.15, 0.04)	0.14* (0.03, 0.26)	0.05 (-0.03, 0.13)	0.04 (-0.06, 0.13)	0.04 (-0.06, 0.15)	0.02 (-0.10, 0.13)
Discussion	0.05 (-0.05, 0.15)	0.09* (0.01, 0.17)	0.08 (-0.02, 0.17)	-0.06 (-0.15, 0.03)	0.04 (-0.09, 0.18)	0.04 (-0.05, 0.13)	0.01 (-0.10, 0.11)	0.05 (-0.05, 0.16)	0.11* (0.01, 0.20)

Note. Data were weighted using HRS individual-level survey weights. Sample sizes presented are the unweighted totals of HRS respondents. DID model was adjusted for age, gender, marital status, race and ethnicity, religion, educational attainment, wealth quartile, born in the United States, self-reported good health, number of diseases, CES-D depression score, and year-based fixed effects. Multiple imputation was used for missing values. Standard errors were clustered by state. Estimates are presented as percentage points; CI is the confidence interval, shown in parentheses. +*p* < .10. **p* < .05. ***p* < .01.

ITS Results

Table 3.5 presents the regression results from the simple ITS model with time-variant controls in the total population and stratified by race and ethnicity. Overall, the ITS results provided more detailed insights regarding the positive policy effects among older White participants and nonsignificant results among older minorities identified by the DID models. In the total sample, there was a significant increase in having a living will ($\beta = .10, p < .05$) and DPAHC ($\beta = .12, p < .05$) in the first year of policy implementation (level change). The increases were then followed by slight decreases over time, but those slope changes were not statistically significant.

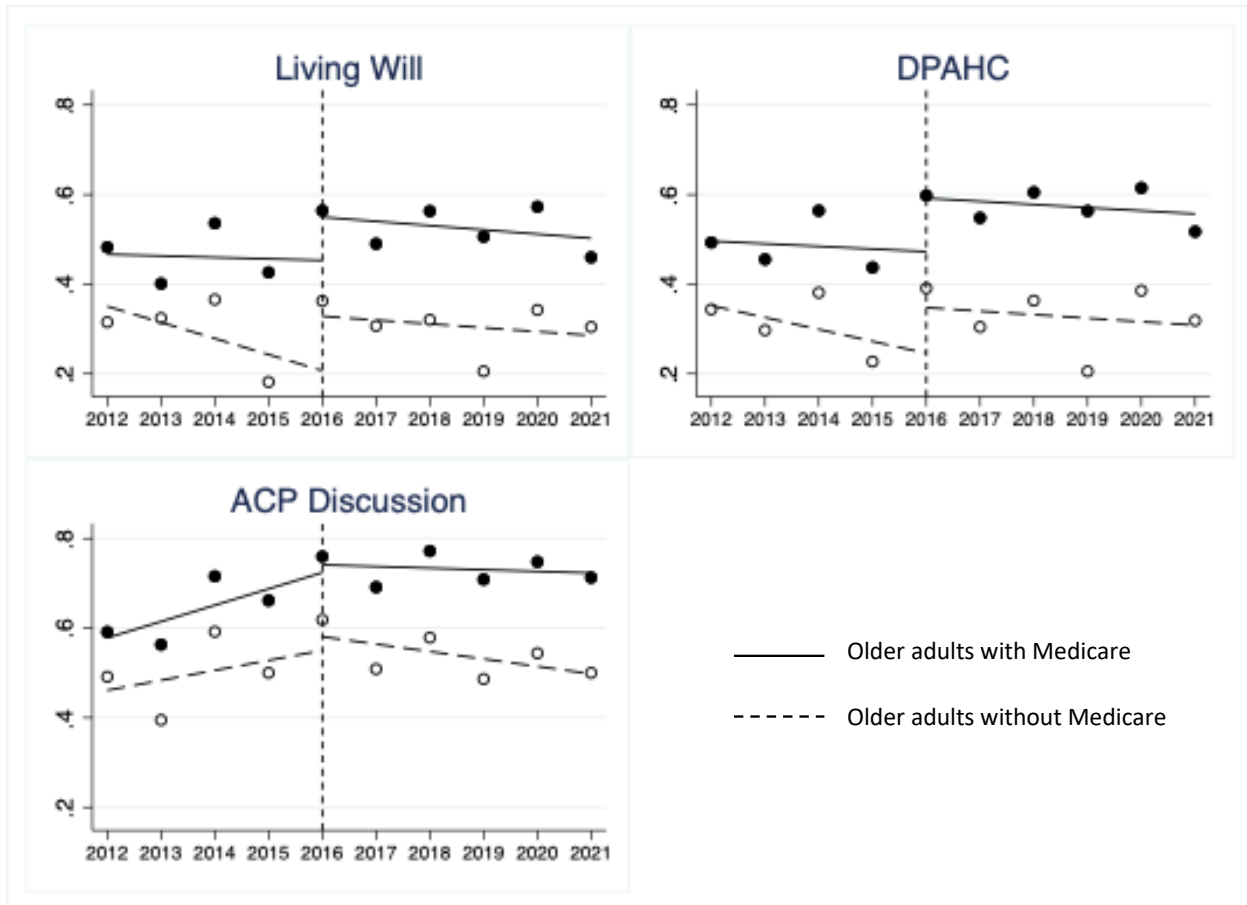
However, analyses in stratified samples revealed that the positive policy immediate effects were only significant for older Whites, but not for Black, Hispanic, or Asian and Native American older adults. On the other hand, the immediate (1-year) level increase in having ACP discussions after the policy implementation was only marginally significant ($\beta = .03, p < .10$), followed by a significant decrease from 2017 to 2020 ($\beta = -.04, p < .05$). The negative slope change was significant among older Whites ($\beta = -.05$) at a .01 level and marginally significant ($p < .10$) among older minorities.

Table 3.5: Results of Simple ITS with Time-Variant Controls ($N = 47,982$)

	Living Will				
	Total	White <i>(n = 36,858)</i>	Black <i>(n = 5,767)</i>	Hispanic <i>(n = 4,025)</i>	Other <i>(n = 890)</i>
Pre-trend	-0.01	-0.00	0.10	0.00	0.08+
Post-trend level change	0.10*	0.10*	0.07+	0.04	-0.13
Post-trend slope change	-0.00	-0.01	-0.01	0.00	-0.09+
	DPAHC				
	Total	White	Black	Hispanic	Other
Pre-trend	-0.01	-0.01	0.02+	0.02+	0.03+
Post-trend level change	0.12*	0.13*	0.04+	0.02	0.02
Post-trend slope change	-0.00	0.01	-0.02+	-0.03*	-0.03
	ACP Discussions				
	Total	White	Black	Hispanic	Other
Pre-trend	0.03+	0.04**	0.04+	0.03+	0.07*
Post-trend level change	0.03+	-0.00	0.03	0.01	-0.10
Post-trend slope change	-0.04*	-0.05**	-0.03+	-0.03+	-0.05+

Note. Data were weighted using HRS individual-level survey weights. The ITS model was adjusted for time-variant controls: age, marital status, wealth quartile, self-reported good health, number of diseases, and CES-D depression scores. Standard errors were clustered by state. Estimates are presented as percentage points. Multiple imputation was used for missing values. + $p < .10$. * $p < .05$. ** $p < .01$.

Figure 3.2: Predicted Segmented Regression Lines from ITS with Comparison Group ($N = 47,982$)



Note. ITS model adjusted for time-variant controls: age, marital status, wealth quartile, self-reported good health, number of diseases, and CES-D depression scores.

Results of the comparative ITS model with controls are visualized in Figure 3.2. The detailed results are included in the Appendix (Table B.2). Prior to the policy implementation, there were significant mean level differences between older adults with and without Medicare; however, differences in the trend slope between the two groups were not significant. This result is aligned with the visual inspection of the DID parallel assumption. After the policy implementation, the mean level differences between the two groups were no longer significant. Moreover, I didn't identify significant differences in slope changes before and after the policy implementation between the treatment and comparison groups.

DISCUSSION

This study is among the first to explore whether the Medicare coverage expansion on end-of-life care planning benefits under ACA was effective among U.S. older adults with diverse backgrounds. Using quasi-experimental designs, the analyses yielded three key findings that may help policy makers improve policies to enhance rates of ACP. First, in the total population, the ACA Medicare benefit expansion policy was associated with a significant increase in the proportion of older adults who completed a living will and designated a DPAHC, but not for having an ACP conversation. Second, although there were immediate positive policy effects, the increase in the ACP outcomes driven by the ACA Medicare benefit expansion didn't persist. Finally, I found no evidence that the ACA Medicare benefit expansion was effective in improving the rates of ACP among Black, Hispanic, Asian, Native American, or non-U.S.-born older adults. I also identified heterogeneous policy effects by SES.

First, I found that the ACA Medicare coverage expansion on end-of-life care planning significantly increased the rates of completing a legal healthcare document—a living will or DPAHC—in the total population. It is encouraging to see the positive impacts of the policy on the documentation of end-of-life care wishes, especially because the current policy doesn't require completion of any ADs at the end of the session for physicians to bill for ACP services (CMS, 2015). Prior to the policy, doctors reported a preference to have “somebody else” initiate discussions about filing AD documents (Pfeil et al., 2015). The results may indicate that the policy has somewhat changed physicians' perceptions of whether a medical professional is responsible for initiating the ACP process. Documenting health care wishes before any medical crisis is critical, because the documents provide health care providers and family members with

guidance on making difficult life decisions for dying patients (Brinkman-Stoppelenburg et al., 2014).

However, the policy was not associated with an increase in rates of discussing end-of-life care preferences with anyone. This result may seem to be confusing, because the policy reimburses physicians who have ACP conversations with their patients. However, it may reflect the more medical-oriented nature of physician–patient end-of-life care discussions, instead of a value-based activity. Physicians may focus more on explaining the health care documents, potential health concerns, and available treatment options, rather than helping patients reflect on their end-of-life values and preferences. Therefore, older adults may feel informed and motivated to file a living will or DPAHC after the conversations, but did not necessarily share their preferences and wishes during or after the discussions.

Second, upon closer look, the identified policy effect was mainly due to immediate effects (level change) rather than sustained effects (slope change), aligned with the hypothesis supported by FCT. Additionally, the rates of ACP outcomes gradually decreased after the initial significant increase, though the changes in trends were not statistically significant regarding the living will and DPAHC outcomes. This may be due to the fact that most hospitals don't provide training, support, and incentives to geriatricians to initiate ACP conversations with patients. As such, doctors may feel unmotivated or unprepared to have those difficult discussions without systematic support. Moreover, this may also be due to the perceived relatively low payment rates for this service. Doctors in a qualitative study stated that the current rate (\$86 to \$103 for a 45-minute conversation depending on the health care setting) is “not very good at all,” in addition to the fact that ACP conversations are time intensive; as such, doctors said they felt less motivated

to provide this new service under the current compensation structure that favors billing as many services as possible (He et al., 2020).

Third, and potentially the most concerning finding, the ACA Medicare benefit for end-of-life care planning only improved ACP outcomes among older U.S.-born Whites and was not effective among older minorities and immigrants. This further increases the well-documented disparities in end-of-life care planning based on race and ethnicity and immigration background that existed prior to the policy implementation. Based on FCT, one potential reason is that the policy didn't address the fundamental cause—the inequality of resources linked to health care behaviors. In this case, although the policy intends to make ACP services available to everyone, older minorities and immigrants may not have timely access to culturally competent doctors with whom they have trusted relationships or adequate knowledge, health literacy, and awareness to engage with doctors on ACP topics. In other words, the policy simply “opened the door” to these benefits for older adults, but it didn't remove the barriers that older minorities and immigrants face on the way to the door.

Alternatively, the ineffectiveness of the ACA Medicare benefit expansion of ACP benefits for older minorities may be due to cultural differences in the understanding of ACP. For example, Hispanic culture traditionally expects family members to make decisions and thus, tends to view ACP, especially documenting ADs, as an irrelevant and unnecessary formal approach, even when older adults are conscious (Carr, 2011, 2012a). Moreover, it is common for a Hispanic family to not disclose a diagnosis and prognosis to older patients because they consider nondisclosure as a way to maintain hope, mental health, and social life (Gonella et al., 2019). Similarly, nondisclosure of diagnosis and avoidance of planning have been observed in Asian and Indigenous cultures, which are more collectivist, family focused, and unaccepting of

unpleasant medical conditions (McLaughlin & Braun, 1998). For example, in Chinese culture, it is considered “sacrilegious, blasphemous, and disrespectful” to talk about death and thus, any planning regarding death is believed to be inappropriate and will hasten death (Cheng et al., 2019; Zou et al., 2013). Black culture is also more family oriented than White people and highly intertwined with religious beliefs. Black people have the highest rate of being conservative Protestants, who strongly believe in God’s control over life and death, and are thus less likely to engage in ACP than other people of other religions (Carr, 2012a; Garrido et al., 2013).

The study also identified heterogeneous policy effects among older adults with different SES backgrounds. The Medicare coverage expansion on end-of-life benefits was most effective among older adults with at least a GED or high school degree, indicating that adopting ACP requires a higher level of knowledge and health literacy (Hemsley et al., 2019), in addition to an insurance-reimbursed free or low-cost opportunity to discuss end-of-life wishes with doctors. Older adults with lower educational attainment may not acknowledge the importance of ACP and thus, didn’t find it necessary to discuss their end-of-life wishes with doctors (Black et al., 2008). For those who took advantage of the service, the extent to which older adults understood and interpreted medical information correctly also depended on their education level (Nouri et al., 2019). The results are aligned with previous findings on the significant role of education and health literacy in medical decision-making (Inoue, 2016).

However, the results regarding how Medicare effects varied by individual wealth were mixed. First, I found that the policy was associated with an increase in the rates of ACP behaviors among the wealthiest participants (75th to 100th percentile). The wealthiest older adults have sufficient resources to engage in ACP without Medicare intervention, such as having a trusted primary doctor (Hong et al., 2018). Moreover, wealthy older adults are more likely to

have opportunities to participate in ACP, such as routine wellness visits and going to hospitals or practitioners with better training on end-of-life care and updated policies (Hemsley et al., 2019). They are also more likely to engage in financial or estate planning given their wealth, which in turn, trigger ACP as a part of the planning process (Koss & Baker, 2018). Stated otherwise, the policy effect was not significant among older adults with relatively low wealth (those in the 0 to 50th percentile range). Although Medicare pays for ACP services, there are hidden costs for older adults to utilize this benefit, such as transportation to a doctor visit and potential out-of-pocket expenses.

Counter to the hypothesis, the poorest group (those in debt) experienced a significant increase in DPAHC appointment that was associated with the ACA Medicare benefit expansion. This may indicate that the policy granted access to ACP services to a group of people who would not have been able to participate in ACP without the policy. Indeed, older adults in the poorest group had the lowest ACP rate across groups before the ACA Medicare benefit expansion, according to these data. However, more research is needed to understand what aspects of the policy are particularly useful to older adults who are in debt, but not older adults with low wealth (0 to 25th percentile).

Limitations

Taken together, the results show that the Medicare expansion had immediate positive policy effects on ACP outcomes, with the most significant effectiveness among U.S.-born White older adults. The analyses do have several limitations, however. First, although the study adopted a quasi-experimental design, I could not ascertain causal effects because the comparison group (older adults without Medicare) was not the ideal counterfactual control unit (to older adults with Medicare). I did conduct robustness checks using coarsened exact matching to see whether the

bias was significant. Also, other confounders might affect older adults' motivation to participate in ACP that I didn't control for due to the nonavailability of those variables, such as family relationships and supports, loss of loved ones in the year of the interview, and characteristics of primary doctors that may highly influence the doctor-patient relationship and quality of conversations. Additionally, due to restricted data availability, I only had data for 5 years before and 5 years after the policy, which may have caused an underestimation of the policy effects, given that it usually takes a longer time to allow health policies to influence human behaviors (Glanz et al., 2015). Statistically, although four time points before the intervention are enough to estimate a baseline trend (St. Clair et al., 2016), 5 years of pre-policy data for the ITS model is not ideal. Research with more years of data should be conducted to establish more accurate estimations.

Policy, Practice, and Research Implications

Despite these limitations, the analyses suggest promising recommendations for health care policy and practice to improve the participation rate in end-of-life care planning and related outcomes. First, the lack of sustained effects of the newly initiated ACA Medicare benefit expansion on ACP services suggests that the treatment embedded in the policy—physician-led end-of-life care planning consultations—needs improvements. Although physicians' role in ACP is irreplaceable, prior research, including the most famous multisite intervention, the Study to Understand Prognoses and Preferences for Outcome and Risks of Treatments, found weak evidence that patient–physician discussion was effective in ACP, patient, or care outcomes (Connors et al., 1995; Scheunemann et al., 2015; Scheunemann et al., 2011). It is time to rethink what kind of behavioral intervention to fund with Medicare insurance. More research is thus

needed on potentially cost-effective interventions that feasibly can be delivered through Medicare.

Second, given that the policy was associated with increased rates of legal form completion but not conversations, it is important for health care providers to encourage older adults to communicate their wishes and decisions with their loved ones. In the context of end-of-life care planning, conversations are more important than forms (Boerner et al., 2020). Lack of communication or miscommunications between family members and older adults may have significant negative impacts on the effectiveness of physician–patient discussions on goal-concordant care. Because the treatment choices made by older adults in a living will only apply to certain specific situations, in clinical settings, physicians often need to follow the decisions of family surrogates, whose decision-making power is legally protected (Sabatino, 2010). Without conversations, only 60% to 68% of designated proxies accurately report the wishes of their older family members (Barrio-Cantalejo et al., 2009; Shin et al., 2015). In practice, toolkits on how to have ACP talks can be developed and distributed to older adults to help them initiate these conversations. Regarding research, studies can explore why the Medicare intervention is more effective in increasing the rate of filing legal documents rather than having conversations—its original goal—to inform policy improvement.

Third, as discussed, the Medicare policy to reimburse physician–patient discussions alone cannot decrease disparities in end-of-life care planning because it doesn't address the resource inequality in access to these services, per FCT. More health care policies are needed to help older minorities and older immigrants find culturally appropriate health care services and maintain stable and trusting relationships with primary care doctors, probably through establishing incentive mechanisms for doctors in underserved communities. Moreover, more funding

opportunities should be provided to educational programs aiming to improve health literacy in long-term and end-of-life care among older adults with disadvantaged backgrounds. Similarly, research on structural barriers faced by older adults with disadvantaged backgrounds and how to mitigate them should be encouraged and funded. The ACA Medicare benefits on end-of-life care planning, together with structural improvements to mitigate inequalities in the ability to access and use ACP services, have great potential to improve the participation rate among older minorities and immigrants and ultimately, remedy injustices in the end-of-life care field.

Chapter 4: To Tell or Not: Chinese Older Chinese Adults'

Preferences for Disclosing or Concealing Serious Illness Diagnoses¹

INTRODUCTION

End-of-life care in most western nations prioritizes patient autonomy in decision-making, such that patients are informed of their illness diagnosis, and make informed decisions regarding their medical care, either autonomously or in consultation with family members and health care professionals (Institute of Medicine, 2014). While autonomous or delegated decision-making is a widely accepted concept in most Western countries, the right to be informed of one's diagnosis by a physician is not protected by law in most Asian countries including China (Jimenez et al., 2018). China is home to the largest and most rapidly growing population of older adults in the world (Shen, 2021). Alongside population aging comes the challenge of providing respectful medical care to patients at the end of life, most of whom are suffering from chronic illnesses including cancer, heart disease, and Alzheimer's disease and related dementias (Zhou, 2016). A critical first step towards attaining a "good death" and receiving care concordant with one's wishes is a knowledge of one's health diagnosis and prognosis. An understanding of the likely course of one's symptoms and the efficacy of different treatment options is critical for forming and articulating one's treatment preferences.

However, in China, physician disclosure of a patient's illness diagnosis, especially in the case of serious illness like cancer, is not guaranteed (Liao et al., 2019). In the absence of a legal

¹ A revised version of this paper has been published with coauthors Dr. Jinyu Liu and Dr. Deborah Carr. I am the leading author. I designed the study, conducted statistical analyses, and wrote the manuscript. Dr. Liu and Dr. Carr supervised the design and analyses and reviewed and edited the manuscripts. Reference for the publication is: Lou, Y., Liu, J., & Carr, D. (2022). To Tell or Not: Chinese Older Adults' Preferences for Disclosing or Concealing Serious Illness Diagnoses. *The Gerontologist*.

mandate for patient's informed consent, doctors typically inform family members of the patient's diagnosis and prognosis, and then let family members decide among themselves whether to inform the patient (Xing et al., 2017). If a Chinese older adult reaches a critical period in which a major medical decision is required, the decision typically falls to their family members, who may be unaware of the patient's preferences for or against life-sustaining treatments (Liao et al., 2019). The withholding of information from patients occurs even among those who are cognitively capable of understanding their diagnosis and making appropriate health-care decisions. Concealing a diagnosis from a patient deprives them of autonomous decision-making and informed consent, and may render them vulnerable to care that is inconsistent with their wishes and potential family conflicts regarding the desired course of care (Lai et al., 2016).

While many health care professionals in China report that they are uncomfortable concealing diagnostic information from their ill patients, this practice remains common (Stocklassa et al., 2021). Providers reference death taboo and the desire to obtain family consent first as reasons for not informing patients directly (Zeng et al., 2011). These practices are generally welcomed by the patient's family members, who tend to prefer nondisclosure and believe that concealing a diagnosis is a way to protect the patient's optimism and psychological well-being (Zheng et al., 2015). Surprisingly little is known about the preferences of patients themselves, however. Do they prefer to be informed of their diagnosis, do these preferences vary based on what their diagnosis is, and do they hold the same preferences for self versus a significant other with terminal illness?

This paper aims to address these gaps. We use data from a sample of community-dwelling midlife and older adults in Shanghai, to document: (1) preferences regarding to whom doctors should disclose a serious illness diagnosis (i.e., patient, family, both); (2) the desire to be

informed of one's own diagnosis in the case of early versus late-stage cancer; and (3) the belief that significant others (i.e., spouse, parents) should be informed of their own diagnosis in the case of early- versus late-stage cancer. We use LCA to identify profiles of preferences regarding disclosure, and document the sociodemographic factors, health care experiences, and religious and cultural beliefs associated with preferences for disclosure versus concealment of one's own and others' diagnoses. Documenting the levels and correlates attitudes regarding disclosure will be critical for refining health care policy and practice to meet the needs of contemporary cohorts of aging adults. Changes in cultural attitudes may necessitate structural changes that facilitate the disclosure of serious illness to those patients who desire the information (Riley et al., 2004).

LITERATURE REVIEW

Diagnosis Disclosure in China

In mainland China, no laws or policies currently require doctors to inform patients of their diagnoses, undermining the patient's capacity for informed and autonomous consent (Zhu et al., 2020). Across recent studies, only 3.8% to 10 % of terminally ill patients in China were informed by physicians of their diagnosis or illness prognosis (Stocklassa et al., 2021). Despite the potential harm to patient well-being of concealing diagnoses, the practice persists in part because health care providers and family members view this concealment as a benevolent act that is consistent with values of filial piety, Confucianism, and familism (Zeng et al., 2009).

Family members are informed of the patient's diagnosis and prognosis, and are thus charged with decision of whether to disclose. They also are entrusted with making medical decisions for the patient. Complex decisions regarding treatment are viewed as the domain of the entire family, with core family members including spouse or adult children typically informed first and taking the lead in medical decisions (Zhou & Zeng, 2009). Studies of doctors and nurses

in China find that nearly 20 percent report that even if patients clearly indicate their willingness to know the truth, they would still conceal the diagnosis in “good faith” to try to “maintain dying patients’ hopes in the death-denying cultural context” if the family prefers nondisclosure (Dong et al., 2016; Zeng et al., 2011).

These pervasive practices intended to “protect” the dying patient may undermine their autonomy and ultimately lead to treatments that are discordant with the patient’s wishes. Yet little is known about whether, for which illnesses, and from whom Chinese older adults want to be informed about their illness diagnoses. Emerging evidence suggests a contemporary shift in preferences, such that most older patients in China want to be informed by their doctors about their diagnosis and prognosis (Stocklassa et al., 2021). For example, a study of 150 hospitalized cancer patient-caregiver dyads reveals that while less than one-fifth (18.7%) of family members believe that patients should know the truth of their own diagnosis, nearly all the patients (98%) say they would like to be informed of their condition (Li et al., 2012). However, to our knowledge, research is limited to patients with particular illnesses like cancer, or who are at the end of life (e.g. Huang et al., 2018; Li et al., 2012). Illness disclosure may be too little, too late for patients at this advanced disease stage (Makaroun et al., 2018). Documenting the preferences of relatively healthy, community-dwelling midlife and older adults is essential for establishing a foundation for productive conversations regarding end-of-life preparations and decisions (Inoue, 2016).

Theoretical Frameworks on Information-Seeking and Avoidance

The benefits of being informed of one’s diagnosis and prognosis are well documented; this knowledge is critical for patient autonomy and receipt of care that is concordant with one’s preferences (see Hancock et al., 2007 for a review). Despite these benefits, individuals may wish

to be spared of this potentially disturbing information, especially in stressful contexts like managing chronic illness (Sweeny et al., 2010). A patient's desire for or against diagnosis disclosure is not merely an individual matter, however; preferences are formed, articulated and shared within social and relational contexts, according to the Theory of Motivated Information-Management (TMIM). TMIM emphasizes the relational nature of communicating stressful and uncertain information, such as illness diagnoses (Afifi & Weiner, 2004). Information seekers (and providers) are considered both subjects and objects who interpret, evaluate, and decide whether to seek (or disclose) the information based on "each other's perspectives both toward self and toward other" (Bochner, 1989). Meta-analyses have confirmed the mutually influential impacts of seekers and providers, consistent with core themes of TMIM (see Kuang & Wilson, 2021 for a review).

TMIM's emphasis on the relational context of information exchange provides a framework for understanding the disclosure or concealment of serious illness diagnoses in China, where the concept of self is relational and people are expected to make personal decisions cooperatively with family members (Stocklassa et al., 2021). Family members act as both information seekers from doctors and information providers to the patients. Chinese families are expected to play a more central role in decision-making process than patients themselves, and thus make difficult decisions about whether to disclose the physician's diagnosis to the patient (Tang, 2019).

According to TMIM, an individual patient's preferences for learning one's own diagnosis are affected by individual-level factors like a desire for autonomy, as well as one's assessment of how they will manage the news and how much anxiety they will experience. Similarly, family members' preferences for concealing (versus sharing) the patient's diagnosis reflect their

assessment of the patient's capacity to cope with the news, as well as their perceptions of their own capacity to provide emotional or instrumental support after the patient receives the diagnosis (Afifi et al., 2006).

Past studies have focused exclusively on patient preferences alone or family member preferences alone, treating each set of preferences as independent processes. However, TMIM underscores the interactive and mutually influential nature of preferences; this may especially be the case in China, where decision-making across a broad range of domains takes place within the family context. Further, research to date reveals an important yet unexplored paradox; studies of patients reveal their desire to know their diagnosis (Li et al., 2012), whereas studies of family members reveal their tendency to conceal diagnosis from patients (Zhou & Zeng, 2009). Family members who conceal may someday be patients themselves who desire yet do not receive diagnosis information. Likewise, patients who desire their own diagnoses may someday be informed by a doctor of their loved one's diagnosis, prior to this information being divulged to the loved one. Thus, an important yet under-researched topic is whether individuals hold coherent versus divergent preferences for disclosure (or concealment) of their own versus a family member's diagnosis. Divergent preferences for disclosure of own versus a family member's diagnosis may be a function of underlying desire to protect loved ones. Chinese adults may wish to know their own diagnosis in an effort to spare family members from the difficulty of making decisions about their care. At the same time, individuals may prefer to conceal family members' diagnoses them, in the spirit of protecting them from the potentially distressing information.

Identifying similarities or differences in preferences for disclosing one's own versus a significant other's diagnosis will be important for practitioners to understand one's underlying

end-of-life values. Thus, our first analytic goal is to document complex subtypes of disclosure preferences, which incorporate attitudes toward disclosure of own, spouse, and parents' condition, as well as preferences regarding the order in which the physician's disclosure of this information should take place (inform patient first, family first, both at same time).

Factors Influencing Preferences of Diagnosis Disclosure

Our second goal is to identify psychosocial, demographic, and health factors that may affect one's attitudes towards the disclosure of own versus other's diagnoses. Given the relational nature of disclosure, especially in the Chinese health care context, we expect that familism will be an important correlate of disclosure preferences. Familism emphasizes one's devotion and loyalty to family and kin, and is considered a foundational attribute of China's collectivist culture (Benson, 1954; Kim, 2010). These values emphasize that the family is a source of protection, in which family members should help, support, and protect each other when facing difficulties (Zheng et al., 2020). Endorsement of familism beliefs may be highly relevant to disclosure preferences because medical decision-making is considered a family-level rather than individual-level process in China, where family harmony and interdependence are prioritized over individual autonomy (Choi & O'Brien, 2019).

As such, we expect that Chinese older adults who agree strongly with the principles of familism may prefer that family rather than patient are informed first of the patient's diagnosis, and may prefer to conceal this diagnosis from the patient. Concealing the illness diagnosis may be seen as a way to protect older patients from potentially distressing news, and also spares the patient of difficult decision-making and care arrangements— tasks that may be seen as best borne by family members (Kwak & Salmon, 2007). It is less clear how familism will bear on one's preferences for disclosure versus concealment of one's own diagnosis. On one hand, patients

with strong adherence to familism beliefs may prefer not to know their diagnosis, trusting that their family members will make decisions that align with the best interests of the patient and the family. Conversely, strong adherence to familism beliefs may be associated with a greater desire to learn one's diagnosis, in an effort to spare loved one's of managing this potentially distressing information and related care decisions.

Sociodemographic factors also may be associated with preference for disclosure versus concealment. In general, younger age, higher levels of educational attainment, and adherence to a secular (rather than religious) world view are associated with behaviors and values that are more modern and individualistic, rather than more traditional and familistic. As such, we control for age, educational attainment, and religion as these factors may affect one's preferences for or against disclosure (Arora et al., 2007; McCloud et al., 2013; Vrinten et al., 2014). We control further for marital status and sex given that being married and female is founded to be associated with better coping ability and desire to seek information illness (Sweeny et al., 2010). Exposure to health care encounters also may affect one's desire for transparency or concealment subjects (Chae et al., 2020; Hou et al., 2019); we expect that persons who have direct knowledge of or experience with health care, such as hospitalization or making medical decisions for family members, would have a greater desire for information about own and family members' diagnoses. Thus, we control for self-rated health, insurance status, experiences of hospitalization, and experiences with medical decision making.

The Current Study

In sum, this study examines Chinese older adults' attitudes towards and preferences for physician disclosure of illness diagnoses. We have two specific goals: (1) to document subtypes of preferences regarding whether, to whom, and for which diseases doctors disclose older

patients' illness diagnoses; and (2) to identify the sociodemographic, health, and cultural correlates of each preference type. The results of the study can inform health care policy and practice, especially with respect to honoring patients' autonomy and engagement in long-term care and treatment decision-making at the end of life in China, and other culturally similar contexts.

METHOD

Sample

We conducted a survey of community-dwelling adults aged 50 and older in Shanghai, China from September 2021 to January 2022. Shanghai was selected as the study site because it is considered one of the most “westernized” cities in China and has a highly developed hospice system (Lu et al., 2018). As such, older adults in Shanghai are likely to feel comfortable discussing a sensitive topic like terminal illness disclosure. Participants were recruited with study flyers posted on WeChat groups widely used by older adults (e.g. older adult computer learning groups, dance groups, or groups for participants in senior centers). WeChat is a Chinese multi-purpose instant messaging, social media, and mobile payment app with over 1 billion monthly active users (Wang et al., 2020).

Participants were invited to complete a 15 to 20 minutes online survey assessing their attitudes towards health concerns including preferences for diagnosis disclosure in the case of serious illness. The survey also includes an open-ended question for older adults to submit their additional thoughts of the topic. For participants who didn't have access to the Internet or were not able to complete an online survey independently due to health limitations (e.g., vision problems) or technology issues (n=69), the first author administered the survey by telephone in Shanghainese or Mandarin per participants' preferences. All questions are closed-ended with an

additional response option of “I don’t know/refuse to answer.” All participants who completed the survey were mailed either an umbrella or a set of soaps as gifts (at approximately \$5/25RMB value). When the first author contacted each participant to confirm the mailing address for the gifts, she further encouraged them to refer their peers to the survey. The data collection protocol was approved by the University’s Institutional Review Board (protocol #AAAS3968).

A total of 1,176 people indicated interest in the survey and clicked the survey link. Of these, 712 passed the screening questions (age older than 50 and Shanghai residence), signed the consent form, and started to answer questions. Nearly one-third ($n = 212$) of respondents dropped out in the middle of the survey, perhaps due to the sensitivity of the survey topics. Our analytic sample includes 571 respondents who answered all questions in the survey sections relevant to our analysis (sociodemographic characteristics, health, and diagnosis disclosure). Our analytic sample is limited to middle-aged persons ages 50 to 65 for three reasons: they are relatively healthy and few have immediate concerns about their own serious chronic illness; their cohort is likely to benefit from potential policy changes in China regarding physician disclosure of illness; and they are likely to serve as medical decision-makers for their aged parents now confronting their own serious illnesses.

Measures

Illness Diagnosis Disclosure Preferences

Our focal measures capture preferences for whether, to whom, and under what health conditions they would want their own diagnosis disclosed versus concealed. We also consider attitudes towards informing a spouse or parent of their own major health diagnosis. These items form the basis of our latent class analyses, in which we identify subtypes of preferences based on one’s responses to seven preference questions.

Respondents are first asked a general question regarding to whom their doctor should disclose their health diagnosis: “In general, who should know your diagnosis and conditions of critical illness from your doctor?” where response options are (1) only me; (2) only me first and I will decide whether my doctor should tell my family; (3) both me and my family; (4) only my family; and (5) only my family first, and they can decide whether my doctor should tell me. We recoded these five response categories into three broader categories capturing one’s general preferences for disclosure: (1) doctor should tell me first; (2) doctor should tell me and my family members at the same time; and (3) doctor should tell my family members first.

Respondents also were asked about their preferences for being informed of their own diagnosis of cancer, and their beliefs that their significant others should be informed should they receive a cancer diagnosis themselves. The desire to know one’s *own* diagnosis was assessed with the question “If one day I have early-/late-stage cancer, I don’t want to know the diagnosis.” Response options are (1) yes, I want to know and (2) no, I don’t want to know. Preferences for informing their significant others of their own cancer diagnosis were assessed with the items: “If your parents were diagnosed with early-/late-stage cancer, would you inform them of the diagnosis? If you have experienced this situation, select the choice you made.” and “If your spouse were diagnosed with early-/late-stage cancer, would you inform them of their diagnosis? If you actually experienced this situation, select the choice you made.” Response categories are (1) yes, I will inform then and (2) no, I will hide the diagnosis. We focus on cancer diagnoses because cancer is widely perceived by Chinese persons to be an incurable life-limiting disease (Yeo et al., 2005). Our preliminary data also support this assumption; 76 percent of respondents said “no, I will only hide cancer diagnosis” when answering the question “Thinking about other

diagnoses (e.g. Alzheimer's, renal, heart, liver, respiratory diseases, or other diseases), are there any diagnosis that you would be hesitate to inform your loved ones like a cancer diagnosis?"

Covariates

In our multivariate analyses, we seek to identify the sociodemographic, health, and cultural factors associated with particular preference profiles. Demographic variables include age (1 = 50-59 [reference group], 2 = 60-69, and 3 = 70 and older), gender (1 = female, 0 = male), marital status (1 = being married, 0 = widowed, divorced, or never married), religion (1 = Buddhist, 2 = other religion, 3 = no religion [reference group]), and total number of children. SES characteristics include highest educational degree (1 = no formal education [reference group]; 2 = high school degree; 3 = some college); monthly personal income (1 = <3000 RMB [reference group], 2 = 30001-5000 RMB, 3 = 5000 or above RMB), and health insurance type (1 = government [reference group], 2 = urban employee or resident, 3 = new cooperative/rural resident). We did not include an indicator of one's household registration status because only 29 respondents were rural HuKou, which would not enable adequately powered analyses.

Health characteristics include self-reported health (1 = very good or good, 0 = fair, poor, or very poor) and total number of current chronic illnesses (including hypertension, diabetes, stroke, heart diseases, kidney problems, obstructive airway disease, liver disease, cancer, or other). Direct experiences with illness refer to whether one has ever been hospitalized and whether one has experience of making medical decisions for family members. Respondents were asked "Have you been hospitalized?" and "Do you have any experience making medical decisions (e.g., medication, surgery, chemotherapy, etc.) for your family members?"

We measure cultural values with a 16-item scale capturing familism ($\alpha = 0.81$), a construct capturing one's tendency to put the needs of one's family above the needs of an

individual (Bardis, 1959). Factor analyses indicate that the scale contains two main factors: nuclear family integration (10 items) and extended family integration (Blair, 1972). The scale includes items such as “the family should have the right to control the behavior of each of its members completely” and “the family should consult close relatives concerning its major decisions.” Each item was scored on a 5-point Likert scale (from 0 = *strongly disagree* to 4 = *strongly agree*); responses were summed up and scores range from 0 to 64. A higher score reflects stronger familism beliefs. The scale has been validated in Chinese population in Hong Kong (Yeung & Fung, 2007).

Analytic Plan

We first carried out LCA to identify distinctive types of preferences for disease disclosure based on the seven indicators described above. LCA is a model-based clustering method for determining underlying classes of subjects, using maximum likelihood estimation (Nylund et al., 2007). We fitted models with two to five latent classes, and selected the optimal one based on model fit and interpretability of the latent classes. Model fits statistics included AIC, BIC, entropy, and *p*-value for Vuong-Lo-Mendeall-Rubin Likelihood Ratio test for models with *k* classes versus *k*-1 class (Nylund et al., 2007). Larger decreases in either AIC or BIC between two models indicate stronger evidence for improved model fit (Anderson & Burnham, 2004) and higher entropy reflects better classification quality (Celeux & Soromenho, 1996).

After identifying and constructing the latent classes, we contrast the personal characteristics of members of the subgroups. We use Chi-squared tests and ANOVA to identify statistically significant differences in the covariates across the classes. We then estimate multinomial logistic regression to isolate the distinctive effects of demographic, SES, health conditions and experiences, and cultural predictors on the odds of belonging to a particular latent

class. Two missing cases (answered “refuse to answer/I don’t know”) across all the predictors in regression analysis were addressed by listwise deletion. Data preparation, bivariate analyses, and regression models were conducted in STATA 17.0 and LCA were done in MPLUS 8.7.

RESULTS

Table 4.1: Means (and Standard Deviations) or Proportions, All Measures Used in Analysis (N=571)

	Percentage/ Mean (SD)
Demographics	
Age	
50 - 59	47.29
60 - 69	34.85
70 and older	17.86
Female	69.70
Married	87.22
Religion	
None	56.92
Buddhist	18.04
Other	25.04
Total number of children (range: 0 – 4)	1.16 (0.53)
Socioeconomic status (SES)	
Highest educational degree	
No formal education	25.86
High school	27.43
Some college	46.71
Monthly personal income	
<= 3000 RMB	16.64
3001 – 5000 RMB	31.00
> 5000 RMB	52.36
Insurance type	
Government medical insurance	18.91
Urban employee or resident insurance	56.04
New Cooperative / other insurance	25.04
Health conditions and experiences	
Self-reported health is good/very good	55.17
Number of chronic illnesses (range: 0 – 5)	0.93 (0.92)
Ever hospitalized	27.07
Any experience making medical decisions for family members	60.63
Culture	
Familism (range: 11 – 64)	43.85 (6.43)

Table 4.1 (Continued): Means (and Standard Deviations) or Proportions, All Measures Used in Analysis (N=571)

	Percentage/ Mean (SD)
Preferences on Informing Significant Others of Their Diagnoses	
Won't/hadn't disclose diagnosis to parents if they have early-stage cancer	57.97
Won't/hadn't disclose diagnosis to parents if they have late-stage cancer.	64.62
Won't/hadn't disclose diagnosis to spouse if he/she has early-stage cancer	42.86
Won't/hadn't disclose diagnosis to spouse if he/she has late-stage cancer	51.33
Preferences for Disclosure Regarding Own Diagnosis	
If one day I have early-stage cancer, I don't want to know the diagnosis	18.07
If one day I have late-stage cancer, I don't want to know the diagnosis.	22.99
In general, who should know your diagnosis and conditions of critical illness from your doctor in the first place? (%)	
Only me : I will decide whether my doctor should tell my family.	56.02
Both me and my family	31.93
Only my family: they can decide whether my doctor should tell me the truth.	12.04

Descriptive statistics for all measures used in the analysis are presented in Table 4.1.

Most sample members prefer that their doctors tell them first that they have a critical illness (56 percent), while one-third prefer that they and their family are informed together (32%) and just 12 percent prefer that their family is informed first. A minority of respondents say they do not want to be informed of their own diagnosis should they have early-stage (18 percent) or late-stage (23 percent) cancer. However, respondents report dramatically higher levels of reluctance to inform their parents or spouse of their cancer diagnoses, with greater reluctance in the late-versus early-stage scenario. More than half (58 percent) say they would not inform their parent if the parent had an early-stage cancer diagnosis, and fully 65 percent would not disclose in the case of late-stage cancer. Similar, albeit less dramatic, patterns are observed for spousal diagnoses, with 43 percent preferring not to tell their spouse they have early-stage cancer, and 51 percent preferring to conceal their spouse's diagnosis of late-stage cancer.

Latent Class Model Results

Table 4.2 shows the model fit statistics of LCA with two to five classes. Larger decreases in either AIC or BIC between two models indicate stronger evidence for improved model fit and higher entropy reflects better classification quality (Anderson & Burnham, 2004). The three-class model is optimal, as the decrease in AIC and BIC from three-class to two-class models ($\Delta AIC = 209.63$, $\Delta BIC = 170.50$) is more substantial than the decrease from the four- to three-class ($\Delta AIC = 121.47$, $\Delta BIC = 82.34$) or five- to four-class ($\Delta AIC = 38.91$, $\Delta BIC = 0.15$) models. The three-class model also has the best separation of classes and classification quality according to its highest entropy.

Table 4.2: Comparison of latent class analysis models with two to six classes (N = 571)

Number of classes	<i>df</i>	AIC	BIC	Entropy	P-value for VUONG-LO-MENDELLETTI LIKELIHOOD RATIO TEST
2	17	4267.078	4340.983	0.865	0.000
3	26	4057.448	4170.480	0.909	0.000
4	35	3935.983	4088.142	0.891	0.000
5	44	3897.077	4088.293	0.905	0.001

Note: AIC = Akaike’s Information Criterion; BIC = Bayesian Informal Criterion. Text in bold indicates the selected latent class model.

We selected the three-class model also due to its superior accuracy and interpretability of the classification; *mcaP* is the relative size of the class assignment, and the differences between *mcaP* and model estimated proportions for the sizes of any given class (third row in the Table 4.3), if any, reflect the classification error (Nylund-Gibson et al., 2022). *AvePP* reflects the proportion of respondents in each class that is classified correctly, with a value of 1 indicating most accurate classification and a threshold of 0.7 for adequate classification precision (Nagin, 2005). *OCC* describes the odds of model estimated class assignment relative to random assignment by class proportion. A higher *OCC* indicates better classification accuracy with a minimum threshold of 5 (Nagin, 2005). Shown in Table 3, our three-class solution has minimal classification error based on the nearly zero differences between *mcaP* and class proportions as

well as great classification accuracy given its high AvePP (> 0.7 ; ranges from 0.96 to 0.97) and OCC (> 5 ; ranges from 32.22 to 126) of each class.

Table 4.3 also reports item-response probabilities and defining characteristics of each of the three classes. Item-response probability is the estimated likelihood of endorsing each item among persons in each class (See Figure 4.1 for a graphic representation of item-response probabilities). The first class, labelled “Transparent,” accounts for one-third of the sample (34%). Persons in this category believed that diagnoses should be disclosed to the patient, with similar preferences for one’s own and significant others’ diagnoses. The probabilities of persons in the “transparent” category preferring to conceal significant others’ diagnoses from them ranged from 1% (spouse with early-stage cancer) to 7% (parents with early/late-stage cancer), whereas the probability of wanting to avoid knowing their own early- and late-stage cancer diagnoses were 4% and 3%, respectively. By contrast, “transparent” persons had a high likelihood (57% of probability) of wanting their doctor to tell them first of their illness and allowing them to decide whether to share with their family. Just 1% preferred that the doctors tell only their family first.

The second class, which we label “Contradictory,” is the most common preference type and accounts for half the sample (50.22%). Persons in this category prefer to be informed of their own illness, yet prefer to conceal such a diagnosis from their significant others who may be ill. Specifically, persons in this group were very likely to endorse concealing their parents’ (0.82 and 0.94 of probabilities for early- and late-stage cancer, respectively) or spouses’ (0.51 and 0.71 of chances for early- and late-stage cancer) diagnoses from them, but they did not want to be shielded from their own diagnoses (probabilities = 0.02 and 0.15 for early- and late-stage cancer). They also were very likely to prefer that their doctor tell them of their illness (.61), and

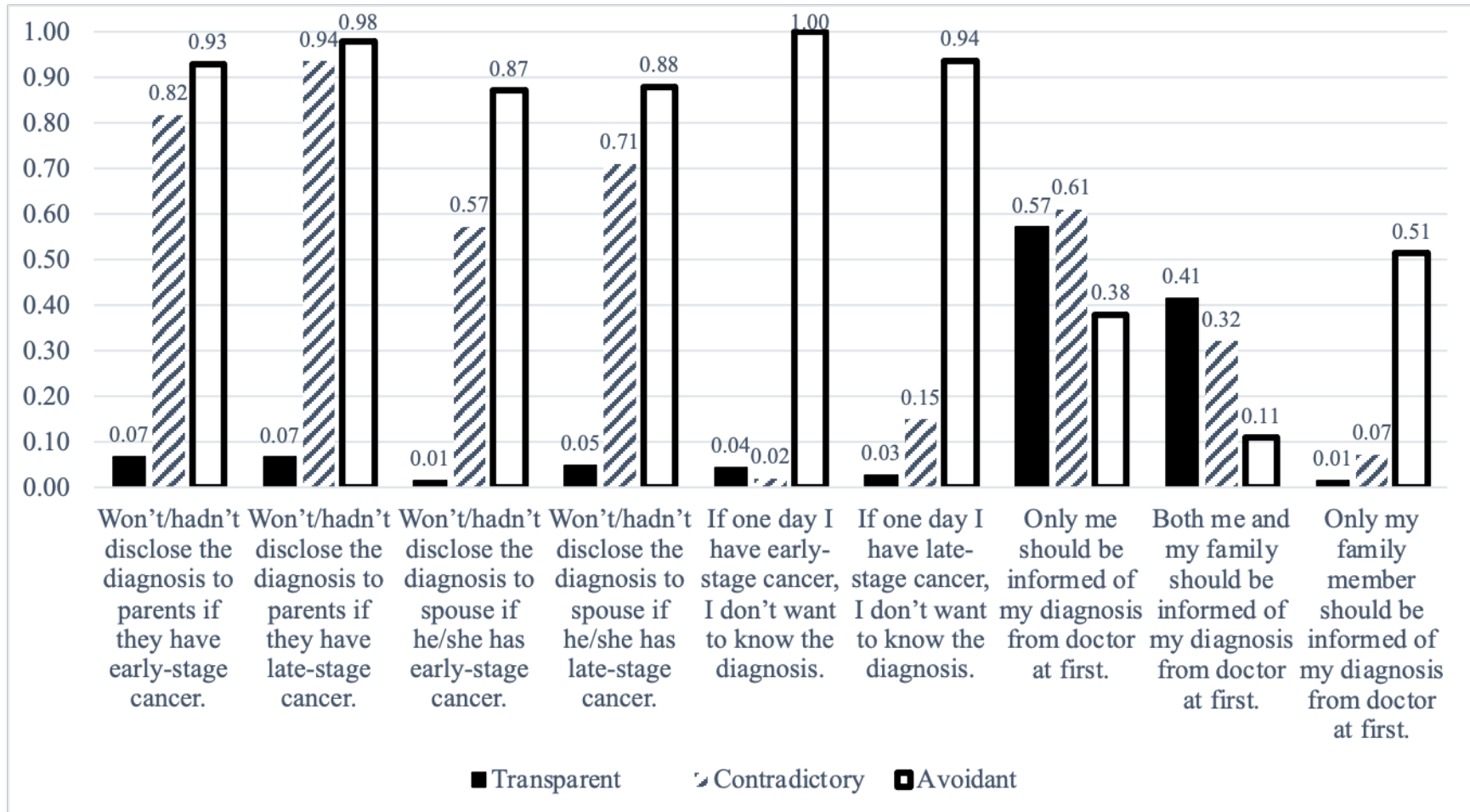
were less likely to prefer that doctors inform both self and family (.32) and dramatically less likely to believe that their family only should be informed (0.07).

The smallest group, accounting for just 16 percent of the sample, includes persons who are “avoidant” in their preferences. Persons in this category prefer not to know their own diagnosis, and similarly prefer that their family members are shielded from receiving their own cancer diagnoses. All preferred to not know their own late-stage cancer diagnosis, and a slightly lower fraction preferred not to be informed of their early-stage diagnosis (.94). Likewise, nearly all persons in this category prefer that their parents be shielded from their own late- and early-stage cancer diagnoses (.98 and .93, respectively), with only slightly lower probabilities regarding their spouse’s diagnoses (.88 and .87, respectively). More than half preferred that doctors share their illness diagnosis with family first (.53), a preference held by less than 10 percent of persons in the other two classes.

Table 4.3: Three-class Model of Preferences for Disclosure of Critical Illness Among Older Adults in China (N=571)

Variable	C1: Transparent	C2: Contradictory	C3: Avoidant
<i>Model Classification Proportions and Accuracy</i>			
Latent class prevalence (Counts)	34.50% (197)	50.09% (286)	15.41% (88)
Modal Class Assignment Proportion (mcaP)	0.34	0.50	0.16
Average Posterior Probabilities (AvePP)	0.96	0.97	0.96
Odds of Correct Classification (OCC)	46.59	32.33	126
<i>Item-response probabilities</i>			
Won't/hadn't disclose diagnosis to parents if they have early-stage cancer.	0.07	0.82	0.93
Won't/hadn't disclose diagnosis to parents if they have late-stage cancer.	0.07	0.94	0.98
Won't/hadn't disclose diagnosis to spouse if he/she has early-stage cancer.	0.01	0.57	0.87
Won't/hadn't disclose diagnosis to spouse if he/she has late-stage cancer.	0.05	0.71	0.88
If one day I have early-stage cancer, I don't want to know the diagnosis.	0.04	0.02	1.00
If one day I have late-stage cancer, I don't want to know the diagnosis.	0.03	0.15	0.94
In general, who should know your diagnosis and conditions of critical illness from your doctor at the first place?			
Doctor should tell me first.	0.57	0.61	0.38
Both me and my family.	0.41	0.32	0.11
Doctor should tell my family members first	0.01	0.07	0.51
<i>Defining characteristics</i>	Prefers control over disclosing own diagnosis and respects significant others' rights to know their own diagnoses.	Holds contradictory attitudes toward diagnosis disclosure. Prefers to know own diagnosis but would not disclose significant others' diagnoses to them.	Prefers to conceal information from patient. Wants to delegate control over own diagnosis to family members, and conceal family members from their own diagnoses.

Figure 4.1: Item Response Probabilities of Three-class Model of Preferences on Diagnosis Disclosure of Critical Illness Among Older Adults in China



Correlates of Latent Class Membership

Bivariate Results

Table 4.4 presents and contrasts descriptive statistics of sociodemographic, health, and cultural factors for each of the three classes. Table 4.4 shows that respondents in the “transparent” category were more likely to have no religious affiliation, higher levels of post-high school education, and higher monthly income relative to persons in the “contradictory” or “avoidant” groups. However, they also reported significantly more health problems, a higher rate of hospitalizations, and greater involvement in making medical decisions. We found no differences across the three categories regarding age, gender, marital status, number of children, insurance type, self-reported health, and familism values.

Multinomial Results

Table 4.5 shows the fully adjusted associations between the study covariates and preference group membership. As with the bivariate analyses, we found little evidence of sociodemographic differences, with no significant effects for age, sex, marital status, education, income, or insurance type. However, we did find that cultural factors, like religious denomination and familism beliefs, and direct experience with health care (measured as hospitalizations) are robust predictors. Persons belonging to a religious denomination other than Buddhism are roughly twice as likely as those with no religion to be avoidant ($RRR = 2.25, p < .01$). Higher levels of familism increase the odds that one holds contradictory views ($RRR = 1.03, p < .05$). Persons who have direct experience making medical decisions for family members have reduced odds of being in the contradictory class ($RRR = 0.47, p < 0.001$) and marginally lower odds of being in the avoidant class ($RRR = .59, p < .10$). Persons who have been hospitalized also have lower odds of being in the avoidant category ($RRR = .48, p < .05$).

Stated otherwise, persons with direct experience with own or others' health care are more likely to be in the reference category of "transparent."

Table 4.4: Means (and Standard Deviations) and Proportions, by Latent Class Group (N = 571)

	C1: Transparent	C2: Contradictory	C3: Avoidant
Demographics			
Age			
50 - 59	46.7	48.6	44.32
60 - 69	35.53	32.87	39.77
70 and older	17.77	18.53	15.91
Female	67.51	71.68	68.18
Married	86.29	87.06	89.77
Religion ^b			
None ^b	63.96	55.94	44.32
Buddhist	14.72	19.58	20.45
Other ^{b, c}	21.32	24.48	35.23
Total number of children (range: 0 – 4)	1.19 (0.57)	1.12 (0.46)	1.22 (0.62)
Socioeconomic Status (SES)			
Highest educational degree ^{a, b}			
No formal education	23.35	22.73	22.73
High school ^{a, b}	19.8	30.77	37.5
Some college ^{a, b}	56.85	46.5	39.77
Monthly personal income ^a			
<= 3000 RMB	16.24	15.38	21.59
3001 – 5000 RMB ^a	22.34	37.06	30.68
> 5000 RMB ^{a, b}	61.42	47.55	47.73
Insurance type			
Government medical insurance	18.78	18.18	21.59
Urban employee or resident insurance	55.33	58.04	51.14
New Cooperative / other insurance	25.89	23.78	27.27
Health conditions and experiences			
Self-reported health: very good/good	53.30	55.24	59.09
Number of chronic illness (range: 0-5) ^{b, c}	0.98 (1.02)	0.95 (0.89)	0.72 (0.74)
Ever hospitalized ^b	32.82	25.87	18.18
Any experience making medical decisions for family members ^{a, b}	72.31	53.50	57.95
Culture			
Familism (range: 11 – 64)	43.32 (6.27)	44.14 (6.43)	44.06 (6.78)

Note: Statistically significant difference ($p < .05$) between subgroups indicated with superscripts: a=Transparent vs. Contradictory, b= Transparent vs. Avoidant, c= Contradictory vs. Avoidant.

Table 4.5: Multinomial Logistic Regression Predicting Disclosure Preference Class

M1 (ref: Transparent)	Contradictory		Avoidant	
	RRR	CI	RRR	CI
<i>Demographics</i>				
Age (ref: 50 - 59)				
60 - 69	0.70	(0.43 - 1.12)	1.03	(0.55 - 1.95)
>= 70	0.99	(0.53 - 1.83)	0.97	(0.41 - 2.28)
Female	1.03	(0.66 - 1.62)	0.74	(0.40 - 1.37)
Married	1.11	(0.62 - 1.98)	1.41	(0.60 - 3.31)
Religion (ref: none)				
Buddhist	1.49	(0.87 - 2.58)	2.08+	(1.00 - 4.35)
Other	1.29	(0.80 - 2.07)	2.25**	(1.21 - 4.16)
# of children	0.77	(0.51 - 1.15)	1.11	(0.66 - 1.87)
<i>Socioeconomic status</i>				
Education (ref: never went to school, elementary school, or middle school)				
High school	1.60	(0.90 - 2.86)	2.10+	(0.97 - 4.54)
>= Associate	1.05	(0.58 - 1.89)	0.83	(0.36 - 1.90)
Monthly personal income (ref: <= 3000 RMB)				
3001 – 5000 RMB	1.66	(0.87 - 3.14)	0.89	(0.38 - 2.09)
> 5000 RMB	0.79	(0.41 - 1.52)	0.52	(0.22 - 1.25)
Insurance type (ref: government medical insurance)				
Urban employee or resident insurance	0.78	(0.45 - 1.33)	0.53+	(0.25 - 1.11)
New Cooperative / other insurance	0.69	(0.37 - 1.31)	0.54	(0.23 - 1.26)
<i>Health conditions and experiences</i>				
Self-reported good health	1.04	(0.67 - 1.61)	0.89	(0.49 - 1.63)
# of chronic diseases	0.97	(0.76 - 1.24)	0.70+	(0.49 - 1.01)
Has been hospitalized	0.74	(0.47 - 1.15)	0.48*	(0.24 - 0.94)
Has experience of making medical decisions for family members	0.47***	(0.31 - 0.72)	0.59+	(0.34 - 1.04)
<i>Culture</i>				
Familism	1.03*	(1.00 - 1.07)	1.02	(0.98 - 1.07)

Note: Relative risk ratios (RRR) are shown. 95% confidence intervals (CI) are reported in parentheses. Statistical significance denoted as *** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$, + $p < 0.10$. Number of observations for final models is 568, after listwise deletion of 2 observations who are missing on covariates (ever hospitalized and any experience making medical decisions for family members).

DISCUSSIONS

Our study is the first we know of to explore midlife and older Chinese adults' complex and even contradictory beliefs regarding the disclosure of their own and their loved one's illness diagnosis. Our analyses, based on a sample of adults in Shanghai, China, yielded two major

findings. First, we identified three statistically and conceptually distinct types of preferences regarding diagnosis disclosure, revealing the diversity of attitudes held by Chinese older adults. A small minority (16%) unequivocally endorsed shielding patients from their diagnoses (i.e., “avoidant”), with considerably larger shares supporting “transparency” in disclosure (34%) or “contradictory” views (50%) which endorsed conflicting preferences for self versus significant others. Second, two covariates were most strongly linked with one’s preference type: familism attitudes and health care experiences. We elaborate on these findings, and highlight their implications for health care policy and practice in China and other Asian nations.

First, we observed three distinct clusters of attitudes towards disclosing serious illness diagnoses, with only a small minority (11 percent) holding unequivocal preferences for concealing a disclosure from the patient. In stark contrast, fully one-third strongly endorsed transparency, believing that persons who have either an early- or late-stage cancer diagnosis should be informed, with similar views for self, spouse, or parents. Our results are broadly consistent with suggest that, like the studies with Chinese cancer patients (Huang et al., 2018), general public in China are now more open to discussing serious illness and end-of-life-related issues than we assumed before. Also, older adults with this preference type are more likely to be not religious, with higher SES, and to have certain health experiences related to medical decision-making. This is aligned with previous studies on information seeking that people who have more resources and experiences are more likely to be “monitors” who prefer to amplify the available information to be prepared and cope with potential threatening messages (Sweeny et al., 2010; Vrinten et al., 2014).

The least prevalent type (16%) is avoidant, who tries to avoid the diagnosis information as much as possible, both towards self (e.g., 100% on early-stage cancer diagnosis and 94% on

late-stage cancer diagnosis) and towards significant others. Most of them also think that the doctors should communicate their medical information with family members directly instead of with them. Compared to transparent type, people in this latent class are more likely to have religious faiths like Catholic, Protestant, traditional Chinese folk beliefs, and Islam and believe that God or other superpower controls the length of lives in those religions; as such, people with those beliefs may not feel necessary to know the diagnosis of serious illness and to do care planning in advance (Garrido et al., 2013). Nevertheless, more studies are needed to get a deeper understanding of why those older adults prefer to avoid the diagnosis information to inform better services to support communications on medical information with their significant others and doctors.

The largest latent group in our sample is contradictory, who wanted to be informed of their own diagnosis as much as the transparent type, but preferred to not disclose the diagnosis information when their significant others have serious illnesses. We cannot ascertain whether it is because they assumed their significant others don't hold the same preference towards diagnosis information as them, or it is because they didn't know whether their significant others want to know the information or not. Another possibility is that those older adults wanted to respect their significant others' autonomy in medical care, but just didn't know how to communicate on such a sensitive topic. We attempted to offer our insights through the results from the following question, where we asked respondents to select all the applicable reasons why they decided to hide the diagnosis. The choices are created based on the themes generated from previous studies with Chinese and Korean older adults on end-of-life diagnosis and prognosis disclosure (Kwak & Salmon, 2007; Sun et al., 2015). Shown in Appendix Figure C.1, most

people (66.92%) agreed that not telling the truth is meant to give patients hope and less than 20% of them thought that their significant others didn't want to know that they were dying.

It is also worthwhile to note that, among contradictory people, nearly 90-percent of them decided not to disclose diagnosis to parents, but in 30- to 40-percent of cases, they would tell the truth to their spouses. In other words, contradictory people are more likely to disclose the diagnosis information to their spouses than parents. This may be due to the thought that hiding diagnosis is a form of filial piety, or adult children's sense of responsibility to support and care for their parents, to protect older family members from emotional distress (Kim, 2010). Future studies can focus on the impact of relationships between communicators and the preferences of diagnosis disclosure process.

Further, our multivariate analyses revealed that higher levels of familism were associated with being in the contradictory class. Our results suggest that a core dimensions of familism – the desire to protect members of one's immediate family from distressing information – may underlie Chinese older adults' contradictory beliefs. It may be a core belief of familism that medical decisions are the domain of the nuclear family rather than the individual patient (Zeng et al., 2009). A more nuanced look at the attitudes held by those in the contradictory class reveal slightly different preferences regarding disclosure of illness to one's aged parents versus one's spouse. Nearly 90 percent prefer to shield parents of their diagnosis, yet just 60 to 70 percent would similarly prefer to conceal their spouse's diagnosis from them. This greater preference for concealing their parents' diagnosis may reflect the norm of filial piety. Filial piety may encompass adult children's sense of responsibility to support and care for their parents, or to protect older family members from emotional distress (Kim, 2010).

Finally, direct experiences with own or others' health care were strongly linked with disclosure preferences. Those who had direct experience with a family member's end-of-life decision-making were significantly less likely to be in the avoidant or contradictory categories, relative to the transparent category. Previous health care encounters may provide midlife and older adults with a greater knowledge and understanding of end-of-life symptoms, treatments, and preparations (Hou et al., 2019). As such, they may prefer to actively seek diagnosis information and to be prepared. Prior studies suggest that the pathways linking end-of-life observations to behavior may occur via either positive or negative role models. Those who witnessed "good deaths" may take steps to replicate the experience, whereas those who witnessed "bad deaths" may avoid those behaviors or practices that led to a painful, protracted, or conflicted end of life (Carr, 2012).

Limitations

Our analyses have several limitations that may weaken the generalizability of our results. First, given the cultural sensitivity of end-of-life issues and the relatively high rate of partial completions of the survey (one-third), our results may be biased towards those with greater comfort with and thus a greater preference for illness disclosure. The proportion of our sample holding contradictory or avoidant views may lower be than in the Chinese population at large. Moreover, given our data collection approach, we were not able to reach the older adults who were socially isolated and thus limited the study's generalizability. Relatedly, our sample includes respondents from Shanghai only, the largest metropolitan city in China, thus our results may not be generalizable to less urbanized areas. However, studies carried out in other parts of China (e.g., Chenzen; Tang, 2019) found that roughly equal shares of family caregivers reported

that the cancer patient did (versus did not) discuss their dying experiences, which suggests the diffusion of death acceptance to other parts of China.

Second, our analyses do not directly address whether the family members actually have or had a cancer diagnosis. However, the disclosure questions were worded to capture either attitudes in hypothetical scenarios (e.g., “I wouldn’t disclose to parents...”) or actual behaviors (i.e., “I didn’t disclose to parents...”), allowing study participants to respond in a way that best reflected their experiences. Finally, we controlled for only a limited set of covariates, given availability of data and sample size. However, future studies should further examine the extent to which factors like health literacy, quality of family relationships, the nature of the physician-patient relationship, and social networks affect one’s preferences for or against diagnostic disclosure and whether type of cancer may affect older adults’ preferences.

Lastly, it should be noted that the results are based on data collected during the COVID-19 pandemic period, during when older adults may be more reflective or open-minded regarding the death-related topics while witnessing suffering and/or dying experiences of people they know. Therefore, the results may have overestimated Chinese older adults’ willingness of being informed of diagnoses and prognoses of serious illnesses. The unique social event (public health emergency) happened during the study period may also confound the relationship between preferences and socio-environmental predictors.

Policy, Practice, and Research Implications

Despite these limitations, our analyses suggest promising recommendations for health care policy and practice in China. First, we encourage health care providers in China (and other nations in which disclosure is not the norm) to ask patients whether they would like to know and discuss their diagnosis and prognosis. They also should talk to patients about precisely whom

they would like to inform about their diagnosis, and make notes of these preferences in the patient's medical record. This formal recording will help to guide care in a way that is consistent with patient preferences.

Second, we recommend that health care providers in China convey to family caregivers that disclosure may indeed be beneficial to the patient, allowing them to play a more direct, well-informed and autonomous role in health care decisions at the end of life. Disclosure may be a way to enhance rather than detract from the well-being of the patient, and to strengthen collaborative family decision-making – values that are consistent with the core themes of familism. Our analyses showed that familism beliefs were inversely related to “transparent” attitudes, and that the main motivation for concealing diagnoses were to uphold the hope and emotional well-being of patients. However, our results suggest that health care decisions entered into knowingly by patients in consultation with family and health care providers, also may be a path to patient well-being at the end-of-life stage (e.g., Morita et al., 2015).

Third, our results suggest that now is the time for China to follow the lead of other nations also distinguished by cultural values of filial piety, and to encourage autonomous or shared decision-making among patients, family, and health care providers at the end of life (Mori and Morita, 2020). The governments and professional health care associations in several Asian countries – most notably Hong Kong, Japan, Korea, Singapore, and Taiwan - have recently established guidelines, laws, and policies that elevate the goal of patient autonomy in decision making (Mori & Morita, 2020). Our results showed that the vast majority of respondents preferred to be told of their own cancer diagnosis, or be told either first or alongside their family members of their illness diagnosis. These results suggest that midlife older adults are ready and willing to seek out information that has largely been withheld from them. Cultural changes often

precede structural changes however, necessitating revised laws and policies to help facilitate individual patients' goals of autonomous or shared medical decision making (Riley et al., 1994). However, since our results only reflect preferences of a selected sample of older adults who were willing to share their thoughts on end-of-life care in Shanghai, death and dying may be more sensitive to talk about than what we suggest in this paper. Future research should investigate public attitudes with larger and representative sample of Chinese older adults to better inform local or national policies.

Fourth, our results suggest that a “one size fits all” approach may not be appropriate, given that one-fifth of adults did not want to know their own diagnosis, and roughly half did not believe that their spouse or parent should be informed of their own diagnosis. Consistent with the far-ranging attitudes documented in our study, clinicians should recognize the heterogeneity and inconsistency of preferences among adults in China, based on factors like their religion or direct experiences with health care. Efforts to promote culturally sensitive care that takes cultural and religious beliefs into account may help health care providers to devise tailored strategies regarding disclosure and the engagement of both patients and families in the discussions and subsequent decision-making processes.

Chapter 5: Conclusions

ACP is the cornerstone of goal-concordant end-of-life care. However, only 1 in 3 U.S. adults has documented their end-of-life wishes (Yadav et al., 2017). The dominant intervention currently on the ground is physician–patient ACP discussions, which doctors are responsible for initiating and leading. The approach is also adopted by Medicare policy through its reimbursement mechanism. In this dissertation, I examined whether doctor–patient end-of-life care discussions work for older adults with diverse backgrounds in the United States and China. More specifically, it comprehensively investigated whether, to what extent, for whom, and how this intervention approach (doctor-led ACP consultation) is effective in the United States by using HRS data from a nationally representative sample of older adults. The dissertation then explored whether discussing end-of-life care wishes with doctors is feasible for older adults in China by using survey data collected in Shanghai, China.

In Chapter 2, I studied to what extent doctor–patient ACP conversations were associated with different types of end-of-life experiences and whether the relationship was mediated by the completion of ADs. I found that the discussions increased the possibility of being an extensive service user with uncomfortable death, and the association was partially mediated by AD completion. In Chapter 3, I explored whether insurance coverage of physician-led ACP consultation under the ACA was an effective mechanism to improve older adults' ACP rates. Specifically, I studied the heterogenous effects of this ACA Medicare benefit expansion by race and ethnicity, immigration background, and SES. I found that the Medicare policy was associated with a significant increase in the proportion of older adults who completed legal documents, but not their ACP discussions, in the older White population. The policy is not effective among older Blacks, Hispanics, immigrants, and adults with lower educational

attainment. Additionally, only an immediate policy effect was observed. Last, in Chapter 4, I investigated whether discussing the diagnosis and prognosis of serious illness is culturally appropriate for older adults in China. I found that most Chinese older adults preferred to know diagnosis information in a timely manner and make medical decisions for themselves. I also identified a group of older adults who held a contradictory view on diagnosis disclosure; they preferred to know their diagnosis but preferred that their significant others not be informed of their own diagnoses. These older adults were more likely to have higher familism values.

The study findings highlight the limited effectiveness of doctor–patient ACP discussions, especially among older adults with disadvantaged backgrounds in the United States. Structural efforts, such as policies, to improve the equity of ACP and end-of-life care in the long run should consider addressing the fundamental cause of the issue—inequality of resources, such as knowledge of end-of-life care and planning, and access to preferred doctors—due to social factors (e.g., race and ethnicity and SES). Meanwhile, extra support from practitioners is needed to help older minorities, immigrants, and adults with lower education levels overcome systemic barriers to care planning and achieve better access to and use of ACP services. Targeted services may include care coordination to identify trusted doctors to discuss end-of-life care wishes and make sure the whole health care team is aware of the preferences, educational workshops to improve awareness and knowledge of end-of-life care and planning, and family consultation to facilitate difficult conversations among family members.

The study emphasizes the importance of culturally appropriate ACP services. First, ACP is a concept that is embedded in individualist culture. End-of-life care decision making is considered a family issue rather than an individual one in cultures that value familism or collectivism (Choi & O’Brien, 2019). For example, to work with older adults from more

collective cultural backgrounds, practitioners should be aware of the concerns those older adults may have in the ACP process, such as hoping to grant leeway to family members even if their thoughts are conflicted (Lee et al., 2020). Second, death and dying is a cultural taboo in some communities, and practitioners need to be very cautious about the language they use in these conversations. Lack of culturally appropriate responses may influence rapport building, disengage patients from the conversations, and jeopardize the efficacy of discussions on ACP behaviors and end-of-life outcomes. Therefore, it is important to develop policy and organizational efforts, such as targeted funding and collaborative platforms, to support researchers, practitioners, and community partners to develop, improve, and deliver culturally appropriate ACP interventions.

The study in Chapter 4 provides strong evidence to promote patient autonomy in end-of-life care in China and suggests that encouraging physicians to discuss end-of-life care wishes may be a feasible approach to increase ACP and goal-concordant care in China. The results reveal that many older Chinese now prefer to have autonomy in health care decisions and are open to discussing end-of-life-related topics, such as diagnoses and prognoses of serious illnesses. Local government could consider legalizing the right of patients regarding end-of-life care such as informed consent based on the observed public attitudes. Moreover, my findings on older adults who hold a contradictory or avoidant view on disease diagnosis disclosure emphasize the necessity of developing targeted social services to help them navigate uncomfortable care planning, health communication, and decision-making processes.

To conclude, this dissertation provides policy and practice suggestions on supporting the “good death” of older adults with disadvantaged backgrounds nationally and globally. It has strong research implications for future studies to understand motivations, barriers, and efficiency

related to communicating end-of-life care wishes with health care professionals among older adults with diverse backgrounds. The project is especially timely given that the COVID-19 pandemic has further exacerbated the inequalities in death and dying; older adults with disadvantaged backgrounds have significantly higher hospitality and mortality rates without ACP and more stressful dying experiences (Auriemma et al., 2022; Moorman et al., 2020).

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Appendix A

Appendix for Chapter 2

Table A.1: Prevalence of Latent Class and Item-Response Probabilities from 4-Class Model

	C1	C2	C3	C4
<i>Latent class prevalence (n)</i>	40.43	17.80	16.75	25.02
<i>Item-response probabilities</i>				
Hospitalization	0.41	1.00	0.46	1.00
ICU	0.00	0.79	0.75	0.39
Life support	0.00	0.54	0.56	0.14
Kidney Dialysis	0.00	0.15	0.14	0.04
Surgery	0.08	0.25	0.30	0.14
Specialized facilities	0.17	0.40	0.21	0.35
Hospice/palliative care	0.17	0.17	0.03	0.49
Satisfied with end-of-life care	0.79	0.73	0.79	0.80
Wishes being respected in end-of-life care	0.56	0.51	0.51	0.54
Troubled with pain	0.48	0.79	0.52	0.60
Difficulty Breathing in last year of life	0.39	0.81	0.47	0.54
Depression in the last year of life	0.42	0.70	0.37	0.56
Location of death				
Home	0.39	0.31	0.00	0.30
Hospital	0.23	0.45	1.00	0.00
Specialized facilities	0.38	0.24	0.00	0.70

Appendix B

Appendix for Chapter 3

Table B.1: Changes in Advance Care Planning Outcomes associated with ACA Medicare Benefit Expansions on End-of-life Care Planning (n = 47,982)

	DV: Living Will		DV: DPAHC		DV: ACP Discussion	
	Coef.	SE	Coef.	SE	Coef.	SE
Key Estimators						
Post # Medicare (Treat)	0.05*	(0.02)	0.05*	(0.02)	0.04+	(0.02)
Year						
2013	-0.03	(0.02)	0.01	(0.02)	0.03	(0.02)
2014	0.05***	(0.00)	0.07***	(0.00)	0.12***	(0.00)
2015	0.00	(0.03)	-0.00	(0.03)	0.10***	(0.03)
2016	0.02	(0.02)	0.05*	(0.02)	0.12***	(0.02)
2017	-0.01	(0.02)	0.02	(0.02)	0.07**	(0.02)
2018	0.03	(0.02)	0.06**	(0.02)	0.14***	(0.02)
2019	0.00	(0.03)	0.03	(0.03)	0.09**	(0.03)
Medicare (Treat)	0.05*	(0.02)	0.05**	(0.02)	0.04+	(0.02)
Covariates						
<i>Demographics</i>						
Age	0.01***	(0.00)	0.01***	(0.00)	0.00***	(0.00)
Female	0.06***	(0.01)	0.04***	(0.01)	0.11***	(0.01)
Married	-0.02**	(0.01)	-0.05***	(0.01)	-0.02*	(0.01)
Race (Ref: Non-Hispanic White)						
Non-Hispanic Black	-0.19***	(0.01)	-0.12***	(0.01)	-0.16***	(0.01)
Hispanic	-0.19***	(0.02)	-0.15***	(0.02)	-0.15***	(0.02)
Asian, Pacific Islander, or Indigenous	-0.13***	(0.03)	-0.09***	(0.03)	-0.14***	(0.03)
Religion (Ref: None)						
Protestant or Catholic	-0.05+	(0.03)	-0.01	(0.03)	-0.01	(0.02)
Other	-0.04	(0.03)	-0.01	(0.03)	0.02	(0.02)
<i>SES</i>						
Educational Attainment (Ref: < High School)						
GED	0.09***	(0.01)	0.06***	(0.01)	0.10***	(0.01)
Some college	0.14***	(0.01)	0.11***	(0.01)	0.16***	(0.01)
College or above	0.20***	(0.01)	0.17***	(0.01)	0.20***	(0.01)
Wealth (Ref: < 0 in debt)						
0 – 25 percentiles	0.03*	(0.01)	0.01	(0.01)	0.02*	(0.01)
25 – 50 percentiles	0.08***	(0.01)	0.06***	(0.01)	0.04**	(0.01)
50 – 75 percentiles	0.13***	(0.01)	0.12***	(0.01)	0.07***	(0.01)
75 – 100 percentiles	0.21***	(0.01)	0.20***	(0.01)	0.11***	(0.01)

Table B.1 (Continued): Changes in Advance Care Planning Outcomes associated with ACA Medicare Benefit Expansions on End-of-life Care Planning (n = 47,982)

	DV: Living Will		DV: DPAHC		DV: ACP Discussion	
	Coef.	SE	Coef.	SE	Coef.	SE
Born in U.S.	0.07***	(0.01)	0.08***	(0.01)	0.09***	(0.01)
<i>Health and Mental Health</i>						
Self-reported Good Health	0.01	(0.01)	0.01	(0.01)	0.01	(0.01)
Number of Diseases	0.02***	(0.00)	0.02***	(0.00)	0.03***	(0.00)
CES-D Depression Score	-0.01**	(0.00)	-0.00*	(0.00)	-0.01***	(0.00)

Note: Data are weighted using HRS individual-level survey weights; Ns presented are unweighted totals of HRS respondents; Difference-in-difference model adjusted for age, gender, marital status, race and ethnicity, religion, educational attainment, wealth quartile; born in the U.S., self-reported good health, number of diseases, CES-D depression scores, and year fixed effects; Multiple imputation is used; Standard errors clustered by state; Estimates are presented as percentage points; CI is the confidence interval. Statistical significance denoted as *** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$, + $p < 0.10$.

Table B.2: Results of Comparative ITS with Time-varying Controls (n = 47,982)

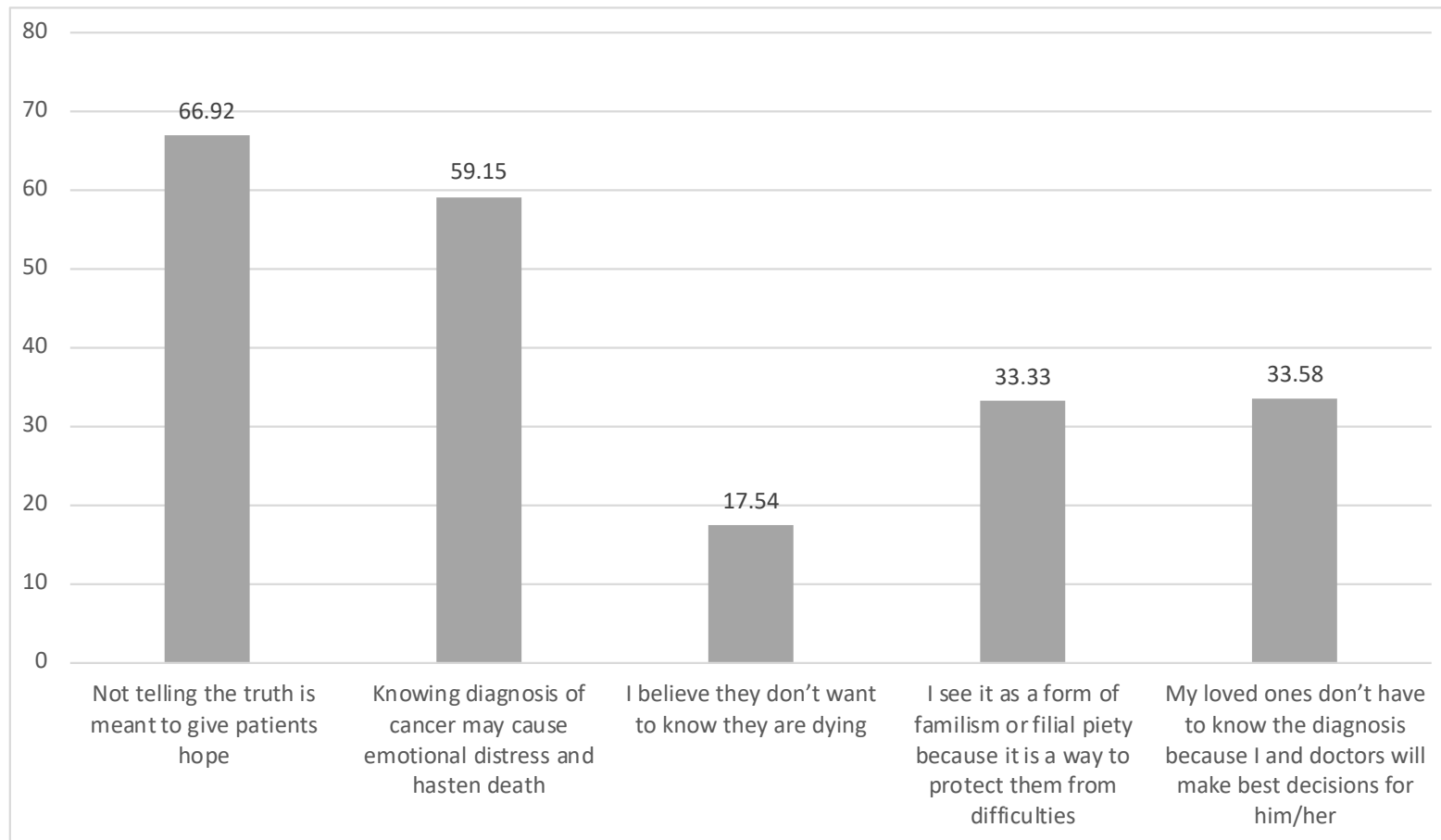
	DV: Living Will	DV: DPAHC	DV: ACP Discussion
Control Pre- Trend β_1	-0.036	-0.027	0.022
Treatment/Control Pre- Level Difference β_4	0.116*	0.144**	0.117+
Treatment/Control Pre- Trend Difference β_5	0.033	0.021	0.014
Control Post- Level Change β_2	0.123	0.103	0.033
Control Post- Trend Change β_3	0.026	0.017	-0.040
Treatment/Control Post- Level Difference β_6	-0.025	0.017	-0.015
Treatment/Control Change in Slope Difference Pre- to Post β_7	-0.035	-0.020	-0.001

Note: Data are weighted using HRS individual-level survey weights; Ns presented are unweighted totals of HRS respondents; Difference-in-difference model adjusted for age, gender, marital status, race and ethnicity, religion, educational attainment, wealth quartile; born in the U.S., self-reported good health, number of diseases, CES-D depression scores, and year fixed effects; Standard errors clustered by state; Estimates are presented as percentage points; CI is the confidence interval. Statistical significance denoted as *** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$, + $p < 0.10$.

Appendix C

Appendix for Chapter 4

Figure C.1: Reasons Respondents Would Prefer to Not to Disclose Significant Others' Diagnoses



Note: Proportions shown. Respondents can indicate more than one response; thus, percentage totals exceed 100.