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FACTORS ASSOCIATED WITH ADVANCE CARE PLANS AND END-OF-LIFE CARE CHOICES AMONG ELDERLY AMERICANS: AN ANALYSIS OF HEALTH AND RETIREMENT STUDY DATA

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DEDICATION

To those older Americans who spent their lives in building this nation; to those who participated in Health and Retirement Study; to my parents who always encouraged me to pursue education relentlessly; to my elder sister and her family for their support in settling and acclimatizing in the U.S; to my wife and children for their unwavering support and love throughout the doctoral studies.

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ABSTRACT

Introduction

Advance care plans (ACP) allow people to plan for their end-of-life care before they become incompetent to make their treatment decisions. The umbrella term Advance Care Plans (ACP) includes the three most commonly used end-of-life care plans: Advance Care Planning Discussions (ACP discussions) and two advanced directives: living will and Durable Power of Attorney for Health Care (DPAHC). The ACP discussions are the verbal discussions about end-of-life plans, whereas the advance directives are written documents.

ACPs are distinct nuances of end-of-life care planning. ACP discussions address a wide array of end-of-life care issues, including terminal care, funeral, burial and the place of death, etc. A living will outlines specific end-of-life care choices and elicits yes or no responses. The choices pertain to use of artificial respiration; artificial feeding and hydration; dialysis; or antibiotics; etc. A DPAHC, appoints a proxy to make treatment decisions on behalf of the incompetent patient at a terminal stage of life.

While previous studies have used ACPs as distinct outcomes, in real life the ACPs exist in combinations. People who undertake ACP discussions are more likely to complete advance directives. More than 25 states have combined directives forms. Therefore, it is imperative to evaluate the factors associated with the combinations of ACPs: No ACP; ACP discussions only; a directive (a living will or DPAHC); a directive

and ACP discussions; both directives (a living will and DPAHC); and all ACPs (a living will, DPAHC and ACP discussions).

Among the factors associated with ACPs, health status has shown an inconsistent association. Some studies have shown that poor health is associated with higher ACP uptake rates, whereas others have noted no association. The possible reasons for inconsistent association include 1) examining the association without controlling for the change in health status and other health factors — prior research shows health status and change in health are closely related in influencing the uptake of ACPs and the end-of-life care choices 2) use of each ACP as a separate outcome instead of using them in combinations. Therefore, our first study attempted to clarify the association between health status, change in health status and interaction between the two measures with the combinations of ACPs.

Our second study determined the factors associated with end-of-life care choices. Prior concerning the association between health status and end-of-life care choices have used prospect theory. However, previous research has used convenience samples and end-of-life care scenarios. We tested the prospect theory using a representative population-based sample and using the choices that people make considering their own health status and possible end-of-life circumstances.

Methods

We used the Health and Retirement Study (HRS) panel data from 1992-2014 and the HRS exit interview data from 2002-2014. The HRS captures health and retirement characteristics of a representative sample of Americans over 50 years using biennial panel surveys since 1992. It also conducts one-time post-death interviews with the next-of-kin of HRS decedents in the survey waves following their death. The post-death surveys collect information about medical care expenditures and use; advance care planning and end-of-life care choices and distribution of assets towards end-of-life.

We used the Analytics Software and Solutions SAS version 9.4 to examine the association between health status and ACPs, we used a multinomial regression model. The combinations of ACPs were used as the study outcome. To study the association between health status and choices, a separate logistic regression model was used for each choice — limit care in certain situations, comfort care and all care possible.

Results

In study 1, self-reported health was not associated with any category of ACP combinations. However, change in health status was associated with ACPs — "worse or somewhat worse" change in health status since the last survey wave was associated with a higher uptake of "two directives" and "all ACPs", compared with "much or somewhat better or the same". The number of health conditions and a history of cancer were also associated with "all ACPs".

In study 2, we did not find association between self-reports of health and its change with the two care-limiting choices, including "limit care in certain situations" and "comfort care". However, change in health status was associated with the "all care possible" option — a decline in health status since the last wave was associated with a higher likelihood of "all care possible" choice than improvement or no change in health status since the last wave. Among other health factors, a psychiatric illness was associated a higher uptake of "all care possible" and a lower uptake of "comfort care". The decedents with a history of stroke chose less "limit care in certain situations" option.

Recommendations

We recommend further research on the factors associated with the combinations of ACPs. Future research should also use the combinations to determine the effects of ACPs on the cost and quality of end-of-life care.

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LIST OF ABBREVIATION

ACP	Advance Care Planning
AD	Advance Directives
ADL	Activities of Daily Living
AED	Automated external defibrillators
AHRF	Area Health Resource File
BMI	Body Mass Index
CCRC	Continuing Care Retirement Community
CCU	Coronary Care Unit
CPR	Cardiopulmonary resuscitation
DNH	Do not hospitalize
DNI	Do not intubate
DNR	Do not resuscitate
DPAHC	Durable Power of Attorney for Health Care
GDP	Gross Domestic Product
GED	General Education Diploma
GFI	Groningen Frailty Index
HMO	Health Maintenance Organization
HRS	Health and Retirement Study
ICD	International Classification of Diseases
LADS	La Crosse Advance Directive Study

MDS	Nursing home Minimum Data Set
MEPS	Medical Expenditure Panel Survey
NHATS	National Health and Aging Trends Study
NHC	Nursing Home Component
NI	Israeli Institute of National Insurance
NIA	National Institute of Aging
NJ	New Jersey
NM	Not mentioned
PSDA	Patient Self-Determination Act
RAND	Research and Development Corporation
VA	Veterans Affairs
WLS	Wisconsin Longitudinal Study

CHAPTER I: INTRODUCTION

1.1. BACKGROUND

The United States is undergoing a demographic transition as baby boomers are coming to retirement age (U.S. Census of Bureau, 2012). The 76 million baby boomers, born from 1946-64, are now in their 50s and 60s. Therefore, the country expects to see a growth in the elderly population in the decades to come. In 2013, the people aged 65 years and older numbered 44.7 million, an increase of 8.8 million (24.7%) since 2003 (Administration on Ageing. Administration for Community Living. U.S. Department of Health & Human Services, 2014; Van Leuven, 2012). In the next 25 years, the population aged 65 and older will reach to 72 million, comprising about 20% of the total population in 2030 (National Center for Chronic Disease Prevention and Health Promotion: Division of Population Health, 2013).

Older age increases the risk of chronic diseases and disabilities, requiring costly and long-term care (Morhaim & Pollack, 2013; Paez, Zhao, & Hwang, 2009). These changes, along with, increasing life expectancy, higher spending on technology and a fragmented health care system implicate rising health care cost (Morhaim & Pollack, 2013).

The health care industry currently consumes 18% of the country’s Gross Domestic Product (GDP) (Berwick & Hackbarth, 2012; Ginsburg, 2008; Mary Martini, Garrett, Lindquist, & Isham, 2007; Moses et al., 2013). Given that the annual health care spending is expected to increase at a rate of 5.5% annually from 2018-2026, the overall cost is expected to reach to $5.7 trillion in 2026 (Centers for Medicare & Medicaid

Services, 2018) and life expectancy and access to be lower than the comparable countries (Anderson & Frogner, 2008), the U.S. health care seeks for efficient solutions.

Medicare provides coverage to the most individuals 65 years and older and certain younger individuals with disabilities and end-stage renal disease (U.S. Department of Health and Human Services, 2014). If the current growth in health care spending persists, the program expects to consume 8% of the GDP — an unprecedented consumption by a single program in the country (Thorpe, Ogden, & Galactionova, 2010). The increasing trends in longevity, size of the elderly population, prevalence of chronic diseases and use of technology foretell further rise in health care cost. Therefore, Medicare, the largest insurer of the elderly, is under a financial stress and searches for efficient cost solutions.

1.2. ADVANCE CARE PLANNING AND PATIENT CENTERED END-OF-LIFE CARE

Recently, the patient centered approach received attention as a potential solution to the health care cost and quality conundrum (Epstein, Fiscella, Lesser, & Stange, 2010). The approach premises that information empowers patients, that is, when provided with relevant clinical information, patients make decisions that best fit the treatment needs (Epstein, et al., 2010).

Research indicates patients tend to choose less costly and less intense end-of-life care choices (hereafter also mentioned as choices) (Tschirhart, Du, & Kelley, 2014). For instance, most patients wish to die at home and choose less aggressive terminal care (Barnato et al., 2007; Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005; S. Fischer, Min, Cervantes, & Kutner, 2013; Fried, Van Doorn, O'Leary, Tinetti, & Drickamer, 1999; Wilkinson, Wenger, & Shugarman, 2007). Further, a recent study demonstrated that while doctors tend to choose aggressive terminal care for patients, they would forego such aggressive care for themselves in similar medical circumstances (Periyakoil, Neri, Fong, & Kraemer, 2014). Therefore, the Institute of Medicine (IoM) emphasizes the use of patient centered end-of-life care (Institute of Medicine, 2014).

Advance care planning (ACP) extends patient centered approach into terminal care decisions (Carr, 2012a; Laakkonen, 2005; Nelson & Nelson, 2014). ACP limits end-of-life care, as the default end-of-life care is “everything that can be done” (Benson WF & Aldrich N 2012; Choudhry, Ma, Rasooly, & Singer, 1994; Layde et al., 1995; Sonnenblick, Friedlander, & Steinberg, 1993; Uhlmann, Pearlman, & Cain, 1988).

The ACP results in informal and formal advance care plans. The most frequently applied advance care plans include an informal advance care plan, called Advance Care Planning discussions or “ACP discussions”, and two formal written directives, also called “advance directives” — living will and Durable Power of Attorney for Health Care (DPAHC) (President's Council on Bioethics, 2005). The living will and DPAHC are included in the official advance care planning documents of all the U.S. states (Commission on Law and Aging, 2009).

1.3. TYPES OF ADVANCE CARE PLANS

Advance care planning discussions

ACP discussions allow a patient to discuss broad end-of-life care issues, namely treatment choices; long-term care and housing plans; place of death; fear of death and religious aspects and values related to end-of-life care (Detering, Arnold, Savarese, &

Silveira, 2016; Institute of Medicine, 2014). A person can discuss these issues with their spouse; child; relative; friend; colleague; physician or clergyman, etc. (President's Council on Bioethics, 2005; Wilkinson, et al., 2007). Although, ACP discussions are broad in scope, they have limited legal value because of the absence of documentary evidence. That said, however, these discussions provide valuable insight about person’s end-of-life care choices. ACP discussions also facilitate documentation of end-of-life care plans (Douglas K. Martin, Emanuel, & Singer, 2000).

Advance directives: living will and Durable Power of Attorney for Health Care

The umbrella term “Advance directives” (AD) embodies written documentation about end-of-life care plans. The two most common types of directives are the living will and the Durable Power of Attorney for Health Care (DPAHC) (Shannon M Dunlay & Strand, 2016). These directives are universally included in the advance directives forms of all the U.S. states (Commission on Law and Aging, 2009).

In the current study we included ACP discussions, living will and DPAHC as forms of advance care plans. The advance directives, including living will and DPAHC, are recorded and have a legal status. The declarants are required to sign the directives in the presence of a witness and also, in some states, get the directives notarized (Arkansas Innovative Performance Program, 2002; McEwan & Silverberg, 2016; South Carolina Department of Mental Health, 1993). The directives are completed before a person becomes terminally ill or incapacitated to communicate (South Carolina Department of Mental Health, 1993).

A living will is the only commonly used directive that includes documented end-of-life care choices (McEwan & Silverberg, 2016). It is called the “living will” as it goes into effect while a person remains alive, but the person can no longer make treatment decisions and the attending doctor certifies that the patient is in a terminal condition or a permanent vegetative state (AssistedLivingFacilities.Org, 2017). A terminal condition is defined as an incurable and irreversible medical condition for which medical treatment will only prolong death. Without the use of medical care the death will ensue in a relatively short time (Hickey, 2006). The choices in a living will pertain to the use of medical interventions including mechanical ventilation; cardiopulmonary resuscitation (CPR); invasive diagnostic tests; dialysis; major and minor surgery; antibiotics; blood products and artificial nutrition and hydration (Arkansas Innovative Performance Program, 2002).

A "DPAHC" nominates an agent, who makes the treatment decisions on behalf of an incapacitated patient. The role of an agent is invoked when a patient moves into a temporary or permanent coma. In contrast to a limited scope of a living will in dealing with terminal care decisions, a DPAHC agent can decide broad treatment choices in a real end-of-life care scenario (Detering, et al., 2016). However, an agent's values and preferences can differ from the choices the patient would have made (Lynn et al., 2000). For instance, to avoid future regret, an agent tends to choose more care for a patient than a patient would have chosen for him/herself (Travis et al., 2002).

1.4. CONTENT OF ADVANCE DIRECTIVES: END-OF-LIFE CARE CHOICES

Among the two directives, DPAHC and a living will, the latter records the end-of-life care choices. The literature uses the terms "choices", "end-of-life care choices", "end-of-life care preferences" and "end-of-life care wishes" interchangeably (Bakitas et al., 2008; Carr, 2012a; Djulbegovic, Hozo, Schwartz, & McMasters, 1999; Hammes, Rooney, & Gundrum, 2010; F. P. Hopp & Duffy, 2000; Thompson, Barbour, & Schwartz, 2003). However, in the current study, we used the term "end-of-life care choices" or "choices" to refer to end-of-life care people wish to receive. The choices can limit or extend end-of-life care and pertain to treatments such as CPR, surgery, intubation and mechanical ventilation (Detering, et al., 2016; Schneiderman, Pearlman, Kaplan, Anderson, & Rosenberg, 1992; Thompson, et al., 2003).

1.5. TRENDS IN ADVANCE CARE PLANNING AND END-OF-LIFE CARE CHOICES UPTAKE

The Patient Self-Determination Act (PSDA) provides patients a legal right to accept or deny life-prolonging measures including CPR, artificial ventilation and artificial feeding (C. P. Sabatino, 2010). The law mandates the health care organizations receiving funds from Medicare and Medicaid to inform patients about their right to formulate and document advance directives (C. P. Sabatino, 2010).

In addition to PSDA, Terri Schiavo's case also played a role in increasing the public awareness and uptake of advance directives in 1990s and later (Lynch, Mathes, & Sawicki, 2008; Perry, Churchill, & Kirshner, 2005; PRNewswire, 2005; Sanburn., 2015). Terri Schiavo remained comatose for 15 years after falling into a coma in 1990.

Recent studies have demonstrated an ACP rates of 50% – 76% among people aged 65 and above (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; Khosla, Curl, & Washington, 2015; Rao, Anderson, Lin, & Laux, 2014; Silveira, Kim, & Langa, 2010;

Silveira, Wiitala, & Piette, 2014). The studies by Bischoff et al., Khosla et al. and Silveira et al. are based on Health and Retirement Study (HRS) data.

The HRS is a biennial survey of a representative sample of Americans aged 51 years and older. The survey interviews next-of-kin of HRS decedents to elicit information about decedent’s advance care plans. The survey uses four independent questions to elicit information about decedent’s end-of-life care choices (Table 3-2). The questions relate to “all care possible”; “comfort care”; “withhold certain care” and “limit care in certain situations”. Among the latter two, “limit care in certain situations” is a more commonly used indicator of care-limiting end-of-life choice (Bischoff, et al., 2013; Lauren H Nicholas, Bynum, Iwashyna, Weir, & Langa, 2014; L. H. Nicholas, Langa, Iwashyna, & Weir, 2011; Silveira, et al., 2010).

Bischoff et al. reported that 76% of HRS decedents had ACP (Bischoff, et al., 2013). Khosla et al. found an uptake rate of 60.6%, 50.2% and 65.1% respectively for ACP discussions, living will and DPAHC in 2010. Silveira et al. reported that 45% HRS decedents had a living will and 57% had a DPAHC, with 63% having either and 38% having both, using the HRS data from 2000 to 2010. Despite a higher uptake of ACP among older population, rates are lower among the younger Americans. Using the HealthStyle survey data of 2009-2010, Rao et al. reported an 26.3% among individuals age 18 years and older Americans.

Further, with the changing trends in advance directives, end-of-life care choices among people with a living will also fluctuated (Narang, Wright, & Nicholas, 2015; Silveira, et al., 2010). The choices can extend or limit the use of life-prolonging treatment at the time of death. The care-limiting choices include “do not resuscitate” (DNR) or no "cardiopulmonary resuscitation" (CPR); "do not intubate" (DNI) or no tube feeding and hydration, no use of dialysis, respirator, surgery and antibiotics at the terminal stage of life (Dy et al., 2015; LoPresti, Dement, & Gold, 2016). Terri Schiavo's case swayed the choices in the decades of 1990s and 2000s (Blendon, Benson, & Herrmann, 2005). Narang et al. reported a rise in the care extending ("all care possible") choices among cancer patients (Narang, et al., 2015).

1.6. HEALTH STATUS AND THE UPTAKE OF ADVANCE CARE PLANS

Several factors, including patient and ecological characteristics have been found to be associated with the uptake of advance care plans and end-of-life care choices. However, health status and religion drew most attention from researchers. In a recent study, Koss resolved a part of the puzzle by unfolding an interaction between race, religiosity and religious affiliation. She found that race mediates relationship between religious affiliation and religiosity with the uptake of ACP (Koss, 2017).

The literature also reports a vague association between health status and ACP, however, it lacks a study like the Koss's study that determines the factor underlying the mixed association. Some studies report health status, advance care plans and end-of-life care choices are not associated with the ACP or the choices (Beck, Brown, Boles, & Barrett, 2002; Carr & Khodyakov, 2007; Carr & Moorman, 2009; Garrido, Idler, Leventhal, & Carr, 2013; Gerst & Burr, 2008; Gordon & Shade, 1999; Faith P. Hopp, 2000; A. S. Kelley, Ettner, Wenger, & Sarkisian, 2011; Sharp, Carr, & Macdonald, 2012), while others demonstrate an association (Harrison, Adrion, Ritchie, Sudore, &

Smith, 2016; Lenert, Treadwell, & Schwartz, 1999; L. L. Phillips et al., 2011; Winter, Lawton, & Ruckdeschel, 2003; Winter & Parker, 2007).

Prior research has included self-reported health status (also referred to as overall health status or global health status) or specific health rating scales, including SF-12, or Activities of Daily Living (ADL) measures. Research has also used number of comorbidities as a health status measure. Further, change in health status has also been used. However, no study has yet determined the association between self-reported health status and ACP and end-of-life care choices after controlling for other health measures including ADL, comorbidities and recent change in health status.

The reason that we controlled for the other health measures is because prior research has shown an association between self-reported health, self-reported diseases, change in self-reported health and self-reported functional limitations (Bailis, Segall, & Chipperfield, 2003; Han, 2002; Manor, Matthews, & Power, 2001; Wilcox, Kasl, & Idler, 1996). For instance, Manor et al. found self-reported illnesses and functional limitations being associated with the self-reported change in health status (Manor, et al., 2001). Bailis et al. found baseline self-reported health a strongest predictor of change in self-reported health (Bailis, et al., 2003). A decline in self-reported health at six weeks after hospitalization is a strong predictor of disability after six months (Wilcox, et al., 1996). Other studies have also reported associations between these health measures (Hu YN, Hu GC, Hsu CY, Hsieh SF, & Li CC, 2012; Latham & Peek, 2013; Manor, et al., 2001). However, no study has yet determined their interaction, especially, with the uptake of ACP

Most prior studies on the association between health status and ACP uptake did not include community or population-based samples. In other words, the studies sampled patient populations, which were non-representative of the general population (Table 2-3). Patient population can be different in terms of their health status, morbidity patterns, severity of disease and end-of-life care choices than a general population of similar demographics and socioeconomic status in communities.

For instance, Beck et al. and Gordon et al. conducted their studies on patient populations using mail surveys (Table 2–3). Garrido et al. interviewed patients visiting the outpatient department of two hospital clinics and a cancer center in New Jersey (Garrido, et al., 2013). The two studies by Carr et al. used Wisconsin Longitudinal Survey (WLS) data — a follow-up study based on participants who graduated from Wisconsin High School in 1957 (Carr & Khodyakov, 2007; Carr & Moorman, 2009). Inability to include population-based sample was a major limitation of these studies.

Conversely, a few studies reported no association despite using representative samples (Table 2–3). Gerst et al., used HRS wave of 2000 (Gerst & Burr, 2008). Hopp used Asset and Health Dynamics among the oldest-old (AHEAD) (F. P. Hopp & Duffy, 2000). The study included a representative sample of 520 Americans of age 70 years and older who were born in 1923 or earlier.

Among the studies with vague results, the study by Carr et al. was based on a more generalizable sample (Carr, 2012b). They included 2,111 married (70%) or cohabiting (30%) elderly Americans participants of age 18–64 years. They found self-reported health being associated with ACP discussions, but not with a living will. In another study, Carr et al. noted an association between self-reported health and ACP discussions, but not with a living will and DPAHC, using WLS data (Carr, 2012c). Karches et al. used a scale of 0 –100 for self-reported health. The study was based on hospital patients. The authors categorized self-reported health into categories of 20 units each. The ratings of 0 - 20 were associated with higher likelihood of a living will, however, no other category demonstrated significant association with the advance care plans.

Among the studies that showed an association between health status and ACP and end-of-life care choices, the only study that had broader generalizability was conducted by Harrison et al. The authors used the National Health and Aging Trends Study — a nationwide study on Medicare beneficiaries of age 65 and older (Harrison, et al., 2016). The authors used each advance care plan as a separate outcome and noted a significant association between self-reported health and ACP discussions, a living will and DPAHC — compared with the excellent health, poor/fair or good was associated with more likelihood of ACP discussions, a living will and DPAHC.

1.7. RESEARCH GAPS AND JUSTIFICATIONS FOR THE STUDIES

Study 1: Association between health status and combinations of ACPs

The studies that determined the association between health status and ACP have shown mixed results. While a few studies have reported no association, the others have reported an association between health status and ACP.

In real life the ACPs are used in combinations, however, research mostly considers them as distinct outcomes. Research also shows that the use of one type of ACP is associated with use of other ACPs. For instance, people who discuss their end of life plans are also more likely to devise advance directives (Detering, et al., 2016; D. K. Martin, et al., 2000). Several U.S. states use combined directives forms. Such forms combine a living will and DPAHC into a single document (C. P. Sabatino, 2010). Thus, we consider using the combinations of ACP more pragmatic and realistic approach than using each ACP as a separate outcome.

Several studies have reported an independent and a simultaneous association between self-reported health, its change and health outcomes; however, no research exists yet on the interactive effect of self-reported health and its change on health or health care choices and outcomes. Prior research has shown a strong association between self-reported health and change in health status (Bailis, et al., 2003). An association between self-reported health, change in health status and ACP uptake has also been reported. However, there remains a question as to whether the people who report both poor health and decline in health status are more likely to complete directives than those who report good health and an improvement or no change in health status. Thus, we studied the association between health status, change in health status and interaction between the two measures and the combinations of ACPs: No ACP; a directive (living will or DPAHC); ACP discussions only; both the directives (living will and DPAHC); a directive and ACP discussions and All ACPs (Both the directives and ACP discussions).

Study 2: Association between self-reported health status and end-of-life care choices

The prior studies reporting on the association between self-reported health status and end-of-life care choices have used a restricted sample. Hays et al. and Woolley et al. studied end-of-life care choices in retirement communities in Central North Carolina and mid-size Midwestern metropolitan area respectively (Hays, Galanos, Palmer, McQuoid,

& Flint, 2001; Woolley, Medvene, Kellerman, Base, & Mosack, 2006). O'Brien and associates conducted their study in a nursing home in Philadelphia (O'brien et al., 1995). Goodlin et al. included seriously ill patients from five U.S. hospitals from different census regions (Goodlin et al., 1999).

While the U.S. studies lacked a generalized sample, a few non-US studies have used more representative samples. Carmel et al. conducted two studies on a random sample of the Jewish population of age 70+ receiving a monthly payment from Israeli Institute of National Insurance (Carmel & Mutran, 1997a, 1997b). The studies used the broad category of end-of-life care choices, that is, the use of life-sustaining measures as the study outcome (Carmel & Mutran, 1997a, 1997b). The outcomes for the other studies were more specific including place of death (Hays, et al., 2001); cardiopulmonary resuscitation (Goodlin, et al., 1999; O'brien, et al., 1995) and use of a defibrillator (Woolley, et al., 2006).

Further, the other research have studied the role of health status in influencing the stability of the end-of-life care choices over time (Auriemma et al., 2014; Carmel & Mutran, 1999; Ditto, Jacobson, Smucker, Danks, & Fagerlin, 2006; Fried, O'Leary, Van Ness, & Fraenkel, 2007; Wittink et al., 2008); concordance between the choices and actual end-of-life care (S. Fischer, et al., 2013; Hakim et al., 1996); concordance between the patient and physician reported choices (Desharnais, Carter, Hennessy, Kurent, & Carter, 2007); and concordance between person and proxy reported choices (Pruchno, Cartwright, & Wilson-Genderson, 2009).

Research notes an association between end-of-life care choices uptake and stability, self-reported health and change in health status. Several studies have shown that poor self-reported health and a decline in health status increases the likelihood of life extending terminal care choices (De Gendt, Bilsen, Vander Stichele, & Deliens, 2013; Wagner, Riopelle, Steckart, Lorenz, & Rosenfeld, 2010; Winter, et al., 2003; Winter, Moss, & Hoffman, 2009; Winter & Parker, 2007). However, the literature has not yet reported on an interaction between self-reported health and change in health status in affecting end-of-life care choices. A combination of poor self-reported health and self-reported decline in health can influence the choices differently than a combination of good health and an improvement or no change in health status. Thus, it is imperative to study the association between the self-reported health, change in health status and interaction between the two health measures and end-of-life care choices in a representative population sample.

1.8. STUDY OBJECTIVES AND HYPOTHESES

We undertook two studies: study 1) to determine the factors associated with the combinations of advance care plans among HRS decedents from 2002-2014; and study 2) to determine the factors associated with end-of-life care choices among HRS decedents with a living will from 2002-2014.

Study 1

Objective: To determine the factors associated with the combinations of advance care plans among HRS decedents between 2002-2014

Hypotheses

i) Poor self-reported health is associated with a higher uptake of “all ACPs” (ACP discussion, living will and DPAHC) compared to an excellent self-reported health among HRS decedents between 2002-2014.

ii) A self-reported decline in health status is associated with a higher uptake of "all ACPs" compared to a self-reported improvement or no change in health status among HRS decedents between 2002-2014.

iii) A combination of poor self-reported health and a self-reported decline in health is associated with a higher uptake of "all ACPs" compared to the combination of excellent self-reported health and a self-reported improvement or no change in health among HRS decedents between 2002-2014.

Study 2

Objective: To determine the factors associated with each end-of-life care choice, including limit care in certain situations, comfort care and all care possible among HRS decedents with a living will between 2002-2014

Hypotheses

All care possible choice

i) Poor self-reported health is associated with a higher uptake of "all care possible" choice compared to an excellent self-reported health among HRS decedents between 2002-2014.

ii) A self-reported decline in health is associated with a higher uptake of "all possible care choice" compared to self-reported improvement or no change in health status among HRS decedents between 2002-2014.

iii) A combination of poor self-reported health and a self-reported decline in health is associated with a higher uptake of "all care possible" choice compared to the combination of excellent self-reported health and a self-reported improvement or no change in health status

Limit care in certain situations

i) Poor self-reported health is associated with a lower uptake of “limit care in certain situations” choice compared to an excellent self-reported health among HRS decedents between 2002-2014.

ii) A self-reported decline in health status is associated with a lower uptake of “limit care in certain situations” choice compared to self-reported improvement or no change among HRS decedents between 2002-2014.

iii) A combination of poor self-reported health and a self-reported decline in health is associated with a lower uptake of “limited care in certain situations” choice compared to the combination of excellent self-reported health and self-reported improvement or no change in health status.

Comfort care

i) Poor self-reported health is associated with a lower uptake of “comfort care” choice compared to an excellent self-reported health among HRS decedents between 2002-2014.

ii) A reported decline in health status is associated with a lower uptake of “comfort care” choice compared to self-reported improvement or no change in health status among HRS decedents between 2002-2014.

iii) A combination of poor self-reported health and a self-reported decline in health is associated with a lower uptake of “comfort care” choice compared to the combination of excellent self-reported health and self-reported improvement or no change in health status.

CHAPTER II: BACKGROUND

2.1. ADVANCE CARE PLANNING: A HISTORICAL AND LEGISLATIVE BACKGROUND

Wills for assets and estate planning date back to centuries (De Coulanges, 2012). Salon, a Greek magistrate, wrote the first law for an estate will in 600 BC (De Coulanges, 2012). However, the health care will is a more recent phenomenon. Such a will guides provider and family in fulfilling wishes of the patient, who faces incapacity to speak or decide treatments (Davidson et al., 2015).

In 1969, America became the first country to formally engage in discourse on a health care will. In the aftermath of the discovery of close-chest massage and 'right-to-die with dignity' movement, Luis Kutner, the Illinois based attorney, formally wrote for the first time in 1968 about a need for a health care will (Kutner, 1968). He asserted that a health care will should be documented and notarized. Kutner's document provided an impetus to the right to die movement. Later, first in 1968 and then in 1973, Dr. Walter F. Sackett, an elected member of the Florida State legislative body, tried to convince the state legislature to pass a bill on the health care will (Calder, 1992). However, the bill failed both times (Calder, 1992).

The right-to-die with dignity movement and advance medical will got life after the favorable court decisions on the Karen Ann Quinlan's case in 1976 and Nancy Beth Cruzan's case in 1989 (Annas, 1990; Lawrence & Brauner, 2009). Both women remained in a vegetative (minimally conscious) states for several months after being comatose.

Given that the health care wills were unknown, the parents of the aforesaid women fought the legal battles to withdraw the life-prolonging measures.

After the Quinlan case, in 1976 California became the first state to pass a law called “Natural Death Act” to legitimize the living will for the end-of-life treatment (Jacobs & Martyn, 1984). The impetus provided by Kutner’s initiative, ‘right to die with dignity movement’ and aforesaid cases culminated in the first nationwide Act on health care will in 1991 — the Patient Self Determination Act (PSDA) (Greco, Schulman, Lavizzo-Mourey, & Hansen-Flaschen, 1991).

The Act made it mandatory for the health care institutions, receiving reimbursements from Medicare and Medicaid, to must discuss with the patients about the possibility of formulating an advance care plan, including a living will and DPAHC (Refolo, 1992). PSDA and Terri’s case played a substantial role in influencing advance directives and end-of-life care choices in 1990s and 2000s (Blendon, et al., 2005; PRNewswire, 2005; J. Teno et al., 1997).

2.2. ADVANCE CARE PLANS

The majority of the literature has used the term “advance directives” to indicate formal or documented advance care plans, including living will and DPAHC, and “ACP discussions” to refer to informal plans (Barocas, Erlandson, Belzer, Hess, & Sosman, 2015; Bischoff, et al., 2013; K. Black & Reynolds, 2008; Carr, 2012c; Gerst & Burr, 2008; Mahon, 2011; Meeussen et al., 2011; Rao, et al., 2014; Silveira, et al., 2010; Wilkinson, et al., 2007). Further, studies have used the terms “advance care planning” or advance care planning process” encompassing a process of formulating formal and informal advance care plans.

However, the literature also vary in use of terminology. For instance, President Council on Bioethics referred to ACP discussions as advance care planning and indicated living will and DPAHC as separate directives (President's Council on Bioethics, 2005). Suri et al. used the term ‘care directives” instead of advance directives (Suri, Egleston, Brody, & Rudberg, 1999). The report also referred to DPAHC as “proxy directives”. Bischoff et al. used the term Durable Power of Attorney (DPOA) for DPAHC (Bischoff, et al., 2013). The same authors used the term advance directives for a living will and mentioned DPAHC as a separate directive (Bischoff, et al., 2013). Phipps et al. used the term advance directive for a living will and the term proxy directives for a DPAHC (Phipps et al., 2003). Aldrich et al. used the term advance directives for the directives that include both a living will and DPHAC in a combined document (Benson WF & Aldrich N 2012).

However, for the sake of this study, we have used the term “advance care planning” or ACP as a process of development of advance care plans. Advance care plans include informal plans (ACP discussions) and formal directives (living will and DPAHC).

2.3. DISTINCT NUANCES OF ADVANCE CARE PLANNING

Living will and DPAHC are recognized as legal documents across all the states (Detering, et al., 2016; Lo & Steinbrook, 2004). ACP discussions shape the end-of-life care choices, therefore, these plans have distinct importance (D. K. Martin, et al., 2000).

These directives also influence end-of-care choices and terminal care experience differently.

ACP discussions entail end-of-life discussions between patient, family members and providers. It allows width to discuss varied topics related to end-of-life and end-of-life care, relating person, social or economic aspects of terminal care. In contrast, a living will provides limited choices that apply to situations of incapacity due to terminal illness. These choices relate to limiting and extending terminal care measures, e.g., cardiopulmonary resuscitation, artificial ventilation or feeding tube, and organ donations. A DPAHC documents an agent, a proxy decision maker, to make decisions on behalf of patients, if the patient loses the capacity to make or communicate decisions (Detering, et al., 2016). It reduces the confusion related to end-of-life care among family members (Detering, et al., 2016). However, agents can also misinterpret patient's wishes and choose more care to avoid future regret (Travis, et al., 2002).

2.4. RATE OF ADVANCE DIRECTIVES UPTAKE

As noted earlier, the PSDA and Terri Schiavo's case influenced an upward trend in advance directives (J. Teno, et al., 1997). Several studies, based on HRS, a biennial panel survey that tracks health and retirement indicators among older Americans, reported consistently rising trend of advance directives uptake. For instance, Bischoff et al. reported an uptake rate of 76% between 1993 and 2007 (Bischoff, et al., 2013); Silveira et al. reported 67% between 2000 and 2006 (Silveira, et al., 2010); Khosla et al. reported an increase in the ACP discussion rate by 12% and the DPAHC rate by 24% between

2002 and 2010 (Khosla, et al., 2015). In another study, Silveira et al. reported an increase from 47% to 72% between 2000 and 2010 (Silveira, et al., 2014).

2.5. THEORY AND CONCEPTUAL FRAMEWORK

The terms theory and conceptual framework are distinct concepts (Andersen, 1997). Whereas, a theory encompasses related and testable statements that demonstrate a law like generalizability in explaining and predicting a phenomenon, a conceptual framework provides a logical network of positive and negative associations among the factors and phenomenon that are reported in prior theoretical or empirical researches (Andersen, 1997). In other words, a framework provides a snapshot of how researcher perceives the phenomenon under study and its associated factors. The sections below describe the theory and conceptual framework of our study.

2.6. PROSPECT THEORY

We will use prospect theory as a theoretical lens for our study 1, which probes an association between health status and uptake of advance care plans. In 1979, Kahneman and Tversky proposed prospect theory, a framework for how people decide between comparable choices under uncertainty of outcome (Kahneman & Tversky, 1979). As part of theories of bounded rationality, the prospect theory asserts that people do not always analyze the decision choices based on real probabilities, but rather use intuitions and heuristics to decide (Raue, Streicher, Lermer, & Frey, 2015). Such decisions are based on the highest subjective utility of the choice, irrespective of the objective gains (Raue, et al., 2015).

Prospect theory indicates choice utility under uncertainty as an asymmetrical s-shape curve, concave over gains and convex at losses (Figure 2.1) (Lenert, et al., 1999). In end-of-life care, peak gain and loss domains are perfect health and death, respectively. Winter and Parker asserted healthier person falls more towards the gain domain, while sicker falls in the loss domain (Winter & Parker, 2007). Due to an s-shaped utility curve, healthier patient finds less difference between a future unhealthy state (loss of mobility or coma) and death, due to the flatter convex utility curve for such patients (Figure 2.1). However, the sick patient falls towards the loss domain. Such patients perceive a higher difference between unhealthy state and death. Therefore, they tend to choose more life-extending measures.

Prospect theory suggests that healthy persons would choose not to extend life in situations in which they lose their health. This is because for a healthy person, death is a distant outcome and therefore for them living with a sickness or disability and death represents no real advantage over death. Therefore, they weigh the utility of death and sickness equally. However, for a sick person, death is a closer event. They can concretely distinguish between the utility of being alive with sickness and being dead. Therefore, sick patients prefer to remain alive and choose more life-extending treatments, even if the additional years of life come with sickness or disability.

The theory also explicates that choices vary by choice framing (gain versus loss frame) and temporality to an outcome (Clarke, Evans, Shook, & Johanson, 2005; Winter, et al., 2003; Winter & Parker, 2007). Psychological distance with time (temporality) results in reliance on construal (reality construction) (Raue, et al., 2015). Construal influences decisions. For proximal outcomes, people take decisions with concrete (objective) mindset, while for distal outcomes with an abstract (construal) mindset (Raue, et al., 2015). In other words, proximal outcomes are analyzed based on feasibility, while distal based on desirability. Patient in poor state takes more concrete decision due to a more concrete visualization of the unhealthy state than a healthy person.

The prospect theory has been tested extensively in health and end-of-life care researches (Lenert, et al., 1999; L. L. Phillips, et al., 2011; Winter, et al., 2003; Winter & Parker, 2007). Two critical applications of theory in the arena include, health status interacts with end-of-life care choices (Lenert, et al., 1999; L. L. Phillips, et al., 2011; Winter, et al., 2003). Patient in poor health tends to choose life-extending measures (L. L. Phillips, et al., 2011). The literature indicates that a reference of the person and temporality of choices affects the choices. For instance, sick persons see death as more proximal outcome than healthy people.

The association between health status and end-of-life care choices: Use of prospect theory as a theoretical lens

The majority of the studies that reported the association between health status and end-of-life care choices are atheoretical (Carmel & Mutran, 1997b; Goodlin, et al., 1999; O'brien, et al., 1995; Woolley, et al., 2006). However, the studies that determined an association between health status and end-of-life care choices as their primary objective have used prospect theory as a theoretical lens (Lenert, et al., 1999; Winter, et al., 2003; Winter, et al., 2009; Winter & Parker, 2007). Prospect theory holds that poor health status is associated with life-extending end-of-life care choices (Kahneman & Tversky, 1979).

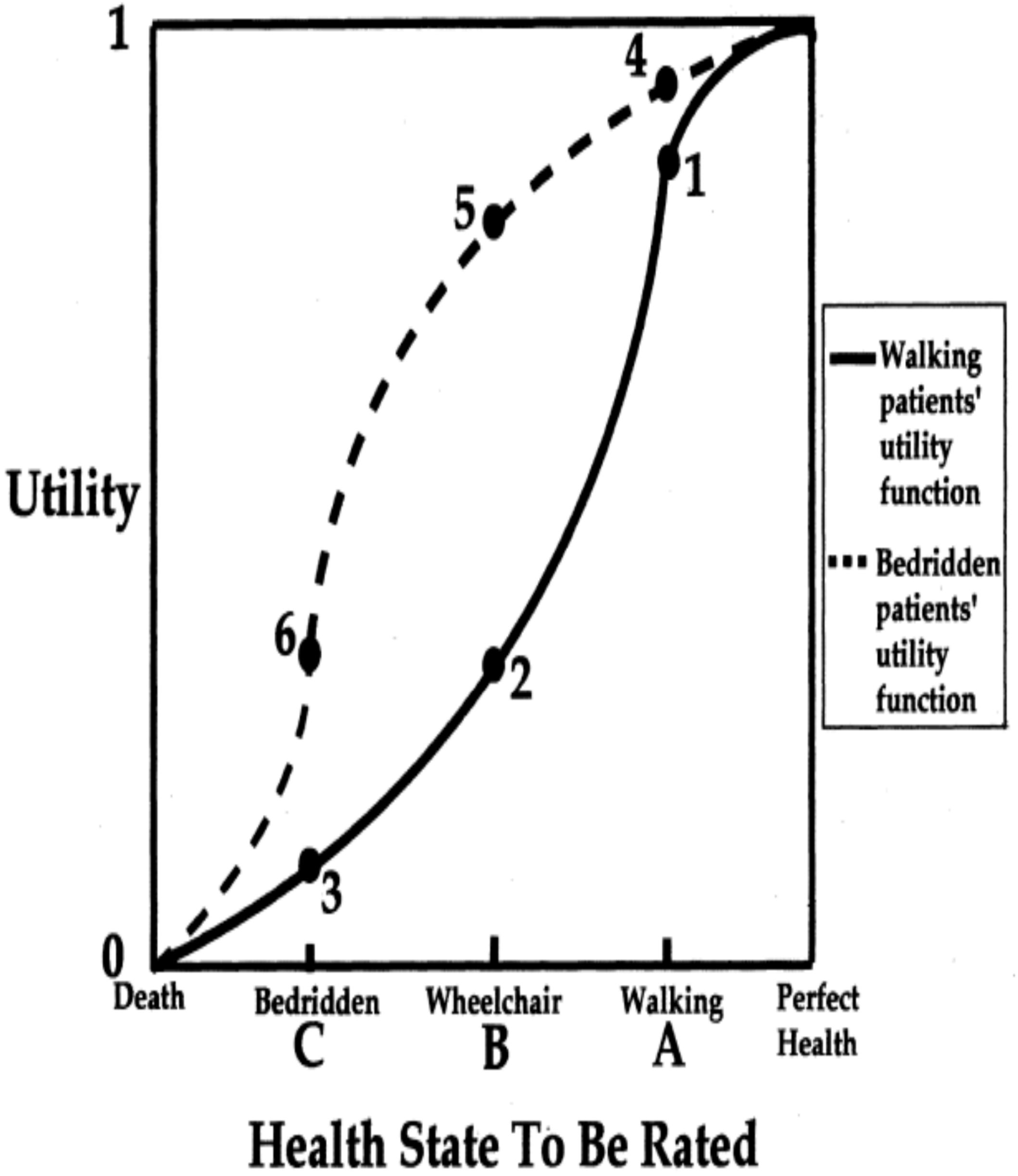

FIG. 1. Prospect Theory predicts that the utility curves for health are S shaped and that the position of the curve will depend on the reference level of health of the individual. This figure shows the hypothetical utility curves for two individuals, one healthy (*solid line*) and one that is ill (*dashed line*). When the healthy person values states B and C, these are far below his reference level states, and, as a result there is little difference between the utility between the two states (point 2 vs. point 3). However, when an ill person values these states, because the inflection point in his utility curve occurs at a lower health status, the difference in utility between will be large (point 5 vs. point 6). For further

Figure 2.1: Prospect theory

Reproduced from: Lenert, L. A., Treadwell, J. R., & Schwartz, C. E. (1999). Associations between health status and utilities implications for policy. *Medical care, 37*(5), 479-489

However, the theory-based studies exploring the relationship between health status and the choices have their own limitation. These studies are based on convenience or non-random samples rather than a population-representative samples. A representative sample allows for a greater generalizability of results (Lenert, et al., 1999).

Further, previous studies examining the association between health status and ACP have used scenarios to elicit end-of-life care choices. The respondents were posed with possible end of life care scenarios to elicit the choices (Lenert, et al., 1999; Winter, et al., 2003; Winter, et al., 2009; Winter & Parker, 2007). The studies reported a higher uptake of life-prolonging choices among individuals with poor health status.

However, in real life people make end-of-life care choices considering their own health and possible end-of-life care circumstances. Further, despite a close association between self-reported health and change in health status, no study has yet examined the association between health status and ACP after controlling for change in health status. Therefore, it is imperative to test the association between health status and end-of-life care choices using prospect theory on a representative sample and people's real-life terminal care choices.

2.7. SELF-REPORTS OF HEALTH STATUS

The end-of-life care literature has frequently adjusted for health status in studying ACP uptake and end-of-life care choices. The information about health status could be extracted from the administrative (also called medical records or claims data) or elicited by using self-reporting of subjective health assessment. The administrative data include physician-diagnosed diseases or disabilities. The validity and reliability of such data are higher than self-reported diseases (M. Baker, Stabile, & Deri, 2004). However, researchers using such data face two issues. First, they report specific diseases, but not health. Health is a complete mental, physical, social, sexual and spiritual health and not merely the absence of disease or infirmity (World Health Organization, 1995). Therefore, the absence of disease does not necessarily mean good health. Second, these data are not easy to access. Therefore, researchers have devised alternative methods to measure disease and health. The measures include self-reported global (overall) health; self-reported change in health status; self-reported diseases and self-reported physical functioning. The literature uses the terms self-rated; self-reported; self-assessed and self-perceived interchangeably.

Table 2-1 provides summary of prior studies on four self-reported measures of health: self-reported global health status; self-reported change in health status; self-reported health conditions and self-reported physical functioning.

Study predictors: self-reported health and self-reported change in health status

Self-reported global health

Self-reported global or overall health is a widely used indicator of health status (Leinonen, Heikkinen, & Jylhä, 1998; McCullough & Polak, 2006; Sulander, Pohjolainen, & Karvinen, 2012). The information is elicited by asking respondents to rate their overall health on a 5-point Likert scale: excellent, very good, fair, poor and worse. In their subjective assessment, respondents consider health conditions; morbidities; perceptions about health conditions and morbidities; physical functioning and vitality (Au & Johnston, 2014; M. Baker, et al., 2004; Doiron, Fiebig, Johar, & Suziedelyte, 2015; Idler, Hudson, & Leventhal, 1999; Layes, Asada, & Kephart, 2012; Wilson, Elliott, Eyles, & Keller-Olaman, 2007). Age, gender, race and education and socioeconomic status influence the rating (N. Black, Johnston, Shields, & Suziedelyte, 2017; Layes, et al., 2012; Sulander, et al., 2012). Respondents vary in use and relative weights of factors in their health assessments. Some people give more weight to health conditions, whereas the others to physical functioning. Therefore, it is not easy to determine what constitutes the overall health rating for each person. Despite this limitation, self-reported global health is considered as a single, simple, valid and reliable predictor of mortality, morbidities and health care use (Badawi et al., 2013; Jylhä, 2009). Poor ratings are associated with a higher mortality, morbidities and health care use (Ambresin, Chondros, Dowrick, Herrman, & Gunn, 2014; Idler & Benyamini, 1997; Idler & Kasl, 1991; Wilcox, et al., 1996). Further, the ratings are also associated with perceptions and trajectory of aging and behaviors including retirement planning and advance care planning (Ekerdt & Bosse, 1983; Sargent-Cox, Anstey, & Luszcz, 2012).

The sections below present the prior research on the four self-reported health status measures including self-reported global health status; self-reported change in health status; self-reported health conditions and self-reported physical disabilities.

Self-reported change in health status

The change in self-reported health is a dynamic measure of health. Research also show that a dynamic measure of health can predict health behaviors and outcome better than static or baseline health status. A higher health care use is associated with a change in health status from fair to worse. Further, change in self-reported health from premorbid (before illness) to postmorbid (after illness) is a better predictor of disability than pre-morbid self-reported health.

Other self-reported health conditions

The self-reports of health conditions are elicited by asking questions with a binary response (‘yes’/’no’) about the common conditions: diabetes, cancer, stroke and psychiatric illnesses, etc. The comparison of self-reports with the physician’s diagnosed diseases reported in the administrative data showed varied results. Martin et al. found that the probability of reporting a disease when it is present (sensitivity) varied by the type of disease among a managed care patient population in the U.S; hypertension 83%; diabetes 73% and hypercholesteremia 59% (L. M. Martin, Leff, Calonge, Garrett, & Nelson, 2000). The probability of not reporting a disease when it is not present ranged from 86% to 99%. Research notes that sensitivity and specificity tend to be higher for serious illnesses (e.g., heart diseases, stroke and cancer) than less serious illnesses (e.g., migraine and eczema) (Doiron, et al., 2015; Manor, et al., 2001). Conversely Baker et al. reported low sensitivity (50%) and specificity (50%) for self-reported health conditions a low validity (M. Baker, et al., 2004). They also found an endogeneity between labor market phenomenon and self-reports of health conditions. Seeking early retirement was associated with a higher reporting of health conditions. Despite varying results, the change in health status has been widely used in the end-of-life research.

Self-reported physical functioning

Self-reports of physical functioning are also an important part of self-assessment of health. Successful aging is reported to be associated with ADLs (Depp & Jeste, 2006;

Era et al., 1997). The functioning is assessed by asking the questions about activities of daily living (ADL): eating; drinking; bathing; walking; sitting; dressing; and taking a shower. Respondents are asked to rate each activity using 1-5 Likert scale; 1 being no assistance is needed and 5 being most assistance needed. The comparison between self-reports of ADL and clinically used performance-based physical functioning measures has shown a close relationship between self-reported physical functioning and performance-based physical functions (Bravell, Zarit, & Johansson, 2011).

Factors associated with self-reports of health conditions

The commonly reported factors associated with self-reported health and physical functioning include age; gender; socioeconomic status; culture; physical and mental health; and vitality.

An interaction between self-rated health and change in self-rated health status

The literature has used self-rated health and change in self-rated health as distinct factors of life quality and health outcomes (Beckett et al., 1996; Leinonen, et al., 1998; Schulz et al., 2006). Bandura and Waltz noted that an effective adaptation to life with a chronic disease is associated with both self-rated health and its change (Badura & Waltz, 1984). However, with mortality, self-reported health has shown association most consistently than change in health status.

Despite a known association between self-reported health and mortality, the factors underlying the association between self-reported health and mortality are largely unknown. Christian et al. noted an association between poor health and elevated serum inflammatory markers. The markers are associated with mortality (Christian et al., 2011). However, the same study did not report an association between change in health status and the markers. Thus, the study refuted the assumption that people consider the recent changes in health in their assessments of self-reported health. The self-reported health and its change should be included as distinct factors in a model explaining life quality and health outcomes.

Researchers are also divided on the importance of self-reported health or change in health status in predicting health outcomes and health care utilization. Some research emphasizes on using change in health status as it is a more dynamic and holistic measure of health status than self-reported health (H.-L. Lee, Huang, Lee, Chen, & Lin, 2012). That said, however, most research has either used the self-reported health or used both the self-reported health and change in it in their analyses. Using both measures in the study, Thomas et al reported a weakening of association between self-reported health and mortality when the change in health status was added to the model (Thomas, Kelman, Kennedy, Ahn, & Yang, 1992). Similarly, Wolinsky et al. noted that addition of change in health status in the model led to a loss of significance in its association between self-reported health and mortality (Wolinsky, Callahan, Fitzgerald, & Johnson, 1993).

Several studies have shown that subjective and objective measures of health are associated with each other (Hamid, Krishnaswamy, Abdullah, & Momtaz, 2010; Murata, Kondo, Tamakoshi, Yatsuya, & Toyoshima, 2006; Park & Lee, 2013; Shooshtari, Menec, & Tate, 2007). However, surprisingly, limited research exists on whether the two variables interact to affect health outcomes. In a singular study, Ambresin explored the interaction between the self-reported health and time, using different parameter of self-reported health in each follow-up year, to determine the effect of change in health status over time on the long-term prognosis of depression (Ambresin, et al., 2014). They found an association between self-reported health and prognosis of depression in all the years of 5-year follow-up period.

The literature lacks a study on an interaction between self-reported health and change in health status in their effect on the uptake of ACPs. Research also reports a strong association between self-reported health and change in health status. The literature also notes that poor health and a decline in health are associated with higher likelihood of completing ACPs and choosing life-extending terminal care options. Thus, people with poor health and a decline in health status can vary in their treatment choices than those who enjoy good health or an improvement or no change in health status.

2.1. FACTORS ASSOCIATED WITH ADVANCE CARE PLANNING AND RELATED CHOICES

Since the choices are part of ACPs, therefore, several studies have reported on both ACPs and choices (Table 2.2). Further, most of the factors associated with the ACPs and the choices are also common (Table 2.3). Therefore, the sections below present the literature on the factors associated with ACPs and the choices.

The literature indicates the demand side (patient) factors influence the ACPs and end-of life care choices and terminal care experience more than the supply side (provider) factors (Dobalian, 2006; Prigerson & Maciejewski, 2012).

Dobalian et al. investigated the role of predisposing (personal), societal (ecological) and facility (provider) factors in the uptake of living will and DNR choice and use of feeding tube during end-of-life care (Dobalian, 2006). The study showed, while

Table 2.1: Summary of the literature reporting on common self-reported health measures

Author	**Title**	**Year**	**Objective**	**Variables**				**Major finding**
				Self-reported global health	Self-reported illnesses	Self-reported change in health status	Self-reported functional status	
Doiron	Does self-assessed health measure health?	2014	To determine if self-reported health predicts the future health and health care utilization	Y	Y	N		Self-assessed health predicts the serious chronic illnesses better than less serious illnesses. Among elderly, the self-reported health and observed measures of health were similar in predicting mortality. However, among younger individuals the self-reports were the only significant predictors of mortality.

Author	**Title**	**Year**	**Objective**	**Variables**				**Major finding**
				Self-reported global health	Self-reported illnesses	Self-reported change in health status	Self-reported functional status	
Baker	What Do Self-Reported, Objective, Measures of Health Measure?	2004	To validate the self-reported specific diseases with objective measures of health	Y	Y	N		Self-reported health conditions provide information that objective measures do not provide. However, they are subject to considerable reporting error. A potential endogeneity was found between self-reports and the labor market phenomena.
Leinonen	"Self-Rated Health and Self-Assessed Change in Health in Elderly Men And Women - A Five year Longitudinal Study"	1998	To determine the gender differences in self-assessed health and change in self-assessed health between the assessments performed at baseline and at follow-up.	Y		Y		People, who reported their change in health status as worse, reported their self-reported health as same or better

Author	**Title**	**Year**	**Objective**	**Variables**				**Major finding**
				Self-reported global health	Self-reported illnesses	Self-reported change in health status	Self-reported functional status	
Sulander	Self-rated health (SRH) and socioeconomic position (SEP) among urban home-dwelling older adults	2012	examine the association of education and adequacy of income with self-rated health (SRH)	Y	N	N		Education and income were associated with SRH
Badawi	Self-rated health: A predictor for the three-year incidence of major depression in individuals with Type II diabetes		To determine an association between self-rated health and incidence of major depression over a three-year follow-up of patients with Type II diabetes.	Y				The diabetics who reported their health as fair and poor were more likely to develop depression.

Author	**Title**	**Year**	**Objective**	**Variables**				**Major finding**
				Self-reported global health	Self-reported illnesses	Self-reported change in health status	Self-reported functional status	
Marja Jylha	What is self-rated health and why does it predict mortality? Towards a unified conceptual model	2009	To determine the process of evaluation which produce self-ratings of health. To determine association between self-rated health and mortality	Y				Patients vary in their use of health and contextual factors in their health ratings. They also vary in assigning weight to each factor that they consider in their ratings. Controlling for health conditions and change in health increases the predictability of self-rated health for mortality Factors including age, culture and gender and physical and mental health affect self-rated health

Author	**Title**	**Year**	**Objective**	**Variables**				**Major finding**
				Self-reported global health	Self-reported illnesses	Self-reported change in health status	Self-reported functional status	
Audrey Layes,	Whiners and deniers - What does self-rated health measure?	2012	To conceptualize the construct of self-rated health	Y				Self-rated health consists of two components: latent health and reporting behavior.
Nicole Au	Self-assessed health: What does it mean and what does it hide?	2014	To determine what components of health Self-assessed health, represent and if the use of self-assessed health conceals important health effects	Y				Respondents considered vitality the most important component in the assessment of health
Nicole Black	Who provides inconsistent reports of their health status? The	2017	To determine the consistency in responses to a standard self-assessed question	Y				The inconsistent reports of health were associated with age, education, cognitive ability, and time

Author	**Title**	**Year**	**Objective**	**Variables**				**Major finding**
				Self-reported global health	Self-reported illnesses	Self-reported change in health status	Self-reported functional status	
	importance of age, cognitive ability and socioeconomic status		by a same individual in a close temporal proximity					between responses are associated with the inconsistent responses
Sargent-Cox	Change in Health and Self-Perceptions of Aging Over 16 Years: The Role of Psychological Resources						Y	The perception of aging associated with decline in ADLs is mediated by psychological resources (self-esteem and expectancy control).
Beth Han	Change in Self-Rated Health and Mortality Among Community-Dwelling Disabled Older Women		To determine if the change in self-rated health is a better predictor of mortality than self-rated health among disabled older women	Y		Y		A change in self-reported health is a stronger predictor of mortality than recent or baseline self-rated health reported

Author	**Title**	**Year**	**Objective**	**Variables**				**Major finding**
				Self-reported global health	Self-reported illnesses	Self-reported change in health status	Self-reported functional status	
Wilcox	Self-Rated Health and Physical Disability in Elderly Survivors of a Major Medical Event	1996	To compare the ability of premorbid and post-illness health perceptions in predicting physical disability independently of medical, psychosocial, and behavioral variables.					Post morbid self-rated health, that is self-rated health at 6 weeks after the illness, predicted disability at 6 months better than premorbid self-rated health, suggesting that changes in health perceptions due to illness influenced the recovery process. The mechanisms by which health perceptions influence recovery, however, was unclear.
Nancy Hoeymans	Age, Time, and Cohort Effects on Functional Status and Self-Rated Health in Elderly Men	1997	To investigate the association between functional status and self-rated health and age	.	Y	Y		Functional status declined with age, but self-rated health did not vary with age among men aged 70 years and older.

individual characteristics and health status influenced a living will, DNR choice and feeding tube use, supply side factors, including facility size, location and for-profit and chain status did not.

The literature also includes sex, age, race/ethnicity, marital status, education, income, religion, home ownership, the estate will and health status as factors associated with ACP and choices (Carr & Khodyakov, 2007; Detering, et al., 2016; Dobalian, 2006; Amy S Kelley, Morrison, Wenger, Ettner, & Sarkisian, 2010; Prigerson & Maciejewski, 2012). Further, the role of health status (Bambauer & Gillick, 2007; Winter, et al., 2003; Winter, et al., 2009; Winter & Parker, 2007) and religion (Daaleman & VandeCreek, 2000; Garrido, et al., 2013; Koenig, 2012; Koss, 2017) on ACP and choices has been studied more closely (Amy S Kelley, et al., 2010; Prigerson & Maciejewski, 2012).

Patient factors

Sex

Analogous to the trends in other health domains in the U.S., most end-of-life care research reports sex does not influence ACP and choices (Barocas, et al., 2015; Dobalian, 2006; Gordon & Shade, 1999; Lovell & Yates, 2014; Mahaney Price et al., 2014). Nonetheless, a few studies have reported sex influences ACP and choices. Alano et al. reported females being more likely to have advance directives (Alano et al., 2010).

However, the study was based on 125 patients aged >65 years from three tertiary care facilities in New York. Conversely, Carr et al. reported females being less likely to report a living will and more likely to report ACP (Carr & Khodyakov, 2007).

Table 2.2: A review of studies on factors associated with advance care plans and end-of-life care choices

Author	Year	Data	Advance Care Plans			Other directives		End-of-life care choices			Details
				Advance directives		DNR *	DNH †	Care-limiting choices	Life-extending choices	Comfort care	
			ACP discussions	Living will	DPAHC §						
Barocas	2015	University of Wisconsin (UW) Hospital and Clinics in Madison, Wisconsin		X	X						
Khosla	2015	HRS‡	X	X	X						
Lovell	2014	Review of studies	X								
Nicholas	2014	HRS		X							
Eunjeong Ko	2014	Community survey of low income elderly - homeless, transitional housing,		X	X						

Author	**Year**	**Data**	**Advance Care Plans**			**Other directives**		**End-of-life care choices**			**Details**
				Advance directives		**DNR ***	**DNH †**	**Care-limiting choices**	**Life-extending choices**	**Comfort care**	
			ACP discussions	**Living will**	**DPAHC §**						
		single room occupancy motels and community residing individuals									
Rao	2014	HealthStyles Survey		X	X						
Waite	2013	Patients visiting federally qualified health centers in Chicago, Illinois		X	X						
Puente	2013	Interviews of patients visiting two health centers in the Albacete		X	X						

Author	Year	Data	Advance Care Plans			Other directives		End-of-life care choices			Details
				Advance directives		DNR *	DNH †	Care-limiting choices	Life-extending choices	Comfort care	
			ACP discussions	Living will	DPAHC §						
		Health District, Spain									
Fischer	2013	3 hospitals affiliated with the University of Colorado School of Medicine Internal Medicine Residency program						X	X		Location of death
Hirschman	2012	Interviews with long-term services and support dwellers		X	X						

Author	**Year**	**Data**	**Advance Care Plans**			**Other directives**		**End-of-life care choices**			**Details**
				Advance directives		**DNR ***	**DNH †**	**Care-limiting choices**	**Life-extending choices**	**Comfort care**	
			ACP discussions	**Living will**	**DPAHC §**						
Johnson	2012	All adult patients admitted to the 16-bed CCU at Duke University Medical Center from March 2008 through June 2009		X	X						
Koen Meeussen	2011	Review of studies	X	X	X						
Alano	2010			X	X						
Pruchno	2009	Telephone survey of ESRD patients in the U.S.							X		Dialysis

Author	Year	Data	Advance Care Plans			Other directives		End-of-life care choices			Details
				Advance directives		DNR *	DNH †	Care-limiting choices	Life-extending choices	Comfort care	
			ACP discussions	Living will	DPAHC §						
Triplett	2008	Records of Maryland Nursing Home		X	X						
Gerst	2008	HRS	X	X	X						
Black	2008	Telephone survey of older women in Manatee and Sarasota Counties in Southwest Florida	X	X	X						
Ramsaroop	2007	Review of studies		X	X						
Campbell	2007	Convenient sample of community dwellers in Tennessee		X	X						

Author	**Year**	**Data**	**Advance Care Plans**			**Other directives**		**End-of-life care choices**			**Details**
				Advance directives		**DNR ***	**DNH †**	**Care-limiting choices**	**Life-extending choices**	**Comfort care**	
			ACP discussions	**Living will**	**DPAHC §**						
Carr	2007	Wisconsin Longitudinal Study	X	X	X						
Fried	2007							X	X		Inconsistency in EOL choices
Dobalian	2006	Nursing Home Component (NHC) of the Medical Expenditure Panel Survey (MEPS)		X				X			
Ditto	2006	Advance Directives, Values Assessment, and Communication Enhancement							X		

Author	Year	Data	Advance Care Plans			Other directives		End-of-life care choices			Details
				Advance directives		DNR *	DNH †	Care-limiting choices	Life-extending choices	Comfort care	
			ACP discussions	Living will	DPAHC §						
		(ADVANCE) project.									
Wooley	2005	Interviews with residents of continuing care retirement community (CCRC)							X		CPR
Levy	2005	Medicare skilled nursing home data				X	X				
Buchanan	2004	Nursing home Minimum Data Set (MDS)									
Rosnick	2003	Charlotte County (Florida)		X	X						

Author	Year	Data	Advance Care Plans			Other directives		End-of-life care choices			Details
				Advance directives		DNR *	DNH †	Care-limiting choices	Life-extending choices	Comfort care	
			ACP discussions	Living will	DPAHC §						
		Healthy Aging Study									
Beck	2002	Randomized Controlled Trial		X	X						
Hays	2001	continuing-care retirement community (CCRC) in Central North Carolina						X	X		Place of death
Suri	1999	CMS - Minimum Data Set+ (MDS+)		X	X	X					
Goodlin	1999	The study to understand prognosis and preferences for outcomes							X		CPR

Author	**Year**	**Data**	**Advance Care Plans**			**Other directives**		**End-of-life care choices**			**Details**
				Advance directives		**DNR ***	**DNH †**	**Care-limiting choices**	**Life-extending choices**	**Comfort care**	
			ACP discussions	**Living will**	**DPAHC §**						
		and risks of treatments (SUPPORT 1989-94)									
Morrison	1998	HRS			X						
Hammes	1998	La Crosse Advance Directive Study (LADS)		X	X						
Bradley	1998	Six nursing homes in Connecticut		X	X						
Carmel	1997	Records of the Israeli Institute of National Insurance (NI)							X		
Murphy	1996	Senior Citizen Center in LA		X	X						

Author	**Year**	**Data**	**Advance Care Plans**			**Other directives**		**End-of-life care choices**			**Details**
				Advance directives		**DNR ***	**DNH †**	**Care-limiting choices**	**Life-extending choices**	**Comfort care**	
			ACP discussions	**Living will**	**DPAHC §**						
Hakim	1996	5 teaching hospital		X	X				X		
O'Brien	1995	Interviews with nursing home residents in Consolidated Metropolitan Statistical Area in PA							X		
Sugarman	1992	Interviews with Veterans visiting VA medical facility at Durham, NC		X							

Note: * Do not resuscitate; † Do not hospitalize; ‡ Health and Retirement Study; § Durable Power of Attorney for Health Care

Table 2.3: The studies reporting on the association between health status, advance care plans and end-of-life care choices

Author	**Year**	**Data**	**Setting/patient population**	**Theory**	**Sample size**	**Community / population-based sample**	**Health rating**	**Other health status related variables**	**Finding**	**Other details**
Studies showing no association between health status and ACP										
Beck et al.	2002	Author driven	HMO patients	NM*	735	No	Self-reported	#	No association	59% response rate
Gordon et al.	1999	Authors driven	Large HMO patients	NM	5117	No	Self-reported	Heart attack, Angina or stroke in the past year	No association	80% on 4th attempt Data imputed
Gerst et al.	2008	HRS decedent	Community	NM	1102	Yes	Self-reported	Number of illnesses/ Comorbidities	No association	Decedents in 2000
Garrido et al.	2013	Patients in outpatient care in NJ	Two hospital clinics and Cancer center in New Jersey	Common sense model	305	No	Self-reported	Number of chronic conditions and ADL/IADL average difficulty score	No association	

Author	Year	Data	Setting/patient population	Theory	Sample size	Community / population-based sample	Health rating	Other health status related variables	Finding	Other details
Hopp	2000	AHEAD † (HRS) - Public release	Community based 70 years and old Americans	Cantor's hierarchical compensatory model	520	Yes	Self-reported	#	No association	
Carr et al	2009	WLS‡	Participants who graduated from Wisconsin High School in 1957	Theory of reasoned action	5106	No	Self-reported	Depression and life-threatening illness	No association	
Carr et al	2007	WLS	Participants who completed telephonic or phone interview in 1992-1993 and 2003-04	NM	3838	No	Self-reported	#	No association	
Studies showing a mixed association between health status and ACP										
Sharp et al	2012	WLS	Participants who completed telephonic or	Classic secularization theory (as religion	2678	No	Self-reported	-	Life-extending choices if faced	

Author	Year	Data	Setting/patient population	Theory	Sample size	Community / population-based sample	Health rating	Other health status related variables	Finding	Other details
			phone interview in 1992-1993 and 2003-04 who received questions on EOL care and religion	was the focus of the study)					with severe cognitive impairment but not physical pain	
Karches		Hospital data	Patient population	NM	8308	No	Self-reported	Charlson Comorbidity Index	Self-reported scores of 0-20 associated with a living will but no other category of score was associated with a living will or DPAHC	

Author	**Year**	**Data**	**Setting/patient population**	**Theory**	**Sample size**	**Community / population-based sample**	**Health rating**	**Other health status related variables**	**Finding**	**Other details**
Carr	2012	WLS		Link and Phelan theory	2111	No	Self-reported	#	Self-reported scale and ACP discussions but not with a living will or DPAHC	
Studies showing association between health status and ACP										
Harrison et al.	2016	NHATS §	Medicare beneficiaries of age 65 and over	NM	2015		Self-reported	ADL Dementia Number of chronic conditions	Significant association between health status and ACP discussions, living will and DPAHC. People with good or	

Author	**Year**	**Data**	**Setting/patient population**	**Theory**	**Sample size**	**Community / population-based sample**	**Health rating**	**Other health status related variables**	**Finding**	**Other details**
									poor/fair health were less likely to have ACP discussions, a living will or DPAHC	
Lenert	1999	Author driven	Two primary care practices in Los Angeles and suburban Maryland	Prospect	139	No	SF-12	Descriptive analysis of seven chronic conditions commonly reported among elderly	Poor health was associated with higher utility among sick than healthy patients	Scenario based questions
Winter	2003	Author driven	Elderly in retirement communities in PA‖	Prospect	394	No	Self-reported	#		Scenario based questions

Author	**Year**	**Data**	**Setting/patient population**	**Theory**	**Sample size**	**Community / population-based sample**	**Health rating**	**Other health status related variables**	**Finding**	**Other details**
Winter	2007	Author driven	Elderly in PA invited via center posters, mails and newspaper ads	Prospect	364	No	Activities of daily living	Scenarios based on common health/ terminal conditions	Less healthy people chose more life-prolonging measures	Scenario based questions
Winter	2009	Author driven	Subset of a quality of life study (n=603) - elderly were informed and invited via posters, mails and ads	Prospect	230	No	Activities of daily living	#	Healthier people live shorter when quality of life deteriorates	Scenario based questions

Notes: * NM: Not mentioned; † AHEAD: Asset and Health Dynamics among the Oldest Old; ‡ WLS: Wisconsin Longitudinal Study; § NHAT: National Health and Aging Trend Study; || PA: Pennsylvania; #: Included no other health status indicator

Reports also indicate end-of-life care choices vary by sex. Women fear death more than men (Cicirelli, 2001), discuss meaning of death more (K. E. Steinhauser et al., 2000), opt less for cardiopulmonary resuscitation (R. S. Phillips et al., 1996) and intubation (Dales et al., 1999). Carr et al. argued that women tend to forego life-prolonging measures, because being caregivers themselves, they understand the toll their families will face in taking care of them in conditions like coma (Carr & Moorman, 2009).

Age

Older age increases frailty, physical vulnerabilities and health risks (Carr, 2012a). Therefore, elderly are more likely to plan for end-of-life care (Bravo, Dubois, & Paquet, 2003; Lambert et al., 2005; J. M. Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007; U.S. Department of Health and Human Services, 2008). Older age also increases the likelihood of foregoing life-extending measures (Dobalian, 2006). Dobalian et al. reported higher rates of DNR among patients aged 75+ (Dobalian, 2006).

Rao et al. studied rate of advance directives among people aged 18 or older. They reported an overall uptake of 26.3%, with 12% of 18–34 years and 51% of 65 and older possessing advance directives (Rao, et al., 2014). Teno et al. indicated 70.7% elderly having written directives (Joan M Teno et al., 2004). In another study, Teno et al. reported a mean age difference of about 7 years among those with and without advance directives (J. M. Teno, et al., 2007). Mahaney Price et al., reported an average age of veterans with a living will 10 years higher than without it (Mahaney Price et al., 2014). Barocas et al. reported a higher advance directives completion rate among HIV patients aged 45 years and older, compared with those aged less than 45 years (Barocas, et al., 2015).

Race and ethnicity

Several researchers have studied race and ethnicity as correlates of ACP and related choices (Eleazer et al., 1996; S. Fischer, et al., 2013; McKinley, Garrett, Evans, & Danis, 1996; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998; Sugarman, Weinberger, & Samsa, 1992; Wagner, et al., 2010). Race influences social perceptions, attitudes and behaviors towards health care (Levin, 1999). Studies show a higher mistrust and distrust among blacks about the health care system (Institute of Medicine, 2014; Kwak & Haley, 2005; Searight & Gafford, 2005). Minorities also tend to live in poor neighborhoods limiting their access to resources including health care (Subramanian, Acevedo-Garcia, & Osypuk, 2005).

As with other health behaviors and outcomes, advance care plans and terminal care choices rates vary by race (Dobalian, 2006; Mack et al., 2012; Rao, et al., 2014; U.S. Department of Health and Human Services, 2008). Minorities view health care and advance directives discriminatory and prejudicial (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Kwak & Haley, 2005). Blacks and other minorities demonstrate lower advance directives rates than Whites (Alano et al., 2010; Bullock, 2011; Dobalian, 2006; S. M. Fischer, Sauaia, Min, & Kutner, 2012; Giger, Davidhizar, & Fordham, 2006; F. P. Hopp & Duffy, 2000; Johnstone & Kanitsaki, 2009; Koss, 2017; Kwak & Haley, 2005; Lovell & Yates, 2014; Mack, et al., 2012; Mahaney Price, et al., 2014; Rao, et al., 2014; J. M. Teno, et al., 2007; U.S. Department of Health and Human Services, 2008). Further, blacks tend to keep directives informal, rather than documenting them as a living will or

DPAHC (Dupree, 2000). Finally, blacks are also more likely to choose aggressive end-of-life care options (Eleazer, et al., 1996; McKinley, et al., 1996).

Socioeconomic status (Education and income)

The definition of socioeconomic status varies in the literature. Most research utilized education, occupation and income to determine socioeconomic status (Adler & Ostrove, 1999; Alano, et al., 2010; Dow et al., 2009; High, 1993; Johnson, Kuchibhatla, & Tulsky, 2008; Khosla, et al., 2015; Murphy et al., 1996; Phipps, et al., 2003; Reczek, Liu, & Brown, 2014; Shoham, Vupputuri, & Kshirsagar, 2005), however, a few other researchers have also included health insurance and home and car ownership as part of the measurement of socioeconomic status (Carr, 2012b; S. M. Fischer, et al., 2012; Muni, Engelberg, Treece, Dotolo, & Curtis, 2011).

In their seminal work, Link and Phelan defined socioeconomic status as a fundamental cause of mortality disparity (Link & Phelan, 1995). They used income, occupation and education classify socioeconomic status (Link & Phelan, 1995; Jo C. Phelan, Link, & Tehranifar, 2010). Link and Phelan posited socioeconomic status influences social conditions that determine the access to community resources. The authors asserted more than proximal factors, such as race, socioeconomic conditions influence health. Thus, the authors labeled socioeconomic status as a fundamental cause of mortality differences.

Link and Phelan recommended four distinct criteria to qualify a fundamental cause — it must 1) influence multiple disease outcomes; 2) affect outcomes through multiple risk factors; 3) demonstrate its association with mortality over time and with different intervening mechanisms; and, 4) most importantly, reduce the access to resources that are necessary to avoid disease and its consequences (Link & Phelan, 1995). Previous researches have used Link and Phelan's theory to demonstrate racial and ethnic differences in ACP (Carr, 2012b, 2012c; Khosla, et al., 2015).

As mentioned earlier, the other end-of-life care researchers did not mention Link and Phelan theory explicitly, albeit using one or more individual socioeconomic factors (Carr, 2012a; Dobalian, 2006; Khosla, et al., 2015; Miesfeldt et al., 2012; Winter, et al., 2009). For instance, Dobalian et al. reported people living in <400% of the federal poverty line are less likely to document a living will (Dobalian, 2006).

Several other studies have also demonstrated a higher ACP uptake rate among educated and high income earners (Alano, et al., 2010; Detering, et al., 2016; Dobalian, 2006; Ko & Lee, 2014; Prigerson & Maciejewski, 2012; Rao, et al., 2014; J. M. Teno, et al., 2007; Waite et al., 2013). Studies have also demonstrated that education influences both informal and formal ACP (Carr & Khodyakov, 2007; Lovell & Yates, 2014); (Bradley, Wetle, & Horwitz, 1998; Detering, et al., 2016; Palker & Nettles-Carlson, 1995).

Further, educated individuals are also more likely to forego aggressive care (O'brien, et al., 1995; Suri, et al., 1999). Finally, studies have also reported on an interplay between education, estate planning and ACP (Institute of Medicine, 2014; Khosla, et al., 2015; Lovell & Yates, 2014; Mahaney Price, et al., 2014); (Carr, 2012a; Joffe, Mello, Cook, & Lee, 2007; Amy S Kelley, et al., 2010; Van Leuven, 2012).

Converse to a general trend, Khosla et a. reported income associated with DPAHC, but not with the other types of ACP (Khosla, et al., 2015). The authors posited higher education increases the likelihood of estate planning, which attorneys use to encourage individuals to complete DPAHC (Khosla, et al., 2015). Similarly, Alano et al. reported education, but not income associated with advance directives completion (Alano, et al., 2010).

Marital status

Prior studies determining predictors of ACP, end-of-life care choices, terminal care experiences and mortality, have adjusted marital status as a potential confounder (Bischoff, et al., 2013; Carr, 2012a; Degenholtz, Rhee, & Arnold, 2004; Dobalian, 2006; Hammes, et al., 2010; Joffe, et al., 2007; Jo C Phelan, Link, Diez-Roux, Kawachi, & Levin, 2004; Silveira, et al., 2010; Winter, et al., 2009). Carr et al. reported married people are more likely to hold end-of-life care discussions and mostly (90%) with their partners (Carr & Khodyakov, 2007).

The majority of studies, however, did not report an association between marital status and ACP or end-of-life care choices (M. J. Campbell, Edwards, Ward, & Weatherby, 2007; Carr & Khodyakov, 2007; Dobalian, 2006; Gordon & Shade, 1999; Hammes & Rooney, 1998; Joffe, et al., 2007; Koss, 2017; Resnick & Andrews, 2002). Among the few studies that reported an association, Silveira et al. and Teno et al. reported a lower advance directives rate among married (Silveira, et al., 2014); (J. M. Teno, et al., 2007). Conversely, Mack et al., Triplett et al. and Halper et al. reported a higher rate among married (Mack, et al., 2012; Triplett et al., 2008); (Halpern et al., 2013). Further, Wooley et al. demonstrated married persons having a positive view about automated external defibrillators (AED) — an automated portable device that restores normal heart rhythms in case of arrhythmias (Woolley, et al., 2006).

Religion

Religion provides coping with poor prognosis and bad news (Steinberg, 2011). Garrido et al. found spirituality associated with less likelihood of having an advance directives including living will and DPAHC (Garrido, et al., 2013). Believing in miracles and in the notion that those who believe in God do not have to plan for end-of-life care reduces the uptake of directives and care-limiting end-of-life choices (Balboni et al., 2007; Institute of Medicine, 2014; Johnson, Elbert Avila, & Tulsky, 2005).

Several studies have probed religious affiliation or religiosity as covariates of advance directives (C. L. Campbell, Williams, & Orr, 2010; Daaleman & VandeCreek, 2000; Garrett, Harris, Norburn, Patrick, & Danis, 1993; Halpern, et al., 2013; McMahan, Knight, Fried, & Sudore, 2013). Religious affiliations could be different forms of Christianity and other religions and no religion. Religiosity relates to belief in God and attending religious sermons and congregations. Research reports that the wishes about hastening of death are associated with having “no religion”, whereas the fear of death is associated with poor health status (Sullivan, Ormel, Kempen, & Tymstra, 1998). Most religions prohibit euthanasia (mercy killing), but allow for limiting end-of-life care considering the finite nature of life (Steinberg, 2011).

Daaleman et al. found religious affiliation to be negatively associated with advance directives — Catholics and Protestants were less likely to engage in ACP than the persons with no religion (Daaleman & VandeCreek, 2000). Using religion to cope with life stresses, called ‘positive religious coping’, is also associated with documenting advance directives (Maciejewski et al., 2012; Phelps et al., 2009). Religious affiliation is also associated with life-prolonging are choices and wish for more years of life (L. L.

Phillips, et al., 2011). Catholics choose more life-prolonging care choices than people with no religion (Alano, et al., 2010; Malloy, Wigton, Meeske, & Tape, 1992).

While most research reports an association between religion and ACP and care choices, some research also reports no association (Ehman, Ott, Short, Ciampa, & Hansen-Flaschen, 1999; Heeren, Menon, Raskin, & Ruskin, 2001; Karches, Chung, Arora, Meltzer, & Curlin, 2012). Koss et al. reported religious affiliation associated with ACP discussions but not with written directives (Koss, 2017). The same study found that service attendance and

The studies on religiosity and end-of-life care choices have yielded mixed results. While Carmel and Mutran reported religiosity being associated with life-extending end-of-life care choices (Carmel & Mutran, 1997a, 1997b), the studies show no association (Morrison, et al., 1998; Resnick & Andrews, 2002; Wright et al., 2008).

Research also reports an interplay among religious affiliation, religiosity, race and health status and ACP uptake. Powel et al. noted religiosity reduces cardiovascular risks by mediating a healthy lifestyle (Powell, Shahabi, & Thoresen, 2003). Daaleman et al. blacks being more religious than whites (Daaleman & VandeCreek, 2000). Karches et al. reported while white Catholics, Protestants and Evangelicals preferred not have life-extending measures in the face of disease where cure is impossible, their black counterparts preferred “do as much as you can” option (Karches, et al., 2012). Protestant blacks and other religion whites were less likely to engage in ACP (Daaleman & VandeCreek, 2000).

Health Insurance

Uninsured individuals demonstrate poor health care access and health outcomes (D. W. Baker, Sudano, Albert, Borawski, & Dor, 2001). However, the end-of-life care literature generally reports no association between insurance and ACP and related choices (S. M. Fischer, et al., 2012); (Barocas, et al., 2015; S. M. Fischer, et al., 2012; J. M. Teno, et al., 2007; Wright, et al., 2008). However, Dobalian et al. found Medicaid beneficiaries being less likely to report advance directives than Medicare population (Dobalian, 2006). Rhodes et al. reported palliative and hospice providers indicating lack of insurance among black patients a barrier to ACP (Rhodes, Batchelor, Lee, & Halm, 2015).

Health status

Like religion, health status has also been addressed extensively as a factor influencing ACP, choices and care experience. Several studies reported variation in ACP uptake by individual health status (Barocas, et al., 2015; Carr, 2012a; Douglas K Martin, Thiel, & Singer, 1999; Sullivan, et al., 1998; Van Leuven, 2012). Sullivan et al. reported bad health associated with fear of death (Sullivan, et al., 1998), which relates with either not having any plans for end-of-life care or choice of life-prolonging measures (Carr, 2012c; Larson & Tobin, 2000). Cicirelli noted higher fear of death among females and younger individuals (Cicirelli, 2001). The same author also noted that the fear of death drives a choice to live longer and achieve more in life (Cicirelli, 2001).

The literature has also studied a role of health status in ACP in the light of prospect theory. Winter et al. demonstrated poor health associated with life-extending measures (Winter, et al., 2003; Winter, et al., 2009; Winter & Parker, 2007). Conversely, Ditto et al. reported patients were less likely to opt for life-extending measures after hospitalization, compared with before hospitalization (Ditto, et al., 2006). They suggested experience of direct discomfort of hospitalization changed patient minds.

Notably, the definition of health status varies in end-of-life care literature. Studies have also used self-reported mobility, physical health or comorbidities as a proxy to health status (Ditto, et al., 2006; Joffe, et al., 2007; Musich, Wang, Hawkins, & Yeh, 2015; O'brien, et al., 1995; Resnick & Andrews, 2002; J. M. Teno, et al., 2007). However, most studies used global Self-reported health scale (Carr, 2012a; Carr & Moorman, 2009; Gordon & Shade, 1999; Harrison, et al., 2016; Koss, 2017; McMahan, et al., 2013; K. E. Steinhauser, et al., 2000; Woolley, et al., 2006).

Self-perceived overall health status entails individuals to rate their health on a Likert rating scale ranging from excellent to poor (Idler & Kasl, 1991). Research indicates use of single item self-perceived wellbeing as a valid and reliable measure of overall health (Andrews & Withey, 1974). The scale has demonstrated excellent validity and reliability in predicting health care utilization and patient survival (Chamberlain et al., 2014; Idler & Benyamini, 1997). Reviewing studies from 1980s and 1990s, Idler and Benyamini reported consistent reports on a high correlation between Self-reported health and mortality (Idler & Benyamini, 1997). They called the Self-reported overall health as “global Self-reported health”. Recently, Chamberlin et al. have also reported heart failure patient rating health as poor or fair respectively, were 70% and 50% more likely to experience hospitalization or emergency visit, compared with those rating their health as good or excellent (Chamberlain, et al., 2014). Therefore, we will use single item global

Self-reported health as a measure of overall health in our study. The other specific health scales used in end-of-life care literature include, SF-12 (S. M. Dunlay, Swetz, Mueller, & Roger, 2012) and Groningen Frailty Index (GFI) (Van Leuven, 2012) and other disease specific scales to assess health status (Zhang et al., 2009).

A less than 6% deaths are truly sudden with most people living a long life with progressive comorbidities and disability (US Department of Health Human Services, 2006). Comorbidities influence prognostication of patient outcomes and therefore helps care provider determine the futility or usefulness of end-of-life care (Charlson, Szatrowski, Peterson, & Gold, 1994; Elixhauser, Steiner, Harris, & Coffey, 1998; Institute of Medicine, 2014; Menendez, Neuhaus, van Dijk, & Ring, 2014). Further, people with older age suffer from comorbidities that reflect on their health status (US Department of Health Human Services, 2006). Therefore, studies have utilized comorbidities along with the global health status or physical mobility to determine health status (Happ et al., 2002; Heyland et al., 2013; Waite, et al., 2013).

Researchers also vary in their selection and dealing with comorbidities. In their recent report to congress, the U.S. Department of Health and Human Services, identified cancers; organ system failure (mainly heart, lung, liver and kidney failure); dementia, and stroke as the leading causes of death in the U.S (US Department of Health Human Services, 2015).

Some other researchers have used validated composite comorbidity indices, including Charlson and Elixhauser indices measure patient comorbidities based on the International Classification of Diseases (ICD) codes (Charlson, et al., 1994; Elixhauser, et al., 1998). Charlson uses 17 comorbidities, while Elixhauser includes 31 comorbidities

(Menendez, et al., 2014). The indices use weighting and scoring algorithms to assign a score to a patient (Menendez, et al., 2014). Musich et al. utilized both Charlson comorbidity index and individual health problems including heart problems; stroke; breathing problems; digestive problems; musculoskeletal; diabetes and depression as correlates of advance directives (Musich, et al., 2015). Conners et al. categorized diseases in four categories, namely, acute organ failure, chronic diseases, non-traumatic coma and cancers (Connors, Jr, Dawson, Desbiens, & et al., 1995). Further, researchers have also included Self-reported health, body mass index (BMI) and smoking status along with comorbidities as part of health status determination (Musich, et al., 2015).

Waite et al. aggregated morbidities into a single variable (Waite, et al., 2013). However, comorbidities also differ in their effect of directives and choices. For instance, Danis et al. reported depressed patients demonstrate less stable and more aggressive end-of-life care choices (Danis, Garrett, Harris, & Patrick, 1994). Heyland et al. reported a higher ACP uptake rate among hospitalized elderly patients with Chronic Obstructive Pulmonary Disease (COPD), Congestive Heart Failure (CHF) and Cancer (Heyland, et al., 2013).

Studies have also used dependency and functional impairment as a proxy to health status and found them associated with the ACP and choices uptake (De Gendt, et al., 2013; J. M. Teno, et al., 2007; Wagner, et al., 2010). A higher physical mobility is found to be associated with a higher ACP rate and care-limiting end-of-life choices (McMahan, et al., 2013; Morrison, et al., 1998; Shadbolt, Barresi, & Craft, 2002). However, O’Brian et al. reported nursing home residents with high physical mobility were more likely to opt for cardiopulmonary resuscitation (CPR) (O'brien, et al., 1995).

Finally, a change in health status or hospitalization can also trigger ACP or change end-of-life care choices (Emanuel, Barry, Emanuel, & Stoeckle, 1994; Fried, et al., 2007; Lovell & Yates, 2014). Leuven et al. reported a lengthy decline in health status with multiple hospitalization associated with ACP (Van Leuven, 2012). Change in health status also couples with change in end-of-life care choices (Ditto, Hawkins, & Pizarro, 2005; Emanuel, Emanuel, Stoeckle, Hummel, & Barry, 1994). Fried et al. showed worsening health associated with care-limiting choices (Fried, et al., 2007).

Given that reports indicate change in choices in the face of the actual situation (Lynn, et al., 2000), Maxfield et al., Detering et al. and Kass-Bartelmes et al. recommended a review of end-of-life care choices whenever patient health status changes (Detering, et al., 2016; Barbara L Kass-Bartelmes & Ronda Hughes, 2004; Maxfield, Pohl, & Colling, 2003). Poor health also couples with life-extending end-of-life care choices (Winter, et al., 2003; Winter, et al., 2009; Winter & Parker, 2007). Psychiatric illnesses interact with health and value for health (Lenert, et al., 1999). However, some others have found no difference in advance directives uptake by health status (Beck, et al., 2002; A. S. Kelley, et al., 2011).

For study one, we will include the Self-reported or global health status and comorbidities that can possibly be associated with the ACP. We will also include the medical conditions that are most commonly reported to be associated with death, including cancers; organ system failure (mainly heart, lung, liver and kidney failure); dementia, and stroke (U.S. Department of Health and Human Services, 2008; Wilkinson, et al., 2007). Finally, we will include the variables related to the difficulty in performing activities of daily living (ADL). The ADL indicators included in the HRS data include difficulty in eating, dressing, bathing and getting in and out of bed and walking across the room.

2.2. SELF-REPORTED HEALTH AND CHANGE IN HEALTH STATUS AS THE STUDY PREDICTORS

Health status has been among the factors that have received more attention from the studies reporting the factors associated with ACP. However, the previous research has remained equivocal in reporting the association between self-reported health and ACP. While few studies have shown no association between health status and ACP, the others have shown an association (Table 2.3). Therefore, in our first study, we attempted to clarify the relationship between health status and ACPs. We used self-reported health and self-reported change in health status and interaction between the two factors as the study predictors and combinations of ACPs as the outcome. We used the combinations of ACPs as in real life the ACPs exist in combinations more than independently.

In our second study, we explored the association between health status and end-of-life care choices using prospect theory as a theoretical lens. The theory proposes that people in poor health will choose life-extending end-of-life care measures. No study has yet reported tested the role of prospect theory in predicting the association between health status and end-of-life care choices on a representative population sample. Therefore, we are the first to report the association on a representative population using prospect theory as a theoretical lens.

We undertook two studies with the objectives: 1) to determine the factors associated with the combinations of advance care plans among HRS decedents from

2002-2014 and 2) to determine the factors associated with end-of-life care choices among HRS decedents with a living will from 2002-2014. The objectives and measurements are discussed in the next chapter.

CHAPTER III: METHODS

Since we used the same data sources for the two study questions, the section below describes the data sources for the two studies. The sections following the description of the data sources present the methods for each study.

3.1. DATA SOURCES

We used the four publicly available datasets — HRS core data from 1992-2014, HRS exit interviews from 2002-2014; Area Health Resource File (AHRF), 2014; Dartmouth Atlas end-of-life care and chronic illness data from, 2000-2014. The HRS datasets yielded individual information, while the AHRF and Dartmouth provided the ecological data.

Health and Retirement Study Data

The HRS is a biennial longitudinal surveys of a representative sample American population of age 51 and older (Institute of Social Research, 2015; Amy S Kelley et al., 2014). Funded by the National Institute on Aging (NIA), the HRS elicits information about labor force participation and health status transition towards the latter part of work and life (Institute of Social Research, 2016; Juster & Suzman, 1995; Wallace & Herzog, 1995). The surveys have been administered every two years since 1992.

The publicly available HRS data include core files and exit and post exit interview files. The core file from 1992-2014 includes panel or follow-up data on all the HRS participants. The data contains information on fixed and changing demographic, social, economic, health and retirement characteristics of HRS participants.

The exit interviews include the information elicited in the interviews conducted with next-of-kin of HRS decedents. The HRS contacts next-of-kin of decedents in the wave following the death of the HRS participant. The exit file contains information about assets distribution and health care use towards the end of life. The sections below provide more information on HRS core and exit data.

Health and Retirement Study Core Data (1992-2014)

The HRS has been compiling the follow-up biennial panel survey data since 1992. The panel design allows for the follow-up of the same individuals over the years and interview on the same topics to document the change. Each contact or survey occasion is called a wave. The data include the information on demographic characteristics; heath conditions and health status; health care use; cognitive and physical functioning; household and family characteristics; health insurance; employment; retirement; disability; occupation; income; assets; and estate planning; etc.

Health and Retirement Study Post-death or Exit Interviews (2002-2014)

In addition to collecting core data using follow-up surveys, HRS also conducts one-time exit interviews with a knowledgeable next-of-kin after the death of the HRS participants (Institute of Social Research, 2016). The next-of-kin include surviving spouse, child or any other knowledgeable informant. The interviews are conducted in the latest wave after the participant’s death (Bischoff, et al., 2013). The exit interviews have been incorporated as part of biennial surveys since 2002. Therefore, the exit interviews are cross sectional surveys embedded in the HRS longitudinal core data. HRS reported completing exit interviews for 93% of decedents until 2010 (Sonnega et al., 2014).

The next-of-kin of the decedents since the last wave are interviewed in the following wave. An exit interview elicits information about decedent's advance care plans, end-of-life care choices and end-of-life care experience and how assets were distributed following the death (Institute of Social Research, 2016; Amy S Kelley, et al., 2014). The exit interviews can be accessed after signing up with HRS at the URL: http://hrsonline.isr.umich.edu/index.php?p=reg. Tables 3.1 and 3.2 below present the HRS questions pertaining to the ACP and end-of-life care choices.

The questions listed in Table 3.1 are used to elicit information about the three types of advance care plans including ACP discussions, living will and DPAHC. Table 3.2 presents questions related to the end-of-life care choices included in the HRS exit interview questionnaire. The choices are only reported for the decedent who documented a living will before death. The two questions "Limit care in certain situations" and "Withhold certain treatments" pertain to if a decedent chose certain limits in care. The comfort care allows for pain management and exclusion of extensive life-prolonging measures. Finally, "all care possible" option allows for all care including the life-prolonging measure that can be rendered at the end-of-life. The HRS, however, does not define the terms "certain situations", "certain treatments", "extensive life-prolonging measures" in their documentation.

RAND's Health and Retirement Study Cross Wave Core Data

HRS multi-wave core data require complex merging of data files (Servais, 2010). Therefore, for ease of users, the Research and Development Corporation (RAND) corporation collates cross-waves HRS files into a single user-friendly database. The RAND database uses easy to follow naming algorithm that identifies variable names along with respective wave for the publicly available core data (Center for the study of Aging: A RAND labor and population center, 2016; Clair et al., 2011).

We used the most recent RAND HRS file that includes cross-wave HRS participant characteristics from 1992—2014. All the decedent characteristics, were extracted from the 2014 RAND HRS file. These covariates include demographic, socioeconomic and health indicators (See appendix. Further information on RAND file can be accessed from the URL: http://www.rand.org/labor/aging/dataprod/hrs-data.html.

3.2. DATA MERGING

We merged the exit interviews from 2002-2014. The merged exit interview file was then merged with the RAND publicly available core data file (1992-2014). The former provided information about advance care plans and latter included information on the independent variable, that is, health status, and covariates.

Dealing with multiple-year data: Defining the index year

The HRS core file includes multiple survey data. The data include fixed and dynamic (changing over time) characteristics of the HRS participants. For example, the variables like race, ethnicity, religion, and sex remain fixed across the waves, whereas the age, health status, health insurance, and socioeconomic status change over time.

To determine which survey wave to use for dynamic variables, we analyzed the subset of HRS decedents for whom a year of advance directive was reported (Table 3.3). We marked the survey wave corresponding to the year of advance directive as the “index wave" (Table 3.4). We included the self-reported health from the index wave. In case of missing data in the index wave, we tracked the preceding HRS survey waves to include elf-reported health from the nearest wave with a valid value. Thus, for example, if the year of the directive was 1998, the next nearest backward date would be 1996; if self-reported health status was not present in that year, 1994 would be examined, and so on.

We then calculated the average years between the advance directive and death (hereafter "interval 1") and the average years between advance directive and self-reported health (hereafter "interval 2") (Figure 3.1). The average "interval 1" was 4 years and "interval 2" was 1 year. Because HRS is administered biennially, interval 1 was considered equivalent to two HRS waves and interval 2 to one wave.

To determine index wave and a trackback approach for the decedents with a missing or not applicable (no ACP or ACP discussions only) date of advance directive. The wave which was two waves prior to the death was specified as index wave. Restricting the trackback period to one wave, the information on predictors and covariates was extracted from either the index wave or a wave preceding the index wave. Thus, for an individual who died in 2012 with no directives or missing date of directives, the index year would be 2008. The information on predictors and covariate was included from 2008 (the index wave) or, if missing, then from 2006 (a wave prior to the index wave). We treated the predictors or covariates missing if both 2008 and 2006 waves included missing values. The sections below describe the datasets.

Table 3.1: Advance care planning questions in the Health and Retirement Study

Advance directives	Question in HRS module
ACP discussions	Did decedent ever discuss with you or anyone else the treatment or care (she/he) wanted to receive in the final days of (her/his) life?
Living will	Did decedent provide written instructions about the treatment or care (she/he) wanted to receive during the final days of)'s life?
Durable Power of Attorney (DPAHC)	Did decedent make any legal arrangements for a specific person or persons to make decisions about (her/his) care or medical treatment if (she/he) could not make those decisions (herself/himself)? This is sometimes called a Durable Power of Attorney for Health Care.

Source: Health and Retirement Study concordance tool, from the URL: http://hrsonline.isr.umich.edu/concord

Table 3.2: End-of-life care choice questions in the Health and Retirement Study

Care choices	**Question in HRS module**
Limit care in certain situations	Did these instructions [living will] express a desire to limit care in certain situations?
Withhold certain treatments	Did these instructions express a desire to have any treatment withheld?
Comfort care	Did these instructions express a desire to keep (her/him) comfortable and pain free, but to forego extensive measures to prolong life?
All care possible	Did these instructions express a desire to receive all care possible under any circumstances to prolong life?

Source: Health and Retirement Study concordance tool, from the URL: http://hrsonline.isr.umich.edu/concord

3.3. STUDY OBJECTIVES

Study 1

To determine the factors associated with the combinations of advance care plans among HRS decedents between 2002-2014.

Study sample and study outcome

Our study sample is comprised of HRS decedents for whom next-of-kin exit interviews were conducted. The HRS has been conducting next-of-kin interviews since 2002. The initial merging of data yielded 9023 such interviews: n=1468 in 2002; n=1200 in 2004; n=1281 in 2006; n=1309 in 2008; n=1398 in 2010; n=1151 in 2012 and n=1216 in 2014. Merging the HRS exit interviews file with the RAND collated HRS core data yielded 9.010 records. Excluding records with missing data on covariates yielded 4,244 records. The tables 3.5 to 3.6 below show the distribution of ACPs and their combinations in complete data (n=9,010). We found no difference in the demographic and health factors of the decedents included in the full and restricted datasets: gender (p=0.29); age (p=0.07); self-rated health (p=0.36); change in health status (p=0.73); cancer (p=0.31); heart diseases (p=0.49); psychiatric diseases (p=0.42); number of health conditions (p=0.41); and stroke (p=0.71).

Health status

Main exposure: Self-reported health status and change in health status

We used HRS publicly available RAND file to include the information on self-reported health status, change in health status and other health measures and covariates. For the decedents with a valid advance directive date, we included the self-reported health from the earliest wave prior to the ACP date (index date).

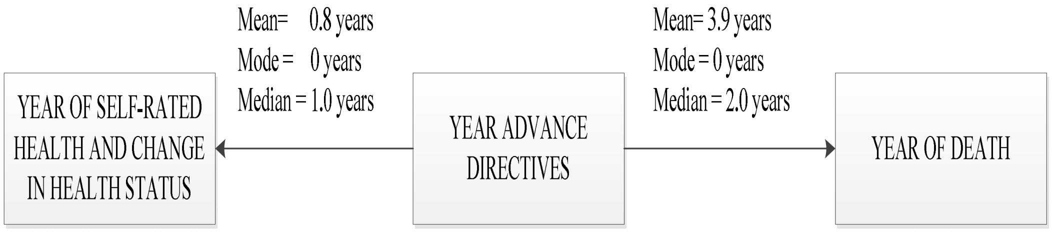

Figure 3.1: Average years between self-reported health, death and advance directive among the Health and Retirement Study decedents for whom a a date of directive was reported

Table 3.3: Dates reported for the advance directives formulated by Health and Retirement Study decedents from 2002-2014 (n=5,665) *

Advance directive	N	Date of directive reported (n)	%
All directives	2485	1575	63.4%
Living will only	213	87	40.8%
DPAHC† only	826	393	47.6%
Living will & DPAHC	817	454	55.6%
Living will & ACP discussions	438	241	55.0%
DPAHC & ACP discussions	886	533	60.2%
All	5665	3283	58.0%

Source: Health and Retirement Study exit interview data from 2002-2014

Note:
* The decedents for whom the date of the ACP was reported are included in this analysis

Table 3.4: Index wave of Health and Retirement Study (HRS) Core data for each type and combinations of advance directives in the HRS exit interview data

Directives	**Date available**	**Index wave**
One directive (Living will or DPAHC)	Yes	Reported year of living will
ACP discussions only	No	The wave corresponding the average interval between year of death and year of advance directives*
Both directives (Living will and DPAHC)	Yes	Earlier year in any of the two (a living will or DPAHC)
A directive and ACP discussions	Yes	Reported year of living will
All directives	Yes	Earlier year between DPAHC and a living will
Missing date for the reported directives	No	The wave corresponding the average interval between year of death and year of advance directives*
No directives	No	The wave corresponding the average interval between year of death and year of advance directives*

Note:
* The average interval was determined using the data of decedents for whom next-of-kin reported directives and date of directives (n=3,283)

Table 3.5: Advance directives among Health and Retirement Study decedents from 2002-2014 (n=9,010)

	Frequency	%*
Living will		
Yes	3949	43.8
No	5061	56.2
DPAHC†		
Yes	5007	55.6
No	4003	44.4
ACP discussions‡		
Yes	4989	55.4
No	4021	44.6

Source: HRS exit interviews, 2002-14

* Unweighted estimates
† Durable Power of Attorney for Health Care
‡ Advance Care Planning

Table 3.6: All combinations of advance care plans among Health and Retirement Study decedents from 2002-2014 (n=9,010)

	Frequency	%*
No directives	748	17.6
One directive	302	7.1
ACP discussion	462	10.9
Both directives	513	12.1
One directives and ACP discussion	541	12.7
All ACPs	1678	39.5

Source: HRS exit interviews, 2002-14
* Unweighted estimates
† Advance Care Planning discussions

Note: Due to small numbers we merged the categories “living will only” and “DPAHC only” into “one directives only”. Further, we also merged the “Living will and ACP discussions” and “DPAHC and ACP discussions” into a single category: “one directive and ACP discussions”.

However, if the data were missing in the index wave then we included the information from the first earlier wave before the index wave that included non-missing information. For the decedents for whom the next-of-kin reported no ACP or ACP discussions only and did not report the date of advance directives, we included the information on health status and covariate from the waves preceding the index wave including the valid data.

Other health and mortality characteristics

Using HRS RAND data, we included the information about Assistance with ADL. The variable sums up the binary responses on five daily living activities including eating, dressing, bathing and getting in and out of bed and walking across the room. Further, we also included common medical conditions associated with ACPs including heart diseases, psychiatric disease and stroke.

Demographic and socioeconomic factors

We used the HRS RAND file to include individual demographic, socioeconomic and health characteristics. Demographic variables include age, sex, race/ethnicity, religion and marital status. Socioeconomic indicators include, education (categories), estate will and government insurance (Appendix 2). Smoking status was included as a marker of health behavior.

Study 2

To determine the factors associated with each end-of-life care choice, including limit care in certain situations, comfort care and all care possible among HRS.

Study 2: Study sample and study outcome

The HRS reports the end-of-life care choices only for the decedents with a living will. Therefore, our study sample for the objective 2 included HRS decedents for whom next-of-kin reported a living will in post death exit interviews (n=3953). Excluding the records with a missing value in any covariate yielded 2,326 records. The distribution of end-of-life care choices are shown in the table 3.7 below. We found no difference in age, race, religion and education among the decedents included in the two datasets with n=3,949 and n=2,326 (p-value ≥ 0.14).

The study predictors: Self-reported health

The study predictors included the self-reported health, self-reported change in health status and interaction between the two factors. We included the information on health status and its change and other covariates from the index wave (prior wave closest to the date of year of ACP). In case date of the ACP was not reported or not applicable or missing, we included the information from earliest wave within the average interval between the year of directives and year of self-reported health that contained a valid value (Table 3.4).

We used HRS publicly available RAND file to include the health status. HRS captures self-reported health on a five-rating Likert scale: excellent, very good, good, fair and poor. The appendix presents the list of the study variables.

Other health and mortality characteristics

Using HRS RAND data, we included the sum of five binary variables that

Table 3.7: End-of-life care choices among Health and Retirement Study decedents with a living will from 2002-2014 (n=2,326) *

	Yes	%
Limit care	2063	88.69
Comfort care	2094	90.03
All care possible	144	6.19

Source: HRS exit interviews, 2002-14
* Decedents without a living will (n=5061)
† Unweighted estimates

captured assistance in daily living activities (eating, dressing, bathing and getting in and out of bed and walking across the room) for which the decedent needed assistance. Further, we also included number of health conditions and specific diseases associated with ACP including heart problems, psychiatric disease and stroke.

Demographic and socioeconomic factors

We used the HRS RAND file to include individual demographic, socioeconomic and health characteristics. Demographic variables included age, sex, race/ethnicity, religion and marital status. Socioeconomic indicators include, education, estate will and government insurance (Appendix). We also included smoking status as a marker of health behavior.

3.4. ANALYSIS PLAN

Study 1

Frequencies and means respectively, for categorical and continuous variables are presented as part of the descriptive data analysis. Further, the bivariate association between the combinations of ACPs and covariates were run to determine the independent effect of predictors and covariates. The bivariate association between the interaction between health status and change in health status was evaluated and was included in the adjusted model if it was significant in bivariate analysis.

A binary logistic regression model was developed using the combinations of advance directives as the outcome and covariates, with self-reported health status being the key exposure. An example of the multinomial logistic estimation, comparing the log odds of all directives versus no ACP is shown below.

Example 1: Comparison of one directive versus no ACP

$$\begin{aligned}&\ln(\frac{(P(One\ directive)}{(P\ (No\ ACP)} = \text{ß}_0 + \\ &\text{ß}_1\ (SRH) =' fairor\ poor\ vs.excellent\ or\ very\ good') + \\ &\text{ß}_2\ (CHS) =' wose\ or\ somewhat\ worse\ vs.\text{Much or somewhat better }') + \\ &\text{ß}_3\ (Interaction = ('Fair\ or\ Poor\ (SRH) * \\ &Worse\ (CHS)'\ vs.\ Excellent\ or\ very\ good\ (SRH) * \\ &Much\ or\ somewhat\ better(CHS)') + \text{ß}_4 X \ldots \ldots \ldots. + \varepsilon\end{aligned} \qquad (1)$$

Where,

SRH = Self-reported health

CHS = Change in health status

ß_0 = constant term

ε = error term

Example 2: Comparison of "all APCs" versus no ACP

$$\begin{aligned}&\ln(\frac{(P\ (All\ ACPs))}{(P\ (No\ ACP)} = \text{ß}_0 + \\ &\text{ß}_1\ (SRH) =' fairor\ poor\ vs.excellent\ or\ very\ good') + \\ &\text{ß}_2\ (CHS) =' wose\ or\ somewhat\ worse\ vs.\text{Much or somewhat better }') + \\ &\text{ß}_3\ (Interaction = ('Fair\ or\ Poor\ (SRH) * \\ &Worse\ (CHS)'\ vs.\ Excellent\ or\ very\ good\ (SRH) * \\ &Much\ or\ somewhat\ better(CHS)') + \text{ß}_4 X \ldots \ldots \ldots. + \varepsilon\end{aligned} \qquad (2)$$

Study 2

We calculated frequencies and means respectively, for categorical and continuous variables as part of the descriptive data analysis. Further, the bivariate association between each end-of-life care choice and covariates were run to determine the independent effect of covariates on each choice. The bivariate association of interaction term between self-reported health and change in health status was tested. The term was added to the multiple logistic regression analysis if it showed significance at the bivariate level.

A separate logistic regression model was developed using combinations of advance directives as the outcome and covariates, with self-reported health status and change in health status as predictors. A model comparing the log odds of “fair or poor” self-reported health with “excellent or good health status” among decedents who chose comfort care, limit care and all care possible are shown in the examples below.

Example 1: A comparison of fair or poor health vs. excellent or very good health among decedents who chose comfort care

$$
\begin{gathered}
\ln(\frac{(P(Comfort\ care\ (Yes)}{(P\ Comfort\ care(No)} = \text{ß}_0 + \\
\text{ß}_1\ (SRH) = '\ fair\ or\ poor\ vs. excellent\ or\ very\ good') + \\
\text{ß}_2\ (CHS) = '\ wose\ or\ somewhat\ worse\ vs. \text{Much or somewhat better}\ ') + \\
\text{ß}_3\ (Interaction = ('Fair\ or\ Poor\ (SRH) * \\
Worse\ (CHS)'\ vs.\ Excellent\ or\ very\ good\ (SRH) * \\
Much\ or\ somewhat\ better(CHS)') + \text{ß}_4 X \ldots \ldots \text{....} + \varepsilon
\end{gathered}
\tag{3}
$$

Where,
SRH = Self-reported health
CHS = Change in health status
ß_0 = constant term
ε = error term

Example 2: A comparison of fair or poor health vs. excellent or very good health among decedents who chose limit care in certain situations

$$
\begin{gathered}
ln(\frac{(P(Limit\ care\ in\ certain\ situations\ (Yes)}{(P\ (Limit\ care\ in\ certain\ situations(No)} \\
= \text{ß}_0 + \text{ß}_1\ (SRH) = '\ fairor\ poor\ vs. excellent\ or\ very\ good') \\
+\ \text{ß}_2\ (CHS) = '\ wose\ or\ somewhat\ worse\ vs. Much\ or\ somewhat\ better\ ') \\
+\ \text{ß}_3\ (Interaction = ('Fair\ or\ Poor\ (SRH) \\
*\ Worse\ (CHS)'\ vs.\ Excellent\ or\ very\ good\ (SRH) \\
*\ Much\ or\ somewhat\ better(CHS)') + \text{ß}_4 X \ldots \ldots \ldots . + \varepsilon
\end{gathered}
\tag{4}
$$

Example 1: A comparison of fair or poor health vs. excellent or very good health among decedents who chose all care possible care

$$
\begin{array}{l}
\ln(\frac{(P(All\ care\ possible\ (Yes)}{(P\ (All\ care\ possible(No)} = \text{ß}_0 + \\
\text{ß}_1\ (SRH) =' fairor\ poor\ vs.\, excellent\ or\ very\ good') + \\
\text{ß}_2\ (CHS) =' wose\ or\ somewhat\ worse\ vs.\, \text{Much or somewhat better }') + \\
\text{ß}_3\ (Interaction = ('Fair\ or\ Poor\ (SRH) * \\
Worse\ (CHS)'\ vs.\ \ Excellent\ or\ very\ good\ (SRH) * \\
Much\ or\ somewhat\ better(CHS)') + \text{ß}_4 X \ldots \ldots \ldots .+ \varepsilon
\end{array}
\tag{5}
$$

CHAPTER IV: FACTORS ASSOCIATED WITH THE COMBINATIONS OF ADVANCE CARE PLANS: AN ANALYSIS OF HEALTH AND RETIREMENT STUDY DATA (1992-2014)[1]

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[1] Agha A., Probst J.C., Brooks J.M., Hardin J.W., & Teixeira A. To be submitted to *American Journal of Public Health, Journal of Aging and Health, Journal of Palliative Medicine, Journal of the American Geriatrics Society, or British Medical Journal*

4.1. ABSTRACT

Introduction

Advance care plans (ACP) are distinct and complementary components of end-of-life care planning. The three major plans include advance care planning discussions, living will and Durable Power of Attorney for Health care. The previous research has used each plan as a distinct outcome to determine its associated factors. However, in the real life the plans exist in combinations. Further, the literature varies in its report on association between self-reported health and ACPs. While some studies have shown poor health associated with a higher uptake of the ACPs, the other have shown no association. Therefore, we attempted to clarify the association between self-reported health status and combinations of ACPs using self-reported health, change in health status and interaction between the two as the study predictors and combinations of ACPs as the study outcome.

Objective

To determine the association between self-reported health, change in health status and interaction between the factors and combinations of ACPs using the Health and Retirement Study (HRS) decedents from 2002-2014.

Methods

Our cross-sectional study included individual-level covariates using the Research and Development Corporation (RAND) collated HRS multi-wave core file (1992-2014) and HRS exit interview file (2002-2014), and neighborhood covariates using the Dartmouth Atlas Data (2001-2014), Area Health Resource File (2015) and the United States Department of Agriculture data (2000 and 2013).

We tested the interaction between self-reported health and change in health status in the bivariate analysis. In multinomial regression analysis, we determined the association between self-reported health and change in health status and combinations of ACPs: “no plan”; “one advance directive”; “both advance directives”; “an advance directive and advance care planning discussions and “All plans” as the outcome.

Results note changed order

While self-reported health was not associated with any combination of ACPs, self-reported change in health status was associated with both directives and “all ACPs”. We did not find an interaction between the self-reported health and change in health status when predicting the uptake of the combinations of ACPs. The uptake of all ACPs was also associated with number of health conditions and a history of cancer.

Discussion

The self-reported change in health status to “worse or somewhat worse” was associated with the uptake of both directives and “all ACPs” (both directives and ACP discussion), compared with the self-reported change in health status to “much or somewhat better or the same”. The other studies also report that poor health associated with higher likelihood of advance care planning. Further, the literature also emphasizes on using dynamic measure of self-reported health, that is, change in health status than the self-reported health at baseline or at the time of survey. We recommend future studies to determine the association between end-of-life care intensity and quality and combinations of advance care plans.

Key words: Advance care planning, Advance directives, self-reported health and change in health status

4.2. INTRODUCTION

Advance care plans (ACP) allow people to inform their loved ones and care providers about how they would like to be cared for at the end-of-life (Maxfield, et al., 2003). The three major types of plans include “advance care planning discussions” (ACP discussions) and the two advance directives — namely, “living will” and “Durable Power of Attorney for Health Care” (DPAHC) (Detering, et al., 2016).

Each ACP has its strengths and weaknesses (Baum, 2009; Detering, et al., 2016; D. K. Martin, et al., 2000). While ACP discussions allow for conversations on breath of topics related to death and dying, these conversations are not documented and therefore may not be legally binding (Karen E Steinhauser et al., 2001). Conversely, advance directives (living will and DPAHC) are documented and are legally binding. A living will provides limited choices to choose from (Detering, et al., 2016; Garrido, et al., 2013; Lo & Steinbrook, 2004; D. K. Martin, et al., 2000). DPAHC allows a person to choose surrogate decision-makers (i.e. proxies) to take end-of-life care decisions on behalf of the person (Travis, et al., 2002). While proxies take decisions based on a real end-of-life situation; however, they can also misinterpret patient wishes.

In real life, the ACPs exist in combinations. Many states use combined directives forms, that is, living will and DPAHC in a single form (C. P. Sabatino, 2010). Prior research on the factors associated with ACPs has used each plan as a distinct outcome. In the current study, we dealt with these plans more realistically by using the combinations: “no ACP”; “ACP discussions only”; “one directive”; “both directives”, “one directive and ACP discussions” and “all ACPs” (i.e., both the directives and ACP discussions).

Despite a high uptake of ACPs among elderly Americans, disparities still exist. White and educated individuals are more likely to engage in advance care planning. However, the association between the ACPs and some other factors are not clear. For instance, health status has shown an ambiguous association with advance care planning. While several studies have shown no association between health status and ACP uptake (Beck, et al., 2002; Carr & Khodyakov, 2007; Carr & Moorman, 2009; Garrido, et al., 2013; Gerst & Burr, 2008; Gordon & Shade, 1999; Faith P. Hopp, 2000; A. S. Kelley, et al., 2011; Sharp, et al., 2012), others have reported a significant association (Harrison, et al., 2016; Lenert, et al., 1999; L. L. Phillips, et al., 2011; Winter, et al., 2003; Winter & Parker, 2007).

We attempted to clarify the association between health status and ACPs by using the interaction between self-reported health and change in health status. We hypothesized that the combination of worse current health status and decline in health status is associated with a higher uptake of “all ACPs”.

Our work, therefore, contributes two novel features to the current end-of-life care literature 1) uses the combinations of ACPs as the study outcome and 2) attempts to clarify the association between self-reported health status and the uptake of the plans, using the interaction between self-reported health status as the study predictor.

4.3. METHODS

This cross-sectional study used individual data — HRS core (1992-2014) and exit interviews (2002-2014); and ecological data — Area Health Resource File (2015), United

States Department of Agriculture data (2000 and 2013) and Dartmouth Atlas data (2001-2014).

Data sources

Health and Retirement Study exit interviews

In 1992, the HRS started conducting biennial surveys in a nationally representative American population of age over 50 years (Institute of Social Research, 2015). The panel data, also called core data, track health and employment history. The HRS also conducts post-death interviews (also called exit interviews) with the knowledgeable next-of-kin in the wave following the death. The survey prefers to interview widows, widower or close relatives. The interview elicits information about medical care — including end-of-life care choices and end-of-life care experience — and expenditure; distribution of assets following death and family decisions during the latter part of life. The studies comparing HRS data with other data sources have shown a high reliability of exit data (Weir, 2016).

Health and Retirement Study core files

We drew the information on the covariates using HRS core data from the biennial surveys. The biennial interviews were conducted with the decedents before death. We included the commonly reported covariates of ACP uptake — age at death; sex; race; religion; marital status; education; estate will; self-reported health; change in health status; number of comorbidities and health insurance. While covariates such as sex, religion and marital status remain fixed and are captured when the participant is included in the HRS, others such as self-reported health and change in health status change over time.

Due to the multi-wave nature of the core data, we first determined the wave from which the information on dynamic covariate would be extracted. We categorized the HRS decedents into two groups: 1) those with a reported year of advance directive and 2) those for whom year was either missing or was not applicable (no ACPs or ACP discussions only).

We first restricted our analysis to the group 1 decedents — the group with a reported year of directive. We called the wave corresponding the year of directive as "index wave". Starting from the index wave, we tracked the waves backward to include the self-reported health from the first wave with a valid information for each decedent. We calculated the average years between directives and death (interval 1) and directives and self-reported health (interval 2). The average of interval 1 was about 4 years and interval 2 was about 1 year. The interval 2 was used to determine the number of waves we could track backwards starting from the index wave to include the information on the change in health status and other covariates. For instance, if the index was 2008, we tracked the covariates in 2008 and 2006 and treated the information as missing if both the years included missing information.

Using the information from the group 1, we determined the index wave and track-back approach for the group 2 decedents. Starting from the year of death, we tracked-back two waves (corresponding 4 years) to specify the index wave. The predictors and covariate information were extracted from the index wave or, if missing, then from the wave preceding the index wave.

Study population

The HRS exit data included 9,023 next-of-kin exit interviews. Merging the exit data with core data yielded 9,010 records. To merge the HRS exit data with the core data, we appended all exit interview records from 2002-2014 in a single file Then, we merged the exit interviews with the RAND collated HRS core data file, which included all the survey records from 1992-2014 in a single file.

Excluding records with missing information yielded 4,244 records — 472 in 2002; 477 in 2004; 626 in 2006; 637 in 2008; 800 in 2010; 625 in 2012 and 607 in 2014. We found no difference among the decedents included in the complete data (9,010) and restricted data (n=4,244) in gender (p=0.29); age (p=0.07); self-rated health (p=0.36); change in health status (p=0.73); cancer (p=0.31); heart diseases (p=0.49); psychiatric diseases (p=0.42); number of health conditions (p=0.41); and stroke (p=0.71).

Study variables

Dependent Variable

The questions related to advance care plans are as follows:

- ACP discussions: “Did decedent ever discuss with you or anyone else the treatment or care (she/he) wanted to receive in the final days of (her/his) life?” No (n=1563, 36.8%); Yes (n= 2681, 63.2%)
- Living will: “Did decedent provide written instructions about the treatment or care (she/he) wanted to receive during the final days of)'s life?” No (n=1672, 39.4%); Yes (n=2572, 60.6%).
- Durable Power of Attorney (DPAHC): “Did decedent make any legal arrangements for a specific person or persons to make decisions about (her/his)

care or medical treatment if (she/he) could not make those decisions (herself/himself)? This is sometimes called a Durable Power of Attorney for Health Care?" No (n=1591, 37.5); Yes (n=2653, 62.5).

We collated the ACPs into six categories: 'no directive', 'ACP discussions only', 'one directive only', 'ACP discussions and a directive', 'both directives' and 'all ACPs'.

Predictor variables

Self-reported health, change in health status and the interaction between the two were used as the predictor variables. HRS elicits self-reported health using a five-point Likert scale varying from excellent to poor. Similarly, it captures change in health status since the previous wave using a five-point Likert scale: much better, somewhat better, same, somewhat worse and worse.

Given that our outcome, combinations of advance directives, was categorical (six categories) and the sample size was limited, we collapsed the categories for the categorical predictors. Self-reported health was collapsed into two categories: "excellent, very good or good" (57.5 ± 0.9%)" and "fair or poor" (42.5 ± 0.9%)]. Similarly, change in health status was combined into two categories: "much better, somewhat better or the same" (65.8 ± 0.8%)" and "worse or "somewhat worse" (34.2 ± 0.8%).

Other covariates

We outlined the possible covariates of ACPs using two global reviews of ACP factors by Van der Steen et al. (van der Steen et al., 2014) and Lovell et al. (Lovell & Yates, 2014). Van der Steen et al.'s restricted their work on the studies that reported ACP factors on patients with dementia. They classified the ACP factors into four domains: patient (age, sex, race, health status and health care utilization pattern); family (living arrangement and family's involvement in the formulation of advance care plans), provider (lack of time and attitude about advance care planning), health care context (ACP interventions going on at the healthcare systems level) and healthcare system (unspecified and unexplained variability between facilities). Lovell et al. added a domain of legal factors — provider's perceptions about the legal validity of ACPs. Data did not allow us to include all the possible factors. Figure 4.1 shows the factors identified by Lovell and associates. The "(+)" sign denotes the factors that the data allowed us to include.

Sociodemographic covariates

We included known demographic covariates of ACP, including age at death, sex, religious affiliation, religiosity and marital status. Race was categorized as White (89.0 ± 0.5%) and other (11.0 ± 0.5%). Further, we combined other religions (Jewish; None/no preference and others) into a single category, making three categories of religion — Protestant (63.3 ± 0.8%), Catholic (26.5 ± 0.8%) and others (10.2 ± 0.6). Marital status was merged into three categories including married/partnered (61.1 ± 0.9) and divorced/separated/never married/widowed (38.9 ± 0.9). We collated "How important is religion in your life?" in three categories from "not too important" to "very important".

As an indicator of religiosity, we used the HRS biennial survey question, "How important is religion in your life; is it very important, somewhat important, or not too important? We combined the "somewhat important" and "not too important" into a single category to make two categories: very important (47.3±0.9) and "somewhat important/not too important (52.7±0.9).

Health status

We also included number of health conditions and specific health conditions that earlier studies identified as the covariates of ACP: psychiatric illness; stroke; cancer; heart disease and number of health conditions (categorized into two categories: ≤1 and ≥2). Due to a significant missingness in ADL variable (41.1%), we excluded the variable from our analysis.

Data analysis

First, the bivariate association between the combinations of ACPs and the interaction between self-reported health (X_1) and change in health status (X_2) was tested using the model shown below.

$$Y = \beta_0 + \beta_1 X_1 + \beta_2 X_2 + \beta_3 X_1 * X_2 \qquad (1)$$

We found no interaction between self-reported health and change in health status ($p = 0.17$). Therefore, further analysis, did not include the interaction term.

A multinomial regression model was used to determine the association between the combinations of the ACPs (study outcome), self-reported health and change in health status (study predictors) at an alpha of 0.05. We adjusted the analysis for demographic, socioeconomic and health factors including number of health conditions and specific diseases including stoke, cancer, heart disease and psychiatric illness. All analyses accounted for sampling weights.

Ethical approval

The Institutional Review Board of University of South Carolina exempted the study from the full ethical review.

4.4. RESULTS

Table 4.1 shows the distribution of combinations of ACPs, demographic and health indicators of the decedents included in the study. The mean age of decedents was 78.4 (±0.15)

years. Most decedents were White race (89.0±0.5%); Protestant (63.3±0.7%); completed more than a high school education (70.5±0.9%); married or partnered (61.1±0.9%); covered by a government health insurance plan (66.3±0.8%) and devised an estate will (65.0±0.8%).

The most common to least common ACP combinations included "all ACPs" (43.6±0.9%); "no ACP" (14.6±0.6%), "ACP discussions and one directive" (12.8±0.6%); "ACP discussions only" (9.0±0.5%); "one directive" (6.5±0.4%) and "two directives" (13.4±0.6%).

About 57.5% (±0.9) decedents rated their health as "excellent or very good or good". Compared with the previous wave, change in health status was reported as "much or somewhat better or the same" by 65.8% (±0.8) and "worse or somewhat worse" by 32.8% (±0.7).

Decedents had about two health conditions (2.22±0.02), on average, with 37.1%±0.8 having one or less condition. A history of heart disease was reported by 31.7% (±0.8); cancer by 18.9 (±0.7); psychiatric illness by 14.1% (±0.6) and stroke by 12.7% (±0.6). Hospital stay in the previous 12 months was reported by 33.9% (±0.8). A history of ever smoking was reported by 66.9% (±0.8).

Selection of ACP Alternatives

Table 4.2 shows the distribution of decedents' characteristics across the ACP

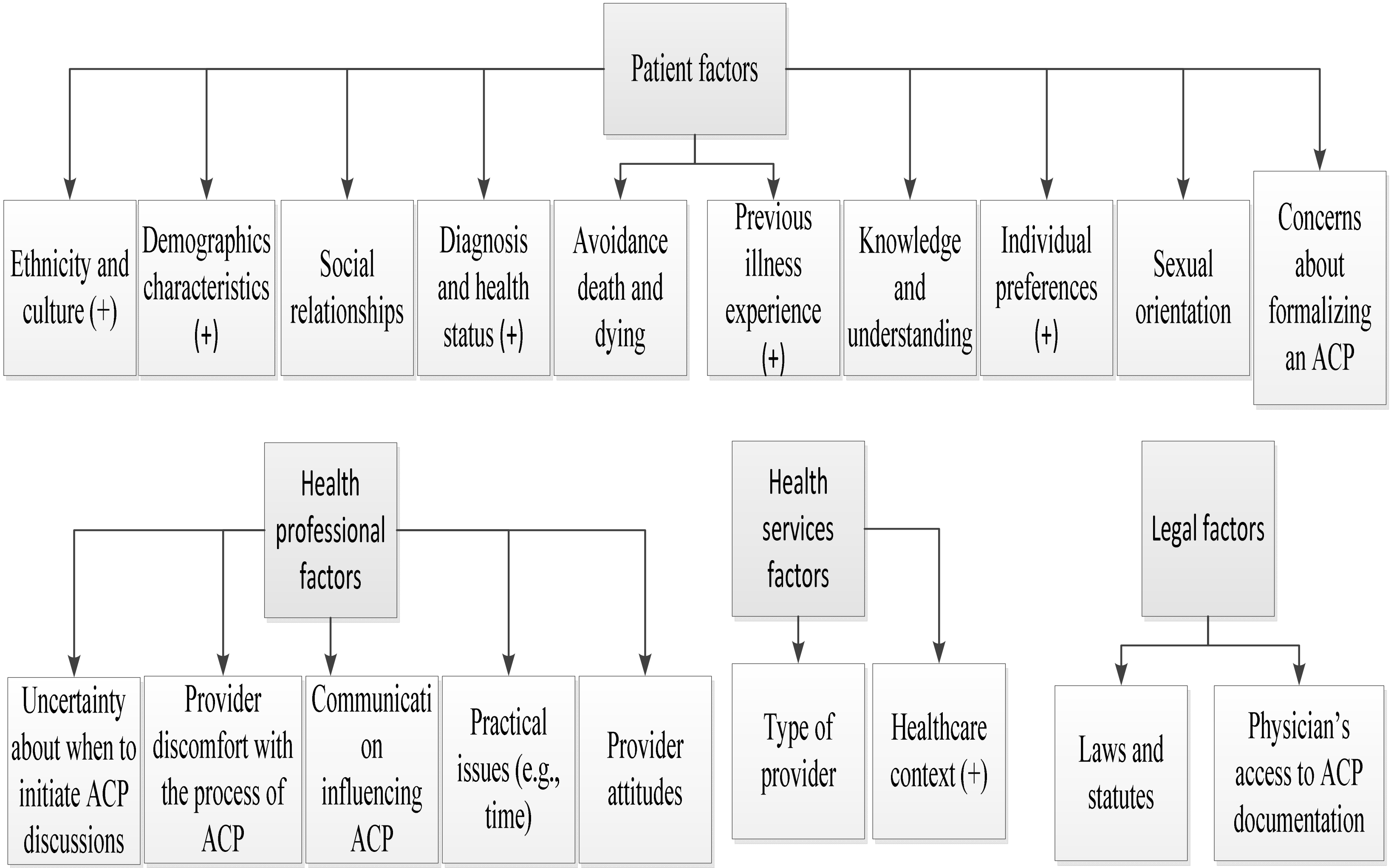

Figure 4.1: The literature reported factors associated with Advance Care Planning

combinations; Table 4.3 shows the bivariate associations. In bivariate analysis all variables, except religiosity (p-value <0.59) showed a significant association with the combinations of Advance Care Plans (p-value ≤ 0.007).

The majority of the decedents who reported self-reported health as “fair or poor” (47.4±1.4%) or change in health status as “worse or somewhat worse” (55.0±1.5%) had chosen “all ACPs”. Similarly, a higher proportion of decedents with a history of cancer (62.8±2.0); stroke (60.6±2.4%); heart disease (54.4±1.5%); psychiatric illness (49.5±2.4%) and hospital stay in the past 12 months (57.4±1.5%) chose “all ACPs”.

The decedents with “no ACP” (72.4±0.25 years) and “ACP discussions only” (73.0±0.31 years) were on an average younger than the decedents who completed one (76.8±0.5) or both directives (81.8±0.44) or one directive with ACP discussions (76.5±0.4) and all ACPs (81.3±0.25).

In bivariate analysis, no health factor was associated with ACP discussion only (Table 4.3). Self-reported health; change in health status; and histories of cancer, heart disease, and hospital stay in the previous 12 months showed association with all the other combinations. Stroke and psychiatric illnesses did not show association with “one directive only” in addition to “ACP discussion only”.

Being female and non-Christian was associated with an increased likelihood of completing “both directives” or “all ACPs”. White race; more than high school education; having an estate will; and unmarried/unpartnered status were associated with all the combinations of ACPs.

Adjusted analysis

Self-reported health was not associated with any combination of ACP (Table 4.4). However, change in health status showed an association with "both directives" (AOR: 2.06; 95% CI: 1.30, 3.19) and "all ACPs" (AOR: 1.98; 95% CI: 1.35, 2.89). Regarding the other health covariates, a history of cancer and hospital stay in the past 12 months was associated with all the combinations, except ACP discussions only. A history of heart disease was associated with "one directive and ACP discussion" and a history of two or more health conditions was associated at all ACPs. The histories of stroke or psychiatric disease were not associated with any combination.

Insurance by a government plan, having an estate will and age were associated with a higher likelihood of all the combinations, except "ACP discussions only. Females were more likely to use "Both directives"; "One directive and ACP discussions" and "all ACPs". Whites were more likely to use all the combinations of ACPs except "One directive. A high-school level education was associated with "Both directives"; "One directive and ACP discussions" and "All ACPs". Moreover, not being partnered and married were associated with "Both directives"; "One directive and ACP discussions" and "All ACPs". The decedents from Midwest and West were more likely to complete "Both directives" and "all ACPs. The decedents from Midwest were also more likely to use a combination of "a directive and ACP discussions".

4.5. DISCUSSION

Previous research examining the factors associated with ACPs used each typical ACP as a distinct outcome or combined the advance directives into a single category or summed number of ACPs as the study outcomes. The present study improves upon previous efforts by using a more realistic approach, that is, using the combinations of three typical ACPs. In real life, ACPs exist in combinations. The literature also promotes the use of combined directives (living will and DPAHC) (Doukas & Hardwig, 2003). The ACP discussions are associated with a higher likelihood of documenting directives (Detering, et al., 2016; C. P. Sabatino, 2010). More than half U.S. states use a combined directives form (Gunter-Hunt, Mahoney, & Sieger, 2002; C. Sabatino, 2007).

Several important findings emerged from our study. First, self-reported health was not associated with any combination of ACP, but, the change in health status to "worse or somewhat worse" was associated with the use of both directives and all ACPs. Second, while histories of stroke and psychiatric illness were not associated with any of the combinations of ACPs, a history of cancer or a hospital stay in the past 12 months were associated with all the combinations ACPs that involved documenting an advance directive. The history of heart disease was associated with the use of "ACP discussions and a directive".

The variation in the uptake of ACPs by disease perhaps could explained by different trajectories they follow towards the end of life. Patients with psychiatric disease see a slow and long-term degradation of health. Such patients need long term care and avoid advance care planning because of the skepticism that such plan will legitimize the health care system to not provide them the treatment they will need in future. Stroke is an acute event. Many patients have comparatively healthier lives before the stroke. Conversely, cancer patients foresee the terminal nature of disease and thus plan ahead for their disease. The hospital stay is perhaps associated with a higher likelihood of advance care planning as Medicare mandates the facilities receiving reimbursements from the program to educate patients about ACPs, provide advance directives forms and encourage them to complete them.

The coverage by the government health insurance plan was associated with all combinations, except “ACP discussions only”. The most likely reason for the pattern is that the Patient Self-Determination Act (PSDA) of 1991 mandates all health care institutions that receive funds from Medicare and Medicaid to inform patients about their right to devise advance directives and share the advance directive forms with them (H.R.4449, 1990). The association between a hospital stay within 12 months of formulation of ACP, perhaps also relates to the PSDA mandate. Earlier reports also note that inpatient admission is associated with a higher completion rate of advance directives (Cugliari, Miller, & Sobal, 1995). The association between estate will and the combinations that included a directive is plausible in the light that attorneys encourage their clients to complete advance directives as part of completing an estate will (Carr, 2012a).

Using the combinations as the study outcome instead of the individual ACP, we found some consistent. The literature generally reports more use of ACPs among White, educated and insured populations. The literature also reports older age; white race; female gender; number of children; government insurance; education; an estate will and no religion are significant predictors of advance care planning (Carr, 2011).

There were several limitations to our study. First, the information on ACP was based on proxy reports and therefore was subject to recall bias. Nonetheless, proxy reports are frequently used in end-of-life care literature as medical records do not provide enough information (Silveira, et al., 2010). Further, studies have also reported a high accuracy between proxy reports and Medicare claims data of elderly patients (Corder, Woodbury, & Manton, 1996). Second, due to a limited sample size, we could not separate out the directives (a living will and DPAHC) to make distinct combinations with and without ACP discussions. Therefore, we use "one directive and ACP discussions" category, which does not make a distinction between the type of directive (living will and DPAHC). Third, the data did not allow us to include some of the known covariates of ACPs: provider factors and family and patient attitudes and beliefs towards end-of-life care planning. Fourth, due to a cross-sectional design, this study reports the associations only.

That said, however, our study adds to the literature by using the combinations of ACPs. We consider this approach more realistic than the general approach of dealing with each ACP as a separate outcome. We found that neither self-reported health and nor change in health status was associated with ACP uptake. However, the interaction between the two factors was. The decedents who reported self-reported health as "fair or poor" and change in health status as worse or somewhat worse" were more likely to use "All ACPs".

Future studies could include family and provider factors to develop more robust models for the ACP factors. Further, the association between combinations of ACPs and health care cost and quality could also be explored.

Table 4.1: Health and socioeconomic characteristics and living will choices among Health and Retirement Study decedents from 2002-2014

Variables		Frequency (unweighted observations)	Weighted percent	
			%	SE
Advance Care Plans and health				
Advance Care Plans	No Advance Care Plan (ACP)	748	14.6	0.6
	1 directive (living will or DPAHC)	302	6.5	0.4
	ACP discussion	462	9.0	0.5
	Both directives (living will and DPAHC)	513	13.4	0.6
	1 directive and ACP discussion	541	12.8	0.6
	Both directives and ACP discussion	1678	43.6	0.9
Self-rated health	Excellent or very good or good	2421	57.5	0.9
	Fair or poor	1823	42.5	0.9
Self-reported change in health since last wave	Much or somewhat better or the same	2848	65.8	0.8
	Worse or somewhat worse	1396	34.2	0.8
Health conditions	0-1	1636	37.1	0.8
	≥2	2608	62.9	0.8
Cancer	No	3507	81.1	0.7
	Yes	737	18.9	0.7
Stroke	No	3724	87.3	0.6
	Yes	520	12.7	0.6
Psychiatric illnesses	No	3661	85.9	0.6
	Yes	583	14.1	0.6
Heart disease	No	2931	68.3	0.8
	Yes	1313	31.7	0.8

Variables		Frequency (unweighted observations)	Weighted percent	
			%	SE
Hospital stay in the past 12 months	No	2864	66.1	0.8
	Yes	1380	33.9	0.8
Health behaviors				
Ever smoke	No	1383	33.1	0.8
	Yes	2861	66.9	0.8
Socio-demographics				
Gender	Male	2126	49.4	0.9
	Female	2118	50.6	0.9
Age (mean)			78	0.2
Race	White	3519	89.0	0.5
	Others	725	11.0	0.5
Education	Less than high school	1397	29.5	0.8
	High school or GED	1486	35.7	0.8
	More than high school	1361	34.8	0.8
Marital Status	Married or partnered	2676	61.1	0.9
	Divorced/separated/widowed/never married	1577	38.9	0.9
Religion	Protestant	2792	63.3	0.8
	Catholic	1073	26.5	0.8
	Others	379	10.2	0.6
Religiosity	Very important	2108	47.3	0.9
	Somewhat important or not too important	2136	52.7	0.9
Number of children	≤ 2	1749	42.7	0.9
	3	869	21.2	0.7

Variables		Frequency (unweighted observations)	Weighted percent	
			%	SE
	4	647	15.2	0.6
	≥ 4	979	21.0	0.7
Region	Northeast	661	18.0	0.7
	Midwest	1045	26.2	0.8
	South	1810	36.3	0.8
	West	728	19.5	0.7
Health insurance and estate will				
Estate will	Yes	2565	65.0	0.8
	No	1679	35.0	0.8
Covered by a government plan	No	1526	33.7	0.8
	Yes	2718	66.3	0.8

Table 4.2: Distribution of advance care plan combinations (ACP) by health status and socioeconomic characteristics among Health and Retirement Study decedents from 2002-2014

		No ACP			1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		N	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE
Self-rated health	Excellent or very good or good	482	17.2	0.8	174	6.6	0.5	291	10.3	0.6	297	13.6	0.8	306	12.4	0.7	871	39.9	1.1
	Fair or poor	266	11.0	0.8	128	6.4	0.6	171	7.3	0.6	216	13.4	0.9	235	13.4	0.9	807	47.4	1.4
Self-reported change in health since last wave	Much or somewhat better or the same	622	18.4	0.8	221	7.2	0.5	381	11.3	0.6	303	12.1	0.7	377	13.5	0.7	944	37.5	1.0
	Worse or somewhat worse	126	7.3	0.8	81	5.2	0.6	81	4.5	0.6	210	16.3	1.1	164	11.7	1.0	734	55.0	1.5
Health conditions	0-1	458	24.4	1.2	140	8.1	0.7	271	14.6	0.9	154	10.9	0.9	223	13.9	1.0	390	28.1	1.3

		No ACP			1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		N	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE
	≥2	290	8.8	0.6	162	5.6	0.5	191	5.7	0.5	359	14.9	0.8	318	12.3	0.7	1288	52.7	1.1
Cancer	No	725	17.5	0.7	261	6.8	0.5	443	10.7	0.5	399	12.7	0.7	454	13.2	0.6	1225	39.1	0.9
	Yes	23	2.2	0.5	41	5.3	0.8	19	1.9	0.5	114	16.4	1.6	87	11.4	1.3	453	62.8	2.0
Stroke																			
	No	711	15.8	0.6	277	6.9	0.4	440	9.9	0.5	438	13.3	0.7	487	13.0	0.6	1371	41.0	0.9
	Yes	37	5.9	1.1	25	4.0	0.9	22	2.8	0.7	75	15.0	1.7	54	11.7	1.7	307	60.6	2.4
Psychiatric illnesses																			
	No	672	15.4	0.6	272	6.9	0.4	418	9.5	0.5	438	13.2	0.6	457	12.3	0.6	1404	42.6	0.9
	Yes	76	9.4	1.2	30	4.4	0.9	44	6.0	1.0	75	14.8	1.8	84	15.9	1.9	274	49.5	2.4
Heart disease																			

		No ACP			1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		N	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE
	No	645	18.5	0.8	230	7.2	0.5	396	11.4	0.6	311	12.1	0.7	366	12.3	0.7	983	38.5	1.0
	Yes	103	6.2	0.7	72	5.2	0.6	66	4.0	0.5	202	16.3	1.1	175	14.0	1.1	695	54.4	1.5
Hospital stay in the past 12 months																			
	No	654	19.4	0.8	233	7.6	0.5	401	12.1	0.6	285	11.5	0.7	375	13.0	0.7	916	36.4	1.0
	Yes	94	5.2	0.6	69	4.5	0.6	61	3.1	0.4	228	17.2	1.1	166	12.5	1.0	762	57.4	1.5
Ever smoke																			
	No	218	12.6	1.0	87	6.0	0.7	110	6.4	0.7	209	16.6	1.1	155	11.0	1.0	604	47.5	1.5
	Yes	530	15.5	0.7	215	6.8	0.5	352	10.3	0.6	304	12.1	0.7	386	13.8	0.7	1074	41.5	1.1
Gender																			

		No ACP			1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		N	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE
	Male	426	17.3	0.9	168	7.2	0.6	273	10.9	0.7	248	13.0	0.9	286	14.0	0.9	725	37.6	1.2
	Female	322	11.9	0.7	134	5.9	0.5	189	7.2	0.6	265	14.1	0.9	255	11.6	0.8	953	49.4	1.2
Age in years			72.4	0.2		76.8	0.5		73.0	0.3		81.8	0.4		76.5	0.4		81.3	0.2
Race	White	468	12.1	0.6	223	6.1	0.4	345	8.4	0.5	476	14.3	0.7	461	13.0	0.6	1546	46.0	0.9
	Blacks/others	280	34.4	2.0	79	10.3	1.3	117	13.9	1.5	37	6.6	1.3	80	11.2	1.3	132	23.5	2.1
Education	Less than high school	348	21.4	1.2	124	8.5	0.8	189	11.3	0.9	117	9.5	0.9	175	13.5	1.0	444	35.8	1.5

		No ACP			1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		N	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE
	High school or GED	241	14.0	1.0	91	6.0	0.7	158	8.7	0.7	180	13.1	1.0	217	14.2	1.0	599	44.0	1.4
	More than high school	159	9.5	0.8	87	5.4	0.6	115	7.4	0.7	216	17.1	1.2	149	11.0	1.0	635	49.6	1.5
Marital Status	Married or partnered	570	18.4	0.8	212	7.4	0.5	378	12.4	0.7	289	11.9	0.7	372	14.4	0.8	852	35.4	1.1
	Divorced/separated/widowed/never married	178	8.5	0.7	90	5.1	0.6	84	3.8	0.4	224	15.8	1.1	169	10.4	0.9	826	56.4	1.4
Religion	Protestant	513	15.1	0.7	189	6.4	0.5	325	9.6	0.6	326	12.7	0.7	352	12.8	0.7	1087	43.4	1.1
	Catholic	185	15.1	1.2	83	7.0	0.8	113	9.1	0.9	130	13.9	1.3	152	14.1	1.2	410	40.7	1.7
	Others	50	10.2	1.6	30	6.3	1.2	24	5.2	1.2	57	16.6	2.3	37	9.8	2.0	181	51.8	3.0

		No ACP			1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		N	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE
Religiosity	Very important	404	15.5	0.8	153	6.9	0.6	240	9.1	0.6	241	13.5	0.9	260	12.3	0.8	810	42.7	1.2
	Somewhat important or not too important	344	13.8	0.8	149	6.2	0.5	222	8.9	0.6	272	13.4	0.8	281	13.3	0.8	868	44.4	1.2
Number of children	≤ 2	274	12.4	0.8	122	6.6	0.6	160	7.3	0.6	252	15.9	1.0	218	12.0	0.9	723	45.8	1.4
	3	141	14.1	1.2	65	6.5	0.9	82	8.2	1.0	103	12.6	1.3	85	10.1	1.2	393	48.5	1.9
	4	105	14.2	1.5	46	6.9	1.1	80	10.5	1.2	71	11.9	1.5	98	14.9	1.5	247	41.4	2.2
	≥ 4	228	19.9	1.4	69	6.1	0.8	140	12.2	1.1	87	10.3	1.2	140	15.8	1.4	315	35.6	1.8

		No ACP			1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		N	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE
Region	Northeast	108	14.5	1.5	54	7.4	1.1	66	9.5	1.2	91	13.8	1.5	81	14.0	1.5	261	40.9	2.1
	Midwest	120	9.3	0.9	67	5.4	0.7	86	7.0	0.8	146	14.8	1.2	137	12.6	1.1	489	50.9	1.7
	South	422	20.2	1.1	141	7.8	0.7	250	11.4	0.8	170	11.2	0.9	235	12.6	0.9	592	36.9	1.3
	West	98	11.5	1.2	40	5.0	0.8	60	7.0	1.0	106	15.6	1.5	88	12.4	1.4	336	48.4	2.0
Covered by a government plan	No	554	32.8	1.4	149	9.2	0.8	353	20.1	1.1	59	5.1	0.7	243	16.8	1.1	168	15.8	1.3
	Yes	194	5.3	0.4	153	5.1	0.4	109	3.4	0.4	454	17.7	0.8	298	10.7	0.7	1510	57.6	1.0
Estate will	Yes	195	6.9	0.5	148	5.2	0.5	155	5.2	0.4	412	16.5	0.8	315	12.1	0.7	1340	54.0	1.1

		No ACP			1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		N	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE	n	%	SE
	No	553	28.8	1.2	154	8.9	0.8	307	16.1	1.0	101	7.7	0.8	226	14.2	1.0	338	24.1	1.3

Table 4.3: Unadjusted associations between health and socioeconomic characteristics and advance care plans (ACP) among Health and Retirement Study decedents from 2002-2014

		1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI	
Self-rated health	Excellent or very good or good															
	Fair or poor	**1.5**	1.1	2.0	1.1	0.8	1.5	**1.5**	1.2	2.0	**1.7**	1.3	2.2	**1.9**	1.5	2.3
Self-reported change in health since last wave	Much or somewhat better or the same															
	Worse or somewhat worse	**1.8**	1.3	2.6	1.0	0.7	1.4	**3.3**	2.5	4.5	**2.2**	1.6	2.9	**3.7**	2.9	4.8
Health conditions	0-1															
	≥2	**1.9**	1.4	2.6	1.1	0.8	1.4	**3.8**	2.9	4.9	**2.4**	1.9	3.1	**5.2**	4.2	6.4
Cancer	No															
	Yes	**6.1**	3.4	10.7	1.4	0.7	2.7	**10.1**	6.1	16.8	**6.8**	4.1	11.4	**12.6**	7.9	20.1

		1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI	
Stroke	No															
	Yes	1.6	0.9	2.9	0.8	0.4	1.5	**3.0**	1.9	4.9	**2.4**	1.5	4.1	**4.0**	2.6	6.1
Psychiatric illnesses	No															
	Yes	1.05	0.65	1.72	1.04	0.68	1.60	**1.85**	1.26	2.72	**2.12**	1.45	3.11	**1.93**	1.42	2.61
Heart disease	No															
	Yes	**2.15**	1.48	3.12	1.06	0.72	1.55	**4.03**	2.95	5.50	**3.39**	2.47	4.65	**4.22**	3.24	5.49
Hospital stay in the past 12 months	No															
	Yes	**2.28**	1.54	3.37	0.95	0.65	1.40	**5.57**	4.05	7.66	**3.57**	2.57	4.96	**5.85**	4.44	7.70
Ever smoke	No	1.08	0.78	1.51	0.76	0.56	1.03	**1.69**	1.30	2.25	0.98	0.74	1.31	**1.41**	1.13	1.75

		1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI	
	Yes															
Age (5-year increase)		**1.06**	1.04	1.07	1.01	1.00	1.02	**1.12**	1.10	1.14	**1.05**	1.04	1.07	**1.11**	1.10	1.13
Gender	Male															
	Female	1.19	0.88	1.61	0.96	0.74	1.26	**1.58**	1.22	2.03	1.21	0.94	1.56	**1.91**	1.57	2.33
Race	White	**1.67**	1.20	2.33	**1.72**	1.27	2.32	**6.17**	3.97	9.59	**3.31**	2.42	4.52	**5.54**	4.23	7.26
	Blacks															
Education	Less than high school															
	High school or GED	1.07	0.75	1.52	1.17	0.86	1.58	**2.07**	1.51	2.89	**1.61**	1.20	2.14	**1.88**	1.50	2.38
	More than high school	**1.43**	0.99	2.07	**1.48**	1.06	2.07	**4.07**	2.94	5.63	**1.85**	1.33	2.52	**3.11**	2.42	4.01
Marital Status	Married or partnered															

		1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI	
	Divorced/separated/widowed/never married	**1.49**	1.05	2.05	**0.66**	0.47	0.91	**2.92**	2.23	3.74	**1.59**	1.20	2.11	**3.42**	2.75	4.25
Religion	Protestant															
	Catholic	1.09	0.77	1.55	0.94	0.69	1.28	1.09	0.81	1.47	1.09	0.82	1.45	0.93	0.74	1.17
	Others	1.47	0.86	2.50	0.79	0.45	1.40	**1.90**	1.21	3.00	1.13	0.65	1.96	**1.77**	1.22	2.57
Religiosity	Very important															
	Somewhat important or not too important	0.98	0.73	1.32	1.09	0.84	1.42	1.12	0.87	1.44	1.21	0.94	1.54	1.16	0.96	1.41
Number of children	≤ 2	**1.73**	1.18	2.56	0.97	0.70	1.35	**2.50**	1.78	3.52	1.22	0.89	1.68	**2.08**	1.62	2.69
	3.0	1.50	0.96	2.34	0.96	0.65	1.41	**1.72**	1.15	2.55	0.91	0.62	1.34	**1.93**	1.44	2.58
	4.0	1.58	0.96	2.59	1.21	0.80	1.83	**1.63**	1.04	2.53	1.33	0.89	1.97	**1.64**	1.18	2.28
	≥ 4															

		1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI		OR	95% CI	
Region	Northeast															
	Midwest	1.12	0.70	1.80	1.15	0.73	1.80	**1.66**	1.11	2.50	1.40	0.93	2.12	**1.93**	1.39	2.69
	South	0.76	0.49	1.16	0.86	0.59	1.27	0.58	0.40	0.85	0.65	0.45	0.93	0.65	0.48	0.87
	West	0.86	0.50	1.46	0.93	0.57	1.51	1.42	0.92	2.19	1.12	0.71	1.76	**1.49**	1.05	2.12
Covered by a government plan	No															
	Yes	**3.45**	2.52	4.71	1.03	0.75	1.40	**21.31**	14.81	30.67	**3.89**	2.97	5.15	**22.34**	17.08	29.22
Estate will	Yes	**2.45**	1.79	3.34	**1.34**	1.01	1.78	**8.86**	6.50	12.09	**3.49**	2.67	4.56	**9.33**	7.42	11.73
	No															

Table 4.4: Adjusted association between self-reported health and advance care plans combinations (ACP) among Health and Retirement Study decedents from 2002-2014

		1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		AOR	95% CI		AOR	95% CI		AOR	95% CI		AOR	95% CI		AOR	95% CI	
Self-rated health	Excellent or very good or good															
	Fair or poor	1.24	0.83	1.85	1.35	0.96	1.89	0.80	0.54	1.19	1.17	0.82	1.67	0.91	0.64	1.28
Self-reported change in health since last wave	Much or somewhat better or the same															
	Worse or somewhat worse	1.24	0.81	1.91	0.90	0.60	1.35	**2.06**	1.30	3.19	1.30	0.88	1.91	**1.98**	1.35	2.89
Health conditions	0-1															
	≥2	1.19	0.80	1.76	1.11	0.78	1.57	1.38	0.91	2.08	1.11	0.78	1.54	**1.78**	1.24	2.52

		1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		AOR	95% CI		AOR	95% CI		AOR	95% CI		AOR	95% CI		AOR	95% CI	
Cancer	No															
	Yes	**4.15**	2.27	7.60	1.27	0.62	2.61	**4.84**	2.71	8.66	**4.13**	2.38	7.19	**5.57**	3.25	9.55
Stroke	No															
	Yes	1.03	0.55	1.95	0.75	0.38	1.49	1.14	0.64	2.01	1.25	0.72	2.19	1.40	0.84	2.34
Psychiatric illnesses	No															
	Yes	0.77	0.44	1.34	1.06	0.65	1.71	1.11	0.67	1.86	1.40	0.89	2.19	1.00	0.66	1.53
Heart disease	No															
	Yes	1.18	0.74	1.87	0.95	0.62	1.46	1.41	0.93	2.14	**1.70**	1.15	2.52	1.33	0.92	1.93

		1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		AOR	95% CI		AOR	95% CI		AOR	95% CI		AOR	95% CI		AOR	95% CI	
Hospital stay in the past 12 months	No															
	Yes	**1.59**	1.02	2.49	0.94	0.61	1.44	**3.09**	2.04	4.67	**2.16**	1.46	3.25	**2.76**	1.90	4.01
Ever smoke	No	0.87	0.60	1.28	0.72	0.52	1.00	1.11	0.77	1.58	0.83	0.59	1.15	0.88	0.64	1.22
	Yes															
Age (5 year increase)		**1.05**	1.03	1.08	1.02	1.00	1.04	**1.06**	1.04	1.08	**1.04**	1.02	1.06	**1.05**	1.03	1.07
Gender	Male															
	Female	1.33	0.93	1.89	1.06	0.79	1.42	**1.59**	1.16	2.32	**1.41**	1.04	1.91	**1.96**	1.45	2.69

		1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		AOR	95% CI		AOR	95% CI		AOR	95% CI		AOR	95% CI		AOR	95% CI	
Race	White	1.27	0.86	1.88	**1.57**	1.13	2.18	**2.92**	1.68	5.07	**2.37**	1.61	3.50	**2.86**	1.97	4.16
	Blacks															
Education	Less than high school															
	High school or GED	1.05	0.70	1.57	1.11	0.80	1.54	**1.97**	1.32	2.93	**1.50**	1.07	2.12	**1.79**	1.29	2.50
	More than high school	1.53	0.97	2.41	**1.49**	1.03	2.16	**4.67**	3.05	7.16	**1.88**	1.27	2.78	**3.61**	2.49	5.25
Marital Status	Married or partnered															
	Divorced/separated/widowed/never married	1.23	0.83	1.84	0.70	0.49	1.00	**2.09**	1.44	3.04	**1.53**	1.08	2.15	**2.47**	1.79	3.41
Religion	Protestant															
	Catholic	1.09	0.73	1.64	0.82	0.59	1.17	1.13	0.76	1.67	1.01	0.72	1.42	0.99	0.71	1.39
	Others	1.73	0.94	3.17	0.75	0.41	1.38	**2.16**	1.18	3.94	1.13	0.63	2.05	**2.03**	1.18	3.51

		1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		AOR	95% CI		AOR	95% CI		AOR	95% CI		AOR	95% CI		AOR	95% CI	
								2.2	0.80	3.94				2.03	0.91	3.51
Religiosity	Very important															
	Somewhat important or not too important	0.96	0.68	1.36	1.02	0.76	1.36	1.21	0.84	1.70	1.22	0.90	1.65	1.25	0.93	1.68
Number of children	≤ 2	**1.58**	1.03	2.42	0.95	0.67	1.34	**1.64**	1.07	2.51	0.98	0.68	1.41	1.36	0.94	1.96
	3.0	1.48	0.90	2.44	0.89	0.60	1.33	1.29	0.79	2.11	0.80	0.53	1.23	1.47	0.97	2.23
	4.0	1.48	0.87	2.50	1.12	0.74	1.72	1.17	0.70	1.95	1.11	0.72	1.72	1.16	0.76	1.78
	≥ 4															
Region	Northeast															
	Midwest	1.39	0.81	2.49	1.08	0.68	1.71	**2.55**	1.53	4.26	**1.74**	1.10	2.76	**2.93**	1.87	4.59
	South	1.00	0.60	1.66	0.86	0.57	1.30	0.90	0.55	1.47	0.94	0.61	1.44	1.03	0.69	1.55

		1 directive (living will or DPAHC)			ACP discussions only			Both directives (living will and DPAHC)			1 directive and ACP discussions			Both directives and ACP discussions		
		AOR	95% CI		AOR	95% CI		AOR	95% CI		AOR	95% CI		AOR	95% CI	
	West	0.97	0.56	1.83	0.85	0.51	1.41	**1.83**	1.04	3.08	1.37	0.83	2.26	**1.90**	1.19	3.02
Covered by a government plan	No															
	Yes	**1.92**	1.27	2.92	0.99	0.68	1.44	**9.04**	5.73	14.25	**2.06**	1.45	2.96	**8.83**	6.22	12.36
Estate will	Yes	**2.13**	1.50	3.03	1.13	0.84	1.53	**6.33**	4.36	9.17	**3.06**	2.26	4.22	**7.60**	5.58	10.35
	No															

CHAPTER V: FACTORS ASSOCIATED WITH LIVING WILL CHOICES: A CROSS SECTIONAL ANALYSIS OF HEALTH AND RETIREMENT STUDY DATA[2]

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[2] Agha A., Probst J.C., Brooks J.M., Hardin J.W., & Teixeira A. To be submitted to *American Journal of Public Health, Journal of Aging and Health, Journal of Palliative Medicine, Journal of the American Geriatrics Society, or British Medical Journal*

5.1. ABSTRACT

Introduction

End-of-life care choices are associated with the actual end-of-life care experience. However, little data exist on the factors associated with end-of-life care choices. Health status is one of those factors that influence end-of-life care choices, and to identify that influence most studies relied on prospect theory as the theoretical lens and hypothetical health status scenarios to elicit the choices. We test the association using a representative U.S. elderly population with a documented living will.

Method

Our study used Health and Retirement Study (HRS) exit interviews from 2002-2014 and HRS core 1992-2014. The HRS core or panel data include the biennial survey data. These data include information about demographic, socioeconomic, health and retirement characteristics of a representative sample of 20,000 Americans of age over 50 years. The one-time exit interviews elicit information about the distribution of wealth and health care experience towards the end-of-life from next-of-kin of the decedents since the last wave. Exit interviews include information about the distribution of wealth and health care experience towards the end-of-life, including the end-of-life care choices. The choices are reported using four broad categories — "comfort care", "limit care in certain situations", "withhold certain care" and "all care possible" — which are based on specific choices in a living will. The literature has used limit care in certain situations than withhold certain care choices. Therefore, we included three choices in our study including comfort care, limit care in certain situations and all care possible.

Restricting the analysis to decedents with a living will (n=3,949) and with valid sample weights yielded 2,326 records. Three logistic regression models with weights were run using each of the broad choices as outcomes at for which hypothesis tests were evaluated at the 5% level of significance. Self-reported health and change in health status and their interaction was used as predictors. All models were adjusted for demographic, socioeconomic and health characteristics, including physician diagnosed diseases — a history of stroke, psychiatric illness and heart disease.

Results

Comfort care was chosen by 90.3%, limit care in certain situations by 89.3% and all care possible by 5.8% decedents. About 52.5% decedents reported their health as "excellent, very good or good" and 58.2% reported the change in health status as "much better, somewhat better or the same".

Self-reported health and change in health status since the previous wave were not associated with care-limiting choices — limit care in certain situations and comfort care. The "all care possible" choice was associated with the change in health status. The decedents with worse or somewhat worse health were less likely to choose "all care possible" choice than the decedents with "much better, somewhat better or the same" self-reported change in health. A psychiatric illness was associated with a higher likelihood of "all care possible" choice but a lower likelihood of comfort care. A history of stroke was associated with a lower likelihood of "limit care in certain situations" choice.

Conclusions

We found dynamic measure of self-reported health associated with an end-of-life care choice but not the self-reported health. The decedents who reported psychiatric illness were less likely to choose comfort care and more likely to choose all care. Prior research also reports fear among psychiatric patients of getting less care than they would need. Patients with stroke were less likely to choose “limit care choice”. We do not know the underlying reason of this association; however, a stroke is an acute episode and people generally enjoy good health before stroke. The aggressive treatments such as mechanical ventilation and artificial hydration have also shown more promise in treating some stroke patients.

5.2. INTRODUCTION

People fear receiving aggressive and painful end-of-life care (Connors, et al., 1995). Aggressive or intense care centers around disease-focused medical interventions at the expense of good palliation (Henson et al., 2016). Health care providers may poorly interpret patient’s preferences (Desharnais, et al., 2007) and provide more aggressive end-of-life care than a patient would prefer (Periyakoil, et al., 2014). Such care is associated with a higher cost and lower quality (Zhang, et al., 2009). Therefore, people use advance care plans (ACPs) to let their loved ones and health care providers know the end-of-life care they wish to receive, in case they become incompetent to make treatment decisions by themselves (Scott, Mitchell, Reymond, & Daly, 2013).

The three ACPs that are typically recognized in the U.S. include ACP discussions and two advance directives — living will and DPAHC (Detering, et al., 2016). A living will documents specific end-of-life care choices about the use of life-sustaining treatments — artificial ventilation; CPR; artificial nutrition and hydration; dialysis; surgery; blood transfusion; pain medication and antibiotics — and organ and tissue donation (Geldart, Shashy, & Kalb, 2000). The choices can extend or restrict end-of-life care.

Although studies in the 1990s used either a single question to elicit end-of-life care choices (R. S. Phillips, et al., 1996) or specific choices (O'brien, et al., 1995), recent studies have used specific living will choices. The studies have used either distinct choices (e.g., use of the ventilator or CPR, etc.) (Dobalian, 2006; Hakim, et al., 1996; Woolley, et al., 2006) or broad categories of choices based on the distinct choices (e.g., whether a patient chose care-limiting or care-extending choices) (Ditto, et al., 2006; Fried, et al., 2007). Most recent studies on ACPs and end-of-life care choices in the U.S. are based on Health and Retirement Study (HRS) data (Bischoff, et al., 2013; Joan M Teno, Fisher, Hamel, Coppola, & Dawson, 2002). The HRS classifies choices into broad categories, including “limit care in certain situations”; “comfort care” and “all care possible” (Bischoff, et al., 2013; Lauren H Nicholas, et al., 2014; Silveira, et al., 2010).

The majority of the existing literature on choice has focused on two areas, 1) concordance between a living will choices and actual care experience (S. Fischer, et al., 2013; Unroe, Hickman, Torke, & Group, 2016) and 2) stability of living will choices over time (Bischoff, et al., 2013; S. Fischer, et al., 2013; Fried, et al., 2007; Pecanac, Repenshek, Tennenbaum, & Hammes, 2014). The few studies that have reported on the association between health status and choices have used non-representative samples and hypothetical health status scenarios to determine the association between the choices and health status (Lenert, et al., 1999; Winter, et al., 2009; Winter & Parker, 2007). These studies have used prospect theory as a theoretical lens (Lenert, et al., 1999; L. L. Phillips, et al., 2011; Winter, et al., 2003; Winter & Parker, 2007).

Prospect theory provides a framework for decisions under uncertainty (Kahneman & Tversky, 1979). The seminal theory provided a robust model to explain individual's behavior under risk in wide array of industries, including insurance and health care. In contrast to the expected utility theory, prospect theory proposed a non-linear relationship between objective and subjective utility. The theory proposes an s-shaped utility curve between the actual (objective) and the perceived (subjective) value a person assigns to a prospect, including money or health (Figure 5.1).

The s-shaped curve reflects that people assign different weights to gain or loss depending on their reference point. The x-axis of the curve plots the objective value of a decision — the left-hand side of axis shows loss and right-hand side represents a gain (Figure 5.1). Similarly, the y-axis plots the subjective value, part above zero showing the gain and below zero the loss. The curve is concave in the gain and convex in loss domain, showing people are loss averse.

Further, the curve is steeper near the reference (zero) and flattens out away from the reference. Therefore, any change near the reference (steeper part) seems bigger than a change near the flatter part of the s-shaped curve. For example, a gain of $1 from $1 to $2 will be perceived bigger than a gain of $1 from $3000 to $3001. Although, the objective value of $1 will be the same, but the subjective perception of value could be different. Therefore, the prospect theory proposes that subjective overweighting of small probabilities near the reference results in irrational choices.

Several end-of-life care studies have used prospect theory (Hess, 2015; Jou, Shanteau, & Harris, 1996; Lenert, et al., 1999; L. L. Phillips, et al., 2011; Verma, Razak, & Detsky, 2014; Winter, et al., 2003; Winter & Parker, 2007). The other notable tenet of the theory that is closely associated with end-of-life care decisions is that health status at the time of decision interacts with end-of-life care choices. The choices closer in time (temporally proximal) have a higher subjective utility than distal choices. In the context of health care, death is a more proximal outcome for an unhealthy or bedridden person than a healthy person. Further, poor health is associated with a positive view about future life in sickness and disability. Therefore, people in poor health are more likely to choose life-extending measures than a healthy person.

In a midlife context, the best gain scenario is a complete health and worse loss scenario is death (Jou, et al., 1996). However, an end-of-life situation is different. The possibility of a limited gain in health due to medical interventions in terminal conditions could make a healthy individual even more treatment averse.

To the best of our knowledge, no study has yet determined the association between the subjective measures of health status, including self-reported health and change in health status, and end-of-life care choices using a representative sample Therefore, we examined the association between self-reported health, change in health status and the interaction between the two, and end-of-life care choices, including “limit care in certain situations”, “comfort care” and “all care possible”, and, after adjusting for the demographic, socioeconomic and other health factors including assistance in daily living activities, number of health conditions and history of stroke, psychiatric illness and heart disease.

5.3. METHODS

Study Participants

The HRS is a panel survey of a representative American population of age over 50 years. The survey has been administered biennially since 1992. It captures health and retirement data in the later part of life. Since 2002, the HRS also conducts one-time post-death interview (also called an “exit interview”) with a knowledgeable next-of-kin of decedents (usually a surviving spouse or family member) since the previous wave. The exit interview elicits information about estate will, distribution of wealth and advance care planning and end-of-life care experience.

Since a living will is the only typical ACP that documents the end-of-life care choices, the HRS reports end-of-life care choices only for the participants with a living will (Health and Retirement Study, 2006). From 2002-2014, HRS conducted 9,010 next-of-kin interviews. A living will was reported for a 3,949 HRS participants. Excluding the records with missing values yielded 2,326 records. We found no difference in age, race, religion and education among the decedents included in the two datasets with n=3,949 and n=2,326 (p-value $\geq$ 0.14).

Data sources

Health and Retirement Study core and exit interview data

The HRS core data comprises of the biennial panel survey data. RAND collates the multi-wave core data into a single file using an easy-to-follow naming algorithm. The latest RAND file includes core data from 1992-2014. The HRS exit interviews elicit information about medical expenditures, distribution of wealth and end-of-life care planning and experience from next-of-kin of HRS decedents since the previous wave (Servais, 2010).

Data merging

We first appended all the HRS exit interview files from 2002 to 2014 into a single data file. We then merged the exit interview file with the RAND collated HRS core file, using HRS identification number as a unique identifier.

Variables

Dependent variables

HRS elicits information about living wills and choices using binary (yes/no) questions:

> Living will: "Did [FIRST NAME] provide **written instructions** about the treatment or care (he/she) wanted to receive during the final days of (his/her) life?".

End-of-life care choices

> "Did these instructions express a desire to receive **all care possible** under any circumstances in order to prolong life?"

> "Did these instructions express a desire to **limit care in certain situations**?"

> "Did these instructions express a desire to keep (him/her) **comfortable and pain free**, but to forego extensive measures to prolong life?"

Independent variables

HRS elicits information about self-reported health and change in health status using a five-point Likert scale — "self-reported health": 1) excellent; 2) very good; 3) good; 4) Fair; and 5) poor and the "change in health status since the last wave": 1) much better; 2) somewhat better; 3) same; 4) somewhat worse; and 5) worse. The HRS measures assistance in daily living activities using sum of five daily living activities: bathing; eating; dressing; walking across a room; and getting in or out of bed. A score of zero represents that a person does not need any assistance and a score of ‘5’ shows that a person needs assistance with all daily living activities.

The five-point self-reported health and change in health status Likert variables were combined to create binary categories — self-reported health: “excellent, very good or good” and “Fair or poor” and change in health status since last wave: “Much better, somewhat better or the same” and “Worse or somewhat worse”. Similarly, 0-5 scale of assistance needed in daily living activities were combined to create binary categories: “No assistance needed” and ‘assistance needed in one or more activity”. The numbers of health conditions were binned into four categories: ≤1, 2, 3 and 4 or more.

Covariates

Based on previous literature on the factors associated with end-of-life care choices (Chao, Pagán, & Soldo, 2008); stability of choices over time (Emanuel, Emanuel, et al., 1994; Fried, et al., 2007); concordance between the choices and end-of-life or terminal care experience (Desharnais, et al., 2007; S. Fischer, et al., 2013); and the association between the choices and end-of-life care quality (Carr, 2012a), we included demographic and socioeconomic (age, sex, race, education and estate will); health (self-reported health; change in health status; assistance needed in the activities of daily living and history of stroke, heart disease and psychiatric illness) and health care (number of hospital stays in the past 12 months, coverage by health insurance plan) factors. The analysis was not adjusted for income levels as lifetime assets than income reflect wealth better among elderly (Gjonca, Tabassum, & Breeze, 2009). Further, the association between income and health has been criticized for simultaneity or bidirectionality (Brown, 2002; Carr, 2012c). Low income is associated with poor health, but poor health can also result in low income (Brown, 2002).

Since, HRS core data include multi wave data, we included the information on the variables that can vary over time from the wave that was close to the year that the living will was documented. For the decedents with a missing data on the date, we included the information on the variable from the earlier wave that included a valid date.

The categories of education and marital status were combined to form binary variables — education ("Less than high school" and "High school or more") and marital status ("Married or partnered" and "Divorced/separated/never married/widowed").

Data analysis

We tested the bivariate association between the interaction term (self-reported health*change in health status) and each end-of-life care choice category at an alpha level of 5% (Equation 1). The interaction term was not significant at the bivariate analysis for any of the three outcomes: "all care possible", comfort care and limit care in certain situations. Thus, we did not include tbe interaction term in the adjusted model.

$$A = \beta_1 X_1 + \beta_2 X_2 + \beta_1 X_1 * X_2 \qquad (6)$$

We ran three multiple logistic regression models with weights to evaluate the association between the interaction between self-reported health and change in health status and each broad category of living will choices at an alpha level of 5%. We found no multicollinearity among the predictors in the final models (Variation Inflation Factor ≤ 1.85).

5.4. RESULTS

Descriptive

Socioeconomic factors

About 53.2% (±1.2) decedents were females (Table 5.1). Most participants were White (92.7 ± 0.6%); had high school or more education (75.1 ± 0.9%); married or partnered (55.8 ± 1.1) and devised an estate will (77.4 ± 1.0%). The mean age was 79.7 ± 0.3 years.

Dependent variable and predictors

Comfort care was chosen by 90.3±0.7%, limit care in certain situation by 89.3 ± 0.7% and all care possible by 5.8 ± 0.6% (Table 5.1). Health was rated as “excellent, very good or good” by 54.5 ± 1.1% decedents. Change in health status was reported as “much better, somewhat better or the same” by 52.5 ± 1.2%. About 49.9% decedents had three or more health conditions. Heart disease was reported by 40.2 ± 1.1%; psychiatric illness by 16.1 ± 0.9% and stroke by 14.7± 0.8. About 43.2% (±1.2) reported a hospital stay within 12 months before death.

End-of-life care choices

Limit care in certain situations

In unadjusted (bivariate) analysis, the care-limiting choice was associated with race (Odds Ratio (OR): 2.69; 95% Confidence Interval (CI): 1.81-4.02), the estate will (OR: 1.91; 95% CI: 1.40-2.62) and education (OR: 1.51; 95% CI: 1.11-2.05) (Table 5.2). The interaction term between self-reported health and change in health status was not associated with the limit care choice (p-value 0.26); therefore, it was not included in the adjusted model.

In the adjusted model, we found race, estate will and stroke as factors significantly associated with the limit care choice. White race (Adjusted Odds Ratio (AOR): 2.29; 95% Confidence Interval (CI): 1.52-3.46) and estate will (OR: 1.73; 95% CI: 1.22-2.44) were associated with a higher likelihood of choosing "limit care". However, a history of stroke was associated with less likelihood of choosing the limit care choice (AOR: 0.6; 95% CI: 0.4-1.0).

Comfort care

The choice of comfort care was associated with race (OR: 2.71; 95% CI: 1.81-4.06), education (OR: 1.57; 95% CI: 1.12-2.19) and estate will (OR: 1.60; 95% CI: 1.13-2.27) in the unadjusted analysis (Table 5.3). The interaction between self-reported health and change in health status was insignificant (p-value 0.74).

In the adjusted analysis, race (AOR: 2.34; 95% CI: 1.50-3.64) and estate will (AOR: 1.64; 95%: 1.18-2.27) showed significant associations. The history of psychiatric illness was associated with less likelihood of choosing comfort care. On the other hand, white race and estate will were associated with a higher likelihood of selecting comfort care.

All care possible

The all care possible was the only outcome that showed significant association with more than one health factor in the unadjusted analysis — interaction between self-reported health and change in health status was insignificant (p-value 0.69); number of health conditions, psychiatric disease, history of stroke and hospital stay in the past 12 months (Table 5.4). Further, race, marital status, estate will and education were also associated with the choice.

In the adjusted analysis, we found change in health status (AOR: 0.54; 95% CI: 0.33-0.90), psychiatric illness (AOR: 1.79; 95% CI: 1.03-3.09); race (AOR: 0.20; 95% CI: 0.13-0.33); marital status (AOR: 0.50; 95% CI: 0.31- 0.78) and estate will (AOR: 0.44; 95% CI: 0.28-0.69) being associated with the all care possible choice. We also found that two health conditions/comorbidities (AOR: 2.04; 95% CI: 1.08-3.83) were associated with a higher likelihood of all care possible.

To further interpret the above results, the decedents who reported “worse or somewhat worse” change in health status since previous wave were less likely to opt “all care possible” choice compared to decedents reporting “better/somewhat better”. Decedents with a history of psychiatric illness and with two health conditions were more likely to choose all care possible choice. Conversely, the decedents who were white, possessed an estate will and were not married or partnered were less likely to choose the all care possible choice.

5.5. DISCUSSION

The literature shows that end-of-life care choices are closely associated with the terminal care experience. However, limited research exists on the factors associated with end-of-life care choices. We determined the association between self-reported health and change in health status and the interaction between the two factors and the three broad categories of end-of-life care choices — “limit care in certain situations”, “comfort care” and “all care possible” — using a representative American population of age over 50 years who documented a living will. We adjusted our analysis for known covariates of the end-of-life care choices including demographic and socioeconomic characteristics;

subjective measures of health including self-reported assistance needed in activities of daily living and self-reported diseases —heart disease, stroke and psychiatric illnesses —; and the number of health conditions.

We used prospect theory to analyze the association between health factors and end-of-life care choices. The theory proposes that sick persons are more likely to choose life-extending end-of-life care measures than healthy individuals. We found the association between decedent's self-reported diseases with the end-of-life care choices more consistent with the axiom of prospect theory than the subjective measures (e.g., self-reported health, change in health status and assistance needed in daily living activities). Our study showed the decedents reporting a history of stroke were less likely to choose "limit care in certain situations" and those reporting a history of psychiatric illness were more likely to choose "all care possible" choice.

However, a history of cardiovascular disease was not associated with any choice. This could be because cardiovascular disease follows a different trajectory than a psychiatric illness or stroke (Barbara L. Kass-Bartelmes & Ronda Hughes, 2004). While patients with cardiovascular face sudden and severe episodes of illness requiring immediate hospitalizations along with a gradual decline in health, in psychiatric illnesses and stroke the course of decline remains gradual and patients are often not aware that their disease is terminal (Barbara L. Kass-Bartelmes & Ronda Hughes, 2004). Research also shows that psychiatric patients are more likely to choose aggressive end-of-life care (Foti, Bartels, Van Citters, Merriman, & Fletcher, 2005; Wilkinson, et al., 2007).

We found that the change in health to "worse or somewhat worse" was associated with a lower uptake of "all care possible" choice. This could be because people, who perceive that their health is poor and declining, realize better the futility of end-of-life care and fear a poor quality of life after such care episodes. However, we recommend more research on as to explore this phenomenon.

With regards to the demographic and socioeconomic factors, we found race and estate will being associated with all the choices. Whites and those with an estate will were more likely to choose care-limiting choices (limit care in certain situations and comfort care) and less likely to choose care-extending options (all care possible). Previous research has also shown that Black respondents are less likely to formulate ACPs and are more likely to choose aggressive end-of-life care (Eleazer, et al., 1996; McKinley, et al., 1996). The all care possible choice was also associated with marital status — decedents who were not married or partnered were less likely to choose all care possible.

The “all care possible” choice showed association with more factors that other choices — interaction between self-reported health and change in health status; stroke; psychiatric illness; race; estate will and marital status. The living wills are primarily devised to limit care as the default end-of-life care option is all care. Therefore, those who devise a living will to choose all care possible could be different from those who devised it to limit care.

Our study has several limitations. First, due to a cross sectional design, we could only report association. Second, HRS collects information about ACPs and the end-of-life care choices of HRS participants from next-of-kin in the wave following the death of the participants. Therefore, recall bias could be an issue. However, end-of-life care literature has frequently used proxy reports to elicit information about decedents due to the insufficient information in the medical records (Silveira, et al., 2010). Further, high accuracy has been reported between proxy reports and medical claims data (Corder, et al., 1996; Silveira, et al., 2010). The previous research has noted two limitations of prospect theory, which include not considering the role of 1) disease prognosis along with the health status as a factor influencing the end-of-life care choices (Romo, Dawson-Rose, Mayo, & Wallhagen, 2016) and 2) risk characteristics and behaviors including age, sex and personality type, etc. (S. S. Lee, 2008). For instance, youth and male sex are associated with risk-taking behaviors. Therefore, our third limitation includes not adjusting for the disease prognosis and risk-taking tendencies of the decedents.

Despite the limitations, our study adds to the literature by using a representative sample to determine the association between health status and end-of-life care choices using prospect theory as a lens. We found that the association of self-reported illnesses and the end-of-life care choices. The decedents with a self-reported history of psychiatric illness were more likely to choose "all care possible" choice and the decedents with a history of stroke were less likely to choose the "limit care in certain situation choice". Further research that adjusts for disease prognosis and risk characteristics and behaviors, using a large representative sample, could illuminate the association between health measures and end-of-life care better in the light of prospect theory.

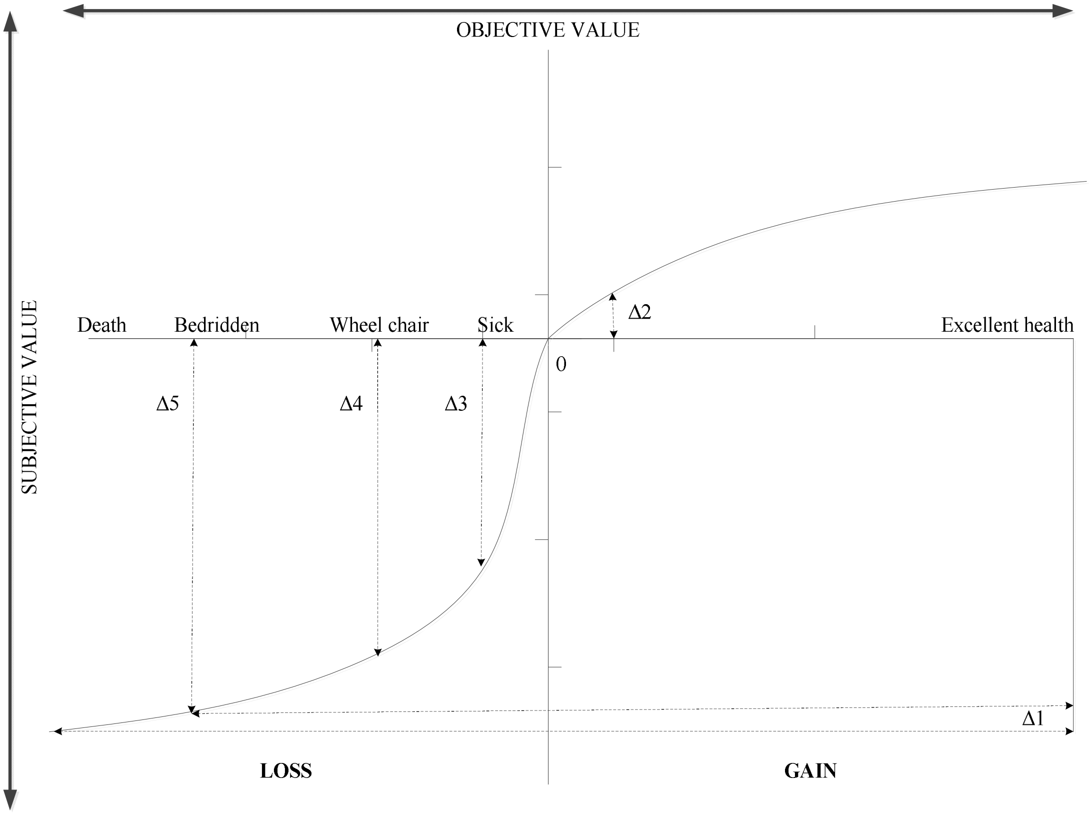

Figure 5.1: Value function across the continuum of health status in gain and loss scenarios

Table 5.1: Health and socioeconomic characteristics and living will choices among Health and Retirement Study decedents from 2002-2014

Variables		n=2326	%	SE
Advance Care Choices and health				
Limit care	No	263	10.7	0.7
	Yes	2063	89.3	0.7
Comfort care	No	232	9.7	0.7
	Yes	2094	90.3	0.7
All care possible	No	2182	94.2	0.6
	Yes	144	5.8	0.6
Self-rated health	Excellent, very good or good	1216	52.5	1.2
	Fair or poor	1110	47.5	1.2
Change in health status since previous wave	Much better, somewhat better or the same	1351	58.2	1.2
	Worse or somewhat worse	975	41.8	1.2
Number of activities of daily living*	None	1607	69.3	1.1
	One or more	719	30.7	1.1
Number of health conditions				
	0-1	597	26.2	1.0
	2	556	23.9	1.0
	3	519	21.9	1.0
	4 or more	654	28.02	1.06
Heart disease	No	1372	59.8	1.1
	Yes	954	40.2	1.1
Stroke	No	1966	85.3	0.8
	Yes	360	14.7	0.8
Psychiatric disease	No	1968	83.9	0.9
	Yes	358	16.1	0.9
Hospital stay in the past 12 months	No	1312	56.8	1.2
	Yes	1014	43.2	1.2
Health behaviors				
Smoking	No	795	34.3	1.1
	Yes	1531	65.7	1.1
Socio-demographics				
Gender	Male	1092	46.8	1.2
	Female	1234	53.2	1.2
Age				

Variables		n=2326	%	SE
Race	White	2091	92.7	0.6
	Other	235	7.3	0.6
Religion	Protestants	1485	62.0	1.2
	Others	587	25.8	1.0
		254	12.2	0.8
Education	Less than high school	630	24.9	1.0
	High school or more	1696	75.1	1.0
Marital status	Married or partnered	1287	54.5	1.2
	Divorced/separated/never married/widowed	1039	45.5	1.2
Region	Northeast	396	18.6	0.9
	Midwest	628	28.4	1.1
	South	846	31.4	1.1
	West	456	21.5	1.0
Health insurance and estate will				
Covered by government plan	No	265	13.5	0.9
	Yes	2061	86.5	0.9
Estate will	Yes	1762	76.2	1.0
	No	564	23.8	1.0

Notes:

*Activities include the five tasks: bathing, eating, dressing, walking across a room, and getting in or out of bed.

Table 5.2: Association between self-reported health and "limit care in certain situations" among Health and Retirement Study decedents with a living will from 2002-2014

		Did not choose to limit care (n=263)			Chose to limit care (n=2063)			OR	95% CI		AOR	95% CI	
		n	%	SE	n	%	SE						
Health													
Self-rated health	Excellent, very good or good	140	10.9	1.0	1076	89.1	1.0	1.0					
	Fair or poor	123	10.5	1.1	987	89.5	1.1	1.05	0.78	1.41	1.26	0.88	1.81
Change in health status since the previous wave	Much better, somewhat better or the same	156	10.8	0.9	1195	89.2	0.9	1.0					
	Worse or somewhat worse	107	10.6	1.1	868	89.4	1.1	1.03	0.76	1.39	0.97	0.69	1.361
Number of activities of daily living	None	179	10.6	0.9	1428	89.4	0.9	1.0					
	One or more	84	11.0	1.3	635	89.0	1.3	1.04	0.75	1.43	0.93	0.65	1.34
Number of health conditions													

		Did not choose to limit care (n=263)			Chose to limit care (n=2063)			OR	95% CI		AOR	95% CI	
		n	%	SE	n	%	SE						
	0-1	74	10.5	1.3	523	89.5	1.3	1.0					
	2	52	9.2	1.4	504	90.8	1.4	1.16	0.75	1.79	1.32	0.85	2.05
	3	61	12.0	1.6	458	88.0	1.6	0.87	0.57	1.31	1.01	0.65	1.58
	4 or more	76	11.2	1.4	578	88.8	1.4	0.94	0.63	1.39	1.40	0.82	2.38
Heart disease	No	155	10.2	0.9	1217	89.8	0.9	1.0					
	Yes	108	11.5	1.2	846	88.5	1.2	0.87	0.64	1.18	0.82	0.57	1.17
Stroke	No	213	10.2	0.8	1753	89.84	0.76	1.0					
	Yes	50	14.0	2.2	310	86.0	2.2	0.7	0.47	1.03	**0.6**	0.4	1.0
Psychiatric disease	No	218	10.5	0.8	1750	89.5	0.8	1.0					
	Yes	45	11.7	2.0	313	88.3	2.0	0.88	0.59	1.33	0.87	0.56	1.37
Hospital stay in the past 12 months	No	154	10.6	0.9	1158	89.4	0.9	1.0					
	Yes	109	10.9	1.1	905	89.1	1.1	0.97	0.72	1.31	1.07	0.76	1.52
Health behaviors													
Smoking	No	96	10.5	1.2	699	89.5	1.2	1.03	0.76	1.4	1.01	0.73	1.40
	Yes	167	10.8	0.9	1364	89.2	0.9	1.0					
Socio-demographics													

		Did not choose to limit care (n=263)			Chose to limit care (n=2063)			OR	95% CI		AOR	95% CI	
		n	%	SE	n	%	SE						
Gender	Male	124	10.9	1.1	968	89.1	1.1	1.0					
	Female	139	10.5	1.0	1095	89.5	1.0	1.04	0.78	1.41	0.96	0.67	1.38
Age*			78.7	0.8		79.8	0.3				1.01	0.99	1.03
Race	White	206	9.8	0.7	1885	90.2	0.7	**2.69**	1.81	4.02	**2.29**	1.52	3.46
	Others	57	22.6	3.2	178	77.4	3.2	1.0					
Religion	Protestants	166	10.5	0.9	1319	89.5	0.9						
	Catholic	70	11.2	1.4	517	88.8	1.4	0.93	0.67	1.29	0.95	0.66	1.37
	Others	27	10.7	2.4	227	89.3	2.4	0.98	0.58	1.67	0.92	0.53	1.59
Education	Less than high school	94	13.9	1.5	536	86.1	1.5	1.0					
	High school or graduate diploma	169	9.7	0.8	1527	90.3	0.8	1.51	1.11	2.05	1.34	0.97	1.85
Marital status	Married or partnered	152	11.4	1.0	1135	88.6	1.0	1.0					
	Divorced/separated/never married	111	9.9	1.0	928	90.1	1.0	1.16	0.86	1.57	1.24	0.86	1.81
Region	Northeast	49	12.4	1.8	347	87.6	1.8	1.0					

		Did not choose to limit care (n=263)			Chose to limit care (n=2063)			OR	95% CI		AOR	95% CI	
		n	%	SE	n	%	SE						
	Midwest	72	11.3	1.5	556	88.7	1.5	1.12	0.72	1.72	1.15	0.73	1.81
	South	103	11.3	1.3	743	88.7	1.3	1.11	0.74	1.68	1.15	0.73	1.81
	West	39	7.7	1.3	417	92.3	1.3	1.44	0.94	2.21	1.48	0.94	2.32
Health insurance and estate will													
Estate will	Yes	167	9.1	0.8	1595	90.9	0.8	**1.91**	1.40	2.62	**1.73**	1.22	2.44
	No	96	16.0	1.8	468	84.0	1.8	1.0					
Covered by government plan	No	36	11.9	2.3	229	88.1	2.3	1.0					
	Yes	227	10.5	0.8	1834	89.5	0.8	**1.14**	0.73	1.79	1.01	0.59	1.75
*Means are calculated													

Table 5.3: Association between self-reported health and "comfort care" among Health and Retirement Study decedents with a living will from 2002-2014

		Did not choose comfort care (n=232)			Chose comfort care (n=2094)			OR	95% CI		AOR	95% CI	
		N	%	SE	n	%	SE						
Health													
Self-rated health	Excellent, very good or good	126	10.1	1.0	1090	89.9	1.0	1.0			1.0		
	Fair or poor	106	9.3	1.0	1004	90.7	1.0	1.10	0.8	1.51	1.34	0.85	2.09
Change in health status since previous wave	Much better, somewhat better or the same	145	10.2	0.9	1206	89.8	0.9	1.0			1.0		
	Worse or somewhat worse	87	9.1	1.1	888	90.9	1.1	1.13	0.82	1.57	1.09	0.73	1.61
Number of activities of daily living	None	169	9.9	0.8	1438	90.1	0.8	1.0			1.0		
	One or more	63	9.3	1.3	656	90.7	1.3	0.94	0.65	1.34	0.83	0.55	1.26
Number of health conditions													
	0-1	68	9.3	1.2	529	90.7	1.2	1.0			1.0		
	2	48	8.9	1.5	508	91.1	1.5	1.05	0.67	1.64	1.14	0.73	1.78

		Did not choose comfort care (n=232)			Chose comfort care (n=2094)			OR	95% CI		AOR	95% CI	
		N	%	SE	n	%	SE						
	3	51	9.6	1.5	468	90.4	1.5	0.97	0.63	1.49	1.08	0.67	1.74
	4 or more	65	10.9	1.5	589	89.1	1.5	0.84	0.56	1.27	1.14	0.66	1.99
Heart disease	No	135	9.3	0.9	1237	90.7	0.9	1.0			1.0		
	Yes	97	10.3	1.2	857	89.7	1.2	0.89	0.65	1.23	0.9	0.6	1.30
Stroke	No	197	9.4	0.7	1769	90.6	0.7	1.0			1.0		
	Yes	35	11.5	2.2	325	88.5	2.2	0.80	0.51	1.27	0.76	0.45	1.29
Psychiatric disease	No	192	9.1	0.7	1776	90.9	0.7	1.0			1.0		
	Yes	40	13.1	2.3	318	86.9	2.3	0.7	0.4	1.0	**0.62**	0.41	0.95
Hospital stay in the past 12 months	No	132	9.5	0.9	1180	90.5	0.9	1.0			1.0		
	Yes	100	10.1	1.1	914	89.9	1.1	0.94	0.68	1.29	0.96	0.67	1.37
Health behaviors													
Smoking	No	79	9.5	1.2	716	90.5	1.2	1.04	0.74	1.45	0.97	0.69	1.37
	Yes	153	9.8	0.9	1378	90.2	0.9	1.0			1.0		
Socio-demographics													
Gender	Male	118	10.2	1.0	974	89.8	1.0	1.0			1.0		
	Female	114	9.3	1.0	1120	90.7	1.0	1.11	0.81	1.53	1.17	0.81	1.70

		Did not choose comfort care (n=232)			Chose comfort care (n=2094)			OR	95% CI		AOR	95% CI	
		N	%	SE	n	%	SE						
Age*			77.7	0.8		79.9	0.3	1.02	1.01	1.03	1.01	0.99	1.04
Race	White	178	8.9	0.7	1913	91.1	0.7	**2.71**	1.81	4.06	**2.34**	1.50	3.64
	Other	54	20.8	3.0	181	79.2	3.0	1.0			1.0		
Religion	Protestants	144	9.4	0.9	1341	90.6	0.9	1.0			1.0		
	Catholic	62	10.1	1.3	525	89.9	1.3	0.93	0.65	1.33	0.9	0.62	1.30
	Others	26	10.4	2.3	228	89.6	2.3	0.90	0.53	1.52	0.8	0.47	1.37
Education	No degree	78	12.9	1.6	552	87.1	1.6	1.0			1.0		
	High school or more	154	8.7	0.8	1542	91.3	0.8	1.57	1.12	2.19	1.19	0.86	1.63
Marital status	Married or partnered	126	9.3	0.9	1161	90.7	0.9	1.0			1.0		
	Divorced/separated/never married/widowed	106	10.2	1.1	933	89.8	1.1	0.91	0.66	1.25	0.86	0.58	1.27
Region	Northeast	37	9.2	1.5	359	90.8	1.5	1.0			1.0		
	Midwest	66	10.7	1.4	562	89.3	1.4	0.85	0.53	1.35	0.83	0.52	1.33
	South	95	11.2	1.3	751	88.8	1.3	0.81	0.52	1.25	0.80	0.51	1.25
	West	34	6.8	1.3	422	93.2	1.3	1.40	0.81	2.41	1.42	0.82	2.47
Health insurance and estate will													
Estate will	Yes	159	8.7	0.8	1603	91.3	0.8	**1.60**	1.13	2.27	**1.64**	1.18	2.27

		Did not choose comfort care (n=232)			Chose comfort care (n=2094)			OR	95% CI		AOR	95% CI	
		N	%	SE	n	%	SE						
	No	73	13.1	1.7	491	86.9	1.7	1.0			1.0		
Covered by government plan	No	36	11.5	2.1	229	88.5	2.1	1.0			1.0		
	Yes	196	9.4	0.7	1865	90.6	0.7	1.25	0.8	1.95	1.13	0.63	2.03

Table 5.4: Association between self-reported health and "all care possible" among Health and Retirement Study decedents with a living will from 2002-2014

		Did not choose all care possible (n=2182)			Chose all care possible (n=144)			OR	95% CI		AOR	95% CI	
		n	%	SE	n	%	SE						
Health													
Self-rated health†	Excellent, very good or good	1149	94.3	0.8	67	5.7	0.8	1.00					
	Fair or poor	1033	94.2	0.8	77	5.8	0.8	1.02	0.69	1.52	0.73	0.42	1.27
Change in health status since previous wave†	Much better, somewhat better or the same	1265	93.5	0.8	86	6.5	0.8	1.00					
	Worse or somewhat worse	917	95.3	0.7	58	4.7	0.7	0.71	0.48	1.06	**0.54**	0.33	0.90
Number of activities of daily living	None	1516	94.7	0.6	91	5.3	0.6	1.00					
	One or more	666	93.2	1.1	53	6.8	1.1	0.76	0.50	1.16	0.98	0.57	1.69
Number of health conditions	0-1	575	96.8	0.7	22	3.2	0.7						
	2	519	93.4	1.2	37	6.6	1.2	**2.15**	1.17	3.94	**2.04**	1.08	3.83
	3	489	94.1	1.2	30	5.9	1.2	**1.93**	1.03	3.60	1.70	0.88	3.27

		Did not choose all care possible (n=2182)			Chose all care possible (n=144)			OR	95% CI		AOR	95% CI	
		n	%	SE	n	%	SE						
	4 or more	599	92.7	1.2	55	7.3	1.2	**2.43**	1.36	4.33	1.77	0.84	3.73
Heart disease	No	1281	94.3	0.7	91	5.7	0.7	1.00					
	Yes	901	94.2	0.9	53	5.8	0.9	1.00	0.66	1.52	0.75	0.46	1.22
Stroke	No	1855	94.9	0.5	111	5.1	0.5	1.00					
	Yes	327	90.6	1.9	33	9.4	1.9	**1.92**	1.17	3.17	1.71	0.95	3.10
Psychiatric disease	No	1859	94.9	0.5	109	5.1	0.5	1.00					
	Yes	323	90.7	1.9	35	9.3	1.9	1.92	1.16	3.16	**1.79**	1.03	3.09
Hospital stay in the past 12 months	No	1245	95.3	0.7	67	4.7	0.7	1.00					
	Yes	937	92.9	0.9	77	7.1	0.9	1.54	1.03	2.30	1.37	0.82	2.29
Health behaviors													
Smoking	No	744	94.2	0.9	51	5.8	0.9	1.00					
	Yes	1438	94.3	0.7	93	5.7	0.7	1.01	0.66	1.53	1.07	0.68	1.69
Socio-demographics													
Gender	Male	1022	93.9	0.8	70	6.1	0.8	1.00					
	Female	1160	94.5	0.6	74	5.5	0.7	0.89	0.60	1.33	1.03	0.66	1.62

		Did not choose all care possible (n=2182)			Chose all care possible (n=144)			OR	95% CI		AOR	95% CI	
		n	%	SE	n	%	SE						
Age ‡			79.8	0.3		76.9	1.2	0.97	0.95	1.00	0.99	0.96	1.02
Race	White	1996	95.5	0.5	186	78.1	3.4	**0.17**	0.11	0.26	0.20	0.13	0.33
	Others	95	4.5	0.5	49	21.9	3.4	1.00					
Religion	Protestants	1384	94.2	0.7	101	5.8	0.7	1.00					
	Catholic	555	94.1	1.2	32	5.9	1.2	1.01	0.63	1.62	1.17	0.71	1.94
	Others	243	94.9	1.8	11	5.1	1.8	0.86	0.40	1.85	1.00	0.46	2.17
Education	No degree	574	92.1	1.2	56	7.9	1.2	1.00					
	High school or more	1608	95.0	0.6	88	5.0	0.6	0.62	0.41	0.93	0.81	0.53	1.24
Marital status	Married or partnered	1199	93.2	0.8	88	6.8	0.8	1.00					
	Divorced/separated/never married/widowed	983	95.5	0.7	56	4.5	0.7	0.65	0.43	0.98	0.50	0.31	0.78
Region	Northeast	370	94.2	1.2	26	5.8	1.2	1.00					
	Midwest	598	94.8	1.1	30	5.2	1.1	0.88	0.48	1.62	0.79	0.41	1.50
	South	783	93.2	1.0	63	6.8	1.0	1.18	0.69	1.99	1.09	0.60	1.97
	West	431	95.0	1.1	25	5.0	1.1	0.85	0.45	1.60	0.80	0.40	1.62
Health insurance and estate will													

		Did not choose all care possible (n=2182)			Chose all care possible (n=144)			OR	95% CI		AOR	95% CI	
		n	%	SE	n	%	SE						
Estate will	Yes	1683	95.9	0.5	79	4.1	0.5	0.35	0.23	0.52	**0.44**	0.28	0.69
	No	499	89.0	1.5	65	11.0	1.5	1.00					
Covered by government plan	No	250	95.2	1.5	15	4.8	1.5	1.00					
	Yes	1932	94.1	0.6	129	5.9	0.6	1.24	0.64	2.40	1.63	0.70	3.81

† Associations are not shown for the variable as the interaction between the factors was significant at the bivariate level (p-value 0.006)

‡ Means are calculated

CHAPTER VI: CONCLUSIONS

This dissertation addressed twofold objectives, the factors associated with the combinations of ACPs and the factors associated with the broad categories of living will choices. The ACPs provides people an opportunity to decide about the terminal care they would like to receive should they become incompetent to take treatment decisions due to a coma or unconsciousness. The three typical ACPs include ACP discussions, living will and DPAHC. The latter two are documented and called advance directives. People use living wills to document specific end-of-life care choices. DPAHC are used to nominate a proxy decision maker who takes end-of-life care decision on behalf of an incompetent patient.

Our cross-sectional study used HRS data. The HRS reports the health and retirement indicators of a representative American sample of age over 50 years. The survey has conducted biennial panel surveys since 1992. Further, it also conducts one-time post-death interviews with next-of-kin of decedents in the wave following the death of a participant. The post-death interviews collect information about the distribution of wealth and health care use towards the end-of-life. The information about advance directives and end-of-life care experience is included in the post-death interviews.

To address the first objectives, that is, the factors associated with the combinations of ACPs, we included all the post-death interviews since the inception of these interviews, that is, 2002. However, for the second objective, that is, to determine the factors associated with living will choices, we restricted our analysis to HRS decedents with a living will. This is because a living will is the only typical ACP that documents specific end-of-life care choices. The choices pertain to cardiopulmonary resuscitation; artificial nutrition and hydration; surgery; dialysis; use of antibiotics and pain medications and organ and tissue donation.

We used the literature to identify the factors associated with ACPs and adjust them in our model. Further, we used prospect theory as a theoretical lens to determine the association between health status and end-of-life care choices. The theory proposes that people in poor health will be more likely to choose care-extending end-of-life care choices.

For study 1, we used the combinations of ACPs as our study outcome. In study 2, we used the broad categories of the end-of-life care choices — comfort care, limit care in certain situations and all care possible — as distinct outcomes. The self-reported health and the change in health status were used as the predictors. We adjusted our analysis for demographic and socioeconomic factors and other health factors, including the number of health conditions; a history of stroke and psychiatric illness and difficulty in daily living activities.

6.1. KEY FINDINGS

i) Study 1

The self-reported health and change in health status were not associated with the uptake of the combinations of ACPs. However, a decline in health status was associated with an increase uptake of “both directives” and “all ACPs”. Among other health factors, histories of cancer and a hospital stay in the past 12 months were associated with all combinations of ACPs: “one directive”; “ACP discussions only”; “a directive and ACP discussions”; “both directives”; and “all ACPs”. A history of heart disease was associated with “one directive and ACP discussion”. A history of two or more health conditions was associated with a higher uptake to “all ACPs”, compared with a history of 0-1 health condition. Histories of stroke and psychiatric illness were not associated with any combination of ACPs.

The analysis of sociodemographic factors showed female gender; white race; older age; high school education; being married or partnered; insurance by a government plan; having an estate will; and living in Midwest or West were associated with a higher uptake of one or more combinations of ACPs.

ii) Study 2

The self-reported health did not show an association with any of the three end-of-life care choice categories. A higher uptake of “limit care in certain situations” was associated with white race and an estate will. Conversely, a history of stroke was associated with a lower uptake. A higher use of “comfort care” choice was associated with white race and an estate will. However, decedents with a self-report of psychiatric illness were less likely to choose “comfort care”. The “all care possible choice” was less likely among decedents who reported the change in health status since the previous wave as “worse or somewhat worse”, compared with the decedents whose health status improved or remained the same. The decedents with a history of psychiatric illness chose the “all care” option more. Conversely, being white and married or partnered, and having an estate will were associated with a less likelihood of the all care choice.

iii) Overarching results of the two studies

Self-reported health did not show an association with any of the combinations of ACPs or end-of-life care choices. However, the change in health status was associated with the combinations and the “all care possible” choice. The decline in health status since the previous survey wave was associated with less uptake of the “all care possible” option. The prospect theory proposes that decline in health is associated with a higher use of life-extending end-of-life care choices. However, we found an opposite association — decedents reporting a decline in health since the last survey wave were less likely to choose “all care possible” option. We recommend more test of the prospect theory in predicting the association between health status and end-of-life care choices using large population-based samples.

6.2. THE NOVEL ASPECTS OF OUR WORK

We are the first to report the factors associated with the combinations of ACPs. We used the three typical ACPs The ACPs exist in combinations in the real world; therefore, we consider using the combinations a more realistic approach towards the true assessment of the factors. Similarly, we are the first to evaluate the prospect theory on a representative sample to determine the association between health status, its change and end-of-life care choices.

6.3. RECOMMENDATIONS

We recommend further studies on factors associated with ACPs using the combinations of ACPs. In the future, studies should examine the association between combinations of ACPs and the cost and quality of end-of-life care. Future research should also test the role of prospect theory in predicting the association between health status and end-of-life care choices using representative population samples.

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APPENDIX A: STUDY VARIABLES

Table A.1: Advance directives (Outcome study 1 and key exposure study 2)

Directives	Question	Variable
Living will	Did [RESPONDENT FIRST NAME] provide written instructions about the treatment or care (she/he) wanted to receive during the final days of)'s life (Living Will)	ST190*
DPAHC	Did [RESPONDENT FIRST NAME] (also) make any legal arrangements for a specific person or persons to make decisions about (her/his) care or medical treatment if (she/he) could not make those decisions (herself/himself)? This is sometimes called a Durable Power of Attorney for Health Care (DPAHC)	ST206*
ACP discussions	Did [RESPONDENT FIRST NAME] ever discuss with you or anyone else the treatment or care (she/he) wanted to receive in the final days of (her/his) life? (Advance Care Planning)	ST213*

Source: HRS exit interviews, 2002-2014

*The prefix ‘S’ is assigned to the year 2002. For the following years, the prefixes follow the alphabetical order. For instance, TT for 2004 and UT for 2006 and so forth.

Individual level factors

Table A.2: Key exposure study 1 and covariate study 2 — Health status

Directives	Question	Variable
Health status	Would you say your health is excellent, very good, good, fair, or poor?	R1SHLT*
Year will documented	About when were these written instructions dated (approximately)? YEAR:	ST192†

Source: HRS Rand file
*Number ‘1’ in variable represent first HRS wave. The variable names change to R2SHLT for wave 2 and R3SHLT for wave 3 and so forth.

†The prefix ‘S’ is assigned to the year 2002. The variable name changes to TT191 in 2004 and UT191 in 2006 waves

Other covariates

Table A.3: End-of-life care choices

Choice	Question	Variable
Limit care in certain situations	Did these instructions express a desire to limit care in certain situations?	ST194*
Withhold certain treatments	Did these instructions express a desire to have any treatment withheld?	ST195*
Comfort care	Did these instructions express a desire to keep (her/him) comfortable and pain free, but to forego extensive measures to prolong life?	ST196*
All care possible	Did these instructions express a desire to receive all care possible under any circumstances in order to prolong life?	ST193*

Source: HRS exit interviews, 2002-2014
*The prefix 'S' is assigned to the year 2002. See notes in section 2.3.1 in this appendix above.

Table A.4: Other health and mortality characteristics

Characteristic	Question	Variable
Self-rated health (overall)	Would you say your health is excellent, very good, good, fair, or poor?	R1SHLT
Need assistance in	Sum of five binary daily activity variables (bathing+ eating + dressing + walking across a room + getting in and out of bed	R1ADLWA
Change in health status since the previous HRS wave	Compared with 1 year ago, would you say that your health is much better now, somewhat better now, about the same, somewhat worse, or much worse than it was then?	R1SHLTC
Comorbidities	Reports heart problem in this wave Reports stroke in this wave Reports psychiatric problem in this wave	R1HEART R1STROK R1PSYCH

Source: HRS publicly available RAND data (cross wave equivalents for the variables are identified), 2014

Table A.5: Demographic and socioeconomic information

Characteristic	Question	Variable
Age at death		R1AGEM_B*†
Sex		RAGENDER*
Race	Race of respondent	RARACEM* RAHISPAN*
Religion		RARELIG*
Marital status	Please remind me, are you currently married, living with a partner, separated, divorced, widowed or have you never been married?	R1MSTAT*
Education	Years of education	RAEDYRS*
Estate will	Does 'R' have an estate will?	ST156‡

*Source: HRS publicly available RAND data (cross wave equivalents for the variables are identified), 2014
‡ Source: HRS advance directives module, 2002-2014
† Numeral '1' in the variable name denotes wave. The numbers correspond with the wave. For wave 2, the variable is named as R1AGEM_B, and so forth.

Table A.6: Health insurance

Characteristic	**Question/details**	**Variable**
Insurance	Are you currently covered by any government program?	R1HIGOV*

*HRS publicly available RAND data (cross wave equivalents for the variables are identified)