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## **PUBLICATIONS**

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### Peer Reviewed Journal Articles (Published)

1. Cheon, J., Coyle, N., Wiegand, D. L., & Welsh, S. (2015). Ethical issues experienced by hospice and palliative nurses. *Journal of Hospice & Palliative Nursing*, 17(1), 7-13.
2. Noh, J.W., Jo, M., Huh, T., Cheon, J., & Kwon, Y.D. (2014). Gender differences and socioeconomic status in relation to overweight among older Korean people. *PLoS One*, 9(5), e97990.
3. Sherman, D. W., McGuire, D. B., Free, D., & Cheon, J. Y. (2014). A Pilot study of the experience of family caregivers of patients with advanced pancreatic cancer using a mixed methods approach, *Journal of Pain and Symptom Management*, 48(3), 385-399.
4. Chu, S. H., Lee, W. H., Yoo, J. S., Kim, S. S., Ko, I. S., Oh, E. G., Lee, J. H., Choi, M., Cheon, J. Y., Shim, C. Y. & Kang, S. (2014). Factors affecting quality of life in Korean patients with chronic heart failure. *Japan Journal of Nursing Science*, 11(1), 54-64.
5. Liu, W., Cheon J., & Thomas, S. A. (2014). Interventions on mealtime difficulties in older adults with dementia: A systematic review. *International Journal of Nursing Studies*, 51(1), 14-27.
6. Wiegand, D. L., Grant, M. S., Cheon, J., & Gergis, M. A. (2013). Family-centered end-of-life care in the ICU. *Journal of Gerontological Nursing*, 29(8), 60-68.
7. Kim, S. S., Kim, E. J., Cheon, J. Y., Chung, S. K., Moon, S. & Moon, K. H. (2012). The effectiveness of home-based individual tele-care intervention for stroke caregivers in South Korea. *International Nursing Review*, 59(3), 369-375.
8. Sherman, D. W. & Cheon, J. (2012). Palliative care: The paradigm of care responsive to the demands for health care reform in America. *Nursing Economic*, 30(3), 153-166.
9. Kim, S. S., Lee, W. H., Cheon, J., Lee, J. E., Yeo, K., & Lee, J. (2012). Preferences for advance directives in Korea. *Nursing Research and Practice*. (E-pub)
10. Kim, S. S., Cheon J. Y., Kwon, I. S., Cho, Y. M., & Moon, S. (2011). Development and evaluation of a web-based education program on appropriate antibiotic use in Korean adolescents. *The Korean Journal of Fundamentals of Nursing*, 18(3), 383-391.

## BOOK CHAPTERS

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1. Wiegand, D. L., & Cheon, J. (2016). End-of-life care. In K. K. Carlson & American Association of Critical-Care Nurses (Eds.), AACN advanced critical care nursing. St. Louis: Saunders/Elsevier.
2. Sherman, D. W., & Cheon, J. (2014). Family caregivers. In M. Matzo & D. W. Sherman (Eds.), Palliative care nursing: Quality care to the end of life (pp. 147-167). New York: Springer Publishing Company.

## PRESENTATIONS

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1. Friedmann, E., Galik, E., Thomas' S. A., Hall, S., Cheon, J., Han, N, Kim, H, & Gee, N. (2016, July 7-10). The relationship of health-related outcomes to behaviors with a dog during the Pet Assisted Living (PAL) study intervention for assisted living residents with cognitive impairment. The International Society for Anthrozoology (ISAZ), Barcelona, Spain.
2. Cheon, J. (March 9, 2016). Advance care planning and its influence on life-prolonging treatments before patients' deaths. Annual Assembly of the AAHPM and HPNA, Chicago, IL.
3. Wiegand, D. L., Zhu, S., Scharf, B., Tomlin, S., & Cheon, J. (October 14, 2015). Experiences of family members of the chronically ill at the end of life. The Council for the Advancement of Nursing Science: 2015 Special Topics Conference, Washington DC.
4. Cheon, J. & Johantgen, M. (February 26, 2015). Advance Directives and its Influence on Surrogates' Decision Making before Patients' Deaths, Top Student Poster Presentation, The 29th Annual Conference of the Southern Nursing Research Society (SNRS). (Podium type)
5. Kim, H., Steinhoff, A., & Cheon, J. (November 8, 2014). Role Conflict and Social Service Use in Baby Boomer Caregivers, The Gerontological Society of America's 67th Annual Scientific Meeting, Washington DC, United States.
6. Liu, W., Cheon, J., & Thomas, S. A. (November 12, 2012). Interventions on Meal time Difficulties in Older Adults with Dementia: A Systematic Review. The Washington Regional Nursing Research Consortium (WRNRC) 3rd Annual Doctoral Student Research Conference, Washington DC, United States.
7. Cheon, J., Liu, W. & Thomas, S. (October 26, 2012). Interventions for family caregivers of terminal cancer patients: Systematic review. Chicago International Nursing Conference: "Advances in Nursing Education, Research, and Practice/Service: World View", Chicago, United States.

8. Cheon, J., Kim, S. S., Cho, E. H., Moon, K. H. & Kim, D. Y. (October 30, 2009). Burden and its related factors of the family caregivers caring for patients with stroke, The 7<sup>th</sup> International Nursing Conference, Seoul, Korea.
9. Lee, J., Kim, S. S., Lee, W. H., Cheon, J., Lee, J. E. & Yeo, K. (July 3, 2009). The advance directives in Korea International Council of Nurses (ICN) 24<sup>th</sup> Quadrennial Congress, Durban, South Africa.
10. Lee, J., Lee, W. H., Kim, S. S., Lee, J. E., Yeo, K. & Cheon, J. (May 31, 2008). Attitudes and perceptions on advance directives among people in Korea. The 10th Korean Gerontological Nursing Association International Conference, Seoul, Korea.

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## ABSTRACT

Title of Dissertation: End-of-life discussions as a component of advance care planning and their associations with care received near death

Jooyoung Cheon, doctor of Philosophy, 2016

Dissertation Directed by: Dr. Debra Wiegand, PhD, MBE, RN, CCRN, CHPN, FAHA, FAAN, Associate Professor, University of Maryland School of Nursing

**Background:** Advance care planning (ACP) is an ongoing process of communication of end-of-life (EOL) preferences between patients, families, and health care professionals (HCPs). ACP includes having EOL discussions, durable power of attorney for health care (DPAHC), and living will (LW). Engagement in DPAHC and LW can lead to less aggressive treatments and more comfort care, but little is known about the effects of EOL discussions of patients' preferences on their outcomes. **Purposes:** The purposes of this study were: 1) to examine patient characteristics influencing engagement in ACP; 2) to determine the effect of engagement in EOL discussions alone and the combined effect of EOL discussions with DPAHC and/or LW on EOL care; and 3) to examine the effect of EOL discussions and DPAHC on congruency between patients' preferences for care and care they received. **Method(s):** This study was a secondary data analysis using the Health and Retirement Study Exit Interviews of 6,001 decedents aged 50 years or older. Five different types of engagement in ACP were selected for this study. Sequential logistic regression and multivariable logistic regression were used.

**Results:** Decedent characteristics significantly associated with engagement in ACP were different by the types of engagement. Engagement in EOL discussions only was not a predictor of receiving all possible care to prolong life but was a predictor of receiving comfort care. Engagement in all three types of ACP was the strongest predictor of receiving both all possible care to prolong life and comfort care. Among decedents who had a LW, there was a synergistic effect of engagement in EOL discussions and DPAHC on receiving care consistent with decedents' preferences for EOL care. Engaging in more types of ACP was associated with lower odds of receiving all possible care, higher odds of receiving comfort care, and higher odds of receiving care consistent with decedents' preferences. **Conclusions:** Findings suggests that there was a synergistic effect of engagement in EOL discussions, DPAHC, and LW on receiving EOL care. HCPs should make more effort to communicate with patients and their families about their preferences at the EOL.

End-of-life discussions as a component of advance care planning and their associations  
with care received near death

by  
Jooyoung Cheon

Dissertation submitted to the Faculty of the Graduate School of the  
University of Maryland, Baltimore in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
2016



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## Dedication

I dedicate my dissertation to my mother and father who have always loved me unconditionally. I also dedicate my dissertation to my other family members (four sisters, a brother, three brothers-in-law, two nieces, and two nephews). They all have supported and encouraged me throughout the process. I love all my family members dearly and am truly thankful for having them in my life.

## Acknowledgements

I would never have been able to finish my dissertation without the contribution of my dissertation committee members and support from my family and friends. My deepest and most sincere gratitude goes out to them.

I owe my deepest gratitude to Dr. Debra Wiegand, who served as my dissertation committee chair and advisor. She provided the necessary wisdom and support in guiding me through the dissertation process. Her patience and constant encouragement was very important. I would not have completed my dissertation without her mentorship, and support and her faith in me. I also would like to thank the members of my dissertation committee. I am extremely thankful to Dr. Meg Johantgen for her exceptional contribution to this dissertation. She has provided me invaluable advice on a developing theoretical framework and conducting the secondary data analysis. I am grateful to Dr. Erika Friedmann for her excellent guidance, support, and encouragement. She gave me the confidence that I could manage the complex survey data for a thorough, detailed analysis. I sincerely thank Dr. John Cagle for his invaluable support and advice. He has extensive experience doing analysis with the data set I used and was willing to share his expertise with me. I would also like to thank Dr. Anita Tarzian for her valuable insights and support. She is an expert on advance care planning and ethical issues at the end-of-life and has given careful thought and attention to this study.

My colleagues and friends at University of Maryland were wonderful in their guidance, care, and concern as I worked through this process. Special thanks go to my fellow doctoral students in nursing, especially to Narae Han, whose friendship and support helped me throughout every stage of this more than she knows. Thanks also go to both Barbara Scharf and Sarah Tomlin, who listened to me talk about my study and gave me positive energy. I would like to thank Dr. Kathleen Griffith and Dr. Shijun Zhu for their valuable comments and support. Many thanks go to Jane Sellman for her guidance and support of my writing efforts over the years. I am always grateful for having had such fine colleagues and friends with whom to share both the joys and the trials of this path.

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## List of Abbreviations

ACP: advance care planning  
AD: advance directive  
CMS: Centers for Medicare and Medicaid Services  
CPR: cardiopulmonary resuscitation  
DPAHC: durable power of attorney for health care  
DNI: do-not intubate  
DNR: do-not-resuscitate  
EOL: end-of-life  
HCP: health care professional  
HRS: Health and Retirement Study  
LST: life-sustaining treatment  
LW: living will  
MOLST: Medical Orders for Life-Sustaining Treatment  
POLST : Physician Orders for Life-Sustaining Treatment  
PSDA : Patient Self-Determination Act  
SES: socioeconomic status

## CHAPTER 1: INTRODUCTION

### 1.1. Background and statement of the problem

This chapter provides the background, statement of the problem, and significance of the problem. The background describes: 1) decision making at the end-of-life (EOL), 2) surrogate decision-making, 3) definitions of advance directive (AD) and advance care planning (ACP), 4) history of ADs and ACP, 5) engagement in ADs, and 6) discussions of patient preferences at the EOL. The significance of the problem to health care professionals and nursing is also described. The purpose of the research, research questions, and theoretical framework are described to guide this study.

#### 1.1.1. Decision making at the end-of-life

Advances in medical technology have changed medical treatments provided to people at the EOL. These advances have prolonged the lives of patients but have sometimes prolonged the inevitable dying process. Life expectancy at birth increased from 62.9 years in 1940 to 78.8 years in 2013 (Centers for Disease Control and Prevention, 2015). As people approach the end of their lives, they are likely to have diseases such as heart disease, stroke, cancer, diabetes, physical/cognitive/mental disabilities, or other chronic conditions, which may lead to increased need for long-term care and costly health care services (Centers for Disease Control and Prevention, 2013; Xu, Kochanek, Murphy, & Tejada-Vera, 2010).

Decedents who were in their last year of life accrued an average expenditure of \$53,295 compared to \$8,681 for other beneficiaries (survivors) in 2012. Medicare spending for decedents is six times greater than spending for survivors (Hogan & Neuman, 2015). Average out-of-pocket spending in the last 5 years of life was \$38,688 for decedents, which led to a financial burden for patients and their families at the EOL (Kelley, McGarry, Fahle, Marshall, Du, & Skinner, 2013a). When people age and have an increasing illness or disability, they need to make decisions about what services are essential and what types of care they want to receive.

However, as decision-making at the EOL has become increasingly complicated, individuals and their family members face more difficult medical decisions because of the many moral, ethical, legal, and practical considerations (McMahan, Knight, Fried, & Sudore, 2013; Tejwani et al., 2013). Approximately 70% of adults at the time of death are not able to make their own treatment decisions (Silveira, Kim, & Langa, 2010). Among patients who die in the hospital, 65% lack decision-making capacity on admission, and 80% lose consciousness at least two days before their deaths. In the intensive care unit (ICU), 71.1% of patients needed surrogate involvement in decision-making, and 43.4% of patients needed the surrogate to make the decisions (Torke et al., 2014). These findings highlight the current need for strategies to help patients and their surrogates make EOL decisions. ACP offers patients a means to express their values and priorities with the goal of preparing for care or decision-making that might be needed at the EOL, particularly if they lose decision-making capacity (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014).

### 1.1.2. Surrogate decision-making

A surrogate is defined as a person who is appointed by an individual to make medical decisions if the person is not able to make his or her own decisions (Buchanan & Brock, 1989). Surrogate is often used interchangeably with proxy. Most patients want their close family members to make decisions in consultation with the physician and other HCPs when they lack decision-making capacity because they believe family members would know their preferences and could make decisions (Hinderer et al., 2015; Kelly, Rid, & Wendler, 2012). Most patients (93%) with a malignant tumor chose their next-of-kin as their health care proxy, which included mostly spouses (60%) or adult children (24%) (Trarieux-Signol et al., 2014). Surrogates made decisions respecting patients' wishes, using their knowledge of what the patients would have wanted, and considered what was in the patients' best interests (Fritsch et al., 2013).

Surrogates need more information about patients' preferences, but approximately half of patients have not discussed their wishes for EOL care in advance (Carr, 2012a; Moorman & Inoue, 2013; Rao, Anderson, Lin, & Laux, 2014) and at least a quarter did not provide formal ADs (Carr & Khodyakov, 2007; Carr, 2012a; Moorman & Inoue, 2013; Rao et al., 2014). As a result, family members often need to make complex EOL decisions with little preparation (Hickman & Pinto, 2014). These decisions may include whether to continue or discontinue life-sustaining treatments (LSTs), place a feeding tube or a tracheostomy, or agree to cardiopulmonary resuscitation (CPR) in the event of a cardiac arrest (Fritsch et al., 2013; Jox et al., 2012). In a review of 19 studies regarding surrogate decision making for LST, surrogates reported experiencing high levels of stress, anxiety, and depression (Melhado & Byers, 2011). Distress experienced by surrogates is

associated with psychological chaos; conflict between patients, families, and HCPs; and delayed decision making, which leads to unwanted LST (Melhado & Byers, 2011). At least one-third of surrogates have experienced emotional burden when they made decisions for patients who lacked decision-making capacity (Wendler & Rid, 2011).

ACP provides information about patients' preferences and can lessen decisional burden among families and HCPs (Brinkman-Stoppelenburg et al., 2014; Hickman & Pinto, 2014). Approximately, 70% of surrogates find the ACP process helpful (Becker et al., 2007).

### 1.1.3. Definitions of advance directives and advance care planning

ADs provide a standardized process for ensuring an individual's autonomy at the EOL and are important legal tools that individuals can use to state their treatment preferences and to name a proxy decision maker (Institute of Medicine [IOM], 2015). ADs refer to several types of patient-initiated documents, including a LW and a DPAHC. A LW is a written document that states a person's EOL care preferences and may include language describing specific conditions that need to be met, such as terminal prognosis and/or persistent vegetative state (Goede & Wheeler, 2015; IOM, 2015). A DPAHC is a document that designates an individual (e.g., family member, friend) that he or she would like to make health care decisions on the person's behalf if he or she should become incapacitated (Goede & Wheeler, 2015; IOM, 2015).

ACP is a broader concept than ADs and is defined as the process of having early EOL discussions so that preferences are known and patients receive medical care that is aligned with their preferences (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; IOM,

2015). ACP discussions should be reviewed and discussed occur over time with patients, their families, and the health care team, and allow for flexible decision-making based on the patients' current diagnosis, prognosis, and treatment options (IOM, 2015; Lum, Sudore, & Bekelman, 2015; Talebreza & Widera, 2015). ACP includes all types of AD documents (i.e., LW and DPAHC) and discussions of EOL care preferences with others (e.g., family members, friends, and HCPs). Medical orders (e.g., Physician Orders for Life-Sustaining Treatment [POLST], do-not-resuscitate [DNR], and do-not-intubate [DNI]) which are signed by the HCPs are also considered as a type of ACP (IOM, 2015).

#### 1.1.4. History of advance directive advance care planning

The first AD was proposed in the U. S. at the end of the 1960s and was legally recognized in 1976 (Kutner, 1969; New Jersey Supreme Court, 1976). The term LW, the oldest form of AD, was first mentioned by Luis Kutner, an attorney, in 1969 (Kutner, 1969). Kutner defined a LW as a document for people to express their wishes about to what extent they would consent to treatment if and when they lacked decision-making capacity.

The case of a young woman, Karen Ann Quinlan in 1976 was a seminal one in surrogate decision-making (In re Quinlan, 1976). Karen Quinlan was admitted to the hospital on April 15, 1975 because she became unconscious after she consumed alcohol and sedatives. She was assisted by a medical ventilator for her breathing and required enteral nutrition. Physicians diagnosed Ms. Quinlan as being in a persistent vegetative state. Her father, who had been appointed guardian, asked the physicians to discontinue the ventilator, but the physicians refused to discontinue her life support treatment without

a court order. The New Jersey court refused his request for an order for the withdrawal of the ventilation. He appealed the case to the New Jersey Supreme Court.

The New Jersey Supreme Court ruled that Karen's "right of privacy" included a right to decline medical treatment and her father could assume what she would want. The Supreme Court gave permission for withdrawal of the LST based on the "right of privacy" (New Jersey Supreme Court, 1976). Her parents did not want artificial nutrition and hydration stopped, but wanted to withdraw the ventilator. After the removal of ventilator support, she continued to breathe on her own for nine years and died in 1985 in the nursing home. This was the first legal decision related to the concept of the right to die (or right to refuse LST, even if this refusal might hasten death) and surrogate decision-making for people who lack decision-making capacity (In re Quinlan, 1976; New Jersey Supreme Court, 1976).

California was the first state to enact a "Natural Death Law," which was known as "Death with Dignity Act or Living Will Act" (Natural Death Act, 1976). This law acknowledged that patients have the right to make decisions to withhold or withdraw LST if they are in a terminal condition or permanent unconscious condition. A LW provides specific instructions to HCPs regarding what type of LST an individual would or not want if they should lack decision-making capacity.

In 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research recommended the use of DPAHC as an additional option. People were encouraged to designate someone (called a "surrogate") to make decisions on their behalf and/or provide information about their preferred care if they should be unable to express what treatment they might want (President's Commission for

the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). California enacted the first Durable Power of Attorney for Health Care Decisions Act in 1983 (Uniform Durable Power of Attorney for Health Care Decisions Act, 1983).

Another seminal case involved Nancy Cruzan (U.S. Supreme Court, 1990). Nancy Cruzan was a 32-year-old woman who was in a persistent vegetative state as a result of a car accident that occurred in February of 1983. Despite subsequent rehabilitative efforts, her medical team determined that there was no hope that she would recover from her brain damage. In 1987, her parents, who had been appointed as her coguardians, wanted to remove her feeding tube. Her parents believed that their daughter would not want to continue her life based on a statement that Nancy had made to her roommate when she told her that she would not want to continue her life unless she could live at least halfway normal. For this reason, a Missouri trial court authorized her parents to have the tube feeding and hydration discontinued.

However, both the state and the director of the Missouri Department of Health appealed. The Supreme Court of Missouri refused to authorize to terminate Nancy Cruzan's artificial nutrition and hydration because 1) even though she was in a persistent vegetative state, she did not meet the Missouri's definition of death or terminal illness, 2) the Missouri Living Will statute embodied a state policy strongly favoring the preservation of life, 3) Nancy Cruzan's statement to her roommate was unreliable for the purpose of determining her intent, and 4) no person could assume that choice for an incompetent person in the absence of the formalities required by the Living Will statute or "clear and convincing evidence" of the Nancy Cruzan's wishes (U.S. Supreme Court, 1990). The family appealed to the U. S. Supreme Court.



The U. S. Supreme Court recognized the right of a patient to refuse treatment, but refused Nancy Cruzan's parents' request for the withdrawal of LSTs because the state law required clear and convincing evidence of a patient's wishes. Due to the publicity around the case additional people that Nancy had known came forward and stated that Nancy had told them she would rather die than live in certain circumstances, such as a persistent vegetative state. The Missouri court finally authorized Nancy's parents to stop her artificial nutrition and hydration. After withdrawal of artificial nutrition and hydration in December of 1990, Cruzan died two weeks later. This case is the first "right to die" case to be heard by the U. S. Supreme Court and led to the passage of the Patient Self-Determination Act (PSDA) in 1990 (PSDA, 1990).

The purpose of the PSDA was to increase awareness of ADs and to encourage their use so that patient's wishes would be known in advance, thus preserving patient autonomy. The PSDA mandated that all healthcare institutions receiving Medicaid or Medicare reimbursement must 1) provide written information to all adult patients on their rights to make decisions concerning medical care and the right to execute ADs under state law at the time of admission, 2) maintain written policies and procedures regarding ADs and inform patients about the policies and procedures, 3) document in the medical record whether patients have ADs, 4) ensure compliance with the requirements of state laws regarding ADs at facilities of the provider or organization, and 5) educate staff and community about ADs (PSDA, 1990; New Jersey Bioethics Commission, 1991). At present, all 50 of the states in the U.S. and the District of Columbia have laws supporting ADs.

Almost two decades ago the IOM published a report, “Approaching Death: Improving Care at the End of Life,” which broadly reviewed conversations and policies surrounding EOL care and identified many barriers that impede the delivery of high-quality care for dying people (IOM, 1997). This report stressed the importance of continuing public discussions to promote a better understanding of the experience of dying people, available resources for people near the EOL, and the role of communities to help dying people and their families (IOM, 1997).

Even though the PSDA encouraged the use of ADs in the health care institution, ADs were not always completed by patients and used by HCPs. According to the IOM report, patients and their families often lacked an awareness of ADs and did not think they really need to complete an AD. Also, there was lack of support from physicians and other providers who may not be willing to adhere to ADs and institutions not sufficiently prepared to assist patients with the completion of ADs (IOM, 1997). The report looked at ACP in a broader sense. ACP encompasses the process of communication between patients, their families (or surrogates), and their HCPs. It includes support to develop LWs, DPAHCs, and encourage discussions with family members and HCPs about individuals’ preferences about (or beliefs regarding) future health care and EOL care (IOM, 1997).

Another initiative designed to improve end-of-life care are physician and medical orders for LSTs. In the early 1990s, the Center for Ethics in Health Care at Oregon Health and Science University started the physician orders for life-sustaining treatment (POLST) paradigm and developed a form that could be completed with seriously or chronically ill patients with the goal of ensuring that patient preferences regarding LST

are communicated and honored. Medical Orders for Life-Sustaining Treatment (MOLST) is a program modified from the original POLST program. The goal of MOLST is also to honor a patient's treatment preferences concerning LST (New York State, 2015). The original POLST document was completed with a patient, surrogate and physician. The MOLST document can be completed with a patient, surrogate and a physician, a physician assistant or an advance practice nurse. Most states now have POLST and MOLST legislations. Some states use different names such as Physician Orders for Scope of Treatment (POST), Clinician Orders for Life-Sustaining Treatment (COLST), and Transportable Physician Orders for Patient Preferences (TPOPP). In 2016, most states had or are developing some form of POLST legislation, but only 3 states, Alabama, Arkansas, and South Dakota, have not yet begun POLST (National POLST, 2016).

POLST Taskforce-endorsed forms have specific sections and ordering but not all states' forms use this sections and ordering. There are some variations in the POLST documents from state to state. One section addresses the patient's preferences for CPR and intubation. Another section addresses the patient's preferences for treatments. Treatment options include: 1) full treatment, which aims to prolong life using life-sustaining measures; 2) limited (or selective) treatment, which aims to treat health conditions while avoiding burdensome measures; and 3) comfort-focused treatment, which aims to minimize symptom distress and maximize comfort. Additional section includes a patient's preferences for antibiotics: 1) use of antibiotics for comfort care only; 2) limited use of antibiotics; and 3) use of antibiotics in all conditions; and addresses artificially administered nutrition and hydration: 1) no artificial nutrition and hydration; 2) defined trial period of artificial nutrition and hydration; and 3) long-term artificial

nutrition and hydration (National POLST, 2015; Hickman et al., 2015). Depending the state form adopted additional sections may include a patients preferences for hospitalization and/or transfer between facilities, options for blood transfusion, dialysis, and other treatments a patient may or may not want (Maryland MOLST, 2015; New York State, 2015). See Appendix 1.1 for examples of POLST and MOLST documents.

The IOM report stressed that ACP is essential to improving the quality of EOL care (IOM, 2015). The report recognized that ACP can occur at any age, even if individuals are healthy, and may change as a person's health changes. As individuals reach a stage of advanced progressive illness, ACP discussions should occur in advance and be specific. However, previous approaches to ACP have been less successful and the current health care system fails to encourage people to engage in the ACP process. Key barriers to engaging in the ACP process include lack of time of HCPs, lack of reimbursement for ACP discussions, and lack of efforts to have conversations about death and dying. Continuing communication between patients, their loved ones, and HCPs about EOL care values, goals, and preferences should be encouraged to improve the ACP process. Incentives, quality standards, and system supports are necessary to promote this communication, which should be initiated by HCPs (IOM, 2015).

On October 30, 2015, the Centers for Medicare and Medicaid Services (CMS, 2015) finalized two rules for ACP consultation: 1) code 99497: "ACP including the explanation and discussions of ADs such as standard forms, with completion of such forms, when performed, by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate" and 2) code 99498: "ACP including the explanation and discussions of ADs such as standard

forms, with completion of such forms, when performed, by the physician or other qualified health care professional; each additional 30 minutes (list separately in addition to code for primary procedure)" (p. 350). Physicians or other qualified HCPs (e.g., nurse practitioner, clinical nurse specialist, and clinical social worker) will be paid for ACP consultation on or after January 2016. The reimbursement is \$86 in a physician office or \$80 in a hospital setting for the first 30 minutes of consultation regarding ACP (code 99497) and up to \$75 for an additional 30 minutes (code 99498). The CMS, health institutions, and HCPs expect that this reimbursement will increase continuing ACP discussions between patients, family members, and HCPs.

#### 1.1.5. Engagement in advance directives

Since the PSDA (PSDA, 1990) mandated that all healthcare institutions receiving Medicaid or Medicare reimbursement must provide information regarding AD documents at the time of admission, engagement in ADs has increased over time. Among adults aged 60 years or older, the proportion of those having ADs (i.e., LW and DPAHC) increased from 47% in 2000 to 72% in 2010 (Silveira, Wiitala, & Piette, 2014). Among the general population, the completion rate of ADs ranges from 24% to 66% (Carr, 2012a; Carr & Khodyakov, 2007; McCarthy et al., 2008; Moorman & Inoue, 2013; Rao et al., 2014).

Even though AD completion rates have increased and are publicly supported, there are still many shortcomings to the completion of AD documents. Two thirds of adults in the general population have heard about LWs, but have not completed one, and 57% have heard about DPAHCs, but have not completed one (Kelly, Masters, & DeViney, 2013). Common reasons why people do not complete an AD include a fear of

thinking about their illness, the dying process, and their own mortality (Carr, 2012a; Golden, Corvea, Dang, Llorente, & Silverman, 2009; Moorman & Inoue, 2013); lack of information about ADs (Carr, 2012a; Moorman & Inoue, 2013; Rao et al., 2014); their health is good (Carr, 2012a; Moorman & Inoue, 2013); a lack of awareness about their preferences for future EOL care (Carr, 2012a); and a belief that their family members know their wishes (Carr 2012a; Rao et al., 2014).

ADs can lead to less aggressive treatments and more comfort care provided at the EOL. In studies including approximately 3,000-4,000 Americans in a nationally representative dataset (called the Health and Retirement Study, HRS), ADs have been associated with decreased in-hospital deaths and decreased hospitalizations before death (Bischoff et al., 2013; Nicholas, Langa, Iwashyna, & Weir, 2011; Silveira, Wiitala, & Piette, 2014), increased use of hospice care (Bischoff et al., 2013; Nicholas et al., 2011), less aggressive interventions (Nicholas, Bynum, Iwashyna, Weir, & Langa, 2014), and increased comfort care (Silveira et al., 2014).

#### 1.1.6. Discussions of patient preferences at the end-of-life

In addition to completion of ADs, it is important for patients, family members and HCPs to have discussions related to EOL preferences for care (IOM, 2015). These discussions help family members (surrogates) to prepare for the patient's death and lessen the burden resulting from EOL decision-making (Apatira et al., 2008; Hickman & Pinto, 2014). Research on the effect of discussions related to patient preferences on actual EOL care is limited. Only a few studies have examined the effect of EOL discussions on patient outcomes. Cancer patients having discussions were less likely to receive

aggressive care (e.g., chemotherapy in the last 14 days of life, mechanical ventilation, and CPR) and acute care in the last month (e.g., emergency room visits, hospitalizations, and hospital deaths), and were more likely to limit or withhold treatments, receive hospice care, and to have hospice initiated earlier (Mack et al., 2012a; Narang, Wright, & Nicholas, 2015; Wright et al., 2008).

Previous studies regarding the effect of discussions of patient preferences on EOL care targeted cancer patients. No studies examined the association between EOL discussions on EOL care in the general population or among patients with non-cancer diseases. The limitations of the previous studies are that the presence of ADs was not addressed when the researchers examined the association of discussions of patient preferences with EOL care even though ADs could affect EOL outcomes, and most patients had EOL discussions with their physicians. Also, there were few studies that specifically examined the effect of having discussion of EOL care on receiving comfort care.

EOL discussions improve the completion of ADs. Individuals who have had EOL discussions about their preferences with their family members were seven times more likely to have a LW and a DPAHC (Carr & Khodyakov, 2007). Another study also reported that patients who had discussions about EOL preferences with their physicians were more likely to complete an AD (Keary & Moorman, 2015; Wright et al., 2008). These findings suggest that researchers should consider the relationship between having discussions of patient preferences and the completion of ADs when they conduct their analyses. A randomized trial examined the effect of ACP on a physician's decisions (using vignettes describing clinical situations involving difficult medical decisions).

Having both a LW and a DPAHC had a stronger effect on forgoing medical intervention than did having a LW only or a DPAHC only (Escher, Perneger, Rudaz, Dayer, & Perrier, 2014). No studies have compared the effect of having EOL discussions of patient preferences with the combined effect of EOL discussions, LW, and/or DPAHC.

If AD documents aren't completed people may receive aggressive care at the EOL in an ICU setting (Camhi et al., 2009). Halpern and colleagues (2011) reported the most patients designated their DPAHC when they were critically ill because they felt the need to find someone to make decisions for their treatments. In addition, a lack of discussions regarding EOL care preferences can result in care that is discordant with patient wishes (Mack, Weeks, Wright, Block, & Prigerson, 2010). Therefore, there is a need to encourage EOL discussions between patients, family members, and HCPs. The reimbursement decision of CMS enhances the essential role of having EOL discussions in EOL decision-making and allows HCPs to spend more time encouraging patients and families to engage in ACP (CMS, 2015). Understanding the engagement in EOL discussions and their effect on EOL care will help HCPs initiate ACP discussions.

#### 1.1.7. Summary

Engagement in ACP has increased over time in the general population. It is evident that engagement in ADs helps people make EOL decisions with less in-hospital death, more use of hospice care, less LST, and more comfort care. However, there are still barriers. Many individuals still have a fear of talking about ADs, designate their DPAHC too late in the process, and are reluctant to complete LWs. Also, ADs are often not readily available when needed. This may occur because family members and/or HCPs



are not aware that the documents exist. It may also occur because discussions have not occurred. In addition, HCPs may not document the presence of an AD in the patient's medical record.

Recent studies and policies stress the importance of ongoing EOL preference discussions between individuals, their family members, and HCPs. CMS now is reimbursing for these important discussions. However, little is known about the effects of these discussions of individuals' preferences on individuals' outcomes at the EOL. Previous studies focused on the effects of formal ADs (i.e., LW and/or DPAHC) on individuals' EOL care. Individuals received fewer LST when they shared their ADs with physicians. Little is known about the relationship of EOL discussions with LST and comfort care at the EOL. Therefore, the proposed study will examine what characteristics influence engagement in EOL discussions and determine the effect of having the EOL discussions on EOL care.

## 1.2. Significance of the problem to health care professionals

Lack of understanding of patient treatment preferences at the EOL may lead to patient suffering, unwanted prolongation of life, conflicts between patients, family members, and HCPs, inappropriate use of medical resources, and higher medical expenditures (Bernacki, Block, & American College of Physicians High Value Care Task Force, 2014; Mack, Weeks, Wright, Block, & Prigerson, 2010; Melhado & Byers, 2011). HCPs can play a key role by initiating EOL discussions about patients' preferences. Patients and families need accurate information about patient prognosis and treatment options from HCPs (Barnes et al., 2011; Hajizadeh, Uhler, & Perez Figueroa, 2014).

Patients want HCPs to initiate these discussions (Barnes et al., 2011; Detering, Hancock, Reade, & Silvester, 2010; Epstein, Shuk, O'Reilly, Gary, & Volandes, 2015).

Patients who were asked by HCPs about LW and DPAHC were 10.8 times more likely to complete LW and 1.7 times more likely to appoint a DPAHC compared those who were not asked (Van Scoy, Howrylak, Nguyen, Chen, & Sherman, 2014). Discussions of patients' preferences with families and other HCPs based on ACP improves patient satisfaction with hospital care and family satisfaction with the quality of their family member's death and reduces emotional distress experienced by family members (Detering et al., 2010). HCPs can improve the quality of EOL care through sharing prognostic information with patients and families, identifying patients' preferences in advance, understanding why patients fear talking about their EOL, and encouraging family involvement in shared decision-making (Bernacki et al., 2014).

### 1.3. Significance of the problem to nursing

Nurses are in a unique position to facilitate ACP discussions with patients and their families and to improve shared decision-making at the EOL (Haras, Astroth, Woith, & Kossman, 2015). According to the American Nurses Association Position Statement (ANA, 2010), nurses have a responsibility to act as a patient advocate, to support the identification of treatment preferences of patients and their families, and to promote informed decision-making for patients. Also, they have an ethical responsibility to their patients to promote ACP (HPNA, 2013). Timely ACP discussions with patients, families, and other HCPs about the current diagnosis, prognosis, expectations for treatment options,

and patients' preferences will help reduce the suffering of patients and families, and avoid conflicts and delayed decision-making at the EOL.

Adams and colleagues (2011) found that nurses play three roles in EOL decision-making: information broker, supporter, and advocate. Patients often talk with nurses about their treatment preferences. Nurses commonly make certain that patients share their wishes with their family members and with the other members of the health care team. Nurses also provide an important source of emotional support for patients and their family members (surrogates) as difficult EOL decisions are made. Nurses have an important advocacy role and often facilitate discussions between patients, family members, physicians and other members of the health care team.

Nurses can discuss patient treatment preferences and goals of EOL care, and advocate for and support decisions consistent with expressed patient wishes. Identifying predictors influencing ACP can let nurses know what types of interventions (e.g., education and training programs for patients and nurses and campaigns in hospitals to encourage engagement in ACP) should be implemented.

#### 1.4. Purpose of the study and research questions

The purpose of this study is to determine the association of the engagement in ACP with EOL care. Using nationally representative data, the engagement in ACP was categorized into five types of engagement: 1) no engagement in ACP, 2) engagement in EOL discussions, 3) engagement in EOL discussions and durable power of attorney for health care (DPAHC), 4) engagement in EOL discussions and living will (LW), and 5) engagement in EOL discussions, DPAHC, and LW. The investigator compared the

reference group (no engagement in ACP) with groups of other types of engagement including engagement in EOL discussions.

This study had four research questions:

- 1) What are the characteristics associated with the types of engagement in ACP?
- 2) Are the types of engagement in ACP associated with receiving all possible care to prolong life?
- 3) Are the types of engagement in ACP associated with receiving comfort care?
- 4) Among individuals who have a LW, are engagement in EOL discussions and engagement in DPAHC associated with congruency between patients' preferences for EOL care and the care they received?

#### 1.5. Theoretical framework

For this proposal, the health care utilization model (Andersen, 1995) was used to support the proposed study. Health care utilization was developed by Andersen to help understand why families use health services and to promote accessibility to the health care system. This model has been used to examine the multiple influences of population characteristics (predisposing characteristics, enabling resources, and need for health services) on health behavior (personal health practices and use of health services), and health status outcomes (perceived health status, evaluated health status, and consumer satisfaction). This model uses numerous iterations and feedback loops to explore how health outcomes may be affected by a change in an individual's characteristics, environment, resources, and need for health services.

Environment characteristics consist of the health care system and external environment. Health care system characteristics indicate the policies, resources, organization, and financial arrangements that influence the utilization of medical care services (Phillips, Morrison, Andersen, & Aday, 1998). External environment factors reflect "the economic climate, relative wealth, politics, level of stress and violence, and prevailing norms of the society (p. 576)" (Phillips et al., 1998). A component of environment includes region, location (urban or rural), population density (e.g., percentage of urban areas in state), and health care system characteristics (e.g., type of primary care delivery model, availability of services within the community, and Medicaid policies).

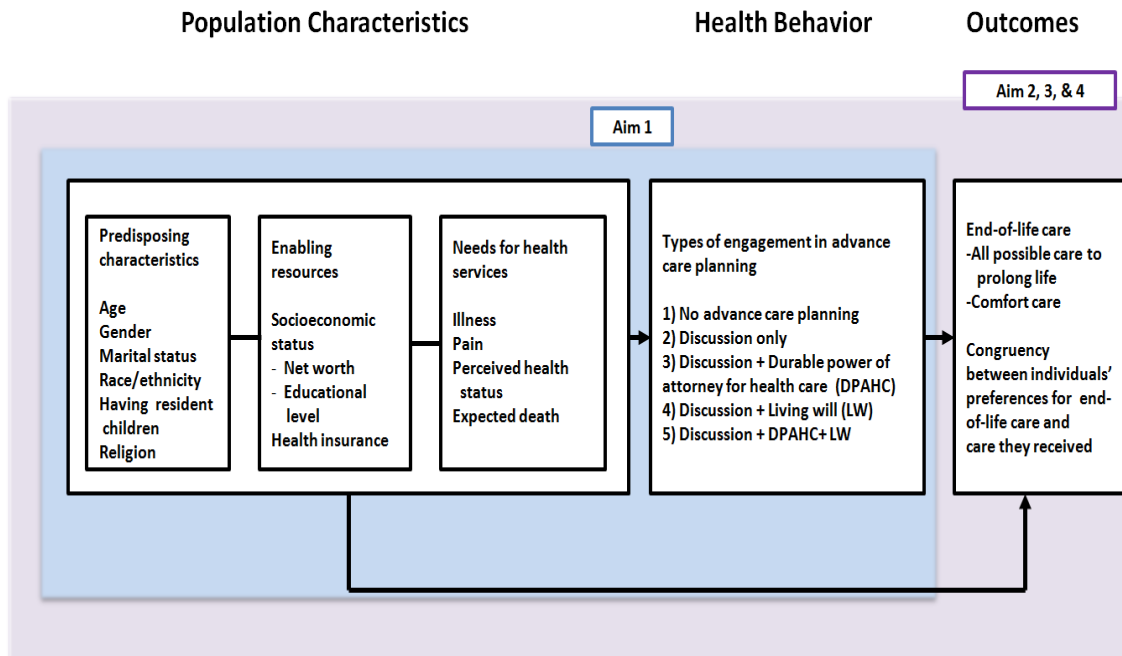
Population characteristics include predisposing characteristics, enabling resources, and need. Predisposing characteristics indicate biological imperatives suggesting the likelihood that individuals will need health services. Individuals who believe health services are useful for treatment will more likely utilize those services than will those who do not believe health services will be helpful. These characteristics include the demographic characteristics (e.g., age and gender), race/ethnicity, family structure (e.g., having children, cohabitant), religion, health beliefs, and cultural norms (Andersen, 1995; Babitsch, Gohl, & von Lengerke, 2012). Enabling resources indicate individuals' ability to access services. These factors include financing and organizational factors, such as socioeconomic status (education and income), health insurance status, language, health care expenditures, physician and hospital density, education programs, and health policies (Andersen, 1995; Babitsch et al., 2012). Need for health services include perceived need (e.g., perceived health, functional status, pain, and symptoms) and

evaluated need (professional judgment regarding individuals' health status and their need for medical care)(Andersen, 1995).

Health behaviors consist of personal health practices (e.g., diet/alcohol/smoking /drug use and physical activity) and use of health services (e.g., physician visits, health care facility visits, and reason for visits), and act as an antecedent to health outcomes. Health outcomes include perceived health status, evaluated health status, and consumer satisfaction (Andersen, 1995; Guilcher et al., 2012).

The health care utilization model provided the theoretical framework for this study. As shown in Figure 1.1, predisposing characteristics (age, gender, marital status, race/ethnicity, having resident children, religion), enabling resources (net worth, educational level, having private insurance policy), and need for health services (illness, pain, perceived health status, expected death) will have a direct influence on health behaviors (engagement in ACP) (Aim 1). Received care before death (receiving all possible care to prolong life/comfort care) as a health outcome will be affected by predisposing characteristics, enabling factors, need for health services, and health behaviors (Aim 2 & 3). Among individuals who have a LW, congruency between the individual's preferences and EOL care will be associated with predisposing characteristics, enabling factors, their need for health services, and health behaviors (Aim 4).

Figure 1.1. Theoretical framework for this study



## Chapter 2: REVIEW OF THE LITERATURE

This chapter provides an overview of the current research regarding ACP and EOL care. Key aspects of the literature are described including: 1) patient characteristics influencing ACP, 2) engagement in ACP, 3) effect of ADs on EOL care, 4) effect of EOL discussions on EOL care, 5) patient characteristics influencing end-of-life care, 6) patients' preferences and EOL care, and 7) congruency between patients' preferences and EOL care.

### 2.1. Patient characteristics influencing advance care planning

#### 2.1.1. Age

As people age, their physical and psychological functions gradually decline and their morbidity and mortality increase. Older individuals are more interested in EOL issues than are younger individuals (Carr, 2012). The likelihood of having an AD (LW or DPAHC) and EOL discussions increase with age (Carr, 2012a; Gerst & Burr, 2008; House & Lach, 2014; Kumar et al., 2010; Moorman & Inoue, 2013; Rao et al., 2014).

House and Lach (2014) reviewed medical records of 5,330 hospitalized patients. Patient completion rates of ADs among five age groups of 18-29, 30-44, 45-59, 60-74, and 75 and older were 2.1%, 6.8%, 15.4%, 34.8%, and 40.8%, respectively. Older patients had higher completion rates of ADs than did younger patients. In another study, age was divided into four groups: 18-34, 35-54, 55-64, and 65 or older (Rao et al., 2014). People 65 years or older were 8.1 times more likely to complete ADs compared with people between 18 and 34 years of age (reference group). People between 55 and 64 and



between 35 and 54 were 3.3 times more likely to complete ADs compared with the reference group. In a chart review of 512 patients hospitalized in the cardiac care unit and the intensive care unit (ICU) (Kumar et al., 2010), there were significant differences in ADs among three age groups: 65 or less (18%), 65-79 (25%), and 80 or older (32%).

The likelihood of having ADs increased with age (4% per 1-year increase in age) among 2,150 participants aged 18–64 (Moorman & Inoue, 2013). Similarly, the odds of having a living will (LW) have increased by 6% in married and cohabiting adults aged 18 to 64 per 1-year increase in age (Carr, 2012a). The odds of having a durable power of attorney for health care (DPAHC) have increased by 3% in community dwelling adults aged 50 or older per 1-year increase in age (Gerst & Burr, 2008). Advancing age was also associated with a greater likelihood of having discussed EOL treatment preferences with family members or health care professionals (HCPs) (Moorman & Inoue, 2013). For each additional year of age, the likelihood of having an EOL discussion was increased by 3% (Carr, 2012a).

### 2.1.2. Gender

There are gender differences in illness understanding (Fletcher et al., 2013). Among 68 advanced cancer patients, women showed a better understanding that their illness was incurable and was at an advanced stage compared to men (Fletcher et al., 2013). Women also showed higher engagement in EOL discussions compared to men. In 195 chaplain interviews of adults aged 30-75 years receiving palliative care and/or having DNR orders, men were reluctant to initiate their EOL discussions compared to women (Skulason et al., 2014). Women showed 37-40% higher odds of engaging in EOL

discussions of EOL treatment preferences with family members compared to men in the general population (Carr & Khodyakov, 2007; Gerst & Burr, 2008).

However, there are conflicting findings regarding if there is a gender difference in AD completion rates. Among 512 inpatients, there were no significant differences in the completion rates of LW and DPAHC among men (4% and 18%) and women (5% and 20%) (Kumar et al., 2010). In another investigation, among 2,154 adults aged 50 and older, women had a 40% higher odds of engaging in ADs compared to men (Huang, Neuhaus, & Chiong, 2016). Rao (2014) reported that among 7,946 adults aged 18 and older, men had a 32% lower odds of engaging in ADs compared to women. A telephone interview with adults who were 64 and 65 years old with at least a high school education was conducted in Wisconsin (Carr & Khodyakov, 2007). Women had 19% lower odds of engaging in completing LWs compared to men. These conflicting findings might be due to the investigations being conducted in different health care settings with different population characteristics, such as age, and different types of ACP.

### 2.1.3. Marital status

Marital status has a significant effect on the health and mortality of individuals in mid-life and older ages. Those who are divorced and single, especially men, generally have poorer health and a higher mortality risk than those who are married (Manzoli, Villari, Pirone, & Boccia, 2007; Robards, Evandrou, Falkingham, & Vlachantoni, 2012). Those who are married typically have another person who is interested in their spouses' health behaviors and the couple tends to have the financial resources that enable access to healthcare services (Greenleaf, Cooper, & Hollenbeak, 2016). Even with evidence of the

effect of marital status on access to care and health outcomes, few studies have examined the association of marital status with engagement in ACP.

Only a few studies have examined the association between marital status and engagement in ACP. Among 130 inpatients, widowed patients had higher rates of completion of LWs and DPAHCs than did married, single, and divorced persons (Van Scoy et al., 2014). Another study reported that among 197 patients with cancer, married patients or patients with a partner were 2.4 times more likely to have a DPAHC than single patients. This investigation found that marital status was not associated with the completion of a LW (Trarieux-Signol et al., 2014). Among 3,838 community dwelling persons, married persons were more likely than formerly married and unmarried persons to engage in EOL discussions with family members, which led to increased completion rates of LWs and DPAHCs (Carr & Khodyakov, 2007).

#### 2.1.4. Race/Ethnicity

Disparities exist in overall health outcomes, insurance coverage, and access to health care services (Gulley, Rasch, & Chan, 2014; Peterson-Besse, Walsh, Horner-Johnson, Goode, & Wheeler, 2014). Differences exist in racial and ethnic minorities in regards to engagement in ACP. Caucasians are more likely than non-Caucasians to complete LW and DPAHC documents, and to have EOL discussions about their EOL treatment preferences with family members and HCPs (Gerst & Burr, 2008; Hirschman, Abbott, Hanlon, Prvu Bettger, & Naylor, 2012; Zaide et al., 2013). Rao and colleagues (2012) conducted a study with 7,946 individuals from the general population and reported that Caucasians are more likely to have ADs compared to African Americans

and Hispanics. Another investigation conducted by Hirschman and colleagues (2012) in a long-term care setting found that the likelihood of Caucasians having a LW was 2.9 times higher than non-Caucasian adults.

Another investigation conducted with 1,102 individuals from the general population reported that African Americans are 51% less likely than Caucasians to discuss EOL treatment preferences with family members or anyone else and were 55% less likely to have a DPAHC (Gerst & Burr, 2008). Huang and colleagues (2016) reported that older African Americans were 58% less likely than older Caucasian Americans to engage in the completion of AD documents. These findings may be affected by different cultural beliefs of African Americans compared to Caucasians. A few studies found that Caucasians are more engaged in ACP compared to other ethnicities, including African Americans, Hispanics, and Asians, but this finding was moderated by socioeconomic status (SES) and cultural differences (Car, 2012a; Gerst & Burr, 2008; Rao et al., 2014).

Bullock (2011) conducted interviews and focus group discussions with adults age 55 or older and examined their cultural beliefs related to EOL decision-making. Caucasians wanted to let their family members know their wishes and believed that ACP would be helpful. However, African Americans believed that ACP would not make any difference in their dying process. Caucasians preferred to discuss their wishes with their physicians, whereas African Americans tended to mistrust physicians and preferred their family members to be present when they met with physicians. Caucasians preferred to quit futile care when physicians recommended it, whereas African Americans had a fear that ACP may result in unwanted withdrawal or withholding of care at the EOL.

Carr (2012a) investigated racial differences in the rate of ACP among 2,111 adults ages 18 to 64. Racial differences between Caucasians and African Americans were moderated by education and home ownership. African Americans who graduated from college were more likely than their Caucasian counterparts to have a LW, but African Americans who graduated from high school were less likely than their Caucasian counterparts to have a LW. African Americans who owned homes had a greater likelihood of having discussions about EOL treatment preferences. Thus, African American engagement in ACP was affected by their SES (i.e. educational level and home ownership). Asians were 1.56 times more likely than Caucasians were to have a LW, but 42% were less likely to have discussions about EOL treatment preferences with family members or others. Asians preferred to complete a LW document, but did not want to discuss their EOL preferences because of a fear that such discussions may cause death. Latinos were less likely than Caucasians to have discussions and to have LWs because they lacked understanding of ACP and did not know how to have EOL discussions.

#### 2.1.5. Children

Having children may be associated with health behavior. The relationship with children and the characteristics of children influenced how parents coped with their own or their families' changes in health conditions (Umberson, Crosnoe, & Reczek 2010). There were conflicting findings regarding the association between having children and engagement in ACP. Patients with children were more likely than those without children to have engaged in ACP among adults who were 64 and 65 years old (Carr & Khodyakov, 2007). Interestingly, patients with advanced cancer with dependent children (18 years old

or less), were less likely to engage in ACP (Nilsson et al., 2009). Having children and the number of children influences the likelihood of having a LW (Greenberg, Weiner, & Greenberg, 2009). Patients who have a greater number of children may have more potential people to serve as a DPAHC and to discuss their EOL preferences with, which may lead to an increased likelihood of engaging in ACP (Carr & Khodyakov, 2007; Van Scoy et al., 2014).

#### 2.1.6. Religion

People often make decisions about EOL based on their religiosity and affiliation. A belief in God's control over EOL and length of life can influence decisions made about which EOL treatments to receive, the timing of death, the place of death, and whether to engage in ACP (Black & Reynolds, 2008; Carr & Khodyakov, 2007; Garrido, Idler, Leventhal, & Carr, 2013; Huang et al., 2016).

Garrido and colleagues (2013) examined the association between religion and ACP among 305 adults aged 55 or older. Strong beliefs about God's control over life's length were associated with low completion rates of LWs and DPAHCs, and with a lower likelihood of having EOL planning discussions. Strong beliefs about having a natural death were associated with higher engagement in ACP. Conservative Protestants and Catholic respondents were less likely to engage in ACP than were respondents who were Jewish or who had no religion. Protestants had a strong belief in God's control over life's length and had a weaker belief in death as a natural part of life, so they may not have felt a need to engage in ACP (Garrido, Idler, Leventhal, & Carr, 2013). Persons who showed strong beliefs in God's will and thought that ACP was not consistent with their religious

beliefs might have been hesitant to engage in any kind of ACP, while persons who believed that they could control their EOL situation were more likely to engage in ACP (Garrid et al., 2013). For African Americans, quitting EOL treatments and engagement in ACP were considered to be against their beliefs in miracles and God's plan (Bullock, 2011).

Conservative Protestants (e.g., Baptists and other Evangelicals) and Catholic respondents were less likely to engage in ACP compared to those who were Jewish, or indicated no religion among adults aged 64 or older (Black & Reynolds, 2008; Carr & Khodyakov, 2007). Similarly, being Evangelical or Catholic was associated with 50% lower odds of engaging and completing AD documents compared to those who were mainline Protestants (Huang et al., 2016). People who regularly attended religious or spiritual services are more likely to have a DPAHC compared with those who do not attend (Kelly et al., 2013). People with religious affiliations may have more opportunities to have EOL conversations in their faith communities (i.e, churches or synagogues) (Van Scoy, 2014).

#### 2.1.7. Education level

It is important that people understand ACP and why it is important to engage in the process (Carr & Khodyakov, 2007; Mueller, Reid, & Mueller, 2010). Mueller and colleagues (2010) reviewed 62 AD forms from the 50 states and the District of Columbia. They reported that the average readability of the AD forms was at a 12th-grade level, much higher than the average readability of U.S. adults which is at an 8th-grade level; the

recommended level by the National Work Group on Literacy and Health is at the 5th-grade level (Mueller, Reid, & Mueller, 2010).

Higher level of education was a significant predictor of having an AD. Hirschman and colleagues (2012) examined the factors associated with ADs among adults in long-term care. Adults with greater than 12 years of education had a 2.5 times higher odds of completing a LW and 1.7 times higher odds of completing a DPAHC than did adults with less than 12 years of education. Among 7,946 adults aged 18 years and older, the odds of completing an AD were 1.9 times higher among respondents who had graduated from high school, 2.2 times higher among those who had some college, 3.2 times higher among those who had graduated from college, and 3.1 times higher among those who had post-graduate training compared to those who did not graduate from high school (Rao et al., 2014). Similarly, among 2,154 adults aged 50 and older, the odds of completing an AD were 1.7 times higher among those who had some college and 2.2 times higher among those who had a bachelor's or higher degree compared to those who had only graduated from high school (Huang et al., 2016). Having a college education is associated with having a greater likelihood of completing a LW (Carr, 2012a). Caucasians adults with greater than 16 years of education were more likely to have a LW, DPAHC, and EOL discussions about their preference with family members than those who only graduated high school. With each additional year of education, the likelihood of having a DPAHC increased by 6% (Gerst & Burr, 2008). Although most studies demonstrate that higher education increases ACP, a recent study reported that years of education of adults did not predict engagement in LW, DPAHC, or discussions of EOL preferences (Khosla, Curl, & Washington, 2015).



### 2.1.8. Net worth

Net worth is considered a key component to measure SES. A higher total household income is positively associated with completion of a LW (Carr, 2012a), a DPAHC (Khosla, Curl, & Washington, 2015), and with having discussions of EOL preferences with family members or others (Carr, 2012a; Gerst & Burr, 2008). People with greater financial resources may be able to maintain a healthy lifestyle and gain access to health care planning (Carr, 2012b).

Ko and Lee (2014) conducted an investigation with 256 low-income adults and found that people with an income level of more than \$10,000 were 2.4 times more likely to engage in ADs than were those with an income level of less than \$10,000. Among 2,111 adults ages 18-64, total household income was associated with engagement in completion of a LW and engagement in EOL discussions with family and HCPs about EOL treatment preferences (Carr, 2012a). Among 634 adults ages 23-100, the individuals in the higher income group were 12% more likely to have a LW and 13% more likely to have a DPAHC than were individuals in the lower income group (Kelly et al., 2013). As the logged net worth increased, the odds of engaging in EOL discussions increased by 35% among 1,102 adults ages 48-105, and the odds of completing a DPAHC increased by 32% (Gerst & Burr, 2008). A higher income provides more options and resources, which may increase the completion of AD documents (LW and DPAHC) and discussions with family members and HCPs.

#### 2.1.9. Insurance

Having health insurance is one of the measures of SES and it has an impact on health care utilization. Being insured was significantly associated with higher odds of health service use and lower odds of delay of health care (Babitsch et al., 2012). People who do not have insurance have 61% lower odds of contacting physicians (Blackwell, Martinez, Gentleman, Sanmartin, & Berthelot, 2009).

There are inconsistent findings regarding the relationship between having an insurance policy and engagement in ACP. A study conducted by Van Scoy and colleagues (2014) reported that there was no association between the type of insurance (e.g., Medicaid, Medicare, private, and no insurance) and completion of ADs among 130 inpatients (Van Scoy et al., 2014). However, House and Lach (2014) conducted a review of medical records of 5,330 inpatients 18-89 years old and found that having Medicare was associated with having ADs. Another investigation that included 1,121 patients in the ICU found that having private insurance was positively associated with having a LW, whereas having Medicaid was negatively associated with having a LW (Halpern et al. 2011).

#### 2.1.10. Health condition

The health status of individuals influences their awareness of the need for engagement in ACP (Kelly et al., 2013). One of the reasons that people do not engage in ACP is that they are currently healthy (Carr, 2012a; Moorman & Inoue, 2013), whereas, a diagnosis of cancer was associated with an increased completion of ADs (Park et al., 2015). Another study found that patients with cancer had a 20% higher odds of engaging

in EOL discussions with physicians compared to non-cancer patients among 5,199 Medicare beneficiaries ages 53-91 (Keary & Moorman, 2015). Among 7946 adults aged 18 years or older, patients who had a chronic illness were 1.6 times more likely to have ADs (Rao et al., 2014). Van Scoy and colleagues (2014) reported that patients after discharge who had been admitted to the hospital due to chronic diseases, defined as a progression of an ongoing underlying illness, were more likely to complete a LW than those who had been admitted due to acute diseases, defined as newly diagnosed illnesses. This finding indicated that having a hospitalization experience due to a chronic disease encouraged patients to think about their EOL planning and led them to engage in ACP (Van Scoy et al., 2014).

Moorman and Inoue (2013) measured the perceived health status of people by asking: "In general, would you say your health is excellent, very good, good, fair, or poor?" People who perceived their health status was poor were more likely to discuss EOL health care treatments than were those who perceived their health status as good, very good, or excellent. Carr (2012a) supported this finding. She reported that people who perceived their health status as fair or poor were 56% more likely to have a LW, and 35% more likely to have discussions of their EOL treatment preferences with family members and others than were those who perceived their health status as good or better.

EOL discussions between patients, family members and HCPs are more likely to occur when a patient's death is expected. These discussions result in patients receiving the EOL care that they prefer (Ahluwalia et al., 2015; Mack et al., 2010). Gerst and Burr (2008) reported that family expectation of death was associated with having more EOL EOL communication with others (67%), having a DPAHC (95%), and having a LW

(77%). Kelly and colleagues (2011b) also reported that expectation of patients' deaths influenced the decisions for patients' EOL care and the place of death.

## 2.2. Engagement in advance care planning

As stated in chapter one the number of people engaging in ACP behaviors has increased over time. According to Khosla and colleagues (2015), the proportion of individuals who have any type of ACP increased from 12% to 23% every two years from 2002 to 2010. The completion rate of DPAHCs is often higher than that of LWs. Also, the proportion of those having discussions about EOL preferences with family members and HCPs is generally higher than the proportion of those completing a LW or a DPAHC.

Engagement in ACP varies in different health care settings. In the general population, the rate of having a LW ranges from 24% to 56% (Carr & Khodyakov, 2007; Carr, 2012a; Kelly et al., 2013; McCarthy et al., 2008); the rate of having a DPAHC ranges from 27% to 66% (Carr & Khodyakov, 2007; Carr, 2012a; Kelly et al., 2013; McCarthy et al., 2008); and the rate of having discussions of EOL preferences with family members and/or HCPs ranges from 37% to 75% (Carr & Khodyakov, 2007; Carr, 2012a; McCarthy et al., 2008; Moorman & Inoue, 2013; Rao et al., 2014; Wright et al., 2008). Carr and Khodyakov (2007) conducted a survey with adults aged 64-65 and found 56% had a LW, 53% had a DPAHC, and 75% had discussed their EOL preferences with family members or others. EOL discussions were often with the next-of-kin. Most married adults (90%) had discussed their EOL preferences with their spouses. Two-thirds of adults had discussed their EOL preferences with their adult children.

Kelly and colleagues (2013) surveyed adults aged 23 to 100 (mean age: 60.5) and reported that 3.1% of adults had not heard of LWs, 62.2% had heard of LWs, but had not completed one and 34.8% of adults had a LW. In the same study 9.1% of the adults had not heard of a DPAHC, 57.0% had heard about them, but had not completed one, and 33.9% had a DPAHC. Approximately, half of respondents had discussed their treatment preferences if they were critically ill. One-third of respondents aged 55 years or older had ADs, whereas two-thirds of respondents 54 years or younger did not have ADs (Rao et al., 2014). Among adults who were aged 84 to 100 years old, the proportions of those having a LW, a DPAHC, or having had a discussion about EOL preferences were 55%, 66% and 69%, respectively (McCarthy et al. 2008). Of the respondents who had discussed EOL preferences, 91% of them had discussed their wishes with their family members, 17% with a physician or other HCP, and 3% with a member of the clergy.

Hirschman and colleagues (2012) investigated the proportions of adults aged 60-98 with LWs and DPAHCs in three health care settings: assisted living facilities, nursing homes, and those using home and community based services (Hirschman et al., 2012). In the assisted living facilities, the proportions of those with a LW and a DPAHC were 84.3% and 79.7%, whereas the proportions of those with a LW and a DPAHC in the nursing homes were 39.1% and 40.7%, respectively. Among adults who received home and community-based services, 22.9% of them had LWs and 36.1% had DPAHCs (Hirschman et al., 2012). In a review of medical records of 226 deceased patients in the hospital, 6.6% of them had a LW, and 22.1% had a DPAHC (Becker et al., 2007). Two-thirds of the DPAHCs were filled out during each patient's last admission. Two-thirds of patients had DNR orders that were completed approximately 6 days before each patient's

death. Van Scoy and colleagues (2014) also conducted a study in the hospital setting and found that 21% of inpatients had a LW and 35% had a DPAHC. In the ICU, the rate of having LWs ranged from 5% to 16%, and the rate of having DPAHCs ranged from 19% to 47.6%. Few patients 65 years and older admitted to the ICU have LWs (7%) and DPAHC (25%) (Torke et al., 2014).

Kumar and colleagues (2010) also conducted a chart review of patients who were admitted to the cardiac care unit and the ICU. The proportions of LWs and DPAHCs were 2% and 19%, respectively, in adults aged 65 or less; 9% and 20%, respectively, in adults between 65 and 79, and 5% and 17%, respectively, in adults aged 80 or older. Among patients with cancer admitted to the ICU, 15.7% had a LW, 47.6% had a DPAHC, and 36.7% did not have a LW or a DPAHC (Halpern et al., 2011). Kwak and researchers (2014) investigated engagement in ACP among 60 patients with Parkinson disease. Most patients (95%) had a LW, and shared a copy of the LW with their proxy (90.6%) and with their physician (37.5%). However, 42% of family members reported that they did not know the patient's preferences for one or more treatments (e.g., CPR, ventilator, feeding tube).

There has been an increase in engagement in EOL discussions, DPAHC, and LW in all health care setting over time. Old age, terminal/degenerative health condition, and admission to long-term care facilities (e.g., assisted living facilities and nursing homes) were related to higher engagement in ACP. Engagement in ACP often occurs very late in the course of a patient's illness in the hospital.

### 2.3. Effect of advance directives on end-of-life care

Although most of the researchers who have studied the effect of ADs on EOL care are positive, two research teams reported that the presence of a LW or a DPAHC did not influence ICU use, length of the ICU stay, hospital length of stay, and use of LSTs (i.e., mechanical ventilation, hemodialysis, chemotherapy, CPR) (Dobbins, 2007; Halpern et al., 2011). In the general population, decedents with a LW and/or a DPAHC were less likely to die in the ICU than those without a LW and/or a DPAHC, which led to less use of LST in the last month of life (Teno et al., 2007). Also, decedents with a LW and/or a DPAHC had used fewer feeding tubes compared to those without a LW and/or a DPAHC. Among 477 patients who died in an ICU, patients with LWs were less likely than those without LWs to receive CPR (9% vs. 23%) (Hartog et al., 2014). Having a LW, a DPAHC, or both was independently associated with forgoing a medical intervention in hypothetical life-limiting medical conditions (e.g., massive stroke, advanced multiple myeloma, and chronic obstructive pulmonary disease [COPD]). Also, the combination of a LW and a DPAHC had a stronger influence on forgoing medical intervention than having only a LW or a DPAHC (Escher et al., 2014).

Nicholas and researchers also found that having a LW was associated with less aggressive treatments at the EOL, but simply having a DPAHC without a LW did not show any association with aggressive treatments (Nicholas et al., 2011). Camhi and researchers however did find that treatments in the ICU are limited when a patient had just a DPAHC. Lastly, but of great importance, patients with ADs are more likely to receive supportive care at the EOL (Becker et al., 2007; Franklin, Cannon, Smith, Harbrecht, Miller, & Richardson, 2011; Silveira et al., 2010).). Among 347 patients who

died due to trauma, having a LW or a DPAHC was associated with receiving comfort care (Franklin et al., 2011).

#### 2.4. Effect of discussions on end-of-life care

Discussions about EOL treatment preferences may reduce conflicts between patients, families, and HCPs and reduce the distress involved with EOL decision-making (Apatira et al., 2008; Hickman & Pinto, 2014; IOM, 2015). Limited research has been conducted to determine the effect of EOL discussions on actual EOL care.

Wright and researchers (2008) examined the association between EOL discussions with physicians and aggressive interventions in 332 patients with terminal cancer. Patients were asked, "Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying?" Approximately one third of the patients (37%) discussed their EOL care with their physicians. Patients who had EOL discussions were less likely to receive mechanical ventilation than those who did not (1.6% vs. 11%). EOL discussions were associated with lower rates of CPR (4.1% vs. 12.4%) and earlier hospice referrals (65.6% vs. 44.5%). Another study examined the association between EOL discussions and EOL care in 1,231 patients with terminal lung or colorectal cancer. Patients who had EOL discussions with their physicians were less likely to receive chemotherapy in the last 2 weeks of life, receive acute care in the last month of life, or be admitted to an ICU in the last month of life (Mack et al., 2012a).

Ahluwalia and colleagues (2016) conducted another study with patients with terminal cancer. Among the 665 decedents 46.8% had documentation of EOL discussions



with their physicians within the first month after receiving the cancer diagnosis (Ahluwalia, 2016). These discussions were associated with 33% lower odds of receiving acute care at the EOL. In a study using the nationally representative data (called HRS), engagement in ACP (LW, DPAHC, and discussions of EOL care preferences) was associated with patients receiving LST among 1,985 cancer patients who died between 2000 and 2012 (Narang et al., 2015). Investigators asked proxies, “Did the patient ever discuss with you or anyone else the treatment or care he/she wanted to receive in the final days of his/her life?” Engagement in EOL discussions was associated with two times the odds of limiting or withholding life-prolonging EOL care. Among patients who had both a LW and discussions of EOL care preferences, 88% limited or withheld treatments at the EOL, while only half of the patients who did not have a LW or discussions limited or withheld life-prolonging treatments at the EOL.

Limitations exist for the studies reviewed above. Participants in all four studies had cancer. Thus, the findings cannot be generalized to the general population or patients with conditions other than cancer. In three of the investigations (Ahluwalia et al., 2016; Mack et al., 2012a; Wright et al., 2008), ADs were not adjusted to examine the association between EOL discussions and receiving EOL care. Previous findings in the literature stressed that there is a significant relationship between ADs and EOL care. Therefore, the presence of ADs should be considered in determining the effect of EOL discussions on receiving LST. Narang and colleagues (2015) used all three types of ACP. They examined the association of LWs, DPAHCs, and EOL discussions with EOL care, respectively. Also, they reported that 88% of patients who had both a LW and an EOL discussion, limited or withheld treatment, whereas only 53% who did not have a LW or

an EOL discussion limited or withheld treatment. They did not describe other combinations of ACP types compared with each ACP type. No study could be found that examined the effect of EOL discussions on comfort care at the EOL.

## 2.5. Patient characteristics influencing end-of-life care

Patient characteristics influencing EOL care include age, gender, race, religion, functional status, diagnosis, and financial burden. Older patients are more likely than younger patients to ask to have LST to be withheld and/or withdrawn (Melhado & Byers, 2011; Quill, Ratcliffe, Harhay, & Halpern, 2014; van Wijmen, Pasman, Widdershoven, & Onwuteaka-Philipsen, 2014) and are less likely to receive aggressive care (Maciejewski et al., 2012). Women are more likely than men to forgo LST and are more likely to have surrogate decision-makers (Melhado & Byers, 2011; Quill et al., 2014; van Wijmen et al., 2014). Women and anyone who witnessed the painful death of a loved one were more likely to refuse aggressive treatment (Carr & Moorman, 2009). In addition, African Americans are more likely than Caucasians to withhold and/or withdraw LST (Quill et al., 2014; van Wijmen et al., 2014) and are more likely to receive aggressive treatments (Miesfeldt, Murray, Lucas, Chang, Goodman, & Morden, 2012). Caucasian patients are 2.52 times more likely to ask that LST be withheld or withdrawn than were patients of other ethnicities (Cesta, Cardenas-Turanzas, Wakefield, Price, & Nates, 2009). Patients with no religious affiliation, mainline Protestants, and persons who are pessimistic about their own life expectancy are more likely to refuse aggressive treatments at the EOL (Carr & Moorman, 2009; van Wijmen et al., 2014). Patients with higher education are also more likely to refuse LST (Pruchno, Lemay, Feild, & Levinsky, 2006; van Wijmen

et al., 2014). Lastly, surrogates with financial burden are more likely to forego LST (Melhado & Byers, 2011).

Research that has been conducted with patients with a cancer diagnosis prefer comfort care when compared to patients with cardiovascular diseases (Becker et al., 2007). Patients with COPD and heart failure are more likely to receive care to prolong life (Cosgriff, Pisani, Bradley, O'Leary, & Fried, 2007). A study showed that severity of health conditions (e.g., current health, significant cognitive impairment, severe stroke, serious physical impairment, and terminal cancer) was associated with spouses' preferences for receiving LSTs (McDade-Montez, Watson, & Beer, 2013).

## 2.6. Patient preferences and end-of-life care

Researchers have found that EOL treatment preferences are fairly stable and consistent even as illnesses progress (Auriemma et al., 2014; Khan, Gomes, & Higginson, 2014). Most patients prefer to receive limited LST and more comfort care. Among patients with advanced cancer who were aware of their terminal conditions, 17% wanted to receive LST (Mack et al., 2010). In another study, 2 % of patients with a LW wanted to receive all possible care to prolong their lives (Silveira et al., 2010). Winter, Parks, and Diamond (2010) interviewed 202 community-dwelling residents who were 70 years old or older. Most residents wanted their physicians to withhold or withdraw LST, while 9% wanted to receive LST. Before hospitalization, most patients (76%) had thought about EOL care, and only 12% wanted to receive LST (Heyland et al., 2013).

McCarthy and colleagues (2008) interviewed 220 community-dwelling respondents. Most respondents (80%) preferred to receive comfort care. Fewer

respondents preferred death to living out their lives attached to LST, such as a ventilator [63%] or a feeding tube [64%]. Patients who recognized their terminal illnesses were more likely to prefer comfort care (Mack, Weeks, Wright, Block, & Prigerson, 2010). Having EOL discussions with physicians was positively associated with the preferences for comfort-oriented care, and negatively associated with preferences for receiving aggressive care to sustain life, including ICU admission, CPR, intubation, and mechanical ventilation (Tang, Liu, Liu, Chiu, Hsieh, & Tsai, 2014). More than 80% of patients preferred to receive comfort care or supportive care (McCarthy et al., 2008; Silveira et al., 2010).

## 2.7. Congruency between patients' preferences and end-of-life care

The goal of ACP is helping people receive care that is aligned with their treatment preferences (Bischoff et al., 2013; IOM, 2015). Previous studies have focused on congruency between patients' wishes and surrogates' wishes, or between patients' wishes and HCPs' wishes. Only one study examined the relationship of EOL discussions with receiving care consistent with people's treatment preferences at the EOL. Engagement in ACP was associated with health care proxies' decision-making for patients with advanced Parkinson's disease (Kwak et al., 2014). In the hypothetical EOL situation, half of family members (53%) chose comfort care, and 6% of family members chose treatments to prolong life. The majority of family members (72%) wanted patients to receive comfort care, and 9% wanted patients to receive CPR, a ventilator, and a feeding tube. Of interest, family members' choices for the patients were not consistent with patients' preferences for the use of LST. Even though patients had ADs, some family members stated that they

did not know patients' preferences. In actual EOL situations, patients who shared their ADs with physicians were less likely to receive LST, such as CPR and a feeding tube (Kwak et al., 2014).

Engagement in ACP is associated with the accuracy of proxies' predictions about patients' preferences (Barrio-Cantalejo et al., 2009). Investigators randomly assigned 171 pairs of patients and their proxies to three groups: control group (a single session to complete Life Support Preferences Questionnaire [LSPQ] including several hypothetical scenarios involving medical conditions), AD intervention group (a single session to complete an AD form and LSPQ), and discussion intervention group (two sessions with a trained nurse to complete LSPQ including different hypothetical scenarios involving medical conditions and a discussion relating to treatment preferences in different medical scenarios) (Barrio-Cantalejo et al., 2009). The discussion intervention group showed the highest accuracy of proxies' predictions about patients' wishes (84.5%) compared to the AD intervention group (58.3%) and the control group (50.3%).

Patients who wanted to receive intensive treatments (defined as a desire for invasive therapies despite more than a 50% chance of death) were more likely to receive care consistent with their initial preferences than those who did not (Cosgriff et al., 2007). Hickman and colleagues (2011) determined the consistency between the POLST orders and treatment received in nursing facilities. More than 90% of patients received the care (e.g., CPR, intensity of medical intervention, and antibiotics) they wanted. The consistency between POLST orders and feeding tubes provided was 63.6% (Hickman et al., 2011). Patients who expressed their preferences for receiving LST (e.g., CPR, artificial nutrition and hydration, antibiotics, and mechanical ventilation) were seven

times more likely to receive a specific treatment they chose than those who did not want to receive LST. Also, patients who did not want to receive LST were six times more likely not to receive LST (Pasman et al., 2013).

In a study conducted by Silveira and colleagues (2010), 83.2% of patients who requested limited treatment and 97.1% of patients who requested comfort care received care consistent with their preferences. Mack and colleagues (2010) examined the relationship of engagement in EOL discussions with receiving care consistent with preferences. Unfortunately 13% of patients received LST in the last week of life even though they stated they wanted to receive comfort care, however, patients who engaged in EOL discussions with their physicians had a 2 times higher odds of receiving care consistent with preferences compared to those who had no EOL discussions. Other significant predictors of receiving care consistent with preferences were if the patient was female and if the patient was aware of his or her terminal illness (Mack et al., 2010).

## 2.8. Research gap

Engagement in ACP has increased over time and plays an important role in making decisions at the EOL. The presence of a LW and/or a DPAHC was associated with less aggressive treatments and more comfort care. Individuals with a LW and/or a DPAHC were more likely to have treatment withdrawn, less likely to use a feeding tube, and more likely to receive comfort care than those without a LW and/or a DPAHC. Even though EOL discussions of individual preferences for EOL care are the major component of ACP, few studies have examined the association of EOL discussions with EOL care. The studies that examined EOL discussions with physicians found they were associated

with less aggressive treatments (Ahluwalia et al., 2016; Mack et al., 2012a; Narang et al., 2015; Wright et al., 2008). No studies compared the sole association of EOL discussions on EOL care with the combined effect of EOL discussions, a LW, and/or a DPAHC.

ACP aims to help individuals receive care consistent with their preferences. Previous studies reported that the majority of patients did not want to receive LST and wanted to receive comfort care. Most patients received the care they wanted. In particular, patients who had documentation, such as ADs, DNR, or POLST, were more likely to receive care consistent with their known wishes than those who did not. Limited evidence is available to determine the effect of EOL discussions and DPAHC on receiving LST and comfort care. Only one study found that having discussions with physicians was associated with higher consistency between patients' preferences and care received (Mack et al., 2010). Little is known about the effect of EOL discussions and a DPAHC on the consistency between patients' preferences and the EOL care they received. Since the CMS decision to now reimburse for ACP discussions, more attention has been given to EOL discussions of patients' preferences for EOL care with family members and HCPs, and their association with LST and comfort care. Previous studies focused more on ADs, rather than EOL discussions as a key component of ACP. Therefore, the proposed study will examine the effect of EOL discussions alone and the effect of EOL discussions combined with ADs on EOL care received. The proposed investigation will also determine the association between EOL discussions and DPAHC on congruency between patients' preferences for EOL care and the care they received.

## CHAPTER 3: METHODOLOGY

### 3.1. Design and data source

This study used the data from the Health and Retirement Study (HRS), which is an ongoing longitudinal study conducted by the Survey Research Center at the Institute for Social Research, University of Michigan (HRS, 2015; Juster & Suzman, 1995). The HRS was designed to survey a representative sample of approximately 22,000 U.S. residents over age 50 years every two years (called the HRS core interview). The HRS examines how Americans prepare for their economic and health requirements with advancing age and the relationship between their health, economic behavior, family status, and public and private support systems in the later part of life (Wallace & Herzog, 1995).

The HRS began with two distinct surveys: the original HRS and the Asset and Health Dynamics among the Oldest Old (AHEAD) study. The original HRS began in 1992 as a nationally representative sample of Americans between the ages of 51 and 61 (born in the years 1931 through 1941). The AHEAD survey began in 1993 as a nationally representative sample of Americans age 70 and older (born in 1923 or earlier). These two cohorts were interviewed every two years until the two surveys were merged in 1998. In 1998, two new cohorts were added: the Children of the Depression Era (CODA), born in 1924-1930, and War Babies (WB), born in 1942-1947. Since 1998, new cohorts have been added every six years. In 2004, a new cohort (Early Boomers) was added to make the total sample representative of those born in 1948-1953, and thus approximately age 51 and older. In the 2010 wave, the Mid-Baby Boomer cohort (born in the years 1954



through 1959) was added, and the Late Baby Boom cohort (born in the years 1960 through 1965) is scheduled to be added in 2016.

The HRS sample design is a multi-stage area probability sample of households based on the Survey Research Center's 84 strata National Sample frame. The oversamples are designed to increase the numbers of African American (1.86:1) and Hispanic (1.72:1) respondents as well as the number of HRS respondents who are residents of the state of Florida (2:1). Sampling weights are provided on all HRS data sets to compensate for the unequal probabilities of selection between the core and oversample domains.

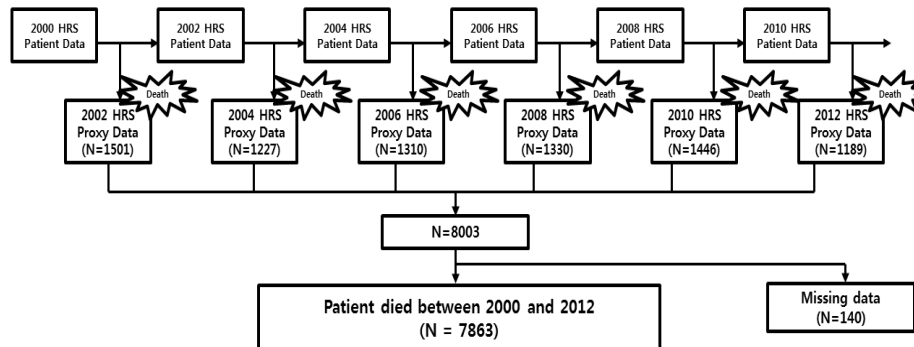
The HRS has conducted core interviews every two years since 1992 and conducted exit interviews every two years since 1994. The purpose of the exit interview is to identify the status and activities of the respondents before their deaths and to examine the circumstances of the deaths between the time of the last interview and the time of the respondents' deaths. The death of a respondent is discovered in one of three ways. First, a family member contacts the HRS study team to let the team know of the death of the respondent. Second, the death is discovered when an interviewer attempts to contact the respondent for a core interview. Last, the HRS uses the Social Security Death Index and the National Death Index to identify the respondent's death.

When a respondent dies, the HRS conducts an "Exit" interview with the person who is considered to be the most knowledgeable about the deceased respondent's situation at the EOL. This exit interview is conducted within 2 years of a respondent's death. The proxy informants are usually a widow, widower, adult child, another family member, friend, or others who are most knowledgeable about the deceased respondent's

EOL situation, such as medical care, expenditures, disposition of assets following death, family interactions, family decision-making, and other circumstances during the final stages of life (HRS, 2015). The HRS provides respondents with a \$60 payment for each participant. Since 1998, the number of exit cases has fluctuated around 1,200-1,500, and the response rate has ranged between 84% - 93%. The HRS provides the cross-wave tracker file that contains demographic information (e.g., gender, education, and race/ethnicity) and weight-related variables.

This study used data from the HRS exit interview which were collected in 2002, 2004, 2006, 2008, 2010 and 2012. The HRS 2012 Tracker file and the RAND HRS data were merged to obtain demographic data and to obtain information related to wealth and religiosity. As shown in Figure 3.1, six waves of HRS exit files, the tracker file, and the RAND HRS data were merged into one large file. Preliminary analysis revealed that the sample size was 8003 after merging. Respondents were excluded who died before 2000 or after 2012 because the sample size was too small. Therefore, the initial sample size prior to data analysis was 7863.

Figure 3.1. Sampling process



### 3.2. Research questions

The following research questions were examined:

Research question 1: What are the characteristics associated with the types of engagement in ACP?

1.1. Are there differences in characteristics associated with engagement in at least one ACP (having EOL discussions, DPAHC, and/or LW) compared with no engagement in ACP?

1.2. Are there differences in characteristics associated with engagement in EOL discussions and at least one AD (DPAHC and/or LW) compared with engagement in EOL discussions only?

1.3. Are there differences in characteristics associated with engagement in EOL discussions, DPAHC, and LW compared with engagement in EOL discussions and DPAHC?

1.4. Are there differences in characteristics associated with engagement in EOL discussions, DPAHC, and LW compared with engagement in EOL discussions and LW?

Research question 2: Are the types of engagement in ACP associated with receiving all possible care to prolong life?

2.1. Is engagement in EOL discussions only associated with receiving all possible care to prolong life compared with no engagement in ACP?

2.2. Is engagement in EOL discussions and DPAHC associated with receiving all possible care to prolong life compared with no engagement in ACP?

2.3. Is engagement in EOL discussions and LW associated with receiving all possible care to prolong life compared with no engagement in ACP?

2.4. Is engagement in EOL discussions, DPAHC, and LW associated with receiving all possible care to prolong life compared with no engagement in ACP?

Research question 3: Are the types of engagement in ACP associated with receiving comfort care?

3.1. Is engagement in EOL discussions only associated with receiving comfort care compared with no engagement in ACP?

3.2. Is engagement in EOL discussions and DPAHC associated with receiving comfort care compared with no engagement in ACP?

3.3. Is engagement in EOL discussions and LW associated with receiving comfort care compared with no engagement in ACP?

3.4. Is engagement in EOL discussions, DPAHC, and LW associated with receiving comfort care compared with no engagement in ACP?

Research question 4: Among individuals who have a LW, are engagement in EOL discussions and engagement in DPAHC associated with congruency between patients' preferences for EOL care and the care they received?

4.1. Is engagement in EOL discussions associated with congruency between decedents' preferences for all possible care to prolong life and the care they received before their deaths?

4.2. Is engagement in DPAHC associated with congruency between decedents' preferences for all possible care to prolong life and the care they received before their deaths?

4.3. Is engagement in EOL discussions associated with congruency between decedents' preferences for receiving comfort care and the care they received before their deaths?

4.4. Is engagement in DPAHC associated with congruency between decedents' preferences for receiving comfort care and the care they received before their deaths?

### 3.3. Hypotheses

The specific hypotheses were described for each of the research questions.

Hypothesis 1. It is hypothesized that the characteristics are associated with engagement in advance care planning will differ among the types of engagement.

Hypothesis 2. It is hypothesized that the likelihood of receiving all possible care to prolong life will differ among the types of engagement in ACP.

Hypothesis 3. It is hypothesized that the likelihood of receiving comfort care will differ among the types of engagement.

Hypothesis 4. It is hypothesized that the likelihood of receiving care consistent with their preferences for EOL care will differ among those who engage in EOL discussions and engage in DPAHC.

### 3.4. Inclusion criteria

The inclusion criteria are described based on the research questions. For the first research question, the inclusion criteria were: 1) decedents who died between 2000 and 2012, and 2) decedents who belonged to one of five groups: (1) no engagement in ACP, (2) engagement in EOL discussions, (3) engagement in EOL discussions and DPAHC, (4) engagement in EOL discussions and LW, and (5) engagement in EOL discussions, DPAHC, and LW. The sample size prior to data analysis was 6,001. For the second and third research question, the inclusion criteria were: 1) decedents who died between 2000 and 2012, 2) decedents who belonged to one of five groups, and 3) decedents who made decisions about their treatment. The sample size was 2,677. For the last research question, the inclusion criteria were: 1) decedents who died between 2000 and 2012, 2) decedents who made decisions about their treatment, and 3) decedents who had a LW. The sample size was 1,634.

### 3.5. Power estimation

Sample size guidelines for multivariable logistic regression indicated a minimum of 10 cases per predictors (Hosmer & Lemeshow, 1989). In general the preferred ratio of valid cases to predictors is 20 to 1. The number of predictors is determined by the lowest sample size. For example, in this study, the lowest sample size was 133 as shown in Appendix 4.16 (research question 4). Therefore, the maximum possible number of predictors was 6-7. As shown in Table 4.9, the final model included 7 predictors. The sample sizes of the other research questions were sufficient in logistic regression.

The investigator conducted a secondary data analysis using a known sample size, therefore, post-hoc power analysis was applied to determine the power for each outcome

of four research questions separately, based on the guidelines established in G\*Power 3.1.7 (Faul, Erdfelder, Buchner, & Lang, 2007; Faul, Erdfelder, Buchner, & Lang, 2015). It used the given alpha, obtained sample size, and effect size (or OR) to determine what the power was in the study. The power for each outcome was obtained determining the final model of each research questions in chapter 4.

### 3.6. Conceptual and operational definitions

#### Advance care planning (ACP)

Theoretical definition. ACP was theoretically defined as the process of communication between individuals, their families, and their health care team about future medical care, personal beliefs/values, and individual preferences with the goal of helping individuals receive care consistent with their preferences (Institute of Medicine [IOM], 2015; Lum et al., 2015). This communication can start at any time. ACP often includes all types of AD documents, medical orders, and discussions of EOL care preferences with others (Bischoff et al., 2013; IOM, 2015).

Operational definition. ACP was operationally defined as having any type of AD and/or having discussions about individual's preferences for EOL care with family members and/or HCPs.

#### Advance directive (AD)

Theoretical definition. AD was theoretically defined as several types of written documents of an individual's preferences about future medical care in the event that the individual would become incapacitated and no longer able to make decisions (Institute of

Medicine [IOM], 2015; National Hospice and Palliative Care Organization, 2015). Ads included two types of legal documents: LW and DPAHC.

Operational definition. AD was operationally defined as having formal written instructions, such as a LW and/or a DPAHC, relating to the decision-making at the EOL when the individual would be incapacitated.

#### Living will (LW)

Theoretical definition. LW was theoretically defined as written (or video) statements that described individual wishes about the types of medical care the person would want to receive in circumstances in which they would be no longer able to express their own wishes (IOM, 2015).

Operational definition. LW was operationally defined as written instructions about the treatments individuals would want to receive during the final days of their lives.

#### Durable power of attorney for health care (DPAHC)

Theoretical definition. DPAHC was theoretically defined as a document designating the individual or the health care agent who would be legally designated by patients to make decisions about medical treatments in circumstances in which the individual could not make decisions themselves (IOM, 2015; Kasman, 2004).

Operational definition. DPAHC was operationally defined as a legal document designating a person or persons to make decisions about the individual's care if they did not have capacity to make a decision.



### Patient preferences

Theoretical definition. Patient preferences were theoretically defined as the individuals' judgments about anticipated treatments or health outcomes (Brennan & Strombom, 1998). Patients expressed their preferences through statements or actions. Patient preferences provided direction for selecting health care treatment options.

Operational definition. Patient preferences were operationally defined as the individual's choice of one or more options from many possible treatment options. Patient preferences were measured by assessing if patients wanted to receive all possible care under any circumstances in order to prolong life (called all possible care to prolong life) or if patients desired to be kept comfortable and pain free and to forego all possible care to prolong life.

### All possible care to prolong life

Theoretical definition. All possible care to prolong life was theoretically defined as any medical intervention administered to a patient with the goal of prolonging life and delaying death (Berlinger, Jennings & Wolf, 2013). Examples included CPR, mechanical ventilation, vasoactive agents, cardiac mechanical assist devices, renal replacement therapy, nutrition, hydration, antibiotics, and blood replacement products.

Operational definition. All possible care to prolong life was operationally defined as all treatments which had the potential to prolong the length of the patient's life.

### Comfort care

Theoretical definition. Comfort care was theoretically defined as care that helped patients to prevent or relieve suffering while respecting the dying patients' wishes and dignity (Kasman, 2004; NIH, 2015).

Operational definition. Comfort care was operationally defined as care that focused on relieving pain and other distressing symptoms.

### Congruency

Theoretical definition. Congruency was theoretically defined as the agreement between two decisions or perspectives about treatments (Dubler& Marcus, 1994; Cedraschi et al., 1996).

Operational definition. Congruency was operationally defined as the agreement between an individual's preferences for EOL care and the EOL care they received. Congruency was measured by comparing the answer (yes/no) about whether patients desired to receive all possible care to prolong life/comfort care and with the answer (yes/no) about whether deceased patients received all possible care to prolong life/comfort care.

### 3.7. Measures

The predictors in this study were described based on five components of the theoretical framework: predisposing characteristics, enabling resources, needs for health services, health behaviors, and health outcomes. The specific questions are shown in Appendix 3.1.

### 3.7.1. Predisposing characteristics

Predisposing characteristics included each decedent's age at death, gender, marital status, race, having resident children (i.e., children who lived with decedent), and religion. Decedent's age at death was used as a continuous variable. Gender was divided into two groups: male (reference group) and female. Marital status was categorized as three groups: married, widowed, and separated/divorced/never married (reference group). Race was categorized as two groups: non-African American (reference group) and African American. Number of resident children was dichotomized to whether the decedent had children who lived with the patient or not. Religion was divided into two Catholic and non-Catholic, which includes those who were Protestant, Jewish, or indicated no religion (reference group).

### 3.7.2. Enabling resources

Enabling resources included net worth, educational level, and having private health insurance policy. Net worth in the HRS was calculated by subtracting total debts from total assets. The inflation rate was adjusted in the raw values in 2010 using the Consumer Price Index (CPI) (The Bureau of Labor Statistics, 2015). Net worth was categorized as two groups based on the 50% quartile. The lower 50% net worth was a reference group. Educational level was divided into three groups: less than high school diploma (reference group), high school diploma, and some college or more. Having private insurance plans was categorized into two groups: "0" (reference group) and "1 or more."

### 3.7.3. Needs for health services

Needs for health services included illness, pain, perceived health status, and expected death. Illness included the main illness that led to the person's death ("What was the major illness that led to patient's death?") and the past history of illness ("Had a doctor ever told patient that [he/she] had [disease]?"). The main illness that led to death was categorized into two groups: cancer and non-cancer (reference group). The past history of illness included lung disease, heart disease, and stroke. Each past history was dichotomized into yes or no (reference group).

Pain was categorized into yes or no (reference group) as an answer to the question: "Was patient often troubled with pain?" Perceived health status came from the Core data (patient data). It was measured by the following question: "Would you say your health is excellent, very good, good, fair, or poor?" Perceived health status was categorized into two groups: "excellent/very good/good" and "fair/poor" (reference group). Expected death was categorized into expected death or unexpected death (reference group) as an answer to the question: "Was the death expected at about the time it occurred, or was it unexpected??"

### 3.7.4. Health behavior

Health behavior included five types of engagement in ACP. Each type of engagement in ACP was assessed using three questions: 1) "Did patient ever discuss with you or anyone else the treatment or care [he/she] wanted to receive in the final days of [his/her] life?" (EOL discussions), 2) "Did patient make any legal arrangements for a specific person or persons to make decisions about [his/her] care or medical treatment if

[he/she] could not make those decisions [herself/himself]? This is sometimes called a “Durable Power of Attorney for Health Care” (DPAHC), and 3) “Did patient provide written instructions about the treatment or care [he/she] wanted to receive during the final days of [his/her] life? This is sometimes called a Living Will” (LW). The investigator created eight types of engagement in ACP using the earlier three questions: 1) no engagement in ACP, 2) engagement in LW, 3) engagement in DPAHC, 4) engagement in EOL discussions, 5) engagement in LW and DPAHC, 6) engagement in EOL discussions and LW, 7) engagement in EOL discussions and DPAHC, and 8) engagement in EOL discussions, DPAHC, and LW.

The investigator selected five types of engagement in ACP: 1) no engagement in ACP, 2) engagement in EOL discussions, 3) engagement in EOL discussions and DPAHC, 4) engagement in EOL discussions and LW, and 5) engagement in EOL discussions, DPAHC, and LW. These five groups were chosen to determine the effect of EOL discussions alone and the effect of EOL discussions combined with a DPAHC and/or a LW on EOL care. The reference group (no engagement in ACP) was compared with the other four groups including EOL discussions.

#### 3.7.5. Health outcomes

Outcomes included: 1) all possible care to prolong life and 2) comfort care. The process to determine the outcomes was as follows. The respondents were asked to answer a prerequisite question of “Did any decisions have to be made about the care and treatment of patient during the final days of [his/her] life?” If yes, final decision-making was coded as present, and the two following questions were answered: 1) “Did those last

decisions involve a desire to give all care possible unconditionally in order to prolong life?" (receiving all possible care to prolong life) and 2) "Did those last decisions rest largely on keeping the patient comfortable and pain free without taking extensive measures to prolong life?" (receiving comfort care). For each question, the answering options were yes and no.

The process to determine the congruency between decedents' preferences for EOL care and received care was as follows. The respondents were asked to answer a prerequisite question of "Did patient provide written instructions (sometimes called a LW) about the treatment or care [he/she] wanted to receive during the final days of [his/her] life?" If yes, LW was coded as present, and the two following questions were answering: 1) "Did these instructions express a desire to receive all care possible under any circumstances in order to prolong life?" (preference for all possible care to prolong life) and 2) "Did these instructions express a desire to keep [him/her] comfortable and pain free but to forego extensive measures to prolong life?" (preference for comfort care). For each question, the answering options were yes and no.

Congruency between decedents' preferences for EOL care and received care was determined by comparing decedents' preferences for all possible care to prolong life with received all possible care to prolong life and was created by comparing decedents' preferences for comfort care with received comfort care. Four groups were created as follows: 1) a group of decedents who received all possible care to prolong life as they preferred to receive it (group 1), 2) a group of decedents who received all possible care to prolong life even if they did not prefer to receive it (group 2), 3) a group of decedents who did not receive all possible care to prolong life as they preferred not to receive it

(group 3), and 4) a group of decedents who did not receive all possible care to prolong life even if they preferred to receive it (group 4). These four groups merged into two groups: congruency group and incongruency group. The congruency group included group 1 and 4. The incongruency group included group 2 and 3. The same process was applied to determine the congruency for comfort care.

### 3.8. Human Subjects Protection

The HRS obtained University of Michigan Institutional Review Board (IRB) approval prior to the initiation of contact with study participants. Most interviews were conducted by telephone. All respondents were read a confidentiality statement when first contacted, and gave oral or implied consent by agreeing to do the interview. Prior to public release, the HRS data files went through an iterative process to ensure data confidentiality. When raw data files were created after removing or masking variables for confidentiality, the data files were subject to final review and approval by the HRS Data Protocol committee. Finally, the HRS distributed its data to the public via a secure website. All investigators can download the data files after online registration and obtaining permission from the HRS. The investigator obtained permission to use the public data and downloaded the exit files between 2000 and 2012. This study conducted a secondary data analysis using publicly available data. There was no risk to the study population. The investigator obtained the approval from the Institutional Review Board (IRB) for non human subjects research at the University of Maryland.

### 3.9. Statistical analysis plan

SPSS 21.0 statistical program was used to conduct statistical analysis. Means and standard deviations were used to describe continuous variables, and numbers and percentages were used to describe categorical variables. Because the HRS has a complex sample design, three sampling weights (strata [STRATUM], clusters [SECU], and person-level weights [xWGTR]) were used to account for geographical stratification and clustering in the estimation of standard errors.

Prior to the analysis for the study, the characteristics of the original sample were compared to the characteristics of the study sample. The differences in characteristics of the original sample and the study sample were described (Appendix 4.1). Univariate and bivariate analysis were conducted to explore differences in group characteristics between the five types of engagement in ACP. The investigator conducted descriptive statistics using the data. Independent t-tests or one-way ANOVAs were used for continuous variables and chi-square statistics were used for categorical variables.

For research question 1, bivariate analyses were conducted to compare the predisposing characteristics, enabling resources, and the need for health services with the types of engagement in ACP. Then, the sequential logistic regression was used to examine the association of the predisposing characteristics, enabling resources, and need for health services with the probability of engagement in ACP: 1) no engagement in ACP (N=1807), 2) engagement in EOL discussions (N=997), 3) engagement in EOL discussions and DPAHC (N=752), 4) engagement in EOL discussions and LW (N=348), and 5) engagement in EOL discussions, DPAHC, and LW (N=2097). For research questions 2 and 3, bivariate analyses were conducted to compare the predisposing characteristics, enabling resources, need for health services, and health behaviors with



EOL care (all possible care to prolong life or comfort care). Then, the multivariable logistic regression was used to examine the association of engagement in ACP with the probability of receiving EOL care, after controlling for the environment, predisposing characteristics, enabling resources, and need for health services. For research question 4, bivariate analyses were conducted to compare engagement in the EOL discussions and engagement in DPAHC with receiving care consistent with preferences. Then, the multivariable logistic regression was used to examine the association of engagement in ACP with the probability of receiving care consistent with preference, after controlling for the environment, predisposing characteristics, enabling resources, and need for health services.

Modeling for complex samples was conducted using a three-step approach. First, bivariate analyses using weighted values were conducted to identify differences in baseline characteristics among two groups, using independent t-tests for continuous variables and chi-square test for categorical variables. Second, simple logistic regression analyses using weighted values were conducted to examine the association between a single dummy variable and a dichotomous dependent variable. The variables that were significant at an alpha of .05 were chosen to be entered into the multivariable logistic regression. Third, a multivariable complex design logistic regression was conducted to build the initial model using the predictors selected in the previous analyses. The importance of each predictor in the multivariable model was verified using Wald chi-square statistics. The process of entering and deleting the predictors was conducted until it appeared that all the significant predictors were included in the final model. The interaction terms were checked and added if they were significant.

## Chapter 4: RESULTS

This chapter presents the results of the study. The purpose of the study was to examine the association of EOL discussions with end-of-life (EOL) care and the combined association of EOL discussions, durable power of attorney for health care (DPAHC) and/or living will (LW) with EOL care. Sample characteristics in this study were compared with the original sample characteristics. Then descriptive statistics, bivariate analysis and multiple logistic regression analysis were addressed in the same order of each research question. This chapter summarizes the results of each research question.

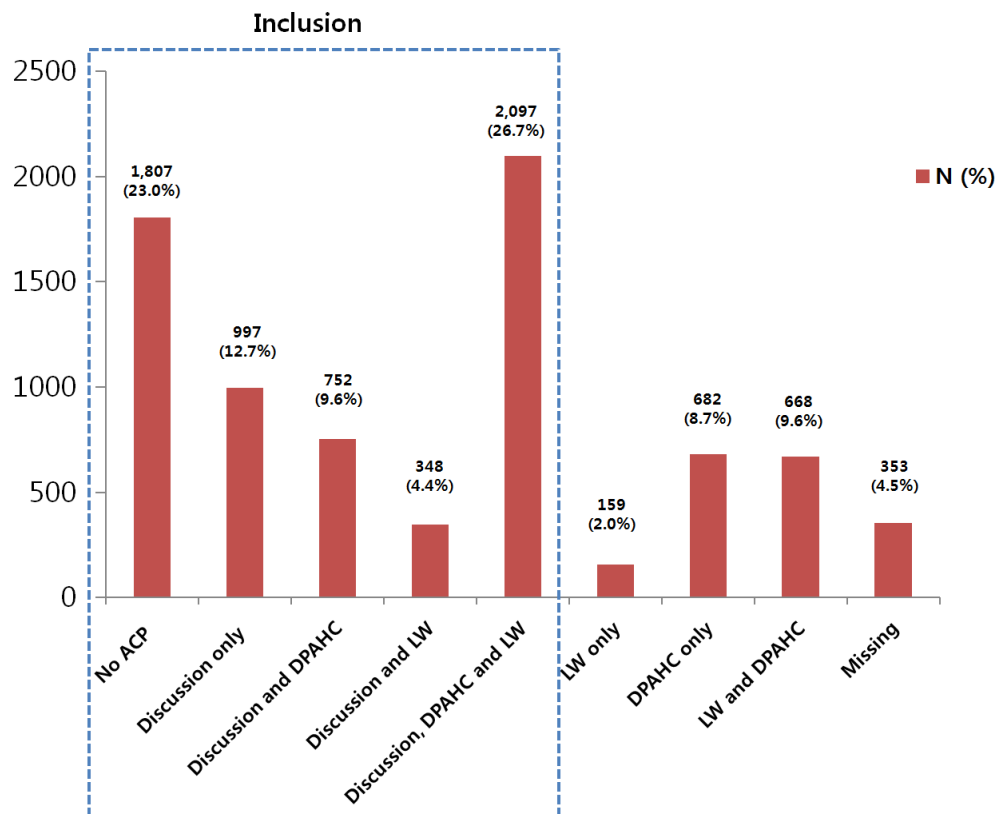
### 4.1. Sample characteristics: the original sample and the study sample

The original sample included the HRS exit data (proxy interviews) from the period between 2002 and 2012. A total of 7,863 decedents died between 2000 and 2012. In the unweighted results, 3,340 (42.5%) had a LW, 4,259 (54.2%) had a DPAHC, and 4,282 (54.4%) had EOL discussions with others about the EOL care they wanted to receive. Frequencies of the advance care planning (ACP) types were estimated based on the complex sample design. An estimated 48.7%, representing 215,681,724 decedents aged 50 years or older, had a LW, 61.0% (267,777,132) had a DPAHC, and 60.0% (268,402,956) had EOL discussions with others. Eight options for engagement in ACP were identified (See Figure 4.1). Based on the research questions for this investigation, five types of engagement in ACP were selected for this study. These included 1) no engagement in ACP, 2) engagement in EOL discussions, 3) engagement in EOL

discussions and DPAHC, 4) engagement in EOL discussions and LW, and 5) engagement in EOL discussions, DPAHC, and LW. The characteristics of the original sample and the sample in this study are compared in Appendix 4.1.

The average age at death was 80.1 (standard deviation [SD]=10.7) years in the original sample and 79.5 (SD=10.7) in the study sample. Respondents (proxies) in the study sample were decedents' spouse/partner (34.0%), children (45.8%), relatives (16%) and others (4.0%), which was similar to the results of original sample. Half of the decedents were female and four in ten decedents were married in both groups. There were more African American decedents in the study sample than in the original sample (10.8% in the original sample and 17.7% in the study sample).

Figure 4.1. Eight types of engagement in advance care planning



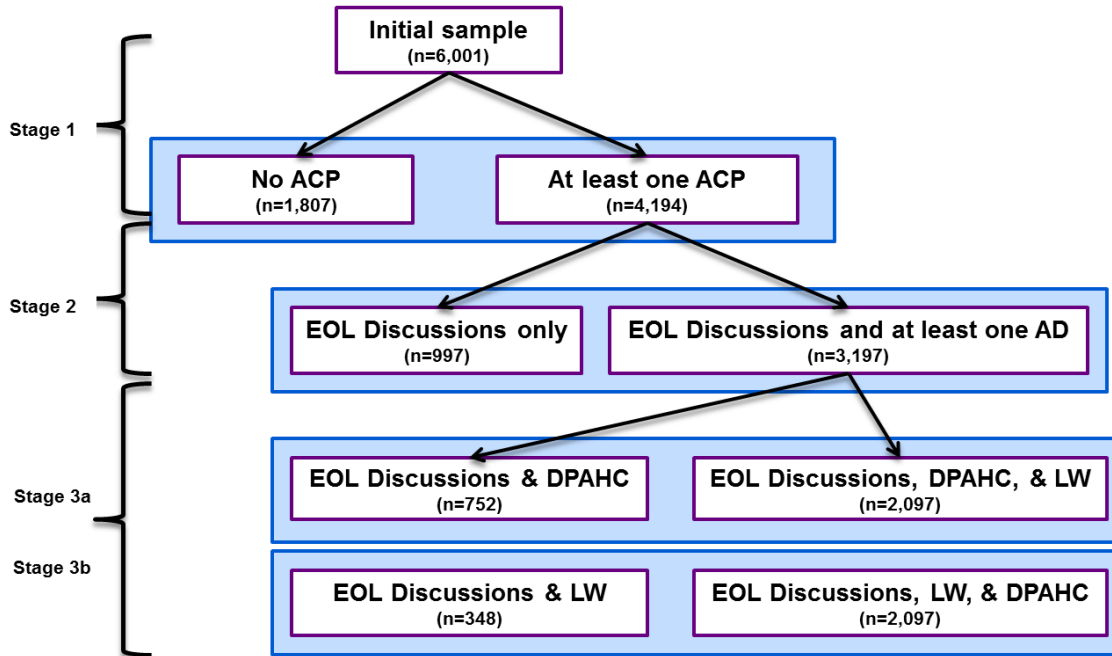
Eight in ten decedents did not live with children in both samples. A quarter was Catholic in both groups. Four in ten decedents did not graduate from high school in both groups. Half of the decedents had at least one private insurance policy in both samples. A quarter of decedents died due to cancer in both samples. One-fourth had been diagnosed with lung disease in the past. Also, 54% had been diagnosed with heart disease, and 28% had a history of having a stroke. Six in ten decedents suffered from pain during the last year before their deaths and perceived their health status as fair or poor. Six in ten decedents' deaths were expected in both samples.

#### 4.2. Research question 1

*What are the characteristics associated with the types of engagement in advance care planning?*

To examine the characteristics associated with engagement in ACP, the four-level response was modeled in three stages. As shown in Figure 4.2, the stage 1 model, which fits all subjects, described the log-odds of engaging in at least one ACP (EOL discussions, DPAHC, and/or LW). The stage 2 model, which fits only the subjects that engaged in at least one ACP, described the log-odds of engaging in EOL discussions and at least one advance directive (AD) versus engaging in EOL discussions only. The stage 3a model, which fits only the subjects that engaged in at least one AD, was described the log-odds of engaging in all types of ACP versus engaging in EOL discussions and DPAHC. The stage 3b model described the log-odds of engaging in all types of ACP versus engaging in EOL discussions and LW.

Figure 4.2. Sequential responses: engagement in advance care planning



*Note.* ACP, advance care planning; EOL, end-of-life; AD, advance directive; DPAHC, durable power of attorney for health care; LW, living will

#### 4.2.1. Stage 1

*Are there differences in characteristics associated with engagement in at least one advance care planning (having EOL discussions, durable power of attorney, and/or living will) compared with no engagement in advance care planning?*

#### *Descriptive statistics and bivariate analyses*

Weighted results were estimated based on the complex sample design. The bivariate analyses were conducted using weighted results. Refer to Appendix 4.2 for the unweighted and weighted frequencies and percentages of the predictors. The sample size was 6,001, representing 162,061,218 decedents aged 50 years or older in the complex

sample design. The numbers and percentages of no engagement in ACP ("no engagement group") and engagement in at least one ACP ("engagement in at least one ACP group") were 1,807 (30.1%), representing 84,216,780 decedents (24.3%), and 4,194 decedents (69.9%), representing 262,307,106 decedents (75.7%), respectively.

The average age at death in the "engagement in at least one ACP group" ( $79.5 \pm .27$ ) was significantly ( $t = 348.746, p < .001$ ) greater than in the "no engagement group" ( $76.4 \pm .40$ ). The percentage of females in the "engagement in at least one ACP group" (53.3%) was significantly ( $\chi^2 = 12.857, p = .003$ ) higher than the percentage in the "no engagement group" (47.7%). There was a significant difference between the two groups in marital status ( $\chi^2 = 74.568, p < .001$ ). The percentage of African Americans in the "no engagement group" (23.0%) was significantly ( $\chi^2 = 244.452, p < .001$ ) higher than the percentage in the "engagement in at least one ACP group" (7.5%).

A quarter of decedents in the "no engagement group" lived with children, while 20% in the "engagement in at least one ACP group" lived with children; there was a significant difference between the two groups in having resident children ( $\chi^2 = 13.114, p = .005$ ). The percentage of Catholics in the "engagement in at least one ACP group" (28.5%) was significantly ( $\chi^2 = 12.452, p = .014$ ) higher than the percentage in the "no engagement group" (24.6%). The percentage of decedents who had graduated from high school in the "engagement in at least one ACP group" (48.4%) was significantly ( $\chi^2 = 118.868, p < .001$ ) higher than the percentage in the "no engagement group" (34.5%). There were significant differences between the two groups in belonging to the upper 50% net worth ( $\chi^2 = 79.850, p < .001$ ) and having at least one private insurance policy ( $\chi^2 = 113.523, p < .001$ ).

The percentage of decedents who had been diagnosed with cancer as a main illness that led to death in the "engagement in at least one ACP group" (26.7%) was significantly ( $\chi^2 = 33.891, p < .001$ ) higher than the percentage in the "no engagement group" (18.6%). There were significant differences between the two groups in diagnosis with lung disease ( $\chi^2 = 7.772, p = .013$ ), diagnosis with heart disease ( $\chi^2 = 22.620, p < .001$ ), and having pain during the last year ( $\chi^2 = 17.655, p < .001$ ). The percentage of decedents' deaths expected in the "engagement in at least one ACP group" (64.6%) was significantly ( $\chi^2 = 157.084, p < .001$ ) higher than the percentage in the "no engagement group" (45.1%). Simple logistic regression analyses using complex samples were conducted (See Appendix 4.3.)

#### *Multivariable logistic regression*

Multivariable complex samples logistic regression analyses were conducted to determine the predictors associated with engagement in at least one ACP (see Table 4.1.). The model explained between 10.3% (Cox and Snell  $R^2$ ) and 15.7% (Nagelkerke  $R^2$ ) of the variance in the likelihood of engagement in at least one ACP. The model fit was good and it was significant ( $F = 32.162, p < .001$ ).

Significant independent predictors of engagement in at least one ACP were: age, African American, Catholic, high school graduate, college and more graduate, having at least one private insurance policy, cancer as a main illness that led to death, heart disease as a past history, pain during the last year, and expected death. The strongest predictor was African American with an effect size (OR) of .337 (converted OR=2.97), which indicates a medium effect.

Table 4.1. Stage 1: Predictors associated with engagement in at least one advance care compared with no engagement in advance care planning (N=6,001)

Predictor	Reference group	OR	95% CI	
			Lower	Higher
Age	-	1.024*	1.011	1.037
Female	(Male)	1.123	.921	1.371
African American	(Non- African American)	.337*	.257	.443
Catholic	(Non-Catholic)	.653*	.528	.806
Education level				
High school graduate	(Less than high school graduate)	1.719*	1.370	2.157
College and more	(Less than high school graduate)	1.393*	1.026	1.893
Upper 50% net worth	(Lower 50% net worth)	1.243	.998	1.549
Having at least one private insurance policy	(No private insurance policy)	1.476*	1.156	1.885
Cancer as a main illness that lead to death	(Non-cancer)	1.506*	1.160	1.954
Heart disease as a past history	(No history of heart disease)	1.392*	1.173	1.651
Pain during the last year	(No pain)	1.442*	1.196	1.739
Expected death	(Unexpected death)	1.888*	1.586	2.248

Note. Model F = 32.162,  $p < .001$ ,  $R^2 = .103$  (Cox & Snell), .157 (Nagelkerke); \* $p < .05$ ; OR, odds ratio; CI: confidence interval



Being African American was associated with 66% lower odds of engaging in at least one ACP compared to non-African Americans after adjusting for all other variables in the model. There were no significant interactions between predictors. Using the G\*Power (Faul, Erdfelder, Buchner, & Lang, 2007; Faul, Erdfelder, Buchner, & Lang, 2015), post-hoc power analysis was applied to determine the power of this model. After inputting the parameters of the OR of 2.97, the probability of engaging in ACP of .70, a sample size of 6,001, and a two-tailed alpha of .05, the power of this model exceeded .99.

#### 4.2.2. Stage 2

*Are there differences in characteristics associated with engagement in EOL discussions and at least one advance directive (durable power of attorney and/or living will) compared with engagement in EOL discussions only?*

##### *Descriptive statistics and bivariate analysis*

Weighted results were estimated based on the complex sample design. The bivariate analyses were conducted using complex samples. Refer to Appendix 4.4 for unweighted and weighted frequencies and percentages of the predictors. The sample size was 4,194, representing 262,307,106 decedents aged 50 years or older in the complex sample design. Approximately, a quarter of decedents (N=997, 23.8%), representing 53,993,766 decedents (20.6%), had EOL discussions only ("EOL discussions only group") and 3,197 (76.2%) had EOL discussions and at least one formal document of AD ("EOL discussions and at least one AD group"), representing 208,313,340 decedents (79.4%).

The average age at death in the "EOL discussions and at least one AD group" ( $80.5 \pm .28$ ) was significantly ( $t = 295.622, p < .001$ ) greater than in the "EOL discussions only group" ( $75.7 \pm .47$ ). The percentage of females in the "engagement in at least one ACP group" (55%) was significantly ( $\chi^2 = 16.135, p = .004$ ) higher than the percentage in the "no engagement group" (47%). There was a significant difference between the two groups in marital status ( $\chi^2 = 75.807, p < .001$ ). The percentage of African Americans in the "EOL discussions only group" (13.8%) was significantly ( $\chi^2 = 57.864, p < .001$ ) higher than the percentage in the "EOL discussions and at least one AD group" (5.9%). A quarter of decedents in the "EOL discussions only group" lived with children, while 18% in the "EOL discussions and at least one AD group" lived with children; there was a significant difference between the two groups in having resident children ( $\chi^2 = 22.611, p < .001$ ).

The percentage of decedents who had graduated from college and more in the "EOL discussions and at least one AD group" (19%) was significantly ( $\chi^2 = 39.710, p < .001$ ) higher than the percentage in the "EOL discussions only group" (12%). There were significant differences between the two groups in belonging to the upper 50% net worth ( $\chi^2 = 31.272, p < .001$ ) and having at least one private insurance policy ( $\chi^2 = 26.803, p < .001$ ). The percentage of decedents' deaths expected in the "EOL discussions and at least one AD group" (67.4%) was significantly ( $\chi^2 = 46.891, p < .001$ ) higher than the percentage in the "EOL discussions only group" (54.3%). Simple logistic regression analyses using complex samples were conducted (See Appendix 4.5).

### *Multivariable logistic regression*

Multivariable complex samples logistic regression analyses were conducted to determine the predictors associated with engagement in at least one AD among decedents who had EOL discussions (see Table 4.2). Model 1 included predisposing characteristics, enabling resources, and need for health services. Two interaction terms (female\*married and female\*widowed) were added in Model 2 because the two variables of female and marital status were highly correlated with each other. The model fit improved after adding two interaction terms, evidenced by the Nagelkerke pseudo- $R^2$  (.132 to .136). The model explained between 8.7% (Cox and Snell  $R^2$ ) and 13.6% (Nagelkerke  $R^2$ ) of the variance in the likelihood of engagement in at least one AD among decedents who had EOL discussions. The model fit was good and it was significant ( $F = 17.889, p < .001$ ).

Significant independent predictors of engagement in at least one AD among decedents who had EOL discussions were: age, being married, African American, having resident children, high school graduate, college and more graduate, having at least one private insurance policy, and expected death. The strongest predictor was graduating from college and more with an effect size (OR) of 2.12, which indicates a small-to-medium effect. Graduating from college and more had a 2.1 times higher odds of engaging in EOL discussions and at least one AD compared to those who had not graduated from college after adjusting for all other variables in the model. Using the G\*Power (Faul, Erdfelder, Buchner, & Lang, 2007; Faul, Erdfelder, Buchner, & Lang, 2015), post-hoc power analysis was applied to determine the power of this model. After inputting the parameters of the OR of 2.12, the probability of engaging in AD of .76, a sample size of 4,194, and a two-tailed alpha of .05, the power of this model exceeded .99.

Table 4.2. Stage 2: Predictors associated with engagement in at least one advance directive among decedents who had informal discussions (N=4,194)

Predictor	Reference group	Model 1		Model 2	
		OR	95% CI Lower Higher	OR	95% CI Lower Higher
Age	-	1.032*	1.020 1.044	1.031*	1.019 1.044
Female	(Male)	1.090	.834 1.425	.486	.193 1.221
Marital status					
Married	(Separated/divorced, never married)	.697	.482 1.009	.609*	.408 .908
Widowed	(Separated/divorced, never married)	1.426*	1.013 2.006	1.052	.706 1.568
African American	(Non-African American)	.567*	.410 .784	.549*	.400 .753
Having resident children	(No resident children)	.660*	.500 .871	.654*	.495 .865
Education level					
High school graduate	(Less than high school graduate)	1.318*	1.022 1.698	1.319*	1.022 1.703
College and more	(Less than high school graduate)	2.118*	1.335 3.359	2.120*	1.342 3.349
Upper 50% net worth	(Lower 50% net worth)	1.310*	1.000 1.717	1.296	.992 1.692
Having at least one private insurance policy	(No private insurance policy)	1.335*	1.031 1.728	1.332*	1.028 1.726
Expected death	(Unexpected death)	1.665*	1.365 2.031	1.682*	1.375 2.058
Female*Married	(Male* Separated/divorced, never married)			.695	.452 1.068
Female*Widowed	(Male* Separated/divorced, never married)			1.183	.826 1.694
Model Wald F (p)			20.916 (<.001)		17.889 (<.001)
R <sup>2</sup> :Cox & Snell; Nagelkerke			.084, .132		.087, .136

Note. \*  $p < .05$ ; OR, odds ratio; CI: confidence interval

#### 4.2.3. Stage 3a

*Are there differences in characteristics associated with engagement in EOL discussions, durable power of attorney, and living will compared with engagement in EOL discussions and durable power of attorney?*

##### *Descriptive statistics and bivariate analysis*

Bivariate analyses were conducted. Appendix 4.6 provides unweighted and weighted frequencies and percentages of the predictors. Weighted results were estimated based on the complex sample design. The sample size was 2,849 representing 186,178,230 decedents aged 50 years or older in the complex sample design. A total of 752 (26.4%) decedents, representing 46,782,666 decedents (25.1%), engaged in EOL discussions and DPAHC ("EOL discussions and DPAHC group") and 2,097 (73.6%), representing 139,395,564 decedents (74.9%) engaged in EOL discussions, DPAHC, and LW ("all ACP group").

The average age at death in the "all ACP group" ( $81.4 \pm .34$ ) was significantly ( $t = 273.451, p < .001$ ) greater than in the "EOL discussions and DPAHC group" ( $79.1 \pm .59$ ). The percentage of African Americans in the "EOL discussions and DPAHC group" (11.6%) was significantly ( $\chi^2 = 53.885, p < .001$ ) higher than the percentage in the "all ACP group" (3.9%). The percentage of decedents who had graduated from college and more in the "all ACP group" (22%) was significantly ( $\chi^2 = 26.929, p = .001$ ) higher than the percentage in the "EOL discussions and DPAHC group" (13%). There were significant differences between the two groups in belonging to the upper 50% net worth ( $\chi^2 = 35.460, p < .001$ ) and having at least one private insurance policy ( $\chi^2 = 23.041, p$

<.001). Simple logistic regression analyses using complex samples were conducted (See Appendix 4.7).

#### *Multivariable logistic regression*

Multivariable complex samples logistic regression analysis was conducted to determine the predictors associated with engagement in LW among decedents who engaged in EOL discussions and DPAHC (see Table 4.3). The model explained between 4.4% (Cox and Snell  $R^2$ ) and 6.5% (Nagelkerke  $R^2$ ) of the variance in the likelihood of engagement in LW among decedents who engaged in EOL discussions and DPAHC. The model fit was poor and it was significant ( $F = 7.003, p < .001$ ).

Significant independent predictors of engagement in LW among decedents who engaged in EOL discussions and DPAHC were: age, African American, college and more graduate, and belonging to the upper 50% net worth. The strongest predictor was African American with an effect size (OR) of .406 (converted OR=2.46), which indicates a medium effect. Being African American was associated with 59% lower odds of engaging in all ACP compared to non- African Americans after adjusting for all other variables in the model. There were no significant interactions between predictors. Using the G\*Power (Faul, Erdfelder, Buchner, & Lang, 2007; Faul, Erdfelder, Buchner, & Lang, 2015), post-hoc power analysis was applied to determine the power of this model. After inputting the parameters of the OR of 2.46, the probability of engaging in LW of .74, a sample size of 2,849, and a two-tailed alpha of .05, the power of this model exceeded .99.

Table 4.3. Stage 3a: Predictors associated with engagement in living will among decedents who had informal discussions and a durable power of attorney (N=2,849)

Predictor	Reference group	OR	95% CI	
			Lower	Higher
Age	-	1.020*	1.008	1.033
Female	(Male)	1.109	.833	1.477
African American	(Non- African American)	.406*	.269	.614
Education level				
High school graduate	(Less than high school graduate)	1.093	.852	1.403
College and more	(Less than high school graduate)	1.767*	1.147	2.723
Upper 50% net worth	(Lower 50% net worth)	1.431*	1.075	1.906
Having at least one private insurance policy	(No private insurance policy)	1.253	.986	1.593

Note. Model F = 7.003,  $p < .001$ ,  $R^2 = .044$  (Cox & Snell), .065 (Nagelkerke); \*  $p < .05$ ; OR, odds ratio; CI, confidence interval

#### 4.2.4. Stage 3b

*: Are there differences in predictors associated with engagement in EOL discussions, durable power of attorney, and living compared with engagement in EOL discussions and living will?*

#### *Descriptive statistics and bivariate analysis*

Bivariate analyses were conducted using complex samples. Appendix 4.8 provides unweighted and weighted frequencies and percentages of the predictors. Weighted results were estimated based on the complex sample design. The sample size was 2,445 representing 161,530,674 decedents aged 50 years or older. A total of 348 (14.2%) decedents, representing 22,135,110 decedents (13.7%), engaged in EOL discussions and LW ("EOL discussions and LW group") and 2,097 (85.8%), representing 139,395,564 decedents (86.3%), engaged in EOL discussions, DPAHC, and LW ("all ACP group").

The average age at death in the "all ACP group" ( $81.4 \pm .34$ ) was significantly ( $t = 273.306$ ,  $p < .001$ ) greater than in "EOL discussions and LW group" ( $77.7 \pm .83$ ). There was a significant difference between the two groups in marital status ( $\chi^2 = 57.130$ ,  $p < .001$ ). The percentage of decedents who had graduated from college and more in the "all ACP group" (22%) was significantly ( $\chi^2 = 19.268$ ,  $p < .001$ ) higher than the percentage in the "EOL discussions and LW group" (13%). There were significant differences between the two groups in belonging to the upper 50% net worth ( $\chi^2 = 16.562$ ,  $p = .002$ ) and having at least one private insurance policy ( $\chi^2 = 25.530$ ,  $p < .001$ ).

The percentage of decedents who had been diagnosed with lung disease in the "EOL discussions and LW group" (40.4%) was significantly ( $\chi^2 = 20.761$ ,  $p = .002$ ) higher



than the percentage in the "all ACP group" (27.7%). The percentage of decedents' deaths expected in the "all ACP group" (67.7%) was significantly ( $\chi^2 = 11.175, p = .024$ ) higher than the percentage in the "EOL discussions and LW group" (57.9%). Simple logistic regression analyses using complex samples were conducted (Refer to Appendix 4.9).

#### *Multivariable logistic regression*

Multivariable complex samples logistic regression analysis was conducted to determine the predictors associated with engagement in DPAHC among decedents who had EOL discussions and an LW (see Table 4.4). Model 1 included predisposing characteristics, enabling resources, and need for health services. Two interaction terms (female\*married and female\*widowed) were added in Model 2 because the two variables of female and marital status were highly correlated with each other. The model fit improved after adding two interaction terms, evidenced by the Nagelkerke pseudo- $R^2$  (.118 to .124). The model explained between 6.8% (Cox and Snell  $R^2$ ) and 12.4% (Nagelkerke  $R^2$ ) of the variance in the likelihood of engagement in at least one AD among decedents who had EOL discussions. The model fit was good and it was significant ( $F = 5.948, p < .001$ ).

Significant independent predictors of engagement in DPAHC among decedents who had EOL discussions and LW were: female, college and more graduate, belonging to the upper 50% net worth, having at least one private insurance policy, lung disease as a past history, and expected death.

Table 4.4. Stage 3b: Predictors associated with engagement in durable power of attorney for health care among decedents who had informal discussions and living will (N=2,445)

Predictor	Reference group	Model 1			Model 2		
		OR	95% CI Lower	Higher	OR	95% CI Lower	Higher
Age	-	1.011	.991	1.032	1.011	.990	1.032
Female	(Male)	.704	.401	1.236	.309*	.100	.956
Marital status							
Married	(Separated/divorced, never married)	.704	.401	1.236	.546	.275	2.086
Widowed	(Separated/divorced, never married)	2.101*	1.163	3.797	1.450	.808	2.601
Education level							
High school graduate	(Less than high school graduate)	1.280	.797	2.056	1.299	.809	2.088
College and more	(Less than high school graduate)	2.450*	1.300	4.617	2.453*	1.311	4.592
Upper 50% net worth	(Lower 50% net worth)	1.598*	1.126	2.268	1.587*	1.115	2.259
Having at least one private insurance policy	(No private insurance policy)	1.654*	1.136	2.407	1.667*	1.147	2.423
Lung disease as a past history	(No history of lung disease)	.648*	.440	.954	.654*	.449	.954
Expected death	(Unexpected death)	1.524*	1.013	2.292	1.521*	1.012	2.285
Female*Married	(Male* Separated/divorced, never married)				.596	.302	1.173
Female*Widowed	(Male* Separated/divorced, never married)				.993	.604	1.633
Model Wald F (p)			20.916 (<.001)			5.948 (<.001)	
R <sup>2</sup> :Cox & Snell, Nagelkerke			.064, .118			.068, .124	

Note. \*  $p < .05$ ; OR, odds ratio; CI, confidence interval

The strongest predictor was female with an effect size (OR) of .309 (converted OR=3.24), which indicates a medium-to-large effect. Among decedents who engaged in EOL discussions and LW, females had 69% lower odds of engaging in DPAHC compared to males after adjusting for all other variables in the model. Using the G\*Power (Faul, Erdfelder, Buchner, & Lang, 2007; Faul, Erdfelder, Buchner, & Lang, 2015), post-hoc power analysis was applied to determine the power of this model. After inputting the parameters of the OR of 3.24, the probability of engaging in DPAHC of .86, a sample size of 2,445, and a two-tailed alpha of .05, the power of this model exceeded .99.

#### 4.2.5. Summary of research question 1

*What are the predictors associated with the types of engagement in advance care planning?*

Significant predictors associated with the types of engagement in ACP were analyzed by using different comparisons. Table 4.5 included all predictors in multivariable logistic regression. Age was a significant predictor across all stages except stage 3b. For each additional year of age, the likelihood of engaging in EOL discussions and at least one AD increased by 2-3% in stage 1 and 2. Among decedents who engaged in EOL discussions and DPAHC in stage 3a, for each additional year of age, the likelihood of engaging in a LW increased by 2%. However, age was not a significant predictor of engaging in a DPAHC among decedents who engaged in EOL discussions and a LW. Age was significantly associated with the engagement in a LW, but not associated with engagement in a DPAHC.

Table 4.5. Changes of predictors associated with types of engagement in advance care planning

Reference group Comparison group	Stage 1 (N=6,001)		Stage 2 (N=4,194)		Stage 3a (N=2,849)		Stage 3b (N=2,445)	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
No ACP (N=1,807)								
At least one ACP (N=4,194)								
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Age								
Female	1.024*	1.011-1.037	1.031*	1.019-1.044	1.020*	1.008-1.033	1.011	.990-1.032
Male	1.123	.921-1.371	.486	.193-1.221	1.109	.833-1.477	3.09*	.100-.956
Marital status								
Married			.609*	.408-.908			.546	.275-2.086
Widowed			1.052	.706-1.568			1.450	.808-2.601
African American	.337*	.257-.443	.549*	.400-.753	.406*	.269-.614		
Having resident children			.654*	.495-.865				
Catholic	.633*	.528-.806						
Educational level								
High school graduate	1.719*	1.370-2.157	1.319*	1.022-1.703	1.093	.852-1.403	1.299	.809-2.088
College and more	1.393*	1.026-1.893	2.120*	1.342-3.349	1.767*	1.147-2.723	2.453*	1.311-4.592
Upper 50% net worth	1.243	.998-1.549	1.296	.992-1.692	1.431*	1.075-1.906	1.587*	1.115-2.259
Having at least one private insurance policy	1.476*	1.156-1.885	1.332*	1.028-1.726	1.253	.986-1.593	1.667*	1.147-2.423
Cancer as a main illness that lead to death	1.506*	1.160-1.954						
Heart disease as a past history	1.392*	1.173-1.651					.654*	.449-.954
Lung disease as a past history								
Pain during the last year	1.442*	1.196-1.739						
Expected death	1.888*	1.586-2.248	1.682*	1.375-2.058			1.521*	1.012-2.285
Female*Married			.695	.452-1.068			.596	.302-1.173
Female*Widowed			1.183	.826-1.694			.993	.604-1.633
Model Wald F (p)		32.162 (<.001)		17.889 (<.001)		7.003 (<.001)		5.948 (<.001)
R <sup>2</sup> :Cox & Snell, Nagelkerke		.103, .157		.087, .136		.044, .065		.068, .124

Note. \* p<.05; OR, odds ratio; CI, Confidence interval; ACP, advance care planning; AD, advance directive; DPAHC, durable power of attorney for health care; LW, living will

After adjusting for the interaction between gender and marital status, being female was the strongest predictor of engagement in a DPAHC among decedents who engaged in EOL discussions and a LW with a medium-to-large effect in stage 3b. Females had lower odds of engaging in a DPAHC compared to males. Being married was a significant predictor of engagement in at least one AD in stage 2, which indicated that being married was associated with lower odds of engagement in at least one AD compared to being single, separated or divorced among decedents who engaged in EOL discussions. Race was a significant predictor across all stages except stage 3b.

Being African American was the strongest predictor with a medium effect size in stage 1 and stage 3a. African Americans had lower odds of engaging in at least one ACP in stage 1. Among decedents who had EOL discussions in stage 2, African Americans were associated with a 34% lower odds of engaging in at least one AD compared to non-African Americans. Among decedents who engaged in EOL discussions and a DPAHC in stage 3a, the odds of engaging in a LW were significantly lower (59%) among African Americans compared to non-African Americans. However, being African American was not a significant predictor of engaging in a DPAHC among decedents who engaged in EOL discussions and a LW. Being African American was significantly associated with the engagement in a LW, but not associated with engagement in a DPAHC.

Having resident children was a significant predictor of engaging in at least one AD in stage 2. Decedents who lived with children had lower odds of engaging in at least one AD compared to those who did not live with children among decedents who engaged in EOL discussions. Religion was a significant predictor of engaging in at least one ACP

in stage 1. Being Catholic was associated with lower odds of engaging in at least one ACP compared to those who were non-Catholic.

Educational level was a significant predictor across all stages. Also, college graduate and more was the strongest predictor with a small-to-medium effect size in stage 2. College graduate and more was a significant predictor associated with engagement in all types of ACP across all stages compared to those who did not graduate from high school. Higher educational level was associated with higher engagement in ACP. Graduating from high school was associated with engagement in at least one ACP in stage 1 and engagement in at least one AD in stage 2, but was not associated with the types of ADs (stage 3a and stage 3b). This indicated that being a high school graduate was associated with engagement in EOL discussions and at least one AD, while being a college graduate and more was associated with the engagement in both a LW and a DPAHC.

Upper 50% net worth was a significant predictor in stages 3a and 3b, which indicated that the odds of engaging in both a LW and a DPAHC were higher among decedents who belonged to the upper 50% net worth as compared to decedents who belonged to the lower 50% net worth among decedents who engaged in EOL discussions and at least one AD. Among decedents who had EOL discussions and a DPAHC in stage 3a, belonging to the upper 50% net worth were associated with higher odds of engaging in a LW. Among decedents who had EOL discussions and a LW in stage 3b, those who belonged to the upper 50% net worth had higher odds of engaging in a DPAHC.

Having at least one private insurance policy was a significant predictor across all stages except stage 3a, which indicated that the odds of engaging in EOL discussions and

at least one AD, especially engaging in a DPAHC, were higher among decedents who had at least one private insurance policy compared to decedents who did not have any private insurance. Among decedents who engaged in EOL discussions in stage 2, having at least one private insurance policy was associated with higher odds of engaging in at least one AD compared to those who did not have private insurance. Among decedents who engaged in EOL discussions and a LW in stage 3b, the odds of engaging in a DPAHC were significantly higher among decedents who had at least one private insurance policy as compared to decedents who did not have any private insurance.

Cancer as a main illness that led to death, having heart disease, or having pain during the last year were associated with the engagement in at least one ACP in stage 1. Lung disease was associated with 35% lower odds of engaging in a DPAHC among decedents who engaged in EOL discussions and a LW (stage 3b). Expected death was a significant predictor across all stages except stage 3a. As the deaths of decedents were expected, decedents had higher odds of engaging in EOL discussions and engagement in at least one AD. Among decedents who engaged in EOL discussions and a LW in stage 3b, the odds of engaging in a DPAHC were significantly higher among decedents whose deaths were expected compared to those whose deaths were not expected. However, expected death was not a significant predictor of engaging in a LW among decedents who engaged in EOL discussions and a DPAHC. Expected death was significantly associated with the engagement in a DPAHC, but not associated with engagement in a LW.

### 4.3. Research question 2

*Are the types of engagement in advance care planning associated with receiving all possible care to prolong life?*

#### *Descriptive statistics and bivariate analysis*

Bivariate analyses were conducted using complex samples. Refer to Appendix 4.10 for the unweighted and weighted frequencies and percentages of the predictors. Weighted results were estimated based on the complex sample design. The sample size was 2,677 representing 160,050,024 decedents aged 50 years or older in the complex sample design. A total of 629 decedents (23.8%), representing 38,176,824 decedents (23.9%), received all possible care to prolong life ("receiving all possible care group"), and 2,010 (76.2%), representing 121,873,200 decedents (76.1%), did not received all possible care to prolong life ("not receiving all possible care group")

Based on the research questions, the relationship between five types of engagement in ACP (no engagement in ACP, engagement in EOL discussions, engagement in EOL discussions and DPAHC, engagement in EOL discussions and LW, and engagement in EOL discussions, DPAHC, and LW) and binary outcome (whether to receive all possible care to prolong life) was examined. Approximately, 49.6% of decedents in the "not receiving all possible care group" had engaged in all three types of ACP (EOL discussions, DPAHC, and LW), while only 21% in the "receiving all possible care group" had engaged in all three types of ACP. Of decedents who had not engaged in ACP, 278 (13.8%) were in the "not receiving all possible care group" and 224 (35.6%)



were in the "receiving all possible care group." There was a significant difference between these two groups in the types of engagement in ACP ( $\chi^2=217.852, p <.001$ ).

The average age at death in the "not receiving all possible care group" ( $79.7\pm.39$ ) was significantly ( $t= 227.397, p < .001$ ) greater than in the "receiving all possible care group" ( $76.9\pm.61$ ). The percentage of African Americans in the "receiving all possible care group" (19.5%) was significantly ( $\chi^2=82.329, p <.001$ ) higher than the percentage in the "not receiving all possible care group" (6.7%). Eighteen percentage of decedents in the "not receiving all possible care group" lived with children, while 30% in the "receiving all possible care group" lived with children; there was a significant difference between the two groups in having resident children ( $\chi^2=41.572, p <.001$ ). The percentage of decedents who had graduated from college and more in the "not receiving all possible care group" (20.9%) was significantly ( $\chi^2=48.313, p <.001$ ) higher than the percentage in the "receiving all possible care group" (12.2%). There were significant differences between the two groups in belonging to the upper 50% net worth ( $\chi^2=38.509, p <.001$ ) and having at least one private insurance policy ( $\chi^2=51.760, p <.001$ ).

The percentage of decedents who had pain during the last year in the "receiving all possible care group" (71.2%) was significantly ( $\chi^2=16.572, p =.006$ ) higher than the percentage in the "not receiving all possible care group" (61.8%). The percentage of decedents' deaths expected in the "not receiving all possible care group" (70%) was significantly ( $\chi^2 =20.604, p =.001$ ) higher than the percentage in the "receiving all possible care group" (60%). Refer to Appendix 4.11 for the simple logistic regression analyses using complex samples that were conducted.

### *Multivariable logistic regression*

Multivariable complex samples logistic regression analysis was conducted to determine the predictors of receiving all possible care to prolong life (see Table 4.6). Model 1 included predisposing characteristics, enabling resources, and the need for health services. Model 2 demonstrated the effect of engagement in ACP on receiving all possible care to prolong life after adjusting for predisposing characteristics, enabling resources, and the need for health services. The model fit improved after adding engagement in ACP, evidenced by the Nagelkerke pseudo- $R^2$  (.114 to .182). The model explained between 12.1% (Cox and Snell  $R^2$ ) and 18.2% (Nagelkerke  $R^2$ ) of the variance in the likelihood of receiving all possible care to prolong life. The model fit was good and it was significant ( $F = 18.251, p < .001$ ).

Among four variables regarding the types of engagement in ACP, the strongest predictor was engagement in EOL discussions, DPAHC, and LW with an effect size (OR) of .231 (converted OR 4.33), which indicates a large effect. Using the G\*Power (Faul, Erdfelder, Buchner, & Lang, 2007; Faul, Erdfelder, Buchner, & Lang, 2015), post-hoc power analysis was applied to determine the power of this model. After inputting the parameters of the OR of 4.33, the probability of receiving all possible care of .23, a sample size of 2,677, and a two-tailed alpha of .05, the power of this model exceeded .99.

Table 4.6. Predictors of receiving all possible care to prolong life (N=2,677)

Predictor	Reference group		Model 1		Model 2	
	OR	95% CI	OR	95% CI	OR	95% CI
Age	.982*	.969-.996	.988	.974-1.002		
Female	.976	.735-1.296	.989	.728-1.342		
African American	2.502*	1.699-3.686	1.926*	1.266-2.929		
Having resident children	1.819*	1.385-2.388	1.720*	1.305-2.267		
Educational level						
High school graduate	.615*	.459-.825	.688*	.498-.951		
College and more	.523*	.320-.854	.633	.392-1.024		
Having at least one private insurance policy	.677*	.516-.887	.768	.577-1.023		
Expected death	.677*	.518-.885	.725*	.544-.966		
Types of engagement in ACP						
Discussion only			.712	.468-1.084		
Discussion + DPAHC			.537*	.379-.761		
Discussion + LW			.347*	.177-.681		
Discussion + DPAHC + LW			.231*	.156-.343		
Model Wald F (p)		15.559 (<.001)		18.251 (<.001)		
R <sup>2</sup> : Cox & Snell, Nagelkerke		.076, .114		.121, .182		

Note. \*  $p < .05$ ; OR, odds ratio; CI, confidence interval; ACP, advance care planning; DPAHC, durable power of attorney for health care; LW, living will

Engagement in EOL discussions, DPAHC, and LW was associated with a 77% lower odds of receiving all possible care compared to decedents who did not engage in any ACP after adjusting for age, gender, race, having resident children, educational level, having at least one private insurance policy, and expected death. Engagement in EOL discussions only was not a significant independent predictor of receiving all possible care.

Engagement in EOL discussions and DPAHC was associated with 46% lower odds of receiving all possible care compared to decedents who did not engage in any ACP after adjusting for age, gender, race, having resident children, educational level, having at least one private insurance policy, and expected death. Engagement in EOL discussions and LW was associated with a 65% lower odds of receiving all possible care compared to decedents who did not engage in any ACP after adjusting for age, gender, race, having resident children, educational level, having at least one private insurance policy, and expected death. Other significant predictors of receiving all possible care included being African American, having resident children, being a high school graduate and having an expected death.

#### 4.3.1. Summary of research question 2

*Are the types of engagement in advance care planning associated with receiving all possible care to prolong life?*

In multivariable analysis, engagement in EOL discussions only was not a significant predictor of receiving all possible care to prolong life, while engagement in EOL discussions combined with DPAHC and/or LW was associated with lower odds of

receiving all possible care. Engagement in all ACP (EOL discussions, DPAHC, and LW) was the strongest predictor of receiving all possible care to prolong life with a large effect size. Decedents who engaged in LW had lower odds of receiving all possible care than those who engaged in DPAHC. Engaging more types of ACP was associated with lower odds of receiving all possible care to prolong life.

#### 4.4. Research question 3

*Are the types of engagement in advance care planning associated with receiving comfort care?*

##### *Descriptive statistics and bivariate analysis*

Refer to Appendix 4.12 for a description of the unweighted and weighted frequencies and percentages of the predictors. Weighted results were estimated based on the complex sample design. Sample characteristics were described based on unweighted results, but the bivariate analyses were conducted using complex samples. The sample size was 2,677 representing 160,050,024 decedents aged 50 years or older in the complex sample design. A total of 183 decedents (6.9%), representing 11,297,112 decedents (7.0%), did not receive comfort care ("not receiving comfort care group"), and 2,468 (93.1%), representing 149,990,784 decedents (93.0%), received comfort care ("receiving comfort care group"). The average age at death in the "receiving comfort care group" ( $79.3 \pm .40$ ) was significantly ( $t = 232.048, p < .001$ ) greater than in the "not receiving all possible care group" ( $76.3 \pm 1.05$ ). There was a significant difference between the two groups in the types of engagement in ACP ( $\chi^2 = 104.064, p < .001$ ). The percentage of

females in the "receiving comfort care group" (55.9%) was significantly ( $\chi^2=21.559, p=.001$ ) higher than the percentage in the "not receiving all possible care group" (37.6%).

There was a significant difference between the two groups in marital status ( $\chi^2=12.194, p=.039$ ) and in having at least one private insurance policy ( $\chi^2=14.205, p=.005$ ). The percentage of decedents' deaths expected in the "receiving comfort care group" (70%) was significantly ( $\chi^2=34.201, p<.001$ ) higher than the percentage in the "not receiving all possible care group" (47%). Simple logistic regression analyses using complex samples were conducted (see Appendix 4.13).

#### *Multivariable logistic regression*

Multivariable complex samples logistic regression analyses were conducted to determine the predictors of receiving comfort care. Refer to Table 4.7 for description of the log-odds of the multivariable complex samples logistic regression. Model 1 included predisposing characteristics, enabling resources, and the need for health services. Model 2 demonstrated the effect of engagement in ACP on receiving comfort care after adjusting for predisposing characteristics, enabling resources, and the need for health services. The model fit improved after adding engagement in ACP, evidenced by the Nagelkerke pseudo- $R^2$  (.078 to .147). The model explained between 5.8% (Cox and Snell  $R^2$ ) and 14.7% (Nagelkerke  $R^2$ ) of the variance in the likelihood of receiving comfort care. The model fit was good and it was significant ( $F = 10.402, p < .001$ ).

Table 4.7. Predictors of receiving comfort care (N=2,677)

Predictor	Reference group	Model 1		Model 2	
		OR	95% CI	OR	95% CI
Age	-	1.014	.988-1.041	1.008	.980-1.036
Female	(Male)	2.109*	1.313-3.387	2.111*	1.300-3.426
Having at least one private insurance policy	(No private insurance policy)	1.971*	1.256-3.092	1.546	.957-2.496
Expected death	(Unexpected death)	2.561*	1.666-3.937	2.264*	1.462-3.504
Types of engagement in ACP					
Discussion only	(No advance care planning)			1.852*	1.027-3.337
Discussion + DPAHC	(No advance care planning)			3.104*	1.613-5.975
Discussion + LW	(No advance care planning)			3.837*	1.162-12.666
Discussion + DPAHC + LW	(No advance care planning)			6.066*	3.150-11.680
Model Wald F (p)			8.413 (<.001)		10.402 (<.001)
Intercept Wald F (p)			2.003 (.163)		8.911 (.004)
R <sup>2</sup> :Cox & Snell, Nagelkerke			.031, .078		.058, .147

Note. \*  $p < .05$ ; OR, odds ratio; CI, confidence interval; ACP, advance care planning; DPAHC, durable power of attorney for health care; LW, living will

Among four variables regarding the types of engagement in ACP, the strongest predictor was engagement in EOL discussions, DPAHC, and LW with an effect size (OR) of 6.066, which indicates a large effect. Using the G\*Power (Faul, Erdfelder, Buchner, & Lang, 2007; Faul, Erdfelder, Buchner, & Lang, 2015), post-hoc power analysis was applied to determine the power of this model. After inputting the parameters of the OR of 6.066, the probability of receiving comfort care of .93, a sample size of 2,677, and a two-tailed alpha of .05, the power of this model exceeded .99.

Engagement in EOL discussions, DPAHC and LW was associated with a 6 times higher odds of receiving comfort care compared to decedents who did not engage in ACP after adjusting for age, gender, having resident children, and expected death. Engagement in EOL discussions only was a significant independent predictor of receiving comfort care after adjusting for age, gender, having resident children, and expected death.

Decedents who engaged in EOL discussions and DPAHC were 3.1 times as likely as those who did not engage in ACP to receive comfort care after adjusting for age, gender, having resident children, and expected death. Engagement in EOL discussions and LW was associated with 3.8 times higher odds of receiving comfort care compared to decedents who did not engage in ACP after adjusting age, gender, having resident children, and expected death. Other significant predictors of receiving comfort care were being female and having an expected death.

#### 4.4.1. Summary of research question 3

*Are the types of engagement in advance care planning associated with receiving comfort care?*



In multivariable analysis, all four types of engagement in ACP were significant predictors associated with receiving comfort care. Engagement in all ACP (EOL discussions, DPAHC, and LW) was the most powerful predictor for receiving comfort care with a large effect size. Decedents who engage in LW showed higher odds of receiving comfort care than those who engage in DPAHC among decedents who had EOL discussions. In conclusion, all types of engagement in ACP had an effect on receiving comfort care. Engaging more types of ACP was associated with higher odds of receiving comfort care.

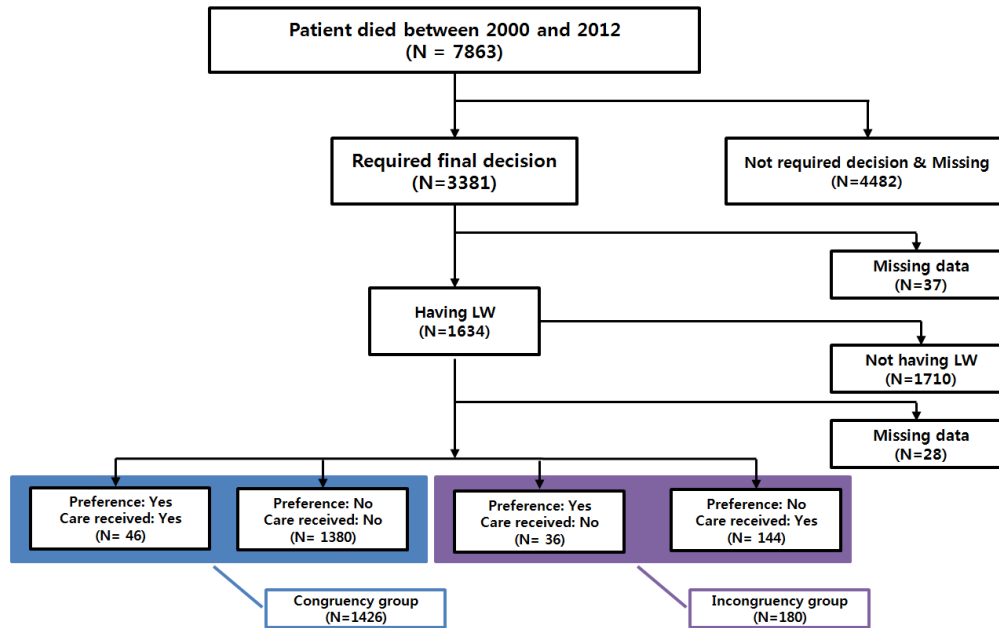
#### 4.5. Research question 4

*Among decedents who have a living will, are engagement in end-of-life discussions and engagement in durable power of attorney for health care associated with congruency between decedents' preferences for end-of-life care and the care they received?*

##### 4.5.1. Research question 4a

*Among decedents who have a living will, are engagement in end-of-life discussions and engagement in durable power of attorney for health care associated with congruency between decedents' preferences for all possible care to prolong life and the care they received before their deaths?*

Figure 4.3. Congruency between decedents' preferences for all possible care to prolong life and the care they received before their deaths



### *Descriptive statistics and bivariate analysis*

Weighted results were estimated based on the complex sample design. The bivariate analyses were conducted using complex samples. Refer to Appendix 4.14 for the unweighted and weighted frequencies and percentages of the predictors. The sample size was 1,634, representing 104,672,454 decedents aged 50 years or older in the complex sample design. A total of 180 decedents (11.2%), representing 12,712,776 decedents (12.1%), did not receive care consistent with their preferences for all possible care to prolong life ("incongruity group"), and 1,426 (88.8%), representing 91,959,678 decedents (87.9%), received care consistent with their preferences for all possible care to prolong life ("congruency group") (see Figure 4.3). Three quarters of decedents in the

"incongruency group" had engaged in EOL discussions, while 80.5% in the "congruency group" had engaged in EOL discussions. Decedents who had engaged in DPAHC were 155 (86.1%) in the "incongruency group" and 1,249 (88.5%) in the "congruency group."

The average age at death in the "congruency group" ( $80.9 \pm .40$ ) was significantly ( $t = 230.249, p < .001$ ) greater than in "incongruency group" ( $80.7 \pm .94$ ). A quarter of decedents in the "incongruency group" lived with children, while 15% in the "congruency group" lived with children; there was a significant difference between the two groups in having resident children ( $\chi^2 = 11.149, p = .019$ ). There were also significant differences between the two groups in belonging to the upper 50% net worth ( $\chi^2 = 6.981, p = .033$ ) and having at least one private insurance policy ( $\chi^2 = 6.531, p = .022$ ). Simple logistic regression analyses using complex samples were conducted (see Appendix 4.15).

#### *Multivariable logistic regression*

Multivariable complex samples logistic regression analyses were conducted to determine the predictors associated with congruency between decedents' preferences for all possible care and the care they received (see Table 4.8). Model 1 included predisposing characteristics, enabling resources, and the need for health services. Model 2 demonstrated the effect of engagement in DPAHC on receiving care consistent with decedents' preferences for all possible care to prolong life after adjusting for predisposing characteristics, enabling resources, and the need for health services. Model 3 demonstrated the effect of engagement in EOL discussions on receiving care consistent with decedents' preferences for all possible care to prolong life. Model 4 included the effect of engagement in both DPAHC and EOL discussions on receiving care consistent

with decedents' preferences for all possible care to prolong life. The model fit improved after adding engagement in DPAHC and EOL discussions, evidenced by the Nagelkerke pseudo- $R^2$  (.021 to .027).

The model explained between 1.4% (Cox and Snell  $R^2$ ) and 2.7% (Nagelkerke  $R^2$ ) of the variance in the likelihood of receiving care consistent with decedents' preferences for all possible care to prolong life. The model fit was poor and it was not significant ( $F = 2.129$ ,  $p = .054$ ). Engagement in EOL discussions was only one significant independent predictor of receiving care consistent with decedents' preferences for all possible care to prolong life after adjusting for age, gender, race, educational level, and private insurance policy. Effect size (OR) was 1.479, which indicates a small effect. Using the G\*Power (Faul, Erdfelder, Buchner, & Lang, 2007; Faul, Erdfelder, Buchner, & Lang, 2015), post-hoc power analysis was applied to determine the power of this model. After inputting the parameters of the OR of 1.479, the probability of receiving care consistent with decedents' preferences for all possible care of .89, a sample size of 1,634, and a two-tailed alpha of .05, the power of this model exceeded .99.

#### 4.5.2. Research question 4b

*Among decedents who have a living will, are engagement in end-of-life discussions and engagement in durable power of attorney for health care associated with congruency between decedents' preferences for comfort care and the care they received before their deaths?*

Table 4.8. Predictors of receiving care consistent with their preferences for all possible care to prolong life (N=1,634)

Predictor	Reference group	Model 1		Model 2		Model 3		Model 4	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Age	-	1.000	.977-1.024	1.002	.977-1.024	1.002	.979-1.027	1.002	.979-1.026
Female	(Male)	.982	.574-1.677	.972	.570-1.658	.975	.571-1.666	.963	.566-1.641
African American	(Non-African American)	.695	.346-1.396	.700	.350-1.402	.683	.339-1.378	.688	.343-1.382
Educational level									
High school graduate	(Less than high school graduate)	1.311	.800-2.151	1.298	.795-2.118	1.350	.831-2.192	1.337	.827-2.163
College and more	(Less than high school graduate)	2.023	.927-4.415	1.986	.901-4.380	2.081	.941-4.598	2.040	.913-4.558
Having at least one private insurance policy	(No private insurance policy)	1.373	.962-1.961	1.348	.953-1.905	1.348	.939-1.934	1.323	.931-1.881
DPAHC	(No DPAHC)			1.295	.690-2.431			1.312	.703-2.448
Discussion	(No discussion)					1.451	.981-2.147	1.479*	1.006-2.174
Model Wald F (p)		1.730 (.136)		1.587 (.165)		2.147 (.059)		2.129 (.054)	
Intercept Wald F (p)		4.208 (.045)		4.111 (.045)		2.964 (.091)		2.813 (.100)	
R <sup>2</sup> :Cox & Snell, Nagelkerke		.011, .021		.012, .023		.013, .026		.014, .027	

Note. \*  $p < .05$ ; OR, odds ratio; CI, Confidence interval; DPAHC, durable power of attorney for health care

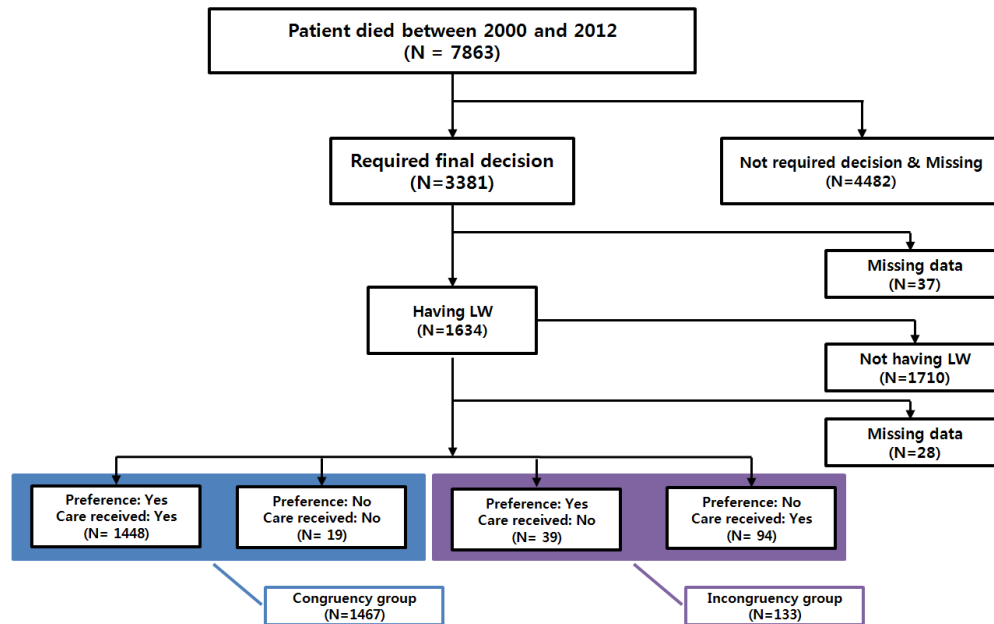
### *Descriptive statistics and bivariate analysis*

Bivariate analyses were conducted using complex samples. Unweighted and weighted frequencies and percentages of the predictors were determined (Refer to Appendix 4.16). Weighted results were estimated based on the complex sample design. The sample size was 1,634 representing 104,672,454 decedents aged 50 years or older in the complex sample design. A total of 133 decedents (8.3%), representing 8,720,874 decedents (8.4%), did not receive care consistent with their preferences for comfort care ("incongruency group"), and 1,467 (91.7%), representing 95,537,166 decedents (91.6%), received care consistent with their preferences for all possible care ("congruency group") (Figure 4.4).

Three-quarters of decedents had discussed EOL care with others in the "incongruency group," and 80.6% had discussions in the "congruency group." Eighty-six percent of decedents in the "incongruency group" engaged in DPAHC, while 89% in the "congruency group," there was a significant difference between the two groups in engagement in DPAHC ( $\chi^2=7.797, p=.033$ ). The average age at death in the "congruency group" ( $81.2\pm.40$ ) was significantly ( $t=221.776, p<.001$ ) greater than in "incongruency group" ( $77.6\pm1.38$ ).

The percentage of African Americans in the "incongruency group" (7.0%) was significantly ( $\chi^2=3.646, p=.019$ ) higher than the percentage in the "congruency group" (3.5%). The percentage of decedents' deaths expected in the "congruency group" (71.2%) was significantly ( $\chi^2=18.814, p<.001$ ) higher than the percentage in the "incongruency group" (52.1%). Simple logistic regression analyses using complex samples were conducted (Refer to Appendix 4.17).

Figure 4.4. Receiving care consistent with decedents' preferences for comfort care



### *Multivariable logistic regression*

Multivariable complex samples logistic regression analyses were conducted to determine the predictors associated with congruency between decedents' preferences for comfort care and the care they received. Refer to Table 4.9 for the log-odds of the multivariable complex samples logistic regression.

Model 1 included predisposing characteristics, enabling resources, and the need for health services. Model 2 demonstrated effect of engagement in DPAHC on receiving care consistent with decedents' preferences for comfort care after adjusting for predisposing characteristics, enabling resources, and the need for health services. Model 3 included the effect of engagement in EOL discussions on receiving care consistent with decedents' preferences for comfort care. Model 4 demonstrated the effect of engagement in both DPAHC and EOL discussions on receiving care consistent with decedents' preferences for comfort care.

Table 4.9. Predictors of receiving care consistent with their preferences for comfort care (N=1,634)

Predictor	Reference group	Model 1		Model 2		Model 3		Model 4	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Age	-	1.027	.999-1.057	1.031	.999-1.063	1.032*	1.002-1.064	1.034*	1.004-1.065
Female	(Male)	1.187	.691-2.036	1.107	.650-1.885	1.189	.688-2.057	1.108	.644-1.906
Catholic	(Non-Catholic)	1.478	.827-2.640	1.496	.824-2.719	1.525	.859-2.706	1.559	.865-2.811
Expected death	(Unexpected death)	2.182*	1.473-3.233	2.011*	1.330-3.043	2.168*	1.464-3.210	1.984*	1.314-2.997
Participation of patient	(No participation of patient)	.967	.571-1.637	.925	.545-1.571	.934	.540-1.615	.888	.514-1.533
DPAHC	(No DPAHC)			1.945	.991-3.821			2.024*	1.034-3.959
Informal discussion	(No informal discussion)					1.577	.866-2.871	1.718	.932-3.164
Model Wald F (p)		4.011 (.004)		3.671 (.005)		3.255 (.010)		3.281 (.007)	
Intercept Wald F (p)		.007 (.935)		.024 (.879)		.043 (.836)		.279 (.600)	
R <sup>2</sup> :Cox & Snell, Nagelkerke		.023, .052		.026, .061		.025, .058		.030, .069	

Note. \*  $p < .05$ ; OR, odds ratio; CI, Confidence interval; DPAHC, durable power of attorney for health care



Model 1 included predisposing characteristics, enabling resources, and the need for health services. Model 2 demonstrated effect of engagement in DPAHC on receiving care consistent with decedents' preferences for comfort care after adjusting for predisposing characteristics, enabling resources, and the need for health services. Model 3 included the effect of engagement in EOL discussions on receiving care consistent with decedents' preferences for comfort care. Model 4 demonstrated the effect of engagement in both DPAHC and EOL discussions on receiving care consistent with decedents' preferences for comfort care.

The model fit improved after adding engagement in DPAHC and EOL discussions, evidenced by the Nagelkerke pseudo- $R^2$  (.052 to .069). The model explained between 3% (Cox and Snell  $R^2$ ) and 6.9% (Nagelkerke  $R^2$ ) of the variance in the likelihood of receiving care consistent with decedents' preferences for comfort care. The model fit was poor and it was significant ( $F = 3.281, p=.007$ ). Engagement in DPAHC was a significant independent predictor of receiving care consistent with their preferences for comfort care after adjusting for age, gender, religion, expected death, and participation of patient. Effect size (OR) was 2.024, which indicates a small-medium effect. The odds of receiving care consistent with their preferences for comfort care were 2 times higher among decedents who engage in DPAHC compared to decedents who did not engaged in DPAHC. Engagement in EOL discussions tended to be associated with higher odds of receiving care consistent with their preferences for comfort care. Other significant predictors of receiving comfort care include age and expected death. Using the G\*Power (Faul, Erdfelder, Buchner, & Lang, 2007; Faul, Erdfelder, Buchner, & Lang, 2015), post-hoc power analysis was applied to get the power of this model. After

inputting the parameters of the OR of 2.024 the probability of receiving care consistent with decedents' preferences for all possible care of .92, a sample size of 1,634, and a two-tailed alpha of .05, the power of this model exceeded .99.

#### 4.5.3. Summary of research question 4

*Among decedents who have a living will, are engagement in end-of-life discussions and engagement in durable power of attorney for health care associated with congruency between decedents' preferences for end-of-life care and the care they received?*

Among decedents who had a LW, engagement in EOL discussions was a significant predictor of receiving care consistent with decedents' preferences for all possible care. Engagement in a DPAHC was a significant independent predictor of receiving care consistent with their preferences for comfort care, but engagement in EOL discussions was not. Engagement in EOL discussions without adding engagement in DPAHC (Model 3) was not a significant predictor of receiving care consistent with decedents' preferences for all possible care, but engagement in EOL discussions after adding engagement in DPAHC (Model 4) was a significant predictor (see Table 4.8). Engagement in DPAHC without adding engagement in EOL discussions (Model 3) was not a significant predictor of receiving care consistent with their preferences for comfort care, but engagement in DPAHC after adding engagement in EOL discussions (Model 4) was a significant predictor (see Table 4.9). The odds of engagement in EOL discussions and engagement in DPAHC in model 2 and 3 were increased in the final model (see Table 4.8 and 4.9).

In conclusion, engagement in EOL discussions was associated with receiving care consistent with decedents' preferences for all possible care, while engagement in DPAHC was associated with receiving care consistent with their preferences for comfort care. The engagement in EOL discussions with DPAHC had a stronger influence on receiving care consistent with their preferences for all possible care than engagement in EOL discussions without DPAHC. Similarly, the engagement in DPAHC with EOL discussions had a stronger influence on receiving care consistent with their preferences for comfort care than engagement in DPAHC without EOL discussions.

## Chapter 5: DISCUSSION

This study examined what predictors influenced engagement in EOL discussions as a component of ACP and determined the effect of having EOL discussions on patients' EOL care. The specific purposes of the study were; 1) to explore predictors influencing engagement in ACP; 2) to examine the association of the types of engagement in ACP with receiving EOL care; and 3) to explore the effect of EOL discussions and DPAHC on congruency between patients' preferences for care and EOL care among decedents who had a LW. This chapter includes a review of the findings of the current study based on the theoretical framework and discusses how the findings support the current science related to ACP and advances the science. Study limitations as well as recommendations for HCPs are also described.

### 5.1. Engagement in advance care planning

Since the PSDA (1990) encouraged the use of ADs and the IOM report stressed the importance of ACP (IOM, 1997), engagement in ACP has steadily increased. ACP includes the entire process of planning and includes discussions of EOL care preferences with others (e.g., family members, friends) and the completion of AD documents. In the current study, 48.7% of decedents had a LW, 61.0% had a DPAHC, and 60.0% had EOL discussions with others. These percentages were similar to earlier studies (Carr & Khodyakov, 2007; McCarthy et al., 2008) which examined the engagement in ACP among community-dwelling adults aged 64 or older.

The percentages were higher than those of studies that were conducted among the general population, including young adults aged 18-64 (Carr, 2012a; Kelly et al., 2013; Moorman & Inoue, 2013; Rao et al., 2014). This may reflect differences in the age of study participants in those studies. The percentages of engagement in ACP in this study were also higher than those of studies that were conducted among patients who were admitted to a hospital or ICU (Becker et al., 2007; Halpern et al., 2011; Kumar et al., 2010; Torke et al., 2014; Van Scoy et al., 2014). Previous studies found a negative relationship between engagement in ACP and hospitalization, in-hospital deaths, and ICU deaths (Bischoff et al., 2013; Nicholas et al., 2011; Silveira et al., 2014; Teno et al., 2007). Individuals who are engaged in ACP may be less likely to be admitted to the hospital or ICU; therefore, the rates of engagement in ACP for those admitted to a hospital may be less than those who are not admitted to a hospital or ICU. Patients admitted to the hospital or ICU may have had a sudden, unexpected change in health, thus they may be unprepared, have little time to think about ACP, and may lack decision-making capacity. The percentages of engagement in ACP in the current study were lower than in two studies in which patients were admitted to assisted living facilities (Hirschman et al., 2012) and were diagnosed with advanced Parkinson's disease (Kwak et al., 2014). The individuals in those two studies may have been motivated to engage in ACP or systems may have been in place to encourage and/or assist with ACP.

In an effort to examine the role of EOL discussions at the EOL this investigation focused on five types of engagement, which account for 76.4% of the decedents who died between 2000 and 2012. Twenty-three percent of decedents had not engaged in ACP, 12.7% had engaged in EOL discussions, 9.6% had engaged in EOL discussions and

DPAHC, 4.4% had engaged in EOL discussions and LW, and 26.7% had all ACP (EOL discussions, LW, and DPAHC). Even though EOL discussions of individuals' preferences for EOL care are a key component of ACP, few researchers have focused on EOL discussions, in combination with AD documents. This is the first known study to use five types of engagement in ACP, specifically focusing on EOL discussions. The current findings provide important information about the proportion of the specific ACP types and will contribute to developing strategies for improving engagement in ACP.

## 5.2. Research question 1

*What are the characteristics associated with the types of engagement in advance care planning?*

In the current study, several predictors were explored in relationship to the types of engagement in ACP, including patient age, gender, marital status, race, religion, resident children, educational level, net worth, private health insurance policy, the main illness, past history, pain, and expected death.

### 5.2.1. Age

Advancing age was associated with a greater likelihood of engaging in ACP. For each additional year of age, the likelihood of engaging in EOL discussions and at least one AD increased by 2-3%. This finding is consistent with previous findings that age is an important predictor of engaging in ACP and the odds of engaging in ACP increase with age (Carr, 2012a; Gerst & Burr, 2008; Moorman & Inoue, 2013; Rao et al., 2014). Older adults tend to be more interested in EOL issues than are young adults.

It is interesting that age was associated with engagement in LW, but not engagement in DPAHC among decedents who had EOL discussions. This suggests that it was important to individuals to document their preferences in a LW along with having a discussion about their EOL preferences with others. They may not have felt that a DPAHC was needed.

#### 5.2.2. Gender and marital status

Previous research has shown that there are conflicting findings regarding the relationship of gender with engagement in ACP. In this study, females were less likely to engage in DPAHC among those who engaged in EOL discussions and LW. This finding is contrary that of Kumar and colleagues (2010), who found there were no significant differences in the completion rates of ADs between men and women, and two studies indicating that females were more likely to complete ADs compared to males (Huang et al., 2016; Rao et al., 2014).

In this study, being female was not a significant predictor of engaging in DPAHC among decedents who engaged in EOL discussions and a LW before adjusting for interaction between gender and marital status. However, after adjusting for interactions, being female was a significant predictor. In bivariate analysis, two-thirds of females were widowed, while a quarter of the male were widowed. Females who have had a spouse die may have less opportunity to engage in DPAHC because many patients designate spouses as their DPAHC (Trarieux-Signol et al., 2014).

Differences in previous findings and the current study may be due to whether marital status was adjusted for outcomes. Kumar and colleagues (2010) did a bivariate

analysis to examine the relationship of gender with engagement in AD without controlling for marital status. Rao and colleagues (2014) also did not adjust for marital status as a control variable when they examined the likelihood of completing AD among females and males. Another possible reason for conflicting findings is that previous studies did not include EOL discussions in their model when they examined the association between female and engagement in AD. Huang and colleagues (2016) conducted a multivariable logistic regression after adjusting for age and marital status, but there was no specific information about EOL discussions.

In this study, being female was a significant predictor of engaging in DPAHC among decedents who engaged in EOL discussions and had a LW. This suggests that when females have discussions about EOL treatment preferences with family members or others and have a LW, they may not feel that designating a DPAHC is necessary.

In this study, being married was associated with lower odds of engaging in at least one AD compared to those who did not marry, were separated, or divorced among decedents who had EOL discussions with others. This finding is not consistent with other reports that married persons had higher odds of engaging in DPAHC compared to formerly married and unmarried persons after controlling for age and gender (Traieux-Signol et al., 2014). This difference may be due to different patient characteristics. The target population of the study conducted by Traieux-Signol and colleagues (2014) were patients with hematological malignancies who may have been more motivated to complete a DPAHC document.

This finding also not consistent with the finding that married persons had higher odds of engaging in EOL discussions, which increase the likelihood of engaging in AD



(Carr & Khodyakov, 2007). Differences in age and marital status may influence the conflicting findings. The participants in the study conducted by Carr and Khodyakov (2007) were adults aged 64-65, while the average age of this study was 80 years old. Approximately, 80% of participants were married in the study of Carr and Khodyakov (2007), while 40% of decedents were married in this study. Married decedents were significantly younger than widowed decedents in bivariate analysis even though there were no significant interaction terms of age and marital status in the multivariable model in this study. It might be assumed that having EOL discussions among young married adults is positively associated with engagement in ADs, while older married adults had a lower engagement in ADs if they had EOL discussions.

### 5.2.3. Race

There were differences in engagement in ACP between African Americans and non-African Americans. Compared to non-African Americans, African Americans had 64% lower odds of engaging in at least one ACP, 34% lower odds of engaging in at least one AD among decedents who had EOL discussions with others, and 59% lower odds of engaging in LW among decedents who had at least one AD. The findings of the current study were similar to previous findings that that being African American was associated with lower odds of completing ADs and engaging in discussions about EOL treatment preferences with others (Gerst & Burr, 2008; Hirschman et al., 2012; Huang et al., 2016; Rao et al., 2014).

Interestingly, African Americans had lower odds of engaging in LW among decedents who had EOL discussions with others and had a DPAHC, yet there was no

association between African Americans with engagement in DPAHC among decedents who had EOL discussions and LW. Bullock (2011) reported that African Americans preferred their family members to be their advocate when they met physicians and were fearful that they may not receive sufficient EOL care even though they wanted to receive it. These cultural beliefs may be an obstacle to improving engagement in ACP among African Americans. Educational intervention studies may help to engage African Americans in ACP.

#### 5.2.4. Having resident children

In the current study, decedents who lived with children had lower odds of engaging in at least one AD compared to those who did not live with children among decedents who had EOL discussions. This finding is consistent with the findings of Nilsson and colleagues (2007), who concluded that advanced cancer patients with younger, dependent, children (i.e., less than 18 years) had lower odds of engaging in ACP. By contrast, a few studies reported that having children and the number of children were associated with higher engagement in EOL discussions, DPAHC, and LW (Carr & Khodyakov, 2007; Greenberg et al., 2009; Van Scoy et al., 2014).

It is difficult to compare studies that refer to children. Studies use different terms including "living children patient had" (Carr & Khodyakov, 2007), "having children" (Greenberg, Weiner, & Greenberg, 2009), or "number of children" (Van Scoy et al., 2014). Researchers do not clearly define what they mean by "children." Future studies should consider the characteristics of children and the relationship of having children with engagement in ACP. One possible reason for conflicting findings is that previous

studies did not include EOL discussions in their model when they examined the association between having children and engagement in AD. When decedents have discussions about EOL treatment preferences with family members or others, they may not feel that engagement in AD is necessary. Another possible reason is that multiple children may have different opinions regarding EOL treatment preferences of decedents and who should be responsible for DPAHC, which may hinder the completion of ADs.

#### 5.2.5. Religion

The findings in this study indicated that Catholics had lower odds of engaging in at least one ACP compared to those who were non-Catholic. These findings were similar to those of Huang and colleagues (2016), who found Catholic religious affiliation was negatively associated with engagement in ADs. The findings were also supported by past research, which has found that Catholics also had lower odds of engaging in ACP than were persons who were Jewish or who had no religion (Black & Reynolds, 2008; Carr & Khodyakov, 2007; Garrido et al., 2013).

In this study, religion was divided into two groups: Catholic and non-Catholic. Most non-Catholic respondents were Protestant. The reason that Protestant was included in non-Catholic groups was that only being Catholic was significantly associated with engagement in ACP in bivariate analysis when religion was divided into three groups: Catholic, Protestant, and Jewish/other/no religion. Researchers have reported that conservative Protestants (e.g., Baptists, Evangelicals) had lower odds of engaging in ACP compared to those who were Jewish, or indicated no religion (Black & Reynolds., 2008; Carr & Khodyakov, 2007). These findings were not consistent with the findings of the

current study. According to Huang and colleagues (2016), participants who reported Evangelical religious affiliations had lower odds of engaging in AD than did those who were mainline Protestants among 2,154 American adults aged 50 and older. The specific Protestant denomination may influence engagement in ACP.

#### 5.2.6. Education level

The finding of the current study indicated that being a high school graduate was associated with engagement in at least one ACP. The findings of this study were consistent with past research, which has found that adults who graduated from high school had higher odds of engaging in AD compared to those who did not graduate from high school (Hirschman et al., 2012; Rao et al., 2014; Koss & Baker, 2016). Being a high school graduate was related to engaging in ACP, but was not associated with the type of AD, such as LW and DPAHC.

Being a college graduate was a significant predictor associated with engagement in all types of ACP compared to those who did not graduate from high school. This finding is similar to past research, which has found that college graduates were associated with higher odds of engaging in EOL discussions, DPAHC, and LW compared to those who had graduated from high school (Carr & Khodyakov, 2007; Carr, 2012a; Gerst & Burr, 2008; Huang et al., 2016).

The interesting finding of the current study was that being a high school graduate was not an influence on engagement in DPAHC or LW if decedents had EOL discussions, while being a college graduate still had a significant effect on engaging in another type of AD (e.g., DPAHC or LW). For example, among decedents who had discussed their EOL

preferences with others and had a DPAHC, being a college graduate was associated with 77% higher odds of engaging in LW compared to those who did not graduate from high school. Similarly, among decedents who had discussed their EOL preferences with others and had a LW, college graduates were associated with 2.45 times higher odds of engaging in DPAHC as those who did not graduate from high school. These findings suggest that higher educational level was associated with higher engagement in all types of ACP.

Attending college is associated with a greater likelihood of using several types of preventive care compared to those who have graduated from high school (Fletcher & Frisvold, 2009). Attending college may encourage people to learn and understand the need for ACP may then lead to engagement in ACP. Future studies should consider the relationship between educational levels and engagement in types of ACP.

#### 5.2.7. Net worth

In the current study, individuals in the upper 50% net worth tended to have a higher engagement in EOL discussions and at least one AD, but this was not significant. Previous researchers have demonstrated that there is an association between people in the higher household income and higher odds of engaging in EOL discussions of EOL preferences with family members or others (Carr, 2012a; Gerst & Burr, 2008). It is unclear why no significance was found in the current study. Net worth may not have accurately represented the decedents' financial status.

Among decedents who had EOL discussions and a DPAHC, those who were included in the upper 50% net worth had a 1.4 times higher odds of engaging in LWs

compared to those who were included in the lower 50% net worth. Among decedents who had EOL discussions and LW, those who were in the upper 50% net worth showed 1.6 times higher odds of engaging in DPAHC compared to those who were in the lower 50% net worth. Net worth was associated with the engagement in DPAHCs and LWs if decedents had EOL discussions. The findings were consistent with past research, which found that there was a positive association between household income and engagement in ADs (DPAHC and LW) (Carr, 2012a; Kelly et al., 2013; Khosla et al., 2015; Rao et al., 2014). These findings suggest that having a higher income provides more options and resources that people can then use to complete ADs. Thus, people with a higher income can consult with HCPs, go to health clinics, and participate in educational programs, which may lead to them having a better understanding of ACP and engagement in ADs.

#### 5.2.8. Having private health insurance policy

Decedents who had at least one private insurance policy had higher odds of engaging in EOL discussions and at least one AD, especially engaging in DPAHCs. Previous research has shown inconsistent findings. In one study, patients who had commercial insurance had higher odds of engaging in LWs (Halpern et al. 2011). There is no significant difference between the type of insurance (e.g., Medicaid, Medicare, private, and no insurance) and engagement in ADs (Van Scoy et al., 2014). In the current study, having a private insurance policy was positively correlated with net worth and was negatively correlated with having Medicaid, which indicated that having private insurance policy was related to socioeconomic status. Having private insurance gives people greater access to health care as does being of high net worth.

A limitation of previous studies and this study was that the type of private insurance plans for each decedent was not indicated. For example, in Health Maintenance Organizations (HMO) plans, people choose a primary care physician and are covered for a broader range of preventive healthcare services, including assistance with ACP, which may lead to increased engagement in ACP and completion of ADs. Further studies are needed to examine the relationship between the type of private insurance plans (i.e., coverage for ACP) and engagement in ACP. CMS pays for ACP discussions between patients and physicians (and other HCP) since January 2016 (CMS, 2015). Further studies should also compare differences in engagement in ACP before and after CMS' new policy.

#### 5.2.9. The main illness that led to death and past history

Cancer as the main illness was associated with the engagement in at least one ACP, but was not associated with engagement in ADs among decedents who had EOL discussions. This finding was consistent with findings reported by Keary & Mooram (2015) that patients with cancer patients are engaged in at least one ACP. Park and colleagues (2015) found that patients with cancer had a higher completion rate of ADs (Park et al., 2015). The researchers did bivariate analysis to examine the relationship between cancer and engagement in AD not adjusting for age, gender, and having EOL discussions. Their target population included patients with cancer who died in hospital.

Heart disease was associated with the engagement in at least one ACP. This finding was consistent with the report of Keary & Mooram (2015). Interestingly, decedents who had lung disease had 35% lower odds of engaging in DPAHCs compared

to those who did not have lung disease. Studies regarding ACP have largely focused on patients with cancer, not patient with other chronic illnesses, including lung disease. The timing of diagnosis of disease (chronic or acute), the progression of the disease, and general symptoms that patients experience may influence engagement in ACP. Further studies need to examine the differences ACP in patients with a variety of acute and chronic illnesses.

Having pain during the last year was associated with the engagement in at least one ACP but was not associated with engagement in ADs among decedents who had EOL discussions. Pain may have caused decedents to engage in EOL discussions. This finding was similar to past research which found that patients who wanted to relieve pain had 54% higher odds of engaging in EOL discussions (Wenger et al., 2001).

#### 5.2.10. Expected death

If the deaths of decedents were expected, decedents had higher odds of engaging in EOL discussions and completing ADs. The findings of this study supported earlier research which found that there was a significant relationship between expected death (or poor prognoses) and engagement in EOL discussions (Ahluwalia et al., 2015; Gerst & Burr, 2008; Hickman et al., 2013; Kelly et al., 2011; Mack et al., 2010). ). It is interesting that expected death was a significant predictor of engaging in DPAHCs, but not a significant predictor of engaging in LWs among decedents who had EOL discussions. When the deaths of the decedents were expected, most decedents discussed their EOL treatment preferences with their family members (Trarieux-Signol et al., 2014), which led to engagement in DPAHCs. Most patients believed that their family members would



know their preferences and could make decisions based on their preferences (Hinderer et al., 2015; Kelly et al., 2012). Decedents did not feel the need to complete LWs when death was expected. This may occur as patients believe their family members will make the appropriate decisions if needed (Hinderer et al., 2015; Kelly et al., 2012). In addition, decedents may have had little time to think about LWs due to imminent decline, lack of decision-making capacity and possible conflicts within the family.

### 5.3. Research question 2

*Are the types of engagement in advance care planning associated with receiving all possible care to prolong life?*

As described earlier, CMS began to reimburse ACP discussions by HCPs because discussions about EOL treatment preferences improve quality of life and the quality of EOL care (CMS, 2015). No studies have compared the association of EOL discussions on EOL care. This is the first study to explore the effect of EOL discussions with and without a DPAHC and with or without a LW on EOL care.

Engagement in EOL discussions was not a significant predictor of receiving all possible care to prolong life in the current study. Engagement in EOL discussions and DPAHC was associated with 46% lower odds of receiving all possible care compared to decedents who did not engage in any ACP. Engagement in EOL discussions and LW was associated with 65% lower odds of receiving all possible care compared to decedents who did not engage in any ACP. Engagement in EOL discussions, DPAHC, and LW was associated with 77% lower odds of receiving all possible care compared to decedents

who did not engage in any ACP. Engagement in EOL discussions without a DPAHC and/or a LW did not have an effect on receiving all possible care. The odds of receiving all possible care to prolong life decreased when decedents engaged in more types of ACP. Engagement in all ACP (EOL discussions, DPAHC, and LW) was the most powerful predictor for receiving all possible care.

The finding that engagement in EOL discussions was not a predictor of receiving all possible care was not consistent with the findings that having EOL discussions were associated with lower odds of receiving aggressive care (Ahluwalia et al., 2015; Mack et al., 2012a; Wright et al., 2008). This may be due to whom decedents had discussed their EOL treatment preferences with. While most participants in the current study had EOL discussions with their family members, most participants in previous studies had EOL discussions with their physicians. Discussions with family members are more than likely very different from discussions with physicians.

EOL discussions between patients and their family members may occur as both the patients and their family discuss a diagnosis, prognosis, treatment options, and preferences for EOL care (IOM, 2015; Lum et al., 2015; Talebreza & Widera, 2015). These discussions can help patients and their family members prepare for the EOL (Apatira et al., 2008; Hickman & Pinto, 2014). Discussions with family members or others may not be planned. This may result in patient and family confusion, family conflicts, and delayed decision-making at the EOL, which may lead to unwanted LSTs (Melhado & Byers, 2011). By contrast, HCP could help patients reflect on their goals and values and how these goals and values could direct treatment (Bischoff et al., 2013; Brinkman-Stoppelenburg et al, 2014; IOM, 2015), which may help patients and family

members make decisions with more confidence. There is evidence that EOL discussions with HCPs can help patients interested in completing AD documents (Keary & Moorman, 2015; Wright et al., 2008). In the current study, decedents who had a LW had lower odds of receiving all possible care than those who had a DPAHC. This indicated that engagement in LWs had more influence than engagement in DPAHC for patients to receive all possible care.

Those people in the upper 50% net worth tended to have higher engagement in EOL discussions and at least one AD (this was not significant). Previous research has reported that people with a higher household income had higher odds of engaging in EOL discussions of EOL preferences with family members or others (Carr, 2012a; Gerst & Burr, 2008). In this study, net worth may not accurately represent decedents' financial status because they are retirement age adults (average age of 80 years old), which may influence the finding that upper 50% net worth was not a significant predictor of engaging in EOL discussions and at least one AD.

Another significant predictor of receiving all possible care to prolong life was being African American race, which was consistent with the finding of Miesfeldt and colleagues (2012) that African Americans showed higher odds of receiving aggressive EOL care. Racial differences in receiving all possible care to prolong life may be affected by African Americans' socioeconomic status, cultural beliefs, access to appropriate resources, engagement in ACP, trust in current health care system, and relationship with HCP (Bullock, 2011; Carr, 2012a; Gerst & Burr, 2008; Huang et al., 2016).

Having resident children was also a significant predictor of receiving all possible EOL care. This finding was similar to that of Nilsson and colleagues (2007) that patients

who had dependent children (i.e., less than 18 years) were more likely to prefer aggressive treatments. Nilsson and colleagues (2007) reported that patients with advanced cancer who have dependent children were more anxious, less at peace, and had a worse quality of life at the end of their lives. The average age of the decedents in the current study was 80 years old, thus the majority of resident children were adult children (however this was not clearly stated in the HRS data). Therefore, it is difficult to compare the findings of Nilssons and colleagues' (2007) study with this study's findings. Another possible explanation for the findings of this study is that having multiple children may lead to family conflicts because each child could have a different perspective on receiving life-prolonging treatments. Family conflicts may lead to delayed decision making at the EOL, which may result in continuation of life-prolonging treatments. Future studies need to clearly define "children" before they explore the relationship of having children with receiving EOL care.

Being a high school graduate was associated with not receiving all possible care to prolong life in this study, which was supported by past research which has found that higher education was associated with lower odds of receiving LSTs (Pruchno et al., 2006; van Wijmen et al., 2014). Educational levels influence the opportunities to have access to information about ACP and help understand the information, which may help patients and their family members make EOL decisions (Carr & Khodyakov, 2007; Mueller et al., 2010).

Expected death was a significant predictor of not receiving all possible care to prolong life. If a decedent's death were expected, they had lower odds of receiving life-prolonging treatments. No other studies have reported this finding. It seems reasonable

that patients, their family members, and HCPs would not want life-prolonging treatment when patients' deaths are expected.

#### 5.4. Research question 3

*Are the types of engagement in advance care planning associated with receiving comfort care?*

Being free from pain and other distressing symptoms is an essential part of EOL care (WHO, 2015). The current study found that engagement in EOL discussions was a significant predictor of receiving comfort care. Decedents who engaged in EOL discussions and completed a DPAHC had a 3.1 times higher odds of receiving comfort care compared to those who did not engage in ACP. Engagement in EOL discussions and LW was associated with a 3.8 times higher odds of receiving comfort care compared to decedents who did not engage in any ACP. Engagement in EOL discussions, DPAHC, and LW was the most powerful predictor for receiving comfort care and was associated with a 6 times higher odds of receiving comfort care compared to decedents who did not engage in any ACP. The odds of receiving comfort care increased when decedents engaged in more types of ACP.

No studies were found that explored the effect of EOL discussions on comfort care at the EOL. This was the first study that explored the relationship of engagement in ACP, specifically focusing on EOL discussions, with receiving comfort care. Most patients and their family members wanted patients to receive comfort care. They knew that comfort care was not aimed at a cure and was only aimed at controlling pain (McCarthy et al., 2008; Kwak et al., 2014). EOL discussions with family members or

others may help patients as they express their preferences. These discussions, including discussions focused on comfort care, may prevent and minimize discomfort at the EOL.

The findings of the current study were similar to past research, which found that having an AD was associated with receiving supportive care (Franklin et al., 2011). Franklin and colleagues (2011) found that 50% of patients who had an AD received supportive care, while 32% who had an AD did not receive supportive care. This finding was the result of a bivariate analysis, thus other variables were not adjusted for. The findings of the current study provide strong evidence for the effect of engagement in ACP on receiving comfort care.

Decedents who had a LW had higher odds of receiving comfort care than those who had a DPAHC (among decedents who had EOL discussions). This indicates that completion of a LW had more influence than completion of a DPAHC on receiving comfort care. Having LWs that describe decedents' preferences for comfort care, under certain specific conditions, may make the decision-making process easier for families.

One other significant predictor of receiving comfort care was being female. There were no studies found that relationship of gender with receiving comfort care. The literature has shown that female showed 1.4 times higher odds of engaging in EOL discussions of treatment preferences with family members compared to men (Gerst & Burr, 2008), and lower odds of receiving LSTs (Carr & Moorman, 2009; Quill et al., 2014; van Wijmen et al., 2014). Additional studies are needed that investigate gender differences in receiving EOL care.

Expected death was a significant predictor of receiving comfort care. As the deaths of decedents were expected, decedents had a 2.3 times higher odds of receiving

comfort care. The findings of this study were consistent with previous research that found that when patients are close to death, most patients prefer to receive comfort care (Mack et al., 2010; McCarthy et al., 2008; Tang et al., 2014; Walling, Ettner, Barry, Yamamoto, & Wenger, 2011).

#### 5.5. Research question 4

*Among persons who have a living will, are engagement in end-of-life discussions and engagement in durable power of attorney for health care associated with congruency between decedents' preferences for end-of-life care and the care they received?*

Patients who express their EOL preferences receive care consistent with their preferences (Cosgriff et al., 2007; Hickman et al., 2011; Mack et al., 2010; Pasman et al., 2013; Silveira et al., 2010). Little is known about specific predictors associated with the congruency between patients' preferences for care and the care they receive. The current study explored which predictors were associated with congruency between decedents' preferences and the care they received among decedents who had a LW.

Engagement in EOL discussions was the only significant independent predictor of receiving care consistent with decedents' preferences for all possible care to prolong life. Engagement in EOL discussions was associated with a 1.5 times higher odds of receiving care consistent with decedents' preferences for all possible care compared to decedents who did not engage in EOL discussions. Engagement in EOL discussions was not a significant predictor of receiving care consistent with their preferences for comfort care. The odds of receiving care consistent with their preferences for comfort care were 2 times

higher among decedents who engaged in DPAHC compared to decedents who did not engage in DPAHC.

The findings indicate that engagement in EOL discussions is associated with higher odds of receiving care consistent with their preferences for comfort care compared to decedents who did not engage in EOL discussions. These findings were supported by earlier research, which has found that having discussions with physicians was associated with patients receiving care that they wanted (Mack et al., 2010). Patients who had discussed their preferences with physicians had a 2.26 times higher odds of receiving care consistent with their preferences compared to those who had not. Also, patients who preferred to receive comfort care had higher odds of receiving life-prolonging treatments when they did not discuss their preferences with physicians (Mack et al., 2010). The difference between the findings of Mack and colleagues (2010) and the current study may result from whether decedents had discussed their EOL treatment preferences with HCPs or not. While most participants in the current study had EOL discussions with their family members, participants in Mack and colleagues (2010) study had EOL discussions with their physicians. This may indicate that having discussions of preferences with HCPs had more influence on receiving care consistent with patient preferences, than having discussions with family members.

The CMS and HCPs expect that the reimbursement for ACP consultation by HCPs will improve the completion of ADs which ultimately will improve EOL care (CMS, 2015). The current study found that having EOL discussions was essential to receiving care consistent with decedents' preferences. This meets the goal that ACP helps people receive care that is aligned with their wishes (Bischoff et al., 2013; IOM, 2015).



A notable finding is that there was a synergistic effect of engagement in EOL discussions and DPAHC on receiving care consistent with participants' preferences. Regarding all possible care to prolong life, the odds of engagement in EOL discussions were increased when engagement in DPAHC was added in the model. Regarding comfort care, the odds of engagement in DPAHC were increased when engagement in EOL discussions was added in the final model. Previous research has shown that there was a synergistic effect of EOL discussions combined with a LW on EOL care. In cancer decedents, 88% who had both EOL discussions and a LW had LST withheld, while 53% who did not have EOL discussions or a LW had LST withheld (Narang et al., 2015). No previous investigations examined the synergistic effect of engagement in EOL discussions and DPAHC on receiving care consistent with patients' preferences. These findings suggest that EOL discussions with patients about their preferences helped the person designated as the DPAHC (e.g., family members, friends, or others) make decisions, which led to increased congruency between decedents' preferences for care and the EOL care they received.

## 5.6. Limitations

This study has several limitations that need to be considered when interpreting the findings. First, the HRS data were collected for a different purpose and by different methods from the current study. The data were not collected based on a specific theory or model (e.g., health care utilization model in this study) and did not contain all the variables that the researchers wanted to examine. The researcher had no control over the

data collection process, selection of variables, selection of instruments, and definitions, which might reduce the construct validity.

Second, the exit data of the HRS was not collected prospectively. The exit data relied on proxy reports within 2 years after the respondent had died (an average of 13.3 months [median of 12.0 months]), which may lead to concerns about the accuracy of the information provided ("recall bias"). In research on dying persons, their families, and EOL care, proxies are a good source of the information when the researchers want to know about EOL situations before patients' deaths, because most patients near death are unable to participate in data collection, and many proxies (e.g., family members, friends, or others) make decisions on behalf of patients (George, 2002). Consequently, the accuracy of the data depends entirely upon the ability of families or proxies to recall information about ACP documents, the patients' preferences expressed in LWs, cause of death, the real situations near death, and the care patients received, retrospectively. Some families or proxies may answer the questions in a manner that they believe the researchers want as opposed to telling the researchers what really happened, the "social-desirability bias." The timing of data collection is important. Ideally, when researchers obtain information regarding patients' preferences before death, and then collect data from proxies regarding EOL decision-making directly after patients' deaths (a prospective design), the researchers can eliminate these two biases and improve the internal validity and the reliability of data.

Third, the HRS data did not contain information about proxies, access to appropriate resources and regional variations. Decision making at the EOL is also affected by family members' treatment preferences, religion, consensus, health literacy,

and psycho-social factors, such as depression, anxiety, social support, uncertainty, and guilt (Berger DeRenzo, & Schwartz, 2008; Fritsch et al., 2013; Jox et al., 2012; Melhado & Byers, 2011). This study could not include those potential confounders. Also, there is a lack of information regarding variables that may impact willingness to complete formal ACP documents. For example, previous experience as a DPAHC, witnessing the painful death of a spouse or parent, relationships with HCPs, and the experience receiving an intervention related to ACP documents or EOL care might influence EOL decision-making. Additional predictors related to the health care system could not be included, such as the availability of information on ADs, relationship between patients, families, HCPs, Medicare/Medicaid expenditures, and specific costs covered by insurance sources. Also, regional variations in use of ADs, use of palliative and intensive treatment, and EOL Medicare expenditures might play a role in patients' and their proxies' decision making at the EOL (Nicholas et al., 2011).

Fourth, there was no specific information about discussions, LWs, and DPAHCs. For example, even though engagement in EOL discussions was a significant predictor of interest in this study, there was no information about when decedents had EOL discussions, who initiated these discussions, and how frequently they had these discussions. The time of the completion of the LW and the DPAHC was provided, but these variables could not be included in this study due to a high number of missing values. Also, HRS used general questions rather than detailed questions to examine preferences, which weakened the construct validity. For example, in the question, "Did these instructions express a desire to receive all care possible under any circumstances in order to prolong life?" there was no specific explanation about what "all care possible under

any circumstances" indicated. The only answering options were "yes" or "no." Most ADs provide specific explanations about situations (e.g., persistent vegetative state, terminal condition) and treatments (e.g., mechanical ventilator, CPR, artificial nutrition and hydration). Questions that are more precise are required.

Lastly, the finding of the study cannot be generalized to all adults. The study focused on a specific population, aged 50 years or above who were willing to participate in the study. Therefore, the findings of this study are not generalizable to all populations.

## 5.7. Recommendations

### 5.7.1. Research

The findings of the current study enhance the importance of discussions between patients, family members, and HCPs. Future research is needed to develop interventions that improve EOL discussions. A prospective intervention trial is needed to examine causality, which will identify the predictors that are related to the initiation of EOL discussions, how EOL discussions change patients' health outcomes and healthcare utilization, and how EOL discussions are interrelated to DPAHCs and LWs.

There are racial differences in engagement in EOL discussions (Bullock, 2011; Carr, 2012a; Gerst & Burr, 2008). Additional research is needed with larger, diverse racial and ethnic groups including Caucasians, African Americans, Hispanics, and Asians to examine predictors associated with engagement in EOL discussions. This information can help HCPs to better develop tailored interventions based on racial differences. Young age and a healthy condition are common reasons that engagement in EOL discussions

does not occur (Carr, 2012a; Hjelmfors, van der Wal, Friedrichsen, Martensson, Stromberg, & Jaarsma, 2015; Moorman & Inoue, 2013). Future research needs to include diverse age groups (e.g., young adults, middle aged persons, old adults, and very old adults). Factors influencing engagement in ACP for each age group may be different. For example, number of illnesses, cause of death, personal experiences with EOL and/or health literacy will differ between young adults and older adults.

Five percent of the people receiving Medicare are terminally ill (Riley & Lubitz, 2010). People who die have six times greater Medicare spending than people who survive from their serious illnesses (Hogan, 2015) and spend an average of \$38,688 out-of-pocket in the last 5 years of life (Kelley et al., 2013b). This spending may lead to a financial burden for decedents, their family members, and the government. Future research is needed to determine the effect of having EOL discussions on saving non-beneficial/unwated health care expenditures near the EOL. Accessibility to the health care system (location [urban or rural], population density [e.g., percentage of urban areas in state), and health care system characteristics [e.g., type of primary care delivery model, availability of services within the community, Medicare/Medicaid and private insurance care plans]) should be considered when researchers explore the cost-effectiveness of engagement in EOL discussions on the care of the dying.

### 5.7.2. Practice

Good communication between patients, families, and HCPs promotes a better understanding of patients' preferences, leads to increased satisfaction with EOL care, and helps to lessen decisional burden at the EOL (Brinkman-Stoppelenburg et al., 2014;

Hickman & Pinto, 2014; Hinkle, Bosslet, & Torke, 2015). Even though lack of discussions can result in care that is discordant with patient wishes (Mack et al., 2010), EOL discussions between patients, families, and HCPs often do not occur or occur very late in the course of a patient's illness (Keary & Moorman, 2015; Moorman & Inoue, 2013; Mori Ellison, Ashikaga, McVeigh, Ramsay, & Ades, 2013; Rao et al., 2014). Understanding the barriers and facilitators to EOL discussions is important. Educational intervention programs can help patients and their family members engage in EOL discussions with less fear, more knowledge, and more interest in understanding EOL treatment preferences.

HCPs should initiate ACP discussions. The timing of EOL discussions with patients and their family members is important. Triggers for initiating or reviewing EOL preferences include: patients' wishes to have EOL discussions; the diagnosis of advanced illness; the diagnosis of degenerative diseases, such as dementia; changes in health conditions and personal circumstances; and regular clinic visits or evaluation of ACP (Ahluwalia et al., 2015; Mullick, Martins & Sallnow, 2013). HCP should initiate EOL discussions with patients and families before patients lose their decision-making capacity. Early EOL discussions allow the patients and family members adequate time to think about their EOL wishes and the need for engagement in ACP.

HCPs need to assess patients' EOL care values, goals, and preferences; HCPs' understanding of their illnesses and treatment options; family members' understanding of the patient's illness and treatment options, and financial issues. Also, HCPs need to have candid conversations with patients and as appropriate with family members about the patient's prognosis, treatment options, and goals of therapy. HCPs can educate patients

and their family members regarding what ACP is, how to engage in EOL discussions and complete LWs and DPAHCs, how to share their preferences for care with others, and how to make decisions that are aligned with patients' wishes. Most patients believe family members will know their preferences and will make decisions based on their best interests (Hinderer et al., 2015; Kelly et al., 2012). HCPs need to encourage patients to discuss their preferences with their families (or designated surrogates) and HCPs, and to document their specific preferences in ADs. This may lead to less family stress, guilt, and conflict over EOL decision-making.

HCPs should provide interdisciplinary care to patients and their family members at the EOL. The interdisciplinary team (e.g., physicians, nurses/nurse practitioners, social workers, chaplains, and others [e.g., psychiatrists, psychologists, pharmacists, physical therapists, lawyers, and volunteers]) needs to work together to assess the multidimensional care needs of patients (Hui & Bruera, 2016; Meier, 2011). Most HCPs report that physicians should lead EOL communication and need to be responsible for initiating EOL discussions with patients and their preferred family members. Physicians need to work closely with the interdisciplinary team so that support can be provided to the patient and his or her family (Nedjat-Haiem, Carrion, Gonzalez, Ell, Thompson, & Mishra, 2016). In a multidisciplinary cancer program, patients who could name a social worker or nurse practitioner had higher odds of completing AD compared to those who did not name them (Clark et al., 2015). Conflicts between interdisciplinary team members can arise from lack of knowledge and skill and different ethical beliefs regarding EOL discussions and ACP. Educational and ethical training programs can help

interdisciplinary team members gain knowledge and skills and improve their teamwork in EOL communications.

Nurses are in a unique position to establish a therapeutic family-centered approach to facilitate EOL discussions and decision making (Haras et al., 2015). The American Nurses Association (ANA, 2010) Position Statement of "Registered nurses' roles and responsibilities in providing expert care and counselling at the end of life" supports the role and responsibility of nurses to serve in the important role as patient advocate. Nurses provide "expert EOL care and guidance to patients and their families concerning treatment preferences and EOL decision making (p.1)." Palliative nurses are also "in a position to convey a sense of respect, trust, and confidence at a time when patients and families are feeling vulnerable (p. 2)" and "can serve as a model for addressing the needs of the chronically ill (p.2)" ( Hospice and Palliative Nurses Association [HPNA], 2015). Nurses are information brokers, supporters, and advocates in EOL decision making (Adams et al., 2010). Nurses should initiate timely discussions with patients and their family members about the disease process, assumptions, expectations, and integration of information, which can reduce family conflicts and improve family satisfaction (Melhado & Byers, 2011). Nurses need to encourage people to have ACP discussions before patients lose decision-making capacity and help family members to support patient preferences. Identifying conflicts between patients and family members or between family members is an essential role of nurses.

Nurses and other HCPs can use various available ACP programs to help people have increased interest in ACP in a community setting. The "Respecting Choices Program" ([www.gundersenhealth.org/respecting-choices](http://www.gundersenhealth.org/respecting-choices)), organized by Gundersen



Lutheran Health System in LaCrosse, Wisconsin, is an internationally recognized, evidence-based ACP model, and has been implemented in diverse communities. This program includes multiple components: patient education materials (e.g., information card, booklet, planning guide, and video) about ADs to be made available in the community, training of facilitators who can assist people with ACP, and maintaining/documenting/using ADs within the health care organizations. The use of the "Respecting Choices Program" had a strong effect on the completion of ADs and their availability in the medical records in LaCrosse. Eighty-five percent of decedents had a written AD and 95% of ADs were available in the medical records.

"Five Wishes" ([www.agingwithdignity.org/](http://www.agingwithdignity.org/)) helps persons express how they want to be treated if they are seriously ill in certain conditions (e.g., close to death, coma, permanent and severe brain damage, or another condition in which they do not want to be kept alive) or if they lack decision-making capacity. Personal, emotional, and spiritual needs are considered. "Planning for Future Health Care Decisions" ([theconversationprojectinboulder.org/wp-content/uploads/2014/11/Planning-My-Way.pdf](http://theconversationprojectinboulder.org/wp-content/uploads/2014/11/Planning-My-Way.pdf)), developed by the U.S. Department of Veterans Affairs, is a public ACP workbook specially designed for veterans. Information is available regarding selecting a spokesperson, thinking about what matters, thinking about their EOL, talking about their EOL preferences, and completing their ADs.

"Making Your Wishes Known" ([www.makingyourwishesknown.com](http://www.makingyourwishesknown.com)) is an online decision aid to help people with EOL planning. This interactive online program guides people through the provision of information about ACP, including choosing a spokesperson; exploring values and goals regarding medical care, death, dying, and

disability; explaining health conditions; describing EOL treatments that commonly involve EOL decisions; and translating EOL preferences into a detailed AD document (Scubart et al., 2012). "PREPARE" ([www.prepareforyourcare.org/](http://www.prepareforyourcare.org/)) is an online ACP tool that guides people through videos and a five step process: choosing a surrogate decision maker, identifying a person's EOL values and goals, discussions about leeway in surrogate decision making, learning communication with clinicians and surrogates, and documenting EOL preferences (Sudore et al., 2015). "Community Conversations on Compassionate Care (CCCC)" ([www.compassionandsupport.org/](http://www.compassionandsupport.org/)) is a facilitated group discussion and presentation on ACP led by trained HCPs. Using educational materials, such as a booklet and a video, the CCCC program guides people through "Five Easy Steps": learn about advance directives, remove barriers, motivate yourself, complete your DPAHC and LW, and review and update.

### 5.7. 3. Education

There has been a growing interest in education and training for health care teams regarding ACP. Education broadens knowledge and understanding of the importance of ACP and the role of HCPs regarding ACP. There are many continuing education programs to prepare and encourage HCPs to consider their roles in ACP. CDC's Healthy Aging Program, "Advance care planning: An introduction for public health and aging services professionals" (<http://www.cdc.gov/training/ACP/>), is a modular, online courses on ACP, which is designed for HCPs to understand the importance of ACP, describe their roles in assisting older Americans' ACP, which should be done in the event older Americans become seriously ill or lose decision-making capacity, and find reliable

guidance and resources. The National Hospice and Palliative Care Organization (NHPCO: <http://www.nhpc.org/>) is one of largest organizations that provides continuing educational programs about hospice and palliative care for HCPs. Other available resources are the Center to Advance Palliative Care (CAPC: <https://www.capc.org>) and the Education in Palliative and End-of-life Care (EPEC: [www.epec.net](http://www.epec.net)).

According to the Hospice and Palliative Nurses Association (HPNA) Position Statement, "Registered nurses who practice in palliative care are encouraged to seek certification in their specialty (HPNA, 2015, p. 2)." A training program can help them to improve communication skills and health literacy. HCPs and students in training need to pursue continuing education and training programs or other learning opportunities to prepare them to be specialized in EOL care. There are many resources they can use. The End-of-Life Nursing Education Consortium (ELNEC: <http://www.aacn.nche.edu/el nec>) is one of most commonly adopted education programs for nurses. All undergraduate and graduate nursing students, nurses, faculty and educators can participate in this program, and can teach other people about EOL care with great knowledge and experience.

#### 5.7. 4. Health policy

The CMS is now reimbursing for ACP discussions by physicians and other qualified HCPs. The reimbursement decision of CMS allows HCPs to spend time to discuss patients' EOL treatment preferences with them and to encourage patients and families to complete ADs. Everyone expects decreased healthcare costs (due to a decrease in unwanted or futile care) and improved quality of life in dying patients and their family members. There are some challenges, such as the limited time allocated for

ACP discussions, the low reimbursement rate, and possibly a lack of trained HCPs. Patients need adequate time to think about their EOL and ACP plan. It is unclear how much time is needed for ACP discussions, but some HCPs suggest that at least an hour is needed (Detering et al., 2010; Kirchhoff, Hammes, Kehl, Briggs, & Brown, 2012; Walling et al., 2008). Thirty minutes, the time limit by CMS, may not be sufficient for a patient to learn about ACP, have an in-depth discussion with his or her HCP, and complete ADs. The reimbursement rate (\$86 in a physician office or \$80 in a hospital setting) may not be sufficient to motivate healthcare professionals to actively initiate ACP discussions.

Barriers to ACP discussions for HCPs include lack of: confidence to initiate ACP discussions, communication skills, and knowledge about ACP. Lack of trained HCPs is a major obstacle to implement ACP discussions in health care settings. Training programs and structured communication guidelines need to be developed and available to help HCPs prepare for ACP discussions with patients. These guidelines could provide information about who should initiate ACP discussions, the best time and place for these discussions to occur, how often the topic should be revisited, and could include possible scripts. When HCPs feel comfortable and confident having ACP discussions with patients, patients' engagement in ACP will be increased.

LWs and DPAHCs can be augmented by having ACP discussions with patients, family members, HCPs (Bomba, Kemp, & Black, 2012). POLST and MOLST documents are also important supplements to LWs and DPAHCs (Hickman et al., 2011; Hickman et al., 2015). These forms can be used with patients with serious illnesses who might die within one year (National POLST, 2016; Hickman et al., 2015). As described earlier

POLST and MOLST forms focus on shared informed decision-making and requires that HCPs have a conversation with patients and/or their surrogates regarding patients' wishes for EOL care (Bomba & Orem, 2015; Hickman et al., 2015; National POLST, 2016). These documents provide guidance about patient preferences, given certain conditions, and have been found to prevent unwanted LSTs (Bomba et al., 2012). They also have promoted comfort care and care consistent with patient wishes (Hickman et al., 2011; Hickman et al, 2014). In addition, 91% of patients and their surrogates reported that patients' treatment preferences were honored (Schmidt, Olszewski, Zive, Fromme, & Tolle, 2013). As of May 2016, most states have or are developing the POLST/MOLST program and only 3 states (Alabama, Arkansas, and South Dakota) were not developing the program (National POLST, 2016). It is essential that POLST and MOLST programs are supported. The forms are legal, medical orders that can improve the quality of EOL care if properly supported by ACP.

Standardizing the location of ACP documents can help to provide a clear and efficient process so that patient preferences can quickly be accessed and reviewed (Turley et al., 2016; Wilson, Newman, Tapper, Lai, Cheng, Wu, & Tai-Seale, 2013). Among 60,105 patients aged 65 or older, approximately half of patients had at least one ACP, but only one-third of patients who had at least one ACP had scanned documents in the electronic health records (EHR) (Wilson et al., 2013). If patients' ACP documents are not scanned and saved on the EHR, they may not be available when needed. After completing ACP documents, patients should keep the original ACP documents, and physicians or other HCPs should send a copy of the documents immediately to the medical records department to scan and save them in the EMR (Wilson et al., 2013). The

Kaiser Permanente (KP) interregional workgroup has the Care Directives Activity tab in the EHR. This tab has improved the completion rate of ADs and POLST documents (Turley et al., 2016). Government agencies, health care facilities, and other health care institutions need to focus on development of public electronic registries that are easily accessible.

## 5.8. Conclusion

Previous research on ACP has largely focused on DPAHCs and LWs, not EOL discussions. This study is the first to examine the effect of engagement in EOL discussions with and without DPAHCs and LWs on receiving all possible care and comfort care before death. Engagement in EOL discussions was a significant predictor of receiving preferred EOL care. The most notable finding of the current study was that there was a synergistic effect of engagement in EOL discussions, DPAHC, and LW on receiving all possible care and comfort care before death. The findings suggest that engagement in EOL discussions yields favorable outcomes for patients, their family members, and HCPs. Further, public educational training programs should be developed and implemented to encourage HCPs to have early in-depth EOL discussions with patients.

## Appendices

### Appendix 1.1. POLST and MOLST

#### a. POLST form of Oregon State

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT			
Physician Orders for Life-Sustaining Treatment (POLST)			
Follow these medical orders until orders change. Any section not completed implies full treatment for that section.			
Patient Last Name:	Patient First Name:	Patient Middle Name:	Last 4 SSN: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Address: (street / city / state / zip):		Date of Birth: (mm/dd/yyyy) ____/____/____	Gender: <input type="checkbox"/> M <input type="checkbox"/> F
<b>A</b>	<b>CARDIOPULMONARY RESUSCITATION (CPR):</b> <i>Unresponsive, pulseless, &amp; not breathing.</i>		
Check One	<input type="checkbox"/> <b>Attempt Resuscitation/CPR</b> <input type="checkbox"/> <b>Do Not Attempt Resuscitation/DNR</b>		
	If patient is not in cardiopulmonary arrest, follow orders in B and C.		
<b>B</b>	<b>MEDICAL INTERVENTIONS:</b> <i>If patient has pulse and is breathing.</i>		
Check One	<input type="checkbox"/> <b>Comfort Measures Only.</b> Provide treatments to relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. <i>Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.</i> <b>Treatment Plan:</b> Provide treatments for comfort through symptom management.		
	<input type="checkbox"/> <b>Limited Treatment.</b> In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). <i>Transfer to hospital if indicated. Generally avoid the intensive care unit.</i> <b>Treatment Plan:</b> Provide basic medical treatments.		
	<input type="checkbox"/> <b>Full Treatment.</b> In addition to care described in Comfort Measures Only and Limited Treatment, use intubation, advanced airway interventions, and mechanical ventilation as indicated. <i>Transfer to hospital and/or intensive care unit if indicated.</i> <b>Treatment Plan:</b> All treatments including breathing machine.		
	<i>Additional Orders:</i> _____		
<b>C</b>	<b>ARTIFICIALLY ADMINISTERED NUTRITION:</b> <i>Offer food by mouth if feasible.</i>		
Check One	<input type="checkbox"/> Long-term artificial nutrition by tube. <input type="checkbox"/> Defined trial period of artificial nutrition by tube. <input type="checkbox"/> No artificial nutrition by tube.		
	<i>Additional Orders (e.g., defining the length of a trial period):</i> _____		
<b>D</b>	<b>DOCUMENTATION OF DISCUSSION: (REQUIRED)</b> <i>See reverse side for add'l info.</i>		
Must Fill Out	<input type="checkbox"/> Patient (If patient lacks capacity, must check a box below) <input type="checkbox"/> Health Care Representative (legally appointed by advance directive or court) <input type="checkbox"/> Surrogate defined by facility policy or Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion- see reverse side)		
	Representative/Surrogate Name: _____		Relationship: _____
<b>E</b>	<b>PATIENT OR SURROGATE SIGNATURE AND OREGON POLST REGISTRY OPT OUT</b>		
	Signature: <i>recommended</i>	This form will be sent to the POLST Registry unless the patient wishes to opt out, if so check opt out box: <input type="checkbox"/>	
<b>F</b>	<b>ATTESTATION OF MD / DO / NP / PA (REQUIRED)</b>		
Must Print Name, Sign & Date	By signing below, I attest that these medical orders are, to the best of my knowledge, consistent with the patient's current medical condition and preferences.		
	Print Signing MD / DO / NP / PA Name: <i>required</i>	Signer Phone Number:	Signer License Number: <i>(optional)</i>
	MD / DO / NP / PA Signature: <i>required</i>	Date: <i>required</i>	Office Use Only
SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED SUBMIT COPY OF BOTH SIDES OF FORM TO REGISTRY IF PATIENT DID NOT OPT OUT IN SECTION E			

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2014

\*Source: <http://oregonpolst.org/polst-process>

a. POLST form of Oregon State: Continued

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT			
Information for patient named on this form PATIENT'S NAME: _____			
<p>The POLST form is always voluntary and is usually for persons with serious illness or frailty. POLST records your wishes for medical treatment in your current state of health (states your treatment wishes if something happened tonight). Once initial medical treatment is begun and the risks and benefits of further therapy are clear, your treatment wishes may change. Your medical care and this form can be changed to reflect your new wishes at any time. No form, however, can address all the medical treatment decisions that may need to be made. An Advance Directive is recommended for all capable adults and allows you to document in detail your future health care instructions and/or name a Health Care Representative to speak for you if you are unable to speak for yourself. Consider reviewing your Advance Directive and giving a copy of it to your health care professional.</p>			
Contact Information (Optional)			
Health Care Representative or Surrogate:	Relationship:	Phone Number:	Address:
Health Care Professional Information			
Preparer Name:	Preparer Title:	Phone Number:	Date Prepared:
PA's Supervising Physician:		Phone Number:	
Primary Care Professional:			
Directions for Health Care Professionals			
Completing POLST			
<ul style="list-style-type: none"> <li>• Completing a POLST is always voluntary and cannot be mandated for a patient.</li> <li>• An order of CPR in Section A is incompatible with an order for Comfort Measures Only in Section B (will not be accepted in Registry).</li> <li>• For information on legally appointed health care representatives and their authority, refer to ORS 127.505 - 127.660.</li> <li>• Should reflect current preferences of persons with serious illness or frailty. Also, encourage completion of an Advance Directive.</li> <li>• Verbal / phone orders are acceptable with follow-up signature by MD/DO/NP/PA in accordance with facility/community policy.</li> <li>• Use of original form is encouraged. Photocopies, faxes, and electronic registry forms are also legal and valid.</li> <li>• A person with developmental disabilities or significant mental health condition requires additional consideration before completing the POLST form; refer to <i>Guidance for Health Care Professionals</i> at <a href="http://www.or.polst.org">www.or.polst.org</a>.</li> </ul>			
Oregon POLST Registry Information			
<b>Health Care Professionals:</b> (1) You are <i>required</i> to send a copy of <u>both</u> sides of this POLST form to the Oregon POLST Registry unless the patient opts out. (2) The following sections must be completed: <ul style="list-style-type: none"> <li>• Patient's full name</li> <li>• Date of birth</li> <li>• MD / DO / NP / PA signature</li> <li>• Date signed</li> </ul>	<b>Registry Contact Information:</b> Phone: 503-418-4083 Fax or eFAX: 503-418-2181 <a href="http://www.orpolstregistry.org">www.orpolstregistry.org</a> <a href="mailto:polstreg@ohsu.edu">polstreg@ohsu.edu</a>  Oregon POLST Registry 3181 SW Sam Jackson Park Rd. Mail Code: CDW-EM Portland, Or 97239	<b>Patients:</b> Mailed confirmation packets from Registry may take four weeks for delivery.  <div style="border: 1px solid black; padding: 5px; text-align: center;"> <b>MAY PUT REGISTRY ID STICKER HERE:</b> </div>	
Updating POLST: A POLST Form only needs to be revised if patient treatment preferences have changed.			
This POLST should be reviewed periodically, including when: <ul style="list-style-type: none"> <li>• The patient is transferred from one care setting or care level to another (including upon admission or at discharge), or</li> <li>• There is a substantial change in the patient's health status.</li> </ul> If patient wishes haven't changed, the POLST Form does not need to be revised, updated, rewritten or resent to the Registry.			
Voiding POLST: A copy of the voided POLST <u>must</u> be sent to the Registry unless patient has opted-out.			
<ul style="list-style-type: none"> <li>• A person with capacity, or the valid surrogate of a person without capacity, can void the form and request alternative treatment.</li> <li>• Draw line through sections A through E and write "VOID" in large letters if POLST is replaced or becomes invalid.</li> <li>• Send a copy of the voided form to the POLST Registry (<i>required</i> unless patient has opted out).</li> <li>• If included in an electronic medical record, follow voiding procedures of facility/community.</li> </ul>			
For permission to use the copyrighted form contact the OHSU Center for Ethics in Health Care at <a href="mailto:orpolst@ohsu.edu">orpolst@ohsu.edu</a> or (503) 494-3965. Information on the Oregon POLST Program is available online at <a href="http://www.or.polst.org">www.or.polst.org</a> or at <a href="mailto:orpolst@ohsu.edu">orpolst@ohsu.edu</a>			
SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED. SUBMIT COPY TO REGISTRY			

\*Source: <http://oregonpolst.org/polst-process>



b. MOLST form of New York State

**THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN KEEPS A COPY.**

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY/STATE/ZIP \_\_\_\_\_

DATE OF BIRTH (MM/DD/YYYY) \_\_\_\_\_  Male  Female \_\_\_\_\_ eMOLST NUMBER (THIS IS NOT AN eMOLST FORM) \_\_\_\_\_

**Do-Not-Resuscitate (DNR) and Other Life-Sustaining Treatment (LST)**

This is a medical order form that tells others the patient's wishes for life-sustaining treatment. A health care professional must complete or change the MOLST form, based on the patient's current medical condition, values, wishes and MOLST Instructions. If the patient is unable to make medical decisions, the orders should reflect patient wishes, as best understood by the health care agent or surrogate. A physician must sign the MOLST form. All health care professionals must follow these medical orders as the patient moves from one location to another, unless a physician examines the patient, reviews the orders and changes them.

**MOLST is generally for patients with serious health conditions. The patient or other decision-maker should work with the physician and consider asking the physician to fill out a MOLST form if the patient:**

- Wants to avoid or receive any or all life-sustaining treatment.
- Resides in a long-term care facility or requires long-term care services.
- Might die within the next year.

If the patient has a developmental disability and does not have ability to decide, the doctor must follow special procedures and attach the appropriate legal requirements checklist.

**SECTION A Resuscitation Instructions When the Patient Has No Pulse and/or Is Not Breathing**

Check *one*:

- CPR Order: Attempt Cardio-Pulmonary Resuscitation**  
CPR involves artificial breathing and forceful pressure on the chest to try to restart the heart. It usually involves electric shock (defibrillation) and a plastic tube down the throat into the windpipe to assist breathing (intubation). It means that all medical treatments will be done to prolong life when the heart stops or breathing stops, including being placed on a breathing machine and being transferred to the hospital.
- DNR Order: Do Not Attempt Resuscitation (Allow Natural Death)**  
This means do not begin CPR, as defined above, to make the heart or breathing start again if either stops.

**SECTION B Consent for Resuscitation Instructions (Section A)**

The patient can make a decision about resuscitation if he or she has the ability to decide about resuscitation. If the patient does NOT have the ability to decide about resuscitation and has a health care proxy, the health care agent makes this decision. If there is no health care proxy, another person will decide, chosen from a list based on NYS law.

\_\_\_\_\_  
SIGNATURE  Check if verbal consent (Leave signature line blank) \_\_\_\_\_ DATE/TIME

\_\_\_\_\_  
PRINT NAME OF DECISION-MAKER

\_\_\_\_\_  
PRINT FIRST WITNESS NAME

\_\_\_\_\_  
PRINT SECOND WITNESS NAME

**Who made the decision?**  Patient  Health Care Agent  Public Health Law Surrogate  Minor's Parent/Guardian  §1750-b Surrogate

**SECTION C Physician Signature for Sections A and B**

\_\_\_\_\_  
PHYSICIAN SIGNATURE

\_\_\_\_\_  
PRINT PHYSICIAN NAME

\_\_\_\_\_  
DATE/TIME

\_\_\_\_\_  
PHYSICIAN LICENSE NUMBER

\_\_\_\_\_  
PHYSICIAN PHONE/PAGER NUMBER

**SECTION D Advance Directives**

Check all advance directives known to have been completed:

- Health Care Proxy  Living Will  Organ Donation  Documentation of Oral Advance Directive

\* Source: <https://www.health.ny.gov/forms/doh-5003.pdf>

b. MOLST form of New York State: Continued

**THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN KEEPS A COPY.**

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT \_\_\_\_\_ DATE OF BIRTH (MM/DD/YYYY) \_\_\_\_\_

**SECTION E Orders For Other Life-Sustaining Treatment and Future Hospitalization When the Patient has a Pulse and the Patient is Breathing**

Life-sustaining treatment may be ordered for a trial period to determine if there is benefit to the patient. If a life-sustaining treatment is started, but turns out not to be helpful, the treatment can be stopped.

**Treatment Guidelines** No matter what else is chosen, the patient will be treated with dignity and respect, and health care providers will offer comfort measures. *Check one:*

- Comfort measures only** Comfort measures are medical care and treatment provided with the primary goal of relieving pain and other symptoms and reducing suffering. Reasonable measures will be made to offer food and fluids by mouth. Medication, turning in bed, wound care and other measures will be used to relieve pain and suffering. Oxygen, suctioning and manual treatment of airway obstruction will be used as needed for comfort.
- Limited medical interventions** The patient will receive medication by mouth or through a vein, heart monitoring and all other necessary treatment, based on MOLST orders.
- No limitations on medical interventions** The patient will receive all needed treatments.

**Instructions for Intubation and Mechanical Ventilation** *Check one:*

- Do not intubate (DNI)** Do not place a tube down the patient's throat or connect to a breathing machine that pumps air into and out of lungs. Treatments are available for symptoms of shortness of breath, such as oxygen and morphine. (This box should **not** be checked if full CPR is checked in Section A.)
- A trial period** *Check one or both:*
  - Intubation and mechanical ventilation
  - Noninvasive ventilation (e.g. BIPAP), if the health care professional agrees that it is appropriate
- Intubation and long-term mechanical ventilation, if needed** Place a tube down the patient's throat and connect to a breathing machine as long as it is medically needed.

**Future Hospitalization/Transfer** *Check one:*

- Do not send to the hospital unless pain or severe symptoms cannot be otherwise controlled.**
- Send to the hospital, if necessary, based on MOLST orders.**

**Artificially Administered Fluids and Nutrition** When a patient can no longer eat or drink, liquid food or fluids can be given by a tube inserted in the stomach or fluids can be given by a small plastic tube (catheter) inserted directly into the vein. If a patient chooses not to have either a feeding tube or IV fluids, food and fluids are offered as tolerated using careful hand feeding. *Check one each for feeding tube and IV fluids:*

- No feeding tube**
- A trial period of feeding tube**
- Long-term feeding tube, if needed**
- No IV fluids**
- A trial period of IV fluids**

**Antibiotics** *Check one:*

- Do not use antibiotics.** Use other comfort measures to relieve symptoms.
- Determine use or limitation of antibiotics when infection occurs.**
- Use antibiotics** to treat infections, if medically indicated.

**Other Instructions** about starting or stopping treatments discussed with the doctor or about other treatments not listed above (dialysis, transfusions, etc.).

**Consent for Life-Sustaining Treatment Orders (Section E)** (Same as Section B, which is the consent for Section A)

\_\_\_\_\_  
SIGNATURE  Check if verbal consent (Leave signature line blank) \_\_\_\_\_  
DATE/TIME

\_\_\_\_\_  
PRINT NAME OF DECISION-MAKER

\_\_\_\_\_  
PRINT FIRST WITNESS NAME

\_\_\_\_\_  
PRINT SECOND WITNESS NAME

**Who made the decision?**  Patient  Health Care Agent  Based on clear and convincing evidence of patient's wishes  
 Public Health Law Surrogate  Minor's Parent/Guardian  §1750-b Surrogate

**Physician Signature for Section E**

\_\_\_\_\_  
PHYSICIAN SIGNATURE

\_\_\_\_\_  
PRINT PHYSICIAN NAME

\_\_\_\_\_  
DATE/TIME

\* Source: <https://www.health.ny.gov/forms/doh-5003.pdf>

b. MOLST form of New York State: Continued

**THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN KEEPS A COPY.**

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LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT \_\_\_\_\_ DATE OF BIRTH (MM/DD/YYYY) \_\_\_\_\_

**SECTION F** Review and Renewal of MOLST Orders on This MOLST Form

The physician must review the form from time to time as the law requires, and also:

- If the patient moves from one location to another to receive care; or
- If the patient has a major change in health status (for better or worse); or
- If the patient or other decision-maker changes his or her mind about treatment.

Date/Time	Reviewer's Name and Signature	Location of Review (e.g., Hospital, NH, Physician's Office)	Outcome of Review
			<input type="checkbox"/> No change <input type="checkbox"/> Form voided, new form completed <input type="checkbox"/> Form voided, <b>no</b> new form
			<input type="checkbox"/> No change <input type="checkbox"/> Form voided, new form completed <input type="checkbox"/> Form voided, <b>no</b> new form
			<input type="checkbox"/> No change <input type="checkbox"/> Form voided, new form completed <input type="checkbox"/> Form voided, <b>no</b> new form
			<input type="checkbox"/> No change <input type="checkbox"/> Form voided, new form completed <input type="checkbox"/> Form voided, <b>no</b> new form
			<input type="checkbox"/> No change <input type="checkbox"/> Form voided, new form completed <input type="checkbox"/> Form voided, <b>no</b> new form
			<input type="checkbox"/> No change <input type="checkbox"/> Form voided, new form completed <input type="checkbox"/> Form voided, <b>no</b> new form
			<input type="checkbox"/> No change <input type="checkbox"/> Form voided, new form completed <input type="checkbox"/> Form voided, <b>no</b> new form
			<input type="checkbox"/> No change <input type="checkbox"/> Form voided, new form completed <input type="checkbox"/> Form voided, <b>no</b> new form
			<input type="checkbox"/> No change <input type="checkbox"/> Form voided, new form completed <input type="checkbox"/> Form voided, <b>no</b> new form
			<input type="checkbox"/> No change <input type="checkbox"/> Form voided, new form completed <input type="checkbox"/> Form voided, <b>no</b> new form
			<input type="checkbox"/> No change <input type="checkbox"/> Form voided, new form completed <input type="checkbox"/> Form voided, <b>no</b> new form

\* Source: <https://www.health.ny.gov/forms/doh-5003.pdf>

### Appendix 3.1. Questionnaire of this study

Characteristics	Question
<b><u>Predisposing characteristics</u></b>	
Age at death	Age at death
Gender	Gender
Marital status	Marital status
Race/ethnicity	Race/ethnicity
Number of children	Number of resident children
Religion	What is your religious preference?
<b><u>Enabling resources</u></b>	
Net worth	The net value of total wealthy
Educational level	Highest degree of education
Private health insurance policy	Number of private health insurance plans
<b><u>Needs for health services</u></b>	
Main illness that led to death	What was the major illness that led to patient's death?
Lung disease	Had a doctor ever told patient that [he/she] had chronic lung disease such as chronic bronchitis or emphysema?
Heart failure	Did a doctor ever tell patient that [he/she] had congestive heart failure?
Stroke	Had a doctor ever told patient that [he/she] had a stroke?
Pain	Was patient often troubled with pain during the last year or so of life?
Perceived health status	Would patient say his/her health is excellent, very good, good, fair, or poor?
Expected death	Was the death expected at about the time it occurred, or was it unexpected?
Participation of patient in decision making	Was patient able to participate in decisions about [her/his] medical care during the final days of [her/his] life?
<b><u>Health behavior</u></b>	
Having EOL discussion about EOL care	Did patient ever discuss with you or anyone else the treatment or care [she/he] wanted to receive in the final days of [her/his] life?
Having a durable power of attorney for health care (DPAHC)	Did patient 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]?
Having a written instruction about EOL care (LW)	Did patient provide written instructions about the treatment or care she/he wanted to receive during the final days of her/his life? (This is sometimes called a "Living Will")

Appendix 3.1. Questionnaire of this study: Continued

Characteristics	Question
<i>(The prerequisite question of “Did patient provide written instructions about the treatment or care [he/she] wanted to receive during the final days of [his/her] life?” should be answered “Yes”)</i>	
<b><u>Patient’s preferences in LW</u></b>	
All possible care to prolong life	Did these instructions express a desire to receive all care possible under any circumstances in order to prolong life?
Comfort care	(Did these instructions express a desire to) keep patient comfortable and pain free but to forego extensive measures to prolong life?
<i>(The prerequisite question of “Did any decisions have to be made about the care and treatment of patient during the final days of [his/her] life?” should be answered “Yes”)</i>	
<b><u>Outcomes</u></b>	
All possible care to prolong life	Did those last decisions involve a desire to give all care possible unconditionally in order to prolong life?

Appendix 4.1. Characteristics of the sample: the initial sample (N=7,863) and the inclusion group (N=6,001)

Category	Unweighted		Weighted	
	Initial sample (N=7,863)	Study sample (N=6,001)	Initial sample (N=7,863)	Study sample (N=6,001)
Age at death	80.1 (10.7)	79.5 (10.7)	79.3 (.21)	78.8 (.23)
	M (SD)		M (SE)	
	N (%)		N (%)	
Proxy relationship to patient				
Spouse/partner	2575 (32.7)	2043 (34.0)	155185974 (34.2)	122102310 (35.2)
Children	3593 (45.7)	2753 (45.9)	209657076 (46.2)	162005562 (46.8)
Others	1695 (21.6)	1205 (20.1)	453379638 (19.5)	62416014 (18.0)
Gender				
Male	3644 (46.3)	2812 (46.9)	217033548 (47.9)	166587306 (48.1)
Female	4219 (53.7)	3189 (53.1)	236346090 (52.1)	179936580 (51.9)
Marital status				
Married	2610 (40.8)	2027 (41.7)	181518456 (42.1)	141110880 (42.8)
Widowed	2835 (44.3)	2085 (42.9)	180528918 (41.8)	133882338 (40.6)
Separated/divorced, never married	959 (15.0)	752 (15.5)	69519672 (16.1)	54568830 (16.6)
Race				
African American	1267 (16.7)	1020 (17.7)	49031544 (10.8)	39111798 (11.3)
Non-African American	6322 (87.9)	4747 (82.3)	404269212 (89.2)	307333206 (88.7)
Having resident children				
No	6298 (80.1)	4736 (78.9)	363292014 (80.1)	274755132 (79.3)
Yes	1565 (19.9)	1265 (21.1)	90087624 (19.9)	71768754 (20.7)
Religion				
Catholic	1985 (25.4)	1513 (25.3)	116210508 (25.7)	88265490 (25.5)
Non-Catholic	5841 (74.6)	4459 (74.7)	335773860 (74.3)	257286330 (74.5)
Education				
Less than high school	3312 (42.2)	2616 (43.7)	167082990 (36.9)	131957676 (38.1)
High school graduate	3376 (43.0)	2511 (42.0)	208449342 (46.0)	155886162 (45.0)
College and more	1157 (14.7)	858 (14.3)	77752230 (17.1)	58584972 (16.9)
Net worth				
Lower 50% net worth	3522 (50.0)	1353 (25.0)	193717914 (45.7)	148259112 (45.4)
Upper 50% net worth	3521 (50.0)	1350 (25.0)	230176800 (54.3)	178048872 (54.6)
Having at least one private insurance policy				
No	3692 (48.9)	2912 (49.9)	200824392 (46.5)	160248216 (47.7)
Yes	3851 (51.1)	2921 (50.1)	231246198 (53.5)	175610064 (52.3)
Main illness that led to death				
Cancer	1752 (22.9)	1364 (23.3)	108178302 (24.5)	254280480 (75.2)
Non-cancer	5914 (77.1)	4497 (76.7)	333490716 (75.5)	83769504 (24.8)
Lung disease as a past history				
No	5806 (75.0)	4392 (74.0)	324428826 (72.7)	245606196 (71.7)
Yes	1940 (25.0)	1545 (26.0)	121911516 (27.3)	97032504 (28.3)
Heart disease as a past history				
No	3591 (46.3)	2710 (45.6)	200945376 (45.0)	151269630 (44.1)
Yes	4172 (53.7)	3235 (54.4)	245587158 (55.0)	191535726 (55.9)
Stroke as a past history				
No	5585 (72.0)	4296 (72.3)	327634416 (73.3)	251805306 (73.5)
Yes	2171 (28.0)	1642 (27.7)	119353506 (26.7)	90870696 (26.5)
Pain during the last year				
No	3276 (42.6)	2431 (41.3)	181217940 (40.6)	135335646 (39.6)
Yes	4423 (57.4)	3461 (58.7)	264633048 (59.4)	206213268 (60.4)
Perceived health status				
Excellent-Good	2628 (37.5)	1988 (36.9)	164489778 (39.0)	124706490 (38.4)
Fair-poor	4385 (62.5)	3394 (63.1)	257031714 (61.0)	199683528 (61.6)
Expected death				
No	3060 (40.0)	2389 (40.8)	173673846 (39.7)	134262426 (40.1)
Yes	4598 (60.0)	3462 (59.2)	263938926 (60.3)	200440842 (59.9)

Appendix 4.2. Characteristics of the sample: No engagement in advance care planning versus engagement in at least one advance care planning (N=6,001)

Category	Total (N=6001; 100%)	Unweighted		Weighted		t/χ <sup>2</sup> (p)
		No ACP (N=1807; 30.1%)	At least one ACP (N=4194; 69.9%)	No ACP (N=84,216,780; 24.3%)	At least one ACP (N=262,307,106; 75.7%)	
	M (SD) N(%)	M (SD) N(%)	M (SD) N(%)	M (SE) N(%)	M (SE) N(%)	
Age at death	79.5 (10.7)	77.6 (11.4)	80.3 (10.4)	76.4 (.40)	79.5 (.27)	348.746 (<.001*)
Gender						12.857 (.003*)
Male	2812 (46.9)	910 (50.4)	1902 (45.4)	44070804 (52.3)	122516502 (46.7)	
Female	3189 (53.1)	897 (49.6)	2292 (54.6)	40145976 (47.7)	139790604 (53.3)	
Marital status						74.568 (<.001*)
Married	2027 (41.7)	628 (46.6)	1399 (39.8)	37364598 (48.1)	103746282 (41.2)	
Widowed	2085 (42.9)	445 (33.0)	1640 (46.7)	23264928 (29.9)	110617410 (43.9)	
Separated/divorced, never married	752 (15.5)	276 (20.5)	476 (13.5)	17053044 (22.0)	37515786 (14.9)	
Race						244.452 (<.001*)
African American	1020 (17.7)	550 (30.5)	470 (11.2)	19408494 (23.0)	19703304 (7.5)	
Non-African American	4747 (82.3)	1142 (63.3)	3605 (86.1)	64800348 (77.0)	242532858 (92.5)	
Having resident children						13.114 (.005*)
No	4736 (78.9)	1380 (76.4)	3356 (80.0)	63838422 (75.8)	210916710 (80.4)	
Yes	1265 (21.1)	427 (23.6)	838 (20.0)	20378358 (24.2)	51390396 (19.6)	
Religion						8.090 (.023*)
Catholic	1513 (25.3)	481 (26.8)	1032 (24.7)	23927010 (28.5)	64338480 (24.6)	
Non-Catholic	4459 (74.7)	1316 (73.2)	3143 (75.3)	60041442 (71.5)	197244888 (75.4)	
Education						118.868 (<.001*)
Less than high school	2616 (43.7)	1026(57.0)	1590 (38.0)	42508740 (50.5)	89448936 (34.1)	
High school graduate	2511 (42.0)	567 (31.5)	1943 (46.4)	29006418 (34.5)	126879744 (48.4)	
College and more	858 (14.3)	207 (11.5)	651 (15.6)	12664926 (15.0)	45920046 (17.5)	
Net worth						79.850 (<.001*)
Lower 50% net worth	2704 (50.0)	971 (61.1)	1733 (45.4)	44274462 (56.5)	103984650 (41.9)	
Upper 50% net worth	2699 (50.0)	619 (38.9)	2080 (54.6)	34047132 (43.5)	144001740 (58.1)	
Having at least one private insurance policy						113.523 (<.001*)
No	2912 (49.9)	1103 (63.7)	1809 (44.1)	48482490 (60.7)	11765726 (43.7)	
Yes	2921 (50.1)	628 (36.3)	2293 (55.9)	31353330 (39.3)	144256734 (56.3)	
Main illness that led to death						33.891 (<.001*)
Cancer	1364 (23.3)	323 (18.6)	1041 (25.2)	14952930 (18.6)	68816574 (26.7)	
Non-cancer	4497 (76.7)	1411 (81.4)	3086 (74.8)	65263140 (81.4)	189017340 (73.3)	
Lung disease as a past history						7.772 (.013*)
No	4392 (74.0)	1388 (77.9)	3004 (72.3)	61983270 (74.7)	183622926 (70.7)	
Yes	1545 (26.0)	394 (22.1)	1151 (27.7)	21005568 (25.3)	76026936 (29.3)	
Heart disease as a past history						22.620 (<.001*)
No	2710 (45.6)	925 (51.8)	1785 (42.9)	41329836 (49.8)	109939794 (42.3)	
Yes	3235 (54.4)	860 (48.2)	2375 (57.1)	41699304 (50.2)	149836422 (57.7)	
Stroke as a past history						5.920 (.050)
No	4296 (72.3)	1324 (74.3)	2972 (71.5)	63198312 (76.1)	188606994 (72.7)	
Yes	1642 (27.7)	457 (25.7)	1185 (28.5)	1990292 (23.9)	70969404 (27.3)	
Pain during the last year						17.655 (.001*)
No	2431 (41.3)	812 (46.4)	1619 (39.1)	36753816 (44.6)	98581830 (38.0)	
Yes	3461 (58.7)	939 (53.6)	12522 (60.9)	45706722 (55.4)	160506546 (62.0)	
Perceived health status						.149 (.751)
Excellent-Good	1988 (36.9)	587 (37.1)	1401 (36.9)	30224436 (38.9)	94482054 (38.3)	
Fair/poor	3394 (63.1)	997 (62.9)	2397 (63.1)	47446098 (61.1)	152237430 (61.7)	
Expected death						157.084 (<.001*)
No	2389 (40.8)	917 (52.0)	1472 (36.0)	44630916 (54.9)	89631510 (35.4)	
Yes	3462 (59.2)	845 (48.0)	2617 (64.0)	36643638 (45.1)	163797204 (64.6)	

Note. \* p<.05

Appendix 4.3. Stage 1. Simple complex samples logistic regression: Predictors associated with engagement in at least one advance care planning compared with no engagement in advance care planning (N=6,001)

Variable	Reference group	F	p	OR	95% CI	
					Lower	Upper
Age	-	39.767	< .001	1.028	1.019	1.037
Female	(Male)	9.989	.003	1.253	1.086	1.445
Married	(Separated/divorced, never married)	13.356	.001	.756	.648	.881
Widowed	(Separated/divorced, never married)	38.767	< .001	1.832	1.507	2.226
African American	(Non-African American)	125.580	< .001	.271	.215	.343
Having resident children	(No resident children)	8.495	.005	.763	.634	.919
Catholic	(Non-Catholic)	5.461	.023	.819	.689	.972
High school graduate	(Less than high school graduate)	41.491	< .001	1.783	1.489	2.134
College or more	(Less than high school graduate)	2.223	.142	1.199	.939	1.529
Higher 50% net worth	(Lower 50% net worth)	42.971	< .001	1.801	1.504	2.156
Having at least one private insurance policy	(No private insurance policy)	37.465	< .001	1.996	1.592	2.503
Cancer as a main illness that led to death	(Non-cancer)	19.358	< .001	1.589	1.287	1.962
Heart disease as a past history	(No history of heart disease)	15.088	< .001	1.351	1.157	1.578
Lung disease as a past history	(No history of lung disease)	6.634	.013	1.222	1.045	1.428
Stroke as a past history	(No history of stroke)	4.026	.050	1.195	1.000	1.428
Pain during the last year	(No)	13.424	.001	1.309	1.130	1.517
Perceived health status: Fair/poor	(Excellent-Good)	.102	.751	.974	.827	1.148
Expected death	(Unexpected death)	154.474	< .001	2.226	1.956	2.532

Note. OR, odds ratio; CI, Confidence interval



Appendix 4.4. Stage 2. Characteristics of the sample: EOL discussions only versus EOL discussions and at least one advance directive (N=4,194)

Category	Total	Unweighted		Weighted		$\chi^2$ (p)
	(N=4194, 100%)	Discussion only group (N=997, 23.8%)	Discussion only + at least one AD (N=3197, 76.2%)	Discussion only group (N=53,993,766, 20.6%)	Discussion only + at least one AD (N=208,313,340, 79.4%)	
	M (SD)	M (SD)	M (SD)	M (SE)	M (SE)	
Age at death	80.3 (10.4)	76.7 (10.4)	81.5 (10.1)	75.7 (.47)	80.5 (.28)	295.622 (<.001*)
Gender	N (%)	N (%)	N (%)	N (%)	N (%)	16.135 (.004*)
Male	1902 (45.4)	519 (52.1)	1383 (43.3)	28622856 (53.0)	93893646 (45.1)	
Female	2292 (64.6)	478 (47.9)	1814 (56.7)	25370910 (47.0)	114419694 (54.9)	
Marital status						75.807 (<.001*)
Married	1399 (39.8)	398 (51.2)	1001 (36.6)	26835354 (52.8)	76910928 (38.3)	
Widowed	1640 (46.7)	271 (34.8)	1369 (50.0)	25915974 (29.2)	95801436 (47.6)	
Separated/divorced, never married	476 (13.5)	109 (14.0)	367 (13.4)	9155550 (18.0)	28360236 (14.1)	
Race						57.864 (<.001*)
African American	470 (11.5)	206 (21.7)	264 (8.4)	7458030 (13.8)	12245274 (5.9)	
Non-African American	3605 (88.5)	742 (78.3)	2863 (91.6)	46481172 (86.2)	196051686 (94.1)	
Having resident children						22.611 (.001*)
No	3356 (80.0)	744 (74.6)	2612 (81.7)	40209924 (74.5)	170706786 (81.9)	
Yes	838 (20.0)	253 (25.4)	585 (18.3)	13783842 (25.5)	37606554 (18.1)	
Religion						1.616 (.232)
Catholic	1032 (24.7)	261 (26.3)	771 (24.2)	14181588 (26.3)	50156892 (24.1)	
Non-Catholic	31430 (75.3)	731 (73.7)	2412 (75.8)	39701016 (73.7)	157543872 (75.9)	
Education						39.710 (<.001*)
Less than high school	1590 (38.0)	472 (47.5)	1118 (35.0)	22799124 (42.3)	66649812 (32.0)	
High school graduate	1943 (46.4)	418 (42.1)	1525 (47.8)	24797520 (46.0)	102082224 (49.0)	
College and more	651 (15.6)	104 (10.5)	547 (17.1)	6355020 (11.8)	39565026 (19.0)	
Net worth						31.272 (<.001*)
Lower 50% net worth	1907 (50.0)	537 (59.3)	1370 (47.2)	28608378 (55.7)	86986362 (44.3)	
Upper 50% net worth	1904 (50.0)	369 (40.7)	1535 (52.8)	22734516 (44.3)	109512744 (55.7)	
Having at least one private insurance policy						26.803 (<.001*)
No	1809 (44.1)	512 (52.5)	1297 (41.5)	27339768 (51.8)	84425958 (41.5)	
Yes	2293 (55.9)	464 (47.5)	1829 (58.5)	25420920 (48.2)	118835814 (58.5)	
Main illness that led to death						.748 (.553)
Cancer	1041 (25.2)	240 (24.7)	801 (25.4)	13341162 (25.5)	55475412 (27.0)	
Non-cancer	3086 (74.8)	731 (75.3)	2355 (74.6)	39045204 (74.5)	149972136 (73.0)	
Lung disease as a past history						.541 (.567)
No	3004 (72.3)	710 (71.9)	2294 (72.4)	37136160 (69.7)	146486766 (71.0)	
Yes	1151 (27.7)	278 (28.1)	873 (27.6)	16174422 (30.3)	59852514 (29.0)	
Heart disease as a past history						.775 (.403)
No	1785 (42.9)	460 (46.5)	1325 (41.8)	23387268 (43.7)	86552526 (42.0)	
Yes	2375 (57.1)	530 (53.5)	1845 (58.2)	30138216 (56.3)	119698206 (58.0)	
Stroke as a past history						2.055 (.315)
No	2972 (71.5)	747 (75.7)	2225 (70.2)	39541476 (74.7)	149065518 (72.1)	
Yes	1185 (28.5)	240 (24.3)	945 (29.8)	13399002 (25.3)	57570402 (27.9)	
Pain during the last year						2.873 (.156)
No	1619 (39.1)	370 (37.6)	1249 (39.6)	18785076 (35.4)	79796854 (38.7)	
Yes	12522 (60.9)	615 (62.4)	1907 (60.4)	34227510 (64.6)	126279036 (61.3)	
Perceived health status						.026 (.890)
Excellent-Good	1401 (36.9)	327 (36.3)	1074 (37.1)	19354146 (38.0)	75127908 (38.4)	
Fair/poor	2397 (63.1)	575 (63.7)	1822 (62.8)	31527594 (62.0)	120709836 (61.6)	
Expected death						46.891 (<.001*)
No	1472 (36.0)	447 (45.5)	1025 (33.0)	24267852 (45.7)	65363658 (32.6)	
Yes	2617 (64.0)	536 (54.5)	2081 (67.0)	28852062 (54.3)	134945142 (67.4)	

Note \* p<.05

Appendix 4.5. Stage 2. Simple complex samples logistic regression: Predictors associated with engagement in EOL discussions and at least one advance directive compared with engagement in EOL discussions only (N=4,194)

Variable	Reference group	F	p	OR	95% CI	
					Lower	Upper
Age	-	96.348	< .001	1.045	1.036	1.055
Female	(Male)	8.919	.004	1.375	1.110	1.702
Married	(Separated/divorced, never married)	39.561	<.001	.553	.458	.668
Widowed	(Separated/divorced, never married)	76.434	<.001	2.211	1.843	2.652
African American	(Non-African American)	64.160	< .001	.389	.307	.493
Having resident children	(No resident children)	13.220	.001	.643	.504	.820
Catholic	(Non-Catholic)	1.463	.232	.891	.736	1.079
High school graduate	(Less than high school graduate)	1.366	.248	1.130	.916	1.393
College or more	(Less than high school graduate)	10.226	.002	1.756	1.234	2.500
Upper 50% net worth	(Lower 50% net worth)	15.619	< .001	1.584	1.254	2.001
Having at least one private insurance policy	(No private insurance policy)	20.005	< .001	1.514	1.257	1.823
Cancer as a main illness that led to death	(Non-cancer)	.356	.553	1.083	.829	1.413
Heart disease as a past history	(No history of heart disease)	.709	.403	1.073	.907	1.270
Lung disease as a past history	(No history of lung disease)	.332	.567	.938	.751	1.172
Stroke as a past history	(No history of stroke)	1.027	.315	1.140	.880	1.476
Pain during the last year	(No)	2.065	.156	.869	.713	1.057
Perceived health status: Fair/poor	(Excellent-Good)	.019	.890	.986	.809	1.202
Expected death	(Unexpected death)	36.236	< .001	1.737	1.445	2.087

Note. OR, odds ratio; CI, Confidence interval

Appendix 4.6. Stage 3a. Characteristics of the sample: EOL discussions and durable power of attorney versus all advance care planning (N=2,849)

Category	Total (N=2849, 100%)	Unweighted		Weighted		$t/\chi^2$ (p)
		Discussion+DPAHC (N=752; 26.4%)	All ACP (N=2,097; 73.6%)	Discussion+DPAHC (N=46,782,666; 25.1%)	All ACP (N=139,395,564; 74.9%)	
		M (SD) N (%)	M (SD) N (%)	M (SE) N (%)	M (SE) N (%)	
Age at death	81.7 (10.1)	80.3 (11.0)	82.2 (9.7)	79.1 (.59)	81.4 (.34)	273.451 (<.001*)
Gender						.745 (.567)
Male	1222 (42.9)	343 (45.6)	879 (41.9)	21466122 (45.9)	61279146 (44.0)	
Female	1627 (57.1)	409 (54.4)	409 (58.1)	25316544 (4=54.1)	78116418 (56.0)	
Marital status						3.382 (.414)
Married	864 (35.2)	220 (34.6)	644 (35.4)	16253688 (36.2)	49462644 (36.6)	
Widowed	1278 (52.1)	330 (51.9)	948 (52.2)	21652944 (48.2)	68623662 (50.8)	
Separated/divorced, never married	311 (12.7)	86 (13.5)	225 (12.4)	6975930 (15.5)	17063238 (12.6)	
Race						53.885 (<.001*)
African American	232 (8.3)	114 (15.7)	118 (5.7)	5431230 (11.6)	5425932 (3.9)	
Non-African American	2554 (91.7)	612 (84.3)	1942 (94.3)	41335056 (88.4)	133969632 (96.1)	
Having resident children						1.269 (.384)
No	2333 (81.9)	594 (79.0)	1739 (82.9)	37839168 (80.9)	115434384 (82.8)	
Yes	516 (18.1)	158 (21.0)	358 (17.1)	8943498 (19.1)	23961180 (17.2)	
Religion						.405 (.634)
Catholic	680 (24.0)	178 (23.8)	502 (24.0)	11424978 (24.5)	32389944 (23.3)	
Non-Catholic	2157 (76.0)	569 (76.2)	1588 (76.0)	35193666 (75.5)	106663944 (76.7)	
Education						26.929 (.001*)
Less than high school	973 (34.2)	313 (41.7)	660 (31.5)	17212674 (36.8)	40764522 (29.2)	
High school graduate	1368 (48.1)	340 (45.3)	1028 (49.1)	23284578 (49.8)	68175126 (48.9)	
College and more	502 (17.7)	97 (12.9)	405 (19.4)	6285414 (13.4)	30439638 (21.8)	
Net worth						35.460 (<.001*)
Lower 50% net worth	1295 (50.0)	402 (58.9)	893 (46.8)	25401030 (57.6)	57589806 (43.7)	
Upper 50% net worth	1296 (50.0)	281 (41.1)	1015 (53.2)	18706164 (42.4)	74149962 (56.3)	
Having at least one private insurance policy						23.041 (<.001*)
No	1138 (40.8)	345 (47.3)	793 (38.5)	21897678 (48.2)	51160716 (37.5)	
Yes	1649 (59.2)	384 (52.7)	1265 (61.5)	23506074 (51.8)	85166196 (62.5)	
Main illness that led to death						.669 (.556)
Cancer	706 (25.1)	175 (23.6)	531 (25.6)	11753640 (25.4)	37150356 (27.0)	
Non-cancer	2109 (74.9)	568 (76.4)	1541 (74.4)	34539450 (74.6)	100339884 (73.0)	
Lung disease as a past history						.001 (.976)
No	2067 (73.3)	552 (74.5)	1515 (72.9)	33273756 (72.4)	100035660 (72.3)	
Yes	753 (26.7)	189 (25.5)	564 (27.1)	12685050 (27.6)	38251092 (27.7)	
Heart disease as a past history						2.361 (.229)
No	1179 (41.8)	318 (42.8)	861 (41.4)	20547798 (44.4)	56467830 (40.9)	
Yes	1644 (58.2)	425 (57.2)	1219 (58.6)	25766640 (55.6)	81428136 (59.1)	
Stroke as a past history						.977 (.416)
No	1967 (69.7)	508 (68.3)	1459 (70.2)	32651100 (70.5)	100098210 (72.5)	
Yes	855 (30.3)	236 (31.7)	619 (29.8)	13694736 (29.5)	38056764 (27.5)	
Pain during the last year						4.847 (.135)
No	1117 (39.8)	282 (38.1)	835 (40.4)	16386072 (35.5)	55534170 (40.3)	
Yes	1692 (60.2)	458 (61.9)	1234 (59.6)	29817900 (64.5)	82202538 (59.7)	
Perceived health status						.045 (.833)
Excellent-Good	960 (37.2)	257 (37.7)	703 (37.0)	17151474 (38.9)	50337924 (38.4)	
Fair/poor	1621 (62.8)	425 (62.3)	1196 (63.0)	26885147 (61.1)	80742096 (61.6)	
Expected death						2.601 (.145)
No	885 (32.0)	232 (31.8)	653 (32.1)	12868200 (28.9)	43418934 (32.3)	
Yes	1878 (68.0)	497 (68.2)	1381 (67.9)	31631100 (71.1)	90824652 (67.7)	

Note. \*p<.05

Appendix 4.7. Stage 3a. Simple complex samples logistic regression: Predictors associated with engagement in EOL discussions, durable power of attorney, and living will compared with engagement in EOL discussions and durable power of attorney (N=2,849)

Variable	Reference group	F	p	OR	95% CI	
					Lower	Upper
Age	-	11.793	.001	1.022	1.009	1.035
Female	(Male)	.331	.567	1.081	.824	1.417
Married	(Separated/divorced, never married)	.016	.900	1.017	.782	1.322
Widowed	(Separated/divorced, never married)	.863	.357	1.107	.889	1.377
African American	(Non-African American)	36.698	< .001	.308	.211	.450
Having resident children	(No resident children)	.769	.384	.878	.653	1.182
Catholic	(Non-Catholic)	.229	.634	.935	.707	1.237
High school graduate	(Less than high school graduate)	.100	.753	.966	.777	1.201
College or more	(Less than high school graduate)	10.817	.002	1.800	1.258	2.576
Upper 50% net worth	(Lower 50% net worth)	18.543	< .001	1.748	1.348	2.268
Having at least one private insurance policy	(No private insurance policy)	20.624	< .001	1.551	1.278	1.882
Cancer as a main illness that led to death	(Non-cancer)	.352	.556	1.088	.818	1.447
Heart disease as a past history	(No history of heart disease)	1.482	.229	1.150	.914	1.447
Lung disease as a past history	(No history of lung disease)	.001	.976	1.003	.822	1.224
Stroke as a past history	(No history of stroke)	.673	.416	.906	.713	1.152
Pain during the last year	(No)	2.295	.136	.813	.619	1.069
Perceived health status: Fair/poor	(Excellent-Good)	.045	.833	1.023	.823	1.272
Expected death	(Unexpected death)	2.189	.145	.851	.684	1.059

Note. OR, odds ratio; CI, Confidence interval

Appendix 4.8. Stage 3b. Characteristics of the sample: EOL discussions and living will versus all advance care planning (N=2,445)

Category	Total (N=2445, 100%)	Unweighted		Weighted		$\chi^2$ (p)
		Discussion+LW (N=348, 14.2%)	All ACP (N=2097, 85.8%)	Discussion+LW (N=22,135,110; 13.7%)	All ACP (N=139,395,564; 86.3%)	
	M (SD) N (%)	M (SD) N (%)	M (SD) N (%)	M (SE) N (%)	M (SE) N (%)	
Age at death	81.8 (9.7)	79.4 (9.8)	82.2 (9.7)	77.7 (.83)	81.4 (.34)	273.306 (<.001*)
Gender						4.452 (.114)
Male	1040 (42.5)	161 (46.3)	879 (41.9)	11148378 (50.4)	61279146 (44.0)	
Female	1405 (57.5)	187 (53.7)	409 (54.4)	10986732 (49.6)	78116418 (56.0)	
Marital status						57.130 (<.001*)
Married	781 (37.2)	137 (48.2)	644 (35.4)	11194596 (53.2)	49462644 (36.6)	
Widowed	1039 (49.5)	91 (32.0)	948 (52.2)	5524830 (26.3)	68623662 (50.8)	
Separated/divorced/never married	281 (13.4)	56 (19.7)	225 (12.4)	4321068 (20.5)	17063238 (12.6)	
Race						3.759 (.108)
African American	150 (6.2)	32 (9.4)	118 (5.7)	1388112 (6.3)	5425932 (3.9)	
Non-African American	2251 (93.8)	309 (90.6)	1942 (94.3)	20746998 (93.7)	133969632 (96.1)	
Having resident children						3.020 (.246)
No	2018 (82.5)	279 (80.2)	1739 (82.9)	17433234 (78.8)	115434384 (82.8)	
Yes	427 (17.5)	69 (19.8)	358 (17.1)	4701876 (21.2)	23961180 (17.2)	
Religion						4.424 (.080)
Catholic	593 (24.3)	91 (26.3)	502 (24.0)	6341970 (28.8)	32389944 (23.3)	
Non-Catholic	1843 (75.7)	255 (73.7)	1588 (76.0)	15686262 (72.2)	106663944 (76.7)	
Education						19.268 (.017*)
Less than high school	805 (33.0)	145 (41.8)	660 (31.5)	8672616 (39.2)	40764522 (29.2)	
High school graduate	1185 (48.6)	157 (45.2)	1028 (49.1)	10622520 (48.0)	68175126 (48.9)	
College and more	450 (18.4)	45 (13.0)	405 (19.4)	2839974 (12.8)	30439638 (21.8)	
Net worth						16.562 (.002*)
Lower 50% net worth	1113 (50.0)	189 (59.8)	924 (48.4)	12162240 (58.5)	60029262 (45.6)	
Upper 50% net worth	1111 (50.0)	127 (40.2)	984 (51.6)	8634294 (41.5)	71710506 (54.4)	
Having at least one private insurance policy						25.530 (<.001*)
No	952 (39.7)	159 (46.9)	793 (38.5)	11367564 (52.8)	51160716 (37.5)	
Yes	1445 (60.3)	180 (53.1)	1265 (61.5)	10163544 (47.2)	85166196 (62.5)	
Main illness that led to death						1.451 (.422)
Cancer	626 (25.9)	95 (27.9)	531 (25.6)	6571416 (30.3)	37150356 (27.0)	
Non-cancer	1787 (74.1)	246 (72.1)	1541 (74.4)	15092802 (69.7)	100339884 (73.0)	
Lung disease as a past history						20.761 (.002*)
No	1742 (71.8)	227 (65.4)	1515 (72.9)	13177350 (59.6)	100035660 (72.3)	
Yes	684 (28.2)	120 (34.6)	564 (27.1)	8916372 (40.4)	38251092 (27.7)	
Heart disease as a past history						.595 (.567)
No	1007 (41.5)	146 (42.1)	861 (41.4)	9536898 (43.3)	56467830 (40.9)	
Yes	1420 (58.5)	201 (57.9)	1219 (58.6)	12503430 (56.7)	81428136 (59.1)	
Stroke as a past history						.213 (.739)
No	1717 (70.8)	256 (74.1)	1459 (70.2)	16316208 (73.7)	1000982410 (72.5)	
Yes	709 (29.2)	90 (25.9)	619 (29.8)	5818902 (26.3)	38056764 (27.5)	
Pain during the last year						2.509 (.203)
No	967 (40.0)	132 (38.0)	835 (40.4)	7876512 (35.6)	55534170 (40.3)	
Yes	1449 (60.0)	215 (62.0)	1234 (59.6)	14258598 (64.4)	82202538 (59.7)	
Perceived health status						.247 (.100)
Excellent-Good	817 (36.9)	114 (36.2)	703 (37.0)	7638510 (36.9)	50337924 (38.4)	
Fair/poor	1397 (63.1)	201 (63.8)	1196 (63.0)	13082592 (63.1)	80742096 (61.6)	
Expected death						11.175 (.024*)
No	793 (33.4)	140 (40.8)	653 (32.1)	9076524 (42.1)	43418934 (32.3)	
Yes	1584 (66.6)	203 (59.2)	1381 (67.9)	12489390 (57.9)	90824652 (67.7)	

Note. \*  $p < .05$

Appendix 4.9. Stage 3b. Simple complex samples logistic regression: Predictors associated with engagement in EOL discussions, durable power of attorney, and living compared with engagement in EOL discussions and living will (N=2,445)

Variable	Reference group	F	p	OR	95% CI	
					Lower	Upper
Age	-	16.061	<.001	1.038	1.019	1.057
Female	(Male)	2.569	.115	1.294	.937	1.785
Married	(Separated/divorced, never married)	11.840	.001	.508	.342	.754
Widowed	(Separated/divorced, never married)	28.783	<.001	2.897	1.946	4.312
African American	(Non-African American)	0.629	.111	.610	.327	1.138
Having resident children	(No resident children)	1.372	.247	.770	.491	1.205
Catholic	(Non-Catholic)	3.168	.081	.751	.544	1.037
High school graduate	(Less than high school graduate)	.036	.850	1.038	.703	1.532
College or more	(Less than high school graduate)	6.283	.015	1.898	1.136	3.171
Upper 50% net worth	(Lower 50% net worth)	10.585	.002	1.683	1.221	2.320
Having at least one private insurance policy	(No private insurance policy)	14.783	<.001	1.862	1.346	2.575
Cancer as a main illness that led to death	(Non-cancer)	.655	.422	.850	.569	1.271
Heart disease as a past history	(No history of heart disease)	.333	.567	1.100	.790	1.532
Lung disease as a past history	(No history of lung disease)	10.637	.002	.565	.398	.803
Stroke as a past history	(No history of stroke)	.112	.739	1.066	.726	1.565
Pain during the last year	(No)	1.660	.203	.818	.598	1.119
Perceived health status: Fair/poor	(Excellent-Good)	.100	.753	.937	.618	1.420
Expected death	(Unexpected death)	5.356	.025	1.520	1.057	2.187

Note. OR, odds ratio; CI, Confidence interval

Appendix 4.10. RQ2. Characteristics of the sample: All possible care to prolong life (N=2,677)

Category	Total	All possible care to prolong life				$\chi^2$ (p)
		Unweighted		Weighted		
		No (N=2010; 76.2%)	Yes (N=629; 23.8%)	No (N=121,873,200; 76.1%)	Yes (N=38,176,824; 23.9%)	
	M (SD)	M (SD)	M (SD)	M (SE)		
Age at death	79.9 (10.6)	80.6 (10.3)	77.5 (11.2)	79.7 (.39)	76.9 (.61)	227.397 (<.001***)
	N (%)	N (%)	N (%)	N (%)	N (%)	
Types of engagement in ACP						217.852 (<.001*)
No ACP	519 (19.4)	278 (13.8)	224 (35.6)	12925962 (10.6)	10956924 (28.7)	
Discussion only	458 (17.1)	303 (15.1)	148 (23.5)	16170858 (13.3)	9023280 (23.6)	
Discussion + DPAHC	413 (15.4)	303 (15.1)	105 (16.7)	18646506 (15.3)	7031454 (18.4)	
Discussion + LW	153 (5.7)	130 (6.5)	23 (3.7)	7751922 (6.4)	1961766 (5.1)	
Discussion + DPAHC + LW	1134 (42.4)	996 (49.6)	129 (20.5)	66377952 (54.5)	9203400 (24.1)	
Gender						.076 (.835)
Male	1159 (43.3)	869 (43.2)	277 (44.0)	55235916 (45.3)	17552256 (45.0)	
Female	1518 (56.7)	1141 (56.8)	352 (56.0)	66637284 (54.7)	20624568 (54.0)	
Marital status						1.573 (.595)
Married	862 (38.7)	639 (38.7)	213 (39.1)	46009440 (39.5)	15275892 (41.5)	
Widowed	1051 (47.2)	789 (47.8)	246 (45.1)	53439786 (45.9)	157345684 (42.7)	
Separated/divorced/never married	314 (14.1)	223 (13.5)	86 (15.8)	17078250 (14.7)	5830122 (15.8)	
Race						82.329 (<.001*)
African American	398 (15.3)	212 (10.8)	179 (29.8)	8200266 (6.7)	7453290 (19.5)	
Non-African American	2202 (84.7)	1750 (89.2)	422 (70.2)	113672935 (93.3)	30701700 (80.5)	
Having resident children						41.572 (<.001*)
No	2102 (78.5)	1622 (80.7)	450 (71.5)	100451214 (82.4)	26744706 (70.1)	
Yes	575 (21.5)	388 (19.3)	179 (28.5)	21421986 (17.6)	11432118 (29.9)	
Religion						1.368 (.378)
Catholic	677 (25.4)	507 (25.4)	160 (25.6)	30277506 (25.0)	10432350 (27.4)	
Non-Catholic	1959 (74.6)	1493 (74.7)	466 (74.4)	94045272 (75.0)	27668220 (72.6)	
Education						48.313 (<.001*)
Less than high school	1086 (40.7)	740 (36.9)	329 (52.4)	38766840 (31.8)	17740860 (46.5)	
High school graduate	1155 (43.3)	913 (45.6)	229 (36.5)	57594942 (47.3)	15792408 (41.4)	
College and more	429 (16.1)	351 (17.5)	70 (11.1)	25469316 (20.9)	4643556 (12.2)	
Net worth						38.509 (<.001*)
Lower 50% net worth	1205 (50.0)	848 (46.6)	334 (60.6)	48878916 (42.4)	20485716 (57.8)	
Upper 50% net worth	1203 (50.0)	973 (53.4)	217 (39.4)	66270600 (57.6)	14929998 (42.2)	
Having at least one private insurance policy						51.760 (<.001*)
No	1194 (45.6)	808 (41.1)	367 (59.7)	47521890 (40.1)	21185544 (57.3)	
Yes	1424 (54.4)	1158 (58.9)	248 (40.3)	71080008 (59.9)	15816528 (42.7)	
Main illness that led to death						.924 (.461)
Cancer and tumors	653 (24.7)	497 (25.0)	146 (23.5)	31923792 (26.4)	9160464 (24.4)	
Non-cancer	1991 (75.3)	1491 (75.0)	474 (76.5)	88779096 (73.6)	28336530 (75.6)	
Lung disease as a past history						.199 (.720)
No	1955 (73.6)	1472 (73.6)	456 (73.4)	86491866 (71.4)	26420250 (70.5)	
Yes	703 (26.4)	527 (26.4)	165 (26.6)	34581690 (28.6)	11070486 (29.5)	
Heart disease as a past history						2.343 (.259)
No	1186 (44.7)	886 (44.4)	277 (44.5)	53704458 (44.4)	15334692 (40.7)	
Yes	1468 (55.3)	1108 (55.6)	346 (55.5)	67362294 (55.6)	22312554 (59.3)	
Stroke as a past history						2.232 (.297)
No	1814 (68.3)	1370 (68.6)	421 (67.9)	85903116 (70.8)	25457742 (67.6)	
Yes	840 (31.7)	626 (31.4)	199 (32.1)	35353044 (29.2)	12216018 (32.4)	
Pain during the last year						16.572 (.006*)
No	979 (37.2)	757 (38.3)	209 (33.9)	45989982 (38.2)	10865898 (28.8)	
Yes	1654 (62.8)	1222 (61.7)	408 (66.1)	74427528 (61.8)	26812644 (71.2)	
Perceived health status						8.527 (.042*)
Excellent-Good	886 (36.9)	688 (37.9)	184 (33.5)	46834020 (40.8)	11850900 (33.7)	
Fair/poor	886 (36.9)	688 (37.9)	184 (33.5)	46834020 (40.8)	11850900 (33.7)	
Expected death						20.604 (.001*)
No	840 (32.3)	585 (30.0)	239 (39.2)	34706466 (29.7)	14478360 (40.0)	
Yes	1759 (67.7)	1367 (70.0)	371 (60.8)	82056864 (70.3)	21736056 (60.0)	
Participation of patient in final decision-making						1.676 (.293)
No	1686 (68.0)	1269 (68.8)	390 (65.0)	73633836 (65.6)	23049600 (62.6)	
Yes	1686 (68.0)	1269 (68.8)	390 (65.0)	73633836 (65.6)	23049600 (62.6)	
	792 (32.0)	575 (31.2)	210 (35.0)	38570790 (34.4)	13766634 (37.4)	

Note. \* p<.05

Appendix 4.11. RQ2. Simple complex samples logistic regression: Predictors of receiving all possible care to prolong life (N=2,677)

Variable	Reference group	F	p	OR	95% CI	
					Lower	Upper
Age	-	18.100	< .001	.975	.963	.987
Female	(Male)	.044	.835	.974	.756	1.255
Married	(Separated/divorced, never married)	.415	.522	1.086	.840	1.402
Widowed	(Separated/divorced, never married)	1.176	.283	.880	.695	1.115
African American	(Non-African American)	44.776	< .001	3.365	2.339	4.842
Having resident children	(No resident children)	28.019	< .001	2.004	1.540	2.609
Catholic	(Non-Catholic)	.789	.379	1.134	.854	1.506
High school graduate	(Less than high school graduate)	2.734	.104	.787	.588	1.052
College or more	(Less than high school graduate)	10.383	.002	.524	.350	.783
Upper 50% net worth	(Lower 50% net worth)	17.461	< .001	.538	.399	.724
Having at least one private insurance policy	(No private insurance policy)	33.571	< .001	.499	.392	.635
Cancer as a main illness that led to death	(Non-cancer)	.551	.461	.899	.674	1.199
Heart disease as a past history	(No history of heart disease)	1.301	.259	1.160	.894	1.506
Lung disease as a past history	(No history of lung disease)	.130	.720	1.048	.807	1.360
Stroke as a past history	(No history of stroke)	1.109	.297	1.166	.870	1.562
Pain during the last year	(No)	8.226	.006	1.525	1.135	2.048
Perceived health status: Fair/poor	(Excellent-Good)	4.326	.042	1.356	1.011	1.820
Expected death	(Unexpected death)	12.999	.001	.635	.493	.818
Participation of patient in final decision-making	(No participation)	1.129	.293	1.140	.890	1.461
Discussion only	(No advance care planning)	16.849	< .001	2.023	1.434	2.855
Discussion + DPAHC	(No advance care planning)	4.177	.046	1.250	1.004	1.556
Discussion + LW	(No advance care planning)	.522	.473	.797	.425	1.495
Discussion + DPAHC + LW	(No advance care planning)	116.905	< .001	.266	.208	.340

Note. OR, odds ratio; CI, Confidence interval



## Appendix 4.12. RQ3. Characteristics of the sample: Comfort care (N=2,677)

Category	Total	Comfort care				t/x2 (p)
		Unweighted		Weighted		
		No (N=183; 6.9%)	Yes (N=2468; 93.1%)	No (N=11,297,112; 7.0%)	Yes (N=149,990,784; 93.0%)	
	M (SD)	M (SD)	M (SD)	M (SE)		
Age at death	79.9 (10.6)	78.2 (10.4)	80.0 (10.6)	76.3 (1.05)	79.3 (.40)	232.048 (<.001*)
	N (%)	N (%)	N (%)	N (%)		
Types of engagement in ACP						104.064 (<.001*)
No ACP	519 (19.4)	78 (42.6)	431 (17.5)	4431144 (39.2)	20349630 (13.6)	
Discussion only	458 (17.1)	43 (23.5)	411 (16.7)	2634750 (23.3)	22737162 (15.2)	
Discussion + DPAHC	413 (15.4)	22 (12.0)	387 (15.7)	1312788 (11.6)	24459978 (16.3)	
Discussion + LW	153 (5.7)	7 (3.8)	145 (5.9)	521478 (4.6)	9083544 (6.1)	
Discussion + DPAHC + LW	1134 (42.4)	33 (18.0)	1094 (44.3)	2396952 (21.2)	73360470 (48.9)	
Gender						21.559 (.001*)
Male	1159 (43.3)	104 (56.8)	1045 (42.3)	7045242 (62.4)	66110082 (44.1)	
Female	1518 (56.7)	79 (43.2)	1423 (57.7)	4251870 (37.6)	83880702 (55.9)	
Marital status						12.194 (.039*)
Married	862 (38.7)	72 (49.7)	781 (37.9)	5646132 (53.4)	55953756 (38.9)	
Widowed	1051 (47.2)	55 (37.9)	988 (47.9)	3835452 (36.3)	66024264 (45.8)	
Separated/divorced./never married	314 (14.1)	18 (12.4)	292 (14.2)	1084848 (10.3)	22030248 (15.3)	
Race						6.159 (.061)
African American	398 (15.3)	40 (22.6)	352 (14.7)	1708986 (15.1)	13963704 (9.3)	
Non-African American	2202 (84.7)	137 (77.4)	2045 (85.3)	9588126 (84.9)	136005246 (90.7)	
Having resident children						7.016 (.056)
No	2102 (78.5)	135 (73.8)	1944 (78.8)	8058528 (71.3)	119740518 (79.8)	
Yes	575 (21.5)	48 (26.2)	524 (21.2)	3238584 (28.7)	30250266 (20.2)	
Religion						.000 (.999)
Catholic	672 (25.5)	46 (25.3)	626 (25.5)	2890674 (25.7)	38423364 (25.7)	
Non-Catholic	1966 (74.5)	136 (74.7)	1830 (74.5)	8352018 (74.3)	110995164 (74.3)	
Education						.543 (.839)
Less than high school	1086 (40.7)	83 (45.4)	992 (40.3)	3992898 (35.3)	53324238 (35.6)	
High school graduate	1155 (43.3)	76 (41.5)	1070 (43.5)	4946574 (43.8)	68608764 (45.8)	
College and more	429 (16.1)	24 (13.1)	399 (16.2)	2357640 (20.9)	28015680 (18.7)	
Net worth						3.604 (.178)
Lower 50% net worth	1205 (50.0)	94 (58.8)	1097 (49.4)	5494662 (53.6)	64468674 (45.6)	
Upper 50% net worth	1203 (50.0)	66 (41.2)	1125 (50.6)	4763376 (46.4)	76820742 (54.4)	
Having at least one private insurance policy						14.205 (.005*)
No	1194 (45.6)	104 (57.5)	1076 (44.6)	6488592 (58.0)	62834052 (43.1)	
Yes	1424 (54.4)	77 (42.5)	1337 (55.4)	4707546 (42.0)	82951194 (56.9)	
Main illness that led to death						8.638 (.070)
Cancer and tumors	653 (24.7)	26 (14.5)	623 (25.5)	1764084 (16.3)	39744168 (26.8)	
Non-cancer	1991 (75.3)	153 (85.5)	1816 (74.5)	9029382 (83.7)	108690060 (73.2)	
Lung disease as a past history						1.379 (.164)
No	1955 (73.6)	134 (73.6)	1803 (73.6)	7559862 (67.2)	106085814 (71.4)	
Yes	703 (26.4)	48 (26.4)	647 (26.4)	3690462 (32.8)	42466026 (28.6)	
Heart disease as a past history						3.558 (.186)
No	1186 (44.7)	72 (40.0)	1105 (45.1)	4088754 (36.9)	65962344 (44.3)	
Yes	1468 (55.3)	108 (60.0)	1343 (54.9)	7005288 (63.1)	82852686 (55.7)	
Stroke as a past history						.104 (.816)
No	1814 (68.3)	131 (72.4)	1665 (68.0)	7963140 (71.1)	10412388 (69.9)	
Yes	840 (31.7)	50 (27.6)	782 (32.0)	3240618 (28.9)	44840154 (30.1)	
Pain during the last year						1.983 (.263)
No	979 (37.2)	71 (39.7)	898 (37.0)	4599600 (41.2)	52976880 (35.8)	
Yes	1654 (62.8)	108 (60.3)	1530 (63.0)	6574338 (58.8)	95120100 (64.2)	
Perceived health status						1.843 (.306)
Excellent-Good	886 (36.9)	65 (40.6)	810 (36.6)	4544328 (44.3)	54537618 (38.7)	
Fair/poor	1516 (63.1)	95 (59.4)	1406 (63.4)	5713710 (55.7)	86214942 (61.3)	
Expected death						34.201 (<.001*)
No	840 (32.3)	92 (51.4)	730 (30.4)	5475240 (52.7)	43763940 (30.4)	
Yes	1759 (67.7)	85 (48.6)	1670 (69.6)	4907346 (47.3)	100089726 (69.6)	
Participation of patient in final decision-making						1.618 (.297)
No	1686 (68.0)	116 (71.2)	1554 (67.8)	7054146 (69.8)	90593454 (64.7)	
Yes	792 (32.0)	47 (28.8)	737 (32.2)	3048360 (30.2)	49339332 (35.3)	

Note. \*  $p < .05$

Appendix 4.13. RQ3. Simple complex samples logistic regression: Predictors of receiving comfort care (N=2,677)

Variable	Reference group	F	p	OR	95% CI	
					Lower	Upper
Age	-	5.221	.026	1.026	1.003	1.050
Female	(Male)	11.495	.001	2.102	1.355	3.263
Married	(Separated/divorced, never married)	6.169	.016	.554	.344	.892
Widowed	(Separated/divorced, never married)	2.360	.130	1.486	.886	2.491
African American	(Non-African American)	3.578	.064	.576	.321	1.034
Having resident children	(No resident children)	3.749	.058	.629	.389	1.017
Catholic	(Non-Catholic)	.000	.999	1.000	.565	1.770
High school graduate	(Less than high school graduate)	.177	.676	1.083	.741	1.583
College or more	(Less than high school graduate)	.164	.687	.871	.440	1.726
Upper 50% net worth	(Lower 50% net worth)	1.847	.180	1.375	.860	2.198
Having at least one private insurance policy	(No private insurance policy)	8.297	.006	1.820	1.199	2.761
Cancer as a main illness that led to death	(Non-cancer)	3.325	.074	1.872	.939	3.729
Heart disease as a past history	(No history of heart disease)	1.787	.187	.733	.460	1.168
Lung disease as a past history	(No history of lung disease)	1.273	.264	.820	.576	1.167
Stroke as a past history	(No history of stroke)	.054	.816	1.058	.650	1.722
Pain during the last year	(No)	1.277	.264	1.256	.838	1.883
Perceived health status: Fair/poor	(Excellent-Good)	1.064	.307	1.257	.806	1.962
Expected death	(Unexpected death)	16.637	< .001	2.552	1.610	4.045
Participation of patient in final decision-making	(No participation)	1.104	.298	1.260	.810	1.960
Discussion only	(No advance care planning)	5.495	.023	.587	.373	.926
Discussion + DPAHC	(No advance care planning)	1.639	.206	1.482	.800	2.745
Discussion + LW	(No advance care planning)	.256	.615	1.332	.428	4.148
Discussion + DPAHC + LW	(No advance care planning)	19.730	< .001	3.555	2.005	6.303

Note. OR, odds ratio; CI, Confidence interval

Appendix 4.14. RQ4a. Characteristics of the sample: Congruency for all possible care to prolong life among decedents who had a living will (N=1,634)

Category	Total	All possible care to prolong life				t/x2 (p)
		Unweighted		Weighted		
		Incongruency (N=180; 11.2%)	Congruency (N=1426; 88.8%)	Incongruency (N=12,712,776, 12.1%)	Congruency (N=91,959,678, 87.9%)	
	M (SD)	M (SD)	M (SD)	M (SE)		
Age at death	81.8 (9.6)	80.8 (9.5)	81.9 (9.6)	80.7 (.94)	80.9 (.40)	230.249 (<.001*)
	N (%)	N (%)			N (%)	
End-of-life discussion						3.105 (.080)
No	331 (20.3)	42 (23.9)	277 (19.5)	2883474 (22.7)	15856368 (17.3)	
Yes	1296 (79.7)	137 (76.1)	1143 (80.5)	9829302 (77.3)	75890544 (82.7)	
DPAHC						2.946 (.185)
No	190 (11.7)	25 (13.9)	163 (11.5)	1854420 (14.6)	9352848 (10.3)	
Yes	1429 (88.3)	155 (86.1)	1249 (88.5)	10858356 (85.4)	81174054 (89.7)	
Gender						.001 (.986)
Male	672 (41.1)	73 (40.6)	588 (41.2)	5666850 (44.6)	40885734 (44.5)	
Female	962 (58.9)	107 (59.4)	838 (58.8)	7045926 (55.4)	51073944 (55.5)	
Marital status						1.239 (.725)
Married	500 (35.6)	56 (33.7)	435 (35.8)	4521252 (36.3)	32990406 (37.1)	
Widowed	709 (50.4)	86 (51.8)	613 (50.4)	6486510 (52.1)	42969720 (48.4)	
Separated/divorced/never married	197 (14.0)	24 (14.5)	168 (13.8)	1435330 (11.7)	12906690 (14.5)	
Race						2.315 (.094)
African American	97 (6.0)	18 (10.1)	77 (5.5)	748458 (5.9)	3269178 (3.6)	
Non-African American	1508 (94.0)	160 (89.9)	1323 (94.5)	11964318 (94.1)	88690500 (96.4)	
Having resident children						11.149 (.019*)
No	1364 (83.5)	142 (78.9)	1196 (83.9)	9593190 (75.5)	78368022 (85.2)	
Yes	270 (16.5)	38 (21.1)	230 (16.1)	3119586 (24.5)	13591656 (14.8)	
Religion						.003 (.960)
Catholic	383 (24.0)	40 (22.2)	343 (24.2)	2952804 (23.2)	21436440 (23.4)	
Non-Catholic	1216 (76.0)	140 (77.8)	1076 (75.8)	9759972 (66.8)	70091886 (76.6)	
Education						10.023 (.101)
Less than high school	501 (30.7)	69 (38.3)	424 (29.8)	4502658 (35.4)	24169404 (26.3)	
High school graduate	796 (48.8)	87 (48.3)	695 (48.8)	6274734 (49.4)	45759342 (49.8)	
College and more	334 (20.5)	24 (13.3)	304 (21.4)	1935384 (15.2)	22030932 (24.0)	
Net worth						6.981 (.033*)
Lower 50% net worth	736 (50.0)	90 (58.1)	630 (48.9)	6495642 (57.3)	39766968 (46.1)	
Upper 50% net worth	736 (50.0)	65 (41.9)	659 (51.1)	4847274 (42.7)	46581582 (53.9)	
Having at least one private insurance policy						6.532 (.022*)
No	591 (36.9)	85 (47.8)	495 (35.5)	5733816 (45.8)	32105454 (35.9)	
Yes	1011 (63.1)	93 (52.2)	901 (64.5)	6784800 (54.2)	57347736 (64.1)	
Main illness that led to death						.525 (.493)
Cancer	410 (25.3)	46 (25.6)	355 (25.2)	3654912 (28.7)	23801658 (26.2)	
Non-cancer	1208 (74.7)	134 (74.4)	1055 (74.8)	9057864 (71.3)	67059906 (73.8)	
Lung disease as a past history						4.539 (.170)
No	1202 (74.1)	126 (70.0)	1055 (74.5)	8295606 (65.3)	66498936 (72.9)	
Yes	421 (25.9)	54 (30.0)	361 (25.5)	4417170 (34.7)	24728862 (27.1)	
Heart disease as a past history						2.656 (.205)
No	695 (42.8)	74 (41.3)	610 (43.0)	4718202 (37.2)	39858576 (43.7)	
Yes	939 (57.2)	105 (58.7)	808 (57.0)	7948572 (62.8)	1363714 (56.3)	
Stroke as a past history						.795 (.367)
No	1124 (69.1)	113 (63.1)	990 (69.8)	8620176 (67.9)	65191038 (71.2)	
Yes	502 (30.9)	66 (36.9)	429 (30.2)	4070712 (32.1)	26414478 (28.8)	
Pain during the last year						.093 (.811)
No	639 (39.7)	68 (38.0)	558 (39.8)	4901478 (38.6)	36076350 (39.7)	
Yes	971 (60.3)	111 (62.0)	845 (60.2)	7811298 (61.4)	54691044 (60.3)	
Perceived health status						2.551 (.184)
Excellent-Good	566 (38.6)	52 (33.5)	500 (39.0)	3912846 (34.5)	35416062 (41.2)	
Fair/poor	900 (61.4)	103 (66.5)	783 (61.0)	7430070 (65.5)	40623968 (58.8)	
Expected death						2.033 (.246)
No	477 (30.1)	64 (37.2)	402 (29.0)	4223646 (35.3)	36489052 (30.0)	
Yes	1108 (69.9)	108 (62.8)	983 (71.0)	7729998 (64.7)	61920564 (70.0)	
Participation of patient in final decision-making						.669 (.484)
No	1208 (67.9)	108 (63.2)	900 (68.2)	7279536 (60.3)	54321444 (63.5)	
Yes	485 (32.1)	63 (36.8)	419 (31.8)	4794978 (39.7)	31176060 (36.5)	

Note. \*  $p < .05$

Appendix 4.15. RQ4a. Simple complex samples logistic regression: Predictors of receiving care consistent with their preferences for all possible care to prolong life (N=1,634)

Variable	Reference group	F	p	OR	95% CI	
					Lower	Upper
Age	-	.027	.870	1.002	.979	1.025
Female	(Male)	.000	.986	1.005	.589	1.715
Married	(Separated/divorced, never married)	.019	.891	1.037	.612	1.756
Widowed	(Separated/divorced, never married)	.360	.551	.862	.525	1.416
African American	(Non-African American)	2.856	.097	.592	.317	1.107
Having resident children	(No resident children)	5.750	.020	.533	.315	.903
Catholic	(Non-Catholic)	.002	.960	1.011	.653	1.564
High school graduate	(Less than high school graduate)	.005	.944	1.016	.642	1.607
College or more	(Less than high school graduate)	2.960	.092	1.754	.910	3.382
Upper 50% net worth	(Lower 50% net worth)	4.733	.034	1.570	1.035	2.380
Having at least one private insurance policy	(No private insurance policy)	5.552	.022	1.510	1.063	2.144
Cancer as a main illness that led to death	(Non-cancer)	.476	.494	.880	.605	1.278
Heart disease as a past history	(No history of heart disease)	1.643	.206	.765	.503	1.164
Lung disease as a past history	(No history of lung disease)	1.926	.171	.698	.415	1.174
Stroke as a past history	(No history of stroke)	.826	.368	.858	.612	1.204
Pain during the last year	(No)	.058	.811	.951	.626	1.444
Perceived health status: Fair/poor	(Excellent-Good)	1.810	.185	.753	.493	1.150
Expected death	(Unexpected death)	1.375	.246	1.277	.840	1.942
Participation of patient in final decision-making	(No participation)	.497	.484	.871	.588	1.290
End-of-life discussion	(No discussion)	3.167	.081	1.404	.957	2.060
DPAHC	(No DPAHC)	1.788	.187	1.482	.821	2.677

Note. OR, odds ratio; CI, Confidence interval

Appendix 4.16. RQ4b. Characteristics of the sample: Congruency comfort care among decedents who had a living will (N=1,634)

Category	Total	Comfort care				t/x2 (p)
		Unweighted		Weighted		
		Incongruency (N=133; 8.3%)	Congruency (N=1467; 91.7%)	Incongruency (N=8,720,874, 8.4%)	Congruency (N=95,537,166, 91.6%)	
	M (SD)	M (SD)	M (SD)	M (SE)		
Age at death	81.8 (9.6)	78.9 (10.2)	82.1 (9.5)	77.6 (1.38)	81.2 (.40)	221.776 (<.001*)
	N (%)	N (%)	N (%)	N (%)		
End-of-life discussion						1.068 (.393)
No	331 (20.3)	34 (25.8)	284 (19.4)	1879908 (21.6)	17010960 (17.8)	
Yes	1296 (79.7)	98 (74.2)	1178 (80.6)	6821262 (78.4)	78333144 (82.2)	
DPAHC						7.797 (.033*)
No	190 (11.7)	19 (14.5)	167 (11.5)	1553526 (18.2)	9451296 (10.0)	
Yes	1429 (88.3)	112 (85.5)	1288 (88.5)	6983760 (81.8)	85162668 (90.0)	
Gender						2.107 (.290)
Male	672 (41.1)	62 (46.6)	597 (40.7)	4392342 (50.4)	41624976 (43.6)	
Female	962 (58.9)	71 (53.4)	870 (59.3)	4328532 (49.6)	53912190 (56.4)	
Marital status						7.070 (.147)
Married	500 (35.6)	46 (40.7)	446 (35.3)	3536418 (42.3)	34121226 (36.9)	
Widowed	709 (50.4)	47 (41.6)	646 (51.1)	3113310 (37.3)	4822900 (49.5)	
Separated/divorced,/never married	197 (14.0)	20 (17.7)	171 (13.5)	170504 (20.4)	12613608 (13.6)	
Race						3.646 (.019*)
African American	97 (6.0)	16 (12.3)	77 (5.3)	606294 (7.0)	3353442 (3.5)	
Non-African American	1508 (94.0)	114 (87.7)	1364 (94.7)	8114580 (93.0)	92183724 (96.5)	
Having resident children						.028 (.881)
No	1364 (83.5)	107 (80.5)	1226 (83.6)	7381950 (84.6)	80316150 (84.1)	
Yes	270 (16.5)	26 (19.5)	241 (16.4)	1338924 (15.4)	15221016 (15.9)	
Religion						5.115 (.039*)
Catholic	383 (24.0)	25 (18.8)	358 (24.5)	1323492 (15.2)	23022936 (24.2)	
Others or no religion	1210 (76.0)	108 (81.2)	1102 (75.5)	7397382 (84.8)	72082878 (75.8)	
Education						5.709 (.166)
Less than high school	501 (30.7)	38 (28.6)	451 (30.8)	2364354 (27.1)	26485374 (27.7)	
High school graduate	796 (48.8)	74 (55.6)	705 (48.2)	5024040 (57.6)	46103754 (48.3)	
College and more	334 (20.5)	21 (15.8)	308 (21.0)	1332480 (15.3)	22948038 (24.0)	
Net worth						1.789 (.319)
Lower 50% net worth	736 (50.0)	67 (56.8)	649 (49.1)	4320690 (52.9)	41377944 (46.3)	
Upper 50% net worth	736 (50.0)	51 (43.2)	673 (50.9)	3849948 (47.1)	47962038 (53.7)	
Having at least one private insurance policy						.280 (.624)
No	591 (36.9)	50 (38.5)	527 (36.6)	3014424 (35.2)	35166348 (37.7)	
Yes	1011 (63.1)	80 (61.5)	914 (63.4)	5537790 (64.8)	58158252 (62.3)	
Main illness that led to death						.198 (.735)
Cancer	410 (25.3)	38 (28.8)	365 (25.1)	2485140 (28.8)	25450332 (26.9)	
Non-cancer	1208 (74.7)	94 (71.2)	1087 (74.9)	6144510 (71.2)	69079944 (73.1)	
Lung disease as a past history						4.172 (.113)
No	1202 (74.1)	98 (74.2)	1083 (74.3)	5572644 (64.6)	69480570 (73.2)	
Yes	421 (25.9)	34 (25.8)	375 (25.7)	3057330 (35.4)	25415616 (26.8)	
Heart disease as a past history						.000 (1.000)
No	695 (42.8)	60 (45.8)	620 (42.4)	3662148 (42.7)	40549014 (42.7)	
Yes	939 (57.2)	71 (54.2)	841 (57.6)	4917942 (57.3)	54457872 (57.3)	
Stroke as a past history						.689 (.548)
No	1124 (69.1)	95 (72.5)	1004 (68.7)	6390378 (74.2)	67321122 (70.7)	
Yes	502 (30.9)	36 (27.5)	457 (31.3)	2217708 (25.8)	27952782 (29.3)	
Pain during the last year						1.656 (.422)
No	639 (39.7)	40 (30.8)	587 (40.6)	2950548 (34.5)	38264262 (40.5)	
Yes	971 (60.3)	90 (69.2)	860 (59.4)	5612292 (65.5)	56304726 (59.5)	
Perceived health status						2.583 (.184)
Excellent-Good	566 (38.6)	40 (33.9)	514 (39.1)	2726598 (33.4)	36624708 (41.1)	
Fair/poor	900 (61.4)	78 (66.1)	802 (60.9)	5444040 (66.6)	52406754 (58.9)	
Expected death						18.814 (<.001*)
No	477 (30.1)	53 (40.5)	408 (28.7)	3982122 (47.9)	26387538 (28.8)	
Yes	1108 (69.9)	78 (59.5)	1014 (71.3)	4329642 (52.1)	65386524 (71.2)	
Participation of patient in final decision-making						.035 (.882)
No	1208 (67.9)	77 (63.1)	928 (68.2)	5222370 (64.4)	56485998 (63.6)	
Yes	485 (32.1)	45 (36.9)	433 (31.8)	2881758 (35.6)	32390298 (36.4)	

Note \*  $p < .05$

Appendix 4.17. RQ4b. Simple complex samples logistic regression: Predictors of receiving care consistent with their preferences for comfort care (N=1,634)

Variable	Reference group	F	p	OR	95% CI	
					Lower	Upper
Age	-	6.522	.014	1.038	1.008	1.068
Female	(Male)	1.137	.291	1.314	.785	2.199
Married	(Separated/divorced, never married)	.684	.412	.796	.456	1.387
Widowed	(Separated/divorced, never married)	3.461	.069	1.651	.961	2.837
African American	(Non-African American)	5.669	.021	.488	.267	.894
Having resident children	(No resident children)	.023	.881	1.045	.582	1.877
Catholic	(Non-Catholic)	4.402	.041	1.785	1.025	3.109
High school graduate	(Less than high school graduate)	3.367	.072	.686	.454	1.036
College or more	(Less than high school graduate)	2.685	.108	1.753	.881	3.488
Upper 50% net worth	(Lower 50% net worth)	1.010	.320	1.301	.769	2.200
Having at least one private insurance policy	(No private insurance policy)	.243	.624	.900	.587	1.382
Cancer as a main illness that led to death	(Non-cancer)	.116	.735	.911	.526	1.579
Heart disease as a past history	(No history of heart disease)	.000	1.000	1.000	.616	1.623
Lung disease as a past history	(No history of lung disease)	2.573	.115	.667	.401	1.108
Stroke as a past history	(No history of stroke)	.365	.549	1.196	.659	2.172
Pain during the last year	(No)	.652	.423	.774	.408	1.465
Perceived health status: Fair/poor	(Excellent-Good)	1.804	.185	.717	.435	1.180
Expected death	(Unexpected death)	15.062	<.001	2.279	1.488	3.491
Participation of patient in final decision-making	(No participation)	.022	.882	1.039	.621	1.740
End-of-life discussion	(No discussion)	.742	.393	1.269	.728	2.213
DPAHC	(No DPAHC)	4.639	.036	2.004	1.048	3.834

Note. OR, odds ratio; CI, Confidence interval

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