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Disparities Between Patients' End-of-Life Care Preferences and Actual End-of-Life Care Received

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# Disparities Between Patients' End-of-Life Care Preferences and Actual End-of-Life Care Received

by

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# DEDICATION

I dedicate this Dissertation to my two biggest fans and incredible cheer leaders, my children Aliya and Jeremy. Your love, your continual encouragement and your ability to lift me when I was overwhelmed and exhausted made this accomplishment possible. You two are my sunshine and moonlight and you complete my days. My love and thanks!

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# ABSTRACT

**Background:** Data suggest that patients' end-of-life (EOL) care preferences are not consistently followed. Based on these data, in 2015, the IOM called for research to identify the prevalence of the problem of EOL care preferences not honored. The current study used an ethical framework to study this problem.

**Objective:** The purpose was to identify the prevalence of patient's not having their EOL care preferences followed using data from an existing nationally representative study.

**Methods:** A secondary analysis of data from seven biennial waves (2002-2014) of the Health and Retirement Study (HRS) was performed. A cross-sectional analysis was accomplished using primarily the HRS exit interview. All respondents indicating that a written EOL preference had been documented were included. Deceased patients' proxies provided the information about the patient's preferred EOL care and the actual care received. Because proxies could select more than one EOL care option, both a sample and a subsample of proxies who only selected one option were evaluated. Associations between mismatched EOL preferred vs. EOL received care options and respondent characteristics were also evaluated.

**Results:** 3,754 respondents died during the study period, of who 3,660 met the inclusion criteria of having written EOL care instructions. The subsample included 212 respondents. Analysis of the sample found that the most preferred type of EOL care was *comfort care*, followed by *limit care*. The frequencies of both samples revealed that in the four EOL care types for which HRS collects data (*all care possible*, *limit care, withhold treatment, comfort care),* patient preferences were not followed 53-72% of the time.

A question about providers verbally offering EOL care treatments to the patient's proxy were asked and nearly 17% of the time those instructions were not followed.

**Discussion:** Using data from a nationally representative study, this study confirms that regardless of the type of EOL care patients' prefer, and the presence of written instructions, patients do not receive that care greater than 50% of the time, and a significant number are receiving unwanted EOL care.  Further data are needed to ascertain why patients' autonomous preferences are not followed at the EOL.

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# CHAPTER 1

## Disparities Between Patients' End-of-Life Care Preferences and Actual End-of-Life Care Received

Two of the most challenging clinical ethics problems a provider can encounter pertain to determination of end-of-life (EOL) care preferences and dealing with treatment-choice disagreements between health care providers (MDs, RNs) and patients (Breslin, 2005; Huff, 2014; Larson, 2016; Loyola University–New Orleans School of Nursing, n.d.). When these two problems coexist—as when providers contravene patients' EOL instructions—the consequent ethical dilemma can be difficult for all concerned. Given the gravity and ramifications of these circumstances in which the patient–provider relationship of trust may be violated, the lay public might assume that substantial research has elucidated this EOL and ethical concern. However, the body of research on this issue is small, and findings of extant studies conflict. Clearly, providers should possess adequate knowledge about the ethical dimensions of EOL care decision making. Accordingly, one question of importance to both providers and policy makers who issue EOL care guidelines concern the frequency of instances in which providers contravene patients' EOL instructions. To address this deficit in research evidence, this dissertation reports on a study to ascertain the prevalence of disparities between patients' written EOL care preferences and actual EOL care received.

### Background

In 1914 the first legal case – Schloendorff v. Society of New York Hospital – decided that patient's have the right to determine what happened to their own bodies (Murray, 1990). Since the 1970s, various laws, court cases, federal mandates and regulations, and ethical bodies have required or strongly encouraged providers to have EOL discussions with their patients and then act upon the patients' decisions—regardless of the providers' personal beliefs or desires. Given this knowledge about laws, regulations, etc., one might think that the prevalence of patients who have their EOL care preferences followed is high; however, research has not shown this to be true.

Emotional trauma, to patients and their families can result from non-adherence to patients' EOL care preferences. Indeed, such non-adherence violates one of the most profound assumptions of the patient–provider trust relationship (Harrop, Morgan, Byrne, & Nelson, 2016). Patients are frequently encouraged to prepare documents that state the EOL care they would want should they no longer be able to make those decisions themselves. When people prepare written documents—such as an advance directive or a living will—or verbally state how they want their life to end, they trust that the EOL care they receive will be consistent with their directives. This trust is integral to the patient–provider relationship (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Mack, Weeks, Wright, Block, & Prigerson, 2010; Sandsdalen, Rystedt, Grondahl, Hoye, & Wilde-Larsson, 2015; Singer, Martin, & Kelner, 1999). A provider's acting in accordance with a patient's EOL care instructions and preferences is an essential aspect of honoring individuals' autonomous right to determine their care, regardless of whether the patient's wishes were communicated in writing or orally (Beauchamp & Childress, 2009).

## Problem Statement

Dying patients with mental capacity have a legal right to have their autonomous EOL care preferences followed (California Hospital Association, 2016; Legal Information Institute, 2017). These rights are not always honored—as will be shown in the various research articles discussed throughout this writing. Moreover, a provider's intentional or unintentional failure to comply with a patient's EOL care choices has both physical consequences for the patient and emotional consequences for the patient's loved ones. Given these consequences, three issues point to a need for additional research on adherence to patients' EOL care preferences: (a) findings of disparities between preferred EOL care and actual care received, (b) findings of adverse consequences that result from such disparities, and (c) contradictory findings in EOL care research.

**Discrepant findings in EOL care research.** Several studies have reported that the EOL care that patients actually receive is not always consistent with patients' preferences for EOL care (Connors, 1995; Heyland et al., 2013; Mack et al., 2010). Notably, in a recent systematic review of 38 studies of non-beneficial treatment at the EOL, 28% of the patients were subjected to resuscitation attempts—despite the patients' previous stipulations that care not be provided (Cardona-Morrell, Kim, Turner, Anstey, & Mitchell, 2016). In a 2013 Pew Religion and Public Life survey, respondents (*N* = 1,994) who had witnessed a friend's or family member's terminal illness indicated that health care staff disregarded patients' EOL instructions more than 30% of the time (Funk, 2013).

**Adverse consequences of non-adherence to patients' EOL care preferences.** Disparity between preferred EOL care and provided EOL care is defined as the provision of EOL care that is inconsistent with a patient's written EOL care instructions. The consequences of this disparity include an increased cost of EOL care and vitiation of the patient's trust in the patient–provider relationship (Danis et al., 1996). Indeed, several studies have noted that this unfortunate disparity has been associated with a painful and prolonged dying process—which may include artificial breathing through a tube in the lungs, cardiac compressions that frequently cause cracked ribs, and forced sedation in order to make some of the above painful procedures tolerable (Connors et al., 1995; Danis et al., 1996; Heyland et al., 2013; Mack et al., 2010).

## Purpose and Rationale

**Discrepant findings in research on adherence to EOL care preferences.** In addition to concerns about preferred care–actual care disparities and their adverse consequences, another concern involves inconsistent findings in the body of EOL care research itself. Studies comparing EOL care preferences with actual EOL care received have been inconclusive and in some cases contradictory—even when research teams have examined the same data. For example, in a study by Silveira, Kim, & Langa, (2010) that used the Health and Retirement Study (HRS) conducted from 2000 to 2006, the researchers reported that for patients 60 years of age or older who prepared advance directives, EOL care was usually consistent with the patients' stated EOL care directives. In contrast, a study by Kelley et al. (2011) that used the same HRS data and timeframe to determine treatment intensity found that 92% of patients (age range: 65.5 years and older) with EOL preferences for comfort care in fact received EOL care that was more aggressive than indicated in the patients' directives. These discrepant findings reported by Silveira et al. and by Kelley et al. are but one example of discrepancies elsewhere in the EOL care literature (Institute of Medicine, 2015). The reports of patient preferred care–provided care disparities, the unfortunate consequences of these disparities (painful and prolonged dying process, threat to provider trust relationship, increased cost of EOL care), and discrepant findings in the EOL care literature provide the rationale for this dissertation. In addition, my personal witness and observation of such disparities at a southern California hospital has further inspired the research discussed herein.

**Significance.** For providers, the provision of care that is inconsistent with patient preference can be a form of paternalistic medical practice that injures the patient–provider trust relationship and perhaps the patient as well. Ignoring the patient's preference for care is contrary to respecting patient autonomy and to providing patient-centered care as strongly recommended by the Institute of Medicine and as typical, adopted by most U.S. health care systems (Committee on Quality Health Care in America, IOM, 2001; Danis et al., 1996; Mack et al., 2010). It is important to note that in the acute care setting, the presumption of life (patient would choose to live) has been the default approach to the dying patient since cardiopulmonary resuscitation (CPR) was first described in 1960; especially in settings such as the emergency room, out-patient clinics, and in a public setting. Accordingly, many providers have an ingrained trained response to act by providing CPR to a patient who is having a cardiac or respiratory arrest (Burns, Edwards, Johnson, Cassem, & Troug, 2003; IOM, 2015). An underlying assumption of the current research is that it is time to change the approach to the dying patient, move away from the unofficial standard of presumption of life and instead focus on honoring the patient's desires and wishes for their preferred way to die. As many have stated before, this approach will not necessarily be easy and will involve layers of communication between all levels of the health care system (Berlinger, Jennings & Wolf, 2013; Wolf, Berlinger, Jennings, 2015); but in the end a patient's autonomy, their dignity, and their right to self-determination will be honored.

***Patient consent.*** The idea of patient consent has been evolving since 1914, when a series of legal cases resulted in successive judgements about different patient's rights—rights that allowed patients to retain some control of their body (Murray, 1990). Collectively, the recognition of these rights led informed consent to be codified as legal doctrine. *Informed* *consent* is the gold standard principle that ensures that the patient has been informed of the care being given, along with the benefits and consequences of that care (Murray, 1990). The adoption of applying informed consent to EOL decision making came from the 1983 President's Commission report: *Deciding to Forego Life-Sustaining Treatment* (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). The practice of obtaining informed consent is based on the belief that patients are their own best-qualified autonomous decision makers (Beauchamp & Childress, 2009). In essence, the practice of obtaining valid informed consent exemplifies the transition from paternalistic medicine to a patient-centered health care environment (Murray, 1990; Quill & Brody, 1996). In fact, the courts have interpreted that lack of adequate information and discussion by the provider is a breach of duty. The provider–patient discussions about the patient's EOL care preferences—and instructions—and the provider's review of the patient's written wishes are examples of affording informed consent to the patient at the EOL. Danis and Churchill (1991), wrote that in keeping with the American tradition of respect for the individual, "we must put the choice into the patient's hands in order to protect the individual's autonomy" (p. 25).

Responding to patient preferences for their EOL care is the center point of patient-centered care at the EOL and can certainly resemble a balancing act when compared with a provider's obligation to deliver beneficial care (Committee on Quality Health Care in America, IOM, 2001; IOM, 2015). There is no doubt that one of the hardest problems in health care is responding to and harmonizing with these potentially emotionally charged opposing positions (Wolf, 2015). The 2015 IOM report found a deficit in following patient preferences for EOL care that 14 years earlier had been called upon for improvement, also by the same Institute. The *Dying in America* report was comprised of literature reviews, expert meetings, and public forums to review both personal experiences and the most recent research. *Dying in America,* was a timely publication for my dissertation because of its confirmation of continuing instances of patient preference and physician discordant practices near the EOL.

## Thesis Statement

A patient will generally choose to receive either aggressive or symptomatic care at the end of their life. It is an individual's choice as to which types of EOL treatment to receive and some may choose not to receive any treatments; however, research studies have shown that this right to choice of care is not observed consistently. This study evaluates a nationally representative sample and discovers the percentage of EOL preferences for care that are actually followed.

## Definition of Terms

In the literature on EOL care, several terms refer to the process of patients' making their own autonomous decisions—for example, *preference, choice, choose, desire, wish,* and *wishes.* These terms are often used interchangeably in the literature and, therefore, also in this dissertation. In addition, following, honoring, or adhering to a patient instruction are also used interchangeably. Lastly, ethics is a shortened version of clinical ethics in this paper.

# CHAPTER 2

## Literature Review

A search of published literature was conducted to discover relevant studies that investigated the prevalence of adherence to patients' written EOL care preferences. Generally, the few extant EOL studies that have identified the problem of non-adherence to patients' stated or written EOL directives have noted that more research is needed to better understand, quantify, and find solutions to this significant patient care and health care quality problem. The following is an overview of the relevant and significant research studies with a discussion of the remaining gaps that need to be addressed.

### Earlier Relevant Studies

Most of the EOL literature that evaluates honoring patient preferences at the EOL does so by focusing on a particular type of care or disease. For example, a study might evaluate a cancer patient's preferences for chemotherapy in the last week of life, a person with congestive heart failure (CHF) and their preference for CPR, a patient with end-stage renal disease whose preference is against continuing dialysis, or a person with chronic obstructive pulmonary disease and their preference for ventilation (Connors et al., 1995; Danis et al., 1996; Farber et al., 2006; Heyland et al., 2013; Mack et al., 2010; Teno, Fisher, Hamel, Coppola, & Dawson, 2002). This study will focus on patient preferences regardless of their disease state or co-morbidities.

**SUPPORT**. Motivation to conduct the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) arose from concerns regarding the increasing cost of health care and the extensive use of medical technology and aggressive care when the life span of a seriously ill patient is determined to be short (Phillips, Hamel, Covinsky, & Lynn, 2000). The trial's overall objective was to improve EOL decision making and decrease the frequency of prolonged, mechanically supported, painful dying (Connors et al., 1995). The SUPPORT study was a clinical trial, which studied seriously ill hospitalized patients older than 18 years of age who had a life expectancy of 6 months or less (Wenger et al., 2000). It took place in five major U.S. medical centers, and was one of the first research studies to identify the problem of providers' not knowing and following patients' EOL instructions (Wenger et al., 2000). To date, SUPPORT has been the most cited EOL study, and hundreds of researchers have used the data from this study to inform the design of topic specific EOL care (e.g., care given to CHF patients).

Review of the SUPPORT literature revealed that (a) only 47% of physicians knew that their patients preferred not to be resuscitated (Wenger, et al., 2000), (b) 46% of the patients had do-not-resuscitate (DNR) orders written within just the last two days of life, and (c) 50% of the patients with late written DNR orders experienced moderate-to-severe pain in the last two days of life (Connors et al., 1995). Furthermore, at least 9% of the SUPPORT patients had unwanted resuscitation attempts (Wenger et al., 2000), 35% of the patients received care that was inconsistent with their preferences, and 24% of the patients had not discussed their personal goals of care with their providers (Teno et al., 2002).

In a study by Danis et al., (1996) 53% of the patients received life-sustaining treatment contrary to the patients' preference. In the study by Mack et al. (2010), 13% of cancer patients at the end of their lives received life-sustaining treatment that was not in accordance with their preferences. Similarly, in a Canadian study by Heyland et al. (2013), two-thirds of patients received care that was inconsistent with their EOL care preferences.

In an attempt to assist with the difficult task of EOL care, *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life* was published in 1987 and revised and expanded in 2013 (Berlinger, 2013). These ethical guidelines were grounded in moral traditions to assist providers in EOL decision making along with their patients. Although aligned with law and clinical practice, these guidelines were not designed to provide an algorithm for EOL care decisions but to provide an ethical framework within difficult EOL care decisions could be made (Berlinger, 2013). For example, these guidelines were designed to help focus conversations in terms of beneficial treatment and patient choice and autonomy. Wolf et al. (2015) reviewed forty years of work on EOL care, from patient decision making rights to attempts to reform and improve both decision making and systems of care. They found that discussions about the continuing difficulty in ensuring that patient’s preferences are followed and the need for more communication are recurring themes, along with a need for better provider education (Wolf, 2015). Wolf et al., notes that the work of pediatric palliative care providers may have lessons to share with other providers to help them address effective communication during the EOL care period. Given that pediatric providers have frequent conversations with a dying child’s parents, they are accustomed to speaking about EOL care options on a regular basis. This experience with frequent EOL conversations could be beneficial knowledge to share with adult providers.

## EOL Studies with Discrepant Findings

As mentioned in Chapter 1, one weakness in the body of EOL care research is discrepancies in reported findings. One example of discrepant findings comes from the two studies discussed previously that were conducted—by Kelley et al. (2011) and Silveira et al. (2010). Both used the HRS exit survey data from patients over 60 years of age which emanates from proxy data as does the current study. The Silveria et al., data is described as coming from patients’ advance directive documents drawn from the HRS data collection waves conducted from 2000 to 2006. In the study by Kelley et al., which sought to determine treatment intensity and EOL care costs in patients in the last 6 months of life. Kelley et al., reported that 92% of the patients with EOL preferences for comfort care (i.e., pain and symptom treatment only) received EOL care that was more invasive and aggressive than had been stipulated in the patients' directives. In contrast, the study by Silveira et al. (2010) reported that for patients over 60 years of age, EOL care received was usually *consistent* with the patients' stated EOL care preferences. Notably, Silveira et al. evaluated concordance between EOL care preference (as stated in an advance directive) and the actual EOL care received; however, unlike Kelley et al., who evaluated *comfort care adherence,* Silveira et al. evaluated a patient's EOL care preference for *all care possible, limited care, comfort care* but they did not evaluate the care option to have *treatment withheld* nor if the actual EOL care received matched the preference. Moreover, in the body of research examining concordance or disparities between EOL care preferences and actual EOL care, contradictions such as those illustrated by the discrepant findings of Silveira et al. and Kelley et al. are not unique (IOM, 2015). For example, in a study of advanced cancer patients, Mack et al. (2010) found that 13% received life-extending treatment when they had requested comfort care only. These various findings are but one example of the lack of research consistency noted within the same database.

## Views of Other Stakeholders

There are many stakeholders involved in EOL care i.e. health care providers, families, patients, and system administrators. Steinhauser et al. (2000), found that patients and family members view *quality of EOL care* as being a process in which communication and shared decision making reflect patients' and family members' values while adhering to the patient's preferred treatment instructions (Steinhauser, et al., 2000). Families feel guilty if their loved ones are not involved in treatment planning and EOL discussions (Pino, et al., 2016). Lastly, a Canadian study of 107 diverse palliative care providers and administrators found that the most important consideration in EOL care was that the provision of care was in accordance with patients' preferences (Mistry, Bainbridge, Bryant, Toyofuku, & Seow, 2014). There is a paucity of available research in the area of stakeholder views at the EOL.

## National Recommendations and Legal Rulings

In the past Century, and particularly in the past 60 years, a body of legal writings, opinions, recommendations, and mandates by governmental agencies have shaped EOL care, the respect for a person's autonomous decision making, the concept of provider-patient shared decision making—and also elevated the importance of this research topic in public conversation.

### National Recommendations

For example, in 2001, the Institute of Medicine (IOM) published *Crossing the Quality Chasm: A New Health System for the 21st Century,* a report that identified health care system-wide problems that were interfering with the quality of care delivered to patients (Committee on Quality Health Care in America, IOM, 2001). The Committee identified six aims for improvement; the third aim was that health care should become patient-centered (Committee on Quality Health Care in America, IOM, 2001). At the EOL, responsiveness to patient preferences for EOL care demonstrates patient-centered care, yet 14 years after the *Crossing the Quality Chasm* report, such responsiveness is still not consistently manifested in EOL care. In 2015, the IOM published: *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,* a report whose goal was to evaluate medical care for people of all ages with either a serious illness or near the EOL (IOM, 2015). The IOM identified and called for future research in several areas related to EOL care, including studying “the prevalence and nature of care that is neither beneficial nor wanted” (IOM, 2015, p. 98).

Years earlier, in 1978, Senator Edward Kennedy lobbied the U.S. Congress to form The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). The Commission was a biomedical advisory group to the President of the United States and the U.S. Congress. It is comprised of content experts from across the United States and is charged with studying ethical conflicts that may arise in health care or biomedical research; the Commission also tasked these experts with making recommendations to decrease risks to the public and to recommend practice guidelines for approaching ethical issues that arise in medicine and biomedical research (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). In 1983, the Commission wrote a significant report, *Deciding to Forego Life-Sustaining Treatment to Provide Guidance for Physicians and Hospitals,* whose focus was the right of patients to choose to forego life-sustaining treatment. This report was an outgrowth of the 1982 President’s Commission report on *informed consent;* however, the focus of this report was on evaluating the moral and legal instances that may limit the patient’s choice to decide to refuse life-sustaining treatment. Among the report’s several guidelines, four pertain to patient preferences and autonomy:

- The choice to forego resuscitation should be made by a competent, informed patient;
- Making medically and morally appropriate treatment decisions does not mean that legal statutes pertaining to wrongful death or homicide require changing;
- The primary responsibility for ensuring a morally sound process of decision–making lies

with the physician; institutions ensure that proper procedures are in place to enhance the process of a patient’s informed decision making, including that of designating a surrogate;

- The ultimate decision lies with the patient. If unresolvable conflicts arise, the physician may transfer the patient or request a review by an institutional committee or request a judicial review (President's Commission, 1983).

### Legal Rulings

Among legal cases, those of Schloendorff v. Society of New York Hospital (1914) and Natanson v. Line (Kansas 1960) have had the most impact on informed consent (and thus on EOL care). The ruling decided that every patient has the right to determine what shall be done to her or his body and may refuse any life-saving treatment (Murray, 1990). In 1974, the Council on Ethical and Judicial Affairs of the American Medical Association (AMA) became the first organization to propose that the decision to not resuscitate be documented in the patient’s medical record as a do-not-resuscitate (DNR) order (American Medical Association, 1991). The Council recommended only two exceptions to the presumption of consent for CPR: patients’ preferences expressed in advance that they wish not to be resuscitated, and the judgment of the physician that CPR would be futile (AMA, 1991). Therefore, a patient-requested DNR was to be an extension of the patient’s autonomous decisions to refuse treatment (AMA, 1991).

### Legal Cases

Three precedent-setting legal cases—involving patients Karen Ann Quinlan, Nancy Cruzan, and Terri Schaivo—have afforded new legal protections for patients at the end of their lives. These legal cases are representative of the angst that medicine, politics, religion, the media, and what patients experience when faced with difficult decisions about when or how to end a person's life.

**Karen Ann Quinlan.** In 1976, a New Jersey Supreme Court ruling resulted in permission to remove the ventilator from patient Karen Ann Quinlan, who had been unconscious and ventilated for many years. A precedent was set when the court ruled that while evaluating life-sustaining treatment, that a person's quality of life was a legitimate consideration when determining continuation or discontinuation of care (Fine, 2005). Furthermore, the court stated that cases such as that of Ms. Quinlan did not belong in the court room unless in-hospital committees were not able to come to a conclusion. This determination led to the formation of hospital-based ethics committees to consider these issues.

**Nancy Cruzan.** Nancy Cruzan was found at the side of the road following a car accident. Subsequently, as a patient, she remained breathing on her own and in a persistent vegetative state, reliant on a feeding tube to keep her alive. Contrary to the repeated requests of her parents, her doctors refused to remove the feeding tube. After denials at the State level, in 1990, the U.S. Supreme Court ruled that patients had a right to refuse life-sustaining treatments, but added that states retained the rights to regulate the circumstances under which life-sustaining treatments could be withdrawn when patients could not speak on their own behalf (Fine, 2005). Ms. Cruzan was eventually allowed to die.

**Terri Schiavo.** A married hospital patient, Terri Schiavo, suffered a cardiac arrest and remained in a vegetative state for years. Her husband was appointed her legal guardian, and in 1998 he requested that her feeding tube be removed. Mr. Schiavo stated that his wife would not want to live in this dependent state, but Ms. Schaivo's parents were not in agreement. The Florida Supreme Court allowed the tube to be removed; however, the Florida House of

Representatives passed a law (known as Terri's Law) that allowed the then-Governor Jeb Bush to have the tube reinserted. Ms. Schaivo was allowed to die in October 2005 (Fine, 2005).

The Quinlan, Cruzan, and Schiavo cases resulted in three determinations that have had far-reaching ramifications for EOL care: that a person's quality of life was legitimate to deliberate when considering life and death (Quinlan case); that patients had the right to refuse life sustaining treatments (Cruzan case); and that life-sustaining feeding tubes could be removed if that treatment was not in keeping with care the patient would have chosen (Schiavo case).

## Patient Self-Determination Act

The three precedent-setting legal cases led to much public discussion in the media, in houses of worship, and among family members who wanted to make sure that their wishes were known by others and would be honored. The attention from these cases and public conversation led the U.S. Congress to enact the Patient Self-Determination Act (PSDA) in 1990. The Act requires that health care facilities that accept funding from the federal government (a) inquire upon admission if a patient has some type of advance care document and (b) place extant advance directive documents into the patient's record for ease of accessibility (Crane & Doukas, 2005; Ulrich, 1999). This law is the basis for every person's right to decision–making authority regardless of whether or not they have decisional capacity at the time of decision need. The law also established the ethical and legal authority of patients and their surrogates. In essence, the PSDA extended the "ideals of political liberty . . . into the realm of an individual's choice for the direction of their health care" (Ulrich, 1999, p. 11). The PSDA was also founded on the principles of informed consent in that the Act requires that providers respect the patient's right to autonomy in health care decision making. Furthermore, the Act requires that, as part of any EOL discussion, the provider educate the patient regarding the EOL care options for that unique patient (Ulrich, 1999). Advance directives and living wills are legally binding documents designed to be used for communication between the health care team and the patient regarding his or her advance choices for EOL care (Ulrich, 1999). In addition, health care accrediting bodies (e.g., The Joint Commission) require that the advance directive or a patient preference statement be inserted into a patient's health record to avoid having them overlooked and perhaps not honored (Allison & Sudore, 2013; Sehgal & Wachter, 2007).

Given the inevitability of life's conclusion for everyone, the benefits of the PSDA and its ramifications are clear. Unfortunately, however, since the passage of the PSDA 26 years ago, the percentage of U.S. citizens who have prepared an advance directive remains low—only about 35% according to the PEW Research Center (Funk, 2013).

## POLST

Discussion of a patient's right to autonomous decision making would not be complete without a mention of the newest document designed to assist patients achieve their preferences for EOL care: the Physician Order for Life-Sustaining Treatment (POLST).

POLST has been confused by many as an advance directive; the acronym POLST is used in several states but some states have adopted other acronyms (e.g., MOLST in New York) (Coalition for Compassionate Care of California, 2013). A POLST is a medical order written in conjunction with a patient and signed by the patient and the physician which orders the type of EOL care that a seriously ill patient desires; POLST is designed to be an additional advance care planning tool (Coalition for Compassionate Care of California, 2013). However, research has shown that even though a POLST is a written standing medical order, discordance between the patient's preferences and the orders on the POLST form may arise (Hickman, Hammes, Torke, Sudore, & Sachs, 2016).

POLST was originally designed to be used by first responders in the field and is therefore not binding in a hospital. Should a patient arrive to the hospital with a POLST, the admitting physician confirms the patient preferences and then writes an appropriate hospital order that reflects the patient's wishes. Should any of the patient's preferences change during the hospitalization, a new POLST order is to be written when the patient is discharged from the hospital. Unfortunately, the re-writing of a patient's POLST order upon discharge is not always accomplished. A discharge without an updated POLST demonstrates a significant gap in communication that can harm a patient by, 1) not having their EOL care preferences accurately documented and, 2) not having an updated signed POLST reflecting their current preferences in their possession for reference by emergency personnel or future providers.

## Theoretical Framework

To frame this research we will turn to the theoretical frame that was utilized to evaluate the problem of interest for this dissertation. Examination of disparities between patients' EOL care preferences and actual EOL care can be elucidated by a theoretical framework that uses an ethical theory—that is, a theory whose subject is ethics. The field of *ethics*—sometimes also referred to as *moral philosophy*—concerns the systematization, defense, and recommendation of concepts of right and wrong behavior (Fieser, n.d., para. 1). Ethical theories are usually classified under the subject topics of metaethics (analysis of language and reasoning), applied ethics (practical ethics uses norms in the course of deliberation), and normative ethics (answers moral or ethical questions; Beauchamp & Childress, 2009a). For framing the problem of nonadherence to patients' EOL instructions from an ethical perspective, a normative ethical theory is appropriate. *Normative ethical theories* discuss moral standards of right and wrong conduct, which is how ethical theories in general are defined (Beauchamp & Childress, 2009a; (Fieser, n.d.; Summers, 2014). Before discussing the application of normative ethical theory to EOL care, an understanding of ethical theories in general is warranted.

## Ethical Theories in General

Ethical theories typically concern matters that are intangible and abstract (e.g., moral status, moral norms). A person with moral status deserves the protection obtained from moral norms. The moral norms for biomedical ethics are the principles of common morality: autonomy, beneficence, nonmaleficence, and justice (Beauchamp & Childress, 2009a). Moral status is evaluated based on cognitive properties (i.e. self-awareness, choosing, authorizing and the ability to process information).

Ethical theories are rooted in individual values, opinions, or preferences as they apply to particular ethical dilemma. Ethical theories are based on philosophical theories that describe or explain aspects of morality. Specifically, normative ethical theories provide a frame to study what is considered morally right or morally wrong (Summers, 2014).These theories are evaluated on the basis of an individual’s values, morals, and norms that lead to their conclusions about what is right or wrong. For analyzing the ethical and health care problem of non-adherence to EOL care instructions, an ethical theory and framework is appropriate for determining whether moral norms have protected an individual’s moral status (Beauchamp & Childress, 2009a).

It is important to note that in biomedical ethics the concern for moral status arose out of the concern for vulnerable populations (Beauchamp & Childress, 2009a). In addition to the various categories usually thought of as a vulnerable population (racial and ethnic minorities, homeless, incarcerated, etc.) there is concern in bioethics for those who lack decision-making capacity and those who are incapable of protecting themselves because of their illness (2009a).

In reality, bioethics cannot function in the absence of culture (Chukwuneke, 2014). Culture pertains to a group of people who have the same way of life, who have the same beliefs and values that they generally accept without even thinking of them; and thus culture influences the view of illness and diseases. Most cultures have their own moral norms for what is right and wrong and most subscribe to the principles of the "golden rules," do unto others as you would have them do to you (Chukwuneke, 2014). However, because of different values and morals, bioethics cannot necessarily be universal. An inherent limitation for the current study is that specific cultural norms were not able to be evaluated based on the available HRS data.

## Preference Consequentialism

One normative ethical theory that is particularly relevant to patient preference is *preference consequentialism*. This theory, derived from the fields of philosophy and ethics, is one of the "consequentialist" theories, whose focus is the preferred outcomes or consequences (or lack thereof) of an action (Summers, 2014). Consequentialism promotes values as the determinant of the rightness or wrongness of an action (Beauchamp & Childress, 2009). When considering an ethical dilemma from the consequentialist perspective, the central concern is the consequences of an action—regardless of the actor's or provider's intention (Morrison & Furlong, 2014; Sinnott-Armstrong, 2015). For example, with regard to disparities between patients' EOL care preference and actual EOL care received—the problem discussed in this dissertation—the causative "action" would be the administration of some form of EOL care or treatment. The "consequence" would be that the EOL care was contrary to what the patient wanted or that the individual achieves the outcome that they wanted (not getting that care) even if it leads to their death.

I will use the theory of preference consequentialism as a framework for considering the problem of non-adherence to patient preference for their EOL care. As a consequentialist theory, preference consequentialism places the individual at the center of the decision-making process (patient-centered) and claims that what is morally good is the fulfillment of that individual's preferences. The concept in common to both preference consequentialism (ethics theory) and the profession of nursing is the individual—that is, the patient (@Current, 2012; Sinnott-Armstrong, 2015).

Application of preference consequentialism to inform our understanding of disparities between patient EOL care preference and actual EOL care received will be aided by the use of an evaluative framework of the general norms of common morality (Beauchamp & Childress, 2009a). The outcome of the type of EOL care that the patient receives will be compared with the type of EOL care that the patient desired, as was written in the patient's EOL care instructions. The four general norms of common morality that are used in the analytical framework are autonomy, beneficence, non-maleficence, and justice (Beauchamp & Childress, 2009). Each of these norms will be used to assess the concordance and disparity between patients' EOL care preferences and actual EOL care.

*Autonomy* refers to the individual's right to make self-directed decisions—such as in stipulating EOL care—without influence from those we wish not be to be influenced by. For providers, *honoring patient autonomy* is demonstrated when a provider adheres to a patient's health care preferences, regardless of the provider's personal or professional opinions (Beauchamp & Childress, 2009). *Beneficence* refers to the provider's obligation to deliver care that is aligned with the standards of care and in concert with patient preference (Beauchamp & Childress, 2009a). With regard to the health care team, beneficence is expressed in the correspondence between the team's provision of EOL care and the patient's written directives. *Non-maleficence* refers to the health care provider's avoidance of harmful practices (Beauchamp & Childress, 2009a). Non-maleficence is demonstrated when a health care team does not cause patient harm—for example, harm resulting from the performance of painful and/or aggressive EOL care (such as CPR) contrary to the patient's preferences. *Justice* refers to being fair, equitable, or impartial (Beauchamp & Childress, 2009a). Justice is demonstrated when a wrongful act is not committed or when a protection (or right) is not denied; justice is also manifested in the equitable treatment of patients whose preferences and conditions are similar. Notably, respect for persons (autonomy) and justice did not become part of the medical ethical lexicon until the 1900s (Beauchamp & Childress, 2009a).

Utilizing the common norms of morality in our theoretical frame reminds the health care provider of the responsibility they have in carrying out their duty to know and honor the patient preferences and outcomes for their end of their life. Although this framework does not represent a complex evaluation of adherence to patient preferences it provides a mode for determining whether patients receive the EOL care preference/outcome of their choosing, and thus helps evaluate the research question.

## Assumptions

This dissertation studies the prevalence of patients whose actual EOL care is not in accordance with the patients' previously written EOL care instructions. In addition, six demographic variables will be evaluated to see if there are any associations with adherence to EOL care preferences. The variables are: age, sex (gender in database), religious services, marital status, race, and education. Regions in the United States will be examined to determine if there is a regional difference between adherences to patients' EOL instructions. Lastly, conversations between the provider and the patients' proxy, at the very end of life, will be evaluated to determine if there is a higher or lower degree of provider adherence after direct consultation with the proxy about a recommended EOL treatment.

## Research Questions and Hypothesis

The over-arching research question for this dissertation is as follows: "In a multi-year sample from the HRS exit interview, what is the association between patients' written EOL care instructions and the treatment they received, as reported by their proxy?

The hypothesis for this dissertation is based upon the 2013 PEW Research Center's (PEW) survey of family members, who had recent experience with a loved one requiring EOL care. The findings were that patients' preferences are not followed at least 30% of the time (Funk, 2013). In this dissertation, we will test the hypothesis that patients in a nationally representative study (HRS), who have written EOL care instructions, have their EOL care preferences followed more than or equal to 30% of the time.

## Specific Aims

The following are the proposed research aims:

1. What percentage of sample respondents prefer each of the following care options: *all care possible, limit care, withhold treatment*, and *comfort care*?
2. What is the prevalence of disparity between patients' written EOL care preferences and the actual EOL care received, as reported posthumously by the patient's proxy?
3. Do any of the following demographic variables—*age, race, sex, marital–partner status, education*, or *religious services*—influence provider adherence to respondents' written EOL care preferences?

4. Among patients whose proxies were offered but refused medically recommended care, what percentage of patients were nevertheless given the refused care at the "very end of life" (HRS undefined expression)?
5. Does the rate of provider adherence to patients' stated EOL care preferences differ between U.S. population regions?

# CHAPTER 3

# Methodology

## Research Design

The present study was a retrospective secondary data analysis that primarily used the HRS Exit Interview. The study used a cross-sectional analysis of the study variables from the exit interview and a few demographic variables from the HRS core survey. Essentially, I reviewed the data at one point in time to measure the prevalence of adherence to EOL care preferences. The exit interview was a survey conducted with a respondent's proxy, defined as primarily close family members, after the respondent's death. HRS data were collected in biennial "waves" (i.e., discrete periods of time during which data were collected via surveys; these data collection events were conducted every 2 years; Sonnega et al., 2014). Exit interviews were conducted upon notification of death or at the due date of the subsequent HRS core survey deaths and reported in the subsequent biennial wave's exit interview.

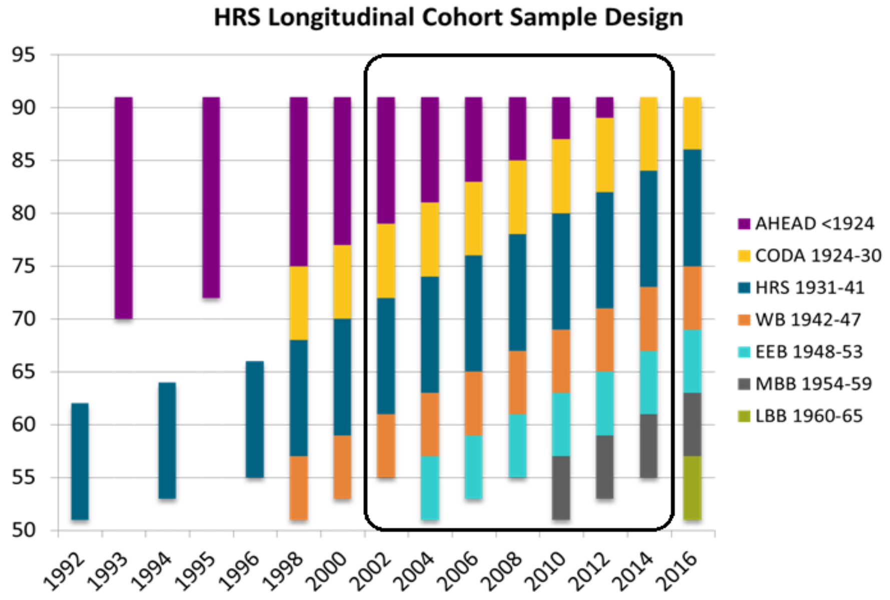

Figure 1. Biennial Waves by Birth Cohort

***Birth cohort definitions.*** Respondents were grouped in birth year cohorts (Figure 1). The oldest old cohort, Asset and Health Dynamics (AHEAD) respondents, were born prior to 1924. Children of the Depression-era (CODA) respondents were born 1924–1930. The first wave of HRS respondents was born 1931–1941. War Babies (WB) respondents were born 1942–1947. Early Baby Boomer (EBB) respondents were born 1948–1953. Middle Baby Boomer (MBB) respondents were born 1954–1959. Late Baby Boomer (LBB) respondents were born 1960–1965. This study's time periods included those born before 1924 and through 1959.

***HRS design.*** HRS participants are drawn from a national probability sample of adults derived from area segments of the U.S. Census "blocks" (i.e., small geographic areas defined by the Census Bureau using visible features (e.g., roads) and nonvisible boundaries (e.g., property lines; Heeringa & Connor, 1995; U.S. Census Bureau, 2011). The HRS uses probability sampling to increase the likelihood that the study's community-level sample is representative of the general population (Heeringa & Connor, 1995).

***HRS interviews.*** Survey interviews were conducted primarily in respondents' homes; however, respondents who moved to a nursing home during the study were followed using onsite interviews (Sonnega, 2016). The study's core (baseline) survey and most exit interviews were conducted face-to-face (Sonnega, 2016); both interviews were offered in English and Spanish. Completion of the core interview required 1½–3 hours. The Institute of Social Research at the University of Michigan (which administers the HRS) conducts most of the exit interviews face-to-face (Sonnega, 2016).

**Institutional review board approval.** The HRS has been approved through 2017 by the University of Michigan Health Sciences–Behavioral Sciences Protocols division (Health and

Retirement Study, 2016).[1] The UCSF Human Research Protection Program deemed this study an Exempt. (see Certificate in Appendix)[2]

## Sample

The data for the current study were collected from proxies from a subset of the nationally representative HRS adult respondents over the age of 50 years who had died; HRS proxies are primarily close family members; no other demographic data is available on the proxies. The sample comprised those proxies of HRS respondents who died and were reported in the biennial waves of 2002 through 2014, representing seven data collection periods. The HRS receives respondent death notifications in one of several ways: family member notification, the HRS review of the National Death Index (NDI), and information at a subsequent core survey date, $M = 12.4$ months after death (Silveira et al., 2010). Data were retrieved one time from the core survey, the tracker cross-wave data, and the exit interview. In addition, demographic data was collected from the respondent's initial survey data collected during their first interview and in the HRS compiled cross-wave tracker database. Data was not available on the demographic data of the proxies. The target sample was the proxies of the HRS respondents who have died—as represented by inclusion in the exit interview.

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[1] HRS IRB numbers: HUM00056464; HUM00061128; HUM00002562; HUM00079949; HUM00080925; HUM000745011; HUM00099822; HUM000103072; HUM000106904; HUM0085942; REP00000046.

[2] UCSF IRB #16-21392, reference #181984.

**Table 1**

*Demographic Frequency Characteristics for Deceased Respondents (N = 3,660)*

| Variable | | Frequency |
|---|---|---|
| Age (years) | 56-73 | 35 |
| | 74-80 | 27 |
| | 81-86 | 28 |
| | >87 | 41 |
| Sex | Male | 1,601 |
| | Female | 2,059 |
| Marital status | Married | 1,231 |
| | Separated/divorced | 296 |
| | Widowed | 1,543 |
| | Never married | 102 |
| | DK[1]/RF[2]/Missing | 488 |
| Education | <High school[3] | 1,000 |
| | High school | 1,948 |
| | High school+ | 712 |
| Race | White | 3,346 |
| | Black | 232 |
| | Other or refuse to answer | 82 |
| Religious<br>(attend service) | ≥Once a week | 1,039 |
| | <Once a week | 982 |
| | Not at all | 1,639 |

**Table 1** (continued)

*Demographic Frequency Characteristics for Deceased Respondents of the Subsample* (*n* = 212)

| Variable | | Frequency |
|---|---|---|
| Age (years) | 44-75 | 630 |
| | 76-83 | 625 |
| | 83-89 | 658 |
| | >903 | 602 |
| Sex | Male | 100 |
| | Female | 112 |
| Marital status | Married | 79 |
| | Separated/divorced | 20 |
| | Widowed | 76 |
| | Never married | 4 |
| | DK[1]/RF[2]/Missing | 33 |
| Education | <High school | 69 |
| | High school | 110 |
| | High school+ | 33 |
| Race | White | 172 |
| | Black | 32 |
| | Other or refuse to answer | 8 |
| Religious (attend service) | ≥Once a week | 71 |
| | <Once a week | 56 |
| | Not at all | 85 |

1 DK: did not know; 2 RK: refused to answer

**Inclusion–exclusion criteria.** Proxy data on respondents who were reported to have written instructions regarding preferences for their EOL care (per their proxy) were included in the study sample for Aims 1, 2, 3, and 5. Specifically, inclusion required an affirmative answer to exit interview question T190: "Did the respondent provide written instructions about the treatment or care that he/she wanted to receive during the final days of his/her life?" This question, as with the entire exit interview, was answered by the respondent's proxy. Aim 4 (questions T234, T235), which addressed providers offering EOL care options to the proxy, had a limited response rate because of a combination of skip patterns and answers of either *don't know* or *refused to answer*; for this reason all proxy respondents who answered affirmative to T234 were used. To date, more than 12,000 HRS respondents have died (Sonnega, 2016); on the basis of question T190—3,660 of these respondents were determined to be eligible for participation in the present study.

## Data Collection Methods

### Techniques and Instruments

Three instruments were used in this dissertation study; two of these instruments were a direct result of HRS surveys and the third "tracker" was an HRS cross-wave compilation of data from all of the core waves. The exit interview was the present study's primary survey, and the HRS core survey and tracker were the study's secondary instruments.

**The HRS core survey.** The HRS core survey collects data on variables that are organized in 36 sections. A partial listing of HRS collected data includes information concerning health conditions and status, retirement status, pension and insurance information, property ownership, relationships of individuals who live with the respondent, and the number of children they have (if any). The HRS database has a tracker file that contains a continuous cross-wave of some of the data variables (all years for specific variables).

**The exit interview.** This study's primary data collection instrument was the HRS exit interview, which is conducted after a respondent's death. Ordinarily, the exit interview is conducted with a surviving spouse or family member (Kelley et al., 2011). The exit interview solicits information about respondents' EOL preferences for care and the actual treatment received in the respondents' final days of life. This interview is either conducted by phone or in person at the respondent's home (Sonnega, 2016).

## Description of Data

**Variables and measurements.** The measures in this dissertation study were HRS survey questions derived from either the exit interview or the core survey and tracker cross-wave data, (see Appendix for survey questions). The variable of interest for the research question and Aims 1, 2, 3, and 5 was the existence of written EOL care instructions; this variable is dichotomous (i.e., in the survey item response, indicated by *yes or no*). The HRS data does not specify what type of format the written EOL care instructions are in, e.g. living will or advance directive. The EOL care preference variables were categorical and were organized into four categories by HRS: *all care possible, limit care, withhold treatment,* and *comfort care* (undefined terms by HRS).

Variable selection began with question T190. If this question was answered affirmatively, then various questions from T193 through T235 were considered (see Appendix A for all variables). All questions were answered by the proxy. Question T234 stands out as the only question that relates to a conversation between the proxy and physician: "Did any doctor(s) recommend any care or treatment that the family or other decision-maker(s) ultimately refused?" pertains only to proxies who refused care on behalf of the respondent. Whether the provider followed that direction was ascertained in question T235: "Did the respondent receive the unwanted treatment?" Demographic variables of interest were *categorical, continuous, nominal* or *ordinal*; these variables include *age, race, sex* (*gender* in the HRS), *marital status, education, religious services,* and *geographic housing region.* Housing location was masked and therefore was reported as a U.S. region of residence using U.S. Census Bureau regional data (see map below; U.S. Bureau of the Census, 1995).

Figure 2. Census Regions and Divisions of the United

This study evaluated respondents' written EOL care preferences as reported by their proxy and as classified in one of four EOL care categories: *all care possible, limit care, withhold treatment,* or *comfort care* (see Table 2). Demographic variables were evaluated to identify any demographic associations or correlations between the respondent's receipt of preferred care.

**Research question and hypothesis**. The variables listed above were used to answer this research question: "In a multi-year sample from the HRS exit interview, what is the association between patients' written EOL care instructions and the treatment they received, as reported by their proxy?" The hypothesis was based upon the PEW research survey data: patients with written EOL care instructions do not have their instructions followed at least 30% of the time" (Funk, 2013). The hypothesis ($H_o$): patients in the HRS who have written EOL care instructions have their EOL care preferences followed more than or equal to 30% of the time. The alternate hypothesis ($H_A$): patients in the HRS who have written EOL care instructions do not have their EOL care preferences followed more than or equal to 30% of the time.

**Rigor.** This HRS sample (respondents) is representative of the U.S. subpopulation whose members are older than 50 years of age (Sonnega, 2016). The HRS uses a sample probability design whereby sample data are drawn from the U.S. Census data. Clustering the sample by census regions strengthens the HRS study sample's credibility, because the Census data are representative of the U.S. population. The HRS core survey response rate is high—currently 85%. Since 1992, the use of the HRS variables in research has resulted in over 1,892 peer-reviewed publications (Health and Retirement Study, 2016)—indicating the overall sample's fidelity.

***Internal and external validity.*** The data source, the HRS parent study, is a descriptive study—and hence does not entail discovery of causality—internal validity was not a concern (Kellar & Kelvin, 2013). Internal validity concerns inference from a manipulated variable, as a prevalence study the variables were not manipulated, so internal validity is not a concern (Polit & Beck, 2012). However, external validity might have been diminished by different types of bias (interviewer, proxy, recall, survivor, attrition); this potential weakening of results by threats to external validity was worth considering. Interviewer bias could result either from study design or during data collection. The HRS uses a structured interview approach for which accurate data collection depends on interviewer consistency and training (Pannucci & Wilkins, 2010). For example, in studies with high turnover rates or deficient training, external validity can undermine the study; however, both the HRS's use of extensive interviewer training and their high interviewer retention rates reduced the likelihood that interviewer bias diminished external validity. In addition, the HRS quality assurance team verifies data collection for 10% of all interviews across all core waves (Gatward, 2016).

With the HRS, another threat to external validity is proxy or recall bias (Kelley et al., 2011). The exit interview is not necessarily conducted soon after the respondent's death (*M* = 12.4 months), so proxies' recollections may be subject to recall bias, especially in an older population (Kelley et al., 2011). Survivor bias is a form of selection bias in which the respondent could be influenced by the trauma or death of the primary respondent (Delgado-Rodriguez and Llorca, 2004). A unique concern is uncertainty about what the proxy knows about the respondent. Klinkenberg et al., (2003) compared the post-death proxy interviews with previous patient documentation and chart reviews and found that in the total study sample ($N$=270), the proxy reports were accurate. Sample attrition can occur via participant discontinuation either by elderly respondents (who may tire during the lengthy survey interview) or following the death of a respondent (Sonnega, 2016). In order to reduce the potential for attrition bias, proxy interviews were incorporated into the HRS data collection very early on (Sonnega, 2016).

In every HRS wave, the study's quality assurance team evaluates the survey for construct and content validity; questions are then revised as needed. Before the data publication of each wave, the HRS research team creates a new codebook and reports any variable or research question modifications from the previous wave on their public data website (Sonnega, 2016). HRS maintains and updates a cross-wave comparison for all variables so that researchers can be certain that variable definitions and equivalencies are the same (Sonnega A. , 2016).

## Procedures

Two types of research procedures were used: HRS registration and unique dissertation research procedures. The research procedures were then followed by analysis and result reporting.

**HRS registration.** In the present study, adherence to HRS registration procedures enabled access and use of the free HRS data. Registration and permission to use the HRS was granted on June 6, 2016.

**Research procedures.** After registration, data were downloaded into the Statistical Analysis System (SAS). Data cleaning of the desired variables of interest from the core, tracker, and exit surveys was quite extensive and time consuming because of the large number of respondents and the need to extract data from the initial core survey for each respondent. For each variable, myself and the statistician began by checking for frequencies while comparing variable definitions and stated frequencies with those listed in the HRS codebooks.

The variable of T190 (presence of written instructions) was used as the inclusion criterion variable for Aims 1, 2, 3, and 5. The variables to answer the primary research question (T193–T196 and T230–T233—EOL care preference type and EOL care type received) were easier to locate than were the various renditions of the demographic variables. The problem encountered with variables T193–T196 (preferred EOL care type) and T230–T233 (received EOL care type) was that many proxies were allowed to answer affirmatively to more than one category of EOL care (they checked more than one box). This is an inherent HRS limitation.

At this point it was necessary to change the data approach, in consultation with the statistician, from individual respondent data to a *Multiple Response Data* approach (Biometrics Advisory and Support Service to DFID, 2001). This is a common approach to survey data when respondents are allowed to answer more than one response. This technique entails utilizing a separate table with two columns (for each type of EOL care match). The first column contains the EOL care preference variables (T193-T196) and the second column contains the received EOL care variables (T230-T233). The length of the columns is equal to the number of respondents. Zero (no) or one (yes) is inserted in the column depending on the response. It also necessitated an evaluation of the proxy sample that only selected one EOL care option.

Locating the demographic variables of the deceased respondents was a greater challenge. The HRS core survey has 36 sections, and finding a complete data set required evaluation of demographic data from several of these sections. Variables for age and sex (gender in the HRS) were straightforward. However, determination of each respondent's race required re-accessing the respondent's initial interview. Because religion was an incomplete variable in all HRS sections, I decided to use the variable *how often did respondent attend religious services in the last year* (B082), which was answered more completely. I equated how often the respondent attended religious services with how important religion was to the respondent; the category of religious service attendance of greater than or equal to one time a week was used to represent a high degree of religiosity. Because respondents' marital status was asked in different locations and in different formats, we used an HRS compiled variable termed *marital status assigned* (B063), which gathered marital status data from all HRS products into one variable. Four variables were created or coalesced into fewer categories—either to facilitate computation or because categories were rarely answered; these variables were *Education, Region, Degree,* and *Wave* (representing the biennial year that the data was collected).

## Analysis Plan

To analyze the data using preference consequentialism as a theoretical frame, the research was designed to focus on whether patient-preferred EOL care preferences were honored. The analytical plan using this framework was to evaluate the EOL care preferences of deceased respondents (3,896) with EOL care written instructions (3,660). Cases with incomplete data were removed from the analyses. EOL care preferences from respondents with complete data sets were matched to the actual EOL care they received, as reported by their proxy.

**Data creation process.** The HRS data were uploaded into the SAS system using the code provided by the HRS. After each data set was uploaded individually, the data for each wave were merged by household identification number (HHID) and respondent's "person number" (PN); this procedure assured that the respondent's data were matched to the corresponding household. All data were then combined by exit data wave (year collected) and coded as "*Wave*." Only respondents with exit data were retained in the sample; this constraint ensured that only deceased respondents were included in the data set. Then the exit data for all waves were merged.

The study sample comprised the HRS waves conducted from 2002 through 2014. The present study did not use all of the HRS variables. For each exit interview wave, the existing HRS variables were retained and merged prior to compiling the formation of the master data set. The variables are presented as follows.

**Variables.** Ultimately, the study used three types of variables: study and demographic variables from the HRS database and created variables that subsumed multiple additional HRS variables.

***Study variables.*** The inclusion variable for Aims 1, 2, 3, and 5 was variable number T190 that corresponded to this question: *did respondent provide written instructions for the treatment or care he/she wanted to receive during the final days of his/her life?* Response options for the preferred type of EOL care (as written in their instructions) were *all care possible (T193), limit care (T194), withhold treatment, (T195),* and *comfort care (T196).* The variables that were associated with the actual decisions that directed the actual EOL care the respondent received were also: *all care possible (T230), limit care (T231), withhold treatment (T232), comfort care (T233).* Data from variable T234 was evaluated; *did any doctor(s) recommend any care or treatment that the family or other decision-maker(s) ultimately refused?* An affirmative answer to T234 meant that we would collect data also on variable T235. T235 asked the question: *did respondent receive this treatment anyway?* From these two variables, I hoped to determine whether adherence to a proxy refusal for provider offered EOL care differed from adherence that was stipulated in a patient's previously written EOL care instructions.

***Demographic variables.*** The variables were *age* (A019), *sex of the individual* (X060_R), *respondent died, state masked* (A126M); *marital status assigned* (an HRS compiled variable; B063); and *how often religious services were attended* (B082). The masked variables were unavailable for review or use with only public data access.

It was necessary to create two variables from the HRS core survey variables, either to condense large categories or to ensure that an adequate amount of data was present for computation. One of the created variables, *Wave*, refers to the wave in which a respondent proxy was administered the exit interview. The variable *Region* was created after recoding the masked variable for *state of death*, A126M, to *Northeast, Midwest, South,* and *West,* the designators used by the U.S. Census regions (U.S. Bureau of the Census, 1995; see Figure 3)**.** If the proxy did not respond to the question, the non-response was coded as missing; the answer categories of *don't know* or *refused to answer* had minimal responses and thus were not included in the data analysis. After these variables were created, a combined data set according to wave was merged with the core survey variables that were being used in the study.

Our last two demographic variables came from the HRS tracker cross-wave data set: *degree* and *race.* In the tracker data set, *Race* was kept like it was but, unfortunately, this variable is incomplete because of its limited response categories of *white, black,* or *other* (an inherent HRS limitation). The *Hispanic* variable was broken into masked categories and was not usable with only public data access; in addition, the HRS surveys do not have a category for Asian ethnicities but data collected is included in the *other race* category. The other variable in the tracker data set, *degree,* was also kept. *Degree* initially had six response categories but was recoded into three because the higher level education categories had limited numbers of responses. *Degree* was recoded into *less than high school*, *high school,* and *more than high school* and if there was no response, it was coded as missing. The addition of the tracker variables *Degree* and *race* completed the master data set that was used for statistical analysis and for obtaining results.

***Missing values.*** For the most part, missing data were minimal; imputing values for missing data was necessary only for Aim 2. Imputation for Aim 2 dealt with missing data in any of the four EOL actual care received categories (T230–T233—*all care possible, limit care, withhold treatment, comfort care).* Any missing data were imputed into a *no* response and excluded from analysis. Notably, missing values were verified by referencing the HRS codebook. For this sample, checking for outliers was unnecessary because the sample comprised indicator and demographic variables, whose range of possible answers was limited; accordingly, outliers were not a concern.

## Statistical Testing

**Analysis testing.** After the data were cleaned, a descriptive analysis was conducted on all the variables in the study (see Appendix A, Study Variables). For each variable we began by computing frequencies. Each of the five aims required different statistical testing which is detailed below under each individual aim. In general, the analyses included running frequencies, percentages, computations of proportions, *p-value*s, construction of confidence intervals, performance of chi-squared tests, *z*-tests for one proportion, odds ratios, the construction of a binary logistic regression model, and Hosmer-Lemeshow goodness-of-fit test.

Prior to any analysis, it was necessary to create variables that corresponded with each category of EOL care preference and a match with the corresponding EOL care category for actual care received (e.g. *limit care* vs. *limit care*) by the respondent. The columns were labeled *all care possible* preferred and received variable was labeled “T193 x T230.” Therefore, if the preference matched the decision, then that variable was coded as “1,” this coding indicated a match and that the actual care received was in accordance with the respondent’s EOL care preference. If the variables did *not* match, then T193 x T230 was coded as “0,” which indicated that respondent preference did not match the actual care received. In the same fashion, similar variables were created for the other EOL care preferred vs. EOL actual care received pairs. These variables were T194 x T231 assesses a match between preferred and received *limited care,* T195 x T232 assesses the match between preferred and received *withholding treatment,* and T196 x T233 assesses a match between preferred and received *comfort care.* If the actual EOL care value was missing in any comparison, or if the proxy did not have a response for the type of received EOL care, then the missing value was imputed to be a *no* answer. For example, if the proxy answered T193 but did not have a response for T230, then a *no* was inserted for the T230 question.

### Statistical methodology by aim.

The HRS collects data at both the household and respondent level. Unless otherwise stated, data were retrieved from respondent level.

***Aim 1.*** What percentage of sample respondents prefer each of the following care options. As reported by the proxy: *all care possible, limit care, withhold treatment,* and *comfort care*? This statistical test was conducted as a univariate analysis for a sample value and calculated on the basis of a normal distribution. The total number of respondents in the sample was 3,660 after eliminating respondents with incomplete information.

To determine which type of care was most preferred, the percentages of each type of preferred care was calculated. The significance level was maintained at 5%, and confidence intervals were calculated.

Given that the number of boxes checked (9,824) exceeded our sample of 3,660, which could mean a possibility of inflated results, a subsample analysis was performed. This analysis was conducted on the respondents whose proxy checked one box (one type of care). These specified preferences were matched to the corresponding received care.

To determine the percentages of preferred EOL care from the sample and subsample, we estimated the population proportion from the sample proportion. Once the proportions or percentages were known, the upper and lower limits of the 95% confidence interval were calculated using the confidence interval formula.

***Aim 2.*** What is the prevalence of disparity between patients' written EOL care preferences and the actual EOL care received, as reported posthumously by the patient's proxy? This aim was computed by noting the preferences for EOL care in the variables T193 (*all care possible*), T194 (*limit care*), T195 (*withhold treatment*), and T196 (*comfort care).* The preference variables were compared with the actual EOL care received variables (see Table 2). A total of 3,660 respondents with written EOL instructions had complete data on variables T193–T196 (preferred care: *all care, limit care, withhold treatment,* and *comfort care*) and T230-T233 (receipt of: *all care, limit care, withhold treatment, comfort care*). The missing values were replaced with 0 (*no),* assuming and that the answer was missing was thus removed from calculation.

We conducted a bivariate analysis with a dichotomous (*yes/no*) comparison between the matching variables of preferred care vs. received care; results were then quantified into the percentage of followed preferences. The following variables were created for this analysis: T193 x T230 (*Preferred all care possible* x *Received all care),* T194 x T231 (*Preferred limited care* x *Received limited care*), T195 x T232 (*Preferred withhold treatment* x *Treatment withheld*), and T196 x T233 (*Preferred comfort care* x *Received comfort care*). The problem we encountered with these created variables was that many proxies answered affirmatively to more than one category of EOL care (they checked more than one box). For this reason, this variable was calculated by category and not by individual respondent – a multiple response data approach (Biometrics Advisory and Support Service to DFID, 2001). A total of 9,824 boxes were checked. Using the multiple response data column approach, we then calculated the proportion of boxes that were checked in each of the four categories and the corresponding confidence intervals. The length of the columns is equal to the number of respondents.

**Table 2**

*Operational Variables, Aims 1 and 2*

| | Respondent's preferences for EOL care<br>Variable number | Actual EOL care –treatment Decisions<br>Variable number | Match |
|---|---|---|---|
| All care possible | T193 | T230 | yes/no |
| Limited care | T194 | T231 | yes/no |
| Withhold treatment | T195 | T232 | yes/no |
| Comfort only | T196 | T233 | yes/no |

Of the 3,660 respondents, 48 checked no boxes (excluded from computation), 212 checked one box, 670 checked two boxes, 2,648 checked three boxes, and 82 checked four boxes. Multiplying the total numbers of boxes checked by the number of respondents who checked no boxes, one box, two boxes, three boxes, and four boxes respectively, yielded the total number of boxes checked, 9,824. Box count is a way of cleaning the data and ensuring that the same number of boxes is used in each step of the analysis. A box with 0 data is not used in the calculations, but its partner in the corresponding row, may have been. In further analyzing these totals, we counted the number of boxes checked by type of EOL care to ensure that we were working with the same data numbers and samples.

Due to the fact that proxies were allowed to choose more than one type of care (check more than one box) the original analysis of the sample was changed from individual patient preferences of EOL care to analysis by category of EOL care; based on multiple response data techniques (Biometrics Advisory and Support Service to DFID, 2001). This is a common approach to survey data when respondents are allowed to answer questions with more than one answer. This technique entails utilizing a separate table with two columns (one for each type of EOL care match). The first column contains the EOL care preference variables (T193-T196) and the second column contains the received EOL care variables (T230-T233). The length of the columns is equal to the number of respondents (3,660). A zero (0) in one column would represent a mismatch, whereas a one (1) in both columns would reveal a match in the type of EOL care preferred and received.

Given that the number of patients did not change in this analysis we acknowledge that the number of mismatches of care may be inflated. For this reason we added an additional bivariate analysis matching preferred EOL care to received EOL care from a subsample comprised of the 212 proxies that checked only one box of care in each EOL care category.

The proportion of preferred and received care matches were computed as percentages using a 95% confidence interval for the sample value and were calculated on the basis of a normal distribution.

A z-test was also conducted. In order to perform the *z*-test, we had to ignore the fact that respondents checked multiple boxes; instead, responses in the four categories were treated as unrelated samples, and analyzed as columns. Had we performed a cross-tab calculation per respondent, we would have been over counting, or counting the data more than once. A z-test for one proportion was tested with the following formula to test for proportions of greater than 30%. In a *z*-test for a single proportion with a fixed alpha significance, or $\alpha$ level, we tested the null hypothesis, $H_0$: true proportion is greater than or equal to 0.30 against the alternative hypothesis, $H_A$: true proportion is less than or equal to 0.30.

The *p-value* is the probability that a standard normal random variable Z is larger than the observed test statistic z; that is, *p-value* = *p* (Z > z). The *p-value* is then compared with (alpha level) $\alpha$. If the *p-value* is smaller than $\alpha$, we reject the null hypothesis because a small *p-value* means that the observed data are unlikely if the null were true. Accepting $H_0$ is equivalent to rejecting the $H_{A,}$ and the conclusions would be that (a) the data support the claim that respondents did have their preferences followed at least 30% of the time and (b) the true population proportion is larger than or equal to 0.30. If the *p-value* is in excess of $\alpha,$ we would fail to reject the null hypothesis, and we would conclude that (a) the claim is false and (b) the true proportion of preferences being followed is less than 0.30.

**Additional exploratory aims.** In addition to the first two aims, this study had three exploratory aims. These aims were designed to explore respondents' preferred types of EOL care differed by region, and whether following respondents' EOL care preferences differed by region. Additionally, we looked for any demographic variations that was or was not associated with following a patient's EOL care preferences. Lastly, we examined whether a conversation between a provider and a proxy resulted in a greater adherence to provider offered EOL treatment at the very end of life.

***Aim 3.*** Do any of the following demographic variables—*age, race, sex, marital–partner status, education,* or *religious services*—associated with provider adherence to respondents' written EOL care preferences?

To answer this question, we began by looking at the variables. *Wave* and *age* are continuous variables, whereas *sex, race, marital status, education* and *religious services* are categorical variables. Some of the multiple levels of the categorical variables were collapsed (*education* and *religious services*) to coalesce numerous categories that contained little data, and then frequency distributions were performed.

Next, four binary logistic regressions were fit that modeled the prevalence odds that the match between variables was no, (a) *Preferred all care* x *Received all care*, T193 x T230 = 0 (*no*); (b) *Preferred all care* x *Received all care*, T194 x T231 = 0; (c) *Preferred limit care* x *Received limit care*, T195 x T232 = 0; and (d) *Preferred withhold treatment* x *Received withhold treatment*; *Preferred comfort care* x *Received comfort care*, T196 x T233 = 0.

Logistic regression is used to test variables that are categorical. Aim 3 has both categorical independent variables (*wave, age, sex, race, marital status, education,* and *religious services*) and dependent variables (matched vs. non-matched care preference) for each of the four types of EOL care: *all care possible, limit care, withhold treatment,* and *comfort care*. To ascertain which of the demographic variables (IVs) were individually associated with the EOL preferred care that was not received (DVs); cross-tab tables were created for each EOL care type and each of the demographic variables (IVs).

In the present study, prevalence odds ratios were calculated to determine the risk of a particular demographic variable (IV) being associated with the preferred type of EOL care (DV) not being received. Chi-squared and *p-value*s were calculated and a Hosmer-Lemeshow test was performed to also test the model's goodness-of-fit. This test compares the predicted model with a hypothetically perfect model (Polit & Beck, 2012). In the Hosmer–Lemeshow test, the observed and predicted values of the dependent variable are separated into deciles, and then the test statistics with the corresponding *p-value*s are computed (Kellar & Kelvin, 2013).

In addition to performing the Hosmer-Lemeshow test, we computed a pseudo *R*-squared because it resembles the coefficient of multiple determination *R-squared*. The two R-squared tests resemble each other in that they are both on a similar scale, with higher values indicating better model fit; however, the maximum of the pseudo *R-squared* is not necessarily equal to unity (in SAS an overlay that is nearly an exact fit of the model), and thus it cannot be interpreted as the proportion of variation in the DV that can be accounted for by the model. To compensate for this lack of precision and as a remedial measure, the max-rescaled pseudo *R-squared* is also commonly reported; *max-rescaled pseudo R-squared* is defined as the pseudo *R-squared* divided by its maximum. The larger the values of pseudo *R-squared* and max-rescaled *R-squared*, the better the model fit.

***Aim 4.*** Among patients whose proxies were offered but refused medically recommended care, what percentage of patients were nevertheless given the refused care at the "very end of life" (undefined expression used by the HRS researchers)? The variables *did any doctor(s) recommend any care or treatment that the family or other decision-maker(s) ultimately refused?* (T234) and *did the respondent receive this treatment anyway?* (T235) were evaluated. The goal of Aim 4 was to determine whether proxy instructions delivered directly to the provider had a better rate of adherence than did written instructions that the patient provided in advance. However, because the inclusion criteria for this question did not require the presence of written EOL care instructions (T190), the stated goal could not be addressed as planned. However, I was able to evaluate the provider adherence to a proxy's refusal for EOL care, at the very end of life.

There were 4,431 boxes checked in response to these variables. This aim did not require the inclusion question of a *yes* answer to T190 (*presence of written instructions*), which is why there are more than the 3,660 respondents used in the sample. A univariate analysis was used to calculate the percentage of *yes* responses to variables T234 (*refused care*) and T235 (*received unwanted care);* a 95% confidence interval was calculated (refer to Formula 1) on the basis of a standard normal distribution. The result of this calculation is the percentage of instances in which proxies refused care on behalf of the respondent, but regardless the respondent received the unwanted care.

***Aim 5.*** Does the rate of provider adherence to patients' written EOL care preferences differ between U.S. population regions?

This variable was computed at the household level instead of at the respondent level. To assist with protecting the identity of the respondent, the HRS masks the identity of states of residence and in turn places respondents into regions. The HRS has nine geographic regions. There were 16 missing observations, from the sample of 3,660, which were discarded; accordingly, the total number of observations that were tested in the sample was 3,644.

We began by using the created variable *Region*, which was a derivation of the U.S. Census Bureau's four national regions of *Northeast*, *Midwest*, *South,* and *West* (U.S. Bureau of the Census, 1995). Next, we sorted the nine HRS regions into the four regions listed above; this created the variable *Region* for each type of preference for EOL care vs. actual care received variables (*all care possible, limit care, withhold treatment,* and *comfort care*). Four 2-way tables were created for the each of the matched care variables: *all care possible* (T193 x T230; *yes/no*), *limit care* (T194 x T231; *yes/no*), *withhold treatment* (T195 x T232; *yes/no*), and *comfort care* (T196 x T233; *yes/no*).

Equality of proportions of *yes* responses, by region, were compared using the Pearson chi-squared test, and the results were judged in relation to the *p-value*s. Specifically, we looked for *p-value*s less than or equal to 0.05; such values would indicate a significant difference between regions. The *p-value* will indicate the strength of the probability of a difference between regions.

For a Pearson chi-squared test for equality of proportions to be applicable, we must have: random samples from independent samples as well as measurements on the same categorical variable. The original HRS data and samples were randomly selected. The data are then arranged in four 2-way tables, created for each of the categories. In these tables, rows typically contain data for the samples, and the columns contain the levels of the categorical variable. The cells in the table contain corresponding frequencies (sometimes called "counts"). Intuitively, we would be interested in testing whether column 1, the proportions of respondents in the samples are the same; and whether proportions are equal across the rows within column 1. Expected values are computed for each cell, which is the row total multiplied by the column total, then divided by the grand total (3,644).

A chi-squared tests the null hypothesis that proportions of *yes* responses are the same in each column. For the alternative hypothesis to be true, all the column proportions are not the same. Expected values are computed for each cell and then compared to the observed values. The test statistic is then computed, and the decision is based on the corresponding *p-value*. If the *p-value* is larger than .05, the null hypothesis is rejected with the conclusion that proportions of following EOL care are not the same in all regions. Otherwise, the conclusion is that the proportions of following EOL care are equal in all regions. Under the null hypothesis, this statistic follows a chi-squared distribution with the degrees of freedom (*df*) computed as the product of the number of rows reduced by one and the number of columns reduced by one, that is, df = (# of rows – 1)(# of columns – 1). All of the tables displaying data in Aim 5 had the same degrees of freedom. In this case, *df* = (2-1)(4-1) = 3.

# CHAPTER 4

## Results

The majority of the findings related to the aims that most directly emanated from the research question were statistically significant. Conclusions related to some of the demographic variables were significant as far as their association with patient preferences' being honored at the EOL (see analysis of aims below).

**Aim 1.** What percentage of sample respondents prefer each of the following EOL care options: *all care possible, limit care, withhold treatment,* and *comfort care*?

***Multiple response sample.*** We calculated the percentages of each type of preferred EOL care of both the sample of 3,660, and the single response subsample total of 212, along with their corresponding 95% confidence intervals (see Tables 3 and 4).

**Table 3**

*Aim 1 results: Multiple Response Sample (N=3,660)*

| Type of Care | Number of Patients Who Wanted Care Type/ Total Sample Size | Proportion, $\hat{p}$ Who Preferred EOL Care type | 95% CI for Sample Percent Wanted Care |
|---|---|---|---|
| *All care possible* | 199/3,660 | 5.44% | [4.70%, 6.17%] |
| *Limit care* | 3,335/3,660 | 91.12% | [90.20%, 92.04%] |
| *Withhold Treatment* | 2,908/3,660 | 79.45% | [78.14%, 80.76%] |
| *Comfort Care* | 3,382/3,660 | 92.40% | [91.55%, 93.26%] |

*Frequencies, Percentages, and CIs for Respondents by Preferred Type of Care*

*Conclusion Aim 1, multiple response sample*. *Comfort care* was the most preferred EOL care according to 92.40% of the proxy respondents. *Limit care* was the next most popular choice of EOL care with 91.12% preferring this care. *Withhold treatment* was the preferred care

79.45% of the time. Lastly, *all care possible* was preferred at the EOL by only 5.44% of the respondents. HRS does not specifically define the EOL period.

***Single response subsample.*** The next analysis was run on the subsample of 212 respondents who chose only one type of care. We drilled down further into this analysis to look at only those respondents who checked only one box, and then evaluated if they received the care of their choice.

**Table 4**

*Aim 1 results: Single Response Subsample (N=212)*

| Type of Care | Number of Patients Who Wanted Care Type/ Total Subsample Size | Proportion, $\hat{p}$ Who Preferred EOL Care type | 95% CI for Subsample Percent Wanted Care |
|---|---|---|---|
| *All care possible* | 32/212 | 15.09% | [10.56%, 20.64%] |
| *Limit care* | 66/212 | 31.13% | [24.97%, 37.83%] |
| *Withhold Treatment* | 18/212 | 8.49% | [5.11%, 13.09%] |
| *Comfort Care* | 96/212 | 45.28% | [38.45%, 52.25%] |

*Frequencies, Percentages, and CIs for Respondents by Preferred Type of Care for the 212 Patients Who Preferred Only One Type of Care*

*Conclusion Aim 1, single response subsample**.*** In the subsample the most preferred EOL care is comfort care, as it was in the sample. When all 3,660 respondents were considered preference for EOL care is in decreasing order: *comfort care, limit care, withhold treatment*, and *all care possible*, whereas in the subsample of 212 respondents, the order of preferred care is: *comfort care, limit care, all care possible*, and *withhold treatment*. In both samples *comfort care* is the most preferred type of EOL care.

## Analysis of Hypothesis and Research Question

**Aim 2.** What is the prevalence of disparity between patients' stated EOL care preferences and the actual EOL care received, as reported posthumously by the patient's proxy? A total of 3,660 respondents with written EOL instructions had complete data on T193–T196 and T230–T233. We conducted a bivariate analysis of the 3,660 proxy respondents, looking for mismatches between the corresponding variables of preferred EOL care and received EOL care. The allowance of multiple boxes to be checked is a HRS limitation. For this reason, the multiple response sample analysis was followed by a single response subsample analysis of the 212 proxies who checked only one box.

**Table 5.**

*Multiple Response Sample Preferred vs. Receipt of EOL care, by EOL care type (N=3,660)*

**T230**
Received: *All Care Possible*

| | Freq | No | Yes | Total |
|---|---|---|---|---|
| **T193**<br>Preferred<br>*All Care Possible* | No | 3291 | 170 | 3461 |
| | Yes | 143 | 56 | 199 |
| | Total | 34.34 | 226 | 3660 |

170+143=313 Mismatches

**T231**
Received: *Limit Care*

| | Freq | No | Yes | Total |
|---|---|---|---|---|
| **T194**<br>Preferred<br>*Limit Care* | No | 263 | 62 | 325 |
| | Yes | 1950 | 1385 | 3335 |
| | Total | 2213 | 1447 | 3660 |

62+1950=2012 Mismatches

**T232**
Received: *Withhold Treatment*

| | Freq | No | Yes | Total |
|---|---|---|---|---|
| **T195**<br>Preferred<br>*Withhold Treatment* | No | 600 | 152 | 752 |
| | Yes | 1775 | 1133 | 2908 |
| | Total | 2375 | 1285 | 3660 |

152+1775 =1,927 Mismatches

**T233**
Received: *Comfort Care*

| | Freq | No | Yes | Total |
|---|---|---|---|---|
| **T196**<br>Preferred<br>*Comfort Care* | No | 173 | 105 | 278 |
| | Yes | 1776 | 1606 | 3382 |
| | Total | 1949 | 1606 | 3660 |

105+1776=1881 Mismatches

As seen in the above tables, out of 199 respondents who wanted *all care possible*, 143 did not receive it (72%), while 170 out of 3,461 (28%) received *all care possible* as unwanted care. Among the 3,335 respondents who requested *limit care* 1,950 (58%) did not get their wishes honored; and for 62 (19%) it was unwanted care. Whereas, of 2,908 respondents who wanted *treatment withheld*, 1,775 (61%) did not have it withheld; and 152 (20%) had care withheld against their wishes. Lastly, of the 3,382 who wanted *comfort care* 1,776 (53%) received it; 105 (38%) received this care against their wishes.

Table 6 below displays the number of respondents who received care that was mismatched or not in accordance with their EOL care preferences. The mismatches included looking at patients who did not receive the EOL care they wanted *and* patients who received unwanted EOL care. These counts were converted into percentages of the total number of respondents (*N* = 3,660), and the corresponding 95% confidence intervals for the true population proportions were calculated.

**Table 6.**

*Aim 2: Frequencies Multiple Response Sample, percent of the total sample (N=3,660)*

| EOL care category | Mismatched Care/ Total Sample Size | Percentage with Mismatched care | 95% CI | *z*-test | *p-value* |
|---|---|---|---|---|---|
| *All care possible* | 313/3,660 | 8.55% | [7.65%, 9.46%] | -28.3152 | > .9999 |
| *Limit Care* | 2012/3,660 | 54.97% | [53.36%, 56.58%] | 32.96826 | < .0001 |
| *Withhold Treatment* | 1927/3,660 | 52.65% | [51.03%, 54.27%] | 29.90228 | < .0001 |
| *Comfort Care* | 1881/3,660 | 51.39% | [49.77%, 53.01%] | 28.24305 | < .0001 |

*95% CI for sample percentage, z-test statistic, and p-value for respondents who did not get their preferences honored separated by EOL care category (total N = 3,660).*

Next, we did a bivariate analysis to test our hypothesis whether each of the four sample proportions were greater than or equal to 0.30. The PEW survey was the reference for setting the hypothesis for this research (Funk, 2013). For these comparisons, the null hypothesis stated that the sample proportion of mismatches of columns was greater than or equal to 0.30, $H_0: p \geq 0.30$, whereas the alternative hypothesis stated that the sample proportion of mismatches of columns was less than 0.30, $H_A: p < 0.30$. Z-test statistics and their *p-value*s are summarized in Table 5 above.

***Conclusion Aim 2.*** When evaluating mismatches, the null hypothesis (preferred care not honored ≥ 30%) was accepted as true for the mismatched categories of EOL care: *limit care, withhold treatment,* and *comfort care* because the *p-value*s were less than 0.05 (a 5% significance level of the test). The alternative hypotheses for the mismatches of EOL care category *all care possible* was not rejected because the *p-value* was very large.

Considering the direct counts (Table 6), of preferred and received care, we accept the null hypothesis (preferred care not honored ≥ 30%) for all categories of EOL care, as all were not honored more than 30% of the time. For patients who wanted *all care possible,* 72% did not receive their preferred choice. For those who wanted to have their *care limited*, 58% did not have their *care limited*. Unfortunately for those who wanted *treatment withheld*, 61% received treatment anyways. And lastly, of the patients who preferred to receive only *comfort care* 53% did not have those choices honored.

The fact that the sample analysis of mismatches of EOL care revealed results for greater than two-and-half times the sample of 3,660 (total number of checked boxes was 9,824), there may be some inflated results but had no way of knowing in which EOL category these inflated results may have occurred.

***Single Response Subsample.*** The single response subsample analysis was conducted by drilling down more specifically to analyze only those who wanted and received one type of EOL care, *N=212.* See Table 7.

**Table 7.** *Single Response Subsample Preferred vs. Receipt of EOL care by EOL care type*

**T230**
Received: *All Care Possible*

| | Freq | No | Yes | Total |
|---|---|---|---|---|
| **T193** Preferred *All Care Possible* | No | 162 | 18 | 180 |
| | Yes | 17 | 15 | 32 |
| | Total | 179 | 33 | 212 |

18+17=35 Mismatches

**T231**
Received: *Limit Care*

| | Freq | No | Yes | Total |
|---|---|---|---|---|
| **T194** Preferred *Limit Care* | No | 119 | 27 | 146 |
| | Yes | 45 | 21 | 66 |
| | Total | 164 | 48 | 212 |

45+27=72 Mismatches

**T232**
Received: *Withhold Treatment*

| | Freq t | No | Yes | Total |
|---|---|---|---|---|
| **T195** Preferred *Withhold Treatment* | No | 154 | 40 | 194 |
| | Yes | 13 | 5 | 18 |
| | Total | 135 | 77 | 212 |

13+40=53 Mismatches

**T233**
Received: *Comfort Care*

| | Freq Percent | No | Yes | Total |
|---|---|---|---|---|
| **T196** Preferred *Comfort Care* | No | 73 | 43 | 116 |
| | Yes | 62 | 34 | 96 |
| | Total | 135 | 77 | 212 |

62+43=105 Mismatches

From the above tables, 17 out of 32 (53%) respondents who requested *all care possible* did not receive it, while 18 out of 180 (1%) who did not want this care nonetheless received it. For *limit care,* 45 of the 66 (68%) who requested this care did not get it, and 27 of 146 (18%) received this as unwanted care. For *withhold treatment,* 13 of 18 (72%) who wanted this care did not receive it, and 40 of 194 (21%) received this unwanted care. For *comfort care,* 62 of 96 (53%) did not receive this care as desired, and 43 of 116 (37%) received this care against their wishes.

**Table 8.**

*Aim 2: Frequency, percent of the single response subsample (N=212)*

| EOL care category | Mismatched Care/ Total Sample Size | Percentage with Mismatched care | 95% CI | *z*-test | *p-value* |
|---|---|---|---|---|---|
| *All care possible* | 35/212 | 16.51% | [11.51%,21.51%] | -4.28636 | > .9999 |
| *Limit Care* | 72/212 | 33.96% | [27.59%,40.34%] | 1.25893 | < .1040 |
| *Withhold Treatment* | 53/212 | 25.00% | [19.17%,30.83%] | -1.58865 | < .9439 |
| *Comfort Care* | 105/212 | 49.53% | [42.80%,56.26%] | 6.204728 | < .0001 |

*95% CI for subsample percentage, z-test statistic, and p-value for respondents in the subsample who did not get their EOL care preferences honored*

***Conclusion single response subsample:*** Considering the mismatches in the subsample as shown in the table 8, the *p-value* is only significant for *comfort care* at 0.0001. In the other three EOL care preference categories, even though the values fall within the confidence intervals, from the *p-value*s we cannot conclude that the true percent of the mismatched care is larger than the hypothesis of 30%.

***Interpretation:*** In both the analyzed sample and subsample, *comfort care* is the most preferred care (per proxy report), and yet in both samples *comfort care* was not followed greater than 50% of the time. The direct counts in the sample and the subsample reveal that the preference to *limit care* is not followed 58% of the time in the sample, and in the subsample 33.96% of the time. Patients who preferred to have *treatment withheld* did not have that choice respected 61% of the time in the sample and 25% of the subsample. Lastly, the choice to receive *all care possible* was not followed 71% of the time in the sample and 16.51% of the time in the subsample.

## Findings of Exploratory Aims

**Aim 3.** Do any of the following demographic variables—*age, race, sex, marital status, education,* or *religious services*—influence provider adherence to respondents' written EOL care preferences?

We ran four binary logistic regressions modeling the prevalence odds in favor of no-match between the preferences for EOL care and the receipt of EOL care: T193 x T230 = 0 (wanted *all care,* did not receive *all care*), T194 x T231 = 0 (wanted *limited care*, did not receive *limited care),* T195 x T232 = 0 (wanted *care withheld, care not withheld*), T196 x T233 = 0 (wanted *comfort care,* did not receive *comfort care*).

The IVs were *wave* and *age,* and these were continuous variables. *Sex, race, marital status, education,* and *religious services* were categorical variables. As mentioned previously, *education* and *religious services* were collapsed to condense numerous categories that contained little data. Frequency tables can be found in Appendix B. The results for the logistic regression analysis are given in Table 9.

**Table 9.**

*Results of Binary Logistic Regression Modeling for the Four Types of Care*

| | POR [95%CI]<br>Prevalence Odds Ratios | | | |
|---|---|---|---|---|
| Independent Variables | ***All Care Possible*** | ***Limit Care*** | ***Withhold Treatment*** | ***Comfort Care*** |
| Age | 0.98 [0.97, 0.99]** | 1.01 [0.997,1.013] | 1.00 [0.995,1.01] | 1.01 [0.998,1.01] |
| Wave | 1.07 [1.03, 1.11]** | 0.99 [0.97, 1.01] | 0.99 [0.97,1.01] | 0.95 [0.97,1.02] |
| Gender | | | | |
| Female | 1.06 [0.81, 1.37] | Reference | Reference | Reference |
| Male | Reference | 1.17 [1.01,1.35]* | 1.09 [0.94,1.26] | 1.16 [1.00,1.34]* |
| Race | | | | |
| Black | 3.43 [1.47, 7.99]** | Reference | Reference | 1.05 [0.63,1.75] |
| White | 1.19 [0.53, 2.64] | 1.04 [0.79, 1.36] | 1.52 [1.15,1.98]** | 1.05 [0.68,1.64] |
| Other/Refused to answer | Reference | 1.28 [0.76, 2.14] | 1.33[0.80,2.21] | Reference |
| Marital status | | | | |
| Married | 1.49 [0.86, 2.59] | 1.26 [0.84, 1.90] | 1.16 [0.89,1.50] | 1.76 [1.15,2.68]** |
| Never married | 1.76 [0.79, 3.90] | Reference | 1.02 [0.65,1.61] | Reference |
| Separated/Divorced | 1.29 [0.68, 2.47] | 1.08 [0.69, 1.70] | 1.23 [0.81,1.57] | 1.59 [1.00,2.52]* |
| Widowed | 1.36 [0.79, 2.35] | 1.10 [0.73, 1.65] | 1.09 [0.84,1.40] | 1.38 [0.91,2.10] |
| DK/RF/Missing | Reference | 1.25 [0.80, 1.97] | Reference | 1.82 [1.15,2.89]* |
| Education | | | | |
| < High school | 2.06 [1.39, 3.05]** | 1.18 [0.96, 1.43] | 1.08 [0.89,1.32] | 1.28 [1.05,1.57]* |
| High school | 1.67 [1.16, 2.40]** | 1.15 [ 0.97, 1.37] | 1.08 [0.90,1.28] | 1.32 [1.10,1.57]** |
| > High school | Reference | Reference | Reference | Reference |
| Religion | | | | |
| ≥ once a week | 1.27 [0.92, 1.75] | 1.08 [ 0.90, 1.28] | 1.15 [0.97,1.38] | 1.09 [0.93,1.27] |
| Less frequent | Reference | Reference | Reference | 1.03 [0.88,1.21] |
| Not at all | 1.21 [0.90, 1.63] | 1.04 [0.88, 1.22] | 1.3 [0.96,1.32] | Reference |

*p < .05, **p < .01

**Table 10**

*Summary for the Binary Logistic Regressions Model – Accuracy and Goodness-of-Fit Measures*

| Type of Care | Pseudo $R^2$ | Max-rescaled pseudo $R^2$ | *p-value* for Hosmer-Lemeshow test |
|---|---|---|---|
| *All Care Possible* | 0.0258 | 0.0583 | .4666 |
| *Limit Care* | 0.0051 | 0.0068 | .6836 |
| *Withhold Treatment* | 0.0052 | 0.0069 | .2278 |
| *Comfort Care* | 0.0098 | 0.0131 | .0826 |

The large *p-value*s calculated from the Hosmer-Lemeshow goodness-of-fit test show that the binary logistic regressions have a good fit. All of the *p-value*s presented in the last column of Table 10 were in excess of 0.05, meaning that the model fits the data well and that the null hypothesis will not be rejected for any type of care. However, the quantities of the pseudo *R squared* and max-rescaled pseudo *R squared* are not very large (see Table 10). These statistics indicate that if the model is used for prediction, the model's accuracy is not great. This finding is not atypical from a model with all or virtually all categorical independent variables (Tranmer, 2008).

The fitted models yield the following interpretations, and as is traditional, the interpretation is done only for statistically significant independent variables (or significant levels of categorical variables).

## Interpretations by Type of Care

**All care possible.** In the *all care possible* model, older patients had a 0.98-fold greater chance to have their preferences *not* honored (*POR* = 0.98). Notably, in the more recent waves, the Black respondents had a 1.07-fold greater chance of *not* getting preferences for *all care possible* honored (*POR* = 1.07). Black respondents had a 3.43-fold greater chance to have their preferences *not* honored than were respondents who identified themselves as *other race* or *refused to answer* (*POR* = 3.43). In comparison with respondents with education beyond high school, respondents with less than high-school education had a 2.06-fold greater chance of *not* getting their preferences honored (*POR* = 2.06). In comparison with respondents with more than high-school education, respondents with a high-school diploma had a 1.67-fold greater chance of having their preferences *not* honored (*POR* = 1.67).

**Limit care.** In the model for *limit care,* in comparison with females, males had a 1-fold greater chance of getting their preferences *not* honored (*POR* = 1.17).

**Withhold treatment.** The regression model for *withhold treatment* establishes that White respondents had a 1.52-fold greater chance to have their preferences *not* honored than were Black respondents (*POR* = 1.52).

**Comfort care.** Summarizing the *comfort care* model, in comparison with males, females had a 1-fold greater chance to have their preferences *not* honored. In comparison with respondents who were never married, respondents who were married had a 1.76-fold greater chance to not have their preferences honored (*POR* = 1.76). Respondents who were in the separated/divorced category had a 1.59-fold greater chance to have their preferences *not* honored (*POR* = 1.59) than were those who were never married. Lastly, in comparison with those who never married, respondents who were widowed had 1.82-fold greater chance of having their preferences *not* honored (*POR* = 1.82).

**Aim 4.** Among patients whose proxies refused medically recommended care, what percentage of patients were nevertheless given the refused care at the "very end of life" (the expression used by the HRS researchers)?

For this aim, questions T234 and T235 were evaluated; these two questions were asked to the proxy and acted upon by the provider (see Study Variables table in Appendix A). The variable T234 corresponds to this question: “Did any doctor(s) recommend any care or treatment that the family or other decision-maker(s) ultimately refused?” The variable T235 corresponds to the question: “Did the respondent receive this treatment anyway?” The goal of Aim 4 was to determine what percentage of the proxy’s direct refusal for EOL treatment when verbally communicated with the provider (as opposed to the written instructions) was followed.

In Aim 4, we calculated the percentages of “yes” and “no” answers to variables T234 and T235. This sample did not require the inclusion question of a “yes” answer to T190, which is why the findings are not comparable to those from the proxy reports on those with documented EOL care preferences. We compared the “yes” responses of variable T234 with the “yes” responses of variable T235. The result of this calculation was the percentage of proxies who refused care on behalf of the respondent, but the respondent received the unwanted care anyways. Questions T234 and T235 had 4,431 responses.

Of 4,431 total responses, the “yes” responses were 3,921. Out of the sample size of 3,921 the “yes” responses to T234 were 510. This response rate represents 13% of the proxies who answered “yes” that they had, in fact, refused care on behalf of the respondent. T235 had 80 “yes” responses out of the 510 who answered this question; which means nearly 16% of the respondents received unwanted care that was directly refused by their proxy. The corresponding confidence intervals were also computed and are shown in Table 11 that follows.

**Table 11.**

*Percentages and 95% CIs for Aim 4 (care refused, unwanted care received). N=3,912*

| Variable | % Calculated | 95% CI |
|---|---|---|
| T234 | 13.01% (n=510) | [11.95%, 14.06%] |
| T235 | 15.69% (n=80) | [12.53%, 18.84%] |

**Aim 5**: Does the prevalence of provider adherence to patients' written EOL care preferences differ between U.S. population regions?

This aim was computed at the household level, beginning with HHID number. The variable *Region* was recoded in order to collapse the nine HRS categories into four regional categories: Northeast, Midwest, South, and West. This variable had a total of 3,644 non-missing observations. The variables for provider adherence to patient's written EOL care preferences were the same as those used in Aims 1 and 3.

Four 2-way tables were created for the four EOL care categories: *all care possible* (matched/not matched = *yes/no*), *limit care* (*yes/no*), *withhold treatment* (*yes/no*), and *comfort care* (*yes/no*); preferred and receipt of the same type of care was considered "matched." The variable *Region* also has four levels; therefore, all the 2-way tables contain four rows (four geographic regions) and two columns (*yes/no* for care type). Equality of proportions of "yes" by region were compared using the Pearson chi-squared test, and the results were judged based on the *p-value*s, looking for values less than or equal to 0.05 which would indicate significant difference between regions. The 2-way tables and the corresponding *p-value*s are displayed in Table 12 below.

**Table 12.**

*Differences in Care Adherence by Geographic Region and Chi-squared P-values*

| Type of Care | All Care Possible T193 | | Limited Care T194 | | Withhold Treatment T195 | | Comfort Care T196 | |
|---|---|---|---|---|---|---|---|---|
| Region | Yes % | No % | Yes % | No % | Yes % | No % | Yes % | No % |
| Northeast | 91.24 | 8.76 | 44.11 | 55.89 | 45.38 | 54.62 | 48.25 | 51.75 |
| Midwest | 91.42 | 8.58 | 46.19 | 53.81 | 49.18 | 50.82 | 48.02 | 51.98 |
| South | 90.94 | 9.06 | 44.80 | 55.20 | 47.68 | 52.32 | 49.00 | 50.90 |
| West | 92.77 | 7.23 | 45.18 | 54.82 | 45.82 | 54.18 | 48.80 | 51.10 |
| *p-value*s | .6003 | | .8508 | | .3902 | | .9645 | |

Given that all of the *p-value*s in Table 12 were above 0.05, it can concluded that, regardless of care type, the percent of patient's EOL care preferences that were followed did not significantly differ in the four population regions of the U.S.

# CHAPTER 5

## Discussion

In 2015, the Institute of Medicine published its landmark report, *Dying in America.* In this report, the IOM called for research to determine how to improve the quality of care at the EOL and to ascertain the prevalence of non-adherence to patient preferences for EOL care. The present dissertation's research was designed to contribute to the IOM's call for research to determine the prevalence of instances in which individuals' EOL care preferences are not followed. The nationally representative HRS database was used to conduct a cross-sectional secondary data analysis. This study was conducted with an ethical framework in mind; however it is acknowledged that the underlying assumption was that honoring patient preferences is the correct way to approach EOL care.

### Limitations

The major limitation in using the HRS data set for the current study is that when responding to the exit survey, proxies are allowed to respond to EOL care preferences and EOL care received questions with more than one response, e.g. a proxy could report preference for and receipt of more than one type of care at the EOL. For the current study, which attempted to determine if a patient had their EOL care preference followed, proved a challenge for the sample but less so for the subsample. More importantly, this data collection technique may provide a rationale for discrepant findings in the literature that previously used this data set, although I've not seen this limitation mentioned in the literature.

**HRS limitations.** Further limitations are that these surveys are taken from interviews that are lengthy, 1½–3 hours which could prove a challenge for an older age proxy. The exit interview was not necessarily conducted shortly after the patient's death, occurring on average

12.4 months after death. There is no way to drill down to determine the length of time between death and each proxy interview. External validity may have been jeopardized from multiple forms of bias—interviewer, proxy, recall, survivor, or attrition; however there was no direct evidence of any bias. Race information was limited primarily to *white*, *black*, *and other* from the publically available data. A breakdown of Hispanic data was also not available with public data. I was not able to actually review the respondent's written EOL care instructions, nor could I directly interview the respondents' proxy which could have offered the ability to clarify some questions related to why a question about EOL care preference received multiple answers.

The response options on the survey are also a limitation. HRS limits its EOL care options to four choices: all care possible, limit care, withhold treatment, and comfort care. Furthermore, HRS does not provide definitions of the four EOL care choices. This limitation could explain why proxy's selected more than one option for the respondent's preferred and received EOL care treatment.

**Limitation of a secondary analysis study.** The present study using the HRS data also shared typical limitations with other secondary analyses, for example I had no control of the population chosen for the study. I could also not give input regarding which data were collected, how the data were gathered, which variables were measured, or how the original data analysis was conducted (Hulley, 2007). The study's use of a cross-sectional design was another limitation, in that data are collected at a single point in time—and consequently, the study results cannot determine causation.

# Results

The highest ranked preferred choice for EOL care in both the sample and subsample, as reported by the proxies, was *comfort care,* followed by *limit care. All care possible* was third in the subsample but last in the sample. *Withhold treatment* was the fourth preferred care type in the sample but last in the subsample. Overall, the U.S. geographic regions did not differ in the percentages of EOL care instructions were followed. The balance of the study results are summarized below.

## Results in Relation to Hypothesis

The study's hypothesis was set by the results of a PEW Research Center survey that found that at least 30% of the time care preferences for EOL patients are not followed (Funk, 2013). Any percentage equal to or more than 30% is considered a significant finding of preferences not being followed. Results closer to 100% are most significant and reflect fewer adherences to patient preferences to EOL care. Essentially this study also tested those PEW survey results.

*Comfort care* was significant in both the multiple response sample (53%) and in the single response subsample (65%). *Limit care* was significant in both the multiple response sample (58%) and in the single response subsample (68%). The preference to *withhold treatment* was the most significant not honored EOL care preference in both the multiple response sample (61%) and in the single response subsample (72%). The choice for *all care possible* was also significant, in both the multiple response sample (71%) and the single response subsample (53%). From these results, we accept the null hypothesis as true for all four categories of EOL care preference in both the multiple response sample and single response subsample.

Although, the multiple response sample comprised 3,660 responses, 9,824 boxes were checked which comprised the actual number of question responses. For this reason, a single response subsample of those who checked only one type of preferred EOL care (N=212) were evaluated. Due to the possibility of over-inflated results from the multiple response sample, it can be concluded that the single response subsample is a better representation of the true population.

Mismatches of care were also evaluated, which were comprised of care preferred/not received and unwanted care received for each EOL care category for both the sample and the subsample. For three of the four EOL care preferences in the sample—*limit care, withhold treatment, and comfort care*—patients' EOL care preferences were not followed more than 51% of the time; *p-value*s of <.0001. The respondent preferred choice of *all care possible,* is honored less than desired in both samples which means that preferences were followed less than 30% of the time for both the sample and subsample. In the subsample, the only significant finding of mismatched care was *comfort care* at 50%, p<0001. Therefore, in the multiple response sample we accept the null hypothesis as true (preferences not followed more than 30% of the time) for *limit care, withhold treatment, and comfort care* which is also significant for mismatched care; and accept the alternative hypothesis for *all care possible* because the results were not significant. The single response subsample test for mismatch was not significant for *all care possible*, *limit care, and withhold treatment* (followed less or equal to 30% of the time), however it was significant for *comfort care* (followed more than 30% of the time).

"*All care possible*" was the only type of EOL care preference for which the alternative hypothesis was true in the mismatched testing of both the multiple response sample and single response subsample. These results are interesting as this preference may not always be followed by providers for legitimate reasons.  Providers are not obligated to provide non-beneficial (or futile) care (American Medical Association, 1991; Luce, 1995).  Because the study was a secondary analysis of existing data there was no access to health care records, therefore the rationale for this finding can only be speculated.  Although not following the choice of *all care possible* is contrary to a patient's right to fulfilment of their autonomous wishes (and against their written preference), the provider also has a duty to provide beneficial care (beneficence) that is not harmful (avoiding maleficent care).  Furthermore, many life-sustaining treatments and procedures can be harmful and painful so avoiding them in these situations is equivalent to beneficent care.  This decision dichotomy is also representative of the difficulty in making and carrying out EOL care decisions in general.

Summarizing the statistical results, the frequency data described above, for both the sample and subsample, is more reflective of a true comparison of patients' receipt of preferred care than the analysis of mismatched care.  The mismatched care results herein are reflective of incidental findings within the data and thus it cannot be ascertained from the mismatch results what the patient's preferences actually were or would have been.  The frequency data was based on counts and corresponding percentages which are actual EOL care preference numbers.  The mismatched testing gave more information about respondents who received unwanted care but without knowledge of all of their preference information.  But in the sample and given that multiple answers (boxes checked) for each EOL care type were chosen the results could be interpreted as suspect.  For this reason the single response subsample (one box checked) is a better representation of the true population.

Variables corresponding to questions about EOL care treatment offered by the provider, and refused by the proxy were also examined.  The percentage of instances in which refused care was or was not provided was calculated.  Because the same inclusion variable (T190) was not used for the question in Aim 4, a conclusion can only be drawn about the adherence to a proxy's refusal of treatment in a conversation with a provider, and whether that instruction was followed by the provider.  A comparison to adherence with written EOL care instructions cannot be made without the same inclusion variable.  Information about the time intervals between these EOL care conversations and the initiation of the EOL care was not available.

## Demographic Considerations

To determine whether any demographic characteristics were associated with receipt of care, demographic variables were evaluated according to EOL care preference types.  We found that Black patients, patients with high school education or less, and older patients all had a greater chance for not receiving *all care possible*.

Males had a greater chance of non-adherence for their preference of *limited care*.  White patients had a greater chance of not having *treatment withheld*.  Females had a greater chance for not receiving *comfort care*.  Married respondents had a greater chance of not receiving *comfort care*.  Separated, divorced, or widowed respondents had a greater chance of not receiving *comfort care*.

According to the PEW Research Center, 35% of Americans have completed an advance directive-type document (Funk, 2013).  However, of the HRS population, 45% had completed written EOL care documents.  It is possible that given that every 2 years this population is queried about wills, trusts, and planning, an unintended consequence of this repeated exposure was that the HRS population was more knowledgeable about EOL care and more frequently completed advance directive documents.  If this speculation is correct, then the rates of non-adherence to EOL care preferences discussed in the present study may be even higher in the general population.

## Significance

For nearly 30 years, patients have been hearing about the importance of providing their personal EOL care wishes in writing so that if a time comes when they can no longer make decisions for themselves, their proxies and providers will know their wishes and will be able to follow them. Yet in our study we found that for 3,660 Americans with written instructions, the wishes of individuals who had written EOL care instructions did not have them followed the majority of the time. This included patients who wanted treatments limited and to be kept comfortable, these patients are usually actively dying. Not limiting care and providing comfort may prolong the patient's death and cause additional pain (Mack et al., 2010; Institute of Medicine, 2015). These instances also add to the ever increasing cost of dying (Kelley, et al., 2011).

Not honoring patients' rights to autonomous EOL care can disrupt the established patient–provider–health care system trust relationship (Harrop et al., 2016). Non-adherence to patient preferences can cause distress to patients and health care staff alike. It can also have the unintended consequences for families who have either witnessed their loved ones' receiving unwanted care or have arrived to the hospital to find the patient connected to equipment and receiving treatments that the patient had specifically refused. Family members may succumb to unresolved grief when they believe that their loved one was either not involved with EOL decisions or when those thoughtful decisions were not honored (Chochinov et. al, 2016).

For multiple reasons, health care providers and policy makers must determine why this problem is so difficult to resolve in order to: (a) *not* prolong the dying process or to exacerbate discomfort or pain associated with the process of dying, (b) avoid prolonged unresolved grief, (c) demonstrate respect for patient autonomy, and (d) to preserve the public's trust in the health care system.

Questions that need to be more thoroughly answered include, for example: has the presumption of life become an easy default conclusion for a provider who did not have a discussion with a patient or who did not read the patient's written EOL instructions? Does the hospital environment support maintaining life over honoring patient preferences for their EOL care? Did the family intervene and demand resuscitation at the time of arrest? Was resuscitation begun while someone was procuring the patient's EOL care instructions, and then a decision was made to continue resuscitation regardless of what was written in the instructions? Did the provider's personal preferences interfere with the care that the patient received?

## Conflicting Studies

As discussed in Chapter 2, two studies that used the same HRS exit data have reported discrepant findings (Kelley et al., 2011; Silveira et. al, 2010). The findings of this current study differed from the findings of both of these studies. The present study used a longer time period—from 2002–2014—which could explain some differences. In the Kelley et al. (2010) study, the primary focus was treatment intensity and cost at the EOL; the investigators found that 92% of the time, patients who preferred comfort care did not get that care — which is not in alignment with either of the samples used in the current study. The focus of the Silveria et al. (2010) study was preferred care (per advance directive) and received care; however, the investigators failed to evaluate the respondent EOL care preference to *withhold treatment* as was done in this dissertation. In addition, both studies evaluated patient preferences for their EOL care, but neither study accounts for the multiple responses to the proxy survey questions about the decedents' preferences for and receipt of their EOL care. Not only do the results of this dissertation add more information to the state of EOL care, but by drilling down into the HRS data and discovering the multiple responses to survey questions and then extracting and analyzing the single response preferences for EOL care, I am presenting a cleaner set of data and a truer picture of the state of EOL preferences in the U.S. population from 2002-2014.

## Implications for Nursing

The registered nurse (RN) is a patient advocate; this role develops from the nurse–patient relationship. The RN has the ability to represent the patient and communicate on his or her behalf; which is considered a core quality behavior at the EOL (Hebert et al., 2011). The SUPPORT study used RNs to elucidate EOL care preferences from patients in the second phase of the study (Connors, et al., 1995). Given that "advocacy has been identified as the common thread of quality end-of-life nursing practice," the nurse advocate could improve the quality of EOL care delivered by taking the lead in EOL care and serving as the keeper of bedside knowledge regarding their patient's EOL care preferences (at least CPR status; Thacker, 2008, p. 174).

Emergency department nursing is beginning to adopt methods to implement nursing advocacy at the EOL in their areas (Kellogg, 2017). Among hospital staff members, the bedside RN is in the best position to know patients' EOL care preferences and to honor their autonomy by advocating for patients in times of an emergency that would require a resuscitative intervention. The RN as advocate would be able to support the autonomous preferences of the patient and help prevent unwanted and too much care accompanied by the possibility of receipt of non-beneficial or maleficent care (Thacker, 2008). Having this advocacy ability does not mean that the bedside RN becomes the monitor for EOL care; rather, this stronger advocacy role means that nurses would continue their advocacy throughout the total continuum of care.

Obviously, an RN cannot control the entirety of a patient's care trajectory. On the other hand, just as nurses know whether a patient has a life-threatening allergy, they are also in a position to know whether the patient's preference is for intensive intervention vs. non-intervention. Prior to the Title II Privacy Rule of the Health Insurance Portability and Accountability Act (U.S. Congress, 1996), hospitals were able to post essential patient-specific health care information at the bedside or on the patient's headboard (e.g., low salt diet, NPO, No Code [no CPR]); in the past, this information prevented the provision of contraindicated care and treatments to many patients. Today, however, with the replacement of bedside charts by electronic health record technology, accessing a patient's written instructions to ascertain EOL care instructions or code status requires several electronic steps just to get into an individual patient's health care record; this is definitely an unintended consequence of the requirement for electronic health records. During these several minutes, few providers will wait for the patient's electronic chart to display on a screen. Given the default of the presumption of life, resuscitation procedures are typically begun—and rarely stopped—regardless of patient preference.

As a former bedside RN, I am aware that nurses do not need yet another task to perform; but knowing one's patients' code status is a usual part of care and a way to improve the quality of EOL care. A growing number of health care systems require that incident reports be completed by nurses when an error has been made with a patient's received, missed, or denied care (including CPR given to a patient against their wishes). Instituting the RN as the patients' formal EOL care advocate would become a process of empowering the bedside RN, through education and administrative support, to be the resource for the knowledge of the patient's EOL care status—a piece of patient-specific knowledge that the nurse already possesses from change of shift reporting. Allowing the RN to perform this advocacy role could reduce the number of failures to provide care desired care; not to mention incident reports, unwanted care, and unwanted resuscitations, and law suits.

## Future Research

Going forward, a future study could be conducted as a mixed–methods study, undertaken at multiple hospitals to monitor what actions are taken at the time of a patient arrest. Providers and families alike could then be interviewed about their decisions and about what transpired during the course of care; however, this type of research could be considered too invasive, and many providers, families, and IRB committees might be reluctant to agree to this research. An IRB committee may approve this type of research under the condition that confidentiality agreements are signed to protect all parties involved. Also, an intervention study that tested a possible remedy (e.g., RN EOL advocate) could be designed, instituted, and studied at several acute care health care facilities. A new study could go further than the ethnographic study reported in the book … *And a Time to Die: How American Hospitals Shape the End of Life* (Kaufman, 2005). One of Dr. Kaufman’s conclusions about dying in a hospital was that the environment of care was very influential in determining the type of care that patients receive. Hospital policies shape medical practice through resource distribution, use and availability of biomedical technology, and in some instances communication that staff can share with patients and families. A limited focus study could be undertaken to determine whether or how patient–provider and proxy–provider EOL conversations are documented and available for all providers of care to view and follow. A conversation with providers or a provider focus group would be a research option as well.

## Conclusion

Patients who choose the type of care they want at the EOL are not getting that care—even when their preferences are stated in writing and at times when communicated by their proxy. Regardless of the sample, patients are receiving more aggressive care than they prefer. In the subset study sample herein (Aim 4), proxy provided refusals of care had a threefold higher chance of being followed than the sample who had prepared written instructions. Existing laws, regulations, and professional codes of ethics support or require that patients' autonomous preferences for EOL care be followed—yet, there remains a substantial gap between what the patient wants and what the patient gets, at the EOL.

In light of the findings and in spite of a patient's written EOL instructions, older adults, black patients, and patients with lower levels of education have a higher chance of not having their EOL care preferences followed. Health care providers and others, who counsel or work with patients to create or verify EOL care preferences, must pay more and closer attention to members of these groups when discussing EOL care preferences. Despite the limited EOL care preference options within the HRS data, the results herein demonstrate that providers' not following autonomous choices for EOL care continues to be a problem.

The IOM has identified patient–provider communication as the primary reason that patients' preferences are not followed (Institute of Medicine, 2015). Patient–provider communication refers to EOL conversations and the corresponding review of any existing EOL care instructions. However, in this present study we included only respondents who had written instructions for their EOL care preferences. Regardless of the format that these written instructions came in—advance directive, living will, or patient self-prepared document—they were none the less communication tools that were available for the provider's review. Ongoing patient–provider and proxy–provider communications are vital to high-quality health care and to patient-centered care; however, at the time of an emergency, a patient's proxy is not always present to converse with the providers. Perhaps mandatory, facility-specific health care education could be designed by medical education staff with guidance from the IOM or AMA, about EOL care and providers' legal and ethical obligations to patients at the end of their lives. And perhaps a broader use of the portable POLST forms (medical orders) could assist with bridging communication between various health care settings.

Nationwide, a number of lawsuits have been brought against various health care providers for not following patients' EOL directions (Pope, 2017). Perhaps it is time to be proactive in preventing the potential for legal lawsuits that do not serve the enhancement of EOL care. Legal cases are costly and signal a reason for the public to mistrust providers and health care systems. It would be beneficial and just to avoid irreparable harm to the profession by the publicity that results from these types of legal cases.

To deny requested EOL care to some when others of equal class receive that same care is unjust and not in keeping with respect for persons and a desire for trust in health care providers and systems. In 2002, Drought and Koenig conducted an ethnographic study about patient choice at the EOL and concluded that giving the patient choice assumes that the patient has some control of dying (Drought, 2002). I see allowing patient choice at the of their life, as a process of patient-provider communication whereby the outcome is the patient's informed choice for their self-determined care; and the missing piece in the process is the respect for communication and information that the patient deserves.

Regardless of the reason that patients do not receive preferred care at the EOL—whether environment of care, provider preferences, or family influence—it is time for health care systems in general to pay closer attention to patients’ EOL instructions and ascertain the exact reasons for those instances when patients’ EOL care preferences are not honored. Once the reasons for this problem are ascertained, interventions can be designed and instituted to remedy this quality of EOL care problem.

# REFERENCES

Allison, T. A., & Sudore, R. L. (2013). Disregard of patient's preferences is a medical error: Comment on "Failure to engage hospitalized elderly patients and their families in advance care planning". *JAMA Internal Med, 173*(9), 787-788. doi:10.1001/jamainternmed.2013.203

American Medical Association. (1991). Guidelines for the appropriate use of do-not-resuscitate orders. *Journal of the American Medical Association, 265*(14), 1868-1871. doi:10.1001/jama.1991.03460140096034

Association, C. H. (2016). *Consent manual: Chapter 1, Patient's rights and the basic principles of consent.* Retrieved from California Hospital Association: http://www.calhospital.org/sites/main/files/file-attachments/consent2016_webpreview_0.pdf

Beauchamp, T. L., & Childress, J. F. (2009). Respect for autonomy. In T. L. Beauchamp, & J. F. Childress, *Principles of Biomedical Ethics* (6th ed., pp. 99-140). New York: Oxford University Press.

Beauchamp, T. L., & Childress, J. F. (2009a). *Principles of Biomedical Ethics* (6th ed.). New York: Oxford University Press.

Berlinger, N. J. (2013). *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life* (2nd ed.). New York: Oxford.

Biometrics Advisory and Support Service to DFID. (2001). *Approaches to the Analysis of Survey Data, Multiple Response Data.* Retrieved from The University of Reading Statistical Services Centre: https://www.reading.ac.uk/ssc/resources/ApproachesToTheAnalysisOfSurveyData.pdf

Breslin, J. M. (2005). Top 10 health care ethics challenges facing the public: Views of Toronto bioethicists. *BMC Medical Ethics, 6*(5), 1-8. doi:10.1186/1472-6939-6-5

Burns, J. P., Edwards, J., Johnson, J. A., Cassem, N. H., & Troug, R. D. (2003). Do-not-resuscitate order after 25 years. *Critical Care Medicine,* 1543-1551.

Cardona-Morrell, M., Kim, J., Turner, R., Anstey, M., & Mitchell, I. H. (2016). Non-beneficial treatments in hospital at the end of life: A systematic review on extent of the problem. *International Journal for Quality in Health Care,* 1-14. doi:10.1093/intqhc/mzw060

Chochinov, H., Hack, T., McClement, S., Kristjanson, L., & Harlos, M. (2002). Dignity in the terminally ill; A developing empirical model. *Social Science & Medicine, 54*(3), 433-443. doi:http://dx.doi.org/10.1016/S0277-9536(01)00084-3

Chukwuneke, F. U. (2014). Global bioethics in a pluralistic world: How does culture influence bioethics in Africa? *Annals of Medical and Health Sciences Research, 4*(5), 672-681. doi:10.4103/2141-9248.141495

Coalition for Compassionate Care of California. (2013). *National POLST paradign.* Retrieved from POLST California: http://www.polst.org/wp-content/uploads/2015/01/2013.09.26-Final-POLST-Article.pdf

Committee on Quality Health Care in America, Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century.* Washington, DC: National Academies Press.

Connors, A. F., Dawson, N. V., Desbiens, N. A., Fulkerson, W. J., Goldman, L., Knaus, W. A., . . . Oye, R. K. (1995). A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *Journal of the American Medical Association, 274*(20), 1591-1598. doi:10.1001/jama.1995.03530200027032

Crane, M. K., & Doukas, D. J. (2005). Respecting end-of-life treatment preferences. *American Family Physician, 72*(7), 1263-1269.

Danis, M. C. (1991). Autonomy and the common weal. *Hastings Center Report, 21*(1), 25-31. doi:10.2307/3563343

Danis, M., Mutran, E., Garrett, J. M., Stearns, S. C., Slifkin, R. T., Hanson, L., . . . Churchill, L. R. (1996). A prospective study of the impact of patient preferences on life-sustaining treatment and hospital cost. *Critical Care Medicine, 24*(11), 1811-1817.

Delgado-Rodriguez, M. &. (2004). Bias. *Journal of Epidemiology & Community Health, 58*, 635--641. doi:10.1136/jech.2003.008466

Delgado-Rodriguez, M. L. (2004). Bias. *Journal of Epidemiology and Community Health, 58*, 635-641. doi:10.1136/jech.2003.008466

Drought, T. S. (2002). "Choice" in end-of-life decision making: Research fact or fiction? *The Gerontologist*, 114-127.

Farber, N., Simpson, P., Salam, T., Collier, V. U., Weiner, J., & Boyer, G. (2006). Physicians' decisions to withhold and withdraw life-sustaining treatment. *Archives of Internal Medicine, 166*, 1641-1645. doi:10.1001/archinte.166.5.560

Fieser, J. (n.d.). Retrieved from Internet Encyclopedia of Philosophy, para. 1: http://www.iep.utm.edu/ethics/

Fine, R. L. (2005). From Quinlan to Schiave: Medical, ethical, legal issues in severe brain injury. *Baylor University Medical Center Proceedings, 18*(4), 303-310.

Funk, C. (2013, 11 21). *General views on end-of-life medical treatment.* Retrieved from PEW Forum: http://www.pewforum.org/files/2013/11/end-of-life-survey-report-full-pdf.pdf

Gatward, R. (2016). HRS in the Field: Interviewing and Data Collection. *Examining the Health and Retirement Study (HRS).* Ann Arbor: University of Michigan.

Harrop, E., Morgan, F., Byrne, A., & Nelson, A. (2016). "It still haunts me whether we did the right thing:" A qualitative analysis of the free text survey data on the bereavement experiences and support needs of family caregivers. *BioMed Central Palliative Care, 15*(92), 8. doi:10.1186/s12904-016-0165-9

Health and Retirement Study. (2016, June 16). *Institutional Review Board Information.* Retrieved from Institute for Social Research, Uuniversity of Michigan: http://hrsonline.isr.umich.edu/sitedocs/irb/HRS_IRB_Information.pdf

Health and Retirement Study. (2016). *Publications*. Retrieved from Health and Retirement Study: https://hrs.isr.umich.edu/data-products?_ga=1.23331385.208789863.1462498308

Hebert, K. M. (2011). The nurse advocate in end-of-life care. *The Ochsner Journal, 11*(4), 325-329.

Heeringa, S. G. (1995, 30 May). *Technical description of the Health and Retirement survey sample design.* Retrieved June 7, 2016, from Health and Retirement Study: http://hrsonline.isr.umich.edu/sitedocs/userg/HRSSAMP.pdf

Heyland, D. K., Barwish, D., Pichora, D., Dodek, P., Lamontagne, F., You, J. J., . . . Canadian Researchers at the End of Life, N. (2013). Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Internal Medicine, 173*(9), 778-787. doi:10.1001/jamainternmed.2013.180

Hickman, S. E., Hammes, B. J., Torke, A. M., Sudore, R. L., & Sachs, G. A. (2016). The quality of physician orders for life-sustaining treatment decisions: A pilot study. *Journal of Palliative Medicine, 20*(2), 155-162. doi:10.1089/jpm.2016.0059

Huff, D. J. (2014). Good patient communications: a key to avoiding legal liability. *Journal of the Medical Association of Georgia, 103*(4), 35-36.

Hulley, S. B. (2007). *Designing Clinical Reserach* (3rd ed.). Philadelphia: Lippincott.

Institute of Medicine. (2015). *Dying in America: Improving quality and honoring individual preferences near the end of life.* Washington, DC: The National Academies Press.

Kaufman, S. R. (2005). *And a time to die: How American hospitals shape the end of life.* Chicago: Uiversity of Chicago Press.

Kellar, S. P. (2013). *Munro's Statistical Methods for Health Care Research* (6th ed.). Philadelphia: Wolters Kluwer, Lippincott Williams & Wilkins.

Kelley, A. S., Ettner, S. L., Morrison, R. S., Du, Q., Wenger, N. S., & Sarkisian, C. A. (2011). Determinants of treatment intensity in the last 6 months of life: The importance of patient characteristics. *Annals of Internal Medicine, 154*(4), 235-242. doi:10.7326/0003-4819-154-4-201102150-00004

Kellogg, E. (2017). Understanding advance care documents: What the nurse advocate needs to know. *Journal of Emergency Nursing, 16*, 99-. doi:10.1016/j.jen.2016.12.001

Klinkenberg, M. S.-P. (2003). Proxy reporting in after-death interviews: The use of proxy respondents in retrospective assessment of chronic diseases and symptom burden in the terminal phase of life. *Palliative Medicine, 17*, 191-201. doi:10.1191/0269216303pm66loa

Larson, J. (2016). *Five top ethical issues in healthcare*. Retrieved from Healthcare News: http://www.amnhealthcare.com/latest-healthcare-news/five-top-ethical-issues-healthcare/

*Legal Information Institute.* (2017, April 19). Retrieved from Cornell Law School: https://www.law.cornell.edu/cfr/text/42/489.102

Luce, J. (1995). Physicians do not have a responsibility to provide futile or unreasonable care if a patient or family insists. *Critical Care Medicine*, *23*(4), 760-6.

Mack, J. W., Weeks, J. C., Wright, A. A., Block, S. D., & Prigerson, H. G. (2010). End-of-Life discussions, goals attainment, and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences. *Journal of Clinical Oncolcogy, 28*(7), 1203-1208. doi:10.1200/JCO.2009.25.4672

Mistry, B., Bainbridge, D., Bryant, D., Toyofuku, S., & Seow, H. (2014). What matters most for end-of-life care? Perspectives from community-based paliative care providers and administrators. *BMJ Open, 5*, 1-8. doi:10.1136/bmjopen-2014-007492

Morrison, E. E., & Furlong, B. (Eds.). (2014). *Health Care Ethics: Critical issues for the 21st century* (3rd ed.). Burlington: Jones and Bartlett Learning.

Murray, P. M. (1990). The history of informed consent. *The Iowa Orthopedic Journal,* 104-110.

Pannucci, C. J. (2010). Identifying and avoiding bias in research. *Plastic Reconstructive Surgery, 126*(2), 619-625. doi:10.1097/PRS.0b013e3181de24bc

Phillips, R. S., Hamel, M. B., Covinsky, K. E., & Lynn, J. (2000). Findings from SUPPORT and HELP: An introduction. *American Geriatric Society, 48*(5), S1-S5.

Pino, P., Parry, R., Land, V., Faull, C., Feathers, L., & Seymour, J. (2016). Engaging terminally ill patient in end of life talk: How experienced palliative medicine doctors navigate the dilemma of promoting discussion about dying. *PLoS ONE, 11*(5), 1-18. doi:10.1372/journal.pone.0156174

Polit, D. F. (2012). *Nursing research: Generating and assessing evidence for nursing practice* (9th ed.). Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Pope, T. M. (2017). Legal briefing: New penalties for disregarding advance directions and do-not-resuscitate orders. *The Journal of Clinical Ethics*, 74-81.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1983). *Deciding to forego life-sustaining treatment.* Washington, D. C.: U.S. Government Printing Office. Retrieved 9 1, 2015, from https://repository.library.georgetown.edu/handle/10822/559344

Quill, T. E., & Brody, H. (1996). Physician recommendations and patient autonomy: Finding a balance between physician power and patient choice. *Annals of Internal Medicine*, 763-770.

Sandsdalen, T., Rystedt, I., Grondahl, V. A., Hoye, S., & Wilde-Larsson, B. (2015). Patients' perceptions of palliative care: Adaption of the quality from the Patient's Perspective Instrument for use in palliative care, and description of patients' perceptions of care received. *BioMed Central Palliative Care*, *14*, 54. doi:10.1186/s12904-015-0049-4

Sehgal, N. L., & Wachter, R. M. (2007). Identification of inpatient DNR status: A safety hazard beggin for standardization. *Journal of Hospital Medicine, 2*(6), 366-371. doi:10.1002/jhm.283

Silveira, M. J., Kim, S. Y., & Langa, K. M. (2010). Advance directives and outcomes of surrogate decision making before death. *New England Journal of Medicine, 362*(13), 1211-1218. doi:doi:10.1056/NEJMsa0907901

Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: Patients perspectives. *Journal of the American Medical Association, 281*(2), 163-168. doi:10.1001/jama.281.2.163

Sinnott-Armstrong, W. (2015, Winter). *Consequentialsim.* Retrieved from The Stanford Encyclopedia of Philosophy: https://plato.stanford.edu/archives/win2015/entries/consequentialism/

Sonnega, A. (2016). Examining the Health and Retirement Study. *The Health and Retirment Study: An Introduction.* Ann Arbor: University of Michigan.

Sonnega, A. F. (2014). Cohort profile: The Health and Retirement Study (HRS). *International Journal of Epidemiology, 43*(2), 576-585. doi:10.1093/ije/dyu067

Steinhauser, K. F., Christakis, N. A., Cliff, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians and other care providers. *JAMA, 284*(19), 2476-2482.

Summers, J. G. (2014). Theory of Healthcare Ethics. In E. E. Morrison, B. Furlong, E. E. Morrison, & B. Furlong (Eds.), *Health Care Ethics: Critical issues for the 21st century* (3rd ed., pp. 1-42). Burlington: Jones & Bartlett Learning.

Teno, J. M., Fisher, E. S., Hamel, M. B., Coppola, K., & Dawson, N. V. (2002). Medical care inconsistent with patients' treatment goals: Association with 1-year medicare resource use and survival. *Journal of American Geriatric Society, 40*(3), 496-500.

Thacker, N. (2008). Nurses' advocacy behaviors in end-of-life nursing care. *Nursing Ethics, 15*(2), 174-185.

U.S. Bureau of the Census. (1995, September). *Statistical abstract of the United States: 1995.* Retrieved from U.S. Bureau of the Census: https://www.census.gov/prod/1/gen/95statab/preface.pdf

U.S. Census Bureau. (2011, July 20). *Random Samplings.* Retrieved from United States Census Bureau: http://blogs.census.gov/2011/07/20/what-are-census-blocks/

U.S. Congress. (1996, August 21). The Health Insurance Portability and Accountability Act . *Public Law 104-191.* Washington, D.C.: Health and Human Services.

Ulrich, L. P. (1999). *The Patient Self-Determination Act: Meeting the challenges in patient care.* Washington, D. C.: Georgetown University.

Wenger, N. S., Phillips, R. S., Teno, J. M., Oye, R. K., Dawson, N. V., Liu, H. L., . . . Lynn, J. (2000). Physician understanding of patient resuscitation preferences: Insights and clinical implications. *Journal of American Geriatric Society, 48*(5), S44-S51.

Wolf, S. B. (2015). Forty years of work on end-of-life care - From patients' rights to systemic reform. *New England Journal of Medicine,* 678-682. doi:10.1056/NEJMms1410321

# APPENDICES

# Appendix A

## Study Variables

| Question Number | Variable Name | Variable Question | Measurement Scale |
|---|---|---|---|
| Study Variables | | | |
| T190 | R have written EOL instructions | Did R provide written instructions about the treatment or care he/she wanted to receive during the final days of his/her life? | Dichotomous |
| T193 | EOL all care possible | Did these instructions express a desire to receive all care possible under any circumstances in order to prolong life? | Dichotomous |
| T194 | EOL limit care | Did these instructions express a desire to limit care? | Dichotomous |
| T195 | EOL withhold treatment | Did these instructions express a desire to have any treatment withheld? | Dichotomous |
| T196 | EOL No extensive measures | Did these instructions express a desire to keep him/her comfortable and pain free but to forego extensive measures to prolong life? | Dichotomous |
| T230 | DEC EOL all care possible | Did those last decisions involve a desire to give all care possible un-conditionally in order to prolong life? | Dichotomous |
| T231 | DEC EOL limit care | Did those last decisions involve limiting care in certain situations? | Dichotomous |
| T232 | DEC EOL withhold treat | Did those last decisions involve withholding any treatment? | Dichotomous |
| T233 | DEC EOL pain free only | Did those last decisions rest largely on keeping R comfortable and pain free without taking extensive measures to prolong life? | Dichotomous |
| T234 | Recommended care refused | Did any doctor(s) recommend any care or treatment that the family or other decision-maker(s) ultimately refused? | Dichotomous |
| T235 | R received unwanted treatment | Did R receive this treatment anyway? | Dichotomous |

## Appendix B

### Demographic Variables

| Question Number | Variable Name | Variable Question | Measurement Scale |
|---|---|---|---|
| Demographic Variables | | | |
| A019 | Age | R current age calculation | Continuous |
| RACE | Race/Ethnicity | Black, White, Other | Nominal |
| X060_R | Sex of individual | Verify spelling of first and last name and sex. | Nominal |
| B063 | Marital Status Assigned | An HRS compiled variable, for completeness. (Cross wave data from variables X065, A023, A026, A034, B058, B061). Levels: 1) Married, 2) Never Married, 3) Separated/Divorced, 4) Widowed | Nominal |
| DEGREE | R- Highest degree of education | 0) No degree, 1) GED, 2) High school diploma, 3) 2-year college degree, 4) 4-year college degree, 5) Master's degree, 6) Professional degree | Ordinal |
| B082 | Religious service attendance | How often attend in last year: 1) More than once a week, 2) Once a week, 3) Two or three times per week, 4) One or more times per year, 5) Not at all | Ordinal |
| A126M | R died, state, masked | In what state and county did he/she die? (State is masked and replaced with a U.S. region of residence) | Nominal |
| Created/Re-coded Variables | | | |
| YEAR | Wave | Year of the wave that the data was reported | Ordinal |
| DEGREE | Degree categories | Highest degree of education: Less than High School, High School, more than High School | Ordinal |
| A126M | Region | Regions of residence as designated by HRS. Northeast, Midwest, South, and West | Nominal |
| B082 | Religious services | How often attend religious services in past year: Greater than or equal to once a week, less frequent, not at all or not certain | Ordinal |

# Appendix C

## Demographic Variable Frequencies

| Demographic Variables<br>*N* = 3,660 | Frequency | Percentage |
|---|---|---|
| Sex (HRS gender) | | |
| Male | 1,601 | 43.7 |
| Female | 2,059 | 56.3 |
| Race | | |
| White | 3,346 | 91.4 |
| Black | 232 | 6.3 |
| Other | 82 | 2.2 |
| Marital Status | | |
| Married | 1,231 | 33.63 |
| Separated/Divorced | 296 | 8.09 |
| Widowed | 1,543 | 42.16 |
| Never married | 102 | 2.79 |
| Dk/rf/missing | 488 | 13.33 |
| Education | | |
| < High school | 1000 | 27.32 |
| High school | 1948 | 53.22 |
| > High school | 712 | 19.45 |
| Religion | | |
| ≥ Once a week | 1039 | 28.29 |
| Less frequent | 982 | 26.83 |
| Not at all | 1639 | 44.78 |

# Appendix D

## Study Variables – Frequencies

| Study Variables | Frequency | Percentage |
|---|---|---|
| *N* = 9,824 | | |
| All care possible | 199 | 2.03 |
| Limit care | 3,335 | 33.95 |
| Withhold treatment | 2,908 | 29.60 |
| Comfort care | 3,382 | 34.43 |
| *N* = 3,921 | | |
| Proxy refused care | 514 | 13.11 |
| Received unwanted care | 80 | 15.69 |
| Regions | | |
| *N* = 3,664 | | |
| Northeast | 628 | 17.14 |
| Midwest | 1,037 | 28.30 |
| South | 1,357 | 37.04 |
| West | 622 | 16.98 |

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|---|---|
| Margaret Ingrid Wallhagen, PhD, GNP-BC, AGSF, FAAN | Denise Wishner |

**Study Title:** Disparities in the match between patient end-of-life care preferences and the actual end-of-life care received
**IRB #:** 16-21392
**Reference #:** 181984

**Committee of Record:** Parnassus Panel
**Type of Submission:** Submission Correction for Initial Review Submission Packet
**Certification Date:** 01/26/2017

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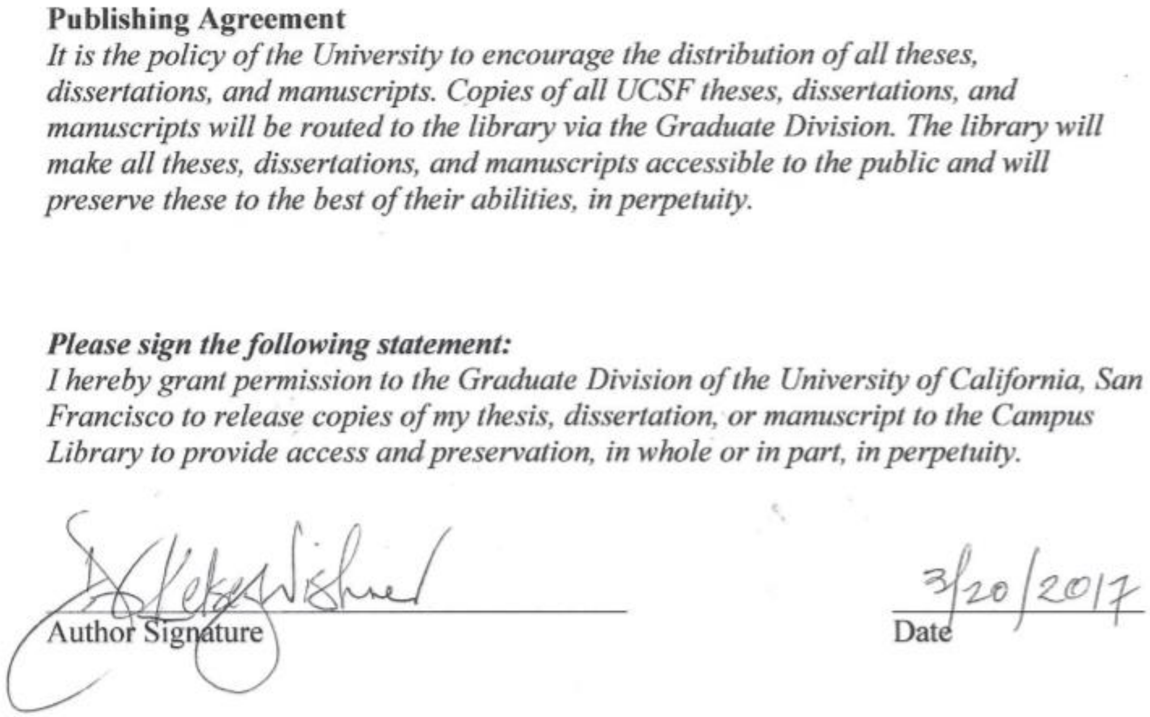

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