The Impact of Advance Directives on the Intensity of Care Received in the Acute Care Setting in Older Adults

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THE IMPACT OF ADVANCE DIRECTIVES ON THE
INTENSITY OF CARE RECEIVED IN
THE ACUTE CARE SETTING
IN OLDER ADULTS

By

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ABSTRACT
THE IMPACT OF ADVANCE DIRECTIVES ON THE INTENSITY OF CARE RECEIVED IN THE ACUTE CARE SETTING IN OLDER ADULTS

Marsha Helen Tyacke, PhD(c), MSN, RN, APNP, ACNP-BC
Marquette University, 2018

The proportion of older adults in the U.S. is rapidly increasing. One-third of Medicare expenditures occur in the final year of life, with nearly half resulting from acute exacerbations of chronic, progressive diseases (Riley & Lubitz, 2010). Older adults prefer comfort over life-sustaining care, and decreased intensity of care is associated with improved quality of life at the end-of-life (EOL). Advance directives (ADs) have been proposed as mechanisms to improve congruence between patient wishes and EOL care; however, the impact of ADs on care delivered in the acute care setting at the EOL for this population is unclear.

A retrospective, correlation design framed by the Quality Health Outcomes Model was used to describe (a) the relationship between ADs and the intensity of care received by older adults in the acute care setting at the EOL, and (b) the congruence between patient preferences within ADs and actual care received.

Four hundred and ninety-six patients, aged 65 and older who died while admitted to a large, academic medical center, were identified using electronic health records. Regression analyses, to determine the association between ADs and indicators of intensity of care, and content analysis, to describe congruence of care, were conducted.

Advance directives were not independently associated with any indicators of high-intensity (i.e., high-cost, high-technology) care. While ADs were independently associated with palliative and hospice referrals, effect sizes were small, and referral timing was late. In a subset of one hundred patients with ADs, less than half received care that was congruent with documented preferences. In approximately one-fourth, patient preferences were vague, and congruence could not be determined.

Advance directives may be ineffective, in their current form, to decrease aggressive care in the acute care setting. Further research is necessary to determine whether this is a function of how ADs are used within acute care or ambiguous preferences within the document. A shift in the approach of healthcare providers may be necessary to promote engagement in advanced care planning discussions, with patients and family members, with an AD serving as the product of those discussions rather than a document completed out of context.
DEDICATION

Marsha Helen Tyacke, PhD(c), MSN, RN, APNP, ACNP-BC

This project is dedicated to my miracles, Devyn, Noah, and Sydney, who will always be the purpose in my life and the reasons I continue to strive to be not only a better person, but to create a better place for them to flourish.

To Devyn, may your curiosity and creativity guide your journey through science and exploration of the unknown.

To Noah, may your persistence and unrelenting determination guide you throughout your pursuit of greatness on and off the field.

To Sydney, as you continue to grow into the beautiful young woman you are becoming, I hope that through my persistence, ambitions, and accomplishments, you have learned, and will continue to recognize, that women can do anything in the world that we set our minds to.
ACKNOWLEDGMENTS

Marsha Helen Tyacke, PhD(c), MSN, RN, APNP, ACNP-BC

The last three years have been a roller coaster. I’d like to thank my chair, Dr. Jill Guttormson, for stepping up and getting on the ride with me. Through her high expectations, persistence, guidance, and encouragement, I have become a better writer and researcher, and am proud to call her a friend and colleague. Dr. Mauricio Garnier-Villarreal, Dr. Kathryn Schroeter, and Dr. Wendy Peltier have provided invaluable feedback and insight that have made this final product possible. To the College of Nursing PhD faculty, thank you for your continued support through this crazy endeavor. To say “thank you” to Amanda King is an understatement. You and I have survived! Without your incredible support, patience, tolerance, and friendship, I would have surely failed.

God clearly had a path defined for me when he exposed me to the healthcare world 27 years ago. While I may not have recognized it then, surviving cancer ultimately defined who I have become. I am who I am today because of the challenges he has carried me through.

Words cannot express what I owe to my parents, who have supported me through everything. My mom has always been a shining example of unwavering love and support a mother has for her children. My dad has taught me the value of hard work and a determined work ethic while being a teddy bear at heart with really big paws. Lisa, you are the best sister ever and have been the rock that I could always depend on.

To Devyn, Noah, and Sydney, thank you for keeping me on task when I procrastinate. Thank you for giving me up every weekend. Without your encouragement and understanding, none of this would have been possible.

And finally, Scott. There are no words that can express what it means that you have remained at my side, supported and encouraged me. Somehow, “thank you” seems grossly understated.

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Chapter I: Introduction

The older adult population is rapidly growing in number (Ortman, Velkoff, & Hogan, 2014). The experience of dying in the United States (U.S.) continues to be an aspect of our current healthcare system that must improve (The Institute of Medicine, 2015). The healthcare community continues to struggle with inadequate discussions of disease prognoses and end-of-life preferences; poor, or absent, communication between patients and family members; and poor understanding of palliative care (The Institute of Medicine, 2015). While older adults prefer comfort over life-prolonging treatment (The Institute of Medicine, 2015; A. A. Wright et al., 2016), one-third of Medicare expenditures occur in the last year of life (Hogan, 2015), with nearly 50% incurred on inpatient hospitalizations (The Kaiser Family Foundation, 2016). Significant resource allocation to the delivery of technologically advanced care at the end of life contradicts the value that older adults place on comfort and raises the concern that care delivered near the end-of-life (EOL) may not optimize quality of life (QOL) or promote care that is congruent with patient preferences.

Advanced care planning (ACP) and advance directives (AD) have been targeted as ways to improve congruence between patient preferences and care, and QOL at the EOL. The benefits of ACP to reduce the intensity of care at the EOL have been well established (Abel, Pring, Rich, Malik, & Verne, 2013; Mack et al., 2012; Martin, Hayes, Gregorevic, & Lim, 2016), however the evidence for the role of AD documents to impact care delivered in the acute care setting at the EOL is inconsistent (Dunlay, Swetz, Mueller, & Roger, 2012; Hart et al., 2015; Nicholas, Bynum, Iwashyna, Weir, & Langa, 2014; Tschirhart, Du, & Kelley, 2014). Legislative actions, such as the Patient Self-
Determination Act (American Bar Association, 2016), have emphasized increasing AD completion to ensure that patients’ rights to individual care preferences are honored, even when incapacitated; however, before increasing efforts to complete these documents, further research is essential to understand better whether these documents truly impact care delivery.

This chapter will open with a brief review of essential concepts for understanding the complex issues that underpin EOL care. Further explication of the challenges of QOL at EOL, what is known about the impact of ACP and AD in the acute care setting, and a discussion of the significance of the problem to nursing practice, vulnerable populations, and healthcare policy will be discussed. The relationship of bioethics to nursing practice and patient care in the context of QOL at EOL for the older adult in the acute care setting will also be considered. Finally, this chapter will close with the purpose this study addressed.

**Key Concepts**

Key concepts within any discussion of the QOL at the EOL include advanced care planning, advance directives, aggressive care, conservative care, palliative care, quality of life, and congruent care. A more in-depth discussion of these concepts will be explicated in chapter two.

Advanced care planning is not a single event, but rather a process of patient education about health conditions and engagement in discussions of preferences for EOL care (National Institute on Aging, 2014). This process of communication is both reciprocal between patients and providers and must be revisited over time. In contrast to the process of ACP, ADs are concrete documents that serve as formal mechanisms for
expressing preferences for care and/or designating surrogate decision-makers (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). Essential to ACP is the complex communication among patients, families, surrogate decision-makers and providers that promotes interpersonal dialogue and collaboration (Dunne, 2005). Communication in ACP and AD includes both discussion and documentation of patient preferences.

Levels of intensity of care must be well-defined when examining ACP and ADs within the acute care setting. Although care is delivered along a continuum of intensity, this study focused on care at the ends of the continuum: categorized into either aggressive or conservative care. Aggressive care is high-technology, high-cost care that includes mechanical ventilation (MV), initiation of dialysis, artificial nutrition, admission to an intensive care unit (ICU), cardiovascular (CV) support, invasive procedures (Dobbins, 2007) and cardiopulmonary resuscitation (CPR) (Dunlay et al., 2012; Hammes, Rooney, Gundrum, Hickman, & Hager, 2012). In contrast to aggressive care, conservative care is defined by this researcher as any non-life sustaining therapies focused on symptom management or limiting of treatment, such as palliative care and hospice referrals, initiation of comfort care, and a code status of do-not-resuscitate (DNR).

The goal at the end of life is to ensure QOL even during the dying process. Quality of life is broadly defined as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (World Health Organization, 2018). High QOL at the EOL can be promoted by providing congruent care—care that is aligned with patients’ preferences. The palliative care team is a valuable resource in the care of
patients of all types, especially those near death, to promote congruent care. Palliative care focuses on improving the QOL for those coping with life-limiting illness through the management of not only physical symptoms but also psychosocial and spiritual needs (World Health Organization, 2017). With the central concepts now defined that will recur throughout these chapters, the discussion now moves to understanding QOL at EOL and the significance of the problem for nursing practice, vulnerability, healthcare policy, and biomedical ethics.

Quality of Life at the End-of-Life

Technological advances have contributed to human longevity and management of chronic conditions; however, at some point, death is an inevitable punctuation mark of life, and the healthcare community is tasked with optimizing QOL at the EOL. Partnering with the palliative team is a way to minimize futile care. Futility is characterized by continuing to deliver care that, despite all efforts, serves no meaningful purpose in achieving the goal of sustaining life (Kasman, 2004). A recent report highlights the inadequacies of how well we manage EOL and the dying process (The Institute of Medicine, 2015). Some of these shortcomings include poor dissemination of information on palliative care and ensuing poor understanding of the role of palliative care; poor quality of communication among providers and patients, particularly regarding prognosis; and lack of overall consensus within the healthcare community on quality measures of EOL care (The Institute of Medicine, 2015). There is much work to be done to improve the care of patients at the EOL in an effort to provide care that is consistent with patient preferences.
When offered a choice, older adults prefer quality of life and comfort over longevity (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; Silveira, Kim, & Langa, 2010; The Institute of Medicine, 2015; Winter & Parks, 2012; A. A. Wright et al., 2016; Yoo, Nakagawa, & Kim, 2013). Yet, a significant amount of overall Medicare expenditures occur in the final 12 months of life (Hogan, 2015) with no better overall health outcomes than in other wealthy Western countries with lower expenditures (Squires & Anderson, 2015). This inconsistency led the Institute of Medicine (2015) to recommend the following – the healthcare community must improve the American population’s understanding of the role of ACP, palliative care, and of the potential for transition into hospice at the most appropriate, and beneficial, time in the course of chronic illness trajectory.

Significant national emphasis has been placed on increasing documentation of ADs to improve QOL at the EOL; however, ACP and AD have varying degrees of impact on promoting congruence of care and on care received at the EOL. Prior to focusing a significant amount of effort and resources into improving AD completion as representative of ACP, we need to better understand if ADs are truly associated with lower intensity of care at the EOL.

**Advanced care planning.** Advanced care planning promotes care that is congruent with patient preferences at EOL (Abel et al., 2013; Houben, Spruit, Groenen, Wouters, & Janssen, 2014; Martin et al., 2016), with much of this occurring through the reduction in aggressive and futile care. Hospitalization rates (Abel et al., 2013; Martin et al., 2016) and costs of healthcare in the final year of life (Abel et al., 2013) are both
significantly reduced in those who receive an ACP intervention. This may reflect support of older adult preferences for comfort and symptom management at the EOL.

Advanced care planning may impact acute care delivered at the EOL through reduced hospitalizations, decreased ICU admissions and ICU LOS, and fewer hospital days in the final year of life (Abel et al., 2013; Khandelwal & Curtis, 2014; Khandelwal et al., 2015; Lopez-Acevedo et al., 2013; Martin et al., 2016; Street, Ottmann, Johnstone, Considine, & Livingston, 2015). Timing may be an essential component of ACP that promotes overall effectiveness of the ACP process. When ACP discussions occur at least 30 days prior to death, aggressive management is reduced with a concurrent increase in the use of hospice services (Lopez-Acevedo et al., 2013; Mack et al., 2012; O'Connor et al., 2015).

While ACP is shown to be a way to improve QOL at the EOL, participation in the process remains low (Abel et al., 2013; Leung, Udris, Uman, & Au, 2012; Stachura, Oberender, Bundscherer, & Wiese, 2015; A. A. Wright et al., 2008). End-of-life planning discussions tend to occur more frequently among terminally ill oncology patients, and unsurprisingly, those who have already transitioned into hospice care (Abel et al., 2013; A. A. Wright et al., 2008). Overall preferences for EOL care remain both inadequately discussed and documented (Roger et al., 2015; Sadeghi, Walling, Romano, Ahluwalia, & Ong, 2016; Song & Ward, 2013). Advanced care planning conversations should be increasing as the older adult population surges and survives longer with chronic comorbidities. However, there is no consensus in the literature as to whether this is occurring (Leung et al., 2012; Stachura et al., 2015; A. A. Wright et al., 2008).
Factors that influence ACP participation include patient and family concerns regarding long-term survival and patient and family knowledge deficits about disease progression. For those individuals who may be concerned that participating in ACP interventions may impact their long-term outcomes, studies have found that ACP does not shorten survival, but rather ensures that patients receive EOL care that is congruent with their expressed preferences (Fischer, Min, Sauaia, & Kutner, 2012). Patients and families have been shown to lack essential knowledge of the trajectories of their chronic diseases (Howie-Esquivel & Dracup, 2012; Klindtworth et al., 2015; Mack et al., 2012; Mayland, Williams, Addington-Hall, Cox, & Ellershaw, 2013). Poor understanding of expectations of underlying disease trajectory may steer patients toward accepting care that is ineffective and may only prolong the dying process (Howie-Esquivel & Dracup, 2012; Klindtworth et al., 2015). Additionally, patients do not always recognize that they have engaged in ACP discussions. In a study to better understand the realities of EOL planning in patients with documented ACP conversations, patients who recounted these discussions were less likely to receive aggressive care at the EOL than those patients who did not recall that these discussions ever occurred (Mack et al., 2012). Lack of awareness of these discussions makes it difficult to ensure that patients receive care that is consistent with their preferences.

**Advance directives.** In contrast to the multifaceted process of ACP, ADs are documents that provide a recognizable means of expressing preferences for EOL care (Teno et al., 2007). The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) was a landmark, multiphase study culminating in a two-year, randomized clinical trial that tested an intervention to improve end-of-life
decision-making and reduce prolongation of the dying process (The SUPPORT Principle Investigators, 1995). The intervention was ineffective with no improvement in patient-provider communication or provider awareness of patient preferences to not be resuscitated. Additionally, time to documentation of DNR orders, ICU length of stay (LOS), mechanical ventilation rates, and use of hospital resources did not decrease (Teno, Lynn, et al., 1997). Even in this comprehensive intervention study, there was no improvement in the effectiveness of ADs, emphasizing the complexities of communication and ACP that limited progress in completing ADs (Teno, Licks, et al., 1997; Teno, Lynn, et al., 1997). The SUPPORT (1995) investigators found that despite wishes to discuss end-of-life care preferences, patients were not always engaged by providers to do so. They suggested that more societal buy-in and proactive interventions prior to hospitalizations may ultimately be necessary to promote effective advanced care planning.

While ACP has been generally shown to be associated with decreased intensity of care at the EOL, the relationship between ADs and care intensity is inconsistent. While some studies suggest that ADs are effective (Nicholas et al., 2014; Silveira et al., 2010; Teno et al., 2007; Tschirhart et al., 2014), other studies have found no demonstrable evidence that these documents decrease care intensity or promote care that is congruent with patient preferences (Dobbins, 2007; Dunlay et al., 2012; Halpern, Pastores, Chou, Chawla, & Thaler, 2011; Hart et al., 2015). It should be noted that those studies that have reported an association between ADs and decreased unwanted and/or aggressive care were also methodologically different from those that did not find this relationship. The investigators determined the presence of the AD document and care received from patient
surrogates without objective electronic health record (EHR) review. Sound methodologic studies that rely on the EHR are necessary to further our understanding of the impact of ADs in acute care. To address other gaps, targeted studies that focus solely on ADs in older adult hospitalized patients are needed.

The literature is inconsistent as to whether ADs are effective in their current form. The absence of an AD may lead to presumed consent for treatment despite a patient’s true wishes (Kong et al., 2015; Stachura et al., 2015). Even with an AD, it is unclear how ADs improve congruence between patient preferences and care delivered. While some have observed congruence with regards to unwanted care (Bischoff et al., 2013; Hammes et al., 2012; Hickman et al., 2011), others have noted discrepancies between documented patient preferences and the care received at the EOL (Hartog et al., 2014; Sommer et al., 2012). Whether the challenges of adhering to ADs result from the conditions required to activate the directive, such as persistent vegetative state (Gutierrez, 2012), or the ambiguous nature of the standardized language of the document itself (Dunlay et al., 2012; Nauck et al., 2014), conflicting results amplify questions regarding the usefulness of ADs in their current form and suggest the need for further study of ADs and their impact on care delivered at the EOL.

Mirroring ACP, there has been little improvement in the frequency of AD completion since SUPPORT (Dobbins, 2007). There are several factors that may influence completion of ADs, including age (Dunlay et al., 2012; Gamertsfelder, Burgher Seaman, Tate, Buddadhumaruk, & Happ, 2016), culture (Kong et al., 2015), functional disability (Dunlay et al., 2012; Gamertsfelder et al., 2016), and chronic illness (Butler et al., 2015; Dunlay et al., 2012; Gamertsfelder et al., 2016), although there is no clear
consensus among studies. While additional research is needed to more closely understand the complex influences at work in consideration of completing ADs, it is first essential to better understand whether efforts to increase completion are wasted on a document that may be ineffective. Additionally, existing research has failed to specifically address the older adult. Objective evaluation targeted at understudied older adults is a logical next step in understanding the relationship between ADs and the delivery of aggressive care at the EOL. This research contributes to the body of knowledge about effective ways to impact care delivered in the acute care setting that is both congruent with older adults’ wishes and consistent with their preferences for comfort at the EOL.

**Significance of the Problem to Acute Care and Nursing Practice**

By the year 2030, adults aged 65 years and older are projected to comprise 20% of the U.S. population, an increase from 13% in 2010 (Ortman et al., 2014). Life expectancy increases result in increased chronic comorbidities, straining an already challenging nursing shortage with increased acute care needs for complex patients (Tri-Council members for Nursing, 2017). A growing older adult population coupled with increasing comorbidities will present a challenge to the healthcare community and will require an increased focus on promoting QOL at EOL.

As the older adult population continues to rapidly grow, their care needs will continue to increase and place increased demand on the already strained healthcare system. The onus is on providers to facilitate ACP discussions to increase participation, improve communication, and promote care that is congruent with patients’ preferences. Providers must improve their ability to initiate these discussions during routine care
(Keary & Moorman, 2015). Patients want to have these difficult conversations with their providers (Leung et al., 2012); however, providers often find it difficult to discuss EOL issues (Johnson, Singer, Masso, Sellars, & Silvester, 2015). Providers must understand that engaging in EOL discussions through ACP fosters patient trust and gives patients a sense that their provider will have a better understanding of their care preferences at the EOL (Johnson et al., 2015; Keary & Moorman, 2015; Leung et al., 2012). A programmed reaction by providers to transfer decompensating patients to the ICU may not prolong life (Kim et al., 2016) and has been found to precipitate poor outcomes in patients with progressive, terminal disease (Gendarova, Sinnarajah, Trotter, Card, & Wu, 2015).

The impact of providing care that is either incongruent with patient preferences or is perceived as not promoting QOL is distressing to care providers. First articulated by Jameton (1984), moral distress occurs when individuals find themselves in a situation in which they are not enabled to do what they know to be right. Moral distress remains a challenge for nursing, particularly in critical care. The complex challenges that befall ICU nurses increase burnout and diminish career satisfaction, often times due to confusion with provider roles, communication issues between nurses, physicians, patients and families; futility issues, and delayed or complete lack of EOL discussions (Flannery, Ramjan, & Peters, 2016). In addition, some ICU nurses have concerns regarding providers’ reinforcement of, or failure to address, unrealistic expectations for recovery as persistent communication challenges (Johnson-Coyle et al., 2016; Whitehead, Herbertson, Hamric, Epstein, & Fisher, 2015). Nurses, particularly those working in the ICU, experience greater amounts of moral distress than their non-ICU, pediatric, or
physician counterparts (Whitehead et al., 2015). Many ICU nurses do not believe that ADs prevent unwanted treatment since many scenarios rarely happen (i.e., persistent vegetative state) (Gutierrez, 2012). In addition, there can be difficulty locating the document or poor surrogate understanding of its content (Gutierrez, 2012). Although not the focus of the current study, understanding that communication of patient preferences to family and surrogates promotes beneficial care for patients by adhering to their preferences may decrease moral distress in nurses in the form of increased satisfaction, decreased burnout, and increased retention.

**Significance of the Problem to Vulnerable Populations**

It is clear that individuals faced with EOL decision making are a vulnerable population. This, coupled with other vulnerabilities of older adults, must be considered in order to optimize QOL at the EOL. Increased dependence and loss of autonomy are key fears within the older adult population with multiple factors contributing to feelings of vulnerability including physical health, socioeconomic status, strength of social support system, perceptions of discrimination, and feelings of depression (Abley, Bond, & Robinson, 2011; Gwyther & Holland, 2014; Moe, Hellzen, & Enmarker, 2013; Moor, de Graaf, & Komter, 2013; Scanlon & Lee, 2007). Chronic and progressive illness may intensify feelings of helplessness (Clarke, Bennett, & Korotchenko, 2014; Moser, Spagnoli, & Santos-Eggimann, 2011). Depressive feelings can serve as both precursors and consequences of perceived vulnerability in older adults (Moser et al., 2011; Myall et al., 2009; Terry, 2006). Understanding contributing factors of older adult perceptions emphasizes the importance of decreasing feelings of vulnerability while promoting patient autonomy to direct care at the end-of-life.
Socioeconomic status also has a meaningful impact on perceived vulnerability among older adults (Andrew & Keefe, 2014; Moser et al., 2011; Van Eeuwijk, 2006). The synergy of physical and socioeconomic vulnerability predicts long-term outcomes more accurately than physical vulnerability alone (Clark, Stump, Miller, & Long, 2007). Those older adults with low socioeconomic status combined with chronic illness are more likely to require additional provider support to manage depressive symptoms and promote autonomous decision-making in order to maintain as much independence as possible.

Feelings of vulnerability result from poor social support systems (Andrew & Keefe, 2014; Moor et al., 2013). Quality of life is reduced due to the social exclusion that results from marginalization (Brocklehurst & Laurenson, 2008), which often times emerges in the form of ageism (Clarke et al., 2014; Moe et al., 2013; Van Eeuwijk, 2006). These vulnerable individuals will require even more support and resources during ACP interventions in addition to discussions regarding potential surrogate decision-makers. This makes ACP that much more essential for the vulnerable.

Advanced care planning is a way to promote autonomous decision-making. Additionally, ACP can identify vulnerable patients with poor social support systems through discussions of potential surrogate decision-makers. Resources may be provided to those with inadequate support systems, thus reducing social exclusion and improving QOL. Advance directive documents can be completed with more attention to details of specific patient preferences to minimize confusion and ambiguity. This study focused on this vulnerable population to better understand the current impact of AD documents on care delivered at the EOL and will guide future research to improve QOL at the EOL.
Significance of the Problem to Healthcare Policy

The landmark SUPPORT study highlighted the failures of EOL care and underscored how essential it is to improve ACP (The SUPPORT Principle Investigators, 1995). Unfortunately, efforts to enhance involvement in ACP have been stifled by politically motivated and unfounded fears of ‘death panels’ (Leonard, 2015; The Institute of Medicine, 2015). Partisan debate gave oxygen to public fears that life-sustaining treatment would be withheld or withdrawn in a climate where unrealistic expectations of the limits of medical science already pervaded (Billings, 2012; Bishop, Brothers, Perry, & Ahmad, 2010). The Affordable Care Act was ultimately passed in 2010 (U.S. Department of Health and Human Services, n.d.) without provisions for reimbursing providers to engage in ACP with their patients.

The pitfalls of EOL care described by The Institute of Medicine (2015) led the consensus group to again call for a reconsideration of Medicare reimbursement for providers who engage in ACP activities with their patients. Effective January 1, 2016, the Centers for Medicare and Medicaid implemented a billing code for the explicit purpose of ACP, both for initial discussions and subsequently revisiting preferences over time (U.S. Department of Health and Human Services, 2015). It is one step supported by the federal government to incentivize ACP engagement by providers. It remains too early at this point to have sufficient data to evaluate the effectiveness of this particular solution; however, it would be a logical next step in understanding if motivating providers with reimbursement may be an aspect of effective ACP.

Medicare is the primary payer for older adult healthcare in the U.S. Approximately one-fourth of Medicare expenditures occur in the final twelve months of
life, with the majority of these incurred in the acute management of chronic and progressive conditions, including hospitalizations and skilled nursing facility care (Riley & Lubitz, 2010). Secondary to the principle aim of ACP to provide care that is consistent with patient preferences, ACP decreases healthcare costs at the EOL without sacrificing length of survival (Fischer et al., 2012).

**Significance of the Problem to Bioethics**

For any study, and particularly one addressing EOL issues, it is essential to consider clinical ethics. Ethical principles serve as a moral compass to guide clinical practice and research. This portion of the discussion will focus on four fundamental ethical principles as well as ethical theory as a guiding framework for end-of-life research.

Autonomy emphasizes the individual and is the foundation of self-determination (Grace, 2014). Autonomous decision-making is rational, intentional, free of internal and external constraints, and based on one’s values and self-determined plan (American Nurses Association, 2015). It is autonomy that guides much of the practices that are pervasive in today’s healthcare environment, particularly informed consent. However, autonomy does not imply that personal choices are free of outside influence. It is this principle that stands to be the most affected by input from family, friends, and providers, and must be cultivated in any ACP intervention. Certainly, caution must be exercised that promoting ACP is not tantamount to encouraging death with dignity or, on a more extreme scale, euthanasia. Rather, the healthcare community must emphasize that participation in ACP and documentation of ADs are mechanisms to ensure individuals’ values and preferences are heard and respected at the EOL.
Autonomy has the potential to be in conflict with beneficence (Grace, 2014). The spirit of beneficence is the duty to do good (Beauchamp & Childress, 2013; Grace, 2014). Doing good can ultimately be in conflict with promoting self-determination in any healthcare setting, but particularly in the acute care setting during EOL.

Simply upholding the spirit of goodwill embodied within beneficence is not sufficient. Doing no harm is the essence of nonmaleficence. In the delivery of EOL care, it is the principle that may result in the greatest ethical dilemma when continuing aggressive management and life-sustaining care despite minimal prospects for recovery.

Justice carries with it the spirit of impartial fairness. It can pertain to the distribution of limited resources, such as blood, medications, or ICU beds. It aims to ensure that each receives what he or she is entitled to and seeks to protect individual and societal rights (Grace, 2014). Ensuring justice prevails for each patient is essential in a climate with limited financial and institutional resources which is likely to continue to pose challenges to the delivery of EOL care.

These four fundamental ethical principles have the capacity for conflict in a variety of commonplace situations within the acute care setting when providing care at the EOL. There is potential for each principle to assert dominance over other principles in any given situation. Ethical theories provide a framework for EOL decision-making and ethical researchers and clinicians studying EOL issues. Deontology, where decisions or choices are guided by moral duty, was influenced by Immanuel Kant and posits that human beings, who are the ends in themselves, have inherent moral value (Rich, 2018). Although moral duty may be perceived differently by individuals involved in the same situation, the inherent worth of each individual patient is not intentionally dismissed
simply to achieve personal desires (i.e., longevity despite futility) of family members or providers. This study primarily embraced a deontological approach, where promoting participation in ACP and adherence to patient wishes at the EOL are a moral duty. It is the moral duty of all nurses to avoid harm while promoting autonomy, beneficence, and justice (American Nurses Association, 2015).

While principally guided by deontology, there are elements of utilitarianism that influenced this study as well. Where considerations must be given to society’s greater good in the utilization of limited healthcare resources such as ICU beds and overall costs of care, which are subsequently passed on to the rest of society, the utilitarian theory of John Stuart Mill suggests that decision-making be guided by what provides the greatest good to the greatest number of individuals (Rich, 2018) – in this case, the population as a whole. Kantian deontology would seem to collide with Mill’s utilitarianism in situations where patients have expressed the desire for all possible treatment and management despite clear futility (deontology) while also giving consideration to the impact on patient dignity, family psychological well-being, and societal costs (utilitarianism) of providing high-technology, expensive care to an individual who has little to no likelihood for meaningful improvement or a quality of life that was previously enjoyed. This study sought to shed light on the capacity of ADs to achieve not only the goals for improved care of the dying but also to contribute to the promotion of ethically competent healthcare for all of society, particularly at the EOL.

It is important to understand the interrelatedness of ethical principles and end-of-life care. The conflict that exists among the various principles adds a level of complexity that underpins this research. Driven by autonomy and egoism, advance directives were
intended to be a way for individuals to express their care preferences in the context of advanced care planning, to promote congruent care and minimize unwanted treatments at the end-of-life. The impact of these documents is not clearly established. Further research is essential prior to exhausting healthcare resources on increasing completion rates for potentially ineffective documents.

**Purpose of the Study**

The purpose of this study was to explore the impact of ADs on acute care delivered at the EOL. The primary aim was to describe the relationship between ADs and the intensity of care received by older adults in the acute care setting. A secondary aim was to describe the congruence between patient preferences explicated within ADs and actual care received. This study was consistent with a recommendation identified by The Institute of Medicine (2015), focusing on the role of clinicians as leaders to promote participation in ACP and facilitate high-quality conversations, as well as with the National Institute of Nursing Research Strategic Plan in the area of EOL and palliative care research to promote planning for EOL decisions. Significant emphasis has been placed on assessing each hospital admission for the presence of an AD document and providing the document to each patient for completion if none has previously been done. Unfortunately, it is unclear whether these documents are truly effective in reducing aggressive and/or unwanted care at the EOL; therefore, additional research was needed to assess whether promotion of ACP in the form of ADs meets these recommendations and goals. This study lays the groundwork for a program of research that focuses on improving QOL at the EOL through interventions to improve the impact of advanced care planning.
Chapter II: Theory and Review of the Literature

Chapter two describes the background and foundation of this study. First, the guiding theory will be discussed including principles, modifications, previous utilization in the acute care setting, and application to this study. Then paradigm and philosophical underpinnings will be presented. Key concepts used will be defined, followed by a comprehensive and critical review of the literature highlighting gaps. Finally, the study research questions and underlying assumptions will be discussed.

Theoretical Framework: Quality Health Outcomes Model

This study was guided by the Quality Health Outcomes Model (QHOM). This section will first describe origins and subsequent revisions of the model that are essential for a full understanding of the application of the QHOM to the study. The previous applications of the QHOM to research in the acute care setting will be highlighted. Finally, the application of the QHOM to this study will be described.

The Quality Health Outcomes Model was originally developed as a modification of Donabedian’s structure-process-outcome framework (Donabedian, 1966) by incorporating patient outcomes (Mitchell, Ferketich, Jennings, & American Academy of Nursing Expert Panel on Quality Health Care, 1998). Mitchell et al. (1998) reimagined the linear framework of Donabedian into a dynamic, bidirectional model with reciprocal relationships that are more applicable to nursing care and the dynamic healthcare system. The model posits that there is no direct effect of interventions on outcomes, but rather the effect is mediated or moderated by client and system characteristics.
Subsequently, Mayberry and Gennaro (2001) modified the QHOM model by inserting a reciprocal relationship between interventions and outcomes based on their findings of a direct impact of interventions on patient outcomes. Radwin (2002) also adapted the original model (Mitchell et al., 1998) by differentiating client components into state and trait characteristics, arguing that while state characteristics, by their dynamic nature, can be affected in the proposed reciprocal relationships of the QHOM, trait characteristics are static and therefore cannot be affected by interventions, system characteristics, or outcomes. This study uses a QHOM framework, modified by this author, that combines the models proposed by Mayberry and Gennaro (2001) and Radwin (2002). The modified model is presented in Figure 1.

![Figure 1. Modified QHOM framework combining Mayberry and Gennaro (2001) and Radwin (2002) models.](image-url)
**Previous applications.** The Quality Health Outcomes Model has been utilized in a variety of acute care contexts including research on second stage labor, heart failure, discharge planning, hospice, infection control, and oncology. This section will illustrate the various populations for whom the QHOM has been utilized as well as how the model has been applied over time.

Use of the model in a study of management of second stage labor resulted in introducing the bidirectional relationship between interventions and outcomes (Mayberry & Gennaro, 2001). Similarly, the model was also applied to a study examining the impact of systems components on outcomes for heart failure patients (Newhouse, Johantgen, Pronovost, & Johnson, 2005). The authors suggested that the model should be studied further with a focus on the interrelationships between all components, including the proposed relationship between interventions and outcomes. In response to this suggestion, a study was conducted to explore efficacy of discharge planning rounds in the reduction of unplanned healthcare utilization after discharge from the acute care setting and found that those patients exposed to the bedside rounds intervention prior to discharge were significantly less likely to be readmitted or visit the emergency room (Salentiny Wrobleski, Joswiak, Dunn, Maxson, & Holland, 2014). There was no further exploration of how outcome findings may or may not have impacted further development or modification of the intervention.

Other studies in the acute care setting that have utilized the QHOM as a framework have focused on infection control and oncology patients. Interventions of a central line bundle to reduce central line-associated bloodstream infections (CLABSI) were examined within an organizational context (Gilmartin & Sousa, 2016). The model
was partially supported. There was a strong link between interventions and organizational factors and outcomes, but no statistically significant association between system characteristics and outcomes. The lack of association was felt to potentially result from the overall low level of CLABSI rates. Finally, the QHOM successfully guided a study of a technology-based intervention to reduce cancer symptoms (Berry, Blonquist, Patel, Halpenny, & McReynolds, 2015). Berry et al. (2015) found that patient characteristics such as voluntary participation, level of education, and employment status influenced the participation in the intervention, which was successful in decreasing symptoms associated with cancer. The QHOM model is particularly useful for guiding identification of a variety of variables when designing nursing research studies (Neale, 2001) and has been utilized across populations and settings. The ability of the QHOM to guide research significant to the acute care setting was fundamental when selecting this model to guide the current study.

**Application of QHOM to the current study.** The following sections will describe how the QHOM was used as a framework to guide this study of the impact of ADs on care received at the EOL of older adults in the acute care setting. Figure 2 combines the more contemporary revisions of the QHOM and applies it to EOL Care and AD in the acute care setting. As this study is a retrospective chart review, all potential variables or relationships propositioned within the model were not evaluated. Those variables that were included in this study are identified in italics.
Patient characteristics. Patient characteristics are differentiated into state and trait characteristics (Radwin, 2002). State characteristics may include attitudes or beliefs, comorbidities, or level of knowledge. Knowledge deficits may significantly impact EOL planning. Patients’ recognition of their own mortality varies, and the expectation of death is significantly different between those with and without advance directives (Teno et al., 2007). Those who complete ADs possess a higher understanding of the inevitability of death. Oncology patients with terminal disease do not always explicitly demonstrate a need for education and palliative care and the failure of providers to identify that need serves as a barrier to the decision-making necessary to optimize QOL at the EOL (Lloyd et al., 2016; Mayland et al., 2013). Patients with chronic progressive
disease may lack understanding of disease trajectory and life expectancy, resulting in unrealistic expectations. Advanced heart failure patients prefer longevity over quality of life (Brunner-La Rocca et al., 2012), which may be a reflection of denial of the terminal nature of their disease (Howie-Esquivel & Dracup, 2012). Unrealistic expectations for prognosis and disease trajectory are a barrier to high-quality EOL care. Patient understanding, or lack thereof, of disease trajectory may complicate communication of EOL goals and preferences (Ahn et al., 2013; Dunlay et al., 2012; Klindtworth et al., 2015; Strömberg et al., 2014). Knowledge deficits of patients and families demonstrated by unrealistic expectations complicate decision-making and decrease quality of death (Brunner-La Rocca et al., 2012; Howie-Esquivel & Dracup, 2012; Lloyd et al., 2016; Mayland et al., 2013).

In contrast to the fluidity of state characteristics, trait characteristics are static and therefore unaffected by interventions or outcomes. However, fixed traits such as age, sex, race, and ethnicity impact completion of ACP and ADs. Age plays a role in the attitudes about ACP, and older patients are more likely to complete ADs (Dunlay et al., 2012; Fonk, Davidoff, Lutzow, Chesley, & Mathiowetz, 2012; Gamertsfelder et al., 2016; Hammes et al., 2012).

Racial and cultural influences also impact communication and decision-making with regards to EOL planning. African Americans and Caucasians view ACP differently (Bullock, 2011). While Caucasians view ACP as a beneficial process that has the potential to strengthen relationships with providers, African Americans perceive barriers in the ACP process that make it unlikely to make a difference in the EOL experience. Bullock (2011) work found that African Americans raise more concerns that completing
ADs will promote withholding of care and hasten the withdrawal of life-sustaining measures. Religious and spiritual beliefs also play a role in EOL planning differences among African Americans and Caucasians. While Caucasians are more likely to express confidence in the medical team, African Americans tend to articulate a stronger faith in miracles and a higher power. This deep-seated belief in a higher power does not allow for acceleration of the dying process using ADs or hospice since this would be perceived as giving up (Bullock, 2011; Carr, 2011).

Differences also exist among the Latino and Asian populations. Latinos are significantly less likely to complete ACP, and by extension ADs, than Caucasians (Carr, 2011). This may result from cultural preferences to involve the entire family in decision-making rather than a single individual. Asian cultures vary in their motivations to complete ADs. A Korean study of terminal cancer patients found that patients were more likely to complete ADs when younger and healthier (Kong et al., 2015), while a Singaporean study identified a more family-oriented model of care in which the DNR code status of alert and decisional patients was determined an overwhelming majority of the time by the family without patient input (Phua et al., 2011). While these studies evaluated different aspects of ACP and were both limited as single-center studies, cultural differences may play a significant role in the motivation to complete ADs and must be considered in planning interventions to improve AD completion. While trait characteristics are static, thereby not amenable to intervention, they remain an important factor to consider within the QHOM and to attend to when designing and evaluating intervention research.
**System characteristics.** Systems are process components (Mitchell et al., 1998) and are important in mediating or moderating the relationship between interventions and outcomes. When considering ACP/AD and outcomes, communication and decision-making are key. Communication is a complex process that facilitates interpersonal interactions (Dunne, 2005). As such, communication is not a single action but rather an interplay of many. Communication encompasses provider, patient, and family discussions as well as documentation of EOL discussions and/or preferences, either in the EHR or in a formal document such as an advance directive. Patient preferences are poorly communicated and inadequately documented (Hinderer, Friedmann, & Fins, 2015; Sadeghi et al., 2016; Song & Ward, 2013; Winter & Parks, 2012). Communication breakdown between patients and their proxies can lead to delivery of unwanted treatments (Winter & Parks, 2012). Strong communication lends itself to effective decision-making, decreased delivery of unwanted treatments, and increased quality of life at the end of life while ineffective communication leads to decisional conflict (Heyland et al., 2015; Lopez-Acevedo et al., 2013; Mack et al., 2012; Mendoza & Burns, 2015).

**Intervention.** Advanced care planning and ADs have been proposed as interventions that can improve QOL at EOL. The passage of the Patient Self-Determination Act (American Bar Association, 2016) provided an incentive for all healthcare organizations to query patients regarding ADs on admission to the acute care setting. Advanced care planning promotes care at EOL that is congruent with patient preferences (Abel et al., 2013; Houben et al., 2014; Martin et al., 2016). Despite understanding that ACP is effective at promoting congruence between preferences and care delivered at the EOL, it is not yet well understood whether simply increasing AD
completion has a similar impact. Using the QHOM as a guiding framework, this study further explored the relationship between AD documents and care delivered to improve QOL at the EOL.

**Outcomes.** The overarching goal of ACP is to optimize the QOL at the EOL. More knowledge of illness and prognosis is associated with improved congruence between patient preferences and care delivered at EOL (Ahn et al., 2013). Increased aggressive care at the EOL is associated with poorer QOL at EOL (A. A. Wright et al., 2008). Conversely, earlier hospice referral is associated with higher QOL at EOL. Advanced care planning discussions with providers are associated with less frequent aggressive care at EOL, such as less frequent mechanical ventilation, resuscitation, or admission to the ICU, and earlier referral to hospice (Lopez-Acevedo et al., 2013; Mack et al., 2012; A. A. Wright et al., 2008).

Advance directives also promote improved QOL at EOL (Ache, Harrold, Harris, Dougherty, & Casarett, 2014). Patients with ADs had longer survival, were less likely to leave hospice voluntarily, less likely to die on an inpatient unit, and more likely to die at home or in a skilled nursing facility. Studies of adults suggest that ACP improves congruence between patient preferences and actual care delivered at the EOL, possibly through increasing completion of ADs (Houben et al., 2014), and more specifically in older adults, participation in ACP discussions may increase congruence between preferences and EOL care (Martin et al., 2016). Martin et al. (2016), however, did not focus exclusively on ADs and so further evidence is needed to explore the impact specifically of these documents.
The Quality Health Outcomes Model as a guiding framework is ideal for this study. It has been revised over time in a way that enhances its applicability to the acute care setting. Figure 2 illustrates how the current study was guided by a combination of two contemporary revisions of the model. This combination extends the original model and allows consideration of the impact of interventions directly on outcomes as well as the integration of the unique aspects of patients distinguished by the specification of both state and trait characteristics.

**Philosophical Underpinnings**

A paradigm is a complex interplay of ontology, epistemology, and methodology that is essential to establish congruence between study aims and the overall study conduct (Houghton, Hunter, & Meskell, 2012). In conducting nursing research, a paradigm provides a lens through which the investigator views the world, which subsequently influences study planning and design (Guba & Lincoln, 1994). A guiding philosophy is crucial to any nursing research endeavor as philosophical inquiry promotes exhaustive, critical thought that engenders questions and illuminates assumptions (Crossan, 2003).

Post-positivism has continued to emerge to guide nursing research. The underlying tenets of post-positivism demonstrate a shift away from the strict cause-and-effect goals of positivism (Houghton et al., 2012; Ryan, 2006). Post-positivism emphasizes meaning and creating new knowledge using a variety of methods and perspectives. Humanity is complex, and therefore research requires more of a holistic view of the person and of the world. There is not one single truth. That which is imperceptible exists and may explain the target concept. In contrast to positivism, post-positivism embraces the inability to remain purely objective and emphasizes the
importance of triangulation to minimize bias, also called critical multiplism.

Additionally, in contrast with positivism, the post-positivist perspective views research as problem-setting, rather than problem-solving.

Post-positivism provides the ideal lens through which to study and understand the challenges of improving QOL at EOL, specifically, the impact of advance directives on the intensity of care received. Each patient, through state and trait characteristics, has a unique influence on both communication and decision-making. There is not one single truth applicable to all patients in all situations. This applies to the relationships among interventions, system/context, and patient outcomes. In employing the underlying principles of post-positivism, triangulation in the form of looking at both medical record review and content of AD documents will enrich the insight gleaned from this research. This study contributes to the body of knowledge that serves to promote problem-setting in order to better understand these dynamic relationships in an effort to ultimately enhance QOL at the EOL for all patients.

**Key Concepts**

Key concepts that underpin this review and study must be clearly defined.

Advanced Care Planning is a process that integrates learning about what healthcare decisions may eventually be faced, giving careful consideration to those choices, making decisions, and expressing them to others (National Institute on Aging, 2014). Advance directives are tangible documentation of care preferences but are not synonymous with ACP; they provide a formal mechanism for expressing preferences for care (Teno et al., 2007). These documents may include living wills, powers of attorney for healthcare, or physician orders for life-sustaining treatments (POLST) and are completed while an
individual is capable of making his/her own decisions. A living will is a document for
use while an individual is alive but unable to make their own healthcare decisions
(Huntsberry-Lett, 2017). It elucidates specific healthcare preferences and guidance for
providers and surrogate decision-makers. A power of attorney for healthcare document is
a mechanism that allows an individual to designate a trusted surrogate to make decisions
on his or her behalf in the event of incapacitation (Huntsberry-Lett, 2017). Presumably,
the individual knows whether or not the designated surrogate will be able to make
decisions that the individual prefers. Physician orders for life sustaining treatments forms
are more specific documents that give more detailed instructions on treatment preferences
such as code status, antibiotics, preferences for hospitalization versus comfort, and can be
more easily reviewed by providers to provide specific direction during acute illness

The World Health Organization (2018) defines quality of life broadly as “an
individual's perception of their position in life in the context of the culture and value
systems in which they live and in relation to their goals, expectations, standards, and
concerns.” Optimizing QOL at the EOL is achieved through providing congruent care—
care that is aligned with patients’ preferences.

Palliative care is a specialty service focused on improving QOL of patients and
families managing life-limiting illness through the recognition and management of
physical symptoms along with psychosocial and spiritual needs (World Health
Organization, 2017). This specialty provides considerable benefit including decreased
hospital length of stay (Bharadwaj et al., 2016; Chen et al., 2015), decreased hospital
readmission rate, and decreased overall costs of care (Yoo, Nakagawa, & Kim, 2012).
Additionally, palliative care improves communication (Chen et al., 2015; Gade et al., 2008) and increases satisfaction with the dying experience (Chen et al., 2015; Gade et al., 2008). The palliative care team not only serves to optimize the care of all patients with symptomatic disease but is invaluable for the promotion of congruent care near death.

Much of this review discusses ACP and ADs in the context of intensity of care. This is defined by this author as the degree of care received in the acute care setting. For this study, aggressive care is high-technology, high-cost care that includes mechanical ventilation (Dobbins, 2007; Dunlay et al., 2012; Hammes et al., 2012), new dialysis (Dobbins, 2007; Dunlay et al., 2012; Hart et al., 2015; Hartog et al., 2014; Kong et al., 2015; Nicholas et al., 2014), artificial nutrition (Dobbins, 2007; Dunlay et al., 2012; Hammes et al., 2012; Kizawa et al., 2013; Kong et al., 2015; Nicholas et al., 2014; Tschirhart et al., 2014), CPR (Dunlay et al., 2012; Hammes et al., 2012; Mack et al., 2012), ICU admission (Dobbins, 2007; Dunlay et al., 2012; Hartog et al., 2014; Nicholas et al., 2014), and vasopressors or other cardiovascular support such as intra-aortic balloon pump (IABP) or extracorporeal membranous oxygenation (ECMO) (Dobbins, 2007; Hartog et al., 2014). Conservative care can be any low-intensity care, but will specifically include palliative care or hospice referrals, the initiation of comfort care order sets, and/or the changing of code status to do not resuscitate. In understanding the relationship with ACP and ADs, intensity of care has been characterized extensively in the literature in a variety of settings and populations.

**Review of the Literature**

Older adults prefer comfort over life-sustaining treatments (Bischoff et al., 2013; Silveira et al., 2010; Winter & Parks, 2012; A. A. Wright et al., 2016; Yoo et al., 2013).
Interviews conducted with family members found that most decedents preferred palliative treatments over life-prolonging treatments and preferred to die at home (A. A. Wright et al., 2016). Similar findings have been identified in community-dwelling older adults (Winter & Parks, 2012; Yoo et al., 2013) and in studies of national databases of older adults (Bischoff et al., 2013; Silveira et al., 2010).

Care received in an ICU may not extend life. Intensive care unit admissions can result in longer hospital lengths of stay with no significant difference in survival (Kim et al., 2016). Additionally, aggressive treatment, or high-intensity care, at the EOL portends poor outcomes. In deceased cancer patients, aggressive treatments, for example, new chemotherapy treatment in the final 30 days of life, are associated with increased frequency of hospitalizations and increased risk of in-hospital death (Grendarova et al., 2015). Advanced care planning, and more specifically advance directives, may play a significant role in reducing ineffective care at the end-of-life.

This literature review will provide the foundation for the necessity of this research to understand the relationship between advance directives and the intensity of care delivered in the acute care setting. Advanced care planning will be described in the context of occurrence of ACP discussions, factors influencing participation in ACP, patient outcomes. The review probes more deeply into the most concrete representation of ACP, the AD. Here, parallels will be explored between the ACP and AD literature including the occurrence of AD completion, factors influencing completion, including barriers, and challenges of ADs. Finally, the focus shifts to the impact of ACP and ADs on the role that these documents have been found to play in shaping patient outcomes and the care delivered in the acute care setting. Much of the literature in this review,
examined the adult population without specific emphasis on older adults. This will be emphasized in the subsequent discussion of gaps and next steps.

**Advanced care planning.**

*Occurrence of advanced care planning discussions.* Advanced care planning discussions continue to occur with adults at exceedingly low rates that range from 11-57% (Abel et al., 2013; Leung et al., 2012; Stachura et al., 2015; A. A. Wright et al., 2008). Advanced care planning discussions tend to occur more frequently in terminally ill oncology patients (A. A. Wright et al., 2008) and those already in hospice (Abel et al., 2013). Other studies examined ICU patients (Stachura et al., 2015) and COPD patients (Leung et al., 2012) with similarly low rates of completion. None of these investigations of ACP completion focused on older adults, and the highest rate of occurrence of ACP was identified within the hospice population suggesting that rates may not be an accurate representation of the older adult without a terminal illness.

The impact of disease severity on the incidence of ACP discussions is equivocal. While A. A. Wright et al. (2008) found that patients who reported more frequent EOL discussions tended to have more advanced disease, others have noted that in COPD there was no association between increasing illness severity and occurrence of EOL discussions (Leung et al., 2012). One might assume that more acutely ill patients might be more likely to have engaged in ACP. In a German study of deceased surgical ICU patients, only 11% had engaged in documented ACP discussions (Stachura et al., 2015). While this was a small, single-center study, it is consistent with the available literature.

*Factors influencing advanced care planning completion.* There are two potential reasons for low rates of ACP engagement: patient and family concerns that
engaging in ACP may shorten survival and knowledge deficits. The relationship between ACP discussions and survival has been explored (Fischer et al., 2012; Martin et al., 2016). In a prospective study of general internal medicine patients, there was no difference in one-year survival among those adults who reported having had ACP conversations or completed ADs (Fischer et al., 2012). Consistent with Fischer’s (2012) findings, a systematic review exploring the effects of ACP in the nursing home resident population found that there was no difference in survival, but rather that residents with ACP receive care that was congruent with their preferences (Martin et al., 2016).

Knowledge deficits may be an obstacle to engagement in ACP conversations. The goals of EOL discussions (Mack et al., 2012; Mayland et al., 2013) and disease trajectories (Howie-Esquivel & Dracup, 2012; Klindtworth et al., 2015; Strömberg et al., 2014) are often misunderstood. Oncology patients have been found to have a poor understanding of EOL trajectory (Mayland et al., 2013) and do not always recognize the occurrence of EOL conversations with their providers. In a study evaluating the characteristics of EOL planning, patients had been asked whether or not ACP discussions occurred with their provider, and chart review was used to identify documentation of these conversations (Mack et al., 2012). Patients with both reported and documented ACP discussions were less likely to receive aggressive acute care than those whose ACP discussions were documented but not reported by patients to have occurred. This discrepancy makes it difficult for patients to receive care at EOL that is congruent with their preferences if they are not consciously aware that their discussions may have future implications. Additionally, poor understanding of disease trajectory has been demonstrated in conditions that require ICD placement or maintenance (Niewald,
Broxterman, Rosell, & Rigler, 2013; Strömberg et al., 2014) or progressive disease such as heart failure (Howie-Esquível & Dracup, 2012; Klindtworth et al., 2015). This may lead patients to accept care at EOL that is ineffective given their disease process and only serves to prolong the dying process. Heart failure patients may have lack of “emergency plans” and poor understanding of heart failure as a life-limiting illness (Klindtworth et al., 2015), and some studies have underscored the need for ACP discussions as part of the consent process prior to placement of ICDs (Niewald et al., 2013). Advanced care planning discussions are an opportunity to have open conversations about individuals’ disease trajectory while revisiting these discussions routinely as disease progression necessitates (The Institute of Medicine, 2015).

**Challenges of advanced care planning.** Communication is essential to establish patient preferences and promote care that is congruent with patient preferences. A primary goal of ACP is to elicit patient preferences to minimize unwanted care or treatments at EOL; however, patient preferences remain poorly communicated to their providers and families and inadequately documented (Roger et al., 2015). In a study conducted at two campuses of the University of California, only half of heart failure patients with explicit preferences for EOL care had those documented (Sadeghi et al., 2016). In addition, it was noted that patients who reported having had EOL discussions had no documentation of these conversations in their medical record. This poor communication of patient preferences is consistent with findings in a hemodialysis population. A study that explored the congruence between named surrogate decision makers and documented emergency contacts found that only 3% of participants had a designated surrogate at the onset of the study (Song & Ward, 2013). Over the course of
the study, all participants chose surrogates; however further review of the EHR revealed inconsistencies between chosen surrogates and listed emergency contacts. This raises concerns for those situations in which a patient presents emergently and is unable to provide information to healthcare personnel, requiring contact with the individual listed as emergency contact. In the case of this contact making urgent decisions in high-pressure scenarios, the door is opened for patients to receive potentially unwanted care. These studies highlight the need for ACP interventions that optimize communication, through improved discussions and documentation, to ensure congruence with patient preferences.

**Advance directives.**

**Occurrence of advance directive completion.** While ACP is a dynamic process (Schubart, Levi, Dellasega, Whitehead, & Green, 2014), ADs are a concrete reflection of that process. There has been little improvement in the rate of AD completion since the SUPPORT study demonstrated the inadequate numbers of ADs and the failure of those ADs to reduce aggressive care (Dobbins, 2007; Teno, Lynn, et al., 1997; The SUPPORT Principle Investigators, 1995). Rates of AD completion range from 12.4-70.8% (Albaeni, Chandra-Strobos, Vaidya, & Eid, 2014; Blechman, Rizk, Stevens, & Periyakoil, 2013; Butler et al., 2015; Dobbins, 2007; Gamertsfelder et al., 2016; Kong et al., 2015; Kwon et al., 2012; Patel, Bhattacharya, Asch, & Kahn, 2016; Silveira et al., 2010; Sommer et al., 2012; Teno et al., 2007). While at first glance it may appear that AD rates have been found to be quite high in some studies, it should be noted that the studies that found the highest completion rates of ADs were also those in which the presence of an AD was reported by a proxy, usually a family member rather than by EHR review (Silveira et al.,
2010; Teno et al., 2007). In studies that obtained AD data from review of the EHR, the rate of AD completion decreased to 12.4-53% (Albaeni et al., 2014; Blechman et al., 2013; Butler et al., 2015; Dobbins, 2007; Gamertsfelder et al., 2016; Kong et al., 2015; Kwon et al., 2012; Patel et al., 2016; Sommer et al., 2012). Secondary analyses of large databases relied on proxy reporting where response or selection bias may have impacted findings. Further exploration using objective data is warranted.

**Factors influencing advance directive completion.** While few people report having an AD, significantly more report having had some kind of ACP conversation with their provider (Fischer et al., 2012), suggesting that ACP discussions do not always translate into the documentation of preferences into a tangible form. Numerous factors influence the completion of ADs including age and comorbidities. Older age has been found to be associated with increased frequency of AD documentation (Dunlay et al., 2012; Fonk et al., 2012; Gamertsfelder et al., 2016; Hammes et al., 2012). This may be a reflection of older adults recognizing their mortality and having a desire to ensure that their preferences are honored if they are no longer able to articulate them. Conversely, one study found that younger age was more associated with AD completion (Kong et al., 2015). In their study of terminal oncology patients, the authors found that patients were more likely to complete directives when younger and healthier. While this contradicts the aforementioned reports, it may reflect cultural differences or disease-specific differences related to the diagnosis of a potentially terminal illness. Kong et al. conducted their study in Korea. While it was a single-center study, limiting generalizability, it may illustrate the differences between Western and Asian cultures.
Chronic illness and functional disability may impact rates of AD completion, but findings are inconsistent across studies. Kong et al. (2015) identified improved rates of AD completion in those with better functional status while other studies have found no relationship (Dunlay et al., 2012; Gamertsfelder et al., 2016). In studies of deceased patients, subjects with a higher number of chronic comorbidities were more likely to have ADs (Fonk et al., 2012; Hammes et al., 2012). This relationship is also consistent among hospitalized heart failure patients (Butler et al., 2015); however, other studies found no association between chronic illness and rates of AD completion (Dunlay et al., 2012; Gamertsfelder et al., 2016). Acute on chronic illness may precipitate the completion of ADs. Butler et al. (2015) found that hospitalized heart failure patients with a length of stay of five or more days were more likely to have a documented AD, suggesting that patients with a higher acuity of illness may feel more compelled to complete directives. These ambivalent findings across multiple studies lead to residual questions for future study.

**Challenges of advance directives.** There are numerous concerns about AD documents. Providers have raised concerns regarding the applicability of ADs and their timing of activation (Gutierrez, 2012). Critical care providers, in qualitative interviews, report that ADs are only applied in cases of impending death or in conditions that rarely occur, such as persistent vegetative states. By these inherent limits, it may suggest that AD documents do not undergo review until either of these scenarios is imminent.

The vague and ambiguous nature of AD documents is a well-documented finding (Dunlay et al., 2012; Gutierrez, 2012; Hartog et al., 2014; Nauck et al., 2014; Street et al., 2015). Verbiage relating to brain impairment, a desire to avoid suffering or vegetating,
or a desire for a good death makes interpretation difficult (Hartog et al., 2014; Nauck et al., 2014). In many cases, very specific preferences or additional instructions other than standardized language were absent, thus resulting in confusion and limited utility (Dunlay et al., 2012; Hartog et al., 2014; Street et al., 2015). Confusion is amplified in the case of multiple documents, that each may contradict the other, often going unrecognized by patients (Nauck et al., 2014). These findings suggest that there may be aspects of the documents themselves that are flawed and that may need revision. Further study is needed to discriminate between the different types of available AD documents to understand which, if any, is more useful to promote patient autonomy and congruence with preferences for treatment at EOL.

**Intensity of care.** The following sections will focus on outcomes related to extremes of intensity of care, both high (i.e., aggressive) and low (i.e., conservative), in the context of both ACP and ADs.

**Outcomes associated with advanced care planning.** Advanced care planning discussions are effective in promoting EOL care that is consistent with patient preferences (Abel et al., 2013; Houben et al., 2014; Martin et al., 2016). In addition to improved congruence, hospitalization rates (Abel et al., 2013; Martin et al., 2016) and costs in the final year of life are also reduced (Abel et al., 2013). Given that we know older adults’ tendencies to prefer comfort and symptom management at EOL, this literature lends support to the necessity to promote effective ACP. It is the influence of the intervention that is an essential component. As previously noted by Song and Ward (2013), ineffective implementation of ACP decisions puts patients at risk of receiving
care that is inconsistent with their preferences, which can lead to unwanted treatments and a prolonged dying process.

Advanced care planning is associated with reduced intensity of care at the end of life, including fewer ICU admissions and decreased ICU length of stay (Khandelwal & Curtis, 2014; Khandelwal et al., 2015; Street et al., 2015). Hospitalization rates are reduced without sacrificing mortality (Martin et al., 2016). In hospice patients, ACP has been associated with significantly fewer hospital days in the final year of life (Abel et al., 2013). Similarly, in a study of deceased women with ovarian cancer, ACP was associated with fewer hospitalizations at the end of life (Lopez-Acevedo et al., 2013). The similarity in these studies may be related, in part, to the populations studied. While Abel et al. (2013) focused on hospice patients, an overwhelming majority of participants were oncology patients. In contrast, there is literature that suggests that ACP in more general older adult populations may not impact hospitalization rates, despite the reduction in LOS, ICU admissions, and fewer 30-day readmissions (Street et al., 2015). With such a significant emphasis on the oncology population in this area of research, there is a void that persists in understanding how ACP impacts other groups with multidimensional illness.

It is not simply ACP alone that reduces intensity of care and healthcare utilization. The timing of these conversations is essential. Early ACP discussions, occurring more than 30 days before death, have been associated with a reduction in aggressive treatment at EOL and an increase in hospice utilization (Lopez-Acevedo et al., 2013; Mack et al., 2012; O'Connor et al., 2015).
Outcomes associated with advance directives. Contrary to the findings highlighting the association between ACP and decreased intensity of care, there is not a clear association between ADs and intensity of care. In a longitudinal study of adults with heart failure, there was no significant difference in the number of hospitalizations in the final month of life or in length of survival between those who did and did not have ADs (Dunlay et al., 2012). The authors also found that while there was a decreased likelihood of mechanical ventilation among those with clearly expressed preferences in AD documents, there was no effect on rates of ICU admission in the final month of life. Similarly, despite the ability of ADs to reduce hospital LOS, ICU admissions, and 30-day readmissions, they do not appear to significantly reduce the number of hospitalizations (Street et al., 2015).

Advance directives can meaningfully impact patient outcomes, both positively and negatively. Lack of ADs can lead to presumed consent or family decisions for treatments that individuals may or may not want (Kong et al., 2015; Stachura et al., 2015). In a study of deceased surgical ICU patients, treatments for nearly half of patients whose ICU length of stay was longer than 11 days (range 11-71 days) were determined by presumed consent (Stachura et al., 2015). While this was a small-scale study, it raises significant concerns when advocating for delivery of care that is congruent with patient preferences. In a study of terminal cancer patients in a single Korean hospice center, patients without preexisting directives may receive care that is decided by family members (Kong et al., 2015). Although this family-centered decision making may be culturally relevant, it may be a mistake to characterize all patients of a specific ethnicity or cultural heritage as being homogenous.
Survival may be extended in those patients with documented ADs (Ache et al., 2014; Kong et al., 2015). In a large-scale study of hospice patients, older adults with ADs experienced longer survival than those without (Ache et al., 2014). Correspondingly, Kong et al. (2015) found that among terminal oncology patients, those who completed ADs lived significantly longer. Critics of this study may note that those with ADs lived 27 days as compared to 16 days for those without ADs. While this is statistically significant, the clinical significance of this difference is less compelling.

In specific populations, ADs have generally been found to be unrelated to the use of life-sustaining treatments. In a study of heart failure patients, age 20 years and older, mixed results were found (Dunlay et al., 2012). In the final month of life, those patients with ADs were less likely to be mechanically ventilated; however, there was no effect on ICU admissions. Other studies have very clearly identified no association between ADs and aggressive care in adults of all ages (Halpern et al., 2011; Hart et al., 2015; Tan & Jatoi, 2011). In their study of critically ill cancer patients, Halpern et al. (2011) found that neither living wills nor healthcare POAs were found to reduce the frequency of aggressive care. Likewise, Hart et al. (2015) found that preexisting preferences for limitations in care do not guarantee that life-sustaining treatment will be withheld. In this large-scale secondary data analysis of critically ill adults, the authors found that 41% of those admitted with preferences for limited care still received at least one form of aggressive life-sustaining treatment. These studies were not exclusively focused on older adults; however, among the limited number of studies that specifically targeted older populations, the results are similar (Dobbins, 2007; Hartog et al., 2014). In a community-dwelling older adult population, approximately 1/3 of patients with a documented AD
still received mechanical ventilation, artificial nutrition, or vasopressors (Dobbins, 2007). Additionally, critically ill older adults remain likely to receive mechanical ventilation, and to a lesser degree, artificial nutrition or circulatory support, despite preexisting refusals (Hartog et al., 2014).

Congruence between documented preferences and care delivery has mixed evidence. On the one hand, various studies suggest that ADs improve the delivery of care that is congruent with patient preferences (Bischoff et al., 2013; Hammes et al., 2012; Hickman et al., 2011). In a study of deceased, older adult nursing facility residents, ADs in the form of POLST documents, promoted congruence in care delivery for those patients who preferred limitations (Hickman et al., 2011). Likewise, POLST documentation was found to effectively facilitate the delivery of comfort care over aggressive treatment in those whose document expressed that preference (Hammes et al., 2012). Bischoff et al. (2013) found that older adults with ADs preferred comfort over life-sustaining treatment and received care that was concordant with those wishes. All of these studies identified the impact of AD documents in reducing unwanted aggressive care at EOL. However, none address the ability of ADs to promote aggressive care when preferred. Conflicting evidence is provided in additional studies. Hartog et al. (2014) concluded that despite having an AD in place, incongruence between written directives and care delivered remained a concern. In this study of critically ill older adults, 62% received ventilator support despite directives that refused such intervention. Additionally, one-third of patients who refused artificial nutrition received it, and approximately one-fourth of patients who refused circulatory support such as vasopressors still received them. A study of older adult nursing facility residents in
Germany found that 61% of residents with directives that specified no CPR lacked a documented order for such limitation, thus suggesting that in the event of a cardiac event, all extraordinary measures would have been implemented (Sommer et al., 2012). Both studies characterize the challenge that lingers within our healthcare system to effectively utilize ADs. In one of the only studies that explored provider perspectives, Gutierrez (2012) found that many critical care nurses and physicians feel that ADs do not prevent unwanted treatment, and in fact, suggest that patients may not share the document with providers for fear of automatic non-treatment of their acute condition. This adds to the body of conflicting evidence on the utility of ADs in their current form to promote the delivery of care that adheres to patient preferences.

There are several methodological concerns that limit drawing conclusions from this review regarding the impact of ADs in reducing healthcare utilization and aggressive care. The use of proxy reporting of ADs as compared to studies where the presence of ADs was confirmed in the EHR impacted study findings. Studies that collected data from proxy sources generally found a significant association between ADs and decreased aggressive or unwanted care (Nicholas et al., 2014; Silveira et al., 2010; Teno et al., 2007; Tschirhart et al., 2014). Among these studies, ADs, regardless of patient preferences, are associated with less frequent aggressive treatment (Silveira et al., 2010). More specifically, ADs were associated with less frequent mechanical ventilation, artificial nutrition, and death while in the ICU in the final month of life (Teno et al., 2007). While these studies using proxy-reported data suggest that ADs may significantly reduce the odds of aggressive care in the final months of life, when controlled for other factors, only intubation, ICU utilization, and the delivery of CPR were found to be
significantly reduced (Nicholas et al., 2014; Tschirhart et al., 2014). Proxy report may ultimately overestimate the impact of ADs. Why proxy-based studies show conflicting results is worth exploring more in-depth as the healthcare community continues efforts to improve EOL care.

A paucity of research evaluating the association between ADs and code status leaves it unclear as to whether ADs impact the frequency of DNR orders and/or CPR. In one of the few studies to evaluate the AD document itself, Hartog et al. (2014) found that those with ADs were significantly less likely to undergo CPR and more likely to have DNR orders. Other studies have been unable to establish a consistent association between AD and CPR occurrence (Hart et al., 2015; Tan & Jatoi, 2011). These opposing studies continue to highlight the conflicting results regarding how advance directives impact the intensity of care at the end-of-life.

If the aggressive management of illness is declined or refused, then the remaining options are to manage conservatively or transition to comfort care. The relationship between ADs and transitioning to comfort care is uncertain. In their study of in-hospital deaths of adults aged 65 years and older, Dobbins (2007) found no relationship between ADs and initiation of a comfort care plan. However, more recent studies have identified a relationship in which ADs are associated with decreased in-hospital mortality and increased frequency of hospice discharges with longer hospice lengths of stay (Ache et al., 2014; Yoo et al., 2013). However, significant methodological limitations including only targeting patients who were already on hospice (Ache et al., 2014) and single-center studies (Dobbins, 2007; Yoo et al., 2013) limit the ability to draw definitive conclusions.
Limited information is available as to the relationship between ADs and referral to palliative care. A single study limited only to military veterans with newly diagnosed advanced stage cancer found no association between ADs and referral to palliative care once controlled for multiple confounding factors (Patel et al., 2016). It is difficult to draw a meaningful conclusion from a single, very limited study. Palliative care provides an invaluable service to patients at all phases of life but can be especially beneficial at the end-of-life. It must be considered for further study as an outcome variable in the context of intensity of care and optimal QOL at the EOL.

Gaps. While studies in this review lend support for the ability of ACP to promote congruence with patient preferences, there are several limitations. Studies for whom proxy report was the primary data source of patient preferences (Bischoff et al., 2013; Silveira et al., 2010) rely on proxy accuracy; however, these studies may be affected by respondent bias. Thoughtful consideration should be afforded to the data sources when evaluating these studies. Of twelve studies that focused on the relationship between ACP and high intensity of care, one each focused on limited populations including ICU patients on mechanical ventilation (Gamertsfelder et al., 2016), out of hospital cardiac arrest (Albaeni et al., 2014), nursing home residents (Sommer et al., 2012), older adult in-hospital decedents (Dobbins, 2007), and hospitalized heart failure patients (Butler et al., 2015). Two studies targeted more general populations through the use of national survey databases, relying on proxy report (Silveira et al., 2010; Teno et al., 2007). Nearly half of these studies included only oncology patients (Blechman et al., 2013; Kizawa et al., 2013; Kong et al., 2015; Kwon et al., 2012; Patel et al., 2016) and most were not exclusively interested in the older adult population (Albaeni et al., 2014; Blechman et al.,
Several studies are small-scale or pilots (Houben et al., 2014; Sadeghi et al., 2016; Song & Ward, 2013), thus requiring additional study with larger samples. Methodological issues create difficulty in synthesizing findings. Both Houben et al. (2014) and Martin et al. (2016) were systematic reviews that initially intended to conduct meta-analyses but were unable to do so due to high variability in study design. Future studies should give strong consideration to sample size and consistent methodologies to improve the ability to draw conclusions across studies.

In trying to better understand the impact of ADs on intensity of care at the EOL, the populations studied have been narrowly limited and include patients only with existing ADs (Silveira et al., 2010), deceased oncology patients (A. A. Wright et al., 2016), and ICU patients (Yoo et al., 2013). Most studies do not exclusively focus on the older adult population (Abel et al., 2013; Houben et al., 2014; Sadeghi et al., 2016; Song & Ward, 2013). Further study of this population is required to improve understanding of their unique circumstances and vulnerabilities. The absence of literature that explores the preferences of older adults more widely, including healthy, chronically ill, and terminally ill with greater attention to the multiple diseases that affect the older adult population, limits the generalizations that can be drawn from this body of literature. Additional study is needed in the vulnerable older adult population in a number of settings.

Few studies explored the older adult population, and while many study samples demonstrated a mean age of 65 or older, these included data from adults of all ages, thus limiting generalizability to the broad older adult population. The following studies
demonstrate the limited focus of studies in older adults. Mechanical ventilation, new dialysis, and artificial nutrition have been studied in single-center studies in a community hospital (Dobbins, 2007) and a German hospital (Hartog et al., 2014) as well as part of secondary data analyses (Nicholas et al., 2014; Tschirhart et al., 2014). CPR has only been included as an outcome in one secondary analysis (Tschirhart et al., 2014). Admission to the ICU has been studied in a community hospital (Dobbins, 2007) and from a secondary analysis (Nicholas et al., 2014), and in one study, ICU length of stay was studied because participants were limited to those already in the ICU (Hartog et al., 2014). Cardiovascular support and antibiotics have been included as part of aggressive management in the older adult population in the community hospital setting (Dobbins, 2007) and in a single German hospital (Hartog et al., 2014). In addition to a community facility (Dobbins, 2007), invasive procedures have only been included as an outcome measuring intensity of care in secondary analyses (Nicholas et al., 2014; Tschirhart et al., 2014).

It is difficult to ascertain the relationship of chronic comorbidities and AD completion in the older adult population. The literature in adults is limited to targeted community studies (Fonk et al., 2012; Hammes et al., 2012) and hospitalized heart failure patients (Butler et al., 2015). Specifically, in older adults, this literature is limited to mechanically ventilated ICU patients (Gamertsfelder et al., 2016). These very targeted studies limit the extrapolation of the findings to the general older adult population. Understanding the impact of chronic illness is crucial to better insight into the motivations behind completing ADs.
There continues to be a need for studies focused on the older adult population with a variety of comorbidities rather than studying populations within silos of disease processes. Additionally, studies exploring the impact of ADs on intensity of care in the acute care setting must focus on obtaining objective data rather than relying on proxy reporting. Additional research must target older adults with multiple comorbidities, EHR review for AD documents, and review of those documents to determine the congruence between care received at the EOL and documented preferences for care.

What ultimately remains unclear is whether ADs truly impact the delivery of care at EOL. To ultimately improve the utility of ACP for optimizing QOL at EOL, it is essential to first understand the true influence of ADs on the intensity of care delivered in the acute care setting. It is unclear whether the documents themselves are inadequate or the process of ACP is inaccurately reflected in the AD document, suggesting a flawed process. Prior to seeking to implement interventions that increase ACP and AD completion, we need a better understanding of the impact of ADs on care delivered in the acutely ill older adult population.

**Research Questions**

The purpose of this study was to describe the association between ADs and the intensity of care received by older adults in the acute care setting at the end-of-life. Specific research questions included:

1. Is the presence of a documented advance directive associated with the likelihood that a patient will be admitted or transferred to the ICU at the end-of-life?
2. Is the presence of a documented advance directive associated with total ICU length of stay in those patients who received ICU care at the end-of-life?

3. Is the presence of a documented advance directive associated with the likelihood that a patient will receive mechanical ventilation at the end-of-life?

4. Is the presence of a documented advance directive associated with the likelihood that a patient will be placed on new hemodialysis or continuous renal replacement therapy (CRRT) at the end-of-life?

5. Is the presence of a documented advance directive associated with the likelihood that a patient will have new enteral nutrition (i.e., tube feedings) initiated at the end-of-life?

6. Is the presence of a documented advance directive associated with the likelihood that a patient will receive cardiovascular support, including ECMO, IABP, ventricular assist device (VAD) placement, or vasoactive medications at the end-of-life?

7. Is the presence of a documented advance directive associated with undergoing an invasive procedure at the end-of-life?

8. Is the presence of a documented advance directive associated with the likelihood of receiving CPR at the end-of-life?

9. Is the presence of a documented advance directive associated with code status at death at the end-of-life?

10. Is the presence of a documented advance directive associated with the initiation of a comfort care order set at the end-of-life?
11. Is the presence of a documented advance directive associated with the likelihood of receiving a palliative care consult at the end-of-life?

12. Is the presence of a documented advance directive associated with the likelihood of receiving a hospice referral at the end-of-life?

A secondary aim was to describe the congruence between patient preferences documented in ADs and actual care delivered by answering the question ‘Does actual care delivered in the acute care setting at the end-of-life correspond to patient preferences as articulated in their advance directive document?’

**Assumptions of the Study**

Several assumptions underpin this study. First, older adults perceive approaching EOL in a unique way, distinct from younger adults. The accumulation of life experience and the emerging awareness of impending mortality provide a unique lens through which older adults view EOL. Through this lens and based on literature, it is also assumed that older adults desire QOL at the EOL over longevity. This quality of life is presumed to include less dependence on invasive medical technology and maintenance of independence.

It is furthermore assumed that older adults share preferences for care that promotes comfort such as being free of pain or a desire to avoid futile care. This includes symptom management and avoidance of care that will not yield a measurable improvement in overall function. Finally, as adults age, the incidence of chronic illness increases. Patients with multiple chronic diseases present unique challenges for care at the EOL distinct from those patients with a singular illness such as only having cancer, chronic pulmonary disease, or heart failure. The patient’s experience of multiple chronic
diseases is felt to play a role in the perception of the necessity to participate in advanced care planning to improve QOL at the EOL.
Chapter III: Research Design and Methods

Study Design

This was a retrospective, associational study that explored the impact of advance directives on acute care delivered at the EOL. The primary aim of this research was to describe the association between ADs and the intensity of care delivered to older adults in the acute care setting. A secondary aim of this study was to describe the congruence between documented patient preferences within ADs and actual care delivered.

**Human subjects considerations.** The Marquette University institutional review board (IRB) deferred review of this study. Institutional review board approval was obtained from the Medical College of Wisconsin (MCW), as it serves as the IRB for Froedtert Hospital where the electronic health record was accessed. Approval was also obtained from the Office of Clinical Research and Innovative Care Compliance at Froedtert Hospital. Since subjects were deceased, the project was not considered human subjects research, and therefore was expedited.

Data were stored on a password-protected computer and backed up onto a passcode protected flash drive. Data collection forms were identified only by a unique study identification (ID) number. Despite all of these protections, there always remains a risk of loss of confidentiality. No known breaches occurred.

**Sample and setting.** A convenience sample was obtained from a large, tertiary, level one trauma center in the Midwest of the United States. Inclusion criteria included adult patients aged 65 years and older, whose death occurred in the hospital between January 2014 and December 2016. Exclusion criteria included patients who were
awaiting or received a solid organ transplant. Transplant patients must agree to aggressive care as part of being placed on the transplant waiting list. Including these patients had the potential to skew the results since they are not able to discuss EOL care in the same way as other patients. Patients were also excluded if they transferred to the hospice service prior to death. These patients were discharged from the acute care setting, readmitted into hospice, and all subsequent care was managed within the same building by an outside hospice agency.

**Sample size.** To address the primary aim, an a priori G-power analysis (Faul, Erdfelder, Lang, & Buchner, 2007) was conducted for a medium effect (Cohen, 1988). The power analysis indicated that a total sample of 485 people was needed to detect a moderate effect and 80% power using binary logistic regression with alpha set to .01 to account for multiple distinct regression analyses in an effort to minimize Type I error. Because significantly more potential patients during the target timeframe were identified than the power analysis suggested, random sampling was utilized to obtain the target number of patients. To address the secondary aim, a subset of 100 patients with preexisting ADs (i.e., completed prior to the hospitalization), scanned into the medical record prior to admission or presented within 24 hours of admission, and retrievable from the EHR, were randomly selected for formal document review.

**Data Collection**

Decedents were identified from the data archives of the Clinical and Translational Science Institute within MCW, who holds the institutional medical data. Each patient was given a unique study ID. Data were abstracted from the EHR of each patient by this investigator and documented on a data collection form identified only by study ID. The
data were subsequently entered into the statistical software program, SPSS, into a password protected file.

**Measures**

**Patient characteristics.** Demographic data (i.e., trait characteristics) including age, sex, marital status, race, and ethnicity were obtained from the EHR.

**Comorbidities.** The Charlson Comorbidity Index (CCI) was used to measure comorbid conditions. The CCI is a predictive tool of one-year mortality based on classifications of comorbid conditions (Charlson, Pompei, Ales, & MacKenzie, 1987). In a systematic review of available methods for measuring comorbidity, the CCI was found to be among those that have demonstrated sustained reliability and validity for use in clinical research (Degroot, Beckerman, Lankhorst, & Bouter, 2003). The original study (Charlson et al., 1987) included both instrument development and validation in a large sample of breast cancer patients. Two cohorts were evaluated at five-year and 10-year follow-ups. Both samples were analyzed for the ability to predict mortality. The number of diagnosed comorbidities significantly predicted one-year mortality, but it was clear that scoring adjustments were required to account for individual prognostic differences among the various medical conditions. The investigators then developed a weighted index, with higher weights portending poorer outcomes, resulting in a tool with 19 comorbid categories. Concurrent validity of the tool was established by comparing the new tool to a well-established method of classifying comorbid conditions by Kaplan and Feinstein (Kaplan & Feinstein, 1974). In comparing the survival curves for both measures, the survival curves were nearly identical. The Charlson Comorbidity Index is an extensively used and well-developed tool that has undergone several revisions. A
number of years following its development, the original tool was validated in patients who underwent elective surgery (Charlson, Szatrowski, Peterson, & Gold, 1994). The authors took into greater account the effects of age on survival and found that combining age with comorbidities into a single score was significantly better at predicting survival. Subsequent applications of the tool use this refined model. A significant revision was conducted in older adult lumbar spine surgery patients, where the comorbidity categories were decreased to 17 after the combination of oncology diagnoses (Deyo, Cherkin, & Ciol, 1992). It has been revised for use with the International Classification of Diseases, version 9 (ICD-9) (Deyo et al., 1992) and ICD-10 (Halfon et al., 2002; Quan et al., 2005; Sundararajan et al., 2004), which are important revisions for the use in clinical research with EHRs.

Validity of the CCI in acute care populations. The Charlson Comorbidity Index has been applied to the following acute care populations: oncology (Wu et al., 2016), emergency (Street et al., 2015), stroke (Tessier, Finch, Daskalopoulou, & Mayo, 2008), and advanced chronic organ failure (Van den Heuvel, 2016). For older adults specifically, the tool was validated in a prospective, longitudinal, cohort study of those acutely hospitalized (Frenkel, Jongerius, Mandjes-van Uitert, van Munster, & de Rooij, 2014), and has been utilized in studies of QOL in diabetics (Brown, Meltzer, Chin, & Huang, 2008), the acutely hospitalized (Parlevliet, MacNeil-Vroomen, Buurman, Rooij, & Bosmans, 2016), and those admitted or transferred to the ICU (Kim et al., 2016).

Predictor variables. To address the primary aim, the presence of an advance directive served as the binary predictor variable (PV), either present or not present. Advance directives included living wills (LW), powers of attorney for healthcare (POA-
HC), and nursing facility documents that delineated preferences for medical treatment. Not unsurprising, there were no official POLST documents. An advance directive was considered present if the formal document was signed by the patient prior to the date of the terminal admission to the facility, was present in the EHR prior to admission, or was made physically available within the first 24 hours of admission and eventually scanned into the EHR. This 24-hour limitation was utilized to allow for the development of the individualized plan of care for a given admission over the first day of admission.

**Outcome variables.** Outcome variables consisted of care received while in the hospital categorized as either aggressive or conservative care.

**Aggressive care.** Indicators of aggressive care for this study were selected based on an extensive literature review, with the most common measures included as outcome variables in the present study:

* mechanical ventilation
* new initiation of enteral nutrition (i.e., tube feedings)
* new dialysis, including standard hemodialysis or continuous renal replacement therapy (CRRT)
* cardiovascular support: including vasopressors, extracorporeal membranous oxygenation (ECMO), new ventricular access device (VAD), or intra-aortic balloon pump (IABP) support
* invasive procedures (i.e., bronchoscopy, paracentesis, thoracentesis, EGD, cardiac catheterization, balloon angioplasty, ERCP, endovascular embolization of vascular abnormalities, cholecystostomy tube placement, chest tube placement, colonic stenting, intracranial pressure monitor
placement, external ventricular drain, lumbar puncture, pacemaker and/or internal cardiac defibrillator placement, stem cell transplant, tracheostomy, permanent feeding tube placement, and any general anesthesia surgeries)

- receipt of CPR
- admission or transfer to the ICU
- ICU length of stay for those who received ICU care

Table 1 below highlights the existing literature that supports the rationale for choices of outcome variables. Including measures that have been utilized in a variety of studies contributes to the potential for meta-analysis in this area of research.

Table 1

*Support for outcome variable selection based on existing literature.*

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Conservative care. Presence or absence of a palliative care consult, a hospice referral, initiation of a comfort care order set, or a DNR order was abstracted from the EHR. Do-not-resuscitate code status was defined as code status at death.

Data Management and Statistical Analysis

Data were entered into SPSS, version 24 (IBM Corp., 2016). This author, mentor faculty, and the study statistician had sole access to the data. Audits of ten percent of the cases were completed by mentor faculty to minimize reliability threats from errors.

Logistic regression (LR) was used to detect differences between groups while controlling for the influence of covariates, including age, sex, race, and comorbidities. Logistic regression is used for data analysis where the outcome variable (OV) is dichotomous, and allows for the analysis of one or more PVs, or predictors, with the objective to predict the probability of the presence of the OVs. Predictors may be continuous or categorical.

The assumptions associated with LR are as follows (R. E. Wright, 1995):

1. Outcome variables must be dichotomous.
2. Outcome variable scores must be independent of each other.
3. The model was correctly specified.
4. Categories assigned to outcome variables are mutually exclusive and exhaustive.

There are several advantages of LR. It permits analysis of nonlinear relationships between the predictor and outcome variables. It uses the logit function to relate the predictors to the binary outcome variable by transforming the outcome variable into the natural log of its odds of being present. Rather than having a linear relationship between
the predictor and outcomes, the logit transforms the outcome variable from a binary variable into a variable that ranges from positive to negative infinity thereby producing an “S” shaped curve that illustrates the relationships between predictors and the probability of an outcome (Pampel, 2000; Polit, 1996).

This statistical analysis produces log odds, where the log odds of the target outcome are the reciprocal of the log odds of the alternative outcome. Higher log odds indicate a higher likelihood of the target outcome. The log odds are transformed via exponentiation into odds ratios (OR). Odds ratios are interpreted as the likelihood of the target outcome occurring.

Model comparisons were completed to determine which predictors were meaningful and should be kept in the regression (Pampel, 2000; Polit, 1996). Significance was set to $\alpha < .01$ to allow for multiple regression analyses and minimize Type I error. Logistic regression models were built using a step-down method, where all predictors were initially included (model 1). This was decided based on the theory of the QHOM underpinning this research, where multiple concepts have relationships to the outcome, none seemingly more than the others. The unique contribution of each predictor variable for a given model was then evaluated. One predictor variable with the least unique contribution to the model (i.e., the highest $p$-value) was removed, and the model was re-run. Regardless of the contribution of the AD predictor, it was the variable of interest and thus was never removed. The process of evaluating each predictor’s unique contribution and re-running the model was repeated until the AD variable alone was in the final model (model 4). This process yielded 4 models for each outcome variable. Model 1 was compared to model 2 using the difference between model chi-
square scores and degrees of freedom ($df$) in the Likelihood Ratio Test. A nonsignificant difference ($p > .01$) resulted in retention of the more parsimonious model (i.e., that model with the fewest predictors). The retained model was subsequently compared with model 3, and the process was repeated. This continued until all models had been evaluated and the most parsimonious model with statistical significance ($p < .01$) was retained (Appendix 1).

For the subgroup of individuals who received ICU care, multiple regression was conducted to evaluate the association between ADs and total ICU LOS. This was done in step-down fashion, with the removal of the least significant predictor, beginning with model 1. Once removed, the analysis was re-run. This process yielded four models. $F$ ratio comparisons were conducted between each model. A small $R^2$ change and associated nonsignificant $p$-value indicated no meaningful difference between the models. In contrast, large $R^2$ change with a significant $p$-value signified a meaningful change in the model as a result of the exclusion of a predictor. The most parsimonious model, without a significant $F$ ratio change, was retained (Appendix 2).

Congruence between the AD document and actual care received was analyzed by reviewing advance directive documents, describing and comparing the content to actual care received. A randomly selected subsample was chosen from those patients who had an AD present within the EHR. The scanned document for each patient was carefully reviewed, noting first, whether patients completed only the required boxes or added additional preferences. Additional preferences were reviewed in detail for content. Descriptive findings will be published in a forthcoming manuscript.
Limitations

Historical threats and social interaction threats may compromise internal validity (Tofthagen, 2012). There is no way to know what events occurred between admission and death that may have influenced the decisions made to proceed with or withhold aggressive care. Social interactions between patients, providers, friends, and family members that may have influenced care decisions will remain unknown. Moreover, there is the possibility that patients may be incorrectly categorized as having no AD if the patient or family did not bring in the document to be scanned into the EHR. The retrospective nature of this study limits analysis to only the available data thereby not allowing for control of all potential confounders that may impact the strength of the association between the predictor and outcome variables.

There are limitations that relate to the acquisition of the data. Comorbidities may have been incompletely documented or incorrectly entered into the EHR and may have limited complete control of covariates. During the timeframe of interest, there was a transition from ICD-9 to ICD-10 coding in the U.S. which may have impacted identification and categorization of comorbidities. Furthermore, given the known low rates of AD completion, it is possible that the rates in this sample were low enough to increase the risk of Type II error.

Finally, limiting participants to those who died within the hospital to the exclusion of those who were discharged to hospice facilities, home hospice, skilled nursing facilities, etc., limits the inferences that can be drawn from these findings. It is unknown whether this cohort of excluded patients would have demonstrated different patterns of decision-making related to the presence or absence of advance directives.
This limitation should be addressed in future research in order to develop appropriate interventional studies to improve ACP efforts.
Advance directives and intensity of care delivered to hospitalized older adults at the end-of-life

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Abstract

**Background:** Older adults prefer comfort over life-sustaining care. Decreased intensity of care is associated with improved quality of life at the end-of-life (EOL).

**Objective:** This study explored the association between advance directives (ADs) and intensity of care in the acute care setting at the EOL for older adults.

**Methods:** A retrospective, correlational study of older adult decedents ($N = 496$) was conducted at an academic medical center. Regression analyses explored the association between ADs and intensity of care.

**Results:** Advance directives were not independently predictive of aggressive care, but were independently associated with referrals to palliative care and hospice; however, effect sizes were small, and the timing of referrals was late.

**Conclusions:** The ineffectiveness of ADs to reduce aggressive care or promote timely referrals to palliative and hospice services, emphasizes persistent inadequacies related to inadequate EOL care. Research is needed to understand if this failure is provider-driven or a flaw in the documents themselves.

*Keywords:* acute care, advance directives, quality of life, end-of-life
Advance directives and intensity of care delivered to hospitalized older adults at the end-of-life

The rapid growth of the aging population places increased demands on an already strained healthcare system. Given the significant expenditures incurred by Medicare in the final year of life, the costs of providing ongoing care for patients who live longer with chronic, progressive disease will only rise. While advanced care planning (ACP) is effective in reducing unnecessary and unwanted care at the end-of-life (EOL), there is a lack of consistent evidence for the effectiveness of an advance directive (AD) to do the same.

Older adults prefer comfort over treatments that prolong life; however, 30% of Medicare expenditures are incurred in the final year of life, with half of these expenses resulting from acute hospitalizations. This inconsistency between patient preferences and delivery of high-technology, high-cost care suggests that care delivered near death may not promote quality of life at the EOL. Advanced care planning and ADs have been proposed as means to improve congruence with patients' preferences. Legislation through the Patient Self Determination Act (PSDA) aimed to increase AD documentation via mandates to acute care facilities. More recently, the Centers for Medicare and Medicaid recognized that financial incentives might motivate providers to more actively engage their patients in EOL discussions.

Advanced care planning is a process by which patients receive personalized education about their health conditions and are engaged in discussions of EOL preferences, while advance directives are formal documents expressing personal care preferences and identifying a designated surrogate decision-maker. Advanced care
planning is consistently associated with a reduction in aggressive care\textsuperscript{3,4,6}, increased hospice utilization \textsuperscript{4,6}, and improved quality of life at the EOL\textsuperscript{6}. However, for ADs, there is no consistent association between the presence of ADs and type of care received. Methodological limitations such as diagnosis specificity, lack of emphasis on the older adult population, and conflicting findings resulting from differences in data collection have contributed to disagreement on the impact of ADs. Much of the research narrowly targets oncology\textsuperscript{4,6,14,15}, heart failure\textsuperscript{16}, or critically ill patients\textsuperscript{15,17-19}, making it unclear if findings generalize to other populations. Additionally, most research includes all adults, neglecting the unique needs of the vulnerable older adult population. Finally, secondary data analyses using national datasets are limited based on available variables and have resulted in the use of patient surrogates for information on the presence or absence of an AD prior to death\textsuperscript{5,20-22}. Overwhelmingly, these proxy studies report the success of ADs to limit aggressive care at the EOL in contrast to studies in which the same data were retrieved directly from the electronic health record (EHR), which do not support this association\textsuperscript{15,17,18,23}. Further objective investigation of the influence ADs exert on care delivery is necessary in an effort to promote quality of life at the EOL for older adults.

The landmark SUPPORT study identified inadequacies within the ACP process\textsuperscript{24} and AD documentation\textsuperscript{25,26} that persists today\textsuperscript{8}. Inadequate documentation of ADs, both through low rates of completion and poor articulation of actual preferences, remains a persistent challenge for EOL care delivery\textsuperscript{8,14,18}. The impact of ADs on the intensity of care delivered to hospitalized older adults at the EOL is unknown. Before exhausting resources to increase AD documentation to improve ACP, it is essential to better understand the impact ADs exert on EOL care for older adults with multiple
comorbidities. The purpose of this study was to evaluate the relationship between the presence of a documented AD within the EHR and the intensity of care received by older adults in the acute care setting at the EOL.

**Theoretical Framework**

This study was guided by the Quality Health Outcomes Model (QHOM)\textsuperscript{27-29}. This dynamic model builds upon Donabedian’s structure-process-outcomes model\textsuperscript{30} and posits that patient outcomes are influenced by patient characteristics, system characteristics, and interventions. Its applicability to the acute care setting has been enhanced over time by revisions that consider the impact of interventions directly on patient outcomes and integrates both patient state and trait characteristics. For this study, the presence of an AD is the intervention, patient demographics are state and trait characteristics, and the intensity of care received at the EOL is the patient outcome. Figure 1 illustrates the concepts of the QHOM with the associated variables examined in this study.

**Methods**

**Study Design and Sample**

A retrospective, correlational study was conducted to explore the relationship between ADs and intensity of care at the EOL using the EHRs of older adult decedents from a large, tertiary access, level one trauma center in the Midwest United States. The sample included patients aged 65 and older, who died during a hospital admission between January 2014 and December 2016. Those who were on a solid organ transplant waiting list or had received a solid organ transplant in their terminal hospitalization were excluded as transplant patients must agree to accept all aggressive care as part of the
listing process and therefore would potentially bias study findings. Patients were also excluded if they were discharged to the inpatient hospice service where care was managed within the same hospital building by an outside hospice agency.

An a priori G-power analysis\(^1\) was conducted for a medium effect\(^2\) and indicated that a total sample of 485 people was necessary to detect a moderate effect with 80% power. Decedents were identified via an institutional self-service cohort discovery tool (i.e., an electronic data warehouse). Date of death was matched with the date of discharge to verify that death occurred during the terminal admission.

**Study Variables**

*Predictor variable*. The presence or absence of an AD, signed before the terminal hospital admission, either present in the medical record prior to admission or added to the EHR within 24 hours of admission, and retrievable from the EHR, served as the binary predictor variable (e.g., yes/no). If the patient signed an AD after hospital admission, this was coded as no.

*Outcome variables*. Variables for intensity of care were selected following an extensive literature review with the most common variables included in this study\(^3-6,15-18,20,22,23\). Outcome variables were differentiated into indicators of either aggressive or conservative care. Aggressive care measures were mechanical ventilation (MV), new initiation of artificial enteral nutrition, admission or transfer to the intensive care unit (ICU) and ICU length of stay, cardiopulmonary resuscitation (CPR), new dialysis including hemodialysis and continuous renal replacement therapy (CRRT), invasive procedures (i.e. bronchoscopy, paracentesis, thoracentesis, EGD, cardiac catheterization, balloon angioplasty, ERCP, endovascular embolization of vascular abnormalities,
cholecystostomy tube placement, chest tube placement, colonic stenting, intracranial pressure monitor placement, external ventricular drain, lumbar puncture, pacemaker and/or internal cardiac defibrillator placement, stem cell transplant, tracheostomy, permanent feeding tube placement, any general anesthesia surgeries), and the use of cardiovascular supports (e.g. vasopressors, intra-aortic balloon pump (IABP), extracorporeal membranous oxygenation (ECMO), or new placement of a ventricular access device (VAD)). Central lines and arterial lines were not considered invasive procedures due to their common use for monitoring in the critical care setting. Measures of conservative care were palliative care (PC) consultation, hospice referral, a do-not-resuscitate code status at death, and use of comfort care order sets.

Confounding variables. Data were collected for age, sex, race, ethnicity, and preexisting comorbidities based on the QHOM underpinnings of this study. The Charlson Comorbidity Index (CCI)\textsuperscript{33,34} was used to measure comorbid conditions. This is an established measure of predicting one-year mortality based on chronic disease and age, with a higher CCI score predicting a higher risk of death. It has been validated in acute care populations including oncology\textsuperscript{35}, emergency medicine\textsuperscript{36}, stroke\textsuperscript{37}, and advanced organ failure\textsuperscript{38}. Additionally, its predictive ability has remained consistent from International Classification of Diseases, version 9 (ICD-9)\textsuperscript{39} to ICD-10\textsuperscript{40-42}.

Data Collection

An institutional self-service cohort discovery tool was used to identify potential patients guided by the following inclusion criteria: age $\geq 65$, deceased, inpatients, and institution. This search yielded 1181 potential subjects. All subjects that did not die
during hospital admission were excluded. The final sample was determined using computerized random selection.

Data were abstracted from the institutional EHR. Every medical record was searched by the author M.T. for each variable of interest and subsequently logged onto a data collection form, identified only by a unique study identifier. Separately, ten percent of data forms were audited by the author J.G for data extraction accuracy.

**Statistical Analysis**

Logistic regression was performed to evaluate the association of predictors with care received in the acute care setting at the EOL. The significance level was set to $\alpha < .01$ to minimize the risk of Type I error throughout the analysis. Rejection of the null hypothesis for any model indicated that the model was able to differentiate between those who did and did not receive the outcome of interest. All analyses were conducted using SPSS, v24\textsuperscript{43}. Modeling began with all four predictor variables (advance directive, age, CCI, and sex) in an intentional, step-down fashion. Predictors for subsequent models were individually removed, based on the statistical significance of their unique contribution to a given model, and the model was re-run with the remaining predictors. This process yielded four models for each outcome variable. Beginning with model 1, containing all predictor variables, models were individually compared using the chi-square and degrees of freedom, for a Likelihood Ratio Test (LRT). A non-significant difference between the two models resulted in retention of the more parsimonious model. This model was then compared to the next model, and so forth, until the most parsimonious model was identified. Model comparisons are summarized in Table 5 and
Table 6. The variance explained by each overall model is reported using Nagelkerke’s pseudo-$R^2 (R_{pseudo}^2)$.

Multiple regression was performed to evaluate the impact of predictor variables on the continuous outcome variable, total ICU LOS, for the subgroup of patients who received ICU care. Modeling was again conducted in an intentional, step-down fashion, removing predictors based on the statistical significance of their unique contribution to a given model, yielding four models. An evaluation was then conducted using $F$ ratio comparisons between each model. A small $R^2$ change coupled with a nonsignificant $p$-value indicated no meaningful difference between the models, whereas a large $R^2$ change and associated significant $p$-value indicated a meaningful change in the model as a result of the exclusion of a predictor. The most parsimonious model, without a significant $F$ ratio change, was retained. It is important to note that the presence of an advance directive was the predictor variable of interest for all outcome variables. Thus this predictor was never removed from the model, regardless of statistical significance with the outcome variables. Logistic regression and multiple regression models are summarized in Table 3 and Table 4, respectively.

Race and ethnicity were excluded as predictors for two reasons. There was an overrepresentation of Caucasians and underrepresentation of all other groups in the sample population relative to the local demographics of the general population\textsuperscript{44}. Additionally, there were a number of patients that were documented within the EHR as “unknown” for race and ethnicity, which would have been analyzed as missing data. Categories for both race and ethnicity were assigned by the healthcare organization from which data were obtained, and therefore it was not possible to retrieve these missing data.
The standardized residuals of CCI, removing the effect of age, served as the CCI variable in all analyses thus eliminating the correlation between age and CCI that was present in preliminary analyses. Descriptive analyses revealed a small number of patients had received CRRT, and therefore, these cases were combined with individuals who received new hemodialysis. Likewise, tracheostomy \((n = 12)\), new feeding tube \((n = 18)\), and other invasive procedures \((n = 204)\) were merged into one invasive procedures outcome variable. Finally, detailed analyses of descriptive data revealed that those patients who received ECMO, IABP, or VAD therapies were already captured within the variable, vasopressors. Analyses of those therapies were subsequently excluded. Probabilities for differences in outcomes associated with ADs are reported regardless of the statistical significance of the AD predictor in the model to report all associations identified between ADs and care delivered.

**Ethical Considerations**

This study was approved by the Medical College of Wisconsin institutional review board and the Froedtert Hospital Office of Clinical Research and Innovative Care Compliance. All data remained password protected.

**Results**

Nine hundred fifty-nine patients met inclusion criteria, and 496 cases were randomly selected for data abstraction and analysis. Demographic characteristics (Table 1) and breakdown of comorbidity burden and outcome variables (Table 2) are presented. Mean ages for women and men were 79.59 ± 8.44 \((n = 242)\) and 77.51 ± 8.61 \((n = 254)\), respectively. 46.8\% of decedents \((n = 232)\) had some form of AD present within their medical record within the first 24 hours of admission, which was not significantly
different among men and women, $\chi^2(1) = 2.514, p = .113$ (Table 1). The explained variances of each retained model are presented in Figure.

**Dialysis**

The null hypothesis was rejected for the model containing AD and age, $\chi^2(2) = 28.855, p < .001, R_{Pseudo}^2 .092$, indicating that the model was able to differentiate between those who did and did not receive a form of new dialysis. Only age, $OR 0.925, 95\% CI [0.896, 0.954], p < .001$, made a significant contribution to the model (Table 3). For a patient of mean age 78.5 years with no AD, the probability of receiving new dialysis was 0.1687. Holding AD status constant, for each one-year increase in age, the probability of receiving new dialysis decreased by 7.5%. Holding age constant, patients with an AD were 10.5% less likely to receive any form of new dialysis, $OR 0.895, 95\% CI [0.556, 1.441], p = .648$.

**Invasive Procedures**

The null hypothesis was rejected for the model including AD and age, $\chi^2(2) = 31.912, p < .001, R_{Pseudo}^2 .084$, indicating that the model differentiated between those who did and did not undergo an invasive procedure. Only age, $OR 0.943, 95\% CI [0.923, 0.965], p < .001$, made a significant contribution to the model. The patient of average age ($M = 78.5$) with no AD had a probability of 0.4472 of undergoing an invasive procedure. For each one year older, the likelihood of undergoing an invasive procedure decreased by 5.7%. In turn, holding age constant, those patients with an AD were 25.5% less likely to undergo an invasive procedure, $OR 0.745, 95\% CI [0.514, 1.080], p = .120$. 
Mechanical Ventilation

The null hypothesis was rejected for the model that included AD, age, and CCI, \( \chi^2(3) = 55.634, p < .001, R_{\text{pseudo}}^2 .145 \), indicating that the model was able to differentiate between those who did and did not receive mechanical ventilation. Both age, \( OR 0.932, 95\% \text{ CI } [0.911, 0.954], p < .001 \); and CCI, \( OR 0.765, 95\% \text{ CI } [0.628, 0.931], p < .001 \), made significant contributions to the model. The probability of receiving mechanical ventilation was 0.6889 without an advance directive in the patient of average age and comorbidity burden. With all other variables held constant, both age and comorbidity burden decreased the probability of receiving mechanical ventilation, 6.8% and 23.5%, respectively. Holding both age and CCI constant, patients with an AD were 38% less likely to receive mechanical ventilation, \( OR 0.620, 95\% \text{ CI } [0.419, 0.918], p = .017 \).

Artificial Nutrition

The null hypothesis was rejected for modeling with AD and age, \( \chi^2(2) = 9.979, p = .007, R_{\text{pseudo}}^2 .028 \), indicating that the model was able to differentiate between those who did and did not receive artificial nutrition. In the absence of an AD, the probability of receiving artificial nutrition was 0.3080 for patients of average age. Only age made a significant contribution to the model, where each one-year increase in age predicted a 3.6% decrease in the likelihood of receiving artificial enteral nutrition (\( OR 0.964, 95\% \text{ CI } [0.942, 0.987], p = .002 \)). Patients with an AD were 2.8% more likely to have artificial nutrition initiated, \( OR 1.028, 95\% \text{ CI } [0.699, 1.512], p = .889 \).

Cardiovascular Support

Modeling containing AD and age rejected the null hypothesis, \( \chi^2(2) = 47.315, p < .001, R_{\text{pseudo}}^2 .121 \), indicating that the model was able to differentiate between those who
did and did not receive CV supports (i.e., vasopressors). Patients of average age without an AD had a probability of 0.5413 of receiving CV supports. Age was the only predictor that made a significant contribution to the overall model, \( OR = 0.930, 95\% CI [0.910, 0.952], p < .001 \). Holding AD status constant, each one-year increase in age decreased the probability of receiving CV supports by 7%. Conversely, when age held constant, patients with an AD were 25% less likely to receive CV supports, \( OR = 0.750, 95\% CI [0.515, 1.087], p = .128 \).

**Admission or Transfer to the ICU**

The model containing AD and age rejected the null hypothesis, \( \chi^2(2) = 15.197, p = .001 \), \( R_{pseudo}^2 = .054 \), indicating that the model was able to differentiate between those who did and did not receive ICU care. The patient of average age had a probability of 0.8928 of receiving care in an ICU in the absence of an AD. Age made a significant contribution to the model, where holding AD status constant, each one-year increase in age decreased the probability of receiving ICU care by 5% (\( OR = 0.950, 95\% CI [0.922, 0.980], p = .001 \)). Holding age constant, those patients with an AD were 35.3% less likely to receive care in an ICU, \( OR = 0.647, 95\% CI [0.383, 1.091], p = .102 \).

**Comfort Care Order Sets**

Modeling with only the AD predictor was the most parsimonious model, however, was not able to reject the null hypothesis, \( \chi^2(1) = 3.076, p = .079 \), \( R_{pseudo}^2 = .008 \), indicating that the model was inadequate, and no predictors made a meaningful contribution to predict who received comfort care order sets. The probability of having comfort care order set initiated was 0.5606. Patients with an AD were 38.1% more likely to have the comfort care order set utilized, \( OR = 1.381, 95\% CI [0.962, 1.983], p = .080 \).
Cardiopulmonary Resuscitation

For cardiopulmonary resuscitation (CPR), modeling with AD and age rejected the null hypothesis, $\chi^2(2) = 16.792, p < .001, R^2_{\text{pseudo}} = .052$, indicating that the model was able to differentiate between those who did and did not receive CPR. The probability of receiving CPR for the average age patient without an AD was 0.2453. Each one-year increase in age, holding AD status constant, decreased the probability of receiving CPR by 4.1%, OR 0.959, 95% CI [0.934, 0.985], $p = .002$. Holding age constant, those patients with an AD were 49.9% less likely to receive CPR, OR 0.581, 95% CI [0.370, 0.912], $p = .018$.

Code Status at Time of Death

There were no predictors that contributed to a model that was able to reject the null hypothesis for the outcome of code status at death. The model containing the AD predictor was the most parsimonious, $\chi^2(1) = 5.281, p = .022, R^2_{\text{pseudo}} = .021$. The probability of being a full code (full resuscitative efforts with CPR) was 0.1364. Patients with ADs were half as likely to be a full code, OR 0.501, 95% CI [0.273, 0.918], $p = .025$.

Palliative Care Consultation

Modeling for palliative care consultation demonstrated that the AD predictor alone produced the most parsimonious model, $\chi^2(1) = 7.860, p = .005, R^2_{\text{pseudo}} = .022$. The probability of receiving a palliative care consultation was 0.2349. An advance directive was associated with a 74.8% increased likelihood of a palliative care consultation, OR 1.748, 95% CI [1.181, 2.587], $p = .005$. 
Palliative care consultation was the first outcome variable to demonstrate a significant association with the AD predictor. Additional analysis was performed to describe the mean difference in the number of days before death of palliative care consultation by AD presence. A $t$-test, equal variances assumed, failed to identify a mean difference between the presence ($n = 80, M = 4.39, s = 5.328$) or absence ($n = 62, M = 3.79, s = 6.135$) of an advance directive and the number of days prior to death that palliative care was consulted, $t (140) = 0.620, p = .536, \alpha < .01, d = 0.104$.

**Hospice Referral**

The advance directive predictor contributed to the most parsimonious model for the hospice referral outcome variable, $\chi^2 (1) = 11.572, p = .001, R_{pseudo}^2 .033$. The probability of receiving a hospice referral was 0.2236, and patients with an AD were 97.2% more likely to receive a hospice referral, $OR 1.972, 95\% CI [1.329, 2.925], p = .001$.

Additional analysis was conducted to describe the mean difference in the number of days prior to death of hospice referral by AD. The $t$ test, with equal variances assumed, did not identify a mean difference between the presence ($n = 85, M = 3.32, s = 3.364$) or absence ($n = 59, M = 3.46, s = 6.516$) of an advance directive and the number of days prior to death of hospice referral, $t (142) = 0.168, p = .866, \alpha < .01, d = 0.027$.

**Total ICU Length of Stay**

For the subgroup of individuals who received ICU care ($n = 426$), multiple regression was conducted to predict total ICU LOS based on the presence of an AD, age, CCI, and sex. The most parsimonious model included only the AD and age predictors. The regression model was able to reject the null hypothesis, $F(2, 424) = 8.352, p < .001$, ...
$R^2 = .038$. In the absence of an AD, the patient of average age spent 4.8 days in the ICU. Total ICU LOS was 0.11 days longer for those patients with an AD, $p = .856$. Older patients had shorter lengths of stay – each year older decreased LOS by 0.15 days, $p < .001$.

**Discussion**

The purpose of this study was to evaluate the relationship between advance directives and the intensity of care received by older adults in the acute care setting at the EOL. This study found no support for the effectiveness of ADs to independently minimize aggressive care at the EOL, and while ADs were associated with increased referrals to palliative care and hospice, they did not impact early initiation of these services.

Advance directives were not independently associated with any measure of aggressive care at the EOL. Any effect ADs exerted toward aggressive treatments was influenced by age, and in the case of mechanical ventilation, by comorbidity burden as well. This is not a unique finding\textsuperscript{15,23,45}, and it begs the question ‘Are ADs effective in their current form?’ Preferences may not be documented with enough detail to guide care at the EOL. If care decisions are more impacted by aging and increased chronic illness, perhaps efforts would best be spent targeting that population with ACP interventions to accomplish improved documentation of preferences within ADs.

Advanced care planning decreases aggressive care\textsuperscript{4,5} in a way that promotes quality of life at the EOL\textsuperscript{6}. Harnessing that success may be a necessary component of improving the effectiveness of ADs to decrease aggressive care. The practice of simply following
the PSDA requirements of providing the bare minimum AD information should no longer be the standard of care.

It would be a mistake to interpret rejection of null hypotheses as having any meaningful clinical value. No model explained more than 14.5% of the variance in any outcome variable, and half of the models explained 5% or less. Simply because a model is able to reject the null hypothesis does not independently determine the measure of the model’s usefulness⁴⁶. The American Statistical Association has endorsed the abandonment of dependence solely upon $p$-value significance testing⁴⁶. Clinical significance reflects a change in the outcome variable that is meaningful to patient outcomes⁴⁷. This study was unable to reject the null hypotheses for predictive models of aggressive care received by patients with or without ADs. This is not, per se, an indication that ADs are ineffective, but rather an indication that their benefits to reduce high-technology, high-cost care may not be fully realized. Although the effect sizes were small, individuals with an AD were less likely to receive ICU care, new dialysis, invasive procedures, mechanical ventilation, cardiovascular supports, CPR, and were more likely to receive palliative and hospice referrals. This suggests that ADs are beneficial to reduce aggressive care, but that more can be done to optimize these benefits to make a clinically meaningful impact on EOL care.

The low overall variance in the outcome variables explained in this study may be, in part, a result of extraneous variables that were unknown or not considered in study models. Retrospective studies, by their nature, are incapable of capturing the context in which EOL decision-making occurs in addition to other influences, such as severity of illness, socioeconomic factors, cultural values and beliefs, support systems, and surrogate
selection. In situations where surrogates must make difficult decisions, known patient preferences and values can often be at odds with surrogates’ own needs and desires to avoid perceived responsibility for a loved one’s death. The inability of surrogates to separate their own interests from those of patients may play a role in decisions made at the EOL, which suggests while documentation of patient preferences is important, communication of those preferences to surrogates and loved ones is essential. Future studies using prospective design are needed to capture these simultaneously occurring extraneous variables.

The proportion of patients with advance directives (46.8%) is consistent with studies methodologically grounded in objective data from the EHR as opposed to a proxy report of AD presence. Careful attention to methodology when reviewing studies in this area is essential. Studies that secure data from surrogate decision-makers tend to be more optimistic regarding the effectiveness of ADs to both minimize aggressive care and promote care that is congruent with patient preferences. Poor awareness of these differences may encourage a false sense of security in documents that may not be effective in their current form.

The inability of this study to establish an independent association between ADs and intensity of care received at the EOL may have been influenced by providers’ inadequacies with regards to ACP. In demonstrating persistently low rates of AD documentation, this study provides additional evidence for the need to increase documentation of patient preferences. Lack of documentation leads to inadequately communicated preferences between patients and their families and increased decisional conflict. Providers have a responsibility to engage with patients and their families, who
want to have EOL discussions\textsuperscript{50}. The trust that patients place in their providers\textsuperscript{51,52} creates opportunities for ACP. Yet all too often, these conversations do not occur\textsuperscript{43,54} and preferences are not documented. Whether patients’ ADs request limits in treatment or all interventions possible, providers are influenced by written preferences\textsuperscript{55}. More must be done in medical and nursing schools to prepare providers to engage in these difficult conversations with a sense of comfort and confidence\textsuperscript{56,57}.

The unique influence of ADs was only present for palliative care consults and hospice referrals; however, the effect sizes were small, potentially related to the smaller number of patients who received these referrals (\(n=143\)) or the delay in requesting them. While the benefit of these services has been previously described\textsuperscript{58}, the current study emphasizes that simply demonstrating an increased number of consultations and referrals with ADs is not enough. Aggressive care was not significantly reduced in the sample overall, and referrals to both palliative care and hospice were late, regardless of AD status. The benefits of early palliative and hospice referrals\textsuperscript{59,60} are overlooked by providers, who may perceive the initiation of these services as failure\textsuperscript{61,62}. Palliative care is an underutilized service that, when integrated within the acute care setting, reduces costs and more importantly, improves the dying process\textsuperscript{63,64}. Additionally, hospice referral more than three days before death is associated with higher quality of death\textsuperscript{7,65}. Changing the culture within healthcare that tends to avoid these services is a major undertaking but a necessary step toward improving EOL care\textsuperscript{8}.

**Limitations**

The exclusion of those who died in hospice may have limited the breadth of data retrieved for assessing the influences of ADs on EOL care decisions. This applies, as
well, to the exclusion of those patients who died outside of the hospital. By only including individuals who died during their hospitalization, extraneous variables that contributed to decision-making within the acute care setting, as previously discussed, may not have been captured.

Those patients who signed an AD document after admission were excluded under the assumption that ACP discussions did not occur until after admission. However, discussions, without formal documentation of preferences, may have occurred well in advance of hospitalization. Likewise, patients without an AD in the EHR were coded as not having an AD. The absence of an AD in the EHR does not in and of itself indicate that there is no AD document or that no ACP discussions have occurred. A prospective study that can elicit the timing of discussions and preferences from patients and families could overcome these limitations and should be considered in future studies.

This study had no access to electronic health records that were held by outside healthcare organizations due to the legal agreement between institutions regarding the use of shared healthcare records. It is unknown if patients who were categorized as having no AD may have had one filed within another healthcare system or whether providers, at the time of the patient’s care, had access to outside records that included an AD.

Finally, this study used a convenience sample at a local medical center, and single-center studies limit generalizability to other settings and locations. Additionally, this hospital system does not currently have a robust, system-wide ACP process in place. Finally, as a large, urban, tertiary medical center, it was anticipated that the population would represent the larger urban community; however, the racial composition of this convenience sample was not found to be representative of the surrounding area.
Caucasian patients were overrepresented with minority underrepresentation, most significant among Hispanic patients. No conclusions could be drawn related to the influence of race and ethnicity relative to ADs and intensity of care received.

**Implications**

If advance directives are ineffective in their current form to decrease aggressive care in the acute care setting, understanding better how providers utilize these documents requires further study. Are ADs routinely reviewed by physicians and advanced practice providers? Are documents reviewed only when a patient is incapacitated, or are they interwoven into the fabric of routine decision-making with decisional patients? Do providers encourage family members and surrogate decision-makers to adhere to documented preferences or are they fearful of litigation if they fail to appease decision-makers? Further illumination of how ADs are utilized or if ADs must be crafted in a way that better directs care through more specific instructions and better attention to detail should be considered before designing interventions to improve congruence between patient wishes and EOL care. The SUPPORT study raised concerns regarding the specificity of AD documents as a barrier to their utility. Further research should ascertain if this remains the case, and if so, investigate the novel intervention that may ultimately remedy that impediment.

What is the ultimate goal of an advance directive? Healthcare providers must come together to clarify this question. Perhaps a shift in the philosophy of ACP is necessary to refocus on what matters. Engagement in dialogue may be the key to improving EOL care, with ADs serving as a tool to illustrate that conversations have occurred rather than as a document completed out of context. With the recent changes
from the Centers for Medicare and Medicaid, providers should consider an increased focus on ACP with patients. Advanced practice nurses would be ideal in this role, employing the tools of nursing praxis in combination with the autonomy of advanced practice to begin normalizing EOL discussions and planning with both patients and their families.

The current healthcare climate is increasingly focused on translational science and interprofessional education and collaboration. Physicians, advanced practice providers, and social workers can work collaboratively to focus efforts on improving ACP and AD documentation. Future research should consider these disciplines when developing targeted interventional studies toward improving ACP and increasing the completion of meaningful ADs that are practical and applicable to bedside providers.

Conclusion

Our healthcare and legal systems have placed a high value on creating a formal AD; however, this value may ultimately be misplaced. This study’s findings mirror others who have failed to consistently confirm the effectiveness of ADs to reduce aggressive care. The time has come for attitudes to shift from document completion for the sake of fulfilling a legislative mandate to increasing efforts to improve the meaningfulness and usefulness of ADs as a reflection of the ACP process. Efforts to improve the quality of EOL care must begin with the acknowledgment that the current system is ineffective to achieve our stated goals to open the door for multidisciplinary discussions aimed to improve quality of life at the EOL.
References


Table 1

Demographic Characteristics

<table>
<thead>
<tr>
<th>Subjects, N (%)</th>
<th>496 (100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>women</td>
<td>252 (48.8)</td>
</tr>
<tr>
<td>men</td>
<td>254 (51.2)</td>
</tr>
</tbody>
</table>

| Age, M (SD) | total 78.52 (8.58) |
|            | women 79.59 (8.44) |
|            | men 77.51 (8.61) |

<table>
<thead>
<tr>
<th>Marital Status, n</th>
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<tbody>
<tr>
<td>Married</td>
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<tr>
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</tr>
<tr>
<td>Widowed</td>
</tr>
<tr>
<td>Divorced</td>
</tr>
<tr>
<td>Legally Separated</td>
</tr>
<tr>
<td>Significant Other</td>
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<tr>
<td>Unknown</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Race, n</th>
</tr>
</thead>
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<tr>
<td>White or Caucasian</td>
</tr>
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<td>Black or African American</td>
</tr>
<tr>
<td>Hispanic</td>
</tr>
<tr>
<td>Asian</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
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<tr>
<td>Other</td>
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<tr>
<td>Unknown</td>
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</table>

<table>
<thead>
<tr>
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<td>Hispanic</td>
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<tr>
<td>Unknown</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Advance Directives on file, n (%)</th>
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</tr>
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<tr>
<td>women</td>
<td>110 (43.7)</td>
</tr>
<tr>
<td>men</td>
<td>122 (48.0)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Types of Advance Directives, n</th>
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<tr>
<td>POA-HC</td>
</tr>
<tr>
<td>LW</td>
</tr>
<tr>
<td>POA-HC and LW</td>
</tr>
<tr>
<td>State DNR</td>
</tr>
<tr>
<td>SNF Form</td>
</tr>
</tbody>
</table>

POA-HC, Power of Attorney for Healthcare; LW, Living Will; DNR, Do Not Resuscitate; SNF, Skilled Nursing Facility
Table 2

Comorbidity Burden and Outcome Variable Distributions Among Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
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</thead>
<tbody>
<tr>
<td><strong>Outcome Variables, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Dialysis</td>
<td>90 (18.1)</td>
</tr>
<tr>
<td>Invasive Procedures</td>
<td>208 (41.9)</td>
</tr>
<tr>
<td>Mechanical Ventilation</td>
<td>310 (62.5)</td>
</tr>
<tr>
<td>Artificial enteral nutrition</td>
<td>156 (31.5)</td>
</tr>
<tr>
<td>Cardiovascular Support</td>
<td>252 (50.8)</td>
</tr>
<tr>
<td>Admission or Transfer to ICU</td>
<td>427 (86.1)</td>
</tr>
<tr>
<td>Comfort Care Order Set</td>
<td>296 (59.7)</td>
</tr>
<tr>
<td>Cardiopulmonary Resuscitation</td>
<td>105 (21.2)</td>
</tr>
<tr>
<td>Code Status at Death (DNR)</td>
<td>353 (71.2)</td>
</tr>
<tr>
<td>Palliative Care Consultation</td>
<td>143 (28.8)</td>
</tr>
<tr>
<td>Hospice Referral</td>
<td>143 (28.8)</td>
</tr>
<tr>
<td><strong>Comorbidity Burden, n</strong></td>
<td></td>
</tr>
<tr>
<td>Acute MI</td>
<td>56</td>
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<tr>
<td>Cerebrovascular Disease</td>
<td>127</td>
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<tr>
<td>Chronic Pulmonary Disease</td>
<td>137</td>
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<tr>
<td>Connective Tissue Disease</td>
<td>29</td>
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<tr>
<td>Dementia</td>
<td>71</td>
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<tr>
<td>Heart Failure</td>
<td>166</td>
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<tr>
<td>Mild Liver Disease</td>
<td>22</td>
</tr>
<tr>
<td>Any non-metastatic malignancy</td>
<td>115</td>
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<tr>
<td>Diabetes without Complications</td>
<td>113</td>
</tr>
<tr>
<td>Diabetes with complications</td>
<td>38</td>
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<tr>
<td>Hemi- or Paraplegia</td>
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<tr>
<td>HIV/AIDS</td>
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<tr>
<td>Metastatic Solid Tumor</td>
<td>57</td>
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<tr>
<td>Moderate or Severe Liver Disease</td>
<td>8</td>
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<tr>
<td>Renal Disease</td>
<td>153</td>
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<tr>
<td>Peptic Ulcer Disease</td>
<td>30</td>
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<tr>
<td>Peripheral Vascular Disease</td>
<td>101</td>
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Table 3

Logistic Regression Models of Intensity of Care Outcome Variables

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Predictors</th>
<th>$B$</th>
<th>$SE$</th>
<th>Wald</th>
<th>$df$</th>
<th>$p$</th>
<th>OR</th>
<th>95% CI</th>
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</thead>
<tbody>
<tr>
<td>Dialysis</td>
<td>Advance directive</td>
<td>-0.111</td>
<td>0.243</td>
<td>0.208</td>
<td>1</td>
<td>.648</td>
<td>0.895</td>
<td>[0.556, 1.441]</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>-0.078</td>
<td>0.016</td>
<td>24.532</td>
<td>1</td>
<td>&lt; .001</td>
<td>0.925</td>
<td>[0.896, 0.954]</td>
</tr>
<tr>
<td></td>
<td>(Intercept)</td>
<td>-1.596</td>
<td>0.171</td>
<td>87.307</td>
<td>1</td>
<td>&lt; .001</td>
<td>0.203</td>
<td></td>
</tr>
<tr>
<td>Invasive Procedures</td>
<td>Advance directive</td>
<td>-0.294</td>
<td>0.189</td>
<td>2.420</td>
<td>1</td>
<td>.120</td>
<td>0.745</td>
<td>[0.514, 1.080]</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>-0.058</td>
<td>0.011</td>
<td>26.056</td>
<td>1</td>
<td>&lt; .001</td>
<td>0.943</td>
<td>[0.923, 0.965]</td>
</tr>
<tr>
<td></td>
<td>(Intercept)</td>
<td>-0.213</td>
<td>0.128</td>
<td>2.770</td>
<td>1</td>
<td>.096</td>
<td>0.809</td>
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<td>Mechanical Ventilation</td>
<td>Advance directive</td>
<td>-0.477</td>
<td>0.200</td>
<td>5.704</td>
<td>1</td>
<td>.017</td>
<td>0.620</td>
<td>[0.419, 0.918]</td>
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<tr>
<td></td>
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<td>0.012</td>
<td>34.610</td>
<td>1</td>
<td>&lt; .001</td>
<td>0.932</td>
<td>[0.911, 0.954]</td>
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<td></td>
<td>CCI</td>
<td>-0.268</td>
<td>0.100</td>
<td>7.119</td>
<td>1</td>
<td>.008</td>
<td>0.765</td>
<td>[0.628, 0.931]</td>
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<td></td>
<td>(Intercept)</td>
<td>0.795</td>
<td>0.140</td>
<td>32.157</td>
<td>1</td>
<td>&lt; .001</td>
<td>2.214</td>
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<td>Artificial Nutrition</td>
<td>Advance directive</td>
<td>0.028</td>
<td>0.197</td>
<td>0.020</td>
<td>1</td>
<td>.889</td>
<td>1.028</td>
<td>[0.699, 1.512]</td>
</tr>
<tr>
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<td>Age</td>
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<td>&lt; .001</td>
<td>0.964</td>
<td>[0.942, 0.987]</td>
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<tr>
<td></td>
<td>(Intercept)</td>
<td>-0.810</td>
<td>0.135</td>
<td>35.994</td>
<td>1</td>
<td>&lt; .001</td>
<td>0.445</td>
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<tr>
<td>Cardiovascular Support</td>
<td>Advance directive</td>
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<td>0.189</td>
<td>2.311</td>
<td>1</td>
<td>.128</td>
<td>0.750</td>
<td>[0.517, 1.087]</td>
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<td>Age</td>
<td>-0.072</td>
<td>0.011</td>
<td>39.373</td>
<td>1</td>
<td>&lt; .001</td>
<td>0.930</td>
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</tr>
<tr>
<td></td>
<td>(Intercept)</td>
<td>0.166</td>
<td>0.129</td>
<td>1.645</td>
<td>1</td>
<td>.200</td>
<td>1.180</td>
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<tr>
<td>Admission or Transfer to ICU</td>
<td>Advance directive</td>
<td>-0.436</td>
<td>0.267</td>
<td>2.673</td>
<td>1</td>
<td>.102</td>
<td>0.647</td>
<td>[0.383, 1.091]</td>
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<tr>
<td></td>
<td>Age</td>
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<td>0.016</td>
<td>10.820</td>
<td>1</td>
<td>&lt; .001</td>
<td>0.950</td>
<td>[0.922, 0.980]</td>
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<td></td>
<td>(Intercept)</td>
<td>2.119</td>
<td>0.201</td>
<td>111.361</td>
<td>1</td>
<td>&lt; .001</td>
<td>8.326</td>
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<tr>
<td>Comfort Care Orderset Use</td>
<td>Advance directive</td>
<td>0.323</td>
<td>0.184</td>
<td>3.061</td>
<td>1</td>
<td>.080</td>
<td>1.381</td>
<td>[0.962, 1.983]</td>
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<tr>
<td></td>
<td>(Intercept)</td>
<td>0.244</td>
<td>0.124</td>
<td>3.860</td>
<td>1</td>
<td>.049</td>
<td>1.276</td>
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<tr>
<td>Received CPR</td>
<td>Advance directive</td>
<td>-0.544</td>
<td>0.231</td>
<td>5.559</td>
<td>1</td>
<td>.018</td>
<td>0.581</td>
<td>[0.370, 0.912]</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>-0.042</td>
<td>0.014</td>
<td>9.161</td>
<td>1</td>
<td>&lt; .001</td>
<td>0.959</td>
<td>[0.934, 0.985]</td>
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<tr>
<td></td>
<td>(Intercept)</td>
<td>-1.123</td>
<td>0.146</td>
<td>59.540</td>
<td>1</td>
<td>&lt; .001</td>
<td>0.325</td>
<td></td>
</tr>
<tr>
<td>Code Status at Death</td>
<td>Advance directive</td>
<td>-0.692</td>
<td>0.309</td>
<td>5.001</td>
<td>1</td>
<td>.025</td>
<td>0.501</td>
<td>[0.273, 0.918]</td>
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<tr>
<td></td>
<td>(Intercept)</td>
<td>-1.846</td>
<td>0.179</td>
<td>105.929</td>
<td>1</td>
<td>&lt; .001</td>
<td>0.158</td>
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<td>Palliative Care Consult</td>
<td>Advance directive</td>
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<td>0.200</td>
<td>7.783</td>
<td>1</td>
<td>.005</td>
<td>1.748</td>
<td>[1.181, 2.587]</td>
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<td>(Intercept)</td>
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<td>0.145</td>
<td>66.182</td>
<td>1</td>
<td>&lt; .001</td>
<td>0.307</td>
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<tr>
<td>Hospice Referral</td>
<td>Advance directive</td>
<td>0.679</td>
<td>0.201</td>
<td>11.389</td>
<td>1</td>
<td>.001</td>
<td>1.972</td>
<td>[1.329, 2.925]</td>
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<td></td>
<td>(Intercept)</td>
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<td>71.067</td>
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<td>&lt; .001</td>
<td>0.288</td>
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Table 4

*Multiple Regression Model for Total ICU Length of Stay Outcome Variable*

<table>
<thead>
<tr>
<th>Predictors</th>
<th>$b$</th>
<th>$SE_b$</th>
<th>$\beta$</th>
<th>$t$</th>
<th>$p$</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total ICU LOS (Intercept)</td>
<td>4.802</td>
<td>0.426</td>
<td>11.283</td>
<td>&lt; .001</td>
<td>[3.965, 5.638]</td>
<td></td>
</tr>
<tr>
<td>Advance Directive</td>
<td>0.114</td>
<td>0.626</td>
<td>0.009</td>
<td>0.182</td>
<td>.856</td>
<td>[-1.116, 1.344]</td>
</tr>
<tr>
<td>Age</td>
<td>-0.148</td>
<td>0.036</td>
<td>-0.195</td>
<td>-4.078</td>
<td>&lt; .001</td>
<td>[-0.220, -0.077]</td>
</tr>
</tbody>
</table>

ICU, Intensive Care Unit; LOS, Length of Stay
Table 5

Logistic Regression Likelihood Ratio Test

<table>
<thead>
<tr>
<th>Model</th>
<th>$\chi^2$ (df)</th>
<th>$p_{model}$</th>
<th>$\Delta\chi^2$ (Δdf)</th>
<th>$p_{difference}$</th>
<th>Model</th>
<th>$\chi^2$ (df)</th>
<th>$p_{model}$</th>
<th>$\Delta\chi^2$ (Δdf)</th>
<th>$p_{difference}$</th>
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</thead>
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<td>.001</td>
<td>1.43 (1)</td>
<td>.2318</td>
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</tbody>
</table>

$\chi^2$, chi square; df, degrees of freedom; $p_{model}$, significance of the individual model; $\Delta\chi^2$, change in chi square between models; $\Delta df$, change in degrees of freedom between models; $p_{difference}$, significance of the $\Delta\chi^2$; ***, retained model.
# Table 6

**Multiple Regression Model Summary**

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<th>Model</th>
<th>R</th>
<th>R²</th>
<th>Adjusted R²</th>
<th>SE</th>
<th>ΔR²</th>
<th>ΔF</th>
<th>df₁</th>
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</table>

a. Predictors: Sex, CCI, Age, Advance Directive  
b. Predictors: CCI, Age, Advance Directive  
c. Predictors: Age, Advance Directive  
d. Predictors: Advance Directive  

Dependent Variable: Total ICU Length of Stay  
*** retained model
Figure 1. Study variables in the context of the QHOM
Figure 2. Percentage of variance explained by each retained model for each outcome variable
Advanced care planning, advance directives, and treatment intensity of hospitalized older adults: An integrative review

Marsha Helen Tyacke, PhD(c), MSN
Jill Guttormson, PhD, RN

Submitting for publication to Research and Theory for Nursing Practice
Abstract

**Background:** The older adult population continues to grow. Understanding individuals' preferences in the context of their current state of health may guide treatment and avoid unwanted or unnecessary care. Advanced care planning (ACP) and advance directives (ADs) may reduce aggressive care at the end-of-life (EOL) and facilitate care that is consistent with patient preferences.

**Purpose:** To examine the impact of ACP and ADs on intensity of care delivered in the acute care setting and the effectiveness of these mechanisms to promote care that is congruent with patient preferences at the EOL.

**Methods:** Using Medline and CINAHL, studies published from 1996-present and limited to adults were identified and included research studies that evaluated the association between ACP or ADs and intensity of care in the acute care setting.

**Results:** Twelve studies met inclusion criteria. Advanced care planning discussions and AD documentation remain low. Advanced care planning was associated with decreased treatment intensity and early hospice referrals. The association between ADs and intensity of care was inconsistent. Life-sustaining care was not always withheld, despite documented preferences for limitations in care. Most studies focused on oncology patients and few exclusively targeted older adults.

**Implications for Practice:** The benefits of ACP to minimize unwanted or aggressive care are well-defined; however, ADs are not consistently associated with reduced intensity of care. There is little research on whether ADs promote care that is congruent with patient preferences. Further research targeting older adults with chronic diseases is needed to improve understanding of AD utilization and the impact of ADs in the acute care setting.

**Keywords:** older adults, advanced care planning, advance directives, intensity of care, acute care
Advanced care planning, advance directives, and treatment intensity of hospitalized older adults: An integrative review

By 2030, older adults will comprise 20% of the U.S. population (Ortman, Velkoff, & Hogan, 2014). With this increase in the aging population, healthcare costs are a concern as approximately one-third of Medicare expenditures occur in the final year of life, primarily in the course of managing acute exacerbations of chronic, progressive conditions (Riley & Lubitz, 2010; The Kaiser Family Foundation, 2016). However, aggressive care may not be what older adults prefer (The Institute of Medicine, 2015; Wright et al., 2016). Increased participation in advanced care planning (ACP) and completion of advance directives (AD) have been proposed as mechanisms for reducing high-intensity care and promoting care that is congruent with patient preferences (The Institute of Medicine, 2015). Although ACP is associated with decreased healthcare utilization in a variety of adult populations and settings (Houben, Spruit, Groenen, Wouters, & Janssen, 2014), little is known about the impact of ACP and ADs for older adults within the acute care setting. Despite growing understanding of the potential value of ACP and a call to improve documentation of end-of-life (EOL) preferences, AD completion rates remain low (The Institute of Medicine, 2015). Before directing resources to increase documentation of patient preferences through ADs, in a climate with dynamic debate over the allocation of limited research funding and healthcare reimbursement, it is essential to understand the impact of ACP and ADs on the intensity of care provided to older adults within the acute care setting.

Aggressive care at EOL is in conflict with patients’ preferences as the literature suggests that older adults prefer comfort over aggressive care (Bischoff, Sudore, Miao,
Boscardin, & Smith, 2013; Yoo, Nakagawa, & Kim, 2013). Aggressive care can be defined as high technology, high-cost care including, but not limited to, critical care, mechanical ventilation, and dialysis (Levinsky, Yu, Ash, & et al., 2001). Given a choice, adults prefer to optimize quality of life (QOL) over the receipt of life-sustaining treatments; nevertheless, in the absence of known patient preferences, treatments goals aim to prolong life (The Institute of Medicine, 2015). Intensive care units (ICU) are often the destination of critically ill and acutely decompensating patients. However, older adult admissions to the ICU have been associated with longer overall hospital lengths of stay without a meaningful improvement in survival (Kim et al., 2016). Additionally, aggressive care at the EOL portends poor outcomes, including increased frequency of hospitalizations and in-hospital death (Grendarova, Sinnarajah, Trotter, Card, & Wu, 2015). Understanding older adults’ preferences in the context of their current state of health may help guide treatment and avoid unwanted or unnecessary care at the EOL. Advanced care planning and advance directives are two mechanisms that may promote achievement of this goal.

Advanced care planning is a dynamic process that includes the following four pillars: 1) integrating health and disease education, 2) considering management options, 3) making decisions, and 4) expressing them to others (National Institute on Aging, 2014; Schubart, Levi, Dellasega, Whitehead, & Green, 2014). Advance directives are tangible documents, including but not limited to living wills, powers of attorney for healthcare, and documented do not resuscitate (DNR) orders, that articulate care and treatment preferences in writing (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007). These documents provide formal mechanisms for expressing preferences for care but are not
synonymous with ACP, which is a dynamic process. Advanced care planning promotes discussions of expected disease trajectory in the context of multiple comorbidities and opens the door for revisiting these discussions as the disease progresses. In hospice patients, decreases in the frequency of hospitalizations, overall hospital length of stay, and overall costs of care have been associated with prior ACP (Abel, Pring, Rich, Malik, & Verne, 2013). Alongside ACP, advance directives have been promoted as mechanisms for improving care at the EOL and encouraging patient autonomy by ensuring preferences for care are documented. However, patient preferences continue to be inadequately communicated to providers and family members (Roger et al., 2015). Failure to document care preferences can lead to presumed consent for treatment (Kong et al., 2015; Stachura, Oberender, Bundscherer, & Wiese, 2015). The failure of patients and their families to meaningfully understand disease processes and/or trajectory may influence treatment decisions to accept ineffective care that negatively impacts QOL at the EOL. Both oncology and heart failure patients have been found to have an inadequate understanding of their illness and expected trajectories that affect EOL choices (Howie-Esquível & Dracup, 2012; Klindtworth et al., 2015; Mayland, Williams, Addington-Hall, Cox, & Ellershaw, 2013).

Concern for the effectiveness and quality of EOL care is nothing new and has sparked legislation to promote improvement. The Patient Self Determination Act (PSDA) was passed in 1990 in an effort to increase AD documentation by patients receiving care in hospitals, long-term care facilities or home health agencies (American Bar Association, 2016). Unfortunately, these mandates may not have been as effective as initially intended, as evidenced by the landmark SUPPORT study in the early nineties
and a more recent Institute of Medicine study. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) highlighted the persistently low rates of AD completion and the failure of ADs to impact decisions for cardiopulmonary resuscitation (CPR) or intensity of care delivered to hospitalized adults (Teno et al., 1994; Teno et al., 1997). Additionally, the investigators found that ADs were not associated with improved communication between patients, family members, and providers and had no impact on decision-making (The SUPPORT Principle Investigators, 1995). More recently, a report from The Institute of Medicine (2015) highlighted persistent failures in EOL care delivered in the U.S, including inadequate communication between patients, families, and providers, uncontrolled healthcare expenditures, and patients’ inadequate knowledge of the necessity of EOL planning. This long-term failure warrants further investigation to improve the care provided at the EOL.

The aging population continues to rapidly grow, requiring costly care that may not be consistent with preferences for comfort and optimization of QOL at the EOL. Advanced care planning and documentation of advance directives have been promoted as mechanisms to reduce costs, decrease high-intensity care, and promote care that is consistent with patient preferences. Given the The Institute of Medicine (2015) report suggesting more must be done to improve EOL care, improving the prevalence of ACP discussions and AD documentation would seem to be the logical next step; however, a better understanding of the impact of ACP and ADs on healthcare delivery at the EOL is essential prior to investing resources into increasing participation and must be further investigated.
Purpose

The purpose of this review is to examine the impact of advanced care planning and advance directives on both the intensity of care delivered in the acute care setting and the effectiveness of these mechanisms to promote care that is congruent with patient preferences at the end-of-life.

Methods

The integrative review is a vehicle to advance nursing science through the synthesis of various study designs (Wittemore & Knafl, 2005). Accordingly, this review includes qualitative and quantitative studies to inform better the current state of understanding of the relationship between advanced care planning and/or advance directives, and the intensity of care delivered to older adults at the EOL in the acute care setting. A literature search was conducted of the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Medline using the following search terms: (advanced care planning OR advance directives) AND (respiration, artificial OR acute care OR critical care OR ICU OR aggressive* care OR health resource utilization). Searches were limited to English language and to the years 1996 or later. This allowed the findings to represent the most current research since the landmark SUPPORT study (The SUPPORT Principle Investigators, 1995). Inclusion criteria included research studies that evaluated the association between advanced care planning or advance directives and intensity of care in the acute care setting. Articles for which full text could not be obtained were excluded. Although the search was limited to adults, it was not limited by age in order to cast the widest possible net. Studies focused on children or young adults were excluded. The Johns Hopkins Nursing Evidence-based Practice (JHNEBP)
evidence rating scale was utilized for the evaluation of each study (Newhouse, Dearhold, Poe, Pugh, & White, 2005). The JHNEBP is a tool used to critique research studies based on both strength of evidence (ranging from levels I—strongest to V—weakest) and quality of evidence (judged from high to low or major flaws).

**Results**

The initial search yielded 578 articles. Twelve articles met inclusion criteria and were included in this review. Figure 1 provides details on exclusion decision-making and rationale.

Only five studies focused on older adults while the remaining seven included all adults. Ten studies were retrospective and two were prospective, longitudinal studies. Retrospective studies varied in their data sources including electronic health records (EHR) \( n = 7 \) and large, national databases \( n = 5 \), including three drawn from the Health and Retirement Survey, one from the CanCORS database, and one from Project IMPACT. Prospective studies limited their populations to heart failure \( n = 1 \) and oncology \( n = 1 \) with neither focused exclusively on older adults. Finally, of the five articles that did focus solely on older adults, one included only ICU patients while the remaining four included older adults with a variety of diagnoses, three of which were based on large-scale national databases using proxy reporting from surrogates for the presence or absence of advance directives. Table 1 provides a summary of the included literature with JHNEBP ratings.

Aggressive care in the acute care setting is defined in a variety of ways across studies (Table 2). All studies included mechanical ventilation as a measure of aggressive care. The next most common measure of aggressive care was an admission or transfer to
the ICU. Therapies less commonly used to measure aggressive care were the last place patient received care, in-hospital or in-ICU death, blood transfusion, and blood draws. This variety of ways to measure or classify, aggressive care is a limitation for synthesis.

Prevalence of ACP and AD completion

The prevalence of both advanced care planning discussions and advance directive documentation vary. Few studies reported the frequency of ACP discussions (Mack et al., 2012; Wright et al., 2008). In a secondary analysis of cancer patients \((n = 1231)\), only 47.8% of subjects reported participating in ACP discussions, which were confirmed by documentation in the medical record (Mack et al., 2012). An additional 16.7% of subjects had documented ACP conversations in the medical record but failed to recognize and report that these discussions occurred while 12.1% had not engaged in these discussions in any form. Similarly, in a prospective, longitudinal study of cancer patients \((n = 332)\), 37% of participants reported engagement in EOL discussions; however, participation varied by study site, with one center having 61.5% participation in discussions while the second center only had 16.2% engagement in ACP.

Similar to the prevalence of ACP discussions, documentation of patient preferences within ADs range widely. While the majority of studies demonstrate that AD rates vary between 13-41% (Blechman, Rizk, Stevens, & Periyakoil, 2013; Dobbins, 2007; Dunlay, Swetz, Mueller, & Roger, 2012; Halpern, Pastores, Chou, Chawla, & Thaler, 2011; Hartog et al., 2014; Wright et al., 2008), a few have identified a much higher rate, ranging from 65-71% (Nicholas, Bynum, Iwashyna, Weir, & Langa, 2014; Silveira, Kim, & Langa, 2010; Teno et al., 2007; Tschirhart, Du, & Kelley, 2014). Those studies reporting higher AD completion rates were based on large databases that did not
collect AD data, prompting investigators to obtain information regarding the presence or absence of ADs by calling decedents’ proxies, or surrogates, rather than objective chart review.

**Impact of ACP and AD on Aggressive Care**

Advanced care planning discussions are consistently associated with decreased aggressive care in the acute care setting (Mack et al., 2012; Teno et al., 2007; Wright et al., 2008). Two studies evaluated the impact of ACP on ICU utilization. Patients who have in-depth ACP discussions with providers and family members without formally documenting preferences have similarly less aggressive care in the final month of life, including a lower incidence of mechanical ventilation, artificial tube feedings, and in-ICU death, as those who formally document their preferences (Teno et al., 2007). Teno et al. (2007) also identified that ACP was associated with increased early referrals to hospice. The timing of ACP also matters. A secondary analysis found that when ACP discussions occurred more than 30 days prior to death, aggressive care was reduced and referrals to hospice doubled, while when ACP was within 30 days of death, aggressive care was higher and hospice referrals were less frequent (Mack et al., 2012). Finally, patient recognition of ACP discussions influences care received. Among patients with advanced-stage cancer, patients and surrogates who failed to realize that they had engaged in discussions for EOL planning, as documented in the EHR, were significantly more likely to receive aggressive treatment at the EOL when compared to those who acknowledged having these discussions with their providers (Mack et al., 2012). This finding supports an earlier, prospective study that found that cancer patients who reported
engagement in EOL discussions were less likely to receive aggressive care at the EOL (Wright et al., 2008).

There is mixed evidence for the effectiveness of ADs to impact the intensity of care at the EOL. Moreover, the evidence is further limited in the older adult population. Of those studies that explored the association between ADs and intensity of care, four found that ADs are associated with decreased intensity of care (Bleichman et al., 2013; Silveira et al., 2010; Teno et al., 2007; Tschirhart et al., 2014) and four found no relationship (Dobbins, 2007; Halpern et al., 2011; Hart et al., 2015; Hartog et al., 2014). Two studies had mixed findings. In a study of dementia patients differentiated by severity, ADs were found to be associated with decreased intensity of care only in those with severe dementia as compared to those with mild or moderate symptoms (Nicholas et al., 2014). Among heart failure patients, ADs were initially found to be associated with decreased frequency of mechanical ventilation and ICU care; however, when controlled for age, sex, and comorbidities, the association was significant only for limiting mechanical ventilation (Dunlay et al., 2012).

Studies that collect data from proxy sources are more likely to show a relationship between ADs and decreased intensity of care. Of the six studies that demonstrated some degree of an association between ADs and treatment intensity, four obtained data regarding the presence or absence of ADs via proxy report (Nicholas et al., 2014; Silveira et al., 2010; Teno et al., 2007; Tschirhart et al., 2014). Three of these studies were drawn from the national Health and Retirement Survey (Nicholas et al., 2014; Silveira et al., 2010; Tschirhart et al., 2014), thereby necessitating the use of proxy information.
Advance directives may not promote care that is consistent with patient preferences and documenting preferences for limitations in care does not necessarily ensure that life-sustaining treatments will be withheld. Of ICU patients who have a documented DNR order prior to hospital admission, one in four still receive CPR (Hart et al., 2015). Three studies evaluated the congruence between the formal AD document and actual care received at the EOL (Dunlay et al., 2012; Hart et al., 2015; Silveira et al., 2010). In a large-scale study of adult ICU patients, those with ADs that specified limitations in treatment still received CPR (Hart et al., 2015). Additionally, over one-third of these patients died in-hospital. Despite the over 275,000 subjects in this study, only 5% had pre-existing limitations in treatment, which may have had a significant impact on the findings. Other studies, however have contrary findings. Among both adult heart failure patients (Dunlay et al., 2012) and hospitalized older adults (Silveira et al., 2010), ADs with specific limitations documented prior to hospitalization have been found to be associated with limiting aggressive treatments. Advance directives were associated with decreased likelihood of mechanical ventilation for patients with heart failure (Dunlay et al., 2012) and a decreased likelihood of receiving “all care possible” for hospitalized older adults (Silveira et al., 2010). Additionally, those whose ADs requested all care possible were significantly more likely to receive it (Silveira et al., 2010). This study did not define “all care possible.”

Discussion

This literature review examined the impact of advanced care planning and advance directives on both the intensity of care delivered in the acute care setting and the effectiveness of these mechanisms to promote care that is congruent with patient
preferences at the EOL. Advanced care planning is consistently associated with decreased aggressive care, increased hospice referrals, and more congruent care among hospitalized adults. However, the association of ADs with care received in the acute care setting is not consistent across studies due, in part, to methodology.

Advanced care planning is an effective mechanism for facilitating the reduction of aggressive care. Not only is aggressive care reduced, but referrals to hospice occur earlier and more frequently. Hospice lengths of stay longer than three days are associated with increased QOL at the EOL, while lengths of stay less than three days are equivalent to no hospice care at all (Wright et al., 2016). By contrast, research findings are inconsistent for determining the ability of ADs to reduce aggressive care at the EOL. While some studies have identified a decrease in aggressive care such as mechanical ventilation and ICU length of stay, others found no association between ADs and the intensity of care received at the EOL. Beyond evaluating intensity of care received as the target outcome variable, one study evaluated QOL at the EOL. In a prospective, longitudinal study of cancer patients, individuals who received higher intensity of care at the EOL were also more likely to have decreased QOL (Wright et al., 2008). Based on this review, ACP is consistently effective for reducing intensity of care, while ADs are not. This lends support for the importance of the process of ACP rather than merely a documentation of wishes within an AD.

Methodologic differences in how the presence of ADs was determined impacted study results. Research using proxy report of AD presence may overemphasize the value of ADs to decrease aggressive care received at the EOL. Studies that utilize proxies as the sole source of information regarding the presence of ADs demonstrated consistently
different findings when contrasted with more objective sources. Advance directive
documentation rates are consistently higher in proxy studies. Additionally, all four
studies utilizing proxies found that ADs were associated with decreased intensity of care.
This may be a result of response bias, where proxies may have been more likely to report
that the patient had an AD when asked in an attempt to provide what may have been
perceived by proxies as a desirable answer. Objective versus subjective sources of data
appear to play a significant role in the differences among these studies.

While ACP has been shown to be associated with congruence between patient
preferences and care received at the EOL (Houben et al., 2014), it remains unclear
whether AD documents ultimately promote care that is congruent with patient
preferences. Few of the studies identified for this review explored the congruence
between the content of an AD document and actual care received, rendering it difficult to
draw meaningful conclusions about the value of ADs to promote care that is consistent
with patient preferences at the EOL. It remains to be seen whether this is a problem with
the documents themselves, how surrogates manage their role as decision-makers, or part
of a greater flaw within healthcare characterized by how providers choose to utilize ADs.
Are the documents vague? Are patient preferences unclear? Do surrogate decision-
makers inject their own preferences that may contradict those previously expressed by the
patient? Retrospective studies limit the ability to answer these questions. Only one
prospective study critically evaluated congruence between AD documents and care
received and interestingly noted that less than half of participants had even addressed
their preferences for CPR, mechanical ventilation, or hemodialysis at the EOL (Dunlay et
al., 2012). Unfortunately, even ADs that request limited care may not always ensure
compliance with care preferences. Individuals who limit interventions such as CPR may still receive it (Hart et al., 2015). Providers have raised concerns regarding the usefulness of ADs due to vague and confusing language and the timing of application at the bedside (Gutierrez, 2012). Ambiguity within written documents leads to confusion. In the ADs of older adult ICU patients, vague instructions (e.g. “advanced brain impairment” or “imminent death”) for the activation of the directives have been associated with no difference in the delivery of aggressive care among patients with or without pre-existing limitations (Hartog et al., 2014). Additional research must focus on determining the effectiveness of ADs to facilitate care at the end-of-life that is consistent with patient preferences, and if ultimately found to be ineffective, identifying the root causes of the failure to adhere to patient wishes, including those concerns raised by providers.

**Implications for Research and Practice**

This review confirmed that the frequency of both ACP discussions and AD documentation generally remains low. This shows little progress in the prevalence of AD documentation since SUPPORT (Teno et al., 1997; The SUPPORT Principle Investigators, 1995), but it is unclear why this has remained a problem. Primary care providers have limited time with patients and may not have adequate opportunities to engage in conversations that result in completed ADs. In a legislative effort to empower patients and ensure their right to direct their own care would endure in the event of incapacity, the PSDA called for patients without an AD to be asked upon admission whether they are interested in completing one. In practice, patients are simply asked without the benefit of an in-depth discussion of the importance of ACP or of their actual care preferences. End-of-life discussions that occur earlier than the final 30 days of life
are associated with decreased intensity of care, including fewer hospitalizations and ICU admissions, increased frequency of hospice referrals, and longer hospice lengths of stay (Lopez-Acevedo et al., 2013). There were efforts to include ACP discussions, in the hopes of improving AD rates, in the original drafting of the Affordable Care Act; however, these efforts were stifled when fears of death panels emerged, resulting in removal of the provision (Leonard, 2015; The Institute of Medicine, 2015; U.S. Department of Health and Human Services, n.d.). In the absence of this provision, providers have potentially been less motivated to engage in meaningful conversations due to time constraints and patient workloads. More recently, the Centers for Medicare and Medicaid implemented a billing code for the express purpose of dedicated time for ACP discussions and documentation of patient preferences for EOL care (U.S. Department of Health and Human Services, 2015). Future research must evaluate whether the implementation of this provision has been effective in improving rates of ACP and AD documentation.

The juxtaposition of ACP with ADs in the context of the intensity of care delivered in the acute care setting at the EOL is illustrated throughout this review. It is difficult to draw meaningful conclusions regarding the capacity for ADs to decrease aggressive care or promote congruent care at the EOL due to the lack of research focused on older adults that also considers the mediating or moderating influence of multiple chronic comorbidities. With just over one-third of these studies evaluating only older adults, the evidence remains inadequate to determine the benefits for older adults of having an advance directive. Future research must give consideration to this vulnerable population when designing studies. It is important to understand whether these
documents are effective in this population or the barriers that may be limiting effectiveness, before investing resources into promoting AD completion for what may not be an effective document. This concern also exists for those who are not only aged but who also have chronic, progressive disease. Making sure to design studies that do not only focus on populations with a single diagnosis (e.g. heart failure, cancer, COPD) without consideration of the interrelatedness of having multiple chronic diseases, will add robustness and rigor to this area of healthcare concern, thus promoting discussion of ways to improve quality of life at the end-of-life in accordance with the Institute of Medicine (2015) recommendations.

**Limitations**

There are several noteworthy limitations of the studies included in this review. Much of the literature in this review is in the oncology population. While this provides insight into the unique needs of this population, it comes at the exclusion of the interrelationships between multiple diagnoses and the challenges presented to those with higher comorbidity burden. Additionally, few studies target the older adult population specifically. This vulnerable population is living longer with multiple comorbidities and has a unique perspective as the courses of their complex disease trajectories change. Third, studies that report the association between ADs and decreased intensity of care delivered at the EOL are limited by proxy reporting bringing into question response bias. This creates methodological concerns that limit inferences that can be drawn when evaluating the entire body of literature on this topic. An additional methodologic issue that impacts findings surrounds differing ways aggressive care has been measured across studies. While all the studies included in this review included mechanical ventilation,
and all but two included ICU care, the remaining measures lacked consistency. This creates confusion when trying to understand the role that ADs serve for reducing unwanted or aggressive care. Future research should give weight to these methodological considerations to promote consistency in the literature and facilitate metaanalysis. Finally, few studies explore the congruence between patient preferences and actual care delivered at the EOL limiting the ability of this review to draw strong conclusions.

This review may also be limited in its design. Only two major databases were explored, and although both Medline and CINAHL are large, comprehensive databases, they may not have been mutually exhaustive. Additionally, the inclusion and exclusion criteria may have excluded studies that could have provided additional insight.

**Conclusion**

The benefits of advanced care planning to minimize unwanted or aggressive care at the end-of-life are well-established. Advance directives have not been consistently associated with reduced intensity of care in the acute care setting or with the delivery of care that is consistent with patient preferences. Further research that focuses specifically on older adults with advanced comorbidity burden is needed to understand better how advance directives are utilized and their impact on care delivery at the EOL in the acute care setting for this vulnerable population.
References


Figure 1. Decision-making summary

578 articles identified through searches on CINAHL and Medline

422 articles > 5 years old

156 current articles related to topic of interest

92 duplicates removed

64 articles with duplicates removed

31 articles excluded based on abstract screening

n = 6 not research article
n = 25 off topic

33 articles related to the association between ACP/ADs and intensity of care at the end of life

21 articles excluded after full review

n = 2 wrong population (age)
n = 1 not research article
n = 15 off topic
n = 2 systematic reviews
n = 1 pilot study only

12 articles met the required criteria and were included in review

Total = 12
<table>
<thead>
<tr>
<th>Author(s) (year)</th>
<th>Objectives</th>
<th>Design</th>
<th>Setting/Sample</th>
<th>Findings</th>
<th>Level of Evidence/Quality*</th>
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</table>
| Blechman, Rizk, Stevens, & Periyakoil (2013)          | Examine the quality of EOL care of hospitalized metastatic cancer patients admitted to the ICU in the last 2 weeks of life | Retrospective Cross-sectional | Single-center academic hospital                                               | • 1/3 of patients reported having an advance directive, however not all were present in the EHR  
  • only 1 in 5 patients reported having a goals-of-care discussion prior to their final hospital admission, which was confirmed in the EHR  
  • nearly all patients who died never left the hospital                                                                                                           | III-C                      |
| Dobbins (2007)                                       | Research questions:  
  1. What is the likelihood of older patients executing formal or informal ADs?  
  2. What is the relationship between the presence of ADs and the health care providers’ decisions to treat patients in the ICU, use of LST, initiate the use of comfort care plans, or use of CPR? | Retrospective Cross-sectional | Single-center community hospital                                               | • approximately ¼ of patients had a documented AD  
  • no relationship was found between the presence of documented ADs and the use of LSTs, with the implementation of comfort care plan, with the use of CPR  
  • patients were more likely to consent to any procedure when family or friends were present                                                                                                           | III-A                      |
| Dunlay, Swetz, Mueller, & Roger (2012)                | 1. Examine the prevalence and predictors of AD completion in community patients with HF.  
  2. Hypothesized that AD specifying limits in care were associated with decreased EOL hospitalizations, ICU admissions, and MV | Prospective, Longitudinal (over 4 yrs) | Multi-center within a single healthcare organization                           | • only 41% had completed ADs  
  • a minority of ADs addressed patient preferences for LSTs: CPR (41%), MV (38.6%), artificial nutrition & hydration (38.6%), HD (10%)  
  • no difference in mortality in patients w/ AD compared to those without  
  • no differences in hospitalizations in the final month of life for those who specified limits compared with those who did not  
  • When adjusted for age, sex, and comorbidities, ADs were only associated with decreased likelihood of MV  
  • key characteristics traditionally associated with poor prognoses are failing to trigger completion of AD in HF patients                                                                                           | II-A                       |
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<th><strong>Author(s) (year)</strong></th>
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<th><strong>Level of Evidence/Quality</strong></th>
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<tr>
<td>Halpern, Pastores, Chou, Chawla, &amp; Thaler (2011)</td>
<td>Explore the prevalence, types, and impact of advance directives in critically ill cancer patients</td>
<td>Retrospective</td>
<td>Single-center</td>
<td>Closed medical-surgical ICU from 1/1/06-4/25/08</td>
<td>• While more patients have designated healthcare proxies than documented LWs, rates remain low for both • LWs or designated healthcare proxies have no impact on care or outcomes</td>
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<td>Hart, Harhay, Gabler, Ratcliffe, Quill, &amp; Halpern (2015)</td>
<td>Examine the proportion of ICU patients admitted with existing treatment limitations</td>
<td>Retrospective cohort</td>
<td>Project IMPACT database</td>
<td>$N = 277,693$ patient admissions in 141 ICUs in 105 hospitals Median age with limits on care = 78 ($n = 13,405$) Median age without limits on care = 61 ($n = 264,288$)</td>
<td>• A very small number of ICU patients presented preexisting limits on care, with approximately $\frac{1}{4}$ receiving CPR in the ICU • 40.9% of patients with treatment limitations received at least 1 LST (vasoactive meds, MV, or initiation of renal replacement therapies) • ICU care is more likely to result in escalation of treatment despite previously expressed wishes for limitations of LST</td>
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<td>Hartog et al. (2014)</td>
<td>Determine whether treatment preferences in patients’ ADs are associated with LST received at EOL in the ICU</td>
<td>Retrospective</td>
<td>Single center study</td>
<td>Patients (age &gt; 60 years) who died in 4 ICUs of a university hospital in Germany $N = 477$ $M_{age} = 72.2$</td>
<td>• Persistently low rates of AD documentation (13%) • AD documents have inherently vague instructions for context of application (e.g., “advanced brain impairment” or “imminent death”) • Compared to patients without ADs, patients with ADs were less likely to receive CPR ($p = .029$) and more likely to have DNR orders ($p = .007$) • Of patients with ADs: 62% received MV despite AD refusing it, 32% received artificial nutrition, 26% received circulatory support</td>
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<td>Mack et al. (2012)</td>
<td>Evaluate the impact of EOL discussion characteristics (timing, involved providers, and location) are associated with the intensity of care received at EOL</td>
<td>Retrospective</td>
<td>Secondary analysis of CanCORS cohort of patients with stage IV disease at diagnosis</td>
<td>$n = 1231$ adults ≥ 21 years old</td>
<td>• Earlier ACP discussions (more than 30 days before death) that are recognized by patients or surrogates as EOL discussions are associated with decreased intensity of care at EOL and increased the likelihood of hospice referral • EOL discussions that occur less than 30 days prior to death (or not at all) are associated with more aggressive EOL care and later hospice referrals</td>
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<td>Author(s) (year)</td>
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| Nicholas, Bynum, Iwashyna, Weir, & Langa (2014) | Explore the interactions of nursing home stays, dementia and the use of ADs with the cost and aggressiveness of EOL care | Retrospective               | Secondary analysis of HRS; Medicare claims for respondents who died in the period 1998-2007 at age +65y/o; \(N=3876\) | • Overall, 36.4% of patients with severe dementia had ADs specifying LST (40.0% nursing home residents vs 27.4% community dwellers)  
• For only community dwellers with severe dementia, ADs, specifically, LWs, were strongly associated with less aggressive care                                                                                                                                                                                                 | III-A                     |
| Silveira, Kim, & Langa (2010)             | Examine the prevalence and predictors of lost decision-making capacity and decision making at the EOL | Retrospective               | Single-center Secondary data analysis of the HRS adults aged 60 and over who died between 2000 and 2006; \(N=3746\) \(M_{\text{age}}=80.5\) years | • For those decedents with LWs, only 2% requested all care possible  
• Non-decisional patients with a LW (regardless of preferences) were more likely to receive limited treatment and comfort care plans than subjects without a LW.  
• Among non-decisional patients, 67.6% had an AD  
• Having a LW or POAHC is associated with EOL care that is congruent with patient preferences                                                                                                                                                                                                                                                | III-A                     |
| Teno, Gruneir, Schwartz, Nanda, & Wetle (2007) | Examine the impact of ADs on quality of EOL care in the U.S. 10 years after the Patient Self Determination Act | Retrospective               | Single center design Data from a mortality follow-back survey conducted with decedents’ family members; \(M_{\text{age}}=79\) (with AD) and 72.6 (no AD); \(N=1130\) (with AD) \(N=423\) (no AD) | • 70.8% reportedly completed an AD  
• ADs are associated with decreased use of LST in the final month of life  
• In the context of no documented ADs, those for whom family reported known specific wishes were more likely to die at home with hospice services, less likely to receive aggressive care at the EOL                                                                                                                                                                                                 | III-B                     |
| Tschirhart, Du, & Kelley (2014)           | Examine individual and regional factors associated with the use of intensive medical procedures in the last 6 months of life | Retrospective Cross-sectional | Single Center Secondary Analysis of the HRS Decedents aged 66 and older for whom a proxy completed a post-death interview between 2002 and 2008 \(n=4,665\) and limited to those with linked Medicare claims; \(N=3,069\) \(M_{\text{age}}=83.2\) years | • Older age, Alzheimer’s, cancer, and having an AD are associated with decreased likelihood of LST; LST reduced by 30% in those with an AD  
• Regional differences in healthcare delivery and Black race double the likelihood of receiving LST                                                                                                                                                                                                                                                                 | III-A                     |
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<th>Author(s) (year)</th>
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<tr>
<td>Wright, et al. (2008)</td>
<td>Examine the association between EOL discussions with physicians, and the medical care that terminally ill cancer patients receive near death</td>
<td>Prospective, longitudinal, cohort study</td>
<td>Multi-center, Coping with Cancer study</td>
<td>• 37% reported having EOL discussions with their physicians, although prevalence differs depending on primary facility of treatment</td>
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<td>Eligibility criteria: diagnosis of advanced cancer, age ≥ 20 years, presence of an informal caregiver, assessed to have adequate stamina to complete the interview</td>
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<td>• poorer performance status, higher symptom burden, and shorter expected survival triggers EOL discussions</td>
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<td>• ACP conversations with physicians are associated with significantly less LST near death and earlier enrollment in outpatient hospice</td>
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<td>• Earlier enrollment in hospice is associated with improved QOL</td>
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ACP = advanced care planning; AD = advance directive; ADL = activities of daily living; CPR = cardiopulmonary resuscitation; EHR = electronic health record; EOL = end-of-life; HRS = Health and Retirement Study; ICU = intensive care unit; LST = life sustaining treatments; LW = living will; MV = mechanical ventilation; PC = palliative care; POAHC = Power of Attorney for Health Care

* Newhouse et al. (2005)
Table 2.

*Measures of aggressive care*

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### Appendix A

#### Logistic Regression Likelihood Ratio Test

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<tr>
<th>Model</th>
<th>$\chi^2$ (df)</th>
<th>$p_{model}$</th>
<th>$\Delta \chi^2 (\Delta df)$</th>
<th>$p_{difference}$</th>
<th>Model</th>
<th>$\chi^2$ (df)</th>
<th>$p_{model}$</th>
<th>$\Delta \chi^2 (\Delta df)$</th>
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$\chi^2$, chi square; df, degrees of freedom; $p_{model}$, significance of the individual model; $\Delta \chi^2$, change in chi square between models; $\Delta df$, change in degrees of freedom between models; $p_{difference}$, significance of the $\Delta \chi^2$. ***, retained model
Appendix B

Table B

Multiple Regression Model Summary

<table>
<thead>
<tr>
<th>Model</th>
<th>$R$</th>
<th>$R^2$</th>
<th>Adjusted $R^2$</th>
<th>$SE$</th>
<th>$\Delta R^2$</th>
<th>$\Delta F$</th>
<th>$df_1$</th>
<th>$df_2$</th>
<th>$p$</th>
<th>Durbin-Watson</th>
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<td>6.411</td>
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<td>0.096</td>
<td>1</td>
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<td>1</td>
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<td>16.627</td>
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</table>

a. Predictors: Sex, CCI, Age, Advance Directive
b. Predictors: CCI, Age, Advance Directive
c. Predictors: Age, Advance Directive
d. Predictors: Advance Directive

Dependent Variable: Total ICU Length of Stay
*** retained model