**Title**

Increasing the Value of End-of-Life Care for End-Stage Renal Disease Patients: The Role of Palliative Care, Advance Directives and Healthcare Value Measurement

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# Increasing the Value of End-of-Life Care for End-Stage Renal Disease Patients: The Role of Palliative Care, Advance Directives and Healthcare Value Measurement

by

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[redacted]

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## Abstract

### Background

ESRD patients frequently receive intensive end-of-life care that may not improve the quality of experience for patients and their families. Expanding access to palliative care and increasing use of advance directives are often promoted as strategies for improving the value ESRD end-of-life care. Delivery of high value end-of-life care for ESRD patients is predicated on determining the value of medical care, understanding the cost and quality implications of medical therapies, and ensuring equitable distribution of high value medical care. Currently, medical literature doesn’t routinely report outcomes in terms of value, and the cost implications of expanding access to palliative care services for ESRD patients have not been quantified. Advance directive completion is acknowledged to represent high value ESRD end-of-life care, however ESRD patients have low rates of advance directive completion, which may result in part from racial disparities in advance directive completion. Although prior research has found significant racial disparities in advance directive completion among non-ESRD patients, racial disparities in advance directive completion among ESRD patients have not previously been evaluated. This issue is particularly salient in ESRD end-if-life care due to the racial composition of the ESRD patient population, which is disproportionately non-white.

### Objectives:

This dissertation seeks to improve the value of ESRD end-of-life care by filling three key gaps in the literature on end-of-life healthcare value. The dissertation aims are to 1) describe the current state of value measurement in medical literature, 2) assess the resource use implications of providing inpatient palliative care for ESRD patients, and 3) evaluate whether racial disparities in advance directive completion exist among nursing-home bound ESRD patients.

**Methods**

The use of value measurement in medical literature was analyzed by reviewing all journal articles in PubMed containing the term ‘high value care’ for conceptual themes, and value measurement techniques. The top three medical, health policy and health economics journals (based on impact factor) were assessed for frequency of occurrence of terms relating to value measurement to compare the use of value measurement techniques across these disciplines.

The association of inpatient palliative care with length of stay and hospital costs was assessed through use of a dataset from the United States Renal Data System. Medicare beneficiaries with ESRD who received palliative care during a hospitalization in 2012 and 2013 were identified, and matched with hospitalized ESRD patients who received usual care using propensity scores. Primary outcomes were length of stay and hospitalization costs. Secondary outcomes were 30-day readmission and hospice enrollment.

Racial disparities in advance directive completion among ESRD patients were evaluated with a dataset derived from three sources: United States Renal Data System, Medicare Claims, and the Minimum Data Set. A cohort of U.S. Medicare beneficiaries who received dialysis for treatment of ESRD, resided in a Medicare- or Medicaid-credentialed skilled nursing facility between 2000 and 2010, and died between 2000 and 2010, was identified. Poisson regression was used to determine the relative risk for advance directive completion of any advance directive, a healthcare power of attorney, and a treatment limiting advance directive by race.

**Results and Conclusions**

The dissertation research finds that the key theoretical link bridging the gap from conceptualization to operationalization of healthcare value measurement lies in economic methods of value measurement (cost effectiveness and cost utility analysis). Use of these tools is recommended as a framework for generating medical research that facilitates prioritizing healthcare services according to value.

The study of inpatient palliative care, length of stay and cost found that among ESRD patients who died in the hospital, inpatient palliative care was associated with shorter hospitalizations and lower costs. For those who survived to discharge, inpatient palliative care was associated with no difference in length of stay, and higher hospitalization costs; which may be offset by increased hospice use and fewer re-admissions in the 30-day post-discharge period.

In the study of racial disparities in advance directive completion among ESRD patients residing in a nursing facility, the prevalence of advance directive completion was low for patients of all races. Patients of Non-Hispanic black and minority races were less likely to complete all advance directive types than Non-Hispanic whites. Non-Hispanic black patients were least likely to complete all advance directive types. Based on the findings of the dissertation research, the value of ESRD end-of-life care would be improved by systematically incorporating value measurement

into medical research, expanding the use of inpatient palliative care for patients nearing the end of life, and increasing the use of advance directives among all ESRD patients.

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# Chapter 1

Healthcare costs in the US are high and rising, accounting for 17.5% of GDP in 2014.[1] Medicare spending totaled $597 billion in 2014, representing 14% of the federal budget.[2] In spite of costly investments in healthcare, national health outcomes fall short of expectations. Growing awareness of unsustainable health care costs juxtaposed with underperformance in population health metrics has given rise to acknowledgement of the need for 'high value healthcare', defined as improved outcomes for lower cost. Although the concept is not new, the Affordable Care Act has focused attention on this objective by mandating adoption of healthcare delivery system changes that will yield high value care and structuring reimbursement around the framework of value based purchasing.

The exigency of improving healthcare value is particularly acute for those suffering from receipt of low value care, characterized by intensive healthcare resource utilization and poor health outcomes. Individuals with end-stage renal disease (ESRD) are one such population, being intensive consumers of healthcare services[3] with high mortality rates,[4] and poor quality of life outcomes[5,6,7] Patients receiving dialysis for treatment of ESRD, a population of approximately 477,000 in 2014,[8] are among the most expensive in the US healthcare system. Dialysis is a form of chronic life support that is administered in outpatient dialysis centers. Individuals with ESRD comprise less than 1% of all Medicare enrollees, but account for 6% of Medicare spending.[9] In 2010, medical spending for these patients made up 1% of the entire federal government budget.[9] Within this population, end of life care is often identified as an episode of care in which intensity of medical care escalates without yielding commensurate benefit in quantity or quality of life.[10,11]

Advance directives and palliative care are often promoted as interventions with the potential to improve the value of end-of-life care for ESRD patients. Advance directives are medical or legal documents that define patient preference for interventions intended to support life. These documents enumerate patient wishes for resuscitation and may also include preferences for hospitalization, parenteral feeding, medication administration and designation of a surrogate decision-maker. According to the World Health Organization, palliative care is a specialized approach to medical care that

> "Improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".[12]

Palliative care focuses on aligning medical care with patient goals, values and priorities to maximize quality of life, thus avoiding delivery of high intensity medical care except when it is expected to improve these patient centered outcomes.[13] The assertion that advance directives and palliative care represent high value care for chronically ill populations rests on several foundational assumptions that are not well substantiated in academic literature.

First and foremost is the proposition that healthcare value can be quantified and classified as 'high'. Review of medical literature related to healthcare value measurement demonstrates a significant gap between conceptualization and operationalization of healthcare value measurement. The concept of high value care as applied in medical literature lacks crucial elements, namely a standardized measure to quantify the value of care across disease states, populations and outcomes. Absent a standardized measure that allows for this method of comparison, value cannot be meaningfully quantified or characterized as 'high' or 'low'. Review of conceptualization and operationalization of health care value in the disciplines of medicine, health policy, and health economics shows that health economics has well developed tools that are often employed in the study of cost relative to outcomes, whereas policy literature less often reports results in this framework and medical literature rarely includes consideration of cost when reporting outcomes. From this survey, it can be concluded that lack of applied value measurement in medical literature reflects prioritization of health outcomes over cost, rather than lack of available measurement tools. The dissertation will describe these findings in detail, explore the historical factors that have led to the current status of value measurement in medical research, examine policy implications of medical research reporting practices, and propose a framework for medical research reporting that is conducive to measuring healthcare value.

In spite of the limitations of applied healthcare value measurement in medical literature, high value care is an important conceptual framework through which to evaluate therapeutic modalities. The working definition of high value care gleaned from assimilation of healthcare value measurement across these bodies of literature will serve as the basis for evaluating whether advance directives and palliative care represent high value end-of-life care for individuals with ESRD.

Review of palliative care literature reveals ample evidence supporting the use of palliative care to improve quality outcomes,[14] but limited data on the cost implications of palliative care and no data specific to ESRD patients.[15,16,17,18] Much published literature promotes use of palliative care to reduce healthcare costs, but limited data substantiate or quantify the benefit of this approach. Assuming that healthcare value is a function of cost and quality, lack of robust data on cost implications of palliative care for ESRD patients is a consequential gap in the literature.

Advance directives are intended to improve quality of life by promoting delivery of care consistent with expressed preferences and reduce healthcare costs by preventing unwanted intensive interventions at the end of life.[19,20] Advance directives have been shown to decrease costs or be cost neutral (**Table 1.1**) and improve patient-centered outcomes in end-of-life care.[21,22,23] Although this data is not specific to ESRD patients, it has held true in other complex chronically ill populations, indicating that ESRD patients would benefit similarly from increased rates of advance directive completion. Using the framework of decreased cost and increased quality as a working definition of improved healthcare value, advance directives improve the value of end-of-life care.

Rates of advance directive completion in the general elderly population have risen in recent decades, with 72% of elderly Americans having an advance directives in place at the time of their death in 2010,[24] However, rates of advance directive completion among ESRD patients has remained low,[25,26,27] even when compared with other chronically ill populations.[28] In a recent study, Kurella et al. found that just 36% of ESRD patients residing in a nursing facility have an advance directive in place at the time of death.[28] The same study finds that ESRD patients with an advance directive in place at the time of death received care congruent with their expressed preferences at the end of life, were less likely to be treated with intensive medical care in the last month of life, and were more likely to enroll in hospice care (which has been linked with increased patient and family satisfaction with end-of-life care).

Racial disparities have been documented in a wide range of healthcare outcomes,[29] including advance directive completion and advance care planning.[30] Given that ESRD patients are disproportionately of minority race,[8] having low rates of minorities completing advance directives among the ESRD population could be a significant contributor to low completion rates of advance directive completion in the ESRD population. Identification of racial disparities in advance directive completion creates an opportunity to increase the value of end-of-life care for vulnerable ESRD populations. Based on what is known about racial disparities in other healthcare sectors, it may be that deficiencies in ESRD end-of-life care are exaggerated in vulnerable ESRD populations by racial disparities in AD completion.

## Summary of the Problem; Low Value Health Care for Individuals with ESRD

**High value care.** Much of the end-of-life care provided to individuals with ESRD is low value; high cost for poor outcomes. Medical research is primarily focused on health outcomes without consideration of cost. Review of medical literature on high value care reveals that conceptual definitions underlying high value care are inconsistent, imprecise, and thematically under-developed. Despite broad consensus on the need for high value care, no agreement exists on what defines high value care or how to manifest it in the clinical setting. Medical research articles addressing high value care frequently refer to increasing quality and/or decreasing cost, but few scholarly works in medical literature address the concept of high value care as a unified measure.

Given the resource constraints that our healthcare system is operating under and the staggering burden that the current cost of medical care has become for the US economy, medical research relevance and applicability will be maximized if cost considerations are included in health outcomes reporting. The tools exist to do so, but are not routinely incorporated into medical research. Use of the high value care lens to evaluate ESRD care brings into clear focus the importance of changing medical care delivery models in ESRD care at the end of life to improve patient-centered outcomes and curtail unsustainable growth of healthcare costs. This dissertation work is intended to encourage reconciliation of traditional medical research approaches with the current realities of the US healthcare delivery system by shedding light on the importance of considering cost as a component of outcomes, outlining the barriers to doing so, and describing the policy implications of adopting this practice.

**Palliative Care.** A rapidly growing body of evidence supports the use of palliative care for chronically ill patients to promote symptom remediation, improved quality of life and rational utilization of medical services.[14] Less is known about the cost implications of palliative care, and among the existing studies none are specific to ESRD. End-stage renal disease patients have distinct patterns of healthcare resource use due to the nature of their disease process and the need for chronic outpatient life support (dialysis). Therefore, the findings of studies on the cost implications of palliative care that are not ESRD-specific cannot necessarily be generalized to ESRD patients. Assuming that improving the value of care connotes increasing quality and reducing costs, the cost effects of palliative care for ESRD patients need to be better studied before definitive conclusions can be drawn about the value of palliative care for ESRD patients at the end of life.

**Advance Directives.** According to the high value care framework of increased quality and reduced costs, advance directives have been demonstrated to improve the value of end of life care by improving quality[31,32] and reducing or stabilizing costs.[33,34] Although this data is not specific to ESRD patients, it has held true in other complex chronically ill populations, indicating that ESRD patients would likely benefit similarly from increased rates of advance directive completion. ESRD patients complete advance directives at lower rates than the general elderly population, in spite of their life limiting diagnosis.[35] ESRD patients are disproportionately of minority race.[8] Therefore, if fewer patients of minority race are completing advance directives, this may contribute significantly to overall low completion rates of advance directives in ESRD patients.

## Dissertation Aims

The overarching aim of the research program outlined in this dissertation is to improve the value of end-of-life care for individuals with ESRD. Within this broad subject area, the dissertation will focus on three specific inter-related research themes: measuring healthcare value, assessing cost implications of palliative care for ESRD patients, and identifying racial disparities in advance directive completion among ESRD patients. Selection of the research program is borne out of clinical experience, which made clear that there is ample opportunity to improve quality of care through more efficient use of healthcare resources for ESRD patients nearing the end of their life. The specific research aims are based on identification of significant gaps in the literature related to high value end-of-life care for ESRD patients. Research conducted within the dissertation and later as part of the broader research program will contribute to improving end-of-life care for ESRD patients by addressing key gaps in existing literature.

**Measurement of healthcare value**. The first dissertation aim is to summarize current conceptualization and operationalization of healthcare value measurement in medical research. The literature review will address the following questions. 1) Why has there been limited adoption of value measurement tools in medical research? 2) What are the historical factors that have contributed to limited adoption of value measurement tools in medical research? 3) What are the barriers to incorporating assessment of healthcare value into medical research? 4) How could value measurement be systematically incorporated into medical research? This work is intended to improve the value of end-of-life care for ESRD patients by promoting the use of standardized measures of value in medical research reporting.

**Palliative care.** The second dissertation aim is to analyze the effect of providing inpatient palliative care services to end stage renal disease patients on length of stay, hospital cost and 30-day mortality and readmission. Palliative care is often promoted as a strategy to increase the value (increase quality and reduce cost) of end of life care for ESRD patients. Palliative care focuses on aligning medical care with patient goals, values and priorities to maximize quality of life, thus avoiding delivery of high intensity medical care except when it is expected to improve these patient centered outcomes.[13] Determination of whether palliative care represents high value care for ESRD patients has important policy and practice implications, and is contingent upon accurate estimation of the resource use implications of palliative care. The study on cost implications of inpatient palliative care seeks to address the following questions: 1) What is the effect of inpatient palliative care on length of stay for hospitalized end stage renal disease patients?; 2) What is the effect of inpatient palliative care on hospital cost (facility and provider) for hospitalized end stage renal disease patients?; and 3) How does receipt of inpatient palliative care affect hospice use, dialysis withdrawal, 30-day mortality and 30-day hospital readmission?

**Advance directives.** The third dissertation aim is to assess whether advance directive completion rates vary by race among ESRD patients residing in a nursing home. This research is intended to improve the value of end-of-life care through identification of unmet advance care planning needs in minority ESRD populations. In the current climate of research which increasingly recognizes the effect of social determinants of health, this will contribute to the body of literature describing the specific impacts of social determinants of health. The primary research questions are: What are the odds of completing an advance directive for blacks, and ‘other’ (non-black, non-white), compared with whites? What other explanatory factors correlate with odds of advance directive completion (disease burden, age, regional healthcare spending)?

## Significance

**Healthcare Value Measurement.** Consistent use of standardized healthcare value measurement methods in medical research could precipitate profound changes in prioritization of healthcare delivery by quantifying the relative value of healthcare services. Historically medical research has focused exclusively on health outcomes without consideration of cost, which is not a sustainable approach in the current climate of demonstrable need for improved population health outcomes and lower healthcare costs. To realize maximum health gains in a resource constrained context, healthcare investments should be allocated so as to realize maximum population health gains per dollar of healthcare resources invested. However, prioritizing healthcare services by this standard requires comparison of healthcare services according to a common unit of measurement which incorporates cost and outcomes. Value is the parlance that has been adopted in medical research for an outcome measure that incorporates cost and outcomes. The concept of value serves as the catalyst for moving from health-outcome focused research to research reporting structured as health gains per dollar of healthcare resources invested. Defining value as an outcome in medical research is essential to facilitating this progress, as value is the conceptual foundation of this paradigm shift.

Accurately assessing the current state of value measurement in healthcare will provide important perspective on the conceptual foundations of high value care in the literature, and move the science of value measurement forward by identifying areas of challenge and opportunity. Although existing methods of value measurement have limitations, broad application of these techniques in medical science and health policy literature would have important implications for health policy, medical research, and clinical care. Application of value measurement techniques to end-of-life care for ESRD patients would appropriately bring attention to areas of medical practice that provide minimal benefit at high cost. Clarity about which elements of ESRD end-of-life care are of the lowest value will motivate decision makers in health policy and health system design to improve outcomes and reduce cost in these areas.

**Palliative Care.** As healthcare systems are increasingly held accountable for quality outcomes and cost of care, data on cost implications of palliative care will inform healthcare delivery system and health policy initiatives related to use of palliative care. Information generated by this study is specific to ESRD patients, which will serve to illustrate delivery system effects of disease-centric palliative care delivery as well as contributing to the larger body of knowledge regarding resource utilization implications of palliative care use for chronically ill populations. Successful achievement of this dissertation aim will provide information required to determine whether providing palliative care for ESRD patients increases the value of end of life care for this population.

**Advance Directives.** In an era of healthcare characterized by overuse of high-tech, high-cost interventions, medical research is demonstrating the value of low tech, high-touch interventions such as advance care planning. Improving healthcare value by translating these findings into clinical practice change must be done equitably, so as to avoid magnifying existing disparities in healthcare and health outcomes. Identifying racial disparities in advance directive completion (a marker of advance care planning) among ESRD patients residing in a nursing home serves as a basis for promoting equitable delivery of high value healthcare service for the most vulnerable populations.

**Conclusion.** In totality, research into these three themes will make a significant contribution to promoting improved value in end-of-life care for ESRD patients by filling in key gaps in the literature. ESRD patients are a medically complex, vulnerable population that suffers from poor outcomes in spite of intensive investment of healthcare resources. Promoting higher value end of life care for this population will require an extensive knowledge base originating in a variety of disciplines from health economics, to policy and clinical research. The broad scope of this issue is reflected in the wide ranging dissertation foci, which are unified by the central theme of increasing the value of end of life care for ESRD patients. Chapter 2 includes a synthesis of published literature on high value care, and the cost/quality implications of using advance directives and palliative care for ESRD patients. Chapters 3, 4 and 5 are publishable papers on the topics of healthcare value measurement, resource use implications of inpatient palliative care for ESRD patients, and racial disparities in advance directive completion among nursing home residents with ESRD.

**Table 1.1** Effect of Advance Directives on Healthcare Costs, Summary of Publications

| Study | N | Independent variable | Outcome | Population | Results | Notes | Study Design |
|---|---|---|---|---|---|---|---|
| *Randomized Controlled Trials (RCTs)* | | | | | | | |
| Molloy et al. (2000)[36] | 1292 | AD | Healthcare resource utilization over 18mos prior to death, HRQoL, mortality | Nursing home residents | Reduced hospitalization, reduced healthcare utilization at end of life with use of AD. No change in HRQoL or mortality | Canadian study | RCT |
| Connors (1995)[37] | 9105 | Provider education on patient prognosis, nurse led ACP with patient and care team | Number of ICU days, hospital resource use, AD completion | Hospitalized adults with life-threatening illness | ACP intervention had no significant effect on hospital resource use, AD completion or patient-provider communication | IV was ACP, not AD completion | RCT |
| Schneiderman, Kronick, Kaplan, Anderson & Langer (1992)[38] | 204 | AD | Pt satisfaction, HRQoL, medical costs in last month of life | VA pts with life threatening illnesses | AD made no difference in cost or quality outcomes | VA study, small N. Only 100 pts died during study period | RCT |
| *Non-RCT Studies* | | | | | | | |
| Kaambwa (2015)[39] | 230 | AD | Total cost in last year of life | Frail Elderly | No association between AD and cost | From Australia | Retrospective analysis |
| Fonk, Davidoff, Lutzow, Chesley & Mathiowetz (2012)[40] | 858 | AD | Cost in last month of life | Medicaid recipients, dual eligibles | No association between AD and cost | In a single health plan in Milwaukee | Retrospective analysis |
| Nicholas, Langa, Iwashyna & Weir (2011)[41] | 3302 | AD | MC EOL expenditures, life-sustaining treatment, hospice care, in-hospital death | MC decedents 1998-2007 | AD lowers costs in high cost regions, no effect in low-med spending regions. AD associated with less in hospital death and more hospice use in high-med cost areas, | Includes ESRD pts, but doesn't report results specific to ESRD. | Retrospective analysis |

| Study | N | Independent variable | Outcome | Population | Results | Notes | Study Design |
|---|---|---|---|---|---|---|---|
| *Non-RCT Studies (cont)* | | | | | | | |
| Kelley, Ettner, Morrison, Du, Wenger & Sarkisian (2011)[42] | 2394 | AD, functional status, chronic disease | EOL healthcare costs | HERS survey, decedents 2000-2006 | Race, disease state, family support and decline in function impacted costs, but AD had no effect | Used regression analysis to identify relationship between predictors and cost outcomes. Includes CKD, as a predictor of EOL costs. | Retrospective analysis |
| Kish, Wallace, Martin, Shaw & Price (2011)[43] | 872 | AD | Ventilation, BP support, resuscitation, dialysis, ICU use, hospitalization, survival | ICU patients | AD results in fewer ICU days and lower ICU charges. AD didn't reduce use of life support technologies after controlling for disease state and severity. | Conducted at an academic medical center | Retrospective case control |
| Taylor, Heyland & Taylor (1999)[44] | *NA* | AD | Hospital resource use | Hospitalized patients | 3 retrospective studies showed decreased hospital resource use with AD. 3 prospective studies (2 randomized, 1 non-randomized) showed no difference in resource use. | | Systematic review |
| (Emanuel, 1996)[33] | *NA* | AD and hospice use | Cost | Variable | 3 randomized trials found no cost savings with AD. Nonrandomized trials found cost savings ranging from zero to 68%. | Identified selection bias, time frame for cost reporting, scope of costs evaluated variability of reported savings and lack of generalizability as key issues with literature | Review |
| Maksoud, Jahnigen, Skibinski (1993)[46] | 852 | AD completion (inpatient versus outpatient) | Hospital cost, inpatient length or stay | Hospitalized decedents of a single center | Reduced cost and shorter length of stay with DNR orders completed prior to hospital admission. Longer hospital stays for pts completing a DNR while admitted. | Very high rates of AD completion – 43-98% depending on disease process. May reflect change over time or regional variation | Retrospective analysis |

HRQoL = Health related quality of life

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# Chapter 2.

# Literature Review

## High Value Care

Review of literature related to current conceptualization and operationalization of value measurement in medical research will serve as a basis for comparison with the use of healthcare value measurement in the disciplines of health policy and health economics. Understanding the state of value measurement science in these fields points to challenges and opportunities for utilizing standardized healthcare value measurement in medical research. Most medical literature doesn't directly refer to value measurement, rather the term 'high value care' is used as shorthand for improving quality and/or reducing cost. Classifying care as high or low value implies the capacity to measure value, therefore published works related to high value care were reviewed to determine the basis for value measurement.

A search of PubMed for publications with 'high' AND 'value' in the title and 'healthcare' (or MeSH term equivalent) in the abstract yielded 51 articles after excluding articles without full text, and articles unrelated to high value care (Ex. *"Visual quality of Q-**value**-guided LASIK in the treatment of **high** myopia"*)[1]. A substantial minority of articles discuss pedagogical models for teaching high value care in medical schools, with the remainder focusing on high value in delivery of healthcare services. **Table 2.1** summarizes the conceptual definitions of high value care utilized in the 44 publications that address value measurement (directly or indirectly) in healthcare services.

**Conceptual themes.** Several themes emerge from review of the publications presented in **Table 2.1**. The most readily apparent is broad consensus among policy makers, healthcare

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[1] Search conducted September 10th, 2016.

providers, health systems and the public on the need to increase value in healthcare services. Robust debate occurs around how to accomplish this aim, but there is unanimous agreement on the need to promote delivery of high value healthcare. A second theme is the great divide that lies between high value care as an aspirational goal and the actuality of standardizing measurement of healthcare value or defining *high* value care. Articles using high value care frequently refer to increasing quality and/or decreasing cost, but rarely does medical research attempt to define the concept of high value care as a unified measure.

On the cost reduction side of high value, literature reveals two important areas lacking conceptual clarity: efficiency versus cost reduction and cost consciousness versus cost reduction. Though fundamentally different, efficiency and cost reduction are often used interchangeably in discussion of high value care. Efficiency is described as the absence of unnecessary care, but this offers no guidance in using technologies that provide small benefit at high cost. A substantial number of studies define high value care as the absence of waste, which creates a binary distinction between value and no value without considering gradation of value.

Defining high value care as the avoidance of waste simply indicates that care provided should have some value, rather than no value. All published articles related to high value care in medical education were based on the conceptual foundation of high value care as lack of wasteful spending, except a single research article, focused on cost awareness.[1] Given that this is the predominant framework used to educate the next generation of medical providers, it will likely be the working definition of high value in the years to come unless the term is further developed in the literature.

Ambiguity regarding cost consciousness and cost reduction result from the assumption that cost consciousness leads to lower cost.[2] However, this assumption is not explored in the literature. Emphasis on cost-consciousness over cost reduction is most prevalent in medical education literature. Post et al. test the effect of instructing medical students about cost of care on cost consciousness, but don't include medical spending as an outcome.[1] Similarly, several studies evaluate cost consciousness of medical providers without examining the relationship between cost consciousness and medical spending.[2,3,4]

Defining the desired outcome as cost consciousness (awareness of cost) as opposed to cost reduction has implications for implementation and evaluation of initiatives aimed at achieving high value care. Given what is known about the influence of financial incentives,[5] local practice patterns, evidence-based guidelines,[6] and cultural norms in medical practice,[7] increasing awareness of high costs may not be adequate to reduce costs. It is not difficult to envision a scenario in which a costly treatment option is chosen over lower cost therapies because the patient, provider or medical delivery system are conscious of cost but prioritize other values in making medical decisions. Using cost consciousness as the desired outcome, this would be deemed a success (because the provider was aware of the cost), although it doesn't result in cost reduction.

**High value care; Definition and application.** The Institute of Medicine defines high value care as "the best care for the patient, with the optimal result for the circumstances, delivered at the right price".[8] The Center for Medicare and Medicaid Services (CMS) doesn't offer a formal definition of high value care, although the concept is used often in CMS literature to describe initiatives aimed at improving outcomes and decreasing cost.  In describing the value-based insurance design model, CMS defines high value clinical services as "those that have the greatest potential to positively impact enrollees".[9] This statement doesn't include cost, but subsequent description of plan design features cost containment as a central aim. An Institute of Medicine (2013) stakeholder roundtable convened to explore increasing value in healthcare services defines high value care as decreasing cost and delivering data-driven care. The Journal of the American Medical Association publishes a patient description of high value care, from which the overriding sentiment is a desire for care that isn't wasteful.[10]

Use of the term 'high value care' to denote improving outcomes and/or decreasing cost doesn't allow for evaluation of health services independent of comparison to existing care delivery or comparison of relative value across healthcare services. For example, a new chemotherapy drug may offer a slight improvement in survival for the same high cost as an existing therapy. Theoretically this represents higher value care if for the same cost outcomes can be improved even slightly. However, most objective observers wouldn't describe this as high value care. As illustrated by this example, when high value care is defined as high*er* quality and/or low*er* cost high value care it can only serve as a relative measure of value, not an absolute designation of high or low value care.

In one of the most often cited articles on high value care, Porter refers to HVC as "health outcomes per dollar spent".[11] This definition implies that value is measured by health outcomes such as infections cured or cancers prevented. Based on this interpretation, healthcare value could not be compared across health outcomes without application of a common unit of measure. This system of value determination is comparable to cost effectiveness analysis, which is often used in health economics.

Medical literature frequently cites improving efficiency of care (avoidance of care that is duplicative or doesn't impact outcomes) as a method of increasing healthcare value. The Institute of Medicine issued a landmark report in 2001 entitled 'Crossing the Quality Chasm' which defines 6 objectives in improving healthcare quality: "safe, timely, effective, equitable, efficient, and patient-centered (STEEEP)”.[12] Conceptually, this subsumes efficiency (understood as a concept comparable to the cost side of cost/quality ratio often used to describe value) as a sub-component of quality, equating it in importance to equity, timeliness, safety and efficacy, rather than weighing cost against health outcomes to understand value. The IOM model is consistent with the established practice in medical research of evaluating health effects as the primary outcome.

High value care is frequently used as a synonym for evidence-based practice. In this utilization of the phrase there is implicit recognition that a substantial proportion of medical care delivered is not indicated according to evidence-based practice guidelines and may not improve outcomes. Delivering care in accordance with evidence-based guidelines is expected to reduce costs by ensuring that every patient receives the right care and only the right care, thus eliminating needless care and increasing quality by preventing exposure to the risks of medical care that offers no benefit.

Numerous articles cite care that doesn’t change outcomes to describe opportunity for promoting high value care. This model presumes that care which has clinical utility is of value, regardless of relative impact or cost. In order to receive high value care, healthcare consumers are advised to ask about the risks, benefits and alternatives to any tests and treatments ordered.[13] Avoiding provision of superfluous care reduces costs and improves outcomes by avoiding exposure to risks of unnecessary medical care. However, elimination of wasteful medical spending resulting from unnecessary care will only make a marginal difference in reducing national healthcare costs and improving population health outcomes. The core element of value relates to obtaining the ‘best health outcomes per dollar spent’, which is not addressed simply by avoiding waste.

The commonly used framework of high value care as reduced cost/and or increased quality characterizes health care that reduces cost without decreasing quality or increases quality without reducing cost as high value. Interventions that result in higher cost and higher quality or lower cost and lower quality can have either a net positive or net negative effect on healthcare value, depending on the relative magnitude of change in cost and quality. This common scenario, in which no dominant strategy is apparent, exemplifies the circumstance in which tools of value measurement are crucial to delivering healthcare that most efficiently benefits population health.

Disparate outcome measures are referenced in the high value literature including subjective and objective outcomes, patient-centered outcomes, population health measures, outcomes over time and outcomes resulting from a single episode of care. Outcomes measures have three primary dimensions: patient population (population, subgroup or individual), provider (entire health system, subset of providers, single provider,), and time (lifetime, limited time period, single episode of care). Selection of the patient population, provider and time parameters will play a large role in determining value, as it impacts both the cost and outcomes associated with a healthcare intervention. For example, intensive diabetes education may increase costs for a single episode of care and provide no short term change in outcomes. However, it may result in long term cost reduction and improved outcomes. The effect of many healthcare services on cost and outcomes is determined largely by the frame of reference, illustrating the importance of thoughtful selection of these outcome dimensions.

The difficulty of selecting appropriate outcome measures is evident when considering the incalculable number of clinical contexts in which health outcomes would ideally be measured and reported. Porter asserts that outcome measures must be patient centered and disease specific.[11] In an article that utilizes a promising method for measurement of outcomes, Kim et al.

evaluate rates of cervical cancer as an intermediate outcome.[14] Changes in screening rates are converted to projected difference in quality adjusted life years (QALYs), allowing for comparison across disease states. Additional outcomes reported include post-colonoscopy complication rates,[15] increased life expectancy,[16] re-hospitalization, hospital days and health related quality of life.[17] Conversion of health outcomes into QALYs (or disability adjusted life years, (DALYs)) is a common practice in health economics research that has not been widely adopted in medical research. Among the more than 100,000 articles in the PubMed database returned by the search term 'ESRD', only 152 include the term 'QALY' just 12 include 'DALY'[2]. Review of health economics literature demonstrates that conversion of clinical outcomes into QALYs and DALYs in the subject of much study,[18,19] and although imperfect, presents an important opportunity for conversion of medical research results into standardized measures that can be used to determine the value of healthcare services.

**Conclusion.** Measurement of health outcomes is a complex, challenging endeavor which has been the subject of much study in recent years. High value care is a complex concept that is often oversimplified in its application. In essence it is a measure of the relationship between healthcare resource expenditures and health outcomes. Most often it is used to describe increasing quality and reducing cost of healthcare services, without deep investigation of the conceptual basis of high value care. High value care is used as a framework to assess whether the use of palliative care and advance directives represent high value end-of-life care for end-stage renal disease patients. Promoting incorporation of cost and standardized outcome measures in medical research will advance the science of value measurement by facilitating application of

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[2] Unless otherwise noted; 1) searches are for term in publication title, abstract and body text, 2) results include MeSH term equivalents, 3) search results are current as of February 19, 2017.

economic methods to relating cost and outcomes. Consistent use of standardized value measurement in healthcare research would allow healthcare delivery systems and policymakers to prioritize healthcare services such that investments in healthcare will yield maximal improvement in population health outcomes. Adoption of this practice would drive increase in value of all healthcare services, including those delivered to ESRD patients at the end of life.

## Palliative Care: Effect on Quality of Life and Healthcare Costs Among ESRD Patients

The following literature review will evaluate literature on the quality of life and healthcare cost implications of providing palliative care for end-stage renal disease patients. This information will be used to determine whether palliative care increases the value of end-of-life care for ESRD patients according to the high value care framework described in the preceding literature review. High value care literature compares costs to health outcomes, usually reported as change in disease burden or mortality risk. For patients with life-limiting illnesses morbidity and mortality are not the most meaningful health outcomes. In this population, research appropriately focuses on patient-centered outcomes such as quality of life, patient and family satisfaction and symptom management. Therefore, review of palliative care and advance directive literature will report quality of life as the ‘health outcome’ component of value.

**Palliative care and quality of life in ESRD.** Literature on the impact of palliative care on quality of care in ESRD is voluminous relative to that describing the cost implications. A title/abstract search of PubMed for the terms ‘ESRD’, and ‘palliative care’ yields 346 results. Much of the information comes from a small group of authors who have published prolifically and passionately on this topic.[20,21,22,23,24,25,26,27] Two clinical trials evaluate interventions targeting symptom remediation and/or quality of life issues for ESRD patients and their caregivers, which are outcomes consistent with goals of palliative care.[28,29] Weisbord et al. find that informing physicians of patients' depression, pain and erectile dysfunction improves management of these symptoms.[28] Chan et al. conducted a pilot randomized controlled trial in Hong Kong to assess the effect of a targeted psychosocial intervention for ESRD patients not receiving dialysis on caregiver burden and anxiety.[29] The study finds a significant reduction in caregiver burden and anxiety at one and three months, and statistically insignificant reduction at 6 months. This lack of statistical significance is likely due to small sample size (n=29) in this pilot study.

In studies of palliative care in ESRD, palliative care is often used to describe the conservative treatment option; thus studies provide information on the use of dialysis versus palliative care, but don't shed light on the use of palliative care compared with no palliative care.[30,31] In this case, patients receiving palliative care are those who have chosen to forego dialysis, limiting ability to evaluate the impact of palliative care for those undergoing hemodialysis. For both advance directives and palliative care, the value of the intervention will depend on what it is compared to.

Expanding the search by removing ESRD from the search terms yields 61 clinical trials, most of which are related to oncology medication trails. Opinion pieces abound, but data is scarce. A randomized clinical trial from Taiwan found reduction of anxiety and symptom burden at 1 and 3 months for pre-dialysis chronic kidney disease patients who received an intervention from palliative care nurses, but no significant difference at 6 months.[32] Sandsdalen and colleagues compared the quality of life impact of palliative care across setting (inpatient, nursing home, home care), but didn't compare quality of life for patients receiving palliative care versus usual care.[33] A recent meta-analysis found that palliative care is associated with improved patient and caregiver satisfaction and no change in survival.[34] This study includes oncology and non-oncology populations, with no stratification of outcomes according to disease state.

No studies of palliative care and quality of life outcomes demonstrated a detrimental impact of palliative care. Few studies have described the effects of palliative care for ESRD patients, but the consistent finding of improved quality of life with use of palliative care in a wide range of acute and chronically ill patients suggests that ESRD patients can expect to realize similar benefits with use of palliative care. The quality of life effects of palliative care for ESRD patients, with emphasis on determining the ideal timing of palliative care initiation, are important areas of future study to better understand how palliative care effects healthcare value for ESRD patients.

**Palliative care and cost.** Currently no published studies describe the impact of palliative care services on the cost of care for ESRD patients.  Therefore, literature will be reviewed for information regarding the impact of palliative care on the cost of healthcare for chronically ill populations. Literature related to oncology patients was excluded because the patient profile and treatment cost associated with oncology differs substantially from those associated with chronic kidney disease and end stage renal disease.

For the purposes of this review palliative care services are defined as consultation by a physician, nurse practitioner, or physician's assistant specializing in palliative care, with or without follow-up care. **Table 2.2** describes the literature search procedure and results. PubMed, Scopus and Cinahl databases were searched using all logical combinations of the terms 'end stage renal disease' 'kidney failure', 'palliative', 'hospice', 'cost' and 'economics'. Hospice was included as a search term because hospice and palliative care are often used interchangeably, although there is a distinction between the services.  Hospice care includes palliative care services, but palliative care services are not limited to end of life as hospice care is. No articles were excluded based on publication date. Results were limited to U.S. publications due to the unique nature of U.S. healthcare funding. Database searches of title and abstract using the terms 'cost' and 'palliative care' yielded over 3000 results, so when using these broad search terms, the search was limited to the title only. The oldest articles are from 1990s with the overwhelming majority of publications dating from after the year 2000. Dr. Balfour Mount of Montreal, Canada is credited with coining the term "palliative care" in 1974, in an effort to differentiate symptom management from end-of-life care.[35] However, the palliative care movement didn't begin to gain traction in the U.S. until the Institute of Medicine released a report in 1997, which detailed glaring deficiencies in end-of-life care.[36] The history of palliative care in the U.S. is consistent with the trends in the volume of published literature on palliative care in recent decades.

Palliative care consultation is the independent variable in all studies reviewed. The definition of palliative care varies widely in palliative care literature, encompassing interventions that range from services provided by an individual nurse, case manager or physician to services provided by a team which may be constituted from personnel with differing levels of licensure and experience in palliative care. The outcome of interest is healthcare costs. Cost can be measured many ways and it is often challenging to standardize across studies. Articles were included if they report any cost measure related to healthcare utilization, regardless of whether the outcome is for a discrete episode of care, total healthcare costs for an individual or costs at a population level. No studies were disqualified due to cost reporting method.

A total of seven studies were selected for review: five retrospective, observational studies on the association between palliative care and cost of inpatient care for non-oncology patients,[37,38,39,40,41] one longitudinal study of cost differences between an inpatient palliative care unit and medical-surgical/intensive care units,[42] and one randomized controlled trial that evaluated the association of home-based palliative care with total healthcare costs.[43] Based on searches of PubMed, Cinahl and Scopus, these appear to be the only published studies on the association between palliative care and cost that are not specific to oncology patients. These studies consistently find that palliative care is associated with reduced healthcare costs, but there are some important limitations to consider when assessing the strength of these findings.

Evaluating the five observational studies of inpatient palliative care in chronological order is illustrative because each builds on previous work. Initially, Penrod et al. conducted a small study in the VA system that showed cost reduction with use of palliative care for patients with terminal hospitalizations.[37] Subsequently, Morrison et al. conducted a larger study outside of the VA that included non-terminal hospitalizations, but excluded patients with a length of stay less than 7 or greater than 30 days.[38] Next, Penrod et al. conducted a larger study at the VA with broader inclusion criteria.[39] Morrison et al. went on to study the question of palliative care and cost in the Medicaid population.[40] Finally, Starks et al. conducted a study of palliative care and cost in the non-VA setting that included patients with length of stay less than 7 and greater than 30 days.[41] Each study contributes valuable information to the knowledge base by filling gaps in previous literature.

Four of the six inpatient studies and the outpatient Kaiser study defined palliative care as a physician led palliative care team.[37,38.39,40,43] Starks, Wang, Farber, Owens and Curtis did not clearly define palliative care consultation, which limits the utility of the information derived from that study.[41] The largest study, by Morrison et al. in 2008, used data from 8 hospitals but only 4 palliative care teams, some of which had only been in existence a short period of time preceding the study period creating a maturity threat (potential for change in palliative care team performance over time).[38] All of the inpatient studies included patients who had even a single episode of care provided by the palliative care service, and did not distinguish between patients who received a consultation versus those who received ongoing care from the palliative care team.

The dependent variable in all studies was healthcare costs. Six inpatient studies evaluated inpatient care costs only,[37,38,39,40,41,42] whereas the outpatient study looked at total healthcare costs.[44] The inpatient studies used varying cost metrics including per diem costs, total hospital costs, cost stratified by length of stay, cost per ancillary service (radiology, lab, nursing, etc.) and number of intensive care unit days. Two studies were conducted in Veterans Administration (VA) hospitals,[37,39] which have a different cost structure than the private healthcare sector. Similarly, the outpatient study was conducted on patients enrolled in the Kaiser system that works on the health maintenance organization (HMO) model, rather than a fee for service basis.[44] This limits generalizability of the findings generated by the VA and Kaiser studies. The inpatient studies conducted in non-VA settings used hospital cost data to determine hospital cost, as opposed to charges or payments.[38,40,41] The fact that hospital cost has limited correlation with charges and payer expenditures was not addressed in any of the studies in their research design or the accompanying narrative. This is an important knowledge gap that limits understanding of the healthcare resource utilization effects of palliative care from a policy and payment system perspective.

Samples selected in the five retrospective, observation inpatient studies differ in important ways. Penrod et al. conducted an initial study in the VA setting and included only patients with a terminal hospitalization.[39] The demographic profile of VA patients is significantly different from the general population and evaluating only terminal hospitalizations confounds palliative care services with hospice care. A later, larger VA study by Penrod et al. alleviates hospice confounding by including non-terminal hospitalizations, but still faces restricted generalizability due to the VA setting.[39] Morrison et al. included non-terminal patients and was set in academic and private hospitals, but excluded patients with a length of stay less than 7 days or greater than 30 days.[38] Starks, Wang, Farber, Owes and Curtis found that patients with length of stay less than 7 and greater than 30 days comprised almost half of patients who received palliative care and designed a study to include this population.[41] The Starks study collected data from two non-VA hospitals and had the least restrictive sampling criteria, essentially including all patients who received a palliative care consultation during the study period. Morrison et al. studied Medicaid patients at two non-VA hospitals, but restricted the sample to patients with seven specific admitting diagnoses.[40] White, Stover, Cassel and Smith included all patients referred to a newly-established inpatient palliative care unit, with comparison of hospital costs pre and post transfer to the unit.[42] Brumley et al. studied Kaiser patients receiving palliative care in the outpatient setting.[43] This study limited the sample to patients with a life expectancy of less than 12 months and required patients to have at least one of just three qualifying diagnoses for inclusion.

All five retrospective, observational inpatient studies used a propensity score matched case control group.[37,38,39,40,41] Propensity scoring models differ from study to study and are not extensively described in any study. Propensity score matching allows for comparison of patients who received palliative care to similar patients who did not receive palliative care, thus allowing for attribution of changes in cost to palliative care. All information derived from these studies is based on the comparison of palliative care and usual care patients, the validity of which rests on the accuracy of propensity score matching. For each study, researchers developed a propensity score model that included variables deemed to be of significance such as age, co-morbid illness and number of recent hospitalizations. Propensity scoring is not done according to a standardized model, nor are there established methodologies for testing the accuracy of a propensity score model.[45] In spite of these limitations, use of propensity score modeling has been validated and is common in studies of observational data.[45,46]

The outpatient study by Brumley et al. is a randomized controlled trial, which is relatively rare in the body of palliative care literature.[43] Due to the growing body of evidence demonstrating benefits of palliative care, researchers have questioned whether it is ethical to conduct RCTs in which palliative care is withheld from patients. The randomized controlled trial reviewed is uniquely valuable since this concern may limit opportunity to conduct such studies in the future. The study randomized terminal patients with select diagnoses to receive palliative care or usual care in the home setting. The study was conducted within two Kaiser systems in Colorado and Hawaii. This geographic divergence calls into question the consistency of care provided across locations, since it is well established that patterns of care vary by region. This concern is moderated by the fact that both settings are within the Kaiser system, which can be expected to have greater standardization of care across regions than local health systems.

All studies found a statistically significant reduction in healthcare costs associated with the use of palliative care, with the exception of Starks, Wang, Farber, Owens and Curtis who found a cost reduction only for patients with length of stay less than 30 days.[41] Irrespective of setting, patient population, or cost metric the results are consistent across studies. The majority of studies used general linear modeling to evaluate the association between palliative care and cost, as it handles dependent variables with skewed distribution well. Authors in all studies conclude that use of palliative care reduces costs, and recommend wider utilization of palliative care to increase quality while lowering cost of care.

The primary threat to internal validity in the inpatient studies is the use of propensity scoring as a mechanism to evaluate the cost impact of palliative care. Although the studies are strengthened by the consistency of findings, the findings cannot be considered conclusive until studies utilizing varied methodology produce similar results. Further threat to internal validity stems from applying palliative care interventions to terminal patients, which obscures the distinction between hospice and palliative care. Poor definition of palliative care services was an anticipated threat to internal validity, but was not an issue except in the Starks, Wang, Farber, Owens and Curtis (2013) study.[41] External validity is threatened by the limitations placed on patient sampling and study settings. Two of the seven studies are set in the VA,[37,39] which significantly limits generalizability of both in terms of cost and patient profile. The only randomized controlled trial was conducted with Kaiser HMO patients, thus limiting the extent to which cost impact can be translated into fee for service health care delivery systems.[43] Of the seven studies, three limited their sample to patients with specific diagnoses.[38,40,43] This limits generalizability of the findings, since medical needs and therefore medical costs differ by disease state.

The small body of knowledge regarding impact of palliative care on cost of care in the inpatient setting has demonstrated consistent findings, but had some key limitations. Most of the authors involved in publishing the five retrospective, observational studies participated in more than one study. This indicates that there is a considerable pool of experience within the authorship of these articles, but also creates the opportunity for replication of methodological weaknesses. This is of particular concern related to the use of propensity scoring, which was the basis for identifying a comparator group in all five studies. A central group of leading authors in the field have driven the majority of the research conducted in this area. Their expertise and vision has undeniably shaped the field in this area. Most of these authors are vocal proponents of palliative care and have published numerous op-eds promoting the benefits of palliative care. This does not discredit their work, but it is important to consider the ideological bent of the authors when evaluating the body of work related to palliative care and cost.

**Conclusion.** Review of the literature reveals a dearth of data regarding the impact of palliative care on cost and quality of life outcomes for ESRD patients. This is an important area for future study, considering the issues of cost and quality of life endemic to ESRD patients. Understanding the existing literature regarding palliative care and healthcare costs in the non-ESRD patient population serves as a foundation for developing methods of evaluating the concept in ESRD patient populations. In terms of the larger questions of palliative care and cost, there is a need for more study of the effect on total healthcare costs to extend the information currently available about setting-specific cost implications. Studies based on varied methodologies are needed to evaluate the impact of palliative care on healthcare costs. This nascent body of literature will be significantly more valuable in informing health policy and designing healthcare delivery systems if these knowledge gaps are filled.

Given the information available, it is reasonable to conclude that palliative care will increase quality and reduce cost or be cost neutral for chronically ill patient populations. However, the evidence supporting improvement in quality of life outcomes is stronger than the evidence for cost effects of palliative care. Two published systematic reviews of literature on the cost and quality implications of palliative care reach the same conclusions.[34,48] The change in quality of evidence from 2008 to 2016 is marked, particularly regarding the quality implications of palliative care. The current body of literature is adequate to form the basis for policy enquiry, such as questions of care quality and access for specific populations. Clinical providers would be well advised to increase utilization of palliative care for chronically ill patients to improve quality of life outcomes. Among ESRD patients, palliative care is associated with end-of-life care that has been linked to increased patient and family satisfaction. The cost effects of palliative care for ESRD patients have not been directly evaluated. Information on the cost implications of palliative care for ESRD patients at the end of life is necessary to establish whether palliative care will increase the value of end-of-life care for ESRD patients.

## Advance Directives: Effect on Quality of Life and Healthcare Costs Among ESRD Patients

As with the palliative care cost/quality literature review, the literature review of advance directive effects on quality of life and cost assesses whether advance directives increase the value of end-of-life care for ESRD patients by parsing the question into the foundational elements of cost and quality.

**Advance directives and quality of end-of-life care.** End-stage renal disease patients are acknowledged to have limited life expectancy, thus outcome measures must balance emphasis on quantity and quality of life. Limited data evaluates the effects of advance directives on quality of life directly, but some information can be extrapolated from existing literature. Literature often refers to congruence between expressed wishes and care delivered, capturing the patient-centered element of healthcare delivery quality.[49,50,51,54] In keeping with the prevailing preference for avoidance of futile therapies at the end of life, avoiding dialysis at the end of life can be seen as an indicator of quality of care in the end stage renal disease population.[25] Other commonly used measures of quality are death in a hospital and death in the ICU.[53,54,55] Both are viewed as indicators of lower quality care, given that the majority of patients express a desire to die in the home and forego heroic measures if the care is futile. However, there is a substantial minority of patients who express a preference for life-sustaining treatment, which often results in an in-hospital death. To evaluate quality of care for both patients who wish to receive life-sustaining treatment and those who wish to forego life-sustaining treatment, care congruence with patient preference may be a more meaningful measure. Another important measure of quality is the use of hospice and palliative care services. A large and rapidly growing body of qualitative and quantitative literature describes the beneficial impact of the use of these services on the dying process for both patient and family.[56,57]

Search of the PubMed database for 'advance directive' and 'renal' yields 171 articles, but only 3 clinical trials. A recent study by Kurella and colleagues shows that among ESRD patients residing in a nursing home, the presence of an advance directive was associated with reduced delivery of intensive end-of-life care, and increased hospice enrollment; intermediate outcomes that have been linked to improved patient and family satisfaction with end-of-life care.[58] A pilot study published in nursing literature finds that advanced care planning education administered by trained nurses increased sense of positive involvement in end of life decision making, reduced decisional conflict, and improved patient perception of communication with providers.[59] This trial includes patients with renal disease, but is not limited to this population and doesn't report results specific to renal disease patients. A study of dialysis patients evaluated the efficacy of peer mentoring in promoting advance directive completion and finds that peer mentoring increases completion of advance directives, particularly in minority races.[60] The study evaluated the intermediate outcome of advance directive completion, but does not determine whether advance directive completion translates into improved quality end of life care.

A systematic review of Cochrane Registered Trials between 1966 and 2013 finds that completion of advance directives increased congruence between expressed preferences for care and care delivered.[61] Luckett et al. published a systematic review of the use of advance directives in chronic kidney disease patients, which finds that research is indeterminate regarding the effect of advance directives on quality of end of life care.[62] In contrast, two recent studies evaluating the impact of advance care planning on ESRD patients find improved end of life outcomes.[63,64] Schmidt, Weaner and Long report that the use of advance directives is associated with lower rates of in-hospital death and more frequent hospice utilization.[63] Song et al. find that advance directives improve care congruence with expressed end of life care preferences and reduce caregiver uncertainty.[64]

Thematic synthesis of qualitative work on end of life care for CKD patients reveals that patients and caregivers experience ambivalence and uncertainty about treatment decisions,[65] indicating that guidance and education from providers on advance care planning may help clarify end of life care wishes and thus reduce anxiety and distress about treatment options. In the general elderly population, advance directives have been shown to decrease the likelihood of dying in the ICU,[66] indirectly suggesting improved congruence between patient preferences and care delivery with the use of advance directives; an important measure of healthcare quality.

**Advance directives and cost of care.** Considering the frequency with which end of life care costs are cited as a reason for growing healthcare expenditures,[67,68] surprisingly few studies evaluate the cost implications of advance directive completion. Of those that do many are more than 10 years old.[69,70,71,74] Lack of current research in this area may reflect the polarized political climate around the use of cost as a measure of healthcare outcomes in end of life care. Limited information has been published on the impact of advance directives in the end stage renal disease population. No studies evaluating cost implications of advance directive use in end stage renal disease patients were identified, so the search was broadened to include all patient populations. See **Table 2.3** for a summary of studies on cost implications of advance directive use. Research that uses intensity of end-of-life treatment as an indicator of quality outcomes has demonstrated that advance directives are associated with reduced use of high-intensity interventions at the end of life for ESRD patients,[58] which implies reduced resource use.

One of the most frequently cited articles related to cost implications of advance directives is a systematic review by Ezekiel Emanuel,[69] who later became an influential figure in crafting the Affordable Care Act legislation. His review reports the existence of three randomized controlled trials, none of which find cost savings with use of advance directives. Each of these trials is described as being of inadequate size to generate valid findings and/or having methodological flaws related to assessing cost. Findings from non-randomized trials vary widely and are hampered by inconsistency in cost reporting and selection bias among study populations. His review concludes that data available at that time suggested cost savings of 25-40% in the last month of life, 10-17% in the last 6 months of life and 0-10% over the last year of life, but that the quality of evidence was poor and further study was indicated.

A more recent systematic review of advance care planning efficacy identified five additional studies which included healthcare utilization as an outcome.[61] Of these five articles, three find that completion of advance directives is associated with lower healthcare costs at the end of life and two find no relationship between AD completion and healthcare costs. These studies were limited by methodological issues similar to those noted in Emanuel's 1996 review.

Since this more recent review was published, a small number of studies have further evaluated the relationship between advance directive use and healthcare costs. Garrido, Balboni, Maciejewski, Bao, & Prigerson found that the presence of an advance directive was not associated with changes in healthcare costs in the last week of life regardless of setting (home, hospital, nursing home).[73] A study using survey data from Medicare beneficiaries to evaluate advance directive use and end-of-life costs in Medicare patients finds that advance directive completion is associated with lower costs in high-cost Medicare spending regions, but no difference in lower cost areas.[74] Importantly, no studies find increased cost with use of advance directives.

**Summary.** Completion of advance directives is expected to improve quality of life outcomes by encouraging congruence between patient preference and care delivered. Given that most individuals express a desire to die at home and avoid intensive, futile treatment, it is expected that use of advance directives would decrease end of life healthcare costs. Literature generally supports the use of advance directives to increase quality and decrease costs in end-of-life care. This is moderately well substantiated in the general elderly population. Information specific to ESRD patients is limited in scope, but generally supports use of advance directives to increase quality of end-of-life care. Research in other populations indicates that advance directive completion results in stable or reduced costs,[69,70,72,71,75,77] and improved quality end of life care.[78,79]

A recent Institute of Medicine Report recommends increasing rates of advance directive completion to increase quality and decrease cost of end of life care for chronically ill populations.[80] Advance directive completion is often recommended as a focus area for Medicare quality measures in response to these concerns. Medicare intends to have 9% of payment tied to quality measures by 2017,[82] making quality measures a focal point for healthcare delivery systems. CMS has taken the important step of reimbursing providers for advance care planning, but hasn't yet tied advance directive completion rates to reimbursement. Based on the state of the evidence, it is reasonable to promote advance directives as high value care, but restraint should be exercised not to overstate the anticipated benefits considering the limitations of current knowledge regarding the impact of advance directive use on cost and quality of end of life care.

## Conceptual Framework

Each aim of the dissertation sheds light on a key component of improving the value end of life care for ESRD patients. The theoretical framework within which the dissertation is embedded broadens the conception of high value care from outcomes related to medical interventions to outcomes related to all factors that affect health, including individual and social characteristics. Considering health as the result of biologic, medical and social factors, the research program outlined in this dissertation promotes higher value medical for ESRD patients. Sociologic theory serves to expand consideration of health inputs into the social domain, thus incorporating social determinants of health into the range of factors assessed in measuring the value of *health* care, rather than limiting the scope of investigation to *medical* care.

Integrating these dissertation aims in sociologic theory acknowledges the reality that improving medical care is only one pillar of improving health. The theories used to assert this framework center on race as a lens through which to understand social determinants of health. This is well aligned with the demographics of the ESRD population, which is disproportionately non-white. Inequity in the incidence and prevalence of ESRD results in substantial personal and societal cost, the majority of which falls upon individuals and communities least equipped to bear this encumbrance. Understanding the origins and manifestations of ESRD in populations with the highest incidence of this disease serves as a foundation for defining high value care from a social perspective.

A blend of three sociologic theories is used to generate a broader, more nuanced definition of high value care, unconstrained by the boundaries of medically defined interventions. These three sociologic theories of health will be applied to the question of high value care in end stage renal disease: cultural health capital, life course perspective, and public health critical race praxis. These theories move in scope from narrow to broad, examining the interaction between individual characteristics and health from the level of granular interpersonal interaction, over the life course and as an element of medical epistemology. See **Figure 2.1** for a depiction of the relationship between these three theories.

Cultural health capital theory is a narrow, applied theory which examines the impact of individual characteristics on the quality medical interactions. Life course perspective is a mid-range theory which extends beyond the cultural health capital framework to describe the effects of race on health across communities and over time. Public health critical race praxis acts as an overarching applied theory, used to inform conceptualization of race and race effects on health. These theories are used to inform conceptualization of social determinants of health, in order to understand high value care from a societal perspective. Use of a sociologic framework illuminates the cumulative effect of social factors that parallel medical disease progression. Insights gained from evaluation of this parallel pathway introduce the possibility that the highest value interventions for populations at risk for ESRD fall far beyond the traditional realm of medical care, such as creating equal access to education and economic opportunity.

## Conclusion

Understanding healthcare reform within the framework of high value care underscores the importance of rational resource utilization to improve population health outcomes. Although high value care remains an imprecisely defined term, salient components of the concept provide a useful perspective through which to evaluate interventions aimed at remediating an area of healthcare service widely acknowledged to represent low value care; end of life care for ESRD patients. Conceptual definitions of high value care identified in the literature serve as a framework for investigating the cost implications of palliative care and racial disparities in advance directive completion. This unifying theme aligns all dissertation research with the core guiding principle of improving the value of end-of-life care for individuals with ESRD.

**Table 2.1** Summary of High Value Care Conceptual Definitions

| **Citation** | **Summary** | **Value Conception** | | **Significant Contributions** |
|---|---|---|---|---|
| | | **Cost** | **Quality** | |
| *Research* (n=5) | | | | |
| Kim et al.* (2015) [47] | CEA in cervical cancer screening | Cost of screening | Change in QALYs,<br>Lifetime cost implications of screening<br>Willingness to pay | -No HVC comparison across disease states<br>-Compares economic cost/benefit (measured as change in QALYs and WTP) of screening<br>-Captures subjective and objective quality measures<br>-WTP used as a measure of subjective value placed on outcomes |
| Lawson et al. (2014)[48] | Evaluates relationship between risk-adjusted cost and quality for colonoscopy | Risk adjustment applied to cost measure (cost for episode of medical care) | Complications and mortality | -Used hospital level data to compare cost and outcomes<br>-Found that lower cost facilities were associated with better quality outcomes, concluding that represents HVC |
| Veenstra (2014)[49] | Evaluates difference in cost and outcomes for colon cancer care in various settings | Medical cost only | Complication rate | -No exploration of HVC concept<br>-Used as shorthand for lower cost, higher quality |
| Ubel et al. (2012)[50] | Survey evaluates cost/year of life tradeoff in MD decision making (oncologists) | Cost of specific therapy | Increased life expectancy | -Uses high value care and cost-effectiveness interchangeable<br>-Finds wide variance in provider valuation of patients life years |
| Naylor et al. (2013)[51] | Evaluates cost of care and outcomes for small patient group | Inpatient costs over defined time period | Re-hospitalization, hospital days, HRQOL score | |
| *Opinion* (n=28) | | | | |
| Qaseem et al.* (2012)[52] | Use of screening and diagnostic testing test for high value, cost conscious care | Efficiency- avoid overuse of tests. | Quality defined by whether test will change management. | -Distinguishes between cost and value, based on effect on outcomes<br>-Looks at ratio of false positives to true positives as a measure of value (sometimes >1 in low risk patients). |
| Bohmer* (2011)[53]* | Contribution or organizational characteristics to HVC | Cost | Outcomes | -Identifies habits of organizations that provide HVC.<br>-Refers to HVC as ratio of cost to outcomes |
| Owens, Qaseem, Chou, Shekelle, & Clinical Guidelines Committee of the American College of Physicians Bohmer* (2011)[54] | Describes a method for evaluating the benefits, harms and costs of medical interventions | Costs- of test/treatment and all downstream effects | Quality measured by: Benefit: harm ratio, health benefits | -Identifies stages of improving value in care<br>1. Eliminate unnecessary medical treatment<br>2. Provide care that is commensurate with cost<br>- Uses incremental cost effectiveness ratio to define cost/benefit; additional cost to obtain additional health benefit |

| Citation | Summary | Value Conception | | Significant Contributions |
|---|---|---|---|---|
| Porter* (2010)[55] | Assessing value in healthcare | Global cost of care for disease specific treatment | Patient centered outcomes: disease specific, multidimensional | -Understanding cost in this way (as compared with FFS) encourages investment in areas that reduce overall costs and improve outcomes.<br>-No process or resource measures |
| Parikh, Kakad, & Bates (2016)[56] | Predictive analytics and HVC | Efficiency | Right care, right patient | Cost reduction/quality improvement with precision delivery |
| Bosch & Fleming (2015)[57] | When the use of CPR is HVC | Cost of futile care (implied) | Effectiveness of intervention (survival) | Outcomes show low success rate at high cost indicating low value care |
| McCarthy (2015)[58] | HVC screening recommendations | Not included, assumed to be cost of screening | Quality only based on screening yield | -Consensus based guidelines.<br>-No explicit description of criteria underlying recommendation for/against specific cancer screenings |
| Chou & High Value Care Task Force of the American College of Physicians (2015)[59] | Advice for determining when diagnostic imaging is HVC for back pain | Cost reduction through targeted use of technology | Care that is data driven | Consensus guidelines |
| Korenstein D. (2015)[60] | Patient perceptions of HVC | Global cost of care | Maximize benefit, minimize harm | HVC not a conceptual focus |
| Charalel et al. (2015)[61] | Radiology as HVC | Reduced cost | Improving clinical outcomes | HVC used to mean evidence-based practice. |
| Baron & Davis (2014)[62] | Accelerating adoption of HV primary care under new Medicare system | Resource use | Patient outcomes | Advocates linking cost/outcomes to payment system |
| Weiner (2014)[63] | HV cardiac imaging | Overuse of technology, efficiency | Effectiveness (subjective/objective change in health status) | -Advocates patient centered definition of HVC rather than test based definition or criteria.<br>-Uses a broad measure of cost, including false positives, QALYs and effect of test/treatment.<br>-References the concept of 'health outcomes per dollar spent' |
| Roski, Bo-Linn, & Andrews (2014)[64] | Policy implications of creating healthcare value through use of big data | Cost | Quality | |
| Betancourt (2014)[65] | Improving quality in equity in healthcare transformation | Cost conscious | Quality | Includes equity as a component of value |
| Gomella (2013)[66] | Cost containment in prostate cancer | Cost of each additional unit of care | Years of life gained | -Links survival gained to incremental increase in cost.<br>-Conceptual basis comparable to marginal cost for marginal gain<br>-Poorly worded analysis |
| Baugh & Schuur (2013)[67] | Inpatients observation care- HVC or cost shifting? | Indirectly refers to cost shifting to patient | No measure | -HVC concept not incorporated into framework of article, just in the title |

| Citation | Summary | Value Conception | | Significant Contributions |
|---|---|---|---|---|
| Wilt & Qaseem (2012)[68] | HVC in DM, Hgb A1c targets and high cost meds | Using lowest cost alternative | Absence of harm | Defines low value care; high cost, low benefit |
| Robbins, Garman, Song, & McAlearney (2012)[69] | Role of systems in driving HVC | Cost | Quality | -No defined measures<br>-HVC conception inferred from description of health systems factors associated with high/low value care |
| Gabow, Halvorson, & Kaplan (2012)[70] | Encouraging HVC leadership | Decrease cost, efficient, targeted services, optimal utilization of resources | Effective, consistent care, harm reduction (less exposure to unnecessary medical care). | -Checklist of 10 principles for delivering HVC.<br>-Key factors in HVC delivery: culture of CQI, organizational leadership, patient-focused evidence-based care. |
| Naylor, 2012[71] | Use of nursing in transitional care management to promote HVC | Total cost of care | Hospitalization, ER visits, patient satisfaction | Includes subjective and objective health outcomes |
| Yeung, Burns, & Loiacono (2011)[72] | Evaluation of ACO impact on promoting HVC | Cost | Quality | |
| Kurtzman (2010a)[73] | Recommendations for HV inpatient nursing care | | | -HV care only in title<br>-Promotes transparency and accountability |
| Kurtzman (2010b)[74] | Contribution of nursing to cost/quality in healthcare | Cost | quality | Focuses on why nursing isn't at the table in national discussion of healthcare value |
| Markus & Rosenbaum (2010)[75] | Promoting access to high quality HVC for Medicaid patients | | | -Article only describes quality<br>-HVC used in the title, not in the body of the article |
| Chernew (2009)[76] | Looks at economic impact of high healthcare costs and promotes the role of health services research | | | -HVC only mentioned in the title and abstract<br>-Describes med adherence as an example of HV care |
| Baicker (2008)[77] | Describes parameters of debate in providing HVC to all | Cost | Quality | -Maintaining quality and reducing costs versus choosing between alternatives accounting for cost and quality<br>-Operationalization of evaluating cost/quality not discussed<br>-Ties rationing to high cost of care, thus decreased costs expected to increase access. |
| Fendrick & Chernew (2007)[78] | Value based insurance design for high deductible plans | Cost, focus on cost borne by consumer. | Evidence based -care | -Posits that providing high-value care will stem from provider/system design side, not be consumer driven<br>-Looks at impact of high deductible plans on value (lowering cost and increasing quality) |
| Bertodano Id (2003)[79] | History of Costa Rican health system | Global cost | Healthcare access, health outcomes, waiting times, accountability | System was designed at a national level from a perspective of stewardship, not by providers. |

| **Citation** | **Summary** | **Value Conception** | | **Significant Contributions** |
|---|---|---|---|---|
| *Expert Panel Guidelines/Recommendations* (n=4) | | | | |
| Van Citters et al. (2014)[80] | HVC for arthroplasty | Reduce waste | Improve care | Recommends improved communication |
| American College of Physicians (2011)[81] | HVC in use of radiology for LBP | Cost of test only | Testing only when indicated defined as the measure of quality | -HVC mentioned only in title<br>-Recommends improving care by avoiding tests that offer no benefit |
| Jolivet, Corry, & Sakala (2010)[82] | Transforming maternity care | | | HV in title only |
| Carter et al. (2010)[83] | Prescription for HV maternity care | Cost | Improved health outcomes | -Looks at quality and value<br>-Value defined as optimal cost to quality ratio |
| *Review* (n=7) | | | | |
| Thomson, Schang, & Chernew (2013)[84] | Incentivizing patients to seek HVC | Increase efficiency | More health out of each dollar spent. Use of lower cost alternatives | -Value based cost sharing.<br>-Cost reduction with equivalent outcomes increases value of care |
| Hood & Weinberger (2012)[85] | Cost conscious care initiative | Waste | | High cost a problem worldwide |
| Hibbard, Greene, Sofaer, Firminger, & Hirsh (2012)[86] | Driving high cost consumers to choose HVC | Global healthcare costs | Quality | Promotes decreasing cost and preserving outcomes |
| Chou, Qaseem, Owens, Shekelle, & Clinical Guidelines Committee of the American College of Physicians (2011)[87] | Evaluates cost and outcomes of diagnostic imaging for low back pain | Cost, reduce waste | Maintain/improve quality with less tests | Elimination of low value imaging as both cost reduction and quality improvement |
| Brennan, Lee, Wilk, Lyttle, & Weiss* (2010)[88] | Measuring cost for colonoscopy | Cost of a single episode of care | | -Work by high value healthcare project<br>-First stage of project to tie cost to quality, will define outcomes later to create composite measure of value<br>-Procedure specific assessment of value rather than developing a global definition |
| Teisberg & Wallace (2009)[89] | Creating high value healthcare system | Cost | Health outcomes | |
| Kristensen & Jacobsen (1994)[90] | Looks at cost assessment, methodologic issues | Cost | | -Article from Norway<br>-Evaluates techniques for defining and measuring cost |

*Includes attempt to define relationship between cost/quality
CEA = Cost effective analysis
ACO = Affordable care organization
DM = Diabetes Mellitus
FFS = Fee for service
Hgb A1c = Hemoglobin A1c (measure of diabetes control over time)
HVC = high value care
QALYs = quality adjusted life

**Table 2.2** Palliative Care; Literature Search Strategy and Results

| | ESRD AND palliative care (MeSH) AND cost | ESRD AND hospice care (MeSH) AND cost | ESRD AND palliative care AND economics (MeSH) | Kidney failure, chronic (MeSH) AND hospice care (MeSH) AND cost | Kidney failure, chronic (MeSH) AND palliative care (MeSH) AND cost | Kidney failure, chronic (mesh) and palliative care/economics (MeSH) | Palliative care AND cost AND NOT oncology, malignancy, cancer, chemotherapy |
|---|---|---|---|---|---|---|---|
| Pubmed | 29 | 5 | 4 | 3 | 9 | 2 | 20 |
| Scopus | 10 | 8 | 0 | 21 | 49 | 7 | 21 |
| Cinahl | 1 | 1 | 2 | 1 | 2 | 7 | 23 |

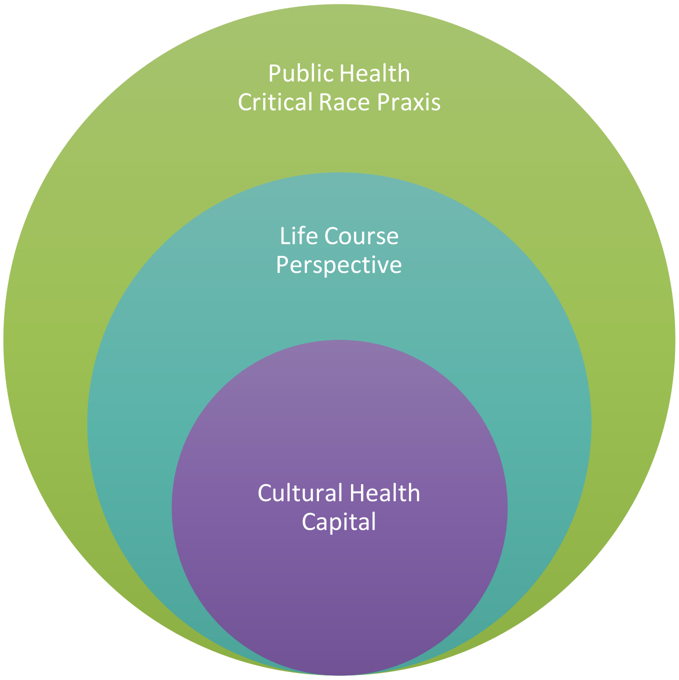
**Table 2.3** Effect of Advance Directives on Healthcare Costs, Summary of Publications

| Study | N | Independent variable (IV) | Outcome | Population | Results | Notes | Study Design |
|---|---|---|---|---|---|---|---|
| *Randomized Controlled Trials* | | | | | | | |
| Molloy et al. (2000)[36] | 1292 | AD | Healthcare resource utilization over 18mos prior to death, HRQoL, mortality | Nursing home residents | Reduced hospitalization, reduced healthcare utilization at end of life with use of AD. No change in HRQoL or mortality | Canadian study | RCT |
| Connors (1995)[37] | 9105 | Provider education on patient prognosis, nurse led ACP with patient and care team | Number of ICU days, hospital resource use, AD completion | Hospitalized adults with life-threatening illness | ACP intervention had no significant effect on hospital resource use, AD completion or patient-provider communication | IV was ACP, not AD completion | RCT |
| Schneiderman, Kronick, Kaplan, Anderson & Langer (1992)[38] | 204 | AD | Pt satisfaction, HRQoL, medical costs in last month of life | VA pts with life threatening illnesses | AD made no difference in cost or quality outcomes | VA study, small N. Only 100 pts died during study period | RCT |
| *Non-RCT Studies* | | | | | | | |
| Kaambwa (2015)[39] | 230 | AD | Total cost in last year of life | Frail Elderly | No association between AD and cost | From Australia | Retrospective analysis |
| Fonk, Davidoff, Lutzow, Chesley & Mathiowetz (2012)[40] | 858 | AD | Cost in last month of life | Medicaid recipients, dual eligibles | No association between AD and cost | In a single health plan in Milwaukee | Retrospective analysis |
| Nicholas, Langa, Iwashyna & Weir (2011)[41] | 3302 | AD | MC EOL expenditures, life-sustaining treatment, hospice care, in-hospital death | MC decedents 1998-2007 | AD lowers costs in high cost regions, no effect in low-med spending regions. AD associated with less in hospital death and more hospice use in high-med cost areas, | Includes ESRD pts, but doesn't report results specific to ESRD. | Retrospective analysis |
| Kelley, Ettner, Morrison, Du, Wenger & Sarkisian (2011)[42] | 2394 | AD, functional status, chronic disease | EOL healthcare costs | HERS survey, decedents 2000-2006 | Race, disease state, family support and decline in function impacted costs, but AD had no effect | Used regression analysis to identify relationship between predictors and cost outcomes. Includes CKD, as a predictor of EOL costs. | Retrospective analysis |

| Study | N | Independent variable (IV) | Outcome | Population | Results | Notes | Study Design |
|---|---|---|---|---|---|---|---|
| Kish, Wallace, Martin, Shaw & Price (2011)[43] | 872 | AD | Ventilation, BP support, resuscitation, dialysis, ICU use, hospitalization, survival | ICU patients | AD results in fewer ICU days and lower ICU charges. AD didn't reduce use of life support technologies after controlling for disease state and severity. | Conducted at an academic medical center | Retrospective case control |
| Taylor, Heyland & Taylor (1999)[44] | *NA* | AD | Hospital resource use | Hospitalized patients | 3 retrospective studies showed decreased hospital resource use with AD. 3 prospective studies (2 randomized, 1 non-randomized) showed no difference in resource use. | | Systematic review |
| (Emanuel, 1996)[33] | *NA* | AD and hospice use | Cost | Variable | 3 randomized trials found no cost savings with AD. Nonrandomized trials found cost savings ranging from zero to 68%. | Identified selection bias, time frame for cost reporting, scope of costs evaluated variability of reported savings and lack of generalizability as key issues with literature | Review |
| Maksoud, Jahnigen, Skibinski (1993)[46] | 852 | AD completion (inpatient versus outpatient) | Hospital cost, inpatient length or stay | Hospitalized decedents of a single center | Reduced cost and shorter length of stay with DNR orders completed prior to hospital admission. Longer hospital stays for pts completing a DNR while admitted. | Very high rates of AD completion – 43-98% depending on disease process. May reflect change over time or regional variation | Retrospective analysis |

HRQoL = Health related quality of life

**Figure 2.1** Relationship of Sociologic Theories



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# Chapter 3

# The Past, Present and Future of Healthcare Value Measurement in Medical Research

## Abstract

U.S. healthcare costs are high and rising. Despite broad consensus among clinicians and policymakers on the need for high value care (HVC), the conceptualization of value measurement in medical literature is inconsistent and imprecise, and application is limited in scope. Health economics research frequently uses cost effectiveness analysis to measure healthcare value, but doesn't describe such analyses as measurement of healthcare value. Identifying cost effectiveness analysis as the conceptual equivalent to healthcare value measurement provides a key theoretical link that bridges the gap from conceptualization to operationalization of healthcare value measurement, and creates a framework for generating medical research that facilitates prioritizing healthcare services according to value. This paper proposes a value-based framework for medical research reporting, and describes: use of HVC in medical literature, historical and policy factors affecting value measurement in medical research, commonly-used health economics value measurement methods, and barriers to value measurement in medical research.

## Introduction

Healthcare costs in the U.S. are high and rising, accounting for 17.5% of GDP in 2015[1] Medicare spending totaled $597 billion in 2014, with expenditures on Medicare and Medicaid comprising 23% of the federal budget.[2] In spite of costly investments in healthcare, national health outcomes fall short of expectations. The United States has well documented deficiencies in key health outcomes, including infant/maternal mortality rates, chronic disease management, and life expectancy.[3] Growing awareness of unsustainable healthcare costs, juxtaposed with underperformance in population health outcomes has given rise to acknowledgement of the need for "high value care" (HVC), defined as the highest quality care at the lowest possible cost.[4] Review of health literature demonstrates that the authors publishing in the journals most frequently read by medical providers and policymakers frequently opine on the need for increased healthcare value, but rarely report results in a format conducive to designing healthcare systems around delivery of high value care; i.e. cost per standardized outcome measure.

Despite broad consensus among clinicians and policymakers on the need for HVC, conceptualization of value measurement in medical literature is inconsistent and imprecise, and application of value measurement in medical research is limited in scope. Cost effectiveness analysis, a well-validated method commonly utilized by health economists, is conceptually equivalent to measuring healthcare value. However, this equivalence is not generally recognized in medical or health economics literature. Identifying cost effectiveness analysis as the conceptual equivalent to healthcare value measurement provides a key theoretical link that bridges the gap from conceptualization to operationalization of healthcare value measurement, and creates a framework for conducting medical research that facilitates prioritizing healthcare services according to value. This paper describes the use of HVC in medical literature, historical and policy factors affecting value measurement in medical research, commonly-used health economics value measurement methods, and barriers to value measurement in medical research. Finally, a framework for medical research reporting conducive to promoting HVC is proposed.

## High Value Care in Medical Literature

### Definition and Application

The Institute of Medicine defines HVC as “the best care for the patient, with the optimal result for the circumstances, delivered at the right price”.[5] In alignment with this statement from IOM, HVC is frequently used as a synonym for evidence-based practice in medical literature. In this context, evidence-based practice is considered HVC because restricting provision of healthcare to evidence-based therapies is expected to reduce costs by ensuring that patients avoid extraneous care, and improve outcomes by preventing exposure to the risks of medical care for which efficacy is not well established.

The most commonly used conceptualization of HVC characterizes care as high value if it reduces cost and/or improved outcomes. Commonly, clinical interventions result in higher cost and better outcomes, or lower cost and poorer outcomes. Such interventions can have a net positive or negative effect on healthcare value, depending on the relative magnitude of change in cost and health outcome. This common scenario, in which no dominant strategy is apparent, exemplifies a circumstance in which tools to measure value are essential to delivering healthcare that most efficiently benefits population health.

Use of HVC to denote increasing quality and/or decreasing cost does not allow for evaluation of health services independent of comparison to existing care delivery, or comparison of relative value across healthcare services. For example, a new chemotherapy drug may offer a slight improvement in survival for the same high cost as an existing therapy. Theoretically this represents higher value care, if for the same cost outcomes can be improved even slightly. However, most objective observers wouldn't describe this as HVC. As illustrated by this example, when HVC is defined as high*er* quality and/or low*er* cost HVC can only serve as a relative measure of value, not an absolute designation of high or low value care.

### Conceptual themes.

Medical literature on HVC lacks conceptual clarity in two important areas: efficiency versus cost reduction and cost consciousness versus cost reduction. Though fundamentally different, efficiency and cost reduction are often used interchangeably in discussion of HVC. Efficiency is described as the absence of unnecessary care, which creates a binary distinction between value and no value, rather than a graduated scale of value. This model presumes that care which has clinical utility is of value, regardless of relative impact or cost. Avoiding provision of superfluous care reduces costs, but elimination of wasteful medical spending will only make a marginal difference in reducing national healthcare costs and improving population health outcomes.[6,7] The core element of value relates to obtaining the 'best health outcomes per dollar spent', which is not addressed simply by avoiding waste.

A review of articles in PubMed containing the term "high value care" from 2005 to present found that articles related to pedagogical models for teaching medical students how to deliver high value care were, with one exception,[8] based on the conceptualization of HVC as lack of wasteful spending. Given that this is the predominant framework used to educate the next generation of physicians, it will likely be the working definition of HVC in the medical field for years to come unless the term is further developed in medical research. Interestingly, no publications address the provision of HVC by non-physician healthcare provider such as physician assistants, and nurse practitioners. This is an important area for future study, because currently 26% of primary care providers are nurse practitioners and physician assistants, and this number is expected to rise in the coming decades due to physician shortages.[9]

Ambiguity regarding cost consciousness and cost reduction results from the assumption that cost consciousness leads to lower cost.[10] Multiple studies evaluate cost consciousness of medical providers without examining the relationship between cost consciousness and medical spending.[10,11] Given what is known about the influence of financial incentives,[12] local practice patterns, evidence-based guidelines,[13] and cultural norms in medical practice,[14] increasing awareness of high costs may not be adequate to reduce costs. It is not difficult to envision a scenario in which a costly treatment option is chosen over lower cost therapies because the patient, provider or medical delivery system are conscious of cost but prioritize other factors (which lead to delivery of higher-cost medical care) in making medical decisions. According to the framework of HVC as cost consciousness this would be deemed a success (because the provider was aware of the cost), regardless of the fact that costs were increased.

### Role of Health Policy

The schism between HVC as an aspirational goal and the exiguous manifestation of value measurement in medical literature stems in part from conflicted policy mandates that affect research funding streams. The triple aim (improving patient experience of care, improving population health, reducing per-capita healthcare costs) was promoted as a priority for the Centers for Medicare and Medicaid Services (CMS) under the leadership of Don Berwick, who was appointed to head CMS shortly following passage of the Affordable Care Act (ACA).[15] CMS doesn't offer a formal definition of HVC, but HVC is often used in CMS reports to describe initiatives aimed at improving population health and decreasing cost. In contrast to this explicit expression of intent to reduce healthcare costs, the ACA created the Patient-Centered

Outcomes Research Institute to advance comparative effectiveness research, which compares benefits and harms of medical therapies, without consideration of cost. The ACA's emphasis of comparative effectiveness research is consistent with prior legislation. The Medicare Modernization Act of 2003 includes a provision requiring the use of comparative effectiveness research, and prohibiting the use of cost effectiveness analysis (comparing cost per outcome) in determination of prescription drug coverage.[16] Medicare funds 20% of national health expenditures,[17] and serves as a model on which private health insurers pattern healthcare benefits. As a result, Medicare's approach to defining and measuring value is influential for all healthcare consumers. The influence of stakeholders (primarily payers and providers) in healthcare legislation is apparent, and has contributed to policy and regulation that is at odds with incorporating value measurement in medical research.

## Evolution of Value Measurement in Healthcare

Use of the term HVC in medical literature has become increasing common since innovators in the early 1990s began to publish work on value-based insurance design.[18] Since that time, concurrent developments in technology, health policy, and health economics have moved the study of HVC forward. Increased use of electronic health records has allowed for reporting of population-based health outcomes. Rising healthcare costs have driven policymakers to legislate sweeping health reforms, many of which focus on conversion from paying for volume to paying for "quality". Econometric models have become increasingly sophisticated in their capacity to model healthcare costs, thus creating tools that can be coupled with standardized outcomes to measure healthcare value. Historically, policymakers, providers and healthcare consumers have expressed concerns about the implications of including cost in health-care system design, and healthcare research.

Policymakers have assumed that the public views cost-benefit analysis of healthcare services unfavorably,[19] and feared backlash from constituents in response to explicit consideration of cost in designing policy mandates related to insurance benefits, such and requiring coverage of pre-existing conditions. However, recent decades have seen significant shifts in public opinion as concern about unsustainable increases in U.S. healthcare costs increase.[20] In actuality, cost consideration is inevitably integrated into decisions regarding health insurance benefits, which ultimately transform clinical care.[21] Use of the term HVC reflects this shift, and has allowed for inclusion of cost as an element of public discourse on healthcare in a way that seems to be palatable for both healthcare providers and consumers.

Philosophically, the medical community has reservations about valuing life and health in terms of dollars.[22] However, the U.S. healthcare delivery model that has evolved around current healthcare financing structures clearly defines medical practice to a great extent.[22] In past decades, healthcare providers considered inclusion of cost in medical research antithetical to their obligation to provide the best care for every individual patient regardless of cost, and have been apprehensive that cost consideration would lead to loss of provider autonomy in medical decision-making.[23] In contrast, a recent survey of physician attitudes towards healthcare cost reduction found that more than 90% of physicians believe it is fair to ask clinicians to be cost conscious.[24]

Healthcare consumers have expressed antipathy towards cost containment due to fear that it would lead to healthcare rationing.[25] However, de facto healthcare rationing occurs in the current healthcare system, as a result of inequitable access to services, and weighted share of cost which preferentially pays for some medical services over others.[21] Weighted share of cost refers to the varied price charged to healthcare consumers across healthcare services and providers, to incentivize use of particular healthcare services and providers. An example of weighted share of cost is differential coverage of healthcare services, based on healthcare provider network affiliation. In the preferred provider organization (PPO) insurance design, patients are required to pay for a higher proportion of their healthcare if they seek care outside of the preferred provider network. Theoretically, patients enrolled in a PPO have access to any provider. In practice, the cost of receiving care from non-network providers makes such care prohibitively expensive for many. In this model, access to care from non-network providers is effectively restricted to patients affluent enough to afford it. In a more overt form of rationing, Medicaid reimburses for medical services at such a low level that many providers opt out of the network, leaving Medicaid beneficiaries with little or no access to specialty care in many regions. Consumer cost-sharing for healthcare services is intended to reduce healthcare costs and encourage utilization of high value healthcare. However, research shows that consumers have limited capacity to identify and select HVC [26]; and high deductible health plans have a negative affect on medication adherence,[27] and cause delay or avoidance in seeking necessary care.[28,29]

As healthcare premiums have risen, and consumers are increasingly responsible for medical costs through cost-sharing insurance design (such as high-deductible plans, co-pays and co-insurance), public desire for price transparency has grown. A recent study found that healthcare consumers ranked price transparency as their second most important concern, outranked only by personalized attention from their healthcare providers.[30] However, public attitude towards inclusion of cost considerations in health policy or provider decisions is less clear. There is public demand for reduced health insurance premiums, but as demonstrated by the notorious outcry over “death panels” in the 2012 presidential primary, the public continues to harbor significant enmity towards cost-containment when it is viewed as a threat to personal choice in medical decision-making. Public response to cost-containment as a component of healthcare delivery system design seems to be driven largely by the manner in which it is presented, and to whom it is applied. Situating discourse on cost-containment within a framework of promoting high value care conveys a positive message. This is an important benefit of using of HVC terminology in medical research. However, healthcare value needs to be linked with the econometric tools that allow for operationalization of the concept to realize it's stated aim; increasing healthcare value. Consistently reporting the healthcare value implications of medical interventions  would allow for open discussion about prioritization of healthcare services, and create an opportunity to design policy that reflects societal values and preferences for care delivery, rather than the current model in which irrational use of healthcare resources results from navigating the cost side of healthcare delivery blinded to the relationship between cost and outcomes.

## Value Measurement Across Disciplines: Medical Research, Health Policy, and Health Economics

Medical research is primarily focused on health outcomes without consideration of cost. Medical science and health policy literature often use the concept of healthcare value theoretically, whereas health economics offers applied methods for measuring healthcare value. A survey of the top journals in medical science, health policy, and health economics shows that articles containing "cost", "cost effectiveness analysis", and "cost utility analysis" occur much less frequently in medical and policy journals than in health economics journals (**Table 3.1**). Among the top three medical journals, the term "cost" occurs on average in only 8% of articles, with articles containing "cost effectiveness analysis" and "cost utility analysis" occurring in just 1% of articles. The average frequency of occurrence of "cost", "cost effectiveness analysis" and “cost utility analysis” in policy journal articles is, 38%, 2%, 1%, and in health economics journal articles is 82%, 16% and 13% respectively (**Table 3.1**).[1]

The lack of cross-pollination in value measurement methodology between health disciplines has important implications for improving healthcare value. The reporting standards and subject matter preferences adopted by top journals in any field define the work their readership is exposed to. Clinicians and policymakers, who are called upon to drive increases in the value of healthcare services are not routinely receiving information which would inform them in doing so. Research finds that public opinion on healthcare cost-containment is more influenced by physicians than by policymakers.[31] This trickle-down effect magnifies the impact of the research providers consume, because providers then sway public opinion. Health economists routinely use value measurement tools (cost effectiveness analysis, cost utility analysis), but generally do not refer to this methodology as measurement of healthcare value, contributing to the disconnect between HVC theory and practice in medical research.

## Economic Methods of Measuring Healthcare Value

### Standardized Outcome Measures

Quality adjusted life years (QALYs) are a disease-burden measure comprised of quantity of life, adjusted for quality of life in the time lived. Disability adjusted life years (DALYs) are similar conceptually, but measure health adjusted life years lost rather than years gained.[32] For the purposes of research and policymaking, the cost per QALYs and DALYs have been compared against threshold dollar values, the amount of which varies depending on the context.

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[1] Journal with the highest impact factors selected from each discipline. Search results include publications from 1/1/2015-4/20/2017 (date search was preformed).

Assignment of monetary value to a QALY/DALY produces a system through which to compare the relative value of medical therapies.

QALYs and DALYs have important limitations as health outcome measurement tools. Estimation of short and long term effects requires comprehensive outcome data not available for many medical therapies. Value estimation is only as valid as the data it is based on, thus value calculations based on erroneous assumptions may not accurately estimate the value of a therapy. Calculation of QALYs/DALYs is not standardized, nor are the assessment components used to compile the score. As a result, QALYs/DALYs are not consistently comparable across studies.[33] Tools used to generate data from which QALYs/DALYs are calculated vary in their reliability and validity, and have not been validated in all populations.[34] Estimated value of therapies based on QALYs and DALYs may not reflect societal valuation of outcomes. For example, treating many people to relieve minor symptoms could generate the same cost to QALY/DALY ratio as treating a few people for a life threatening illness.[35] However, most people would prioritize treatment of life threatening illness over symptomatic relief from a minor illness, resulting in a circumstance where QALY/DALY equivalent doesn't have equivalent value in the eyes of society.

## Relating Cost to Outcomes

**Cost effectiveness analysis.** Cost effectiveness analysis compares cost and effectiveness of interventions that achieve a common outcome, expressed in terms of a natural outcome of the intervention. Early application of cost effectiveness analysis to healthcare was motivated by concern that developing countries were missing opportunities to achieve better health outcomes with limited resources by investing in health services that cost more per health outcome than other available treatment options.[36] This brought cost effectiveness analysis into the public eye, and promoted more widespread application of the technique in assessment of healthcare services.

The cost effectiveness ratio of an intervention is dynamic across outcome degrees. For example, the cost of reducing the incidence of ventilator associated pneumonia among intubated patients in an intensive-care unit from 10 cases per month to 9 cases per month will differ from the cost of subsequent reductions (9 cases to 8 cases, etc.). Graphing the cost effectiveness ratio of achieving initial and subsequent outcomes demonstrates this, as seen in **Figure 1**. Examining healthcare resource investment from this perspective suggests that rather than determining whether to treat one disease state over another, increasing the value of care may be a function of optimizing investment in each disease state by choosing the point on the treatment curve that captures the majority of benefit for the minimum investment. The ideal location along this line would vary depending upon the shape of the curve, valuation of the health benefit gained and the moral/ethical implications of treating (or not treating) particular disease states. For example, it may be considered ethical to deny treatment for minor illness at a different threshold than would be acceptable for a life threatening condition.

Cost effectiveness analysis is attractive to policymakers because outcomes are not monetized, therefore skirting the politically sensitive issue of assigning monetary value to quality and quantity of life. However, using disease-specific outcome measures limits the utility of cost effectiveness analysis in comparing outcomes across disease states. For example, cost effectiveness analysis could be used to identify the most cost effective HIV treatment for achieving an undetectable viral load, but could not determine whether population health outcomes would be most improved with investment in HIV treatment as compared with treatment of another disease state, such as hepatitis or cardiovascular disease. This key limitation of cost effectiveness analysis motivated development of cost utility analysis.

**Cost utility analysis.** Cost utility analysis is a subset of cost effectiveness analysis in which the outcome is defined as a measure of utility (quantity/quality of life measured in QALYs, DALYs), allowing for comparison of the cost per unit of change in 'life utility' across disease states and interventions. Generally cost utility analysis is reported in QALYs, but there are examples in the literature of cost utility analysis reported as DALYs.[37] Conversion of health outcomes to a metric that can be compared across disease states has significant implications for the measurement of healthcare value. If all health outcomes could be quantified according to QALYs or DALYs, healthcare outcome:cost ratios could be compared across interventions. From a health systems perspective, this adds a crucial dimension to assessment of healthcare value. Ranking medical treatments according to value (cost per QALY/DALY) makes a compelling case for prioritizing resource allocation to maximize QALYs/DALYs gained per healthcare dollar invested.

Measuring cost utility analysis in terms of QALYs/DALYs links cost effectiveness analysis to the large body of economic literature that attempts to quantify health and longevity. Furthermore, it allows for development of threshold designations for high/low value medical care. The World Health Organization indexes cost per DALY to gross domestic product (GDP) per capita, designating an international standard of very cost effective (<1xGDP per capita/DALY avoided), cost effective (1x-3x GDP per capita/DALY avoided) and not cost effective (>3x GDP per capita/DALY avoided).[38] These necessarily broad designations could be adjusted by revising the scale to reflect finer distinctions, depending upon the intended application. Cost effectiveness analysis with use of QALYs or DALYs satisfies the core criteria for measuring healthcare value, but application in medical research remains limited in scope for a variety of reasons.

The central challenges of cost utility analysis application lie in defining parameters of cost calculations, and accurately estimating QALYs/DALYs based on available outcome data.[39,40] Prominent health economists have promoted the use of a reference case described as "a standard set of methods to serve as a comparison across studies".[35,39] The cost utility analysis reference case should be constructed from a societal perspective, accounting for benefits, harms and costs to all parties.[40] Using a standardized methodology supports implementation of a universally applicable value measurement, rather than a circumstantially defined measure.

**Incremental cost effectiveness ratio.** The incremental cost effectiveness ratio is a measure used in cost effectiveness analysis and cost utility analysis for calculation of the additional cost required to achieve a one-unit increase in the outcome. The incremental cost effectiveness ratio allows one to order interventions from least costly to costliest per outcomes.

## Barriers to Measuring Healthcare Value in Medical Research

### Converting Health Outcomes to Standardized Measures.

Determining healthcare value requires data on health outcomes, in a format compatible with conversion to standardized outcome measures. Translation of health outcomes, particularly subjective outcomes, to standardized units, (QALYs, DALYs or dollars) raises issues of validity and generalizability.[41] Traditional measures of utility in health outcomes do not incorporate outcomes that may have important indirect effects on health and quality of life.[42] For example, increasing access to contraceptive therapies among women of reproductive age has been linked with a reduction in poverty,[43] which is associated with decreased rates of chronic illness and increased longevity.[44] These health effects are far-removed from the initial intervention, and interpreting the effect of these factors on QALYs/DALYs often requires modeling of health effects based on associative data rather than causal connection. Similarly, the total cost implications of increasing contraceptive access would be hard to quantify if the majority of cost benefit came from increased productivity, contribution to the U.S. tax base through labor force participation, or reduced use of healthcare services due to improved health. Measuring the effect of health-promotion interventions on non-health outcomes, such as social mobility, educational achievement and subjective well-being, on cost and QALY/DALY outcomes introduces yet another set of methodological challenges.[42]

The difficulty of converting health outcomes into standardized units is evident when considering the incalculable number of clinical contexts in which health outcomes would ideally be measured and reported. Many disparate outcome measures have been referenced in the HVC literature. Defining outcome parameters has important implications for conversion of medical research data into units that can be interpreted in terms of healthcare value. Developing the capacity to measure comprehensive, patient-centered, subjective outcomes is crucial to deriving a true measure of healthcare value, and will give policymakers and providers the tools to transform medical practice by incentivizing the delivery of care that promotes patient centered health outcomes.

### Measurement of Healthcare Costs.

Healthcare cost can be calculated based on resource use (cost), amount billed for care (charges), or reimbursement rate (payments). These metrics generate cost estimates that vary by an order of magnitude or more. Cost data can be adjusted for geographic variation, indexed to inflation rates and controlled for differences in patient level characteristics. Increasingly, healthcare cost measurement challenges stem from raw data issues related to lack of price transparency and complexities of reporting mechanisms, rather than lack of analytic methods. Prevailing national trends favor obligatory reporting of cost data. The private sector has advanced this trend through development of innovative price-transparency tools for healthcare consumers. Movement in this direction will continue to advance the science of cost measurement.

Improved access to cost data and increasingly sophisticated analytic methods are essential for development and application of healthcare value measurement. As with outcomes, cost can be measured according to varying parameters across the dimensions of patient, provider and time. For example, the cost impact of a diabetic education intervention could be assessed on the day of delivery, for the subsequent 6 months, or any other designated time period. Within the designated time period, the cost impact could be measured as changes in diabetes-related healthcare utilization, or more broadly as changes in total healthcare utilization. The population could be defined as a subset of patients receiving the intervention, all patients receiving the intervention, or an entire patient population. The cost to outcome ratio will vary widely depending on how these parameters are defined. Additional cost considerations include indirect costs (lost productivity), societal cost of illness when treated/untreated, and the opportunity cost of using a dollar on healthcare which could otherwise have been spent elsewhere.

## Path Dependency

The U.S. healthcare system is an immense economic engine with tremendous momentum. Policy theory describes the effect of institutional momentum as path dependency, in which what *has been* shapes what *is*, which in turn influences what *will be*. Organizational concern for perpetuating systems seen as favorable to their continued existence supersedes agendas related to promoting societal ideals,[45] such as HVC. Structural resistance to redesigning payment systems and care delivery models around healthcare value will come from medical providers who are habituated to providing care according to existing standards, individual patients who may be adversely impacted by healthcare policies that benefit population health, organizational momentum behind contemporary care delivery patterns, and stakeholder resistance to modification of payments/policy systems upon which would obviate their business models.

## Roadmap for Improving Healthcare Value Through Value Measurement

Value-based healthcare system design is premised upon prioritization of healthcare services according to cost per unit of health gained. Designing healthcare systems based on this methodology requires analysis of cost relative to standardized health outcomes. The path toward doing so lies through modification of medical research reporting practices, and improvements in economic methods for translating health outcomes into standardized measures of value.

Medical research must generate data required for value-based system design by systematically incorporating cost into outcome reporting, and adopting the practice of reporting health outcomes in terms of QALYs/DALYs. QALYs/DALYs serve as the outcome measure in multiple economic methods as they are adaptable, portable across disease states and reflect multidimensional outcomes (quantity and quality of life) in a single metric.

Modification of medical research and reporting practices will make an important contribution to improving healthcare value, but faces a number of practical obstacles to implementation. Using econometric tools (cost effectiveness analysis, cost utility analysis) to report outcomes in terms of healthcare value would require medical researchers to acquire a distinct skill set that is independent of medical expertise. Not all outcomes are amenable to quantification according to standardized outcomes measures, and value measurement imposes a framework that may complicate decisions regarding intervention and outcome parameters.

Changing medical research practices would require translation of health outcome into standardized measures, and incorporation of cost assessment. Both are feasible, but associated with numerous theoretical and practical challenges.

Secondarily, tools that facilitate conversion of morbidity/mortality and quality of life outcomes into standardized outcomes can be improved, and thus increase the range of health outcomes that can be readily converted to standardized outcome measures. This may ultimately be the more promising avenue, because where medical research has historically had an aversion to cost consideration, understanding outcomes in terms of cost is central to health economics. Developing flexible, standardized, validated systems for translating outcomes of medical research to QALYs/DALYs is an important horizon for the science of value measurement. Ultimately, it may be a convergence of modifications to medical research outcome reporting, and improved value measurement techniques that results in conversion to healthcare value measurement as the standard for medical research.

## Conclusion

In recent years, CMS has begun transitioning from a fee-for-service payment model to a shared risk/reward model, in which providers are held accountable for cost and outcomes. Using the powerful lever of reimbursement structures, CMS has focused the healthcare sector on defining and measuring cost and quality, the elements that must be ideally balanced to achieve HVC. Medicare is gradually implementing alternative payment models, which require providers to assume financial risk for healthcare costs and achieve defined quality outcomes for patient populations under their care. Alternative payment models are expected to be the predominant payment mechanism by 2018.[46] This fiscal pressure will accelerate the study of value measurement, as success of healthcare delivery systems will depend upon their capacity to deliver HVC.

The legacy approach to medical research has focused exclusively on health outcomes without consideration of cost, which is not sustainable in the current climate of evident need for improved population health outcomes and lower healthcare costs. Value is the parlance that has been adopted in medical research for outcome measures that incorporate cost. The concept of value serves as a catalyst for moving from health-outcome focused research, to research reporting structured as health gains per dollar of healthcare resources invested. Defining value as an outcome in medical research is essential to facilitating this progress, as value is the conceptual foundation of this paradigm shift.

The science of measuring cost and quality has made significant advances in recent years, in large part because value-based purchasing has created a focus on reduced costs, and begun to tie reimbursement to achievement of quality targets. Cost analysis provides ever more sophisticated methods for comprehensive modeling of cost, including factors such as productivity, healthy days, caregiver burden, cost of symptom burden, and cost of interventions that return false positives. Achieving HVC will require consistent application of reliable, valid, quantifiable indicators of subjective and objective health outcomes in medical research.

Much of measurement science underlying healthcare valuation originates from economic theory. Economic literature presents methodologically sound approaches to measuring healthcare costs, and relating costs to standardized outcome measures. Imperfections exist in these tools (as with any methodology) and widespread application will identify circumstances that stretch the limits of their utility. Although further study is needed, existing methods for measurement of healthcare value are adequately developed to support implementation of value-based medical research. Advancement of healthcare value measurement depends on promoting value as an institutional priority in medical research, and restructuring standards of medical research reporting accordingly. Interpreting outcomes of medical research in terms of healthcare value will promote improved population health outcomes and reduced healthcare costs through rational use of healthcare resources.

**Table 3.1** Journal articles containing search terms related to care value measurement in the top three medical, health policy, and health economics journals*

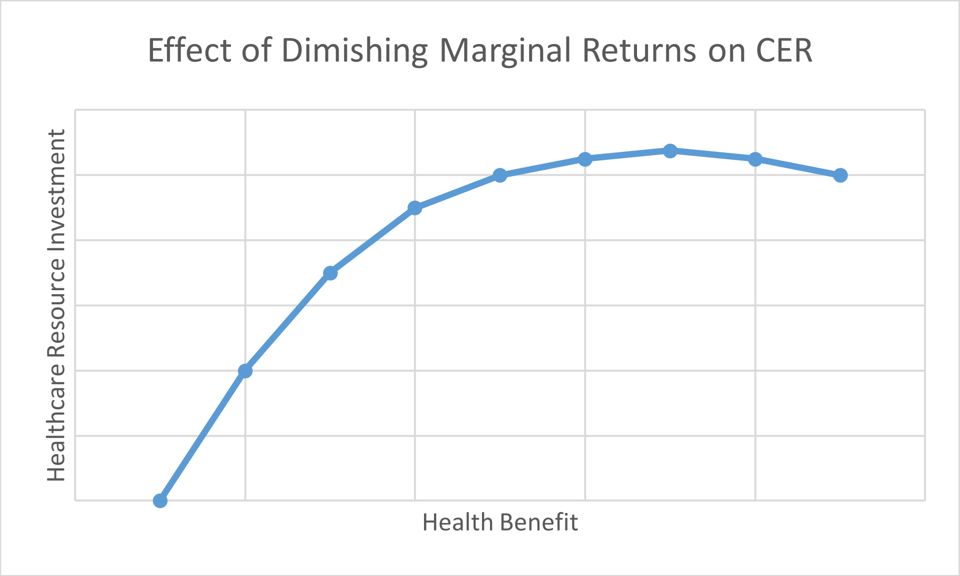
| | Cost | | Cost effectiveness analysis | | Cost utility analysis | | QALY | | *Total number articles published* |
|---|---|---|---|---|---|---|---|---|---|
| | % | (N) | % | (N) | % | (N) | % | (N) | |
| **Medical journals** | | | | | | | | | |
| JAMA[1] | 12 | (349) | 1 | (22) | 1 | (20) | 0 | (12) | 2805 |
| Annals of Internal Medicine | 8 | (95) | 2 | (26) | 2 | (23) | 1 | (16) | 1182 |
| NEJM[2] | 6 | (213) | 0 | (13) | 0 | (13) | 0 | (8) | 3649 |
| *Average, medical journals* | 8 | | 1 | | 1 | | 0 | | |
| **Policy journals** | | | | | | | | | |
| Health Affairs | 26 | (237) | 1 | (10) | 0 | (1) | 0 | (1) | 921 |
| Health Policy Journal | 50 | (217) | 5 | (23) | 4 | (16) | 1 | (5) | 434 |
| Health Services Research | 39 | (165) | 1 | (4) | 0 | (2) | 0 | (1) | 418 |
| *Average, policy journals* | 38 | | 2 | | 1 | | 0 | | |
| **Health Economics** | | | | | | | | | |
| Journal of Health Economics | 77 | (161) | 2 | (5) | 2 | (4) | 0 | (1) | 210 |
| Health Economics | 80 | (329) | 11 | (43) | 9 | (35) | 4 | (15) | 409 |
| Journal of Medical Economics | 89 | (301) | 36 | (121) | 27 | (91) | 25 | (86) | 340 |
| *Average, Health econ journals* | 82 | | 16 | | 13 | | 10 | | |

*Search fields: title, abstract and text. Articles published between 1/1/2015 and 4/20/2017

[1] Journal of the American Medical Association

[2] New England Journal of Medicine

**Figure 3.1** Effect of Diminishing Marginal Returns of Healthcare Investment on Cost Effectiveness Ratio



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# Chapter 4

## Association of Inpatient Palliative Care with Length of Stay, Hospitalization Costs, and Post-Discharge Outcomes Among Medicare Beneficiaries with End-Stage Renal Disease

### Abstract

**Importance**

Palliative care improves quality of life and may reduce the cost of care for patients with chronic illness, but utilization and cost implications of palliative care in the end-stage renal disease (ESRD) population have not been evaluated.

**Objectives**

Assess the association of inpatient palliative care with length of stay, hospitalization costs, and post-discharge outcomes for ESRD patients.

**Design, Setting, Participants and Measures**

In an analysis stratified by whether patients died during the index hospitalization, we identified Medicare beneficiaries with ESRD who received palliative care during a hospitalization in 2012 and 2013. These patients were matched to hospitalized patients with ESRD who received usual care using propensity scores. Primary outcomes were length of stay and hospitalization costs. Secondary outcomes were 30-day readmission and hospice enrollment (non-decedent cohort).

**Results**

Among the decedent cohort (N=1,338), inpatient palliative care was associated with a 25% shorter length of stay (-5.4 days, 95% CI -7.4, -3.4 days) and 17% lower total hospitalization cost (-$14,020, 95% CI -$22,078, -$5962) compared to usual care. Among the non-decedent cohort (N=5008), inpatient palliative care was associated with no difference in length of stay (0.4 days,

95% CI -0.1, 1.0) and an 11% increase in total hospitalization cost ($4192, 95% CI $1983, $6401) compared to usual care. In the 30-days post-discharge period, patients who received inpatient palliative care had higher likelihood of hospice enrollment (HR 5.8, 95% CI 4.8, 7.0) and lower likelihood of re-hospitalization (HR 0.7, 95% CI 0.6, 0.8).

**Conclusions**

Among ESRD patients who died in the hospital, inpatient palliative care was associated with shorter hospitalizations and lower costs. Among those who survived to discharge, inpatient palliative care was associated with no difference in length of stay and higher hospitalization costs, which may be offset by increased hospice use and fewer re-admissions in the 30-day post-discharge period.

**Disclosures**

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## Introduction

A rapidly growing body of evidence supports the use of inpatient palliative care to promote patient-centered care for patients with chronic illness.[1,2] Previous studies have found that inpatient palliative care also reduces hospitalization costs under most circumstances,[3,4,5,6,7] an effect attributed to limiting use of expensive care practices intended to prolong life when these are not aligned with the patient's goals and preferences.

Patients receiving dialysis for treatment of end-stage renal disease (ESRD), a population of approximately 477,000 in 2014[8] are among the costliest in the U.S. healthcare system. Individuals with ESRD comprise less than 1% of all Medicare enrollees, but account for 6% of Medicare spending.[9] Forty percent of Medicare expenditures for patients with ESRD are attributable to inpatient costs.[10] In spite of this intensive investment in healthcare services, patients with ESRD have high mortality rates[11] and poor quality of life.[12,13,14] More than 80% of patients with ESRD are hospitalized during the last three months of life.[15] These intensive, inpatient-focused patterns of care are associated with lower satisfaction and quality of care at the end of life as reported by bereaved family members, and they may be inconsistent with patient goals and preferences.[16]

Expansion of inpatient palliative care services shows promise as a strategy for improving quality and reducing costs of ESRD care.[17,18] However, in the absence of robust data on cost and resource implications of increasing palliative care utilization, the degree to which access to palliative care should be prioritized in the current climate of finite healthcare resources and overburdened healthcare delivery systems is uncertain. To address this question, we sought to compare length of stay, hospitalization costs and post-discharge outcomes among a nationally representative cohort of hospitalized Medicare beneficiaries receiving maintenance dialysis based on whether they received inpatient palliative care.

## Methods

### Data Source

We used data from the United States Renal Data System (USRDS), a national registry of almost all patients treated for ESRD with dialysis or kidney transplant in the United States. The Stanford University School of Medicine Internal Review Board approved the study. Per University of California San Francisco Human Research Protection Program guidelines, this study satisfies criteria for exemption from Internal Review Board approval.

### Study Population

We used the USRDS Medicare Physician Supplier and Institutional Claims files to identify all hospitalizations of three or more days occurring between January 1, 2012 and December 31, 2013 among adult Medicare beneficiaries who had received maintenance dialysis for at least 90 days on the admission day of the hospitalization (index date of hospitalization). We excluded patients who: were aged <18 or >110 years, lacked continuous Medicare A and B coverage from six months preceding the index date to 30-days post-discharge, were admitted to an inpatient rehabilitation facility, received hospice and/or palliative care within the 90 days prior to index date, received a functional renal transplant or had recovered renal function, and those in whom we were unable to determine ESRD treatment modality. Additionally, we excluded patients who were lost to follow-up in the USRDS during the study period, and hospitalizations of patients who had no Medicare claims in the 6 months prior to index date.

The analytic sample available was comprised of 723,913 hospitalizations occurring among 232,452 patients. We divided eligible hospitalizations into a decedent cohort (N=25,847) and a non-decedent cohort (N=698,066), depending on whether the patient survived to discharge, to account for important differences in costs, utilization and relevant outcome measures for terminal vs. other hospitalizations.[7,19,20,21]

## Outcomes

The primary outcome was length of inpatient hospitalization. Cost was a secondary outcome for both the decedent and non-decent groups. We constructed the cost variable by applying Medicare-specific, facility (hospital) level cost-to-charge ratios from the Centers for Medicare and Medicaid Inpatient Prospective Payment System (CMS IPPS) Impact Files for the relevant year to the facility charges for each hospitalization. Use of the CMS Impact file cost-to-charge ratio to derive cost from charges has been validated by previous studies,[22,23] and is recommended by CMS for cost analysis.[24] We added provider payments to the hospital cost to determine the total cost of each hospitalization. Cost outcomes were available for all hospitalizations except a small fraction missing hospital cost-to-charge ratios in the CMS Impact file (4% decedent cohort, 3% non-decedent cohort).

For the non-decedent cohort, we examined the competing events of hospice enrollment, re-hospitalization and mortality in the 30-day post-discharge period. We categorized deaths based on whether they were preceded by dialysis discontinuation. We ascertained re-hospitalization and hospice enrollment from the USRDS Institutional Claims File, and dialysis discontinuation from the USRDS Patients File.

## Exposure

We identified inpatient palliative care consultations using provider specialty code 17 from the Physician/Supplier Claims file.[25] After excluding hospitalizations with discharge dates after December 1, 2013 to allow for ascertainment of 30-day post-discharge outcomes, we identified 3,173 hospitalizations with a first inpatient palliative care consultation; 669 in the decedent cohort and 2504 in the non-decedent cohort. We refer to hospitalizations in which the patient did not receive a palliative care consultation as "usual care."

## Patient Characteristics

We ascertained age, sex, race, time since dialysis initiation, dialysis modality, and Medicare/Medicaid eligibility from the USRDS Patients, Treatment History, and Payer History files at the time of the index date. We ascertained ability to ambulate or transfer from the USRDS Medical Evidence Form (2728). We identified the co-morbidities listed in **Table 4.1** using International Classification of Diseases Ninth Revision (ICD-9) (**Appendix Table 4.1A**) from USRDS Institutional and Physician Supplier files, with a look-back window of six months prior to the index date. We also determined the number of days spent in the hospital during the six-month period before the index date, whether the patient experienced a serious infection in the month prior to the index hospitalization, and whether the patient was in a skilled nursing facility, nursing facility or custodial care center during this time. We characterized the index hospitalization as a critical care admission, surgical admission and/or admission through the emergency department using Current Procedural Terminology (CPT) and ICD-9 codes (**Appendix Table 4.1A**). To account for variance in regional medical spending, we assigned patients to hospital referral regions based on the zip code of the facility in which their index hospitalization occurred. We categorized hospital referral regions by quintiles of average

Medicare spending per decedent in the last two years of life, as reported in the Dartmouth Atlas for the year 2012.[26]

## Analysis

**Propensity score matching.** Using the variables listed in **Table 4.1,** we fit logistic regression models to estimate the propensity score, which represents an individual's probability of receiving inpatient palliative care, during a hospitalization**.** We ran separate propensity score models for the decedent and non-decedent cohorts. Using the propensity scores, we matched hospitalizations in which patients received inpatient palliative care 1:1 with hospitalizations in which patients received usual care. Hospitalizations were "hard matched" for characteristics deemed to be defining traits: nursing home residence, surgical admission, and hospital length of stay equal to or greater than the hospitalization day on which the palliative care consult took place. We defined the maximum acceptable difference in the matched-pair propensity score as 0.0005 in the decedent cohort and 0.0001 in the non-decedent cohort. If the hospital cost-to-charge ratio was unavailable for the matched usual care hospitalization, we re-matched with the next closest usual care hospitalization. Once a matched pair was identified, we removed all other hospital records of that patient from the matching pool to ensure that each hospitalization included in the cohort occurred in a unique individual.

We compared the characteristics of palliative care and usual care hospitalization groups using standardized differences. We considered standardized differences higher than 10 per cent to be indicative of covariate imbalance.[27] Due to baseline differences between the inpatient palliative care and usual care groups, we conducted all analyses in the propensity-score matched cohorts. This method yielded a decedent cohort of 1,338 patients and a non-decedent cohort of

5,008 patients (**Appendix Figures 4.2A, 4.3A)**. After matching, both decedent and non-decedent cohorts were well balanced on all characteristics (**Table 4.1, Appendix Table 4.2A** and **4.3A**).

**Outcome analyses.** The propensity score models balanced all measured characteristics between the two groups in both cohorts, so subsequent analyses were not further adjusted. We used a generalized linear model (Gamma family with log link) with robust standard errors, adjusted for matched pairs, to estimate the marginal mean difference in length of stay and hospitalization costs between the two groups.[28] In addition to total hospital costs and total hospital payments, we analyzed the facility and provider charges separately to better understand the source of variation in cost associated with receipt of inpatient palliative care. Based on the supposition that timing of inpatient palliative care might moderate the association between palliative care and healthcare resource utilization, we assessed length of stay and cost according to the hospital day on which the initial inpatient palliative care consultation occurred (within the first 2 days, 3-7 days, after 7th day of hospitalization).

In the non-decedent cohort, we graphically depicted the cumulative incidence of the first discharge event: re-hospitalization, hospice enrollment, and death with or without dialysis discontinuation in the first 30 days after discharge from the index hospitalization. We then estimated the sub-distribution hazard ratio (and 95% CI) for each of these outcomes in a competing risk framework using a Fine and Gray model.[29] Statistical analyses were performed using SAS, version 9.4 (SAS Institute, Inc., Cary, NC) and Stata version 13.1 (StataCorp, College Station, TX).

## Results

### Decedent Cohort - Length of Stay and Hospitalization Costs

Length of stay was 25% shorter (-5.4 days, 95% CI -7.4, -3.4 days) and hospitalization costs were 17% lower (-$14,020, 95% CI -22,078, -$5962) among patients who received inpatient palliative care compared to those who received usual care (**Table 4.2**). In addition, inpatient palliative care was associated with an 18% reduction in total Medicare expenditures (-$7989, 95%CI -$12,445, -$3533) compared to usual care, including lower payments to hospitals and providers. The association between inpatient palliative care and length of stay, total hospitalization costs and total Medicare expenditures did not differ according to the timing of palliative care (**Table 4.3**).

### Non-Decedent Cohort - Length of Stay and Hospitalization Costs

There was no significant difference in length of stay for patients who received inpatient palliative care as compared to those who received usual care (**Table 4.2**). For patients who received inpatient palliative care, total hospitalization costs were 11% higher ($4192, 95% CI $1983, $6401) and total Medicare expenditures were 6% higher ($1363, 95% CI $137, $2590) than for patients who received usual care (**Table 4.2**), including slightly higher (non-significant) payments to hospitals and 11% higher payments to providers ($312, 95% CI $180, $443). There were no differences in the association between palliative care and length of stay, total hospitalization costs and total Medicare expenditures based on the timing of inpatient palliative care (**Table 4.3**).

### Non-Decedent Cohort – 30-Day Post-Discharge Outcomes

The cumulative incidence of the first event to occur in the 30-day post-discharge period is depicted in **Figure 4.1**. When we accounted for these outcomes in a competing risk analysis, inpatient palliative care was associated with a lower risk of re-hospitalization, and a higher risk of hospice enrollment and death compared to usual care (**Figure 4.2**). Among patients (n=1607) whose first post-discharge event was death, 33% were preceded by dialysis discontinuation for patients who received palliative care, compared to 17% among those who received usual care. See **Appendix Figure 4.4A** for description of post-discharge outcomes.

## Discussion

In this study of hospitalized Medicare beneficiaries with ESRD, inpatient palliative care during a terminal hospitalization was associated with shorter length of stay and lower hospitalization costs compared to usual care. Among patients who survived to discharge, inpatient palliative care was associated with no difference in length of stay and a modest increase in total hospitalization costs compared to those who received usual care. Patients who received palliative care were substantially less likely to be readmitted, more likely to enroll in hospice and more likely to discontinue dialysis in the month after discharge; thus higher inpatient costs may be offset by less intensive post-discharge care. Taken together, these findings suggest that expanded access to inpatient palliative care, currently utilized in fewer than 1% of ESRD hospitalizations, could shorten hospitalizations, reduce costs, and substantially impact outcomes after discharge among patients with ESRD who are nearing the end of life.

Our study confirms cost savings from inpatient palliative care during a terminal hospitalization, and extends these findings to patients with ESRD; a population targeted for payment and policy reforms to improve quality and reduce costs of care, but not included in most prior studies of inpatient palliative care.[5,7,30] Larger cost reduction in the decedent cohort than the non-decedent cohort is consistent with prior studies of inpatient palliative care in patients with other serious illnesses.[7,19,31] In the decedent cohort, cost savings were accompanied by shorter length of stay, an important outcome for health care systems independent of cost due to its influence on hospital crowding and patient experience.[32] These associations were similar in magnitude when stratified by timing of palliative care consultation, which suggests that inpatient palliative care may yield similar benefits irrespective of when it occurs during a hospitalization.

To our knowledge, few studies exist which have examined the association between inpatient palliative care and Medicare expenditures. In addition to lower costs, we observed lower Medicare expenditures among patients who received inpatient palliative care in the decedent cohort compared to those who received usual care. The mean cost borne by hospitals and providers to deliver inpatient care ($75,874) was considerably higher than the mean Medicare reimbursement ($41,375), indicating that hospitals and providers realize a net loss when caring for this population. In the decedent group, hospitals realized a larger reduction in the cost required to provide care than the reduction in Medicare reimbursement, implying that inpatient palliative care simultaneously reduced Medicare expenditures and attenuated hospital and provider losses.

Although the non-decedent cohort did not have similar reductions in length of stay, hospitalization costs and Medicare expenditures, post-discharge utilization patterns suggest that higher index hospitalization costs and expenditures associated with inpatient palliative care may lead to reduced total healthcare costs due to higher use of hospice and fewer readmissions. In a previous study of Medicare beneficiaries who withdrew from dialysis between 2001 and 2002, median expenditures were $3020 lower in the last week of life for hospice users compared to non-users. This cost saving associated with hospice was primarily attributable to lower rates of hospitalization among hospice users.[33]

Our findings align with previous work in non-ESRD populations which has shown that patients receiving inpatient palliative care were more likely to enroll in hospice.[32] More frequent hospice use and dialysis discontinuation prior to death for patients who received inpatient palliative care suggests that the higher frequency of death that we observed reflects goal-concordant care. In this context, the efficacy of medical therapy in maximizing quality of life and improving patient centered outcomes is the salient research focus. In a study of veterans, Wachterman et al. found that patients who died from ESRD experienced poorer quality end-of-life care compared to patients dying from dementia or cancer.[16] These differences were largely explained by differences in the frequency of inpatient palliative care, do-not-resuscitate orders, and the setting of death. This work, coupled with our findings of increased likelihood of medically supported death and reduced hospital readmission for patients receiving inpatient palliative care, suggests that expanded use of inpatient palliative care may improve the quality of end-of-life care for patients with ESRD.

The association between inpatient palliative care and 30-day readmissions is inconsistent in the literature.[1,32] Using a competing risk framework, we found substantially lower 30-day readmissions among patients who received inpatient palliative care. This finding has important policy implications, because 30-day readmissions are a quality metric for the Medicare ESRD program. Starting in 2017, dialysis facilities experience payment reductions if 30-day readmission rates are above the expected range.[35] As Medicare shifts from fee-for-service reimbursement to value-based payments, policy makers are seeking to reward provision of high value care by incentivizing healthcare delivery systems that increase quality and decrease costs. The results of our study suggest that expanded use of inpatient palliative care services for patients with ESRD could be beneficial to healthcare systems (and payers) from a resource utilization and cost perspective.

Our study's strengths include the examination of a nationally representative population of patients with ESRD, and comprehensive ascertainment of hospitalizations and post-discharge outcomes. We took advantage of the opportunity afforded by our retrospective design to improve the validity of comparison between inpatient palliative care and usual care patients by requiring that the usual care patient in each matched pair had a length of stay at least as long as the day on which the first inpatient palliative care consultation took place for the palliative care patient. By doing so, we avoided spurious comparisons among paired patients; a strength that mitigated the fact that we could not randomize patients at admission. Our study also has several important limitations. Due to our study's retrospective design, we cannot conclusively determine whether inpatient palliative care directly led to the observed outcomes. To reduce potential confounding from selection bias, we used propensity scores to identity pairs of patients closely matched on measured characteristics. Propensity score matching creates a setting within which "treatment effects" can be estimated without making major parametric assumptions; however, matching depends on observed variables, and unmeasured patient, provider, health system, or regional characteristics that impact health care utilization may differ between matched pairs. In addition, we were unable to determine if palliative care reduced per-diem hospitalization costs or out of pocket costs. Finally, we could not determine what palliative care interventions were delivered, and whether palliative care enhanced goal-concordant care or improved the patient's experience.

In summary, our study provides a strong rationale for health care systems to expand access to inpatient palliative care for patients with ESRD. As systems of ESRD care are redesigned around new payment models that hold providers and health care systems accountable for reducing costs and achieving quality targets,[36] inpatient palliative care may be a resource-efficient mechanism to provide health care that is patient-centered and focused on improving the experience of patients and their families at the end of life.

**Table 4.1** Characteristics of decedent and non-decedent cohorts after matching

| | Decedent cohort | | | Non-decedent cohort | | |
|---|---|---|---|---|---|---|
| | **Palliative care (%) (N=669)** | **Usual care (%) (N=669)** | **Std diff[1]** | **Palliative care (%) (N=2504)** | **Usual care (%) (N=2504)** | **Std diff[1]** |
| Age at admission (years) | 67 ± 13 | 67 ± 13 | 5.5 | 66 ± 15 | 65 ± 14 | 5.6 |
| Age category (years) | | | | | | |
| 18-50 | 10 | 11 | -3.4 | 14 | 15 | -1.9 |
| 51-60 | 18 | 17 | 3.1 | 18 | 19 | -2.5 |
| 61-70 | 28 | 30 | -4.3 | 26 | 27 | -2.3 |
| 71-80 | 28 | 28 | 2.0 | 25 | 25 | 0.4 |
| >80 | 15 | 14 | 2.6 | 17 | 15 | 6.9 |
| Female | 46 | 47 | -3.3 | 50 | 50 | -0.7 |
| Race | | | | | | |
| White | 68 | 67 | 1.3 | 64 | 63 | 2.9 |
| Black | 29 | 29 | 0.7 | 32 | 33 | -3.1 |
| Other[2] | 3 | 4 | -4.6 | 4 | 4 | 0.4 |
| Hospitalization 2012 (vs 2013) | 47 | 47 | 0.9 | 48 | 50 | -3.8 |
| Years receiving dialysis | | | | | | |
| < 1 | 10 | 9 | 2.1 | 12 | 12 | -0.9 |
| 1-3 | 28 | 25 | 6.1 | 31 | 29 | 4.3 |
| > 3 | 63 | 66 | -6.9 | 57 | 59 | -3.5 |
| Dual eligibility (Medicare/Medicaid) | 39 | 42 | -5.8 | 40 | 41 | -1.5 |
| Dialysis type | | | | | | |
| Hemodialysis (vs PD) | 89 | 90 | -1.9 | 89 | 89 | 1.3 |
| Hospital-based outpatient dialysis clinic (vs freestanding) | 8 | 7 | -2.9 | 8 | 8 | 1.8 |
| HRR spending quintile (lowest to highest) | | | | | | |
| 1 | 23 | 24 | -2.8 | 26 | 25 | 2.7 |
| 2 | 15 | 14 | 3.8 | 19 | 18 | 2.1 |
| 3 | 24 | 22 | 2.5 | 19 | 18 | 1.3 |
| 4 | 21 | 21 | 0.4 | 21 | 22 | -2.9 |
| 5 | 18 | 19 | -3.5 | 16 | 18 | -3.5 |
| Nursing home resident | 40 | 40 | 0.0 | 36 | 36 | 0.0 |
| Inability to ambulate or transfer[3] | 6 | 5 | 5.4 | 6 | 7 | -3.1 |
| Admission characteristics | | | | | | |
| Emergency room admission | 88 | 85 | 7.5 | 87 | 88 | -4.2 |
| Surgical admission | 29 | 29 | 0.0 | 23 | 23 | 0.0 |
| Critical care admission | 2 | 3 | -1.0 | 1 | 1 | 1.8 |
| Comorbidities | | | | | | |
| Diabetes | 82 | 80 | 4.5 | 79 | 81 | -3.5 |
| Atrial fibrillation | 47 | 47 | 0.3 | 45 | 46 | -3.4 |
| Myocardial infarction | 31 | 30 | 1.3 | 28 | 29 | -2.7 |
| Heart failure | 83 | 81 | 5.0 | 80 | 80 | -0.6 |
| Peripheral vascular disease | 66 | 63 | 7.5 | 63 | 65 | -3.3 |
| Stroke | 25 | 25 | -0.4 | 29 | 30 | -3.0 |
| Liver disease | 38 | 40 | -4.0 | 34 | 36 | -3.5 |
| Lung disease | 59 | 62 | -6.4 | 59 | 61 | -4.0 |
| Cancer | 24 | 22 | 5.0 | 25 | 23 | 3.1 |

| Cont. | Decedent cohort | | | Non-decedent cohort | | |
|---|---|---|---|---|---|---|
| | Palliative care (%) (N=669) | Usual care (%) (N=669) | Std diff[1] | Palliative care (%) (N=2504) | Usual care (%) (N=2504) | Std diff[1] |
| Dementia | 18 | 20 | -6.1 | 18 | 18 | 0.0 |
| Depression | 48 | 47 | 2.1 | 50 | 52 | -5.2 |
| Gastrointestinal bleeding | 6 | 8 | -7.9 | 6 | 7 | -4.7 |
| Peptic ulcer disease | 45 | 46 | -3.3 | 42 | 44 | -3.8 |
| Failed transplant | 14 | 15 | -1.3 | 12 | 12 | -0.3 |
| History of infection in the month prior to admission | 56 | 54 | 2.7 | 52 | 52 | 0.2 |
| Number of hospital days in prior six months | 20 ± 23 | 23 ± 26 | -10.0 | 20 ± 23 | 22 ± 24 | -9.7 |

Results are presented as mean ± SD or per cents, as appropriate

[1] A standardized difference greater than 10 is considered to indicate covariate imbalance.

Abbreviations: SD – standard deviation, Std Diff - Standardized difference, HRR- hospital referral region, PD – peritoneal dialysis

[2] Other races includes Asian, Native American and Other

[3] Ascertained at start of dialysis

**Table 4.2** Association of inpatient palliative care with length of stay, hospitalization costs, and Medicare payments

| | **Decedent cohort** | | **Non-decedent cohort** | |
|---|---|---|---|---|
| | Usual care mean | Estimated mean difference associated with palliative care[1] (95% CI) | Usual care mean | Estimated mean difference associated with palliative care[1] (95% CI) |
| Length of stay (days) | 22 | -5.4 (-7.4, -3.4) | 13.6 | 0.4 (-0.1, 1) |
| Total hospitalization cost ($) | 82,857 | -14,020 (-22,078, -5962) | 39,784 | 4,192 (1983, 6401) |
| Hospital (facility) costs ($) | 61,983 | -11,510 (-17,847 , -5173) | 29,113 | 2,415 (774, 4056) |
| Total Medicare expenditures ($) | 45,369 | -7,989 (-12,445, -3533) | 22,993 | 1,363 (137, 2590) |
| Payment to hospitals ($) | 40,050 | -6,969 (-11,126, -2811) | 20,259 | 1,052 (-90, 2193) |
| Payment to providers ($) | 5,319 | -1,021 (-1,499, -542) | 2,734 | 312 (180, 443) |

[1] Negative values indicate reduction in length of stay, costs and payments in comparison to usual care.

Note: In the decedent cohort there were N=1338 patients included in the length of stay analysis and N=1286 patients included for costs and expenditure. In the non-decedent cohort there were N=5008 patients included in the length of stay analysis and N=4856 patients included for costs and expenditures.

Cost is not reported for providers because cost data is not available. Total hospitalization cost uses provider charges plus cost-to-charge ratio adjusted hospital charges.

**Table 4.3** Association of inpatient palliative care with length of stay, hospitalization costs, and hospitalization payments, by timing of first palliative care consultation, stratified by cohort.

| | Timing of first inpatient palliative care consultation | | | |
|---|---|---|---|---|
| | **Day 1-2**<br>**Estimated mean difference (95% CI)** | **Day 3-7**<br>**Estimated mean difference (95% CI)** | **After day 7**<br>**Estimated mean difference (95% CI)** | **P value[1]** |
| **Decedent cohort** | N=172 | N=528 | N=638 | |
| Length of stay (days) | -2.8 ( -4.8, -.7) | -3.5 (-6.6, -0.4) | -7.7 (-11, -4) | .92 |
| Total hospitalization costs ($) | -11,887 (-20,614, -3160) | -8091 (-19,068, -685) | -19,596 (-35,109, -4,082) | .39 |
| Total Medicare expenditures for hospitalization ($) | -2,982 (-6919, -956) | -4,873 (-9952, 13) | -12,023 (-20,544, -3501) | .89 |
| **Non-decedent cohort** | N=1210 | N=2134 | N=1664 | |
| Length of stay (days) | 0.6 (-0.1, 1.3) | 0.1 (-.4, .6) | 0.8 (-.6, 2.2) | .47 |
| Total hospitalization costs ($) | 3,238 (92, 6384) | 1,546 (-492, 3584) | 8,495 (2,672, 14,318) | .43 |
| Total Medicare expenditures for hospitalization ($) | 1,488 (-510, 3487) | 543 (-612, 1,699) | 2,373 (-761, 5,507) | .66 |

There were 1286 patients in the decedent cohort, and 4856 patients in the non-decedent cohort who had cost and expenditure outcomes available.

[1] P value for interaction between palliative care and timing of palliative care

**Figure 4.1** Cumulative incidence of first discharge event following hospitalization for palliative care patients compared with usual care patients

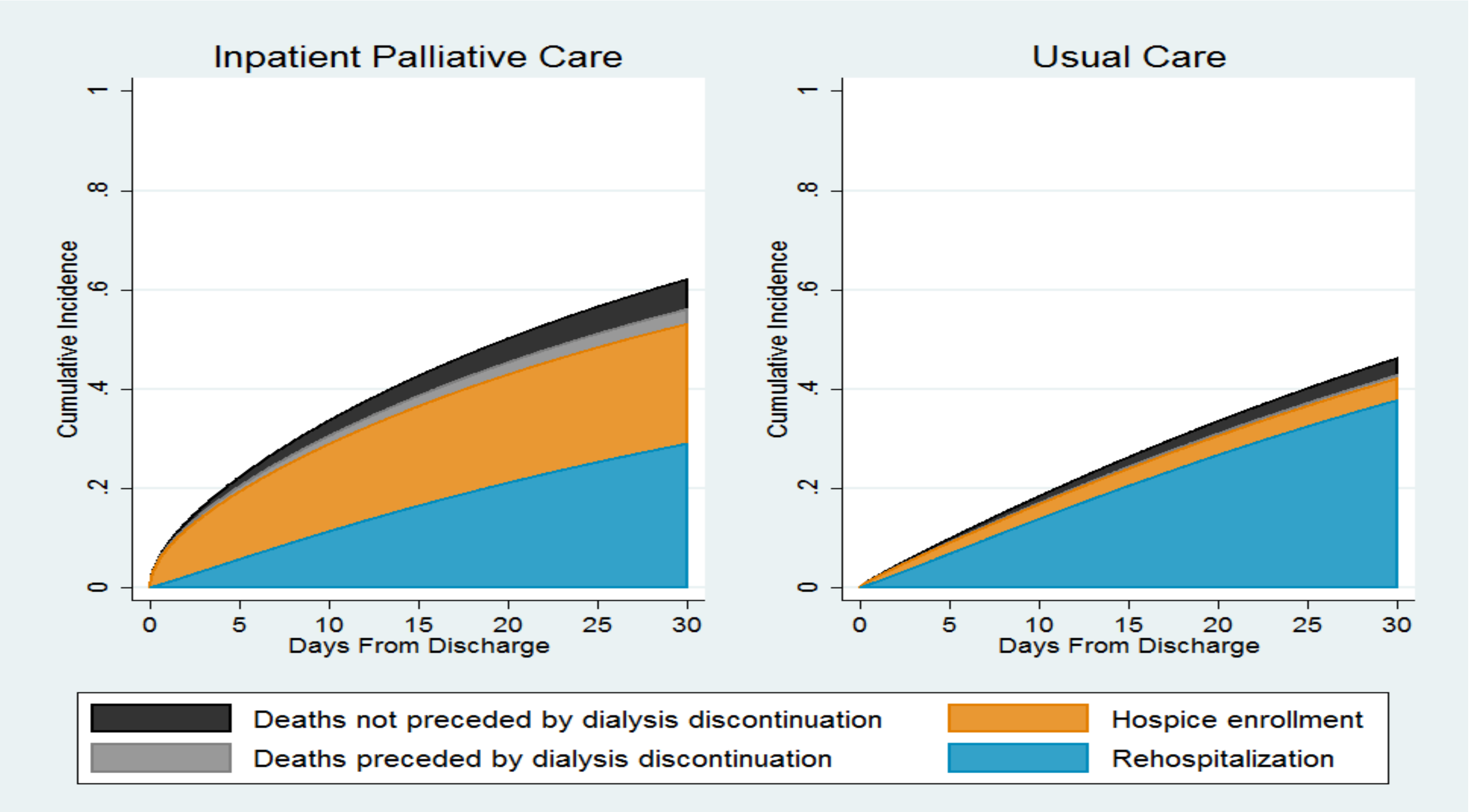
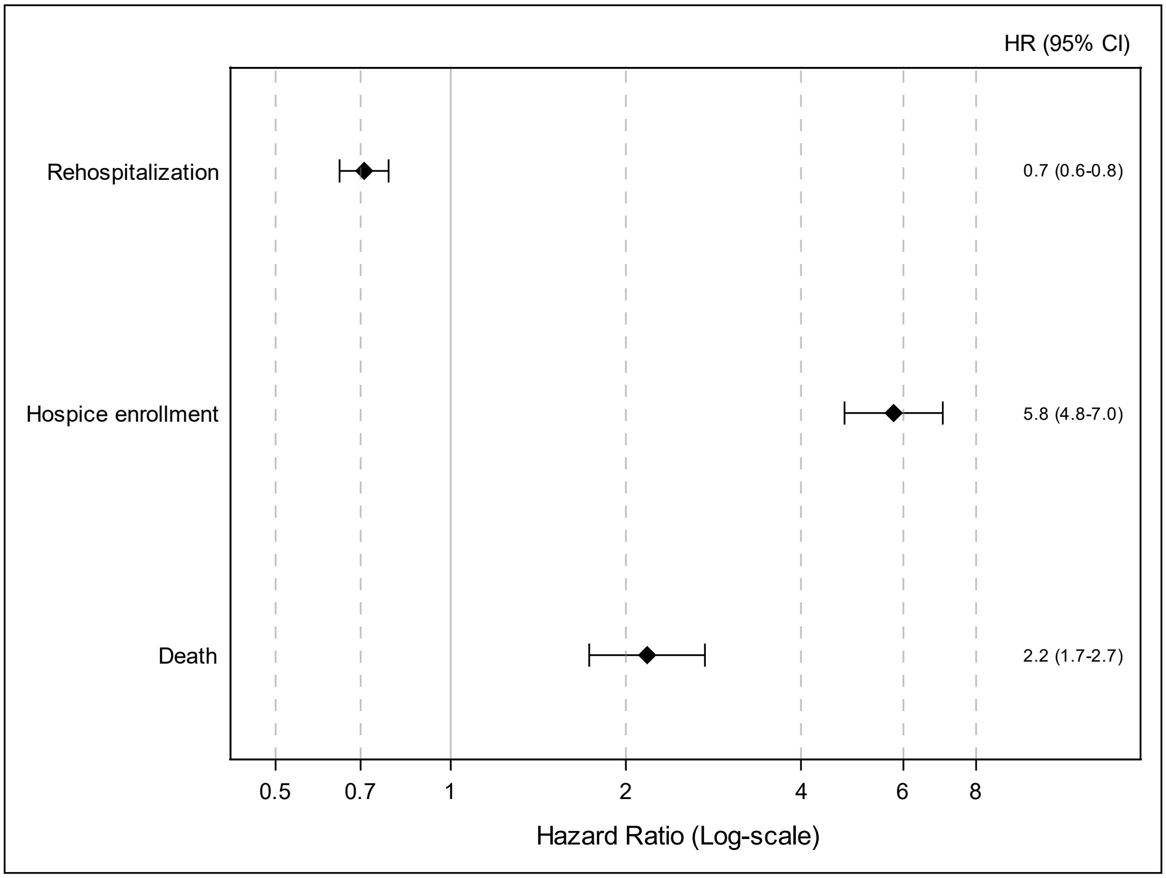


**Figure 4.2** Hazard ratio (HR) and 95 % confidence interval (95% CI) for post-discharge outcomes among patients with ESRD who received inpatient palliative care and survived to discharge. The referent group is patients who received usual care.



# Appendix

**Table 4.1A** Codes used to define comorbid conditions

| Comorbidities | ICD-9 and CPT Codes |
|---|---|
| Diabetes mellitus | 249.x, 250.x, 357.2, 362.0x |
| Atrial fibrillation | 427.3x |
| Prior myocardial infarction | 410.x |
| Heart failure | 398.91, 402.01, 402.11, 402.91, 404.01, 404.03, 404.13, 404.91, 428.x, |
| Peripheral vascular disease | 38.03, 38.04, 38.05, 38.08, 38.33-38.48, 39.22-39.29, 440.2x, 440.3x, 440.4x, 441.x, 443.x, 445.x, 447.10, 557.10, 557.90, v43.4, |
| Stroke | 433.x, 434.x, 436.00 |
| Chronic liver disease | 070.x, 456.1, 456.21, 570-573.x, v42.7 |
| Chronic lung disease | 490, 491.x-496, 500-505, 506.4, 516.x |
| Cancer | 140.x-165.x, 170.x-172.x, 174.x, 175.x, 180.x-209.x, 238.6, 273.3 |
| Dementia | 290.x, 294.1x, 331.x |
| Depression | 296.2x, 296.3x, 296.5x, 296.82, 300.40, 301.12, 309.0, 309.10, 311 |
| Gastrointestinal bleed | 456.00, 456.0, 456.20, 530.21, 530.70, 530.82, 531.0x, 531.2x, 531.4x, 531.6x, 532.2x, 532.4x, 532.6x, 533.0x, 533.2x, 534.0x, 534.2x, 534.4x, 534.6x, 535.x1, 537.83, 537.84, 562.02, 562.03, 562.12, 562.13, 569.3, 569.85, 578.x |
| Peptic ulcer disease | 531.7, 531.0, 531.71, 531.9, 531.90, 531.91, 532.7, 532.70, 532.71, 532.9x, 533.7x, 534.7x, 534.9x |
| **Admission type** | |
| Surgical | Exhaustive list of surgical ICD9 codes, previously validated in the literature[37] |
| Critical care | 99291 or 99292 |
| Emergency room | 0450, 0451, 0452, 0453, 0454, 0455, 0456, 0457, 0458, 0459 |

Note: We classified admission type based on codes present on index date.

**Table 4.2A** Characteristics of decedent cohort pre- and post-matching

| | **Pre-matching** | | | **Post-matching** | | |
|---|---|---|---|---|---|---|
| | **Palliative care N=689** | **Usual Care N=21,706** | **Std diff[1]** | **Palliative care N=669** | **Usual care N=669** | **Std diff[1]** |
| Age at admission (years) | 67 ± 13 | 67 ± 13 | 5.5 | 67 ± 13 | 67 ± 13 | 5.5 |
| Age category (years) | | | | | | |
| 18-50 | 11 | 10 | 0.9 | 10 | 11 | -3.4 |
| 51-60 | 19 | 17 | 3.7 | 18 | 17 | 3.1 |
| 61-70 | 28 | 28 | 1.8 | 28 | 30 | -4.3 |
| 71-80 | 28 | 27 | 2.1 | 28 | 28 | 2.0 |
| >80 | 14 | 18 | -9.3 | 15 | 14 | 2.6 |
| Female | 46 | 46 | -1.5 | 46 | 47 | -3.3 |
| Race | | | | | | |
| White | 68 | 63 | 10.8 | 68 | 67 | 1.3 |
| Black | 29 | 32 | -7.0 | 29 | 29 | 0.7 |
| Other[2] | 3 | 5 | -9.5 | 3 | 4 | -4.6 |
| Hospitalization 2012 (vs 2013) | 47 | 53 | -13.4 | 47 | 47 | 0.9 |
| Years receiving dialysis | | | | | | |
| < 1 | 9 | 9 | 1.9 | 10 | 9 | 2.1 |
| 1-3 | 28 | 27 | 1.0 | 28 | 25 | 6.1 |
| > 3 | 63 | 64 | -2.1 | 63 | 66 | -6.9 |
| Dual eligibility (Medicare/Medicaid) | 39 | 42 | -7.1 | 39 | 42 | -5.8 |
| Dialysis type | | | | | | |
| Hemodialysis (vs PD) | 89 | 91 | -5.8 | 89 | 90 | -1.9 |
| Hospital-based outpatient dialysis clinic (vs freestanding) | 8 | 6 | -4.4 | 8 | 7 | -2.9 |
| HRR spending quintile (lowest to highest) | | | | | | |
| 1 | 23 | 22 | 1.1 | 23 | 24 | -2.8 |
| 2 | 15 | 15 | 0.4 | 15 | 14 | 3.8 |
| 3 | 24 | 19 | 12.7 | 24 | 22 | 2.5 |
| 4 | 21 | 25 | -9.3 | 21 | 21 | 0.4 |
| 5 | 17 | 19 | -4.9 | 18 | 19 | -3.5 |
| Nursing home resident | 41 | 38 | 6.2 | 40 | 40 | 0.0 |
| Inability to ambulate or transfer[3] | 6 | 6 | -2.2 | 6 | 5 | 5.4 |
| Admission characteristics | | | | | | |
| Emergency room admission | 87 | 88 | -3.1 | 88 | 85 | 7.5 |
| Surgical admission | 28 | 26 | 4.5 | 29 | 29 | 0.0 |
| Critical care admission | 3 | 2 | 8.9 | 2 | 3 | -1.0 |
| Comorbidities | | | | | | |
| Diabetes | 82 | 82 | -1.1 | 82 | 80 | 4.5 |
| Atrial fibrillation | 46 | 49 | -4.4 | 47 | 47 | 0.3 |
| Myocardial infarction | 30 | 34 | -8.6 | 31 | 30 | 1.3 |
| Heart failure | 82 | 85 | -7.0 | 83 | 81 | 5.0 |
| Peripheral vascular disease | 67 | 68 | -2.8 | 66 | 63 | 7.5 |
| Stroke | 25 | 29 | -9.1 | 25 | 25 | -0.4 |
| Liver disease | 38 | 36 | 2.9 | 38 | 40 | -4.0 |
| Lung disease | 59 | 63 | -7.9 | 59 | 62 | -6.4 |
| Cancer | 25 | 23 | 2.9 | 24 | 22 | 5.0 |

| **Cont.** | **Pre-matching** | | | **Post-matching** | | |
|---|---|---|---|---|---|---|
| | **Palliative care N=689** | **Usual Care N=21,706** | **Std diff[1]** | **Palliative care N=669** | **Usual care N=669** | **Std diff[1]** |
| Dementia | 17 | 19 | -3.3 | 18 | 20 | -6.1 |
| Depression | 49 | 42 | 12.8 | 48 | 47 | 2.1 |
| Gastrointestinal bleeding | 6 | 6 | 0.7 | 6 | 8 | -7.9 |
| Peptic ulcer disease | 45 | 44 | 0.7 | 45 | 46 | -3.3 |
| Failed transplant | 14 | 13 | 4.6 | 14 | 15 | -1.3 |
| History of infection in the month prior to admission | 55 | 56 | -2.6 | 56 | 54 | 2.7 |
| Number of hospital days in prior six months | 20 ± 23 | 23 ± 26 | -10.0 | 20 ± 23 | 23 ± 26 | -10.0 |

Results are presented as mean ± SD or per cents, as appropriate

[1] A standardized difference greater than 10 is considered to indicate covariate imbalance.

Abbreviations: SD – standard deviation, Std Diff - Standardized difference, HRR- hospital referral region, PD – peritoneal dialysis

[2] Other races includes Asian, Native American and Other

[3] Ascertained at start of dialysis

**Table 4.3A** Characteristics of non-decedent cohort pre- and post-matching

| | Pre-matching | | | Post-matching | | |
|---|---|---|---|---|---|---|
| | **Palliative care N=2,530** | **Usual care N=637,739** | **Std diff[1]** | **Palliative care N=2504** | **Usual care N=2504** | **Std diff[1]** |
| Age at admission (years) | 66 ± 15 | 62 ± 15 | 30.4 | 66 ± 15 | 65 ± 14 | 5.6 |
| Age category (years) | | | | | | |
| 18-50 | 14 | 22 | -21.2 | 14 | 15 | -1.9 |
| 51-60 | 18 | 22 | -9.6 | 18 | 19 | -2.5 |
| 61-70 | 26 | 26 | -0.2 | 26 | 27 | -2.3 |
| 71-80 | 25 | 20 | 12.7 | 25 | 25 | 0.4 |
| >80 | 17 | 10 | 19.8 | 17 | 15 | 6.9 |
| Female | 50 | 49 | 0.5 | 50 | 50 | -0.7 |
| Race | | | | | | |
| White | 64 | 57 | 10.8 | 64 | 63 | 2.9 |
| Black | 32 | 39 | -7.0 | 32 | 33 | -3.1 |
| Other[2] | 4 | 5 | -9.5 | 4 | 4 | 0.4 |
| Hospitalization 2012 (vs 2013) | 48 | 53 | -13.4 | 48 | 50 | -3.8 |
| Years receiving dialysis | | | | | | |
| < 1 | 12 | 9 | 9.9 | 12 | 12 | -0.9 |
| 1-3 | 31 | 30 | 2.7 | 31 | 29 | 4.3 |
| > 3 | 57 | 61 | -8.7 | 57 | 59 | -3.5 |
| Dual eligibility (Medicare/Medicaid) | 40 | 50 | -20.8 | 40 | 41 | -1.5 |
| Dialysis type | | | | | | |
| Hemodialysis (vs PD) | 89 | 91 | -6.5 | 89 | 89 | 1.3 |
| Hospital-based outpatient dialysis clinic (vs freestanding) | 8 | 6 | -8.9 | 8 | 8 | 1.8 |
| HRR spending quintile (lowest to highest) | | | | | | |
| 1 | 26 | 23 | 5.4 | 26 | 25 | 2.7 |
| 2 | 19 | 16 | 9.0 | 19 | 18 | 2.1 |
| 3 | 18 | 19 | -1.9 | 19 | 18 | 1.3 |
| 4 | 21 | 25 | -10.1 | 21 | 22 | -2.9 |
| 5 | 16 | 17 | -2.1 | 16 | 18 | -3.5 |
| Nursing home resident | 36 | 24 | 27.3 | 36 | 36 | 0.0 |
| Inability to ambulate or transfer[3] | 6 | 5 | 4.7 | 6 | 7 | -3.1 |
| Admission characteristics | | | | | | |
| Emergency room admission | 87 | 83 | 10.2 | 87 | 88 | -4.2 |
| Surgical admission | 23 | 23 | 0.0 | 23 | 23 | 0.0 |
| Critical care admission | 1 | 0 | 7.5 | 1 | 1 | 1.8 |
| Comorbidities | | | | | | |
| Diabetes | 79 | 81 | -4.3 | 79 | 81 | -3.5 |
| Atrial fibrillation | 45 | 35 | 20.4 | 45 | 46 | -3.4 |
| Myocardial infarction | 28 | 27 | 2.1 | 28 | 29 | -2.7 |
| Heart failure | 80 | 77 | 5.3 | 80 | 80 | -0.6 |
| Peripheral vascular disease | 63 | 58 | 9.5 | 63 | 65 | -3.3 |
| Stroke | 29 | 25 | 7.8 | 29 | 30 | -3.0 |
| Liver disease | 34 | 35 | -2.8 | 34 | 36 | -3.5 |
| Lung disease | 59 | 58 | 3.3 | 59 | 61 | -4.0 |

| Cont. | Pre-matching | | | Post-matching | | |
|---|---|---|---|---|---|---|
| | Palliative care N=2,530 | Usual care N=637,739 | Std diff[1] | Palliative care N=2504 | Usual care N=2504 | Std diff[1] |
| Cancer | 25 | 18 | 16.5 | 25 | 23 | 3.1 |
| Dementia | 19 | 15 | 10.7 | 18 | 18 | 0.0 |
| Depression | 50 | 45 | 9.9 | 50 | 52 | -5.2 |
| Gastrointestinal bleeding | 6 | 7 | -5.3 | 6 | 7 | -4.7 |
| Peptic ulcer disease | 42 | 40 | 4.5 | 42 | 44 | -3.8 |
| Failed transplant | 12 | 13 | -2.8 | 12 | 12 | -0.3 |
| History of infection in the month prior to admission | 52 | 52 | -0.3 | 52 | 52 | 0.2 |
| Number of hospital days in prior six months | 20 ± 23 | 15 ± 19 | 22.5 | 20 ± 23 | 22 ± 24 | -9.7 |

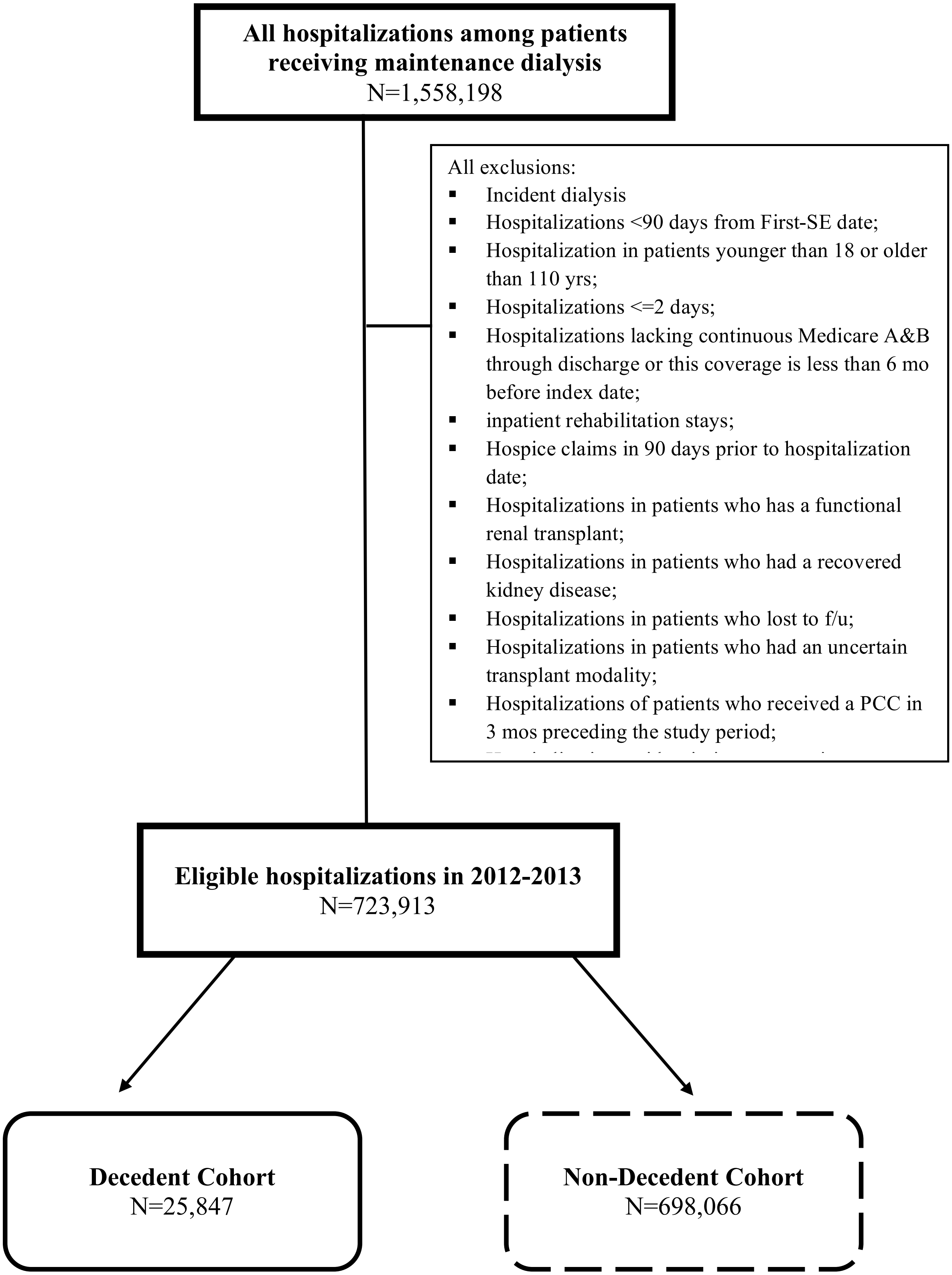
Abbreviations: SD – standard deviation, Std Diff - Standardized difference, HRR- hospital referral region, PD – peritoneal dialysis
Results are presented as mean ± SD or per cents, as appropriate

[1] A standardized difference greater than 10 is considered to indicate covariate imbalance.

[2] Other races includes Asian, Native American and Other

[3] Ascertained at start of dialysis

**Figure 4.1A** Study Flow Chart



**All hospitalizations among patients receiving maintenance dialysis**
N=1,558,198

All exclusions:

- Incident dialysis
- Hospitalizations <90 days from First-SE date;
- Hospitalization in patients younger than 18 or older than 110 yrs;
- Hospitalizations <=2 days;
- Hospitalizations lacking continuous Medicare A&B through discharge or this coverage is less than 6 mo before index date;
- inpatient rehabilitation stays;
- Hospice claims in 90 days prior to hospitalization date;
- Hospitalizations in patients who has a functional renal transplant;
- Hospitalizations in patients who had a recovered kidney disease;
- Hospitalizations in patients who lost to f/u;
- Hospitalizations in patients who had an uncertain transplant modality;
- Hospitalizations of patients who received a PCC in 3 mos preceding the study period;

**Eligible hospitalizations in 2012-2013**
N=723,913

**Decedent Cohort**
N=25,847

**Non-Decedent Cohort**
N=698,066

**Figure 4.2A** Matching procedure for decedent cohort

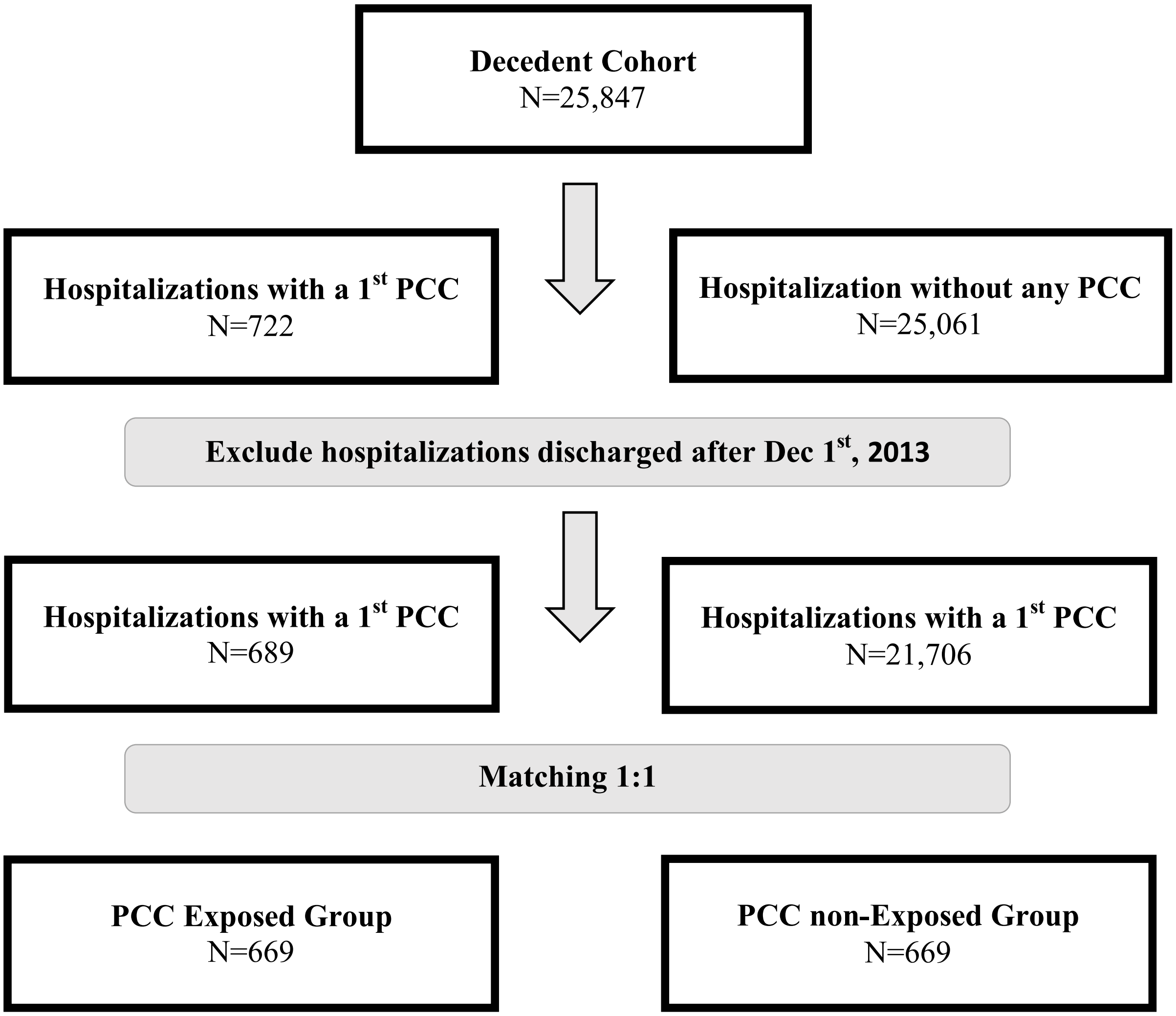


**Figure 4.3A** Matching procedure for non-decedent cohort

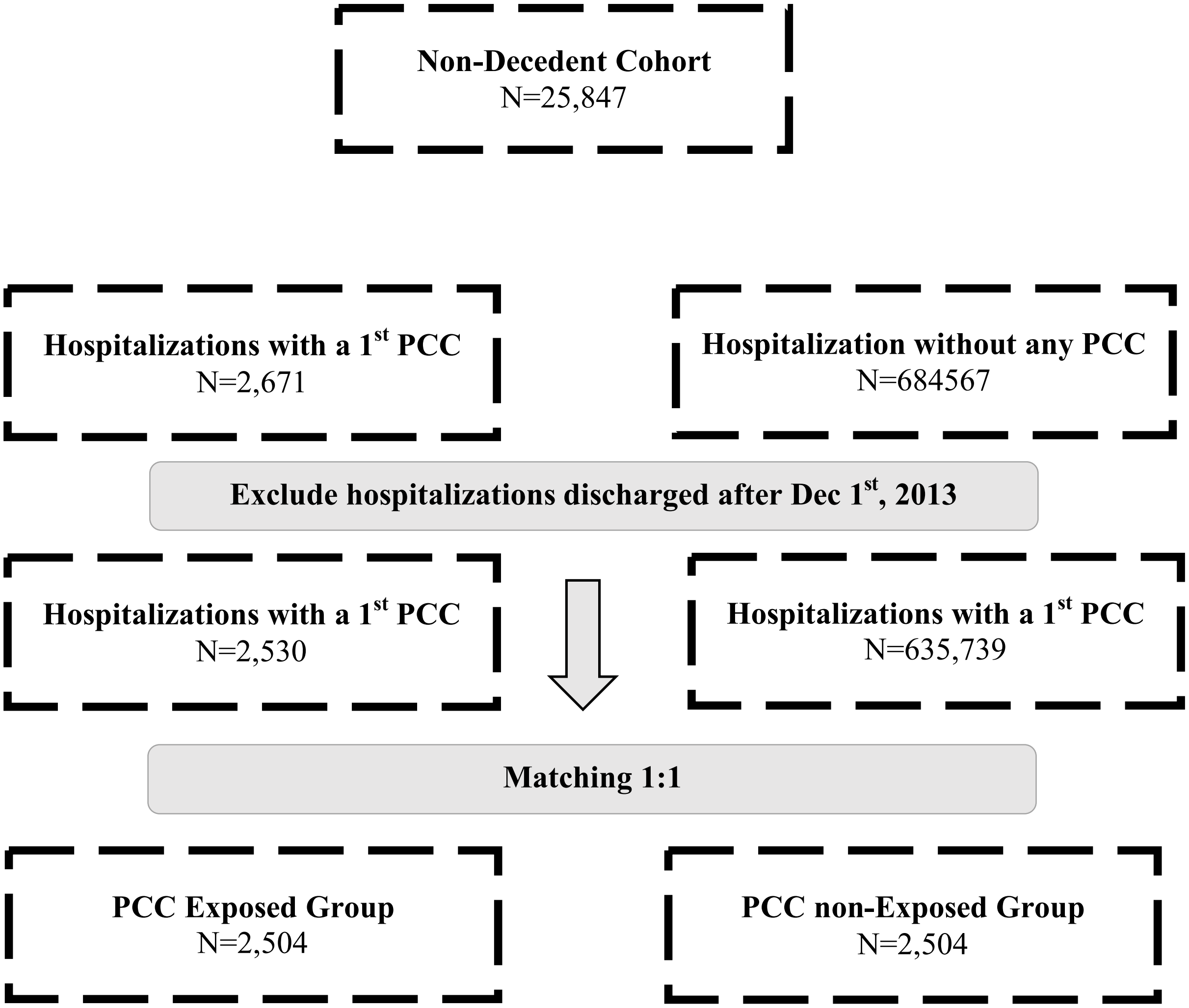
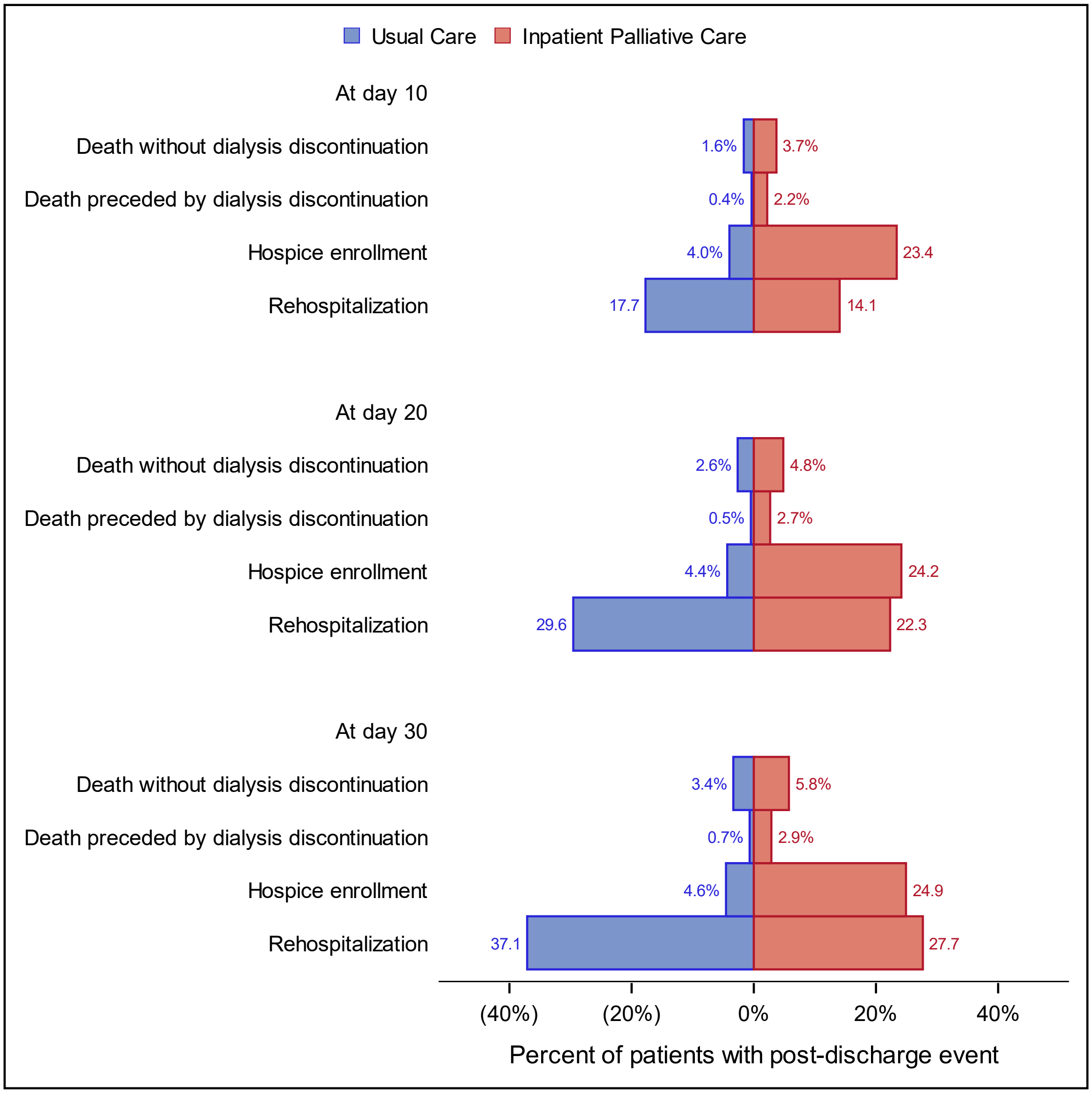


**Figure 4.4A** Post-discharge Outcomes



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# Chapter 5.

# Racial Disparities in Advance Directive Completion Among End-Stage Renal Disease Patients Residing in a Nursing Home

## Abstract

### Importance

End stage renal disease (ESRD) patients frequently receive aggressive end-of-life care that may not contribute to improved quality of patient and family experience. Advance directives (ADs) improve the value of end-of-life care by aligning delivery of healthcare services with patient preferences. Although racial disparities have been documented in the delivery of numerous healthcare services areas, and ESRD patients are disproportionately of non-white race; to date no studies have evaluated the association between race and AD completion among ESRD patients.

### Objectives

To determine if frequency of AD completion varies by race among ESRD patients residing in a skilled nursing facility. Secondarily, to compare preference for treatment-limiting ADs across racial groups.

### Design, Setting, Participants and Measures

We assembled a cohort of U.S. Medicare beneficiaries, receiving dialysis for treatment of ESRD, who resided in a Medicare- or Medicaid-credentialed skilled nursing facility between 2000 and 2008, and died between 2000 and 2010. We used Poisson regression to quantify the relative risk of completing an AD for patients of non-Hispanic (NH) black and other minority races, as compared with NH white patients.

### Results

The prevalence of having completed any AD, a treatment-limiting AD, and a healthcare power of attorney was 41%, 30%, and 19%, respectively. The relative risk of completing any AD, a treatment-limiting AD and healthcare power of attorney was lower for NH blacks (0.50 [95% CI 0.49-0.51], 0.47 [95% CI 0.46, 0.48], and 0.41 [95% CI 0.40, 0.42] respectively) and other minority races (RR 0.75 [95% CI 0.69, 0.81], RR 0.75 [95% CI 0.68, 0.83], RR 0.53 [95% CI 0.46, 0.61] respectively) than for NH whites.

**Conclusions**

Among ESRD patients residing in a nursing home, the prevalence of AD completion was low for patients of all races. Patients of NH black and minority races were less likely to complete all AD types than NH whites. Non-Hispanic black patients were least likely to complete all AD types.

**Disclosures**

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## Introduction

Individuals receiving dialysis for treatment of end-stage renal disease (ESRD) have high mortality rates[1] and often receive intensive end-of-life care that may not improve the quality of patient or family experience.[2,3] Advance directives (ADs) are medical or legal documents that define patient preference for interventions intended to support life. These documents enumerate patient wishes for resuscitation and may also include preferences for hospitalization, parenteral feeding, medication administration and designation of a surrogate decision-maker. Advance directives are associated with reduced use of heroic measures,[4] improved quality of end-of-life care,[5] and increased congruence of care delivered with expressed preferences.[6] These findings have held true in multiple chronically ill populations,[7] including ESRD patients.[6] Advance directive use is associated with increased use of hospice and reduced risk for in-hospital death,[6] both of which have been linked to patients and their family experience of high quality end-of-life care[7] and reduced healthcare costs for ESRD patients at the end of life.[8]

Intensive end-of-life care is costly to the healthcare delivery system. Spending on ESRD care consumed 1% of the federal budged in 2013,[9] with 25% of lifetime healthcare dollars spent in the last year of life.[10] Spending on ESRD end-of-life care is highest in regions where patients are least likely to receive hospice care and most likely to die in a hospital.[11] Previous work evaluating cost effects of ADs is limited in scope, and comprised primarily of observational studies. The largest randomized controlled trial to date found that implementation of an advance care planning intervention led to no changes in end-of-life care cost,[12] however observational trials have shown more positive results.[7,13,14] Irrespective of cost effects, there is widespread consensus that patients with a life threatening illness, such as ESRD, should have their goals of care elicited and documented in ADs, and have a designated surrogate medical decision-maker in place. However, ADs remain underutilized by ESRD patients, with less than half of ESRD patients having an AD completed at the time of death.[6,15] Racial disparities have been documented in AD completion and advance care planning.[16] To our knowledge, no studies have evaluated racial disparities in the use of AD for individuals with ESRD. Given what is known about racial disparities in other healthcare sectors, we posit that the low prevalence of AD completion among ESRD patients is exaggerated in ESRD patients of non-white race. This analysis is organized around the hypothesis that patients of non-Hispanic (NH) white race will have higher rates of AD completion than patients of NH black or other minority races.

## Methods

### *Data source*

The dataset used for this analysis was derived from three sources: United States Renal Data System (USRDS), Medicare Claims, and the Minimum Data Set (MDS). The USRDS is a national registry of patients who receive treatment (dialysis or transplant) for ESRD. The MDS is a Centers for Medicare and Medicaid Services (CMS)-mandated survey administered to nursing home residents at time of admission and quarterly thereafter,[17] which includes assessment of demographic data, physical and cognitive functioning, disease status and AD completion. The MDS is administered by specially trained nurses (LVNs or RNs). From 2000-2010 the USRDS was linked with the MDS. Per University of California San Francisco Human Research Protection Program guidelines, this study satisfies criteria for exemption from Internal Review Board approval.

### *Study population*

We linked the USRDS to the MDS to identify all ESRD patients (N=153,285) who were residents of a Medicare or Medicaid credentialed nursing facility (skilled nursing facility or nursing home) between 2000 and 2010, died between 2000 and 2010, had Medicare as a primary payer, were admitted to a nursing facility more than 30 days before death, and resided in a nursing facility for more than 14 days in the 18 months preceding death. No age restriction was placed on the sample. Patients missing information on treatment-limiting ADs were excluded from analyses related to that outcome (n=14,223).

### *Race*

MDS uses the race categories mandated by the Office of Management and Budget (OMB) in 1996: NH white, Hispanic, Asian, black, Native American, and other. All racial categories other than Hispanic are presumed to be NH. The MDS is designed to be collected by nursing home staff based on nursing assessments, and information obtained from the medical record. Nursing home staff receives training in survey administration. Staff are instructed to elicit self-reported race from residents, or from family if patients are unable to provide the information. Self-reported race is considered to be the preferred method when utilizing race as a socio-cultural construct.[18] If a patient was unable to respond and family cannot provide the information, staff are instructed to assign a racial category that most closely fits the patient. The MDS administration manual provides no guidance on reporting race for multi-racial individuals.

Previous analysis of MDS data has demonstrated moderate to high reliability on the majority of survey items.[19] Numerous studies have used MDS race data, but we found no data on reliability and validity of racial classification in the MDS reported in the literature; presumably due to the absence of a gold-standard for defining racial classification. Racial designations utilized by the OMB are consistent with race categories found in census data, and reflect race classifications frequently used in medical research. In order to preserve adequate sub-group sample size when assessing per type of AD, we collapsed racial categories into NH white, NH black and “other minority races”. Hispanic patients are included in the “other minority races” category, so the black racial designation denotes patients of NH black race.

### *Advance directive completion*

Advance directives are legal documents that describe end-of-life treatment preferences. The MDS survey asks respondents whether patients have: 1) a living will, 2) a designated healthcare power of attorney, and 3) a treatment restriction related to resuscitation, hospitalization, feeding, medications or “other”. Completion of an AD does not necessarily indicate a preference for reduced intensity of care. For example, a patient may have completed a living will which expressed a desire for administration of all available life support measures. To determine patient preference for treatment limitation among those who completed an AD, we created a composite outcome that identified the presence of any treatment-limiting directive (defined by the presence of one or more of treatment restrictions). Categories of ADs are not mutually exclusive. Advance directive survey items from the MDS have been validated in multiple studies.[20]

### *Patient characteristics*

We ascertained gender, age at death and duration of dialysis therapy at time of death from USRDS files. We utilized comorbidities reported in the USRDS Medical Evidence Form (2728) at the time of dialysis initiation, and in the last available MDS survey completed between 31 and

365 days prior to death. For assessment of decision-making capacity, we used a measure of impaired decision-making from the MDS. For this measure, nursing home staff assign patients a ranking of 0-3 (0= independent decision-making; consistent, reasonable independent decision-making, 1= modified independence, 2=moderately impaired; decisions poor, cues/supervision required, 3=severely impaired; never/rarely makes decisions). We considered patients with a score of 0-1 to have unimpaired decision-making, with the remainder (score of 2 or 3) classified as having impaired decision-making. We obtained information about functional status from the MDS Activities of Daily Living (ADL) score. The ADL score, as reported by MDS, was tabulated from answers to multiple questions on a range of ADL activities. ADL scores ranged from 0-28, with a higher score indicting greater functional impairment.

### *Analysis*

For each dependent variable in the primary outcome analysis (any AD, treatment-limiting AD, healthcare power of attorney), we constructed a Poisson regression model with robust standard errors. We selected this method of statistical modeling because Poisson regression has been shown to be reliable for analysis of rare outcomes,[21] and yields outcomes in terms of relative risk, which is consistent with our intent to compare the “risk” for completing ADs among NH blacks, and other minority races as compared with NH whites. Use of robust standard errors increases reliability of model performance, and ensures resilience against violation of regression assumptions.[22] The unadjusted model included race as the only predictor. The adjusted model included all covariates with clinical significance, and co-morbidities with clinical or statistical significance (**Table 5.1A)**. Statistical analyses were performed using Stata version 13.1 (Stata Statistical Software:Release 13; StataCorp.,College Station,TX).

## Results

### *Race and advance directive completion*

In this cohort, 41% of patients had an AD in the year before death, 30% had a treatment limiting AD, 19% had a DPOA, and 10% had both a treatment limiting AD and DPOA. Even among NH whites, who were most likely of all races to complete an AD of any type, the prevalence of ADs was low; less than half of NH-white patients had any AD component (**Table 5.2**) in place at time of death. Only 23% of NH blacks and 35% of patients of other minority races had completed any AD component at the time of death. The prevalence of ADs was lower still for specific AD components (**Table 5.3**). A do-not-resuscitate(DNR) AD, which was the most commonly completed treatment-limiting AD for all races, was only present at time of death for 33% of NH whites, 15% of NH blacks, and 25% of patients of other minority races. Less than 5% of patients of any race completed a treatment-limiting AD related to medication or hospitalization.

As compared with NH whites and other minority races, NH blacks had the lowest relative risk of completing all AD types: any AD (RR 0.50, 95% CI 0.49, 0.41), treatment-limiting AD (RR 0.47, 95% CI 0.46, 0.48), and healthcare power of attorney (RR 0.41, 95% CI 0.40-.42), followed by patients of other minority races: any AD (RR 0.74, 95% CI 0.71, 0.77), treatment-limiting AD (RR 0.78, 95% CI 0.75, 0.82), and healthcare power of attorney (RR 0.52, 95% CI 0.48-.56) (**Table 5.2)**.

Among patients who completed ADs, 75% of NH whites, 70% of NH blacks, and 80% of patients of other minority races specified treatment-limitations (**Table 5.3)**. The relative risk of completing a treatment-limiting AD among those who completed ADs was 0.92 (95% CI 0.91, 0.94) for NH blacks and 1.06, (95% CI 1.04, 1.08) for patients of other minority races, as compared with NH whites. Although not all results achieved statistical significance, patients of other minority races were more likely to complete all types of treatment-limiting ADs, and NH blacks were less likely to complete all types of treatment-limiting ADs than NH whites (**Figure 5.1)**.

## Discussion

We found that race is correlated with presence of an AD prior to death among ESRD patients residing in a nursing home setting. Non-Hispanic whites were most likely to complete each AD component, followed by patients of other minority races. Non-Hispanic blacks had the lowest likelihood of completing all AD components. Lower prevalence of each AD component among ESRD patients of NH black and other minority races suggests reduced engagement in advance care planning, rather than a preference for higher-intensity care partially underlies the low use of ADs in minority-race ESRD populations. In particular, the low rate of DPOA designation, which is unrelated to treatment preferences, suggests lack of engagement in advanced care planning.

We found low overall prevalence of AD completion, which is consistent with previous studies of AD completion among ESRD patients. For example, Kurella and colleagues reported that 47% of ESRD patients residing in a nursing home had an AD at time of death,[6] while Feely et al. found that 49% of patients receiving maintenance dialysis in a hospital-based dialysis center had an AD in place.[15] Even among NH whites (the group most likely to complete all AD components), the prevalence of AD completion was only 49%. In contrast, the prevalence of ADs in the nursing home population exceeds 60%, and in the general elderly population the prevalence of ADs exceeds 70%”.[23,24,25] In spite of prolonged, frequent interface with multiple facets of the healthcare system, ADs were not adequately utilized by patients of any race within this medically-fragile ESRD patient population.

Previous analyses have consistently found racial disparities in advance directive completion,[16,26,27,28] but prior work investigating the causal pathway between race and differential AD completion rates has produced varied results. Some studies attribute racial disparities in AD completion to lack of provider outreach for advance care planning,[16] while other researchers attribute lower rates of AD completion among non-white patient populations (as compared with NH whites) to a preference for more intensive end-of-life care,[29,30] spiritual beliefs,[31,32] and mistrust of the healthcare system.[31] Although AD completion can be patient-initiated, AD completion often results from receipt of advance care planning services; an important component of medical care for patients with life-limiting illnesses. Prior studies have used AD completion as an outcome when evaluating advance care planning interventions.[12,33] In our study; among those who completed an AD, patients of other minority races were the most likely of any racial group to specify treatment limitations. Among patients who completed an AD, the proportion requesting a treatment-limitation was similar across racial groups, whereas within the entire study population (including patients who did not complete an AD), there were substantial racial differences in the likelihood of AD completion. These findings further support the interpretation of racial disparities in AD completion as a function of lack of efficacious advance care planning, rather than a racially- or culturally-based aversion to limiting intensity of end-of-life care.

Although the majority of studies on ADs and healthcare quality have found that use of ADs improves quality of care at the end of life,[7,24,34] results have not generally been stratified by race. Loggers et al. evaluated the effect of ADs on end-of-life care according to race, and found that among NH white patients, ADs increased congruence of care with expressed preferences; whereas completion of ADs did not confer the same benefits for NH black or Hispanic patients.[35] This result speaks to the complexity of interactions between race, ethnicity, and end-of-life care. It also suggests that future research on end-of-life care should focus on endpoints such as patient and family satisfaction with care, rather than intermediate outcomes (Ex. AD completion, receipt of advance care planning) which may not relate to goals of care as expected in minority populations.

The Patient Self Determination Act (PDSA), enacted in 1990, requires Medicare and Medicaid accredited healthcare facilities (but not individual providers) to offer patients information on advance care planning, and inform them of their right to accept or refuse treatment. Since enactment of the PDSA, numerous organizations have published guidelines recommending expanded use of AD.[36,37] In 2015, Medicare began reimbursing providers for time spent with patients on advance care planning to increase provider participation in advance care planning.[38] These efforts have had modest success in increasing use of ADs in the general population, yet ESRD patients continue to receive inadequate advance care planning services. Our results indicate that race is associated with variance in AD completion among ESRD patients, but the question of underutilization of ADs among all ESRD patients remains largely unexplained.

Multiple published sources recommend advance care planning,[39,40,41,42,43] and completion of advance directives for ESRD patients.[42,44] ESRD patients residing in a nursing facility have an additional compelling indication for addressing end-of-life care wishes.[45] A Canadian study found that implementation of an advanced care planning initiative in nursing homes resulted in increased use of ADs, reduced end-of-life medical costs, less in-hospital deaths, a four-fold increase in palliative care referrals, and improved patient/family reported end-of-life care quality.[46] Our study highlights the need for similar interventions among nursing-home bound ESRD patients, with emphasis on providing culturally sensitive advance care planning for patients of NH black and other minority races.

Patients receiving dialysis for treatment of ESRD engage frequently and repeatedly with dialysis centers; a distinct set of healthcare providers dedicated to treatment of a single disease state. This presents a unique opportunity to implement disease-specific advance care planning interventions at the dialysis center level. Incorporating provision of advance care planning in the suite of services provided by dialysis centers is a promising strategy for improving the value of end-of-life care for ESRD patients, a much needed outcome for patients and the healthcare delivery system.

Our study had several important limitations. As this was an observational study, we could not definitively conclude that race was the cause of the observed variance in AD completion. Categorization of race into discrete designations disregards the reality that race is fluid, with indistinct boundaries. Complexities of racial categorization were compounded by the MDS mandate for nursing home staff to assign a racial designation for patients unable to self-report. Furthermore, our use of collapsed racial categories obscured finer racial and ethnic distinctions that may be important in understanding the interaction of race and AD completion. Race and socioeconomic status are strongly correlated in the general population. We lacked a reliable indicator of socioeconomic status, so were unable to control for socioeconomic status in our analyses. As a result, we may have misattributed differences in AD completion to race, when in actuality they stemmed from unobserved differences in socioeconomic status. Whether race is directly associated with AD completion or a proxy for socioeconomic status, it serves as an important marker for populations at increased risk for inadequate advance care planning. The U.S. healthcare system is fragmented, with poor coordination of care and no common platform for information exchange. This introduces the possibility that patients had an AD which was not captured in the MDS database.

The current U.S. healthcare delivery system provides resource intensive end-of-life care that frequently yields poor quality outcomes for ESRD patients.[47,48] Research conducted in recent decades has brought into stark relief the disparities in health outcomes that fall along racial and socioeconomic lines. It is becoming apparent that in the 21st century, the greatest challenges to improving population health lie in addressing the social determinants of health and longevity. In an era of healthcare characterized by overuse of high-tech, high-cost interventions, medical research is demonstrating the value of low tech, high-touch interventions such as advance care planning. Improving healthcare value by translating these findings into clinical practice change must be done equitably, so as to avoid worsening existing disparities in healthcare and health outcomes.

Identification of racial disparities in AD completion among ESRD patients residing in a nursing home serves as a basis for promoting equitable delivery of high value healthcare services for the most vulnerable ESRD populations. However, remediation of low rates of AD completion among ESRD patients will require more than simply targeting patients of NH black and other minority races for advance care planning services, as ADs are underutilized by ESRD patients of all races. Much remains to be learned about how to define ideal end-of-life care, how to design systems to provide such care, and how to judge whether this objective is achieved. As this process unfolds, it will be critical to remain vigilant for racial disparities in healthcare. The results of our study indicate that efforts to increase use of ADs should be more widely promulgated among all ESRD patients, with enhanced efforts to engage patients of NH black and other minority races in advance care planning.

**Table 5.1** Characteristics of ESRD patients at time of death, by race

| | NH White<br>N=103,194 | NH Black<br>N=44,612 | Other minority races*<br>N=5479 |
|---|---|---|---|
| **Age at death** (in years, mean ±SD) | 73 ±11 | 69 ±12 | 72 ±12 |
| **Gender** (male) % | 50 | 56 | 52 |
| **Year of death** % | | | |
| 2000-2001 | 14 | 13 | 13 |
| 2002-2003 | 17 | 17 | 17 |
| 2004-2005 | 19 | 20 | 19 |
| 2006-2007 | 20 | 20 | 20 |
| 2008-2009 | 20 | 20 | 20 |
| 2010 | 10 | 10 | 10 |
| **Time on dialysis** (in years, mean ±SD) | 3.5 ±3.4 | 4.8 ±4.1 | 4.3 ±3.6 |
| **Days of nursing home residence in prior 18 months** (mean ±SD) | 65 ±52 | 67 ±50 | 64 ±51 |
| **Impaired decision-making** % | 27 | 38 | 36 |
| **Activities of Daily Living score** (mean ±SD)** | 16 ±7 | 18 ±7 | 17 ±7 |
| **Comorbidities** % | | | |
| Diabetes | 80 | 89 | 91 |
| Coronary artery disease | 83 | 78 | 81 |
| Dysrhythmia | 39 | 39 | 40 |
| Depression | 49 | 42 | 40 |
| Congestive heart failure | 90 | 89 | 89 |
| Lung disease | 66 | 58 | 58 |
| Peripheral vascular disease | 76 | 77 | 73 |
| Cancer | 26 | 26 | 21 |
| Stroke | 40 | 54 | 47 |
| Dementia | 29 | 41 | 32 |

*Other minority races includes Native American, Asian/Pacific Islander, Hispanic

** Activities of Daily Living score range from 0-28, with higher values indicating greater functional impairment

**Table 5.2** Relative risk and percent AD completion for patients of NH black and other minority races, compared with NH whites, among ESRD patients residing in a nursing home

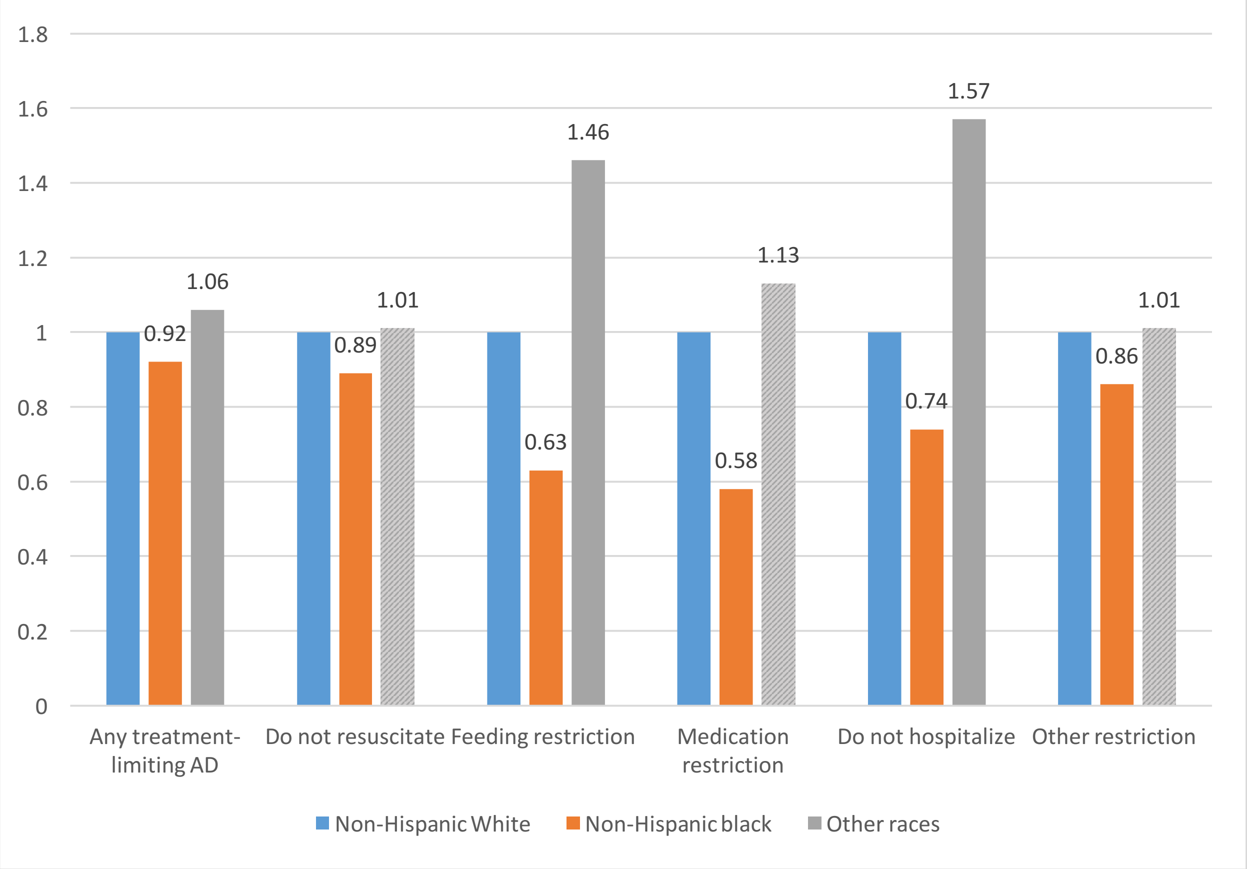
| | Any AD | | | Treatment-limiting AD | | | Healthcare Power of Attorney | | |
|---|---|---|---|---|---|---|---|---|---|
| | RR (95% CI) | % | N | RR (95% CI) | % | N | RR (95% CI) | % | N |
| NH White | 1 (referent) | 49 | 103,194 | 1 (referent) | 36 | 103,104 | 1 (referent) | 24 | 93,505 |
| NH Black | 0.50 (0.49, 0.51) | 23 | 44,612 | 0.47(0.46, 0.48) | 16 | 44,612 | 0.41 (0.40, 0.42) | 9 | 40,639 |
| Other minority races | 0.74 (0.71, 0.77) | 35 | 5479 | 0.78 (0.75, 0.82) | 28 | 5479 | 0.52 (0.48, 0.56) | 12 | 4918 |

RR model was adjusted for age at death, gender, time on dialysis, nursing home residence, impaired decision-making, and comorbidities listed in Table 5.1.
N differs for AD outcomes due to missing data

**Table 5.3** Among those who completed an AD; proportion of patients who specified a treatment restriction, by race

| | **NH white** | **NH Black** | **Other minority races** | **Chi$^2$** |
|---|---|---|---|---|
| | % (N) | % (N) | % (N) | P value |
| Any restriction | 75 (37,560) | 70 (7313) | 80 (1552) | <.001 |
| Restriction related to | | | | |
| Resuscitation | 69 (34,599) | 63 (6,537) | 68 (42,508) | <.001 |
| Feeding | 13 (6165) | 8 (780) | 18 (337) | <.001 |
| Medication | 3 (1592) | 2 (186) | 3 (68) | <.001 |
| Hospitalization | 2 (1134) | 2 (180) | 4 (70) | <.001 |
| Other | 10 (4761) | 8 (841) | 10 (180) | <.001 |

**Figure 5.1** Relative risk of specifying a treatment restriction among ESRD patients residing in a nursing home who completed an AD by race



Striped bars represent results that are not statistically significant (p<.05)
RR model was adjusted for age at death, gender, time on dialysis, nursing home residence, impaired decision-making, and comorbidities listed in Table 5.1

# Appendix

**Appendix Table 5.1A** Adjusted model for predictors of completing AD types by race and other covariates

| | **Any AD** | | **Treatment-limiting AD** | | **Healthcare POA** | |
|---|---|---|---|---|---|---|
| | RR (95% CI) | P | RR (95% CI) | P | RR (95% CI) | P |
| **Race** (NH White) | | | | | | |
| NH Black | 0.50 (0.49, 0.51) | <.001 | 0.46 (.48, 0.48) | <.001 | 0.41 (0.40-0.42) | <.001 |
| Other minority races | 0.74 (0.71, 0.77) | <.001 | 0.78 (0.75, 0.82) | <.001 | 0.52 (0.48-0.56) | <.001 |
| **Age at death** | 1.02 (1.02, 1.02) | <.001 | 1.02 (1.02, 1.02) | <.001 | 1.02 (1.02, 1.03) | <.001 |
| **Gender** (male) | 1.06 (1.05, 1.08) | 0.01 | 1.08 (1.07, 1.10) | <.001 | 1.05 (1.03, 1.07) | <.001 |
| **Years receiving dialysis** | 1.00 (1.00, 1.00) | .236 | 1.00 (1.00, 1.00) | <.001 | 1.00 (1.00, 1.00) | .436 |
| **Days admitted to a nursing home*** | 1.00 (1.00, 1.00) | <.001 | 1.00 (1.00, 1.00) | <.001 | 1.00 (1.00, 1.00) | <.001 |
| **Impaired decision-making** | 1.17 (1.16, 1.19) | <.001 | 1.24 (1.22, 1.27) | <.001 | 1.15 (1.13, 1.18) | <.001 |
| **ADL score** ** | 1.00 (1.00, 1.00) | <.001 | 1.00 (1.00, 1.00) | <.001 | 1.00 (1.00, 1.00) | .745 |
| **Comorbidities** | | | | | | |
| Diabetes | 0.96 (0949, 0.97) | <.001 | 0.95 (0.94, 0.97) | <.001 | 0.96 (0.93, 0.98) | .002 |
| Coronary artery disease | 0.98 (0.96, 0.99) | .004 | 0.95 (0.93, 0.97) | <.001 | 1.02 (0.99, 1.04) | .272 |
| Dysrhythmia | 0.94 (0.93, 0.96) | <.001 | 0.92 (0.91, 0.93) | <.001 | 0.97 (0.95, 0.99) | .003 |
| Depression | 1.09 (1.08, 1.11) | <.001 | 1.09 (1.08, 1.12) | <.001 | 1.14 (1.11, 1.17) | <.001 |
| Congestive heart failure | 0.95 (0.94, 0.97) | <.001 | 0.95 (0.92, 0.97) | <.001 | 0.96 (0.93, 1.00) | .045 |
| Lung disease | 0.98 (0.97, 0.99) | .001 | 0.98 (0.97, 1.00) | .049 | 0.95 (0.93,0.98) | <.001 |
| Peripheral vascular disease | 0.97 (0.96, 0.99) | <.001 | 0.96 (0.94, 0.97) | <.001 | 0.97 (0.95, 1.00) | .029 |
| Cancer | 1.01 (0.99, 1.02) | .301 | 0.99 (0.97, 1.00) | .256 | 1.02 (0.99, 1.04) | .141 |
| Stroke | 1.01 (1.00, 1.03) | .018 | 1.02 (1.01, 1.04) | .002 | 0.99 (0.97, 1.02) | .703 |
| Dementia | 1.01 (0.99, 1.02) | .284 | 1.01 (0.99, 1.03) | .315 | 1.02 (1.00, 1.05) | .046 |
| **Intercept** | 0.10 (0.09, 0.10) | <.001 | 0.05 (0.05, 0.06) | <.001 | 0.04 (0.03, 0.04) | <.001 |
| **Wald Chi Square** | 17,536 | <.001 | 14,901 | <.001 | 6987 | <.001 |

RR = relative risk

*In the 18 months prior to death

** Activities of Daily Living score range from 0-28, with higher values indicating greater functional impairment

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# Chapter 6

## Overview

Prior to the advent of dialysis and transplant, kidney failure was a terminal diagnosis. Although these therapies offer treatment for a previously terminal diagnosis, the mortality risk for patients treated with dialysis remains high. Mortality risk for ESRD patients treated with dialysis is almost ten times that of the general population, and double that of patients with cancer, heart failure or stroke.[1] From the time of dialysis initiation, half of patients die within three years (49%), and two thirds of patients (65%) die within five years.[1]These statistics describe mortality risk for the entire ESRD population. Very elderly patients (<85 yo), the group with the most rapidly rising rate of dialysis initiation in the U.S., face a higher mortality risk than younger ESRD patients, with a mean survival time of 12 months and 8 months for patients 85-90 years of age and >90 years old, respectively.[2] In spite of the poor prognosis associated with ESRD, end-of-life care has not yet been consistently incorporated into the ESRD care model. As a result, ESRD patients continue to receive medical treatment that does not adequately meet their end-of-life care needs, and is costly for health systems to provide.

This dissertation research originates from the experience of acting as a healthcare provider in a healthcare delivery system that provides resource intensive end-of-life care for individuals with ESRD, which is often at odds with improving the quality of patient and family experience. Intellectual exploration of this subject area led to investigation of methods for measuring healthcare value, and the role of palliative care and advance directives as high value end-of-life care. Based on the information gained through this exploration, the dissertation research addresses areas identified as key gaps in current knowledge related to improving the value of end-of-life care for ESRD patients: measurement of healthcare value in medical research, cost implications of palliative care for ESRD patients and racial disparities in advance directive use. The knowledge gained serves to promote improved healthcare value for individuals with ESRD at the end of life by describing methods for reporting medical research required for value-based healthcare delivery system design, providing information required for assessment of the value of palliative care for ESRD patients, and identifying the impact of racial disparities on receipt of high-value end-of-life care among ESRD patients.

## Summary of Findings

### High Value Care

Contemporary medical research is primarily focused on health outcomes, and rarely reports costs or relates outcomes to cost. In the context of scarce healthcare resources, and crushingly burdensome individual and national healthcare costs; reporting of health outcomes without consideration of cost yields information of limited utility for designing systems of care capable of efficiently maximizing population health. Assessing health outcomes independent of cost blinds policy-makers, providers and healthcare delivery systems to information foundational to rational use of medical therapies in a resource constrained environment. Study of healthcare value measurement reveals that tools for measurement of healthcare value are readily available, but not consistently applied in medical research. Health economics offers a set of well-validated tools (cost effectiveness analysis, cost utility analysis), which could be used to quantify healthcare value based on health outcomes research if this were defined as the standard for medical research results reporting. The primary barriers to implementation of value reporting in medical research are policy mandates that affect research funding streams, stakeholder resistance to inclusion of cost in medical research reporting, and institutional barriers to modification of research methodology. Current trends in public opinion, provider perception, and policy mandates favor a shift in medical research reporting practices to routine inclusion of value measurement, however evolution of research practices occurs incrementally.

## Cost Implications of Palliative Care

Prior work has demonstrated that palliative care improves patients and family experience of end-of-life care for ESRD patients and other chronically ill populations.[3,4] Previous studies show that palliative care is generally associated with reduced healthcare costs, however these studies are few in number and not specific to ESRD patients.[5,6,7,8,9,10,11] This research extended these findings to ESRD patients in the inpatient setting, and evaluated post-discharge outcomes associated with inpatient palliative came among patients who survive to hospital discharge. Inpatient palliative care was associated with reduced inpatient costs, reduced Medicare expenditures, and shorter length of stay for patients who died in the hospital. For patients who survived to discharge, length of stay was unchanged and hospital costs were higher than for patients who did not receive inpatient palliative care. Among the non-decedent cohort, Medicare expenditures for hospital costs were unchanged, but expenditures on provider care were increased. This implies that increased Medicare expenditures resulted from payment for services delivered by palliative care providers. In the 30-day post-discharge period, patients who received palliative care were more likely to enroll in hospice services or withdraw from dialysis; both indicators of a medically supported death. Increased hospice enrollment and dialysis withdrawal indicate a less resource-intensive patterns of care, so although hospital costs were higher for patients among the non-decedent cohort who received inpatient palliative care, palliative care is not necessarily associated with increased total healthcare costs. An important finding of this research is that hospitals face significant losses when providing care for this population; the cost to facilities for providing care to the ESRD patients in the study cohort was substantially higher than the payments facilities received from Medicare for provision of inpatient care. Prior studies have evaluated cost only from a facility perspective, whereas this research included Medicare payment for inpatient hospitalizations. Furthermore, the research demonstrated that variance in cost associated with provision of inpatient palliative care was consistent when stratified by timing of palliative care. For example, patients in the decedent cohort had reduced hospitalization costs regardless of whether they received an initial palliative care consultation in the first 2 days of hospitalization, between days 3 and 7, or after day 7. Information provided by this study is valuable for facilities considering implementation of an inpatient palliative care program, and payers (primarily Medicare) determining whether to incentivize delivery of inpatient palliative care.

## Racial Disparities in Advance Directive Completion

The research on racial disparities in advance directive completion found that patients of non-Hispanic white race were more likely to complete advance directives than patients of other races. This is consistent with previous work in non-ESRD patients, which has shown that non-white patients are less likely to receive advance care planning services[12,13] or palliative care,[14] and are less likely to complete advance directives.[12,15,16,17] Previous analyses have consistently found racial disparities in advance directive completion, but prior work investigating the cause of racial disparities in advance directive completion has produced varied results. Some studies attribute racial disparities in advance directive completion to lack of provider outreach for advance care planning,[12] while others attribute lower rates of advance directive completion among non-white patient populations (as compared with Non-Hispanic whites) to a preference for more intensive end-of-life care,[18,19] spiritual beliefs,[20,21] or mistrust of the healthcare system.[20] The research found that within the entire study population (including patients who did not complete an advance directive), there were substantial racial differences in the likelihood of advance directive completion. This finding, coupled with the relative consistency of preference for treatment limitations across racial group, suggests that lower prevalence of advance directive completion among ESRD patients of Non-Hispanic black and other minority races resulted from lack of efficacious advance care planning engagement, rather than a preference for higher-intensity end-of-life care.

## Implications for Practice, Research and Policy

### Practice implications

**High value care.** Since it's inception, the discipline of medical research has iteratively reinvented itself in response to intrinsic and extrinsic factors such as scientific advances, developments in the fields of epidemiology and genetics, and imposition of standards of ethical conduct. In response to the relentless pace of growth in U.S. healthcare costs, medical research must again reinvent itself to remain relevant and impactful. Medical science can no longer conduct research absent cost considerations, when cost of therapies shapes access to care, and determines the fiscal health of the medical system itself. Perpetuating medical care that results in escalating healthcare costs, and threatens the health of the U.S. economy, is a health risk to those adversely impacted by high medical costs and restricted access to healthcare services. Medical research has an obligation to respond to this risk by implementing research practices that support increasing the value of healthcare services. For medical research to make the next evolutionary step, health outcomes must be routinely converted to standardized units of measure (QALYs and DALYs), and cost must be consistently reported in parallel with health outcomes.

**Palliative care.** Nephrology patients have high mortality rates, and significant unmet needs for patient-centered end-of-life care. According to the framework of healthcare value as improved quality of care and/or reduced healthcare cost, expanding access to palliative care services will likely increase the value of end-of-life care for ESRD patients. Early access to outpatient palliative care is associated with improved end-of-life care as compared with inpatient palliative care,[22] however access to outpatient palliative care is limited in many geographic areas due to a shortage of palliative care providers.[23,24] As a result, inpatient palliative care has become the most prevalent model for delivery for palliative care services.[24] This research indicates that provision of inpatient palliative care to ESRD patients is a fiscally viable proposition for hospitals, and will reduce costs for Medicare beneficiaries if delivered to patients during a terminal hospitalization. Nephrologists and other stakeholders seeking to improve the quality of end-of-life care for ESRD patients may be able to use this data to encourage inpatient facilities to develop palliative care programs. The research indicates that the value of inpatient palliative care is maximized for ESRD patients if it is delivered at the end of life, but this may be due to the outcome metric used in the study (cost of inpatient care, versus total healthcare costs).

Results of this research provide information on targeting and timing of inpatient palliative care. Facilities and payers seeking to improve ESRD end-of-life care quality, and reduce inpatient costs, may preferentially provide inpatient palliative care for patients at highest risk for a terminal hospitalization. Results of this research indicate that facilities designing an inpatient palliative care delivery model with cost reduction in mind need not be primarily concerned with timing of inpatient palliative care within a hospitalization, as it was not a determinant of the association between inpatient palliative care and cost. The mixed results yielded by this research serve as a reminder that healthcare services cannot simply be characterized as high or low value; value is contingent upon optimal targeting of therapies based on patient parameters, timing and setting of care delivery.

**Advance directives.** The healthcare system must deliver high value end-of-life care equitably among the ESRD population. This research reaffirms that ESRD patients who reside in a nursing home complete advance directives at low rates, and found that within this population fewer non-white ESRD patients are completing advance directives than their Non-Hispanic white counterparts. As part of improving the value of ESRD end-of-life care, advance care planning should include patient engagement related to end-of-life care wishes for all ESRD patients, and particularly for those with low functional status and high co-morbid disease burden (such as ESRD patients residing in a nursing home). Healthcare providers tasked with caring for CKD and ESRD patients, such as nephrologists, primary care providers and dialysis centers, should incorporate education and counseling on advance directive completion as a routine component of care, with supplemental support for patients of non-white race. The Patient Self Determination Act (1995) prohibits requiring patients to complete advance directives, but ESRD patients should be encouraged to codify their end-of-life care wishes in advance directive documents, to increase the likelihood they receive end-of-life care consistent with their preferences. Health systems and providers should ensure that these efforts include culturally-sensitive education and outreach for non-white patients, given the disparities in advance directive completion among nursing home bound ESRD patients.

### Future research

**High value care.** Based on the dissertation findings, future research related to improving healthcare value should focus on two general areas: applying value measurement techniques in medical research, and improving the capacity of standardized outcome measures (QALY/DALY) to convert health-outcomes research into standardized units. Each of these will facilitate reporting of value in medical research, which is a crucial step towards increasing value of healthcare for all patients, including ESRD patients at the end of life. Medical research must generate data required for value-based system design by systematically incorporating cost into outcome reporting, and adopting the practice of reporting health outcomes such that they are readily convertible into QALYs/DALYs.

**Palliative care.** In assembling this dissertation, several research priorities related to defining the value of palliative care for ESRD patients at the end of life have become apparent. Although there is widespread agreement that increased access to palliative care would be beneficial for ESRD patients, there is no consensus on the ideal model of delivery. Some of the key questions are: 1) efficacy of team based versus an individual provider, 2) ideal setting of care delivery (inpatient versus outpatient or dialysis-center based), 3) optimal timing of palliative care initiation relative to CKD/ESRD progression.

Even with the current underutilization of palliative care for chronically ill patient populations, demand for palliative care services far outstrips the existing supply of palliative care providers. The number of practicing palliative care providers will need to increase dramatically for all patients who satisfy palliative care referral criteria to receive palliative care services. Potential solutions to the current undersupply of palliative care providers include increased utilization of providers who are not exclusively specialized in palliative care provision (such as physician assistants and nurse practitioners; and primary care physicians, nephrologists, and other specialists for whom palliative care is relevant) to deliver palliative care. In practice, contemporary care patterns often include use of non-pallaitive care specialist to provide palliative care.[25] However, much research on outcomes assocated with palliative care evaluates provision of care by a palliative care specialist.[26] In determining the merits of potential models for expansion of palliative care services, it will be important for future research to evaluate whether palliative care delivered through novel care pathways yields benefits comparable to those seen when palliative care is delivered by palliative care specialists.

The goals of palliative care relate primarily to improving quality of life, thus traditional measures of morbidity and mortality are not meaningful outcomes for gauging the effect of palliative care on ESRD end-of-life care. Increasingly, patient-centered outcomes and subjective measures of well-being are being utilized as outcomes in the study of ESRD end-of-life care, but much remains to be learned about how to quantify the impact of care aimed at improving the value of end-of-life care for individuals with ESRD. Another important research focus required to determine the value of palliative care is investigation of the impact of palliative care on total healthcare costs. Most research on cost implications of palliative care in non-oncology populations describes cost of a single episode of care, rather than total healthcare costs.

**Advance directives.** Based on the quality of current evidence, it cannot be definitively concluded that advance care planning increases the value end-of-life care.[27,28] Research specific to advance directive completion lacks randomized controlled trials. Observational studies have generally demonstrated improvements in end-of-life care quality,[29,30] and stable or reduced healthcare costs.[28,31,32] Among clinicians, there is widespread consensus that completion of advance directives represents high value care for patients with a life threatening illness (such as ESRD),[33,34] but further evidence is required to substantiate the effects of advance directive completion on end-of-life cost and quality outcomes. Demonstrating the effect of advance care planning and advance directive completion on quality and cost of care in large-scale randomized controlled trials is an important research priority, which will inform efforts to improve the value of end-of-life care for ESRD patients.

Based on the findings of this research (lower prevalence of advance directives at time of death among non-white ESRD patients), future study should seek to determine the ideal method of delivering culturally sensitive advance care planning, and increasing the use of advance directives among diverse populations. This area of study is particularly relevant due to the changing demographics of the U.S., which is expected to become predominantly non-white by 2050.[35] Most studies of advance care planning and advance directive completion have not stratified results by race. Loggers et al. evaluated the effect of advance directives s on end-of-life care according to race, and found that among Non-Hispanic white patients, advance directives increased congruence of care with expressed preferences; whereas completion of advance directives did not confer the same benefits for Non-Hispanic black or Hispanic patients.[36] This result indicates that more data is needed to understand the interaction of race and advance care planning. It also suggests that future research on end-of-life care should focus on endpoints such as patient and family satisfaction with care, rather than intermediate outcomes (ex. advance directive completion, receipt of advance care planning), which may not relate to goals of care as expected in minority populations. Finally, future research should address defining the ideal content of advance directives for ESRD patients, since ESRD patients face unique decision-making challenges at the end of life related to dialysis initiation/cessation.

## Policy Implications

**High value care.** Improving the capacity to measure comprehensive, patient-centered, subjective outcomes according to standardized units of value (QALYs/DALYs) in medical research is crucial to deriving a true measure of healthcare value, and will give policymakers and providers the tools to transform medical practice by incentivizing the delivery of care that efficiently promotes patient centered health outcomes. Legislative priorities dictate funding streams for medical research and healthcare services, which has important consequences for the future of medical science. Consistently reporting medical research in terms of healthcare value would allow for open discussion of funding priorities in medical research and healthcare services. This creates the opportunity to design policy reflective of societal values and preferences for care delivery. Value measurement in medical research will be accelerated by increased price transparency in the healthcare sector. Prevailing national trends favor obligatory reporting of cost data; movement in this direction could be accelerated by legislative efforts requiring private insurers to disclose price data.

**Palliative care.** The dissertation research found that among the patients who died in the hospital, Medicare expenditures during the hospitalization were lower for patients who received inpatient palliative care than for those who received usual care. As Medicare shifts from fee-for-service reimbursement to value-based payments, policy makers are seeking to reward provision of high value care by incentivizing healthcare delivery systems that increase quality and decrease costs. Identifying palliative care as a service that improves the value of end-of-life care for ESRD patients signals to policymakers that they should incentivize provision of palliative care for this population.

For patients who survived to discharge, we found substantially lower 30-day readmissions among patients who received inpatient palliative care. This finding has important policy implications, because 30-day readmissions are a quality metric for the Medicare ESRD program. Starting in 2017, dialysis facilities experience payment reductions if 30-day readmission rates are above the expected range [37]. The results of this research suggest that expanded use of inpatient palliative care services for patients with ESRD could be beneficial to healthcare systems and payers from a resource utilization and cost perspective.

**Advance directives.** Policy plays an important role in the delivery of end-of-life care for ESRD patients. The majority of ESRD patients interact regularly with dialysis centers, a healthcare delivery setting that has been utilized as a testing ground for innovative policy efforts to improve quality and reduce costs of ESRD care. Most ESRD patients are Medicare beneficiaries, so changes in CMS policies and payment systems are especially impactful for this population. Nursing facilities are obligated to adhere to standards set by Medicare in order to be eligible for crendentialing and payment, thus there is opportunity to incentivize improved advance care planning by implementing nursing facility quality metrics related to advance care planning and advance directive use. Policy efforts should encourage best-practices in end-of-life care for ESRD patients, including increased use of advance directives among ESRD patients. As Medicare implements advanced alternative payment models, there is opportunity to promote higher value ESRD end-of-life care by tying process, outcome and resource quality measures related to end-of-life care to reimbursement rates for care of individuals with ESRD. Policy mandates for end-of-life care should be carefully crafted, to ensure that they are effective in both improving value of ESRD end-of-life care, and reducing racial disparities in end-of-life care among ESRD patients.

## Conclusion

Unsustainably burdensome healthcare costs have focused policymakers, healthcare delivery systems, clinicians, and healthcare consumers on improving healthcare value. This presents an opportunity to refocus healthcare system design around value, and thus promote improved population health outcomes and reduced healthcare costs. In many cases, improving population health requires investment of additional healthcare resources. Evidence regarding ESRD end-of-life care indicates that improving quality of care may also also reduce healthcare costs; truly a win-win for this medically fragile, vulnerable population that consumes a disproportionately high volume of healthcare resources.

Value-based healthcare system design is premised upon prioritization of healthcare services according to cost per unit of health. Designing healthcare systems based on this methodology requires exhaustive analysis of cost relative to standardized health outcomes. The path toward doing so lies through modification of medical research reporting practices, and improvements in economic methods for translating health outcomes into standardized measures of value.

Palliative care is a promising strategy for improving the value of end-of-life care value for ESRD patients, but key questions remain unanswered; namely the ideal delivery model for palliative care services, and the effect of palliative care on total healthcare costs. As systems of ESRD care are redesigned around new payment models that hold providers and healthcare systems accountable for reducing costs and achieving quality targets,[38] inpatient palliative care may be a resource-efficient mechanism to provide health care that is patient-centered and focuses on improving the experience of patients and their families at the end of life.

Increasing use of advance directives is an important component of improving the value of ESRD end-of-life care. Advance directives are underutilized by the ESRD population. Among nursing home bound ESRD patients, low rates of advance directive completion were compounded for non-white patients by racial disparities in advance directive completion. Advance directive completion should be encouraged for all ESRD patients, with particular attention to engaging patients of non-white race in the advance care planning process. Enactment of the Affordable Care Act precipitated profound changes in the U.S. healthcare system. In the weeks preceding completion of this dissertation, congress passed the American

Healthcare Act, President Trump’s signature “repeal and replace” healthcare legislation. Although the bill faces an uncertain future in the Senate and may never become law, current efforts at legislative healthcare reform have introduced a high degree of uncertainty for the healthcare delivery system and healthcare consumers. The Trump administration’s proposed legislative reforms relies on market forces to lower health insurance premiums through reduced coverage and restricted access, rather than incentivizing higher value healthcare through payment mechanisms or policy design. Meanwhile, payers and providers continue to implement payment systems (set in motion by the Affordable Care Act) intended to improve population health outcomes and reduce healthcare costs. Whether driven by legislative mandates or market forces, the healthcare system will continue to undergo transformation aimed at improving outcomes and reducing the cost of care. This research adds to the body of work informing efforts to increasing the value of ERD end-of-life care, and complements the national trend of increasing healthcare value for all populations.

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