Published in final edited form as:
J Pain Symptom Manage. 2017 December ; 54(6): 789–797. doi:10.1016/j.jpainsymman.2017.08.013.

End-of-Life Experience of Older Adults Dying of End-Stage Renal Disease: a Comparison with Cancer

Melissa W. Wachterman, MD, MSc, MPH, **Stuart R. Lipsitz, ScD**, **Karl A. Lorenz, MD, MSHS**, **Edward R. Marcantonio, MD, SM**, **Zhonghe Li, MS**, and **Nancy L. Keating, MD, MPH**
VA Boston Healthcare System (M.W.W.), Boston, Massachusetts; Brigham and Women's Hospital (M.W.W., S.R.L., N.L.K.), Boston, Massachusetts; Dana Farber Cancer Institute (M.W.W.), Boston, Massachusetts; Harvard Medical School (M.W.W., S.R.L., E.R.M., N.L.K.), Boston, Massachusetts; RAND Health (K.A.L.), Santa Monica, California; VA Palo Alto Health Care System (K.A.L.), Palo Alto, California; Stanford School of Medicine (K.A.L.), Stanford, California; Beth Israel Deaconess Medical Center (E.R.M.), Boston, Massachusetts; Harvard T.H. Chan School of Public Health (N.L.K.), Boston, Massachusetts

Abstract

Context—Older adults with end-stage renal disease (ESRD) are a rapidly growing group of seriously-ill patients. Yet, despite a mortality rate almost twice that of cancer, less is known about ESRD's impact on patients' end-of-life experience.

Objective—To compare the end-of-life experience of older adults who died of ESRD versus cancer.

Methods—We used data from the Health and Retirement Study (HRS), a nationally-representative survey of older adults. Our sample included 1883 HRS participants who died of cancer or ESRD between 2000 and 2010 and their family respondents. We compared advance care planning, treatment intensity, and symptoms between the two groups, and used propensity score weighting to adjust for differences by diagnosis.

Results—Among propensity-weighted cohorts, older adults with ESRD, compared with similar patients with cancer, were less likely to have end-of-life instructions (adjusted proportions 38.5% vs. 49.7%, P=.005) and were more likely to die in the hospital (53.5% vs. 29.0%, P<.001) and to use the ICU in the last two years of life (57.1% vs. 37.0%, P<.001). Decedents with ESRD and cancer had similarly high rates of moderate or severe pain (53.7% vs. 57.8%, P=.34) and all other symptoms.

Conclusion—Older adults dying of ESRD had lower rates of advance care planning and higher treatment intensity near the end of life than similar patients dying of cancer; both groups had

---

Corresponding Author: Dr. Melissa Wachterman, VA Boston Healthcare System, 150 South Huntington Ave., Bldg. 9, Boston, MA 02130, mwachterman@partners.org, Phone: (617) 821-5110; Fax: (857) 364-6990.

Conflicts of Interest:
The authors have no conflicts.

Contributors:
Gabrielle Kate Alicante, BS, and Tarikwa Leveille, BA, MA, Harvard Medical School, assisted with administrative tasks related to drafting of the manuscript including data entry and table creation, but did not meet the criteria for authorship.

similarly high rates of symptoms. Efforts are needed to make treatment more supportive and alleviate suffering for older adults with ESRD and their families near the end of life.

Keywords

end-stage renal disease; end-of-life care; treatment decision-making; symptom burden; Health and Retirement Study

INTRODUCTION

With shifting demographics and advances in medicine, an increasing number of older Americans are living longer with high chronic disease burden. Yet, for many advanced conditions associated with aging and high comorbidity, scant data exist about patients' end-of-life experiences. End-stage renal disease (ESRD) is a key case in point. Adults over the age of 70 are the fastest growing group of individuals with end-stage renal disease (ESRD) (1). Yet, despite a mortality rate for older adults with ESRD that is almost twice that for older adults with cancer (2), substantially less is known about the end-of-life experience of these seriously-ill older adults. There have been some studies assessing the symptom burden experienced by patients with ESRD (3–9). However, few studies have focused on symptoms among older adults with ESRD near the end of life, and those that have been conducted primarily assessed patients managed without dialysis (10, 11). Among older adults on chronic dialysis, rates of completion of advance directives are low (12) and treatment intensity in the last month of life is high (13, 14). Furthermore, none of these studies have used nationally-representative data.

We undertook this study to compare advance care planning and end-of-life decision-making, treatment intensity, and symptoms for older Americans dying of ESRD with those dying of cancer. We chose to compare ESRD with cancer because cancer provides important well-characterized benchmarks for key outcomes, and differences provide insight into how palliative care services designed primarily for those with cancer might need to be modified to meet ESRD-related needs.

METHODS

Data Source

We used data from the Health and Retirement Study (HRS), a nationally-representative longitudinal survey of community-dwelling adults aged 51 years or older. Details of the study design and data collection procedures have been published previously (15). HRS participants complete a Core Interview every two years until death. Then, after each participant's death, a proxy informant (usually a family member) who is knowledgeable about the deceased participant completes the Exit Interview. Response rates for the Exit Interview, our study's primary data source, ranged from 85–92% across 5 study waves between 2002 and 2010 (16).

Study Cohort

We identified all HRS decedents from the 2002–2010 Exit Interview waves whose proxy-reported cause of death was either “kidney disease” (hereafter referred to as ESRD) or “cancer”. The Exit Interview question on cause of death asks proxies, “What was the major illness that led to your loved one’s death?” and proxies can list up to two causes, without reporting whether one was more important. We excluded decedents for whom both kidney disease and cancer were listed (n=12), leaving 1,552 cancer decedents and 358 ESRD decedents. We also excluded decedents with missing data on education (n=3), race (n=1), or survey weights necessary to account for the complex sample design (n=24). The final cohort included 1883 decedents, of whom 358 died of ESRD and 1525 died of cancer.

Outcomes

We assessed older adults’ experiences near the end-of-life using Exit Interview questions focused on three major domains – 1) advance care planning and end-of-life decision-making, 2) treatment intensity, and 3) symptoms. For advance care planning and end-of-life decision-making, we examined whether decedents had written end-of-life care instructions; whether treatment decisions needed to be made in the final days of life; and, among this subset, whether they were able to participate in these decisions. For treatment intensity, we examined location of death (hospital, home, nursing home, hospice/assisted living/other); whether they used the intensive care unit in the last 2 years of life; and “whether they used life support equipment, such as a respirator” in the last 2 years of life. For symptoms, we examined whether decedents experienced each of the following: pain, dyspnea, frequent vomiting, depression, and/or periodic confusion. Questions for all symptoms except pain asked whether the decedent had the symptom for at least 1 month in the last year of life. For pain, a screening question asked whether the decedent was often troubled by pain in the last year of life. A follow-up question asked about the degree of pain (mild, moderate, severe) if present. As in previous work, we classified decedents as having clinically significant pain if their proxies reported “moderate” or “severe” pain (17, 18).

Statistical Analyses

All analyses used sampling strata, clusters, and weights to account for the complex survey design and thus provide nationally-representative estimates. ESRD and cancer decedents differed with respect to many important sociodemographic and clinical characteristics (Table 1, left columns). Therefore, we used propensity score weighting (19) to adjust for these differences. Specifically, for each decedent, we developed a score that reflected his or her propensity to be a cancer (vs. ESRD) decedent, using a logistic regression model that included age at death, sex, race (white, non-white), highest educational level (less than high school, graduated high school/GED, at least some college), marital status, net worth (categorized in quintiles, along with a category for missing data [n=96]), and the presence of each of 8 comorbidities (heart disease, high blood pressure, diabetes, lung disease, psychiatric disorder, arthritis, stroke, and dementia). We then weighted each decedent’s data by the inverse of the estimated probability of being in his/her decedent group (cancer or ESRD). We assessed covariate balance before and after propensity weighting using standardized differences. Past literature suggests that standardized differences <10% reflect well-balanced covariates (20). We then used chi-square statistics to compare adjusted proportions of our outcomes for ESRD and cancer decedents in analyses that included survey strata, clusters, and weights to account for the complex sampling design and propensity weights to adjust for the aforementioned patient characteristics.

Outcomes in the advance care planning/decision-making domain were missing for a low proportion of decedents (≤ 2%), except for the “patient able to participate in end-of-life care decisions” outcome (missing=11%). The sample for this latter question included only those who faced treatment decisions in the final days of life (n=886). In the treatment intensity domain, the location of death outcome had no missing data, while use of the ICU and life support equipment in the last 2 years of life were missing for 14% and 15% of decedents, respectively. Symptom outcomes were not consistently assessed in the 2002 wave of the HRS due to a survey administration error; therefore, as has been done in previous work (18), we excluded that wave from those particular analyses. For outcomes with more than 5% participant non-response, we conducted separate propensity score models among the patients without missing data for that outcome to calculate a unique propensity weight for each of those outcomes, which should minimize the bias due to missing data (21).

The Partners HealthCare Human Research Committee deemed the study exempt from human subjects review. All analyses were conducted using SAS statistical software, version 9.4, Cary N.C. Two-sided P values <0.05 were considered statistically significant.

RESULTS

The study population included 1883 decedents, 358 patients who died of ESRD and 1525 patients who died of cancer. Table 1 presents their characteristics before and after propensity weighting. Before propensity weighting (left columns of Table 1), ESRD decedents were older than cancer decedents, less likely to be married or high school educated, and more likely to be in the bottom quintile of net worth. ESRD decedents tended to be less likely to be White (P=.05), and were equally likely to be male. The ESRD decedents were more likely to have a range of different comorbidities including heart disease, diabetes, and dementia. After propensity weighting, the groups looked very similar (right columns of Table 1) and standardized differences were <10% for all covariates (Appendix).

The left columns of Table 2 show unadjusted rates for outcomes in each of our three domains – advance care planning/decision-making, treatment intensity, and symptoms. The right columns show adjusted rates for these outcomes after propensity weighting to adjust for observed differences in patient characteristics. We primarily report only adjusted rates, and, for the majority of our outcomes, results were fairly similar in unadjusted versus adjusted analyses. For example, in the advance care planning/decision-making domain, in both unadjusted and adjusted analyses, people dying of ESRD were significantly less likely to have written end-of-life instructions than similar people dying of cancer (unadjusted proportions 41.7% vs. 50.7% P=.02; adjusted proportions 38.5% vs. 49.7%, P=.005). In adjusted analyses, in almost half of cases, treatment decisions needed to be made in the final days of life for both groups (49.9% and 46.9%, respectively, P=.48). Less than one-third (30.9%) of people dying of ESRD versus 41.0% of those dying of cancer were able to participate in end-of-life care decisions, although this difference was not statistically significant (P=.12).

In the treatment intensity domain, all comparisons differed significantly in both unadjusted and adjusted analyses. In adjusted analyses, location of death differed for ESRD and cancer patients, with 53.5% of decedents with ESRD dying in the hospital compared with 29.0% of similar decedents with cancer (P<.001). Compared with decedents with cancer, decedents with ESRD were also significantly more likely to use intensive care unit in the last two years of life (57.1% vs. 37.0%, P<.001) and to use life support equipment in the last two years of life (38.5% vs. 19.2%, P<.001).

Finally, in adjusted analyses, people dying of ESRD and cancer had similarly high rates of moderate or severe pain (53.7% vs. 57.8%, P=.34), as well as all other symptoms assessed including dyspnea (61.1% vs. 53.5%, P=.115), depression (53.1% vs. 54.2%, P=.83), periodic confusion (41.4% vs. 44.2%, P=.52), and frequent vomiting (14.9% vs. 20.7%, P=.086), in the last year of life.

DISCUSSION

In this study of a nationally-representative population of older adults who died of ESRD or cancer, we observed important differences in the end-of-life experiences of these two groups. In propensity score weighted analyses, older adults with ESRD—compared with similar decedents with cancer—had lower rates of advance care planning, higher treatment intensity, and a similarly high symptom burden in the last year of life. Our findings highlight the need for improvements in both symptom management and communication about goals of care for the rapidly increasing number of older adults dying of ESRD, a patient population whose end-of-life care needs have been underappreciated.

Specifically, we found that, compared with similar individuals dying of cancer, those dying of ESRD were less likely to have written end-of-life instructions—only approximately one-third had such instructions, compared with one-half of those with cancer. This is particularly concerning since decedents with ESRD also tended to be less able to participate in end-of-life decisions than decedents with cancer, although this finding did not reach statistical significance. Nevertheless the difference (31% vs. 41%) could be clinically important. Notably, the power to detect a statistically significant difference was diminished because this question was only asked of the approximately half of patients (n=886) who faced treatment decisions in the final days of life. Our finding of low rates of advance directives among ESRD decedents is consistent with a study conducted over 15 years ago at two dialysis units (12). Thus our study documents that these trends have held true over time and that they exist at the population level.

We also found that decedents with ESRD were more likely to use the ICU and/or life support equipment in the last two years of life than those dying of cancer and more likely to die in the hospital. These measures of high treatment intensity near the end of life are associated with lower family-rated quality of end of life care (22) (which are highly correlated with patients' assessments of quality (23) and worse bereavement outcomes (24).

There are several potential explanations for our findings of lower rates of advance care directives and higher rates of more aggressive care near the end of life among older adults dying of ESRD compared to those dying of cancer. First, the typical trajectories of advanced cancer and ESRD can be quite different, which may lead to lower rates of advance care planning and higher treatment intensity among individuals with ESRD. Advanced cancer is often characterized by a relatively predictable decline with more certainty that the end-of-life is approaching, which allows for more advance care planning and better understanding about the likely lack of utility of aggressive care. ESRD can follow a less predictable trajectory, characterized by acute declines that may be reversible or stabilize, but at some point lead to death (e.g. dialysis catheter/fistula infection, myocardial infarction, volume overload, hypotension) (25). This more variable trajectory may lead to greater uncertainty about the need for advance care planning and about the utility of aggressive treatment. Thus, given the challenge of accurately prognosticating in ESRD and the unpredictable nature of the final episode that leads to death, different models for approaching goals of care discussions than those developed primarily for cancer patients may be necessary. Models for ESRD, and potentially other conditions with similar trajectories, such as congestive heart failure and chronic obstructive pulmonary disease (25), may need to include more “on the spot” support for patients and families around medical decision-making in the context of acute crises. In addition, counseling patients on the importance of “hoping for the best, while preparing for the worst” in the face of uncertainty may be helpful (26).

A second potential explanation for our findings could be that older adults with ESRD may have more optimistic expectations about prognosis than those with cancer. It is known that patients with more optimistic prognostic expectations are less likely to engage in advance care planning and more likely to pursue aggressive treatment (27, 28). Our previous work showed that 81% of seriously-ill hemodialysis patients predicted there was at least a 90% chance that they would be alive in 1 year (28). In comparison, a study of advanced cancer patients found that only 59% thought there was at least a 90% chance they would be alive in *6 months* (27). There are likely a number of factors that contribute to higher rates of unrealistically optimistic prognostic expectations among ESRD patients compared to cancer patients. For example, our previous work showed that rates of prognostic disclosure by nephrologists to dialysis patients are very low (28), while the rates by oncologists to cancer patients are higher (29). While these differences may be, in part, due to the fact that prognostication can be more difficult in ESRD than advanced cancer, there may also be differences in training and comfort with discussing prognosis. Interventions to help oncologists communicate effectively about prognosis and goals of care have been successful (30), and similar interventions are being developed for nephrologists (31). Medicare’s recent move to reimburse doctors for goals of care conversations is an important step forward and is evidence of the growing recognition by policymakers that addressing advance care planning is valuable. Ensuring that doctors are well-trained to conduct these often nuanced conversations will be critical to the policy’s success.

Third, differences in the rates of hospice and/or palliative care use may also contribute to our findings. Use of hospice and palliative care is less frequent among those dying of ESRD than those dying of cancer (14, 32), and both hospice and palliative care may provide support for advance care planning and facilitate death at home rather than in a hospital.

Differences in hospice and palliative care use are potentially related to the differences in both disease trajectories and prognostic expectations. In addition, there is a potential regulatory barrier to hospice for those dying of ESRD. Medicare will not pay concurrently for dialysis and hospice for patients whose primary life-limiting illness is ESRD. Therefore, such patients must discontinue dialysis to enroll in hospice under Medicare. Since patients often die within days of dialysis discontinuation and almost uniformly die within 1–2 weeks of discontinuation, there is a very short period of time that this patient population can receive hospice services. Our findings demonstrate that there is great need for the expertise that hospice and palliative care clinicians have in symptom management and advance care planning in the ESRD population. Therefore, it is unfortunate that the Center for Medicare and Medicaid Services (CMS) decided not to include ESRD as a qualifying diagnosis for enrollment in the Medicare Care Choices Program, a program which allows for the continuation of curative services concurrently with hospice (33). Our findings suggest a potential need to reexamine Medicare hospice policy.

The similarly high prevalence of moderate/severe pain and other non-pain symptoms in ESRD and cancer decedents that we observed challenges the common perception that cancer has a uniquely high symptom burden, and points to the need to improve symptom management for both groups of patients. Our findings are consistent with a small study of symptoms among 22 individuals with cancer or ESRD (34). Our findings may reflect both a truly higher symptom burden in individuals with ESRD than is typically appreciated and also a possible reluctance among some physicians to prescribe medication to treat symptoms (particularly opioids for pain) in individuals with ESRD because of concern about toxicities in the face of renal failure. Additional research on physicians' use of and perspectives on symptom-oriented medications in patients with ESRD may be needed. Although the patients with ESRD and cancer had notable differences in demographic and clinical characteristics (ESRD patients were older, less likely to be White or to be married, more likely to be of lower SES, and had more comorbidities), results of adjusted analyses were generally similar to results of unadjusted analyses.

The greater burden of comorbid disease that we observed for patients with ESRD versus cancer is consistent with our previous research findings (14). This multimorbidity presumably leads patients with ESRD to have contact with more health care clinicians who, ideally, should share ownership of these patients' end-of-life experience. However, interestingly, a recent qualitative research study suggests that, at least when it comes to advanced care planning, the opposite seems to be true: each of the multiple health care providers who care for patients with advanced kidney disease (e.g. nephrologists, primary care physicians, and other non-nephrology specialists) often assumed that another provider was, or should be, taking responsibility for engaging in advanced care planning with these patients (35). In contrast, it may be that oncologists take more primary responsibility for end-of-life planning for patients with advanced cancer. Therefore, there is clearly an opportunity for better integration of different providers' efforts to improve the care of ESRD patients near the end of life.

Our study has several limitations. First, while our propensity score methods adjusted for observed confounders, we could not account for unobserved differences between seriously-ill older adults with cancer versus ESRD that could be associated with our end-of-life outcomes. For example, one possible explanation for the differences we saw in treatment intensity is that patients who die of ESRD have an unmeasured preference for more aggressive end-of-life care. However, in a recent study that included Veterans dying of ESRD, we found that more aggressive end-of-life care often appeared to be undesired, reflected in worse family ratings of the quality of that care (14). Second, HRS does not have detailed information on dialysis use and does not distinguish between those dying of chronic versus acute renal failure, for whom end-of-life experiences could differ, although epidemiologic data indicate that the vast majority of those dying of renal disease in fact have chronic kidney disease (36). A related consideration is that in our study, cause of death was based on proxy report. Another approach would be to use death certificate data to categorize patients; however, past research has shown diagnoses listed on death certificates to be inaccurate (37, 38). While proxy report could also be inaccurate, family members are likely aware of major illnesses experienced by their loved one. We also used proxy-reported outcomes; past research suggests proxies can accurately report on end-of-life experiences, although accuracy of reported symptoms is less well understood (23, 39). Finally, unfortunately, HRS does not reliably assess hospice use or palliative care involvement. Therefore, we were unable to examine the role that hospice use and palliative care might play in mediating the differences we see, an area worthy of future research.

In conclusion, we observed that older adults dying of ESRD have lower rates of advance care planning and higher treatment intensity than similar individuals dying of cancer. The two groups have comparably high symptom burden in the last year of life. Our findings suggest the need for interventions to promote and enhance communication about advance care planning and goals of care, interventions to improve symptom management, and potentially changes to Medicare policy to improve end-of-life care for the rapidly increasing number of older adults dying of ESRD.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Funding:

This work was supported by the National Palliative Care Research Center Junior Faculty Career Development Award and by the National Institutes of Health (K23AG049088, K24AG035075, K24CA181510, R01NR013372).

References

1. National Institute of Diabetes and Digestive and Kidney Disease. United States Rllenal Data System: USRDS 2013 Annual Data Report: Atlas of End-Stage Renal Disease in the United States. 2013. Available from: http://www.usrds.org/atlas.aspx. Accessed December 2, 2016
2. National Institute of Diabetes and Digestive and Kidney Disease. United States Renal Data System: USRDS 2012 Annual Data Report: Chapter 5 - Mortality. 2012. Available from: http://www.usrds.org/2012/pdf/v2_ch5_12.pdf. Accessed December 2, 2016
3. Davison SN. Pain in hemodialysis patients: prevalence, cause, severity, and management. Am J Kidney Dis. 2003; 42:1239–1247. [PubMed: 14655196]

4. Merkus MP, Jager KJ, Dekker FW, et al. Physical symptoms and quality of life in patients on chronic dialysis: results of The Netherlands Cooperative Study on Adequacy of Dialysis (NECOSAD). Nephrology Dialysis Transplantation. 1999; 14:1163–1170.
5. Parfrey P, Vavasour H, Henry S, Bullock M, Gault M. Clinical features and severity of nonspecific symptoms in dialysis patients. Nephron. 1988; 50:121–128. [PubMed: 3065660]
6. Yong DS, Kwok AO, Wong DM, et al. Symptom burden and quality of life in end-stage renal disease: a study of 179 patients on dialysis and palliative care. Palliat Med. 2009; 23:111–9. [PubMed: 19153131]
7. Murtagh FE, Addington-Hall J, Higginson IJ. The prevalence of symptoms in end-stage renal disease: a systematic review. Adv Chronic Kidney Dis. 2007; 14:82–99. [PubMed: 17200048]
8. Curtin RB, Bultman DC, Thomas-Hawkins C, Walters BA, Schatell D. Hemodialysis patients' symptom experiences: effects on physical and mental functioning. Nephrol Nurs J. 2002; 29:562–574. [PubMed: 12596605]
9. Watnick S, Kirwin P, Mahnensmith R, Concato J. The prevalence and treatment of depression among patients starting dialysis. Am J Kidney Dis. 2003; 41:105–110. [PubMed: 12500227]
10. Murtagh FE, Addington-Hall J, Edmonds P, et al. Symptoms in the month before death for stage 5 chronic kidney disease patients managed without dialysis. J Pain Symptom Manage. 2010; 40:342–52. [PubMed: 20580200]
11. Murphy EL, Murtagh FE, Carey I, Sheerin NS. Understanding symptoms in patients with advanced chronic kidney disease managed without dialysis: use of a short patient-completed assessment tool. Nephron Clin Pract. 2009; 111:c74–80. [PubMed: 19088482]
12. Holley JL, Hines SC, Glover JJ, et al. Failure of advance care planning to elicit patients' preferences for withdrawal from dialysis. Am J Kidney Dis. 1999; 33:688–93. [PubMed: 10196010]
13. Wong SP, Kreuter W, O'Hare AM. Treatment intensity at the end of life in older adults receiving long-term dialysis. Arch Intern Med. 2012; 172:661–663. [PubMed: 22529233]
14. Wachterman MW, Pilver C, Smith D, et al. Quality of end-of-life care provided to patients with different serious illnesses. JAMA Intern Med. 2016
15. Juster FT, Suzman R. An overview of the Health and Retirement Study. J Hum Resour. 1995:7–56.
16. The Health and Retirement Study Sample Sizes and Response Rates. 2011. Available from: http://hrsonline.isr.umich.edu/sitedocs/sampleresponse.pdf. Accessed DEcember 2, 2016
17. Smith AK, Cenzer IS, Knight SJ, et al. The epidemiology of pain during the last 2 years of life. Ann Intern Med. 2010; 153:563–569. [PubMed: 21041575]
18. Singer AE, Meeker D, Teno JM, et al. Symptom trends in the last year of life from 1998 to 2010: a cohort study. Ann Intern Med. 2015; 162:175–83. [PubMed: 25643305]
19. Rubin DB. Estimating causal effects from large data sets using propensity scores. Ann Intern Med. 1997; 127:757–763. [PubMed: 9382394]
20. Austin PC. Using the standardized difference to compare the prevalence of a binary variable between two groups in observational research. Communications in Statistics-Simulation and Computation. 2009; 38:1228–1234.
21. Moore CG, Lipsitz SR, Addy CL, et al. Logistic regression with incomplete covariate data in complex survey sampling: application of reweighted estimating equations. Epidemiology. 2009; 20:382–390. [PubMed: 19289959]
22. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. JAMA. 2004; 291:88–93. [PubMed: 14709580]
23. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? Soc Sci Med. 2003; 56:95–109. [PubMed: 12435554]
24. Kross EK, Engelberg RA, Gries CJ, et al. ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU. Chest Journal. 2011; 139:795–801.
25. Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. JAMA. 2003; 289:2387–92. [PubMed: 12746362]

26. Feuz C. Hoping for the best while preparing for the worst: a literature review of the role of hope in palliative cancer patients. Journal of Medical Imaging and Radiation Sciences. 2012; 43:168–174.

27. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. JAMA. 1998; 279:1709–14. [PubMed: 9624023]

28. Wachterman MW, Marcantonio ER, Davis RB, et al. Relationship between the prognostic expectations of seriously ill patients undergoing hemodialysis and their nephrologists. JAMA Intern Med. 2013; 173:1206–14. [PubMed: 23712681]

29. Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. Ann Intern Med. 2001; 134:1096–105. [PubMed: 11412049]

30. Back AL, Arnold RM, Baile WF, et al. Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. Arch Intern Med. 2007; 167:453–460. [PubMed: 17353492]

31. Schell JO, Green JA, Tulsky JA, Arnold RM. Communication skills training for dialysis decision-making and end-of-life care in nephrology. Clin J Am Soc Nephrol. 2013; 8:675–680. [PubMed: 23143502]

32. O'Connor NR, Dougherty M, Harris PS, Casarett DJ. Survival after dialysis discontinuation and hospice enrollment for ESRD. Clin J Am Soc Nephrol. 2013; 8:2117–2122. [PubMed: 24202133]

33. Centers for Medicare & Medicaid Services. Medicare Care Choices Model. 2014. Available from: https://innovation.cms.gov/files/x/mccm-rfa.pdf. Accessed November 29, 2016

34. Saini T, Murtagh FE, Dupont P, et al. Comparative pilot study of symptoms and quality of life in cancer patients and patients with end stage renal disease. Palliat Med. 2006; 20:631–636. [PubMed: 17060257]

35. O'Hare AM, Szarka J, McFarland LV, et al. Provider perspectives on advance care planning for patients with kidney disease: whose job is it anyway? Clin J Am Soc Nephrol. 2016; 11:855–866. [PubMed: 27084877]

36. Centers for Disease Control and Prevention. Compressed Mortality File: Underlying Cause of Death. 2016. Available from: http://wonder.cdc.gov/mortSQL.html. Accessed December 2, 2016

37. Smith Sehdev AE, Hutchins GM. Problems with proper completion and accuracy of the cause-of-death statement. Arch Intern Med. 2001; 161:277–84. [PubMed: 11176744]

38. Wachterman M, Kiely DK, Mitchell SL. Reporting dementia on the death certificates of nursing home residents dying with end-stage dementia. JAMA. 2008; 300:2608.

39. Clipp EC, George LK. Patients with cancer and their spouse caregivers. Perceptions of the illness experience. Cancer. 1992; 69:1074–1079. [PubMed: 1735074]

Table 1

Characteristics of the Study Population by Diagnosis Before and After Propensity Score Weighting (N=1883)

Characteristic	Before Propensity Weighting[a]			After Propensity Weighting[b]		
	ESRD[c] (N=358)	Cancer (N=1525)	*p*[d]	ESRD[c]	Cancer	*p*[d]
Age, median (25th, 75th percentile)	78 (68, 85)	74 (65, 81)	<0.001	75 (68, 83)	75 (66, 82)	0.99
Sex			0.83			0.36
Male	170 (51.1)	789 (51.8)		54.8	51.5	
Race			0.05			0.73
White(vs. Non- White)	276 (81.6)	1231 (86.3)		84.3	85.2	
Education			<0.001			0.96
Less than high school	161 (41.6)	521 (29.9)		33.5	32.4	
Graduated high school/GED[e]	113 (34.5)	501 (33.3)		33.5	33.4	
At least some college	84 (23.9)	503 (36.8)		33.0	34.2	
Marital Status			0.01			0.93
Married/partnered(vs. Unmarried/unknown)	139 (38.8)	748 (47.8)		46.4	46.0	
Net Worth[f]			0.005			0.93
1st quintile	95 (27.1)	262 (17.4)		20.6	19.7	
2nd quintile	67 (19.0)	286 (19.1)		18.3	19.2	
3rd quintile	68 (18.4)	291 (18.9)		16.6	18.5	
4th quintile	64 (17.7)	296 (19.2)		22.6	18.9	
5th quintile	44 (13.2)	314 (21.2)		18.3	19.5	
Unknown	20 (4.7)	76 (4.2)		3.7	4.1	
Comorbidities						
Heart disease	256 (70.5)	649 (41.6)	<0.001	50.0	47.4	0.53
High blood pressure	300 (83.3)	934 (59.9)	<0.001	67.1	64.5	0.62
Diabetes	156 (41.6)	367 (23.7)	<0.001	30.5	27.7	0.48
Lung disease	85 (23.5)	420 (28.6)	0.08	31.7	27.8	0.33
Psychiatric Disorder	99 (27.8)	323 (22.0)	0.08	20.8	23.4	0.37
Arthritis	263 (73.1)	1028 (66.6)	0.04	64.0	67.9	0.37

Characteristic	Before Propensity Weighting[a]			After Propensity Weighting[b]		
	ESRD[c] (N=358)	Cancer (N=1525)	P^d	ESRD[c]	Cancer	P^d
Stroke	131 (32.8)	303 (19.4)	<0.001	25.2	22.2	0.35
Dementia	81 (22.0)	149 (9.4)	<0.001	13.6	12.2	0.57

[a] Data are presented as unweighted (observed) N (survey-weighted percentage) unless otherwise noted. Survey-weighted percentages incorporate HRS's sampling weights and thus reflect national estimates.

[b] Data are presented as percentages unless otherwise noted, and are both survey-weighted and propensity-weighted. Propensity score weights based on a logistic regression model that included all demographic characteristics and comorbid conditions listed in Table 1.

[c] ESRD= end-stage renal disease

[d] For age at death, based on the complex survey Wilcoxon rank-sum test. For all other covariates listed, based on the Chi-square test.

[e] GED= general equivalency diploma

[f] Listed from lowest to highest quintile.

Table 2

Unadjusted and Adjusted Proportions for End-of-Life Outcomes by Diagnosis

	Unadjusted Proportions (%)[a] (Before Propensity Weighting)			**Adjusted Proportions (%)[b] (After Propensity Weighting)**		
Outcomes[c]	**ESRD[d]**	**Cancer**	***P*[e]**	**ESRD[d]**	**Cancer**	***P*[e]**
Advance Care Planning/Decision-making						
Written end-of-life care instructions (n=1845)	41.7	50.7	0.02	38.5	49.7	0.005
Need to make treatment decisions in final days of life (n=1847)	53.4	46.8	0.07	49.9	46.9	0.48
Patient able to participate in end-of-life care decisions[f] (n=790)	39.4	44.3	0.33	30.9	41.0	0.12
Treatment Intensity						
Location of death:(n=1883)			<0.001			<0.001
Hospital	47.0	29.4		53.5	29.0	
Home	22.4	38.7		20.5	37.6	
Nursing home	18.4	14.3		13.6	15.9	
Hospice/assisted living/other	12.2	17.7		12.5	17.5	
Used the ICU[g] in the last 2 years of life (n=1614)	55.2	37.3	<0.001	57.1	37.0	<0.001
Used life support equipment in the last 2 years of life (n=1607)	32.7	19.6	<0.001	38.5	19.2	<0.001
Symptoms						
Often troubled by moderate/severe pain during last year of life (n=1864)	54.4	57.8	0.33	53.7	57.8	0.34
Dyspnea[h] (n=1466)	62.5	53.0	0.03	61.1	53.5	0.12
Frequent vomiting[h] (n=1444)	17.0	21.1	0.21	14.9	20.7	0.09
Depression[h] (n=1445)	60.5	54.1	0.11	53.1	54.2	0.83
Periodic confusion[h] (n=1466)	51.5	42.9	0.04	41.4	44.2	0.52

[a] Percentages are survey-weighted and thus reflect national estimates.

[b] Analyses adjusted through propensity score weighting for age at death, sex, race, education, marital status, net worth, heart disease, high blood pressure, diabetes, lung disease, psychiatric disorder, arthritis, stroke, and dementia. Percentages are both survey- and propensity-weighted.

[c] Those with missing data on a given outcome were not included in the analysis for that outcome. For each outcome with greater than 5% non-response, a separate propensity model was run to obtain appropriate propensity weights for these outcomes. Sample size for each analysis represented by n.

[d] ESRD= end-stage renal disease

[e] Based on the Chi-square test.

[f] Sample for this analysis was limited to the 886 patients who needed to make treatment decisions in the final days of life

[g] ICU=intensive care unit

[h] Symptom present for at least one month during the last year of life. Due to an error in survey administration in the 2002 Exit Interview, 41% of respondents were not asked the non-pain symptoms; we excluded the full 2002 wave (N=386) from our analysis of these outcomes, leaving a sample of 1,497.