

Chapter 11: USRDS Special Study Center on Palliative and End-of-Life Care

Introduction

Although it is often assumed that dialysis will restore health, this is not always the case. Patients who are disabled often become more disabled after initiation of dialysis (Kurella et al., 2009), and the prevalence of frailty and disability in the end-stage renal disease (ESRD) population is extremely high even among younger patients (Johansen et al., 2007). Despite improvements in survival among patients receiving maintenance dialysis over the past two decades, mortality rates in the ESRD population remain disturbingly high. When taken in this context, the limited survival of many patients with ESRD and their very high levels of disability, frailty and functional impairment provide a strong rationale for efforts to integrate a more palliative and patient-centered approach — focusing on relief of suffering and enhancement of quality of life — into traditional disease-based models of care (Kurella and Meier, 2013; Davison, 2011; Kurella and Cohen, 2010; Cohen et al., 2006; Moss, 2001). Key elements of a more palliative approach include a focus on symptom control, recognition of the importance of the role of family and caregivers and of efforts to coordinate care across settings, and a focus on delivering care that is congruent with each patient's goals, values and preferences (Morrison and Meier, 2004).

While palliative care is often viewed as a treatment of last resort to be offered only when all other treatment options have been exhausted, there is emerging evidence to suggest that disease-based and palliative models of care can be complementary and synergistic rather than mutually exclusive (Temel et al., 2010). Support is now growing for a much broader deployment of palliative care within existing disease based-frameworks, beginning at the time of diagnosis and expanding to accommodate changing needs during the course of serious illness (National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for Quality Palliative Care, 2004).

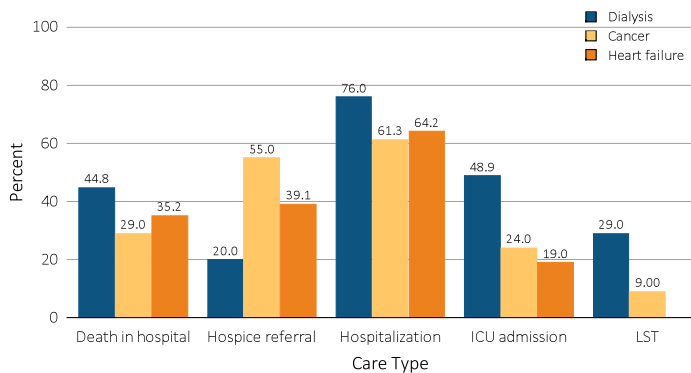
Intensive and Variable Patterns of End-of-Life Health Care Utilization in Patients with ESRD

Available information from existing USRDS and Medicare sources indicates that the majority of elderly dialysis patients receive aggressive care at the end of life that is focused on life prolongation (Figure 11.1). Almost half (44.5 percent) of older dialysis patients die in a hospital setting as compared with 35.2 percent of Medicare beneficiaries with other severe chronic illnesses (including congestive heart failure, advanced liver disease, dementia and chronic obstructive pulmonary disease) (Wong et al., 2012). Rates of hospitalization (76 percent) and ICU admission (49.0 percent) are also substantially higher than reported for other older Medicare beneficiaries, including those with cancer (of whom 61.3 percent are hospitalized and 24.0 percent are admitted to an ICU) and heart failure (of whom 64.2 percent are hospitalized and 19.0 percent are admitted to an ICU) (Wong et al., 2012). Older dialysis patients spend twice as many days in the hospital during the last month of life compared with Medicare beneficiaries with cancer (9.8 vs. 5.1 days), and are three times more likely than cancer patients to undergo an intensive procedure (29.0 percent vs. 9.0 percent). In contrast, rates of palliative care and hospice utilization among dialysis patients at the end of life are extremely low (Murray et al., 2006). Referral to hospice occurs much less commonly among dialysis patients than among cancer patients, even after a decision has been made to discontinue dialysis. Fewer than 1 in 5 U.S. dialysis patients are referred to hospice before death compared with 55.0 percent of Medicare beneficiaries with cancer and 38.1 percent of those with heart failure (Murray et al., 2006).

Patterns of care at the end of life among older dialysis patients are highly variable, and seem to be shaped much more by regional treatment practices than by individual patient characteristics. Rates of referral to hospice and dialysis discontinuation before death vary

by more than twofold across hospital referral regions, with the lowest rates observed in regions with the highest levels of end-of-life health care spending among Medicare beneficiaries (O'Hare et al., 2010). As for other populations, patterns of end-of-life care among patients with ESRD also vary dramatically by race. Rates of hospice referral and dialysis discontinuation among Black patients are less than half of those among White patients, with the most marked racial differences in patterns of end-of-life care observed in regions with the highest levels of end-of-life health care spending (O'Hare et al., 2010; Thomas et al., 2013).

vol 2 Figure 11.1 Patterns of health care utilization during the last month of life among older Medicare beneficiaries with ESRD vs. other conditions (adapted from Wong et al., 2012)



Abbreviations: ICU, intensive care unit; LST, life-sustaining treatment.

Unmet Palliative Care Needs of Patients With ESRD

Although dialysis is intended to address the signs and symptoms of advanced kidney disease, it is becoming increasingly clear that patients receiving maintenance dialysis have a high symptom burden, similar to that of patients with terminal cancer (Murtagh, 2007). A number of single center studies have now documented extremely high rates of untreated pain and other debilitating symptoms as well as a large unmet need for spiritual and palliative support (Davison, 2003; Davison and Jhangri, 2010). Patients treated with maintenance dialysis face a singularly complex set of treatment decisions toward the end of their lives, often in a setting of great uncertainty about the relative benefits and harms of recommended interventions (Kaufman et al., 2006; Murtagh et al., 2007). Many ultimately discontinue this therapy before death (Murtagh et al., 2007).

Limited data suggest that patients with ESRD may not be aware of their prognosis and have unrealistic expectations about their expected disease course

and appropriate treatment options (Wachterman et al., 2013). To date, no prior studies have provided nationally representative information about treatment preferences, palliative care needs, engagement in advance care planning (ACP) or prognostic expectations among patients with ESRD. Nor have prior studies evaluated the extent to which downstream patterns of care toward the end of life among patients with ESRD are congruent with their preferences.

Study Rationale

Prior USRDS Special Study Centers have augmented existing registry data with detailed information relevant to several important domains of care not captured in standard CMS sources, including nutritional status, rehabilitation, disease burden and quality of life. However, these studies have not explicitly addressed palliative and end-of-life care — a domain with a high degree of relevance to this population and for which nationally representative data are currently lacking. Most single center studies of palliative and end-of-life care have been cross-sectional, and thus, have not examined the downstream effects of ACP or other interventions that may enhance the quality of end-of-life care in this population.

Study Goals

The overarching goal of the USRDS Special Study Center (SSC) on Palliative and End-of-Life Care is to provide the nephrology community with innovative, rigorous and nationally representative information about a domain of ESRD care for which little information is currently available to guide policy and practice.

The SSC will conduct prospective surveys using previously validated instruments among patients with ESRD to obtain information across a range of domains related to palliative and end-of-life care. Specifically, we will collect information from patients on symptom burden, palliative care needs, engagement in advance care planning, preferences for life-sustaining treatment, and knowledge of prognosis and treatment options, including hospice and dialysis discontinuation.

The SSC will also collect information from family members of patients with ESRD about their level of involvement in the patient's care, the impact of the patient's illness on their own health and their understanding of the patient's preferences for life sustaining treatment, readiness to engage in advance

care planning and knowledge of treatment options. Ultimately, information collected prospectively from patients and family members will be linked to information for each patient on patterns of health care utilization at the end of their life.

In parallel with these prospective data collection efforts, the SSC will conduct secondary analyses of existing Medicare and USRDS sources to gain a broad understanding of patterns of health care utilization and costs during the final months and years of life among patients with ESRD, including trends over time, across regions, and among different subgroups of patients.

References

- Cohen LM, Moss AH, Weisbord SD, Germain MJ. Renal palliative care. *J Palliat Med* 2006;9(4):977-992.
- Davison SN, Jhangri GS. Existential and religious dimensions of spirituality and their relationship with health-related quality of life in chronic kidney disease. *Clin J Am Soc Nephrol* 2010.
- Davison SN. Integrating palliative care for patients with advanced chronic kidney disease: recent advances, remaining challenges. *J Palliat Care* 2011;27(1):53-61.
- Davison SN. Pain in hemodialysis patients: prevalence, cause, severity, and management. *Am J Kidney Dis* 2003;42(6):1239-1247.
- Johansen KL, Chertow GM, Jin C, Kutner NG. Significance of frailty among dialysis patients. *J Am Soc Nephrol* 2007;18(11):2960-2967.
- Kaufman SR, Shim JK, Russ AJ. Old age, life extension, and the character of medical choice. *J Gerontol B Psychol Sci Soc Sci* 2006;61(4):S175-S184.
- Kurella M, Cohen LM. Should there be an expanded role for palliative care in end-stage renal disease? *Curr Opin Nephrol Hypertens* 2010;19(6):556-560.
- Kurella M, Covinsky KE, Chertow GM, Yaffe K, Landefeld CS, McCulloch CE. Functional status of elderly adults before and after initiation of dialysis. *N Engl J Med* 2009;361(16):1539-1547.
- Kurella M, Meier DE. Five policies to promote palliative care for patients with ESRD. *Clin J Am Soc Nephrol* 2013;8(10):1783-1790.
- Morrison RS, Meier DE. Clinical practice. Palliative care. *N Engl J Med* 2004;350(25):2582-2590.
- Moss AH. Shared decision-making in dialysis: the new RPA/ASN guideline on appropriate initiation and withdrawal of treatment. *Am J Kidney Dis* 2001;37(5):1081-1091.
- Murray AM, Arko C, Chen SC, Gilbertson DT, Moss AH. Use of hospice in the United States dialysis population. *Clin J Am Soc Nephrol* 2006;1(6):1248-1255.
- Murtagh F, Cohen LM, Germain MJ. Dialysis discontinuation: quo vadis? *Adv Chronic Kidney Dis* 2007;14(4):379-401.
- Murtagh FE, Addington-Hall JM, Edmonds PM, Donohoe P, Carey I, Jenkins K, et al. Symptoms in advanced renal disease: a cross-sectional survey of symptom prevalence in Stage 5 chronic kidney disease managed without dialysis. *J Palliat Med* 2007;10(6):1266-1276.
- National Consensus Project for Quality Palliative Care: Clinical practice guidelines for quality palliative care, executive summary. *J Palliat Med* 2004;7(5):611-627.
- O'Hare AM, Rodriguez RA, Hailpern SM, Larson EB, Kurella Tamura M. Regional variation in health care intensity and treatment practices for end-stage renal disease in older adults. *JAMA* 2010;304(2):180-186.
- Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;363(8):733-742.
- Thomas BA, Rodriguez RA, Boyko EJ, Robinson-Cohen C, Fitzpatrick AL, O'Hare AM. Geographic variation in black-white differences in end-of-life care for patients with ESRD. *Clin J Am Soc Nephrol* 2013;8(7):1171-1178.
- Wachterman MW, Marcantonio ER, Davis RB, Cohen RA, Waikar SS, Phillips RS, et al. Relationship between the prognostic expectations of seriously ill patients undergoing hemodialysis and their nephrologists. *JAMA Intern Med* 2013;1-8.
- 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(8):661-663;discussion:663-664.

