

Reengineering Dialysis: The Role of Palliative Medicine

Molly A. Feely, MD,¹ Keith M. Swetz, MD, MA,¹ Kathryn Zavaleta,² Björg Thorsteinsdottir, MD,³
Robert C. Albright, DO,⁴ and Amy W. Williams, MD⁴

Abstract

Background: End-stage renal disease is a life-limiting illness associated with significant morbidity. Half of all individuals with end-stage renal disease are unable to participate in decision making at the end of life, which makes advance care planning critical in this population.

Objective: We sought to determine the feasibility of embedding palliative medicine consultations in the hemodialysis unit during treatment runs and the impact of this intervention on advance care planning and symptom management.

Design: Single-center, prospective cohort study.

Setting/Subjects: Adults receiving in-center hemodialysis at a single outpatient unit were eligible. All consultations occurred during the patients' hemodialysis runs between January 1 and June 30, 2012.

Measurement: Medical records were reviewed for documentation of advance directives, resuscitation status, and goals of care discussions before and after palliative medicine intervention. Symptom surveys with the Modified Edmonton Symptom Assessment Scale (validated for end-stage renal disease) were performed pre-intervention and postintervention.

Results: Ninety-two patients were eligible; 91 underwent palliative medicine consultation. Symptoms were well controlled at baseline prior to any intervention. After palliative medicine consultation, the prevalence of unknown code status decreased from 23% to 1% and goals of care documentation improved from 3% to 59%.

Conclusion: Palliative medicine consultation during in-center outpatient hemodialysis was well received by patients and clinical staff. Patients' symptoms were well managed at baseline by the primary nephrology team. The frequency of goals of care documentation and clarification of code status improved significantly. Embedded palliative medicine specialists on the dialysis care team may be effective in improving multidisciplinary patient-centered care for patients with end-stage renal disease.

Introduction

END-STAGE RENAL DISEASE (ESRD) is a life-limiting illness. Patients undergoing hemodialysis have a shortened life expectancy compared with age-matched peers,¹ an often unrecognized high symptom burden,²⁻⁴ and more aggressive end-of-life care compared with other patients with life-limiting diseases.⁵ Although 25% of patients withdraw from dialysis at the end of life,¹ hospice remains underutilized.⁶

Patients receiving hemodialysis have threefold higher rates of cognitive impairment than age-matched peers in the general population, with up to one-third showing some degree of cognitive impairment.⁷ Patients with ESRD and dementia are twice as likely to withdraw from dialysis than those without dementia⁸ and nearly one-half of patients on hemodialysis lack decision-making capacity at the end of life,⁹ with a

surrogate often making the decision to discontinue hemodialysis. Such surrogate-dependent decisions can be stressful, particularly when patients' wishes and values are unclear.¹⁰ To address these challenges, the Renal Physicians Association published recommendations in 2010 focused on shared decision-making for patients with ESRD, including advance care planning and specialist palliative medicine (SPM) clinician involvement to address quality of life and symptom burden.¹¹ Others have outlined similar needs for this patient population.¹²

To address this recommendation, we designed a pilot study to understand the impact of including SPM physicians on the ESRD care team to provide consultation to every patient in our largest hemodialysis unit. The hypothesis was that embedded SPM clinicians would increase the prevalence of advance directives and improve patients' symptoms.

¹Division of General Internal Medicine, Section of Palliative Medicine, ²Systems and Procedures, ³Division of Primary Care Internal Medicine, ⁴Division of Nephrology and Hypertension, Mayo Clinic, Rochester, Minnesota.
Accepted December 29, 2015.

Methods

This study was approved by the Mayo Clinic's Institutional Review Board. All adult patients (age >18 years) receiving hemodialysis at a single outpatient center were eligible. Only those who declined consultation were excluded. Interpretive services were available for all non-English-speaking patients. Family input was sought for patients with cognitive impairment. All consultations were performed by two board-certified SPM physicians and occurred chair-side in the hemodialysis unit, during patients' hemodialysis runs unless a private room was requested. Medical records were reviewed for documentation of advance directives, resuscitation status, and goals of care discussions before and after intervention. Demographics and end-of-life data were abstracted from the electronic medical record. The severity of comorbid conditions was abstracted, calculated, and scored using an age-adjusted Charlson comorbidity index calculator.¹³

The Modified Edmonton Symptom Assessment Scale (MESAS) validated for ESRD was used to assess symptom burden.¹⁴ An assessment of muscle cramps was added. Symptoms were rated on a scale of 0 to 10 with 0 being absent and 10 being severe. Assessments were done 2 weeks prior to the pilot run-in (December 2011) and 2 weeks after pilot completion (July 2012). The patients' usual care team managed ESRD and primary care needs (nephrologist, advanced practice provider, dialysis registered nurses, dialysis master's level social worker, and renal dietician).

Data were evaluated using descriptive statistics. Preintervention and postintervention MESAS scores were compared using paired *t*-test, while paired analysis of advance directive and goals of care documentation was done using McNemar's test.

Results

Ninety-two patients were eligible; 91 underwent SPM consultation (1 patient was hospitalized and unavailable for consultation but was included in the analysis). Only 1 patient requested the use of a private consultation room during follow-up visit to discuss hemodialysis discontinuation with family. Demographics are summarized in Table 1. One-third of patients were at or near poverty level, qualifying for

TABLE 1. DEMOGRAPHICS

Median age (range)	68.5 years (27–95)
Male gender	57 (62%)
Caucasian race	78 (84.8%)
Deceased at last follow-up (March 26, 2015)	33 (35.9%)
Highest education achieved	
8th grade or less	9 (9.8%)
Some high school, did not graduate	8 (8.7%)
High school grad or GED	34 (37%)
Some college or 2-year degree	24 (26%)
4-year college degree	11 (12%)
Postgraduate degree	4 (4.3%)
Missing data	1 (1.1%)
Medical assistance insurance	31 (33.7%)
Age-adjusted Charlson comorbidity score, mean	7.27 ± 2.76
Average Kt/V	1.47 ± 0.27

TABLE 2. SYMPTOM ASSESSMENT

Symptom	Observed	Median	Mean	p
Pain	Baseline	0	1.34 ± 2.39	0.04
	Follow-up	1	2.04 ± 2.47	
Fatigue	Baseline	2	2.98 ± 3.22	0.02
	Follow-up	5	4.06 ± 2.69	
Nausea	Baseline	0	0.43 ± 1.66	0.96
	Follow-up	0	0.42 ± 1.76	
Drowsy	Baseline	1	1.90 ± 2.60	0.029
	Follow-up	2	2.78 ± 2.88	
Depression	Baseline	0	0.96 ± 1.99	0.70
	Follow-up	0	0.87 ± 2.29	
Anxiety	Baseline	0	0.98 ± 1.82	0.80
	Follow-up	0	1.08 ± 2.86	
Anorexia	Baseline	0	0.83 ± 1.94	0.0001
	Follow-up	2	2.62 ± 2.89	
Itching	Baseline	0	1.25 ± 2.24	0.32
	Follow-up	0	1.66 ± 2.96	
Muscle cramps	Baseline	0	0.75 ± 1.45	0.0005
	Follow-up	0	1.93 ± 2.67	
Dyspnea	Baseline	0	0.34 ± 1.06	0.009
	Follow-up	0	1.06 ± 1.95	
Well-being	Baseline	0	1.40 ± 2.35	0.011
	Follow-up	2	2.36 ± 2.26	

medical assistance insurance (Minnesota's Medicaid program). Fifty-five percent of patients had a high school education or less. Medical comorbidity was high with an average age-adjusted Charlson comorbidity score of 7.27.

Fifty-three patients completed symptom assessment with results summarized in Table 2. Prior to SPM intervention, 66 patients were full code, 21 had an unknown code status, and 5 were do-not-resuscitate (DNR) status. After intervention, the number of patients electing full code increased (75 versus 66, $p < 0.0001$), 1 had an unknown code status, and 16 were DNR. (Table 3). Prior to intervention, only 3 patients had a documented goal of care discussion, improving to 54 patients postintervention ($p < 0.0001$). Documented advance directives increased from 38 patients to 42 ($p = 0.22$). As of March 26, 2015, 33 patients had died, with 22 discontinuing hemodialysis at the end-of-life, and 11 of those enrolled in hospice.

Discussion

SPM consultation in the outpatient hemodialysis unit was well received by patients, and overall, patients preferred to engage in discussions while on dialysis in the open setting of the hemodialysis unit despite offered available private settings. Considering prior efforts to refer patients receiving hemodialysis to a geographically distinct outpatient SPM clinic were less effective, the completed consultation rate of 98.9% (91/92) was interpreted as success. The significant amount of time involved with outpatient dialysis treatments including travel time in combination with the fatigue and malaise often experienced postdialysis, added to the burden of comorbid illness, frequently precludes other same-day activities. Consequently, patients' nondialysis days become too precious to participate in medical-related activities—including outpatient SPM consultations. By co-locating SPM consultation in the hemodialysis unit when patients are

TABLE 3. ADVANCE CARE PLANNING

	<i>Preintervention</i>	<i>Postintervention</i>	<i>p (McNemar's)</i>
Do-not-resuscitate code status	5/92 (5%)	16/92 (17%)	<0.0001
Documentation of an advance Directive	38/92 (41%)	42/92 (46%)	0.22
Documentation of a goals of care discussion	3/92 (3%)	54/92 (59%)	0.0034

geographically bound, we discovered patients readily accepted these private and intense discussions and appreciated discussing quality-of-life issues. Additionally, other members of the ESRD care team could easily engage in the conversation, translating teamwork at bedside and ensuring timely, accurate communication of concerns and recommendations ensuring seamless care.

Contrary to previous studies,²⁻⁴ our patients had low baseline MESAS scores suggesting minimal reported symptom burden or excellent control prior to SPM involvement. This finding is key because it suggests that the nephrology care team can promote effective management of symptoms and quality of life for patients undergoing long-term hemodialysis. To our knowledge, such successful symptom control by nephrologists for patients receiving dialysis has not been reported in the literature. This raises the question of why this dialysis unit was so successful in achieving symptom control. At the time of the pilot study the dialysis unit was a closed unit functioning within an integrated nephrology practice dedicated to optimizing the trajectory of chronic kidney disease along its continuum. The unit had a single nephrologist, who rounded twice per month for all 92 patients, and two advance practice providers who rounded weekly along with an involved nurse manager strongly focused on symptom management. We hypothesize that the combination of increased provider availability and consistency, and team dedication to symptom management combined with ESRD best practice adherence resulted in excellent symptom control for this population receiving dialysis. Furthermore, we surmise that this particular combination (provider consistency and availability, ESRD best practice adherence, and team focus on symptom management) is not the exception to dialysis care, but rather the aspirational goal.

While engagement by the multidisciplinary dialysis care team was high, there were no particular socioeconomic or other demographic metrics differentiating this cohort from reported in-center hemodialysis (ICHD) populations in the upper Midwest.¹ The patients receiving dialysis in this unit were predominantly Caucasian but were neither wealthy nor highly educated. Similarly, the comorbidity burden was significant (average age-adjusted Charlson comorbidity score of 7.27) suggesting this population was quite ill at baseline. The average Kt/V value of 1.47 suggests that they were dialyzed adequately.

Interestingly, some patients' symptoms (7/11 assessed) were worse 6 months after the SPM intervention (Table 2). Changes to pain, drowsiness, muscle cramps, fatigue, dyspnea, and overall well-being were statistically significant after SPM intervention. However, prior studies of MESAS in patients with advanced cancer suggest that to be a clinically significant deterioration the minimal difference should range from 1.1-1.8 units,¹⁵ therefore, these changes may not be clinically relevant.

Anorexia did have both a statistically and clinically significant deterioration postintervention with an unclear eti-

ology. This may be due to chance alone. Other explanations include the possibility that the additional process of inquiry regarding symptom control during SPM consultation resulted in patients being more forthcoming about symptoms at follow-up. Knowing the high burden and progression of comorbid disease in this population, the most likely cause of increased anorexia and other symptoms is the progression of disease status during the 6 months of the pilot study resulting in progressive symptoms.

Documentation of goals of care and clarification of code status both improved after SPM consultation (predocumented versus postdocumented goal of care: 3% versus 59%; unknown code status: 23% versus 1%), addressing previous observations that advanced care planning for patients on hemodialysis is often lacking or inadequate.¹⁶ While the increase in DNR was anticipated, the increase in full code status postconsultation was surprising and could be interpreted as improved decision-making in light of the shift away from undecided status (21 versus 1 patients). Notably, although the ESRD team in this study was successful in managing patients' symptoms, the addition of targeted SPM consultation improved documentation of goals of care. The paucity of baseline goal of care documentation may reflect the ESRD teams' lack of training or discomfort in approaching these discussions as has been shown in prior studies,¹⁷ with the improved documentation of goals of care reflecting the value added of SPM partnership.

Previous work has documented factors leading to reluctance among patients receiving hemodialysis in completing advance directives.¹⁸ It is unclear why SPM intervention improved goals of care documentation, yet failed to significantly increase advance directive completion for our patients. One possible factor is the relatively high baseline rate of completion (41%) compared with the U.S. population, in which reported rates of advance directive completion range between 4% and 25%.^{19,20} Additionally, it is possible that patients believed that since a thorough discussion with SPM experts occurred, further written documentation was superfluous. More likely, the failure to improve advance directive documentation in this study reflects complex factors that are unable to be overcome in a single consultation with SPM.

In this study, only one-half of patients who discontinued hemodialysis (11/22) utilized hospice, in line with previous work showing hospice referral rate for patients on hemodialysis (including those who discontinued hemodialysis) was less than half compared to those dying from cancer.⁶ Interestingly, the 11 patients who discontinued hemodialysis without hospice died in hospital or at skilled nursing facilities. Hospice referral rates prior to SPM intervention are unknown, thus, we are uncertain if this intervention affected hospice utilization, or if other reasons existed, such as rapid clinical decline in the hospital setting resulting in death without hospice care.

We believe this study has several strengths. All patients from the hemodialysis unit were included in the analysis, the

SPM intervention rate was high, and validated measures (MESAS) were utilized. However, the study was conducted at a single center, and our population was overwhelmingly Caucasian with suburban/rural demographics. These results may not be generalizable to other populations, but served well as a feasibility study to inform practice redesign at our institution. Longer term studies are needed to assess the impact of this collaborative model on overall and end-of-life hospitalization rates, length of hospital stay, cost of end-of-life care, quality of life, and hospice referrals. In addition, patient and caregiver satisfaction will be valuable to inform subsequent practice redesign. Fortunately, the entire multidisciplinary ESRD care team has been receptive to this collaborative model leading to diffusion of the embedded SPM consultation/partnership across the study institution's hemodialysis system.

Conclusion

Embedded SPM consultation within a hemodialysis unit was well-received by patients and the ESRD care team and accomplished improved documentation of patients' goals of care and clarification of resuscitation status. Encouragingly, excellent symptom control was noted at baseline in our practice, suggesting an effective coordinated approach to ESRD care via a dedicated team may improve patient-centered outcomes. Further studies are needed to determine embedded SPM consultation effects on hospitalization, cost of care, hospice use, quality of life, and patient and caregiver satisfaction.

Author Disclosure Statement

No competing financial interests exist.

References

1. U.S. Renal Data System: *USRDS 2013 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2013.
2. Davison SN: Pain in hemodialysis patients: Prevalence, cause, severity, and management. *Am J Kidney Dis* 2003; 42:1239–1247.
3. Murtagh FEM, 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.
4. Weisbord SD, Fried LF, Mor MK, et al.: Renal provider recognition of symptoms in patients on maintenance hemodialysis. *Clin J Am Soc Nephrol* 2007;2:960–967.
5. 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, discussion 663–664.
6. Murray AM, Arko C, Chen SC, et al.: Use of hospice in the United States dialysis population. *Clin J Am Soc Nephrol* 2006;1:1248–1255.
7. Kurella TM, Yaffe K: Dementia and cognitive impairment in ESRD: Diagnostic and therapeutic strategies. *Kidney Int* 2011;79:14–22.
8. Kurella M, Mapes DL, Port FK, Chertow GM: Correlates and outcomes of dementia among dialysis patients: The Dialysis Outcomes and Practice Patterns Study. *Nephrol Dial Transplant* 2006;21:2543–2548.
9. Neu S, Kjellstrand CM: Stopping long-term dialysis: An empirical study of withdrawal of life-supporting treatment. *N Engl J Med* 1986;314:14–20.
10. Wendler D, Rid A: Systematic review: The effect on surrogates of making treatment decisions for others. *Ann Intern Med* 2011;154:336–346.
11. Renal Physicians Association: *Shared Decision-Making in the Appropriate Initiation of Withdrawal from Dialysis, 2nd ed.* Rockville, MD: Renal Physicians Association, 2010, pp. 39–92.
12. Kurella TM, Cohen LM: Should there be an expanded role for palliative care in end-stage renal disease? *Curr Opin Nephrol Hypertens* 2010;19:556–560.
13. Hall WH, Ramachandran R, Narayan S, et al.: An electronic application for rapidly calculating Charlson comorbidity score. *BMC Cancer* 2004;4:94.
14. Davidson SN, Jhangri GS, Johnson JA: Longitudinal validation of a modified Edmonton symptoms assessment system in haemodialysis patients. *Nephrol Dial Transplant* 2006;21: 3189–3195.
15. Bedard G, Zeng L, Zhang L, et al.: Minimal clinically important differences in the Edmonton symptom assessment system in patients with advanced cancer. *J Pain Symptom Manage* 2013;46:192–200.
16. Kurella Tamura M, Goldstein MK, Perez-Stable EJ: Preferences for dialysis withdrawal and engagement in advance care planning within a diverse sample of dialysis patients. *Nephrol Dial Transplant* 2010;25:237–242.
17. Davison SN, Jhangri GS, Holley JL, et al.: Nephrologists' reported preparedness for end-of-life decision-making. *Clin J Am Soc Nephrol* 2006;1:1256–1262.
18. Holley JL, Stackiewicz L, Dacko C, Rault R: Factors influencing dialysis patients' completion of advance directives. *Am J Kidney Dis* 1997;30:356–360.
19. Nishimura A, Mueller PS, Evenson LK, et al.: Patients who complete advance directives and what they prefer. *Mayo Clin Proc* 2007;82:1480–1486.
20. Perkins HS: Controlling death: The false promise of advance directives. *Ann Intern Med* 2007;147:51–57.

Address correspondence to:
 Molly A. Feely, MD
 Department of Medicine
 Mayo Clinic
 200 First Street SW
 Rochester, MN 55905

E-mail: feely.molly@mayo.edu

This article has been cited by:

1. Cheung Katharine L., Periyakoil Vyjeyanthi S., Senior Associate Editor. 2016. Renal Palliative Care Studies: Coming of Age. *Journal of Palliative Medicine* 19:6, 582-583. [[Citation](#)] [[Full Text HTML](#)] [[Full Text PDF](#)] [[Full Text PDF with Links](#)]