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A survey of views and practice patterns of dialysis medical directors toward end-of-life decision making for patients with end-stage renal disease

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Abstract

Background—Patients with end-stage renal disease report infrequent end-of-life discussions, and nephrology trainees report feeling unprepared for end-of-life decision making, but the views of dialysis medical directors have not been studied.

Aim—Our objective is to understand dialysis medical directors' views and practice patterns on end-of-life decision making for patients with ESRD.

Design—We administered questionnaires to dialysis medical directors during medical director meetings of three different dialysis organizations in 2013. Survey questions corresponded to recommendations from the Renal Physicians Association clinical practice guidelines on initiation and withdrawal of dialysis.

Setting/participants—There were 121 medical director respondents from 28 states.

Results—The majority of respondents felt “very prepared” (66%) or “somewhat prepared” (29%) to participate in end-of-life decisions and most (80%) endorsed a model of shared decision making. If asked to do so, 70% of the respondents provided prognostic information “often” or “nearly always.” For patients with a poor prognosis, 36% of respondents would offer a time-limited trial of dialysis “often” or “nearly always”, while 56% of respondents would suggest withdrawal from dialysis “often” or “nearly always” for those with a poor prognosis currently receiving dialysis therapy. Patient resistance and fear of taking away hope were the most commonly cited barriers to end-of-life discussions.

Conclusion—Views and reported practice patterns of medical directors are consistent with clinical practice guidelines for end-of-life decision making for patients with end-stage renal disease but inconsistent with patient perceptions.

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Keywords

Terminal care; end-stage kidney disease; decision making; renal dialysis; physician practice patterns

Introduction

The annual mortality rate of patients with end-stage renal disease (ESRD) on dialysis remains over 20%,¹ and symptom burden is often high.^{2,3} Although a majority of patients feel comfortable discussing prognosis and end-of-life care, more than 90% of patients report that their nephrologists have not discussed these issues with them.⁴ Documentation of advance care planning also occurs infrequently for patients with ESRD.⁵ Perhaps as a result, many patients with ESRD receive intensive interventions at the end of life and the majority dies in the hospital.⁶

The Renal Physician Association (RPA) published clinical practice guidelines, Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis, to assist nephrologists, patients, and families in making decisions to initiate and withdraw dialysis.⁷ These guidelines are endorsed by several professional organizations, including the American Society of Nephrology and American Nephrology Nursing Association.^{7,8} However, the extent to which these guidelines are reflected in clinical practice is unknown. Nephrology fellows consider training in end-of-life care important, but have limited exposure to these aspects of practice during their training and feel less prepared to manage end-of-life issues compared to other aspects of nephrology practice.⁹ Dialysis medical directors, as leaders of the dialysis unit, have considerable influence on quality care and oversight of dialysis unit practices; however, little is known about their views and practice patterns regarding end-of-life care for patients with ESRD.

We surveyed dialysis medical directors to determine their views and practice patterns regarding end-of-life decision making for patients with ESRD. We wished to determine whether their approach to end-of-life decision making reflected RPA recommendations and patient perceptions.

Methods

Between October 2013 and April 2014 we distributed anonymous surveys to the medical directors of outpatient dialysis clinics from three medium-sized dialysis organizations. In aggregate, these three dialysis organizations account for 10% of the total dialysis market share. For one organization, electronic surveys were distributed at the annual medical director's meeting using Survey Monkey (www.surveymonkey.com) after a presentation on end-of-life care. For the remaining two organizations, paper surveys were distributed at the end of a presentation on end-of-life care led by a different speaker. This study received an exemption from the Institutional Review Board at Stanford University.

In addition to demographic information, the survey assessed several domains of dialysis decision making and practice patterns, corresponding to key elements of the RPA guidelines.

The RPA guidelines recommend that providers fully inform patients about their prognosis and consider forgoing dialysis (withdrawal or not initiating dialysis) for those with a poor prognosis. A time-limited trial is suggested for patients with uncertain prognosis or where a consensus cannot be reached. Using a five-point Likert scale, the survey assessed how frequently prognostic information was provided to the patient, and how frequently providers suggested a time-limited trial of dialysis or dialysis withdrawal for patients with a poor prognosis (full survey provided in Appendix). The style of dialysis decision making was assessed with a five-point graded scale (never, rarely, sometimes, often, nearly always). Self-perceived preparedness to participate in end-of-life decisions was assessed with a four-point scale (very prepared, somewhat prepared, a little prepared, not at all prepared). Respondents were asked to assess, using a binary Yes/No scale, which factors influenced their approach to dialysis decision making: clinical urgency, competing health priorities, patient interest, length of encounter, presence of family members, patient demographics, availability of resources, reimbursement, previous negative experience, and concern for malpractice. Finally, respondents were asked to identify the main barriers to discussing end-of-life care: patient resistance, lack of training, lack of resources, lack of social work, lack of models to predict prognosis, fear of taking away patients' hope, poor continuity across outpatient and inpatient settings, and multiple providers making responsible party unclear.

We used descriptive statistics to characterize responses. In exploratory analyses, we assessed whether respondent characteristics were associated with practice patterns concerning dialysis withdrawal and time-limited trials and with perceived barriers to end-of-life care. We considered the following provider characteristics: sex, years in practice (≥ 20 vs <20 years), US region, for-profit versus not-for-profit provider, preparedness for end-of-life decisions, and frequency of providing prognostic information. For these analyses, we grouped the outcome variable responses as follows: often or nearly always versus other; and very prepared or somewhat prepared versus other. Exact binomial distribution was used to calculate 95% confidence intervals. We used SAS 9.4 (www.sas.com) to perform statistical analysis. A p -value < 0.05 was considered statistically significant.

Results

Of the total 190 surveys distributed, 121 medical directors responded, a response rate of 64%. The characteristics of medical directors are presented in Table 1. All of the respondents were nephrologists. The majority was male (80%), most had between 10–29 years in practice (62%) and they practiced in 28 different states.

Self-reported preparedness to participate in end-of-life decisions is summarized in Table 2. The majority of medical directors felt very prepared (66%) or somewhat prepared (29%) to participate in end-of-life decisions for patients with ESRD.

The preferred style of dialysis decision making is summarized in Table 3. Eighty percent of medical directors preferred some form of shared decision making. Among these medical directors, a slightly higher percentage endorsed a style of decision making which included providing a recommendation in addition to describing the treatment options. A minority of medical directors had patients or surrogates make the decision after describing options

(17%), or had patients or surrogates make the decision with minimal input from the physician (<1%). No medical directors reported that decision making was solely done by the physician.

Table 4 shows reported end-of-life practice patterns. Medical directors reported that they provided prognostic information quite frequently if asked; almost 70% surveyed said that they did so “often” or “nearly always.” For patients with a poor prognosis, 36% of respondents would suggest a time-limited trial of dialysis “often” or “nearly always.” Similarly, 56% of respondents would suggest withdrawal from dialysis for patients with a poor prognosis who were currently receiving dialysis therapy.

Patient interest (91%), clinical urgency (88%), competing health priorities (75%) and presence of family members (69%) were the most common factors cited that influenced the preferred approach to dialysis decision making for patients (Figure 1). Patient resistance (72%), fear of taking away hope (52%), and poor continuity of care across inpatient and outpatient settings (42%) were the most frequently cited barriers to discussing end-of-life care for patients with ESRD (Figure 2).

Provider self-reported preparedness for end-of-life decision making and practice patterns did not materially differ by medical director demographic characteristics, including the providers’ sex, US region, years in practice, and dialysis organization (data not shown). There was a trend toward a higher reported use of time-limited trials among providers with greater than 20 years in practice, but this was not statistically significant (45% vs 29%, $p = 0.06$). Compared to providers who never, rarely, or sometimes provided prognosis, providers who reported that they provided prognosis often or nearly always were less likely to report lack of validated models to predict prognosis (28.8% vs 55.9%, $p = 0.01$) and lack of training in end-of-life communication (12.5% vs 38.2%, $p < 0.01$) as barriers to discussing end-of-life care. There were no significant associations between providers’ self-reported frequency of providing prognosis and factors influencing dialysis decision making.

Discussion

In this survey of dialysis medical directors, the majority endorsed a model of shared decision making and reported practice patterns consistent with RPA guidelines for initiation and withdrawal of dialysis. Most respondents reported providing patients with prognostic estimates if asked, and recommending dialysis withdrawal or time-limited trials for patients with poor prognosis. Considering prior studies of patient perceptions, our results suggest gaps in patient–provider communication, rather than lack of nephrologist engagement in end-of-life issues, as the main barrier to end-of-life decision making.

Davison et al. surveyed practicing nephrologists in 2005 to determine how prepared they felt to make end-of-life decisions. Of the 260 respondents, only 39% reported being very prepared to make such decisions, with older nephrologists, those with more exposure to dialysis withdrawal, and those aware of RPA guidelines feeling more prepared compared to their peers.¹⁰ In contrast, 66% of providers participating in our survey felt very prepared to discuss end-of-life issues. In contrast, nephrology fellows’ reported preparedness for end-of-

life decision making has not changed much over the same time period. Compared to a 2003 survey, a survey of 104 nephrology fellows in 2013 did not detect improvement in fellowship education on end-of-life issues; nor did the respondents feel more prepared to manage end-of-life issues in the more recent decade. In this survey, recent nephrology fellows reported less teaching and lower levels of preparedness for end-of-life issues relative to clinical management of dialysis.⁹ Taken together, these studies indicate greater awareness and self-reported preparedness for end-of-life decision making among practicing nephrologists over time. The gap in preparedness between nephrology fellows and medical directors suggests confidence in these skills was acquired after fellowship.

In contrast to prior patient surveys in which fewer than 10% of patients reported having prognostic discussions with their nephrologist,⁴ almost 70% of dialysis medical directors in the current study reported providing prognostic information if asked “often” or “nearly always.” The discrepancy between provider-reported and patient-reported frequency of prognostic discussions might be explained by differences in expectations of who should initiate such discussions. That is, patients might expect that physicians initiate these discussions whereas physicians might feel comfortable having such discussions only “if asked.” We were unable to determine how often nephrologists initiate prognostic discussions. Consistent with the idea that physicians discuss prognosis primarily when prompted by patients, in our survey, the most common factor influencing approach to dialysis decision making was “patient interest” and the most common barrier to discussing end-of-life care was “patient resistance.” Prior research provides conflicting information on this subject. Whereas some studies indicate that patients welcome and value such discussions, others note that some patients may resist discussion until the clinical situation is urgent.¹¹

Alternatively, the discrepancy between patient- and medical director-reported frequency of prognostic discussions might reflect ineffective communication of prognostic information. Providers might initiate discussions when patients are not receptive, or in a way that patients do not understand. Prior studies have shown that physicians’ recognition of patients’ emotional response and expression of empathy are crucial for engaging patients in difficult, challenging discussions.¹² In one study of hemodialysis patients, >60% of patients felt that the decision-making process could have been improved by providing more information or more sensitive delivery of bad news.¹¹ It is interesting in this regard then, that 75% of medical directors in the current study felt lack of training in end-of-life communication was not a barrier to discussing end-of-life care. This may reflect the high level of experience in our survey cohort, or the fact that clinicians might overestimate their skills¹³ or overlook specific skills such as checking for patient and family understanding and addressing prognostic uncertainty. Training in end-of-life communication might also be best targeted to trainees¹⁴ or other members of the health care team,¹⁵ since some patients might prefer to discuss end-of-life care with their nurses or social worker.⁴

Rates of dialysis withdrawal in the United States exceed 20%. This may be in part due to the lack of conservative care programs, leading to higher rates of patient regret about starting dialysis and eventual dialysis withdrawal.¹⁶ Patient specific factors, including older age, white race, and high symptom burden¹⁷ are associated with dialysis withdrawal. RPA

guidelines state for ESRD patients on dialysis “who experience major complications that may substantially reduce survival or quality of life, it is appropriate to reassess treatment goals, including consideration of withdrawal from dialysis.”⁸ In our study, more than 50% of respondents would offer dialysis withdrawal for patients with a poor prognosis. A 2005 survey of US nephrologists found that 90% of respondents would withhold dialysis from a permanently unconscious patient and 53% would stop it in a severely demented patient, both higher percentages compared to prior survey of nephrologists performed in 1990 preceding RPA guidelines.¹⁸

Less information is available regarding the prevalence of time-limited dialysis trials, perhaps because they are difficult to execute properly. RPA guidelines recommend that a time-limited trial of dialysis be offered for patients with uncertain prognosis, or for whom a consensus cannot be reached. In our study, 36% of respondents would offer a time-limited trial for those with poor prognosis, a lower percentage compared to the percentage that would offer dialysis withdrawal. More than 60% of nephrologists in the 2005 survey by Davison et al.¹⁰ would offer time-limited trials, although the specific clinical circumstances are not defined in the survey. Nephrologists must invest time up front to develop a reasonable plan and frequently revisit a patient’s progress during such trials, and currently empirical evidence to support such trials is limited.¹⁹

Just over half of the respondents in our survey cited “fear of taking away hope” as a barrier to end-of-life discussions. Contrary to medical directors’ perceptions, prior research suggests that discussing end of life and prognosis is necessary to instill hope in patients with ESRD.^{20,21} By providing more information to the patients, patients are better able to envision possibilities for a future that are consistent with their values, which in turn gives hope. A substantial portion of respondents to our survey also cited “lack of validated models to predict prognosis.” Although there are validated models for predicting the risk for short-term mortality among hemodialysis patients,^{22,23} these models have not been validated in large populations. As such, prognostication remains difficult in clinical practice. Increased familiarity with these tools and approaches for acknowledging uncertainty might facilitate more effective communication.

Clinical urgency and competing health priorities highly influenced the approach to dialysis decision making. In patients with advanced chronic kidney disease (CKD), in addition to other serious health conditions, the risk of death is likely much higher than risk of progression of ESRD.²⁴ Patients and providers alike may delay difficult discussions even in cases where both parties are aware of poor prognosis.²⁵ Deferring discussion of end-of-life care until there is an acute crisis makes the discussion more difficult and often shifts responsibility for decision making to surrogates. In aggregate, more than 70% of respondents believed that poor continuity of care and the lack of clarity regarding which provider should assume responsibility for facilitating decision making were major barriers to discussing end-of-life care. Indeed, patients with ESRD often have multiple specialists caring for them, spanning both inpatient and outpatient settings, making it especially difficult for patients to identify a single healthcare provider with whom to make complex decisions as they navigate a fragmented, complicated health care system.²⁶

Interestingly, few respondents cited lack of reimbursement, fear of malpractice, or lack of social work or hospice resources as factors influencing their decision-making style or barriers to end-of-life discussions. Several quality improvement initiatives have demonstrated that targeted efforts can increase rates of advance care planning documentation. For example, a quality improvement project in which residents received training and financial incentives for documentation of inpatient advanced care planning resulted in a 70% increase in such documentation during the study period.²⁷ Increased documentation of advance care planning was also observed in a Medicare ESRD Disease Management Demonstration Project which did not include separate reimbursement for advance care planning.²⁸ Thus it is unclear whether financial incentives are necessary elements of these programs. Approximately half felt the lack of decision aids influenced their approach to decision making, pointing to a potentially unfilled need. More research is needed to determine the general utility of decision aids for advance care planning in patients with ESRD.

There are several limitations to this study. Non-response bias is a concern in survey research. The response rate in our study was comparable to a recent study of nephrology fellows and substantially higher than a prior study of practicing nephrologists. As in any survey study, respondent bias is also possible due to recall bias or social pressure. An important limitation of the current study is that we did not assess whether reported practices agreed with actual practice. Surveys were provided after presentations on end of life, potentially creating a bias in survey responses, especially in regards to respondents feeling more confident about the topic. Finally, the sample size was small, and there was limited power to identify differences in practice patterns according to provider characteristics.

In summary, views and reported practice patterns of medical directors are consistent with clinical practice guidelines for end-of-life decision making for patients with ESRD but inconsistent with patient perceptions. This study identifies several aspects of end-of-life decision making for patients with ESRD from the perspective of dialysis medical directors that might be targeted for improvement. Strategies to help clinicians address perceived patient resistance, fear of taking away hope, and prognostic uncertainty could help address the complexity of end-of-life decision making for patients with ESRD.

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What is already known about the topic?

- Patients with end-stage renal disease (ESRD) report infrequent discussions about end-of-life care with their nephrologists.
- Many nephrology trainees feel unprepared for end-of-life discussions.

What this paper adds?

- Dialysis medical directors reported high levels of preparedness for end-of-life discussions and frequently discussing prognosis with patients, if asked.
- Many dialysis medical directors reported suggesting dialysis withdrawal or time-limited trials to patients with poor prognosis.

Implications for practice, theory, or policy

- Views and reported practice patterns of dialysis medical directors are consistent with clinical practice guidelines for end-of-life decision making for patients with ESRD but inconsistent with patient perceptions.
- Strategies to address perceived patient resistance, fear of taking away hope, and prognostic uncertainty could improve end-of-life decision making for patients with ESRD.

Figure 1.
Factors influencing approach to dialysis decision making reported by dialysis medical directors.

Figure 2.
Barriers to discussing end-of-life care reported by dialysis medical directors.

Table 1

Characteristics of medical directors.

	<i>N</i>	%
Sex		
Male	98	81.0
Female	21	17.3
No response	2	1.7
US regions		
Northeast	32	26.5
Midwest	12	9.9
South	38	31.4
West	25	20.7
No response	14	11.6
Years in Practice		
<10	12	9.9
10–19	42	34.7
20–29	34	28.1
30–39	18	14.9
40	6	5.0
No response	9	7.4
Organization		
For profit	61	50.4
Not for profit	60	49.6

Table 2

Medical directors' reported preparedness for end-of-life decision making.

How prepared do you feel to participate in end-of-life decisions for patients with ESRD?		
	<i>N</i>	% (95% confidence interval)
Very prepared	80	66.1 (57.0–74.5)
Somewhat prepared	35	28.9 (21.0–37.9)
A little prepared	6	5.0 (1.8–10.5)
Not at all prepared	0	0.0 (0–3.0)

ESRD: end-stage renal disease.

Table 3

Preferred dialysis decision-making style for medical directors.

Which of the following best describes your preferred style of dialysis decision making for patients with ESRD?		
	<i>N</i>	% (95% confidence interval)
Patients and/or surrogates make the final decision, physician input is minimal	1	0.8 (0.0–4.5)
Physicians describe options, patients and/or surrogates make the final decision	21	17.4 (11.1–25.3)
Physicians describe options and elicit patient preferences, and make decision jointly with patients and/or surrogates	41	33.9 (25.5–43.1)
Physicians describe options, elicit patient preferences, provide a recommendation, and make decision jointly with patients and/or surrogates	55	45.5 (36.4–54.8)
Physicians make the final decision	0	0 (0–3.0)
No response	3	2.5 (0.5–7.1%)

Table 4

Medical directors' reported practice patterns based on patients' prognosis, % (95% confidence interval).

	Never	Rarely	Sometimes	Often	Nearly Always
How often do you provide prognostic estimates to patients, if asked?	1.7 (0.2–5.8)	5.0 (1.8–10.5)	24.0 (16.7–32.6)	34.7 (26.3–43.9)	34.7 (26.3–43.9)
How often do you suggest time-limited trials of dialysis for patients with ESRD who have a poor prognosis? *	8.3 (4.0–14.8)	16.7 (10.5–24.6)	39.2 (30.4–48.5)	25.8 (18.3–34.6)	10.0 (5.3–16.8)
How often do you suggest dialysis withdrawal for patients with ESRD who have a poor prognosis or high symptom burden?	0 (0–3.0)	9.9 (5.2–16.7)	33.9 (25.5–43.1)	46.3 (37.2–55.6)	9.9 (5.2–16.7)

ESRD: end-stage renal disease.

* One participant did not respond to this question.