



## ORIGINAL ARTICLE

# An end-of-life practice survey among clinical nephrologists associated with a single nephrology fellowship training program

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## Abstract

**Background:** Our nephrology fellowship requires specific training in recognition and referral of end-stage renal disease patients likely to benefit from palliative and hospice care.

**Methods:** To identify end-of-life (EOL) referral barriers that require greater training emphasis, we performed a cross-sectional, 17-item anonymous online survey (August–October 2015) of 93 nephrologists associated with the program since 1987.

**Results:** There was a 61% response rate (57/93 surveys). Ninety-five percent practiced clinical nephrology (54/57). Of these, 51 completed the survey (55% completion rate), and their responses were analyzed. Sixty-four percent were in practice >10 years; 65% resided in the Southern USA. Ninety-two percent felt comfortable discussing EOL care, with no significant difference between those with ≤10 versus >10 years of practice experience ( $P = 0.28$ ). Thirty-one percent reported referring patients to EOL care ‘somewhat’ or ‘much less often’ than indicated. The most frequent referral barriers were: time-consuming nature of EOL discussions (27%); difficulty in accurately determining prognosis for <6-month survival (35%); patient (63%) and family (71%) unwillingness; and patient (69%) and family (73%) misconceptions. Fifty-seven percent would refer more patients if dialysis or ultrafiltration could be performed in hospice. Some reported that local palliative care resources (12%) and hospice resources (6%) were insufficient.

**Conclusions:** The clinical nephrologists surveyed were comfortable with EOL care discussion and referral. Patient, family, prognostic and system barriers exist, and many reported lower than indicated referral rates. Additional efforts, including, but not limited to, EOL training during fellowship, are needed to overcome familial and structural barriers to facilitate nephrologist referral for EOL care.

**Key words:** dialysis, end-of-life, hospice, nephrology, palliative care

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## Introduction

Discussion and implementation of end-of-life (EOL) care is particularly relevant for many end-stage renal disease (ESRD) patients. Frail, elderly patients with multiple comorbidities who begin dialysis are more likely to require nursing home care or hospitalization, have higher mortality and rates of withdrawal from dialysis, and are more likely than cancer or heart failure patients to receive ICU care in their final month of life [1–4]. Moreover, in a recent retrospective survival analysis, ESRD patients >80 years of age initiated on chronic dialysis had no mortality advantage over those managed with conservative care alone [5]. The Renal Physicians Association (RPA) provides detailed guidance and a toolkit to facilitate shared decision-making with patients and families regarding EOL care and dialysis in patients with frailty, multiple comorbidities or terminal illnesses in addition to their kidney disease [6]. Communication frameworks exist for addressing dialysis decision-making in such patients [3, 7]. The Center for Medicare Services recommends that ESRD patients on dialysis have an advanced directive, and encourages hospice referral for patients who withdraw from dialysis or are dying on dialysis. Many ESRD patients would probably benefit from palliative care, either in combination with chronic dialysis or without, and tools have been developed that allow prediction of 6-month mortality in patients on chronic dialysis [8–10].

There has been increasing focus on training nephrologists to discuss advance directives and EOL issues with ESRD patients, and to recognize and refer patients who may benefit from palliative and hospice care [11, 12]. Our training program has been proactive in this area. Nearly all of our chronic dialysis patients have prepared an advance directive, and EOL issues are regularly discussed at our weekly fellow-led dialysis multidisciplinary conference. Five years ago, specific training for second year fellows was initiated, under the direction of the nephrology faculty, in which they prepared a written counseling plan for a hypothetical case of a frail elderly patient with ESRD, using the available literature and the RPA ‘shared decision-making’ guidelines and toolkit [6]. Despite research interest in this area, data on nephrologists’ attitudes and practice patterns regarding hospice and palliative care are limited, and nephrologists’ perceived barriers to appropriate hospice and palliative care referral have not been well studied.

In order to identify EOL practice issues that require greater emphasis in fellowship training within our program, we anonymously surveyed graduates and faculty of our training program from the last 28 years to assess EOL care practice patterns and perceived barriers to EOL planning and referral among ESRD patients in their practices. We explored whether responses differed between time in practice ( $\leq 10$  years,  $>10$  years) and geographic area.

## Materials and methods

Ninety-three nephrologists consisting of former and present faculty and all fellows who graduated from the Nephrology Fellowship Program at Walter Reed Army Medical Center/Walter Reed National Military Medical Center (WRAMC/WRNMMC) between 1987 and 2015 were identified using the training program database of graduated fellows. There were 18 faculty who had not trained at WRAMC/WRNMMC, or who had graduated from the program before 1987. There were 75 graduated fellows, of whom 24 became faculty at the program between 1987 and 2015. The protocol (#401409) was determined to be exempt from

Institutional Review Board review by the WRNMMC Department of Research Programs as an anonymous survey.

All were contacted by either e-mail (83) or fax (10) beginning on 20 August 2015, requesting their participation in the EOL Survey, and a reminder e-mail or fax was sent again in September 2015. The survey was closed 21 October 2015, the last response having been received on 7 October. The survey (Supplement 1), consisting of 17 items, was programmed in SurveyMonkey™ (Palo Alto, CA, USA), and respondents were invited to take the survey through a web link. The survey was allowed to be taken only once from the same device, and all responses were anonymous (IP addresses were blocked). The first question asked whether the respondent was ‘working as a nephrologist in clinical practice managing nephrology patients’. If the answer was ‘no’, the respondent was directed away from the survey to a ‘Thank you for your participation’ page. If the answer was ‘yes’, the respondent was directed into the full survey.

The complete survey is available as Supplement 1. Questions 2–5 were demographic. Specifically, respondents were asked to indicate their number of years in practice (including fellowship training), how many ESRD patients they were seeing monthly, their present geographic area of practice (based on United States Census divisions), [13] and whether the practice was primarily rural, suburban or urban. Questions 6, 8–9 and 11–13 used a five-point Likert-type construct specific response scale to assess agreement with declarative statements about EOL care in patients with ESRD, and question 7 used a five-point Likert-type scale to assess self-reported frequency of referral for EOL care in ESRD patients when indicated. Questions 10 and 14 assessed the annual number of patients referred by the responding nephrologist to hospice and palliative care, respectively. Questions 15 and 16 asked respondents to report whether more than half of their ESRD and chronic kidney disease (CKD) stage 5 patients, respectively, had advanced directives. Question 17 assessed barriers preventing EOL referral by the responding nephrologist. Respondents were presented with a list of 12 possible barriers and asked to select all applicable barriers, and were given the opportunity to list additional barriers in question 18.

Predetermined primary outcomes were the (i) proportion of respondents with  $\leq 10$  years of clinical practice and those with  $>10$  years of practice who were comfortable discussing EOL issues with ESRD patients, and (ii) proportion of respondents in the Southern versus other US geographic regions who were comfortable discussing EOL issues with ESRD patients.

## Statistical analysis

Categorical data are reported as percentages. Statistical comparisons were performed using Fisher’s exact test, with significance threshold set at  $P < 0.05$ .

## Results

There was a 61% response rate (57/93 surveys). Fifty-four were actively practicing clinical nephrology (95%). Of these, 3/54 elected not to respond to the questions after entering the survey, for a completion rate of 55% (51/93). Of the 51 active clinical nephrologists who completed the survey, 65% ( $N = 33$ ) had been in practice  $>10$  years, and 65% ( $N = 33$ ) practiced in the Southern USA. Demographic features of the respondents are shown in Table 1. A summary of survey responses to questions 6–17 is presented in Table 2.

The majority of respondents agreed or strongly agreed that hospice (98%) and palliative care (100%) were suitable options

**Table 1.** Demographics and clinical practice setting of respondents in active practice who completed the survey (N = 51)

Demographic or clinical feature	N = 51
Years of practice, number (%)	
<5 years	6 (11.8)
5–10 years	12 (23.5)
>10–20 years	20 (39.2)
>20 years	13 (25.5)
Region of USA, number (%)	
Southern	33 (64.7)
Midwest	2 (3.9)
West	10 (19.6)
Northeast	6 (11.8)
Locale, number (%)	
Urban	23 (45.1)
Suburban	19 (37.3)
Rural	9 (17.6)
Individual ESRD cases seen per month (office, dialysis unit and inpatient), number (%)	
1–50	27 (52.9)
>50–250	21 (41.2)
>250	3 (5.9)

for some of their patients with ESRD. Ninety-two percent indicated that they felt comfortable or very comfortable discussing EOL care, with no significant difference between those with  $\leq 10$  years and those with  $>10$  years of practice experience (18/18 versus 29/33;  $P=0.28$ ). Thirty-one percent reported referring ESRD patients to EOL care 'somewhat' or 'much less' often than indicated. Those who felt they referred patients to EOL care less often than indicated were no more likely to have  $\leq 10$  years versus  $>10$  years practice experience (7/18 versus 9/33;  $P=0.53$ ). There were no differences in geographic location (South versus Non-South) among those who felt they referred patients to EOL care less often than indicated (10/33 versus 6/18;  $P=1.00$ ).

Fifty-five percent of respondents indicated that more than half of their patients with ESRD on dialysis had advance directives; 28% were unsure. Eight percent thought that more than half of their patients with CKD stage 5 not yet on dialysis had an advance directive; 53% were unsure. One respondent suggested that including an inquiry about advance directives on the dialysis-rounding checklist might improve the number of ESRD patients on dialysis with advance directives. Another indicated that although the Dialysis Unit Social Worker provides education on advance directives and EOL issues, most patients 'dismiss addressing the issue electively'.

The frequency with which each of the 12 potential barriers were selected by respondents as preventing referral of patients

**Table 2.** Summary of survey responses regarding EOL counseling and referral (N = 51)

Survey questions	Responses	N (%)
Q6. I feel comfortable discussing EOL care with my patients with ESRD.	Agree or strongly agree Neither agree or disagree Disagree or strongly disagree	47 (92.2) 2 (3.9) 2 (3.9)
Q7. How often do you refer ESRD patients for EOL care?	Much more or somewhat more than indicated As often as indicated Somewhat or much less often than indicated	0 (0) 35 (68.6) 16 (31.4)
Q8. Hospice care is a suitable option for some of my patients with ESRD.	Agree or strongly agree Neither agree or disagree Disagree or strongly disagree	50 (98.0) 1 (2.0) 0 (0)
Q9. Hospice care is readily available in my area.	Agree or strongly agree Neither agree or disagree Disagree or strongly disagree	48 (94.1) 2 (3.9) 1 (2.0)
Q10. On average, how many patients do you refer to hospice care per year?	None 1–10 11–25 >25	1 (2.0) 44 (86.2) 5 (9.8) 1 (2.0)
Q11. I would refer more patients to hospice care if they could receive dialysis or ultrafiltration while in hospice.	Agree or strongly agree Neither agree or disagree Disagree or strongly disagree	29 (56.9) 12 (23.5) 10 (19.6)
Q12. Palliative care is a suitable option for some of my patients with ESRD.	Agree or strongly agree Neither agree or disagree Disagree or strongly disagree	51 (100) 0 (0) 0 (0)
Q13. Palliative care is readily available in my area.	Agree or strongly agree Neither agree or disagree Disagree or strongly disagree	44 (86.3) 3 (5.9) 4 (7.8)
Q14. On average how many patients do you refer to palliative care per year?	None 1–10 11–25 >25	4 (7.8) 40 (78.4) 4 (7.8) 3 (5.9)
Q15. More than half of my patients with ESRD on dialysis have advance directives.	Yes No Unsure	28 (54.9) 9 (17.6) 14 (27.5)
Q16. More than half of my patients with CKD stage 5 not yet on dialysis have advance directives.	Yes No Unsure	4 (7.8) 20 (39.2) 27 (52.9)

with ESRD to EOL care are shown in Table 3. All of the respondents chose at least one barrier. The median (range) number of barriers chosen was 4 (1–8). The most frequently chosen barriers preventing EOL referral were: time-consuming nature of EOL discussions (27%); difficulty in accurately determining prognosis for <6 month survival (35%); patient (63%) and family member (71%) unwillingness; and patient (69%) and family member (73%) misconceptions. One respondent indicated that the disagreement of other non-nephrology providers (either out of ignorance or guilt) may be a barrier to initiating EOL care. Those who indicated the time-consuming nature of EOL discussions as a barrier did not feel they referred ESRD patients to EOL care less often than indicated versus those who did not perceive it as a barrier (7/14 versus 9/35;  $P = 0.10$ ). Those who felt it was difficult to determine prognosis were no more likely to be in practice  $\leq 10$  years versus  $> 10$  years (7/18 versus 11/33;  $P = 0.76$ ).

Fifty-seven percent indicated they would refer more patients if dialysis or ultrafiltration could be made available during hospice care, but these were no more likely to refer less often than indicated versus those who did not perceive it as a barrier (8/29 versus 8/22;  $P = 0.55$ ). One respondent commented that in the local practice area, it was not possible to refer a dialysis-dependent ESRD patient to hospice without discontinuing dialysis, regardless of the cause of the fatal illness.

Some observed that local palliative care resources (12%) and local hospice resources (6%) were insufficient. Notably, 100% of respondents with rural and suburban practices reported that hospice care was readily available in their areas, while 13% (3/23) of those with urban practices did not feel that hospice care was readily available. Seven percent (2/28) of respondents with rural and suburban practices reported that palliative care was not readily available, while 22% (5/23) of urban practitioners reported palliative care as not readily available. Overall, 26% (6/23)

of urban practitioners reported that hospice and/or palliative care was not readily available versus 7% (2/28) of rural and suburban practitioners ( $P = 0.12$ ).

## Discussion

Our findings indicate that nearly all nephrologists completing our survey, and who were fellows and/or faculty at a single training program over a 28-year period, felt that hospice and palliative care were suitable options for some ESRD patients, and 92% were comfortable or very comfortable discussing EOL care. Similarly, in a recent survey of US dialysis directors, 95% of medical directors reported feeling 'very' or 'somewhat' prepared to participate in EOL decision making [14]. The majority of respondents in both surveys reported patient resistance or unwillingness to be the most common barrier to discussing EOL care. However, in a 2008 Canadian survey of patients with advanced CKD (about half of whom were receiving dialysis), 66% reported being 'very' or 'somewhat' comfortable discussing EOL issues with the nephrology staff [15]. This suggests a disparity between patient and nephrologist perceptions of patient willingness to participate in EOL discussions.

Our training program has provided specific training in EOL care for second-year fellows for the past 5 years, requiring that they develop a written plan of EOL counseling in a hypothetical, elderly, frail patient with advanced congestive heart failure. They are asked to use the RPA Shared Decision Making Toolkit, after reading selected papers in the area [1–3, 6, 7]. Our survey methodology does not permit direct conclusions about the effectiveness of this education, but comparison of responses between more recent graduates and those with longer practice experience may provide some insight. All of respondents with  $\leq 10$  years of practice experience reported feeling comfortable discussing EOL care. Additionally, those with  $\leq 10$  years experience were no more likely to list difficulty determining patient prognosis as a barrier to EOL discussion or report referring for EOL care less often than indicated than those in practice  $> 10$  years, who likely gain confidence with experience and self-directed learning.

In contrast, 16% of respondents in a 2013 nationwide survey of US nephrology fellows reported having reviewed the RPA clinical practice guideline [12]. In an on-line survey of the nephrologist members of the RPA and the Canadian Society of Nephrology in 2005, 39% of respondents considered themselves very well prepared to make EOL decisions [11]. Year of fellowship completion associated more strongly than any other factor with preparation for EOL discussion, and recent graduates were less than half as likely to report feeling prepared. In the survey of dialysis medical directors, fewer than 10% of respondents had been in practice  $< 10$  years [14].

Our study provides the most comprehensive assessment to date of nephrologists' perceived barriers to EOL care referral, and to our knowledge is the first to assess nephrologists' self-reported rates of referral for EOL care in indicated cases. Although the majority of surveyed nephrologists reported comfort with EOL discussions and the perception that EOL care is suitable for some ESRD patients, more than 30% reported referring ESRD patients to EOL care less often than indicated. A larger sample size is needed to fully evaluate for associations between specific barriers to EOL referral and self-reported referral rates.

Our study specifically looked at barriers to referral for palliative and hospice care in ESRD patients perceived by the nephrologists. Aside from the barrier associated with unwillingness or misconceptions on the part of patients and families, the

**Table 3.** Barriers to EOL counseling and referral ( $N = 51$ )

Q17. Which of the following are barriers that prevent you from referring patients with ESRD to EOL care?

Potential barrier	Number (%) of respondents selecting barrier
EOL care is rarely indicated for the patient with ESRD on dialysis.	1 (2.0)
It is difficult to accurately determine if patient prognosis for survival is <6 months.	18 (35.3)
EOL discussions can be too time-consuming.	14 (27.4)
Patients are unwilling to engage in EOL discussions.	32 (62.7)
Family member(s) are unwilling to engage in EOL discussions.	36 (70.6)
Patients have misconceptions about EOL care.	37 (72.5)
Family member(s) have misconceptions about EOL care.	35 (68.6)
Local palliative care resources are insufficient.	6 (11.8)
I am not comfortable discussing insurance benefits for palliative care.	4 (7.8)
Local hospice care resources are insufficient.	3 (5.9)
I am not comfortable discussing insurance benefits for hospice care.	4 (7.8)
I prefer that other members of the ESRD care team discuss EOL issues with patients and/or family members.	6 (11.8)
Other	3 (5.9)

respondents frequently cited the time-consuming nature of such discussions (27%), and difficulty in determining prognosis (35%). The time-consuming nature of EOL discussions has not been previously studied as a potential barrier. Although our training over the past 5 years has required recognizing that a 'no' answer to the Surprise Question (Would you be surprised if your patient died within the next 6 months?) is a predictor of mortality [8], respondents with  $\leq 10$  years of practice were no less likely to report determining prognosis as a barrier than those with  $>10$  years of practice. Approximately 35% of respondents in the dialysis director study also indicated determining prognosis as a barrier to discussing EOL care in ESRD patients [14]. An ongoing study of protocolized EOL communication intervention, using the Surprise Question to determine prognosis and trained social workers to provide support, education and referral, may address the time-consuming nature of these discussions and uncertainty surrounding prognosis [16].

Our results suggest that the inability to continue chronic dialysis for palliation in some EOL care settings is a significant barrier to hospice referral. Although the Medicare ESRD dialysis benefit continues for patients whose hospice diagnosis is not related to ESRD, in some this is not straightforward. Hospice programs may turn down patients who wish to continue dialysis in such cases, so as to avoid having to undertake the cost of dialysis under the hospice benefit alone. The American Society of Nephrology has suggested that the Center for Medicare and Medicaid Services offer both hospice and dialysis service benefits for patients with dialysis-dependent ESRD and life expectancy  $<6$  months, who wish to continue dialysis [17]. Discontinuation of dialysis in such patients may considerably hasten death [18] or increase discomfort, and 57% of our respondents felt referral would be easier if dialysis or ultrafiltration could be continued after hospice referral.

Limitations of our study include a small sample size and the fact that all of the surveyed practitioners were originally nephrology fellows or faculty at a single academic military medical center. However, the respondents were dispersed geographically (both in terms of region and locale), and varied in duration of practice, training vintage and volume of practice. Our survey compares reasonably well with a recent survey of dialysis directors in terms of number surveyed (190 dialysis directors versus 93 nephrologists in our survey) and response rate (64% versus 61%) [14]. The survey of nephrologist members of the RPA had a response rate of  $<20\%$ , and was conducted over 10 years ago, in 2005 [11].

Other potential limitations are participation and response bias. Respondents more comfortable with EOL discussions may have preferentially responded to the survey. Social desirability bias, which has been shown to affect self-reported physician adherence to practice guidelines [19], may incline respondents to overestimate their comfort with EOL discussions. Respondents who perceived fellowship EOL training as useful may be inclined to overestimate their comfort with EOL discussions. However, 31% reported not referring patients to EOL care as often as indicated, 27% were unsure as to whether their ESRD patients on dialysis had advance directives and 35% felt it was difficult to accurately assess 6-month survival, suggesting respondents were self-aware and honest about their practice.

Our results provide important insights into specific barriers to EOL referral as perceived by nephrologists, and suggest that limited availability of dialysis and/or ultrafiltration may prevent hospice referral in some ESRD patients for whom such care is indicated. Our recent graduates' comfort with EOL discussions, exposure to attendant clinical practice guidelines and rates of

appropriate referral compare favorably to those respondents with more clinical practice experience. Responses of fellows and less experienced nephrologists from other surveys suggest that our easily reproducible methods of EOL care education could be a model for other fellowship programs wishing to optimize this education for their trainees.

## SUPPLEMENTARY DATA

Supplementary data are available online at <http://ckj.oxfordjournals.org>.

## Conflict of interest statement

The views expressed in this article are those of the authors and do not reflect the official policy of the Department of Army/Navy/Air Force, Department of Defense or the US Government. The identification of specific products or scientific instrumentation does not constitute endorsement or implied endorsement on the part of the author, Department of Defense or any component agency.

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