

Nephrologists' Reported Preparedness for End-of-Life Decision-Making

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Nephrologists commonly engage in end-of-life decision-making with patients with ESRD and their families. The purpose of this study was to determine the perceived preparedness of nephrologists to make end-of-life decisions and to determine factors that are associated with the highest level of perceived preparedness. The nephrologist members of the Renal Physicians Association (RPA) and the Canadian Society of Nephrology were invited to participate in an online survey of their end-of-life decision-making practices. A total of 39% of 360 respondents perceived themselves as very well prepared to make end-of-life decisions. Age >46 yr, six or more patients withdrawn from dialysis in the preceding year, and awareness of the RPA/American Society of Nephrology (ASN) guideline on dialysis decision-making were independently associated with the highest level of self-reported preparedness. Nephrologists who reported being very well prepared were more likely to use time-limited trials of dialysis and stop dialysis of a patient with permanent and severe dementia. Compared with Americans, Canadian nephrologists reported being equally prepared to make end-of-life decisions, stopped dialysis of a higher number of patients, referred fewer to hospice, and were more likely to stop dialysis of a patient with severe dementia. Nephrologists who have been in practice longer and are knowledgeable of the RPA/ASN guideline report greater preparedness to make end-of-life decisions and report doing so more often in accordance with guideline recommendations. To improve nephrologists' comfort with end-of-life decision-making, fellowship programs should teach the recommendations in the RPA/ASN guideline and position statement.

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More than 79,812 chronic dialysis patients die each year in the United States, with an unadjusted mortality rate of 22 to 25% (1). The ESRD population increasingly is composed of older patients with multiple comorbidities, high symptom burden (2,3), and a shortened life expectancy; withdrawal from dialysis represents the second leading cause of death in these patients (1,4). Because of these factors, nephrologists commonly engage in end-of-life decision-making with patients with ESRD and their families. The purpose of this study was to determine the perceived preparedness of nephrologists to make end-of-life decisions, the factors that are associated with the highest level of nephrologists' self-reported preparedness to make these decisions, and the extent to which the Renal Physicians Association (RPA) and the American Society of Nephrology (ASN) clinical practice guideline *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis* (5) and position statement *Quality Care at the End of Life* (6) are used by nephrologists in making end-of-life decisions. We also compared nephrologists' practices in

dialysis decision-making in the United States with those in Canada.

Materials and Methods

In 2005, the 2500 nephrologist members of the RPA were invited by e-mail to participate in an online survey of their attitudes and practices toward end-of-life decision-making. The invitation was sent in January 2005. Monthly reminders to participate in the online survey were sent by e-mail in February, March, and April 2005. The 325 members of the Canadian Society of Nephrology also were invited to participate in the same online survey. All methods adhered to the Declaration of Helsinki. The West Virginia University School of Medicine Office of Research and Graduate Studies reviewed and approved the Institutional Review Board for the Protection of Human Subjects application for exemption.

Questionnaire

A questionnaire that was similar to that used in an earlier study to determine nephrologists' attitudes and practices in end-of-life decision-making (7) was developed. Nephrologists were asked to report their level of preparedness to make end-of-life decisions and their awareness and use of the RPA/ASN clinical practice guideline *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis* and RPA/ASN statement *Quality Care at the End of Life*. Information on dialysis unit policies on withdrawal of dialysis and cardiopulmonary resuscitation was sought. The survey also elicited nephrologists' practices with regard to withdrawing dialysis, time-limited trials of dialysis, hospice referrals, and practices of withholding or withdrawing dialysis

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in four hypothetical scenarios (a patient in the intensive care unit with multiple-organ system failure, a patient with permanent and severe dementia, a permanently unconscious patient as a result of either persistent vegetative state or multiple strokes, and a competent patient who asked to stop dialysis). Demographic data such as the number of dialysis patients cared for, year of nephrology fellowship completion, affiliation with a medical school, ownership status of the dialysis unit in which they have the most patients, and age were collected. A copy of the survey is available from the authors upon request.

Statistical Analyses

SPSS 14.0 for Windows (SPSS, Chicago, IL) was used to perform statistical analyses. $P < 0.05$ was considered for statistical significance. American and Canadian nephrologists' responses were compared as were the responses of nephrologists who identified themselves as very well prepared with those who felt less well prepared to make end-of-life decisions. χ^2 test was used to compare the differences in proportions in categorical variables. An independent samples t test was used to detect a difference between means for normally distributed continuous variables (year of fellowship completed). The remaining continuous variables (number of patients cared for, number of patients withdrawn from dialysis in the past year, and number of patients referred to a hospice in the past year) were positively skewed. These variables were log-transformed and then analyzed using a t test. Logistic regression analysis was conducted to find the variables that were associated with nephrologists' being very well prepared to make end-of-life decisions. Age data were collected as 5-yr intervals (20 to 35, 36 to 45, 46 to 55, 56 to 65, and 66+). Approximately equal percentages were very well prepared in the first two age categories, and approximately equal

percentages were very well prepared in the last three age categories. The similar age groups were combined for use in the logistic model. Similarly, the year of fellowship completion had a nonlinear relationship and was categorized into quintiles. Approximately equal percentages were very well prepared in the first three quintiles (1960 to 1978, 1979 to 1984, and 1985 to 1992), and approximately equal percentages were very well prepared in the last two quintiles (1993 to 2002 and 2003 to 2005). These similar groups were combined for use in the logistic model. The number of dialysis patients cared for, the number of patients withdrawn from dialysis during the past year, and the number of patients referred to a hospice in the past year all had a nonlinear relationship and were categorized into tertiles. Multivariate logistic regression model was adjusted by country of practice. Age and year of fellowship completion were highly correlated, and only age was used in the multivariate logistic model.

Results

A total of 360 nephrologists responded: 296 American nephrologists (12% of RPA membership), 61 Canadian nephrologists (19% of the Canadian Society of Nephrology membership), and three unknown (Table 1). Compared with Americans, Canadian nephrologists were younger, more likely to be affiliated with a medical school (89 versus 46%; $P < 0.001$), and not practicing in for-profit units (0 versus 57%; $P < 0.001$). Canadian nephrologists reported stopping dialysis of a higher number of patients in the preceding year (6.3 versus 4.2; $P = 0.018$) and reported referring fewer to hospice (2.5 versus 3.8; $P < 0.001$) than American nephrologists. They practiced in units that were less

Table 1. Comparisons of characteristics of nephrologists according to country of practice^a

| Characteristic of Nephrologists | Within Nephrologists' Country of Practice (Mean \pm SD or %) | | P |
|---|---|--------------------|--------|
| | United States (n = 296) | Canada (n = 61) | |
| Year fellowship completed | 1988 \pm 11 | 1992 \pm 12 | 0.006 |
| Age (yr) | | | 0.001 |
| 20 to 45 | 40 | 62 | |
| 46 to 65 | 54 | 28 | |
| 66+ | 6 | 10 | |
| No. of patients cared for | 106 \pm 104 | 139 \pm 121 | 0.549 |
| No. of patients stopped dialysis in past year | 4.2 \pm 4.0 | 6.3 \pm 6.4 | 0.018 |
| Use time-limited trials of dialysis | 79 | 82 | 0.614 |
| No. of patients referred to hospice in past year | 3.8 \pm 3.9 | 2.5 \pm 4.0 | <0.001 |
| Practice in units that refer patients to hospice | 85 | 61 | <0.001 |
| For-profit chain affiliation | 57 | 0 | <0.001 |
| Medical school affiliation | 46 | 89 | <0.001 |
| Very well prepared | 42 | 30 | 0.075 |
| Unit policy on withdrawal of dialysis | 30 | 7 | <0.001 |
| Unit policy on CPR | 86 | 47 | <0.001 |
| Practice in units in which CPR is routinely discussed | 89 | 84 | 0.200 |
| Aware of RPA/ASN guidelines | 61 | 49 | 0.075 |
| Use RPA/ASN guidelines ^b | 51 | 55 | 0.706 |
| Aware of RPA/ASN statement | 57 | 41 | 0.026 |
| Use RPA/ASN statement ^b | 54 | 76 | 0.040 |

^aCPR, cardiopulmonary resuscitation; RPA/ASN, Renal Physicians Association/American Society of Nephrology.

^bNumbers and percentages are based on nephrologists who are aware of guidelines/statement.

likely to have policies on dialysis withdrawal (7 versus 30%; $P < 0.001$) and cardiopulmonary resuscitation (CPR; 47 versus 86%; $P < 0.001$). Canadians were slightly less aware of the RPA/ASN guideline (49 versus 61%; $P = 0.075$) and RPA/ASN statement *Quality Care at the End of Life* (41 versus 57%; $P = 0.026$). However, of those who were aware, there was comparable usage. Canadian nephrologists reported being more likely to stop dialysis of a patient with severe dementia (71 versus 53%; $P = 0.009$; Figure 1). Their practices regarding withholding dialysis from a permanently unconscious patient or stopping dialysis at the request of a competent patient were similar to that of American nephrologists.

Thirty-nine percent of overall respondents perceived themselves to be very well prepared to make end-of-life decisions. Compared with the less than very well prepared, nephrologists who reported being very well prepared were older, had been in practice longer, had withdrawn more patients from dialysis in the preceding year (5.6 versus 3.8; $P < 0.001$), were more likely to use time-limited trials of dialysis (87 versus 74%; $P = 0.003$), were less likely to consult an ESRD Network Ethics Committee for difficult patient

treatment decisions (40 versus 57%; $P = 0.002$), and were more aware of the RPA/ASN clinical practice guideline (70 versus 52%; $P < 0.001$) and statement on *Quality Care at the End of Life* (62 versus 48%; $P = 0.007$; Table 2). Nephrologists who felt very well prepared to make end-of-life decisions reported being more likely to stop dialysis if a patient develops permanent and severe dementia (66 versus 50%; $P = 0.003$; Figure 1). Withholding dialysis of a permanently unconscious patient and stopping dialysis if requested by a competent patient did not vary by level of perceived preparedness. Multiple logistic regression analysis identified age ≥ 46 yr (odds ratio [OR] 2.77; 95% confidence interval [CI] 1.70 to 4.53; $P < 0.001$), six or more patients withdrawn from dialysis in the preceding year (OR 2.58; 95% CI 1.43 to 4.66; $P = 0.002$), and awareness of the RPA/ASN guideline (OR 1.78; 95% CI 1.10 to 2.90; $P < 0.001$) to be independently associated with the highest level of self-reported preparedness (Table 3).

Discussion

With the significant symptom burden, comorbidity, and limited survival of the aging dialysis population, nephrologists who care for patients with ESRD increasingly are deciding with patients and/or families whether to withhold or withdraw dialysis. In fact, withdrawal from dialysis precedes death in up to 30% of chronic dialysis patients (8). The Institute of Medicine Committee for the Study of the Medicare End-Stage Renal Disease Program recommended that guidelines that could assist nephrologists, patients, and families in reaching clinical decisions on whether to initiate or to stop dialysis be developed (9,10). In the past 10 to 15 yr, there has been an increase in the research that is devoted to these issues, and the RPA and the ASN published a clinical practice guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, and a position statement, *Quality Care at the End of Life* (5), to address the issues of appropriate initiation of and withdrawal from dialysis. Despite these efforts, most nephrologists (61%) do not feel very well prepared to make these difficult end-of-life decisions (Table 1).

Awareness of the RPA/ASN guideline concerning end-of-life decision-making was an independent predictor for nephrologists' reporting greater preparedness in dealing with these issues. These nephrologists also were more likely to report making end-of-life decisions in accordance with the guideline such as offering time-limited trials of dialysis, withdrawing dialysis from a patient with severe dementia, and referring patients to hospice. Despite the existence of this guideline to aid decision-making, there continues to be considerable variation in reported practice, especially concerning the patient with dementia. Even among nephrologists who report being very well prepared, only 66% were comfortable withdrawing dialysis from a patient with severe dementia when no clear previous wishes had been established. Recommendation 7 in the RPA/ASN guideline notes that it is reasonable to consider withdrawing dialysis for patients who have "all forms of severe irreversible dementia" if they are "unable to cooperate with the dialysis pro-

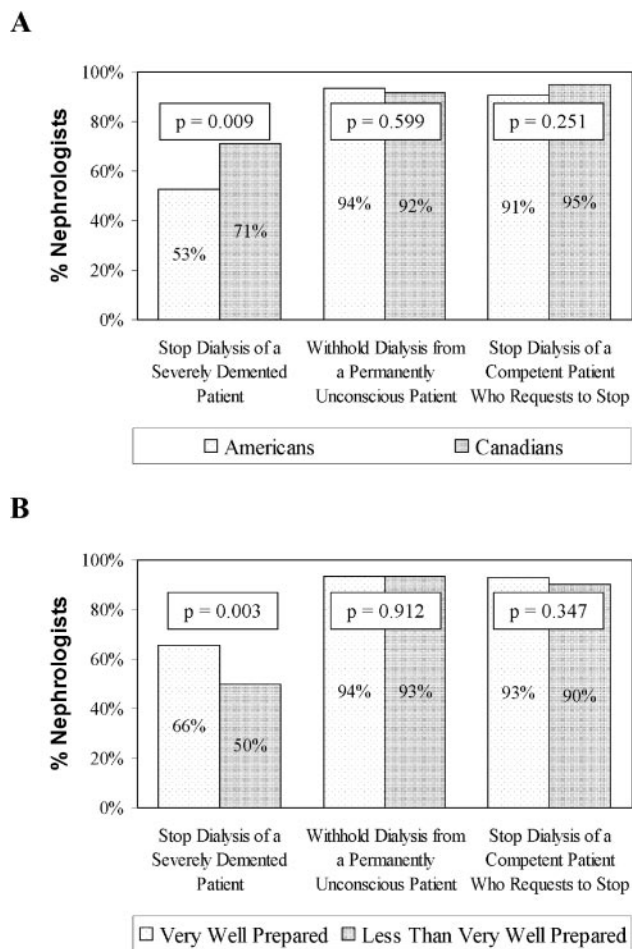


Figure 1. Practices to withhold or stop dialysis: Comparison between American and Canadian nephrologists (A) and between nephrologists who are very well prepared and less than very well prepared for end-of-life decision-making (B).

Table 2. Comparisons of characteristics of nephrologists according to level of preparedness

| Characteristic of Nephrologists | Within Nephrologists Level of Preparedness (Mean \pm SD or %) | | P |
|--|--|---|--------|
| | Very Well Prepared (n = 143) | Less than Very Well Prepared (n = 211) | |
| Year fellowship completed | 1985 \pm 11 | 1992 \pm 12 | <0.001 |
| Age (yr) | | | <0.001 |
| 20 to 45 | 27 | 55 | |
| 46 to 65 | 64 | 39 | |
| 66+ | 8 | 6 | |
| No. of patients cared for | 114 \pm 83 | 109 \pm 122 | 0.033 |
| No. of patients who stopped dialysis in past year | 5.6 \pm 5.1 | 3.8 \pm 3.9 | <0.001 |
| Use time-limited trials of dialysis | 87 | 74 | 0.003 |
| No. of patients referred to hospice in past year | 3.9 \pm 4.1 | 3.3 \pm 3.9 | 0.039 |
| Practice in units that refer patients to hospice | 87 | 76 | 0.013 |
| Medical school affiliation | 52 | 54 | 0.644 |
| Country of practice, United States | 87 | 80 | 0.075 |
| Unit policy on withdrawal of dialysis | 31 | 22 | 0.062 |
| Unit policy on CPR | 80 | 79 | 0.812 |
| Practice in units in which CPR is discussed routinely | 93 | 85 | 0.029 |
| Likely to consult an ESRD Network Ethics Committee for difficult patient treatment decisions | 40 | 57 | 0.002 |
| Aware of RPA/ASN guidelines | 70 | 52 | <0.001 |
| Use RPA/ASN guidelines ^a | 58 | 48 | 0.155 |
| Aware of RPA/ASN statement | 62 | 48 | 0.007 |
| Use RPA/ASN statement ^a | 59 | 55 | 0.613 |

^aNumbers and percentages are based on nephrologists who are aware of guidelines/statement.

cess. . ." (11). Although only 66% of the surveyed nephrologists would feel comfortable following this guideline, in 1990, only 32% of surveyed nephrologists reported being comfortable withdrawing dialysis in such a patient (7). Comfort with stopping dialysis in competent patients who request to withdraw from dialysis and withholding dialysis from a permanently unconscious patient seem to be more uniform, with the vast majority (90 to 95%) supporting such decisions.

Nephrologists who reported greater preparedness had been in practice longer and were caring for a greater number of patients. This suggests that clinical experience rather than education during training prepares nephrologists to deal with the complex end-of-life decision-making that is required when caring for patients with ESRD. This is not surprising given that end-of-life care is not well addressed in renal fellowship training (12). Second-year fellows report feeling unprepared to care for their dying patients (12). Our findings also are supported by other survey data that suggest that personal experience with end-of-life care affects health professionals' comfort in discussing end-of-life issues with patients (13). A core curriculum in palliative care that deals with pain and symptom management, psychosocial and spiritual support of patients and families, advance care planning,

and ethical issues surrounding initiation and withdrawal of dialysis was developed recently for nephrology fellows (14). In conjunction with the published guideline, this core curriculum may help to address the deficiencies of training programs in this area of clinical practice by overcoming a lack of training and/or experience with end-of-life issues and facilitating the acquisition of skills in this arena.

There were differences in the reported practices of American and Canadian nephrologists. Canadian nephrologists reported withdrawing more patients from dialysis and seemed more comfortable withdrawing from dialysis a patient with severe dementia. This finding confirms a similar difference among Canadian and American nephrologists on an earlier survey that used hypothetical cases (15). This study cannot ascertain the reasons, but these differences may reflect a health care system with less financial incentive to continue dialyzing patients. Worries about medical malpractice also may contribute to these observed differences among American and Canadian nephrologists (15). Canadian nephrologists also more often are associated with a medical school rather than with for-profit organizations. This potentially could be another factor that contributes to ethical decision-making. However, Canadian nephrologists reported being less likely to refer to hospice. Differences in economic,

Table 3. Nephrologists who reported being very well preparedness, logistic regression model^a

| Characteristics of Nephrologists | Univariate Analysis | | Multivariate Analysis | |
|---|---------------------|----------|-----------------------|----------|
| | OR (95% CI) | <i>P</i> | OR (95% CI) | <i>P</i> |
| Year fellowship completed ^b | | | | |
| 1993 to 2005 (<i>n</i> = 131) | 1.00 (Reference) | | | |
| 1960 to 1992 (<i>n</i> = 199) | 4.07 (2.49 to 6.65) | <0.001 | | |
| Age (yr) | | | | |
| 20 to 45 (<i>n</i> = 155) | 1.00 (Reference) | | | |
| 46+ (<i>n</i> = 199) | 3.26 (2.06 to 5.14) | <0.001 | 2.77 (1.70 to 4.53) | <0.001 |
| No. of patients cared for | | | | |
| ≤55 (<i>n</i> = 113) | 1.00 (Reference) | | | |
| 56 to 100 (<i>n</i> = 111) | 1.57 (0.91 to 2.71) | 0.105 | | |
| 101+ (<i>n</i> = 117) | 1.83 (1.07 to 3.14) | 0.027 | | |
| No. of patients who stopped dialysis in past year | | | | |
| 0 to 2 (<i>n</i> = 137) | 1.00 (Reference) | | | |
| 3 to 5 (<i>n</i> = 111) | 1.67 (0.99 to 2.80) | 0.055 | 1.77 (1.03 to 3.06) | 0.040 |
| 6+ (<i>n</i> = 88) | 2.39 (1.38 to 4.16) | 0.002 | 2.58 (1.43 to 4.66) | 0.002 |
| No. of patients referred to hospice in past year | | | | |
| 0 to 1 (<i>n</i> = 111) | 1.00 (Reference) | | | |
| 2 to 3 (<i>n</i> = 110) | 1.44 (0.83 to 2.48) | 0.194 | | |
| 4+ (<i>n</i> = 121) | 1.84 (1.08 to 3.13) | 0.024 | | |
| For-profit chain affiliation | | | | |
| no (<i>n</i> = 187) | 1.00 (Reference) | | | |
| yes (<i>n</i> = 165) | 1.33 (0.87 to 2.03) | 0.195 | | |
| Medical school affiliation | | | | |
| no (<i>n</i> = 166) | 1.00 (Reference) | | | |
| yes (<i>n</i> = 189) | 0.91 (0.59 to 1.38) | 0.644 | | |
| Country of practice ^b | | | | |
| Canada (<i>n</i> = 60) | 1.00 (Reference) | | | |
| United States (<i>n</i> = 295) | 1.72 (0.94 to 3.12) | 0.077 | 1.41 (0.73 to 2.75) | 0.309 |
| Unit policy on withdrawal of dialysis | | | | |
| no (<i>n</i> = 260) | 1.00 (Reference) | | | |
| yes (<i>n</i> = 90) | 1.58 (0.98 to 2.56) | 0.063 | | |
| Aware of RPA/ASN guidelines | | | | |
| no (<i>n</i> = 146) | 1.00 (Reference) | | | |
| yes (<i>n</i> = 210) | 2.18 (1.39 to 3.41) | <0.001 | 1.78 (1.10 to 2.90) | <0.001 |
| Aware of RPA/ASN statement | | | | |
| no (<i>n</i> = 165) | 1.00 (Reference) | | | |
| yes (<i>n</i> = 190) | 1.81 (1.18 to 2.79) | 0.007 | | |
| Use time-limited trials of dialysis | | | | |
| no (<i>n</i> = 72) | 1.00 (Reference) | | | |
| yes (<i>n</i> = 280) | 2.38 (1.33 to 4.77) | 0.003 | | |

^aSee Materials and Methods for an explanation of the variables. CI, confidence interval; OR, odds ratio.

^bModel is adjusted by country of practice, although this variable is statistically NS.

cultural, and medical practice would have to be explored to discern possible factors for these observed differences.

Despite the significant symptom burden and the high mortality, hospice use among dialysis patients is low in both Canada and the United States. Recommendation 9 in the RPA/ASN clinical practice guideline stresses a palliative care approach that allows patients to decide whether they wish to die in a health care facility or at home with hospice care. Hospice care emphasizes supportive care of the patient

and the family, enabling families to continue caring for their loved ones at home while they die. Hospice care provides for home nursing and pastoral care and focuses on treating symptoms while neither prolonging life nor hastening death. Factors that play a role in hospice underuse likely include a lack of physician knowledge about the benefits of hospice, patient and family refusal of hospice referral, availability of hospice services, and reimbursement policies to hospices that accept dialysis patients (16). A recent study demon-

strated that 41.9% of patients who have ESRD and die after withdrawal of dialysis and 3.4% of patients who die while still receiving chronic dialysis have been referred to hospice programs before death (16). The RPA, the Forum of ESRD Networks, and the National Hospice and Palliative Care Organization are working with the Center for Medicare and Medicaid Services to improve understanding of the Medicare hospice coverage for patients with ESRD and dialysis providers so that patients can receive hospice while continuing dialysis. The lower rate of hospice referrals in Canada may underlie a philosophical difference in the provision of hospice care between Canada and the United States. The costs of dialysis care in Canada are borne by the provincial governments and would not be the responsibility of the hospice program. Nonetheless, Canadian hospice programs, as a rule, will not admit a dialysis patient while he or she is continuing with dialysis, despite a prognosis of <6 mo. Although providing hospice care for patients who remain on dialysis remains controversial, hospice programs, in conjunction with the nephrology team, can help patients come to terms with their impending death, help resolve conflicts, and aid in end-of-life decision-making that, for some, ultimately may result in the withdrawal of dialysis.

CPR policies in dialysis units vary tremendously and range from recognizing “no codes” to mandating CPR should an arrest occur in the dialysis unit, even if unwanted by the patient. Although beyond the scope of this survey, further research is required to determine how various CPR policies affect end-of-life care. Why so few Canadian dialysis units have policies on “do not resuscitate” and withdrawing dialysis is not clear. However, given that litigation is not as prevalent in Canada, there has not been the same legal incentive to establish these policies as there is in the United States. Nephrologists who practice in units where CPR is discussed routinely feel more prepared to discuss end-of-life issues, regardless of the existence of a unit policy. It is likely that the practice environment, as well as time in practice and practice experiences, affects nephrologists’ comfort with end-of-life decision-making.

There are several limitations to this study. The sample size was relatively small, and response rates for American and Canadian nephrologists were only 12 and 19%, respectively. However, response rates from online surveys are known to be lower than those for postal surveys and are considered a cost-effective administration method that provides equivalent results to mailed surveys with samples from professional organizations (17,18). Also the number of respondents in this study was comparable to that in other studies of nephrologists’ attitudes and practices that have yielded useful results (7,15). Nephrologists’ perception of their preparedness to make end-of-life decisions is not necessarily the same as their actual preparedness, training, and skill in this area. However, physicians’ comfort with dealing with these difficult issues remains an important factor in providing quality end-of-life care. Also, self-report of end-of-life practices may vary from actual practices because of difficulties in recall and/or nephrologists’ desire to provide socially ac-

ceptable answers. These results may overestimate the extent of nephrologists’ comfort with end-of-life decision-making because nephrologists who are most interested in end-of-life care may have been the ones who primarily answered this survey.

The results of this study suggest that increased clinical experience and knowledge of the RPA/ASN guideline and position statement seem to promote comfort with end-of-life decision-making and clinical practice in conformance with the recommendations in the guideline. Because only approximately 50% of the respondents were aware of the RPA/ASN clinical practice guideline and position statement, additional educational efforts likely are needed to inform American and Canadian nephrologists and nephrology fellows of them. While comfort with end-of-life decision-making is, in and of itself, an important outcome for nephrologists, actual end-of-life practices and skills and ultimately the quality of end-of-life care that is delivered by nephrologists who are knowledgeable of the guideline and position statement need to be assessed to determine their full impact and benefit.

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