Nephrologists’ Changing Practices in Reported End-of-Life Decision-Making

Jean L. Holley,* Sara N. Davison,† Alvin H. Moss‡

*Division of Nephrology, University of Virginia Health System, Charlottesville, Virginia; †Division of Nephrology and Immunology, University of Alberta, Edmonton, Canada; ‡Section of Nephrology and Center for Health Ethics and Law, West Virginia University, Morgantown, West Virginia

Because the dialysis patient population is increasingly composed of older patients with high symptom burden, shortened life expectancy, and multiple comorbid conditions, nephrologists often engage in end-of-life decision-making with their patients. In the 1990s, reported practices of nephrologists’ end-of-life decision-making showed much variability. In part as a reaction to that variability, the Renal Physicians Association (RPA) and the American Society of Nephrology (ASN) developed a clinical practice guideline on end-of-life decision-making. To determine whether nephrologists’ attitudes and reported practices had changed over time, survey responses from 296 nephrologists completing an online survey in 2005 were compared with 318 nephrologists who completed a similar mailed survey in 1990. In 2005, less variability was noted in reported practices to withhold dialysis from a permanently unconscious patient (90% would withhold in 2005 versus 83% who would withhold in 1990, P < 0.001) and to stop dialysis in a severely demented patient (53% in 2005 would stop versus 39% in 1990, P < 0.00001). In 2005, significantly more dialysis units were reported to have written policies on cardiopulmonary resuscitation (86% in 2005 versus 31% in 1990, P < 0.0001) and withdrawal of dialysis (30% in 2005 versus 15% in 1990, P < 0.0002); nephrologists were also more likely to honor a dialysis patient’s do-not-resuscitate order (83% in 2005 versus 66%, P < 0.0002) and to consider consulting a Network ethics committee (52% in 2005 versus 39%, P < 0.001). Nephrologists’ reported practices in end-of-life care have changed significantly over the 15 years separating the two surveys, suggesting that the development of the clinical practice guideline was worthwhile.


Materials and Methods

In January 2005, the 2500 nephrologist members of the RPA were asked to participate in an online survey of their attitudes and practices related to end-of-life decision-making. Monthly reminders requesting participation in the online survey were sent via e-mail in February, March, and April 2005. A total of 296 nephrologists (12% of the RPA membership) completed the online survey. Portions of the study addressing aspects of end-of-life care decision-making by nephrologists have previously been described (10). Additional survey results from the 2005 online questionnaire were compared with those from a mailed survey of physician directors of hemodialysis units in April 1990 (4) and comprise the data for this report. The 1990 survey was mailed to a random sample of 524 dialysis medical directors from a mailing list provided by the 18 ESRD Networks. Nonrespondents were sent two follow-up requests for responses at 4-wk intervals. Three hundred eighteen surveys were returned (61% response rate). Although the 2005 online survey was completed by RPA nephrologist members and not...
specifically by medical directors of hemodialysis units (the study population of the 1990 survey), 95% of RPA members are medical directors of hemodialysis units (personal communication, Dale Singer, RPA, January 2005), and therefore the two survey populations were deemed sufficiently comparable for the purposes of this study.

Questionnaire

A survey instrument similar to the 1990 questionnaire (4) was developed. Each survey included the same three hypothetical scenarios addressing withdrawing and withholding dialysis:

1. One of your dialysis patients has become permanently and severely demented. The patient has not previously expressed wishes for future care nor completed advance directives. What would you usually do?
2. If a competent patient asked to stop dialysis, how would you usually handle the request?
3. If you were requested to begin dialysis of a permanently unconscious patient (e.g., persistent vegetative state or multiple strokes), what would you usually do?

Each scenario was followed by closed-ended questions asking about decisions to stop or withhold dialysis. Possible responses to the first and second questions were “probably continue dialysis” or “probably stop dialysis.” Responses to the third question included “probably begin dialysis” or “probably not begin dialysis.” Additional questions explored the decision-making process for each hypothetical scenario by asking how likely the nephrologists would be to consult with various individuals or groups in making their decisions. Nephrologists were also asked how well prepared they felt to make end-of-life decisions with their dialysis patients and families. The 1990 survey asked a yes/no question: On the basis of your medical training, do you feel prepared to make decisions to continue, withdraw, and withhold dialysis with patients and families (answer options: very well prepared, prepared, somewhat prepared, somewhat unprepared, and unprepared)?

Both the 1990 and 2005 surveys asked questions about existing dialysis unit policies on withdrawing patients from dialysis and DNR orders. Survey respondents in both 1990 and 2005 were asked about the likelihood of consulting a Network Ethics Committee to assist in decision-making in specific situations. Demographic information on the nephrologists was collected in each survey and included respondent age, affiliation with for-profit dialysis corporations, number of dialysis patients followed, and number of their dialysis patients withdrawing from dialysis in the past year.

Statistical Analysis

SPSS 14.0 for Microsoft Windows was used for statistical analyses (SPSS Inc., Chicago, IL). Data are reported as mean values ± SD. A P value <0.05 was considered significant. A χ² test was used to compare differences in proportions among categorical variables. Age data were separated into five intervals (20 to 35 yr, 36 to 45 yr, 46 to 55 yr, 56 to 65 yr, 66+ yr). In the 2005 survey, the continuous variables (number of patients cared for, number of patients withdrawn from dialysis in the past year) were positively skewed and were log transformed and then analyzed using a t test. The 2005 study was approved by the Institutional Review Board for the Protection of Human Subjects and the West Virginia University School of Medicine Office of Research and Graduate Studies.

Results

Table 1 shows the demographic features of the nephrologists in 1990 and 2005. In 1990, 90% of the nephrologists reported feeling prepared to make end-of-life decisions. In 2005, 42% of the nephrologists reported feeling very well prepared and 38% felt prepared to make such decisions.

Table 2 details the presence of dialysis unit policies on withdrawal from dialysis and CPR. Written policies on both were more common in dialysis units in 2005 compared with 1990. Similarly, DNR status was more often recognized and honored in 2005 than in 1990 (83% versus 66%, P = 0.0002). In 2005, more nephrologists reported being likely to utilize Network ethics committees to assist in the decision-making process in difficult and/or complex situations (52% versus 39%, P = 0.001).

Figure 1 illustrates the nephrologists’ responses to the hypothetical cases presented in the surveys. Significantly more nephrologists in 2005 were willing to stop dialysis in a severely demented patient (53% versus 32%, P < 0.00001) and to withhold dialysis from a permanently unconscious patient (90% versus 83%, P < 0.001). Most nephrologists in both surveys would respect the request of a competent patient to stop dialysis. When asked whom they would consult to assist in decision-making for each of these hypothetical cases, ≥98% would consult the patient’s family in each scenario in both 1990 and 2005.

The 2005 survey asked which specific members of the multidisciplinary dialysis team nephrologists would be likely to consult about withdrawing and dialysing in the three hypothetical scenarios. Nephrologists were also asked whether they would consult ethics committees in the process of decision-making in these scenarios. Unfortunately, the 1990 survey did not include these questions, so comparative data are not available. In the 2005 survey, dialysis unit social workers would be consulted by 95% of nephrologists and dialysis nurses consulted by 92% of nephrologists when deciding whether to stop dialysis in a demented...
If a competent dialysis patient wished to stop dialysis, 86% of nephrologists would consult the dialysis unit social worker and 93% would consult the dialysis unit nurses. Ethics committee consultation was more likely to be considered when decision-making involved starting dialysis in an unconscious patient: 80% of nephrologists would request ethics committee input compared to 44% who would use ethics committee input in stopping dialysis in a competent patient ($P < 0.0001$) or 57% who would request ethics committee input to stop dialysis in a demented patient ($P < 0.0001$). More than half of the nephrologists surveyed in 2005 would consult the RPA/ASN guideline and/or statement to assist in decision-making in these hypothetical scenarios (57% in the case of the demented patient, 52% in the case of the competent patient choosing to stop dialysis, and 56% in the scenario involving initiating dialysis in the permanently unconscious patient).

**Discussion**

The need for the development of the RPA/ASN guideline (8) was strongly supported by studies suggesting that wide variability in end-of-life decision-making among nephrologists existed (4–7). One of these landmark studies was the 1990 survey by Moss et al. (4). Fifteen years later, and five years after the publication of the RPA/ASN guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, we wanted to assess the impact of the guideline and the increased attention given to end-of-life decision-making about dialysis among nephrologists. Thus, the online survey of RPA nephrologist members was developed and performed. There has been significant change in the reported practices of nephrologists, with more nephrologists now likely to withdraw a demented patient from dialysis and fewer likely to initiate a permanently unconscious patient on chronic dialysis. Our findings show less variability than in 1990 in both withholding dialysis from a permanently unconscious patient and in honoring a patient’s request for a DNR order in the dialysis unit. This shift in clinical decision-making reflects the recommendations of the RPA/ASN guideline and suggests that the development and dissemination of the guideline has been associated with an improvement in nephrologists’ end-of-life decision-making.

Although the actual practices of nephrologists cannot be assessed by our survey, responses to hypothetical scenarios are a commonly accepted tool to examine practice issues as they identify variation in ethical decision-making (11). Moreover, significantly more nephrologists now practice in dialysis units where written policies on CPR and DNR as well as withdrawal from dialysis exist. Thus, there is evidence of more active engagement in end-of-life decision-making of both institutions (dialysis units) and nephrologists related to the care of chronic dialysis patients. More than half of the nephrologists reported awareness and consultation of the practice guideline. The observed change in the reported practices from 1990 to 2005 suggests that the efforts of the RPA and ASN to develop and promote a practice guideline in the area of end-of-life care have been worthwhile.

There are some limitations to our study. Although the response rate to the online survey was less than that of the 1990 mailed survey, this is to be expected and does not negate the cost-effectiveness of the online method for yielding results equivalent to mailed surveys (12,13). As with any survey study, respondent and therefore study bias is possible. The 2005 survey was completed by RPA members only and their responses
may not be generalizable to the nephrologist community as a whole. In addition, the nephrologists in the 2005 survey were older than those participating in the 1990 survey (Table 1) and less likely to be medical directors of a dialysis unit (the population surveyed in 1990). The two survey populations were therefore possibly not comparable in terms of practice experience, a factor that affects dialysis decision-making (10). Nephrology fellowship training in palliative care is generally poor (14) and may be a factor contributing to the small proportion of 2005 respondents who reported feeling very well prepared to address end-of-life decision-making. Recent inclusion of palliative care among fellowship curricula topics (15) and the dissemination of the RPA/ASN guideline may be influencing nephrologists’ comfort and preparedness to deal with end-of-life issues. Significantly more nephrologists now report an interest in using ESRD Network ethics committees to assist in difficult patient management decisions. It may therefore be that the recognition of ethical and legal issues throughout medicine and not specifically within the nephrology community has influenced our findings. There is no way we could control for a change in the ethical and legal climate in the United States regarding a greater acceptance of withholding and withdrawing life-sustaining treatments (16–18). Nonetheless, our study does confirm that changes occurring in end-of-life care of other patients with chronic diseases have also occurred with dialysis patients.

Another study limitation is the fact that the survey addresses reported rather than actual practices. However, the sample sizes were fairly large and the same hypothetical scenarios were used in both surveys. Thus, although actual practice was not assessed, reported practice has changed significantly over the 15 years separating the surveys.

In 2005, compared with 1990, nephrologists are more likely to honor a dialysis patient’s wish for DNR status, to work in a dialysis unit that has written policies on CPR/DNR and dialysis withdrawal, to consider consulting a Network Ethics Committee in difficult patient situations, and to withhold dialysis as well as stop dialysis in patients with significant cognitive impairment. More than half of the surveyed nephrologists rely in some part on the RPA/ASN guideline addressing medical decision-making in end-of-life issues in dialysis patients. The changing attitudes and reported practices of nephrologists over time suggests that the development of this clinical practice guideline addressing end-of-life medical decision-making has been worthwhile and has advanced the end-of-life care for chronic dialysis patients.

Appendix
The Questionnaire

1. One of your dialysis patients has become permanently and severely demented (e.g., Alzheimer’s disease or multi-infarct dementia). The patient had not previously expressed wishes for future care nor completed advance directives. What would you usually do?

   probably continue dialysis probably stop dialysis

2. In making the decision in #1, please indicate how likely you would be to consult with each of the following (possible responses = very likely, somewhat likely, unlikely):

   patient’s family
dialysis unit nurses
dialysis unit social workers
ethics committee or consultant
patient’s clergy
psychiatric consultant
RPA/ASN guidelines and statements
other

3. If a competent patient asked to stop dialysis, how would you usually handle the request?

   probably stop dialysis probably continue dialysis

4. In situations like that in #3, please indicate how likely you would be to consult with each of the following in making the decision (same possible responses as in #2 above).

5. If you were requested to begin dialysis of a permanently unconscious patient (e.g., persistent vegetative state or multiple strokes), what would you usually do?

   probably begin dialysis probably not begin dialysis

6. In making the decision in #5, please indicate how likely you would be to consult with each of the following (same possible responses as in #2 above).

7. In the dialysis unit in which you have the most patients, is there a written unit policy on withdrawal of dialysis?

   yes no

8. In the dialysis unit in which you have the most patients, is there a written unit policy on cardiopulmonary resuscitation (CPR)? If you answer yes, please answer #9.

   yes no maybe

9. Does the unit policy state that CPR is to be performed on all patients who have a cardiac arrest in the dialysis unit regardless of patients’ preferences?

   yes no

10. In the last 12 months, how many of the patients for whom you are responsible to care at least 25% of the year had dialysis stopped either because of personal choice or a physician/family decision to stop?

11. If your ESRD Network started an Ethics Committee that you could consult for difficult patient management decisions, would you use it?

   yes no maybe

12. Are you aware of the RPA/ASN clinical practice guideline, Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis?

   yes no

13. Do you ever refer to the guideline in making dialysis decisions?

   yes no

14. Please record the total number of dialysis patients you care for at present.

15. What is the ownership status of the dialysis unit in which you have the most patients?

   for-profit chain owned and operated
   hospital owned and operated
   private-practice owned and operated
   not-for-profit owned and operated
   other

16. Which age group are you in?

   20 to 35 35 to 45 46 to 55 56 to 65 65+

17. On the basis of your medical training, how well prepared do you feel to make decisions to continue, withdraw, and withhold dialysis with patients and families?

   very well prepared prepared somewhat prepared not at all prepared
Acknowledgments
Support for this research was provided by the Renal Physicians Association. This work was presented in abstract form at the ASN Annual Meeting, Philadelphia, PA, 2005 (J Am Soc Nephrol 15: 307A, November 8 to 13, 2005).

Disclosures
None.

References