Meeting the Guidelines for End-of-Life Care

Gillian Brunier, David M.J. Naimark, Michelle A. Hladunewich

The number of patients initiating dialysis in most countries continues to increase, with the greatest increase being in the oldest age group. Clinical practice guidelines have been developed to help the nephrology team with end-of-life care for patients on dialysis. The aim of the project reported here was to assess if we were meeting the guidelines.

We conducted a retrospective cohort study of all patients 80 years of age and older who had started dialysis at our center. Our cohort included 105 patients (50% men; median age: 84.5 years; age range: 80 – 95 years), of whom 55% were on hemodialysis and 45% were on peritoneal dialysis (PD). Overall life expectancy was 2.1 years.

Among the 59 patients who died while still part of our program, 92% had a do not resuscitate order in place, and 46% had withdrawn from dialysis. Palliative care was consulted in 46% of cases. Dyspnea and pain were the two most common symptoms in the last 24 hours of life. Of these 59 patients, 71% died in hospital. Only 6 patients died at home, all of these being on home PD.

End-of-life care for this elderly cohort of dialysis patients could be improved on several measures to meet clinical practice guidelines, especially with greater access to palliative care units and community palliative care programs.

Key words
End-of-life care, palliative care, end-stage renal disease, ESRD

Introduction
The number of patients initiating dialysis in Canada, the United States, and Europe continues to increase, with the greatest increase being in the oldest age group (1–3). These elderly patients have more concurrent illnesses and a much higher mortality rate than do younger patients (2,4). Thus, today, one of the greatest challenges for nephrology health care practitioners is to provide end-of-life care as quality of life declines for these many elderly patients on dialysis.

Over the past 5 years, clinical practice guidelines have been developed both in the United Kingdom and the United States to help the nephrology team provide end-of-life care for patients on dialysis (5–7). The guidelines promote the principles of shared decision-making, involvement of palliative care, and support for patients’ wishes with regard to place of death and family presence. Prognostication, or estimation of how long an individual has to live, is also considered part of best practice in end-of-life care.

The present retrospective cohort study examined life expectancy and how well we met current best practice guidelines for end-of-life care in all patients aged 80 and older with chronic kidney disease who had commenced dialysis in our program over the past 5 years. We wanted to identify barriers to implementation of best practice guidelines for end-of-life care and areas for improvement.

Patients and methods
Our nephrology program maintains a prospective database that acts as an electronic patient record, enabling the identification of all patients aged 80 years and older who initiated dialysis at our center or transferred into our program between January 2000 and December 2005. Data obtained from the nephrology database included information on dialysis start date, dialysis modality, date of death, and demographic data. We also reviewed hospital charts for evidence of shared decision-making around decisions for do not resuscitate (DNR) and withdrawal of dialysis orders, presence or absence of a palliative care consult before death, and place of death. Further information was obtained from hospital charts on the presence of symptoms during the last 24 hours before death, using a symptom scale developed by Cohen et al. (8); on medications prescribed during the last 24 hours before death; and on the presence of family at time of death.

Survival analyses, including life-table and Kaplan–Meier (KM) curves, were constructed using either the
date of dialysis initiation, the date of palliative care consultation, or the date of dialysis withdrawal as the origin and death as the event of interest. All other outcomes were considered to be right-censored observations. Life expectancy for the individuals on a given KM curve was approximated by the area under a simple declining exponential curve that had a value of 1.0 at the origin and that passed through 0.5 at the median survival time. The latter area was calculated as

\[-\frac{t_{1/2}}{\ln (0.5)}\]

where $t_{1/2}$ is the median survival time as estimated by the SPSS survival procedure [SPSS version 13.0 (SPSS Inc., Chicago, IL, U.S.A.)]. Approval for the study was obtained from the Research Ethics Board at Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada.

**Results**

The cohort consisted of 105 patients. Of these 105 patients, 15 transferred to other dialysis programs, and we were able to identify only baseline characteristics and the date of death from the area dialysis registry for transferred patients who died. Only 3 of the transferred patients were still living at the time of writing. The baseline characteristics for the entire patient cohort were as follows: 52 men, 53 women (50%/50%); 57 widowed (54%); 93 Caucasian (89%); and 35 with diabetes (33%). Median age was 84.5 years (range: 80 – 95 years). For 58 (55%), the dialysis modality was hemodialysis (HD), and for 47 (45%), it was peritoneal dialysis (PD). Most of the cohort [73 (70%)] initiated dialysis during an inpatient hospital stay.

**Survival**

During the study period, 71 patients (68%) died, 59 of whom were still enrolled in our dialysis program. Life expectancy for the entire cohort from time of dialysis initiation was 2.1 years. Of the patients who died, 26 (25%) did not survive 3 months, and a further 16 (15%) did not survive 12 months; 17 (16%) died before discharge from the hospital.

**Shared decision-making**

Among the 59 patients who died while still enrolled in our dialysis program, 54 (92%) had a DNR order in place. All the progress notes contained documentation by the attending physician of discussions with the patient or the family concerning the DNR order. In 32 of the cases, the patient was part of the discussion; in 19 of the cases, the family alone had to make the decision with the physician. (Discussion participants in 3 cases were unknown.) Only in 16 cases (27%) was clear information with respect to advance directives present, either written or communicated. Half were for patients who were residents of the chronic care section of the hospital, where advance directives are part of the admissions policy.

In 5 cases, death occurred after a cardiac or respiratory arrest wherein full resuscitation was attempted. All 5 patients expired within 2 days of the resuscitative effort.

In 27 cases (46%), dialysis was withdrawn before death (16 men, 11 women; 15 on PD, 12 on HD). The life expectancy after withdrawal from dialysis was 2.8 days. All of the patients’ charts contained documentation concerning discussions between physician and patient or physician and family about withdrawal of dialysis. However, in only 7 of the 27 cases was the patient able to take part in the discussions. In the remaining 20 cases, the family, most often sons and daughters, had to make the decision for dialysis withdrawal with the attending nephrologist and renal team. The decisions were difficult, and more than one family meeting was often necessary.

**Palliative care and symptom management**

Of the 59 patients who died while on our program, 27 (46%) received a palliative care consult before death. Life expectancy after a palliative care consult was 8.7 days. Interestingly, of the patients who received a consult, only 19 actually withdrew from dialysis. The other 8 continued on dialysis until death, most of them on PD.

In reviewing symptoms and medications in the 24 hours before death, we found complete information on 42 of the 59 patients. During the last 24 hours, 6 of the 42 patients were unresponsive or comatose; thus we could assess symptoms only on 36 patients.

Dyspnea was the most common symptom present in the patients before death (42%), but the dyspnea was judged to be severe in only 1 case. None of the patients who withdrew from dialysis required extra dialysis to treat dyspnea. Scopolamine as a subcutaneous injection was prescribed to 30% of the patients to dry respiratory secretions.

Pain was the second most common symptom present in the patients (30%), but it was never judged
to be severe. Narcotics were prescribed in 87% of the cases, predominantly given as scheduled subcutaneous doses of hydromorphone with breakthrough injections as required.

Agitation was present in 22% of the patients and was treated with either sublingual lorazepam or subcutaneous injections of haloperidol.

**Place of death**

Of the 59 patients who remained on our program, 42 (71%) died in an acute care hospital—4 of them in an intensive care unit. Another 6 died at home, all of whom were on home PD. Only 4 died in the palliative care unit of our hospital, none of whom remained on PD. Families of 85% of patients had visited in the last 24 hours, and family members were present at death for 52% of the patients.

**Discussion**

Our single-center retrospective cohort study examined end-of-life care in a most-elderly group of dialysis patients: those aged 80 years and older at dialysis initiation. The life expectancy for the group was reasonable at 2.1 years from dialysis initiation, which is comparable to other published data. The U.S. Renal Data System (USRDS) 2005 report (2) indicated that life expectancy for U.S. patients on dialysis aged 80 – 84 years was 2.2 years, and for those older than 85, 1.8 years. However, the USRDS data exclude patients who die within the first 90 days of dialysis.

Although the survival rates for the patients in our study are quite reasonable, the life expectancy of members of the Canadian general population who have attained the age of 80 years is, on average, 7.24 years for men and 9.28 years for women (9). Thus, our very elderly patients on dialysis had a dramatically decreased life expectancy as compared with the Canadian general population. We found it especially troubling that 25% of our very elderly patients starting dialysis did not survive 3 months, and 16% did not leave the acute care hospital. Clearly, as highlighted by the Renal Physicians Association/American Society of Nephrology (RPA/ASN) 2000 guidelines (6), more research is necessary to examine which of the very elderly patients starting dialysis today benefit from the treatment. With improved prognostic information, it would be possible to better identify those patients who are unlikely to survive 3 months or be discharged from hospital and, thus, who receive limited benefit from dialysis treatments.

Shared decision-making around end-of-life care is now an integral part of our nephrology practice. Of the very elderly patients in our study, 92% had established a DNR order, and 46% were withdrawn from dialysis—percentages that compare favorably with an earlier, single-center study of elderly patients in the United Kingdom, where dialysis was withdrawn in 38% of the patients (10). The 2005 USRDS reported an average rate of withdrawal from dialysis of 22% across the United States (2), but the USRDS and the Dialysis Outcomes and Practice Pattern Study (11) both found increased rates of dialysis withdrawal in older dialysis patients.

Only a minority of our elderly patients were able to participate in their own end-of-life decisions. In most cases, it was left to adult children to make decisions on behalf of a seriously ill parent. Such decisions were emotionally difficult for the families and could be quite time-consuming for the nephrology team, because, oftentimes, multiple family meetings were necessary.

For the unfortunate 5 patients who had no documented advance directives, death occurred within 2 days of full cardiopulmonary resuscitation. Clearly, we need to assist elderly patients initiating dialysis in communicating their wishes with respect to end-of-life care to their families and the nephrology team before these patients become too ill to take part in the discussions. For patients admitted to the chronic care section of our hospital, the standard practice is for the social worker to arrange a family meeting with the attending physician 6 weeks after admission to identify and document advance directives with the patient and family. This practice would be reasonable to adopt for all elderly patients initiating dialysis.

We know of no best practice studies that have identified when a palliative care consult should be considered for elderly patients approaching the end of life on dialysis. In our study, life expectancy after a palliative care consult was 8.7 days, which is likely too short a time for the patient and family to benefit. As proposed by Cohen et al. (8), more studies to look at best practices with regard to when and how to involve palliative care for these very elderly patients and their families would be helpful. Interestingly, not all patients who received a palliative care consult withdrew from dialysis; almost 30% continued on dialysis treatment (usually PD) until death.
For the patients who died at our center and for whom medical information was available, dyspnea and pain were the two most common symptoms in the 24 hours before death, and both symptoms were judged to be fairly well managed. Dyspnea was the most troublesome symptom present (42% of cases), but it was judged to be severe in only 1 case. None of the patients who withdrew from dialysis required extra dialysis treatments to treat dyspnea. In Cohen’s earlier study (8), 42% of patients who had discontinued dialysis were judged by caregivers and family members to be in pain at the end of life. In contrast, in our study, pain was judged to be well managed, largely by use of regularly scheduled hydromorphone injections administered through a subcutaneous injection site with frequent breakthrough dosing.

Our study is undoubtedly limited by its retrospective design and reliance on information obtained from hospital charts. Further, data that were missing because of lack of access to medication records for patients who died at home or in other acute care hospitals hindered the completeness of our study in this important area. Interviews or surveys of patients and their families, as conducted by Cohen et al. (8,12), would have produced a more accurate assessment of pain and symptom management in this group of patients. More information on this topic of best practices in pain and symptom management at the end of life for patients on dialysis—obtained through prospective studies and interviews with patients, family members, and caregivers—is undoubtedly necessary.

The most common place of death for this very elderly group of patients was an acute-care hospital (71%). We could find no comparable studies in Canada, but we note that the USRDS 2005 report (2) of a large cohort study shows “hospital” as being the site of death for 63% of patients. Interestingly, the 6 patients who died at home in our study were all on home PD. In contrast, no patient on home PD in our study was able to access the palliative care unit at our center; 1 patient who continued on HD transferred to the palliative care unit. The authors of the USRDS cohort study also note that, as compared with oncology patients, dialysis patients have limited access to hospice or palliative care programs (2). More education of health care professionals, patients, and their family members is needed to increase access for dialysis patients to palliative care units. More palliative support in the community would enable more patients, especially those on home PD, to be able to die at home with their families.

Conclusions
Overall, end-of-life care for our elderly cohort of patients on dialysis could be improved on several measures to meet clinical practice guidelines. First, greater understanding concerning the characteristics or medical problems that predispose these patients to survival of 3 months or more would help in providing better survival information to patients before they chose to initiate dialysis. Second, much more effective communication is needed with these patients regarding the importance of discussing advanced directives ahead of time with their families and the nephrology team. Third, more studies that look at how and when to involve palliative care in end-of-life care for patients and more detailed analyses of the most effective medication regimens for symptom management at the end of life are both necessary. Interviews with patients and their families, although difficult, are likely the most appropriate way of gathering information on pain and symptom management. Fourth, we need to advocate for greater access to palliative care units and community palliative care programs so that our dialysis patients are on an equal footing with oncology patients in this regard.

Acknowledgment
The authors thank the members of the multidisciplinary nephrology team and palliative care consult service at Sunnybrook Health Sciences Centre, Toronto, Ontario, for help with the compilation and verification of the information for this study. We would also like to thank Anne Cherry from the Toronto Region Dialysis Registry for her assistance in verifying data.

References
1 Canadian Institute for Health Information. Treatment of end-stage organ failure in Canada 2002 and 2003. Ottawa: Canadian Institute for Health Information; 2005.
End-of-Life Care


Corresponding author: Gillian Brunier, RN MScN CNeph(c), Sunnybrook Health Sciences Centre, 2075 Bayview Avenue, Room E206B, Toronto, Ontario M4N 3M5 Canada. E-mail: gillian.brunier@sunnybrook.ca