

End-of-Life Care Preferences and Needs: Perceptions of Patients with Chronic Kidney Disease

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Background and objectives: Despite high mortality rates, surprisingly little research has been done to study chronic kidney disease (CKD) patients' preferences for end-of-life care. The objective of this study was to evaluate end-of-life care preferences of CKD patients to help identify gaps between current end-of-life care practice and patients' preferences and to help prioritize and guide future innovation in end-of-life care policy.

Design, setting, participants, & measurements: A total of 584 stage 4 and stage 5 CKD patients were surveyed as they presented to dialysis, transplantation, or predialysis clinics in a Canadian, university-based renal program between January and April 2008.

Results: Participants reported relying on the nephrology staff for extensive end-of-life care needs not currently systematically integrated into their renal care, such as pain and symptom management, advance care planning, and psychosocial and spiritual support. Participants also had poor self-reported knowledge of palliative care options and of their illness trajectory. A total of 61% of patients regretted their decision to start dialysis. More patients wanted to die at home (36.1%) or in an inpatient hospice (28.8%) compared with in a hospital (27.4%). Less than 10% of patients reported having had a discussion about end-of-life care issues with their nephrologist in the past 12 months.

Conclusions: Current end-of-life clinical practices do not meet the needs of patients with advanced CKD.

Clin J Am Soc Nephrol 5: 195–204, 2010. doi: 10.2215/CJN.05960809

Despite improvements in dialysis technology, the annual mortality rate of dialysis patients is 20% to 25% (1). The burden of symptoms for dialysis patients and those with advanced chronic kidney disease (CKD) who choose conservative care (*i.e.*, no dialysis) is high (2), with the number and severity of symptoms (such as pain, nausea, anorexia, shortness of breath, insomnia, anxiety, and depression) rivaling those of many cancer patients (3–5). An increasing number of patients are dying after withdrawal of dialysis (10% to 15% in 1990; 20% in 2004) (1), representing the second leading cause of death after cardiovascular disease. Unfortunately, the majority of patients are not involved in these decisions because they lack decision-making capacity at the time the decision to withdraw dialysis is made (6). The vast majority of patients with CKD die in acute care facilities, without accessing palliative care services (7). Despite this, surprisingly little research has been done to study how these patients die or their preferences for end-of-life care. The objective of this study was to evaluate end-of-life care preferences of CKD patients. This will help identify gaps between current end-of-life care practice and patients' preferences and will help prioritize and guide future innovation in end-of-life care policy.

Materials and Methods

This study was part of a larger initiative to establish an end-of-life care approach for patients with CKD in the Northern Alberta Renal Program, a Canadian, university-affiliated renal program. Patients age 18 years or older with CKD receiving any form of chronic dialysis or kidney transplant and patients with stage 4 or 5 CKD (as per the Modification of Diet in Renal Disease formula for estimation of GFR <30 ml/min per 1.73 m²), who were cognitively able to complete the questionnaire in English (as perceived by their dialysis or clinic nurse), with or without the use of a translator, were eligible to participate. This involved the Home Dialysis Program (including peritoneal dialysis and home hemodialysis patients), in-center hemodialysis, and seven rural satellite hemodialysis units. Patients were consecutively sampled as they presented to dialysis, transplantation, or predialysis renal insufficiency clinics between January and April 2008. Transplantation patients were deemed appropriate for inclusion in this study because their kidney function was deteriorating.

An extensive review of the literature identified the factors considered important by patients and families for quality end-of-life care (8–11). The key elements were incorporated into a patient-complete survey to identify CKD patients' preferences and expectations for both patient and professionally derived indicators of quality end-of-life care, such as place of death, symptom treatment, and advance care planning. Preferences for hypothetical clinical end-of-life scenarios and demographic information were also included. Pilot testing of this survey was extensive: the survey was reviewed by physicians, nursing staff, allied health professionals, and administrators within the Northern Alberta Renal Program for face validity. It was then piloted in four dialysis units among 100 patients for construct validity and to address feasibility issues, such as patient understanding and acceptance. The survey was then approved by both the University of Alberta Research Ethics Board and the Northern Alberta Renal Program for implementation.

Received August 24, 2009. Accepted November 23, 2009.

Published online ahead of print. Publication date available at www.cjasn.org.

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Patients were permitted to complete the self-administered survey in clinic or at home, returning them when they next presented for treatment. The project coordinator and assistants were available to help with the completion of the survey and to answer questions as they arose. Because the purpose of this study was descriptive, a formal sample size was not calculated. A convenience sample of at least 200 eligible patients from each treatment category or >50% of the total number of patients in those renal programs that had less than 400 patients was thought to be sufficient to represent patient preferences. Descriptive statistics were used to report the frequency for each of the response options from each survey question. The study was not powered to allow meaningful comparisons among predialysis, dialysis, and transplantation patients. In tables, the elements were ranked on the basis of the proportion of patients who rated each element as important.

Results

Of 680 eligible patients that were approached, 584 patients (86%) completed the survey. Patient characteristics can be seen in Table 1. Although the numbers of peritoneal dialysis and home hemodialysis patients are small, they represent 51.4% and 61.5% of all patients in their respective programs. A total of 80% of the patients were white, slightly higher than the general dialysis population in this center, where approximately 73% of all patients are white.

Table 1. Patient characteristics (N = 584)

Characteristics	% (n)
Age, yr, mean (SD)	68.16 (14.4)
Sex (male)	54.1
Type of treatment	
Predialysis	40.8 (238)
HD	38.0 (222)
PD	12.5 (73)
Transplant	8.7 (51)
Months on dialysis (HD and PD only)	27.3 (22.1)
Marital Status	
Married	59.8
Single, separated, divorced, widowed	40.2
Education	
Less than high school	31.5
High school	31.3
Trade school/technical college	21.9
University	8.8
Graduate/postgraduate	6.5
First language English	80.0
Race	
White	80.5
Aboriginal	7.2
Asian	8.1
African	1.4
Other	2.4

HD, hemodialysis; PD, peritoneal dialysis.

Patients' self-reported knowledge is presented in Table 2. Most patients (84.6%) felt that they were well informed regarding their medical condition and prognosis, yet only 17.9% felt that their health would deteriorate over the next 12 months. The majority reported not knowing what palliative care and hospice are (83.4% and 71.8%, respectively). The importance of various elements of end-of-life care from patients' perspectives is presented in Table 3. Over 90% of participants responded that it was important that they receive detailed information about their medical condition, including prognostic information. Similarly, between 80% and 85% of patients responded that it was important to be informed about treatment options, including withdrawal from dialysis, planning for the future in case of death, and having physical symptoms, including pain, managed by the nephrology team. Most patients also felt it was important that nephrology programs incorporate quality of life, psychosocial, and spiritual concerns into nephrology care.

Patients' end-of-life care preferences are reported in Table 4. Although 89% of patients rely on family and friends for social and emotional support, over 50% of patients also rely on their nephrologist and nephrology nurse for this support. Many patients (35%) also report that they would want their nephrologist to be the one making medical decisions for them in the case of incapacity. The vast majority of patients did not report relying on support counselors or spiritual advisors for either their social/emotional support (15.8% and 13.5%, respectively) or surrogate decision-making (4.3% and 3.1%, respectively). Patients clearly rely on their nephrologist (79.5%) and their family physician (65.8%) for medical information. The majority

Table 2. Patients' self-reported knowledge

Question	Rating, %
How informed are you in regards to your medical condition and how your medical condition will change over time?	
1 Very/Somewhat uniformed	
2 Unsure	7.6
3 Very/Somewhat informed	5.8
How do you see your health in the next 12 months?	
1 Worsening slightly	17.9
2 No Change	52.1
3 Improving	29.7
Do you know what palliative care is?	
1 Yes	12.3
2 Unsure	14.4
3 No	69
Do you know what a hospice is?	
1 Yes	22.1
2 Unsure	22.3
3 No	49.5

Where data were missing, percentages were calculated out of the total number of study patients (N = 584).

Table 3. Importance of elements related to end-of-life care from patients' perspective

Question	Extremely/Somewhat Unimportant	Unsure	Extremely/Somewhat Important
How important is it for you to be informed about your prognosis (<i>i.e.</i> , how your illness will progress)?	6.0	2.2	90.6
How important is detailed information about your medical condition?	3.3	2.7	90.6
How important is it for you to be informed about treatment options such as withdrawing dialysis?	6.9	4.3	85.1
How important is it for you to have your physical symptoms (<i>e.g.</i> , pain, nausea) treated by the nephrology staff?	8.2	5.5	84.4
How important is it for you to be prepared and plan ahead in case of death?	5.5	7.7	83.2
How important is it to you to have access to information on alternative ways to manage your physical symptoms (<i>e.g.</i> , traditional medicine, new treatments, holistic care, <i>etc.</i>)	8.5	8.0	80.5
How important is it to you for your family to be actively involved in medical decision making?	11.5	6.3	79.3
How important is it for your "quality of life" responses to affect your future care?	6.7	13.2	76.1
How important is it for you to discuss your "quality of life" regularly with our nephrology staff?	13.2	8.4	72.1
How important is it for you to have your social, psychological, or spiritual concerns attended to by nephrology staff?	22.9	15.2	56.5

Values are percentages. Even where data were missing, percentage was calculated out of the total number of study patients ($N = 584$).

of dialysis patients (60.7%) regretted their decision to start dialysis. When asked why dialysis had been chosen over conservative care (no dialysis), 51.9% reported that it was their physician's wish, and 13.9% stated that they chose dialysis because it was the family's wish. There were no differences in age, gender, race, time on dialysis, education, or marital status between patients who regretted their decision to be treated with chronic dialysis compared with those who did not regret their decision.

Questions around the issue of advance care planning showed that patients are comfortable discussing end-of-life issues with both family (69.7%) and nephrology staff (65.6%). However, 90.4% of patients reported that their nephrologist had not discussed prognosis with them, and only 38.2% had completed a personal directive. For those patients who report having completed an advance directive, 36.6% wanted full resuscitation and 17.5% were unsure of what decision they had made. Regardless of whether patients had completed an advance directive or not, all participants were asked their current preference

for resuscitation in the event they had a cardiac arrest: 39% wanted to be resuscitated and 19% were unsure. Less than 18% of patients, however, preferred a course of treatment focused on extending life at the expense of prolonging pain and discomfort. More patients wanted to die at home (36.1%) or in an inpatient hospice (28.8%) compared with in a hospital (27.4%). Most of the patients (51.9%) reported not having had a discussion regarding end-of-life care preferences in the past 12 months, with less than 10% having had such a discussion with their nephrologist. Almost 50% of patients wanted to have these discussions with their nephrologist, 39% with their family doctor, and 20% wanted to involve their nephrology nurse. Patients felt that these discussions should be ongoing when the need arose (as defined by the medical team).

The elements of end-of-life care that patients most wanted incorporated into an end-of-life care program included greater education and support for both staff, patients, and families with respect to end-of-life issues, greater involvement of family in both care and decision-making, a greater focus on pain and

Table 4. Patients' end-of-life care preferences

Question	Rating, %
Who do you rely on for social and emotional support during your illness and treatments? ^a	
Family/friends	89.0
Physician	55.3
Nurse	51.4
Hospital support counsellor	15.8
Spiritual advisor	13.5
Other ^b	5.3
If you are physically or mentally unable to make a decision yourself, who would you choose to make decisions about your medical care for you? ^a	
Family/friends	89.2
Physician	35.6
Nurse	10.8
Hospital support counsellor	4.3
Other ^c	3.4
Spiritual advisor	3.1
How do you normally get information that will help you make a personal decision regarding your health/well-being? ^a	
Specialist (e.g., kidney doctor)	79.5
Family physician	65.8
Family/friends	43.8
Paper resources	25.7
Internet	16.1
Television/media	12.8
Other ^d	5.5
If you are currently receiving dialysis, do you regret the decision to start dialysis?	
Yes	60.7
No	39.3
If you are currently receiving dialysis, why did you choose dialysis over conservative care (no dialysis)?	
Your doctor's wish	51.9
Your own personal wish	34.2
Your family's wish	13.9
How comfortable are you in discussing end-of-life issues with family members?	
Very/somewhat comfortable	69.7
Unsure	11.0
Very/somewhat uncomfortable	15.3
How comfortable are you in discussing end-of-life issues with the nephrology staff?	
Very/somewhat comfortable	65.6
Unsure	15.4
Very/somewhat comfortable	13.7
Have you thought about what might happen with your illness in the future?	
Yes	82.7
Has your doctor talked to you about how much time you have to live?	
No	90.4
Have you completed any of the following? ^a	
Will	67.3
Personal directive	38.2
None of the above	22.6
Health care agent	5.7
Enduring power of attorney	38.0
Don't know	2.6

(continued)

Table 4. (Continued)

Question	Rating, %
If you have completed an advance directive, what did you request be done in the case that your heart stopped beating?	
Resuscitate (“full code”) (We will restart your heart if possible)	36.6
No resuscitation (“no code”) (We will not try to restart your heart)	45.9
Do not know	17.5
There are a number of things doctors can do to try to revive someone whose heart has stopped beating, which usually includes a machine to help breathing. Thinking of your current condition, what would you want your doctor to do if your heart stopped beating?	
Restart my heart, if possible, including using a breathing machine	38.9
Allow me to die—do not try to restart my heart or use a breathing machine	35.4
Don’t know	18.7
If you had to make a choice at this time, would you prefer a course of treatment that focuses on extending life as much as possible, even if it means prolonging pain and discomfort, or would you want a plan of care that focuses on relieving pain and discomfort as much as possible, even if that means not living as long?	
Relieve pain or discomfort and improve quality of life as much as possible	57.2
Don’t know	21.1
Live as long as possible	17.8
Where would you prefer to die?	
At home (with a visiting palliative care support team keeping you as comfortable and pain free as possible)	36.1
In a hospice (palliative care) centre with a special focus on keeping you as comfortable and pain free as possible	28.8
Hospital	27.4
Other ^e	5.0
Nursing home	2.2
During the past 12 months, have you had a discussion with any of the following people about your choices concerning end of your life care?	
I have not had a discussion about these matters during the last 12 months	51.9
Family member or health care proxy	32.7
Kidney doctor (nephrologist)	9.9
Friend	8.7
Family doctor	8.2
Nurse or other staff person from the dialysis clinic	6.3
Social worker from the dialysis clinic	3.4
Spiritual advisor	3.3
Some other person	2.4
Hospital support counsellor	1.5
Which members of the Health Care Team would you like to talk with about end-of-life issues? ^a	
Kidney doctor (nephrologist)	47.6
Family doctor	39.2
Nurse	20.2
No one	16.4
Spiritual advisor	15.9
Other ^f	15.1
Hospital support counsellor	14.2
Social worker	12.0
When would you like to have these end-of-life conversations?	
When you become seriously ill or when the needs arises (as defined by your medical team)	39.2
When you specifically request it	23.5
Before you are started on dialysis	13.5
After you start dialysis but before becoming ill	10.3

(continued)

Table 4. (Continued)

Question	Rating, %
How often would you like to have your end-of-life care plan reviewed?	
Whenever the need arises	50.0
Whenever I ask for this plan to be reviewed	22.6
On a regular basis (<i>i.e.</i> , annually, semi-annually)	12.3
Other	1.7
Where would you like to have these end-of-life discussions?	
In a clinic	34.2
While on dialysis but in a private room	29.1
While on dialysis	7.2

Where data were missing, percentage was calculated from $N = 584$.

^aPatients could specify all that were relevant to them.

^bOther supports specified by patients included home care staff, dietician, pets, social worker, God, various health organizations (*e.g.*, Canadian Mental Health Association), and themselves.

^cOther individuals specified by patients included home care staff and attorneys.

^dOther sources of information specified by patients included clinic staff, nurses, alternative medicine resources, dieticians, and pharmacists.

^eNo other options were specified.

^fOther individuals specified by patients include family, friends, and home care staff.

symptom management, and routine end-of-life care discussions with greater physician involvement (Table 5). The end-of-life issues patients most wanted more knowledge of were what to expect clinically near the end of life, palliative care and hospice services, and symptom management.

Discussion

The illness trajectory of patients dying with CKD differs from that of patients with cancer (12–14). There are also unique end-of-life issues, such as the withdrawal of dialysis, that are specific to these patients. The existence of different pathways to death has important implications for health care delivery; end-of-life issues that are important to CKD patients may differ from patients dying with other illnesses. Identifying these elements and preferences for care is essential for optimizing CKD care near the end of life.

Communication of prognosis and discussions related to planning for future death are lacking in the routine care of CKD patients. The vast majority of these patients did not appreciate the likelihood of clinical deterioration over the next year. Given the mean age of 68 years, these patients have a 50% survival rate of less than 3 years (1). These patients, however, feel it is important that they receive prognostic information and plan for future death. Most patients reported that they think about their future health and that they are comfortable talking about end-of-life care issues with both family and renal staff. Even those less comfortable with having these discussions still feel they needed to occur. This is consistent with a Canadian study where 97% of 100 general nephrology patients during their first visit to a nephrologist wanted detailed information about survival before obtaining informed consent for chronic dialysis and felt that the physician should provide this information without being prompted (15). Sentinel events (hospitalizations, acute illnesses) present opportunities to engage in end-of-life care discussions (16). Answering yes to a simple question

“Would you be surprised if this patient died with the next year?” should also prompt the nephrology team to initiate these discussions (17).

Although patients want to primarily involve family and friends in end-of-life discussions, nephrologists and family physicians are considered integral to the process, and a substantial proportion of patients reported that they would rely on their nephrologist to make medical decisions on their behalf should they become incompetent to make decisions for themselves. Unfortunately, neither physicians nor family members are accurate in predicting patients' desires about life-sustaining treatments, including wishes for ongoing dialysis. In a study of 398 dialysis patients, only 44% of physicians correctly predicted the patient's current preference for cardiopulmonary resuscitation (CPR), 47% their wish for dialysis in a severely demented state, and 43% their wish for dialysis if they had terminal cancer. The corresponding figures for family members were 50%, 44%, and 47% (18). The majority of nephrologists do not feel well prepared to make end-of-life decisions for their patients (19). Physicians are often hesitant about having these conversations with their patients because of concerns about destroying patients' hope. Evidence is emerging, however, that for many dialysis patients, the opposite is true and that focusing on immediate clinical care without attention to future goals is a barrier to maintaining hope (20). Unfortunately, over 90% of patients in this study reported having had no discussion about prognosis with a doctor. Less than 10% have engaged in any form of end-of-life care discussion with their nephrologist, and even fewer with other healthcare professionals. In fact, most of these patients have no advance directive. Unless advance care planning that outlines goals for end-of-life care is systematically integrated into the care of ESRD patients, their end-of-life care needs are unlikely to be adequately met.

Patients clearly need enhanced education with respect to end-of-life care issues. Most patients in this study prefer care

Table 5. Importance of end-of-life care program elements from the patient's perspective

Question	Rating, %
What would you like to see as part of an end-of-life care program for patients dying with kidney disease?	
Education and support for patients and their families	47.8
Greater family involvement in end-of-life care discussions and care	45.4
A greater focus on pain and symptom management	42.1
Education and training for all staff on end-of-life care for kidney failure patients	35.1
Greater physician involvement in end-of-life care discussions and care	32.4
Routine discussions with patients regarding their end-of-life preferences	31.7
Resources available on palliative care options (e.g., pastoral, hospice care)	27.2
Greater involvement of nursing and social work staff in end-of-life care discussions and care	22.6
Use of a palliative care team	19.9
Greater emphasis on spiritual care	13.4
Greater access to hospice services	10.6
Other ^a	2.8
Annual memorial service for patients who have died	2.7
What issues surrounding end-of-life care would you like to know more about?	
Information about the end-of-life process	42.3
Information about palliative care services	39.7
Symptom management (e.g., alleviation of pain)	39.2
Information about hospice	29.1
Financial support for individuals in need	25.5
Availability of services such as counselling, support groups	23.8
Availability of resources specifically in your community	21.9
Conflicting beliefs about care when a cure is no longer possible	15.8

Results do not include responses that were not applicable or were missing but percentage was calculated from $N = 584$.

^aOther end-of-life care aspects specified by patients were burial options and plans, wills, and better emotional and spiritual support.

focused on decreasing pain and suffering; only 18% of patients preferred clinical care that focuses on extending life, even if at the expense of prolonging pain and discomfort. Unfortunately, dialysis patients typically have poor knowledge of their chances of survival after CPR (21,22). Despite the fact that CPR rarely extends survival for dialysis patients (23–26), over a third of these patients would want to be resuscitated.

Many of these patients regret their decision of dialysis over conservative care. Although symptoms or a history of depression were not elicited, given the high prevalence of depression in CKD, depression could have been an important driver of some patient responses. Regardless, these patients reported that their decision to be treated with dialysis reflects physicians' and family members' preferences rather than personal choice. This highlights the need to reevaluate decision-making around the initiation of dialysis and involving patients in discussions about prognosis and goals of care (27). New tools for facilitating advance care planning in CKD are available, and an approach that emphasizes a relational, patient-centered process that focuses on broader goals of care has been developed (28,29). The lack of knowledge of palliative care will obviously hinder patients' appreciation

for the supportive care services that could be made available to them, especially if they choose conservative care.

Not surprisingly, symptom management was clearly a priority for patients who felt that this was a responsibility of their renal care team. Unfortunately, pain in CKD is both under-recognized (30) and undertreated (31). The nephrologist and nephrology nurse are also perceived as important for providing emotional, social, and spiritual support. This supportive role was once recognized as an integral component of medicine. However, with the advent of modern technology, physicians have departed from this role, with emotional and spiritual support falling largely to nursing staff and allied health professionals, such as social workers, spiritual counselors, and pastoral care. The vast majority of these patients do not rely on support counselors or spiritual advisors for their social and emotional support. This may reflect a lack of presence of these members of the multidisciplinary team in our renal program. How open patients would be to these allied health professionals if they were more readily available is not clear.

Previous studies involving palliative patients suggest a preference for dying at home followed by inpatient hospice care (32). However, more recently, a Canadian study of hospitalized

Table 6. Recommendations for end-of-life care practices in chronic kidney disease

1. Identify patients who would benefit from palliative care interventions
 - a. Those who are being managed conservatively; *i.e.*, a GFR \leq 15 ml/min per 1.73 m² with no dialysis.
 - b. High risk of death within the next year. Consider using an integrated prognostic model (34) or the Surprise Question (17).^a
2. Screen for and manage pain and other physical symptoms routinely.
 - a. A simple tool such as the Edmonton Symptom Assessment Scale (ESAS) is appropriate and has been validated in CKD (3,4,35,36).
3. Screen for and manage emotional, psychosocial, and spiritual distress; refer to allied health professionals as appropriate.
 - a. The ESAS is also appropriate for screening for anxiety and depression.
 - b. A simple question such as “Do you have any spiritual needs or concerns that your health care providers may help address?” may be appropriate for screening for spiritual distress.
4. Assess patients’ desire for prognostic information.
5. Enhance predialysis education.
 - a. Educate regarding conservative care options.
 - b. Education should include available palliative care and hospice services
6. Routine advance care planning (ACP). How to facilitate these discussions is described elsewhere (16,28,29,37,38).
 - a. Ensure patients and families are aware of the relevance of these discussions (*i.e.*, have an understanding of their overall health state and prognosis).
 - b. Consider initiating ACP at the time that patients are being educated with respect to conservative care and renal replacement options.
 - c. Include discussions of patients’ goals of care, health states that the patient would no longer want dialysis, and preferred location of death.
 - d. Establish a surrogate decision-maker.
 - e. Ensure that family and other important people (as identified by the patient) are present for these discussions, especially the surrogate decision-maker.
7. Increase access to specialist palliative care, including hospice.
8. Provide bereavement support to patients’ families where necessary.
9. Incorporate palliative care training for all nephrology fellows with an emphasis on symptom management and advance care planning.

^aSurprise Question: “Would you be surprised if this patient died in the next 12 months?” An answer of “No” would indicate that the patient is appropriate for palliative care interventions, such as advance care planning.

patients with cancer and end-stage medical conditions suggested that only half of all patients and family caregivers report a preference for a home death (33). Our data confirm that although approximately one fourth of patients preferred to die in hospital, 65% of patients preferred to die either at home or in a hospice. Given the poor self-reported knowledge of palliative care and hospice, this proportion of patients may increase as they are made aware of the potential benefits associated with palliative and hospice care. Unfortunately, the vast majority of dialysis patients die in acute care facilities, without accessing palliative care services (7). End-of-life care policies and resources should be directed toward ensuring that patients die in their location of choice, which includes not only home but within-institutional settings, such as in-patient hospice.

There are several limitations of this study, some of which are intrinsic to the use of questionnaires. Responses can be difficult to interpret because patients’ understanding of questions and reasons why they answer as they do are not sought directly. These findings are limited predominantly to white, English-speaking patients. Our data, however, highlight end-of-life

clinical practices that do not meet the needs for patients with CKD. Changing attitudes and improving the knowledge of renal health care professionals and patients about palliative care are going to be the key to improving renal supportive care. We also need to define the role that various members of the multidisciplinary team will play in the provision of end-of-life care, such as symptom management, advance care planning, and psychosocial and spiritual support. This study, however, is a first step in identifying gaps between current end-of-life care practice and patients’ preferences and will hopefully help prioritize and guide future innovation in renal end-of-life care policy. Recommendations for end-of-life care practices that should be integrated into CKD care are outlined in Table 6.

Acknowledgments

I would like to thank Susan Hughes, Connie Maitland, Oceanna Hall, and Lorna Kot for project coordination and facilitation of data gathering, as well as Sandi Prinse for data entry and Tammy Bach for help with the data analysis, without whose help this project would not have been possible.

Disclosures

None.

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See related editorial, "Education and End of Life in Chronic Kidney Disease: Disparities in Black and White," on pages 163–166.

EMBARGOED FOR RELEASE until January 14, 2010 – 5:00 PM (EST)

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ASN: Leading the Fight Against Kidney Disease

END OF LIFE CARE FALLS SHORT FOR KIDNEY DISEASE PATIENTS

Survey Finds Medical Decisions Clash With Patient Preferences

Washington, DC (January 11, 2010) — Patients with advanced chronic kidney disease (CKD) often do not receive adequate end-of-life care and are unhappy with the medical decisions made as their conditions worsen, according to a study appearing in an upcoming issue of the *Clinical Journal of the American Society Nephrology* (CJASN). The findings indicate that end-of-life care should be improved to meet the needs of CKD patients.

Although many CKD patients die prematurely, surprisingly little research has been done to study CKD patients' preferences for end-of-life care and how those preferences align with the care they receive. Sara Davison, MD, FRCP(C) (University of Alberta, Canada) surveyed 584 late stage CKD patients as they came to dialysis, transplant, or pre-dialysis clinics in a Canadian, university-based kidney program between January and April 2008.

Patients reported that they would like their kidney care team to help them plan for the future in case they become incompetent to make decisions. If seriously ill, patients indicated interest in receiving help with managing pain and other symptoms and psychosocial and spiritual support. These services were not routinely integrated into their kidney-related care. Patients were often unaware of palliative care options and of the status and progression of their illness. Of the patients studied, 61% regretted starting dialysis, noting that the decision to start the treatment reflected physicians' and family members' preferences rather than their own personal choice.

While the vast majority of dialysis patients die in hospitals, more patients in this survey wanted to die at home (36.1%) or in a hospice facility (28.8%) than in a hospital (27.4%). Less than 10% of patients reported having discussed end-of-life care issues with their kidney specialists in the past year.

"This study helps us identify gaps between current end-of-life care practice and patients' preferences and will hopefully help prioritize and guide future innovation in renal end-of-life care policy," wrote Dr. Davison.

MORE

Dr. Davison noted that study limitations included the study being single-centered with predominantly white patients and that the answers were provided in response to a questionnaire, making it difficult to interpret patients' understanding of the questions.

In an editorial published in the same issue of CJASN, Daniel Cukor, PhD (State University NY) and Paul Kimmel, MD, FACP (National Institute of Diabetes Digestive and Kidney Diseases) noted that while more detailed studies are needed to provide clearer pictures of CKD patients' needs regarding end-of life care, Dr. Davison's findings serve as a call to kidney care teams to inquire more about patients' preferences. "While we labor to increase the quantity of life for our patients, we must be cognizant of its quality as well," they wrote. Within the editorial, the doctors also emphasized the role of patient and provider education regarding these issues in the future.

Disclosures: Dr. Davison, Dr. Cukor, and Dr. Kimmel reported no financial disclosures.

The article, entitled "End-of-Life Care Preferences and Needs: Perceptions of Patients with Chronic Kidney Disease," (doi 10.2215/CJN.05960809) and the editorial, entitled "Education and End-of-Life in Chronic Kidney Disease: Disparities in Black and White," (doi 10.2215/CJN.09271209) will appear online at <http://cjasn.asnjournals.org/> on January 14, 2009.

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Founded in 1966, the American Society of Nephrology (ASN) is the world's largest professional society devoted to the study of kidney disease. Comprised of 11,000 physicians and scientists, ASN continues to promote expert patient care, to advance medical research, and to educate the renal community. ASN also informs policymakers about issues of importance to kidney doctors and their patients. ASN funds research, and through its world-renowned meetings and first-class publications, disseminates information and educational tools that empower physicians.

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