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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.

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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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