

**EMBARGOED FOR RELEASE until June 28, 2018 – 5:00 PM (ET)**

**Contacts:** Tracy Hampton • (312) 339-9067 • [thampton@nasw.org](mailto:thampton@nasw.org)  
Christine Feheley • (202) 640-4638 • [cfeheley@asn-online.org](mailto:cfeheley@asn-online.org)

## **KIDNEY DISEASE PATIENTS' EXPERIENCE OF CARE AND ILLNESS CAN TAKE A LARGE EMOTIONAL TOLL**

### **Highlight**

- Patients with advanced kidney disease described feelings of isolation, abandonment, alienation, mistrust, and even self-blame that would likely be surprising to the clinicians taking care of them.

**Washington, DC (June 28, 2018)** — For patients with advanced kidney disease, interactions with clinicians and with the wider health system, combined with patients' own struggle to understand their illness, can exact a large emotional toll. The findings, which come from a study appearing in an upcoming issue of the *Clinical Journal of the American Society of Nephrology* (CJASN), indicate that a deeper appreciation of patients' emotional experiences may offer important opportunities to improve care.

Like patients with many other forms of chronic illness, patients with chronic kidney disease (CKD) must deal with challenging symptoms and a limited life expectancy. Prior studies have shown that they may experience their illness and care in ways that might be surprising to clinicians. When a team led by Ann O'Hare, MA, MD (VA Puget Sound Health Care System, the University of Washington, and the Kidney Research Institute, a collaboration between Northwest Kidney Centers and UW Medicine, Seattle) and Janelle Taylor, PhD interviewed 27 patients with late stage CKD, 3 themes related to patients' emotional experience of care and illness emerged:

- When providers seemed to lack insight into the patient's experience of illness and treatment, this could engender a sense of mistrust, abandonment, isolation and/or alienation;
- Patients could also be impacted by how care was organized, which could similarly lead to feelings of mistrust, abandonment, isolation and/or alienation;
- Patients struggled to make sense of their illness experience, worked to apportion blame, and were quick to blame themselves.

Dr. O'Hare noted that the primary focus of the research was on advance care planning, not specifically on patients' emotional well-being. "As part of our effort to understand how they approach medical decision-making, we wanted to learn about the illness experiences of patients with advanced kidney disease. Our questions were intentionally open-ended and we encouraged patients to talk freely about what was important to

them,” she said. “It was striking to us that strong themes emerged related to patients’ emotional experience of illness even though we did not ask any questions that were specifically designed to learn about this.”

The researchers hope that the findings provide greater awareness of patients’ emotional experience of illness and care. “This is a dimension of chronic illness that can be of immense importance to patients that is often invisible to clinicians. We hope that this work will heighten sensitivity among clinicians, health system leadership, and policy-makers to patients’ emotional experience of illness and the ways in which providers and health systems work may unintentionally contribute to patients’ emotional distress.”

In an accompanying Patient Voice editorial, Denise Eilers, BSN, RN, provides a perspective based on her dual roles as a registered nurse and a former home hemodialysis care partner for her husband. She noted that the study is especially timely given the large number of aging baby boomers in society. “That generation, of which I am a member, has been described in various terms such as goal oriented, self sufficient, questioning and involved,” she wrote. “The sheer numbers of these older non-traditional adults will make it necessary to move the needle further toward shared decision making as in the interpretive model. This study offers a guide from which to develop tools to facilitate discussions.”

Study co-authors include Claire Richards, RN PhD, Jackie Szarka, PhD, Lynne V. McFarland, PhD, Whitney Showalter, Elizabeth K. Vig, MD MPH, Rebecca L. Sudore, MD MPH, Susan Crowley, MD, Ranak Trivedi, PhD.

Disclosures: This work was supported by the VA Health Services Research and Development Service (VA IIR 12-126, PI O’Hare). Dr. Trivedi was supported by a VA HSR&D Career Development Award (CDA-09-206, PI Trivedi). Dr. Richards was supported by the VA Office of Academic Affiliations’ Advanced Fellowship in Health Services Research and Development (#TPH 61-000-22). None of the funding sources for this project had a role in the design and conduct of the study; including collection, management, analysis, and interpretation of the data; in preparation, review, or approval of the manuscript; or in the decision to submit the manuscript for publication. In the past three years, Dr. O’Hare has received speaking honoraria from Fresenius Medical Care, Dialysis Clinics Inc., The Japanese Society for Dialysis and Transplantation, the University of Alabama and the University of Pennsylvania. She receives an honorarium from UpToDate and is currently participating in the Health and Aging Policy Fellows Program supported by the John A. Hartford Foundation and the American Political Science Association Congressional Fellowship Program. The authors are extremely grateful to the patients with advanced kidney disease who participated in this study.

The article, entitled “Emotional Impact of Illness and Care on Patients with Advanced Kidney Disease,” will appear online at <http://cjasn.asnjournals.org/> on June 28, 2018, doi:

10.2215/CJN.14261217.

The accompanying editorial, entitled “Person-Centered Approach to Deciding on Dialysis Treatment,” will appear online at <http://cjasn.asnjournals.org/> on June 28, 2018.

*The content of this article does not reflect the views or opinions of The American Society of Nephrology (ASN). Responsibility for the information and views expressed therein lies entirely with the author(s). ASN does not offer medical advice. All content in ASN publications is for informational purposes only, and is not intended to cover all possible uses, directions, precautions, drug interactions, or adverse effects. This content should not be used during a medical emergency or for the diagnosis or treatment of any medical condition. Please consult your doctor or other qualified health care provider if you have any questions about a medical condition, or before taking any drug, changing your diet or commencing or discontinuing any course of treatment. Do not ignore or delay obtaining professional medical advice because of information accessed through ASN. Call 911 or your doctor for all medical emergencies.*

*Since 1966, ASN has been leading the fight to prevent, treat, and cure kidney diseases throughout the world by educating health professionals and scientists, advancing research and innovation, communicating new knowledge, and advocating for the highest quality care for patients. ASN has more than 18,000 members representing 112 countries. For more information, please visit [www.asn-online.org](http://www.asn-online.org) or contact the society at 202-640-4660.*

# # #

Tweet: Kidney disease patients’ experience of care and illness can take a large emotional toll.  
@annmohare

Facebook: For patients with advanced kidney disease, interactions with clinicians and with the wider health system, combined with patients’ own struggle to understand their illness, can exact a large emotional toll. The findings, which come from a study appearing in the *Clinical Journal of the American Society of Nephrology*, indicate that a deeper appreciation of patients’ emotional experiences may offer important opportunities to improve care.

Media contacts: Francie Fitzpatrick [fitzf@uw.edu](mailto:fitzf@uw.edu) and Brian Donohue [bdonohue@uw.edu](mailto:bdonohue@uw.edu).